The Safeguards Letter

A Publication of OHIO SAFEGUARDS

Number Thirty-nine *Spring 2007*

IMPORTANT UPCOMING WORKSHOP – MARK YOUR CALENDARS!

"Crafting a Coherent Stance on the Sanctity of All Human Life," September 17-21, 2007
Catherine Spaulding Retreat & Conference Center, Nazareth, Kentucky *(near Bardstown).*

Presented by Susan Thomas, and Associates of the Training Institute of Syracuse University. **Wolf Wolfensberger will present a part of this workshop.** This event is intended for (a) those who perceive that there is a gathering momentum in the world that works toward "deathmaking;" and (b) those who are uncomfortable with a pick and choose approach that objects to some deathmakings but endorses others, and who would like the work toward a more **coherent** position on the sanctity of human life.

This event attempts to accomplish four aims:

a. Awaken people to the reality that there is growing support in our society for various forms of deathmaking of people who are impaired, elderly, or devalued for any reason. Deathmaking includes any practices that outright kill people, greatly hasten death, or lead other people to act so as to bring about a person's or group's death. Many practices that participants see all the time, and may even participate in, will be shown to contribute to deathmaking.
b. Orient participants to the disguises and interpretations that are given to deathmaking so as to make it less obvious and less repugnant.
c. Elucidate the societal dynamics and values that have been leading to these developments.
d. Help people to see the validity—indeed, the necessity—of a coherent moral stance in defense of all human life, to see what such a stance would entail, and to work toward such a stance.

Special topic: issues of the withholding, withdrawal, and refusal of medical treatment.

For more information, contact Joe Osburn, Director, Safeguards Initiative, at 502-348-1168 or joeosburn@spitfire.net .

AN EFFORT WORTH KNOWING ABOUT: VISIONARIES & VOICES

Visionaries & Voices is a non-profit studio/gallery located in Cincinnati, Ohio and created specifically for artists with disabilities to grow both personally and professionally. V & V assumes that artists with disabilities are valued members of the community and believes they must have opportunities for artistic success and creative growth in an atmosphere of mutual respect, inspiration, and joy. Visionaries & Voices values a world in which artists with disabilities not only create and share their works of art but also are given the chance to show the community at large what it means to be creative and alive without limits.

In 2000, Visionaries & Voices started as a grass-roots effort among Cincinnati area social-workers who were astounded by the art created by people with disabilities in their homes. The early supporters made connections with local galleries to showcase the works, and those shows created enough momentum to help establish a studio-gallery specifically for the artists. On August 1, 2003, Visionaries & Voices opened its doors at Essex Studios in Walnut Hills near downtown Cincinnati. Essex Studios houses close to 100 professional artists, and people who learn or practice their art at V & V make connections with those professionals just by having the studio there. Currently, the studio-coordinator opens the studio every weekday and assists artists with disabilities in purchasing art supplies, learning new techniques, and marketing their works. Over 30 volunteers help out in various ways. United Cerebral Palsy of Greater Cincinnati has partnered with V&V since its inception, and the studio has a small amount of specialized equipment that people with physical handicaps can use to explore their creativity, sometimes for the first time in their lives.

Since coming together, Visionaries & Voices has helped over 300 artists with disabilities create, frame, market and sell their works. It has also introduced the artists' powerful contributions to local culture through exhibits at galleries and arts centers, and through workshops at local libraries and schools. Artists at V & V have developed relationships with artists who are not labeled and who collaborate with V&V artists on paintings, sculptures, public arts projects, and other projects throughout the community.

Give V & V a call if you're interested or for a tour (513) 861-4333. Our address: 2515 Essex Place, Studio # 172, Cincinnati, Ohio 45206. Our web-site: www.visionariesandvoices.com.

The Safeguards Letter is an occasional publication of OHIO SAFEGUARDS. The *Letter* exists to promote affiliation among people who are interested in and thoughtful about those who live outside the sphere of respected community membership--those who are the usual receivers of human services. All material in *The Safeguards Letter* is under OHIO SAFEGUARDS' copyright (©) unless otherwise attributed. Letters, ideas, and items for publication in the *Letter* can be sent to: Editor, *The Safeguards Letter*, 3421 Dawn Drive, Hamilton, OH 45011 (e-mail: jackjr441@earthlink.net). We welcome our readers' ideas and reactions.

FUNDS TO SUPPORT PUBLICATION

For many years we have not recorded "subscriptions" to *The Safeguards Letter*—and we're not about to start doing that now. Instead of having subscribers we have had financial supporters. Those have been people who saw some value in the publication of *The Letter* and who sent small donations of money to keep it going. The donations have paid for printing and mailing costs. Because we have started to make *The Letter* available on the internet, such costs are reduced. We don't expect, though, that we will entirely stop sending print copies to readers who do not use computers or who really prefer to have *The Letter* come on paper in their mailboxes. It costs about $150.00 per issue to mail the *Letter* to those who do not or cannot receive it on-line.

So, this little section of *The Letter* is an appeal to donors to send small contributions and to be, therefore, supporters of *The Letter*. If everyone who receives *The Safeguards Letter* were to send just a small amount, all of a year's costs for printing and mailing would be met. Also, donors receive the gratitude of OHIO SAFEGUARDS. If you want to contribute, you can send your donation (it's tax-deductible) to: OHIO SAFEGUARDS, 3421 Dawn Drive, Hamilton, OH 45011.

JUST QUOTES

One limitation of programs created under the traditional program structure is that they require intensive government monitoring, which in turn requires that government agencies, rather than individual program recipients, make crucial decisions about program design and execution.

Jason Hardy & Arthur Lyons
"Assessing the Independent Living Needs of People with Disabilities in Ohio," 1997

People think of standards—criteria—as being clear rules against which random experience is measured, thereby helping randomness to seem less vexing and oppressive, like a foul line in baseball or the manual of arms or the rules of admiralty. And in general I don't believe the idea of standards is bad as long as they stay as supple as the experience to be measured.

Richard Ford, "A Sea of Stories"
New York Times Book Review, 10-21-1990

IT WAS THE WORST DAY OF MY LIFE: A NEW LOOK AT THE OLD PROBLEM OF HELPING FAMILIES AFTER THE IDENTIFICATION OF DISABILITY IN A CHILD.

Diane Hannum and Leah Holden (formerly with The Arc of Ohio)

(Not long ago I heard, once again, some professional workers talking with each other about the "grief process" presumably experienced by family members when they first find out that a child of the family might have a condition leading to a disability. I've known many families and have never doubted that the point of first identification sparked strong feelings. But I and others have always objected to the death imagery inherent in the use of the metaphor of "grief" to describe those feelings. More than fifteen years ago, Diane Hannum and Leah Holden, then associated with The Arc of Ohio, addressed the first identification issue in a sensitive and sensible essay. I thought it was time that essay was re-issued. So, it's offered here and—because of its length—in the next two issues of The Letter. Jack Pealer)

Family First is a parent-to-parent program of information and support developed and sponsored by the Arc of Ohio. The curriculum was originally written in 1983-4 with a grant from the Ohio Developmental Disabilities Planning Council. Since then it received funding from the Ohio Children's Trust Fund, the Ohio Department of Health and local United Ways and foundations. It has become a part of Ohio's Family Information Network, a parent-to-parent effort in early intervention, funded under Part H of P.L. 99-457. Arc-Ohio currently receives funding for Family First from the Ohio Council of the Knights of Columbus. Most of the parent quotes in this paper are taken from the 1991 videotape series, "On This Journey Together," produced by The Arc of Ohio and the Ohio Department of Mental Retardation and Developmental Disabilities.

Over the past decade, we have had opportunities to travel across Ohio, talking with and learning from parents of children of various ages and diagnoses in urban, suburban and rural communities. One of the most persistent and controversial topics we have discussed with parents and professionals is how to interpret the experiences of parents whose child has just been diagnosed with a disabling condition. The interpretation put forth most often is that they are "going through the grief process." Family First has never included material about "the grief process," although many people pressured us to do so. We encourage people, instead, to help families understand their experiences in terms of crisis. This paper explains why we recommend this way of thinking about what happens to families when they are told, "Something is wrong with your child."

> We didn't find out anything was wrong with Lacie until she was six months old. I kept on telling my doctor that she threw up all the time, and then my mother kept on saying she didn't think she could see, and so we kept on telling him. He finally said, "We'll send you to Children's Hospital in Columbus." We went to the Handicap Clinic. They looked her over, and they laid everything right out on us and just told us how it was. It was the worst day of my life. But we picked up and moved on.
>
> --- Kathleen Cannon

> They diagnosed the CMV two and a half, three months after Lindsay was born, but there was no real way to tell exactly the totality of the damage. We thought she had colic for six to eight months, and we found out then that she was having seizures. ... Nobody really knows how much damage was caused. We really have no idea what she's going to be able to do or what she can't do. We think by now we've got the medical problems basically diagnosed. So we just kind of live with it day by day.
>
> --- Carl Habekost

> The first week was kind of a blur. I don't remember very much about it. I remember before we got the actual diagnosis hearing people a couple of times say the word "retarded" and I can remember wondering to myself -- Trevor was so sick in neonatal intensive care and so small -- I couldn't figure out how they could possibly know

that he was mentally retarded, and Down Syndrome never dawned on me till they gave me the diagnosis.
--- Diane Hannum

Sarah's my oldest. She was born supposedly normal. Her Apgars were all normal. She was a whiny baby. I would always complain that she cried too much and whined too much, and they would always tell me they thought she had colic, but they wanted to see her again. I'd come back in and they'd check her, but they could not find anything wrong. By the time she was five and a half to six months old, she started doing a quick jerk with her head. It looked like she was startled. I didn't know what it was. Finally I took her in to the doctor, and he put her into the hospital the next day. He thought it might be seizure. As soon as I put her in the hospital they got a lot worse... We had already gone through a lot of tests. [The resident] was in checking her, doing some routine checks. I had never met him before. I asked, "Do you know the results or have you heard anything they have come up with?" He said, "She has infantile spasm, and she has an 80 to 90% chance of being retarded. And then he just left. Then I was there by myself and thought to myself, "No, this is not right. I've got to talk to somebody else. He's crazy." About ten minutes later my mother called on the phone to see how things were going, and I went out in the hall and told her what he told me. As soon as I said it out loud, I fell apart there in the middle of the hallway, made a big scene. They had to haul me away with a box of Kleenex.... It was like she was retarded. So it was a shock...
-- Ann-Marie Satterthwaite

Aric was a 30-week baby, so he was ten weeks premature. I had spent the week before in the hospital and we were able to keep labor from coming for another week. He was born at 3 pounds 5 ounces, beautiful little boy... He wasn't breathing when he was born, so they immediately took him over to the NICU at Children's, where he spent six and a half weeks. It was relatively uneventful... When we took him home, we were told we had a healthy, normal, happy, healthy baby. Go home and enjoy peewee football, little League baseball, and live happily ever after. We knew that because of his prematurity he was going to be delayed. ... So he was slow in development. Even with the give time that we were allotted, we noticed he wasn't holding his head up, and he didn't seem to be trying to crawl or pull himself up. None of the developmental stages that I was looking for.... At nine months we went in again for his checkup through neonatal follow up, and a doctor walked in and just blurted out to us that he was severely cerebral palsied, severely mentally retarded, he would never speak, he would never eat, that we should find a nice institution and put him in it. And he turned around and walked out the door. That was our introduction to the world of disabilities. --- Tina Murray

Why do parents who have just learned that their child has a disability experience shock, denial, anger and depression? They are responding in understandable, human ways to a particular crisis -- the identification crisis.

If we understand that families experience this crisis in a society which still devalues and segregates individuals who have disabilities (and, often, their families), I think it is fair to understand the identification crisis as a "degradation ceremony."[1] This is a sociological term that refers to the process of transforming someone's identity into something looked on as lower and less worthy. The new identity, in this case a "disabled" identity, is not just added on to the person's existing identity. The person's identity is transformed to account for their history as well as for future actions.

We didn't find out she had Down Syndrome until she had open-heart surgery. She was a normal kid until she was six months old. She had open-heart surgery at five and a half months, and then she "caught" Down Syndrome.
--- Ray Thomas

By characterizing her label as a diagnosis like any other diagnosis, say, of measles or the flu, this father whittles away at the power of the label to redefine who his daughter really is. He refuses to permit -- even looking back on it -- his daughter's degradation ceremony. But he knows well, as do other parents, that a label of Down

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[1] Harold Garfinkel (1956) "Conditions of Successful Degradation Ceremonies." The American Journal of Sociology. 61: 420-24 (March).

Syndrome or cerebral palsy or autism is still a likely first step on a path to segregated educational programs, social and recreational opportunities and ultimately residences and places of work. Without sustained, effective action on the child's behalf, usually led by the parents, a life of devaluation, exclusion and loneliness is still the most likely result of the attachment of such a label.

One mother reported that most of the pain she endured came from hearing over and over all the things her daughter Samantha would never do, and professionals using the label of Down Syndrome over and over. When she spoke of a positive future for Samantha and how things could be different, she was told, "You're lucky to have any services at all," and early intervention staff discussed how she hadn't "accepted" Samantha's disability.

Some crises occur routinely to most people as they progress through the life cycle. Some depend on the existence of unusual situations. Situational crises bring individuals and families face-to-face with circumstances they did not expect or predict, and which they may believe themselves unprepared to face.

> I have a friend who had young children of her own and used to volunteer to watch Eric and Kelsey while I took Trevor to therapy. She was a big help. Later on, when she told me she was expecting her third child, she confided that she had always been fearful of having a child with a disability like mental retardation, but since knowing Trevor, she wasn't afraid any more.
>
> --- Diane Hannum

Crises challenge a person's ability to cope with new demands. Unlike wars, earthquakes and other events that affect groups of people, some situational crises single out individuals. The experience of having a child identified as having a delay or disability is one of these. We know that one of the most common experiences for parents is isolation, the feeling of being all alone, the sense that "no one has gone through what I am going through."

> I think the things I used to focus on that made us unique don't seem to hold water any more. I really found I kept saying, "We're different, we're different." I think every family is different. It would be a pretty boring world if we were all the same. I used to say my daughter's needs are more complex. All those things tended to draw me back and added to that feeling of isolation, but when I focused on what I had in common, the love I have for my daughter I find in every parent, we all share that.
>
> --- Cindy Norwood

The identification crisis thrusts parents into the world of human services, some for the first time. They may face confusing decisions about medical treatment, early intervention or family support, and often these choices must be managed in a language full of jargon and unfamiliar communication patterns.

Parents often find their sense of family and community quickly falling apart. Members of the extended family, friends and neighbors may be no better prepared for the arrival of a child with a disability than the parents, who themselves rarely are prepared to negotiate complex human service and health care systems, which tend to be confusing enough for people who work in them every day.

> Jess' condition was one of always being on the balance of life and death, and I think that many people are afraid of facing death or afraid of facing a potential sorrow. My family really withdrew, friends really withdrew. My daughter's medical needs really led to a feeling to isolation, that she was so unique and that our situation was so unique. I really felt very alone and very isolated. It was a very isolating situation, completely. So the way my family responded was first to be there for me at home, but my daughter's first year and a half of life was spent in a hospital, and they didn't very often come down to see her, and some of them not at all. Even when we first brought her home, it was very, very isolating. Family withdrew and a lot of friends withdrew. We relied very heavily on paid service providers, doctors, nurses, social workers in the hospital.
>
> --- Cindy Norwood

> I had a "good friend" who called me at the hospital the day after Trevor was born, unaware of anything except that I'd had the baby. She asked how he was doing, and I explained he was in Neonatal Intensive Care. She quickly said she'd call me back. She called, all right -- nine

months later. (Guess she'd finally worked through her denial.)

--- Diane Hannum

When I first got LaMar, my life was completely different. I hadn't carried him for nine months, I wasn't expecting a baby. All my children were grown and off, so my life had changed. You rearrange your life after your children grow up and leave home, then I had to rearrange mine again, because I had another child in the home. I had to limit my activities. My friends that I thought were friends turned out to be acquaintances, because they kind of shied away. LaMar was a very funny-looking little kid when he was young. He had a huge head, big eyes and a little tiny body. He weighed nine pounds at birth, and at six months he was weighing six pounds, something like that, so it was kind of scary, and I guess they really didn't know how to handle it. I probably didn't either, because if they didn't want to be involved, that was okay, I just shut them out. I had no problem with that. I've always been, "If you don't want to be bothered with me, that's okay, that's your problem, it's not mine. But what I didn't realize was that I couldn't do everything for LaMar myself. I needed other people, but I needed people that wanted to be involved with him, not people that were paid to be involved with him.

--- Peggy Miller

Families and their supporters may struggle with learned devaluation of people who have disabilities and the love they feel for their child.

I'm going to admit it, maybe I was like this before we had Lindsay, you see a person with a problem and you want to kind of ignore it, you don't want to face them. It's that kind of thing. I think because we've become so convinced about thinking Lindsay deserves a quality life, because it's easy for people to push children like Lindsay away, under the carpet, so they don't have to deal with it. So as a parent you really have to counteract that. You have to really be an advocate for your child. People don't do it on purpose, but it's just the way society is.

--- Carl Habekost

My feelings about people who were mentally retarded interfered with my ability to come to an understanding of Trevor having Down Syndrome. I thought it was about the worst possible thing that you could be, and it took me some time to appreciate the fact that Trevor had a whole lot of things going for him, and that it really wasn't as big of a deal as what I thought it was. It gave me a whole different perspective on what quality of life means, and that intelligence doesn't necessarily have a very big bearing on your quality of life. It was kind of a gradual process of coming to appreciate Trevor. I can remember holding him and always thinking: Down Syndrome. Even when I was cuddling him and loving him, it was, "Trevor had Down Syndrome..." I began to appreciate him more and began to think about Trevor, because Trevor was a wonderful individual who brought a lot of good things into my life, and I quit thinking about Down Syndrome.... I guess there was a certain day when I didn't think about it until later in the day, and when I thought about it later in the day, it occurred to me that I hadn't thought about it earlier in the day. He was about six months old.

--- Diane Hannum

(To be continued in the next issue of The Safeguards Letter)

WOULDN'T YOU OBJECT?

This item is reprinted from Update, published by the International Task Force on Euthanasia and Assisted Suicide, Vol. 20, No. 3, June 2006

Residents of a Zurich apartment complex are gathering signatures to evict Dignitas, the assisted-suicide provider group that uses a fourth-floor flat as the place to end people's lives. Describing it as a "house of horrors," Gloria Sonny, a six-year resident of the complex, said, "This is meant to be a residential flat, but some days you'd think it was a morgue." For many residents, the worst part is seeing these suicidal people in the halls and elevator on their way up to the apartment to die. "The look in their eyes haunts me," Sonny explained, "particularly if they are young." For other occupants, seeing the corpses in body bags propped up in the corner of the communal three-person elevator is the most disturbing. Since the elevator isn't big enough for a coffin, Dignitas uses a body bag to bring the corpse down to a waiting hearse. "Almost every day the bodies of people…are taken down in the lift," Sonny said. Kelvin Leneveu, another resident added, "It's very creepy. The floors are thin and when we hear movements upstairs, we know that means they're up there, and someone's going to die." [*British Medical Journal*, 6/3/06; *Daily Telegraph*, 6/4/06]

A VIEW FROM THE BACK WINDOW

People with Disabilities and their Money (2)

The last time I wrote in this space I shared some worries about people with disabilities and their money. This time I want to expand a bit on one of those worries—a specific result of people's utter dependence on Medicaid as the source of funds to pay for day-to-day living support. That specific result is called "patient liability."

> Most Americans living with significant intellectual disabilities receive Medicaid, the dominant and often only payer for key services. Few families, even among the affluent, could provide care without it. So they do what they legally can to maintain eligibility. States recognize these realities by establishing (or tolerating) asset-shielding arrangements. Many families are nonetheless forced to resort to backhanded strategies that create unforeseen complications. Some nominally disinherit a disabled child, leaving funds to an able-bodied sibling who is honor-bound to help. These arrangements have no legal force, and they create new difficulties. Some able-bodied siblings die or divorce. Others borrow funds intended for their sibling…. When caregivers die, persons with disability face the loss of Medicaid if they inherit assets or if they must cross state lines to establish new living arrangements.
>
> Harold Pollack, "Learning to Walk Slow: America's Partial Policy Success in the Arena of Intellectual Disability*." Journal of Policy Histor*y, Vol. 19, No. 1, 2007

In the late 1970's when I supervised a "District Office" for Ohio's state mental retardation agency, the office would occasionally be visited by agents of Ohio's Bureau of Support, as it was customarily called. Actually the official title was "Section on Reimbursement Services." When I found out that the agents were there to gather information that would help them, in effect, garnish the wealth of the poorest Ohioans (people with disabilities living in institutions or community residences), I tried to have them barred from the office. One phone call from Columbus set me straight. There was to be no interference with <u>that</u> work.

I didn't know that people who lived (and who often were hurt) in the crappy places the state (my employer) made available to them were accumulating bills for the services they used. Foolish and naïve youngster! The practice of placing claims on the meager wealth of poor people has, it turns out, deep historic roots, and it extends down into the present in the process that Medicaid calls "patient liability."

As far as I can tell, patient liability is either the deductible or the co-payment (maybe both) that a patient—an "insured" in customary insurance-talk—has to pay as part of the Medicaid long-term care scheme. Many of us have some kind of health insurance (although many others do not). Users of health insurance have learned that they will have to pay a certain percentage of the cost of medical service and a flat fee (mine happens to be $25) every time they have appointments with their doctors.

Suppose, though, that I go to my doctor, pay my $25, and claim $65 in additional cost for the appointment from my insurance company. Then, a week later, I win $500 in the lottery (highly unlikely because I don't buy tickets, but that's another story), and those funds go into my bank account. I would not expect my health insurer to send agents to my doctor or to my bank to gather information so that they could recover the $65 because I had an unexpected financial windfall. But if I were claiming a benefit under a Medicaid "long-term care policy" that's exactly what would happen. As a poor person (I'd have to be poor to qualify for Medicaid in the first place), I would be building up a bill for every day I lived using, say the services of an intermediate care/mental retardation (ICF-MR) program or a Medicaid "waiver." If used such a service and I had even a small windfall, state agents whose job it is to make sure I pay my "patient liability" bill would be likely to find me before I could consider any other use of my money.

Does that sound like an incentive for productive employment for someone who uses a Medicaid waiver to pay for the supports on which she relies? Does it sound like a policy that encourages families to contribute to the economic life of family members who have disabilities? Does "patient liability" enhance people's ability to assume places as respected and productive citizens?

Actually, "patient liability" policies—together with chronic unemployment of people with disabilities—are the engine of perpetual dependency. Although ways to slow that engine (e.g., establishment of a "Medicaid pay-back trust" that defers "patient liability" payments until the life of the trust beneficiary ends) have sometimes worked, those ways are relatively unknown, are hard to use, and consequently are not practically available to most people who use Medicaid to pay the cost of long-term support. What people may really need is either the elimination of policies like "patient liability" (with the resultant savings in the costs-of-collection) or—even better—ways to accomplish long-term support without reliance on the Medicaid system at all.

Jack Pealer

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Number Forty *Summer 2007*

REMINDER!! IMPORTANT UPCOMING WORKSHOP

"Crafting a Coherent Stance on the Sanctity of All Human Life," September 17-21, 2007
Catherine Spaulding Retreat & Conference Center, Nazareth, Kentucky *(near Bardstown).*

Presented by Susan Thomas, and Associates of the Training Institute of Syracuse University. **Wolf Wolfensberger will present a part of this workshop.** This event is intended for (a) those who perceive that there is a gathering momentum in the world that works toward "deathmaking;" and (b) those who are uncomfortable with a pick and choose approach that objects to some deathmakings but endorses others, and who would like the work toward a more **coherent** position on the sanctity of human life.

This event attempts to accomplish four aims:

a. Awaken people to the reality that there is growing support in our society for various forms of deathmaking of people who are impaired, elderly, or devalued for any reason. Deathmaking includes any practices that outright kill people, greatly hasten death, or lead other people to act so as to bring about a person's or group's death. Many practices that participants see all the time, and may even participate in, will be shown to contribute to deathmaking.
b. Orient participants to the disguises and interpretations that are given to deathmaking so as to make it less obvious and less repugnant.
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d. Help people to see the validity—indeed, the necessity—of a coherent moral stance in defense of all human life, to see what such a stance would entail, and to work toward such a stance.

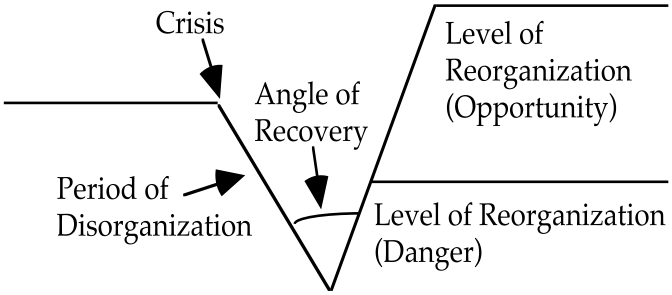
Special topic: issues of the withholding, withdrawal, and refusal of medical treatment.

For more information, contact Joe Osburn, Director, Safeguards Initiative, at 502-348-1168 or joeosburn@spitfire.net .

CONTINUATION: It Was the Worst Day of My Life: A New Look at the Old Problem of Helping Families after the Identification of Disability in a Child. Diane Hannum and Leah Holden (formerly with The Arc of Ohio)

Unfamiliarity with human service language and procedures, isolation from usual sources of support, suddenly being faced with devaluation and segregation, and the emotional work required of anyone in crisis can combine to interfere dramatically with parents' abilities to act on behalf of their young child or on their own behalf. If we understand power as "the capacity to act," then we can see why empowerment of families of young children who have been identified as having or being at risk of delays or disabilities is such a critical task and such an integral part of early intervention. It is not that anyone else -- parent or professional -- has power to transfer or give families in crisis, but rather that certain things seem to help families regain (or gain) their bearings and increase their sense of self-direction and control.

One benefit of interpreting families' experiences in terms of crisis is that we know some things about families and how they respond to crisis.We know, for example, that crisis represents both danger and opportunity, as the following diagram shows:



Reuben Hill, Families Under Stress

This, incidentally, is the same trajectory organizations follow in adapting to change.

We know, too, that a new crisis can occur before the first one is resolved. One day the baby is diagnosed and the next day the family must make decisions about surgery. Before a new level of reorganization is reached, while the family is still on its downward plunge of disorganization, it may face a new challenge. The experience of having to make new decisions and adapt to more change is different, depending on whether someone feels organized or disorganized.

The literature tells us that families in crisis must master four tasks:

1) preserving life and maintaining physical health;
2) identifying and expressing feelings related to the crisis;
3) understanding the crisis event, clarifying and adjusting personal beliefs, values and goals;
4) making needed adjustments in daily patterns of work, play and relationships in light of the crisis event.

Small wonder that families often do not have the time, energy or other resources for much beyond dealing with the crisis. Clearly an approach that reduces everything to emotional factors is not adequate to help people in crisis.

Crisis, then, does not call for "crisis therapy" or some other treatment. It requires assistance and support for individuals and families to master each of the four tasks, taking advantage of the opportunities and avoiding the dangers.

The usual way of interpreting families' experiences

For many years it has been widely assumed by parents and professionals alike that parents of children with disabilities "go through the grief process," characterized by stages of confusion, denial, anger, guilt, etc., as they work toward acceptance. The most famous of the feeling states (actually a protection against feelings) is denial. Rarely does a gathering of professionals talking about parents of children with disabilities end before someone asks: But what about the parent who is in denial? (Parents of children with disabilities don't just deny things. They are "in denial.") Ken Moses, the most widely quoted writer and teacher about "the grief process," warns, "Denial is the feeling state that is most often identified as a destructive parental attitude."

One of the first experiences for many parents whose child is being or has recently been diagnosed is being pulled back and forth between those who say: "Don't worry about it; it's only a stage," and those who scold, "And why didn't you bring her in sooner?" This push-and-pull process intensifies feelings of confusion, frustration and guilt, and makes it difficult for parents to know who to believe. Not an ideal way to begin a "career" of parent-professional relationships.

We know that parents, particularly mothers, are the persons most likely to notice their child's delays. Parents often report having sought out professionals to confirm their suspicion of their child's delay or disability, only to be told repeatedly: She'll grow out of it, or: You're just too anxious, Mother. Yet we do not obsess about professional denial.

> We knew right from the very beginning [something was wrong], because she cried for eight months. ... The doctor was saying, 'Take a six-pack to the back of the yard and drink it, and then you can take care of your child.' I said, 'I'm not an iratemother. There's something wrong.' It was very hard for us, trying to convince the professionals that there was something wrong. When we finally did cross that bridge, when they figured out something was wrong, the problem escalated. They found more and more things wrong.
>
> --- Denise Habekost

The idea of denial assumes that the parent has access to the same information and understanding as the one who claims the parent is in denial. Parents generally don't know what the professionals know. Sometimes what is labeled as denial is simply ignorance about the condition.

> I will not soon forget the day when, after five months of searching, I found people who knew about my daughter's condition and what to do about it. Nor will I soon forget overhearing a nurse saying that parents of children with this condition don't seek treatment sooner because they are "in denial." I thought about the five months I spent seeking information from medical caregivers and mental health workers. If I had received information from these people promptly, there would have been no delay in getting treatment.
>
> --- Leah Holden

Denial, when that is what it is, is a functional psychological defense. If we make it our mission to break through someone else's denial, we may force the person to retreat more. Denial has been described as "a healthy way of dealing with [an] uncomfortable and painful situation," and as "a buffer after unexpected shocking news, [which] allows the [person] to collect himself and, with time, mobilize other, less radical defenses." (Kubler-Ross, 1969, p. 39) People deal with things when they (not we!) are ready to deal with them. People are most likely to change, paradoxically, when they feel accepted as they are.

