The Central Role of Expectations in Communication and Literacy Success: A Parent Perspective

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Abstract: The author chronicles the search for augmentative and alternative communication (AAC) technology for her daughter Anna, who is now age 21. Though Anna has severe cognitive, visual and orthopedic disabilities, a more significant obstacle to finding a functional AAC system has been low expectations of her capability. Because Anna could not perform prerequisite skills for using even basic systems, more sophisticated technology was not tried for years. However, because her rich experience of inclusion had led Anna's parents to have "unrealistic" dreams for her, they insisted that Anna try more complex devices. Anna's subsequent success with the Vanguard™ and the Vantage™, by Prentke Romich Company, supports the author's conclusion that prerequisite skills should not be used to restrict access to AAC. In many cases, sophisticated technology may be just what people with the most complicated impairments need. Though Anna is still not fluent with her AAC device, the competencies she has demonstrated with it are way beyond anything she had been able to show with less complex technology. She has also gained a new sense of Self, through communicative assertiveness and a higher social regard by others. Anna's experiences should serve as an example for many underserved people who could benefit from AAC, including individuals with apparently severe and profound cognitive disabilities.

Keywords: Communication, Cortical vision impairment, Inclusion, Severe disabilities

My daughter, Anna, a young woman of 21, is in the process of learning to use augmentative and alternative communication (AAC) technology. Our family's search for AAC tools and strategies for Anna provides the chronology for this article. The ups and downs of our journey through the years provide the basis for my conclusions and lessons learned. Were my husband, Tim, and I to have the opportunity to raise Anna all over again, the main thing we would change would be expectations for her communication ability. Had we more fully acknowledged the communication skills she already used, and had we believed she 'had it in her' to learn the rest, the effect on her life would have been significant. There is no reason to despair. Anna's resiliency, and that of others having severe and profound cognitive disabilities, is remarkable. Once released from the trap of low expectations, and provided with the teaching they deserve, these students are free to grow into the unique individuals they were meant to be.

The beneficial effect of high expectations on children's performance has long been known, but low expectations are still prevalent, particularly for students with severe cognitive disabilities. Why do many educators and therapists continue to base their recommendations on the most cautious predictions for a child with disabilities? Sometimes it is based on the idea of not wanting families and students to "get their hopes up" and be subject to disappointment. However, this misguidance prevents parents from having dreams for their children, and dreams are the foundation for hope and for

action. Encouraging families to accept that their children will not progress beyond a certain level is the main practice which assures that they won't.

Inclusive Education

In order to fully understand our efforts to help Anna find her voice, it is necessary to look at her life in the context of her educational and community experience. Though challenged with multiple disabilities, including cerebral palsy, a seizure disorder, and cortical vision impairment, Anna has grown up attending regular schools and recreation programs in our community of Davis, California. Recently, she has moved into her own apartment in the community, through the benefit of supported living services. In retrospect, it is clear that this context of inclusive school and community has played a major role in our call to high expectations for our daughter.

After considerable advocacy struggles, Anna was allowed to attend her neighborhood school instead of the county's developmental center, using special education support in the kindergarten classroom. Tim and I were both special education teachers before Anna's birth, and we believed in our state's directive for least restrictive environment. Anna's elementary school years were full of wonderment for Tim and me. We were impressed with the astute observations of children, and felt relief in their perspective of life. This is not to say that these weren't also years of great difficulty, due to our "unrealistic" goals and the challenges presented by our only child, but we were always soothed by the other students' fresh "take" on Anna. Who else would speak of her as "lucky" to get a purple wheelchair, when she could no longer walk by herself? Who else would throw a party when she'd made it to one year without a seizure? The children intuitively understood the meaning of

inclusion as "supported education". They insisted on teachers seeing the difference between adults doing things "for" Anna and peers helping her "do it herself".

It wasn't only the peers who knew imaginative ways to include Anna meaningfully in school. Once teachers got past their initial fears, they applied their creative curricular skills to Anna. Her second grade teacher, with special education support, used Anna's abnormal EEG at sharing time to talk about the brain. In third grade the classroom teacher, countering the stereotype of helplessness, cast Anna in the role of heroic rescuer of the drowning prince. The band teacher turned the bass drum on its side, so Anna could play it from her standing frame.

