



THE COMMUNICATOR



A Publication of the Autism National Committee

Getting a Cure or Getting a Life, and Who Gets to Decide?

By Anne Bakeman

If Christopher Reeve lobbied for everyone to have personal care attendants, can you imagine how powerful that would be? -- Kenny Fries, 2002

We're a privileged bunch, we allies and champions of people with significant disabilities of communication. In getting to know them, we've been allowed to discover the force of their characters: how they've put their own spin on Aunt Ethel's flair for drama or Grandpa's offbeat humor, how they've worked to become their own people. We are privy to what excites our sons and daughters, sisters and brothers, students and teachers – and what turns them off. We only have to watch like hawks for the clues.

Through the years we notice how this person we've come to fiercely love struggles to make sense of the world, to communicate her ideas, to take care of her caregivers. We may be permitted to witness the painstaking and convoluted ways he goes about accomplishing a goal he has set for himself – teaching himself to read, perhaps, or learning to handle overwhelming situations with dignity. Bringing these heroic efforts to our attention is no easy task for our family members, friends and students. The barriers confronting them are overt sensory difficulties, movement disturbances that affect the way they initiate and interrupt an activity, and serious trouble with communication. For us, though we may make intuitive leaps about what's going on for them (assisted by their creative and patient cuing), the problem may be that we need constant reminders. Nevertheless, most of us eventually get to the point of remembering to presume their competence.

We would go to the ends of the earth to make our loved ones more comfortable or less anxious. Would we go to the ends of the earth for a cure? In their "cured" form, they would be different from the people they are now; is that what we want? More important, is that what they want? I believe from both corners the answer is a resounding "No."

Here's what I've learned from my daughter: She just wants to live her life. She wants to keep her place in



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the world as a valued family member, friend, worker, and citizen. She wants to know that everything is in order (although the news is hardly reassuring in that regard) and that people are getting a fair shake. When something strikes her as funny, everyone around her is infected by her laugh. On Election Day, having studied the brochures, she votes for the candidates she likes best, and it's none of my business.

My business is to do what I can, in alliance with her, to divert attention and money toward investment in people with challenges who are trying to get a life. The people themselves seem to know they have something to offer, that the world needs them just as they are. Instead of "Research for the Cure," they would earmark funding for the things that will make a tangible difference in their lives: support and accommodations to participate in the basic activities and adventures (chosen and directed by them) that are part of the human experience.

When everyone has access to the journey, everyone wins. The ship of life takes on an air of vibrant diversity. Our sons and daughters, teachers and students, get to be on board with the supports they need. We allies are lucky enough to be going along on the adventure, or standing on the pier, waving.

A Good Life By Kathy Grant

Last month I took the Greyhound bus to Kansas City for a friend's wedding, then two days later, I went to Topeka to visit another friend of mine for a week. The reason why I mention this is because even though I am autistic, I have a life that is more than my autism, and even if autism has something to do with it, it is just one thing out of many.

In fact, most of what I do in my life has nothing to do with autism at all. And many of my friends on the spectrum forget this because all they do is concentrate on their disability and how "different" they are from other people and forget that they are human first with much to offer and that life is to be lived and not bitched and moaned about.

Let me tell you about what has been going on in my life in the last six weeks.

1. When I was in Topeka visiting my good friend, Barbara Moran, we did many things. We did things like visit the gorgeous gothic hunk, Gracie and we went to the Orthodox museum together and she was patient with me as I talked to the cashier. Also one day when I was there it was 105 F. with a heat index of 118. That is when I realized that I acclimated to the semi-desert conditions of Denver. And since Topeka is the capital of KS, we saw the capitol building and I thought that CO was better.