The importance to the helper of cracking through denial is illustrated by Cathy and her mother.

What is it about denial that raises so much anxiety in the rest of us, (the ones who happen not to be denying something for the moment)? Why is it so hard for us to let someone deny what is too difficult to bear, for now? Why does their version of events have to match ours? How can we deal with our own anxiety about a family's dilemma? How can we wait patiently and nonjudgmentally until they are ready to face it? How can we avoid projecting our own unresolved grief from past losses onto parents of newly diagnosed children, whom we assume must be experiencing a loss? How can we become instead part of a supportive, respectful, informative environment that will enable families to make their own sense of their dilemmas?

These are important questions for parent-to-parent workers in early intervention, particularly. The availability of early intervention may (if it doesn't already) come to carry with it the presumption that families must utilize it, as early as someone makes an identification of eligibility. Families that don't, because of denial or for any other reason, may be on the receiving end of negative judgments. If we are going to have family-centered early intervention, we are going to have to respect families' choices about timing and deal with our own anxieties about it.

The name most closely associated with grief has been Ken Moses, a clinical psychologist who has written and lectured widely about the grieving parents do following the diagnosis of disability in a child. He wrote in 1977,

> When an initial diagnosis of developmental disabilities is received by a parent, a grief process begins. The parental dreams□are almost always shattered by learning of the disability. To be actualized, dreams generally require a wholly intact child. Therefore, the initial diagnosis often marks the destruction of a cherished and significant dream. In order to continue with their lives the parents must grieve the loss of their dreams.... Grieving is primarily an emotional process... Grieving starts spontaneously and appears to require no learning period.

This is a completely psychological interpretation of parents' experiences. Virtually everything is reduced to psychological states: denial, anxiety, guilt, depression, anger. What is the source of these feelings that occur "universally"?

> Parents who are frustrated by the birth of an impaired child feel anger toward that child who has intruded upon their lives and substantially disrupted them. To have an impaired child is expensive, embarrassing, time-consuming, energy-consuming, and shattering to the entire family constellation. On a more psychologically primitive level, most parents feel that all this disruption and pain has been "caused by" the impaired child. (Moses, 1977)

These ideas, produced fifteen years ago, are still widely circulated in training about parents and in parent-to-parent training. In a more recent paper ("The Impact of Childhood Disability: The Parent's Struggle," Ways magazine, Spring, 1987) Moses disavows using the grief process as a "recipe to produce acceptance," but he continues to insist that it is the disability, rather than social responses to disability, that lead necessarily to grief. He assumes that having a child with an impairment is a "devastating and continuing loss."

> Here is another common statement of belief about parents and stages of the "grief process:" There are various characteristic emotional reactions of the parents to the mentally retarded child. Shock, refusal, guilt, bitterness, envy and rejection are different reactions manifested, and all parents experience these whether they realize it or not. (Love, 1973)

Should we be surprised that parents who do not consciously and actively express grief, according to prescribed models, are often met with anxious insistence that parents must "go through the grief process"? Woe to parents who claim that their experience is something other than grief. (They must be "in denial.")

> Denial is used as a way of undermining a parent's claims about reality that do not match a professional's. Thus parents fighting for integrated services -- or any particular service -- can be seen as acting out their anger, which is really anger at the injustice of having a child with a disability or perhaps even anger at the child with the disability. I have never had a professional who had high expectations for Trevor tell me I was in denial or that I needed to grieve the loss of my dreams. But I have had (more than once) professionals try to get me to accept a lower standard for Trevor by using denial, anger, guilt and grief to invalidate my opinion and convince me to accept segregation and/or poor services. In the first six months of Trevor's life I was presented with the grieving process over and over. I experienced stress over the fact that it did not represent what I felt and confusion because other parents felt that it did. I also felt anger with early intervention staff who insisted that but refusing to acknowledge it. My son's first home based teacher visited weekly and wrote a summary at the end of the visit. One of the things she included in her summary was how I was doing, or her evaluation of my feelings. She also talked to me about how other parents were doing, whether they were "in denial" or how close they were to "acceptance."
>
> --- Diane Hannum

Why we don't teach parents about grief

"The grief process" has been comforting to some parents as they struggled to come to terms with their child's diagnosis. It is promoted by parent-to-parent programs as often as by formal services. No course or inservice program on parents of children with disabilities is considered complete without "the grief process." Few parent-to-parent sessions omit it. Often the first early intervention provider to meet a family may begin teaching them about it.

One mother told how very honored she was to be invited to a local college to speak to special education majors every time they discussed parents of children with disabilities in their curriculum. She speaks of how she thoughtfully prepared her presentation to give the students the information most likely to be of benefit to families that they would eventually be working with. Then she speaks of the shock, hurt and betrayal she felt when she found out that the students' assignment after her presentation was to evaluate in which stage of the grief process she was.

Why has "the grief process" been so appealing to parents of children who have been labeled? Parents may experience comfort and relief when they are told about "the grief process," for several reasons. Perhaps it is the first time anyone has acknowledged the strong feelings they experienced when they learned of their child's diagnosis. It probably comes as a tremendous relief to find that these feelings are natural and normal. In this way "the grief process" gives some routine quality to parents' experiences as they personally confront their child's label for the first time.

Parents may gain self-acceptance and understanding from seeing that their apparently chaotic feelings and behavior following their child's diagnosis have, in fact, a logical order and progression. They may find hope in the idea that shock, denial and anger are steps on the road to acceptance. They may for the first time have an opportunity to discuss these feelings without shame and guilt. Professionals, too, may welcome a way to account for the strong and disturbing feelings parents express, sometimes at them. It is not too surprising then that "the grief process" has been so popular and enduring a concept, but we have not adequately explored its costs.

What we believe about families does tend to change and evolve over time, even as our notions and values about families change. The grief process and its modifications were developed in the 1960s. This was pre-early intervention, pre-94-142, pre-deinstitutionalization, pre-everything we take forgranted these days. Yet our beliefs and assumptions about families sometimes lag behind the real changes in our world. The Turnbulls have helpfully contrasted "traditional" assumptions with "state-of-the-art" assumptions. [See "Old Views/New Views"]

The assumptions behind "the grief process" are the "old views" identified by the Turnbulls. But we are in the midst of a nearly completed paradigm shift from old views to family-centered assumptions. The "grief process" preserves the old paradigm and allows it to continue influencing families' lives.

Interpreting parents' experiences as "going through the grief process" has had a number of other unfortunate consequences for perceptions of families and of persons with disabilities. Why do we reject the "grief process" as applied to parents of children with disabilities?

1) "Grief" is not an accurate description of what happens to families whose child is diagnosed as having a disability, and calling it "the grief process" confuses what actually does happen. The identification crisis is a different kind of crisis from the loss of a loved one. They are similar in some ways, in that they are both crises. But the identification crisis is not an example or type of grief. Rather, grief and the identification crisis are both examples or types of crisis. One of the major challenges for a person who is truly grieving revolves around the loss of roles and relationships that may result in a diminished self-image. While parents of children who have been identified as having a disability may in some instances feel thatthey have lost valued roles (sports coach or booster, in-law, etc.,) one of the greatest challenge comes from added roles and responsibilities.

> Jamie's needs have been very complex. They were the types of things where at times I resented the fact that I was more her doctor than I was her mother. I was doing very medically involved things at home. She was in oxygen at home, she was on a feeding machine, she was on IVs, she was on a heart monitor, and all of these things I resented, simply because I felt it didn't always leave time just to sit and be her mom. I was more her nurse or her doctor.
>
> --- Diane Frazee
>
> One of the most difficult things we faced very early on unfortunately was life and death decisions. My daughter was very dependent on that new technology, respirators and life-support machines, all those medical interventions. This was my first child. I can look back now and say, I know I had no confidence. I don't know how many new parents do. You don't have much time to prepare for this. I didn't feel that I was prepared to face the decision they were giving me about another human life. I had hardly had a chance to get to know that life.
>
> --- Cindy Norwood

2) The use of the term "grief" is costly and risky both for persons who have disabilities and for their families. For most people the word "grief" is used most often, if not exclusively, to describe a response to death. The terms "mourning" and "bereavement" make this association clearer. Through the process of devaluation and segregation, people with disabilities have ofoften -- with tragic results -- been associated with death. The word "grief" and the way "the grief process" is conceptualized and explained reinforces associations between children who have disabilities and

death. In seeking to soothe or comfort parents we may overlook the child who is alive. We may mourn "the lost dream child" and forget to celebrate the real child. And in strengthening the association between disability and death, which is already taught in many ways, we reinforce the very segregation that families struggle to overcome.

The association of death and people who are dying with people with disabilities is all too real. Maybe because so many people feel that people with disabilities would be better off dead, the grieving processassociated with a child with a disability seems natural. I'm certain that when Trevor was in neonatal intensive care, well-meaning relatives prayed for his death. Maybe we should have purchased two plots: one for Trevor and one for the "dream." Many people thought that when Trevor was born with Down Syndrome, he would not live long. And of course that would be a "blessing." First, you've been blessed with Heaven's Very Special Child, and then blessed if they die.

--- Diane Hannum

3) The "grief process" assumes that the "process" parents "go through" is related to or caused by the child's disability. It overlooks the devaluation and segregation of the child following the identification of disability. Moses says, "The impairment, not the child, irreversibly spoils a parent's fundamental, heart-felt yearning" (1987). We would say that it is devaluation and segregation, not the disability.

It's not so much the child and accepting their disability. It's how the world treats them or the lack of how the world responds to them in a positive way that seems to get in the way.

--- Cindy Norwood

4) The assumption that someone is grieving becomes a possible excuse for discrediting them and minimizing and trivializing their experiences. ("You're just going through the grief process," one parent is counseled.) It can become a weapon for silencing parents. ("You're in denial!" a parent is told by an angry professional, pointing a finger at her, during a discussion of ways parents and professionals can work together for inclusion.) A parent who dreams of a life of interdependence, inclusion and contribution for his/her child may be told, "You haven't reached acceptance yet." Acceptance of the disability or acceptance of the status quo? At times they seem to be presented as the same thing, though we know they can be separated with thoughtful planning and hard work. Often when parents ask for appropriate services for their child, they are told that they are not realistic, that they have not "accepted" their child's disability. This comes from not having completely "worked through the grief process." Rejection of services may be interpreted as a denial of the child's disability. One mother, who refused segregated preschool for her son nearly ten years ago, has for years been seen as unable to accept her son's disability. No one understands or accepts his disability as well as his family, but they had a philosophical disagreement about available services. Parents can be labeled as "not accepting" or "in denial" merely because they won't "go with the flow" of available services. This means they are living in a state of denial, which makes their wishes and requests on behalf of their child invalid. We ought to be giving up, not refining and polishing, our rationales for insisting that parents of children with disabilities are not to be believed.

People are not likely to give a lot of attention to what you're saying about your child if you're "going through a stage." Many people still think I'm going to "get over" my dreams for Trevor. Someday I'm going to understand his disability and see how wrong I was about inclusion. Having gone through other crises in my life, I can say that during those my thinking was not discredited or denied. Even though "things had to be worked through," people did not invalidate my ideas or reactions during times of crisis, or dismiss them because I was in an "anger stage." --- Diane Hannum

(To be concluded in the next issue of *The Safeguards Letter*)

JUST QUOTES

Where once there were places, we now find *nonplaces*. In real places the human being is a person. He or she is an individual, unique and possession a character. In nonplaces, individuality disappears. In nonplaces, character is irrelevant and one is only the customer or shopper, client or patient, a body to be seated, an address to be billed, a car to be parked. In nonplaces one cannot be an individual or become one, for one's individuality is not only irrelevant, it also gets in the way. (p. 205)

The individual's present relationship to the collective is as empty as it is equitable: community does nothing for them and they do nothing for community. And we continue to shape the environment as if to preserve that perilous arrangement. Segregation, isolation, compartmentalization, and sterilization seem to be the guiding principles of urban growth and urban renewal. (p. 285)

Ray Oldenburg
The Great Good Place

The Safeguards Letter is an occasional publication of OHIO SAFEGUARDS. The *Letter* exists to promote affiliation among people who are interested in and thoughtful about those who live outside the sphere of respected community membership--those who are the usual receivers of human services. All material in *The Safeguards Letter* is under OHIO SAFEGUARDS' copyright (©) unless otherwise attributed. Letters, ideas, and items for publication in the *Letter* can be sent to: Editor, *The Safeguards Letter*, 3421 Dawn Drive, Hamilton, OH 45011 (e-mail: jackjr441@earthlink.net). We welcome our readers' ideas and reactions.

VIEW FROM THE BACK WINDOW

Good-bye Mr. (and Miss) TIPS

Since summer 1981 I have looked forward to the occasional arrival in the mail of a fat envelope from the Training Institute at Syracuse University. Those envelopes contained the latest numbers of "TIPS"—the Training Institute Publication Series—written and edited by Editor Supreme (original title) Wolf Wolfensberger. The original Editor Sub-Supreme was Carolyn Bardwell Wheeler, but for the vast majority of the past twenty-six years the Editor has been ably assisted in his TIPS-editorship (as in many other things) by Susan Thomas. Now, the last numbers of Volume 26 have announced that TIPS publication is ceasing, and the first three numbers of Volume 27, which arrived in a combined issue, have confirmed that announcement. TIPS will be no more. Long-time subscribers will miss it, but apparently they were too few, which is likely one of perhaps several reasons why TIPS will no longer be coming. It's certain that TIPS has not stopped because the Editor and Assistant have run out of observations about the contemporary scene or the many unfortunate (and some fortunate) ways we try to render service to vulnerable people. From now on, those observations can be found in other publications, including Wolf Wolfensberger's regular column in the new *SRV Journal* (journal@srvip.org).

I think I possess every issue of TIPS. I suspect, based on purely anecdotal evidence, that many other long-time subscribers do too. After I learned that it wouldn't be coming any more, I looked back through my TIPS binders and made some observations that I'll gently offer here as tokens of my appreciation for twenty-six years of faithfulness.

- My copy of Volume 1, Number 1 of TIPS is date-stamped August 3, 1981, which indicates that day as its date-of-arrival at the office I then occupied at 425 Chestnut Street, Chillicothe, Ohio. My name and address were hand-written. The total postage cost was 18 cents.

- The TIPS logo—the overhead projector displaying the publication's title in the background—has changed little over the years. I did notice that, some time along the way, the representation of the cooling vent on the projector was transformed from the original circle to a rectangular grid. Was that verisimilitude? Was it a technological advance? Or was it because the editor discerned that the circle looked too much like a disembodied head that somehow found its way into the TIPS logo?

- My search tells me that it was the combined Volume 14, Number 2 and Volume 14, Number 3 (August, October 1994) when TIPS started to be compiled on a word processor. Until that time it looked like it was typescript—a considerable achievement in itself.

- The longest single issue if TIPS seems to have been that of April—October 1997 (Volume 16, Number 5 through Volume 17, Number 3). It is 124 pages long, exclusive of the customary "last page." I remember being astounded at the size of the thing. I did read it all, felt satisfied with myself, and then recalled how much effort it must have taken to write and edit it. I keep lots of old documents, but I don't have the envelope that issue came in. That means I don't know how much it cost to mail it.

- There were occasional complaints alluded to by the editor—complaints about the surfeit of "bad news." I suspect that the ratio between "bad" news and "good" news in TIPS was a subjective matter for readers anyway; no two readers would have been likely to agree on a true and correct proportion. I think that the editor, for his part, believed that it was "good" news that readers were getting better understanding of the "bad" news about society and its services.

- The customary December issue brought readers a much needed—although maybe not wanted—reminder of the traditional works of mercy—visiting the sick or imprisoned, feeding and clothing the poor.

- The terms "politically correct"—abbreviated as "PC"—and "liberal" began to appear as regular adjectives (or could we say pejoratives) some time in the 1990's. I confess that, every time I read them, I felt a little sting.

Thank you, Wolf, Susan, Mrs. Flowers, and Carolyn for starting this work and keeping it going for so long. My copies have permanent space on my bookshelves as long as I have bookshelves.

Jack Pealer

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The Safeguards Letter

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TWO UPCOMING WORKSHOPS OFFERED BY THE WEST VIRGINIA DEVELOPMENTAL DISABILITIES COUNCIL

PASSING, March 9-14, 2008

This workshop **may only be attended by** those who have previously attended either a Social Role Valorization or SRV-10 workshop, as it is a training on the practical application of Social Role Valorization (SRV). PASSING is an instrument for evaluating the quality of any human service according to how well it implements SRV theory. As with SRV workshops, it is a very intense training for those who are interested in learning more about SRV by visiting and analyzing two human service settings using the 42 rating tools in the PASSING manual. For most participants, it helps provide further understanding and clarification of the issues raised in an SRV workshop by actually observing, through the eyes of the service recipient as much as possible, a daily routine.

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

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

The locations of these events—in West Virginia, of course—have not yet been announced. If you have questions, please contact **Linda Higgs** either via this e-mail address (lindahiggs@wvdhhr.org), or by phone at 304-558-4884.

CONCLUSION: IT WAS THE WORST DAY OF MY LIFE: A NEW LOOK AT THE OLD PROBLEM OF HELPING FAMILIES AFTER THE IDENTIFICATION OF DISABILITY IN A CHILD.

Diane Hannum and Leah Holden (formerly with The Arc of Ohio)

(This is the third installment of a response by Diane Hannum and Leah Holden to the notion that families whose children are linked with the possibility of disability endure a "grieving" process as they come to terms with that possibility. I thought it was time that essay, written more than fifteen years ago, be re-issued. JRP)

What helps?

We must begin with an accurate description of the crisis families are experiencing, if we wish to avoid confusion about how to help. It is not that parents of children who have just been diagnosed have experienced the death of a loved one, even a fantasized loved one. If we assume, as Ken Moses does, that families have experienced a loss related directly to their child's impairment, and that their difficulties are emotional in nature, we can easily end up on the wrong track.

Individuals who have lost a loved one are living through a crisis -- the crisis of grieving. Parents of children who have been diagnosed with a disabling condition are living through a crisis, but it is a different kind of crisis. If a child has a life-threatening or terminal condition, then grief is certainly an accurate term. But if a child is not expected to die but is expected to have physical impairments or intellectual limitations or chronic health problems, then the challenge for the family is adapting to the child's limitations and recognizing the child's gifts, in the midst of a society that is likely to value this child less than others. This is the nature of the identification crisis.

> I think possibly my own survival is probably the most surprising of all, simply based on the fact of all these horrible things that were told to me in the beginning. It certainly sounded like insurmountable problems that we were facing. How were we ever going to get through them, emotionally, financially, physically? I had two other children at the time. I have had another child since Jamie, so that gives me four kids, and it certainly does provide for a very busy lifestyle. But as time goes on, Jamie of course simply became a part of our family. She was just another member of the family. Really quite honestly did not take up any more time than the others when I thought about it, because they all had their certain demands, their wants, their needs. But as far as time actually spent with her, no. And we have all survived, possibly because we didn't know any better. It just happened.
>
> --- Diane Frazee

> There was a time a couple of years ago that I was in deep depression over it, and I couldn't get over it. All of a sudden one day I looked at him and said, "He is a beautiful child. I can't sit back here and do this." I had family members telling me, "Why don't you sit down with him with flash cards, the way you did with [you other son]?" It could not be done. I had to find other ways. I have to do what I have to do for him. My goals are still the same for him. I want the best education for him possible. That's what I have to go with. That's what brought me out of it. I stopped thinking about, "Was it that time I got permission form the doctor to get drunk when I was six months pregnant with him? Was it those aspirins I took when I had a cold? Was it this? Was it that?" I stopped thinking like that. I had to. It could have been anything. It could have been genes. But I don't worry about that any more. I worry about him.
>
> --- Melissa Smith

> I've really filled my life with people that are positive, that see the capacities instead of the deficits. Probably when I'm down the most, I look to other people to give me those words of encouragement.
>
> --- Cindy Norwood

What is it that families of children identified as having a delay or a disability really need? What helps?

•Family members say over and over that they want good current information about their child's condition. They want to be told about their child's condition in a way that is respectful of them and of their child's worth. They want plain English (or another native language.)

> We were young [when Joey was born} and the doctors acted like they really didn't think we were going to understand what they were telling us, so they wouldn't tell us. We had to go around them to find out. It got to the point where, when he was six months old, we just told them, "Look, this is our baby, and we want to know. Don't not tell us, if we ask a question. Give us a straight answer." That changed a lot, because I think after we did that, they started looking at us as people.
>
> --- Beth Scott

> There's been a thousand times that we'd have to say, "We really don't understand what you're saying," and sometimes they would get pencil and paper out and draw us pictures and explain to us what they meant. We still might not have known what some of the words meant, but we knew what he was talking about then.
>
> --- Earl Scott

> The thing that strikes me about some of that initial labeling or diagnosis was that it was never really followed with much opportunity to get information... I was just told, "We really expect her to die," and not all the details of it. Many, many months and even years later I found out more about some of the conditions, but that information was never really shared.It was always assumed that somebody else told me. The other thing was that there was not a lot of follow up to ask questions. Pretty typically when they would say something -- doctors, nurses -- they'd just kind of drop the bomb and walk out. Not very often did they say, "You might have

some questions about this. Why don't we set up a time next week to talk," or something like that. The struggling feeling that I would have after that was, "What does this mean? Where's a book? How can I read about it?" Things like that. And some of the new technology created new labels or disabilities for my daughter.There weren't books about it. So those resource people, those doctors and nurses, didn't follow through very often.
--- Cindy Norwood

We had an adult neurologist treating her at first, and they were just up against a wall. They could not control her seizures. They didn't know what to do. There were getting nowhere. They called in a pediatric neurologist, which they should have done in the first place... He took one look at her and said, "Oh yes, I know what this is and I know what we're going to do, and this is what we're going to try." It was about two weeks after she had been in the hospital, and I think it was the first time I ate a full dinner in two weeks, because I felt good, because somebody actually knew something they were going to try.
--- Ann-Marie Satterthwaite

Initially Jamie was not diagnosed until she was two months old, which is not a long time. She was still in the hospital. There were lots of hints that there was brain damage, there might be this, there might be that, but nothing real clear. Then of course the day came where they were going to run the big test that would tell us whether or not there was brain damage. The doctor called me at home. It was not handled very well, but it was explained that there was definitely brain damage. I remember feeling very unsure about calling my husband at work. "How do I tell him? What's his reaction going to be?" It was frightening. I finally did call him at work and said, "There is definitely brain damage." He says, "Okay, now we can get off the tightrope. I just feel like I've been walking a tightrope. I didn't know whether to get off or not, but now we know. The evidence is in, and now we can deal with it." We were ready to move forward. That's really all I needed to hear. Okay, he's right, we've got our answer. It wasn't the one we really wanted, but we've got an answer, so let's go with it.
--- Diane Frazee

Learning professional language was a gradual thing, a process of osmosis, one acronym at a time, one huge word at a time. I literally had to go to the library. I finally got smart and said, "Excuse me, would you explain that?" Inthe early years it was literally a matter of stopping them and asking, "What does ARC mean?" Alphabet soup, it was a constant sea of alphabet soup.... It took years. Each new year there was new jargon, and I'm learning every day... I have since then decided that on my tombstone I would just have acronyms, and anyone who would see it would scratch their head and wonder what it was I did in life.
--- Nancy Ray

Every child's different. There's not a book on each one of these children telling you what's going to happen. There's no guidelines. You have to set them as you go. It's worked out real well for us just staying active with the other parents that are members of these [support] groups, because little bits and pieces you put together for your own book.
--- Denise Habekost

•Rather than lumping a parent's feelings together and calling them grief, or being satisfied when we can determine the stage a parent has reached, we ought to be listening and learning what that parent is feeling and experiencing, in that parent's terms, without preconceived ideas or judgments.

What would have helped during the days, weeks and months following my son's diagnosis? First, it would have been helpful if people had seen what I was going through, and helped me to see it as a crisis, rather than as grief. I've lived through my share of crises, but no one helped me see that the things I had learned from previous crises could get me through this one. It would have been helpful if someone had paid attention to what I was feeling. While judgments were abundant, careful, empathic, respectful, nonjudgmental listening was in short supply. My feelings were often categorized, but they were not often heard and understood.
--- Diane Hannum

•Parents often want to know about other parents who have lived through similar circumstances, the living proof that this crisis can be weathered.

> Other parents definitely help, talking to other parents that have the same problem. The fact that you feel like you're not all along in the situation. And then you listen to what they might hope for for their child, and you get other ideas of what you should expect or might expect... It helps as soon as you can to be with other parents that have the same problem, just to realize you're not alone, because initially you feel like you're the only person in the world that this has happened to, and it's awful. Just to talk and share your experiences and also get other ideas of help and other places to go or other things to do. That would be the major, major things I would suggest, that helped.
>
> --- Ann-Marie Satterthwaite

> When Trevor was small, before he was six months old, I met the other mothers whose children were in the early intervention program. At one point, Trevor and two little girls were singled out by the staff as needing to learn sign language, because the [segregated] County Board of Mental Retardation School used total communication, and Trevor, Samantha and Stephanie would eventually be attending that school. Fortunately, Trevor's, Ssamantha's and Stephanie's mothers had different ideas. We began to talk together, to phone each other and to visit one another's homes. And we shared our dreams for our children. June and I also started an independent parent group. Currently Trevor attends a regular preschool where he is fullly included. So does Samantha, and she also takes ballet class and does very well. (This is because an early intervention professional told June, "Your daughter will never be a ballerina.") Stephanie attended Head Start and last fall went to regular kindergarten. And of course, when they were infants, we were unrealistic, were in denial and didn't accept our children's disabilities.
>
> --- Diane Hannum

> Knowing that they're there, that you're not alone, it's so important to know there are people out there that you can reach out to and can help you, just for support sometimes. You think, "Oh my God, I'm at my wit's end. I don't know what I'm going to do." Not thinking that you're totally crazy.
>
> --- Denise Habekost

• Family-centered early intervention, based on partnerships between the family and professionals and community members, when it is available, helps greatly.

> The first year of Trevor's life, he and I drove over 30,000 miles. He was evaluated and therapied from top to bottom. The merit of Trevor having the opportunity to spend time at home with a two-year-old sister and a four-year-old brother in a normal environment was not something that was acknowledged as valuable. The early intervention professional encouraged me to take Trevor's brother and sister to a sitter so they wouldn't be there when she made home visits. As his mother I was seen as an extension of the early intervention program.
>
> --- Diane Hannum

•Perhaps even more important than the presence of paid service workers and formal programs, especially in the long run, is the family's ability to maintain its place in the community, surrounded by supportive people.

> I do think what works universally for everybody is having other people. It's not necessarily having other people who happen to have a child with a disability, but just from the very beginning sharing this information with your family and your friends, whoever makes up your own little group. I know I was guilty of this, because Jamie had so many special needs medically that I thought it was impossible for my neighbors and my friends to learn all of the care that went along with Jamie. I don't know who I thought I was, that I was so brilliant that I could learn all of this and nobody else could, but nevertheless as time went on I did loosen up enough that I did allow others to take care of family and to learn about Jamie.
>
> --- Diane Frazee

•One challenge for all new parents, but perhaps more challenging for parents who have additional roles and responsibilities, is finding time and space to rest and recover from the day-to-day grind.

> You think your child is going to get better, and when that doesn't happen, then you need someone. At first you think, "Well, I'll handle it myself," and you just can't do it all by yourself.
> --- Denise Habekost

> It is important to have a life. It's not always easy, you know, to find something that you find rewarding and give yourself permission to do it. I think that does help. It's learning from little things that you do with yourself to get yourself out of a hole, if you fall in a hole. It's talking to a friend. I think faith does have a lot to do with it, too.
> --- Linda Hasecke

> On a bad day, you go shopping -- I do -- or don't get out of bed, which is one of my favorite things to do, or you go to a movie, or you go on vacation. I do whatever I have to do to renew and rejuvenate myself in ways that I enjoy, and I call that "mental health days."
> --- Nancy Ray

•We can also be sure to celebrate every life. Too often we are so busy teaching parents to mourn that we forget to join with them in celebrating and affirming the value of each life.

> The day Trevor was born I went to the hospital for another stress test, the fourth in two weeks. I was standing at the desk in the maternity ward waiting for a nurse and I could hear a baby being delivered down the hall. I heard someone yell, "It's a girl!" and everyone broke out in cheers and applause. I began to cry. It was my first realization that others were not going to celebrate child's birth. And then there was the absence of "congratulations on your new baby" cards, and the "friends" that didn't come to see him. Everyone would look at Trevor's picture and say, "Oh, how cute." Most four-pound infants who are dehydrated and covered with fecal matter and blood and in stress are not "cute." Trevor was no exception. The first time someone looked at the pictures and said, "Oh, my God!" I could have kissed her. Of all the things that happened, one of the most meaningful for me was a certificate I received from my state legislator, Jack Cera. It said that Trevor was a citizen.
> --- Diane Hannum

•We have to celebrate in spite of the disability, not in ignorance of it, because if the child is not celebrated as he/she is, the parents feel the rejection as a palpable part of the identification crisis. Parents want others to celebrate and accept their children as they are. One mother's experience was the silent birth, and the presentation of a little girl who looked very different. Then she was told by everyone, "You have a beautiful, healthy little girl." Cheryl said, "After I took Stephanie home I wanted to die and I wanted her to die. I knew she looked different and I knew she had problems and everyone denied it-- my husband, our families, and the doctors. I just wanted someone to agree with me."