During these inclusive elementary school years, we not only learned about the spirit of children and teachers, we also learned about Anna's spirit and personality. Had she been placed within medical model strictures, we might have had to remind ourselves that our child with severe disabilities HAD a personality, that not everything she did was related to her impairments. Thankfully, Anna's personality insisted on being noticed for what it was. She revealed that her interest in music wasn't just because it made her happy. Her attraction to woodworking projects wasn't because they were basic and "hands-on." Her interest in enigmatic poems wasn't just a mystery. Rather, singing and dancing, using technical equipment, and curiosity about language were emerging as interests to be fostered. In a setting other than a regular school, we might have seen these interests primarily as therapy tools or incentives for compliant behavior.

The opportunity to choose electives in junior high and high school made education even more flexible for Anna than in her elementary school years. Just as for the other secondary students, there were many subjects from

which to choose. Among other courses, Anna was able to take World History, Drama, Weight Training, Modern Dance, Auto Shop, Biology and Photography. Within the six or seven class schedule each day, there was always a period or two of resource room work with special education staff and students, providing the best of both worlds, general and special education. This also created regular opportunities for Anna to touch base with her childhood friends with disabilities, important relationships to sustain.

Search for Communication Methods

Parallel to our family's advocacy work for inclusive education, we were constantly striving to figure out how Anna could expand her communication, beyond body language, facial expressions and the sounds that she made. The earliest method that held some promise for her was sign language, but she had a lot of trouble using her hands in certain formations, so she only learned about six signs overall. Communication boards didn't work well at first either, whether photos or drawings were used. Anna wanted to grab the pictures no matter how firm we were in directing her to point to them. Finally we realized that if she were to grab a picture of what she wanted and give it to us, we could use that as her system. Anna responded well, off and on, to this choice board and we used the method over the course of several years, with quite a collection of laminated photos of objects. One day Anna just wouldn't use the board anymore. I took a lot of fresh pictures, of new things in her life, but this did not make any difference and she pushed the board away.

Early alternative computer keyboards looked promising, so we bought equipment for home use and set up a learning station just for Anna. This attracted the neighborhood kids, which was fun, but Anna remained apparently indifferent to the wealth of imaginative

software on her computer. Meanwhile, we were also becoming aware of other assistive technology items, and we made a good purchase: some large "jelly bean" switches to activate Anna's cherished tape player and radio. She loved having this technical control of her environment, limited as it was. And for my sake, I was glad Anna could now make something happen on her own. I felt that if one more person asked me if she understood "cause and effect", I would definitely lose my composure.

Anna's friend Nicholas, who could use his speech-generating device very well to speak his mind, was inquisitive about why Anna didn't have a device like his. I never knew what to say. I felt like I ought to explain that she wasn't yet able to use one, and that she couldn't even point to a picture of a cat or a house when asked, and that she really was so far behind in her learning that it would never be possible. But I couldn't say those things. How could I? In spite of my discouragement, I felt like I still didn't really have a clue about Anna's capabilities. Eventually Anna did get a few simple voice output devices, one after another, into which her classmates could record things they hoped she'd like to say. These devices, one of which got mounted on her wheelchair, were good for supporting inclusive participation. A peer could prompt Anna to say the Pledge of Allegiance, or to take her turn in reporting the weather. This didn't seem to have anything to do with real communication, but it didn't matter anyway, because Anna rarely used these devices of her own volition, except as something tactile on which to tap a beat.

Asking Questions, Questioning Assumptions

It was slowly occurring to me that we really should start questioning current assistive technology practices in the same way we had questioned special education practices. I kept

