

The Safeguards Letter

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IN MEMORIAM, RAY GAGNE

Ray Gagne was a companion at a retreat in which I participate every October at Sebago Lake, Maine. Ray spent 18 years at Paul Dever State School in Massachusetts; he told the story of those years in a chapter, titled "A Self Made Man," in *Creating Individual Supports for People with Developmental Disabilities* (Valerie Bradley, John Ashbaugh, and Bruce Blaney, eds.). He called his years at Dever the "years of no power." Ray died at his home--his own home--in Harrisburg, PA in early March; he had a distinguished career as a teacher and organizer with groups in both Massachusetts and Pennsylvania. He was proud of his work, and he had a right to be so.

When we were at Sebago Lake for the 1999 gathering, Ray and I were catching up on a year's worth of news. One of the things we talked about was the death of John F. Kennedy, Jr. Ray appreciated John Kennedy's work in the interest of people with disabilities and spoke of his continuing sadness over Mr. Kennedy's death. Then Ray asked: "Do you know where I was when I heard the news?" And when I, of course, did not, he told me. But, as often happened in our conversations, I couldn't understand the words. I couldn't "get" what he was saying. He tried explaining it another way. I still couldn't get it. He grew inventive, trying a variety of examples or stories, but I wasn't able to connect through any of them. We had to give up and go on to something else.

Later we were in another conversation with some other folks. We were talking about something that another person had sold or bought. Ray suddenly asked: "How much would you have paid for this coat?" When someone volunteered a price, he asked someone else: "And what would you pay?" That person answered, and Ray then asked: "What are we doing?" The right answer was "bidding". Then he turned to me and said, "That's where I was when I got the news (about JFK, Jr.). I was at an auction." Now, hours later, I could understand. And you have to understand that Ray thought and worked and maybe worried about a way to communicate with his friends. Patience, thoughtfulness, and inventiveness in the interest of friendship. Ray was a genius at these. Thanks, Ray. We will miss you.

Jack Pealer

GARBO'S BIRTHDAY AND OTHER INDIGNITIES

Don Trites

(Note: Our long-time friend Don Trites lives in Jefferson, Maine. JRP)

The chart on the wall near my Mother's room listed all the activities for each day in the month of September. There were times to share stories of the past, times to read the paper, times for singing, times for games and times for exercise; each day was to be "filled" with activity to keep the mind and body stimulated. All of this was to occur in a new facility, one of four units for the care and treatment of elders with Alzheimer's disease or other forms of dementia. The wallpaper is new, the paint fresh, the furniture also new and chairs and couches gathered around a gas fire place. The separate TV room has a new set, with a VCR and the living room has a radio/tape/CD player. All the comforts of home. Each bedroom is to be decorated with things from the past and each room is identified on the outside with pictures or memorabilia to help a person find her own room. And the calendar for September listed the birth dates of famous people, Greta Garbo on the 18th of the month for one.

That's the sales picture of care for those "fortunate" enough to afford the \$3,000-\$5,000 a month for care at this level. But what of reality? In the dozens of hours of visiting over 3 years, I never saw one of the activities actually being done. Staff provided reasonable custodial care, dressing, changing, preparing meals, etc., but interaction with the 8 women who live in the unit was minimal at best and often non-existent. Women sat on the couches and watched the gas fire, dozed silently, argued over pillows or stared around the room. "Take away the new wallpaper," one visitor commented, "and you have the same

old nursing home." No activity, no conversations, no connection to the past or the present; daily waiting for death. The endless hours of sitting, the unexplained bruises, the notices and warnings about continual medication errors, the accusation by one woman of sexual abuse by a staff member--all had the familiar ring of all the institutional facilities designed to hide away those whom society views as too troublesome or unpleasant or inconvenient to deal with, those from whom entrepreneurs can now make significant money.

Staff turned over at the usual furious rate, leaving all of the women wondering who was there and who was coming next. Even administrative staff turned over, with at least 4 directors in 3 years. The past of each woman was lost to the unconcern of ever-changing staff over who the women had been and overwhelmed by who they now "appeared" to staff to be. On two occasions I watched as staff questioned one woman to see if her hearing aid was working. In one case it was not; in the other it was. But since no one talked to her except to see if the aid was working, did it really matter? For the Christmas morning "enjoyment" of the women, rap music blared from the CD player when 11 of us arrived, after our 3,000 mile journey, to share what might have been my Mother's final Christmas. No hymns, no carols, no Kate Smith, no Bing Crosby and White Christmas, just Ice Cube and Natural Born Killaz. My Mother, who was placed in this "Garden" by her daughter who believes places like this are "better" than home or family care, was surrounded by things not of her own, but by leftovers from her daughter's home. Not her bed, not her dresser, not her table nor chairs, not even her pillow or blankets came from her past. Only some of the pictures on the wall were reminders of people or places that once had meaning. Three thousand miles away were most of my Mother's relatives, all of her friends and all of her possessions, accumulated over a life time. No fresh wallpaper or regular visits from a daughter could replace those things.

