

# The Safeguards Letter

A Publication of OHIO SAFEGUARDS

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## WOLF WOLFENSBERGER IN CLEVELAND. PLEASE MARK YOUR CALENDAR!

OHIO SAFEGUARDS is working with ARC/Cuyahoga County and possibly with other organizations to present a unique learning opportunity. On November 16 and 17, 1992, in the Cleveland area, Dr. Wolf Wolfensberger and his associate Susan Thomas will offer two separate but related workshops about the history of human services in general and developments in the field of disability in particular.

Not everyone likes the study of history, but everyone is affected by history. This "everyone" includes people who are connected to human services--those who use services, those who provide them, those who manage them, and those who are concerned about the expenditure of tax money to support services. On Monday, November 16, Dr. Wolfensberger and Ms. Thomas will present a survey of the history of human services in the western world. The full title of this workshop is "*A One-Day Presentation on the History of Human Services, with Emphasis on the Origins of Some of our Major Contemporary Service Patterns, & Some Universal Lessons for the Planning & Structuring of Our Services which can be Learned from this History.*" The presentation features several hundred slides that Dr. Wolfensberger has taken or accumulated over the last 30 years. The information presented and the insight to be gained through this workshop is probably unavailable through any other forum. Dr. Wolfensberger's description of the workshop notes:

The material presented has relevance to every human service worker, from those on the direct clinical level to those at the highest planning levels. This includes service professionals and non-professionals, clinicians, advocates, volunteers, administrators, planners, theorists, and analysts. Attendance at the presentation can help anyone gain a better understanding of the service challenges that they are up against, some of the dangers that lurk everywhere, and what sorts of service patterns to strive for.

Dr. Wolfensberger and Ms. Thomas will spend Tuesday, November 17, offering "*Reflections on Human Service Developments since the 1950's: What is Still the Same, What has Gotten Better, What has Gotten Worse, and What Lies Ahead*". From Dr. Wolfensberger's more than 30 years of experience as a participant, leader, and critic of human services, he will trace service developments from the abysmal conditions that prevailed prior to the reforms that started in the 1950's, up to the present day. This presentation:

- explains the ideas that gave rise to the deplorable pre-1950's conditions and that, in part, still linger today;
- inventories the major positive changes that have taken place in services since then, as well as some of the things that have NOT changed (or that may actually have gotten worse); and
- explains some of the overarching challenges that Dr. Wolfensberger perceives to lie ahead to confront people with disabilities and their allies in the future.

On three occasions during the day there will be a panel of other people, from northeastern Ohio, with long experiences in human services who will respond to the various parts of the presentation.

We do not know right now exactly where these workshops will be held, except that they will be in the Cleveland area. We are uncertain about how much it will cost to attend either or both of the events. We are trying to find funds to cover part of the cost so that the registration fee can be kept as low as possible, so that lots of people can afford to come. By the time the next edition of *The Safeguards Letter* appears, we will be able to supply further details. Now, we wanted readers to know about these events, mark their calendars, and plan to attend.

HOLDING A PLACE IN LINE Sandra Landis

I have some clear childhood memories of standing in line. We used to have to stand in line at the nurse's office in school to get our polio shots, and my brother always fainted. We stood in line before every recess and lunch period in elementary school. We even stood in line to walk to the bathroom. And on Saturdays, at one o'clock, my brothers and I would stand in line to buy our tickets for the kids' matinee.

One memory has to do with being yanked out of line. Our family was traveling, visiting for a couple of days in New Orleans. We walked around a section of the city with lots of shops and a wonderful bakery that made French crullers. I stepped away to the water fountain, into line behind two grownups. A woman I didn't know grabbed me by the back of the neck, pulled me out of line, and directed me to the fountain marked WHITE.

Now I stand in line at the grocery store, sometimes at restaurants and the print shop. I also live with the idea that there is another line--of human experience--that I am always a part of and that I influence in small ways. The distinction between literally standing in line and figuratively holding a place in the line of human experience became much clearer about ten years ago when I showed up at the unemployment office. May I never be requested to stand in a line that long again. It stretched ahead for twenty-six weeks.