thinking about the rich literacy-filled environment Anna had every day at school, and the wealth of social communication that swirled around her in her community. By now, I believed she was taking it all in, and I was afraid we were running out of tools to try that she could use to express herself. I still didn't realize that attitude and lack of expectations might be the biggest obstacle to overcome. I wanted to learn more about some of the sophisticated devices that children like Nicholas had been using, and began to wonder if Anna could learn to use one. We inquired, but specialists gingerly let us know that we were being unrealistic about our daughter's limitations. According to them, not only had she not shown enough motivation to communicate, she certainly couldn't use a complex device until she had learned basic communication skills and was able to follow directions. Hearing that, I should have known that being called "unrealistic" could once again indicate that we were on the right track. Might it be that assumed truths about communication prerequisites were wrong? Might it be possible that the developmental model, like the medical model, could hinder teaching rather than promote it? Ultimately, even if we weren't on the right track, what harm would it do to try? A standstill like this in communication isn't about being able to order a pizza or not. It is about self-preservation, possibly even about one's soul living or dying. With something this crucial at stake, it is only fair to think in terms of what Anne Donnellan in 1984 called "The Criterion of the Least Dangerous Assumption", a guideline we adopted when deciding school placement: "When we cannot be sure, because we have too little information, we should base our efforts on assumptions which, if wrong, will have the least dangerous effect on outcomes" (Donnellan & Leary, 1995, p. 15).

I decided to take Anna to see her ophthalmologist, a specialist in neurological (cortical) vision impairment (CVI). I took a borrowed dynamic screen display device with me and asked the doctor whether he thought Anna capable of using something like this, given her visual processing disability and severe developmental delay. He looked at me and said, "I think she should have whatever works." His words floored me in their simplicity. Was he suggesting that we actually operate on a basis of common sense? I chuckled at the apparent incongruity of using common sense to guide us in the pursuit of unrealistic goals, but it really resonated with me. This man's matter-of-fact point of view was liberating, and in retrospect I should have expected it from him. He was the one who always asked Tim or me questions like, "Where do YOU think Anna has the best field of vision?" "Do YOU think her delayed response is due to vision processing?" He said we were the ones who knew her best and he needed our observations. CVI, like language impairment, is very complicated and he didn't mind telling us he couldn't determine exactly how Anna processed visual information. I decided to view language processing in a similar way, with respect for how much is unknown, and with trust in our own perspective. I became adamant about finding AAC people who would evaluate Anna in a more open way, listening to her family, assuming her competence, admitting they don't know everything, and looking for "whatever works".

In the process of my search, I was encouraged to learn that a number of researchers and clinicians had been voicing concern about the imposition of prerequisites for access to AAC and communication training (Kangas & Lloyd, 1988; Reichle & Karlan, 1985). Reichle (1991) refers to a lack of data supporting the need for prerequisites: "Despite this lack of evidence, some interventionists persist in demanding cognitive prerequisites. As a result, a learner may be forced to learn inappropriate and non-functional series of tasks aimed at teaching presumed cognitive prerequisites, or

a learner may be prohibited from receiving any communication instruction at all" (p. 41).

This was indeed a sinking feeling of déjà vu for me. In looking for information about AAC, we were in yet another situation in which the field practices were clearly lagging behind research-indicated best practices. Earlier, when Tim and I were seeking school inclusion for Anna, authorities seemed unaware of the concept of education in the least restrictive environment (LRE), even though it had been directed by the Federal Government more than 10 years prior (Education for All Handicapped Children Act of 1975). There was also a more insidious aspect to both of these roadblock situations, and it should be mentioned. Even educators who were well versed in LRE philosophy had assumed the policy did not refer to students with the most severe disabilities - "those kids." Now, I was recognizing similar conclusions being made regarding the use of AAC, for which "those kids" were not considered candidates. Enjoying the company of our intriguing daughter, it often slipped my mind that she belonged to the historically most devalued category of citizens: individuals with cognitive disabilities (Wolfensberger, 1975). But that reality once again hit me in the stomach, and I knew I'd better keep it in mind, even when trying to enlist the support of other AAC users, who had struggled for years to prove they were not cognitively impaired.

