

The Safeguards Letter

A Publication of OHIO SAFEGUARDS

Number Thirty-six

Summer 2005

EARLY NOTICE: IMPORTANT OPPORTUNITIES TO LEARN

1. MORAL FUNCTIONING IN A DYSFUNCTIONAL WORLD - JUNE 2006

Yes, it's a long way away, both in time and space (for Ohioans anyway). But it would be well worth considering participation in "**How to Function Morally, Coherently & Adaptively in a Dysfunctional (Human Service) World.**" This seven-day workshop, which was designed by Dr. Wolf Wolfensberger, will take place June 10 through June 16, 2006 in Calgary, Alberta, Canada. Dr. Wolfensberger will **not** be in attendance (although his ideas will certainly be present) at the workshop, which will be presented by associates with many years of experience and relevant knowledge.

Anyone involved in the field of human services (whether through work, volunteer, family connections) has seen first hand many of the problems of services in today's world. These problems may come from economy, laws and regulations, society, etc., and they seem to be mounting, which bodes ill for people dependent on such services.

This workshop proposes that human services are inherently limited, dysfunctional, and to some degree unfixable, and that this dysfunctionality manifests itself in pervasive tendencies of service efforts toward decay, disorder, and even violence. Organized agency services especially do not work well over the long run and often end up doing the opposite of the noble purposes they started with or still claim. In the face of this, what is a committed "server" to do? The workshop will first outline these unpleasant realities and the contemporary societal and service dynamics that aggravate them. It will then propose adaptive strategies that may enable workshop participants to (better) perceive the nature of these realities and to achieve a greater degree of moral coherency and integrity in how they live and act, particularly in their service roles.

In view of the length and depth of seriousness of this workshop, the tuition cost is a bargain at \$475.00 Canadian. For more information, you can contact Bill Forman at (403) 262-8515 (forman@telusplanet.net) or Carla Hamarsnes at (403) 249-1554 (chamarsn@ucalgary.ca).

2. PLAN ON ATTENDING -- Fourth International Conference on *Social Role Valorization* (SRV)

DATES: May 14 to 18, 2007

THEME: *Crafting Valued Social Roles*

PLACE: Ottawa, Ontario, Canada

Description: For devalued persons, occupying valued social roles seems to be an effective way of achieving the good life. The theme of the 2007 conference goes to the very heart of Social Role Valorization (SRV). Plenary speakers, discussants and workshop presenters will describe how valued social roles can be crafted for vulnerable people of different ages (*from early childhood to old age*), in key life spheres (*education, work, living situation, family and friendship relations, religion and spirituality and culture and leisure*), and in various service fields (*including mental handicap, child*

welfare, mental health, early intervention and medicine). The crafting of valued social roles will be approached on a number of levels such as *individual, familial, organizational and societal* and from several perspectives including practice, policy and research.

For more information, please contact Joëlle Pelland-Lavolette at: jpelland@instvalor.ca

About THE SAFEGUARDS LETTER

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

Editor's Note: About a year ago, I learned that Wolf Wolfensberger had assembled much of his thinking about the situation of families with children with disabilities into a new book, which the Training Institute in Syracuse had published. I longed for families to read, react to, and review that book. What follows are a "response" and a "review" by friends Mary Beth and Peter Paul of Westerville, Ohio. Beyond all the other things that Mary Beth and Peter do in their lives, they are the sometimes puzzled but often proud parents of Peter Ben.

Jack Pealer

BOOK RESPONSE: Wolf Wolfensberger. *The Future of Children With Significant Impairments: What Parents Fear and Want, and What They and Others May Be Able to Do About It.* Syracuse, NY: Training Institute for Human Service Planning, Leadership and Change Agency (Syracuse University), 2003.

When Jack Pealer, editor of *The Safeguards Letter*, held out a copy of this book at an advocacy meeting and said, "Would anyone like to read/review this?" I couldn't volunteer fast enough. After reading it, I gave it to my husband, Peter Paul. We couldn't stop talking about it. Thus *The Safeguards Letter* gets a double report!

This slim (111 pp.) book can be covered in an evening. (Keep a pencil handy for writing your own notes in the margins.) I want to share with you my response and reaction upon reading this text, and Peter will provide the more traditional review.