Twenty-six weeks seemed like entirely too long a time for anyone to just stand in line, so I soon began to think about it in that other

sense, as preserving a place for a useful role in that line. While I was there, what would I stand for? During the first couple of weeks I watched other people and learned the routines. It looked to me like a number of people had

already filled the expert roles. Others had become the silent observers and still others the vocal cynics. One person chose to use the time to read stories to two small children. I decided to be one of the "look people in the eye and be cheerful" people. There didn't seem to be many people representing that position.

I found there was a difference in the standing-in-line experience, depending on how I thought about being there. I ended up meeting some interesting people and hearing some amazing stories. I understood, as well, that my choice to be a cheerful person in line was a relatively easy one because I was certain that I would not repeat this experience. I did have a lot of time to think while I was standing there, and there were a lot of things I needed to make decisions about. At the time I was trying to figure out how I could begin to do useful work without having a job or position. I wanted to earn enough to live and support my sons but not generate much tax liability. Uncertainty seemed to dominate my attempts to begin my future. Standing in that line was a concrete example of what I seemed to be facing in lots of other areas of my life. Just as I wanted to choose something to stand for and preserve a place for in that temporary line, I wanted my life's activity to preserve a small place for living and working hopefully in the uncertainty that surrounds all of us humans.

When I noticed that cheerful persons seemed a minority in line, it seemed clear that there was room for one more. Why not be that one, especially if I were only going to be around for one twenty-six week stint? In the same way, with only one lifetime, why not continue to choose hope? As far as I could tell the scarcity of cheerfulness in the unemployment line paralleled a scarcity of hope in the lives of many people outside that place.

There was another feeling too. When I looked at the worn, cracked seats on the chairs or at the tiled floor where the pattern had been worn away, I knew that people had been there long before me. I imagined that some of them had come to stand in line and some of them had come to hold a place. Though I would never know them, I felt that I had colleagues in the same activity. Even though we had stood in line on different days, in different years, we were contemporaries, sharing a common experience or performing a common task. This identification with people as sharing "of the same time" experiences with me is a notion that I've happily taken license with ever since. It's been a way of expanding my sense of the present, approaching what John O'Brien calls the "200 year present". By beginning to describe the present in terms of common activity and interest and by stretching my sense of the present through relations with others, I experienced an immediate growth in my circle of allies and intimates. This expanded idea of what constitutes the present has put me in closer touch with my heroes.

I realized that I was just one of many who had stood through a common experience, and I understood that someone before me had also chosen to bring cheerfulness to the line. Because someone did that, keeping the expectation alive, there was a chance for me to do the same when I showed up. There was a connection through activity that I only recognized because of circumstance. Ordinary people decide about the roles they will fill or the ideas they will stand for; thereby, they preserve those roles and ideas in the places where life takes them. Only the particulars limit their influence. Sometimes the decisions of ordinary

people in particular situations turn those people into heroes.

I continue to live with these ideas and keep finding work to do that I regard as consistent with keeping a place open for hope, through activity. I've become more practiced at acknowledging small acts of heroism in others, and in myself. I have noticed that my expectations about heroic activity have increased. And, through the happy coincidence of circumstance and opportunity I live now in what I think of as collegial association with a

few of my longtime heroes. This is of great comfort to me, and it happened so easily.

I have read Myles Horton's autobiography, *The Long Haul*. Myles became one of my heroes on the day when I met him. As a young man, Myles had developed a simple, clear idea about how people learn useful things. Then he spent his life creating opportunities for that to happen. When he was trying to figure out what direction to take in his work, Myles visited Chicago and spent some time with Jane Addams. They met early in his life and relatively late in hers. Myles admired Ms. Addams' ideas about democracy and leadership within democracy. These ideas, she claimed, were influenced by her father, who, in turn, believed his ideas to have been influenced by Abraham Lincoln. As I read this, I felt closer to understanding why Jane Addams and Abraham Lincoln have been my heroes for a long time. And for the first time I had an appreciation that Ms. Addams, Mr. Lincoln, Mr. Horton, and I are "of the same time". What a wonderful comfort to affiliate with these people through a chain of ideas, activity, experience, and personal relationship (however casual)! This connection buoys my spirit and strengthens my resolve to act and work to preserve a small space for hope through what I do.