2. I am involved at my church and one of the activities is the Sisterhood Presidency to which the women of the parish elected me at the beginning of this year. As Sisterhood President, one of the things I did until July was go to the monthly neighborhood meetings. I went to these meetings so the people of Baker neighborhood could get familiar with St. Augustine's church. And in late June, I even volunteered for the neighborhood garage sale and handed out flyers to people who passed by and told them to stop by St. Augustine's. Also two weeks ago our Bishop visited the parish for the first time in several years. This is a major event in a church's life and I made sure that the church was neat and clean. I also made certain that the parish's families knew what they would bring for the potluck brunch after the service. And doing this was an interesting challenge because the Bishop eats according to the church's guidelines (because he is a monk and monks

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don't eat meat) and at the same time providing a variety of foods for everybody. The Bishop's visit was quite successful and everyone at the church benefited from his sermon and visit and enjoyed the meal and fellowship afterwards.

On a sadder note, the church secretary, Alice "Monica" Howard died in mid-July after successful major surgery. Alice helped me a lot with the duties of the Sisterhood and our conversations covered a variety of topics. When I was in Topeka, I was very homesick and didn't know why, nor did I know that Alice had died during my time there. I called her home several times and left a message thinking that she was too sick or too weak to answer the phone. When I came back to Denver, I learned about Alice's death, which explained my homesickness and why the phone wasn't answered. Needless to say, this affected me and I am still grieving. Since that time Alice's daughter, AngelaRose "Anthousa" and I have begun a friendship. AngelaRose is following her mother's footsteps in helping me with the duties of being Sisterhood President. Alice's death has facilitated the quick development of our friendship, particularly as we realize how much we have in common and therefore are able to support and encourage each other. This has been evident in coping with the sadness of hearing about the recent death of our priest's Dad, who died in Atlanta. Fr. Michael was there for the last couple of weeks of his Dad's life. AngelaRose and I have been there for each other.

3. I have a new kitten, Quiero, and as a cat owner I feel that it is my responsibility to make sure it goes to the vet. Queiro has been to the vet three times to get shots and to make sure he is in top condition. For a time before I left for KC and Topeka, I was worried that Quiero had a feline form of AIDS and the vet suggested that it get blood work done to really make sure. That test cost over \$130 and I had to wait a week to find out the results. Thank God the results came back saying that Queiro is just a healthy kitten with no feline AIDS. My other cat, Vivir, has asthma and gets a shot every six to eight weeks.

4. On Labor Day, I will be going with three or four friends of mine to Broomfield to go to the mall. I have never been to Broomfield before and it will nice to spend Labor Day among friends.

I live a full life and appreciate every minute of

it. I am too busy doing things to moan and groan about what I don't have or the opportunities that I am missing simply because I am active. I just wish that more of my friends on the spectrum realize that life is to be lived.

New Disability Policy Website

A new disability policy website went online on September 1, 2003 containing training materials, policy papers and policy briefs prepared by ROBERT "BOBBY" SILVERSTEIN. Bobby is the Director of the Center for the Study and Advancement of Disability Policy (CSADP) in Washington, D.C. and former staff director and chief counsel to the U.S. Senate Subcommittee on Disability Policy, chaired by Senator Tom Harkin. The address for the website is: <http://www.disabilitypolicycenter.org>.

The website is organized by relevant topic areas. The following topics are included:

- . Advocacy Training Materials
- . Americans with Disabilities Act (ADA).
- . Disability Policy, In General
- . Individuals with Disabilities Education Act (IDEA)
- . Olmstead Supreme Court Case
- . Personal Assistance Services (PAS)
- . Rehabilitation Act (See Vocational Rehabilitation)
- . State Medicaid Buy-In Programs and State Work Incentive Initiatives (See also Ticket to Work and Work Incentives Improvement Act)
- . Temporary Assistance for Needy Families (TANF)
- . Ticket to Work and Work Incentives Improvement Act (TWWIIA)
- . Vocational Rehabilitation
- . Workforce Investment Act (WIA)

In addition, the website includes hot links to other disability policy-related websites.

Bobby can be reached by email at: Bobby@CSADP.org. Melanie, Bobby's assistant, may be reached at: Melanie@CSADP.org.



AUTCOM'S 2003 DISTINGUISHED DISSERVICE AWARD: COSAC TRIBUTE

Where would people with autism be without advocacy organizations? In New Jersey, the answer is: a lot further toward enjoying their human rights and civil rights.