First barrier: Wolfensberger's language. If one has read even a few of his writings, it is easy enough to hear his unique voice. However, I began wincing at each mention

of "mentally retarded" or "impaired person". I found myself thinking of all the people I would love to have reading this book along with me, but I know most find these labels offensive and would not be open to reading further. Wolfensberger gives a rationale for his terminology choices on p.2. He has obviously heard every possible critique about this problem, and does not apologize for using what he calls "traditional and informal idiom(s) that might be used by ordinary citizens."

Yet these "ordinary citizens" are *not* the same audience as the parents and human service workers for whom he writes. Parents I know have taught one another to use what is considered highly respectful labels and person-first terminology. It seems that Wolfensberger is not following his own caveat that appears in the body of his work about Social Role Valorization: the very people who have been historically devalued need to be treated with the highest possible dignity and respect. That certainly should include the language used to reference them!

The message is too important, however, to let Wolfensberger's idiomatic use keep parents from hearing it. So please read on.

I found myself wanting to ask parents about their own fears that Wolfensberger refers to in the title. (He cites many stories in the news that back up his points, such as terrible murder/suicides as well as parents who have suffered divorce, financial ruin, etc. so as to afford the care for a child with a life-long dependency.) I want to gather the older siblings and parents and have them talk to the newer families of kids with disabilities. I want to ask the teachers and support people in my son's life how we can apply some of the tenets to my son's education. I want to have heart to hearts about issues surrounding guardianship, self-determination, and inclusion. Because Wolf even rejects the term "quality of life", I would love an evening devoted to thinking with others about that.

According to Wolfensberger, polite, well-groomed, nicely mannered folks who have some special skill to contribute will likely fare better than those who have not learned these attributes. He makes a frank and somewhat uncomfortable point about teaching "good followership". Yes, uncomfortable, but also irrefutable, in my opinion.

The points he makes about the dangers of parents' isolation, of feeling that "no one could possibly understand the difficulties we face," of the old-fashioned virtue of obedience, are all provocative and worth deeper reflection.

I also have imagined a dialogue with Wolfensberger. I would tell him how our own family life has played out some of the perils that he describes. I would tell him that I have indeed found great support from other parents, but not in the way he describes. (On-line communities have been as helpful and compassionate as many flesh-and-blood friends.) The other thing I would tell him is that this book can be very, even extremely, depressing. (He admits this.) He has a fondness for listing all kinds

of bad reports. Even when he does have something good to say about a service or strategy, he uses the tongue twisting "least worst" to describe it.

Wolfensberger's solutions to the fears that we parents have? He exhorts us to have *strategies* in place, as there is no such thing as a *solution* to the problems we parents face. On pp. 70-72 he covers societal values and ways people reject our loved ones with disabilities. He then proposes radical steps parents might take to make changes in their own lives. He lists the noblest ways in which parents can rise above their own family's troubles and personal prejudices and help others. (Sort of a Maslow's Hierarchy of Moral Development of Parents of Children with Disabilities!) An existing, helpful strategy he recommends is "Citizen Advocacy". These are local, volunteer efforts that he proposed and helped establish years ago, but cannot be accessed in every state.

Wolfensberger surprisingly omits any mention of *l'Arche* (founded by Jean Vanier) communities or their sister *Faith and Light* communities. I would want to reference them as viable, hopeful, joyful places and ways for people with disabilities and their loved ones to support and be supported.

He also fails to reference the *Microboards* that Faye and David Wetherow created as a way to develop individual supports. Nor does he mention *A Good Life* by Al Etmanski, a practical, hope-filled futures-thinking guidebook.

Nonetheless, I can imagine using his book, *The Future of Children with Significant Impairments...* as a course for parents, teachers, and human service providers. It should be required reading for "Partners in Policymaking" as well as teacher training programs. This book should be in the hands of lawyers who help with special trusts and estate planning, medical students, theologians, and the like.

Even though I still wince at some of Wolf's terminology, I believe his book is so important that our family's future may depend on how seriously we heed his advice.

