

# The Safeguards Letter

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## A COLLECTION OF NOTES AND WISHES

Here was my invitation to readers of The Letter: *I'm looking ahead to the Winter or holiday-season issue. One reader suggested that I might ask all the readers for their sense of "how things are at the end of 2007" and print some of those comments in the next issue. I've taken the idea just a little bit further.*

*I'm wondering whether you would be willing to write just a paragraph or two that finishes this sentence: "As 2007 comes to a close, I'd like to say...."*

*You could let other readers know about what you're most thankful for, as 2007 comes to a close. Or, you could write a bit about what worries you most, as 2007 comes to a close. You might want to let the rest of us know about the state of services/supports for vulnerable people in the place where you live (highs and/or lows), as 2007 comes to a close. Or, perhaps you would want to offer a sample of how vulnerable people take part (or don't) in the life of your community. Maybe you would just like to let others in on what's going on with you, your family, or your friends, as 2007 comes to a close.*

*In any case, if you're willing, put a few thoughts together--just a couple of paragraphs. If you write long essays, I won't have room for them in the Letter, at least not this time. I'll try to get as many of the submissions into the Winter issue as possible; if any are left they'll show up in the spring.*

The collection that follows includes everyone's response to the invitation. I thought about trying to place the responses in some sort of sequence—for example, the order in which they were received, or the distance from which they came, or from critical to hopeful. I decided I'd be running the risk of misinterpreting someone else's thoughts or that the whole thing could turn more artificial than I want it to be. Besides, trying to organize these is just too much work.

So, here are some things that are on the minds of readers of *The Safeguards Letter*, as 2007 comes to a close.

⇒ As 2007 comes to a close, I'd like to say this must surely be the most exciting time yet to be working in this field. The evolution of our communities and the heightened awareness of people with disabilities and professionals are leading to the advent of acceptance and inclusion. We see this happening before our very eyes! A more wondrous sight I can barely imagine. I am watching come to fruition the environment I have worked, hoped and prayed for for 25 years. What is next? I am not sure, but I'm ready for the journey and will be thankful for any part I may have in it.

Melody Brauning  
Cincinnati, Ohio

⇒ As 2007 comes to a close I'd like to say that the work of the Medical Safeguards Project of Shriver Clinical Services in Massachusetts is a flash of light in a darkening arena. This little gem is a modest project employing seven nurses and one physician. They accompany people with

impairments when they go to the hospital to protect their lives and to make sure that excellent standards of care are upheld. The main work of the project is to ask pointed questions of medical providers who make negative treatment or non-treatment decisions based on the devalued status of the patient with impairments. I convene the group on a monthly basis to teach about deathmaking and to help hone advocacy skills. I am often impressed with the notion that lives are saved with a well put phrase, a plea for reflection, and/or a heartfelt statement on the truth of the inherent dignity of all human life. These men and women do what they do quietly, with grace and persistence, and having to face many failures and often insurmountable odds. But when they do win, lives are preserved, health is maintained, and those medical practitioners involved had a life changing experience that will serve to protect future patients. Not a small thing.

It is a great privilege to be a part of this effort. When I reflect on the year's work I recall many sad stories and tears shed. Still I am heartened by the sure knowledge that some will celebrate Christmas in 2007 who otherwise would not be here. I am reminded of the words of another person with impairments whom we all know, but whom we have never met : God bless us everyone!

Jo Massarelli  
Worcester, Massachusetts

⇒ I am thankful that there is only one year left of the Bush administration and that a few more people got out of institutions and nursing homes. I'm thankful for Joni Mitchell's new album "Shine" and the last of the red leaves hanging on the tree outside of my office. I'm thankful for the love of my life, Cyndi, my two boys Joe and Sam, a good dog, and caffeine. Best wishes-

David Pitonyak  
Blacksburg, Virginia

⇒ I am worried that:

1. All (OK, most) research has identified, re-identified and re-identified the same problems with little action on practical solutions. Oh, lack of transportation...how surprising!!!! Instead of making transportation a big budget item tied directly to "accomplishing program goals", let's do some more research! Oh, people want to have friends, romantic relationships, marriage....let's spend more money on researching employment; discrimination; staff-resident ratios!
2. Natural relationships have to become formalized and then formally-funded. Oh, Best Buddies, what a good idea!
3. Direct care staff STILL are greatly underpaid.
4. The cause of Down syndrome will be discovered.
5. Medicaid still will pay for pulling a person's teeth and providing false teeth, but not repairing and otherwise saving a person's teeth.
6. Lastly (at least for now) I am worried that any time a group of people get together to organize a program or service, the first major agenda item is to acquire a building. I continue to see this as the first sign of impending segregation

As 2007 comes to a close, I am happy that my 59-year old sister with Down syndrome continues to fly (direct, no transfers) from Cleveland to Boston by herself about 6 times a year to see me.

