

The Safeguards Letter

A Publication of OHIO SAFEGUARDS

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LEARNING OPPORTUNITY IN NEARBY WEST VIRGINIA

A Revised Conceptualization of Social Role Valorization, Including 10 Related Themes: A High-Order Concept for Addressing the Plight of Socially Devalued People, & For Structuring Human Services

- To be held **Tuesday, March 28 through Friday, March 31, 2006**
- at the **Summit Conference Center, 129 Summers Street, Charleston, WV 25301**
- taught by Joe Osburn of the Safeguards Initiative and Jo Massarelli of the SRV Implementation Project

Description of the workshop: This workshop provides an introduction to Social Role Valorization (SRV), using the core themes developed by Dr. Wolf Wolfensberger, considered one of the most influential thinkers in the field of mental retardation in the world. Dr. Wolfensberger's work helped lay the foundation for many current human service trends, including integration, safeguarding of individual rights, and the deinstitutionalization movement.

SRV is a systematic and universally applicable concept for structuring human services, strongly anchored in the empiricism of psychology, sociology, and long and broad human experience. SRV suggests a close relationship between the socially perceived value roles that people hold, and whether people in those roles will be accorded opportunities and other good things of life. Bad things tend to get done to people who are seen in devalued roles, and good things tend to be afforded to people in positively valued roles.

Topics to be explored will include: the universality of social devaluation; the defining power of roles in people's lives; strategies for pursuing socially valued roles, or at least less devalued roles, for devalued people, with an aim toward improving their life conditions; enhancement of people's social images; and enhancement of people's competencies.

Who the workshop is intended for: Planners and managers who are interested in the lives of people who are disenfranchised from society because of mental retardation, mental illness, poverty, homelessness, autism, age (elders), physical impairment, or learning impairment, service recipients, family members, advocates, citizens, and paid or unpaid human service workers. The workshop is taught at a college-level, with long hours and hard work. The information presented is quite complex in its entirety, requiring a systematic exposition of multiple ideas.

Format of the workshop: The workshop is taught in lecture format, with extensive use of overheads and slides. Time is built into the schedule for audience discussion and questions, *although there are no small group exercises in this format.*

Tuition: Because the WV DD Council is committed to providing valuable and worthwhile information to policymakers, human service workers, and others to benefit citizens who have

developmental disabilities and their families, the tuition will be only \$100. This includes handouts, refreshments, and 4 lunches. Some assistance with expenses will be made available to people with developmental disabilities and their family members.

Deadline for registering is March 1, 2006. For more information, call 304-558-4884, or e-mail LindaHiggs@wvdhhr.org

IN MEMORY

As 2005 comes to an end, we note and mourn the deaths, during the past year, of two gentle men. Both of them were devoted to helping people with disabilities and those people's families lead richer lives. Both were convinced of the accuracy and utility of the principles of (earlier) normalization and, more recently, social role valorization as the foundation for assistance to people who have been socially devalued.

Ray Newnam was, for many years, a guiding force at the Developmental Disabilities Training Institute at the University of North Carolina at Chapel Hill. Ray saw to it that training in normalization and social role valorization was widely available in North Carolina and nearby states. Such training established a sound base for developmental disabilities services in North Carolina and helped enable hundreds of people to leave institutions, find and hold jobs, and assume valued places in their communities.

Conrad O'Donnell was one of the good companions who gather every October at Sebago Lake in Maine. Conrad was the guiding hand and spirit behind Shriver Clinical Services Corporation and Shriver Nursing Services/Family Lives in the Boston area. A student and colleague of Gunnar Dybwad, Conrad devoted his energy and intelligence to finding ways to support very vulnerable children in their families. The announcement from Shriver Clinical Services Corporation on the day of Conrad's death pledges "...to continue the work he began, and to build in his honor the best medical safeguarding services this state and this country have ever seen."

Let's lift a glass to honor and remember the work of these two fine men. They will be missed.

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.

