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THE COMMUNICATOR

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Quality of Life

by Gail Gillingham Wylie

This spring our Board of Directors had the opportunity to read an article on **Quality of Life** by Katie Snow which was published in the March, 2007, issue of the **Disability is Natural Free Press** (<http://www.disabilityisnatural.com/email/2007-03.htm>). Katie begins her article discussing the reality for those with disabilities who experience a lifetime of treatments, interventions, and services which are claimed to be devoted to improving a person's quality of life. She then moves on to a very important question — **exactly who defines quality of life, and is there a definition embraced by all?** This led us to a decision to ask members of AutCom what quality of life means to each of us. This issue of the newsletter illustrates the variety of responses to that question, highlighting how personal the concept of **quality of life** is.

Personally I have come to the realization that true quality of life for me is not defined by money, a house and car or by the amount of stuff I have accumulated. Instead, I focus on the interactions that I have with family and friends and with this incredible world that we share. My focus is illustrated by this picture of my granddaughter Ebony and I, high on a mountain overlooking the town of Jasper, Alberta. I hope that this newsletter will give you the impetus to stop and think about the meaning of quality of life for you and for others. Only then can we effectively advocate for those we care about.



Gail and her granddaughter, Ebony

Quote from Kathie Snow's Article

"Consider this other lesson about quality of life: on your deathbed, as you're reviewing your life for the last time, will you think, "I'm so glad I learned how to walk [or talk or read at grade level or perform any other functional skill]?" Or will you be thinking, "I'm so grateful for my wonderful family and friends and all the great times we spent together..." These thoughts — about **relationships and experiences** — reflect the measuring stick of **real** quality of life!"

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MY QUALITY OF LIFE: THE VIEW AT 50

by Anne Carpenter

When one thinks of "Quality of Life," there is much to think about and to take into account—the work one does, living arrangements, amount of money being made, and, most important of all, relationships with family, friends, spouse, and coworkers. This broad concept is especially important when it comes to people with disabilities, because it is automatically assumed that if one can't do something physically, such as see, hear or control body movements, as in the case with people with autism or cerebral palsy, then one can't live a full and happy life. Often, the opposite is true. When one is handed everything on a silver platter, there is nothing to strive for, nothing to be accomplished, so boredom and dissatisfaction set in. People need challenge and a sense of accomplishment. One can live a life working only part-time and not earning much money, yet be supremely happy, as I am, because of the loving relationships with one's family and friends and because of the challenging, rewarding work involved in my job at the Autism Society of Michigan. I have also discovered that as I get older, life gets better. Now that I have turned 50, I am feeling happier and more positive than ever. I feel better able to meet difficult challenges because of all of the difficulties that I faced in 2006, that best year I ever hated. I now feel as though I can do anything and solve almost any problem coming my way. This is an important part of "quality of life,"— being able to meet challenges head-on, in a calm, positive way.

Because I am so much happier and less anxious, everything seems beautiful and wonderful to me—the sun is brighter, the clouds in the sky are beautiful, movies and TV and what I read are interesting. Being present in the Moment is an important aspect of a good life and makes it possible to nip problems in the bud before they grow into bigger problems. Adding to a wonderful quality of life is seeing the uniqueness of each day—every day is one-of-a-kind, just like snowflakes. Each day has a

particular "flavor." For example, today, Sunday, April 15th of 2007, I found a lovely, multicolored skirt on sale for ten dollars, and I enjoyed walking home from Friends Meeting in the sunshine, even though it was on the chilly side. I was feeling better, after a touch of flu, so I felt happy though somewhat tired, so that was the "flavor" of my day. This makes life so much more interesting. Another thing that really enhances my quality of life is knowing how complex, and therefore fascinating, life is. I watch the news with fascination, despite all of the awful stuff going on, because I know that among the terrible things going on there is a lot of delight, possibility and wonder. I mix all of this interest and wonder at life with having dinner with my mother every Wednesday, involvement with my work with the Autism Society of Michigan, working on my book, reading, going to movies, travel, and visits from my two stellar sisters twice a year, in November for Thanksgiving and in the summer. This, along with my ordinary day-to-day life, is all blended into a wonderful stew. This is my Quality of Life.