> My family doesn't accept that Shane and Shaun are deaf. They don't talk about it, but when they do, they're sad. That really pisses me off.
> --- Eddie, father of five young children

Conclusion In summary, how can we best assist and support families following their child's diagnosis? We can pay attention to each task of managing crisis:

1) preserving life and maintaining physical health;
2) identifying and expressing feelings related to the crisis;
3) understanding the crisis event, clarifying and adjusting personal beliefs, values and goals;
4) making needed adjustments in daily patterns of work, play and relationships in light of the crisis event.

That is, we can encourage people to take care of themselves physically, we can encourage them to express their feelings and listen nonjudgmentally when they do, we can help them make sense of their experience and develop personal beliefs that will help them negotiate change, and we can "walk with" them, as they make necessary changes in habits, relationships and patterns of living in response to change.

We can help families understand what they are experiencing as a crisis and help them learn from other crises they and other people have experienced. We can help them see the opportunity as well as the danger in their crisis. We can stop interpreting their experiences as grief.

The stress of having a child with a disability is not something one can "work through," "accept" and then move on, unless of course through "grieving" one comes to accept devaluation and segregation as normal facts of life. On the contrary, it is rejecting devaluation and opposing segregation in all its manifestations that offers hope for families of children with disabilities or chronic illnesses. It is a vision of an inclusive world that offers hope for us all.

> Initially when you find out you have a child with a disability, it does hurt, and you do feel pretty raw, and you do feel pretty lonely, but I guess we're here to say you do heal, too, and that life does go on, and there's quite a wonderful quality to that life, of being able to realize what's really important and what's not so important. I think Jamie and Adam have brought a tremendous amount into our lives and into the lives of our other kids.
> --- Linda Hasecke

> My dream is that the birth of every child be celebrated -- whether or not that child has Down Syndrome or some other disability. I say this with a heavy heart, because I did not celebrate Amy's birth. What a breach of faith that was! She has had to rise up against all my early misgivings, sadness and disappointment. I worry that she knows somewhere deep inside that in those first few hours after her birth I didn't want her. I wanted the baby who fit my ideas and my standards. Little did I know then that I had been given a gift -- a daughter who would give true meaning to spirit, courage, love and joy. If only I'd known in those first dark hours that our life together would be more ordinary than extraordinary. If only I'd known that this daughter would more than fit my ideals and standards -- she would fit hers which are higher than mine... At 19, Amy is so typical that it's difficult to define her disability and what it means. Certainly, she still needs support daily in ways other 19-year-olds may not, but her days are full and rich. Amy goes to school, works part-time, saves her money for things like clothes and jewelry, has a boyfriend, goes on dates and is very excited about going to her Junior Prom in a few weeks... It fills me with joy and pride to see her doing these things -- what more could a parent ask for? What more could I have wanted when she was born?
>
> Emily Murgo, "If Only I'd Known," reprinted in the Family Support Bulletin, Spring, 1992, UCPA

> People still remark to me that I'm defensive or angry. It always makes me think of Dumbo's mother. She was "crazy" too, until others learned to appreciate her son. That's all I want, too -- for people to appreciate Trevor, just the way he is. And if it doesn't happen, they might have to chain me in a circus wagon, too. Trevor is a gift, as my other children are. He has never been a source of grief, either now or at his birth. I have indeed been through a crisis and have experienced pain, but he was not the source. He has many times been the consolation.
> --- Diane Hannum

The Safeguards Letter is an occasional publication of OHIO SAFEGUARDS. The *Letter* exists to promote affiliation among people who are interested in and thoughtful about those who live outside the sphere of respected community membership--those who are the usual receivers of human services. All material in *The Safeguards Letter* is under OHIO SAFEGUARDS' copyright (©) unless otherwise attributed. Letters, ideas, and items for publication in the *Letter* can be sent to: Editor, *The Safeguards Letter*, 3421 Dawn Drive, Hamilton, OH 45011 (e-mail: jackjr441@earthlink.net). We welcome our readers' ideas and reactions.

AN EFFORT WORTH KNOWING: Highlands Nature Sanctuary

The words "wilderness" and "Ohio" haven't been used meaningfully in the same sentence for a long time, unless that sentence indicates absence. For example: "There isn't any wilderness left in Ohio." I've been told by historians that, when European settlers first arrived in Ohio, it would have easily been possible for a squirrel living in the forest canopy to walk/jump from one side of the state to the other (of course, there was no "state" then) without touching the ground. Now, Ohio is likely seen as a place with lots of farms (still true), a good many moderate-to-large cities afflicted with air pollution and traffic (also true), and lots of coal-fired power plants that friends to the north and east blame, with justification, for acid rain. Usually if Ohioans seek wilderness they go somewhere else.

But, for the past dozen years or so, at least one group of Ohioans has been trying to change that situation. That group, which organized in 1995 under the name "Highlands Nature Sanctuary," says:

> …wilderness in the East seems to be a dimming possibility. But though it is the 11th hour, 59th second for wilderness, it is not too late to call it back and give it a place of refuge. It wasn't by accident that these soils grew one of the richest forests in the world. The deep youthful soils of Ohio, coupled with a relatively mild climate, could enable a relatively quick return of an old-growth forest, if only we could give the forest the simple gift of space and time…. Such a gift doesn't take magic, scientific studies, or complicated technology…it merely takes money. Land is expensive, but we only have to buy it once.

What the Highlands Sanctuary organizers did was figure out ways to buy land, starting with the area around the Rocky Fork Gorge in Highland County, south central Ohio, between the towns of Bainbridge and Hillsboro. Two people who had worked for the Ohio state park system knew of the remaining beauty and comparative isolation of the Gorge. They tried to convince others to preserve the land but found they were more effective after they formed a small non-profit corporation and began systematically attracting others to the dream and the work. The Sanctuary started with a 47-acre purchase in late 1995. Now, in 2007, Highlands Sanctuary has purchased a total of more than 2,000 acres near the Gorge, acquired 500 other acres in what, as naturalists, they call "biological hotspots" along the edge of the Appalachian foothills, and recently led an effort to preserve an ancient Hopewell culture site called "Spruce Hill" near Chillicothe. The latest effort supplements the work of the U.S. National Park Service and its Hopewell Culture National Historic Park.

The ultimate dream is an effort with others to create what they call the "Arc of Appalachia"—an unbroken stretch of preserved forest between Chillicothe in the mid-Scioto valley bending west and south to the Ohio River near Manchester or Aberdeen. They hope to join with groups like the state of Ohio (forestry, parks), The Nature Conservancy, local parks, and other associations so that the possibility of the old-growth Appalachian forest can begin to be revealed. Most of this land will be treated as wilderness, and if the confidence of the Sanctuary founders, members, and volunteers is not misplaced, some day the words "wilderness" and "Ohio" will again belong in a sentence that refers not to absence but to presence.

To learn more about Highlands Nature Sanctuary—and to see the great photographs of budding wilderness—you can visit the Sanctuary web site at www.highlandssanctuary.org.

JUST QUOTES

We are not interested in reforming the social service system and its institutions. Instead, we want to create a different approach--an approach that relegates the social service system to the background.

Al Etmanski, Preface, A Good Life

When ends become subservient to the tools chosen for their sake, the user first feels frustration and finally either abstains from their use or goes mad. Compulsory maddening behavior in Hades was considered the ultimate punishment reserved for blasphemy. Sisyphus was forced to keep rolling a stone uphill, only to see it roll back down. **When maddening behavior becomes the standard of a society, people learn to compete for the right to engage in it.** Envy blinds people and makes them compete for addiction.

Ivan Illich, *Tools for Conviviality*

Just as an article being processed through an industrial plant must be followed by a paper shadow showing what has been done, what is to be done, and who last had responsibility for it, so a human object moving through a system must be followed by a chain of informative receipts detailing what has been done to and by him and who had most recent responsibility for him.

Erving Goffman, *Asylums*, (1961)

History is not an agreed-on fiction but what gets made in a crowded room; what is said isn't what's heard, and what is heard isn't what gets repeated. Civilization is an agreement to keep people from shouting "Fire!" in a crowded theatre, but the moments we call historical occur when there is a fire in a crowded theatre; and then we all try to remember afterward when we heard it, and if we ever really smelled smoke, and who went first, and what they said. The indeterminacy is built into the emotion of the moment. The past is so often unknowable not because it is befogged now but because it was befogged then, too, back when it was still the present.

Adam Gopnik, "Angels and Ages."
The New Yorker, May 28, 2007

It was born of a romantic dream and it was aimed at glory, and glory was out of date, a gauzy wisp of rose-colored filament trailing from a lost world. Victory could no longer be imagined as a bright abstraction, lying like the sunrise at the end of a shining road. It was an ugly juggernaut that would crush and smash many values and many lives into the everlasting mud, and it was the only thing that counted nowadays. The longer the war lasted the more victory was going to cost, and a dazzling cavalry raid would not even be the small change of the final purchase price.

Bruce Catton, *A Stillness at Appomattox* (1953)

A VIEW FROM THE BACK WINDOW The Governor and the Institutions

On September 1, 1970 I started work as an administrator for the then-called Delaware County (Ohio) Board of Mental Retardation. I knew almost nothing of a technical nature about "mental retardation." I've always thought of that lack of knowledge as a blessing. One of the ways I tried to learn, though, was to visit the institution where some people from the area were in residence. It was then called the Columbus State Institute. I left that visit convinced that no such place should be allowed to exist. No people should be put into such conditions. More than thirty years later the outward appearance of the institutions has changed—they're usually cleaner and more orderly. But, they're still institutions, operating under essentially the same rules that have governed them for many years. They still shouldn't be allowed to continue. That's why I wrote the following letter to Ohio's new governor, after I learned that he has decided that closing institutions won't be a part of his policy.

> Dear Governor Strickland: I've worked for 37 years with Ohioans who have developmental disabilities and with their families. Right now I am employed by the Butler County Board of MRDD. The opinions I express in this letter, however, should not be interpreted as those of my employer nor of any other group of which I'm a member. The opinions are my own. I just want to offer what journalists usually call full disclosure.
>
> On May 30, 2007 the Director of the Ohio Department of Mental Retardation and Developmental Disabilities announced, in a departmental newsletter, that "we are not closing any Developmental Centers." He went on to describe ways that the Department intends to "spotlight" or enhance the work of the ten "developmental centers." The decision to reverse Ohio's earlier direction about state institutions for people with developmental disabilities is a big one, and I assume that you approved it. So, I'm writing to you about that decision.
>
> It's the wrong decision. Residence in an institution has at least three bad effects on people with disabilities.
>
> First, institutional living clusters large groups of people physically away from other citizens and the community places where citizens make their lives together. If you're living in an institution there's practically no chance that you will go to school, go to work, go shopping, or have fun in the same places where other citizens do those things. By definition, institutions are separate worlds.
>
> Second, institutions portray the people who live in them as very different from ordinary citizens. That may not be the intent of an institution, but happens all the same. The fact of the collection together in a separate place of a large group of labeled people carries messages about difference and, more worrisome, messages about potential dangerousness. Difference and implied or inferred threat are poor bases for identification or relationship. Like it or not, most people are reluctant to offer friendship easily to others with whom they think they can't easily identify. And, it's relationship—not rules or inspectors—that offers people with disabilities the greatest chance for safe and vital life experiences. Institutions prevent relationships between the people who live there and ordinary citizens who might welcome those people into their lives.
>
> Third, the institutions don't live up to the euphemistic titles they've operated under for the past twenty years—"developmental centers." Learning works best when people try out new things in contexts that are challenging and when the learners are in the company of skilled others as guides or models. Hardly any such conditions exist in institutions. That means they offer very low levels of "developmental" support. One of the best known and most powerful ways that people learn—new skills and abilities, for example—is imitation of others who perform the to-be-learned skill or ability very well. The grouping that institutions enforce means that the "models"—those whom we'd want people to learn from—are simply unavailable in sufficient numbers, and no amount of "programming" can overcome that deficiency. Institutions are, then, by their very nature actually anti-developmental, if "development" is taken to mean the acquisition of skills and roles that promote close relationships with others and a richer life in community for the learner.
>
> You can find a better policy about how Ohio should support people with developmental disabilities by turning from a reliance on institutions and by committing the state to live up to "The Community Imperative," originally drafted by the Center on Human Policy at Syracuse University in 1979. That statement says:
>
> ***In the domain of Human Rights:***
>
> - *All people have fundamental moral and constitutional rights.*

- *These rights must not be abrogated merely because a person has a mental or physical disability.*
- *Among these fundamental rights is the right to community living.*

In the domain of Educational Programming and Human Services:

- *All people, as human beings, are inherently valuable.*
- *All people can grow and develop.*
- *All people are entitled to conditions which foster their development.*
- *Such conditions are optimally provided in community settings.*

Therefore:
In fulfillment of fundamental human rights and in securing optimum developmental opportunities, all people, regardless of the severity of their disabilities, are entitled to community living.

Continued reliance on institutions to try to support Ohioans with developmental disabilities says that we lack confidence in the ability of Ohio's communities to be good places to live for all their citizens. I don't think that's something we really want to say. Why not presume communities' competence? Why not turn away from an outdated service form that isolates some people and maintains them in poverty and ignorance? Why not bring people home?

Sincerely,
Jack R. Pealer Jr., Hamilton, Ohio

I doubt that this letter will have much effect, although of course I got a reply. Maybe someone else out there would like to try.

Jack Pealer

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The Safeguards Letter

A Publication of OHIO SAFEGUARDS

Number Forty-two *Holidays 2007*

A COLLECTION OF NOTES AND WISHES

Here was my invitation to readers of *The Letter*: *I'm looking ahead to the Winter or holiday-season issue. One reader suggested that I might ask all the readers for their sense of "how things are at the end of 2007" and print some of those comments in the next issue. I've taken the idea just a little bit further.*

I'm wondering whether you would be willing to write just a paragraph or two that finishes this sentence: "As 2007 comes to a close, I'd like to say…."

You could let other readers know about what you're most thankful for, as 2007 comes to a close. Or, you could write a bit about what worries you most, as 2007 comes to a close. You might want to let the rest of us know about the state of services/supports for vulnerable people in the place where you live (highs and/or lows), as 2007 comes to a close. Or, perhaps you would want to offer a sample of how vulnerable people take part (or don't) in the life of your community. Maybe you would just like to let others in on what's going on with you, your family, or your friends, as 2007 comes to a close.

In any case, if you're willing, put a few thoughts together--just a couple of paragraphs. If you write long essays, I won't have room for them in the Letter, at least not this time. I'll try to get as many of the submissions into the Holidays issue as possible; if any are left they'll show up in the spring.

The collection that follows includes everyone's response to the invitation. I thought about trying to place the responses in some sort of sequence—for example, the order in which they were received, or the distance from which they came, or from critical to hopeful. I decided I'd be running the risk of misinterpreting someone else's thoughts or that the whole thing could turn more artificial than I want it to be. Besides, trying to organize these is just too much work.

So, here are some things that are on the minds of readers of *The Safeguards Letter*, as 2007 comes to a close.

⇒ As 2007 comes to a close, I'd like to say this must surely be the most exciting time yet to be working in this field. The evolution of our communities and the heightened awareness of people with disabilities and professionals are leading to the advent of acceptance and inclusion. We see this happening before our very eyes! A more wondrous sight I can barely imagine. I am watching come to fruition the environment I have worked, hoped and prayed for for 25 years. What is next? I am not sure, but I'm ready for the journey and will be thankful for any part I may have in it.

Melody Brauninger
Cincinnati, Ohio

⇒ As 2007 comes to a close I'd like to say that the work of the Medical Safeguards Project of Shriver Clinical Services in Massachusetts is a flash of light in a darkening arena. This little gem is a modest project employing seven nurses and one physician. They accompany people with impairments when they go to the hospital to protect their lives and to make sure that excellent standards of care are upheld. The main work of the project is to ask pointed questions of medical providers who make negative treatment or non-treatment decisions based on the devalued status of the patient with impairments. I convene the group on a monthly basis to teach about deathmaking and to help hone advocacy skills. I am often impressed with the notion that lives are saved with a well put phrase, a plea for reflection, and/or a heartfelt statement on the truth of the inherent dignity of all human life. These men and women do what they do quietly, with grace and persistence, and having to face many failures and often insurmountable odds. But when they do win, lives are preserved, health is maintained, and those medical practitioners involved had a life changing experience that will serve to protect future patients. Not a small thing.

It is a great privilege to be a part of this effort. When I reflect on the year's work I recall many sad stories and tears shed. Still I am heartened by the sure knowledge that some will celebrate Christmas in 2007 who otherwise would not be here. I am reminded of the words of another person with impairments whom we all know, but whom we have never met : God bless us everyone!

Jo Massarelli
Worcester, Massachusetts

⇒ I am thankful that there is only one year left of the Bush administration and that a few more people got out of institutions and nursing homes. I'm thankful for Joni Mitchell's new album "Shine" and the last of the red leaves hanging on the tree outside of my office. I'm thankful for the love of my life, Cyndi, my two boys Joe and Sam, a good dog, and caffeine. Best wishes-

David Pitonyak
Blacksburg, Virginia

⇒ I am worried that:
1. All (OK, most) research has identified, re-identified and re-identified the same problems with little action on practical solutions. Oh, lack of transportation...how surprising!!!! Instead of making transportation a big budget item tied directly to "accomplishing program goals", let's do some more research! Oh, people want to have friends, romantic relationships, marriage....let's spend more money on researching employment; discrimination; staff-resident ratios!
2. Natural relationships have to become formalized and then formally-funded. Oh, Best Buddies, what a good idea!
3. Direct care staff STILL are greatly underpaid.
4. The cause of Down syndrome will be discovered.
5. Medicaid still will pay for pulling a person's teeth and providing false teeth, but not repairing and otherwise saving a person's teeth.
6. Lastly (at least for now) I am worried that any time a group of people get together to organize a program or service, the first major agenda item is to acquire a building. I continue to see this as the first sign of impending segregation

As 2007 comes to a close, I am happy that my 59-year old sister with Down syndrome continues to fly (direct, no transfers) from Cleveland to Boston by herself about 6 times a year to see me.

Deb Metzel
Boston, Massachusetts

⇒ We are most thankful for our son and his vibrant enjoyment of life. He continues to bring awareness to us and many others the reality that we all have an abundance of potential and interests if only given the opportunity to utilize and engage ourselves in them. Community employment, attending his local Community College, dance classes at a local dance studio, sports, caring for his animals, friendships...are some of his enjoyments.
Our family and friends that value his interests and quality of life are those we keep close...connecting with others is invaluable in providing opportunities.

Julie Thompson
Troy, Ohio

⇒ As 2007 comes to a close I'd like to say.....as a person several decades removed from daily support to and intensive interactions with people labeled as "developmentally disabled" I notice how little the general community gives thought to or spends time thinking about the lives of people so labeled. At the same time, I'm encouraged that acceptance of and inclusion of people so labeled in the course of daily life doesn't appear to be a matter of significant resistance among the general population. It appears to be much more a matter of how creative and adaptive they, and the people who support them, are in finding ways to be present as valued fellow citizens. It really seems to be a matter of creativity, thoughtfulness and persistence.

Hope that this message finds you in the presence of light at this time of darkness on the planet. Peace.

John Winnenberg
Glouster, Ohio

⇒ As 2007 comes to a close I am doing what I always do.. I am trying to listen and learn from people and offer them a chance to cross the boundary of difference, invest in one another's lives and reap the benefit of being together. It's a small response to a pervasive pattern.

I am trying to strengthen the organization that supports this work without spending too much time away from the work.

My wife and I are watching our two girls, 15 and 17, grow into what look like good solid people so far. I am walking 3 mornings a week, reading some magazines, less books, drinking a few beers and cursing at the computer more than is healthy for it or me.

Tom Kohler
Savannah, Georgia

⇒As 2007 comes to a close, I'd like to say ….that I'm ever more appreciative of the pantheon of persistently passionate people from whom we've all benefited so much over the years. I came into this field in the early 1970s, a great and exciting time when conventional thinking and practices were being challenged by new information and expectations. To name only a few of the groundbreakers: Azrin and Foxx, Wolfensberger introducing Normalization, Marc Gold with Trying Another Way, Lou Brown saying "Pre Means Never", and Winfred Kempton advocating for socialization and sexuality education, Beth Mount doing futures planning, John and Connie O'Brien, Dave Hingsburger, David Pitonyak, John McGee … We have been blessed with these leading lights, and with the thousands of people who carry their passions and practices into their daily work and the lives of people around the world.

Paul Tabor
Bowdoinham, ME

⇒ As 2007 comes to a close, I'd like to do a movie review. The day after Thanksgiving I saw *Lars and the Real Girl*. When I first read about this movie, I was afraid it might be a little too pleased with its own sense of taboo-breaking, trendy and mean-spirited like a lot of independent movies can be sometimes. I was pleasantly surprised. What it turned out to be is a parable about how to support people. The plot concerns a guy named Lars who lives in a little town in the garage behind his brother and sister-in-law's house. Lars is a lonely, mysterious guy who keeps to himself, intentionally shutting himself off from the rest of the world. One day a co-worker mentions the idea of an anatomically correct, full-sized doll men buy to -- well you fill in the blank.

Lars ends up buying one of these dolls named Bianca, but instead of using Bianca as a "sex toy," he uses Bianca as the object of his most innocent affections. As soon as Bianca arrives in her big wooden crate, Lars asks his brother and sister-in-law if Bianca might stay in the house with them, because he does not want to seem too forward. Lars courts Bianca, crooning love songs to her, doting on her, asking his sister-in-law if Bianca can borrow some of her clothes.

Needless to say, Lars' brother and sister-in-law freak out. Turns out the town doctor, though, is wise, and after seeing Lars and Bianca tells Lars' family to treat Bianca as if she were a real person. To go along with it. Eventually, this spirit spreads throughout the town, and church-members, co-workers, and other folks pretend along with Lars that Bianca is real.

The way this pretending works itself out is a joyous sight to behold, so I won't reveal any other plot points. Just go see it. In a culture that tries to correct and eliminate "what's wrong" with people, *Lars and the Real Girl* is a movie about listening to what people need without judging them for what they want. And while on the surface purchasing an anatomically correct doll seems perverse and sad, the way the doctor and the rest of Lars' town react to the situation is the exact opposite of perversity and sadness: they show Lars how much he means to them by empathizing beyond telling him what to do. They give him the respect and tenderness he needed before he had to resort to buying Bianca. In other words, they use the situation as a way to reinvent the way they see and treat him. And while the movie does gloss over a lot of complications, simplifying things a little too much, it is a joyous simplicity we are witnessing, the kind that just might happen if we used our imaginations more and our sense of outrage less.

Keith Banner
Cincinnati, Ohio

⇒ On the eve of my 30th year working in "the field," doing the things we do... I'm feeling a little bit weary and a little bit cranky. Now I'd rather say I'm feeling encouraged, energized and even enthusiastic. Part of my frustration and my problem, no doubt, is my temptation to romanticize about what I like to recall about the dedication, energy, and perseverance present 30 years ago. Of course back then, there was more to "fix." Let's face it; the problems were easier to see, and efforts to make things better, including many that were pretty darned rough around the edges, delivered what seemed to be dramatic, life changing, hopeful results. Today of course, much of what what's troubling is more nuanced, obscured, or intentionally concealed. I've come to realize how I need to be careful NOT to discount today's good YOUNG passionate people enlisting for the cause. We'll always have good people. Nowadays they need better eyes, ears and noses. I want to do a better job of cheering them in the struggle – being encouraging, energizing and even enthusiastic.

Milton Tyree
Louisville, KY

⇒ William (Bill) Roe is a unique individual who has an interesting story to tell. Bill attended a session in March called "The Settlement of the Martin Law Suit" at a two-day legislative event in Columbus. The 1989 law suit, formerly known as "Claude vs. Governor Richard Celeste," called for Medicaid funding to allow Ohio citizens with developmental disabilities the opportunity to leave institutions and move into the community. During a presentation by the Ohio Legal Rights Service Director, Bill raised his hand to make a comment. After being called upon, Bill said: "I just want you to know that Claude Martin was my roommate at Columbus State Institute when we were both seven years old."

Bill's comment quite dramatically changed the tone in the room and made everyone realize that Claude Martin was a "real person" among all of the waiver discussion. The next day, Bill had a pre-arranged meeting with Ohio Senator Robert Schuler where he shared his story about his childhood friend, Claude Martin. After he thanked the senator for supporting the settlement, Senator Schuler invited him and his supporters to a Senate session that afternoon. During the session, Bill was introduced on the Senate Floor to 32 Ohio Senators.

Bill has come a long way since his time at Columbus State Institution, overcoming many obstacles in life yet continuing to advocate for himself and others. He now lives at Geier Apartments in Kennedy Heights with his cat "Lady." He worked at Bob Evans Restaurant for 16 years and currently works at Goodwill Industries.

Mike Fasanella and Jenny Dexter
Cincinnati, Ohio

⇒ As 2007 comes to a close, I've been thinking about the families of impaired children and adults I have had the privilege of meeting this year. The couple who in sadness and desperation got a legal divorce so they could be eligible for government benefits and medical insurance for their child. The father carrying his daughter down 6 flights of stairs while her mother followed behind carrying their daughter's oxygen tank, because they lived in a building without elevators. The daughter who for years has slept every night in her clothes in her mother's bedroom to be ready to get up and help her mother, who had had a stroke. The smiles and laughter shared by a mother and daughter about the daughter's day in school. Such memories inspire, sadden, fortify, and delight me.

Marc Tumeinski
Worcester, Massachusetts

⇒ I find myself planning for and looking forward to a letting-go of some routines and interests that have occupied me for about 40 years. As some colleagues know, it's been a long time since I could work up much enthusiasm for the business of legislators, policy conferences, government or trade-association committees. I'm gratified that it no longer matters whether I'm "certified" to do whatever it is I do. I'm eager to get better at listening to others, recording their ideas, sharing those ideas with more people, and trying to help convert people's hopes into experiences.

Jack Pealer
Hamilton, Ohio

⇒ "I have seen the light at the end of the tunnel and it is Joan of Arc with her hair on fire".
(Kinky Friedman)

In 1975 I started my career in human services. I was hired to be a 'social adjustment counsellor at the then Kinsmen Vocational Centre in Winnipeg, Manitoba. I had no idea what a 'social adjustment counsellor did or what a 'pre-vocational centre' was. On my first day of work I was given eight folks to socially adjust and a room to adjust them in. The room had a pay phone on the wall that was not connected to the outside world, a radio, an iron and ironing board, and nine chairs for group time. In my first hour of work a man stood up, moaned, grabbed his chest like he was having a heart attack, and fell to the floor at my feet. I bolted from the room looking for another 'social adjustment counsellor' to help me. When I told them about the heart attack they said: "That must be Bill, he does that". Those were the days! Good old segregated, congregated, socially isolated services rooted in professional dominance. Those were the days when a person like myself whose major life achievement to date had been learning the words to the song, "Louie, Louie" by the Kingsmen could be a 'social adjustment counselor.

In 2007 I teach in the Disability and Community Support Program at Red River College in Winnipeg, Manitoba. I have lived and worked long enough to witness Normalization trigger a transformation in human services and morph into Social Role Valorization. I have seen ideas like Person-Centered Planning, Supported Living, Support Networks free people from 'other-determined' lives. I know people who are both free and happy because they bumped into those ideas and people who knew how to make them a reality. I think in some ways I have been witness to a revolution in human services. In other ways, not so much!

In 2007 too much remains the same here as it was in 1975. Institutions persist and at times seem to be gaining momentum. Sheltered Workshops and segregated day services remain the dominant option for way too many people. Government ignores innovation and clings to the old ways of 'placement' and 'program'. My big fear is that somewhere out there today some day service is talking about the need to open a pre-vocational centre and hire more social adjustment counselors.

Bob Jones
Winnipeg, Manitoba

⇒ As 2007 comes to a close, I'd like to say how happy I am that more and more parents who have a child or children with a disability are planning for the future. Only a few years ago, parents did not want to consider that their child might outlive them. For many years, we professionals have been talking with parent groups as well as professionals in the field to give them information about life planning for their loved one. From my vantage point, I have seen what appears to be a difference in the generations of parents who have a child with a disability. The oldest generation were told by medical professionals as their children were growing, that they would outlive their child. At first they didn't think their child would live through the first year, and as medical treatments progressed, their children were surpassing all the predictions. These pioneers demanded schooling for their children, then vocational training. Now as it has become apparent that their child may outlive them, many parents have become fearful as they will no longer be able to "protect" the individual from society. Although they know they need to make plans, many tend to put it off. Many parents in the next generation realize that it is probable that their child will outlive them, and are beginning to make plans for their entire family. The younger generation is including their child who has a disability in with the entire family, and include them in all aspects of their lives, including future planning. Of course, it is unrealistic to say that all people do all things. Life Planning has become something that more people seem to be doing, for whatever reason, e.g. receiving a payback, arranging for their legal affairs. Perhaps a what was once almost a "shame" of having a child who has a disability is moving closer to acceptance within the greater community. We can only hope that more families will be planning for the future for their children.