Gaining Access to More Versatile Technology

Fortunately for Anna, we met experienced leaders in the field of AAC who were cognizant of best practices and unwilling to let IQ scores, behaviors or appearances prevent students from having a go at high tech devices. I recruited several of these innovators to evaluate Anna's language and communication skills, and to recommend next

steps for us. From the start, we knew we had the right people, since they treated Anna with great respect, and were not bound by convention or preconceived expectations. Tim and I watched as they tried different devices and access methods with her, all in the context of enjoyable activities and un-pressured interactions. Sadly, even though the hours they spent were engaging for Anna, we still didn't see her perform or prove herself in any way. Our hopes were once again on hold, until we understood with great relief that these new people weren't concerned about an impressive performance or quick "proof." Instead, they were looking for clues as to what Anna's best modes of learning might be, and for her attraction to various technologies. They were looking for the best way to teach Anna to use a device that would give her access to the most language possibilities. The evaluation process and reports were the first we'd seen with such a positive emphasis on teaching. In the past it felt like assessment conclusions came from mere exposure to technology, implying "either you have it or you don't." These new sensitive and sensible assessments, and the menu of teaching methods they offered, helped to change our view of Anna's potential as an AAC communicator.

Five years ago, based upon several thorough evaluations and a videotaped trial period, Anna received funding for a Vanguard dynamic screen display device by Prentke Romich Company. The Vanguard is a speech-generating device with a language system called Minspeak, or Unity, which enables AAC users to create original sentences "from scratch." It has a selection of voices, which use 'Dectalk' to speak the words. The amount of instruction required to learn Unity completely depends on the student's individual needs and experience. In the past, teachers and therapists had been hesitant to show a device like the Vanguard to Anna, *because of* her severe cognitive disabilities and

unpredictable visual processing. However, my experience now convinces me that this is exactly the kind of technology a student like Anna needs, because of these complicated impairments.

Greater Competence Revealed

In training with the Vanguard, Anna was shown how to direct select, using the dynamic screen feature in which one page is linked to another. The sentence-based utterances were pre-programmed for her, based on what was known about her interests. After weeks of teaching and experimenting, Anna was able to recite by herself, "I want to listen to music. Play a tape. Earth, Wind and Fire." She was so excited that she repeated this sequence over and over, pointing to different musical selections as desired, as if delayed movement had never been a problem. As I described earlier, Anna did not form these sentences herself, but in uttering them independently, she demonstrated more enthusiasm and competence than we had ever seen. Indicating the above musical choice took Anna six separate hits, navigating rapidly through four changing screen displays. She was able to use similar sequencing patterns in a matter of weeks, allowing her to ask for her treasured candles and incense, and asking everyone who came to our house, "Do you want to dance?" There were other surprises as well. We had been told for years that Anna's inability to point her finger indicated the need for a large icon target area; that her CVI required at least two inch x two inch size icons; that her degree of cognitive delay meant using no more than four to eight icons per page; and so on. Anna's new skills with the Vanguard, even though inconsistent, changed all that.

The first important feature of this device for Anna was its back lit screen. Whereas paper overlays on her other devices were of little interest to Anna, the Vanguard's screen captivated her. Not only were the colorful icons - all 45 of them on a page - fascinating to Anna, but her visual attention was summoned each time they "jumped" while pressed. It was as if she was glad to see what she was saying. She saw not only icons, but words, because text is included above or below each icon that represents it. Anna's attending span was easily extended it seemed, by the ever-changing screens of icons as she navigated through her pages. People with CVI often see objects more easily when the objects are moving (Roman, 2004), and this device addressed that fact as no other had, even though the icons were only one inch square.

 We could tell that the aspect of predictability was important to Anna from the start, in the placement of her icons on the new device. Again, with the challenges of CVI, familiar activities and things are often more attractive than novel (Roman, 2004), so it is no wonder predictability mattered to her. Anna counted on the icons being in the exact same place on her core page and the other pages she used, so much so that she would become upset if somebody decided there was a "better" place to put them. Stability of icon location proved to be crucial for Anna's motor planning.

The Vanguard's voice, specifically the Dectalk voice "Ursula", seemed to appeal to Anna far more than friends' digitized voices. With the Vanguard, she could predict what she would hear each time, acquire more of a sense of control and have a voice to hear as her own. As for not being able to point, this was solved by a 45-square key guard, a clear plastic grid that allowed Anna to perch her index finger just below an icon square, in order to rock her isolated finger tip in and press the selection. Here she was, learning how to point while learning how to communicate. One prerequisite after another was going out the window!