The organization that works hard to maintain that state of affairs is COSAC (Center for Outreach and Services for the Autism Community), the highly deserving winner of this year's Distinguished Disservice Award. Looking to the future while preserving the past, COSAC lobbies for and participates in a generous level of state funding aimed at eradicating autism through genetic intervention while simultaneously honoring and preserving many autism "treatments" with a rich and colorful past, such as restraints and aversives, which have already been lost in other states. At COSAC the high-tech brave new world of genetic engineering and biochemistry co-exists with time-honored traditions such as 4-point restraints, basket-holds, ammonia inhalants, water squirts in the face, slaps, and hair-pulls -- all of the latter chronicled in a promotional book by COSAC's 2003 "Distinguished Service Award" winner David Holmes, whose Eden Services is a top COSAC donor.

It took courage for COSAC to stand up at the New Jersey legislative hearings of January 2003, before the families of children who had died, been injured, or been traumatized by restraints, and declare that restraints and other aversives are "an effective means of behavioral treatment." It took grit and determination for its Government Affairs Director to lobby vigorously against the passage of "Matthew's

Law" limiting the use of restraints, named for a child with autism who died in a New Jersey placement proximal to 16 months of restraint. But COSAC also showed its softer side -- a sense of humor -- in naming the Assembly member responsible for stalling this bill its "Legislator of the Year."

COSAC's long-promised and awaited "white paper" on restraints and aversives was delivered to an eager public on May 20, 2003. Dubbing these practices with the kinder, gentler name of "restrictive procedures," COSAC unveils a recommendation that is stunning in its simplicity: always include the "restrictive component within the behavior support plan." Indeed, it makes you wonder why no one ever thought of this before, and why COSAC is thinking of it now, and what century we are in. This type of careful historical preservation is what keeps the past alive in the present, and keeps providers' financial presents alive for COSAC.

For our 2003 Distinguished Disservice Award winner, let's hear a drum roll -- or at least the sound of one hand slapping -- for New Jersey's COSAC!

ASK ROB



Some people with high functioning autism have said that Facilitated Communication is not real. How do you respond to that?

I THINK SOMETHING IS WRONG WHEN PEOPLE WHO ARE HIGH FUNCTIONING AUTISM ARE BEING USED AS PAWNS TO USE THEIR VOICES TO DISCREDIT FC. I USE FC AND IT SERVES AS MY WAY OF COMMUNICATION.

AS TO THE USE OF PICTURE SYSTEMS AT MCDONALDS, I HAVE BEEN SO BRAINWASHED WITH THOSE PICTURE CARDS, THAT MY AUTOMATIC RESPONSE IS TO REPEAT THE SAME PHRASES EACH TIME.

IT IS HARD TO DO FC BECAUSE GROUP HOMES, DAY PROGRAMS DON'T ALLOW IT IN MANY CASES. HOW CAN ITS VALIDITY BE DETERMINED UNLESS FULLY IMPLEMENTED? SOME THINK ABA IS REAL, I THINK ITS PUPPETEERING, YES

Living Good Lives: A Community Endeavor

By Alan Kurtz

Positive approaches are about behavior changes through personal growth and mutual responsiveness. This work starts with each person and each group, and as experiences widen and deepen some principles emerge, but they emerge from the lives of the people involved, and are not imported mechanically. Nonaversive technologies are about control and behavior change; positive approaches are about cooperation and personal growth - Herb Lovett

Herb Lovett believed that positive behavior change resulted from interaction among a dedicated and mutually responsive group of people. In his conception of positive approaches everyone grew. For Herb, the behavior of the individual was genuinely inseparable from the social context in which it occurred. When positive growth occurred, it occurred for all participants.

We can think of “living good lives” in a similar way. All those things we think of as being essential to a good life – the satisfaction of physical needs, choice and control, happiness, recognition, and friendship - are defined by and develop within a social context. Living a good life in isolation is inconceivable and the realization of this goal is necessarily a social process.

Living a good life, like positive approaches, is also an ongoing dynamic process. It is a historical process in which individuals continually interact to create and recreate the conditions that we can all agree are “good.”