Kathy Morris
Cincinnati, Ohio

⇒ As 2007 comes to a close, I'd like to say that we've all finally gotten it with respect to providing needed services and supports to people with developmental disabilities! Bureaucracies finally understand the importance of assisting families and individuals with developmental disabilities in their homes and communities by providing the supports they need there, rather than in special places for special people. Children are finally allowed to attend the school in their neighborhood with their peers, with the extra supports they need provided to them there, rather than across town in a special place for special people. Individuals with developmental disabilities have the opportunity to live and work in their community, rather than live in special facilities and spend their days in other special places. People can finally access the services they need in their lives, rather than the services some agency offers and, therefore, decides they need. Government agencies finally realize they exist to work on behalf of the people they serve, rather than believing those individuals should be grateful to them for their lack of response or assistance when needed, and for their attitude that people needing their assistance are somehow "less" than they themselves are. I'd like to say it – but I can't. Not yet, and I'm wondering if ever.

Linda Higgs
St. Albans, West Virginia

⇒ As the end of 2007 begins to appear, I find myself alarmed about the specter of the possible reversal or collapse of much of what I have worked my whole adult to achieve. This was triggered in part by Jack Pealer's letter to the governor of Ohio in the Autumn 2007 *Safeguards Letter* and the news that the State of Ohio has committed itself to revitalized developmental centers, i.e., institutions. Similar news of institution revitalization has recently arisen in other localities as well e.g. Nova Scotia, Manitoba, New South Wales, Ireland etc. after many years of not hearing anything but stories of reasonably successful institutional reduction and closure. I am left wondering if the tide has fundamentally turned. The values and advocacy strength of the "baby boom" generation of leaders in this field no longer seems to have the sway that it did in recent decades. I do not know whether these examples of resurgent legitimization of segregation are a momentary anomaly or whether it presages a deeper erosion of societal commitment to the social inclusion of people with disabilities. Like many others of my generation, I had thought we had proven that institutions were not needed. Yet, we may now face the prospect of having to re-enter this battle with a new generation of people who may well be quite comfortable with segregation. Clearly, the resurgence of governments quite willing to unapologetically endorse institutions is a moral and political fact that has the gravest of implications. It is these emerging realities that I will carry with me into 2008, as I try to evaluate what might be their meaning for my personal priorities. I am grateful for Jack's challenge to the governor, but wonder why so little has been said and done by others, including myself. So, lots to consider.

Michael Kendrick
Holyoke, Massachusetts

⇒ As 2007 comes to a close, I'd like to say how much I'm going to miss Ken Ervin, one of West Virginia's most tenacious advocates for people with disabilities. Ken, 45, died in his sleep from a heart attack this fall, in the midst of a remarkable career. No, not a career, Ken would have said, but a calling, his reason for being here. The Governor, a frequent target of his advocacy, attended the funeral in Ken's home town a few weeks ago. Yesterday, I joined Ken's friends for a ceremony at the Capitol, where the Governor presented the "Distinguished West Virginian" award in Ken's honor to his widow, Darla.

Ken would have dismissed the whole affair as a waste of precious time. He never sought recognition for himself, only the larger cause of liberating people with disabilities from nursing homes and institutions. The issue was intensely personal to him, for he'd spent four years of his youth in a residential "school," where he counted beads on a string for "math class." Two master's degrees later, I crossed paths with Ken when I worked for the Developmental Disabilities Council. He was one of a dozen people whose oral histories were included in a book the Council published about their experiences in and outside of institutions.

Ken was excited about the project, but urged me, the book's editor, to tell the whole truth, to resist the urge to shape the book into ammunition for the deinstitutionalization movement, to include as well people's struggles in communities. He reminded me how easy it is become intoxicated by our own rhetoric, how the integrity of our cause hinges on our honesty with ourselves and with others, however uncomfortable that truth may be. The brutal reality of people's lives often depressed Ken, but he never gave up on his notion of a world that fully includes all of us. Nor, I hope, will I.

Julie Pratt
Charleston, WV

⇒ As 2007 comes to a close, I'd like to say haven't we all said and done this before? I mean, I read the battles and the struggles that folks on at least one list talk about and I think we are back in 1997, or 1987, or 1977 or even 1967. Institutions seem still to be "bad." Sheltered workshops still don't help people find jobs. Some families are so afraid of life for their kids that they "hide them away", not in back rooms, but in those institutions that are or should be, according to these folks, "part of the continuum of care." But what may be new in 2007 and what will be on the horizon for many years to come is the large number of kids who now are labeled in the autism spectrum. What if it's real that 1 of every 150 or 1 of every 140 or whatever really do have autism? And what will we do about it to provide meaningful lives in the community? We haven't exactly "liberated" all the folks we knew about from years past and we re-fight the battles that we thought we'd won when Laconia State School closed. So now we have a huge new cohort to worry over. And I guess we'll say the same things and wrestle with the same issues and win a few and lose many and struggle to find dollars and rebuild old structures for new folks and PASS on to a new generation the struggles that are eternal. The poor (and the frail and the ill and the powerless and the dispossessed and the vulnerable) will always be with us. And so the test is not just to win by building a better program but always a personal one about how will each of us respond to issues that ought to be understood as personal, moral tests, not design issues. That's what I'd say and why I think the vulnerable are not just among us. They are us, in 2007 and more than likely in 2008 as well.

Don Trites
Lincolnville, Maine

AND WITH THAT we'll wish all who read *The Safeguards Letter* good memories of the year that's closing and, of course, much joy and accomplishment in 2008. Jack Pealer, Editor

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The Safeguards Letter

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TWO IMPORTANT LEARNING OPPORTUNITIES THIS SUMMER

Social Role Valorization Workshop in Louisville, KY

Darcy Elks will teach a 3-day reflective workshop on Social Role Valorization in Louisville, KY on June 24-26, 2008. The Human Development Institute, the Kentucky DD Planning Council, Lifeskills, Inc., and Realizations LLC are the workshop's sponsors.

Social role valorization (SRV) grew from what many people have known as "normalization." During this workshop participants will learn about:

- The common life experiences of people who are marginalized and devalued in our society;
- SRV's power to address some of those experiences and to ground support for people to become valued members of their communities, and
- The ten "core themes" of SRV.

Those at the workshop will discuss issues of service-quality—including public attitudes, community acceptance, physical and social integration, and self-determination. The workshop will offer a format that allows for both individual and group reflection, which helps participants consider their personal stance about social devaluation and to form responses at three levels: personal, community, and societal.

Darcy Elks has been a human service provider, trainer, consultant, and advocate for people who are societally devalued for more than 25 years. She has worked in many places with many different people, including people who have themselves been marginalized by society. Her work focuses on encouraging attitudes and structures that promote social value and inclusion for people who have been devalued. She is the mother of three children.

For more information about this important learning opportunity, contact Keisha Jones at 502-498-0885 or Keisha.jones1@insightbb.com .

WEST VIRGINIA DD COUNCIL ANNOUNCES: A Workshop on 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, June 16 through Thursday, June 19, 2008.
- Location: Blessed John XXIII Pastoral Center, 100 Hodges Road, Charleston, WV.
- Taught by Jo Massarelli of the SRV Implementation Project and Joe Osburn of the Safeguards Initiative.

Purpose of the workshop: Human service workers play a critical role in the lives of the children and adults they serve. This workshop helps to lay out a framework for service workers to use in implementing relevant and effective services in the lives of socially devalued people.

Description of the workshop: This workshop is specifically oriented to leadership development. 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. Competency and image enhancement are essential building blocks of valued social roles. SRV will be reviewed with the implications of its positive assumptions about the worth of all people and their belonging in our communities. 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!"*

Who the workshop is intended for: 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 slides.

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 **$100**. 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 LindaHiggs@wvdhhr.org, or by phone at 304.558.4884.

The Safeguards Letter is an occasional publication of OHIO SAFEGUARDS. The *Letter* exists to promote affiliation among people who are interested in and thoughtful about those who live outside the sphere of respected community membership--those who are the usual receivers of human services. All material in *The Safeguards Letter* is under OHIO SAFEGUARDS' copyright (©) unless otherwise attributed. Letters, ideas, and items for publication in the *Letter* can be sent to: Editor, *The Safeguards Letter*, 3421 Dawn Drive, Hamilton, OH 45011 (e-mail: jackjr441@earthlink.net). We welcome our readers' ideas and reactions.

BOOK SUGGESTIONS FROM "MOVEMENT-THINKERS"

When I go to conferences or workshops, I try to pay attention when people recommend books. I had the lucky chance in January 2008 to go to a four-day gathering titled "Thinking Like a Movement." The gathering was organized by PLAN of British Columbia. We got together at a retreat center on Bowen Island in the Strait of Georgia just northwest of Vancouver. Conversation centered on the nature and characteristics of social-change movements. People shared examples of innovative ways of seeking and achieving important changes. Some also shared the authors/titles of some of the books that have been important to them. Below are summaries of two of those books that caught my attention.

1. *Bury the Chains: Prophets and Rebels in the Effort to Free an Empire's Slaves*, by Adam Hochschild. The language and style of efforts toward social change are familiar to all of us by now. We get mail or e-mail messages nearly every day that urge our support or action in one or another cause. Adam Hochschild's *Bury the Chains*, highly recommended by Al Etmanski of Vancouver, lets us see many of the techniques of social change movements when those techniques were new.

Al Etmanski describes "social innovation" as "…a profound change of relationships, attitudes, habits, policies, resources, practices, systems, structures to transform deeply rooted social problems." (PLAN Institute, 2008) Social innovations or movements, thus, strike at some of the most deeply (and often unconsciously) held beliefs of societies. The way toward social innovation can be dangerous. Dangerous or not, the road is bound to be long.

Bury the Chains is a history of the conscious work directed at ending British involvement in the African slave trade in the late 18th and early 19th centuries. On May 22, 1787 twelve men held what turned out to be an organizational meeting for a movement in opposition to slavery and the slave trade. The meeting took place in a print shop at #2 George Yard in London. Adam Hochschild quotes American historian Seymour Drescher on the context in which the May 1787 meeting occurred. Drescher noted that in the 18th century "… freedom, not slavery, was the peculiar institution." As Hochschild describes it, the slave trade and African slavery occupied a place in British society analogous to the place of the oil trade today. Although not many British citizens held slaves in Britain itself, the life of nearly every Briton was daily affected by the products and resultant economics of slavery. Almost everyone used either tobacco or sugar.

Hochschild introduces us to those who gathered at #2 George Yard in May 1878. Prominent among them were:

- Olandah Equiano (also known as Gustavus Vasa, for reasons Hochschild mentions). Equiano was a freed slave with experience in many different parts of Europe and America, including a voyage that made him the first known African to visit the Arctic.
- Granville Sharp. A classical scholar, writer, and musician, Sharp had long been active at rescuing and freeing slaves in England.
- James Stephen. Described by Hochschild as a "dandy" (a sharp dresser? a "playboy?") , Stephen was also a lawyer who, having traveled to the West Indies, learned first-hand about the realities of slavery. He became a lifelong campaigner. He eventually married the daughter of William Wilberforce, who sponsored and spoke for anti-slavery bills in Parliament until one passed.
- John Newton. Newton was a former captain of a vessel in the slave trade. He later became a popular evangelist in England and is remembered as the writer of the hymn "Amazing Grace."
- Thomas Clarkson. Clarkson was a former Cambridge divinity student who turned out to be the principal organizer of the opposition to the British slave trade. He was just 25 years old in 1787. Over the next nearly 60 years of campaigning he

> traveled more than 35,000 miles--mostly on horseback—in Britain, organizing, giving speeches, and distributing written materials about the cause. Without him, Hochschild says, the end of the British slave trade would have been long delayed.

Bury the Chains describes a new kind of campaign for social change. For one thing, the effort to end slavery and the slave trade upheld the rights of people other than the campaigners. It was energized by moral purpose—the confidence that the practice being opposed was utterly wrong. It was an endeavor on behalf of people in another place (Africa and West Indies, mostly), rather than people in the campaigners' own land. The anti-slavery (and anti-slave-trade) campaign successfully made explicit the connections between slavery and both its horrors and its products (tobacco, sugar). Finally, the campaign developed and used tools familiar now but absolutely new in the 19th century. Among those tools were:

*consumer boycott—especially of sugar
*investigative reporting
*local and regional organizing groups
*wide distribution and display of campaign posters
*newsletters to supporters and potential supporters
*instructions/guidance about how to contact legislators

Ultimately, of course, the entire effort succeeded. The bill to abolish the slave trade passed Parliament and was signed into law by King George III on March 25, 1807—almost 20 years to the day after the print shop gathering. It took another 26 years before the practice of slavery itself was outlawed by Parliament and even another 5 years (until 1838) before the emancipation of all slaves in the British Empire became a reality. Adam Hochschild notes: "The Quaker William Allen, who had sworn off eating sugar as an eighteen-year-old in 1789, was now able to put a spoonful in a cup of tea."

My thanks to Al Etmanski for his recommendation of *Bury the Chains* and the story it tells about the hard road that waits for people who seek important social changes.

2. *Orbiting the Giant Hairball: A Corporate Fool's Guide to Surviving with Grace*, by Gordon Mackenzie. Cairine MacDonald from Victoria, BC recommended this book. Thanks very much, Cairine.

Gordon Mackenzie had a 30 year career at Hallmark Cards. If I were to judge from this little handbook, I'd say that he was sometimes a trial to company managers and some colleagues. Their trials can be our blessing, though, as we read and try to live by the advice and stories in this guide.

The Hairball, Bureaucracy, and Entropy. Gordon Mackenzie describes entropy as "the degradation of matter and energy to an ultimate state of inert uniformity" and notes that entropy, so described, is an apt synonym for bureaucracy. My own dictionary (*Webster's New World Dictionary of the American Language*) offers another slant: "…a measure of the degree of disorder in a substance or a system: entropy always increases and available energy diminishes in a closed system." Were I unkind, I'd say that sounds like some places where I have worked.

Mackenzie's theme is the tug-of-war in organizations between entropy and creativity. His chief metaphor for organizational degradation or lifelessness is the "hairball." Organizations tend to rely on their histories—on precedent, on what has "worked" in the past. Every fixed precedent, every policy that delimits action, every rule that's passed to govern performance—each of these is a separate hair in the hairball. Anyone who has been part of a large organization has experienced the entanglement of policies and rules based on "how things are done here." To Gordon Mackenzie this massed entanglement (i.e., the hairball) takes on increasing gravity, such that it sucks in the energy of those who get too close. Kind of like a black hole.

Mackenzie has been a cartoonist. One segment in *Orbiting the Giant Hairball* (hereafter OGH) is a cartoon strip about a continuing argument between two halves of a brain—between the left-brain "brother" and his right-brain "sister." The left brain guards the power of the giant hairball with familiar arguments:

- We can't do that; it's not cost effective.
- It's OK to do that; we've done it lots of times before.
- We have to study that a lot and go slowly; it's never been done here before.

In the cartoon strip, the left-brain brother ultimately quiets his noisy and distracting/distractible right-brain sister by simply holding his "hand" over her mouth. Anything to shut her up.

To Mackenzie the hairball stands for organizations' standard-operating-procedure for genius-suppression. He believes: "There is a Fool in each of us, you know." Hairballs—big complex organizations—fight back against the foolishness of genius using weapons like (as mentioned already) precedent, rules, and teasing non-cooperators. With regard to the latter, Mackenzie regards teasing (i.e., of people who display divergent ideas) the "death of a thousand cuts"--an effective way to keep people from trying very often to escape the gravitational pull of the hairball.

Orville Wright did not have a pilot's license. "Orbiting" is Mackenzie's helpful image for the state between complete submission (to the gravity of the hairball) and utter flight. He describes the purpose of orbiting: "…to find a place of balance where you can benefit from the… resources of an organization without becoming entombed in the bureaucracy of the institution." If you orbit the hairball, you're related to it but aren't sucked in by its centripetal force.

At Hallmark Mackenzie finished his career with the title "Creative Paradox" for the corporation. It's a title he invented, with the consent of his managers. The position and its title conferred on him what he calls the "power of uncertainty." No one else in the organization knew just what to expect, so it was possible for some expectations to be unreasonable or even foolish. And it was possible for foolish expectations to be met. Mackenzie describes trying to buy antique milk cans to serve as furniture in Hallmark's new "Humor Workshop." The hairball's purchasing department responded to his request with the opinion that milk cans were NOT on the approved furniture list. The orbiter (one of Mackenzie's fellow Humor Workshoppers) suggested that they think of the milk cans as "art" instead of as furniture. The purchasing department thought that was a "great idea." Milk cans arrived. Mackenzie says that this taught him a new survival tactic that "has helped me stay out of many a hairball."

> Any time a bureaucrat
> (i.e., a custodian of a system)
> stands between you
> and something you need or want,
> your challenge is to help that bureaucrat
> discover a means,
> harmonious with the system,
> to meet your need.

OGH offers lots of reminders and hints--like the milk can story—that are useful for our own struggles with organizations. It's more important, though, that behind Mackenzie's clever advice (and admittedly his occasional over-cuteness) is guidance for those who try to stand with vulnerable people, whose lives are so often made much more difficult by their dependence on tangled hairballs.

Jack Pealer

JUST QUOTES

Looking back, I can see that when I was in the navy I was preoccupied with success and with trying to win the admiration of my superiors. I loved the spirit and power that came with naval life. Efficiency, not people, was my first concern. Similarly, when I left the navy, it was not primarily people who interested me. I wanted to devote myself to an ideal of peace and to the study of philosophy and theology. It took me some time to discover all my inner brokenness which provoked difficulties in relationships and a fear of others. I was happy to command, teach, obey and learn; but entering into communion with others, making myself vulnerable by forming relationships with them, was far more difficult.

Jean Vanier, *Our Journey Home*

Man goes beyond his own decision
Gets caught up in the mechanism
Of swindlers who act like kings
And brokers who break everything
The dark of night was swiftly fading
Close to the dawn of day
Why would I want him just to lose him again

We'll rise above the scarlet tide
That trickles down through the mountain
And separates the widow from the bride

T-Bone Burnett & Elvis Costello, *The Scarlet Tide*

If the object (i.e., of war) were the diffusion of ideas, the printing of books would have attained that object much more effectively than soldiers. If the object were the progress of civilisation, one may very readily assume that there are other more effectual means of diffusing civilisation than the slaughter of men and the destruction of their property.

Leo Tolstoy, *War and Peace*

TAKE YOUR TURN—AN INVITATION

OHIO SAFEGUARDS has been publishing *The Safeguards Letter* intermittently for twenty-two years now. Lately the Editor (that's me) has been doing most of the writing and/or searching for items that would interest readers. *Letter* reader Don Trites from Lincolnville, Maine suggested that we offer others the opportunity to write about something about which they feel strongly or that especially interests them. He suggested the running title: "It's My Turn."

We think Don had a great idea, so we offer you a chance to contribute some writing for publication in the *Letter*. There will be no deadline. We hope to be able to build a "bank" of "my turn" pieces that we can draw on each time an edition of the *Letter* is assembled. If what you choose to write is time-sensitive (e.g., relevant to an especially current event) we'd get it in print sooner. Contributions should be between 500 and 1,500 words, and it would help if they were sent in MS Word format. We would take them as they come, however, and if you want to send a drawing, a cartoon, etc., that would be OK too.

If you'd be interested in giving this a try, please contact me at jackjr158@earthlink.net or at 513-887-7515.

Jack Pealer

VIEW FROM THE BACK WINDOW

Words Plastic, Words Marshmallow

I start by stealing a device from George Orwell. His 1945 essay "Politics and the English Language argues that:

> (the English language) "…becomes ugly and inaccurate because our thoughts are foolish, but the slovenliness of our language makes it easier for us to have foolish thoughts. The point is that the process is reversible. Modern English, especially written English, is full of bad habits which spread by imitation and which can be avoided if one can take the necessary trouble."

To support his argument, Orwell gives examples of English as it is (as he calls it) "habitually written. That's the device I'm stealing. I have picked out three short sections from recent pieces of writing that are intended to describe how services for people with disabilities ought to be, and how the changes to achieve those ambitions ought to be done. I wrote one of the quoted documents (mea culpa). Here they are, with likely identifiers removed:

1. …the adoption of performance indicators as a quality enhancement method is both a consequence of the change in expectations as well as a method for focusing on person-centered outcomes. As supports become more individualized, relying on strict input and process measures has less utility in a world that emphasizes flexibility, creativity, and tailoring supports to each person's unique capabilities and preferences.

2. (It) … means that the program's ability to act on many of these statements is contingent on either improvements in the financial situation or decisions to exchange previous forms of service for new approaches to service…(disinvesting to reinvest)…. The plan and… budget are tightly interlocked, so it can be said with some confidence that the action statements in the plan are financially possible, given that no unforeseen financial problems develop during the coming year.

3. (agency), in collaboration with stakeholders, should examine training issues, complexity of processes, measured uniformity around service support administration functions. This effort should focus dedicated resources and staff to ensure that meaningful change is put into operation….

Say what? I've read lots of plans and essays about service quality. I'd argue that the above sections are representative. They also are, as Orwell put it, "habitually written."

If we think about these examples, we're faced right away with the question: do any of the writers know what she/he is saying? Do they convey meaning clearly. Do they do so in a way that matches the writers' intentions? German linguist and critic Uwe Poerksen doubts their clarity and purposefulness. His long essay, published in English in 1995 under the title *Plastic Words: the Tyranny of a Modular Language,* identifies 30 to 50 words that mask clarity and purpose. Those words, dubbed "plastic words" by Poerksen, serve as the Lego blocks of speech and writing patterns that planners, futurists, government officials and bureaucrats of all sorts have mastered. The patterns are consistent across all modern languages. Plastic words usually, says Poerksen, "dress up in the authority of science" and then lay claim to the prestige of science but in realms outside proper scientific realms. It's pretty easy to pick out the plastic or Lego words in the examples above. Consider:

performance
outcomes
develop
functions
indicators
service
stakeholders
ensure
quality
action statements
resources

According to Poerksen our learned and habitual use of words such as these in documents like plans or reports fails to communicate very much except the difference in power between the users of the (plastic) words and most of the readers or hearers. Plastic words indicate a barrier between insiders and outsiders—a barrier that stifles conversation and dissent. Think about people's experiences at "IEP" meetings. I think, too, that habitual obscurity in language prevents insiders themselves from understanding one another. One insider, for example, who summarizes his beliefs under a term like "evidence-based practice" cannot really be sure that his colleague means anywhere near the same thing when she nods or uses the same phrase--not, that is, unless they really talk about it, in plain language. Sometimes, insiders are either too proud or maybe too afraid to admit that they (we) don't know exactly what they're (we're) talking about.

Two reasons why this matters occur to me. First, it's important that language should work as it's intended. Language exists for interchange—for conversation in all its richness. Usage that obscures (for whatever reason) violates the purpose of language and will eventually kill it. The examples I've shared above (one committed by me) show language on its sick-bed. Second, the examples' sort of habitual language (language-about-power) stands in the way if our purpose is to support or assist vulnerable people. About 25 years ago I worked for a short time with a group that invented a "curriculum" for teaching and guiding parents who had children with disabilities. We wanted ways to focus immediate attention of both parents and ourselves as teachers on the insider language we teachers had learned to use (and use habitually—without thinking about it). Our strategy? We issued handfuls of mini-marshmallows to parent-participants in the meetings we held. If one of us used one of "those" words, participants were supposed to hurl marshmallows at us, and some did. Out of that practice came the new term for insider language: marshmallow words.

Plastic words… marshmallow words. We can't really have a conversation about things that are important if our mouths are filled with marshmallow. We can't write clearly if the words just come out in plastic. George Orwell noticed that sloppy language leads to foolish thoughts. Haven't we had enough of those?

Jack Pealer

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The Safeguards Letter

A Publication of OHIO SAFEGUARDS

Number Forty-four *Early Autumn 2008*

ANNOUNCING 2009 SOCIAL ROLE VALORIZATION TRAINING IN WEST VIRGINIA
(sponsored by WV Developmental Disabilities Council)

March 16-19, 2009
Social Role Valorization, Including 10 Related Themes: A High-Order Concept for Addressing the Plight of Socially Devalued People, & For Structuring Human Services
Bridgeport Conference Center, Bridgeport, WV

April 14, 2009
Strangers in the House
Bridgeport Conference Center, Bridgeport, WV
This workshop was developed at the request, and with the input, of both in-home service recipients and providers, with the intent of contributing to improvements in in-home service arrangements.

April 15, 2009
Protecting the Lives of Hospital Patients, Especially Those Who are Devalued by Society
Bridgeport Conference Center, Bridgeport, WV

August 4 (Judge Black Conference Center, Parkersburg, WV) and August 5, 2009 (Summit Conference Center, Charleston, WV)
Devaluation and the Service Worker's Role
These one day workshops are designed to give policy makers, providers, and parents a very brief overview of social role valorization and its importance for people with developmental disabilities. Attendance at this workshop does not make you eligible to attend a PASSING workshop.

September 20-25, 2009 (Location to be determined)
PASSING

This workshop **may only be attended by** those who have previously attended either a SRV or SRV-10 workshop, as it is a training on the practical application of Social Role Valorization (SRV). PASSING is an instrument for evaluating the quality of any human service according to how well it implements SRV theory.

For more information, contact Linda Higgs, WV Developmental Disabilities Council, phone: (304) 558-4884, e-mail: Lindahiggs@wvdhhr.org

THANKS VERY MUCH!

Over the past year or so OHIO SAFEGUARDS has received contributions in support of *The Safeguards Letter* from the individuals listed below. We're really grateful for their interest in *The Letter* and their willingness to help support its publication.

Mary Brandstetter, Xenia, Ohio
Dennis Burger, Cincinnati, Ohio
Stella Gola, Coventry, Rhode Island
Deborah Metzel, Waltham, Massachusetts
Julie Pratt, Charleston, West Virginia
Deb Schmieding, Athens, Ohio
Paul Tabor, Bowdoinham, Maine
Milton Tyree, Louisville, Kentucky
Jack Yates, Stoughton, Massachusetts

PATH AND "SERVICE PLANNING": A CONVERSATION WITH DAVE WETHEROW

David Wetherow had the following conversation with a mother about the relationship between "person-centered planning" and the formal planning that goes on in human services—including schools. We asked whether we could share this with readers of The Letter, and Dave agreed. JRP

GINA WROTE: *I was told some of the language that is being using for school aged children is not true self-determination. The other thing I know people are saying and using is person centered planning, however if there is no money attached to it, it is cruel and inhumane.*

Faye and I have been facilitating and teaching person-centered planning (especially PATH) for some time now, so I want to reflect a bit on how we approach this.

When we are teaching, we try to be very clear that, unlike a service plan or an education plan, a PATH is not defined by what the service system or school is prepared to offer. The creative conversation at the heart of PATH (or any other good person-centered planning approach) extends beyond any agency mandate, and the invitation to participate should always extend well beyond the boundaries of the service system.

PATH is not an ISP, IPP, IEP, or any of those other P's. It's not a service-centered plan or a facility-centered plan. When it is thoughtfully undertaken, it offers a broad view of the person's vision for her or his own life--a vision sometimes developed in collaboration with friends and family members, especially when people have great difficulty communicating. With that broad vision in mind, it becomes possible to derive a service plan or an education plan that is consistent with the person's PATH.

The "service" plan that might be derived from PATH is one part of a larger set of understandings and commitments. It is the response of one of the parties (the agency, the school, the system) to a larger expression of the person's life direction. So, at the end of a PATH, the school might say,
"We understand the broad direction that Jack and his family want to take with his life and his education, and we're clear about our role in supporting that direction. Next month, we will develop an IEP to reflect what the school is able to offer Jack to support him on that PATH."

This means that when preparing to create a person-centered plan, invitation is critical. If we limit the invitation to "the usual suspects," we will be missing a rich set of potential connections. On the other hand, if we open up the process to extended family members, friends, neighbors, people from the family's church, etc., we greatly expand the number of people who "get it," who begin to see their role in helping to move things along, and who are available to take action.

Later, if the school (for example) doesn't take action, there are still a lot of people left who are working away at the goal, and also a lot of people who become clearly aware that one of the parties isn't pulling its share of the load. The politics get interesting and rather compelling.

GINA WROTE: *They did a person centered plan on my son 10 years ago and it is still sitting there. I do not even remember what was in it. Gives people too many hopes and dreams and nothing happens. Kevin is still waiting on his hopes and dreams.*

Here's how I read this little bit of history...

First, your words “they did” the plan speak volumes. I suggest that if this had been done well, the overwhelming feeling would have been that “we did'” a plan.

My guess is that the people who “did” (or facilitated) the plan would have been school division employees. This creates a couple of dilemmas right off the bat: A) it becomes far more likely that the plan (the conversation) will be limited by what the school division considers to be its mandate, and certainly limited by what the division thinks it is prepared to actually provide; B) it probably means that people who could have been part of your son's circle of allies were busy facilitating the plan instead of sitting in the circle, listening and contributing; C) you and your son missed the chance to have a facilitator (or facilitation team) in place who could have helped to equalize the power in the room, giving you, your son, and your personal allies an equal voice with the school system (this alone may have made it almost impossible to feel that “we did” the plan).

Second, the fact that it was done ten years ago and not re-done since then speaks volumes. Who among us is exactly following the “plan” that we might have had for our lives ten years ago? All of us change, grow, learn, discover new things, bump up against our limitations, develop new interests and discover new gifts and directions. To me, a ten-year-old plan means either that we have become blind to the fact of growth, or (which is far more likely) that the “person-centered planning process” was just a bureaucratic exercise, or possibly a heartfelt exercise that got buried under the full weight of a bureaucracy. In any event, there was clearly no commitment that we would 'live by' the plan -- which means taking the brave step of re-visiting it often and asking the difficult questions, "How are we doing?", "What are we learning?", and "What do we need to do next?"