WHAT QUALITY OF LIFE MEANS TO ME

by Kathy Grant

What makes my life worth living and fulfilling to me are many. I will list them and give a brief explanation of why each helps me:

1. **Money.** Like it or not, money helps. I am fortunate that I get SSDI and work part-time, and occasionally my family, who has been blessed with wealth, helps me out. Without money, I could not pay my bills, buy groceries and do stuff such as travel. Money makes the world go around, and I know it helps me in my life. Without money, my life would not be as good as it is.
2. **Church.** I am Greek Orthodox. Without God and the Church, I would not be doing as well as I am. My faith gives my life purpose, and God sustains me through the good, the bad, and the indifferent. It is because of God that I am doing as well as I am. He has blessed me beyond measure, and I hope that I am doing things in my life that are pleasing to Him. It is important that I go to church on Sunday, and it is vital for my mental health that I go to the occasional weekday service. It is Christ who sustains me physically, emotionally, psychologically, and in every way. It is God Who has led me to help people on the autism spectrum. God, in His wisdom, told me that I am to help my people. Also, if I did not believe in God, my life would have no meaning. Through church I have gained friends, community, purpose, understanding, and peace of mind.
3. **Job.** I have been at the same job for the past five years. I am a respite provider for a family that has a daughter on the autism spectrum. Everyone in the family is talented and wonderful, including the daughter who is smart and uses FC. I, by nature, need to work, and my job has given me not only income but purpose. So many autistic people are not working and society is poorer because of it. Everyone has something to give, even the most affected person. The person I do



Kathy Grant

respice for has many gifts and talents and will make her mark in the world. Actually, at the age of 20, she already has and will continue to do so. To see this wonderful her family, go to <http://spectrumhouseart.com/>

4. **Travel.** I love to travel. Every year I have traveled somewhere or been to a conference meeting people and sharing information. Traveling has given me skills like planning ahead to arrange flights and/or the greyhound bus. Because I went to Australia four years ago, I know what it is like to show my passport and to wait in the customs line. I know what it is like to catch another flight and how long it takes to travel over the Pacific Ocean. And I know, at least in an English-speaking country, how to find my way around. I used many forms of mass transit in Melbourne, had lunch with friends, and stayed with a good friend for a week. I also experienced staying in a hostel and exploring the sights and sounds of a city 10,000 miles away. I have been to many

(Continued on next page)

(What Quality of Life Means to Me continued)

autism conferences and learned much and met many wonderful people. This year I will be going to Edmonton with my good friend Barbara Moran, and that will be a learning experience on its own. I have had a great education just by the fact that I travel.

5. Friends. I am fortunate that I have friends. Many people on the autism spectrum have few or no friends. I have friends not only in Denver but in other places, too. My friends have helped me in many ways. When I was in college, my friends did not judge me and accepted me as the person I was at that time, no questions asked. And it is true today. God has blessed me with reuniting with a friend from junior high who now lives in Bowling Green, MO. We haven't seen each other in over 20 years. She emailed me, and I was ecstatic and emailed her quickly back. Within a few days, we talked on the phone. My musical tastes came from my friends and the music they listened to. I can talk

about things I like with my friends. Just last night after Liturgy, we talked about Battlestar Galactica and our ideas on what is really happening. And I can say things to my friends that I'd be reluctant to share with anyone else, especially family. I have friends who I take out to dinner every year on their birthday, a tradition that we have been doing for over four years. They enjoy it, and so do I.

6. The professional help that I have had and am still receiving. Right now I have an advocate who, for the last eight years, has helped me in many ways. She helped me to get on SSDI, she helps with my bills and with understanding and dealing with bureaucracy, and we discuss things. This is the person who is a liaison between my family and me, and she helps me to understand the non-autistic world and their customs. Our relationship is of equals. I help her with things and help her understand the autistic world and culture.

Letters and Words Make a Life, Not McDonalds Hamburgers and Fries

by Larry Bissonette

Older assistants of people with disabilities went down a path of totally institutionalized, withdrawn from society, especially paltry in stimulation of language about real feelings and thought, work with autistic individuals.

I lived in an institution, opened in newly-farmed lands of Vermont, and knew amounts of information about the working of society through TV and magazines, but earlier in my life it never occurred to me that that reality was something that was conceivable for me to experience until I had a way to communicate about what life I wanted for myself.

People are most able to speak of all their talents and artistic performances best when speech is augmented with methods like FC and technology, taking words and symbols and linking them up with digitized, actor-like voices.

Rappers talk about problems and worthlessness of existence in the ghetto. People



Larry Bissonette

without a way to communicate live pitifully spare lives that put them in a ghetto of limited expression of emotions and ideas. Teaching letters early in life to light potential for practical and artistic expression or lastwording

openings in conversation to rather empty of activities that stimulate creativity people with speech limitations is absolutely critical.

Looking at ordering quality of life to happen isn't worthwhile unless your person's communication needs are let out of the cage of learned patterns of silence and provided with competently but sensitively positioned supports

that look to skate over rote communication and pursue dormant thoughts and ideas in a person with learning and technology.

That only people like me can put out this issue on a computer isn't promising enough. Let's get this out to the mass media and reality, tasteless but popular, TV.