Over the years my friend Jay¹ has taught me many lessons about both positive approaches and the essentials for living a good life - lessons entirely consistent with the above quote from Herb Lovett. Jay was once notorious for behavior that others found challenging. But over the course of several years this changed dramatically. The positive life changes that Jay experienced did not result from our regrettable attempts at simply controlling his behavior. In fact those approaches failed miserably for everyone. Instead Jay grew as those around him learned to be more responsive and open to mutual change and adaptation. This involved far more than just compromising or “picking one’s battles;” Jay

and those who supported him continually redefined both the content and context of their relationships. From these relationships emerged new ways of communicating that worked for everyone.

While we tried to assist Jay to participate more in his community we gave up on any attempts to make him appear “normal.” There were certainly behaviors that made his participation in the broader community problematic at times. Instead of trying to stop the behavior directly, however, we worked to help Jay feel safer in his community. Often this meant ignoring or even participating in some of the idiosyncratic rituals that made him stand out.

Over time new rituals emerged that helped him navigate his way through a threatening world. They were not Jay’s rituals though; they were shared rituals that emerged from Jay’s ongoing interaction with people who remained open and responsive. An intricate non-verbal dialogue – a dance in which no one took the lead – developed. These rituals were not planned or programmed but truly unfolded spontaneously.

For example, one of the simpler rituals Jay and I developed involved him touching something metal and extending his arm in my direction. I would walk over, touch his outstretched hand and we would move on. When Jay was anxious he learned to touch my shoulder. I responded by touching his hand and saying “thank you.” Jay then touched my elbow and exhaled deeply - a sign that his anxiety had been abated. On walks, when Jay needed to take detours around trees, we stopped trying to correct his behavior. Instead we often joined him in his circuitous divergence from the straight and narrow. I cannot tell you exactly how any of these rituals developed. I do know that we never consciously decided to implement them as part of a plan to “help” Jay. These patterns of action arose spontaneously from our mutual ongoing desire for more relationship/interaction/mutuality. And they worked.

Most of us have seen these kinds of shared rituals among parents and their children with autism. Sometimes these shared rituals can be very complex and always are unique to the individuals involved. April and her family stand out for me in this regard. April is an adult with autism I have known for more than ten years. Over those years I have been fortunate to observe the wonderful ways in which she and her parents interact. These include intricate and complex nightly bedtime rituals, rituals to help her get through

each day and rituals that help April deal with her anxiety in large crowds. As with Jay, April's rituals were not the result of a plan. Nor were they imposed, one person upon another. They were unique ways of interacting that emerged from the unique history of the participants and by April's family remaining open to her needs and ongoing communication.

You see this with some professional support staff as well. Those who really stand out - the ones with the most positive relationships with the people they support - are those who creatively collaborate with individuals with autism. They work together with the person with autism to continually create new ways of being together.

Developmental psychologist Alan Fogel regards this spontaneous creativity as crucial to human growth and development. Novel ways of interacting emerge that are unplanned and impossible to predict. Creativity, according to Fogel "*is characterized by a stance of openness to the partner, a willingness to allow events to unfold and to be shaped by the process*" (Fogel, 1993, p. 31). (Italics added)

In Fogel's dynamic systems-based model, partners *co-regulate* communication. "Co-regulated communication is created as it happens, its process and outcome is partially unpredictable" (Fogel, 1993, p. 19). For Fogel behavior is literally created anew each time partners participate in this co-regulatory communication. Significantly, co-regulated behavior cannot be entirely predicted and controlled. Nor can it be constructed in advance and imposed by one participant on another. It is a genuine "dance of relationships," to draw on a phrase that has been used frequently in these pages.

As people interact with one another their actions join together to "achieve a unique and mutually created set of social actions" (Fogel, 1993). This is exactly what we see in the positive relationships among people with autism and their friends and family. New, previously unimagined complex social actions unfold. Growth for individuals with autism, as with everyone else, occurs as a process that is fundamentally *social, creative, emergent and unpredictable*.

The same can be said for living good lives. Good lives do not come in packaged programs delivered mechanically without regard to the individual's needs and without the active and ongoing participation of individuals with autism. Good lives emerge through "personal growth and mutual responsiveness" -

from relationships in which all participants are open to mutual change. They are indeed a community endeavor.

