

# The Safeguards Letter

A Publication of OHIO SAFEGUARDS

Number Thirty-five

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## IMPORTANT WORKSHOP: *Crafting a Coherent Moral Stance On the Sanctity of All Human Life, Especially in Light of Contemporary Society's Legitimization and Practice of "Deathmaking" of Unwanted and Devalued People*

Sunday, October 16, through Thursday, October 20, 2005 at Christ the King Retreat Center, Syracuse, NY

Presented by Dr. Wolf Wolfensberger, Susan Thomas, and Associates of the Training Institute of Syracuse University

This event is intended for (a) those who perceive that there is a gathering momentum in the world that works toward "deathmaking;" and (b) those who are uncomfortable with a pick and choose approach that objects to some deathmakings but endorses others, and who would like the work toward a more **coherent** position on the sanctity of human life.

This event attempts to accomplish four aims:

- a. Awaken people to the reality that there is growing support in our society for various forms of deathmaking of people who are impaired, elderly, or devalued for any reason. Deathmaking includes any practices that outright kill people, greatly hasten death, or lead other people to act so as to bring about a person's or group's death. Many practices that participants see all the time, and may even participate in, will be shown to contribute to deathmaking.
- b. Orient participants to the disguises and interpretations that are given to deathmaking so as to make it less obvious and less repugnant.
- c. Elucidate the societal dynamics and values that have been leading to these developments.
- d. Help people to see the validity – indeed, the necessity – of a coherent moral stance in defense of all human life, to see what such a stance would entail, and to work toward such a stance.

Special topic: issues of the withholding, withdrawal, and refusal of medical treatment.

Note: this five-day workshop, to include evening sessions, is approved for **54 contact hours** of Continuing Education for Registered Nurses and Licensed Practical Nurses by the Ohio Nurses Association, an accredited approver by the American Nurses Credentialing Center's Commission on Accreditation OBN-001-91. CE contact hours are provided by workshop co-sponsor Family Lives Nursing Services.

Cost of tuition and room and meals is \$650, payable to the Syracuse University Training Institute. Group discounts and flexible tuition for those in need **are available**: call Susan Thomas at 315 / 473 – 2978. Send registration to the Training Institute, Suite 3B1, 800 South Wilbur Avenue, Syracuse NY 13204.

FEELING WELCOME: JOINING OUT OF LONELINESS FOR EACH OTHER. Bruce Anderson

William Stafford, poet and teacher from Oregon, writes that things join “out of loneliness for each other.” At the heart of all community building is the desire to connect citizens with other citizens. These acts of joining, small or large, form the fundamental cure to loneliness. Could those of us strategizing ways to build community make good use of our time by considering what the condition of loneliness means to each of us in our own lives? By joining together, telling our own stories of loneliness, and describing the pathways that guided us through those times, we may locate a collective wisdom we can expand and take back to our work on a larger scale.

Why aren't we talking more about our own loneliness? The stories of times when we have felt disconnected with others take us back to places many of us would choose to forget, if only we could. As part of our organization's community building work, we often ask groups to divide up—in pairs or threes—and have each person tell a story about a time in their life when they felt like they didn't belong. As those stories are shared, many of them told for the first time since the event happened, there is often an initial feeling of darkness and despair. What we have learned, however, is that the darkness is quickly replaced by a feeling of unity and strength as the similarity in the stories is noticed and people begin to remember that the condition of loneliness is part of our common story. We have also learned that each of us has wisdom and unique understanding about loneliness that is useful to share. There is a strength resulting from the telling of these stories that binds people together and increases their commitment to community building action.

Is our unwillingness to “join out of loneliness for each other” because we want to be alone? Not me. I have persistent and haunting memories of each time in my life I have felt lonely...somehow unwanted or unaccepted by others even though I yearned for their touch or their particular nod in my direction. So now, as I consider my own quiet refusal to stand beside those who are lonely, I question the advantage my silence brings me. I get the comfort from not revealing my own stories of loneliness to others who may benefit from hearing them, but also the damaging turbulence that locked up stories bring to my soul. I get the advantage of thinking that my life is put together somehow more completely, and that I need less help than those around me, but also the daily burden of maintaining that false front. I get the “calm before the storm” advantage of delaying facing my own suffering, though not answering that knock at the door creates a deeper dissatisfaction with my own courage.

Sometimes I respond to loneliness by saying “but, in the end, we are alone in the world”. I know when I think or say these words it often comes on the coattail memory of its companion belief—another grim reminder—which begins... “You really can't trust anyone but yourself”. These two half-truths, usually erupting out of some situation in which I did not receive the love or attention I thought I deserved, serve to drive me further into my loneliness by carrying into my psyche the idea that the world is a dangerous and hurtful place. It is that small and afraid voice inside reminding me that when you go out in the world, this is what you can expect. You should have known better. These responses come from a desire to reconcile my feelings of loneliness by pushing them towards hopelessness. Far from courageous introspection, this comfortable hopelessness gives me permission to see loneliness in others and myself and not take action.

