

The Safeguards Letter

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REFRAMING LEADERSHIP: A DAY WITH PETER BLOCK

We long for communities and organizations worthy of our highest hopes and most deeply held values – yet we live and work in places that sometimes seem to conspire against these. We know that our work places and communities need the passion and commitment of its people – yet people often feel disconnected and powerless.

“Reframing Leadership,” sponsored on September 23, 2004, offered participants the opportunity to engage in conversation and reflection guided by Peter Block, whose consulting work and writing has led him to become one of the foremost contributors to useful approaches to these challenges. At “Reframing Leadership” participants considered:

- What’s getting in the way of creating the work places and communities that we want? What patterns, policies, and points of view contribute to keeping us stuck?
- What will it take to create and sustain idealism, depth, and belonging?
- What are some new design criteria that might lead us toward creating more responsive workplaces and communities?
- What new capacities are required and how do we cultivate them?

This event offered a thoughtful challenge to those who are interested in seeing new possibilities in the ways we engage as citizens and members of our organizations.

NOTES FROM A LECTURE BY THOMAS SZASZ

Wolf Wolfensberger

In 11/2000, we attended a lecture by the famed critic of psychiatry, Thomas Szasz, who is himself a psychiatrist and lives in retirement in Syracuse. He has been criticizing certain psychiatric practices all of his career, though he himself claims not to be a critic of psychiatry, but only of psychiatry’s alliance with the state, which we consider to be an understatement. He claims he has no objection to “psychiatry between consenting adults.” Among the points he made at this lecture were the following. There is no such thing as mental illness or mental disease, only overt behavior and misbehavior which can and should be described objectively, somewhat akin to the way that behaviorism has called

for. For instance, “hearing voices” can be stated as “talking to oneself.” Animals have diseases pretty much the same as humans, but there are hardly any analogues in animals to what is called mental illness in humans. Furthermore, humans do not die from mental illness, while they can die from almost all other kinds of diseases. Psychiatry is a secular religion and psychiatrists are successors of the medieval priesthood. He points out that while a disease is a fact, diagnosis is only a word or a verbal phrase, and is tremendously subject to ideological and political pressures. Many of the psychiatric diagnoses are merely reformulations of the seven deadly sins, e.g., lust is not “sex addiction”; what was once the deadly sin of anger has become the psychiatric construct of hostility. If it were true that there is such a thing as mental

illness, then why would it not be neurologists instead of psychiatrists who would be in charge of it? Also, one is allowed to deny that one has some medical affliction, but things go very ill with one if one denies that one is mentally ill when the shrinks have said that one is. It is terrible to call facilities into which "mentally ill" people are put "hospitals," when one is allowed to leave any real hospitals, but mental hospitals are the only ones where one is forcibly detained. To call a place a psychiatric "hospital" if one cannot walk away from it he likened to calling a concentration camp a labor camp. He also noted the irony that one can force people to take psychiatric drugs these days, but cannot force them to take all sorts of other drugs, not even when they have TB. There is also a great irony in that psychiatry has long been invoked to prevent suicides, but is

now recruited to help people, including some identified as insane, to commit suicide. The insanity defense is a travesty. For instance, a person who is called schizophrenic can get away with murder when he claims that God told him to kill his wife, when one would not be equally likely to attribute a claim that God told one to be nice to one's wife as being a symptom of mental illness. He also said that psychiatry is a proselytizing religion in contrast to some religions that are not; and like many proselytizing religions, it is prepared to kill those who resist it. Altogether, he said that the psychiatric cure is worse than the disease.

Wolf Wolfensberger. *TIPS*,
June/August/October, 2000 (reproduced by
permission of the author)

THANKS VERY MUCH!

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Jack Pealer, Sr., Newark, Ohio
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Cathy Heizman, Cincinnati, Ohio
Jack Yates, Stoughton, Massachusetts
Deborah Metzel, Brookline, Massachusetts

JUST QUOTES

The suspicion is not entirely unwarranted that the relatively new profession of bioethics was established to cater to our discomfort and thus to relieve our discomfort. There are things we would not do without professional certification; what is morally doubtful must be certified by expertly guided anguish.