Third, the fact that you “don't even remember what was in it” speaks volumes. One of the things that we like about the graphic aspect of PATH is that it creates a vivid, accurate picture of what we said, discovered and invented, what we learned that we needed to do next, and what we committed to. It creates a record of the conversation, captures the energy and excitement of the event, provides a way of quickly communicating the plan to someone who might not have been there, and provides a platform for re-visiting the conversation, holding ourselves accountable, and adapting the plan. It sounds to me like none of these things happened.

Finally, your words, “Gives people too many hopes and dreams and nothing happens. Kevin is still waiting on his hopes and dreams.” are very painful, and speak volumes. It looks like the process was not well understood or well-conducted in the first place; that many people who probably should have been there were not there; that there was no vivid record of the event that could be followed afterwards; and that there was little understanding or commitment to follow through and hold ourselves accountable.

It is very important to understand that the sin -- the harm -- was not in giving your son the opportunity to fully express his hopes and dreams. We commit a far greater sin when we fail to invite that expression, when we don't listen, and when we don't take that expression seriously. What is “cruel and inhumane” (in your very expressive words) is not being serious about how we respond when we hear those dreams.

It is absolutely possible to invite wholeheartedly, to listen carefully to your son (“think softly,” as Amber would have said), honor his expressions by accurately and vividly capturing them in words and graphics, and then saying, "Kevin, thank you for letting us know about all of this. We will keep all of this in our minds and in our hearts. There are some parts of what you are saying that we can help you with. Here's what they are, and here's what we can do.

"And there are some parts of what you are saying that we can't figure out how to help you with. Here's what they are, and here's what we can do to get closer to figuring them out. But right now it's important to understand that we're not there yet. Let's look at the parts that you can do to help things move along this way, and what we can do together to get stronger and know more."

Finally we can say, "We'll keep our commitments to you, including our commitment to keep this whole picture in mind even if we can't figure it all out now."

When we say "We hear all of it", we are not making an empty promise.

When we say, "This is what we'll do", we are making a promise but it is one that is within our means (we don't always keep all of our promises, but this means that we need to re-visit the conversation, see where we need to make course corrections, and sometimes ask for forgiveness). And when we say, "This is a part that we can't figure out", we are honoring the person with our honesty and vulnerability.

In the end, a well-crafted PATH also invites the hopes and dreams of our friends, family and allies. The person at the center gets to say, "I don't want that to be part of my plan", but he also has a chance to hear the care, commitment, thoughtfulness and hopefulness of the other people around him. It's person-centered, but in some ways it's a shared dream.

GINA WROTE: *To me it should be called individualized budgeting. This has money and using the principles of true self-determination as the main piece of the budget.*

Individualized budgeting can certainly help all of this along. It is very important. But it is not the same thing as good person-centered planning. I think of individualized budgeting as one of the many things that might be upholding the person and their plan. There are other things doing this as well: the love and action of family, friends and allies; a continuous process of inviting more people to get to know your son and his dreams (and your dreams for him) and inviting them to see their role in the picture.

I've been in and around “the system” for a long time. It's very clear to me that if we depend entirely on the system to uphold our future (even when the system is making sense), we're backing ourselves into a corner we might not be able to get out of. I'm not suggesting for a second that we turn away from rightful and appropriate system resources or that we stop asking for what we need, but the core of what we do, the core of moving forward with a person-centered plan, is much stronger when it is anchored in personal relationships and personal commitments.

GINA WROTE: *Again thanks for sending me this web-site. I have not had time to read it all but will.*

You're welcome. There are a couple of additional articles on our website at http://www.communityworks.info/articles.htm that have a bearing on this, and that offer some additional strategies, tools and connections: 14,000 Islands, Community-Building with PATH, Reflections on Friendship, and the article on Microboards. I also highly recommend Al Etmanski's book, *A Good Life*, from http://www.plan.ca, and all of the Inclusion Press materials, at http://www.inclusion.com.

Cheers,
Peace,
Dave Wetherow

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SEEN AT THE MUSEUM

Several colleagues had the chance this past summer to visit an exhibition titled "Out from Under: Disability History and Things to Remember," mounted at the Royal Ontario Museum in Toronto by the School of Disabilities Studies at Ryerson University. Here's the narrative from one portion of the exhibit--about the free labor "contributed" to an institution by people who lived there. Notice the professional control and absence of reference to the evidence for such a practice:

> *Labouring*
>
> Hard working women. May, a housemaid, Audrey, a seamstress and Mathilda, a dining room and laundry worker. Together, they put in perhaps as many as 285,000 hours of labor.
>
> They were never paid a nickel.
>
> It was called "Moral Therapy." Labor-intensive jobs, long hours, no vacation, no retirement package, no pay. From the mid-nineteenth to mid-twentieth centuries, such was the preferred "treatment" for psychiatric patients at the Toronto Hospital for the Insane.
>
> Why? *Domestic duties were believed to make women inmates more "tractable and contented." Little is known about such so-called therapeutic benefits. What we do know is that the unpaid labours of inmates like May, Audrey and Mathilda saved hospital administrators very significant amounts of money.*
>
> They fed and clothed and cared for each other. In so doing, we hope that these women found dignity and belonging in a place that offered neither. (Emphasis added)

JUST QUOTES

Humanity continues on a journey that is both beautiful and disastrous. But, as I believe that the universe and humanity have been well made, that they contain within them elements of balance and healing, there is undoubtedly another way which is unfolding and which will help each one of us, all of us together, to find a new equilibrium and inner peace. This new way which is unfolding will certainly lead human beings to the discovery of a communion that is deeper than fleeting experiences; a communion that involves permanence, covenant, fidelity; a communion that is creativity, liberty, light and life; a communion that is celebration. And this new way will lead to the discovery of a God not 'up there' in the heavens, whom we can only reach through self-denial and obedience to laws, but of a God of love hidden like a tiny child at the heart of creation, at the heart of human suffering, at the heart of daily life.

Jean Vanier, *Our Journey Home*

...politics isn't typically an argument or a search for truth or a vital confrontation of rival visions. It is much more often a conversation among people of remarkably similar temperament who make ineffectual, sympathetic noises while waiting until the last possible moment to make unavoidable changes. We are generally taught that this is what makes politics frustrating, unresponsive, disappointing, and fraudulent. Oakeshott's (Michael Oakeshott--British political philosopher) lesson is that this is what makes it politics.

Adam Gopnik, "A Man Without a Plan"
New Yorker, 10/21-28/1996

A Patriot: The person who can holler the loudest without knowing what he is hollering about.

Mark Twain
More Maxims of Mark

VIEW FROM THE BACK WINDOW Considering the Evidence

I've just finished reading a newsletter from a state government agency. One article said that it's important to "support evidence-based, high-quality, cost-effective models for intervention services for children with autism and other developmental disabilities…." The article further said that such models are important because they will help us better "coordinate" supports in our state for people with developmental disabilities. I only want to direct gaze on that statement a bit. I don't really want to argue with it. It/its authors may be right. I just want to try to figure out what the statement means and think a bit about what difference agreement with it would make to the ways we try to support people with disabilities. Because I've pondered earlier in *The Safeguards Letter* about "cost-effectiveness" (*Summer 1992*), I'll skip that here. I want to think about what this "evidence-based practice" means.

Twenty or so years ago, the statement by the state might well have called for "models" that were "normalized." It was pretty common then for people to attach the idea of normalization—usually undefined and unexplained—to almost every proposal for any kind of service, at least for people with developmental disabilities. Part of my discomfort with the current prominence of "evidence-based practice" (EBP) comes from suspicion that EBP and its twin "best practice" are being used today in about the same way that normalization was used in the past—without explanation or examination. After all, like normalization, "evidence" is something that people seem to think they understand without taking the time to look closer. Today, if you want someone to consider your new idea seriously you'll likely describe it as an evidence-based best practice. But, as was the case with the label of normalization, simple labeling of new proposals as evidence-based isn't enough.

Let's take a look at EBP. To find out its meaning I did what many perfectly respectable 21st-century people do. I used Google to consult Wikipedia and to find references to "treatments that work" at a web-site from Oxford University Press. Here's what I learned.

When people are said to have needs that call for intervention, service, or treatment, there's often a choice among methods. That's noticeable in the medical, social-service, or "mental health" arenas. EBP is a way to inform choices in those and other fields. EBP indicates (says Wikipedia) a <u>preference</u> for service measures (treatments) that have been <u>shown to work</u> by means of <u>empirical</u> evidence. Most who rely on EBP to help them decide among service responses would prefer evidence or empiricism that results from the scientific design known as "randomized clinical trial." That's the way that researchers assess the usefulness and safety of new drugs or older drugs for new purposes. Writers about evidence-based practice usually hold up randomized clinical trials as the "gold standard" for empirical practice.

The idea of EBP apparently developed in the fields of medicine and nursing. Then it moved into psychiatry and "mental health," proceeding later toward influence in other human service areas. The rise of EBP as a determiner of correctness of service measures relates, of course, to the wish of funders of services that the funds they supply be properly used. Those who pay for services—private insurance companies or government agencies like the US Center for Medicare and Medicaid Services (CMS)—want ways by which they can be as certain as possible that payments go for methods that work… measures that help people. Funders also want reasons to reject claims for measures they have doubts about. So, EBP is both meant and used as a way to steer human service organizations and service-users away from practices that have not been professionally approved—in the best of worlds by means of randomized clinical trials.

As far as I can tell, if we rely on EBP to help us determine the right courses of action to take to try to support someone with a developmental disability—which "treatments" to use—we'd have to make at least two commitments. First, we would have commit to being sure that we knew about the empirical evidence (if any) that supports our choice of approach. We'd all have to be consistent students of current research. We'd have to participate, ourselves, in designing and carrying out research on so-far-unstudied questions that we think are important. Second, we would have to possess tools with which to judge the soundness of the research we study. We'd all have to be experts about research design and implementation. Many would likely argue that these are commitments we all ought to make so that we can know that what we're doing to support people is right.

The "likely" in the previous sentence is a tip-off that I don't fully agree. Full reliance on what someone else calls empiricism isn't always the best way to determine right courses. It's not just that such reliance means that many potentially useful/helpful measures we might devise would have to await assembly of the required evidence, even though the wait might be a serious drawback. We also have to take into account the frailties of the method by which evidence is collected. Here are three observations, from three different observers, about the limits of science and research.

> Ultimately, the most important issues in human services (as in life, politics, economics, religion, etc.) have not been, are not, and never will be decided on the basis of "research," or even on the basis of empiricism and evidence. They will be settled on the plane of values and ideologies, or even of passion…. The bulk of human services operates in ideological defiance of empiricism. (Wolf Wolfensberger. "Research, empiricism, and the principle of normalization." In Robert Flynn and Kathleen Nitsch. *Normalization, Social Integration, and Community Services*. Baltimore: University Park Press, 1980. Pp. 117-129)

> Science is not superior to its subjects, nor is it inherently superior to the other disciplines. It becomes markedly inferior when it becomes grandiose in its own estimate of itself. In my opinion, science falsifies itself by seeing itself either as a system for the production of marketable ideas or as a romantic quest for some definitive "truth of the universe." It would do far better to understand itself as a part of a highly diverse effort of human thought, never to be completed, that might actually have the power to make us kinder to one another and to our world. (Wendell Berry, "Is Life a Miracle?" In *Citizenship Papers*. Washington, DC: Shoemaker & Hoard, 2003. Pp. 181-189)

And, finally, a paragraph that I've quoted before. I think it's imprinted on the inside of my eyelids.

> Science, since people must do it, is a socially-embedded activity. It progresses by hunch, vision, and intuition. Much of its change through time does not record a closer approach to absolute truth, but the alteration of cultural contexts that influence it so strongly. Facts are not pure and unsullied bits of information; culture also influences what we see and how we see it. Theories, moreover, are

> not inexorable inductions from facts. The most creative theories are often imaginative visions imposed on facts; the source of imagination is also strongly cultural. (Stephen Jay Gould, *The Mismeasure of Man*. New York: W. W. Norton & Company, 1981.)

Two of those three writers are scientists—Wolfensberger a social scientist and Gould, before his death, a natural scientist. The other writer—Wendell Berry—is a practical scientist, in that he has made his life as a farmer and, thus, as a close observer of the natural world. These writers don't dismiss science or research. They just want science to be kept within proper boundaries. None of them, I think, endorses the exclusive reliance on research as the sole determiner ("decider"?) of what it is right to do. Science is a human activity. We have to be much more humble about its prospects.

Neither—to return to my original point—is it sensible to decide about what's right to do in the lives of other people (what Wolf Wolfensberger has called "human management") on the sole basis of what someone else labels "the evidence." Assumptions about the evidence too easily become tools of expert or professional control. In 1915 Henry Goddard thought he had the evidence for the inherent criminality of people who, he said, possessed "feeblemindedness." People with disabilities and those who care about them still live with the results of his miscalculation.

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 in 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.

Jack Pealer

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The Safeguards Letter

A Publication of OHIO SAFEGUARDS

Number Forty-five *Holidays 2009*

AN IMPORTANT WORKSHOP EARLY IN 2009.

Social Role Valorization, A High-Order Concept for Addressing the Plight of Socially Devalued People, & For Structuring Human Services

- Workshop dates: **Monday, January 26- through Thursday, January 29, 2009.** Each workshop day begins promptly at 8:30am and concludes about 5:30pm
- Workshop Location: **Comfort Inn 5909 Milan Rd Sandusky OH**.

Description of the workshop:

This workshop provides an introduction to Social Role Valorization (SRV), using the core themes developed by Dr. Wolf Wolfensberger. Dr. Wolfensberger's work helped lay the foundation for many current human service trends, including integration, safeguarding of individual rights, and the deinstitutionalization movement. SRV is a systematic and universally applicable concept for structuring human services, strongly anchored in the empiricism of psychology, sociology, and long and broad human experience.

SRV suggests a close relationship between the socially perceived value roles that people hold, and whether people in those roles will be accorded opportunities and other good things of life. Bad things tend to get done to people who are seen in devalued roles, and good things tend to be afforded to people in positively valued roles.

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

This workshop will be conducted by **Jo Massarelli** of the SRV Implementation Project from Worchester, MA and **Joe Osburn** of the Safeguards Initiative from Bardstown, KY.

For online information about Social Role Valorization:

Go to http://www.socialrolevalorization.com/

Who the workshop is intended for:

This workshop is intended for leadership development in regard to the issues addressed. As such, it is relevant for paid or unpaid human service workers at all levels, including direct service staff, as well as service planners and managers, in service to people who are at value-risk due to conditions such as mental retardation, mental illness, poverty, homelessness, autism, age (elders), physical impairment, or learning impairment.

The workshop is taught at a "college-level," demanding sustained attentiveness to the entirety of a comprehensive and systematic exposition of multiple complex ideas.

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

Tuition:

$395.00. This **includes handouts, and refreshments**. Some assistance with expenses will be made available to people with developmental disabilities and family members.

Overnight accommodations:

Individuals are responsible for making their own arrangements if overnight accommodations are needed. Rooms are available at the Comfort Inn at a very reasonable rate. There are many other lodging options in the general area of the Comfort Inn. (**a list can be provided upon request**). Please contact Bob Weinhardt if you are interested in obtaining one.

To register or for more information: Contact: Bob Weinhardt, Renaissance House, Inc. P.O. Box 250, 178 South Washington St. Tiffin, OH 44883. (419-447-7901 or e-mail rweinhardt@renaissanceinc.org) **Deadline for registering is January 16, 2009.**

AND DON'T FORGET:

Social Role Valorization training in West Virginia, with workshops in March, April, August, and September 2009. For more information about those events contact: **Linda Higgs, WV Developmental Disabilities Council,** phone: (304) 558-4884, e-mail: Lindahiggs@wvdhhr.org .

There are many opportunities for folks from Ohio and nearby states to learn about Social Role Valorization during this coming year!

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WE GET LETTERS

Jack- I appreciated your comments re. EBP and best practice. I confess to using "best practice" pretty loosely myself, usually to distinguish between something that's required and something that's not required but should be done because it's the best way to do things, or at least a good way.

I have been asked by colleagues in the mental health field about how we apply EBP in developmental services. I usually ask what they mean, and they say, "Well, what treatment methods do you support?" I ask, "Treatment for what?", and then the conversation gets a little more interesting as I try to point out that there are some discrete conditions that are amenable to specific therapeutic intervention by physicians and therapists, but most of what we do is supporting individuals to have as good a life as possible, and aside from some general principles like Normalization/SRV/Positive Approaches/Person-centered, etc., it's mostly trying to figure out what will work for an individual and adapting as we learn better. It often turns out that that's about what they're trying to do, too, but they're operating in a clinical model that wants to appear more scientific, so everything has to be a "treatment".

I suppose I could say that I personally am engaged in a self-directed and person-centered shared living residential augmented with pet therapy, horticultural therapy, and avian therapy when birds come to the feeder. Also lots of Moral Treatment keeping up with the lawn, the woodpile and the laundry. My day service is more highly structured, with occasional supervision. I am acquiring an increasing complex regimen of medical intervention, as I now have one prescribed pill a day, plus the exercises that I'm supposed to do for my occasionally ailing lower back.

I wholeheartedly agree that Normalization or any other principle is only a buzz word unless everyone in the conversation understands it in considerable breadth and depth. (I was going so use the expression "a high degree of", but I'm not sure what a high degree of depth would actually be.) Be well,

Paul N. Tabor, Developmental Services Training Coordinator
Maine Dept. of Health & Human Services

INSTITUTIONS OF THE MIND

(Editor's Note. I spent a few days in January 2008 "thinking like a movement" with about 25 folks—almost all Canadians—on Bowen Island near Vancouver, BC. It was a wondrous opportunity to learn about social change with a group of change-artists, including some leaders from PLAN of BC. I was assigned to share a suite with the only other non-Canadian there: Bob Rhodes, from the Forest of Dean near Gloucester, England. Bob has helped close institutions and has helped many people with disabilities take charge of their lives through direct control of the funds that are meant to support them. Recently Bob sent these thoughts. I didn't change the English spelling, and readers should remember that "learning disability" is the British term for what North Americans now call "intellectual disability." JRP)

Professionals of my vintage - my career started in the Beatles' era - have lived and worked through some revolutionary changes in the lives of people with learning disabilities. We have gone a long way towards the abolition of isolated and isolating 'institutional' provision. We are all person centred. We protect peoples' rights and safeguard them. We ensure that they have a voice in their own affairs and in the nature of services provided to them. We are in the process of enabling them to self-direct and organise their own support arrangements. We are all committed to the their entitlement to pursue ordinary lives.

I wonder if you, dear reader, are responding to the previous paragraph as I am? "Yes, but" and "You're joking" are my immediate responses to all of these statements and I know that I could rewrite them in a more qualified way with greater honesty. However, our professional and cultural tendency is to pretend to 'evidence based practice' while rationalising and ostracising perspectives that threaten our principled equilibrium. And I guess that is a posh way of saying that we live in a politically correct culture of mutual self-deception. Hence this polemic.

We have shut the large majority of the old mental handicap hospitals and many charities have dispersed their previous campus services but we continue to contain growing numbers of "people with complex and challenging needs" in isolated and isolating specialist services at enormous cost and expose them to allegedly therapeutic regimes that never seem to enable their reintroduction to 'ordinary life'. I wonder if this is not an inevitable consequence of guaranteeing a role for the medical model in the horse-trading that was required to secure the hospital closures? Alternatively you may choose to adopt a pragmatic stance based upon the belief that there will always be a significant population of folk with irremediable behavioural difficulties. That, however, is not my experience and I know lots of people who now pursue pretty socialised and contributing lives who were previously perceived as 'the spawn of the devil'. So I tend to the view that it is all too easy to blame the victim for our own inabilities. It is a truism of problem-solving that, "if you always do what you've always done, you'll always get what you always got". If you buy a brand of car that proves to be unreliable it is likely that you'll buy a different make in future. After all, the breakdowns affect you. You would get very upset if the supplier blamed your driving!

I'm just getting to know *Adam*. He's due to leave school and in his time in specialist and expert settings has acquired a *very challenging* reputation, two to one staffing, and a frightening prognosis. Everything in his life seems to be focused upon containment and, of course, he kicks against this. His relationship network is already diminished to a couple of close family carers and folk who are paid to be with him. We will be working to change this.

Are we all person centred? Frankly, we seem to be increasingly service and cost centred. Person-centred, for me, starts with supporting focus persons to really explore what is important in their lives and essential for their happiness. There are lots of great tools available to help folk do this but they are not used very widely. Professionals whose core roles are concerned with resource gate keeping and management frequently use 'sanitized' versions, with their iconic names retained. According to the Welsh Assembly website people should have a person centred assessment and the necessary proforma is provided. Their milieu is services and services are commodities. We no longer do social (let alone community) work – an activity. Instead we deliver social care – a commodity. Work focused upon assisting people to be more effectively in charge of their own affairs is 'preventative' and by definition low on the eligibility criteria. The services ‘prescribed’ for people who meet the substantial or critical bandings seem, all too often, to replace and disconnect natural family or community supports, often irrevocably. Since the Thatcher/Griffith’s consumerist revolution an urban myth has gained credence. It asserts that what disabled people need, in order to have a decent life, is protection and safe services. People with learning disabilities have bought into this in no small way and self-advocacy organisations ape trades unions in their demands for legislation and services.

Have you noticed that, when we ask people about the lives they want instead of demanding a litany of their dysfunctions and needs in order that they become eligible for our time and the resources we control, they almost invariably want the same things we value?

- Love, friendship, intimacy, companionship, belonging
- To be “comfortably off” – with the choices endowed by economic stability
- To earn citizenship, to enjoy the same rights and responsibilities, and experience the respect of others through the contributions they make to community life
- To have their own home, where they can be themselves – that is not other peoples’ workplace
- To experience the safety and security that derives from the four preceding wants.

On the latter point – bearing in mind the persistent professional liturgies of ‘reflective’ and ‘evidence-based’ practice – I find it unsettling that our policy formulators and legislators compulsively knee-jerk to scandals and fail to recognise the obvious fact that, for all of us, our ‘social security’ depends upon the folk who love and care for us and, hence, look out for us. Over-dependence upon paid care – as repeated institutional exposés, the most recent being Orchard Hill and Cornwall, demonstrate – equates with exclusion and vulnerability. Attempts to reduce risk through regulation and systems seem directed at the symptoms rather than the causes of the malaise and founded upon very devaluing beliefs about both the nature of vulnerable people and ordinary citizens in our communities. It is even more worrying that peoples’ safety and security is being institutionalised under the banner of ‘safeguarding’ – an orthodoxy that is, in practice in our risk-fearful society, synonymous with exclusion.

I have little doubt that there will be those who will defend the advance of regulation and centralisation as evidence of a listening bureaucracy. Self-Advocacy and umbrella groups have been campaigning on these issues for many years. However, it should come as no surprise that this would be welcomed by those who instinctively and single-mindedly see the solutions to all things as residing in greater statutory and professional control. Over the years I have been involved in a great many decision-making exercises in which disabled people and their families are alleged to have an influential voice. Quite recently I was involved supporting folk affected by a re-tendering exercise to participate in the appointment of Provider organisations that were to have a profound impact upon their lives. A lot of time and money was expended on the process yet the recommendations of both the disabled peoples’ and families’ panels were over-ruled by the procurers, unabashedly on the grounds of price. Why the more ‘expensive’ candidates were short-listed in the first place also begs questions about the ethics of the commissioning process. Anecdotally, and in my personal experience, we seem to have institutionalised the ‘Users’ Voice’ into a procedure where the box can be ticked as long as we can demonstrate ‘consultation’. And most of us know it but get on with the work!

“OK”, you say, “we lost our way, what with the Griffith’s ‘reforms’ and our pre-occupations with control and terror in the face of the risks of real life. But ‘personalisation’ will change everything. Self-Direction and Individual/Personal Budgets signify a fundamental transfer of power. He who pays the piper pays the tune.” And I will reply that, while I am convinced that the individualisation of resources has massive potential, a fundamental change in our attitudes and beliefs about people with learning disabilities is necessary if folk are to fully benefit and the walls of the cultural institution that surround them are to come tumbling down.

Far from being person centred the environment that corrals people with intellectual disabilities is service centric; of commodities and consumers, supply and demand, eligibility and money (not resources!), and, like so many manufactured economies, utterly irrational. And, bolstered by organisational systems and cultures plus the career and security aspirations of so many, it is built with subliminal bricks of far greater resilience than the baked and glazed clay of Calderstones or Borocourt.

The drivers for the physical deinstitutionalisation that we've yet to complete – given that obligatory group living is the norm for so many – were philosophical and perhaps best encapsulated by the term "an ordinary life". If, as outlined earlier, we follow PLAN's lead (www.plan.ca), and ask people about their 'good life' rather than what services they need, I believe that we arrive at a point where, instead of majoring on services for a vulnerable group, we have to think about:

- Seeking to ensure that folk have sufficient loving and caring relationships in their lives – addressing the isolation and loneliness that characterises the lives of so many
- Breaking the linkages between benefits and service entitlements and poverty
- Remembering the lessons of social role valorisation and putting contribution and participating citizenship at the centre of our activities
- Having a social housing policy that doesn't treat disabled people like lifelong students
- Ensuring that the services we supply demonstrably supplement and enhance ordinary life
- And actively nurturing and engaging with the extensive resources implicit in families and the wider society – rehabilitating community work and freeing social innovation from the stranglehold of statutory controls and its unnatural and counter-productive preoccupations with systems and managerialism.

If we are to continue the evolutionary, two steps forward and one step back, progress of the last 40 years, we depend upon leaders and groundbreakers who, as a result of experience, communicate a passion founded in belief in the immense potential too often suppressed in people with learning disabilities and within their geographical and personal communities. Concurrently it seems to me that progress depends upon a political leadership that has true business expertise and understands that success derives from encouraging and resourcing diversity and experimentation, and that 'loose' is the necessary balance for 'tight'.

Our prevailing preoccupation with services and concomitant neglect of societal resources derives, as I see it, from a persistent and incredibly deep-set prejudice. Despite all of our liberal rhetoric, people with learning disabilities continue to be defined by their needs rather than their humanity and, if they pass the eligibility criteria, accommodated in institutions of our minds.

Bob Rhodes
Forest of Dean
England

JUST QUOTES

Most American settlers have operated on the principle that the place where they settled should be made to resemble another place, either the place they left or a place they had merely in mind. Their plans, in other words, have not included what was already there. That is why present-day development virtually destroys a place in order to make a building site.

Wendell Berry
Harlan Hubbard: Life and Work

Asmodeus (genie/devil) speaks:
…Hell is heavily departmentalized, and no single devil…can know everything. We have an elaborate and rapidly growing Uncivil Service, composed of departments and sub-departments, bureaux and special committees of investigation, and all the apparatus of government. We are very busy…. The damned are kept busy, toiling away in rooms where there is only artificial light, and the only ventilation is entirely with conditioned air, doing all sorts of dismal jobs which permit them to pay the taxes that maintain the Uncivil Service…. The lake of burning pitch gave place long ago to a system of committees; every damned soul is a member of several interlocking

committees, and the worst of them have what they call working lunches, where they are made to devour bad food and drink disgusting coffee while discussing projects from which all hope has been drained away.

Robertson Davies, "The Perils of the Double Sign"
High Spirits: A Collection of Ghost Stories

Another thing that people with disabilities have revealed to me is their incredible capacity for creating community and bringing people together. Experience has shown that one person, all alone, can never heal another. A one-to-one situation is not a good situation. It is important to bring broken people into a community of love, a place where they feel accepted and recognized in their gifts and have a sense of belonging. That is what wounded people need and want most.

Jean Vanier, "From Brokenness to Community"

God Bless us, every one! Tiny Tim

VIEW FROM THE BACK WINDOW Just Catching Up

Scared by the ADA. Recently I was invited to go to a breakfast seminar about the new amendments to the Americans with Disabilities Act. Because the invitation was relayed by a close colleague and because I didn't know much about those changes to the ADA, I said I would go. I didn't notice until I got there that a) the seminar—held at a local country club—was sponsored by the Society for Human Resource Managers, and b) it was being taught by an attorney from a local law firm known for tending the employers' side (not workers' side) in labor relations. The presentation focused, not surprisingly, on the changes in the employment provisions of the ADA. In the context, I wasn't especially shocked to hear the attorney describe the revised ADA as "scary," and "sobering." At least four times in a 30-minute talk, he said that the ADA should now be thought of as the "Americans with Medical Conditions Act." Apparently he and at least some in the audience disagree with most people who have disabilities—and with the Congress and President of the US—about what constitutes a "disability." A long series of legal decisions had, in the opinion of many who care about the effects of disability (especially in the realm of employment), weakened the original intent of the act. So, Congress (with the support of the National Association of Manufacturers and the US Chamber of Commerce) restored the ADA as closely as they could to its original purpose.

Most of what I understand about the Americans with Disabilities Act (original or restored) I learned from ADA-Ohio, from *Mouth* magazine, and from friends like Jan and David Stewart in West Virginia. It's been said that one in every six North Americans will experience disability at some time in her/his life. If that's so (and even if it's not entirely accurate), then disability could directly affect the lives of 50-60 million people; if we were to count the families and allies of those people, the effects of disability could be felt by half of the population at any given time. Because we're part of a society that, at least in theory, values sharing and mutual assistance, accounting for the effects of disability ("accommodation") may be seen as part of our social responsibility, so that making room for everyone in our communities becomes, as Al Etmanski might put it "part of the water supply." That's my understanding of the purpose of the ADA. I guess that's vexing to at least some of my breakfast-companions at the seminar. And, it's "scary" to the attorney who presented his analysis. There's yet more work to be done.