William Stafford, in a poem called *A Ritual to Read to Each Other*, reminds us of the deep obligation humans have to stay joined and act when we are a witness to disconnection. He writes about a band of elephants holding each other's tails on the way to the park. “But if one wanders”, he says, “the circus won't find the park. I call it cruel and maybe the root of all cruelty to know what occurs but not recognize the fact.”

Loneliness comes from the unmet desire to feel the presence of another in your life. There is a sadness and disconnection with the world that comes with the feeling of loneliness. Being alone, on the other hand, is not the same as being lonely. Being alone does not, in itself, cause loneliness. Being alone simply states that you are standing by yourself, not in the presence of others. That you are “going it alone” for the moment, and acting by oneself. Being alone can involve courage, a feeling of wholeness, and a feeling of deep connection to those around you.

What are we doing to help those around us not feel lonely? And what are we doing to encourage those around us to know the power of standing alone? For myself, I know that helping others find ways out of their loneliness has shattered my own illusion that I am not lonely. I struggle with my own feelings of being unwelcome each time I witness another person taking courageous steps towards connectedness with others. As Wendell Berry says, “true social change may stick, not through large heroic acts of defiance, but rather through the small acts each person makes because their conscience and integrity would be shattered if they did otherwise”. The small acts of standing by that we make each day tell more about our desire to cure loneliness than the heroic programs and principles we pledge our allegiance to.

My fear  
is in getting to know you.  
For in those moments of conversation  
when I begin to see you more clearly,  
I may discover I am not  
the loving person I imagine myself to be.  
Not loving. Me. Now I've said it.

My safety  
is my silence and quiet refusal  
to stand beside you when you need me or I need you.  
I hold my breath tightly, silently,  
trying to stop love from moving through me,  
giving trouble a solid place to stand.  
Forgetting that, like water,  
love moves through all things.  
Like the tides, it washes over dry souls who wait.

If I could have one thing,  
just one thing different,  
it would be to touch that stone-cold part of my soul  
and give it light.

Bruce Anderson

*(Bruce Anderson lives in Vashon, WA. He is a partner in “Community Activators,” an organization devoted to “fresh ideas and tools to build welcoming and productive communities.” He says: “In 1985 I was a fisherman in Alaska who, by a string of events that now seem anything but accidental, ended up sitting in front of John O’Brien in a bad motel meeting room with shaggy red carpeting. It was a PASS workshop, and it changed my life.” JRP)*

About THE SAFEGUARDS LETTER

*The Safeguards Letter* is an occasional publication of OHIO SAFEGUARDS. The *Letter* exists to promote affiliation among people who are interested in and thoughtful about those who live outside the sphere of respected community membership--those who are the usual receivers of human services. All material in *The Safeguards Letter* is under OHIO SAFEGUARDS' copyright (©) unless otherwise attributed. Letters, ideas, and items for publication in the *Letter* can be sent to: Editor, *The Safeguards Letter*, 3421 Dawn Drive, Hamilton, OH 45011. We welcome our readers' ideas and reactions.

JUST QUOTES

Life accepts only partners, not bosses. We cannot stand outside a system as an objective, distant director. There is no objective ground to stand on anywhere in the entire universe. Our disconnection—our alleged objectivity—is an illusion; and even if we fail to realize this, the system will notice it immediately. Systems work with themselves; if we aren't part of the system, we have no potency. Systems do not accept direction, only provocation.

Margaret Wheatley and Myron Kellner-Rogers  
*A Simpler Way*

"The big idea of education, from first to last, is the idea of a better place. Not a better place where you are, because you want it to be better and have been to school and learned to make it better, but a better place somewhere else. In order to move up, you have got to move on. I didn't see this at first. And for a while after I knew it, I pretended I didn't. I didn't want it to be true."  
(Hannah Coulter considering that her children are all far away.)

Wendell Berry, *Hannah Coulter*

In a life with its fair share of darkness, I have found full-body baptism in the plain and glorious particulars of life to be a powerful antidote to despair. The fact is that the details of our natural surrounds offer infallible fascination and a route out of morosity. In a world deeply flawed by the infantile excesses of our own kind, this is no small potatoes.

