The Safeguards Letter

A Publication of OHIO SAFEGUARDS

Number Fifty *Winter 2011*

IMPORTANT LEARNING OPPORTUNITY

Social Role Valorization, Part I, Including 10 Related Themes: A High-Order Concept for Addressing the Plight of Socially Devalued People, & For Structuring Human Services, sponsored by the West Virginia Developmental Disabilities Council

Human service workers play a critical role in the lives of the children and adults they serve. This workshop, together with a practicum experience called PASSING (Part II), lays out a helpful framework for service workers to use in implementing relevant and effective services in the lives of socially devalued people.

When/Where? Monday, March 28 through Thursday, March 31, 2011. • Location: **Summit Conference Center,** 129 Summers Street, Charleston, WV 25301 • Taught by **Jo Massarelli** of the SRV Implementation Project and **Joe Osburn** of the Safeguards Initiative.

This workshop is specifically oriented to leadership development and is Part I of a two-part workshop. It introduces the learner to Social Role Valorization (SRV), using the 10 core themes developed by Dr. Wolf Wolfensberger, one of the most influential thinkers in the field of human services broadly, and mental retardation specifically. His work helped lay the foundation for many current human service trends, including integration, deinstitutionalization, and safeguarding of individual rights. A central goal of SRV is to enable socially devalued people to attain culturally valued roles, with an eye towards having a typical life and gaining access to all that typical citizens enjoy. SRV will be reviewed with the implications of its positive assumptions about the worth of all people and their belonging in our communities. Since competency and image enhancement are essential building blocks of valued social roles, both concepts will be thoroughly explained. Participants are encouraged to reflect on the typical life experiences of socially devalued people, with an eye towards deeper identification with the people they serve. A past participant said of this workshop, *"This training has changed my outlook on human services and has provided me with a better understanding of how expectancies can affect success or performance. Thank you all for your helpful suggestions and educated experiences, it was a truly informative and beneficial training!"*

This workshop is intended for: the well-motivated learner! This includes paid or unpaid human service workers and managers, service recipients, family members, advocates, teachers, board members, and others interested in the lives of people who are disenfranchised due to mental retardation and other developmental disabilities, poverty, homelessness, age, mental illness, or physical impairment. 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. The workshop is taught in lecture format, with extensive use of overheads and images.

What participants will learn:

- To recognize current social trends that affect vulnerable people, including social policies, laws, and cultural values.
- Positive strategies in support of personal social integration and valued social participation, particularly in different areas of social life.
- Essential elements of relevant and effective service, including group size and composition, accessibility, individualization, and interactions.
- A developmental approach to learning and teaching, especially for people with significant intellectual impairment.

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 is only $225**. This **includes handouts, refreshments, and 4 lunches**. Some assistance with expenses will be made available to people with developmental disabilities and family members.

For more information: contact Linda Higgs by e-mail at Linda.s.higgs@wv.gov, or by phone at 304.558.4884.

NUMBER FIFTY

You may have noticed that this is the fiftieth issue of *The Safeguards Letter*. I certainly noticed, though I have to say that it crept up on me. Why numbers like that are so often remarked upon isn't clear to me. In this instance, the back-story to the number 50 is that it's taken 25 years to get there, and an average of two issues a year doesn't seem like that big a deal. I'd say that the unhappy average is more testimony to sloth on the part of the editor than anything else. After all, it's not as though there's a shortage of things to write about. Failures of systems of human services haven't declined in frequency or intensity; systems usher in as much failure now as ever. Neither, fortunately, has there been an absence of interesting and hopeful efforts to help vulnerable people live richer lives; plenty such going on and worthy of notice and comment. And, of course, as one of my sweatshirts says: "So many books; so little time." There is much thoughtful writing to reflect upon. We have vague plans to get all the previous issues collected on the Internet and, of course, to post any new issues as they appear. People say they read *The Letter*. So, I guess we'll stay at it for a while yet. As always, submissions from willing writers are very welcome. JRP

NATIONAL HONOREE AMONG OUR READERS

Recently I learned with great pleasure that a long-time and regular reader of *The Safeguards Letter* has been nationally recognized for her faithfulness and committed work.

Jan Lilly-Stewart of Charleston, WV is one of eight US citizens chosen by the USA Cable Network as winner of the "Characters Unite Award." The cable network says that the award is intended "…to recognize extraordinary individuals who have made significant efforts to fight prejudice and discrimination, while increasing tolerance, respect and acceptance."

OHIO SAFEGUARDS has known Jan since she and three of her colleagues from the West Virginia Developmental Disabilities Council attended a PASS Workshop we held in Cleveland in 1990. I think Jan came to the workshop as a skeptic, but she devoted herself to learning and went home convinced that helping others learn about normalization (and, later, social role valorization) was a critically important thing to do. While working for the DD Council Jan helped organize early PASS training in West Virginia. She has served as a Team Leader and Trainer in PASS workshops on more than one occasion. At the same time, she built a deserved reputation as a fierce advocate for people with disabilities—especially at the West Virginia State Legislature but also in other contexts both inside and outside West Virginia.

The citation from the USA Network that accompanies the notice of Jan's receipt of the "Characters Unite Award" says, in part:

> Jan has been involved in fighting for the rights of people with disabilities all her life. She has worked more than 25 years in counseling and advocacy positions and has earned the admiration and respect of policymakers, colleagues and countless people with disabilities. As Director of the Fair Shake Network, she continues to work tirelessly to give a voice to those with disabilities.

Check out the entire citation at: http://www.charactersunite.com/awards. It's fitting that someone who knows Jan well nominated her for the "Characters Unite Award," and it makes all the sense in the world that the USA Network agreed about her extraordinary contributions. We could not be more proud or happy for Jan. Ms. Lilly-Stewart, you deserve this.

Jack Pealer

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TAKING CARE OF PLACE: SUMMER 2010

(Editor's Note. The following article is reprinted, with permission, from the Summer 2010 issue of Black Diamond Press, the quarterly newsletter of southeast Ohio's Little Cities of Black Diamonds Council. Long-time readers of The Safeguards Letter remember and often ask me about Sandy Landis and John Winnenberg, who were regular contributors to The Letter at one time. As this article notes, both of them still contribute in mighty ways, and this piece may help bring readers up-to-date on their work. JRP)

During this early 21st Century we live in an electronic state where our view of the world often appears on screens: the internet, Facebook, I-phones, satellite TV, etc. On these screens community seems more often to be defined around a particular interest or need--a political perspective, a hobby, or a shopping desire catered to by a particular show, web site, "wall" or blog. In this world of screens it is easy to experience "place" as somewhere out in space, at times not connected to personal reality at all. Despite this sometimes entertaining and educational, sometimes sad and sobering circumstance, there are still people who are caring for real live places.

After having our place defined by *Dateline NBC's Friends & Neighbors* show recently, we once again are struggling with the reality of "our place" being seen as a place of impoverishment, rather than one of rich history and a recovering natural environment. I don't dispute the poverty claim, nor begrudge the need for immediate relief. However, in light of this feature story (one that gets told about us in the major media every few years), I do feel even more compelled to work to highlight our region's assets of history, natural environment, cultural arts and civic effort to provide a more complete picture of who we are as a people. I also contend that by doing this over the long haul, our quality of life will make all of us, including those who live in poverty, less vulnerable.

"This Place Matters!" is the motto being promoted by the National Trust for Historic Preservation these days is as it continues to raise funds to save historic treasures in our country. The motto is a fitting one, shared by Ann Curry of NBC as well as those of us who care about nurturing our many assets. In that spirit this issue of *Black Diamond Press* is devoted to people and organizations that demonstrate that "This place matters" through their hard work this summer, in the midst of the Great Recession, as well as over the years when times seem a bit more hopeful.

Let's start with the late Reverend Paul Johnson of Millfield (who recently passed away) and his counterpart Rodney Galentin of Buchtel, supported by the administration at Hocking College. Neglected and long seen as an intrusion on the pioneer era theme of Robbins Crossing at Hocking, the small white clapboard Don Nunley Mine Museum is in the process of finding a more appropriate home. The museum is off its foundation and sitting on skids ready for a trip to the park in Buchtel where it will be

resurrected as a place to learn about mining in Athens County. This project has taken the determination and persuasive good nature of those two men to remove countless barriers over the past year. Watch on our web site (http://littlecitiesofblackdiamonds.org/) for the date of the rededication of the building at Buchtel.

On the outskirts of Shawnee this summer, dirt is flying at two former mining sites with aquatic life in the nearby streams surprisingly enjoying the benefit. Major mine subsidences at the old Mine #21 site on the south side of Rt. 155 are being closed, and coal waste is being sealed at the headwaters of Sunday Creek's West Branch by the Sunday Creek Watershed Group. In the opposite direction, at the Rock Run mine site just off Rt. 93 south on the road to New Straitsville, the Wayne National Forest in cooperation with the Monday Creek Restoration Project is undertaking an even more extensive project. Once complete, this project will create a small lake and recreation area for local citizens. Both projects will eliminate Acid Mine Drainage (AMD) from these long abandoned mine sites. AMD is created when water mixes with minerals to create a high level of acidity that destroys aquatic life in streams. Hats off to inspired people such Mike Steinmaus at the Monday Creek Restoration Project, Gary Willison at the Wayne National Forest and various folks at the Sunday Creek Watershed Group who have worked hard over the past several decades to bring funding to these much needed projects that make this place a better place for all living creatures!!

In museums at Haydenville and New Straitsville, volunteers are updating exhibits and welcoming guests on a regular basis this summer. In Haydenville the community spirit of the history group has inspired many improvements to the town, including a new playground for children located on the former school lot. In Rendville, volunteers are cleaning up and painting an abandoned house and the Town Hall in anticipation of the dedication of a historic marker there this fall. At Payne's Crossing volunteers assisted Wayne Forest staff in gravestone repair at Payne Cemetery for a historic marker dedication in June. Individuals can do inspiring things as well, as church member Ada Vernon of Salem Hollow demonstrates, She is over half way to her goal of raising $3,100 to save and reopen the historic Mt. Zion Church building near New Straitsville. If you wish to contribute you can do so via a check to LCBD Council-Mt. Zion Church Fund. Call the LCBD office at 740-394-3011 for details.

Place doesn't as seem so important when there aren't people using it, other than in the case of our forest, which we happily see used by creatures ranging from bear (spotted in Athens County on July 31) to Bald Eagles (now nesting at Burr Oak Lake). Thus it is important to recognize those who have been busy this summer keeping our places and spaces alive with activity. Among those deserving a tip of the hat are Michelle Davis Starner at the Corning-Monroe Civic Center where community events ranging from Fish Fries to Scrap Booking workshops improve life for citizens; and Stuart's Opera House where free concerts in downtown Nelsonville are a gift to quality of life here. The list expands to those who keep annual festivals alive such as 4th of July Celebrations in Murray City and Corning; the Ohio Fiesta (formerly Chile Pepper) Festival in Glouster, the Moonshine Festival in New Straitsville, the Congo and Shawnee Homecomings and the season-ending Parade of the Hills in Nelsonville and Old Settlers Reunion in Jacksonville. A lot of volunteer work goes into these events!
Despite the distraction from "place" we attribute to technology, place can matter "on-line" and on television as well. That is the case with the Little Cities Archive as volunteers Lilian Winnenberg and Joe Winnenberg are putting in dozens of hours this summer cataloging and entering photos, artifacts, books and other documents that tell the story of the Little Cities region. We also have enjoyed the support of news reporter Mike Jackson of NBC4 in Columbus to tell our story this summer, with a presence and coverage at the Payne Cemetery celebration in June and expected coverage of the Rendville marker dedication this fall.

Finally, my work along with colleague Sandra Landis and the faithful Sunday Creek Associates board has been, and continues to be inspired by place. SCA cares about the future of this microregion. In this

spirit two developments worthy of sharing are in the works this summer. First, the Ohio Humanities Council has selected Sunday Creek Associates (and the Ohio Hill Country Heritage Area) to work with them to identify what our organization has done during the past twenty years to support "the poetry of place" that leads to what is being popularized as "Civic Tourism". Civic Tourism is defined as tourism that is inspired by witnessing the caring for and improvement of place by its citizens. Next is planning by SCA to convert the first floor of the Tecumseh Theater Building in Shawnee (former library space) into a "space" for multi-purpose learning activities for local citizens and tourists. If a place is cared for and made interesting by its citizens, then others will want to visit and learn about that place's story. If it's any indication of all of our efforts here to understand and improve our "impoverished place," seventeen foreign journalists, 30 northeastern Ohio school teachers and 17 homemakers from the farmlands of northern Perry County all have visited the Little Cities on tours this summer. It wasn't amusement parks and shopping they were looking for. It was the story and importance of this place...its history, its environment and the people who are struggling every day to care of it...to make it a better place. Hats off to all of you who are doing just that--making sure that this place matters!

John Winnenberg, Corning, Ohio

JUST QUOTES

Defence Mechanisms. I often notice anger and a certain defensiveness welling up in me when I am in discussion with someone who holds intellectual, political, social, philosophical or religious views different from mine, especially if there is no communion or friendship that binds us together. I can feel the tone of my voice changing. It is no longer a tone of welcome, openness, listening and tenderness, but a lower, more aggressive tone. Where do these defense mechanisms come from? Do they spring from a fear of being shown to be wrong, of being at fault, of being criticized? Fear that the other person is touching irrational prejudices within me? Fear that they might think that I am closed in an ideology which serves my purposes?

Jean Vanier, *Our Journey Home*, p.68

Long story short: we don't get to make our lives up. We get to receive our lives as gifts. The story that says we should have no story except the story we chose when we had no story is a lie. To be human is to learn that we don't get to make up our lives because we're creatures. Christians are people who recognize that we have a Father whom we can thank for our existence. Christian discipleship is about learning to receive our lives as gifts without regret. And that has the deepest political implications. Much of modern political theory and practice is about creating a society where we do not have to acknowledge that our lives are gifts we receive from one another.

Stanley Hauerwas, *Living Gently in a Violent World*, pp 92-93

Though I am old now, I still operate out of the youthful assumptions that originally attracted me to the Catholic Worker—that basic sense of simplicity and the immediacy of the Gospel put into practice, that call to give up everything and become a disciple to serve those in need, to confront war and injustice, to be a human being, and to do all this outside of the context of an institutional apparatus, whether that be state or church or foundation or nonprofit corporation. To meet human needs in a human way—that is what appealed to the youthful pilgrim in me. Moreover, while I have not seemed to have accomplished anything permanent, the Catholic Worker was not founded with an eye towards permanence. It simply is just a living witness to the Gospel ethic of humans responding humanly to one another.

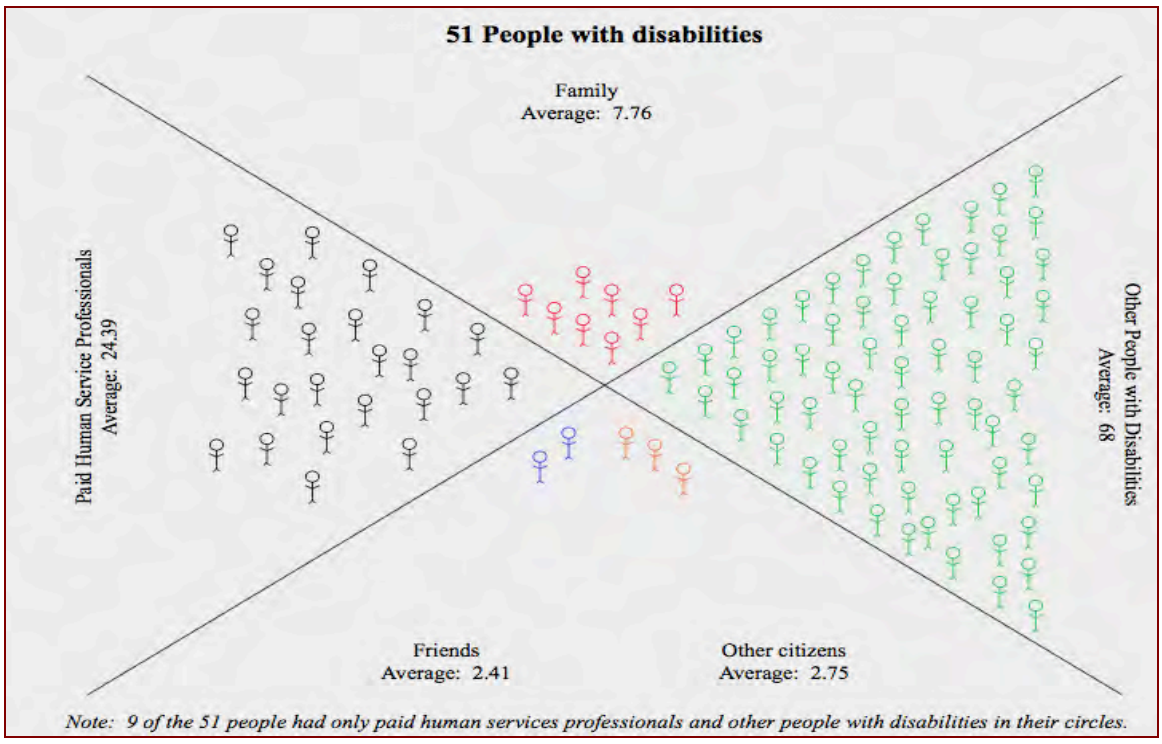
Jeff Dietrich
The Catholic Worker, October-November 2010

A VIEW FROM THE BACK WINDOW An Image of Non-Belonging

A few months ago I was part of a discussion about the social lives and circumstances that many people—including people who have disabilities—experience. I thought about ways to illustrate a common situation that faces many who are regular users of human services. Then, I remembered.