Local "Deviancy Juxtaposition." The September 26, 2008 issue of the local newspaper announced that a new "mental health" service had been "unveiled" in our town. It's called "Community Behavioral Health, Inc." (CBH), and it's located in a former furniture warehouse that was bought by the local hospital and retrofitted to be "green." CBH is a subsidiary of the hospital. Besides the facts that the building is heated geo-thermally, that the lights in its rooms turn off automatically when people leave the room, and that the building "goes to sleep after 9:30 p.m." every day, the principal advantage about the building is its close proximity to the Butler County

Jail. That's because CBH's main customer is the local court system; in fact, the County "Department of Court Services," which administers the courts, occupies the other half of the newly green facility. The jail is a block away. The newspaper quotes the president of CBH, who noted that "…continuity of care will be fabulous." The "care" of which the CBH president speaks consists of "…treatment of mental health and alcohol and drug addiction." This whole enterprise was "unveiled" on the business page of the local paper, right next to the previous day's stock market reports.

It's hard to imagine any local citizen who has problems involving alcohol or drug-use or other problems-in-living showing up on his own to seek help at CBH. The powerful images of the court system and the jail will drive away any potential "clients" who are not brought there by way of the legal system. Many involved in "mental health" work say that STIGMA is the biggest problem faced by people who use "mental health" (the newspaper didn't buy the "behavioral health" euphemism in its story) services. If that's so—and I'm inclined both by temperament and by my experience with normalization to agree—then the developers of CBH didn't do any favors for people with "mental health" difficulties who live in our town.

Book Recommendation. In November 2008 Duke Divinity School's Center for Reconciliation brought together Jean Vanier and Stanley Hauerwas for a set of lectures/conversations on the topic "Living Gently in a Violent World." You can listen to the conversation on-line at: http://www.divinity.duke.edu/reconciliation/pages/programs/teachingcommunitiesweek08audio.html . At the same time, the Center for Reconciliation issued the Vanier/Hauerwas lectures in a book—similarly titled: *Living Gently in a Violent World: The Prophetic Witness of Weakness*. I think the book is more than worth its price.

Jean Vanier, founder of L'Arche, is probably well known to readers of *The Letter*. Stanley Hauerwas may be less so. Hauerwas is a professor (of theological ethics) at Duke Divinity School. He has written much in contemporary theology and has been named, perhaps to his dismay (my own supposition. JRP), as "America's best theologian" by *Time* magazine. (I have to wonder who came in #2.) Hauerwas has a gift for clarifying complex political and philosophical ideas, and that gift is on rewarding display in this short book.

Living Gently is a book about Christian theology and about a violent and divided world—divided not along religious lines but along lines of rich/poor, included/excluded, or "normal"/pushed-aside. Vanier and Hauerwas write about the work of L'Arche and its importance both to the church and to the world in which the church lives. Jean Vanier's simple words describe the mystery of L'Arche ("I never knew quite where I was going…but things started happening."). In L'Arche relationships with society's supposedly-weakest people transform all in those relationships and testify to the church's need to be with people who are on " the other side of the wall" so that the church can exemplify welcome in a world grown very dangerous to all.

Hauerwas sees the life of L'Arche as a critique of both a) the modern impulse to see weakness as a problem to be solved, fixed, cured and b) "liberal political theory" that identifies freedom as humans' ability to invent themselves—to make up their lives as they choose. After a clear but detailed discussion of the difficulties of modern political theory with regard to disability, Hauerwas concludes: "Long story short: we don't get to make our lives up. We get to receive our lives as gifts." And, it turns out, the gifts are at least partially given by each other in a politics of gentleness of which L'Arche stands as an outstanding example.

The book, again, is *Living Gently in a Violent World: The Prophetic Witness of Weakness* (Downer's Grove, IL: IVP Books, 2008).

Jack Pealer

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The Safeguards Letter

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THINKING ABOUT "NOT ENOUGH MONEY"

(Editor's Note. Money dominates all our current worries about services and systems: budget cuts, resource limits, wait lists, economies-of-scale, and on and on. I thought we ought to pay attention to another point-of-view about this before we lose all perspective. This piece is re-printed with the author's permission. Copyright: John O'Brien, Responsive Systems Associates)

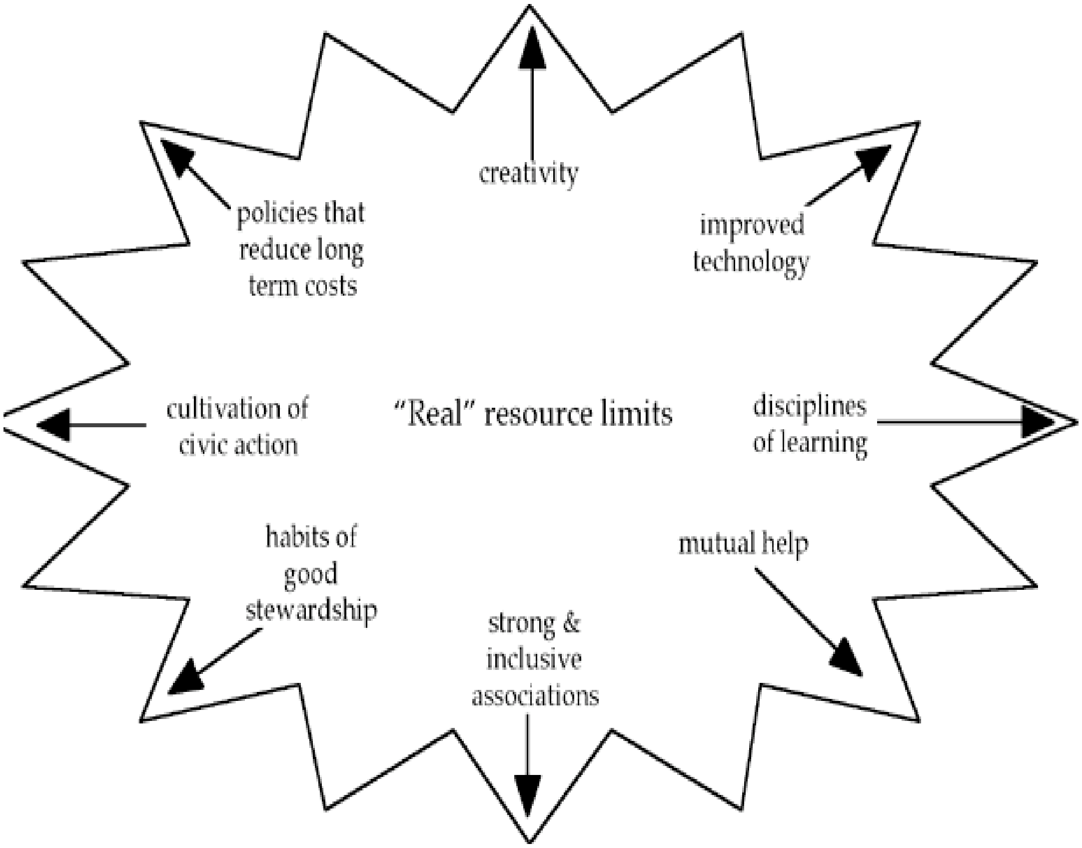
Those of us who work for inclusion hear a lot about "reality" from those looking for good reasons to discourage us. Many such discouragements involve the scarcity of money to pay for necessary assistance or accommodations. Belief in scarcity of money also justifies dominating people's lives in the name of "cost control" and denying the supports people need to participate in community life in the name of "prioritizing scarce funds to assure health and safety."

Few of us actually imagine limitless public resources, though control-seeking policy makers and their allies often accuse us of such fantasies. We know that the costs of honoring people's right to inclusion are both reasonable and offset by many social benefits. But we do need to think clearly about scarcity and act to overcome it's negative effects. In doing so, it helps to distinguish between "real" resource limits and scarcities imposed by policy. Both limits matter, but each calls for a different kind of action.

This diagram suggests the difference. The edge of the star represents such limits as the carrying capacity of the earth and the productivity of the local economy given multiple legitimate demands on natural resources, and public funds, and human energy. The edge of the box represents the scarcity created by the decisions of governments and officials in professional bureaucracies like schools and human service agencies. The area between the edges of the box and the edges of the star represents the resources people can claim to grow in by working "outside the box".

Because the policies that impose scarcities serve important social and political interests –such as minimizing taxation, or distributing wealth to the wealthy, or returning profit to nursing home investors or protecting the working conditions of union members or reducing contact with socially devalued people– the box will fight strongly and skillfully to protect itself. Change will come through organized political action in conflict with the powers the box serves.

Bracketing the *real* in "real" limits with quotation marks acknowledges the ambiguity suggested by this diagram: limits are *both* real *and* subject to purposeful efforts to push them back, such as the eight forms of action listed next to the arrows.



Most of these limit-expanding forms of action lie outside the power of policy makers to command. They lie within the power of groups of people with disabilities and their families and friends and co-workers and schoolmates and neighbors. Policies can create barriers or provide help to these kinds of actions, but people must engage one another in making the most of what is actually available to imaginative people who have the benefit of strong mutual support and access to necessary knowledge, skills, materials, and funds.

John O'Brien, 1999

The Safeguards Letter is an occasional publication of OHIO SAFEGUARDS. The *Letter* exists to promote affiliation among people who are interested in and thoughtful about those who live outside the sphere of respected community membership--those who are the usual receivers of human services. All material in *The Safeguards Letter* is under OHIO SAFEGUARDS' copyright (©) unless otherwise attributed. Letters, ideas, and items for publication in the *Letter* can be sent to: Editor, *The Safeguards Letter*, 3421 Dawn Drive, Hamilton, OH 45011 (e-mail: jackjr441@earthlink.net). We welcome our readers' ideas and reactions.

FUNDS TO SUPPORT PUBLICATION

For many years we have not recorded "subscriptions" to *The Safeguards Letter*—and we're not about to start doing that now. Instead of having subscribers we have had financial supporters--those people who saw some value in the publication of *The Letter* and who sent small donations of money to keep it going. The donations have paid for printing and mailing costs. Because we have started to make *The Letter* available on the internet, such costs are reduced. We don't expect, though, that we will entirely stop sending print copies to readers who do not use computers or who really prefer to have *The Letter* come on paper in their mailboxes. It costs about $140.00 per issue to mail the *Letter* to those who do not or cannot receive it on-line.

So, this little section of *The Letter* is an appeal to donors to send small contributions and to be, therefore, supporters of *The Letter*. If everyone who receives *The Safeguards Letter* were to send just a small amount, all of a year's costs for printing and mailing would be met. Also, donors receive the gratitude of OHIO SAFEGUARDS. If you want to contribute, you can send your donation (it's tax-deductible) to: OHIO SAFEGUARDS, 3421 Dawn Drive, Hamilton, OH 45011.

WHAT'S IN A NAME?

Employees of the state of Texas recently got caught—or caught themselves—on camera staging fistfights between men who live at the Corpus Christi State School. In an instant the state government snapped into action. On June 11, 2009 the Governor of Texas signed a law that rewards the state schools with millions of dollars in new state funds (to be matched, of course, with new Medicaid money). The new law also called for background checks and drug testing for all state school employees (they didn't do this before??) and the installation of surveillance cameras in many areas of the state schools. Maybe the newly-created "ombudsman" will spend her/his time watching the surveillance monitors.

Oh, by the way, the new law requires that what had been called the "state schools" now be called "supported living centers." You heard it first in Texas.

But, I think they've missed several opportunities. After all, why stop with the state schools? If you're going to actively employ euphemism, why not go further?

- Segregated schools where only students with disabilities attend could easily be re-named "Colleges for Intellectual Achievement."
- Behavior management projects could be called "Centers for Personal Mastery."
- Sheltered workshops or work-activity programs might be recast as "Technical and Industrial Development Centers."

Thanks, Texas. Now we have to find something else to call the phenomenon we've been usefully calling "supported living" for quite a while now.

Jack Pealer

JUST QUOTES

Forgiveness and celebration are at the heart of community. These are the two faces of love. Celebration is a communal experience of joy, a song of thanksgiving. We celebrate the fact of being together; we give thanks for the gifts we have been given. Celebration nourishes us, restores hope, and brings us the strength to live with the suffering and difficulties of everyday life.

Celebration expresses the true meaning of community in a concrete and tangible way. So it is an essential element in community life. Celebration sweeps away the irritations of daily life; we forget our little quarrels. The aspect of ecstasy in a celebration unites our hearts; a current of life goes through us.

Celebration is nourishment and resource. It makes present the goals of the community in symbolic form, and so brings hope and new strength to take up again everyday life with more love.

Jean Vanier, *Community and Growth*

It may be, then, that form serves us best when it works as an obstruction to baffle us and deflect our intended course. It may be that when we no longer know what to do we have come tour our real work and that when we no longer know which way to go we have begun our real journey. The mind that is not baffled is not employed. The impeded stream is the one that sings.

Wendell Berry
"Poetry and Marriage: The Use of Old Forms"

THE POWER OF RELATIONSHIPS—A 39-YEAR OLD STORY

This story was originally written in 2002, so when you read the time references, keep that in mind.

This morning, I got an e-mail message from a former colleague who worked as a "workshop specialist" (an old County Board title) in Delaware County when I was there more than 30 years ago. She said, in part:

"You might be interested to know that Earl, his roommate, dog, two birds and a couple of fish are now living in their own house! Earl needed an accessible home and one was obtained through the Habitat program. He says he likes this the best. He's doing great - he's very, very happy and his 73rd birthday is coming up May 8!"

Let's go back about 32 years. The Delaware County Board of MR (no "DD" then) learned—I can't remember how—about a man who had lived all of his 41 years with his mother, in a small, run-down house in a remote part of the county. His mother had died. He was being moved to the "County Home" to live. Would he be able, we were asked, to come to the sheltered workshop during the day? Someone went out to meet him (there were no "case managers" then). It turned out that he hadn't learned many, shall we call them "personal skills." He used the woods, I think, for a toilet, and he didn't change clothes too often. He had, however, learned from his family some colorful (bluntly obscene) ways of expressing himself. Our workshop director, who was the mother of one of the women who came to the shop, was not very happy with the idea that this man might be coming to work there. Once he was there, she was less happy that he might continue.

He learned more-acceptable personal habits rather quickly, with much credit to workers at the County Home. His conversational style continued, though. At the workshop, he met a young workshop specialist who not only took an interest in him but, I think it's accurate to say, fell in love with him. She didn't stay very long on the Delaware County staff because she moved on to other work, but she did stay in touch with Earl. She visited with him, took him out for meals, watched over his situation. She continued to involve him in her life, while her career advanced and she eventually moved into program management, in a neighboring county. She eventually helped him move into one of the county's early supported living arrangements. She stayed in touch, regularly, and has now done so for 32 years. The latest installment that I know of this story is above. Hats off to Earl's friend and to all those unknown (to me, anyway) others who have done as she has.

When I last visited Delaware in May 2008, I met Earl again. He's still enjoying his home, and his friend continues to be a major force in his life.

Jack Pealer

THE IRON CAGE OF BUREAUCRACY

Steven Taylor

(Editor's Note. This response to some silliness or other in services for people with disabilities appeared on a listserv in March 2009. I thought it apt, asked Steve Taylor for permission to print it, and he said yes. JRP)

In a classic work in Sociology, Max Weber referred to the "iron cage of bureaucracy"--the increasing trend in society for things to be determined by impersonal, "rational" rules and rigid structures. As disconcerting as groups like "Voice of the Retarded" (VOR) are, I don't think the major challenge to the full inclusion of people with disabilities in society is the old-time institution. The institutions are dying a slow death, although it's much slower than any of us would like. It's the increasing bureaucratic strangle-hold over the services and supports people receive. Our language has been co-opted, and rules ostensibly created to "protect" people are used to thwart human relationships. I could give many examples, but I'll mention just two recent ones.

First, there was recent media attention on the fire at a "group home" in Wells, New York that killed four residents with developmental disabilities. But that wasn't a "group home." We don't have "group homes" in New York State. We have what are called "Individual Residential Alternatives" or "IRAs." Concepts such as "individualized supports," "self-determination," "inclusion," etc. have become popular in the field-and rightly so. However, bureaucracies take this language and use it to refer to traditional service models.

Second, I'll tell a story recently told to me by a friend (I'll call her Mary) who has worked at a local human services agency for over 15 years. Mary had a family friend (call her Nancy) whom she's known since childhood. Nancy is 76 years old and felt a void in her life. She wanted to do something to help someone else. Mary introduced Nancy to Joan, a woman supported by her agency. Joan was lonely and said she wanted a friend. She has also been let down by other people. Nancy and Joan hit it off right away. But the agency decided that before they could have further contact, Nancy would have to undergo a police background check and be fingerprinted. This would take months. Can you imagine a 76 year old woman who has always been law abiding (and who was vouched for by someone who has known her since childhood) being asked to be fingerprinted to be a friend to a person with a developmental disability?

Now, I'm not against background checks in all circumstances. That's not the issue. The issue is that bureaucracies follow rules-not common sense or the dynamics of human relationships. I think that John O'Brien and Connie Lyle O'Brien wrote years ago that there has to be a way to waive the rules when they make no sense and interfere with human relationships. Things have gotten worse since John and Connie wrote this. Don't get me going. Then there's the example of the parent with a child with autism who wanted funding through "self-determination" and was told she had to prove that her child had a "circle of support." Now, we're implementing the "circle of support rule."

The iron cage.

Steven Taylor
Syracuse University

A VIEW FROM THE BACK WINDOW "Three Quotes and a Story"

Think with me about three quotes from my recent reading and a story or recollection of a meeting that I attended during the past few weeks. My theme is what these quotes and this story may have in common.

First Quote. My brain started churning when I read my friend Candee Basford's blog post called "a cautionary tale." Candee remembered that when her daughter was young someone asked her how old Katie was when she learned to walk. Her quick response was "She took 10 steps 9 out of 10 times when she was 18 months old." As Candee notes, that's not mom-talk. She observes:

> The nature of the service system and viewpoints about people with labels of disabilities constantly push or pull us into this client/provider—fixer of deficits direction. Soon, we begin to use the language of the system. The words we use begin to shape what we see, what we live now and in the future…. Disability professional-like observations and reporting—by the very nature of services and funding streams are based in a rehabilitation view that focuses on individual functioning (isolated) rather than interactions with others (relationships); it tends to be in professional language rather than ordinary words; and is usually NOT the language moms use….[1]

Second Quote. I've been reading Steven Taylor's new book about conscientious objectors during World War II and their organized (eventually) response to the mental institutions where many of them worked. Taylor's book reminds me that something happens on the inside of our services that changes them from what we intended into other things. Services are, of course, affected powerfully by the context (historical, political, social, etc.) in which they take place. Those of us on the inside can lose awareness of the changes, the effects of context. And that's when not-as-good things start to happen to people who use the services. In his study Taylor notes the effect of the institutional context:

> Patient behaviors that were defined in terms of individual pathology were often a reaction to the nature of the institutions themselves. The institutions created or fostered some of the very behaviors that were defined as symptomatic of some underlying mental disturbance and used to justify harsh and coercive measures. In the institutional culture, it was not morally problematic to do things to patients that would not otherwise be done to human beings, save those individuals convicted of crimes through a court of law. CO's, or at least many of them, were part of this culture. It was not as though they could have or should have let mayhem reign on the wards of the mental hospitals and training schools. It was that moral human beings often could not see the immorality of a system in which coercive methods were the only ones available.[2]

The context of services can place limits on our responses. We often can't see those limits.

Third Quote. I confess that my reading of professional journals is usually confined to the abstracts of the articles. The abstract, though, of Philip Ferguson's recent study of parent-professional relations in early 20th century institutions compelled repeated reading. Here is a set of quotations from that article:

> Parents of children and young adults with disabilities have always had a complicated relationship with the professionals in medicine, education, and other fields who <u>claim</u> (*emphasis added, JRP*) special expertise to help, or even

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[1] Candee Basford. "A Cautionary Tale" (blog post), *World of Possibility*, http://candeebasford.wordpress.com , April 23, 2009.

[2] Steven J. Taylor, *Acts of Conscience: World War II, Mental Institutions, and Religious Objectors* (Syracuse: Syracuse University Press, 2009), pp. 222-223.

> cure, their offspring. On the one hand, the families are often grateful for whatever help and support they can find. On the other hand, they equally often end up expressing a desire for more or different types of help than they find available.[3]

From a 1913 letter by a mother to the superintendent of Oregon's "State Institution for the Feebleminded":

> Would you please let me know how my little boys are? Is Frank well and contented? Or does he seem to miss me? Does Lee take any interest n his surroundings? I do so hope they are well and happy. Please tell me just what you think of them.
> It was very hard to send them away but Mr. and Mrs. H. gave such good reports of your home that I am trying to be contented. I hope to hear from you soon.

The Superintendent's reply:

> Your sons are well and contented. They have been here such a short time that we have had no chance to study them yet. Will let you know should either one of them get sick. Please enclose addressed stamped envelope when writing for information.

The outcome, according to Ferguson: Less than 1 month later, Frank was dead. The superintendent wrote the mother again: "Frank died this morning at 10:50. Please let us know what disposition you wish of the remains. I sent it to Lehman and Clough undertakers."[4]

> Rather than a response to pressure from families, the emergence of increasingly specialized and segregative programs and services was in large part a professional initiative. Indeed, professionals devoted much time and attention about how to overcome the active resistance of parents to letting their children attend these programs…. Finally we are left with a portrait of parent-professional relationships from this era that is, in many ways, strikingly similar to that described by current generations of families.[5]

And now a story: A young woman, just out of high school, and her mother enter a human service agency office. They are greeted warmly by the professional people in the room, who are there to listen to and speak with them about assisting with the young woman's search for a good life after high school. The young woman (call her Veronica) and her mom are focused and organized. They have lots to say. One of the professional people asks Veronica about her goals—her ambitions—the interests she wants to pursue. Veronica says that she has long wanted to have work or a career in either the performing arts or in biological research. Her mom confirms that Veronica has spoken extensively about those interests. Veronica says she wants to go to college. She wants to earn some money to pay for her education. The professionals nod and smile in understanding and encouragement. Then, one professional (OK, it was me) offers Veronica a chance to explore her future through structured long-term (person-centered) planning. Another smiles again, gently, and offers her a job as an aide in a local nursing home, and passes the job-application forms across the table to her.

Was anyone listening? It's not that work in a nursing home is dishonorable. It might be enjoyable at times and might contribute to Veronica's wish to earn money for school. It's just that it's so far removed from the ambitions and interests that Veronica had just revealed. The offer had the feeling of something "at hand"—available—to be presented regardless of what Veronica said. It's not that person-centered planning is the wrong thing to do. Many have witnessed its

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[3] Philip M. Ferguson, "The Doubting Dance: Contributions to a History of Parent/Professional Interactions in Early 20th Century America," *Research & Practice for Persons with Severe Disabilities*, 33, 1-2 (Spring-Summer 2008), p. 48.

[4] Ferguson, 54-55.

[5] Ferguson, 57.

power to reveal visions and set direction for people. In this instance, such planning might help to solidify ambitions and make them clear to others who hadn't heard about them earlier. It's just that Veronica had described her goals; she and her mom were clear about where they wanted to go and had already taken some steps in helpful directions. The offer of person-centered planning seemed, like the job offer, an off-the-shelf response in a conversation that was intended to be about personal design.

Think with me. How much do professionals know—about what they profess to be able to do and about the person whom they're expected to help? How are families with members who have disabling conditions affected by the aura of professional knowledge? What's obvious to me from the quotes and story above is that the centrality of these questions has not changed since the early days of "developmental disability" services. Yes, the institutional superintendent cited by Philip Ferguson used raw power over families in the confidence that was the right thing to do, for individual children, for families, and for society. But Veronica's story and Candee Basford's memory tell us that power need not be raw to be real. Somehow the human service setting or context drives those of us who are professionals away from the individual and into that which we think we know. If we're not paying attention, we can find ourselves, like the CO's in World War II era mental institutions, blindly doing or saying things that violate our own sense of what is right. Listening and humility—not bad things for us to practice.

Jack Pealer

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THE SUMMER PASSED SO QUICKLY

Jack Pealer

Just yesterday I planted tomatoes, peppers, and eggplants. The bloom just dropped from the pear trees. The other day I mailed out the "very late spring" issue of *The Letter*. And now I look out the window and see the leaves all down, the winter birds at the feeder, and I'm stunned that I seem to have missed the summer. Well, I didn't really miss it. There were trips taken, surgeries prepared for, a great gardening season with more and better green beans than we've ever seen. And pears! Who knew that those once scraggly trees would yield so many large golden fruits? We're still taking them in lunches or baking them to eat with vanilla ice cream.

But the part of the summer I did miss was *The Letter*. So, this issue that was meant to be in your hands in the summer now has to bear the designation of autumn. Guess that's not a too-bad thing. I hope for forgiveness.

FOR HER OWN GOOD

Julie Pratt

Author's Note: When I moved to West Virginia twenty years ago, the state was dramatically downsizing its institutions for people with mental illness and developmental disabilities. Triggered by two class action lawsuits, the state reinvested its resources in an impressive community-based service system. Now, as the economy falters, community programs are hard pressed to maintain their services and admissions to the state hospitals are on the rise. As we move precariously close to repeating the mistakes of our past, the story of my great aunt Claire weighs heavily on my heart.

Claire sat on a straight-backed chair wedged between her dresser and nightstand. Her head was bent forward, with eyes fixed on the hands folded in her lap. She wore a blue wool dress, a string of pearls, and black, lace-up shoes with thick soles. Her alabaster hair was cut short and set in soft curls. An overcoat and worn leather pocketbook lay neatly on her bed. In another bed a few feet away, a bony woman lay under a thin blanket, curled in a fetal position, sighing with each exhale.

"Hello, Aunt Claire," I said softly from the doorway. "It's me, Julie – Betty's daughter, your brother William's granddaughter."

"Oh, yes… Julie." she said, as fragments of memory reunited in recognition. She smelled of Chanel No. 5 as I bent to kiss her cheek. The rubber soles of her shoes squeaked as I helped her to her feet. Her movements were slow and stiff as she slid her arms into the sleeves of the coat I held open. I breathed deeply when we finally escaped the Lysol-tainted halls of the nursing home into the cold night air. I drove through light snow to the Capitol square, where the streetlights were bedecked with pine boughs and tiny white lights.

"Mother loves Christmas," said Claire. "Will she be joining us?"

"Not tonight," I said, for my great aunt's mother had been dead for more than thirty years.

I pulled into a parking space in front of the Concourse Hotel. On the tenth floor, the restaurant host greeted Claire by name as he led us to a table by the window, the one where she ate dinner with her sister once a month. Claire would send me detailed accounts of these outings, along with verbatim excerpts from letters she received from other relatives. It was like a family newsletter. It worked beautifully as long as you understood that anything you wrote to Claire was subject to publication.

My great aunt had a lot of time to write letters. She'd spent the last sixty-eight years of her life in institutions.

~

I first met Claire on the Saturday before Christmas in 1960, when I was in the first grade and she in her mid-fifties. Claire was living at the county home, a rambling, turn-of-the-century brick building nestled in a stand of gnarled oaks. When we reached her room, I proudly presented her the plate of cookies I helped my mother make, cut in the shapes of bells and reindeer and slobbered with icing and colored sugar.

"Oh, how kind of you to bring me these," Claire said warmly. She took the messy plate and set it on her dresser, next to a two-pound box of Russell Stover chocolates.

"Here," she said as she lifted the cover from the box. "Won't you have a piece? My sisters always bring me chocolates for Christmas. A big box so I can pass it to the staff."

Then, from her top dresser drawer she took a flat package wrapped in a paper bag from a Hallmark card shop. Almost shyly, she handed it to me. Inside the bag were two pillow cases she'd embroidered. I thanked her as I ran my fingers across the intricately stitched bouquets.

"Please have a seat and make yourself at home," she said, brushing her hand across my hair. I sat with my mother on the bed, while Claire and my father sat in two chairs by the window. Her private room overlooked the county home's expansive lawn. Just beyond lay freshly painted barns and white fields textured with the stubble of corn stalks. It had been the county poor farm during the last half of the nineteenth century, when indigent and homeless people came here to earn their keep. Now the farm had been recycled for people with mental illness, staffed by employees and residents to provide milk and eggs and summer produce for their meals.

"Oh, yes, I helped make the decorations," Claire said when my mother commented on the Christmas tree we'd passed in the lobby. She told us about the carolers who had come out from a nearby elementary school the week before and about signing up to help serve dinner on Christmas Day, since she and her sisters always celebrated on Christmas Eve.

Our visits continued twice a year throughout my childhood, one in December and the other in July for her birthday. I imagined Claire's life as that of a nun, satisfying in its own way, separated from the world by choice. Though her mental problems were invisible to me, I didn't question the adult explanations that she needed "special care." Or why she had to live at the county home in order to get it. Or why mentioning Claire's name in front of my grandfather made his body stiffen and made my mother start talking about the weather.