When I ran into Jay's former state case manager a number of years ago, he was genuinely delighted to hear how Jay was doing. He said: "I guess your strategy of just letting him do what ever he wants worked after all." I was too taken aback to be able to respond immediately but I thought about his misconceptions for a long time.

I believe this caseworker seriously missed the point because he was stuck in a worldview that saw behavior as residing in the individual and not as a co-regulated, emergent social phenomenon. From his perspective behavior change took place when one person conditioned or controlled the behavior of another. He failed to see that all behavior takes its form within the creative and unfolding context of a person's interaction with others. He failed to understand that growth can emerge creatively, unmapped, unplanned, unprogrammed, and unpredictably from the interaction among participants who are open and responsive to one another. Most of all, he failed to understand that Jay's growth reflected the quality of his relationships and the hard work of many people who made those relationships successful.

This caseworker's worldview is all too typical and shared by many professionals. Changing the individual becomes the focus of intervention rather than changing relationships. As a result general approaches to intervention in autism seek to improve people's lives by either:

- Changing the individual (behaviorally or medically); or by
- Constructing separate environments (special classrooms, segregated congregate residential facilities and special activities) where messy and unpredictable interpersonal relationships can be controlled.

The first general approach sees people as broken and as needing to be fixed. Increased normality is often viewed as a precondition for full participation in the broader social life of our communities. The second approach simply attempts to segregate those with significant differences from neurotypicals - or at least to significantly limit their interaction. Both approaches exclude individuals with autism from participation in mutual co-regulated growth. Both underestimate the capacity of both individuals and

communities to co-evolve.

It can be difficult for families and friends to buck these trends. When families focus on responsiveness through mutual adaptation instead of enforcing normality they are often criticized for “giving in,” “coddling,” “reinforcing negative behaviors.” “Empowerment” ideologues (like AUTCOM) are criticized for sometimes giving people with disabilities “unbridled license to do whatever they want” (Wolfensberger, 2002).

Participating in that co-evolution is often seen as a loss for one party because empowerment is treated as a zero sum game. Individual empowerment, presumably, must necessarily come at the expense of someone else. Wolfensberger (2002) goes so far as to suggest that empowerment and interdependence are “deeply inimical.”

We need to think of empowerment differently – not as something that resides in an individual but as something that is socially constructed and practiced. It does not mean that one person’s gain in power comes at the expense of someone else. The change in Jay’s quality of life did not come at the expense of others. As Jay and his friends adapted to each other, everyone moved closer to the elusive goal of living a good life. The changes that we made, like the shared rituals discussed earlier, were arrived at mutually.

This kind of mutual co-regulated growth is happening in many places with many people. Individuals with autism and their allies are working together – continually adapting to each other – to create new ways of interacting that make everyone’s life better. In the process many professionals are discovering the extent to which they had previously been dehumanized in their attempts to normalize, and enslaved by their efforts to control.

An understanding of human development as a co-regulated process forces us to revise our views of freedom, empowerment and self-determination. Often we think of freedom as *freedom from* as opposed to *freedom to*. We believe that people with autism deserve lives *free from* coercion, control, incarceration in institutions, and abuse. All of these are important worthy goals, which AUTCOM strives to promote. *Freedom to* goes one step further. It involves creating new conditions for mutual growth and self-actualization and is necessarily a social process. This new perspective allows us to move beyond providing individuals with autism choices among existing alternatives. Instead we can work together to

continually recreate the social reality in which choices are made. Freedom, thus defined, thrives in situations in which individuals are open to new unfolding patterns of interaction that *emerge from the lives of the people involved*.

People who live good lives create those lives cooperatively and in association with others. This is as true for individuals with autism as anyone else. Good lives, for individuals with autism, unfold as they and their community allies work and grow together. In the process everyone becomes empowered and everyone lives more satisfying lives.

References

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- Wolfensberger, W. (2002). Social role valorization and, or versus, “empowerment.” *Mental Retardation*, 40, 252-258.

