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Whose Outcome is it Anyway?

Let's cast some illumination on the murky subject of outcomes in AAC.

What is an Outcome?

We shall begin by asking "What is an outcome?" Taking an example from the sports world, quarterback Steve Young felt exhilarated after winning the Super Bowl. This exhilaration was the result of all the hard work Steve and his teammates put in during the season. Winning the Super Bowl was a very positive outcome for the San Francisco 49ers. Had they lost the contest, Steve would have felt very depressed, and the team would have experienced a very negative outcome to the season.

The American Heritage Electronic Dictionary defines the word "outcome" as

- a natural result; a consequence.

In the rehabilitation and medical fields outcomes can be defined as

- changes in status attributed to a specific intervention or treatment.

Outcomes, then, are results caused by an event or series of events, or an action or series of actions occurring over time. Outcomes can be positive or negative. There usually is an expected outcome for any intervention or course of action.

Measuring Outcomes

Outcomes can be measured and studied. The science of outcomes measurement is defined as systematically measuring and analyzing treatment outcomes and using the findings to change the way care is provided. A person's communications could be measured over time to see if the new communication device he has is improving his functional ability to communicate. Is he talking more effectively with more people with the device than without?

Does It Matter?

Why should anyone care about all this mumbo jumbo? Is all this really that important? Yes, it is, and it's going to be even more important in the years to come. As the dollars for AAC goods and services gets scarce, outcomes will play an ever larger role in the AAC field. Forces within the AAC community, such as consumers, taxpayers, program administrators and funding agencies, want to make sure that goods and services are of value to both the client and to society. In short, people working in the field of AAC should get used to thinking in terms of delivering positive, measurable outcomes as well as goods and services.[1]

Forces in AAC

In preparing to write this issue of *Alternatively Speaking*, I made a table of the various forces that could influence an outcome in AAC. It is rather amazing. The table has thirteen categories in it, and most of the categories include many different points of

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INSIDE THIS ISSUE

Message from the author

I was born in 1937. I tell you this not to reveal my age, but to demonstrate that I am a survivor.

Handling a disability with significant physical impairments is never easy. In the late 1930s and early 1940s it was a formidable task indeed. The base of scientific knowledge on disability was scant at best, the concept of assistive technology was unknown, and attitudes towards people with disabilities were primitive to say the least.

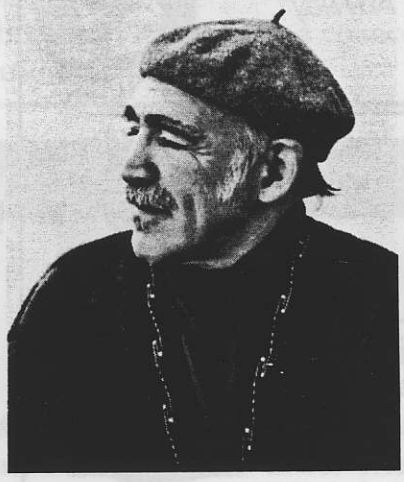
Anyone observing the scene in the delivery room on the night of my birth, wouldn't have given a plug nickel for my future. When I came out into the world, my doctor thought I was dead, and when I proved him wrong on that score, he predicted I would never amount to much. Wrong again, Doctor.

Here I am sitting at my desk writing this when I wasn't supposed to be able to do anything of consequence.

Why? Why have I been able to affect such a positive outcome in my life when others in a similar situation have had outcomes that were less successful?

Surely luck played a part in it. I was born in the right place at the right time. My family was well connected to the civic life in the city in which they lived. Yes, they encountered their share of quacks in their efforts to help me; but in the end, they were able to ask the right questions to find the right people who had the right answers to help me in my seemingly hopeless situation.

How about today? What are the forces that help shape an outcome in AAC? Who are the stakeholders? The main focus of this issue is on: Whose outcome is it anyway? AS



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view, many different stakeholders. There certainly are a lot of forces pulling on AAC outcomes. I've included this table, "Forces in AAC," for your perusal on page three.

In fact, not everyone is working toward the same outcomes. There is no unified team pulling towards the same goal. Indeed, as one looks at the chart of forces in AAC, one can envision many of these forces pulling from opposite ends of the rope. With people pulling from different directions, who has the greater say in the area of outcomes? Certainly the persons who control the money (insurance companies, government funding agencies, tax payers and the like) appear to have more influence in the outcomes area simply because they often are paying the bills.