Mary Beth Pilewski Paul, Westerville, OH
August 2005
ppaul1@columbus.rr.com

REVIEW. Wolfensberger, W. (2003). The future of children with significant impairments: What parents fear and want, and what they and others may be able to do about it. Syracuse, NY: Training Institute for Human Service Planning, Leadership, and Change Agency (Syracuse University). 120 pages.

I have both a personal and professional interest in reviewing this monograph by Wolf Wolfensberger. On a personal level, I am the father of a son who has significant impairments (that is, Down syndrome and autism). Professionally, as a teacher educator who is hearing impaired, I am interested in the inclusion of children with disabilities in education and in the larger society – albeit, most of my scholarly work concerns children who are deaf or hard of hearing. I am familiar with Wolfensberger's concept of normalization and his recent rendition – social role valorization. I have even read about Wolfensberger's theological views, which have affected me pervasively, particularly as they pertain to individuals with mental retardation.

If you are not familiar with Wolfensberger's writing style, this monograph can be difficult to read. In fact, it might be downright repulsive. Although it is not lengthy, I do not recommend that one read the monograph in one sitting. This little book is meant to be chewed and swallowed in little pieces – to paraphrase a line from Francis Bacon – with careful reflection on each piece. As Wolfensberger states in the Introduction, the material of this treatise is based on "more than 40 years of experience I have had working with, or relating to, parents of children with various kinds of impairments" (p. 1). So, even though this is not a primary research work – that is, based on specific survey studies and so on – this work does reflect some of Wolfensberger's developed, long-standing syntheses of research – specifically, his powerful voice – on issues related to individuals with significant disabilities and their parents.

The monograph is divided into three sections with subsections that could be called chapters. The first section is about 62 pages in length and addresses the supervision, care, or situation of an individual with significant impairment when parents or significant others are 'gone.' The second section is brief (about nine pages) and focuses on the responsibilities of parents in addressing the needs of their children. The third section is about 36 pages long and depicts the experiences (bad and good) of parents who have attempted to address their children's needs. There is a one-page Conclusion to the monograph and six pages of References.

There is no best method to summarize Wolfensberger's litany of points. He offers three concluding statements ("depressing thoughts," p. 54) for the first section. Basically, Wolfensberger argues that the needs/advocacy of most individuals with significant impairments are not adequately developed or achieved by family members. Thus, these individuals are at the service of others outside of their family. The second point: Even if the families are competent, they neglect to develop future plans early enough. This second point of Wolfensberger implies that many families procrastinate when it comes to developing financial, residential, and supervisory plans. One of the most powerful statements associated with this point – and an eye-opener for me – appears on page 58: "Some parents are under the impression that services will always be there ... plus they expect that their son or daughter will always have a place in such a service. However, as noted, service funding, and services themselves, come and go." The third

point speaks to the disengagement and isolation of parents as they grow older and attempt to continue to care for their children with severe disabilities. Wolfensberger provides some somber vignettes of parents who have killed their children.

The second section, albeit a short one, provides Wolfensberger's views on the obligations of parents and society in addressing the needs and future of individuals with severe disabilities. Parents are always involved (or should always be involved), especially because this is a lifelong endeavor. Society should pitch in as well and even more so when parents are experiencing too much difficulty or are overwhelmed by the tasks. If you read carefully, you will catch a glimpse of Wolfensberger's theological voice, particularly when he makes a case for a categorical or moral imperative on caring for such individuals who are marginalized or have little chance of speaking for themselves. I had to smile at one of Wolfensberger's examples for this section: "Mother Teresa – a woman of so little learning that many people considered her to be stupid early in her life as a nun – went before the US government leaders and told them very simply: a society that kills its children will become a violent society" (p. 72).

The third section exemplifies Wolfensberger's earlier point (that is, "depressing thought") about the shortcomings of most parents. Some of the flaws include a discussion of the following ideas: (1) someone else will take care of my child; (2) the 'here-and-now' syndrome (that is, not planning for the future); and (3) my situation is unique (resulting in detachment from others or going it alone), and – my favorite – (4) expecting too much or too little. With a strong emphasis on the errors that parents/caregivers make, this section of the monograph can cause a great deal of disillusion, even for parents who think they are doing the right thing. Nevertheless, despite the profound negative, depressing overtones of this little book, I think this serves as a wake-up call to remind parents and others of the need – better yet, the moral obligation – to plan for the future continually. Such planning for individuals with severe impairments should never be taken for granted and, most likely, should never be undertaken alone. It is true that parents are parents for life; however, it requires a tremendous amount of courage, willingness, and love to be effective, never-ending parents for children with 'significant impairments'.