About twenty years ago, when I was part of two fairly large-scale and ambitious training projects in Ohio, I visited developmental disability programs—and the people who used them—in many parts of the state. My intention was to teach local (mostly) professionals ways to carry out the explicit promise we made to people with disabilities and their families: that we would design and carry out "programs" unique to each person who used services. We have always promised that we would approach the work "one person at a time." I tried to carry out my intention by helping local folks learn about what has come to be known as "person centered planning. Local professional staff would somehow select (we helped them think about this) a number of people with disabilities and families who agreed to take part in "personal futures planning." The planning session would either include or be preceded by a conversation with a family—or with others who knew the person well—about "who is in this person's life, right now." We used Beth Mount's "Relationships Map" as a template. I probably facilitated or took part in more than a hundred such conversations over a period of several years. I usually produced the photocopy-able records of those conversations. And, a few months ago I remembered that those copies were still in files in my basement, not having been looked at for nearly twenty years.

So, I took them out and looked at them. It turned out that I had fifty-one (51) relatively complete records of personal futures planning conversations, including the relationship maps. I decided to count the reported relationships attested to on those maps, within the rough categories of relationship "types" that we had used originally. Then, I divided the totals of people represented on all maps in each category by 51 to find an average. Here is an image of what I found. *(Thanks to Tim Vogt of Cincinnati and Bellevue KY for transposing my hand-drawn graphic into the format below.)*



Now, I make no claim that this is research, in any formal sense. I note, though that these 51 people lived in many different settings (cities, small towns, rural) and in residential situations ranging from families' homes to large "ICF-MR" settings. People who came to the planning meetings were: the persons who were the foci of the planning, each person's family and friends, and local service personnel who worked with the person and/or knew the person well. So, I assumed then (and think that assumption holds up now) that planning-groups were the best possible authorities at the time on the relationship-lives of the people who were at the center of each group's activity and attention.

On average, these people had 2.41 "friends"—people closely involved in their lives who wanted such involvement and who were neither related to the focus persons nor paid to be with them. 2.75 other citizens (again, unpaid, but more distant and less-engaged than friends) were part of the average relationship pattern. And people had nearly 8 family members with whom they were connected. But, the average person's life was awash with paid human service workers and other people with disabilities—with whom they were grouped by organized services and with whom they (very likely) had little in common other than a disability categorization.

This image is all about separateness, not about belonging to or in a community. If someone is engulfed by others said to be "like" her/himself and by yet others who have temporary and often-distanced relationships to her/himself, there will be little time or space for other connections. And that's particularly true in an "us and them" world like the one in which we're currently living. The image above depicts a formula for isolation and loneliness, the products of segregation. Enforced separateness is the enemy of community. There's no getting around it.

Jack Pealer

The Safeguards Letter

A Publication of OHIO SAFEGUARDS

Number Fifty-one *Last Days of Summer 2011*

REMEMBERING A DEAR FRIEND

A dear friend of OHIO SAFEGUARDS, Kathryn Gough Boulger, died at her home in Chillicothe on July 12. Long-time readers of *The Safeguards Letter* (those who have been with us for more than 20 years) may recall that OHIO SAFEGUARDS twice carried out teaching and writing projects for the Ohio Developmental Disabilities Council. The second of those projects involved the study, conversation with Ohio citizens, and writing that led to the publication of a booklet titled *The Community Living Paper* in September 1992. That *Paper*, which was jointly issued by OHIO SAFEGUARDS and the Developmental Disabilities Council, intended to provoke discussion of service quality and then-current service practice experienced by Ohioans who had developmental disabilities. As its introduction said, The Community Living Paper hoped to "argue for a greater effort to hear what people with developmental disabilities have to say and to point in some of the directions in which a serious public conversation might lead."

The writers of *The Community Living Paper* (Sandra Landis, Jack Pealer, and John Winnenberg) were all trained to be very image-conscious people. We thought that the *Paper* ought to rely on more than just words to convey its ideas about community life. So, we commissioned a young artist, Kathryn Gough of Chillicothe, to turn some of our words and notions into more-living images. Kathryn was then a student at the Columbus College of Art and Design. We met with her several times to explore ideas and shape the work she produced. We remember, in particular, that we once gathered in a back room at Katzinger's Deli on South Third Street in Columbus so we could go over the work at least one more time.

Images of Community Life, Kathryn Gough, September 1992

We had been moved by a shared appreciation for the woodcuts that had, for nearly sixty (now almost eighty) years, added power to the pages of *The Catholic Worker*. Many of those woodcuts were created by Fritz Eichenberg. We showed some of the Eichenberg images to Kathryn, talked about the ideas we wanted to enhance, and asked her to imagine those ideas in the spirit of Eichenberg. She succeeded with beauty and effectiveness. Above are some of the images that appeared in *The Community Living Paper*.

Many of the observations and conclusions in *The Community Living Paper* are, we think, still accurate nearly twenty years later. Certainly Kathryn Gough's images of community—of conversation, learning, growing, sharing, and celebrating—still carry all their power. We grieve with Kathryn's family and friends. We recall her contribution to our work with appreciation and pride.

OHIO SAFEGUARDS

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JUST QUOTES

(The) movement toward local adaptation necessarily is being led from the bottom. And it confronts a leadership from the top—in government, in the corporate economy, in the universities—that is utterly lacking in imagination, local loyalty, and local knowledge. **Both conservatives and liberals, having accepted the ecological and social damages of industrialism as inevitable, even normal, have conceived the individual as subject alone either to the economy or to the government.** (emphasis added, JRP) In this official numbness, though it is clearly self-doomed, there is for the moment an almost overwhelming power.

Wendell Berry, "American Imagination and the Civil War"

Humanity today is at a crossroads. Technology enables us to do everything, except to bring people together in love and thus make our world a happier and more loving place. Technology alone brings material progress. It gives power. It takes us some way towards conquering the moon and stars. Is it not now time to come back down to earth, to rediscover the beauty of our earth, of humanity, of each one of us? Then we can reach out together to the weak and the poor, using all that is good and humane in technology, so that our hearts and intelligence can be transformed through compassion. What can bring this about? How can we begin to change our world, one heart at a time?

Jean Vanier, *Our Journey Home*

This is what you shall do; Love the earth and sun and the animals, despise riches, give alms to every one that asks, stand up for the stupid and crazy, devote your income and labor to others, hate tyrants, argue not concerning God, have patience and indulgence toward the people, take off your hat to nothing known or unknown or to any man or number of men, go freely with powerful uneducated persons and with the young and with the mothers of families, read these leaves in the open air every season of every year of your life, re-examine all you have been told at

school or church or in any book, dismiss whatever insults your own soul, and your very flesh shall be a great poem and have the richest fluency not only in its words but in the silent lines of its lips and face and between the lashes of your eyes and in every motion and joint of your body.

Walt Whitman, from the Preface to *Leaves of Grass*

Let Evening Come

Let the light of late afternoon
shine through chinks in the barn, moving
up the bales as the sun moves down.

Let the cricket take up chafing
as a woman takes up her needles
and her yarn. Let evening come.

Let dew collect on the hoe abandoned
in long grass. Let the stars appear
and the moon disclose her silver horn.

Let the fox go back to its sandy den.
Let the wind die down. Let the shed
go black inside. Let evening come.

To the bottle in the ditch, to the scoop
in the oats, to air in the lung
let evening come.

Let it come, as it will, and don't
be afraid. God does not leave us
comfortless, so let evening come.

Jane Kenyon, *Collected Poems*

WHY WE SHOULDN'T BLAME THE MURDERS OF DISABLED KIDS ON LOUSY SERVICES

(For a long time I've kept a copy of these thoughts from Dick Sobsey—author of, among many other writings, Violence and Abuse in the Lives of People with Disabilities: The End of Silent Acceptance. They are reprinted from the newsletter of "Not Dead Yet," March 2001. This seemed a good time to re-share them. JRP)

March 2001 -- The murders of a young girl in Montreal and a man in Philadelphia (recently) compels me to write this. It came in the same week that I wrote a letter to a London newspaper on the subject of depressed and underserved parents who kill their children with disabilities and the same week that in Vancouver, the report on the Katie Lynn Baker homicide has focused on how services let a family down and doesn't ask why no one has been charged with that homicide.

There are several points that I feel are essential to make.

1. Clinical depression is an illness that as far as we know is mostly biologically determined and in many cases can be treated successfully. You do not "catch this" illness from having a disabled child or from getting lousy services.

2. The primary service needed by parents who have this problem is not respite care or free diapers or a more inclusive program for their child. They may need these things and deserve all those things and more, but genuine clinical depression has a lot less to do with the circumstances people are in than with internal factors. The primary service these people need is mental health care.

3. Reinforcing the notion that parents are driven to killing their children (and sometimes themselves) by the lack of services is almost certain to do more harm than good. For people who are getting close to the edge of doing violence to themselves and others, certifying their thinking as rational and their behavior as justifiable increases the probability that they will go over the edge.

4. Constructing suicide or homicide as justifiable by the circumstances also stops people in those circumstances, their families, and the people who provide services for them from getting the help they need.

5. I am not saying that these people are necessarily bad people; most are not. I am saying that in many cases they are sick and need treatment, not pity that feeds their sickness.

6. After studying hundreds of these killings, I am convinced that like people who are suicidal, displaced anger is often a factor in these cases. Parents who feel that they have been ignored by the system, their friends, their spouses, or whoever and cannot direct their anger at the real target displace that anger onto their children and sometimes themselves. The feeling of being hard done by may well be justified in many cases, but it would not justify the parent for shooting the school principal who bars a child from school, or the social worker who cuts their services. Neither can it provide any sense of justification for turning that anger against a vulnerable person.

7. When we as parents exploit these cases by saying it shows what crappy services can drive parents to do, we encourage this displaced anger. I am not recommending that we parents kill anyone but I am recommending that we direct our anger into action to change the system.

8. When we say, look what this poor parent was driven to do by the system and if things don't get better more of us parents may just do the same thing, we are holding our children hostages. We are collectively threatening to harm them if society doesn't take a little better care of us. The biggest problem with this is that hostage taking always assumes that the person or people we are trying to influence care more about the hostage than we do. In this case, society does not care more about our kids than we do. Threatening that more parents will hurt kids without better services will not improve services, but it may arouse enough guilt for society to tell us that they understand after parents start killing kids.

9. We need positive image for parents not negative ones. When we rationalize violence as understandable considering the rough situations families face, we are not helping anyone build hope for the future. For very parent who faces "impossible' circumstances and goes to pieces, there are ten who face rougher situations with faith and hope.

10. I love my kid. I realize that I am a lot luckier than a lot of people who have a lot on their plate but I have good days and bad ones. Last week was a bad one. My back went out and I just couldn't move. Maybe this has something to do with carrying a 75-pound kid up seven flights of stairs to the water slide or trying to lift him into the van when some jerk has parked 8 inches away and there is no room to lift properly. Maybe it has to do with averaging 4 hours sleep a night for the last 10 years. I don't really know. Maybe things will get tougher one day. Maybe we will lose the little supports we depend on. No matter how bad things get, I don't think that I will ever want to hurt my kid. If I ever did, it would mean that there was something dreadfully wrong with me, and I couldn't blame that on a lack of supports. I don't think I'm unusual in this. I think it's pretty typical for parents of kids with or without disabilities.

11. Murdered children, with or without disabilities, are typically killed by their parents. Maybe some of them are just plain monsters. Most of them are stressed, depressed, confused, and

generally have mental health issues. A lot of them need help, and some of the killings could have been prevented if we got help to people sooner. If we are going to be compassionate to people who kill their children, lets be compassionate to all of them. If we are going to be punitive, lets be consistent with that, but let's stop pretending that killing children with disabilities is any different than killing any other child.

Dick Sobsey, University of Alberta

A VIEW FROM THE BACK WINDOW In Gratitude for Wolf Wolfensberger

This essay will be much too small for its subject. I offer it anyway because of gratitude for a man's life and the ideas he developed, and because those ideas have been so much a part of my experience. When colleague Steve Wiseman called early in the morning on the last day of February to let me know that Wolf Wolfensberger had died, the first feeling was that the floor had fallen away.

I never directly addressed him as Wolf. The reason is in me. I was always a bit intimidated in his presence and customarily addressed letters to him as Dr. (or Professor) Wolfensberger, even though he signed his idiosyncratic missives to me simply Wolf. I even had to think about how I would refer to him in this little written expression of gratitude. So now, too late, it's Wolf.

Wolf Wolfensberger's words were among the first I read when, forty-one years ago, I entered work with people who have developmental disabilities. The first journals I saw contained a pair of articles titled: "Will There Always Be an Institution?" I read *The Principle of Normalization in Human Services* shortly after its issue in 1972 and went to my first PASS workshop, in southwest Pennsylvania, in the summer of 1975. I met Wolf for the first time in late winter 1976 in Toronto and have listened to and learned from him many times since then. Almost every day my work (and much on my non-work days as well) connects in some way with the big ideas that I learned from him. These are the "big ideas" that have meant most to me.

A very big idea: deviancy juxtaposition. Within the past few days, a colleague mentioned to me that he had heard someone describe a new small business being started by a person with a significant disability. The business: clowning—entertaining as a clown. My colleague then said: "I thought of you right away." I assume he didn't mean that he thought of me as a clown. Instead, I recognized his reference to my well-known trust in the Wolf's ideas and, especially, to the likelihood (over the last 35 years or so) that I would be sensitive to what Wolf called "deviancy juxtaposition." Wolf taught me that it matters very much what we put next to (juxtapose with) people who are already (because of infirmity or hundreds of other characteristics) likely to be seen as unworthy or are subject to rejection by their fellow citizens. Humans, Wolf taught, learn things in pairs; so, what is placed near someone—in space and/or time—carries meaning about that person. Not only that, but we learn (and teach others) by means of those associations (those pairings, those putting-togethers) unconsciously. That is, the meaning moves forward in time and transfers to others without our awareness or the awareness of those who learn from associations perhaps for the first time.

Among the associations that are carried forward by those things that are put next to (juxtaposed with) people with disabilities are associations that derive from the history of the juxtaposed objects/things—which brings me back to clowns. It is unlikely, as I learned from Wolf, that it will be good for people with disabilities to place those people in the context of clownery because the history of clowning is so connected with vice, foolery, victimhood (of tricks and abuses), and sickness leading to death. For example, it's hard to distinguish (as a matter of fact I don't think one can) between the "slapstick" used by harlequin (the clown-fool in commedia del arte) to punish people and the "clapper" that people with leprosy were required to use to warn others away. Why would we want to attach messages that speak about vice, foolishness, and disease to people with disabilities?

Clown-image juxtapositions represent just one tiny example of a practice that appears to be written into the genetic code of modern human services—the unconscious portrayal of the users of service as dangerous, unworthy, sick, everlastingly-childlike, etc. And, it's likely that I would have understood none of this (although I might have lived for years vaguely discomforted by some of it) without the teaching of Wolf Wolfensberger. For me, Wolf's emphasis on how people are interpreted to others is his greatest contribution.

But, he taught other big ideas as well.

A second very big idea: social integration. I started to work in programs for people with developmental disabilities in September 1970. I was hired to direct a "community program" that included a separate 3-class school, a pre-school class, and a small sheltered workshop (or, technically, a "work-activity center") all located in the same abandoned school building five miles into the country from our local county seat town. Segregation was the way of things, and, early in my work, I don't recall anyone questioning the separate arrangements at all. After all, this program was for people who could not (we thought) be a part of the regular world of schools or work places, even though we failed to recognize that many of the people were already part of regular families and neighborhoods. I began my work with the understanding, conveyed by the board to which I reported (and an understanding with which I concurred) that my chief aim was to lead the construction of a new school that would be up-to-date, bright and modern, and—especially—equipped to meet the needs of these children with developmental difficulties. Above all, the building would be for them and for no one else.

I surely don't recall many feelings of joy over the accomplishment of that early aim. The building went up. But, as construction was getting under way, I was off to that first PASS workshop I mentioned, and just after the building was finished and occupied, I met Wolf (Advanced PASS, Toronto) for the first time. It was through the complex but thorough analysis made possible by PASS that I learned (and have tried to teach) the ways that the society and its servants, the human services, structure and maintain the separateness of some of its members. I learned to think of segregation (which, though it's not often so-named, continues to be a chief tool in the design of villages or work-enclaves for people with disabilities) as the main reason for what Wolf (and Jean Vanier) called the "wounding" life-experiences that people endure. Wolf taught that the centrifugal processes that extract some community members are so deeply a part of our social life that it will require intense and regular "engineering" to undo them. I well recall an "overhead" with what seemed like 500 suggestions for how to "engineer" social contacts and possible relationships; in reality there were about 20 or 25 ideas listed. Others through the years have followed on and expanded that list in many different directions. For me, though, understanding the necessity for integration began with Wolf.

A third big idea (for me, anyway): "What, not why." I learned analysis, by means of lots of practice with PASS and a little with PASSING. That is, I learned from Wolf's work how to figure out what was really occurring at a human service setting. The key to such analysis—and a backhanded key to eventual synthesis as well—turned out to be the "what, not why" rule. It's simple. We can only understand a service's effect on people if we're disciplined enough to judge those effects as they really are--ignoring, for the purpose of analysis, why they are that way. If, for example, I visit people with disabilities at their home and find that when one person goes to art classes on Tuesday evening the other must go as well, even though the second person is uninterested in art, the "what" of that situation is that half of the people living there (that is, one of them) are less well supported than they could or should be. For the purpose of "analysis," it doesn't matter "why" one person has to take part regularly in something that disinterests or even bores her. Only when we focus on the "whats" in a program or service can we really understand its effects on its users. Of course, to gain service improvements, we'll eventually have to come to grips with the "whys"—all of the reasons and rationales about why things don't support people as well as they might. But if we skip to the "whys" right away and follow the usual custom of letting them explain or justify the sometimes-bad effects of services on people, we'll give away the power of analysis before it can do its work. Above all, the analytical tools that Wolf devised require clear-headedness—and the discipline to call things what they are before we turn to trying to do something about why.