(Footnotes)

- ¹ I write about Jay because I know his situation most intimately. There are many other stories, however, about persons with autism who have made similar journeys together with cooperating friends, family members and professionals.



CHECK OUT THIS SITE:

<http://isnt.autistics.org/>

THE INSTITUTE FOR THE STUDY OF THE NEUROLOGICALLY TYPICAL

At the site you can:

- learn what NT is;
- discover how surprisingly common it is;
- find links to important papers and abstracts concerning NT;
- learn about new research including new studies on anti-swarming drugs;
- What you can do if you think your child might have this devastating and incurable disorder;
- Take a screening test to see if you have NT.

Don't Sell Us Short Because We are Older

By Tom Page an Adult with Autism

I'm forty-six years old, but it is like being born again to get new opportunities. Some people think, all most of us this age want, are food and shelter. It is important, and I am grateful for them, but many of us want to grow. We can benefit from the new ideas and treatments that have been developed. Here is a little of my story.

What seems obvious may not always be true. When working with non-verbal people, judgments are made without consulting them. Staff and professionals have different ways of making judgments. Many times they are right, but if they are wrong it can lead to many years of frustration and agony. If it is a certain item on which many functions depend, it makes it much worse. When I learned to FC about 10 years ago, I was able to give professionals and staff feedback on many things. It changed my life.

During most of my life I have had trouble looking at people and making eye contact. They thought I didn't care about them or wasn't interested. If I didn't learn or understand things as most people would, they wouldn't stick with me until I could understand how to do them. They thought I didn't want to. They assumed that since I was able to operate in this world and do some of the needed things, that my peripheral vision was pretty well developed but I had little incentive. If they only knew how hard we, persons with autism, work to overcome our deficiencies by special adaptations, they would think differently. Since we had visited a couple of eye doctors, my parents knew that I had some focusing problems, but had no idea how severe my problems were.

One day, after I had learned to communicate through FC with my Mother, she asked me if I wanted to try auditory training. My answer was, "Fix my eyes first." It was a statement out of the blue, because I thought my eyes were just like others, but they weren't. I always wondered how people could do some of the things they did. I never experienced the ability to see accurately and hold a focus. I could get around pretty well when I relaxed and had no pressing need to focus in on things. It is not a good way to operate in this world. Most of the important things require that need for focusing.

My parents investigated for an eye specialist, and my O.T. knew of Dr. Padula, a specialist in Neuro-

Optometric Rehabilitation, that had a good reputation. My first meeting with Dr. Padula was a whole new experience. He was polite to my parents, but his attention was on me. He never assumed what my parents said was true. He is a genius in observation, and a person who can ask questions without being intimidating. You feel like you are talking to a person who cares, but most of all understands your feelings. It is a big step toward the necessary feedback a doctor or therapist needs. I had hoped he could wave a magic wand and cure me, but it is not that easy. We spent many hours tracing my eye problems and they have improved a great deal but have a long way to go. I have asked him to explain my problem of focusing. If I focus in on an object, it breaks up. Keep in mind that this is my problem and may not be yours or others. I use this to illustrate the need for some kind of feed back from the client. The doctor or therapist needs all the help they can get. I had other problems that went on unchecked because they weren't obvious. It is always important to check your findings often, because we are not always stable in our symptoms. Now for Dr. Padula's explanations of my focusing problems. He and four other professionals, that work with me, have written explanations in my new book, *Caught Between Two Worlds*, as to my other problems. This is Dr. Padula's explanation of this one.

THOMAS PAGE: THE CHALLENGE OF FOCUS

By William V. Padula, O.D.

When Tom first came to see me for a neuro-optometric rehabilitation examination, I remember that he was somewhat nervous and had difficulty sustaining his visual performance. He never developed eye contact or looked at anything for any length of time. I recognized, however, that he was using his peripheral vision instead of his central vision to isolate things he tried to look at.

The evaluation determined that Tom had a very difficult time creating focalization through the central part of his eyes. Instead, he had developed a technique of attending to what he looked at through the peripheral part of his eyes. This is not uncommon for persons of an autistic nature.