A Good Model

Consideration of outcomes is great, but how does one think about outcomes, and how does one measure them? The World Health Organization has a theoretical model that can help us think about outcomes. It is called the International Classification of Impairments, Disabilities and Handicaps. As the name implies, this model looks at disability from a three level continuum.[2]

The first level is called "impairment." This focuses on an abnormality of psychological, physiological or anatomical structure or

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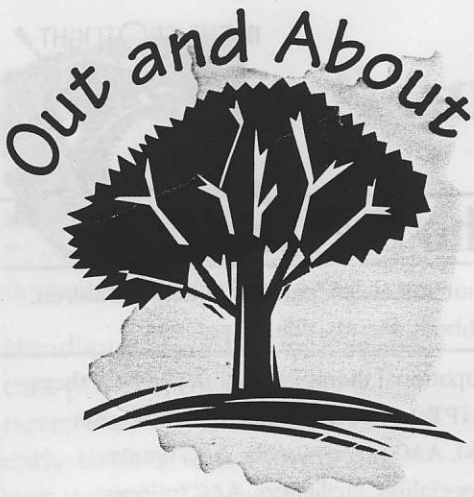
Forces in AAC

The forces	Their stakes	Who they are
People who need AAC services or tools	Becoming participants in society	Consumers, users, parents, families, children, neighbors, friends, clients, patients
People who provide AAC services	Working the front lines of AAC	Occupational therapists (OTs), physical therapists (PTs), speech-language pathologists (SLPs), AAC professionals, AAC teams, AT specialists, facilitators, AAC trainers, rehabilitation engineers, manufacturers, teachers, manufacturers' representatives
People who make AAC tools	Turning the stuff of dreams into reality	Manufacturers, hardware designers, software designers, computer scientists, linguists, researchers, engineers, SLPs, parents, friends, neighbors, rehabilitation engineers
People who live or work with people who need or use AAC services or tools	Showing that AAC techniques and tools work in the real world	Families, parents, guardians, daycare providers, educators, teachers, teacher's aides, professors, group home staff, adult day program staff, employers, co-workers, colleagues, employees, nurses, friends, counsellors
People who pay for AAC services or tools	Getting maximum bang for the buck!	Department of Rehabilitation, Medicaid, Department of Education, school districts, health insurance companies, the public, taxpayers, families, friends, service organizations, churches, charities
People who prescribe AAC services or tools	Passing out the permission slips for needed equipment and services	Physicians, rehabilitation specialists, SLPs, AAC teams
People who sell AAC tools	Convincing payers that their equipment is worthy of consideration	Manufacturers, manufacturers' representatives
People who repair AAC tools	Keeping the communication flowing	Manufacturers, parents, families, children, OTs, PTs, SLPs, rehabilitation engineers
People who direct programs or run facilities	Keeping their programs alive Meeting consumer needs	Administrators, principals, directors, department chairpersons
People who make or influence public policy on AAC	Keeping their constituents happy Carrying out mandates	Elected representatives, advocates, lobbyists, professional organizations, consumer organizations, service organizations
People who advocate for those who use AAC tools and services	Getting what they think will benefit the consumer	Lawyers, advocates, parents, friends, families, physicians
People who do AAC research	Contributing to the field Getting their research funded	University researchers, rehabilitation center researchers, AAC companies' R&D people
People who fund AAC research	Advancing the field Deciding who does research Determining the research priorities	Federal and state agencies, AAC companies, universities, rehabilitation centers, foundations



The Importance of Going Out

Three major impediments hinder people who use AAC from becoming effective members of society:

1. architectural impediments
2. public attitudes
3. private fears

Of this trio of barriers, perhaps the first is easiest to fix if there is the will to do it. It's easy to put in ramps, elevators and grab bars, especially when a building is under construction. But will it get done?

Some people say, "Why go to all that extra expense for access when there aren't any disabled people in our town." I find this most curious. How do they know this? Have they taken a survey of the entire town? Perhaps the civic leaders possess x-ray vision and can see through walls.

"Nope, no people with disabilities in here, Floyd."

"None over here either, Charlie."

Most curious indeed. Are we like those trees in the forest that make no sound when they fall because nobody is there to hear them? Just because people don't see us on the streets, doesn't mean we aren't living in the community.

Berkeley, California is often referred to as the Mecca of the disability movement. Overblown? Sure it is. This is what happens twenty years after the start of a revolution when the backbone of truth gets covered with more than its share of myth and hype.