In the summer of 1984, I got an invitation to a celebration in Syracuse of Wolf Wolfensberger's 50th birthday. I don't know who eventually labeled the celebration as Wolf's "birthshop." In part the invitation read as follows:

> Regardless of their validity, adaptive action principles of service planning, development, and operation are rarely put into practice or sustained by agencies and systems. In consequence, a large number of people who have attempted to function in accord with such valid principles have come to grief. Upon assuming an active rational and moral human service or change agentry role, they have been marginalized, rejected, and in many instances forced out of their jobs or involvements. To many such individuals, these were very traumatic experiences, especially since they were often not fully prepared for them, and/or did not understand (or believe) the extent and subtlety of the dysfunctionalities embedded in human services and the rest of the world.
>
> Are you one of these people? Would you like to be?

Maybe it was a lack of full understanding of "adaptive action principles;" maybe it was lack of courage; maybe it was just dumb luck. Whatever the reason, I never had the experience of marginalization or rejection in my work. Or, maybe I did and just never felt it. In any case, let's say that the question in the birthshop invitation were carried forward to today and re-phrased: "Are you one of those people who honor the life and trust the thought of Wolf Wolfensberger? Would you like to be?" My answer would be yes. Still.

Jack Pealer

PASSING Workshop
(prerequisite: Introduction to Social Role Valorization)
Sponsored by West Virginia DD Council
Parkersburg, WV

Dates: October 30 – November 4, 2011
Contact: Linda Higgs, WVDDC,
Linda.s.higgs@wv.gov
304-558-0416

OHIO SAFEGUARDS
3421 Dawn Drive
Hamilton, OH 45011

The Safeguards Letter

A Publication of OHIO SAFEGUARDS

Number Fifty-two *Very Late Winter 2012*

ANNOUNCING: A WORKSHOP ON **SOCIAL ROLE VALORIZATION**, SPONSORED BY THE WEST VIRGINIA DEVELOPMENTAL DISABILITIES COUNCIL

Human service workers play a critical role in the lives of the children and adults they serve. This workshop, together with a practicum experience called PASSING, lays out a helpful framework for service workers to use in implementing relevant and effective services in the lives of socially devalued people.

"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 **Monday, May 14 through Thursday, May 17, 2012**.
· Location: Summit Conference Center, 129 Summers Street, Charleston, WV 25301
· *Taught by Jo Massarelli of the SRV Implementation Project and Joe Osburn of the Safeguards Initiative*.

This workshop is specifically oriented to leadership development and is Part I of a two-part workshop. It introduces the learner to Social Role Valorization (SRV), using the 10 core themes developed by Dr. Wolf Wolfensberger, one of the most influential thinkers in the field of human services broadly, and mental retardation specifically. His work helped lay the foundation for many current human service trends, including integration, deinstitutionalization, and safeguarding of individual rights.

A central goal of SRV is to enable socially devalued people to attain culturally valued roles, with an eye towards having a typical life and gaining access to all that typical citizens enjoy. SRV will be reviewed with the implications of its positive assumptions about the worth of all people and their belonging in our communities. Since competency and image enhancement are essential building blocks of valued social roles, both concepts will be thoroughly explained. Participants are encouraged to reflect on the typical life experiences of socially devalued people, with an eye towards deeper identification with the people they serve. A past participant said of this workshop, *"This training has changed my outlook on human services and has provided me with a better understanding of how expectancies can affect success or performance. Thank you all for your helpful suggestions and educated experiences. It was a truly informative and beneficial training!"*

The workshop is taught in lecture format, with extensive use of overheads and images.

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. Tuition for this workshop (to be determined) includes handouts, refreshments, and lunches. Some assistance with expenses will be made available to people with developmental disabilities and family members.

If you're interested, contact: Linda Higgs, WV DD Council, 110 Stockton Street, Charleston, WV 25312 (linda.s.higgs@wv.gov or 304-558-4884.

A LITTLE BIT FROM WOLF

(*From now on every time we publish The Safeguards Letter we'll try to include a short excerpt from Dr. Wolfensberger's writing. We'll choose segments that, as far as we know, have not otherwise been re-published. Here is an excerpt from The Limitations of the Law in Human Services [1976]. JRP)*

Perhaps one of the biggest limitations of the law… is its virtually total inability to create constructive human relationships. The law is exceedingly efficient in destroying or severing human relationships, as in divorce; in issuing injunctions which keep people apart; or in taking children away from their natural, foster, or adoptive parents. The law also serves a very effective role in sanctioning relationships which people have already established on their own, as in transacting adoptions or marriages. However, when it comes to the actual creation of relationships, about the only thing the law can do is to create certain favorable preconditions which enhance the probability that constructive relationships are formed. Thus, laws may be passed under which funds might be appropriated to finance social clubs, recreation facilities, family guidance clinics, etc. Laws may set up procedures which facilitate constructive foster placement of children, or which encourage rather than inhibit the adoption of children. However, the law cannot guarantee that a child finds love, that a handicapped person will be genuinely accepted, that a person will have a friend when he needs one, etc.

As a point of illustration, the citizen advocacy schema was created in order to combine some of the strengths of law with the power of human relationships, so as to facilitate the meeting of the instrumental (practical), expressive (emotional), or combined needs of handicapped and disadvantaged persons. Under this schema, a cardinal rule of thumb has been that whenever possible, the least formal and least restrictive alternative should be pursued. This means that in many instances where a person is impaired, another person should be recruited to engage him/herself on an individual level as a highly interested and involved party (and hopefully friend) in order to meet the impaired person's needs, and to represent his/her interests. Where this can be accomplished through an informal friendship, the citizen advocacy schema would not encourage the creation of some kind of guardianship to accomplish the same goals, although some advocates would need to assume various types of guardianship in various circumstances. Yet one of the strongest sources of opposition to the citizen advocacy schema has come from attorneys who, in their absolute faith in the power of law, would seek the solution of the above problems in the establishment of official and highly structured and formalized (especially public) protective services and especially guardianship provisions which are firmly anchored in the law. Such lawyers tend to depreciate the role and power of citizen advocates whose involvement is motivated "merely" by love, friendship, or ideological commitment, rather than being propelled by the empowerment of a formal legal relationship. Specifically, this might mean that such lawyers would rather vest public guardianship in a public trustee or some kind of an agency that would administer the guardianship via hired staff, than in pursuing the establishment of a large number of intense but informal personal relationships. The difference in conceptualization is thus partially an ideological one, and partially one which derives from widely divergent fundamental views of the ole and power of law, and of course its limitations.

Along these lines, I have been struck by two extremes: one extreme is parents who seek security for a handicapped child in the brick and mortar of the institution on the assumption that when everything else fails and collapses, the institution will always be there….

On the other extreme, I see people such as a group I know in Syracuse who moved into a house together with several homeless, somewhat drifting retarded adults. They all threw their income into a pot—which is not very much because some of the non-handicapped members of the house work, and some of the handicapped may or may not work, and many of them have been on public assistance. From this pooled income they live. This group home is not incorporated. It has no documents, no plans, no individual treatment forms, nothing of agencyism at all. It gets not one penny of public subsidies other than the social security checks of some of its members. Some of the handicapped members who do get these social security checks may not even want to throw them into the pot, but try to hold onto them. The whole set-up looks incredibly fragile, but the people in the house love each other dearly, and they are strongly supportive of each other.

Now let us assume for a moment that our society did collapse, or collapsed maybe a little bit. And/or let us assume that the government cut back human service funding by 25%, which is not far-fetched. Agencies would be eliminated, salaries cut, and workers laid off; workshops might close, salaries for social workers and lawyers cut away. What then???? Or, assume that there is a famine, which is not far-fetched either. I read that it only takes one degree of average temperature less, and the Canadian wheat crop would be a dead duck. Canada would no longer be the wheat cradle of the world. Even now, employee theft in many human service settings and nursing homes is almost unmanageable. What would happen when employees are really hungry? Assume that there is warfare, or civil unrest—also not that far-fetched. My friends in that house in Syracuse tell me that under conditions of severe social stress, the only thing that will save retarded people is "community." They will be saved by whoever loves them and will stand by them in dire need, and much less likely by someone who is paid to care for them…. What <u>does</u> promise more security? The law, that today gives us dollars, agencies and salaries—or the sense of love and solidarity between people acting in ordinary people roles, rather than in formal agency service roles?

I have used informal residential community and citizen advocacy only as examples. The point is this: law, itself, cannot create or ensure relationships.

Wolf Wolfensberger

<u>JUST QUOTES</u>

Community means caring: caring for people. Dietrich Bonhoeffer says: "He who loves community destroys community; he who loves the brethren builds community." A community is not an abstract ideal. We are not striving for perfect community. Community is not an ideal; it is people. It is you and I. In community we are called to love people just as they are with their wounds and their gifts, not as we would want them to be. Community means giving them space, helping them to grow. It means also receiving from them so that we too can grow. It is giving each other freedom; it is giving each other trust; it is confirming but also challenging each other. We give dignity to each other by the way we listen to each other, in a spirit of trust and of dying to oneself so that the other may live, grow and give.

Jean Vanier, *From Brokenness to Community*, pp 35-36

Romanticism asserts the supremacy of individual feeling over discipline, learning, or thought. Anybody can feel, and if his feelings are powerful, his discipline bad, his learning small, and his thought trivial, who is to blame him for making his feeling the measure of all things? The Romantic attitude is not a possession of individual writers; it is something which, on the North American continent at least, envelops the whole of society, coloring not only the present, but the popular idea of the past and the popular conception of the future. It is inevitably distorting to all ideas which are uncongenial to it, with the result that discipline is confused with harshness, learning is confused with personality development, and thought, if it inclines toward skepticism, is confused with cynicism. With continents, as with individuals, a preoccupation with feeling tends to isolate the feeler in his own warm, caressing bath of ill-examined sensation.

Robertson Davies
A Voice from the Attic: Essays on the Art of Reading

…a truer nomination for our species than Homo sapiens might be Homo narrans, the storytelling person... we can listen to other people's dreams, fears, joys, sorrows, desires and defeats—and they in turn can listen to ours.

Henning Mankell, "The Art of Listening"
NY Times, December 11, 2011

The chicadee and nut-hatch are more inspiring society than the statesmen and philosophers, and we shall return to these last, as to more vulgar companions. In this lonely glen, with its brook draining the slopes, its creased ice and crystals of all hues, where the spruces and hemlocks stand up on either side, and the rush and sere wild oats in the rivulet itself, our lives are more serene and worthy to contemplate.

Henry David Thoreau, "A Winter Walk"

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. Letters, ideas, and items for publication in *The Letter* can be sent to: Editor, *The Safeguards Letter*, 3421 Dawn Drive, Hamilton, OH 45011 (e-mail: jackjr441@earthlink.net). We welcome our readers' ideas and reactions.

VIEW FROM THE BACK WINDOW

The Evidence—Another Look

A few years ago in *The Safeguards Letter* I shared some thoughts about the current and apparently powerful metaphor, "evidence-based practice" (EBP). In that short essay I quoted three of my teachers (mine in the sense that they have had a big influence on my thinking)—Wolf Wolfensberger, Wendell Berry, and Stephen Jay Gould—to argue that we weaken our approaches to supporting vulnerable people when we make an idol of science. I concluded:

> Mere insertion of the phrases "evidence-based" or "best practice" as modifiers in our claims about services means little. Such evidence as we have is not always clear. Much of it changes—sometimes radically. Some evidence turns up on places we didn't expect. Of course we want the evidence, but it's never all in, and we'll always have to keep looking.

Since then I keep running across scattered tracks of discomfort that's similar to my own. So, I thought it might be time to take another look at this notion of the evidence. I note three patterns in what I've seen:

1) We keep being urged to trust only empirical evidence;
2) Application of the "gold standard" of empiricism is really hard;
3) Important and troubling questions about the trustworthiness of an empiricism-only stance still lurk.

We keep being urged to trust only empirical evidence. Let's start with the September 4, 2011 business pages of the *New York Times*. There, a short article by Jeffrey Pfeffer and Robert Sutton urges business and other organizations to adopt "evidence-based management" as a key to deciding about personnel or about operational strategies.[1] The article offers instances of customary management practices widely used in defiance of well-established evidence. For example, despite clear indications that stable membership of teams correlates with team effectiveness, "… managers often can't resist the temptation to rotate people in and out to minimize costs and make scheduling easier." Pfeffer and Sutton take the straightforward position that business managers ought to repair to the organizational-behavior literature to enhance their managerial performance. (I note, by the way, that most of that literature issues from universities. Pfeffer and Sutton teach at Stanford.) It's pretty simple and hard to argue with: if one pays attention to what's been learned so far about human performance, that performance will improve. Consulting the evidence, Pfeffer and Sutton say, will make things better.

[1] Pfeffer, Jeffrey and Sutton, Robert. Trust the Evidence, Not Your Instincts. (2011, September 4) *New York Times* (Business), p. 8.

We can find a much more complex—and more implicitly threatening—example of the same argument in a document produced by the US Department of Education: "Identifying and Implementing Educational Practices Supported by Rigorous Evidence: A User-Friendly Guide" (available at www2.ed.gov/rschstat/research/pubs/rigorousevid/index.html). This document (I'll call it UFG for short) is a brief for the exclusive use of one standard of evidence to determine whether an educational method should be employed in schools. I suspect, though, that it is more than just an argument. Because it was issued by the US Department of Education the UFG likely influences choices about what kinds of research on educational processes get performed. That is the implicit threat. UFG defines the "gold standard" for production of empirical evidence as randomized controlled trials—"… studies that randomly assign individuals to an intervention group or to a control group, in order to measure the effects of the intervention." That is how the effectiveness and safety of drugs is determined. According to UFG, only randomized controlled trials can deliver "strong" evidence of the effectiveness of an educational measure.

But, let's be real. How many teachers or others in school classrooms would or do have time or interest for the conduct of randomized controlled trials of ways to instruct students, especially given growing class sizes and onerous "accountability" mechanisms? Or, to bridge into a field with which I'm more familiar, what's the likelihood that controlled trials will be the means to determine "evidence-based" ways to support people with developmental disabilities in community life?

Answers to those questions are obvious. It's very unlikely that anyone will use randomized controlled trials—the gold standard—to produce evidence for all methods or procedures used in classrooms or to design supports for people with developmental disabilities. Despite the sub-title of UFG ("user-friendly") the gold standard is hard to apply. That's something that has been recognized by the guest editors of the *American Journal on Intellectual and Developmental Disabilities'* special section on evidence-based practice, September 2010[2]. Writing to and mostly for researchers, those guest editors noted three issues that face the scholar in developmental disabilities with regard to the gold standard:

1) *"… the majority of research involving individuals in this population does not use experimental methods. How and whether it is possible to use descriptive studies to inform evidence-based practice is an important issue for consideration."* In other words, we need to expand the boundaries of the gold standard if we're going to use it to define "evidence" for the ways we try to support people with disabilities.

2) *"… there are many areas of treatment and practice for persons with intellectual disabilities where there is simply not sufficient high quality experimental evidence from which specific recommendations for practice can be made."* Or… a lot of randomized controlled studies will have to be done just to provide "evidence" for things we're already doing, let alone things we might find useful in the future.

3) *"… given the nature of available evidence, it may be important for our field to determine whether we agree with and endorse the guidelines for quality and quantity of studies required to recommend a practice as evidence-based."* Maybe we can't agree that the gold standard is the only way to figure out the better methods to approach support; maybe other standards would work better.

Just scan peer-reviewed articles in formal journals to find lots of examples of the issues that Kaiser and McIntyre have raised. I found a piece about person-centered planning in the December 2010

[2] Kaiser, Ann P. and McIntyre, Laura Lee. "Introduction to Special Section on Evidence-Based Practices for Persons with Intellectual and Developmental Disabilities." *American Journal on Intellectual and Developmental Disabilities* 115 (5), 357-363.

issue of *Intellectual and Developmental Disabilities*.[3] One intention of the authors was "…to discuss the effectiveness of person-centered planning in relation to evidence-based practices." The analysis is too complex to summarize here. It concludes, though, that while the evidence reviewed by the authors is "…weak with regard to criteria for evidence-based research," the use of person-centered planning has shown "… positive, but moderate, impact on personal outcomes" for people with developmental disabilities. So, according to this analysis, a method we've devised and chosen to use works, at least moderately well, but we cannot establish (at least not yet) that the use of this method is well-supported by "evidence." Apparently neither the gold standard nor anything approaching it has been met. The article does not ask (this isn't its intention) whether there's any worth in meeting the gold standard.

So, let's take a peek at how golden the gold standard really is. In the December 13, 2010 issue of the *New Yorker*, Jonah Lehrer reports about randomized controlled studies—across a variety of fields, including pharmacology—and the failure of some of those studies of the "test of replicability."[4] Results that seemed so firm—so true—when first achieved declined or disappeared as experiments were repeated. As Lehrer asks, "If replication is what separates the rigor of science from the squishiness of pseudo-science, where do we put all these rigorously validated findings that can no longer be proved?" He goes on to list and examine several forces that may lead to this "decline effect" in empirically produced results. Among those forces are:

- Regression to the mean, as experiments are repeated;
- The difficulty of getting negative results published in the professional or scientific literature;
- The unconscious selective reporting of data to favor the preferred result (see Stephen Jay Gould, *The Mismeasure of Man*, for numerous examples); Lehrer notes that we humans hate being wrong, love being proved right—a tendency likely made stronger by patterns in our schooling.

So, even the gold standard turns out to carry difficulties. Jonah Lehrer comments on what he terms the "slipperiness of empiricism:"

> The decline effect is troubling because it reminds us how difficult it is to prove anything. We like to pretend that our experiments define the truth for us. But that's often not the case. Just because an idea is true doesn't mean it can be proved. And just because an idea can be proved doesn't mean it's true. When the experiments are done, we still have to choose what to believe.

Let me bend this brief essay toward some sort of conclusion. I'll do that with three quotations and a vignette that speak to me about the ways we come to know things. First, listen to David Brooks in an essay titled "The New Humanism" in the *New York Times,* March 7, 2011:

> We emphasize things that are rational and conscious and are inarticulate about the processes down below. We are really good at talking about material things but bad at talking about emotions…. Many of our public policies are proposed by experts who are comfortable only with correlations that can be measured, appropriated and quantified, and ignore everything else…. Yet while we are trapped within this amputated view of human nature, a richer and deeper view is coming back into view…. First, the unconscious parts of the mind are most of the mind…. Second, emotion is not opposed to reason; our emotions assign value to things and are the basis of reason. Finally, we are not individuals who form relationships. We are

[3] Claes, Claudia, Van Hove, Geert, Vandeveide, Stijn, Van Loon, Jos, and Schalock, Robert L. "Person-Centered Planning: Analysis of Research and Effectiveness." Intellectual and Developmental Disabilities 48 (6), 432-453.