Versatility: The 'High Tech' Inside the Device

I believe versatility is the best way to think about a dynamic screen display device, rather than assuming the linear definition of high tech, as in "cognitively advanced". Complexity and sophistication are other words applied to such devices, but in my experience these words refer to technical aspects, which don't automatically require a particular cognitive level for the user. Years of cognitive effort are expended by the inventors and researchers who create the language system, and design, build and program the devices, but in the end, the complexity on the inside does not have to be reflected on the outside, in the screen that faces the communicator. Technology like the Vanguard is so versatile in its options, that it can be introduced in many ways and at any age, so that student and teacher have all the tools at their fingertips, allowing them to proceed through a completely individual path of learning. This can include the opportunity to begin with full language, rather than use it as a distant goal.

Through Anna, we have learned to leave our fear of technology behind. I'm convinced another reason "high tech" items are not always in the evaluation tool kit has more to do with teacher, parent or therapist intimidation than with user capability. It isn't fair to project this fear onto a child who might be very comfortable with technology. Cousins Kevin and Logan were nine and eleven when Anna got her Vanguard. They learned in about ten minutes the basics of using it and programmed their own jokes for Anna to tell. The demeanor of all of them was not that of trying to fathom a complicated device. Rather, the effect on these three young people was of looking at something fascinating that could be even more fascinating, once they got their hands on it.

Expanded Interaction and More Meaningful Inclusion

Even though Anna's use of the Vanguard fluctuated unpredictably, we could see that her communication was indeed far more than choice making. Anna liked finding keys for asking questions and making comments, even though still using the questions and comments that others programmed for her. She liked hitting the key that had been freshly programmed to tell me something about her day. Though late in life to begin learning AAC, it was beneficial that she was still in high school when she got the device, because her peer tutors were quick to learn how the device worked and happy to provide appropriate teenage vocabulary. Teen AAC users who are at the mercy of polite parents and teachers for their vocabulary may not be given enough opportunities to complain or to insult friends, as their peers like to do, so it was good that her friends gave Anna a way to say negative things. Negativity can be very motivating to young people with newfound control in communication. "This is pissing me off!" became a favorite, as well as "You don't understand!" and "Whatever!" Unfortunately, she has said "Will you please shut up!" and "Leave me alone!" at completely inappropriate times. Then again, who hasn't?

In academic classes, Anna's new technology helped her participate more meaningfully. Though she didn't do biology curriculum at anywhere near the same level as the other students, her teacher was now able to call on her and she could at least say something. Johnny, her assistant in biology, might help her form a comment pertinent to the subject, or then again, she might reply on her own, "This is pissing me off!" The reaction to Anna saying that statement in class would surely show her the power of her spoken words.

I visited one day in auto shop to take some pictures and was able to surreptitiously photograph Anna balancing a tire on her wheelchair tray, with the help of Libby, her peer tutor. The teacher aide who supervised was showing Anna and Libby how to spell "lug nut" on the Vanguard. Here was my daughter referring to lug nuts, something immediate and personally meaningful, saying, hearing and spelling it on the spot in the auto shop garage. What a sight it was! They were able to do this because every Vanguard page Anna uses has a link to a spelling page; any word at all can be included when forming a sentence. Because of the Vanguard's versatility, instruction can occur in context, almost anywhere, even when changing a tire. Again, as Laura "Dollie" Meyers (Meyers & Horton, 2001) has reminded us, "Teaching is the missing key. During most training for professionals specializing in Assistive Technology, there is no focus on implementation. Courses just address choosing the 'right' device…Extensive, intensive teaching during implementation is the key to success."

As a lover of music and dance, Anna has always enjoyed being in performances. Drama class in high school was the ultimate, because now she had the Vanguard with which to say her lines. In one student-scripted scene, Anna played a young woman, jilted by her boyfriend. In another play, she portrayed the voice of God. In yet another, she got laughs as a mother who yelled things at her daughter, such as, "You ungrateful brat! How could you talk to me like that?" These were pre-programmed lines that Anna needed to deliver at just the right moment, a difficult task for someone who has failed for years at turn taking. Peer tutor Maria sat on stage at her side, helping Anna with cues and tapping her elbow if she seemed "stuck" (Donnellan & Leary, 1995).