For Tom, when he attempted to look at things directly through the central part of his eyes, he experienced an over-focalization and what he looked at began to fragment or break apart. For Tom, as well as many other autistic persons, when they look at something directly, the object or person begins to

break apart into pieces creating a mosaic composed of lines, shapes, shadows, and colors that become isolated parts rather than being organized together. To explain this further, it is as if when looking at a person's face, instead of seeing a face, they see an eye, nose, lip, ear, etc. in pieces and parts and lose the ability to relate as a whole. Frequently, a person will see these pieces and parts move. This can be quite disturbing to the individual.

Tom's inability to focus was actually due to over-focalization. This means that he worked so hard at looking at details that he literally broke up the spatial relationships and saw what he was looking at as being in many small pieces or components. Through neuro-optometric rehabilitation, lenses, prisms, binasal occlusion, and other forms of treatment have been used in an attempt to stabilize his use of the spatial part of his visual system to keep his world more whole.

Over time, Tom has improved the organization of his vision, thereby enabling him to develop eye contact and improved fixation on the communication board and during daily living activities. It does not always stay perfect, but Tom now has the ability to see relationships in his visual world. This has caused a much calmer behavior as well as improved ability to achieve the goal of increased independence.

WHAT'S YOUR OPINION?

The following position statement on genetic discoveries and autism was posted on the web by Judy Badner and can be found at: <http://psy-138-006.bsd.uchicago.edu/~jbadner/autgen.htm>

Is this a statement that AUTCOM should endorse? Should AUTCOM develop its own position statement? Send your comments on this or other topics to the editor or email: alan.kurtz@umit.maine.edu

Discoveries in Autism

The autistic community and society in general have become increasingly aware of eugenics movements (efforts to improve human qualities by selection of certain traits) in medical history in the U.S. and abroad and the traditional desire of parents to create perfect, healthy children. Along with other persons affected by genetic disabilities, we are not only concerned as to how our health needs will be met under dramatically changing health care systems, but how the use of genetic technologies will affect our quality of life, medically, as well as socially. What will be the impact of the identification of the genes causing autism, not

only on our personal lives and our needs, but on how society views us as individuals?

Thus far, several genome scans for autism have been performed and there is increasing evidence for a gene contributing to the development of autism on the long arm of chromosome 7. Evidence for the localization of other genes contributing to the development of autism also exists. At this time, it is not known what these genes are or what function they have but given the pace of genetic research, these things may be known within a few years. It is unlikely that a gene will be found that can predict whether or not someone will be autistic in the same way an extra chromosome 21 predicts someone will have Down Syndrome. However, it may be possible to determine if someone has an increased likelihood of being autistic based on their genetic profile.

The history of genetic technologies and Down Syndrome is instructive. Despite the improving quality of life of people with Down Syndrome due to improvements in education, deinstitutionalization, improved treatment of the medical complications of Down Syndrome, there is an increasing push to diagnose and terminate pregnancies with Down Syndrome fetuses. This push appears to be related more to improvements in technologies to prenatally detect Down Syndrome (amniocentesis, chorionic villus biopsy, the "triple-screen") rather than the changes in the quality of life of people with Down Syndrome. When success is measured by the reduction in the number of people with Down Syndrome that are born, then it is clear that it is not the interests of the disabled individuals that are being considered. This should not be occurring for Down Syndrome and it should not occur for autism.

The common thread throughout the discussions of genetic disabilities is that we as disabled individuals are important members of society who must inform the world that, though we face challenges, most of them are related to the physical environment and societal attitudes about our disability and not due to the inherent qualities of our disabilities. We value the opportunity to contribute a unique perspective to the diversity of our society.

We have been educating society and the medical community about the truths of life with autism and working to dispel commonly held myths. With the impending discovery of various genes contributing to the development of autism, our educational and advocacy efforts have become ever more important, in the face of a rapidly changing genetic frontier.

Many thanks to the authors of this position paper.

Autism National Committee



Position on Restraints

The Autism National Committee condemns the widespread and excessive use of mechanical and physical restraints in restricting the civil and human rights of people with disabilities. We believe that the use of restraints is a failure in treatment.