[4] Lehrer, Jonah. "The truth wears off: Is there something wrong with the scientific method?" *New Yorker*, December 13, 2010, 52-57.

> social animals, deeply interpenetrated with one another, who emerge out of relationships.

Second, see what Jared Diamond has to say, near the end of *Guns, Germ, and Steel: The Fates of Human Societies*:

> Thus, the difficulties historians face in establishing cause-and-effect relations in the history of human societies are broadly similar to the difficulties facing astronomers, climatologists, ecologists, evolutionary biologists, geologists, and paleontologists. To varying degrees, each of these fields is plagued by the impossibility of formulating replicated, controlled experimental interventions, the complexity arising from enormous numbers of variables, the resulting uniqueness of each system, the consequent impossibility of formulating universal laws, and the difficulties of predicting emergent properties and future behavior. (p. 424)

I'd add educational researchers, psychologists, sociologists, and (maybe, given the "decline effect," drug researchers) to Diamond's list.

Third, I come back—of course—to Wendell Berry. His essay "Against the Nihil of the Age" (found in *Imagination in Place*, 2010) argues:

> The idea that life is coextensive with its physical forms, and that these forms are or will be completely intelligible within the terms of reductionist science, had already become an intellectual and academic orthodoxy. This orthodoxy still prevails in the universities and in the enterprise of science, technology, and marketing which constitutes industrial culture. Its insignia is the refusal to take seriously anything that was taken seriously in the past…. The result, of which the evidence is now inescapable, is a world in which work based on the recognition of sanctity is less and less possible—which is to say, a world in which we are less and less able to keep from destroying even things of economic or scientific value.

Science is one of the ways that we know things; the word itself comes from the Latin verb *scire,* to know. I have to treat with skepticism, though, any claim by what we usually think of as science to be the only way to know things.

I think about Sy Montgomery's wondrous essay-reflection on octopi and how such creatures (defined as "invertebrate" and lacking anything resembling a brain) come to know anything.[5] At the New England Aquarium Montgomery entered a tank with an octopus named Athena. She reports:

> …to me, Athena's suckers felt like an alien's kiss—at once a probe and a caress. Although an octopus can taste with all its skin, in the suckers both taste and touch are exquisitely developed. Athena was tasting me and feeling me at once, <u>knowing</u> (emphasis added) my skin, and possibly the blood and bone beneath, in a way I could never fathom.

There are so many ways to know. No single way is sufficient. Many are full of mystery. Still, the evidence isn't all in.

Jack Pealer

[5] Montgomery, Sy. "Deep Intellect: Inside the Mind of the Octopus." Orion, 30:6, November-December 2011, 64-71.

The Safeguards Letter

A Publication of OHIO SAFEGUARDS

Number Fifty-three *Autumn 2012*

DAVE

"I am death; I take friend from friend and leave the room empty." (attributed to Thomas Merton).

On August 30, my friend and occasional colleague Dave Hammis died, suddenly and unexpectedly, at the end of his company's annual gathering of teachers and supporters in Montana. Like most who cared about Dave, I'm still in shock…at a loss.

About five years ago I first met Dave after discovering his photo and home address on the Griffin-Hammis Associates' (GHA) web site; I was stunned to learn that he lived just eleven miles from me—in Middletown, Ohio. Two colleagues at the place where I then worked joined me in meeting Dave at "Java Johnny's" coffee house in Middletown. I remember two things from our first talk. Dave made it clear that he was willing to give time and advice to local people (and their families) who were seeking employment; we learned that this willingness was standard practice for Dave. Second, Dave described his interest in trying to change employment-seeking practices in his adopted state of Ohio.

As usual, Dave was better than his quiet words of promise or ambition. Within weeks he helped a local young man and his family as they tried to figure out an employment future, advising them about business-development and benefits questions. If he were with us, Dave would still be in close touch with them. A year or so after we met him, Dave responded to an invitation to meet with the then-director of the Ohio Rehabilitation Services Commission. I sat in as a kind of dumb witness at that lunch meeting, in a restaurant halfway between Cincinnati and Columbus. Dave kept describing teaching that GHA could provide or other services with which they could assist. Whenever he mentioned a focus of staff development or help with local training, the director (Michael Rench) would respond, "We need that." Another form of help; another "we need that, too!" Within a couple of months after the lunch, Dave was in position to fulfill his ambition to work in Ohio, as GHA had a contract for a 15-month teaching and demonstration project across the state. More than 250 people with disabilities started on a path toward employment. At least 50 or 60 people either obtained jobs or started new businesses in the course of this work, and Dave's influence (through his own work and through the work of the trainers he brought to the state) made a difference. It was a big and thorough job.

Through the years, as I've tried to teach others about Wolfensberger's idea of "model coherency" as applied to human service programs, I've often quoted Robert Pirsig (*Zen and the Art of Motorcycle Maintenance*):

> Precision instruments are designed to achieve an idea, dimensional precision, whose perfection is impossible. There is no perfectly shaped part of the motorcycle and never will be, but when you come as close as these instruments take you, remarkable things happen, and you go flying across the countryside under a power that would be called magic if it were not so completely rational in every way. It's the understanding of this rational intellectual idea that's fundamental.

The phrase "dimensional precision" reminds me now of Dave. Powered, I think, by a belief that communities—including local economies—only work when all their members have the chance to make their valuable contributions, Dave used his mind and his precision-oriented learning (he was an engineer) to master the tools people would need so that they could contribute as employees, business-owners, entrepreneurs. Having mastery, he shared it with lots of others—

pointing out the more useful ways to move forward and/or putting others on a path toward similar competence, so that his efforts could be multiplied many times.

Dave's ideological (I don't think it's a bad word) commitment, his high level of technical knowledge and skill, and his eagerness to stay "at it" with people regardless of busy-ness or complications of schedule made for a rare combination. I was awed by him.

I think many of us will miss him for a long, long time.

Jack Pealer

A LITTLE BIT FROM WOLF

(*From now on every time we publish The Safeguards Letter we'll try to include a short excerpt from Dr. Wolfensberger's writing. We'll choose segments that, as far as we know, have not otherwise been re-published. Recently I had a chance to see a new—2012—16-minute film entitled "Willowbrook," which dramatized the infamous hepatitis B experiments at that New York institution. Here is Dr. Wolfensberger's description of the actual background of that new film. This is from the August 1982 edition of TIPS—the Training Institute Publication Series. JRP)*

During the 1960's, Dr. Saul Krugman, N New York pediatrician, distinguished hepatitis researcher, and chairman of the Vaccine Board of the US Food and Drug Administration's Bureau of Biologics, had operated a research program at the Willowbrook State School for the Retarded on New York's Staten Island. In this project, retarded children between the ages of 3 and 10 were experimentally infected with live hepatitis B. Despite all of the exposes of the atrocities committed at Willowbrook, Dr. Krugman proposed as late as 1979 that retarded children should continue to be used as subjects in experiments designed to test out vaccines made from the diseased blood of hepatitis victims. A major rationale he advanced in support of this proposal was that because of crowding, unsanitary conditions, and poor personal hygiene, retarded institution residents would get hepatitis anyway.

On top of the fact that German physicians were pronounced guilty at the WW II medical war crimes trials for experiments of this nature, the ideology of rejection and destruction embodied in such a stance was further underlined by 1979 actions of the New York City Board of Education. In New York State, governmental structures at various levels have waged systematic warfare against retarded people for decades, and tried virtually every ruse to exclude them from services other than institutions, and especially from education. The latest strategy, after all previous strategies had been ruled illegal, was to exclude those retarded pupils from the schools who had been ascertained as being carriers of hepatitis B—the very same condition with which Dr. Krugman had infected the children at Willowbrook. The school board declared that these pupils posed a significant health risk to other children in the schools. After efforts to exclude these pupils from the schools were blocked by the courts, the board fell back on the next typical line of defense: segregation in separate programs. As far as the facts of the school board claims go, hepatitis B is generally thought to be communicated only via blood-to-blood contact, and the judge had ruled that there was no documentation of even one actual transmission from a retarded pupil to another child. The profound irony of it all is that most of the pupils in question had contracted the disease as guinea pigs in Dr. Krugman's Willowbrook researches. This kind of event illustrates the "blaming of the victim," where someone is victimized, then the inflicted affliction is used as an excuse for inflicting even more affliction.

Wolf Wolfensberger

REVIEW: ACTS OF CONSCIENCE by Steven Taylor

Building a sand castle at low tide.

It's not just that your best efforts do not "win," but that a short time afterward, there is not even a trace of those efforts having occurred. Could be discouraging!

Taylor's book tells in great detail about a change effort made by World War II conscientious objectors (COs) to change the mental hospital system in the US, 1943-1950. He begins with background about the conscientious objectors' experience in that war, the program set up for their alternative (to military) service, the assignment of several hundred COs to duty as unpaid state hospital ward attendants, and their outrage at conditions they encountered. The central story, then, is about four COs at the Philadelphia (Byberry) State Hospital who carefully planned a nationwide change effort, their initial amazing impact, and the quick disappearance of that impact.

Early chapters tell some of the background in state hospitals and their reform. Dorothea Dix, in the 1840's and afterward, exposed scandalous conditions in almshouses and had tremendous success in getting many states to rescue insane people from those conditions by building thirty-two state hospitals prompted by her campaign. Taylor notes, however, that twenty and thirty years later "Dix was distressed to find many of the same conditions that she had documented many years earlier, even in some of the asylums founded as a result of her efforts" (p 158). To underline that point, imagine her consternation when she visited in the 1870's and found horrible, inhumane conditions at the Dorothea Dix State Hospital in Raleigh, North Carolina. Turning over in her grave, and not even dead yet!

Clifford Beers in 1908 published an account of his own experience as a patient at state and private psychiatric hospitals, A *Mind That Found Itself,* which exposed their scandalous conditions and had national impact. In his book he meant to emulate the impact of Harriet Beecher Stowe with *Uncle Tom's Cabin,* but as a change agent he went beyond the book and founded the National Committee for Mental Hygiene. Beers felt that his new organization, which quickly gained widespread influence, would be more effective if it were led almost entirely by psychiatrists, and within a few years the National Committee focused entirely on educating the public to accept the concept of mental "illness," and stopped entirely any examination of the conditions of psychiatric hospitals. Taylor notes, "When Clifford Beers died in 1943, his obituary published in the National Committee's journal, *Mental Hygiene*, referred to institutional problems in the past tense." The COs at that very time were gathering the documentation for their own exposes of scandalous conditions.

COs in Cleveland, Philadelphia, Poughkeepsie, and Oklahoma led reporters in exposés, which were reprinted nationally. At Byberry in Philadelphia, four COs went beyond this to orchestrate a strategic change agentry campaign (pp 280-295) with the object of national change, not just local headlines. Harold Burton, Leonard Edelstein, Willard Hetzel, and Phillip Steer gained the support of the institution superintendent, who gave them time and space, and the support of the American Friends (Quaker) Service Committee, which was a sponsor of many COs, the support. Through them, the four gained the acquiescence of the Selective Service (US military draft) to work full-time on institutional reform. They began publication of a newsletter for ward attendants, which gained national attention. They began publicizing a national Attendent of the Year award, which gained nation-wide notice in *Time* and *Newsweek.* They worked with nationally famous journalists Albert Deutsch and Albert Maisel to enable exposes in national magazines, and timed the release of those exposes with the 1946 release of their own big report, *Out of Sight, Out of Mind*, which compiled stories and pictures from forty state hospitals. They wanted to make sure readers did not focus on blame at one or a few institutions, to see instead that this was a systemic problem. The four COs wrote to their national network of COs, "Rather than attempt more exposes of individual institutions, which flare up sensationally and then are forgotten in a week or two leaving complicated administrative issues and sore spots often as injurious as the original problems, we plan to disclose to the public the *inherent weaknesses* of all the institutions we now

serve—those that stem from deep-rooted social causes—as representing the weaknesses of the whole institutional system."

They worked before the release of their report to gain endorsements from Eleanor Roosevelt and several other notables to whom she introduced them, including Pearl Buck, Helen Hayes, Walter Reuther, and William Paley. At the release, they announced the formation of a National Mental Health Foundation, whose chair would be a former Supreme Court justice, Owen Roberts. The four leaders were very conscious of the failure of the Beers-founded National Committee, and they carefully excluded almost all psychiatric participation in their new organization.

There was a tremendous response to their campaign. Taylor reminds us of the impact, in a pre-television age, which pictures and stories in daily newspapers and *Life* and *Reader's Digest* could bring. Several states launched investigations, the National Committee sought to ally itself with the new National Foundation (the COs), even the American Psychiatric Association quickly stopped trying to defend the institutions and talked of reform. So a little band of nobodies, with tremendous commitment and great strategic and tactical sense and some key interpersonal connections—they changed the world, and quickly.

The four COs were the board of the new Foundation, which was designed to keep up the campaign. They arranged to be replaced as the board, so they could be purely staff to the new organization, and there ensued an amazing story of undermining and co-optation such that within three years the new organization had disappeared, subsumed into the ineffectual National Committee and entirely under the domination of the American Psychiatric Association (a stark example of an Empire, in Moral Coherency Workshop terms). Taylor (pages 332-351) describes carefully the steps in that transformation—each a very small procedural or structural decision, each one seeming reasonable at the time—a painful story, tragic in its inexorability.

Many of you reading this can recall vividly your first visit to an institution in the early or middle 1970's, and you know that exactly parallel stories came out in exposes then, and the pictures from Byberry in 1944 were matched by exactly parallel pictures published by Blatt in 1966. Adding insult to failure, later histories of the mental health field have hardly mentioned the COs' change efforts, focusing entirely and deceptively on what Taylor characterizes (p 159) as a dominant "narrative of progress" of the field of mental health and the profession of psychiatry. The last paragraph (p 395) of Taylor's book discusses (in our workshop terms) the merits of "act validity" and "**standing in contradiction**":

"They young COs who exposed the abuses at the nation's institutions and went on to lead a national reform movement did not, in fact, make lasting changes in the care of people with psychiatric and intellectual disabilities in America. That is not the point of their story…. Acts of conscience in the name of benefiting humanity are always good and never bad or even neutral. Acts of conscience are inherently worthy and deserving of praise. Those people who commit acts of conscience need to be remembered and honored."

Jack Yates,
Stoughton, MA

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. Letters, ideas, and items for publication in *The Letter* can be sent to: Editor, *The Safeguards Letter*, 3421 Dawn Drive, Hamilton, OH 45011 (e-mail: jackjr441@earthlink.net). We welcome our readers' ideas and reactions.

JUST QUOTES

Numbers numb, jargon jars and no one ever marched on Washington because of a pie chart.

Andy Goodman

That we live now in an economy that is not sustainable is not the fault only of a few mongers of power and heavy equipment. We are all implicated. We all, in the course of our daily economic live, consent to it, whether or not we approve of it. This is because of the increasing abstraction and unconsciousness of our connection to our economic sources in the land, the land-communities, and the land-use economies. In my region and within my memory, for example, human life has become less creaturely and more engineered, less familiar and more remote from local places, pleasures, and associations. Our knowledge, in short, has become increasingly statistical…. This is the sort of knowledge we now call "data" or "facts" or "information." Or we call it "objective knowledge," supposedly untainted by personal attachment, but nonetheless available for industrial and commercial exploitation…. With the coming of industrialism, the great industrialists, like kings and conquerors, become exploiters of statistical knowledge. And finally virtually all of us, in order to participate and survive in their system, have had to agree to their substitution of statistical knowledge for personal knowledge. Virtually all of us now share with the most powerful industrialists their remoteness from actual experience of the actual world. Like them, we participate in an absentee economy, which makes us effectively absent even from our own dwelling places.

Wendell Berry, Jefferson Lecture, 2012

I'm not opposed to success. I just think we should accept it only if it is a byproduct of our fidelity. If our primary concern is results, we will choose to work only with those who give us good ones.

Fr. Greg Boyle

I asked a man in prison once how he happened to be there and he said he had stolen a pair of shoes. I said if he had stolen a railroad, he would be a United States Senator.

Mother Jones

THOMAS SZASZ, 1920—2012

The titles reveal his ideas—especially *The Myth of Mental Illness* and my personal favorite *Ideology and Insanity: Essays on the Psychiatric Dehumanization of Man*. Budapest-born (and, interestingly, University of Cincinnati educated—medicine degree in 1944) Dr. Thomas Szasz analyzed and found wanting the identification of so-called psychiatric disorders as "illnesses." In his writing, teaching, and speaking careers, Dr. Szasz consistently opposed what he saw as the coercive

aspects of psychiatry, such as involuntary hospitalization or imposition of psychoactive drugs. His point-of-view was, of course, widely attacked by such groups as the American Medical Association and the American Psychiatric Association.

At the time of his death, Dr. Szasz remained an emeritus professor at the State University of New York Health Science Center in Syracuse. For me, Szasz occupies a place in the array of critics of coercion by the powerful; others in my mental-group of such critics are Susan Sontag ("Illness as Metaphor"), Ivan Illich, Stephen Jay Gould, and John McKnight. Almost 25 years ago, when my friend and colleague Sandra Landis and I were teaching an early form of "person-centered planning" to groups around Ohio, Sandy often led off one of the sessions with this quote from *Ideology and Insanity*:

> Among the many foolish things Rousseau said, one of the most foolish, and most famous, is: "Man is born free, and yet everywhere he is in chains." This high-flown phrase obscures the nature of freedom. For if freedom is the ability to make un-coerced choices, then man is born in chains. And the challenge of life is liberation.