Deb Metzel

Boston, Massachusetts

⇒ We are most thankful for our son and his vibrant enjoyment of life. He continues to bring awareness to us and many others the reality that we all have an abundance of potential and interests if only given the opportunity to utilize and engage ourselves in them. Community employment, attending his local Community College, dance classes at a local dance studio, sports, caring for his animals, friendships...are some of his enjoyments. Our family and friends that value his interests and quality of life are those we keep close...connecting with others is invaluable in providing opportunities.

Julie Thompson  
Troy, Ohio

⇒ As 2007 comes to a close I'd like to say.....as a person several decades removed from daily support to and intensive interactions with people labeled as "developmentally disabled" I notice how little the general community gives thought to or spends time thinking about the lives of people so labeled. At the same time, I'm encouraged that acceptance of and inclusion of people so labeled in the course of daily life doesn't appear to be a matter of significant resistance among the general population. It appears to be much more a matter of how creative and adaptive they, and the people who support them, are in finding ways to be present as valued fellow citizens. It really seems to be a matter of creativity, thoughtfulness and persistence.

Hope that this message finds you in the presence of light at this time of darkness on the planet.  
Peace.

John Winnenberg  
Glouster, Ohio

⇒ As 2007 comes to a close I am doing what I always do.. I am trying to listen and learn from people and offer them a chance to cross the boundary of difference, invest in one another's lives and reap the benefit of being together. It's a small response to a pervasive pattern.

I am trying to strengthen the organization that supports this work without spending too much time away from the work.

My wife and I are watching our two girls, 15 and 17, grow into what look like good solid people so far. I am walking 3 mornings a week, reading some magazines, less books, drinking a few beers and cursing at the computer more than is healthy for it or me.

Tom Kohler  
Savannah, Georgia

⇒As 2007 comes to a close, I'd like to say ....that I'm ever more appreciative of the pantheon of persistently passionate people from whom we've all benefited so much over the years. I came into this field in the early 1970s, a great and exciting time when conventional thinking and practices were being challenged by new information and expectations. To name only a few of the groundbreakers: Azrin and Foxx, Wolfensberger introducing Normalization, Marc Gold with

Trying Another Way, Lou Brown saying "Pre Means Never", and Winfred Kempton advocating for socialization and sexuality education, Beth Mount doing futures planning, John and Connie O'Brien, Dave Hingsburger, David Pitonyak, John McGee ... We have been blessed with these leading lights, and with the thousands of people who carry their passions and practices into their daily work and the lives of people around the world.

Paul Tabor  
Bowdoinham, ME

⇒ As 2007 comes to a close, I'd like to do a movie review. The day after Thanksgiving I saw *Lars and the Real Girl*. When I first read about this movie, I was afraid it might be a little too pleased with its own sense of taboo-breaking, trendy and mean-spirited like a lot of independent movies can be sometimes. I was pleasantly surprised. What it turned out to be is a parable about how to support people. The plot concerns a guy named Lars who lives in a little town in the garage behind his brother and sister-in-law's house. Lars is a lonely, mysterious guy who keeps to himself, intentionally shutting himself off from the rest of the world. One day a co-worker mentions the idea of an anatomically correct, full-sized doll men buy to -- well you fill in the blank.

Lars ends up buying one of these dolls named Bianca, but instead of using Bianca as a "sex toy," he uses Bianca as the object of his most innocent affections. As soon as Bianca arrives in her big wooden crate, Lars asks his brother and sister-in-law if Bianca might stay in the house with them, because he does not want to seem too forward. Lars courts Bianca, crooning love songs to her, doting on her, asking his sister-in-law if Bianca can borrow some of her clothes.

Needless to say, Lars' brother and sister-in-law freak out. Turns out the town doctor, though, is wise, and after seeing Lars and Bianca tells Lars' family to treat Bianca as if she were a real person. To go along with it. Eventually, this spirit spreads throughout the town, and church-members, co-workers, and other folks pretend along with Lars that Bianca is real.