Richard John Neuhaus
First Things, March, 1990

Democracy invites us to take risks. It asks that we vacate the comfortable seat of certitude, remain pliable, and act, ultimately, on behalf of the common good. Democracy's only agenda is that we participate and that the majority voice be honored. It doesn't matter whether an answer is right or wrong, only that ideas be heard and discussed openly.

Terry Tempest Williams, "Commencement"
Orion, March-April, 2004

Democracy's three classic values are liberty, equality, and community ("fraternity"). But the only talk now in our nation is about freedom as liberty and how it can be secured. We hear nothing of the other two any more – equality and community. When liberty ideologically trumps all else in a free enterprise model tied to affluence as a way of life, then even democratic government itself is basically about protecting and promoting freedom to acquire wealth and do with it as you please. The right to property and its uses is more basic than, say, government as an equalizing force ("equality") or government as the people's means to achieve the common good together ("community"). We have quietly amputated two-thirds of the democratic vision.

Larry Rasmussen "The Hymn of All Creation"
Trinity Seminary Review, Summer/Fall 2004

MOVING HOME

Alan Tyne

Spending a day thinking with disabled people who are leaving institutions and the staff who support them reminded me that some people move home an awful lot in their lives, and some very seldom. Some moves are just another step along the way, and some are so big they change life forever.

One person said: "When you leave, it's important not to think just of where you're going, but what you leave behind." On her kitchen table she'd left a note:

"Welcome. We hope you'll be happy here like we have been. Our neighbors are expecting you. No doubt they'll introduce themselves. There are two milkmen – one calls about 6:30, and you leave the money in a tin on Friday mornings; the other comes later, and likes to call on Saturday morning for a chat. The Co-op on the corner is good for most things, but if you want really fresh veg it's worth walking down the hill to Green's...."

And so on. Some moves are like that. Others are the kind of move that when you finally pull the door behind you, no one else is ever going to have to live there again – we hope. Oh how we hope! When we move home, we carry many different hopes in our hearts.

At the beginning the move is like a game. "We're thinking of moving. It's just an idea – nothing definite." We look at one or two places, get lists from the estate agents. There's a lot of talking and day dreams and so it can go on – almost forever it seems. Sometimes we think about it, and sometimes we don't. Then one day it changes and becomes serious all at once. We've seen a place we really like; somebody wants our house. The talk is all of dates and times and money and arrangements. We used to have choices, but suddenly we don't any more. Things begin to move to a timetable that we don't control. The further along this path we go, the fewer choices we really have. You only have choices until you've made them. It's a time of gains but also of losses.

We begin to sort through our things – those we'll take and those that will have to go. Our furniture, clothes, books and papers, equipment. There is not room for everything. Moving home is time to make a fresh start. Things we've hung onto "in case we find a use" (but really because we can't bear to be separated from them) are regretfully dumped. Some things will fit just nicely in the new place. Others simply have to go. And so with our relationships – our neighbours, the people in

the local shop, maybe people we've worked with – we know we won't see them again. Well, we promise to write (but will we? Do we ever? Isn't it like when we meet people on holiday – we say we'll write, but we don't, or maybe just once...). That way parting is less painful. Already we are beginning to look forward with excitement and just a little bit of fear.

Throughout the day we spent with people who were moving, the people spoke of two big questions:

- "Will I be in control of my own life?"
- "Will I be safe?"

These seem like pretty reasonable questions. These are questions anyone would want an answer to at a time of change.

One of the things we have been learning from a lot of people who have moved home recently – the kind of moves where the door is shut for the last time behind you – is that you are more likely to be in control of your own life when it is *your name that appears on the rent-book or the lease or the deeds*. You see, if you are someone who "gets moved" as part of someone else's plan, you are likely to wonder: "If they can move me once, what's to stop them moving me again?" Having your name of the rent-book means that it is your house. That makes it possible to be more in control of your own life.