Associating freely with heroes has been a faithful reminder to me that my task can't be to "fix problems". Sometimes I have forgotten that, and those are discouraging times. My task is merely to hold a place for hopeful activity in the midst of painful dilemmas and realities--like the oppression and violence that are part of

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living in this time. The task is to keep the ideas alive as long as alternatives remain. The luxury of living in the extended present is that I am in the company of heroes--the ones I've known and the ones I haven't yet met.

Sandra Landis

MY VISION OF INCLUSION

Debbie Schmieding

My vision of inclusion has me at the center--the responsibility and the benefit. In truth, I work for inclusion not for the poor labelled souls, or for my children or for my neighbors. I do it for myself. My vision involves putting aside fear, timidity, fatigue, and helplessness, for the sake of my own safety and for the richness of my relationships and the depth of my perspective.

Martin Niemöller made an acute and timeless observation, just so that I could hold it up to the light and paraphrase it this way:

They came for the Jews, and I stood in front and said "We are all Jews. You may not take us, but you may join us."

They came for gay men and lesbians, and I stood in front and said, "We are all gays. You may not take us, but you may join us."

They came for the angry people, yelling and banging their heads, and I stood in front and said, "We are all angry. You may not take us, but you may join us."

They came for the people with slurred speech and jerking limbs, and I stood in front and said, "We are all inarticulate. You may not take us, but you may join us."

I had to say these things because by the time they would have come for me, there weren't any of "them" left.

This is my vision of inclusion.

Debbie Schmieding

About THE SAFEGUARDS LETTER

The Safeguards Letter is a quarterly (approximately) publication of OHIO SAFEGUARDS. The Letter is intended to be a vehicle 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, P.O. Box 1943, Chillicothe, Ohio 45601. We welcome our readers' ideas and reactions.

PASS WORKSHOP (TENTATIVELY SCHEDULED)

OHIO SAFEGUARDS has begun the planning for its next presentation of "An Introduction to the Role of Values in Human Services, through the Use of PASS 3." This workshop, which has been offered regularly in Ohio by OHIO SAFEGUARDS for several years, has been tentatively scheduled to take place between Sunday, November 29 and Friday, December 4, 1992 in Chillicothe, Ohio. Complete details about the workshop will be announced in flyers issued by OHIO SAFEGUARDS within the next three months. Fees for the workshop are expected to be in the range of \$200-\$250 per person, not including lodging and meals.

The title of the workshop describes both its intent and its main emphasis. Those who come to the workshop can expect to be immersed in readings, lectures, discussions, and a practicum visit to a human service agency. All of these activities focus on helping participants learn how the values and beliefs of both human-service agencies and of the culture in which we live shape the assistance people who are in need receive. Those values have, as a consequence, powerful influence on the kinds of lives that people in need are enabled to live.

Most participants in past PASS 3 workshops have found them enriching, stimulating, and (yes!) all-consuming. Some people count their first PASS workshop as a high point in their careers. Registration for the workshop can be accomplished using the form that will accompany the descriptive flyer. Those interested in attending are urged to register as quickly as possible following receipt of the flyer, because only 25 participants will be enrolled. If you want to be sure to get a flyer, please contact OHIO SAFEGUARDS at P.O. Box 1943, Chillicothe, Ohio 45601 (phone: 614/773-6191).