The way this pretending works itself out is a joyous sight to behold, so I won't reveal any other plot points. Just go see it. In a culture that tries to correct and eliminate "what's wrong" with people, *Lars and the Real Girl* is a movie about listening to what people need without judging them for what they want. And while on the surface purchasing an anatomically correct doll seems perverse and sad, the way the doctor and the rest of Lars' town react to the situation is the exact opposite of perversity and sadness: they show Lars how much he means to them by empathizing beyond telling him what to do. They give him the respect and tenderness he needed before he had to resort to buying Bianca. In other words, they use the situation as a way to reinvent the way they see and treat him. And while the movie does gloss over a lot of complications, simplifying things a little too much, it is a joyous simplicity we are witnessing, the kind that just might happen if we used our imaginations more and our sense of outrage less.

Keith Banner  
Cincinnati, Ohio

⇒ On the eve of my 30<sup>th</sup> year working in "the field," doing the things we do... I'm feeling a little bit weary and a little bit cranky. Now I'd rather say I'm feeling encouraged, energized and even enthusiastic. Part of my frustration and my problem, no doubt, is my temptation to romanticize about what I like to recall about the dedication, energy, and perseverance present 30 years ago. Of course back then, there was more to "fix." Let's face it; the problems were easier to see, and

efforts to make things better, including many that were pretty darned rough around the edges, delivered what seemed to be dramatic, life changing, hopeful results. Today of course, much of what what's troubling is more nuanced, obscured, or intentionally concealed. I've come to realize how I need to be careful NOT to discount today's good YOUNG passionate people enlisting for the cause. We'll always have good people. Nowadays they need better eyes, ears and noses. I want to do a better job of cheering them in the struggle – being encouraging, energizing and even enthusiastic.

Milton Tyree  
Louisville, KY

⇒ William (Bill) Roe is a unique individual who has an interesting story to tell. Bill attended a session in March called "The Settlement of the Martin Law Suit" at a two-day legislative event in Columbus. The 1989 law suit, formerly known as "Claude vs. Governor Richard Celeste," called for Medicaid funding to allow Ohio citizens with developmental disabilities the opportunity to leave institutions and move into the community. During a presentation by the Ohio Legal Rights Service Director, Bill raised his hand to make a comment. After being called upon, Bill said: "I just want you to know that Claude Martin was my roommate at Columbus State Institute when we were both seven years old."

Bill's comment quite dramatically changed the tone in the room and made everyone realize that Claude Martin was a "real person" among all of the waiver discussion. The next day, Bill had a pre-arranged meeting with Ohio Senator Robert Schuler where he shared his story about his childhood friend, Claude Martin. After he thanked the senator for supporting the settlement, Senator Schuler invited him and his supporters to a Senate session that afternoon. During the session, Bill was introduced on the Senate Floor to 32 Ohio Senators.

Bill has come a long way since his time at Columbus State Institution, overcoming many obstacles in life yet continuing to advocate for himself and others. He now lives at Geier Apartments in Kennedy Heights with his cat "Lady." He worked at Bob Evans Restaurant for 16 years and currently works at Goodwill Industries.

Mike Fasanella and Jenny Dexter  
Cincinnati, Ohio

⇒ As 2007 comes to a close, I've been thinking about the families of impaired children and adults I have had the privilege of meeting this year. The couple who in sadness and desperation got a legal divorce so they could be eligible for government benefits and medical insurance for their child. The father carrying his daughter down 6 flights of stairs while her mother followed behind carrying their daughter's oxygen tank, because they lived in a building without elevators. The daughter who for years has slept every night in her clothes in her mother's bedroom to be ready to get up and help her mother, who had had a stroke. The smiles and laughter shared by a mother and daughter about the daughter's day in school. Such memories inspire, sadden, fortify, and delight me.

Marc Tumeinski, Editor  
The SRV Journal

⇒ I find myself planning for an looking forward to a letting-go of some routines and interests that have occupied me for about 40 years. As some colleagues know, it's been a long time since I

could work up much enthusiasm for the business of legislators, policy conferences, government or trade-association committees. I'm gratified that it no longer matters whether I'm "certified" to do whatever it is I do. I'm eager to get better at listening to others, recording their ideas, sharing those ideas with more people, and trying to help convert people's hopes into experiences.