It's a help for staff too. Staff are in a funny situation. They go to work each day, and like all of us they know how to behave in a work place. They have an office or locker room that's "theirs." They have space and time to gossip and joke with work-mates, maybe make private social arrangements. There are routines that fill up much of the day. Sometimes the office and the routines can make life difficult – they "don't have time," or are "too busy just now" to pay attention to "clients." But when a work place is somebody else's home, that kind of behaviour doesn't really work very well for

the people whose home it is. When you have your name in the rent-book, it helps a lot to remind staff whose place it is, in case they might forget and think it is just another work place.

We've been learning too about what keeps people safe. By and large, safety is other people. You can have bolts and bars and policemen and procedures, but they don't keep you safe. It is the other people who share your life that keep you safe. I'll borrow some lines from my friend John O'Brien to explain this. The first kind of person who helps keep us safe is our "Anchor" person. It seems each of us needs someone special who helps hold the centre of our life together. A famous psychologist, interviewed toward the end of a long lifetime of professional work, was asked if he could put all of his wisdom about people into one sentence. He thought for a while and said:

"Nobody grows unless somebody loves them."

Unless each of us has at least one person who has a quite unreasonable attachment to us, life does not make much sense, and when life makes little sense, we are not safe. It's difficult to know what makes an "Anchor." Some of us have many, and we all know people who seem to have none, and that worries us greatly. We can choose to be someone's "anchor," but it is not something one can pay someone else to do. Sometimes a staff person is someone's "anchor," and that is not because they are paid but because they've chosen to do that.

Another kind of person who keeps us safe is an "Ally." An ally is someone who stands by you, even when times are not good. I made a long voyage in a small sailing-boat in the summer. We were many days away from land. At one point there was a storm. We were not in too much danger, but storms are always a worry. During the day we saw a great ship that showed up out of the waves and the rain, and it just kept station with us for about an hour. He couldn't help

at all. To come close would have put all our lives in danger, but he just kept a watch – to see that we were all right. And we all felt better because of it. An ally is like the ship – standing by you. Sometimes an ally will speak out for us. Sometimes she will give us the courage to speak out for ourselves. Staff are sometimes allies, but often it needs to be an outsider – someone who can speak freely without fear.

The third kind of persons who help keep us safe are Assistants. There are things we need to do each day which we cannot do alone. Assistants are there to help us with those things. Since the things which each of us can or cannot do are quite different, each of us needs assistants who are very clear about us as individuals, who are very clear that their job is to help us to do the particular things we need help with. It may be getting about, ore money, or remembering things, or looking after ourselves, or a host of other things. For each of us it is different, and we need assistants who can be with us for just those specific things.

For many of us, the things we need help with are about home making, and about making our way in the life of our community. Many of us have not had too much experience in these things, and “moving home” is a time when we’ll be doing a lot more of them. So we need assistants who are really good at homemaking and at making a way in the life of our community.

It’s very important of course that we choose the right assistants – not just people we like (sometimes you don’t know if you like someone until you’ve shared some time with them doing something you’re both interested in), but people who are good at what we need help with: home making and community. We’ve been finding that the best way of knowing about assistants is to go home with them. If you go to their house and smell good cooking, see a home that looks really interesting (I don’t mean just clean – anyone can do that), a place with

room for a cat, a place you could be comfortable in yourself – then the chances are they’ll be a really good assistant. If theirs is the sort of house where people feel happy walking about with no clothes on when they’ve had a bath, chances are it’s the sort of house people feel safe in. When you walk with them around their neighbourhood, if they stop and talk with people they obviously know, offer help when it’s needed, are greeted by others, then chances are they’ll know about making a way through community life.

The rest of the things assistants need to know we can easily teach them, but these are the very essentials. They need to know how you help someone else make a home – they need to be home makers. And they need to know how community works – not the kind of knowing that comes from reading books and attending courses, but the kind that comes from living it every day in their own lives.