SUPPORT FOR THE SAFEGUARDS LETTER

This is our annual appeal for donations of money to pay for *The Safeguards Letter*. Regular readers know that there is no "subscription fee" for the *Letter*. The trustees of OHIO SAFEGUARDS agreed more than four years ago that the *Letter* would not be paid for by "subscriptions" but by the voluntary contributions of interested individuals and organizations. This decision saves OHIO SAFEGUARDS from the task of maintaining subscription lists. More important, though, the decision places the responsibility for the future of the *Letter* where it ought to be--in the hands of its readers. For the past three years the intermittent contributions we've received have made it possible for the *Letter* to reach about 400 readers four times a year. Any readers who want to contribute (it's tax-deductible) may send their contributions to: *The Safeguards Letter*, P.O. Box 1943, Chillicothe, Ohio 45601. All money received will be used for the printing and mailing costs of the *Letter*. We thank you for your continued loyalty as readers.

JUST QUOTES...

...being human, whatever that is, is something we have to survive, as there's no prospect of rescue. And, since madness and misery seem to be an inescapable risk of having our particular sort of constitution, the measures that we take to deal with them had better take account of the fact that we don't, and perhaps never will, know what sort of things we are.

Jonathan Miller  
"Madness" (on PBS)

Like a Rabbi or a Mullah, you avoided putting forward theories and told stories instead. All your life you have spoken and written like one who knows that arguments can end merely in conclusions and only stories make sense.

Ivan Illich, to Leopold Kohr

Preface, *The Breakdown of Nations*

UNEQUAL JUSTICE?, by ROBERT PERSKE: A REVIEW

Between 1838 and 1840 a Boston woman (a writer of children's books and a school teacher) named Dorothea Dix traveled through the state of Massachusetts, visiting jails, almshouses, and houses of correction. In January, 1843, Dorothea Dix summarized what she had seen in an address--a "Memorial to the Legislature of Massachusetts". Over the past several years a Connecticut writer (who has also written books suitable for children) has traveled around the United States, again visiting people in prisons. Robert Perske has had no opportunity to speak to a legislature yet (as far as I know), but he has reported some of what he has learned in his new book: *Unequal Justice?* (Nashville: Abingdon Press, 1991).

Dorothea Dix described her purpose this way:

About two years since leisure afforded opportunity and duty prompted me to visit several prisons and almshouses in the vicinity of this metropolis.... Every new investigation has given depth to the conviction that it is only by decided, prompt, and vigorous legislation the evils to which I refer, and which I shall proceed more fully to illustrate, can be remedied. I shall be obliged to speak with great plainness, and to reveal many things revolting to the taste.... But truth is the highest consideration. *I tell what I have seen*--painful and shocking as the details often are--that from them you may feel more deeply the imperative obligation which lies upon you to prevent the possibility of a repetition or continuance of such outrages upon humanity. (Memorial to the Legislature of Massachusetts, January, 1843)

Robert Perske describes what happened to him like this:

Every now and then, people with mental retardation or other developmental disabilities are arrested for crimes they did or did not commit.

Perhaps we have known of such a person--as a customer or co-worker or student or client or patient or parishioner, or even as our own neighbor. And we may have felt a momentary sadness about the arrest, but we usually assume that an arrested person did commit the crime. After all, most of us want to believe that police officers are righteous officials who don't make mistakes. So we watch at a distance....

A decade ago, however--after the surprise arrest of such a person near one of my former neighborhoods--something within me suddenly refused to ever let it go so easily again. Now one question whirls around in my consciousness every time something like that happens:

*Did that person receive equal justice?* Whether guilty or innocent, did the system treat that person as other citizens are treated when charged with the same crime?

*Unequal Justice?* is a report of Bob Perske's attempts to come to grips with that question. The question mark in the title is important. Perske insists on not treating the situation of people with severe disabilities who are accused of "capital" crimes as "a problem". Problems imply solutions. Despite pain ("...something within me...") and obvious anger, Perske refuses to offer answers. In the last chapter, "A Final Thought", he notes that: "This book ends with more questions raised than answered." This restraint, which must have been hard for the writer to maintain, is the book's greatest strength. When asked to think about it, most anyone can come up with a few grand ideas about how to make the criminal justice system work better. Perske invites us to consider such things, but he does so by telling stories. He calls the book "...my flashlight, turned on for you and beaming its light into a few dark corners...." The light lets us see what's there and, seeing, begin to make judgments for ourselves.