Jack Pealer  
Hamilton, Ohio

⇒ "I have seen the light at the end of the tunnel and it is Joan of Arc with her hair on fire".  
( Kinky Friedman)

In 1975 I started my career in human services. I was hired to be a 'social adjustment counsellor at the then Kinsmen Vocational Centre in Winnipeg, Manitoba. I had no idea what a 'social adjustment counsellor did or what a 'pre-vocational centre' was. On my first day of work I was given eight folks to socially adjust and a room to adjust them in. The room had a pay phone on the wall that was not connected to the outside world, a radio, an iron and ironing board, and nine chairs for group time. In my first hour of work a man stood up, moaned, grabbed his chest like he was having a heart attack, and fell to the floor at my feet. I bolted from the room looking for another 'social adjustment counsellor' to help me. When I told them about the heart attack they said: "That must be Bill, he does that". Those were the days! Good old segregated, congregated, socially isolated services rooted in professional dominance. Those were the days when a person like myself whose major life achievement to date had been learning the words to the song, "Louie, Louie" by the Kingsmen could be a 'social adjustment counselor.

In 2007 I teach in the Disability and Community Support Program at Red River College in Winnipeg, Manitoba. I have lived and worked long enough to witness Normalization trigger a transformation in human services and morph into Social Role Valorization. I have seen ideas like Person-Centered Planning, Supported Living, Support Networks free people from 'other-determined' lives. I know people who are both free and happy because they bumped into those ideas and people who knew how to make them a reality. I think in some ways I have been witness to a revolution in human services. In other ways, not so much!

In 2007 too much remains the same here as it was in 1975. Institutions persist and at times seem to be gaining momentum. Sheltered Workshops and segregated day services remain the dominant option for way too many people. Government ignores innovation and clings to the old ways of 'placement' and 'program'. My big fear is that somewhere out there today some day service is talking about the need to open a pre-vocational centre and hire more social adjustment counselors.

Bob Jones  
Winnipeg, Manitoba

⇒ As 2007 comes to a close, I'd like to say how happy I am that more and more parents who have a child or children with a disability are planning for the future. Only a few years ago, parents did not want to consider that their child might outlive them. For many years, we professionals have been talking with parent groups as well as professionals in the field to give them information about life planning for their loved one. From my vantage point, I have seen what appears to be a difference in the generations of parents who have a child with a disability. The oldest generation were told by medical professionals as their children were growing, that they would outlive their child. At first they didn't think their child would live through the first year,

and as medical treatments progressed, their children were surpassing all the predictions. These pioneers demanded schooling for their children, then vocational training. Now as it has become apparent that their child may outlive them, many parents have become fearful as they will no longer be able to "protect" the individual from society. Although they know they need to make plans, many tend to put it off. Many parents in the next generation realize that it is probable that their child will outlive them, and are beginning to make plans for their entire family. The younger generation is including their child who has a disability in with the entire family, and include them in all aspects of their lives, including future planning. Of course, it is unrealistic to say that all people do all things. Life Planning has become something that more people seem to be doing, for whatever reason, e.g. receiving a payback, arranging for their legal affairs. Perhaps a what was once almost a "shame" of having a child who has a disability is moving closer to acceptance within the greater community. We can only hope and that more families will be planning for the future for their children.

Kathy Morris  
Cincinnati, Ohio

⇒ As 2007 comes to a close, I'd like to say that we've all finally gotten it with respect to providing needed services and supports to people with developmental disabilities! Bureaucracies finally understand the importance of assisting families and individuals with developmental disabilities in their homes and communities by providing the supports they need there, rather than in special places for special people. Children are finally allowed to attend the school in their neighborhood with their peers, with the extra supports they need provided to them there, rather than across town in a special place for special people. Individuals with developmental disabilities have the opportunity to live and work in their community, rather than live in special facilities and spend their days in other special places. People can finally access the services they need in their lives, rather than the services some agency offers and, therefore, decides they need. Government agencies finally realize they exist to work on behalf of the people they serve, rather than believing those individuals should be grateful to them for their lack of response or assistance when needed, and for their attitude that people needing their assistance are somehow "less" than they themselves are. I'd like to say it - but I can't. Not yet, and I'm wondering if ever.