Today Berkeley is a most accessible city. It is small and compact and easily traversed by a person in a motorized wheelchair. Berkeley's disabled population is viewed as just another segment of the community.

It wasn't this way twenty years ago. Berkeley was like any other city. There were no curbcuts or ramps, and a general attitude of hostility hung in the air like a pall. Then something happened. The University of California admitted a physically disabled student to its Berkeley campus. This didn't happen without a struggle, but it did happen. Soon after the first student was admitted, another one came and then another one.

All these people had motorized wheelchairs, and they started to use them to explore the community at large. They were greeted with a mixture of curiosity, annoyance and outright hostility. But these people didn't let a few dirty looks, muttered comments or demands they leave a store get them down. They were back on the streets the next day, mingling with the community, serving notice that they couldn't be scared away.

Twenty years later Berkeley has become a city that is relaxed about people with disabilities – even about people who use AAC. Everyday people who use letterboards, head pointers and speech output devices go into stores and get treated like ordinary mortals wanting to buy stuff. Clerks even seem to know enough about people with speech disabilities to immediately get in the proper position to read a person's letterboard and to stick with the task until the task is completed.

Can the outcome of the Berkeley experience be re-created elsewhere in the country and the world? Yes and no. Berkeley had some unique geographical and political factors that could never be replicated in another place.

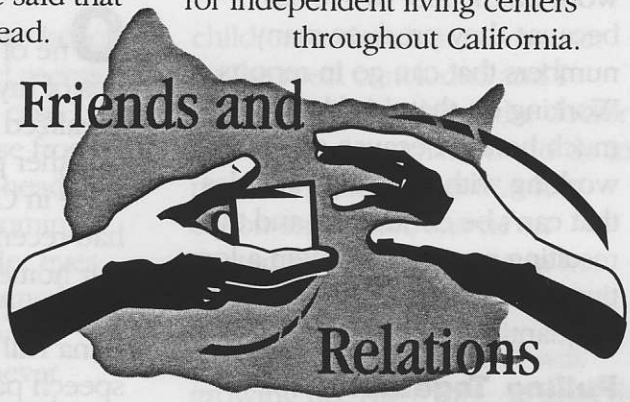
But the Berkeley experience was also one of the mind, spirit and heart. Everyday disabled people woke up and confronted the barriers erected by their own fears, and then went out to confront the barriers to people with disabilities erected by public attitudes.

When people take charge of their own outcomes, good things may happen. That is the lesson of Berkeley. We in the field of AAC should try to learn from it. AS

Ed Roberts: One Tough Vegetable

When Ed Roberts died this Winter at the age of fifty-six he was perhaps the best known disability rights leader on the planet and was fast becoming a legend in his own time.

Ed was a prototypical sports-loving male when he was hit by a near fatal dose of polio. The doctor who saved his life said that Ed might be better off dead. The doctor informed Ed's mother that her son was now a vegetable who would never do anything with his life since he would have to spend the rest of his life in an iron lung.



Some vegetable he turned out to be! Here are some of the things Ed did in his life once he got a portable respirator and he could spend part of his day out of his iron lung:

- Won the right to graduate from his high school in spite of not completing the mandatory physical education and driver's education requirements.
- Became the first significantly disabled student at the University of California at Berkeley while headlines screamed, "HELPLESS CRIPPLE ATTENDS UC IN IRON LUNG."
- Cofounded the first on-campus service center for university students with disabilities in the United States.
- Cofounded the Center for Independent Living, the first independent living center.
- Became the first significantly disabled person to head the California Department of Rehabilitation. A major accomplishment of his eight year tenure at that post was establishing funding for independent living centers throughout California.
- Was given a Macarthur "genius" award.
- Cofounded the World Institute on Disability, a think tank devoted to world-wide disability issues.

These are some of the things Ed did with his life, but he was at his best while working with people.

I first met Ed Roberts in the Spring of 1969. I was newly arrived in Berkeley from Southern California, and I was having a hard time adjusting to a new environment. One day somebody suggested I visit Ed and his mother. Upon hearing that Ed spent a lot of his time in an iron lung, I thought, "Great, just what I want to do, to spend time with another cripple and his overprotective mother.

But I went anyway. Meeting Ed for the first time was a very unusual experience. When I first entered the house I was filled with anxiety. I heard the hissing and clanking of that great mechanical beast that was pushing oxygen into Ed's lungs. As I approached, I could see parts of Ed's body through the small portholes on his iron lung. I situated myself near the front of the machine in the hope that Ed could somehow read my letterboard. I was really nervous. Then I looked up in the mirror that hung over Ed's face and served as his window on the world; there I saw the real Ed Roberts smiling back at me in all his glory. "How's it going?" he said.