What I saw in Perske's stories coalesces around three sub-questions of Perske's larger question (*Did that person receive equal justice?*). I kept being led to think about: a) lawyers' games; b) police officers' points-of-view of about disability and about their role in our communities; and c) the status of confessions as evidence in criminal trials. First, the lawyers. Perske takes us into a number of court rooms where people with disabilities get caught up in a process they do not understand. Many of the people who became defendants didn't even know that the game of "adversary" was being played. It's not a game with which many of them were familiar. Friends and helpers of people with mental retardation have often noticed how anxious many such people are to please others who are around them. Pleasing your opponent (whom you do not recognize as such) is no way to come out ahead in "adversary", as Perske illustrates.

Then there are the police. I wonder about what police officers think their job is when they investigate a crime. Some of the stories Perske tells hint that some police officers think it's their job just to find someone who can be convicted in court. Is that why, in several of the cases, the police seem intent on searching out someone with mental retardation? Is it because police officers know that arrests of such people will raise the odds of a conviction? Or, do police officers share with many other members of our communities a set of beliefs about people with disabilities (i.e., that such people are dangerous, etc.)--beliefs that might predispose the officers to think that such a vicious act must have been done by one of "those people"? One possible conclusion from the stories in *Unequal Justice?* is that, just as people with disabilities are increasingly being taught to be cautious around (and, thus, to fear) "strangers", perhaps it is worth considering similar teaching about the trustworthiness of the police. But, this idea is one that occurred to me. It's in the nature of a "solution", and that's not what Robert Perske offers. He offers a flashlight.

And, what about confessions? The cases described in *Unequal Justice?* share a pattern. A crime is committed. Police find and arrest someone with mental retardation. Under police interrogation, the person arrested confesses to the crime. No evidence other than the confession seems to be offered at the trial. The defendant is convicted--quickly--and is sentenced to a long imprisonment or, often, to death. These stories force us to consider whether statements such as these confessions--statements that lead to such drastic results as life-imprisonment or death--should be capable of being regarded as evidence of guilt. I wondered whether there ought to be a prohibition of the use, as evidence, of confessions obtained from a person with mental retardation without a defense lawyer present. But, again, that's my solution-seeking, not Perske's. He tells his stories, shines his light; and, though he cannot always conceal (nor should he) that he is aghast at the sight, he just shows us what's there.

What's there, as well, is at least one story that warms us. One community, Munnsville, in upstate New York, also felt "something within" when one of its members stood accused of murdering his brother. The story of the trial of Adelbert Ward follows the pattern of many of the other cases with one difference. Mr. Ward was well-known to others in his community and, despite the vigorous action of police and prosecutors, the community would not believe that he was guilty. The community raised funds for his bond and for his defense. Adelbert Ward was acquitted and went back to live on the farm with his other brothers. This may have been made possible by Munnsville's recognition of him--as a person and as one of "their own." Perhaps Munnsville can serve as an example for other places, including the place where I live.

*Unequal Justice?* will be a surprise for readers who pick it up expecting similarities to Robert Perske's other books. This is not *Hope for the Families*, although families of people with disabilities should eventually read it. It isn't about *New Life in the Neighborhood*, although it would be a good addition to a neighborhood library. It certainly isn't *Circles of Friends*. Here, the subjects of Perske's reporting are encircled, but (except for the instance of Adelbert Ward) the circlers are hardly friends. Maybe it should have been called "Circles of Enemies", but that isn't a very good title. Actually, the title is just right. It's a book that raises questions, a book that should start conversations, discussions, and even arguments.

OHIO SAFEGUARDS bought five copies when the book was published, and we've given most of them to public libraries. I've also thought about getting copies for our local Public Defender and for the nearby police departments and prosecutors' offices. Others should consider similar plans.

Maybe sometime in the near future, Bob Perske will find an opportunity to tell these and other stories to legislators. Through this book (and possibly others to come) he has already done something more important. He's started to enlighten some dark corners for the rest of us.