Linda Higgs  
St. Albans, West Virginia

⇒ As the end of 2007 begins to appear, I find myself alarmed about the specter of the possible reversal or collapse of much of what I have worked my whole adult to achieve. This was triggered in part by Jack Pealer's letter to the governor of Ohio in the Autumn 2007 *Safeguards Letter* and the news that the State of Ohio has committed itself to revitalized developmental centers, i.e., institutions. Similar news of institution revitalization has recently arisen in other localities as well e.g. Nova Scotia, Manitoba, New South Wales, Ireland etc. after many years of not hearing anything but stories of reasonably successful institutional reduction and closure. I am left wondering if the tide has fundamentally turned. The values and advocacy strength of the "baby boom" generation of leaders in this field no longer seems to have the sway that it did in recent decades. I do not know whether these examples of resurgent legitimization of segregation are a momentary anomaly or whether it presages a deeper erosion of societal commitment to the social inclusion of people with disabilities. Like many others of my generation, I had thought we had proven that institutions were not needed. Yet, we may now face the prospect of having to re-enter this battle with a new generation of people who may well be quite comfortable with segregation. Clearly, the resurgence of governments quite willing to

unapologetically endorse institutions is a moral and political fact that has the gravest of implications. It is these emerging realities that I will carry with me into 2008, as I try to evaluate what might be their meaning for my personal priorities. I am grateful for Jack's challenge to the governor, but wonder why so little has been said and done by others, including myself. So, lots to consider.

Michael Kendrick  
Holyoke, Massachusetts

⇒ As 2007 comes to a close, I'd like to say how much I'm going to miss Ken Ervin, one of West Virginia's most tenacious advocates for people with disabilities. Ken, 45, died in his sleep from a heart attack this fall, in the midst of a remarkable career. No, not a career, Ken would have said, but a calling, his reason for being here. The Governor, a frequent target of his advocacy, attended the funeral in Ken's home town a few weeks ago. Yesterday, I joined Ken's friends for a ceremony at the Capitol, where the Governor presented the "Distinguished West Virginian" award in Ken's honor to his widow, Darla.

Ken would have dismissed the whole affair as a waste of precious time. He never sought recognition for himself, only the larger cause of liberating people with disabilities from nursing homes and institutions. The issue was intensely personal to him, for he'd spent four years of his youth in a residential "school," where he counted beads on a string for "math class." Two master's degrees later, I crossed paths with Ken when I worked for the Developmental Disabilities Council. He was one of a dozen people whose oral histories were included in a book the Council published about their experiences in and outside of institutions.

Ken was excited about the project, but urged me, the book's editor, to tell the whole truth, to resist the urge to shape the book into ammunition for the deinstitutionalization movement, to include as well people's struggles in communities. He reminded me how easy it is become intoxicated by our own rhetoric, how the integrity of our cause hinges on our honesty with ourselves and with others, however uncomfortable that truth may be. The brutal reality of people's lives often depressed Ken, but he never gave up on his notion of a world that fully includes all of us. Nor, I hope, will I.

Julie Pratt  
Charleston, WV

⇒ As 2007 comes to a close, I'd like to say haven't we all said and done this before? I mean, I read the battles and the struggles that folks on at least one list talk about and I think we are back in 1997, or 1987, or 1977 or even 1967. Institutions seem still to be "bad." Sheltered workshops still don't help people find jobs. Some families are so afraid of life for their kids that they "hide them away", not in back rooms, but in those institutions that are or should be, according to these folks, "part of the continuum of care." But what may be new in 2007 and what will be on the horizon for many years to come is the large number of kids who now are labeled in the autism spectrum. What if it's real that 1 of every 150 or 1 of every 140 or whatever really do have autism? And what will we do about it to provide meaningful lives in the community? We haven't exactly "liberated" all the folks we knew about from years past and we re-fight the battles that we thought we'd won when Laconia State School closed. So now we have a huge new cohort to worry over. And I guess we'll say the same things and wrestle with the same issues and win a few and lose many and struggle to find dollars and rebuild old structures for new folks and PASS on to a new generation the struggles that are eternal. The poor (and the frail and the ill and the powerless and the dispossessed and the vulnerable) will always be with us. And so the test is not just to win by building a better program but always a personal one about

how will each of us respond to issues that ought to be understood as personal, moral tests, not design issues. That's what I'd say and why I think the vulnerable are not just among us. They are us, in 2007 and more than likely in 2008 as well..

Don Trites  
Lincolntonville, Maine

AND WITH THAT we'll wish all who read The Safeguards Letter good memories of the year that's closing and, of course, much joy and accomplishment in 2008. Jack Pealer, Editor

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