It was an extraordinary moment for me, because, in that instant, everything fell away; all my doubts and fears just disappeared.

Ed was very good at making people feel comfortable. Then he would tell you his dreams and convince you they were your dreams, too. And then he'd tell you what you were going to do to make those dreams come true.

Ed taught me to be a human being rather than a cripple and to view other people with disabilities the same way. It's the most important thing I ever learned from a vegetable. AS

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function at the organ level of the individual. For example, a person who has undergone head trauma may have a brain injury.

The second level, "disability," focuses on the limitations caused by the "impairment." Looking at our fellow with the traumatic brain injury, that injury could affect his ability to communicate and solve problems. This level, called "disability," describes a person's limitations which can be measured before and after acquiring any adaptive techniques or tools, such as a communication device.

The third level, "handicap," focuses on the societal disadvantages imposed on an individual as a result of "impairment" or "disability." Our friend with the traumatic brain injury may experience problems in making and keeping new friends, finding employment and getting around in the everyday world.

Specific interventions for this individual by professionals mainly will be aimed at the levels of impairment and disability. These are the areas in which professionals usually work, and these are the areas that produce the most quantifiable results. Our friend can receive traditional speech therapies on the impairment level that can be measured by improvements in articulation, intelligibility and rate of communication. An intervention on the level of disability would include the introduction of AAC devices, techniques and strategies. Improvement could be documented by functional and performance measures such as the number of interactions our friend has with other people.

An intervention at the third, or handicap level, requires working with the individual and the community where he lives, works and plays. Clearly, this is the most difficult level on which to define measurable outcomes, because one is dealing with murky quality of life issues that are very subjective. Most professionals I've spoken with of late would rather work on the first two levels because they produce many numbers that can go in reports. Working on that third level is much harder because one is working with so many variables that can't be controlled, and the resulting pay-offs are often a long time in coming and are not easy to quantify.[3]

Pulling Together

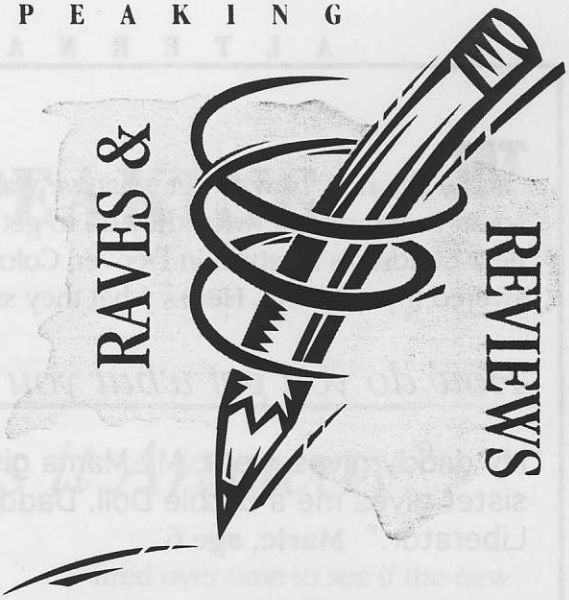
This report ends with a question: Whose outcome is it anyway? Is it the outcome of the people that control the money, the persons who want the quickest intervention at the lowest price? Is it the outcome of the program administrator who is always looking to put up good numbers in order to make his program look effective? Or might it be the outcome of the potential user of AAC? Will he receive and be trained in an AAC system he can use effectively so he can go forth and do battle on that all important third level? Isn't this the outcome we all could be working towards? AS

Memories

One of the most vivid memories of my childhood is of the day I realized I was viewed differently by other people. My mother and I were in Colorado at the time. We had recently moved there from our home in Chicago, Illinois to attend a boarding school run by Edna Hill Young, a pioneering speech pathologist who served clients with severe disabilities. This was unusual for the time, because most speech pathologists were treating traditional speech disorders such as stuttering.

Ms. Young had a cadre of helpers, recruited, I now realize, from the University of Colorado. These people performed various functions in Ms. Young's universe, not the least of which was observation and recording. It seemed like every minute of our day was observed and documented on paper; what was done with all this paper I have no idea. It's all probably gathering dust somewhere in some great archive.