Jack Pealer

THANKS VERY MUCH!

During 1991, OHIO SAFEGUARDS received contributions in support of *The Safeguards Letter* from the following individuals:

Bruce Anderson, Vashon, WA  
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Wisconsin Coalition for Advocacy, Madison, WI

Our thanks to one and all!

THE CHANGES THAT ARE NEEDED FOR PEOPLE TO "GET HOME".  
Winnenberg

John

I have recently read John O'Brien & Connie Lyle O'Brien's fittingly titled monographs *More Than Just A New Address: Images of Organization for Supported Living* and *Down Stairs That Are Never Your Own*. (Both of these are available from Responsive Systems Associates, 58 Willowick Drive, Lithonia, GA 30038.) I am particularly struck by how far we in North America have come during the past decade in

figuring out ways to support people with developmental disabilities to make secure and satisfying homes for themselves in our communities.

Any celebration of progress about this, though, has to be similar to acknowledging the first blades of grass that pop through on a barren piece of strip mined hillside, the history and future potential of which are to support a forest of century-old hardwoods and a rich variety of wildlife and fauna. It will take generations to reclaim what we suppose to be a natural order. I am sobered by visions of thousands of people trapped behind the doors of "facilities" and controlled by others' wishes, practices, needs and conveniences. These visions are the current reality as we attempt to redefine our culture's response to people who are more reliant on others for help than most.

With the O'Briens' work as a helpful background and having the opportunity to be a part of efforts in my home community to assist people to establish places of their own, I have begun to jot down a simple list that describes for me the successful shift from facility-based to "person-centered" community residential supports. I offer this list with the hope that others might add to it as they learn from their efforts. I also offer it in the conviction that, of all the things it will take to see growing numbers of people with developmental disabilities and those closest to them enjoy life in the midst of our culture, some (if not all, in glorious instances) must and will be done without the efforts of paid services.

#### **Change For People With Disabilities:**

- From living in facilities (someone else's home or business) with people you have little choice about . . . to living with people you choose in a place that you can call your own.
- From a situation where you must earn independence in living situations and lifestyle . . . to a situation where your abilities have little to do with your right to make a home that is your own, focused on the choices, needs and desires of you and the people you choose to live with.
- From moving from place to place to get "service" as your needs change. . . to establishing a home and then having "service schemes" change as your needs for assistance change.
- From living in the place owned by someone else, whose idea of what kind of home you want to live in must conform to a wide range of people . . . to owning the furniture you sit and sleep on and choosing a style that fits your taste, age and personality--and if you aren't aware of those subtleties of living, at least having people around you who know you well enough to make the best judgement possible about those sort of things.
- From living in a place where administrators control everything from the menu to the Christmas celebrations . . . to sharing and controlling decisions with the people you choose to live with and have assist you.
- From your life being defined by your deficits and people trying to fix them through a variety of treatment and therapies within the context of your home . . . to being offered the support you need to make a home for yourself, having friends, meeting financial needs, establishing a self-identity and learning within the context of your home.

#### **Change for Organizations**

- From services driven by funding sources, rules & regulations, and current fads in the human service world . . . to support based on an individual's plans, dreams and desires--one person at a time.
- From firmly set administrative policies and procedures telling people (workers and residents) how to act in a facility . . . to firmly held principles about the choice, integrity, and inclusion of the individual

complemented by flexible policies and procedures that encourage support and back-up to a person's desires and plans.

- From an organizational environment of predictability and uniformity . . . to an environment of managing constant change (and often chaos).
- From organizations driven by top-down management . . . to organizations where power is invested in the person with disabilities, those who assist them daily and others who are close to them (family, friends, etc.)
- From an organizational culture where workers constantly turn over and don't get personally involved . . . to organizations where many workers grow close to individuals and commit significant portions of their life to their assistance.
- From organizations isolated from community life unless soliciting charitable contributions . . . to organizations who are *of* the local community fabric with a consciousness about their efforts representing people with disabilities as valued citizens who live as individuals inclusively in the community.
- From organizations where crisis and error create isolation, fear and blaming . . . to situations where error and crisis are seen as opportunities to learn and grow.