One fall afternoon when I was in junior high school, I saw my grandparents' Chevrolet in our driveway as I turned onto my block after school. My grandfather began backing the car out when I was just three doors away. I waved both arms as I ran toward them, but the car kept moving. My grandmother gave me a nervous wave as she rolled up her window. Then I noticed movement in the back seat – Claire pressing her hand to the glass as I disappeared from her view.

~

I remained an all but silent bystander in Claire's life until 1976, when I took a college course on mental illness. I read study after study that challenged the efficacy of treatment in psychiatric institutions, as well as the denial of people's civil liberties. I didn't make a conscious connection to my great aunt, but when my professor suggested I do my research project at the county home, I eagerly agreed.

My task was to make sense of hundreds of pages of follow-up notes on what happened to residents who had been deinstitutionalized during the previous decade. I discovered that during the first few years a troubling number of the people had returned to the county hospital. Most had little experience living beyond the rigid routine of institutional life. They were often dropped abruptly into the foreign landscapes of boarding houses or group homes, where low-paid, poorly trained staff could do little to break their fall. But as community programs and pharmacology improved, people's success rates grew sharply. By the time of my study, it was unusual for someone to come back to the county hospital other than for a brief stay to weather a crisis or adjust medications.

I wrote by hand on ledger pages the names of the people and what had happened to them. As the files testifying to their lives piled up on the table where I worked, so did a mounting sense of iniquity. I became haunted by the question of why the name of my sweet and gentle great aunt was not on the list. People with problems far greater than hers had made it on the outside. Why had she never been given the chance?

The project supervisor was a veteran social worker, an unflappable woman who'd spent much of her career helping people get out of this place and back to their own communities. But she could tell me little about Claire, since my great aunt wasn't part of the study. She did offer a clue late one afternoon, though, as I closed my last file for the day.

"Your great aunt isn't legally committed to this facility," she said. "She's here voluntarily – technically, anyway."

~

Over the years, I've tried to puzzle out what happened to Claire back in 1925, weaving together fragments of stories I've heard about her life, her occasional letters to me, and what I've learned as a social worker about mental illness. My partial and imperfect understanding begins with the black and white studio photograph of a teenaged Claire that I found in a family album. Her light, wavy hair was gently pinned up on top of her head. She had a pretty, slightly rounded face and a playful, seductive smile.

Claire attended the University of Wisconsin at Madison with plans, most likely, to be a teacher. Her parents were disciplined and pragmatic Midwesterners, who would have expected her to support herself – until she attained the ultimate goal of marriage. This would be to a man deemed suitable, one who was similarly educated, preferably a Democrat and non-negotiably a Protestant.

The official family version of Claire's illness began with her "acting strangely" at the beginning of her sophomore year. Her sisters overheard her talking in her bedroom to people who weren't there. She accused her parents of meddling and spying when they inquired about school or her friends. In one semester, her grades dropped from mostly As to all Cs. At a family gathering that winter, she became uncontrollably hysterical for no apparent reason, yelling accusations at family members and slugging one of her sisters. On the advice of the family doctor, she was admitted the next day against her will at a state psychiatric hospital to determine the cause of the problem.

How much of what was to follow was a response to bona fide mental illness? Twenty is a common age of onset for schizophrenia, after all, and the stress of college life a plausible trigger. But so little was known about mental illness at the time. The term "schizophrenia" – Greek for split (schizo) mind (phrene) – had been coined only a decade before. Psychiatrists had catalogued its common symptoms – hallucinations, paranoia, disorganized thinking – but had little to offer in the way of treatment.

But there is another dangling clue that still haunts me. My mother, who was born four years after Claire's hospitalization, recalled whispered conversations during her childhood about a Catholic beau whom she had refused to give up. If Claire's father was as headstrong as his son, William, he would have done everything within his power to prevent their union. I think of the hundreds of accounts of rebellious women getting locked up in psychiatric institutions back then. Had Claire's confinement been as much about controlling her as it was about treating her?

I shudder when I imagine what happened to her, given the state of psychiatry during the first half of the twentieth century. She would almost certainly have experienced the claustrophobic terror of strait jackets and, later, the chemical restraint of mind-deadening drugs. She likely had electrical jolts applied to her skull that caused her entire body to convulse. She could have been subjected to involuntary sterilization, a common practice of the eugenics movement, whose advocates aimed to cleanse the society of what they deemed undesirable traits.

I would like to imagine otherwise. But such treatment was considered state-of-the-art care for mental illness. Claire spent her young and middle adulthood in the self-contained world of the county mental hospital, with occasional day trips to family gatherings. Claire's letters to me contained detailed accounts of her various jobs in the kitchen and laundry until the 1970's, when new state regulations required that patients be paid minimum wage for the work they did. Most of the patients, including Claire, were "laid off." After that, she spent long hours in her room, embroidering and crocheting in rarely broken silence.

~

Five years after my college research project, another social worker at the county home called me about my great aunt. After years of downsizing, the home was going to close altogether, she said. Perhaps I'd like to be involved in helping plan for Claire's move to a new place.

Perfect, I thought, because by then I worked for the county agency that funded group homes for people with mental and physical disabilities. I offered to arrange some tours for Claire to see them for herself.

A week later, Claire and I pulled into the driveway of an attractive one-story brick home, a block away from a small shopping center with a Hallmark card shop and sewing goods store. A forty-something woman named Linda answered the door. Unlike the hospital scrubs worn by the aides at the nursing home, she was dressed in blue jeans and a pink blouse dotted with tiny roses. She led us into the spacious living room, furnished with a couch and matching chairs. A man in his eighties sat in a recliner, reading the newspaper through a magnifying glass.

"Harvey, this is Claire," Linda said. "She's here for a tour."

Harvey looked up, smiled and nodded, and returned to his paper.

In the kitchen, another staff person was rolling out biscuit dough on the kitchen table. A woman about Claire's age was helping from her wheelchair, cutting circles in the dough and placing them on a cookie sheet. Mary introduced us, but my great aunt said nothing. Her eyes were fixed on the two women kneading and rolling and cutting. I gently touched her shoulder.

"I used to make biscuits with my mother," she said.

Mary led us down the hall to a room with a twin-size bed, a dresser with a mirror, and a small desk and chair. The walls had a recent coat of pale coral paint, and a window looked out onto a patio with large pots of red geraniums.

"We encourage people to bring as many of their own things as they like," Mary said. "If you have furniture you prefer, we'll move what's here to the basement. Feel free to hang your pictures on the wall, and bring a radio or tape player if you like music. We want people to do whatever they'd do in their own home, as long as it doesn't disturb others."

Claire sat on the bare mattress and looked around the room. I was dying to know what she felt about all this, but her expression betrayed no emotion.

"Do you have any questions, Claire?" Mary asked. "Anything at all you want to know about us and this place?"

Claire paused, then said politely, "No, I don't, but thank you very much for the tour."

Claire remained silent as we walked to the car.

"What do you think about this place?" I finally asked.

She took a few more steps, eyes on her feet, then stopped and looked up at me.

"It would be nice to live in a home again," she said.

For the first time in our relationship, I felt a grown woman's connection to my great aunt, an empathy that transcended pity. My heart hurt from my new understanding that, while Claire's life had been vastly different from mine, we had the same human desires.

"I'll do everything I can to make that happen," I said, as I opened the car door for her. We talked only a little on the way back to the county home. I was elated by the notion of Claire living at the group home. But I took care to not be pushy. Both Claire and her siblings would need time to get used to the idea. My grandparents had moved to Florida by then, and I suspected my grandfather would defer to his sisters.

I remembered that her sisters had objected to a proposed move once before. But now that the county home was closing, Claire would have to move somewhere. So why not a real home where she would also get the care she needed?

~

A few days later, I was summoned by the county home social worker to a "family conference." When I walked into her office, I was greeted by the stiff smiles of Claire's three older sisters.

"We know you mean well," said Catherine, the oldest. "But this is none – I repeat, none – of your business. Claire is our sister and our responsibility. We are going to make arrangements for her to be transferred to a private nursing home, where she will get the close medical supervision she needs. You must understand that we are doing this is for her own good."

"But she doesn't need to live in a nursing home to get the care she needs," I argued. I put forth all my best arguments. I was considered an expert in this field, after all. I'd testified in a dozen court cases related to deinstitutionalization. I'd worked with county social workers and nonprofit agencies to develop group homes like the one that Claire and I visited. I knew the people who inspected them and could get someone out there immediately if I suspected that anything was amiss.

I may have been only thirty years old, but I had a lot more training and experience in this area than they did, it seemed to me. Unfortunately, my social finesse fell quite a bit short of my professional expertise. Nor was I able to be any more objective about Claire than they were. I'd been a passive witness to the injustice committed against her, and I was determined to make things right.

The longer I talked, the wider the divide between us grew. I left the meeting contemplating the alternatives. Claire didn't even come close to meeting the definition of mentally incompetent. Legally, she had the right to live wherever she wanted. The sisters might try to petition for guardianship, but I worked closely with the county attorney who specialized in this area and felt reasonably sure that we could block such a move.

I stopped by Claire's room while her sisters dictated their instructions to the social worker. Claire was sorting through her large collection of needlework and packing the pieces carefully in a cardboard box.

"What do *you* want, Claire?" I asked as we sat next to each other on the bed.

"I'm going to move to another nursing home," she said. "It's for my own good. My sisters know what's best for me."

I willed myself to be silent while I reined in the urge to throw a chair through her window. I told myself that this wasn't about what anyone else – including me – thought was best for her. It was about making sure that she had a choice and that her decision was honored. I gently probed a little more. I invited her to consider other possibilities, like the group home we visited.

"My sisters know what's best for me," she said louder this time, as she sat straighter and stiffer on the bed. "You don't know me like they do."

She was right, of course. Her sisters knew her as a psychiatric invalid who needed protection. I saw her as an older woman who lacked experience, not capacity. But I understood that her bond with her sisters, however oppressive, was far stronger than her trust in me. After years of institutionalization, her urge to comply was more powerful than her desire for freedom. The only way I would be able to get her into that group home was to abuse the very rights I was trying to uphold and place her at odds with the family members she relied on most.

Within a couple of weeks, Claire and her three boxes of belongings were delivered to the Colonial Manor Nursing Home. I spent the next ten years channeling my energy into doing for others what I'd been unable to do for my dear great aunt. In Wisconsin and later West Virginia, I worked in a movement that liberated hundreds of people with disabilities from nursing homes and institutions. It would become painfully clear how my own profession had been complicit in sending people away in the first place, with the promise of "special care" and the rationalization that it was "for their own good." Despite the good intentions of many families and professionals, what most people experienced was marginal custodial care. At its worst, the care was substandard and even cruel. In all cases, it robbed people of their human dignity and rights.

Claire spent six years in the private nursing home. I continued to send cards and notes after I moved to West Virginia, but she could no longer hold a pen to write a response. She outlived three roommates and most of her siblings. My parents were among the six people at her funeral, held a few days after Christmas the year she turned ninety-two.

Julie Pratt, Charleston, WV

The Safeguards Letter is an occasional publication of OHIO SAFEGUARDS. The *Letter* exists to promote affiliation among people who are interested in and thoughtful about those who live outside the sphere of respected community membership--those who are the usual receivers of human services. All material in *The Safeguards Letter* is under OHIO SAFEGUARDS' copyright (©) unless otherwise attributed. Letters, ideas, and items for publication in the *Letter* can be sent to: Editor, *The Safeguards Letter*, 3421 Dawn Drive, Hamilton, OH 45011 (e-mail: jackjr441@earthlink.net). We welcome our readers' ideas and reactions.

JUST QUOTES

Since I started writing this column snow has begun falling again; I sit in my room watching the re-enactment of this stagy old phenomenon outside the window. For this picture, for this privilege, this cameo of New England with snow falling, I would give everything. Yet all the time I know that this very loyalty, this feeling of being part of a special place, this respect for one's native scene—I know that such emotions have had a big part in the world's wars. Who is there big enough to love the whole planet? We must find such people for the next society.

E. B. White, *One Man's Meat* (1941)

Living in *L'Arche* with people who have an intellectual disability has made me realize how important it is to help them rediscover their own personal histories. Because they have often been rejected and seen as different, they tend to feel as though they do not belong to human history. Since they have been deprived of intellectual means and are not integrated into the usual networks that others around them take for granted, they have few reference points for their own personal histories. It is as if they had no past. Birthday celebrations provide a chance to emphasize certain stages in their lives, highlight their gifts, laugh about their faults or failures, and celebrate each one's unique gifts.

Jean Vanier, *An Ark for the Poor*

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

"On Bedbugs"

I'm just back from another discussion about bedbugs. Bedbugs have come to love life in the Ohio River valley, after a long period of time when DDT and other now-useless poisons kept them away from most folks' awareness. Now, though, we hear about them a lot. I think they like it around here because they're attracted to places where people also have many sinus problems, and we sure have those. Anyway, bedbugs add to the local craziness. Our worries include H1N1 of course. Last week more than 11,000 people gathered in the rain at the local fairgrounds—long lines of cars and people, police directing traffic on a dim-grey October morning—to get the first H1N1 vaccinations. That's many more people than ever come on a single day to July's county fair. We're worried folks these days.

But, back to bedbugs. We've been getting lots of guidance about what to do about them. Some of it contradicts others; it's a little like listening to stock market advice. Most of the guidance points to ways to keep from picking up bedbugs or their eggs from one place and carrying the bugs or eggs to another place—especially one's office or one's home. The places where it's suspected that bedbugs might be found include the homes of some of the people or families we support. So the guidance is about how I should act when I'm in those places. I should, for example, refrain from wearing pants with cuffs so there would be no place for the bugs to crawl inside and hitch a ride. All my pants have cuffs. I should consider wearing plastic booties to cover shoes, as well as (sometimes) plastic gloves—usually for entirely different reasons. I should not use a laptop computer because the bugs may be attracted to the heat. And so on. All of these are reasonable suggestions, because service-workers, including me, are horrified about the possibility of bringing bedbugs home. One Saturday last summer I spent a couple of hours weeding the garden. The next day I had lines of insect bites across my shoulders and back—presumably from mosquitoes or grass fleas. I spent the next several days quietly (without saying anything to anyone) inspecting mattresses and other furniture, looking for bedbugs, afraid of what I might find. I was potentially disgusted with myself.

And I've been thinking about that. People with disabilities have always been poor. Bedbugs, and other creatures we call pests, have always lived closely around poor people—in the places where poor people can afford to live and from which richer people have been able to absent themselves. So, bedbugs are associated with poverty. It's likely that, in the eyes of wealthier people, to have bedbugs in one's home, on one's body, on one's clothing is to be one of "them"—the poor ones. That implicit identification—what bedbugs might say about me—is why I was frantic about the insect bites on my back and shoulders. And that anxiety is a sign of my distance from people, which is not at all a good thing for someone who thinks himself devoted to doing something useful about disability or poverty.

After all, the way we've evolved to offer support to people with disabilities requires our presence. Many have worked for years or even decades so that children with disabilities could remain and thrive with their families or so that people with disabilities could enjoy life in their own homes. But supporting people or families in their own places means we have to be there with them—that we have to share and identify with their situations. And bedbugs sure make us think differently about the conditions under which such sharing happens.

Anxiety about whom one may be seen to be "like" has always been an issue for those trying to help poor people, but it hasn't always been true that the servers sought identification with the wealthier ones. At one time all, or nearly all, of those who offered service to poor people were as poor—or nearly so—as those they tried to help. Wolf Wolfensberger, in his lectures on the history of human services, tells us, for example, that Christians—from the early days of the church until the end of the Middle Ages—were moved to serve others by their apprehension of the "hidden Christ" within poor and afflicted people. This image of the hidden Christ emerges from two places in the New Testament. Matthew records Jesus' words to his disciples just days before his death. His description of the last judgment turns on whether a candidate for membership in God's kingdom has responded well to someone who was hungry, thirsty, homeless, or imprisoned. Within those afflicted ones, Christ is hidden. Jesus says: "I tell you solemnly in so far as you did this to one of the least of these brothers of mine, you did it to me." (*Jerusalem Bible*) And the book of Revelation holds up the image of Jesus as the stranger knocking at the door: "If one of you hears me calling and opens the door, I will come in to share his meal, side by side with him." (*Jerusalem Bible*) Dr. Wolfensberger's point is that regard for Jesus' presence within lowly people moved the faithful toward service—and toward a serving style that recognized the hidden one and acknowledged acts of helping as <u>privileges</u> for the helper. So, it was possible and customary for servers to be grateful—often exceedingly so—to those who allowed them to offer service.

But servers in the Middle Ages aren't the only ones who see purpose in presence with and gratitude toward the ones they serve. Consider the recollection of a Catholic Worker, mentioned off-handedly in a recent "house column" in the newspaper, *The Catholic Worker*: "I remember sleeping on the roof last summer to get a break from the heat and the bed bugs. In the morning, I was awakened by the smell of soup, and it was such a pleasant smell so early in the morning." (J. Breen, "St Joseph House," *CW*, August-September 2009) He says "to get a break...." He doesn't say he's horrified or anxious about the heat and bugs. Or consider the words of Jean Vanier (in *Community and Growth*):

> I am drawn to the communities whose roots are in the poorest neighborhoods, which welcome those who have been deeply wounded, like alcoholics, people just coming out of prison, young people lost in drugs, delinquents or people with mental illnesses. There is not always much joy and fun in these communities, but there is great fidelity and acceptance of woundedness. The faces of the people who work in them are lined with fatigue. But in these communities we feel the presence of God, who is close to the most rejected and wounded people of all.

These portraits of servers honoring the lowly seem to me, who worries about bedbugs, contrary to one understanding of human nature (man as self-protective, self-interested being). These stories reinterpret service from self-aggrandizement into thanksgiving. I hope, when I personally encounter bedbugs, I'll be able to stand it with the equanimity and humility of a J. Breen or J. Vanier.

Jack Pealer

OHIO SAFEGUARDS
3421 Dawn Drive
Hamilton, OH 45011

The Safeguards Letter

A Publication of OHIO SAFEGUARDS

Number Forty-eight *Winter 2010*

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, March 22 through Thursday, March 25, 2010.
- Location: Blessed John XXIII Pastoral Center, 100 Hodges Road, Charleston, WV
    - *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.

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 **$200**. This includes handouts, refreshments, and 4 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) Deadline for registering is February 15, 2010—but it's possible that places may be available up until the beginning of the workshop.

WALKING BAREFOOT

(Editor's Note. I watch for good writing. Nancy Stranahan, author of the essay that follows, is co-founder of a project now called "The Arc of Appalachia"—which has nothing to do with what readers familiar with disabilities usually think about when "The Arc" is mentioned. This arc is a metaphor for a stretch of forest from Chillicothe, OH, where I used to live, to or even across the Ohio River near Maysville, KY. Supporters of this arc envision an eventual return to mostly wildness of the Eastern temperate forest in that area. I was captured by this little "winter" reflection and offer it, with Nancy Stranahan's permission, as a gift to readers. JRP)

The wild turkey lifts her foot. For a moment she suspends it gracefully in the air, toes relaxed and drooping. With a quick flex and twist of her foot, she flicks off a bit of snow. She cocks her head thoughtfully, and then in slow motion, her four-toed foot presses upon the ground until fully extended, once again regaining full contact with earth. A white tail deer stands frozen, wide-eared listening, with three legs on the ground and a fourth cocked in the air. The moment passes and she flicks her ears, swishes her tail, and nervously licks her lips. Gently her leg drops, her black hoof reaching for the earth; glistening like warmed, polished walnut wood. As it bears her weight, her two toes spread apart in the mud, leaving an impression on the ground in the shape of a heart. Each footfall is controlled, yet soft in surrender. A kiss-press against the earth, and then a release.

With our footfalls we forge our relationship with our planet. Below our feet lies only six inches of life-teeming microbial-drenched humus-laden soil. Not much farther below, our world becomes non-living elementals--minerals and water wrapped around a distant core of molten fire. Above us, a thin blanket of air, and then an infinity of empty space: the eternal black void, dusted with far-flung suns and galaxies. We live in the thin place in between, middle earth, a tender skin of life as delicate as a skim of algae floating on the surface of a pond. How improbably compressed is this veneer of life, this rare marriage of sunlight and earthdust. Only where the two realms merge, mineral and sunlight, does fecund life find birth, the miracle child, eternally struggling to reconcile its parents. The animals align their spines parallel to both realms, listening to gravity with their bellies, feeling the sunlight on their backs. Only human beings, … and trees, stand completely erect. Rooted to the earth at one end, our crowns sway in the clouds at the other. Our bodies serve individually as cosmic compasses, one pole pointing to the center of the molten earth, the other pole to a distant star. Our relationship to the universe swirls in our sun-drenched thoughts, sings in the blowing winds. Our relationship to the earth zings through our heels, springs through our toes. Our ecstasy and despair, our holiness and half-heartedness, all pour into the footprints of our lives.

Yesterday I walked in the freshly fallen snow at the Highlands Nature Sanctuary , in front of Tsalima Cave. It was early morning, and no car tracks yet marred the road's snow-smoothed surface. On impulse, I took off my shoes and and placed my feet on the fallen snow as carefully as the turkey hen, following the tracks she left earlier that morning, stepping across the sure-footed heart-prints of a deer. I walked until my feet burned with the cold, and my heart burned with wisdom flowing upward through my soles. Behind me I left melting tracks in the snow, strangely juxtaposed human prints with arched insteps and ten nearly linear toes, footprints that joined the weaving tapestry of footfalls left by friends of hoof and scale.

Surely some of the answers we seek are beneath our feet.

Nancy Stranahan
"Woodland Sprawl "
E-Magazine for the Arc of Appalachia Preserve System
December 2009
http://www.highlandssanctuary.org/

The Safeguards Letter is an occasional publication of OHIO SAFEGUARDS. The *Letter* exists to promote affiliation among people who are interested in and thoughtful about those who live outside the sphere of respected community membership--those who are the usual receivers of human services. All material in *The Safeguards Letter* is under OHIO SAFEGUARDS' copyright (©) unless otherwise attributed. Letters, ideas, and items for publication in the *Letter* can be sent to: Editor, *The Safeguards Letter*, 3421 Dawn Drive, Hamilton, OH 45011 (e-mail: jackjr441@earthlink.net). We welcome our readers' ideas and reactions.

A FEW THOUGHTS ABOUT ILLICH, FRIENDSHIP AND COMMUNITY[1]

For essentially all of my adult life, I would most fairly be described as a liberal, even as an ultra liberal. I have always thought that the proper role of government was certainly to "promote the general welfare" and that would include a variety of "public goods" such as health care and a several other services that would provide a decent floor below which no one would be allowed to fall. As Gandhi said it, "The world has enough for everyone's need, but not for everyone's greed." So if that is true, then we should be able to set a reasonable floor.

But over my life, I have also been very fortunate to hear and meet some very distinguished people. Ivan Illich was one of them. One of my most vivid memories was of Illich speaking to a gathering of our staff from the Georgia Advocacy Office early one morning. Illich spoke for some time while a selection of breakfast pastries kept calling our attention. Finally catching the eye of one of the staff who used a wheelchair to move about and who was slowly inching toward the tray, Illich seemed to realize what the group was really attending to. Without a break in his talk, he scooped up the tray of goodies and walked offering each person in turn a chance to have a pastry. There was a sense in the room that we now understood the sharing of bread and wine in a much more direct sense. Possibly we had witnessed a form of service that was brought about, not by a program, but by a "citizen" attending to our needs.

Now the sharing of pastries does not negate the need for all forms of services, nor eliminate the role of government in attending to the common good. It does, however, point us to ponder just what problem we are confronting, how it might be resolved and just what might compound our difficulties if we choose one solution over another

Let me start with another story. I do that because stories, not data, are the heart of community. The story is about 2 people living in Valdosta, Georgia where a citizen advocacy match had been established between a very capable woman with a good income, 2 fine children and what she believed was a great marriage, and a quite handicapped man with limited movement, difficult communication and who had lived most of his life in a nursing home. The woman visited the man very regularly, taking him things to make his life more comfortable, advocating for better attention to his daily needs in the nursing home, and talking and listening to him as friends often do for one another.

Over a few months some very challenging things happened to this woman. Her marriage fell apart; her children were in distress, caught between their parents; her economic situation changed for the worse and she was struggling to stay above water. When she visited the man in the nursing home, she seemed distracted and somewhat distant. When asked by the man what was the matter, she answered "Nothing." But one day, the man pushed hard for a real answer to the question of what was wrong and the woman said, "I can't tell you because it would just add to your burdens." The man paused and then said, "You are my friend and you have listened to me when no one else was there. You have taught me that friends are there to listen and share in the joys and the sorrows of life. I cannot be your friend if you keep me away from your joys and sorrows." And everything both stayed the same and fundamentally changed because the woman realized just what people are for: they are for friendship, even love. And further, that that there is no program capable of that.

As a parent of more than one child with a disability, I have come to understand that we often misidentify the

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[1] Thanks to Jack Yates for his helpful suggestions on an earlier draft of this essay.

problems our children face, push for solutions that may actually make matters worse and fail to support our children to be people who help our disintegrating communities re-establish themselves. Too often, we commodify our young people, thinking only about "job" in the economic sense of getting and holding a position in the economic order. To do that, we rely on a service to find the job, educate an employer and support our kids on the job.

Illich has suggested that our systems have ruined our imagination. Where can imagination start? It might start with the human factor of people and their relationships in community. If so, what might that mean for those who are seen as "dis-abled?" And how might our kids serve roles in the community that bring people together, possibly build friendships and may even contribute to their economic well being?

I think that we are called now to use our creativity to connect people to others. There was a time when even the economic order operated a bit differently. There was a time when there were neighborhood markets and I grew up in a world where Mr. O'Neil the owner of such a market told my mother that the pork chops were not too good, this week, but the lamb was excellent. It was a world where people could call in the "order" to Mr. O'Neil and he would have the "boy" get it together, load it into the basket of the bike and deliver it. It was a world where milk men delivered milk and bakers delivered bread. It was a local world of connections and sometimes friendships.

Our kids, and probably many others, now need that more than ever. Too much of our world promotes separation, even isolation and sometimes in the name of a misguided independence. We think that it must be someone's “job” to bring our kids into the world of economic well being, that if independence is impossible the only thing to make up for that is a paid contractual relationship. What would happen if your son or daughter, maybe with some starter help from you, went around to neighbors and asked what they might need at the store today or this week? Would they get "an order" from someone and could they go to the store, package the order and deliver it? What would that be worth to an older citizen or someone too busy with things to shop? What else might need to be done? Could I grow some crops "on order" for neighbors? Could I go to the farmers market to get local goods for neighbors? Could I go to the local deer farmer and offer to sell some of the venison to people in the community who didn't drive by or know about the business? Could the bakery succeed if they had a way of matching what they produced to the orders of folks in the community and have a delivery way of matching the orders and the production? And how about grass cutting and leaf pickup and apple harvest from trees that just stand there each year and on and on?

Fitting our children into an economic world that has marginalized them is a tough task. Sometimes it is made possible by good folks who work hard, are creative and make the very best of a service system. But in a world where unemployment is high and government support is low, it may be impossible to find a supply of jobs for everyone who is looking, even with the help of the most creative among us. Even if it works for some, it may still leave our children on the outside or at the "bottom” of an economic order that really doesn't value them, creating wealth for the service system, but very little for themselves.

What if we saw this problem as the way to provide a most valuable role for our children, a chance to rekindle community, to rebuild connections between young and old, where we saw the world not as one without promise for our kids, but loaded with new/old opportunities for helping them become part of a better world than one where they are minor economic cogs? It takes imagination to see and find the way that our kids who need connection can make connections with others who also need connections and can offer the gift of connection to others and who may also need a quart of milk and some of that nice cheese from the farmer's market

Does all of this mean I have traded in my ultra liberal label for something else? I don't think so. But what it surely means is that if we want a more hospitable world for our children to live in, the route to such a world may not be through the usual services, but rather through promoting community, creating friendships and knowing that when we use our imagination we may find new ways to identify and resolve at least some features of the problems faced by our children.

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JUST QUOTES

I once spent an evening with some Franciscans who share an apartment in a black quarter in Chicago. I very much liked their prior, who demanded a real discipline of the novices. They had to sleep for a certain number of hours a night and eat well. "If we do not care for our bodies, and if we do not find a rhythm of life we can sustain for years to come," he said, "it is not worth us being here. Our job is to stay. It is too easy to come and live among the poor for the experience, to exploit them for our own spiritual ends and then to leave. What we have to do is stay."

Jean Vanier, *Community and Growth*

Listening is a mystery. For a body to be able to listen motionless, it must first be developed in movement. It is no coincidence that conductors live so long, as they spend their life constantly exercising and bringing into harmony body, emotion, and thought. The effort of rehearsing and performing draws on all these parts of them—on their bodies like athletes and dancers, on their feelings like singers and lovers, and on their minds like mathematicians and thinkers—simultaneously and in equal proportions. A body developed in this way can eventually stand still and listen.

Peter Brook, *Threads of Time*

Some people are lucky to not get what they want so that they could get what they have, which, after they've had it for a while, they may be smart enough to appreciate as being what they would have wanted had they known about it.

Garrison Keillor, January 7, 1984

On exponential growth: It's as if humankind were living in a huge unbreakable bottle, into which is placed a small drop of exponential water that doubles in size once a day. One day we discover that the water has filled up half the bottle, and we say, well, it's taken an awful lot of time for it to get up to here, we probably have no reason to worry just yet. Surely with our technology we'll be able to adjust to it as we have so far. The next day we drown.