And, oh yes, Greta Garbo's 95th birthday was noted on the Calendar for the month of September. It was just that my Mother's 90th birthday on the 25th was absent.

Don Trites

WE GET LETTERS

Jack, I read with interest your "View out the Back Window." Back in 1984 when you visited Attleboro as part of a PASS based consultation/evaluation team, the concept of circles was the first introduced to us as part of the "feedback" and was later detailed in the report you edited.

Included in the report is a Beth Mount drawing that is similar to your circle in the newsletter (see enclosed). Over the years we struggled with how to move from the pyramid to the "Beta triangle" embedded in the community. One result has been a new organizational chart for Beta (2nd enclosure).

I also found the star design an interesting argument in favor of limited size of an organization. Keep up the good work.

Bill Kelly, Beta Community Services, Attleboro, MA

Jack. I was affected by the "Self-Commodification" article in the "Safeguards Letter". Quite a wake up call. I also want to share something amusing. At lunch the other day co-workers discussed the (agency's) new table of organization, saying that the people we serve will be at the top with those supporting them directly underneath, and, supervisors below, etc. I said, "Nice symbolic attempt, but it needs to be a circle." So you can see how my years here have helped me grow! I was tickled to read "View out the Back Window", which, of course, is much more than a circle, evolving into a star then constellation.
Excellent publication!

Laurel Lovely, Cincinnati, OH

Dear Jack Pealer

I thought you may want this to put in the letter next time: BELIEVE IN YOURSELF! Believe in yourself, in that you have to control your own life day by day. Believe in the strength that you have deep inside you and that will show you the way. Believe in tomorrow and what it will bring. Let a hopeful heart carry you through, for things will work out if you trust and believe there is no limit to what you can do. Blessings on you who care for us all the time; blessings on you who give us yourselves day by day. Blessings on you who do good to others too. In faith there is hope.

Dianne Koehler, Cincinnati, OH

Hi Jack,

Long time no see!! George (Ducharme) & I have been immersed in "building community" on Main Street in Manchester. The time involved to nurture , grow, educate, shape attitudes is incredible but well worth the effort. So many challenges yet so many stories emerging from life on Main Street. And we truly are discovering that this "building community" is for many walks of life & not just a disability one. But maybe someday our paths will cross again to share stories of the journey. I was writing to commend you on such a great piece in your newsletter on self-commodification. I surely related to it from where I have been the last 20 years from the days in the Dept. of Mental Retardation to our journeys with many families & individuals that experience just that. Thanks for putting the thoughts & images down on paper. I'll definitely share it around. Thanks for continuing to do what you do. Hope all is well with Sandy, you & the Ohio contingent. And if you ever get out to Connecticut join us on Main Street at The Place for some storytelling & community. Thanks again. Carry on.

Pat Beeman, Manchester, CT

MY UNCLE DAVE _____ Mary Beth Paul

After attending the funeral of my mother's youngest brother last week, it seemed only fitting that I share some of what Uncle Dave experienced in his life. David Nathal was born in 1938; the youngest of nine from a large extended Italian-American family in Erie, Pennsylvania. Sometime around age five he became ill with a very high fever that changed his life forever. He suffered brain damage that caused mild but permanent cognitive delays. He attended school through most of his teen years, and was able to read, write, and do math. His brothers and sisters continued to help care for him after his mother died when he was 12. His father became ill and died a few years later. When he was 17, my parents invited him to live with their growing family. (They'd been married

for four years at the time, and had my older brother and me by then.) Another brother was born in 1956 and in 1957 our family, including Uncle Dave, moved from an apartment into a 4-bedroom home. He went to work at a candy store and a market. He'd take the bus there, carrying his lunch in a black metal lunch pail like my Dad's. As he matured, he began to have some behavioral problems not unusual for an adolescent trying to cope with the accompanying changes of an adult body. My mother related to me that they decided to take him to the priest that had known her family for years. He suggested that Uncle Dave be seen by a psychologist. The visit to the psychologist yielded little information. Since Uncle Dave was not willing to talk to him, the psychologist made a horrific recommendation. In 1958, there were NO services for people with developmental disabilities