#### **Change for Families & People Who Are Close To People with Disabilities**

- From being on the outside looking in . . . to sharing a vision of the future with the person you care about, and participating in carrying out that vision with them and with paid assistants when necessary.
- From a perception of being in the way of treatment . . . to participating meaningfully in a person's life.
- From turning over responsibility to professionals . . . to sharing responsibility.
- From attending celebrations and traditions in the person's life . . . to in many instances being the reason for such celebrations while at other times helping to plan and carry them out.

#### **Change For Citizens**

- From turning over responsibilities to institutions and facilities . . . to expecting to include people with differences in families, work places, neighborhoods, churches, associations and other forms of community life--sometimes with inconvenient and/or expensive accommodation required

John Winnenberg

#### A VIEW FROM CHILLICOTHE

"Of Costs and Benefits"

Jack R. Pealer, Jr.

From an essay by Norman Cousins in the April 14, 1979 issue of *Saturday Review*:

The familiar last line in T.S. Eliot's *Wasteland* suggests that the world will end not with a bang but with a whimper. I believe Eliot was wrong. The world will end neither with a bang nor a whimper but with strident cries of "cost-benefit ratio" by little men with no poetry in their souls.

Their measuring sticks will have been meaningless because they are not big enough to be applied to the things that really count.

In places where I've been or among people I've met lately there's been a lot of talk about cost-effectiveness, cost-efficiency, or cost-benefit ratios. This kind of talk is always around, but it seems to become more prominent in human services in times when money is especially dear. People slip *cost effectiveness/efficiency* into conversations and discussions and, particularly, into their plans for the future. I'm always a little puzzled about what people mean when they use these terms. I am not a close student of economics (either macro or micro), so my thinking about costs and benefits and efficiency, etc. is (like lots of other stuff I write or talk about) absent of the taint of technical knowledge. Perhaps any economists who read this could set me straight.

I am, however, going to presume to think on paper about these ideas, because they seem to me to be a part of a code that carries information about how our communities and our society as a whole respond to people who have disabilities (or to other people who need assistance). First, I'm going to take those terms (cost-benefit, cost-effectiveness, and cost-efficiency) apart. Then, I'll describe what seem, to me, necessary cautions about the application of these terms in programs that try to help people who need assistance.

First, let's think about *cost*. I looked in my faithful *Oxford English Dictionary*, hoping that I might find some obscure Northern Gothic or Old Slovenian root word that would shed new light on the idea of cost. I didn't. The primary definition of the noun, *cost*, is "...that which must be surrendered or given in order to acquire, produce, accomplish, or maintain something." The equivalent verb, says the *OED*, means "...to be acquired or acquirable (at) so much," or "...to necessitate or involve the expenditure of (time, trouble, or the like), loss, sacrifice of (some valued possession), suffering (of some penalty)." So, *cost* is what we think it is. It is what we give in exchange for something we want.

What about *effectiveness*, *efficiency*, and *benefit*? For help with the first two I turned to a 1983 essay by David Korten ("Social Development: Putting People First"), whose ideas about how organizations learn to do new things have been useful to me for several years. *Effectiveness* is the first thing to be aimed at--it means learning to do well what an organization intends or hopes to do. Effectiveness is about the relationship between aims and achievement. *Efficiency*, says Korten, comes later; it involves reducing unnecessary expense of resources (time, money, etc.) so that expansion of activities can be considered. So, an organization trying new things first has to learn to do these things well, and only later can it expect to do them without sloppiness, without waste. *Benefit*, of course, means some good that comes to a person or a group of people--something desirable that happens to or becomes possessed by a person or group.