NOTES ON DEINSTITUTIONALIZATION

In the last issue of *The Safeguards Letter* I ranted about my home state's apparent lack of interest in ending the practice of institutional living by people with developmental disabilities. Since then, several items that have crossed my desk have strengthened my fear that the

institution— not completely done away with yet— may be starting to build its power and position again. That's not good news for people with disabilities or those who love them.

Item. A "Policy Research Brief" published by the University of Minnesota notes: "Recently, there has been a slowing of the

trend toward deinstitutionalization nationally.” There remain 13 states that have closed NO state institutions, although 8 states have closed all of their state centers for people with developmental disabilities. The research brief further notes: “In some places in the United States there are those who want to maintain and even expand the role of institutions, thus denying their residents (and all those at risk of being placed in institutions) freedom, opportunity, and other benefits of community life.”

(Source: *Policy Research Brief*, September 2005, Vol. 16, No. 1. Available on-line at <http://ici.umn.edu/products/newsletters.html#policy>)

Item. A November 2004 report from the U.S. Department of Justice indicates that someone living at New Jersey’s Woodbridge “Developmental” Center had, between April 2002 and March 2003, a 1 in 120 chance of injury, from whatever source, each day. That means everyone who lived there during that time could expect a statistical average of three injuries every year. A good many of the investigated injuries were quite serious. The institution had 49 days to decide how to “correct the deficiencies,” lest it face a lawsuit. (Source: Dave Reynolds. *Inclusion Daily Express*, November 15, 2004).

Item. New Jersey Protection & Advocacy, Inc. has filed suit against the State of New Jersey. The aim of the lawsuit is the “release of hundreds of New Jersey residents from unnecessary confinement in state institutions for the developmentally disabled.” A staff member of the protection & advocacy agency said: “Individuals have lost years of their lives to unnecessary confinement; those years can never be regained.” (Source: “Lawsuit Charges State with Abandoning Hundreds of Residents in Developmental Centers,” Press Release from New Jersey Protection & Advocacy, Inc., September 29, 2005)

Item. At least temporarily (and who knows for how long) Hurricane Katrina accomplished what federal courts had forbidden—the re-occupation of unused

buildings at Clover Bottom “Developmental” Center near Nashville, TN. Forty people with developmental disabilities who are assisted by two Louisiana agencies fled the hurricane on tour buses. With their support workers, the people stayed in a Tennessee state park east of Nashville until they began to run out of their medicines. Appeals to a nearby hospital pharmacy for medicine-refills led to media coverage about the group. Tennessee state government officials quickly noticed the stories in the media. They were able, fairly quickly, to arrange for the group to move to two buildings at Clover Bottom. One wonders how long it might have taken to organize places in typical community housing. While it’s heartening to learn that state governments can move so quickly in an emergency, it’s also sobering to recall that “unused buildings” sit on many institutional grounds, perhaps waiting again to be use—not only in “emergencies” but also in circumstances when prevailing ideas about people with disabilities might change for the even-worse.

Item. The business page of the Cincinnati *Enquirer* (12-16-2005) announced that a local agency—Resident Home Corporation—has plans for a re-development of its 37-acre “campus” in northwest Cincinnati. The re-development intends to achieve something that “...the Resident Home board hasn’t encountered...elsewhere,” according to the agency director. That unencountered something will be: concentrated housing for up to 200 people who have developmental disabilities and who are “aging.” The agency’s strategy is the construction of a set of different “living options.” They don’t call it a “continuum,” but they probably will. The “options” include one or two-bedroom apartments, “assisted-living” units, and a “nursing-level care facility offering round-the-clock medical and custodial care.” (Cincinnati *Enquirer*) It’s only surprising that the agency officials haven’t “encountered” this kind of pattern before. They could travel to any of Ohio’s state-operated institutions, or to a privately-operated one less than 15 miles north of

their “campus,” where they could “encounter” a pattern-of-service that’s well established and familiar and that their innovation will resemble. “Life-care centers” are institutions. This one will, eventually, be no different.