My S.A.F.E. Dream

by Janice Heath

I have been trying to get people to understand what I've been living with for 57 years. They seem to understand, but nothing ever changes. I still cry my way through the grocery store because of the loud music blasting out of the ceiling and the way too loud motor in the meat cooler. I finally came up with a way to go into the bathroom at the bank. The exhaust fan in there is super loud. I take a flash light into the bathroom so I don't have to turn on the light that also turns on the fan. There are so many other things "out there" that are turning me into a shut-in. I totally dread going anywhere, because it's just too noisy!

I read about Autism Community Farms. I really love animals and gardening (if the neighbors don't get too noisy), so when I found out about these autism farms, I thought it would be good to build one here in North Florida, near Gainesville. I'm trying to get support for the project, both people and money. The way I see it, "birds of a feather flock together." There are villages and communities for retired people, the Amish people have their own community, other groups of "like people" group together in their own villages, so why not autism spectrum persons?

It wouldn't be like a "prison" where the people wouldn't be able to come and go as they pleased. There would be complete freedom while living together with people who understand each other. In other words -- KEEP IT QUIET!! Animals also need a quiet, predictable environment. I made up this acronym: S.A.F.E. = Secure Autism/Asperger/animal Friendly Environment.

The way I see it, there are 2 choices: 1. Drastically change ALL of public society, or 2. Build Autism Community Farms. The farms are totally self supporting, growing all their own food, selling surplus baby livestock, selling art and craft projects, etc. And I even figured out a way to involve Aspies and others who prefer not to live on the farm—a food co-op to which they could donate 10% of their earned money from their job in exchange for food grown on the farm.

I receive disability income because I could not keep a job. It always got too noisy for me to stay at my work station, so I was fired from over one hundred jobs and quit three. I need to live away from noisy people and noisy neighbors, so I believe that an Autism Community Farm might be a good alternative for other autistic people, as well as for me.

S. A. F. E., after all, stands for Secure Autism Friendly Environment, so, if it's Autism-friendly, there's NO stimulation. Calm, Quiet, Gentle, Peaceful = Autism-friendly. You understand "Handle With Care," as in fine china dishes. You would not take a fine china dish out in the street and play Frisbee with it, then get mad or disgusted or freaked-out when it hits the pavement and shatters all over the road. So why do people get mad or disgusted or freak-out or whatever is going through their heads when they "shatter" me by overstimulating me? Keep the "fine china dishes"—the gentle, vulnerable people with autism—in a S. A. F. E. place, like an Autism Farm.

Building a Quality of Life

A Tribute to the Memory of Herb Lovett

by Jenn Seybert

This is the path I follow in my real life and when presenting: I encourage Day Hab staff to always presume competence and get these individuals out of the four wall rooms and into the community so they are seen and not forgotten. Help them discover self-worth.

These individuals have untapped abilities. Scrap the Walmart and mall walking...the sensory stuff is sometimes too overwhelming.

Through well-trained job coaches, our folks can get into nurseries to water plants and help in other areas there. They can shovel walks for elderly or rake leaves; work in a laundry/dry cleaners; belong to flower club groups who design, plant and care for the gardens in the town and parks. Reach out to the Head Start in your area by giving candy canes at Christmas and other small treats on holidays. Go to a nursing home and visit those who don't receive visitors often.

Those more challenged can partake in collecting canned goods for food banks, while newspaper drives offer opportunities to shred them for farmers or an animal shelter. A collection of used eyeglasses can be sent to the Lions Club and used cell phones can be sent to our military.

This can all be documented with the local TV station and newspaper.

There is so much to think about and avenues to explore, so these folks are not in Herb's aptly named "day-wasting programs."

I believe we can push this farther along. The ideas are endless when we are not focusing on "curing autism" or looking for "validation" as to who is doing the typing! We are who we are. Let's make it work!



Remembering Herb Lovett

MEMBERSHIP FORM

Because I endorse the principles of the Autism National Committee, I would like to (circle one):

JOIN NOW

RENEW MY MEMBERSHIP

NAME _____

ADDRESS _____

CITY, STATE, ZIP _____

PHONE _____

E-MAIL _____

I AM A (circle): Family member Person with autism Friend Professional (field _____)

Annual membership: \$30.00. Persons with autism: \$10.00. Supporting membership: \$75.00

I am enclosing an extra \$_____ to speed up the good work.

Make checks payable to Autism National Committee and mail to:

Autism National Committee

Wade Hitzing, Treasurer

1045 Wittman Drive

Fort Myers, FL, 33919

The Autism National Committee is a 501 (c) (3) charitable organization. Your contributions are tax deductible and will be promptly acknowledged for your records

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.

Autism National Committee

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Time to Renew or Join Today!

Annual membership begins in January

(Membership form on page 7)



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