There is a difference between AAC goals for participation and those for communication skills. As long as we know the difference, both are worthy goals. It was during the resource room periods that Anna was able to receive more communication training with her device, another convenience of the secondary school schedule. The practice time was not her favorite, as she didn't always respond well to the sequencing repetitions. During these times, it was more stimulating for Anna when peer tutor Marcus helped her write letters or create short reports for her classes by using her Vanguard connected to the computer. With Intellitalk word processing software, Anna heard and saw what she was saying, first on the Vanguard and then again on the computer in enlarged font. Marcus helped her print out the sentences, reading them to her as she looked at the report. Her delight showed that she was tuning in to the power of her printed words. We began to see that Anna would be approaching AAC and literacy in her own unique way, or not at all. We had to live with this, even though it meant instructive activities had to be highly motivating to her in order for her to do well with them.

Expanded Expertise: Internet Friends Who Use AAC

When I was worried about Anna's obsessive repetition of phrases or words, another of her habits with her new device, I emailed several AAC mentors. The internet and email provide an indispensable resource: direct contact with other people who use AAC. Edwin "Speedie" Marrero (personal communication November 10, 2000) replied ironically, "The best advice I can give you is practice, practice, practice! I used to spend hours just playing with the keyboard. I memorized words I used all the time. I didn't use sentences at first." Indeed motor planning - turning voluntary into automatic movements - appears to be a key focus that works for Anna in learning to use her device.

When Anna first started using her Vanguard, we contacted Snoopi Botten (personal communication, October 13, 2000), a Vanguard user who is also an ingenious software developer and musician, with some questions about the changes we saw in our daughter. Here is what he said: "The key is expectations. I see it everywhere. If someone has very low expectations, they not only don't give a person a chance, but they create an environment that only validates their preconceived expectations. The problem is people don't even realize they are setting up the situation so it won't go beyond what they expect. Anna and her Vanguard is a good example. Before she had her Vanguard, there were things that were never tried just because the expectations weren't there. But now her Vanguard is slowly changing people's views and the expectations are slowly growing."

Snoopi's observations about the change in expectations for Anna really made us think, especially when he asked if we thought Anna could be using a Vantage, which is a smaller, more convenient version of the Vanguard. (The Vanguard weighs 6 lbs. and has a 12 inch diagonal screen, while the Vantage only weighs 3.5 lbs. with an 8 1/2 inch diagonal screen.) When the Vantage came out, we hadn't even thought of showing it to Anna, because it seemed impossibly small for her to see. After Snoopi prompted us with his question, we were humbled when Anna tried the smaller device and selected keys with no difficulty at all, pointing to icons that are 3/4' by 3/4 ' in size. Eventually she was able to get a Vantage, and that is what she is learning on today.

Using All Levels of Technology

All the discussion about versatility of high tech does not mean the exclusion of other types of AAC. By keeping ourselves aware of what works for Anna, we have observed that she wants to use all kinds of means to interact. One of the low tech items that is still in her life is the one hit recorded button (talking picture frame or jelly bean switch), attached to various pieces of furniture in her environment. By the back door one says, "I want to go outside." On the game shelf one says, "Will anyone play Twister with me?" By her bed another says, "Hey, I'm awake!" Anna likes to use a multi-level message recorder to sing the lines of a song. She carries a yes/no/alphabet board in her wheelchair pack. Each morning she goes over her schedule with a wipe-off board of icons and topic words that outline her day. Occasionally Anna also uses an eye gaze frame or a clear rectangle of plexiglass to dwell with her eyes on what she wants, as indicated by icons, words or photos.

Since her ability with all of her AAC tools fluctuates, Anna also relies heavily on her vivid facial expressions (e.g. eyes wide open meaning something hurts), body language (e.g. mock-biting of her hand indicating frustration) and mobility (e.g. moving toward something in answer to a question) for communication. She uses different vocal sounds to indicate emotions (e.g. a soft hum means she's pleased, a throaty groan means she's getting angry). I believe we should honor anything Anna uses to indicate her needs and moods, without trying to replace it with something we think might be better. Initially we didn't understand this and tried to "streamline" all of Anna's communication into her device. In so doing, we confused her. For example she stopped using her precarious "yes" and "no" hand signs, which were almost working consistently for her. We won't make that mistake again. A low tech method may work better than a high tech one, depending on the situation.