Kirkpatrick Sale, *Human Scale*

THE LAST SUNDAY AT ROCKCRAFT

For twenty-five years, most middle-weekends in October have found me traveling to Sebago Lake in Maine for two days of personal retreat, serial reflection, and great food with people who have become some of my best friends. The place where we have gathered, every year but one (and I wasn't there that year) is called Rockcraft Retreat Center—a former lumber dealer's summer home that came into the possession of the United Church of Christ. Last October (2009) was the last time we were to gather at Rockcraft because the church had decided to close the center and maybe dispose of the property. (Later note: the property has been offered for sale, at a price of $3.2 million. We tried to put our pennies together but came up more than a little short.) The theme for reflection for the weekend was "recall," a theme chosen to accord with the last time we would be together in that place. I wasn't able to be with my friends and colleagues for that last visit, so I assembled an invitation-to-reflection that they could use as they wished. Here is that invitation.

Here are a few thoughts for Sunday at Rockcraft. Use them or not, as seems best at the time. I wish I could be with you. Looks like there will be a visible sunrise on Saturday anyway and maybe on Sunday as well.

Rockcraft has been good, both to us and for us. I know it's been good to and for me. The people who gather there each year have heard more stories about my life than (I think) I've told to anyone else anywhere--at least more stories about what I recall as important. I suspect that it's like that for the rest of us too. Perhaps one of the things that makes that so is the rhythm we've established with each other--going away on Sunday (perhaps thoughtful, perhaps inspired, perhaps refreshed, certainly full--over-full-- of great food)--living out our lives, carrying out our purposes for a while--then coming back--here--together--again and again. By now we trust that "recall" or refreshment will happen, and so it does, over and over.

We've all gotten older in this place (true, interestingly, even of those who've just joined us this year for the first time). The places and time we live in and the ways we live together (what we sometimes code as "our society" or "our culture") contain, as we know, some standard and expected rules about what "getting older" means. Just watch the commercials on the Weather Channel to be certain about what those expectations are.

But we have counter-ideas and counter-expectations that got us together in the first place. We gather every year to recall and refresh what Jack Yates calls our solidarity in those ideas/expectations. For many years we've gathered in a place that feels a bit (to me, anyway) like a second home. I'm willing to bet that, if I came back here 10 years from now, I could still find the light-switch inside the boat house door in the dark of an October Saturday night.

Our counter-ideas and our now-long habit of renewing/recalling ourselves here must (I think) have had a regular, if varied, influence on our work, our purposes. I know that's true for me, and were I there in person I'd now repeat some old stories for everyone. If re-calling had not happened, why would we have continued in this place?

So, there's no empirical reason to think that such re-calling will stop or change as we look forward from this Sunday. While you're sitting on the rocks or walking in the woods, reflect on these questions, in any way that makes sense to you:

*How do the ideas and experiences we've shared re-call you: to purpose, to relationship, to contribution?
*What paths lie before you that you feel re-called to try again or try afresh?

It turns out that we have another place to gather in October 2010—in New Hampshire—so the (formerly) Sebago group will continue.

Jack Pealer

VIEW FROM THE BACK WINDOW "Welcome to My Facebook Page"

Although I'd like it to be, welcome might not be the right word. The word, welcome, comes from old German and Saxon words for a glad or hospitable reception offered to visitors. Hospitable does not describe how I feel, so far, about my participation in electronic "social networking" through Facebook.

Some time last fall my wife Renate told me that she had been contacted by a few of my old (college-time—more than 40 years back) acquaintances; the contacts came on her Facebook page. As one of those contacts led to our sitting around a table at brunch with one of my college room-mates and his wife (I had not spoken to him for more than 40 years), and, as I thought that was a good thing to be doing, I signed up with Facebook. I even managed to download—or is it upload—a photo of myself. I chose a picture of myself in a big straw hat; I was posing with my granddaughter. (Later I changed the photo to one of me at age 11, holding a stringer of yellow perch—it's outside my great-uncle's cabin in Michigan). Then, I waited.

Groups started asking if I would be their fan. That only sometimes works out. As many people know, I've been a more-than-devoted fan of the Detroit Tigers for more than fifty years. So, I looked up the Tigers on Facebook and became their Facebook fan. It had to stop soon, though. The Tigers have an active public relations division; they like Facebook and Twitter and other entities I don't know the name of. Every time I opened Facebook I had 10 messages from the Tigers. I'd rather listen to them on the radio or wear their hat. So, I now limit whom or what I "fan."

And people started telling me that they wanted to "friend" me. Some of them actually are my friends, and I could readily agree. Some might sometime become my friends, and I'm glad to entertain that possibility. Maybe we really will meet face-to-face and get to know one another—not an absolute but a pretty strong precondition for friendship as I've known it so far. Also, however, I get "friend" requests from people I've never met and am unlikely to meet. Some requests arrived from people I have met and don't actually like so much. It's hard to know what to do or say to those. I don't actually want to reject outright an offer of relationship, even if it is only electronic. I don't wish to offend anyone, but, as far as I can figure out, Facebook doesn't provide a response that says "thanks for the offer, but we really don't know each other that well." So, right now I have 52 friends. I have to say I feel funny about counting them.

I check Facebook every day. I read what's on everyone's mind. That's the question that's posed at the top of every user's page—"What's on your mind?". I rarely reply, which means, I guess, that there's very little on my mind most of the time. It's hard for me to believe that the 52 folks out there really want to know about how deep the snow is in my driveway or where we went for dinner last Friday or about something our cats did that I found hilarious. I don't say that no one would ever care about those things, but it's hard to credit that people would want to spend their time reading about them.

All this is by way of saying that I just don't "get" Facebook or the rest of the electronic social networking phenomenon. In part, Facebook seems like one of those uses of time that seem to have no immediately perceivable purpose. I spend about one-half hour a day on Facebook (perhaps a low total in comparison with other users); always, at the end, I wonder why. It's like I've created another duty-without-rationale for myself.

Partly, as Renate would be able to confirm for you, it's that I'm slow to adopt new ways of doing things—especially new gadgets or devices. It took me years to get around to agreeing to buy a microwave oven in the 1980's. I sometimes refer to myself as a Luddite. Around 1815 the real Luddites raided mills in industrial England at night to break up the knitting machines that deprived ordinary people of paying labor. I haven't actually tried to destroy a cellphone or PDA (I think that stands for "personal digital assistant"); I haven't smashed a single laptop. I like e-mail, which I've used for about 10 years now, but I've yet to warm up to on-line social networking. Some imply that if I don't FacebookTwitter/RSS enough the world will leave me behind—faster, that is, than it's going to anyway But I don't worry about being obsolete.

Part of me does believe that there's value in the possibilities that these newer ways of communicating and interacting offer. I can learn about people and ideas that would not have crossed my path. I can find people from my past. It would, after all, have been hard—not impossible, but hard--to get in touch with my former roommate. In fact, without his contact through Facebook, it would not have occurred to me that I might want to re-contact him.

Someone on another social-networking site recently posed this question: "What makes an online social network feel welcoming to you?" I read the question but couldn't imagine what it meant. I can describe would make a gathering of people <u>together in one place</u> welcoming: an overall feeling of warmth and an absence of purposeless anger; people listening to one another, showing mutual respect. A welcoming gathering would include people who share at least some important interests Likely there would be food and drink. Maybe a fire, or waves on a beach, or music. Certainly comfortable surroundings. It's not clear to me how most of those same things can work in an online social network.

So, I don't think it's likely that my Facebook page will be very welcoming any time soon, even though I'd like it to be. I'm not planning to shut it down. I'll keep on looking at it and trying to figure out how to use it. But, if you go there and don't find much warmth, please remember that it's hard for me to think of cyber-space as a real place. I'd rather make and keep friends over a cup of coffee or a beer. I'll bet it's going to stay that way.

Jack Pealer

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The Safeguards Letter

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IMPORTANT LEARNING OPPORTUNITIES

Long-time friends at Renaissance House in northern Ohio are sponsoring two outstanding workshops in early August.

Understanding Social Devaluation and the Service Worker's Role: A Social Role Valorization Approach. Offered Tuesday and Wednesday, August 3-4, 2010 at Our Lady of the Pines Retreat Center, 1250 Tiffin Street, Fremont, OH 43420. This workshop is **a** two-day training session consisting of presentation, reflective writing, discussion and exercises to accomplish the goals of assisting staff to:

-Deepen their understanding of and identification with the people they serve
-Reflect on some of the major issues facing people with impairments in contemporary society
-Gain some insights into their own roles as human service workers
-Clarify their purposes and goals as persons in service to others
-Appreciate the importance of valued social roles for living a typical life as valued member of society

This two day session will be presented by Jo Massarelli, who is Director of the Social Role Valorization Implementation Project, a human service training and consultation concern based in Worchester, Massachusetts. She divides her time between teaching Social Role Valorization based workshops, and working with families, human service staff and people with impairments to bring about positive change.

Strangers in the House: The Dilemma of In-Home Services. This one-day workshop, presented by Jo Massarelli (Worcester, MA) and Joe Osburn (Bardstown, KY) will take place on Thursday, August 5, 2010 also at Our Lady of the Pines Retreat Center, Fremont, OH 43420.

Families and individuals who receive in-home support services typically face a major problem of trying to maintain the integrity of their private home and family lives despite the inescapable disruptions that come with service-provider presence in the home, especially when it is very extensive or involves many different workers. This difficulty exists even when such families and individuals presently have good personal relationships with their in-home support personnel, and even when these are adequately sensitive to the issues at stake. When good personal relationships and sensitivity are absent, as so often happens, the situation can become intolerable. This one-day presentation explores this dilemma. It offers insights, practical advice, and strategies for managing the issues involved, and invites participants' reflections on the types of mind-sets that might improve or worsen this dilemma. Specifically, this event: (a) explores the nature of this dilemma; (b) identifies its manifestations for both in-home service users and providers; (c) presents examples of different kinds of in-home service arrangements and illustrates the positive lessons to be learned from them; (d) offers considerations for a positive mind-set toward both the use and the provision of in-home services; and (e) suggests specific action strategies for putting these considerations into practice.

This presentation is for: Individuals who currently use in-home supports or might in the future; families of individuals who use in-home supports, in-home support personnel and other representatives of support-providing services including visiting nurses, hospice workers, home health aides, respite workers, personal care assistants and others.

Contact Robert Weinhardt, Renaissance House, for more information about both of these learning opportunities: 419-447-7901 or rweinhardt@renaissancehouseinc.org .

WE GET LETTERS

In response to the Winter 2010 issue--thoughts about Facebook and other such "social media:"

Jack. You've pretty well captured my feelings about Facebook as well. I, too, "joined" Facebook because I was told that was the best way to keep abreast of events and photos in the lives of family who are scattered across time and space. I have enjoyed seeing some of the photos, but I'm frankly dismayed to read posted messages that are essentially trivial with an even more trivial replies. Somehow the dialog seems more appropriate to speech than to writing, and really only appropriate to private, casual conversation. I certainly remember as a teenager spending hours on the phone talking about nothing significant, and I don't begrudge anyone their right to chatter to their heart's content, as long as I don't need to be an unwilling party to it.

It seems to me that when one makes the effort to put something into print for public consumption, even among friends, that it should at least be worth the time it takes to read it. I suppose I've considered print to be a less casual medium than speech. I realize that this is becoming an outdated notion in the age of e-mail and texting where there is very little effort and spelling and grammar are optional.

There seems to be a lot more superficial communication, but I'm not sure that it's resulting in more connection or understanding, or any perceptible thought given to what one says or means.

I've gone back and corrected several typos and rewritten a few sentences in this message. This could be a sign of my generation or my middle-class preoccupation with correctness, but I'd like to believe that there are among all generations and classes those who make the effort to use words with care.

Paul N. Tabor
Developmental Services Training Coordinator
Maine Dept. of Health & Human Services

The Safeguards Letter is an occasional publication of OHIO SAFEGUARDS. The Letter exists to promote affiliation among people who are interested in and thoughtful about those who live outside the sphere of respected community membership--those who are the usual receivers of human services. All material in The Safeguards Letter is under OHIO SAFEGUARDS' copyright (©) unless otherwise attributed. Letters, ideas, and items for publication in the Letter can be sent to: Editor, The Safeguards Letter, 3421 Dawn Drive, Hamilton, OH 45011 (e-mail: jackjr441@earthlink.net). We welcome our readers' ideas and reactions.

ATTENTION SPAN (from "On-the-road update, July 1992)

(Editor's Note: My friend Jack Yates from southeast Massachusetts used to travel quite often as part of his work. He always traveled by car—still does, mostly. Once in a while he would bring out his typewriter to draft "on-the-road updates" to send to his friends. Some of those updates have been re-printed; others have not. Here are some of Jack's thoughts while "on-the-road" in the summer of 1992. JRP)

It is obviously common sense to assess someone's competence if we are to serve that person well. Right? Whether what competence (broadly defined) is intelligence, adaptive behavior, work skill, gentleness, cooperativeness, housekeeping abilities, attention span, whatever, assessment is an important task and usually should be our first task in service, of course. So it was a little unsettling thirty-three years ago to hear the late Marc Gold use as a key refrain an opposed principle, "train, don't test." He proposed: don't assess vocational skill levels. That's a waste of your time and the time of the person you serve; train the person in a job.

Gold was right, I believe. Don't spend time on assessing competence. Spend time instead on developing competence. It is rather funny as well as rather sad to think of the time and energy that has been spent on the assessment of intelligence: days and years and whole careers of brilliant and caring people, the most highly trained people in special education and other fields, frittered away in reading and writing articles and whole shelves of books trying to answer the question, how intelligent is this person? Why didn't they spend their time, Gold proposed, in better answering the question, how can we make this person more intelligent and competent?

The first question is a waste of time, a red herring. The second question is very worthwhile in setting our tasks of service. I would propose a third question, which I have come to think can be the most fruitful for us to ask: what brings out the competence in this person? What context brings out the intelligence…the gentleness…the adaptive behavior…the work skill…the good housekeeper…the conscientiousness—what context in the way of places, what context in the way of people, what context in the way of task activity, what context in the way of things to look forward to, what context in the way of role expectations? And, having discerned what brings out the best in this person, our task in service goes on to asking the question, how can we do more of that? How can we surround this person more often with those contexts that bring out her or his best?

A formative experience for me in thinking about the primacy of that third question about competence and in confirming the worthlessness of the assessment question came in facilitating, with Doug Watson, an Individual Design Session in New Hampshire many years ago. Keith Ricketson, who was then Director of Residential Services in the Lebanon area, invited me to facilitate a design session for a woman named Deanna. The reason he invited me was that he couldn't afford Herb Lovett; the reason he invited an out-of-stater was that the politics and diplomacy of serving Deanna had gotten complicated. Deanna was, you might say, a legendary client. People in other regions of her state who had not even met her had heard of Deanna, a legend in her own time. Becoming famous as a client is quite a straightforward thing: You do it by hitting staff, which Deanna had done many times over the years. Deanna, then, was not a particularly gentle person.

Doug and I knew that—mainly from stories and from our brief time in meeting Deanna at the staffed apartment. As we planned the questions we should ask as facilitators, then, we felt a key question to invite some really detailed answers should be, what brings out the gentle person in Deanna? Think back over the past week, we asked direct service staff. Think about the periods or even moments in which Deanna was gentle, amicable, cooperative. Where did they occur? In what room? At what time of day? What was she doing? What had she just finished doing? What was she looking forward to? Who was with her? Let's analyze those moments. And then we can ask, how can we replicate that context more often?

After the discussion had gone along for twenty minutes or so, I noticed that one IDS participant was pacing up and down in the middle of the room, muttering angrily. Then he stopped pacing and faced me and said, "This whole discussion is a waste of time, it's a crock! 'What brings out the gentle person in Deanna?' You're talking about five percent of the time, tops. Deanna is not a gentle person!" The session fell apart at that point, as other staff argued, people got to shouting at each other, two men nearly came to blows. I tried and failed to explain: whether Deanna is gentle only five percent of the time or ninety-five percent of the time actually makes no difference to whether this is an important question for use to consider and discuss. What brings out the gentle person in Deanna, and how can we do more of that?

Gentleness is not assessed as formally as intelligence, but it seemed that the session's challenger (and about half the other participants) really was most interested in assessment: how gentle is Deanna? So let's imagine that we had available a formal assessment instrument for "gentleness-quotient," which we could administer and then place in the files for people like Deanna. On a scale of zero to one hundred, how gentle is Deanna? Five, maybe? Then imagine that you are residential staff for St.

Francis of Assisi. On a scale of zero to one hundred, how gentle is St. Francis? Ninety-five? Ninety-nine? I'll bet St. Francis would have been the first to assure you that he did not score one hundred. Nobody scores one hundred. Each of us has anger and violence somewhere in her or his heart to overcome. So what if you were staff for St. Francis? Then an important pair of questions for you to ask would be, what brings out the gentle person in St. Francis, and how can we do more of that? Same questions as for Deanna?

I am not at all denying that some people are, in general, more gentle that others. Nor do I doubt that some people are more intelligent than others, or have longer attention spans than others. I am only saying that it is a worthless question for us to ask. Instead, we should ask, what brings out the gentle person in Deanna? I know she's in there; what would be our most powerful invitation (i.e., bringing into life) of the gentle person in Deanna?

Haven't you said, or heard it said, about a person, "I didn't know she had it in her," or "He's a completely different person with his family"? Each of us has more than one "person" or "side." What contexts are most likely to draw out the good side?

Herb Lovett made this point well in presentations about the context for behavior. He opened a lecture by asking the audience, how many of you made your beds this morning? People chuckle, and only about six hands go up. Herb then asked, how about the rest of you? When is the last time you made your bed? And why? Because company was coming, right? OK, so how can your residential staff get you to make your bed? By charts on the wall, by encouragement, by nagging, by reinforcement, sure. All those things are legitimate. But the most powerful way your staff may have of getting you to make your bed may be to invite your friends (or especially your mother) to visit. What brings out the good housekeeper in you? Asking on a scale of zero to one hundred how good a housekeeper you are is a worthless question. Asking how to make you more competent as a housekeeper is a more worthwhile question. But best of all might be to ask what brings out the good housekeeper in you. He's in there; what is our most powerful invitation to bring him out? Changing a person—that's hard to do! Ask anyone with responsibility (as parent, as staff, as friend) to a person with impairments. You may also doubt that changing another person is even legitimate. But changing the <u>context</u> that surrounds a person—that is legitimate, and it can be effective.

How long is your attention span? There's an assessment question—obviously important enough to enter the answer in your permanent file. How long is your client's attention span? How long is your son's attention span?

When our son Nicholas was five, we went on vacation to Acadia National Park on the coast of Maine. On our first day we had reason to notice that Nicky's attention span was short, just as one might suspect in a five-year-old boy. An eight-hour drive on a hot August day: are we there yet? Three amateurs pitching our new tent: come back here, Nicky, we need your help. Listening in the evening to a ranger talk about local plants and animals: try to sit still, Nicky, leave those people alone. So it was empirically demonstrated: Nicholas has a short attention span.

The ranger mentioned in his talk that he figured many of us might be going to watch the total eclipse of the moon, which would happen that night. We had not heard that there was to be such an eclipse, so we asked him more about it after the talk. He told us the earth's shadow would begin to block out the full moon at about nine-thirty, would move across it until about ten-thirty, and that a good viewing spot would be the nearby Otter Cliffs, which face south over the ocean. Sandy and I had never seen an eclipse of the moon, so we were interested. But would Nicky be in any shape to stay up well past his bedtime and pay any attention to it? After all, it says in his file….

We drove to the cliffs parking area, walked out onto the rocks. We were alone, about thirty feet above the ocean. We sat down on the rocks, huddled against the chill. We twisted our necks to look up at the moon. Now the movement of the earth's shadow is not fast enough to see. If you hadn't stared upward for many minutes you would not have known it was moving. We explained as well as we could to Nicky what was about to happen. And Nicholas sat on the cliff in the dark and the cold and stared, fascinated, immovable, absorbed at the moon for over an hour without pause. So did Sandy and Jack. We will never forget it.

So, does Nicholas have a short attention span or a long attention span? A foolish question. Ask, instead: What brings out good attention and focus in Nicholas? What brings out the best in each of us?

Jack Yates

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*

The people with the best sense of what is essential to a community, of what gives and maintains its spirit, are often doing very humble, manual tasks. It is often the poorest person - the one who has a handicap or who is ill or old - who is the most prophetic. People who carry responsibility must be close to them and know what they think, because it is often they who are free enough to see with the greatest clarity the needs, beauty and pain of the community.

Jean Vanier, *Community and Growth*

The enlargement of industrial technology is thus analogous to war. It continually requires the movement of knowledge and responsibility away from home. It thrives upon the disintegration of homes, the subjugation of homelands. It requires that people cease to cooperate directly to fulfill local needs from local sources and begin instead to deal with each other always across the rift that divides producer and consumer, and always competitively. The idea of the independence of individual farms, shops, communities, and households is anathema to industrial technologists…. The corporate producers and their sycophants in the universities and the government will do virtually anything (or so they have obliged us to assume) to keep people from acquiring necessities in any way except by buying them.

Wendell Berry, "Standing by Words"

(…and, to remind myself…)

Age, n. That period of life in which we compound for the vices that we still cherish by reviling those that we have no longer the enterprise to commit.

Ambrose Bierce, *The Devil's Dictionary*

A VIEW FROM THE BACK WINDOW

Summer Is for Traveling

It's the second day of summer. We're starting to get ready for a summer on the road and inside airplanes—to places like Montana, Ontario, and central Europe. I wanted to have this issue of *The Letter* out to readers before I left. The last issue was "late winter," after all. So here are a couple of memories about places I've been that have meant much to me. *Bon chance* with your summer travels.

Flashing Back to Detroit. A year-and-a-half ago Mitch Albom wrote a piece in *Sports Illustrated* (see: http://sportsillustrated.cnn.com/2009/writers/the_bonus/01/07/detroit/index.html) that touched me right to the core. Albom's piece starts on a Christmas night in a collapsing church in downtown Detroit. I jumped right away to a Thanksgiving weekend trip via Greyhound from Chillicothe to downtown Detroit—about 1977. I went to be part of a crew from Dr. Wolfensberger's Training Institute for a pair of "normalization" workshops—3-days, repeated sessions each day, morning and afternoon. Of course evening sessions were scheduled, but even in 1977 no one wanted to come to that church on Cadillac Square on late autumn nights. I was there with Darcy Miller (now Elks), Mike Morton from Indiana, and at least one other person I can't remember now. I arrived on a Sunday afternoon at the Detroit bus station and walked, carrying my suitcase, a couple of blocks to the small hotel where we were staying. The workshops (mornings for people from the suburbs—Oakland County; afternoons for folks from the city) were well attended, probably because agency-staff were ordered to be there. The presenters were on a stage in a room that was probably designed (60 years earlier) for "Sunday School" assemblies. Participants sat at tables scattered around the room; I remember the war over the back row of tables. Early arrivers at the workshops tended to sit in the back of the room. We countered on the second day by carrying the back row of tables and chairs out of the room before folks arrived. They countered by searching out and finding the removed furniture, which they re-installed at the back of the room, well away from us. Sleep seemed important. One large woman who came to the afternoon sessions sat down front. She wore a fur-trimmed coat and a fur hat, which she left on during each session. About 45 minutes into whatever presentation was happening, she nodded off. I remember that we were all estimating, each to oneself, how long it would be before the hat fell off. The three days taught me much about how not to organize learning opportunities. The church may have been the same one that Albom visited on Christmas. It wasn't leaking then. But few people came there voluntarily, even 32 years ago.

But, like Mitch Albom, I have strong memories of Detroit when it wasn't like that. As I write, I'm looking at a picture of an 11-year old in a white t-shirt and jeans. He's standing before a small fir tree. Behind the tree is a cabin that's clearly in the middle of the woods. The boy is holding a stringer of fish. The picture is too indistinct, but I know that the fish are yellow perch and that there are 25 of them on the stringer. My great-uncle Earl owned the cabin and took me to the lake where I caught the fish. The cabin was about 8 miles east of Atlanta, MI. It was about 1954 (not sure of exact year). From Bay City north to the cabin the state highways were (astounding to me) unpaved—extra-wide gravel roads. Uncle Earl and I stayed about 3-4 days, trying out all the lakes and streams nearby for trout. When we caught no trout we settled for yellow perch. Thus, the stringer.

Earl worked for Ford (in accounting, I think) and lived in Dearborn. He and Aunt Eva lived in a flat near the corner of Greenfield Road and Rotunda Drive. The latter street was named for the Ford Rotunda—a display building originally build by Ford for a World's Fair (1933) and later moved to a park-like area near the Rouge plant in Dearborn. One visited it as though it were a museum, which, in a way, I guess it was—a museum to the American (Ford-made) car. I remember once seeing a 50's era Lincoln—a white convertible with gold, instead of chrome, bumpers and trim. All the newest in Fords were there. In 1962, the Rotunda burned down.

I looked forward to visits with Aunt Eva and Uncle Earl in Detroit (that's how we thought of it, even though they lived in the suburbs). Uncle Earl subscribed to *Field & Stream*, and had a stock of old issues; I read all the fishing articles and ignored the "field" part. We'd go to the zoo (once) or downtown Detroit, to the Dearborn Inn for dinner, or to Belle Isle Park in the Detroit River. I could, in the 1950's, recite the exact sequence of streets that we would cross as we traveled north on Greenfield Road toward the then-impossible northern boundary of the city at Eight Mile Road. Uncle Earl had a 1953 Ford sedan—the first car with automatic/electric windows I ever rode in. As we returned to Detroit from our trip to the cabin in the north country, he had a baseball game on the radio. I must have said something to him about the game or the teams. He turned to me with what I remember as a plaintive look on his face and asked, "Don't you like the Tigers?" Well, I did, starting just then.

And I still do today, of course. Mitch Albom says in his SI piece: "…we live among ghosts." My ghosts have names: Steve Boros, Charlie Maxwell, of course Al Kaline, Harvey Kuenn, Don Mossi, and the Yankee-slayer Frank Lary. And Earl Smith, who knew where the perch could be caught.

Pilgrims Come to Dinner. Some people—myself included—find themselves so powerfully attracted or drawn to an idea or a story that they want to pack up and go to the place where the idea originated or the story happened. That kind of trip may be called a pilgrimage. One major intention behind a pilgrimage (aside from fulfilling a religious obligation) is the attempt to share, even if only vicariously, in the occurrences in the story that so attracts the pilgrim.

So, Renate and I made a pilgrimage to Savannah in May 2009 to share in the story of citizen advocacy at an event that has called to me for years—the Annual Covered Dish Supper and Celebration. Part of what drew us was the story of Waddie Welcome and his circle—still one of the best stories I know about people tying themselves together for the good in the world—but another larger part was the wish to be part, if only for a few hours, of the long-standing body of intention that is citizen advocacy in Savannah.

Chatham-Savannah Citizen Advocacy was born and grew up in the tradition of what used to be called the principle of normalization. Now, reconfigured, that principle is known as "social role valorization," usually abbreviated as "SRV." SRV notices that anyone is more likely to experience good things in life if she/he occupies roles in society that are regarded as valuable by most other citizens. People, like those associated with Chatham-Savannah Citizen Advocacy, who want to bring about more –valued roles for others they care about should, says SRV, focus on two goals: 1) elevating the social image of those others, and 2) improving those people's personal competencies.

I've risked this gloss on SRV so I can say that the 31st Annual Covered Dish Supper and Celebration showed me an organization living out its principles. The big room and patio at Savannah Station made it possible for everyone to be together—all 300+ celebrators. Renate (I confess, a more sensitive soul than I am) noticed right away the warmth of friendship in the room. Large prominently displayed professional photographs of pairs of local citizens linked by advocacy created a gallery and spoke of the central place of those relationships in the life of Chatham-Savannah Citizen Advocacy. The food tasted like it had been lovingly prepared for friends. And the invitations to unknown (to me) artists who decorated/set the tables carried the day. Much thought-at-work yielded elegance. All these together lifted the social image of everyone who entered the room.

The choice to gather people at round tables-for-eight meant that folks (like Renate and me) who arrived perhaps as strangers found themselves drawn into introduction and conversation. Renate quickly involved herself in a recipe-exchange. "Home-Grown Good News"—the main formal program for the evening—enabled people in advocacy relationships to warm us and make us laugh with their stories and repartee. Shared leadership of songs brought us together to raise the roof a bit. And the combination of the room-arrangement and pathways you needed to take to get food created a requirement for competence. You had to negotiate the length of the room with a loaded plate, making or renewing relationships along the way. Any bumps or spillages seemed like happy ones. The Annual Covered Dish Supper demanded skill, and the celebrators met the challenge.

Sometimes an exchange of casual remarks becomes a conversation; conversations can't happen unless they start. Sometimes, too, events—like displaying art, providing music, sharing food—repeated over time (say, 31 years) turn into traditions. Traditions can't happen unless they start. Traditions also spawn stories. And, as I've already mentioned, stories sometimes attract pilgrims. Our pilgrimage to Savannah was sweet. While there we were introduced to "medium-sweet" iced tea. The Annual Covered Dish Supper and Celebration was even sweeter. Thanks for the welcome.

Jack Pealer

REMEMBER:

Understanding Social Devaluation and the Service Worker's Role: A Social Role Valorization Approach. August 3-4, 2010, Fremont, OH

Strangers in the House: The Dilemma of In-Home Services. August 5, 2010, Fremont, OH

More information or to register for either workshop, contact: Robert Weinhardt, Renaissance House, 419-447-7901 or rweinhardt@renaissancehouseinc.org

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