Item. In Illinois the public sector is busily working to anticipate the private Cincinnati “life care center” concept. The Governor of Illinois has, with enthusiasm, revived the former Lincoln “Developmental” Center. Formerly known as the Lincoln State School, the center was immortalized by a 1970 Pulitzer Prize winning photograph in the Chicago *Sun-Times*. The photo shows a nude person in a sheetless crib in a large stark room filled with dozens of other similar cribs and beds. (See: James Trent. *Inventing the Feeble Mind*, following p. 224.) The new plan for Lincoln will mean construction of four housing units with “10 beds” in each unit. A local newspaper (The *Pantagraph* of Bloomington and Normal, IL, November 2, 2005) also reported that: “Other (presumably, remaining-institutional, ed.) buildings could be transformed into retail outlets or state-run medical facilities for developmentally disabled residents.” Guess which option is more likely. Do you think Saks Fifth Avenue or Wal-Mart will be interested in old institutional cottages? So, the likely outcome of this scheme is housing for 40 people right next to a disability-segregated state-operated nursing home. Sounds familiar, doesn’t it? Within a few years, the Chicago papers might get another chance for a photography prize for a picture from Lincoln.

Item. Not everyone in North America accepts plans like the ones in Cincinnati and Lincoln without noisy protest. In early 2005 the government of Manitoba made public its plans to spend \$40 million to renovate buildings at the provincial institution, Manitoba “Developmental” Centre in

Portage la Prairie. Among other results, that decision makes Manitoba the only province in Canada that plans to increase its funding for institutions. On September 29 and 30, 2005, Community Living – Manitoba (an association “... dedicated to the full inclusion in the community of persons of all ages who live with an intellectual disability”) and People First – Manitoba sponsored a conference in Winnipeg. The purpose of the conference was to make a clear statement of opposition to the provincial government’s plans. Conference organizers assembled a full two-day agenda. Self-advocates, including some who knew the Manitoba institution first-hand from having spent portions of their lives there, shared their memories and contrasted their institutional stays with their lives now. Citizens of other Canadian provinces (notably British Columbia) shared the story of the closing of institutions there. James Conroy came from Pennsylvania to describe US institutional closures and their good results for people. On the second day participants (number – about 500) marched, at lunch time, to Memorial Park in downtown Winnipeg to rally/demonstrate against the \$40 million decision. My friend (and *Safeguards Letter* reader) Bob Jones said, in a note: “This was great! We had 400 (number of people living at the Centre, ed.) cut-out cardboard figures on sticks in the ground to symbolize folks in MDC. We had a crowd...music...speeches.” One former institution resident was quoted, in a summary of the rally, “Get them out of danger and into the community where they can be free.”

People are in danger in institutions. Deinstitutionalization is not finished until the last person leaves such places and makes a home in her or his chosen community.

Jack Pealer

WHAT'S MISSING: A REVIEW OF JOHN O'BRIEN'S REFLECTION ON "MOST INTEGRATED" SERVICES

John O'Brien has the fortunate habit of looking behind the curtain of contemporary human services both to reveal weaknesses and to point out directions for useful effort if we want things to be better for people who use services and for our communities. One of his recent examples of this is entitled: **"to interact with non-disabled persons to the fullest extent possible."** **Perspective on 'Most Integrated' Services for People with Developmental Disabilities.** I want, here, to introduce this essay and to recommend it as a helpful look at "social integration," the element that is still missing in the experience of most people who have developmental disabilities and who rely on externally provided support.

The essay begins with a quick review of what we know from our experience (empirically) about promoting social integration, or, as O'Brien puts it: "...skillfully weaving a fabric of relationships that cross exclusionary boundaries separating disabled and non-disabled people." We've learned, he asserts: 1) that the mutual relationships that we seek are possible; 2) that how we design support and the ways we carry it out are crucial to the likelihood that people with disabilities will experience good relationships; and 3) that many, if not most, people with developmental disabilities live their lives in the absence of vital connections with anyone other than their families and those others who are paid to work with them. Anyone who has "facilitated" person-centered planning gatherings knows that the "relationship-maps" that are drawn for people with disabilities reveal this latter absence over and over again.