Finally, Associations help keep people safe – the clubs and societies, groups and classes, informal gatherings which keep us safe by giving us “membership.” By joining, we “belong.” When we belong we have a place. Our place is what keeps us safe. One of the nice things about John O’Brien’s list of people who keep us safe is that they all begin with “A,” which helps us remember: Anchors, Allies, Assistants, and Associations.

Of course, moving home is just the start. It’s an exciting time. There are things to be done, arrangements to be made. It’s a time to by “busy being busy.” But what comes next is different. What comes next is the business of settling down to make a life together for ten, or twenty, or forty years – or for as long as it takes. There may be other moves, but none will ever be quite the same as this one. Mostly life will settle to a more even pace. The occasional excitements are all the more fun against a background of people and places – a home and a community – which doesn’t change too much. We need to make up our minds

about being Anchors, Allies, Assistants and Associates not just for the short-term, not just for "Moving Home," but for the rest of life.

Alan Tyne

(Alan Tyne lives in Wivenhoe, Colchester, England – near the North Sea. He originally wrote this article in 1993, when he was helping people plan their moves from institutions to community life.)

About THE SAFEGUARDS LETTER

The Safeguards Letter is an occasional 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*, 3421 Dawn Drive, Hamilton, OH 45011. We welcome our readers' ideas and reactions.

A VIEW FROM THE BACK WINDOW

"Time to Worry?"

Is it time to worry? Or, to be more precise, is it time to worry even more about how services for people with disabilities may be shape-shifting? I'm often cynical about organized services and systems. But at lots of other times I have to confess naiveté. I've worked at this community-service thing for 34 years. Many colleagues have worked longer and far harder than I have. Surely all that effort and dedication mean that the position of people with disabilities as members of communities-as citizens-is now secure. Doesn't it? Sure, we have to stay alert. But we should, by now, be merely placing the obvious last pieces in the puzzle we started assembling in the 1970's. Shouldn't we?

A quick and over-simplified history lesson. In western Europe until the middle of the 18th century, organized service for people described as "mad" featured coercion and cruelty: "...in losing his reason, the essence of his humanity, the madman had lost his claim to be treated as a human being."¹ That view was abandoned by such late 18th century reformers as William Tuke, a Quaker merchant from north England. Under the influence of the Enlightenment's faith in the capacity of humans for improvement, Tuke and others carried out what became known as a "moral management" or "moral treatment" approach to people with (as Thomas Szasz describes them) "problems in living." Moral treatment featured release from captivity, kind and quiet human interactions in typical houses (often in the country) and intimate and regular interchange between the patient and the moral managers-the doctors. The initial successes of moral treatment and its congruence with then-current ideologies about human capacity led to its widespread imitation and adoption in what we now term "psychiatric" services. For example, the history of the public mental hospital in Williamsburg, Virginia reports a formal shift to moral treatment (reduction of restraints, more regard for patients as growing, healing humans, etc.) after about 1835.² Within 30-40 years after its beginning, however, moral treatment lost much of its persuasive capacity. Perhaps this happened because of the number of people to whom personal approaches had to be applied. For instance, at some point there had to be problems with the sheer cost of the amount of personal attention devoted by doctors to patients. Historian Roy Porter observes that: "It was too personal to be permanent."³ Perhaps, as well, hospital-keepers again grew impatient with their charges, and force or restraint seemed easier or was reportable to superiors as more cost-effective. Does any of this sound familiar?

Moral management has been paralleled, in services for people with mental retardation or developmental disabilities, by a twentieth-century set of ideas initially called the principle of normalization (or re-formulated as the principle of social role valorization). More recently, offshoots of that principle-"the community services movement," "inclusion," or "person-centered supports"-have gained sway. A good many of the readers of *The Safeguards Letter* have spent their lives trying to make the ideas summarized by these terms into reality for people with disabilities.

¹ Howard Becker, *Outsiders*, quoted in Scull, Andrew. *Madhouses, Mad-Doctors, and Madmen*.