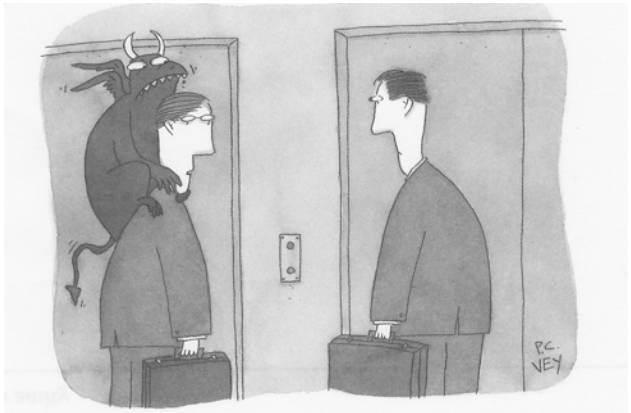
Thank you, Dr. Szasz.

VIEW FROM THE BACK WINDOW

"Daemon Meridianus"

Here's a cartoon I found in the *New Yorker*. I'm going to risk reproducing it here in the confidence that this is a fair use of Peter Vey's wit.

The cartoon shows, with humor, how acedia works. I recently discovered the ancient concept of acedia (sometimes spelled accidie), which is a force, a power that so affects people who do solitary and concentrated work. It was the main complaint and affliction of Christianity's 4th and 5th century "desert fathers," It is one of the "eight evil thoughts" catalogued by Evagrius of Pontus, a fourth century Greek monk who retreated to the Egyptian desert. Evagrius influenced the writing of St. John Cassia who was born in Romania but who eventually founded fifth century monasteries in southern France.



"It came with the job."

Here's how Evagrius described acedia: "…the one who causes the most serious trouble of all. He presses his attack upon the monk about the fourth hour and besieges the soul until the eighth hour. First of all he makes it seem that the sun barely moves, if at all, and that the day is fifty hours long. Then he constrains the monk to look constantly out the windows, to walk outside the cell, to gaze carefully at the sun to determine how far it stands from the ninth hour, to look now this way and now that… he instills in the heart of the monk a hatred for the place, a hatred for his very life itself, a hatred for manual labor…. He depicts life stretching out for a long period of time, and brings before the mind's eye the toil of the ascetic struggle and, as the saying has it, leaves no leaf unturned to induce the monk to forsake his cell and drop out of the fight."

St. John Cassian followed up about this "demon of noontide": "When this besieges the unhappy mind, it begets aversion…towards any work that may be done within the enclosure of our own lair, (and) we become listless and inert. It will not suffer us to stay in our cell, or to attend to our reading: we lament that in all this while, living in the same spot, we have made no progress, we sigh and complain that bereft of sympathetic fellowship we have no spiritual fruit; and bewail ourselves as empty of all spiritual profit, abiding vacant and useless in this place; and we that

could guide others and be of value to multitudes have edified no man, enriched no man with our precept and example."
(Above quotes from http://logismoitouaaron.blogspot.com/2010/03/demon-of-noondayst-cassian-evagrius-on.html)

So, acedia is the influence that distracts; it tempts with thoughts of all the other useful or attractive things one could be doing instead of sitting here to study, to write, to think. If acedia only affected 4th and 5th century monks it would be forgotten by now. But, as the cartoon shows, the noonday demon still climbs on the backs of those who expect to be doing solitary work. I've often felt its weight on me. Or, at least, I've felt something that interferes—that slows me down. An example: I'm proud that today I've only checked my e-mail twice, and it's almost the middle of the morning. I have, though, been out to the mailbox two or three times, written checks for bills that aren't due for weeks yet, fed the cats, filled the bird-feeder and drunk several cups of coffee. But—and this is the thing—I meant to spend the morning or the day writing. It's a familiar routine. Soon the energy and promise of the morning will be gone, and all I'll have on paper is a paragraph—or nothing at all. Sometimes I fantasize about how much more pleasant or more easy this study or writing would be if my "cell" were better—better desk, more comfortable chair, more beautiful view out the window, and so forth.

After the day passes, with all the other distractions answered, the books remain unopened or the pages stay blank, and I'll understand that I'm misusing time (and maybe talent—that's for others to say). I'll be unhappy with my lack of will power, and I'll find myself searching for ways to discipline or maybe trick myself into keeping on with work I really do think is worth doing.

This is beginning to read like a confessional, and I don't intend that. Instead, I want to say that the idea of acedia is oddly appealing and maybe useful. I want to get to know more about it and how it has affected others. It's not that I've suddenly stumbled across something that lets me off the hook about failures. I don't think that learning about acedia provides a conceptual gateway to the evasion of responsibility. Acedia is not—or, not exactly—the same thing as laziness. It's not identical to sloth, one of the seven deadly sins. It's not the same as writer's block, addiction to novelty, procrastination, poor study habits, ennui/boredom, or fear (i.e., of the future). Acedia connects to all of those, but ennui and writer's block, et al are usually thought of as being of internal (to a person, to me) origin. By contrast, the ancient metaphor for acedia is the noonday demon (daemon meridianus). It's clearly thought of as a force coming from outside a person, outside me. And that, somehow, means to me that it can be opposed.

How would I oppose acedia and its effects? Kathleen Norris (*Acedia & Me*) quotes Evagrius: "…it is not in our power to determine whether we are disturbed (by acedia's effects), but it is up to us to decide if they are to linger within us." Norris also notes the monastic view that "…the opposite of acedia is an energetic devotion." I wish for something more exotically powerful, but there it is. If I want to forestall acedia I'll have to work at it. For example:

- I could listen more attentively (and cringe less) when others offer reminders or prompts about some work on which I've delayed.
- I can read and act more often on something Wendell Berry wrote in an essay entitled "Discipline and Hope." I keep this framed on my desk and have done so for about 15 years:

> Human nature is such that if we waited to do anything until we felt like it, we would do very little at the start, even of those things that give us pleasure, and would do less and less as time went on. One of the common experiences of people who regularly do hard work is to find that they begin to "feel like it" only after the task is begun. And one of the chief uses of discipline is to assure that the necessary work gets done even when the worker doesn't feel like it.

- When I'm complaining about my surroundings, I could recall the cells of others who accomplished so much more (see Gandhi, Bonhoeffer, Mandela, Aung San Suu Kyi).

Those seem like a few ways to be energetically "devoted" or to keep acedia from too much power. But, it's a demon (metaphoric or not) after all, and I need all the guidance and support I can get, just as, I'm thinking, you do too. If acedia has affected you and you've found something that helps, I'd surely like to hear about it.

Jack Pealer

The Safeguards Letter

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SINCE 1986…

We started this *Letter* 30 years ago with the hope and expectation that readers would see it four times each year. As a quick calculation will determine, we've not quite managed twice a year on average (almost 30 years, 54 issues). The written promise to readers changed some time ago from "quarterly" to "occasional." More recently, it has not even met that commitment—the last issue of the *Letter* before this was sent in the autumn of 2012. It contained a short essay about "acedia," the noonday demon, the influence that distracts and tempts with thoughts of all the other useful or attractive things one could be doing instead of sitting here to study, to write, to think. No surprise there.

So, this issue of *The Letter*, which will only be sent out as an e-mail attachment, will be the last one under the old dispensation. (I did add to the e-mail list those earlier readers who received *The Letter* on paper and for whom I think I have a current e-mail address.) If there are more issues in the future, and I think there might be, they will go out just as this one has—very occasionally and as an attachment to a message. My e-mail address is jackjr158@earthlink.net. If you don't want to receive *The Letter* in the future, let me know. If you know someone who might want to join the mailing list, send that person's name and e-mail address or let her/him know how to contact me. Thanks.

WHOSE KIND? An Appreciation of *Orderly and Humane: The Expulsion of the Germans after the Second World War*, by R.M. Douglas. (New Haven: Yale University Press, 2012).

I did not know (did you?) that history's perhaps largest forced movement or transfer of an entire identified group of people happened in my own lifetime. In the first paragraph of *Orderly and Humane* R.M. Douglas wastes no time; he summarizes briskly the events that he will describe in detail over the next 300+ pages:

> Immediately after the Second World War, the victorious Allies carried out the largest forced population transfer—and perhaps the greatest single movement of peoples—in human history. With the assistance of the British, Soviet, and U.S. governments, millions of German-speaking civilians living in Czechoslovakia, Hungary, and the parts of eastern Germany assigned to Poland were driven out of their homes and deposited amid the ruins of the Reich, to fend for themselves as best they could. Millions more, who had fled the advancing Red Army in the final months of the war, were prevented from returning to their places of origin, and became lifelong exiles. Others again were forcibly removed from Yugoslavia and Romania, although the Allies had never sanctioned deportations from those countries. Altogether, the expulsion operation permanently displaced at least 12 million people, and perhaps as many as 14 million. Most of these were women and children under the age of sixteen; the smallest cohort of those affected included adult males. These expulsions were accomplished with and accompanied by great violence. Tens and possibly hundreds of thousands lost their lives through ill-treatment, starvation, and disease while detained in camps before their departure—often, like Auschwitz I, the same concentration camps used by the Germans during the Second World War. Many more perished on expulsion trains, locked in freight wagons without food, water, or heating during journeys to Germany that sometimes took weeks;

> or died by the roadside while being driven on foot to the borders. The death rate continued to mount in Germany itself, as homeless expellees succumbed to hypothermia, malnutrition, and other effects of their ordeal. Calculating the scale of the mortality remains a source of great controversy today, but estimates of 500,000 deaths at the lower end of the spectrum, and as many as 1.5 million at the higher, are consistent with the evidence as it exists at present. (1-2)

Douglas' book is the first complete account of the expulsion of German people to appear in English. The book did not appear until 2012.

My wife, Renate (we've been married for almost 42 years) was "transferred" from what became the Czech Republic into neighboring southeastern Germany—also known as the "Sudetenland." Renate was not yet 2 years old in May 1945 and necessarily moved in the company of some members of her family—her grandparents and one of her aunts. Renate's mother was already in Germany and working at the time.

Early in the book, Douglas focuses on an idea that lay behind the attempts to transfer populations. That idea was the long held dream of the nation-state—an entity that absolutely matches (or would match) the identity of a nation (e.g., the "English" nation) with the physical territory where that nation lives and which the nation controls.

> In the most extravagant formulations of its partisans, population transfer appeared as a cure-all for the difficulties that had ensued as a result of the divergent historical evolution of "nations" and "states." According to this view, a major cause of world discord was the lack of correspondence between the two, with members of a given nation residing on the territory of a state that was not their own. After the Great War, an attempt had been made to shift the boundaries of states to accommodate the geographical distribution of nations. This had proven a failure. Ethnic intermixing, the existence of linguistic enclaves and islands, and a lack of goodwill on all sides had defeated the best attempts of experts at the Paris Peace Conference to make the "nation" and the "state" synonymous terms. The situation that resulted was unsatisfactory for everyone. The presence of "foreign" elements on their soil provoked postwar governments to adopt coercive policies of national homogenization and forced assimilation that only alienated their minority populations further. Likewise, the plight of persecuted co-nationals in a neighboring state was a standing temptation to the "mother country" to wage aggressive wars for the purpose of—or, as in Hitler's case, under the pretext of—rescuing them from foreign domination. Population transfers offered a way of cutting this Gordian knot, by making nations accommodate themselves to the existing boundaries of states. Once the operation had been completed, the new international order would start life with the advantage, never enjoyed by its predecessor, of not having to defend itself against peoples bent on its revision in the name of "national self determination." But the window of opportunity to bring about this once-for-all reversal of centuries of European settlement patterns was small indeed. (30-31)

Population transfer as a solution to national or continental problems collided, though, with the history of how peoples moved and joined or established communities in many parts of Europe (and beyond). The hoped-for success of population transfer was also frustrated, of course, by the difficulty of differentiating (especially after long periods of time have passed) the "kinds" of people to be separated. For example, the boundary between the German and the Czech people has been porous for many centuries. The mother of medieval Czech king Ottakar I was German, and, in order to develop industry in his kingdom, Ottakar invited German craftsmen to re-locate into Czech lands. They did so, in substantial numbers, beginning around AD 1200. As people will, "German" and "Czech" people mingled thoroughly in Czech and nearby German lands over a period of 750 years. It was hard to tell what "kind" any person belonged to. If I'm in the expelling group, how do I know with certainty whose "kind"—Czech or German--the other person is? Circumstances were similar, Douglas reports, in other boundary areas between

Germany and nations or peoples to the east (Poland, the Baltic states, Hungary, and nations in the Balkans). But, then, Douglas also shows that eager-to-expel governments and other groups didn't really worry themselves very much about exactness of identification.

Beginning in 1938, of course, Germany under Adolf Hitler began to absorb and then invade the eastern countries where German people had settled for centuries. Life under conditions of cruel oppression created the tension that, when the oppressors were removed because of the end of the war, led to a violent reaction against all German people—beginning almost the very day after the Nazi surrender. May 1945 brought what Douglas calls the "wild expulsions"—not entirely unplanned by Czech and Polish governments-in-exile. For example, Douglas refers to "… the brief but intense outbreak of revenge-taking that occurred across Czechoslovakia in May 1945." (95) Fighting in western Czechoslovakia, near the border with Germany, did not end smoothly or uniformly. Douglas notes the anger of Czechs:

> That Czechoslovak citizens were still dying violently at German hands while the rest of the continent was celebrating the end of the war seemed an especially bitter coda to an occupation that had already lasted longer than in any other country in Europe. (95)

The migration by Renate's grandparents from their land just east of the re-established Czechoslovak border (from 1938 until 1945 the land was in "the Reich") to what became the "American zone" in eventually occupied Germany occurred in May or June 1945. This "migration" was less than 50 kilometers (30 miles) in distance. The place where Renate's grandparents and other family members had lived is, today, just 10 kilometers inside the Czech Republic. They lived in a very small rural village—called (in German) Pampherhutte, just northeast of the town of Zelezna Ruda. There they farmed a bit, kept a small store, and harvested lumber from the Bohemian forest. If "wild expulsions" began after the Nazi surrender in May 1945, how did news reach such a remote spot? A rail line ran (still runs) between Plzen in Czech territory and the border at Zelezna Ruda, so end-of-war news may have traveled by rail. Presumably some people—perhaps many—in Zelezna Ruda possessed and listened to radios, so news may have come that way. Whatever information did arrive apparently carried with it rumors of the approach of the feared Red Army. Something told the family that it was time to go.

Both civilian and military officials of the nations that were called the "Allies" in 1945 were more than aware of the retribution-motives that were at work in the central European countries formerly occupied by the Nazis. Though those motives and the "wild" expulsions that issued from that anger were problems for the US, Britain, and USSR, Allied officials were over-occupied already with the chaos of a largely destroyed Germany. So, the Allies were willing to go along with and sometimes help in the forced relocation of people of German background into postwar German territory. The Potsdam Conference of the Allies in July 1945 tried to establish policy that would bring some sort of order to disordered central Europe. Under the influence of Czech and Polish leaders who had been exiles (e.g., in London) during the war, Potsdam conferees reluctantly approved the expulsion of people of German extraction from Czechoslovakia and Poland, so long as the expulsions were "orderly and humane"—descriptors that, by that July, had already been shown to be naïve.

It's likely that by July 1945 Renate and her aunt and grandparents had already left Pampherhutte and moved west. They fled the rumored (and eventual) approach of the Red Army. They probably also fled expulsive attitudes and actions of some neighbors who had suddenly become local officials. They traveled on foot and at night and hid in the forest to rest during the day. Renate was 19 months old; she walked or was carried by her Aunt Maria. Within days they would have crossed the German border—a border that, three years later, became part of what Winston Churchill called the "Iron Curtain." They found their way to a refugee camp (Renate doesn't know where it was) to wait for help in finding a new home.

The initial "wild expulsions" of the summer of 1945 were succeeded by what Douglas calls the "organized expulsions." The organization (the term should be taken with many grains of salt) was carried out either by the revived central governments—e.g., of Czechoslovakia and Poland--or, more likely, by local governments or other local groups within those countries. The main tools of the organized expulsions seem to have been: a) concentration camps, many of which had been used previously by the Nazis to house other groups of people, b) trains, some of which had hauled other people eastward in the years between 1938 and 1945, and c) forced marches. Any

tool that would get people out would have been used. It implies too great a sense of formal organization to say that camps to house expellees were "established" in territories that were to be emptied of people of German background. The camps were already there. People were collected together (mostly women, children, and older men) and put into them. Douglas summarizes (and offers examples of) conditions:

> Throughout central Europe, those interned at any time during 1945 ran by far the highest risk of execution, torture at the hands of the camp staff, or death through starvation and preventable infectious diseases, in comparison to later detainees. This in turn was in part the result of the abdication or ineffectiveness of any kind of central control over the camps, and the turning over of their administration to what the British ambassador in Prague accurately described as a class of "young thugs." (p. 140)

Those expellees who were not interned in the camps (and, of course, a good many people who did occupy the camps for a time) were herded onto ostensibly westbound trains. Some trains, packed with people, sat on railroad sidings (winter or summer) for days or even weeks while other traffic passed or negotiations with Allied authorities sought permission to move. If camps or trains were unavailable, authorities forced masses of expellees to walk toward Germany.

Douglas reports that by 1946 governments east of Germany—together with officials of the Allies—were arranging celebrations over the "completion" of the movement of people back to their "natural" lands. Douglas notes, for example, the 1946 Christmas broadcast of the Czechoslovak President (Edvard Benes) inviting rejoicing over the fact that "this was Czechoslovakia's first Christmas without the Germans." (p. 227)

Time heals...sort of. By 1946 Renate and her grandparents and aunt had settled in the small farming village of Langdorf—in a one-room apartment next to a barn (the cows are still there) and above a stable. They had no running water or electricity, but, then, no one else in the village did either. It was a place to meet new friends, begin school, and make memories of mountain blueberries and picking mushrooms. Renate's grandparents lived there until their deaths, as did Aunt Maria. Renate left Langdorf and Germany with her mother and adoptive father to emigrate to the US in 1953.