Peter V. Paul
The Ohio State University

Address for Correspondence:
Peter V. Paul, PhD, Professor & Director
School of Teaching & Learning
College of Education, The Ohio State
University
333 Arps Hall, 1945 North High Street
Columbus, Ohio 43210

Electronic mail: paul.3@osu.edu

JUST QUOTES

Cancer is stable. It maintains itself. And, in the small, this is true. But it only maintains itself. Since, in order to maintain itself, it must in the end destroy what is around it – the very organism where it lives – it ultimately too destroys itself, by helping to destroy its surroundings.... The patterns which are alive maintain themselves in the long run, because they do nothing to destroy their immediate surroundings, and they do nothing drastic, in the short run, to destroy themselves.

Christopher Alexander
The Timeless Way of Building

And you, to whom adversity has dealt the final blow
With smiling bastards lying to you everywhere you go
Turn to, and put out all your strength of arm and heart and brain
And, like the Mary Ellen Carter, rise again!

Rise again, rise again - though your heart be broken
And life about to end
No matter what you've lost, be it a home, a love, a friend
Like the Mary Ellen Carter, rise again.

Stan Rogers

Editor's Note: I received the following via e-mail from Robert Perske. I asked whether I could print his concern in The Safeguards Letter. He replied: "I would be thrilled if you printed this concern in The Safeguards Letter. I do hope, however, that the next edition comes out soon. The judge just scheduled Daryl Atkins' execution for this coming December 2nd."

CONCERN FOR DARYL ATKINS

I am deeply concerned about what just happened to Daryl Atkins.

On August 5, a jury in Yorktown, Virginia voted that Mr. Atkins was not mentally retarded.

The jury did so even though the U.S. Supreme Court used the Atkins case when it banned the execution of persons with this disability on June 20, 2002.

Those of us in the field who have followed this case closely know that Mr. Atkins is mentally retarded and that compelling evidence of this was presented at his trial. Leading mental retardation experts testified. Their well-supported opinions were based on objective testing of Mr. Atkins, as well as on detailed descriptive information from numerous schoolteachers, family members, and individuals who had been Mr. Atkins' peers growing up.

So how could this jury conclude that Mr. Atkins was not mentally retarded?

I believe it is because the Virginia court mistakenly allowed the prosecution to designate as an "expert witness" a psychologist whose views are not grounded in science or medicine and who by his own admission is unqualified to diagnose mental retardation.

The prosecution's "expert," Stanton Samenow, is a professional witness, not a helping professional. In trial after trial, and on his website he proclaims the same thing: criminal defendants act as they do because they choose to be evil and because they are too lazy to work at being good.

While Dr. Samenow is of course free to believe as he wishes, his views are politics not psychology. No court should permit him to use trial proceedings to pander to law-and-order jurors when he can support his claims through no methodology recognized in the field of intellectual disabilities.

In Mr. Atkins' case, Dr. Samenow dismissed the relevance of low IQ and relied on Mr. Atkins' own description about his life skills and abilities to conclude that he does not have retardation.

This is absurd. While IQ testing has its limitations, no one working in the field would suggest that it is not the linchpin of a mental retardation assessment.

Similarly, with respect to life skills, known as "adaptive function," no one who knows anything about mental retardation would rely on an individual's self-report for such a determination. The strong tendency to exaggerate their abilities and deny their limitations is perhaps the single best-established attribute of persons with mild mental retardation, and long recognized in the literature.

If courts and juries are going to engage in life-and-death decision-making regarding who is and is not properly diagnosed with mental retardation, they should hear from experts who are qualified by training and experience to render opinions in this area.

Dr. Samenow does not meet this standard.