outside of some kind of special education classes and the state institution system. Since Uncle Dave needed help in coping with his increasing aggressive behaviors, and there were no local services to assist, the family resigned itself to accepting the recommendations. My Mom related that my Dad was insistent that Uncle Dave not be sent to Polk, an institution with a population of about 3000 people from northwestern Pennsylvania. But as the situation was not improving, and after all, the psychologist said that it would be for the best, Uncle Dave was sent to Polk State School and Hospital in 1958. My Mom said she couldn't bear to go with him that day, and another one of her brothers took him. For about the next 14 years, my Mom and Dad and aunts and uncles took turns being responsible for Uncle Dave. Each year one of the seven siblings that lived in Erie took turns being the responsible person for bringing Uncle Dave back home for holidays and family functions. He probably came home at least five times a year. It always seemed like an equitable solution at the time. Besides the trips to pick him up, I remember visiting him at Polk for their annual "circus days". Yes, the old clowns and carnival atmosphere for all 3000 residents, some who spent their days in cages and their nights strapped to beds. I remember being assaulted by the smells and sounds of people who were corralled into inhumane living situations. Uncle Dave did some kind of work there- I think possibly in the kitchens- and was medicated with God knows what. Thorazine was one of the drugs he was given, and I found out years later that he was given electroshock "therapy." We will never know whether the debilitating mood swings and Parkinson-like shakes that he was to experience as he got older were part of the long-term effects of these inhumane treatments. In 1972 the first group homes opened in Erie. By that time, we were a family of six children, including my youngest sister Susie who had Down syndrome and was to survive only one more year due to heart problems. My older brother was in college, majoring in special education. I was to begin college at Clarion in special education the following year; my middle sister graduated with the same degree in 1980. Things were rapidly changing. As deinstitutionalization began to unfold in Pennsylvania, people from Erie who had been sent to Polk began to move back home. I don't know who or what initiated the process for Uncle Dave to return, but by the early 70's he was living in a residential center, and then a group home. In 1976 I had graduated with a degree in special education, but due to a string of providential circumstances ended up living and working with adults with

disabilities in a l'Arche community in Syracuse, New York. My dates are fuzzy, but sometime before the end of the 70's, Uncle Dave went to live with the Erie l'Arche community. L'Arche is an international organization of communal homes for people with and without disabilities. They are intentional faith communities, most with a Christian/Catholic tradition but interdenominational and interfaith in most countries. Jean Vanier founded l'Arche in 1964 in France. Toronto had a community by the end of the 60's, and the first l'Arche home in the U.S. opened in Erie in 1972. I visited that home several times before graduation, and realized that I wanted to work with adults. The biggest differences between l'Arche and other residential settings were that everyone lived together - no "house parents", no "weekend relief staff"- and that there was enormous care and commitment to one another. An air of celebration was often prevalent, and vacations to visit other l'Arche communities were frequent. During the 16 years that Uncle Dave lived at l'Arche, he traveled extensively, visiting other l'Arche communities and going on an international pilgrimage to Lourdes. The extended Nathal family was invited to numerous gatherings and Uncle Dave still spent every holiday with his brothers and sisters, as they continued the "rotating turns" of sharing responsibility. My Nathal family relatives were (and still are) big Detroit Tiger baseball fans, and Uncle Dave went with them to Cleveland to see the Tigers against the Indians many, many times during his life. But even though Uncle Dave was finally back home in a nurturing, stimulating, and caring environment, he was plagued by mood swings, hallucinations, and increasing tremors. He was diagnosed with many different things by many different people. Treatment still included a variety of drugs, but acupuncture was added to the list. He would be hospitalized from time to time for mental health problems, and would have periods of relief. He was highly regarded and valued as a member of his l'Arche household, but when he began to hallucinate he could become aggressive and highly fearful. He finally had become so ill that he required extended hospitalization in a state facility for people with mental illness. For years, he was shuffled around the medical community and not given appropriate treatment because his primary diagnosis was considered mental retardation, not mental illness. (I've heard tell that his IQ was around 75. But the pervasiveness of an unwillingness to treat or even begin to try to understand people with DD and mental health problems still had a stranglehold on the system that he was plugged into.) Unfortunately, the painful decision had been reached that l'Arche was

unable to continue to care for him adequately. He spent the 1990's in some different assisted-living facilities and attended day programs for older adults with disabilities. His l'Arche family still included him in their community activities and celebrations, as well as the Nathal family gatherings. My parents brought him to Ohio to spend Thanksgiving with me and my husband and my sister. By that time he was shaking constantly and had begun to have some problems with incontinence. It was a sad day when my aunts and uncles decided they could no longer bring him home for visits, because his personal care needs were too daunting and they were unable to manage him without help. As my aunts and uncles lost spouses, retired, and had health problems of their own, they continued to carefully monitor his care. I had many calls over the years from my Mom as they were about to meet with caseworkers and staff for his individual program plan. She would go over with me some of her concerns and questions, and we would discuss what she should ask.