The sense of satisfaction expressed through celebrations over the completion of the population transfer could not and did not last. Douglas offers four reasons (pp 226-228) why the celebrations turned out to be hollow:

1. The transfers were not complete and, because of the hundreds of years of intermixing of peoples, could not ever be complete.

2. Expelling governments could not be certain, in the late 1940's, that circumstances would not reverse themselves in the future—that, for example, Germany or some other power might arise to again force populations to shift.

3. The population transfers did considerable damage to the economies and demographic makeup of the expelling countries; border areas remained sparsely populated and economically underdeveloped for many years after the expulsions.

4. The expulsions necessarily meant ignoring or, at best, suspending traditions about law and human rights. What amounted to nationalistic "cleansing" brought violence and cruelty with it, and that cruelty sowed resentments that lingered.

Attempts to align "my kind" of people with "my" territory bring with them the problems created by the history of the mixing of peoples and the impossibility of really identifying who is "my kind" and who is "yours." These same problems clearly contribute to every day's news about conflict or hot-spots in our world—Syria, Afghanistan, Ukraine, Kosovo, India, and, of course, the United States. When and how will we ever learn?

Jack Pealer

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JUST QUOTES

In an African village, when a storyteller comes to the end of his tale, he places the palm of his hand on the ground and says, "I put down my story here." Then, he adds, "…so that someone else may take it up another day."

Peter Brook, *Threads of Time*

If the Golden Rule were generally observed among us, the economy would not last a week. We have made our false economy a false god, and it has made blasphemy of the truth. So I have met the economy in the road, and am expected to yield it the right of way. But I will not get over. My reason is that I am a man and have better right to the ground than the economy. The economy is no god for me, for I have had too close a look at its wheels. I have seen it at work in the strip mines and coal camps of Kentucky, and I know that it has no moral limits. It has emptied the country of the independent and the proud and has crowded the cities with the dependent and the abject. It has always sacrificed the small to the large, the personal to the impersonal, the good to the cheap. It has ridden to its questionable triumphs over the bodies of small farmers and tradesmen and craftsmen. I see it, still, driving my neighbors off their farms into the factories. I see it teaching my students to give themselves a price before they can give themselves a value. Its principle is to waste and destroy the living substance of the world and the birthright of posterity for a monetary profit that is the most flimsy and useless of human artifacts.

Wendell Berry, "Discipline and Hope"

Because you make things of this world your goal,
which are diminished as each shares in them,
Envy pumps hard the bellows for your sighs.

But if your love were for the lofty sphere,
your cravings would aspire for the heights,
and fear of loss would not oppress your heart;

the more there are up there who speak of 'ours,'
the more each one possesses and the more
Charity burns intensely in that realm.

Dante Alighieri, *Purgatorio*
(trans. Mark Musa)

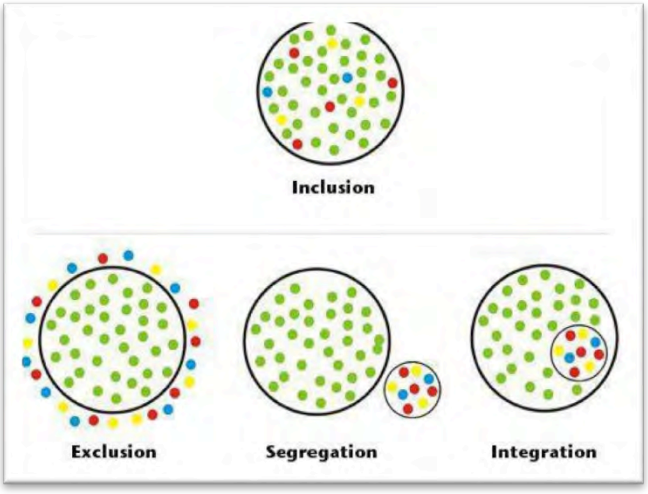
People are now drawn toward cities large and complicated enough to meet our economic desires, and toward families small and portable (and even disposable) enough to make mobility possible. Popular sociology portrays us as victims of these 'movements' and 'trends', as if the woes that accompany modernity has been forced upon us. But no. The destruction of intimate community

has been at our own hands. It has corresponded to our own hierarchy of values ,,,,, which stand largely in tension with the value of total and intimate community. As much as we yearn for community, we yearn even more for the social and economic prizes that individual mobility can bring.

Jean Vanier, *Community and Growth*

VIEW FROM THE BACK WINDOW Thoughts occasioned by an internet meme

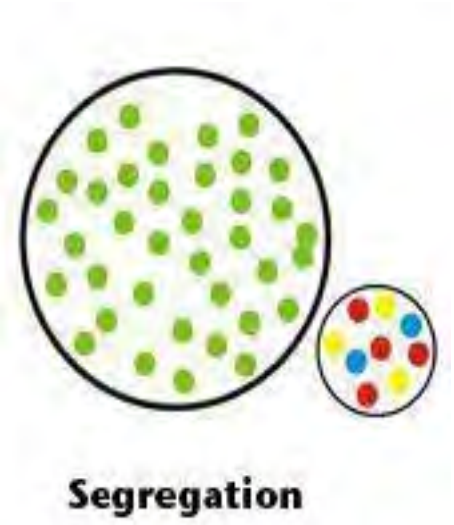
Over the past few months the diagram below has arrived—several times--as an e-mail attachment or a Facebook posting.



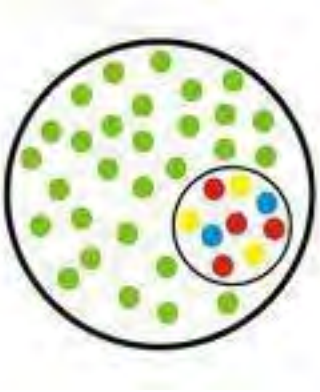
I think this image intends to imply that we (the human service field or perhaps communities in general) are moving or have progressed through a series of steps toward the "inclusion" of previously excluded people into full community life. I was uneasy about the diagram when I first saw it. Part of my unease arose from what I read as an inaccurate depiction of "integration." A greater part came from the fact that relatively few people with disabilities whom I know have lived out the sort of progress the diagram seems to laud. So, I wanted to explore my reactions to the diagram in writing.

First, I note that the entire diagram implies the existence of a continuum along which people must travel so that they can reach the hoped-for top of the diagram. The implied continuum begins at the lower left. I also note that the concept of a continuum requires (as Steven Taylor pointed out 28 years ago) maintenance of the most intrusive options [Taylor, Steven J. (1988). Caught in the Continuum: A Critical Analysis of the Principle of the Least Restrictive Environment. *The Journal of the Association for People with Severe Handicaps (TASH)*. 13:1. 41-53]. Both history and the unconsciousness that prevails in services have driven services toward a casual acceptance of the most intrusive and separate choices for "some" people. In other words, it's possible for the continuum to push either integration or inclusion away and to insist on segregation and intrusion for those who are seen to "need" them. Taylor called (again, this was 28 years ago) for a commitment to integration as a directive for policy, so that communities could "… cultivate, rather than impede, relationships between people with developmental disabilities and nondisabled people." [Taylor, p. 51]. But, let's return to the diagram.

This first picture makes it clear that some people are "in" the valuable place—the neighborhood, the business, the school or classroom—and some other people are left outside, absent whatever good things the valuable place or context has to offer to its insiders. Those kept out are, presumably, excluded because they are thought (mostly unconsciously) by insiders to carry less social value or perhaps because they are customarily the ones who have been kept away. Outsider-ness and all the difficulties that accompany such status characterize the life experiences of those who are beyond the ring.



The next image <u>appears</u> different from the first. But is it, really? Here a small group of people is collected, and the group is kept in a separate ring, outside the valuable place. One group of children is assembled and sent to a separate building or agency for schooling. A town decides that everyone who bears a set of characteristics or a label will live in a building that's set aside from the rest of the community. From the point of view of the people who have been congregated, however, the experience is not likely to be much different from that lived by people in the first ("Exclusion") picture. People are still kept from the good life that is available to those within the ring (the school, the community). So the only real distinction between the first and second pictures has to do with the intent of the powerful insiders. In the picture labeled "segregation," it's more clear—conscious, if you will--that the design has been crafted to keep some people away.

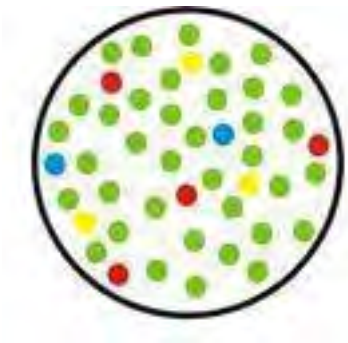


To me, here is where trouble starts. In the overall diagram, this part is labeled "integration." That's a mistake. This is actually another depiction of **segregation**—just not as easily identified to the casual witness. Here we find a wall within walls. This is the separate classroom within the ordinary school. It's the "small" group home in an ordinary community but without significant interaction between those who live there and those who live around them. It's the "enclave" inside the factory, warehouse, or other community business. At <u>best</u>, this picture represents "physical integration"—the location of a service for labeled people proximate to the other citizens of a neighborhood or community. Very likely, from what I've seen, the participants in that service experience a lack of connection to others that's little different from the enforced separateness that results from the actual physical isolation mentioned above. This diagram is not a picture of "integration" as I understand it.

I've been fortunate in my teachers. Chief among them has been Wolf Wolfensberger, who taught me about integration. In his *1998 Brief Introduction to Social Role Valorization* Dr. Wolfensberger wrote:

> From an SRV perspective, "integration" means "personal social integration and valued social participation." This in turn would require (a) valued participation, (b) with valued people (c) in valued activities that (d) take place in valued settings. Among the things this would imply is that as much as possible, devalued people would be enabled: to live in normative housing within the valued community, and with (not just near) valued people; to be educated with their non-devalued peers; to work in the same facilities as ordinary people; and to be involved in a positive fashion in worship, recreation, shopping, and all the other activities in which members of society engage. [Wolfensberger, W. (1998). *A Brief Introduction to Social Role Valorization: A High-order Concept for Addressing the Plight of Societally Devalued People, and for Structuring Human Services* (3rd ed.). Syracuse, NY: Author.]

So, integration means being enabled to actively take part in things together with other citizens. One definition that the Oxford English Dictionary (OED) offers for integration is "restoration to wholeness." The word, "integration" comes from a Latin root that also gave us the words "integral" (consisting of entireness or made up of component parts that together constitute a unity: OED) and "integrity." What may have been broken is restored. What may have been pulled apart (literally, segregated) is put back together, is made whole. Work toward making our neighborhoods and communities whole by restoring to them members who have been shut out—that's useful and necessary to all of us.



Finally we come to the fourth diagram—the one that's been labeled "inclusion." And so it is. To "include", again according to the OED, refers to "containing as a member of an aggregate" or being regarded as "a constituent part of a whole." In this picture, previously-ejected people are on the inside, playing roles that add value to the collectivity and being regarded by others as full participants. Almost the same as integration. The terms are near synonyms—sort of like "exclusion" and "segregation" earlier. I'd be willing to argue that the word "integration" carries with it more implication of purpose or intention than does the word "inclusion." More important, though, I think a person who had endured enforced separateness, perhaps for a long time, would not discern a difference between experiencing "inclusion" in a community and experiencing "integration" in that same place. When either integration or inclusion is phony—when the words are plastered on to efforts that really perpetuate separateness—then both concepts fall into meaninglessness. When, as Dr. Wolfensberger said, either involves doing the long-term work of connecting people to valued places, valued people, and valued activity, we may see the real meaning of inclusion and integration shine. It's been said that abuse wears a thousand faces. I think that segregation wears at least that many, and the faces of segregation are subtle and deeply learned. The work required of "integration" is necessarily hard and will have to be continuous if we are to restore our communities to wholeness. Let's not trivialize it.

Jack Pealer

The Safeguards Letter

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REST IN PEACE, NICK DEFAZIO.

In 1975, after my long-time friend and colleague Sandy Landis and I returned from having taken part in our first "PASS" workshop in Pennsylvania, we were on fire to change the world (or at least Ohio) with the principle of normalization. I thought then that there were just the two of us who had learned about that magical idea. When my brain cooled off, it was hard to think about how we would pull off the changes that were needed. And then (I can't remember exactly how or where) we met another who had a similar experience and who shared the same commitment—a psychologist from Canton named Nick DeFazio. For me, that was the start of a friendship that lasted more than forty years and only ended with Nick's death in mid-April.

There are many Nick-memories. Two stand out for me. Both of them are connected to Nick's professional skill. Some time in the summer of 1989, when I was living in Chillicothe, I had my first anxiety/panic attack—middle of the night, off to the hospital in an ambulance, serious worry about repeats, etc. I didn't know any nearby psychologists or counselors, at least well enough to want to make an appointment, but I did have confidence in (by then) Dr. Nicholas DeFazio who was in private practice in Canton. Nick was more than willing to see me. I made the 170-mile trip for a mid-afternoon appointment. Nick and I sat in his office for quiet, comfortable conversation. He suggested a number of "medical" possibilities that I could discuss with my doctor—things that might have contributed to what had happened. Most of all, though, he taught me to relax. That is the only time I have experienced what I think was hypnosis; all I remember is how at ease I felt and how deep was the well from which I seemed to emerge when the session was done. I think I floated back to Chillicothe. When, some time later, I mentioned Nick's suggestions to my doctor, he affirmed their pertinence. Then he said that I must have a wise counselor. I already knew that.

Second memory. Again, in Chillicothe, around 1990, the leaders of the local agency that was supposed to provide work for people with developmental disabilities re-focused their energy toward helping those people find and hold jobs in local businesses. That was certainly a new idea for Chillicothe and, as I recall, pretty innovative for Ohio as well; not many others had made so concentrated an effort toward what we then called "outside employment." Those local leaders wanted very much to help someone get a job at our biggest, most prominent local business—the Mead Paper Company. Mead employed hundreds of people in the town. One man (Ron) who was supported by the DD agency aspired to work at Mead. The employment service helped Ron apply and be interviewed, and the factory seemed ready to hire him for an entry-level job. But, the Mead plant's physician noticed the words "mental retardation" somewhere in Ron's record and cautioned the plant management against hiring Ron because of that. We needed another professional recommendation to balance or cancel out that of the local doctor.

So, we consulted Dr. Nicholas DeFazio. Workers at the employment service made an appointment and drove Ron to Canton for a vocational/psychological evaluation that Nick undertook. Afterward, Nick wrote an honest and favorable report about Ron's aptitude and capacity for work. The service took the report to Mead. Management was swayed. I have photos of Ron, a few months later, in his hard-hat preparing a room in the Mead plant for a holiday party. Unfortunately, I don't have a photo of Ron's bright red Toyota pickup—the one he was able to get because of his job at Mead. Eventually promoted to other positions in the plant, Ron worked there for many years—thanks, in large part, to the critical work of an exceptional professional psychologist, Nick DeFazio.

I miss my friend.

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VIEW FROM THE BACK WINDOW "Four Windows on Aging and Death"

In December 2017 I passed my 74th birthday. For the last three years I've been reading, re-reading, thinking, and making notes about Atul Gawande's book—*Being Mortal: Medicine and What Matters in the End*. Though I was not (and am not) ill, I do sometimes feel an inkling of mortality, probably because of the book's subject coupled with the rising number on the "age" line of any forms I might complete. On that day three years ago when I began that reading, I received messages announcing two deaths—one of a recent colleague who was near my own age and another of someone younger with whom I had worked many years ago. Every day over the past years I think about my Dad, who died at age 98 early in 2014.

Being Mortal offers an important "window" through which we can look at the situation of aging and dying people in the US just now. But the physician's view—even that of as astute and literate a physician as Atul Gawande—is not the only useful perspective. As I read and thought about *Being Mortal*, I remembered other viewpoints from other writings. So what follows is a brief look through three books and a long story, all of which have to do with how we in the US now think and act about aging and the approach of death.

This is not a sweeping statement about that topic. I know that there are many other windows from which one can look out on what happens at the end of life. I just happened to look through these four. I found each of the views thought provoking and the combination of the four striking. I would like to learn what others think.

Gawande, Atul. *Being Mortal: Medicine and What Matters at the End*. NY: Penguin, 2014.

Atul Gawande practices surgery in Boston. He also participates in policy-making around health/medical issues and writes extensively about them. He is a staff writer for the *New Yorker*, and I've read many of his earlier essays there. He was born in New York to immigrant parents—both his mother and his father were physicians—and, interesting to me, he grew up in Athens, Ohio. Athens appears often in the stories he tells in *Being Mortal*.

Being Mortal leads us on a story-filled (that's one of the book's strengths) journey through the territory where the health difficulties associated with old age in America intersect with the state of American medical practice. The book's chapter titles reveal the signposts of that journey. The beginning marker is the determination of each American to retain her/his "independent self" as long as possible in life. But, as Gawande observes: "Our reverence for independence takes no account of the reality of what happens in life; sooner or later, independence will become impossible." (22-23)

Being Mortal confronts readers with the ways by which, as Gawande puts it, "… scientific advances have turned the processes of aging and dying into medical experiences, matters to be managed by health care professionals." And, it turns out, the medical profession is ill suited for—and quite ineffectual at—helping people at the very end of their lives. Gawande notes that ceding authority over the problems of aging people to medical professionals might be seen as "…an experiment in social engineering, putting our fates in the hands of people valued more for

their technical powers than for their understanding of human needs. That experiment has failed." (128)

Gawande's book describes what doctors and other health professionals face when their patients approach death. Medical staff members are caught between what people want—restoration to full, unfettered vitality and freedom from all disease—and what it's possible for medicine to deliver. Gawande recalls an essay by Stephen Jay Gould written after Gould received a diagnosis of a deadly form of cancer. In that essay Gould asserts his determination to plan to live within the statistical "long tail" of high probability of survival. And Gould succeeded at that for an unexpected twenty years. Gawande notes, though, that the design of our current medical systems imply that most or all patients should expect similar results to Gould's when they face the challenges of aging. He says:

> We've created a multi-trillion dollar edifice for dispensing the medical equivalent of lottery tickets—and have only the rudiments of a system to prepare patients for the near certainty that those tickets will not win. Hope is not a plan, but hope is our plan. (173)

Gawande acknowledges that there was nothing in his medical training that prepared him to support patients who are face-to-face with their mortality. The book also testifies to the consequences, for patients and their families, of failure to be honest and truthful in those situations. And, the book reports on efforts being made by some medical personnel and others to improve responses to people whose deaths are imminent.