Robert Perske

A VIEW FROM THE BACK WINDOW

"A Pledge Not Redeemed"

Over thirty-five years ago, just after I started working with people said to have mental retardation, I visited – for the first time – the place then known as the Columbus State Institute. Before my visit was done I made a private and naïve pledge that, by the time I finished whatever career I was to have, all the people who were living or might live there or in other such places in Ohio would find real homes. They wouldn't have to live in "batches" (see Erving Goffman) any more. They would have meaning in their lives.

I've tried, most of the time, to live up to that pledge. Others can judge the extent of those attempts. It's evident now, though, that I won't see my pledge redeemed.

In mid-July, this year, the state agency that has responsibility for service to people with developmental disabilities in Ohio quietly announced that a contract had been awarded to a private consulting firm. The contract was/is for a study that "...will examine the role and function of Ohio's developmental centers as an integral part of the state's present residential service system for people with disabilities." As far as I can tell, this means two things, neither of them good.

First, the charge to the contractors ("examine the role and function...as an integral part") gives the game away before it starts. The charge doesn't ask outside experts to consider whether such a role or function can exist. The state simply concedes the continuation of state-operated institutions in Ohio. That means Ohio either cannot or will not do what New Hampshire, Vermont, Maine, and our own neighbors West Virginia and Michigan have already done – close all the institutions and invest further in strengthening the possibility of real homes for people with developmental disabilities. Now, just the fact that these other states – including some much less wealthy than Ohio – have taken such a decision means that the step is possible. So it's not a matter of whether it can be done. Ohio's concession to institutional continuance is a matter of will. We Ohioans, the state says, want these places to keep on. Perhaps we want them as depositories for people whom communities find especially challenging or puzzling. Perhaps the bonds issued 20 and 30 years ago to pay for institutional building and rebuilding are not paid off yet, and we need someone to be in the places, generating revenue, so that the debt-service (interest) can be paid. So we pay someone a small amount of money to speculate about the "role and function" of institutions we don't want to part with.

Second and more important, the “role and function” contract constitutes a threat to every Ohio citizen who lives with a disability. An intended product of the “role and function” contract is a report to be titled *The Developmental Centers’ Role in Ohio’s Continuum of Services: A Long Term Plan* (emphasis added). Someone hopes or expects not only continuation of the institutions but that they will continue for the long haul. No one knows how long that is. No one knows for sure who might go to live in those places; it’s not unknown that eligibility criteria change. And, because the collection of people in institutions has always included many who would rather be living somewhere else, the preservation of the institutions will mean regular violations of the “self determination” that the state has said for some time that it favors. Those many people who would rather be somewhere else are threatened with the facts and the effects of segregation and isolation. It’s unlikely that separation and loneliness would be their “choice.”

Twenty-six years ago the Center on Human Policy, founded by Burton Blatt (author of *Christmas in Purgatory*, *Exodus from Pandemonium*, and *Souls in Extremis*), issued what ought to have been the last word on state institutions. It should trump the “role and function” report. It’s called “The Community Imperative,” and it says:

In terms of Human Rights:

- All people have basic human and legal rights
- These rights must not be taken away just because a person has a mental or physical disability
- Included in these basic rights is the right to live in the community

In terms of education and support services:

- All people are valuable
- All people have strength and abilities
- All people have the right to services in their lives that support these strengths and abilities
- These supports are best provided in the community

So:

To meet basic human rights and get the best services, all people, no matter what their abilities, have the right to live in the community

Even longer than 26 years ago – in 1972 (I forget which month) – a large group Ohioans gathered in Cincinnati to listen to Burton Blatt speak--about institutions and their abusiveness--and to talk about the beginnings of community living by Ohioans with developmental disabilities. As I remember it, the conference formally resolved to close all Ohio mental retardation institutions within ten years.

We’re now 23 years late. We’re still paying for studies to justify institutions. Lifelong Ohio citizens have a right to expect something better. Why not simply adopt “The Community Imperative” and get on with the business of living up to it?

But, I’m afraid that a private and naïve pledge I made won’t be redeemed, and I’m sorry.

Jack Pealer

OHIO SAFEGUARDS
3421 Dawn Drive
Hamilton, OH 45011