My mother took no notice of all this recording until one day one of the observers oozed up to my mother like a spreading oil slick and, putting on her best clinical



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airs, said "I'd really like to keep in touch with you. Michael seems like such an interesting case." I thought I saw smoke rise from the top of my mother's head and heard volcanic noises coming from deep inside her. Her eyes brightened like coals fanned by an unseen wind. I knew the young woman would never know what hit her. My mother locked on to her eyes. "My son is not a case," she said in an even handed tone. "He is a little boy." Having spoken her mind, she turned and walked away, leaving the young woman alone with her thoughts.

My mind has returned to this scene often during the intervening years. People with disabilities put up with a lot of measurement in their lives. Teams of medical personnel swarm over us at regular intervals recording our every deviation from the norm. This is often done in a setting that is so cold and impersonal that it affects our ability to respond as well as we can to the test at hand.

My mother once invited my pediatrician, a woman who specialized in the care of disabled children, to lunch at our house. As the meal concluded and I started to do my thing, the doctor was amazed at what I could do in my own milieu. After that luncheon encounter, she never treated me the same way in her office again.

This is how it was when I was growing up. Have times changed? I certainly hope so. We don't need to be ensnared in the medical model of life anymore. Besides, the myth of that paradigm was pretty much exploded in the 1970's by the independent living movement.

The independent living model emphasizes how well a person with a disability functions in his environment rather than on his medical condition or deviation from normalcy. Now we are free to concentrate on the business of living, rather than worrying about how well we do on various medical tests and to be judged on the quality of our lives rather than our medical diagnoses. This should be cause for celebration.

It also should be cause for caution. Consumers in the AAC community should realize that there is much research to be done. We shouldn't let our feelings about what may have been done to us in the past influence the need for research now and in the future. From research comes progress, not to mention prospects for funding from both public and private sources.

Researchers have to realize something, too: Although we augmented communicators are the raw material behind the numbers they crunch, we are also individuals with feelings, hopes and dreams. They should remember this as they are putting us through the Statistical Package for the Social Sciences.™ They also should put us on their research teams. They may be pleasantly surprised to find we have some good insights into the problems they are working on. If they try to reduce us to interesting cases that can be put in a file, they may be faced with an angry mother who will ruin the day, not to mention some punk with a computer who might write an essay about them. AS

We all know how to get what we want some of the time. I asked some young people what they do to get what they want. They live near Children's Hospital in Denver, Colorado. I like how they answered my question. Here's what they said.

"How do you get what you want?"

"My daddy gives me it. My Mama gives me a cookie. My sister gives me a Barbie Doll. Daddy gives me my Liberator." **Marie, age 6**

"I want..." (Then I point and vocalize about the specific thing I want.) **Ellen, age 7**

"Jim. Mommy. Sandra. I need help. Drive my wheelchair. Face. Smiling face. Jim B. I am 7." **Jim, age 6**

"Want." (His mother asked him if that's what he says to get things, and he nodded his head, "Yes.") **Malcolm, age 7**

Thanks to Tracy Kovach for her assistance.
I gave these children pseudonyms because I didn't have a chance to get their parents' permission to use their real names.

I want to know what you liked best about the AAC camp you went to last year. Tell me,

"What do you like about AAC camp?"

You can write to me: Michael Williams, Augmentative Communication Inc., One Surf Way, Suite 237, Monterey, California 93940.

You can send me a fax at (408) 646-5428. Or you can send me electronic mail at mbwill@well.sf.ca.us

Sources & Resources

1. Blackstone, Sarah. (1995) *Augmentative Communication News.* Issue on outcomes. Monterey, CA. 8:1.

2. World Health Organization: International classification of impairments, disabilities, and handicaps. Geneva, WHO, 1980.

3. Some ideas in this section were germinated in the Alliance 95: Outcomes in AAC conference held in Monterey, California February 19-22, 1995.

4. This article was first presented at the Alliance 95: Outcomes in AAC conference held in Monterey, California February 19-22, 1995.

More reading about outcomes

Augmentative Communication News featured Outcomes in the January-February, 1995 issue. The author, Sarah Blackstone, summarizes current professional thinking about outcomes in AAC and discusses the subject from her point of view as a master clinician.

The conference report from **Alliance 95: Outcomes in AAC**, a conference sponsored by Augmentative Communication Inc., will be available soon. It is an easy to read summary of individual participant's view consensus statements and provocative thinking about necessary next steps in outcomes measurement.