Robert Michael Pyle, "Consolation Prize,"  
*Orion*, March-April 2005

Given the constraints imposed by the regulations and service practices that the initiative (i.e., the Robert Wood Johnson self-determination initiative) itself is designed to overcome, it might be said that people with disabilities are being given a chance to participate in a political and social experiment designed to discover how much flexibility and personalized support it is possible to wring out of a hybrid medical system that concurrently, and as a whole, is the object of attempts to control its costs by others who are higher in state and federal bureaucracies.

John O'Brien  
"Notes on Complex Change"

AN APPRECIATION: *Waddie Welcome and the Beloved Community*, by Tom Kohler and Susan Earl. (Toronto: Inclusion Press, 2005) Available from Inclusion Press ([www.inclusion.com](http://www.inclusion.com)) or Chatham-Savannah Citizen Advocacy, 127 Abercorn Street, Suite 100, Savannah, GA 31401.

*Waddie Welcome and the Beloved Community* shows and tells the story of a Georgia native and citizen, the town where he lived, and the people whom this Georgian drew together in a common but radical enterprise. In only a minor way is the book about human services; organized agencies appear mostly by default or omission.

Waddie Welcome was born in south Georgia 138 years to the day after the publication of the Declaration of Independence. He was born 88 years exactly after the deaths of John Adams and Thomas Jefferson; he is only one lifetime removed from the founding fathers. Mr. Welcome lived all his life in southeast Georgia – more than 70 years with his immediate family and more than 80 years in Savannah. After Mr. Welcome passed his 80<sup>th</sup> birthday, people in his neighborhood who knew him and his family worried that remaining family members were unable to take care of him well enough any more. A usual thing to do when people have those worries is to contact local human service agencies, and that's what happened. The outcome of the contact was that Mr. Welcome moved, first to a local nursing home and later, when that home's license was taken away, to another nursing home about 150 miles from Savannah. Mr. Welcome did not agree with those choices, but his disagreement apparently could not be understood. *Waddie Welcome and the Beloved Community* shows and tells how he met people who shared his disagreement, who called others to act in his interest, and who worked and schemed with Mr. Welcome to get him home.

*Waddie Welcome and the Beloved Community* contains surprises; it provokes tears and smiles, sometimes together. I learned just by studying a photo that I'd like to join the Savannah Checker Club. I was astounded by the almost casual reference to Mr. Welcome's guardian who spent many hours asking and listening to Mr. Welcome about his preferences around ways his health would be safeguarded. I never before heard about a guardian who personally selected a cardiologist, from among the guardian's associates, to work with his "ward." I could both cry and laugh with the occasion of Mr. Welcome's funeral, when his community gathered to honor him. I want to remember – and employ when I can – the "social research" methods of Mr. W. W. Law. I can appreciate Tom Kohler's discomfiture when he was first confronted with the direct style of Mr. Welcome's life long friend Mrs. Addie Reeves. And, I can almost taste Mrs. Reeves' cake.

*Waddie Welcome and the Beloved Community* is a testimony about quiet radical social change. There are no position papers. No protest marches (although people probably thought about it along the way). No years of speeches at legislative hearings. Instead, change took place through the daily-ness of sharing meals, telling stories, or celebrating the moving of a bed. And, people did it together. As the authors put it, they "kept the 'social' in social change."

In *The Timeless Way of Building* Christopher Alexander wrote: "We must simply accept the fact that in the process of evolution, there is no final equilibrium. There are passing phases which approach equilibrium, but that is all. The search for equilibrium, the brush in the dark with a moment of stability, the wave which hesitates a moment before it crashes into the sea again – that is the closest constancy will ever come to being satisfied."

Those of us who seek a bit of rest amid chaos take little comfort from Mr. Alexander's words. He wrote, though, as an architect about buildings and about the "languages" that, he says, lead to the growth of good buildings and good towns – places that contain and promote life. Those "languages" change, inexorably, restlessly. Perhaps the growth of what we call "community" proceeds with similar restlessness. Community – people together – always evolves. Perhaps we

can only see the changes at certain times that Mr. Alexander calls “moments of stability” against which we brush in the dark. If that’s so, then *Waddie Welcome and the Beloved Community* reveals one such moment – the crest of a wave against a turbulent sea. For a magnificent instant, the community we look for – the beloved community – reveals itself. Get hold of a copy of *Waddie Welcome and the Beloved Community*, and go there.

Jack Pealer

VIEW FROM THE BACK WINDOW

"*The Struggle Between Me and Us*"

It's easy to worry about me, to focus on me, to see everything in the world from the point-of-view of me. As a matter of fact, seeing anything in the world from the viewpoint of anybody but me takes a lot of effort. Acting like one of us is hard. It doesn't seem to be instinctive. I'm drawn, though, toward any action or enterprise that features mutual effort--effort that involves us. I'm attracted to things that call for us to act in common, one with others. Some examples.