Again, Americans value personal independence. That value is reflected in the high importance of the "individual" in American life and in our public affirmation for the rights of each individual citizen. The natural limits on each human life, however, mean that "the independent life" cannot remain so indefinitely (if "independent" is ever an accurate descriptor of anyone's life). Sooner or later, Atul Gawande says, mortality asserts itself.

Things fall apart for each of us. Our teeth gradually decline; calcium seems to transfer from where it should be (our teeth and bones) to where it should not be, making soft tissues brittle. Our heart muscles thicken but other muscles diminish in strength and mass. While the pattern of these changes often resists predictability in an individual person, it—the pattern—accurately describes what happens to "us" over time. "Things fall apart" is a category that groups together several common experiences:

- People become more frail, more likely to be ill, and more obviously dependent on others.
- Because of society's intolerance for dependence, people's lives fall increasingly under the control of systems—medical, governmental, institutional.
- People become isolated from their families and friends; they become deeply lonely.

Couple that pattern, Atul Gawande says, with the fact that there are now so many of "us"—people whose age has advanced—that our numbers have affected the social and political worlds. Gawande describes the effect of this growing number of older people as the "rectangularization" of survival:

> Throughout most of human history, a society's population formed a sort of pyramid: young children represented the largest portion—the base—and each successively older cohort represented a smaller and smaller group…. Today, we have as many fifty-year-olds as five-year-olds. In thirty years, there will be as many people over eighty as there are under five. (35-36)

That is a big group of people. And many of them are likely to need substantial amounts of help and support. Again, Atul Gawande testifies that doctors, among others, are not equipped for such circumstances. Societies evidently cannot tolerate the tension that attends that situation.

We have a growing ability to help people, medically and otherwise, to live longer than most humans have lived. But, this ability runs up against an increasing, almost unconscious drift toward a resolution that, in the end, almost no one favors. Gawande outlines the beginning and eventual flourishing of America's nursing home and long-term care industry. He provides an accurate summary-history of the growth of the nursing home/institutional industry as our default response to aging. He describes the sometimes hidden or obscured pattern of this journey into what he labels an "alien land."

Gawande tells about a woman he met who voluntarily entered a nursing home because she believed that her declining health and physical abilities made that necessary. She was glad, she said, to be in a place that was safe, but she was also deeply unhappy. Gawande's conclusion: "The trouble was that she expected more from life than safety. (p. 74)

Almost universally disliked and feared by the people who find themselves "placed" (the customary verb for what happens) in them, nursing homes strip away the vestiges of the "independent life" that we so prize. Losing the chance to live out that value shortens people's lives. And, important for Atul Gawande (and for us), we don't talk with each other very much about any of this.

In *Being Mortal* Gawande reports that some thoughtful people have noticed both the unhappiness and the frustrated hopes of people in nursing homes. Those thoughtful people have begun to seek or invent other responses to the situations of those who have started to experience "things falling apart." In chapters titled "Assistance" and "A Better Life," Gawande describes several such inventions—from the rise (and sometimes the perversion) of "assisted living" to the work of Dr. Bill Thomas and others, who devised the "Eden Alternative" (a scheme to re-introduce life, in the forms of plants, animals, and children into the regular experience of nursing home residents) and the "Green House" project, which re-imagined and reorganized the nursing home to be much smaller and much more attuned to the importance of meaning for those who live there.

It turns out, Atul Gawande says, that making <u>meaning</u> is much harder than making people safe. Attending to meaning in the lives of people whose lives are ending—paying attention to what's important to each of those people—is the theme of the last (and best) chapters of *Being Mortal*. Gawande points to the "hard conversations" in which people who aspire to support or help those who approach death are required to participate. That group includes doctors, but a doctor often—or maybe usually—sees his/her role as that of an unbiased, above-the-fray provider of information about disease processes, prognoses, research, etc. Not only that, but the doctor often conveys that information using medical school language that patients and their families don't comprehend. Atul Gawande says:

> Our responsibility, in medicine, is to deal with human beings as they are. People die only once. They have no experience to draw on. They need doctors and nurses who are willing to have the hard discussions and say what they have seen, who will help people prepare for what is to come—and escape a warehoused oblivion that few really want. (187-188)

Gawande reminds us that physicians are not usually trained about those hard conversations. Nor are they generally expected by their peers or the standards of their profession to talk with people who are ill and dying about what those people really <u>want</u> in the life that remains.

What people tend to want, when they face terminal illness, are things that are simple in concept but, apparently, difficult to deliver, at least for medical personnel. Gawande says people seem to want three things:

- They want to strengthen (and maybe repair) their relationships with other people—family, friends, other allies;
- They try to find a sense of completeness of their lives, and
- They want to avoid suffering as much as possible.

The medical or social service establishment is largely unable to do very much about those wants. Medicine has some influence over them—e.g., drugs to relieve pain or other discomforts—but often the best support possible consists of getting usual procedures and requirements out of the way of the important work that a dying person tries to do. Atul Gawande writes:

> I am leery of suggesting the idea that endings are controllable. No one ever really has control. Physics and biology and accident ultimately have their way in our lives. But the point is that we are not helpless either. Courage is the strength to recognize both realities. We have room to act, to shape our stories, though as time goes on it is within narrower and narrower confines. A few conclusions become clear when we understand this: that our most cruel failure in how we treat the sick and the aged in the failure to recognize that they have priorities beyond merely being safe and living longer; that the chance to shape one's story is essential to sustaining meaning in life; that we have the opportunity to refashion our institutions, our culture, and our conversations in ways that transform the possibilities for the last chapters of everyone's lives. (243)

In the end, it is courage that is called for. Gawande identifies courage of two kinds. First is the courage to seek out the truth of one's situation and, thus, to go face-to-face with one's mortality. The second, and harder, form is the courage to act on what we find, on what we learn. Even when the future (as always) is uncertain, unclear. Wendell Berry has written about such uncertainty:

> We may know that we are forming a conclusion on the basis of provisional or insufficient language—that is a part of what we understand as the tragedy of our condition. But we must act, nevertheless, on the basis of final conclusions, because we know that actions, occurring in time, are irrevocable. That is another part of our tragedy. ("Standing by Words," in *Standing by Words: Essays*. San Francisco: North Point Press, 1983, pp. 29-30.)

The illness and death of Atul Gawande's father—himself a physician and surgeon—is the story that moves the book and that shaped his son's thinking in *Being Mortal*. In the Epilogue to the book, the son movingly records his trip back to India to spread the ashes of his father's body in the Ganges. He also wraps up the book by returning to his theme:

> We've been wrong about what our job is in medicine. We think our job is to ensure health and survival. But really it is larger than that. It is to enable well-being. And well-being is about the reasons one wishes to be alive. Those reasons matter not just at the end of life, or when debility comes, but all along the way. Whenever serious sickness or injury strikes and our body or mind breaks down, the vital questions are the same: What is your understanding of the situation and its potential outcomes? What are your fears and what are your hopes? What are the trade-offs you are willing to make and not willing to make? And what is the course of action that best serves this understanding? (259)

Sarton, May. *As We Are Now*. NY: W. W. Norton & Co., 1973.

I seem to remember, though my archives offer no proof of it, that I found this book on a reading list I picked up at one of Wolf Wolfensberger's workshops in the 1970's. I read it then but lost track of it some time later. Reading Atul Gawande's account of the history of the nursing home industry brought May Sarton's short novel back to the front of my mind.

Poet and novelist May Sarton records in first-person the journal of Caroline Spencer, a 76-years old retired high school mathematics teacher. In the novel, Miss Spencer has had a heart attack

and, afterwards, finds herself "placed" in a small private nursing home in a rural area, apparently somewhere in New England. In the novel's first paragraph Miss Spencer is blunt in announcing her new circumstances:

> I am not mad, only old…. I am in a concentration camp for the old, a place where people dump their parents or relatives exactly as though it were an ash can.

The place where Miss Spencer has been dropped (it's name is "Twin Elms") is unlike most nursing homes that we would recognize today. But, it is very typical of such places in years before "long-term care" became industrialized, corporatized, and bureaucratized. One of my own grandfathers died in such a place—an old house (in this instance, in the city) where all the rooms and even the hallways had been stuffed with beds occupied with ill and confused "elderly" people. Twin Elms, where Miss Spencer landed is a small brick house five miles out into the country from the nearest village. It is owned and operated by a woman named Harriet, who earlier worked as an aide in an unnamed state "mental" hospital. Here are some "notes" from Miss Spencer's experience at Twin Elms, as related by May Sarton.

The First Hours. In the initial hours after her brother and sister-in-law bring Miss Spencer to Twin Elms, the pattern of her life shifts radically, strangely.

> "… I could not sleep. I had to get accustomed to the noises, queer little creaks, the groans and snores in the big room where the men are. It seemed a terribly long night. When I went to the bathroom I bumped into a chair in the hall and bruised my leg…. I will ask for note paper and stamps, a daily newspaper, and maybe a bottle of Scotch. It would be a help to have a small drink measured out each evening before supper…. Now I know that good things like that are not going to happen. Old age, they say, is a gradual giving up. But it is strange when it all happens at once."

Miss Spencer's memory of the first hours recalled, for me, the descriptions of the "first day" at a large institution as related in Burton Blatt's *Exodus from Pandemonium*: "Billy" is brought to the state school by his parents when he is 4 ½ years old and ends his first day eating oatmeal alone; "Andy," age 58, ends the first ever day away from his family rocking for hours alone in his "new" sleeping space. The first hours in the setting that's so different from anything previously known is like an initiation-rite—a welcome of sorts into the land of rejection and isolation.

Severed Connections, New Assigned Roles. Miss Spencer learns that at Twin Elms she loses both per precious links with friends and colleagues and the possibility of any new connections: "I witnessed in my own flesh that we become moral lepers here, untouchables, from whom relatives flee because they can't bear what they have done." (27) Those people she does meet and who might become close all make their exits in various ways, including death. This cut-off from others accompanies a gradual but steady loss of vision and diminishment of Miss Spencer's sense of time (plus, she suspects that she's being drugged by the operator of Twin Elms). It's autumn. It gets dark early. The walls seem like they are closing in on her. She says:

> The tide goes out, little by little; the tide goes out and whatever is left of us lies like a beached ship, rotting on the shore among all the other detritus—empty crab shells, clam shells, dried seaweed, the indestructible plastic cup, a few old rags, pieces of driftwood. The tide of love goes out. (121)

Foreseeing no change or improvement in her life at Twin Elms, Miss Spencer devises a plan for a terrible resolution. Readers learn a few details about the plan but do not get to witness its execution. In an "afterword" the novelist leaves us with this:

> This manuscript was found after the fire that destroyed the Twin Elms Nursing Home.

Chast, Roz. *Can't We Talk About Something More Pleasant?* New York, Bloomsbury, 2014.

Roz Chast, long-time cartoonist at the *New Yorker*, explores with experience, sensitivity, and ironic wit, the thoughts, feelings and experiences that wash over families (especially the now-adult children) of people who grow more frail as a consequence of age and related disease. Chast shows us the frequent inability of families—especially of the children of aging parents—to communicate about urgent issues that arise as people grow older. Chast's 2014 graphic memoir, *Can't We Talk About Something More Pleasant?*, traces her involvement, as an only child, with her own parents (Elizabeth and George Chast) as their lives became more difficult and as the way of life they had known "fell apart." Both Chast's mother and father were born in 1912. Her father died in 2007; her mother's death was in 2009.

Chast's first drawn panel in the book sets a theme. Her very tentative attempt to start a conversation with her parents about "things," "plans," and (more specifically) "what you guys WANT… if something HAPPENED" led first to incomprehension and then to laughter from Elizabeth and George. The panel ends "later that same day," with both daughter and parents (separately) relieved, having dodged a tense tough conversation.

That relief, however, is temporary. Parents and daughter continue their mutual silence about how the parents' lives are changing. Roz notices small things at first: her parents' apartment didn't seem to be nearly as clean and orderly as she remembered it. Over time, concerns grow more serious; the idea of her mom and dad driving anywhere (neither could see well) becomes alarming. Chast portrays herself "freaking out" over some other scary event that she learns about:

Freak-outs became routine features of Chast's experience around her parents.

And then there was the isolation. Elizabeth and George Chast were both teachers. Teaching is a calling that brings with it contact and connections with lots of other people—fellow faculty members, students' families, and, of course, the students themselves. After their retirement, however, Chast's parents, staying on in their Brooklyn apartment, lost those connections to time and to the circumstances of life. Earlier acquaintances changed the patterns of their lives or moved away or died. Increased frailty meant that Chast's mom and dad did not leave their apartment very often and did not go beyond their neighborhood at all. By the time they reached their 90's, their only real relationships were with each other and with their daughter, who lived a difficult-to-travel fifty miles away in Connecticut. There was no other person around whom they knew and trusted.

Eventually, physical frailty took over. Chast's memoir describes, especially through her drawings, a set of big and small events that led toward big changes in her parents' lives.

- Roz's anxiety over trying to help her mom and dad, uncertainty about how to help, and her struggle at the same time to keep the rest of her own life as a mother, wife, and artist in good order.

- Elizabeth's fall from a stepladder, at age 93, which resulted in several weeks in the hospital and a loss of her strength.

- George Chast's increasing confusion and his worries about being any place other than their long-time apartment or his franticness when he and Elizabeth were apart from each other. Roz noticed that her dad was "lost" without her mom.

- Elizabeth, George, and Roz still couldn't talk about what was happening and where it was leading. Even when, after they had re-located (to "the place" near where Roz lived), George was failing quickly and approaching death, Elizabeth said: "I do not like to talk about death, and I will not talk about death."

All of this—and much more as related in the book—eventually led to "the move." Roz searched and found a place in Connecticut, about ten minutes from her own home. It was clean and appeared pleasant enough (Roz described the décor as "Old Person Cheerful Genteel"). It had an opening. Her parents were willing to try a "trial stay." They never returned to their old apartment in Brooklyn.

Read Roz Chast's book to follow her as she cleans out—and finds some personal treasures in—the Brooklyn apartment, as she worries about the escalating cost of her parents' care and puzzles through the complexity and paperwork connected with "the place," and as she lives through the deaths first of her father and, two years later, her mother. Readers who have aging family members will likely find resonant stories. Readers of a certain age (like me) will be provoked to re-examine their own outlook on their futures and their organizing for what may lie ahead.

But *Can't We Talk about Something More Pleasant?* is, in fact, a memoir. Roz Chast does not even approach to-do lists or guidance about planning strategies. There's no advice giving. There are no bullet-point lists of helpful suggestions. Instead, we have the memories, collected and illustrated by someone who knows how to do that and who, truth be told, seems still a bit bewildered over what happened. It is an ordinary story, of course, in that the end of life comes to all of us. But, to Roz Chast, it was anything but ordinary. Her skillful telling and showing offer others the possibility that they may be able, despite difficulty, to talk about hard things.

Wendell Berry. "Fidelity," in *That Distant Land: The Collected Stories*. Washington, DC: Shoemaker & Hoard, 2004.

In "Fidelity" Wendell Berry allows readers to witness a loving community as its members absorb and take into their history the death of a beloved member. It was Burley Coulter who named the Port William circle of families and lifetime friends as "members of each other" (see another Berry story, "The Wild Birds"). Now, in "Fidelity," Burley is sick unto death; the story tells about how the Port William membership acknowledges, prepares for, and responds to that death. For one thing, the members guard Burley's death from intrusion by the rules and processes usually accepted or even required in the outside society. Instead, they act out of their long respect and love for Burley and out of their common sense about a way of death that matches Burley's way of life.

I do not know, of course, whether Burley Coulter is one of the author's "favorite" characters (assuming that writers even choose favorites from among the characters they imagine). I am a long-time appreciator of the Port William stories, though, and I can say that Burley is one of <u>my</u> favorites. I would want to spend time in his company. He is one who carries and shares stories and who works hard and leads others through the hard times of the farm season (e.g., he's the deviser and lead singer of the work songs). He is an eager lover of music and is always ready for a dance. A part of Burley, though, loves solitude. He is a man of the woods and streams and has a gift for the wild and the darkness. He is a hunter who often hunts alone. Most of his hunting occurs at night, when he is only in the company of his dogs. When hunting, or just when wandering/exploring the country, Burley sometimes disappears from others' presence for days.

But, at the beginning of "Fidelity," Burley has nearly reached the end of his days. No one names the illness, but both Burley and the others close to him recognize the approach of his death. His family and friends want to help. They are unsure, though, about what to do. Burley's son, Danny Branch, says they should "Take him to the doctor, I reckon. He's going to die." So, they do take him to a doctor, and the doctor visit stretches into admission to a hospital in Louisville, an hour's drive away. The membership visits Burley at the hospital, but members quickly understand the hospital as a different world than the one with which they are familiar:

> They had gone after supper to the hospital in Louisville to enact again the strange rite of offering themselves where they could not be received. They were brought back as if by mere habit into the presence of a life that had once included them and now did not, for it was a life that, so far as they could see, no longer included even itself. (372)

It is that contrast or opposition--between the distant power of the hospital (and of the world of "officials" in general) and the world known to and loved by Burley and his family and friends—that drives the action of "Fidelity." As well, that opposition reveals a stance toward death (in this case, Burley's death) that departs sharply from the possibly unconscious stance of the world of which the hospital is representative. To the hospital death is to be held at bay as long as possible and by whatever means required. The membership, in contrast, regards Burley's (certain) death as just a part of what they and Burley have shared in this specific and beloved place. Wendell Berry often writes about recalling and honoring the dead who have cared for and contributed so much to this land—this place.