The bulk of the essay invites us to consider five different points-of-view from which we can examine and learn more about the meaning of "most integrated services." The first of these perspectives is the legal one, as set forth in the United States Supreme Court's *Olmstead* decision, which proposes the hope in the essay's title—that people with disabilities ought to be enabled "...to interact with non-disabled persons to the fullest extent possible." At issue in the essay is the undependability of *Olmstead* as an explication of social integration, because the determination of what is "possible" is left primarily to professionals and because the legal decision offers no information about how we should work toward the standard it espouses.

The second point-of-view is that of social role valorization (SRV). This perspective offers more valuable assistance to understanding and to practice. SRV helps us know better what "social integration" is and see how customary human service practices can either support or interfere with its realization in people's lives. The essay provides an example of a human service agency that used SRV to uncover for itself and then correct its failings, despite its devotion to person centered work, to support integrative relationships.

Positive psychology, as exemplified in the writing of Martin Seligman and his associates, is the third point-of-view for examining and learning about "most integrated." Positive psychology intends to identify the things that help human beings to thrive and be happy. Its contribution to promoting social integration connects to its usefulness to help human service workers (as O'Brien says) "...reflect on the kind of life it is that (they) aspire to assist people to get." If life is not only to be "pleasant" but to, as positive psychologists describe it, ascend to the status of either "engaged" or "meaningful," then the ones living those lives will have to be in relationship with others. Integration is, then, a key to the good life.

The practice known as "life-sharing," wherein people with disabilities and people without disabilities live in intentional communities and try to shed distinctions among the customary "human service" roles, offers the fourth point-of-view about integration. The best examples of life-sharing are the Camphill and L'arche communities, both of which reach around the world.

The essay notes that people in life-sharing communities have demonstrated, over and over, both the possibility and the vibrancy of social integration. Life-sharing raises some important questions that could serve as the basis for reflection by any group that aspires to support people toward "most integrated" lives (pp. 28-29 of the essay).

The final point-of-view on "most integrated" is that of "social capital," as exemplified in the writing of Robert Putnam (e.g., *Bowling Alone*). The idea of social capital rests on the assertion that a relationship exists between the extensiveness of social connections and the richness of life in general in a given place. Important social benefits flow from the presence of strong social networks. Thinkers about social capital distinguish between "bonding" capital (strong relationships among people who are seen as like oneself) and "bridging" capital, which involves connections with people seen as different from oneself. O'Brien describes the role of the "Community Builder" as one that enables "bridging" to occur. The Community Builder is the helper-to-connect among otherwise isolated people and, thus, acts as a catalyst for the production of greater amounts of social capital.

This essay, **"to interact with non-disabled persons to the fullest extent possible.' Perspective on 'Most Integrated' Services for People with Developmental Disabilities"** is new. If you want to read it, you can eventually download it as a "PDF" document from the Center on Human Policy at <http://thechp.syr.edu/rsapub.htm>. It may not yet be posted. If you want to read it sooner (and I think you should want to do so), e-mail me at jackjr441@earthlink.net and I'll send you an electronic copy.

Jack Pealer

JUST QUOTES

...for proper social connection between people and their community, it is possible to imagine a building process in which groups of families, of a size small enough so people can talk to each other and reach agreements, can themselves work in clusters, have control over their own common land, and lay out their own lots according to their own designs and their own wishes. This is a human solution which places control over the essential issues in the hands of the people who are most affected by these issues, and who understand them best.

Christopher Alexander
The Production of Houses

Memory,
native to this valley, will spread over it
like a grove, and memory will grow
into legend, legend into song, song
into sacrament. The abundance of this place,
the songs of its people and its birds,
will be health and wisdom and indwelling
light. This is no paradisaal dream.
Its hardship is its possibility.

From "Work Song," *The Clearing*, 1977
Wendell Berry

A VIEW FROM THE BACK WINDOW

"Of Costs and Benefits"

(I've been hearing even more than the usual amount of talk about costs, effectiveness, and cost-benefit lately. It's probably because human service money is tight. I'd like to re-offer some thoughts about all that. So, here's a repeat of something that originally appeared in *The Letter* in the spring of 1992. JRP)

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

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