Many years--or several lifetimes--ago, it was my occasional duty to select the hymns that congregations would sing on Sunday mornings. Picking out the hymns was the job of the person who wrote and delivered the sermon at a particular worship service. Besides the attempt to match, somehow, hymn-themes with the themes in Bible readings and the sermon, I only remember that I had one personal rule about hymns. I always went with the "we" hymns instead of the "I" hymns.

Here's the first verse of what I thought of as an "I" hymn--a pretty familiar one, sung to the same tune as the official hymn of the U.S. Navy:

My hope is built on nothing less  
Than Jesus' blood and righteousness;  
No merit of my own I claim,  
But wholly lean on Jesus' name.  
On Christ, the solid rock, I stand;  
All other ground is sinking sand.

Four first-person singular pronouns appear in that first verse. Those pronouns made me uncomfortable.

I wanted plural pronouns. Here are the first two verses of a well-known hymn by Isaac Watts (1674-1748):

O God, our help in ages past,  
Our hope for years to come,  
Our shelter from the stormy blast,  
And our eternal home:

Under the shadow of thy throne  
Thy saints have dwelt secure;  
Sufficient is thine arm alone,  
And our defence is sure.

See the difference? The only singular pronouns are second-person: *thy*, *thine*. All first-person pronouns are plural. They are communal, which is what I thought religious and worship life was supposed to be. I'll bet I picked Isaac Watts' hymn, more than once. But many of the "I" hymns are old favorites. We get caught in a struggle between me and us.

Another example. Not long ago, someone asked me if I had gotten "Sirius." That's not misspelled. "Sirius" is a company that sells radio receivers and access to many commercial-free satellite radio channels. The deal is that you or I can invest \$100 for a receiver and choose a monthly plan, at a price of about \$13 a month. If you or I do this, we can listen to radio free of commercial messages, and we can do this in our homes, in our cars, or in other locations where we can take the receivers. If I want to, I can listen to Martha Stewart--or even Howard Stern. All this comes exclusively to me or to anyone else who buys a radio and pays the monthly fee. It's only available to those who pay.

Another deal comes my way fairly often. I'm regularly offered opportunities to send some money (an amount I get to choose) to any of several "public" radio stations close to where I live. If I "invest" (as they say) in public radio, I can listen, almost without commercial messages, to classical, world, folk, or '40's swing music. If I want to, I can catch a talk show or hear the news from NPR. As the announcers emphasize during pledge-weeks, the side-benefit of public radio seems to be inclusivity. Anyone with an FM radio can listen, without paying. That means my contribution (it could be \$246 per year--about the same price as Sirius) pays for other people to listen. So, the guy in the car next to mine can overhear Beethoven's "Hymn to Joy" or Django Reinhardt playing "Someone to Watch Over Me" on my radio. Then, he can smile and turn on the same music, on my dollar. My neighbors can hear "Tunes from the Crypt" during the Trick-or-Treat hours on Hallowe'en, and they can turn it on too. It would be great to hear the neighborhood echoing with Bernard Herrmann's theme from *Psycho*. The innocent chills the kids get, out in the dark, would be just as innocent but maybe a little bit chillier. And it would be my small investment in a common enterprise that paid for all the neighbors' listening. To me, that seems so much about us, and not just me. But, it's so rare. It seems to go against our nature. We have trouble with a struggle between me and us.

A long time ago in a state other than Ohio I visited a group of people--some with disabilities and some without--who shared a small home. One of the lessons this group taught was about me and us. If they had pooled their money, which would have been a common effort, they could have bought an automatic dishwasher for the house. Then, the dishes would have been cleaned quickly and efficiently--almost with no effort. This might have freed time for house mates to read more, watch more TV, take more walks, or do other things that each one of them preferred. Instead, they chose to wash dishes by hand after each meal and to make a ceremony--complete with singing--of each dishwashing occasion. What might have been a key to improvements for each me in the house turned into a pattern that made us stronger.

It looks like the choice is always there. A favorite movie of mine is John Sayles' *Matewan*. It's about tension between coal miners and mine operators in 1920's West Virginia. Just before the battle that ends the story, a young miner and the union organizer share a moment. The young miner says, with bitterness, "...now you say you're here to help? We've had about all the 'help' we can stand. We've got to take care of ourselves." The organizer quietly replies, "We've got to take care of each other."

In the struggle between me and us, which is easier? Which is right?

Jack Pealer

REMEMBER!!

*Crafting a Coherent Moral Stance On the Sanctity of All Human Life, Especially in Light of Contemporary Society's Legitimization and Practice of "Deathmaking" of Unwanted and Devalued People*

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