People who have survived forceful restraint have reported they feared they would die in restraint, and some have died. A number of tragic cases of restraint-related deaths of children and adults have recently made the national news. Estimates of deaths occurring during or shortly after restraint currently range from 50 to 150 annually. The actual magnitude of such deaths is poorly tracked and subject to under reporting, a fact recently stated by a federal Department of Health and Human Services spokesperson.

Many have reported that they now live with fear and flashbacks that involve a sudden, involuntary re-living of this emotional and physically traumatic experience. Post-traumatic stress disorder is increasingly being diagnosed among persons who have been subjected to the systematic use of restraints.

It is clear that individuals sometimes desperate efforts to communicate are ignored while staff force compliance for oftentimes trivial reasons; that the cumulative effects of repeated restraint can lead to diminished self-image and negative attitudes; and that when restraint is used, struggle is provoked and this natural response increases the danger of physical injury.

In our experiences as professionals, parents, and individuals with autism, we have witnessed too many times the horror and injury done to our citizens with autism. We are weary of seeing our people become victims.

Although any one of us, disabled or not, may at some point in our lives need to be restrained on an emergency basis, that should only occur when there is substantial threat of injury to self and others. Behavioral restraints are neither treatment nor education. They are merely procedures or methods that restrict freedom of choice and adversely affect the human development of people with disabilities. The use of restraints should be considered a failure in treatment. We totally condemn the use of behavioral restraints.

We call on national and state agencies to investigate the widespread mistreatment of people with disabilities through the use of restraints.

We call on Congress and state legislatures to pass legislation to protect people with disabilities; to limit the use of restraints on children and adults with disabilities to brief, emergency situations involving serious threat of injury to the person with disabilities or to others; to require immediate reporting of these incidents; to require thorough investigations of the circumstances that lead to the incident; and to require the development of supports and accommodations to prevent future incidents.

Approved 9-3-99

PRINCIPLES OF THE AUTISM NATIONAL COMMITTEE

As a member of the Autism National Committee I endorse for all people with autism, pervasive developmental disorders, and related disabilities the development of appropriate community services, including education, residences, jobs/job training programs, and of individually appropriate and adequate support services in all locations for both individuals and their family members; of state-of-the-art communication options for all individuals with unique communicative and social needs; of adequate supports to every family to assist them in maintaining their disabled family member in their home at least throughout the childhood and adolescent years; and the dissemination of available knowledge of those aspects of the disability requiring special support and understanding; the promotion of research to provide parents and professionals with greater insight into the unique needs of individuals with autism and related disabilities; and the use, development, and promotion of positive, respectful approaches for teaching every aspect of life.

Moreover, I oppose the use of institutions to separate people from their communities, and deprive them of dignity, freedom and the level of independence they can achieve in supportive community living; the use of procedures involving pain, humiliation, deprivation, and dangerous drugs as a means to alter and control individual's behavior; the increasing use of bizarre technology to control self-injurious and aggressive behavior; the widespread ignorance of the basic social and communicative needs of people with autism; and the widespread disregard for the individual's unique, basic and human needs. I object to programs which disregard the skills, preferences and basic human needs of the people they serve, and I believe that there is no longer need or any justification for using painful and abusive procedures.

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THE COMMUNICATOR is a publication of the Autism National Committee, Inc., a 501 (c)(3) charitable organization founded in 1990 to protect and advance the civil rights of people with Autism/Pervasive Developmental Disorder and related disorders of communication and behavior. Contributions of articles, information, letters and notices are welcome. THE COMMUNICATOR does not carry advertising or fundraising announcements, and we reserve the right to edit all submissions. Your comments are actively sought. Write to the chair of the editorial committee Alan Kurtz, 118 Raymond Road, Palmyra, Maine 04965. THE COMMUNICATOR may be copied in its entirety or individual articles reprinted without permission except where otherwise noted.

Please credit the Autism National Committee

THE AUTISM NATIONAL COMMITTEE
P.O. Box 6175
North Plymouth, MA 02362-6175

(Information and Referral - Roz Forsyth at above address)

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Jeffrey Strully, Treasurer
35657 Anthony Road
Aqua Dulce, California 91390