> I work in absence not yet mine
> that will be mine. In time
> this place has come to signify
> the absence of many, and always
> more, who once were here.
> Day by day their voices
> come to me, as from the air.
> I remember them in what I do.
> (Sabbaths, 1992, VIII)

In "Fidelity" the Port William membership reclaims Burley and honors him in a way that fits him. As family and friends debate about how to help him in his sickness, his niece Hannah Coulter (whom he regards as though she were his daughter) asks: "Are we just going to let him die like an old animal?" Her husband, Nathan (regarded by Burley as a second son) responds: "An old animal is maybe what he wants to die like."

In the middle of the night, after yet another puzzling hospital visit and after Burley has entered a coma, the members have come to believe that they have abandoned him. Danny decides to "go get him" to bring Burley hack to his right place. The others in the membership (the story highlights Danny's wife, Lyda, Hannah and Nathan Coulter, and the father and son attorneys Wheeler and Henry Catlett; other members join the story near its end) understand right away what Danny sets out to do; they fall into cooperation, as though they are taking their places in a familiar dance.

From the point of Danny's decision the story follows three tracks. We go with Danny in the dark to the hospital, where he successfully removes (or rescues) Burley, and we follow them back home to a barn familiar to them on the Coulter land. There, Burley's home-death and burial are accomplished. A second track shows us the membership at work to support Danny and Burley and to protect them from intrusion. The third track puts us in the somewhat unwelcome company of the potential intruders. We learn fleetingly of hospital personnel who are slow to notice Burley's absence. Later we spend a considerable amount of time with Kyle Bode, the state police detective who is assigned to investigate Burley's disappearance (Kyle Bode calls it his "kidnapping") from the hospital. The policeman succeeds the hospital personnel as the

representative of the world of officialdom with its devotion to written laws, regulations, and procedures that must be followed.

On a rainy night when summer turns toward fall, Burley Coulter's life ends in the barn on his land where he and Danny had often met to start their hunts. The story says:

> Now of its long life in this place there remained only this small relic of flesh and bone. In the hospital, Burley's body had seemed to Danny to be off in another world; he had not been able to rid himself of the feeling that he was looking at it through a lens or window. Here, the old body seemed to belong to this world absolutely, it was so accepting now of all that had come to it, even its death. (408)

When the rain ends and bright daylight comes, Danny locates a space among the trees where he can dig Burley's grave. He forms a sort of casket with flat stones--some he has dug and some gathered from a nearby small creek bed. He thinks of his responsibility to others in the membership and knows that he acts for them as well as himself. He wraps Burley's body, lays it in the grave, and carefully covers it with more stones. He gathers wildflowers and strews them into the grave. He stops for a blessing ("Be with him as he has been with us.") before filling the grave. After it is filled, Danny hides all traces of it, scattering leaves and removing all marks of his own presence there. He re-makes the wilderness that he and Burley loved.

While Danny carries out Burley's burial and says the words that act as the graveside service, the others in the membership prepare to gather at the direction of attorney Henry Catlett, at the Catlett law office, which overlooks the courthouse in the county seat. Their purposes turn out to be two: 1) to respond as one to the questions of the state police detective, and 2) to conduct what amounts to the funeral service for Burley Coulter. They assemble in the outer office, and Wheeler Catlett, Henry's father and partner, assumes the lead role in dealing with the mystified Detective Kyle Bode. Wheeler provides the detective with a lesson about the distinction between officialdom's law and the callings of love in human relationships. He tells the detective:

> There are several of us here who belong to Danny and to whom he belongs, and we'll stand by him, whatever happens. After money, you know, we are talking about the question of the ownership of people. To whom and to what does Burley Coulter belong? If, as you allege, Danny Branch has taken Burley Coulter out of the hospital, he has done it because Burley belongs to him. (417)

Wheeler introduces the detective to each of the members. The introductions include each member's specific connection to Burley Coulter, together with a few stories that reveal their fond memories of him. Then, there is the sound of footsteps on the building's stairway, and Danny Branch joins them to complete the assembly. Questioned by the detective about where he has been, Danny responds: "I had an account to settle with one of my creditors." Unknown to the detective (but understood by the membership) that is an <u>exact</u> summary of what Danny has been doing. Having recognized and acknowledged a lifelong debt to Burley, he has been settling it in the best way that circumstances now permit and the best way he knows how.

"Fidelity" concludes with the failure of the detective and, in this context anyway, the failure of his "world" to grasp or appreciate what has happened. Wheeler Catlett closes the story with a version of the ancient Christian benediction: "… peace to our neighbor, Burley Coulter. May God rest his soul."

Regard:

- Some of Atul Gawande's patients—the ones about whom he repented because of his later recognition that he had failed to speak forthrightly to them about their illnesses

- Caroline Spencer, in May Sarton's novel, who found herself having been dumped into a rural nursing home
- Burley Coulter's family and life long friends who sense the abandonment of Burley's person and identity by the medical establishment that claimed his physical body

Each of these shows how vulnerable aging and dying people are to the loss of a place in their communities or among the others with whom they have shared life. Those in Burley Coulter's "membership" acted to keep him in the place and among the others he loved; a part of that action, of course, was Burley's death.

What meaningful places or roles can or should be sought for a person who is clearly dying? Volumes have been and will continue to be written. Songwriter John Prine has given us at least a beginning of an answer. We can start by taking people who are dying into our presence ("Be with him as he has been with us," said Danny Branch). We can start with "hello in there."

Ya' know that old trees just grow stronger
And old rivers grow wilder ev'ry day
Old people just grow lonesome
Waiting for someone to say, "Hello in there, hello"
(John Prine)

You can listen to John Prine singing "Hello In There" at
https://www.youtube.com/watch?v=RfwGkplB_sY

Jack Pealer

The Safeguards Letter

A Publication of OHIO SAFEGUARDS

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TO REMEMBER SANDY

My very good friend and colleague Sandy Landis left us on September 22. She died in Columbus after a period of illness. I am bereft.

Ohio Safeguards, the tiny association that publishes this Letter, was born in 1985 when Sandy, John Winnenberg, and I understood that we needed tools with which to continue to carry out our commitment to the principle of normalization. The stated purpose of Ohio Safeguards is *"…to see to it not only that the beliefs we hold (related to the idea of normalization) are shared with others but also to try to ensure that such sharing can continue into the future. We want, in other words, to safeguard the possibility that such ideas will be taught, in the possible absence of any of us as individuals."* Sandy was a founder, always a leader and guiding spirit in whatever we tried.

The Safeguards Letter has been one of our chosen tools; it has appeared in the hands (or, lately, in the in-boxes) of willing readers since 1986. We have tried to use it share our reflections and, maybe, to provoke others toward change. Sandy regularly contributed thoughtful pieces to The Letter, helping us all toward what the Catholic Workers call "clarity of thought." So that we can remember that clarity in these days after she has left us, we offer a few excerpts from her writings in *The Safeguards Letter*.

Jack Pealer

SANDY WROTE…

March 1987, from "On Being of Use."

I began to think about what I considered to be useful things. What was it that I wanted to learn more about, and what kinds of efforts might I best contribute to?

One of my persisting thoughts was that contributing would require being focused on just a few specific things in a particular place. Another idea was that the kind of contribution I was likely to make might take many years to accomplish. I knew, too, that the things I was most interested in learning more about would require that I become a part of some collaborative effort that involved many people. "Being of use" turned out to mean being an involved member of a community I could see myself being a part of for a long time. This meant a small place, where "needs" are vivid, and it meant the addition of one or a few more people who also wanted to be of good use.

January 1988, from "Regeneration" (about work with Residential, Inc.)

Our strategy for being of good service to the people we were concerned about included several methods. First, we were interested in assisting people in creating and carrying out important, life-defining dreams. To do this, we identified at least one person who would commit their time (paid or voluntary) to being the primary assistant to the other person, as dreams and plans were being created and carried out.

Second, we wanted to expand the number of people (both paid and unpaid) who played important, thoughtful roles in developing policy and making decisions within the organization. To do this we've gradually restructured the organization and have substantially expanded and reassigned the growing leadership corps.

Third, we wanted to influence local and state social policy (and policymakers), inasmuch as those policies and policymakers' decisions affected the people we've chosen to stand with. What we've done is bring the issues facing the people we're concerned about into public forums. Then we've talked, listened, corresponded, and sometimes argued with people about the importance of these issues and the outcomes for all of us.

July 1989, from "About Natural Consequences" (the most frequently requested reprint of all articles ever included in *The Safeguards Letter*)

To talk about natural consequences in the context of the lives of vulnerable people without acknowledging and accounting for that vulnerability seems irresponsible. To fail to regard that vulnerability as a consciously thought-about factor in any set of supports and assists we might design for people seems harmful. To encourage others to support people who are at risk without carefully taking into account the implications of those people's vulnerability seems both irresponsible and naïve.

The things that help keep the natural consequences I experience manageable are things like: lots of relationships with lots of people, lots of practice, others to help pay for things, others to help do the work that needs to be done, confidence that this is only temporary, and being forgiven for mistakes that I make. In other words, it takes lots of real help to offset the severity of natural consequences. My security comes from this help being there when I need it. Most of the help I get comes from people who know me well. If this same kind of help were present in another's life, her or his hurtful experiences would be less painful, the consequences more typical of yours or mine. I think it would be that way for most vulnerable people.

March 1991, from "In Response to this Call to Conscience"

Comparing what we do to live peacefully as families with what we are doing now as a nation of families is very painful. As a nation we have adopted violence as a strategy for peace, and we regard it a reasonable public policy. Yet we know it is not reasonable private policy. By living a mostly private life, one without active public voice with others, I participate in the perpetuation of that unreasonable public policy. Engaging others in conversation about developing a collective hopeful voice is a way for me to begin living a more public life. I hope that conversations will focus on how we can participate in preparing ourselves and our family members to bring the peace of personal experience into the forum of public dialogue and debate. I think we must also bring with us the courage to acknowledge and experience the inevitable suffering that is present, without supporting strategies of violence, force, and oppression.

Summer 1991, from "Another Pot of Stone Soup"

This is one of the ways we've come to visualize our work here at home. We've decided to "begin to make soup," to nourish ourselves and others. We are painfully aware that we start with meager ingredients that by themselves will not nourish anyone very well. We see our work as engaging others by inviting them to help make, tend, and enjoy the soup. How good the soup is doesn't depend very much on any one particular ingredient. Usually it's the variety of ingredients in small amounts simmered and tended for a long time that makes the best soup.

Spring 1992, from "Holding a Place in Line"

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.

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 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.

Autumn 1992, from "The Garden Club Muse"

I think that my gardening tutor and friend has recruited me as a member of the club because she understands a lot about how people learn. Without ever studying learning theories, she knows that surrounding someone who wants to learn with lots of knowledgeable people who, in respectful ways, share what they know nearly always results in learning for everybody involved. Talk about bringing "power" to the learner--as I sat there making my wreath and listening to the talk around the tables, I began to calculate the years of gardening experience around me. I stopped when I got past 200!

Some of that experience has helped me learn a few things in my five or six years as a gardener--things that apply to the rest of my life. One of the things I've tried to learn about is perennial gardens and what helps them thrive. One of the first things I learned is that a mature, healthy perennial garden takes a long time. The best of perennial gardens bloom over the longest possible season and are orderly even when at rest. For that to be possible, as indeed it is, requires a diverse variety of plants and a routine that thins plants as they mature and adds new plants from time to time. New gardens are created by transplanting from the old.

This helps me understand that there are some useful places for transplants. It helps me understand, too, that some gardens depend on compatible transplants to thrive. It doesn't take being there longest to belong. Accepting transplants creates some temporary disruption, but many are very successful in the long run.

Spring 1994, from "Cabin Fever Day"

Another small group of people decided to organize and conduct a community "Cabin Fever Day." An agenda was set, posters made and distributed, and preparation began. Crafts and activities for kids were scheduled to begin at 9 a.m. in the living room and dining room of the Harrop House (our office). Kids started showing up at 8:30. Two basket-making classes for adults were scheduled at 10 a.m. and 2 p.m. These were postponed because the instructor was stranded in New Jersey. A work group was at the museum and rail exhibit laying track and planning the electrical system. A church group was hosting a soup and sandwich lunch for adults at noon at the lodge. Kids were making pizzas as part of their activity and taking them to the lodge at noon, to have lunch with the grown-ups. Ernie Essex was at the lodge playing fiddle music.

After lunch the crowd of kids and adults who were helping took a walk. They walked around town, stopping at the business places that had contributed to the pizza making activity. There were about thirty-five voices saying, "Thanks; the pizzas were good!" Craft activities resumed, and most kids had three small projects by the time they were finished. At 3:30 the "Great Chili Tasting and Jam Session" started at the local volunteer fire department. For fifty cents, folks could taste all of the seven pots of chili prepared and could listen to people play music, sing, and socialize throughout the early evening. Small cash prizes were awarded for the hottest and the best chili. I think that the big winner took home about $10 for his winning recipe.

During the past few years we've used the story of stone soup to help keep ourselves focused. The story is also a way of explaining to others what we think community building is about--the idea of "joining in." I think about the story now. Cabin Fever Day didn't make all my worries go away. It didn't pay anybody's bills. Not everybody thought it was the greatest idea. But it happened, and it helped nourish a good number of people. It appealed to quite a few folks. And the leadership came from families who had been challenged with ice, snow, financial pressures, unusual stresses and strange circumstances for many weeks.

December 1988, from "Thinking about my Heroes"

It's the first snow this winter, and it's welcome here. As daylight came to the woods today, I watched the light and the snow reveal places in the valley and hills that are hidden from me most of the year. It suited my reflective mood.

This month of first snow and shortest days is my customary period of reflection and preparation for the coming year. This year I got an abrupt start in September. A good bit of my thinking during these last few months has been about how I've come to live as I do. I've tried to be thoughtful about what has had a sustaining influence over the years. It hasn't been surprising to me to realize that I've been thinking a lot about heroic figures. I've also been thinking a lot about people I actually know and feel close to. Two separate categories, I thought. Today I don't think so.

Earlier in my life, I recall knowing only absent heroes: Lincoln, Jefferson, Van Gogh, lots of others. They were: mostly men, mostly dead, and each of them a public figure. As I've thought about my heroes in the last few months, I've noticed a difference. I live in the midst of live heroes of both sexes!

I think it was a conversation with my grandmother that helped me start to figure it out. My grandmother celebrated her 90th birthday last July. Earlier in the year I had asked Big Gram if she knew of Dorothy Day. I was reading a biography about Ms. Day, was intrigued by the knowledge that Ms. Day and my grandmother were born about the same time, and was interested in hearing my grandmother's opinion of Ms. Day and her work. As I recall, my grandmother's response to me was: "I don't know of this Dorothy Day you've asked me about.

But if it is as you say, that she was of the poor and loved God, then I would suppose that many of our days would have much in common. The tasks are simple ones, to be willingly done."

As I watched the woods this morning, a thought about many of my current heroes became clear; never before had I thought of them as heroic. Most of them are my family and friends. I feel a little silly and much humbled by my failure to recognize and acknowledge my current heroes before now. Forgive me, folks. But mostly what I feel is relieved. I know that it is the heroic acts of the people who love me that I learn most from and that have a sustaining influence on my life.

I'm visiting some of my heroes in the next few days. You can bet there will be a fine celebration.

I lost my dear friend and 30-year plus year work partner Sandy Landis on Wednesday. It's hard to find a picture of Sandy, because she was devoted to not being photographed or honored for her tireless work on behalf of others and our local community. Smart, strategic, principled and a friend of the underdog, few know how much her vision and skill contributed to better lives for others. Whether it was a person returning to Perry County from a state institution in the 80's seeking dignity and security, or volunteers struggling to save a theater, Sandy found a way to beat the odds and be an agent for remarkable change. Whether it was a community wishing for summer recreation and the arts for their kids, or a historic Main Street begging to be saved, Sandy's vision and organization skills allowed it to happen. Sandy did her best to do the heavy lifting behind the scenes that usually resulted in leaving the person or place better for it. Much like my mother who we said goodbye to last week, Sandy also enriched my life as a strong, able woman, who was humble and kind, but tough and wily. My heart is full of gratitude. How lucky we've been. May she rest in peace!

John Winnenberg

September 30, 2021

Dear Sandy:

You know, I had just picked out your Christmas book for this year when I found out that you would not be able to receive and enjoy it. The news that came from John stunned me. It felt like, suddenly, a critical part of me—of my life—had been amputated. Carrying on with life and work is possible and important, but a big part of the richness has vanished.

We were colleagues and partners for many years, starting with the experience of learning together about normalization and PASS in 1975. In those early days we thought that the two of us were the only Ohioans who had learned about and committed to teaching the normalization principle. Not entirely accurate, it turned out, but that's how I remember things. We helped lead or teach many PASS events—from small one-team workshops in Ohio to larger sessions in Pennsylvania, New York, and Massachusetts. We may have been the first to try to introduce what came to be called "person-centered planning" to others in Ohio. Those were heady times.

In many ways you have been my teacher. I especially remember visiting at the adult day service in Newark when you were the leader there. I watched through an office window as one of the workers—upset about something important to him—held his angry face about an inch from yours and screamed at you. It seemed like it took an hour to calm things. When the encounter was done (and resolved, I guess), you joined me with the comment: "The ultimate consumer… I just <u>love</u> it." Respect for the other outweighed what must have been your discomfort. I hoped to learn.

As well, I learned from your insight (gained, perhaps, during the 1980s wars and rumors of wars) that a way to diminish your support for the nation's military adventures was to reduce your

income. That choice of a lowered income meant you would contribute much less in the form of income tax toward war purposes. You consciously responded to what you called "a call to conscience." It was a too-rare example of answering such a call. Many of us need your kind of clarity.

And, of course, you and I have been friends—in the best sense I can imagine—for nearly fifty years. We have worked to sustain that friendship--despite distance from each other and difference in what has occupied our time--through phone conversations (though I think neither of us likes the phone very much), e-mail exchanges, and the occasional lunch in Columbus or Chillicothe. That has been the best we could arrange; it has certainly been better than losing our connection. Alas, now….

Many people—probably more than you would believe—will feel the lack of your presence and support. I, of course, will miss you for a long, long time.

Jack