² Zwelling, Shomer S. *Quest for a Cure: The Public Hospital in Williamsburg, Virginia, 1773-1885*.

³ Roy Porter. *Mind-forg'd Manacles*.

When ideas are new, their very freshness compels attention and, often, overcomes opposition. Later, though, opponents may re-group. These opponents sometimes find ways to re-describe their old ideas using the newer language (e.g., institutions portrayed as "community-based" services or even "facility-based supported living"). Opponents also, of course, capitalize on the inevitable failings or weaknesses in the implementation of new ideas to which they are opposed. Those failings are interpreted as evidence that discredits an idea like moral management or normalization. If normalization can be discredited, then other (usually less-dignifying to the service-user) idea-sets can be brought forward or, we might say, dragged out of storage.

And that is happening. Here are examples of old, previously discarded ideas brought from the shadows:

- One group of British politicians has plans to arrange for "...pupils with disabilities (to be) removed from the mainstream schools and taught separately." (*Guardian*, August 6, 2004) Proponents of this idea argue that integrated education may both damage children with disabilities (because integration has not been well done in British schools) and dilute the quality of education for other students. If these plans are put into practice, many segregated schools would remain open and others could be expected to start.
- A large church in the Virginia suburbs of Washington, DC will build a "respite center" (70 beds) for "children and youth" with developmental disabilities. This center will include such services as lengthy (week-long-they don't say how many consecutive weeks) respite care, group therapies, and even haircuts or styling and dentistry provided by "volunteer professionals." Those who know the history of institutional respite are aware that the proposed center will quickly become a large permanent residence for 70 people and, depending on how much land surrounds it, the base for even more similar "centers" around it.
- The Virginia legislature recently made it much easier to build and operate group homes under the "Intermediate Care" program than to assist people to establish their own homes with useful supports. Now, public service systems in Virginia have a much greater incentive to develop "12-bed" facilities.
- The Illinois Health Facilities Planning Board has approved the construction (and, presumably, the occupation by "clients") of four 10-bed group homes on the grounds of the former Lincoln Developmental Center in central Illinois. Lincoln State School, as it was formerly known, was the site of Jack Dykinga's well-known and Pulitzer Prizewinning photo "Ward of the Lincoln State School" in the Chicago *Sun-Times* in 1970.⁴ Now, there will be a greater chance of history repeating itself.
- Beatrice State Developmental Center (BSDC) in Nebraska still houses 400 people. Now Nebraska's governor wants to look into sending people with disabilities who "need a higher level of attention" to BSDC. "A higher level of attention" apparently means a

⁴ See Trent, James W. *Inventing the Feeble Mind*, following p. 224.

more-secure location, because this proposal followed an incident when a resident of a "community-based care facility" in Lincoln, NE fatally injured a child.⁵

This last example is particularly telling because Nebraska was the location of North America's first effort to create and maintain an entire comprehensive service system based on the principle of normalization (and other adaptive ideas). To a large extent, ENCOR (the Eastern Nebraska Community Office on Retardation) was built to counter expansion trends at Nebraska's only state-funded "service" for people with mental retardation – the state school (now "developmental center") at Beatrice.

Moral management did not fail; it was abandoned. Normalization has not failed; it hasn't been fully tried. As a matter of record, normalization has furnished the intellectual energy behind more than 30 years of improvement in the life-situation of many thousands of people with disabilities. But, normalization presents an ideal that human services and systems seldom reach. And, when our reach falls short, we often react both by blaming the standard (it's too high or it sets us in the wrong direction) and by abandoning the earlier ideal for others that leave us more comfortable with the results we've produced. "Efficiency" (whatever that means), "cost-benefit," and "security" offer such more apparently reachable goals.

So it is time to worry. And, right now, as I'm singing a worried song, I'm unable to devise an uplifting ending to this little essay. Those who continue to hope and work for better lives for people with disabilities will have to keep on hoping and working and keep on trying to tell others about the ideas and ideals that sustain us.

Jack Pealer

⁵ *Beatrice Daily Sun*, July 10, 2004