Language and Literacy Support

The versatility of the Vantage is what allows complete flexibility in teaching approaches,

and also the ability to program easily, if changes are needed. Anna began her Vanguard training with a combination of Unity core vocabulary, and a linking of custom-created pages. Recently, SLP Kristen Newman Carroll has begun skillfully guiding Anna, and those who support her, through the Unity language system, focusing on building sentences completely from the core page, rather than linking to pages and using one-hit sentences. Anna's progress continues to fluctuate all the way from periods of obvious competency to days in which she barely touches her device. It is probable this would have been easier for Anna to learn, had we started from the beginning in this way, but that is water under the bridge, and it is important to remember that the Vantage can eventually be used in any way that works best for Anna, including her previous combination approach (core word-based page, plus linked custom pages) for different types of conversation situations (Higginbotham, Lesher, Todman, File, & Wilkins, 2002). Also, as one of her evaluation team members has put it, "She had 16 years without a consistently effective communication system. She should have at least that long, if she needs it, to learn what she needs to learn." (K. Weber, personal communication, March 18, 2000)

Anna's present life in Davis includes a volunteer job at a local health clinic, weight training at the athletic club, and a beginning choral group, using Snoopi Botten's (2005) new software to program her Vantage to sing. Anna's schedule still also includes supported education; she is taking a world music class at the community college and a night cooking class for students with disabilities at the adult school. Also included in her day are supported literacy activities, guided by linguist Dollie Meyers' approach to computer work with students who use AAC. In Dollie's words, "…the keys to effective computer use by children with language disabilities are to

implement the computer both as an access tool and as a personal meaning tool; that is, to use the technology to provide access to speech and text, link it to their personal meaning systems, and thereby allow them to participate in the natural processes of language learning" (Meyers, 1994, p. 260).

Support staff helps Anna create books with topics of special interest to her, like dreaming, flowers in nature, medical equipment and playing the drums. Also, some of her favorite authors' books and verses have been transcribed to her Vantage and her computer. Our next task is to set up controls so that Anna can independently come into her bedroom, wake up her eMac, find her current favorite book in Intellipics® Studio, made with her own iPhoto illustrations, and recite it out loud, turning the pages with the click of her switch-adapted mouse.

In poetry Anna has shown us the most effective tool of all with which to draw her into reading and writing. Rhythmic, rhyming fantastical poetry is still the thing that catches her ear and focuses her attention. Caroline Musselwhite refers to poetry's attraction in this way: "Poetry for Life: At the highest levels, poetry helps students express who they are, a possibility that is especially empowering for students who are non-speaking" (Musselwhite, 1995). Cousins Kevin and Logan have recently used Garage Band software on Anna's eMac, to make a CD of rhythmic/harmonic tracks over which Anna can recite her own rhymes. Anna and her team are writing lines, singing lines, and using core vocabulary words to surround the colorful extended vocabulary that emerges from their community activities (Van Tatenhove, 2000). We are experimenting with a floor stand for the Vantage, so Anna can deliver verses between her beats on a real drum. Much like she formerly used a standing frame for weight bearing, she can now stand at a set of tall conga drums (with someone

standing behind her, just in case). Open mike night at the local coffee house will be a good place to start, with plenty of other opportunities for poetry slams on the horizon, if this "takes off".

Outcomes and Benefits

Inclusive education was the catalyst for the rise in expectations for our daughter, because it allowed us to have dreams, and challenged us not to settle for less than those dreams. Anna living a "regular life" in her community has been our first dream fulfilled, and it is providing the backdrop for the other important dream of AAC communication that is in progress now. Many of the benefits for Anna have been described, in the form of greatly increased opportunities for interaction, participation and literacy, as well as the revealing of increased skills and competence. The versatility of her technology, combined with her new-found skills and the power of good teaching, is leading Anna to a brighter communication future. She is maturing amid unsettling changes in her life and she is developing a clear sense of Self. She is also afforded a much higher regard by others, now that she has become more of a vocal presence. Her device has helped enormously to bring Anna "into the action", which has in turn led her to presenting herself as a contributing individual with a right to be recognized. I firmly believe this assertive self-image is in turn making Anna more receptive to the AAC instruction she will need for a long time to come, by showing her what she has to gain.