*Cost-effectiveness*, *cost-efficiency*, and *cost-benefit* are, then, expressions of relationships that are presumed to exist between:

- what we pay to have something done and its accomplishment (Cost-effectiveness);
- a pared-down, leaner price for getting something done, and its continued accomplishment (Cost-efficiency); and
- what we pay to have something done and the presumed good that its accomplishment yields (Cost-benefit).

Are you with me so far? I'm not sure that I am. But let's go ahead and think about these ideas a bit further, particularly about their application to efforts to help people who may need assistance in order to take full parts in community life.

It looks like there are three problems to be considered when we apply *cost-effectiveness et al* to organized efforts to help.

**The idea of *cost* applied to people and their situations.** I looked hopefully to the *OED* for a derivation of *cost* that carried with it a sense that the cost of things has a bit of naturalness or inevitability about it. That kind of sense wasn't there, but I think that it's present, at least a little, in the connotations that have gotten attached to *cost*. The *cost* of services or supports for people somehow means to us something a bit more than the amount that we expend for those services and supports. The notion of cost seems to have transferred to the people themselves, and the implication that there are such people as *costly* people leads us in a dangerous direction. There's just a hint of slavery here.

**The difficulty of determining the cost of doing things.** In human services we have become accustomed to counting *cost* only in terms of money. But, what has to be expended in order to accomplish our aims and to acquire some agreed-upon good for people is not so easily counted that way. It's hard, for example, to figure out how to include in our billing-rates or our unit-of-service fees (these are often believed to be equivalents of *costs*) the value of long-term relationships between the people being helped and those who are doing the helping. But, if we don't account for that value, we are unlikely to be counting the *cost*.

**The difficulty of determining what is *effective* and what is a *benefit*.** Ronald Conley addressed this difficulty in his 1973 book *The Economics of Mental Retardation*: "The measurement of benefits is one of the unsolved problems in most evaluations of investments in people. Data is scanty. Measuring instruments are imperfect or nonexistent for many benefits. By their very nature, many benefits cannot be expressed in terms that are directly comparable." (p. 258) As Conley pointed out, if we're going to develop and use a ratio between costs (if we can be accurate about those) and benefits, we have to attach a numerical value--a money value--to the achievement of our aims and the good that achievement is supposed to do for people who are to be helped. That can be tricky, as Wolf Wolfensberger noted, in a recent (Feb-April, 1992) edition of *TIPS* (Training Institute Publication Series):

In order to apply cost/yield and risk/benefit analysis to pollution, some kind of value must be placed on human life. This is commonly done by valuing people's lives in terms of their lifelong earning power. One consequence is that a poor person's life is worth less than a rich person's. Therefore, one logical outcome of these kinds of reckonings is that poor people may be exposed to more pollution than rich ones. This is precisely what has been happening in the US where the health costs of siting waste incinerators and landfills have been falling disproportionately on the poor (*Greenpeace*, 9 & 10/89).

So, a conversation about *cost-effectiveness* or *cost-benefit* ought to be a careful conversation. It ought to take account of WHO decides the aims or the presumed benefits of an organization's actions. If the decider is the organization itself or its supporters, there is a strong possibility that the aims will produce benefits for the organization first; those aims may produce benefits perhaps only incidentally for the people who need help. The instance of institutional residence for people with disabilities seems a good example. The cost of residential institutions (especially state-operated ones) is high. The expenditure of that cost sometimes helps institutions reach aims--compliance with standards of funders--that are important for the organizations themselves. It looks as though these aims, however, have little to do with an experience of what could be called "the good life" by people who live in such places. The ratios of both cost/effectiveness and cost/benefit depend on whose opinion counts when aims are decided upon and the identity of *what's good* is determined. PASS evaluation teams have often noted that the cost/benefit ratio of a service cannot be higher than zero, regardless of the service's cost, if nothing or harmful things are being done to people.

Counting costs and trying to decide whether we are getting what we wanted in exchange for them, whether we're wasting things, and whether we're achieving good --these are valuable and necessary efforts. Let's just think harder about them, so that we don't find ourselves using these activities to add further to the burdens that are carried by some of the members of our communities and our society.

Jack Pealer