The outcomes for Anna and the beneficial effects on her family and support network are intertwined. Tim and I are no longer paralyzed by low expectations, and have allowed ourselves to be more comfortable with the unknown. This includes perplexing periods of stagnation in progress, as well as strings of triumphant moments that erase all

of our doubts. Humility, intuition, imagination and unlimited brainstorming are the tools we've come to trust in this process, and we will never run out of these tools as long as Anna is leading the way.

Most important for us is what we are learning from paying attention to our part in communicating with Anna, both in direct interactions and in perceptions. We are trying to take the focus off of her as the problem (i.e. the patient) when things are rocky, and learn a more expansive way of regarding communication, which is affected by what both communication partners do or say, in addition to a host of other environmental factors. 'Joint establishment of meaning' is a way of looking at the whole of a communicative interaction, and it has many aspects, from gestural to relationship and time constraints (Wilkins & Higginbotham, 2005). On a profound level, we are learning how to BE during interactions with someone who may be using her device in a slow or repetitive, circuitous way. The thing that really creates true connection when Anna and I are verbally interacting starts with entering her world by leaving the rest of the world behind. When we do this, the focus is there; I can see it in her face and feel it in her touch. We are familiar with that bond, because we have had it for many years within our non-verbal communication. Carrying it forth, with the effort of using words, is a different challenge. But when Anna knows someone is truly present with her, she trusts that she has time to be herself, laying the groundwork for real communication.

Conclusion

It is my hope that our story will provide an example to readers of the need to stretch the boundaries of expectations for their clients and for their children, and to understand that strong advocacy will likely be required. The need to improve

communication services for people with severe disabilities continues to be an ongoing concern. In 1992, the issue was addressed formally by the American Speech and Hearing Association (ASHA) as a human rights concern: "…the opportunity to have communicative effects on one's environment is a basic human right that should be enforced and enabled by the provision of active treatment for persons with severe disabilities…" (National Joint Committee for the Communicative Needs of Persons with Severe Disabilities, 1992, p. 3). Since that time, AAC users, researchers, educators, clinicians and families have produced a wealth of creative materials, including assessment and teaching methods and philosophies, a number of which have been used in supporting Anna (Beukelman & Mirenda, 1998; Erickson & Koppenhaver, 1995; Fried-Oken & Bersani, 2000; Meyers, 1994; Musselwhite & DeBaun, 1997; Rogers , 1999). In spite of these and many other contributions, ASHA still saw the need in 2003 to alert practitioners, in a detailed Technical Paper: "Eligibility policies and practices often preclude children and adults with severe disabilities from accessing needed communication services and supports" (National Joint Committee for the Communicative Needs of Persons with Severe Disabilities, 2003, p. 19).

The words are clear, the strategies are there, but daily reality is a different story. It is necessary to "walk this talk" into classrooms across the country and into programs right around the corner. One will still find children and adults with communication impairments, whose unscientifically determined "low functioning" label continues to perpetuate their social isolation. The inhumane limbo that these people must endure is still often based on faulty prerequisites, labels and purported lack of funding, rather than on any data about their individual language capabilities. According to ASHA, "Eligibility determinations based on a priori criteria…"

…[including] lack of funds or other resources…" "…violate recommended practice principles by precluding consideration of individual needs" (National Joint Committee for the Communicative Needs of Persons with Severe Disabilities, 2003, p. 20.)

Though the challenge of funding AAC tools and services may exist for a long time to come, it is clearly not a legitimate reason to arbitrarily limit assistive technology options. If it requires sophisticated AAC technology to introduce an alert toddler into the world of literacy, then sophisticated technology is what he must have. Likewise, if it takes sophisticated AAC technology to meaningfully bring a marginalized adult into the life-giving world of interactive communication, then sophisticated technology is what she must have.

Ultimately, we may learn all the right strategies to support Anna, and she may grow to be a literate and fluent communicator, at a pace that will hold an ordinary conversation partner's attention. But even if she does not progress to advanced skills with language and literature, Anna and others with her degree of challenges still deserve access to whatever works, for however long it takes, to give them expanded language, truer self expression, and a powerful way to interact with the significant people in their lives. Everyone has a right to communicate. All does mean all.

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