My Uncle Al, the next youngest brother in the family, was the spokesperson for family decisions for Uncle Dave as the years went by. He was fiercely protective of his youngest brother, and would take him shopping for his clothes and make sure he got to the ball games as well as help monitor doctor appointments and recommended treatment plans. As more and more people were involved from the state systems, he became frustrated at times. Who was finally making these decisions? And when there was a high turnover of case managers, social workers and the like, who would understand Uncle Dave's history and put the pieces together properly? Uncle Dave's health began to deteriorate as he aged. In 1989 he had a near-fatal attack of appendicitis, and in the next ten years had more hospitalizations for infections and illnesses that never seemed to be clearly diagnosed. In February of this year, he was hospitalized for a blood infection and not expected to survive. He rallied and lived another two weeks with his remaining brother and sisters at his bedside during the daytime hours. He finally passed away at 4 a.m. on February 26, 2000. His mother had preceded him 50 years ago on February 25. He was 61 years old. There were two days of visitation at the funeral home. My sister, older brother and I went to Erie for Uncle Dave's final farewell on February 28th. All of his extended family, the l'Arche community, and staff from his final residence came to extend their sympathy. People came up to me and said, "I was at Polk with David! We go back a long ways!" I overheard heartfelt prayers and someone kept exhorting "Hope! Hope!" at the cemetery. People from l'Arche

brought up the gifts at his funeral Mass. But the thing that overwhelmed me the most was the procession of family and friends that followed the casket with his remains into the church. Here was a lifetime of love, worry, pain, celebration, and of hope, joining him one last time to say goodbye. We should all be attended to so well at our death; it reflects the same care with which his siblings, family and friends cared for him during his life. Funerals also have the ability to help one reflect on the quality of a person's life. Did it have meaning? Did the person experience love and joy? How did this person take the sufferings that come with life? His work was likely not greatly satisfying (sheltered workshops and day programs). His recreation (most anything to do with sports, especially the Tigers, as well as his great delight in good food, especially homemade Italian meals) was more enjoyable. When he was well, he attended Mass faithfully. He was also an active participant in the spiritual life at l'Arche: prayer, retreat times, community renewal, as well as the pilgrimage to Lourdes. He loved movies (but was careful to watch only those with a "G" or "GP" rating) and had a reputation of being tight with his money. He always had a girlfriend, and at times complained about the cost of a date or buying her gifts. His despair when he was ill, and the frustration of those who cared for him, only succeeded in underlining a lifelong commitment to be a good brother, a good sister, a good friend who would be there no matter what. I felt compelled to share Uncle Dave's story because now as a parent of a child with a disability, my own child as well as our extended family will face similar questions as all our children grow into adulthood: Will my child be able to live at least semi-independently? Who will oversee this plan? Who will be there to hold our hands when we have tough decisions to make? What kind of work will my child do? What will he do for fun? Will he have friends? Will he have a girlfriend or wife? Will there be a community of faith to welcome him? Who will watch out for his safety and wellbeing? Who will be there when he's ill? Who can guarantee that my child will be happy? Can I spare him from pain? And will my son die alone, or will he die with dignity, surrounded by family and friends? On another level, Uncle Dave's story needs to be told because his time line follows a big part of the history of institutions. He arrived at Polk when the populations were at an all-time high. Burton Blatt's Christmas in Purgatory and even Geraldo Rivera's covert expose of Willowbrook began to expose the shame of our nation's criminal treatment of persons with disabilities. The first whisperings of "deinstitutionalization" were soon matched by community based services. The overuse of

psychiatric drugs and physical restraints to control behaviors began to be slowly countered with the use of behavior management strategies and (at least for some) safer drugs. Living and working in the community became commonplace, although meaningful work is still a challenge. Being able to live with one's friends and have family members close at hand are a reality for many, though for many more, poverty and loneliness is the norm. The emergence of mental health services for people with developmental or cognitive delays is finally a reality, though it has a long ways to go. In the light of how he was included during his lifetime, Uncle Dave was educated in the public school system, raised in his family's faith, and had begun an adult life of going to work every day. But the huge gap caused by not being able to meet his emotional needs caused a lifelong problem that never was to heal properly. Still, the Nathals had a lifelong commitment to bring him home from Polk, see him settled in a place of his own in Erie, and include him in everyday family gatherings. This was a powerful example for my generation of the more than two dozen first cousins of the Nathal clan. When my sister Susie was born with Down syndrome in 1968, we kids said to my parents, "We're keeping her, aren't we?" We knew enough to know that often babies like Susie were "put away". There was no question but that she was going to be raised at home with her five siblings, and her brief life had a far-reaching effect on all of us: three of us obtained degrees in and had careers in special education and related services. When my son Peter Ben was born with Down syndrome in 1990, I had the gift of all of this history. I knew not to ever take for granted the kinds of services that were available to him at birth, let alone enormous changes in societal values, in medical research, in education, and in higher expectations for my son's future. But I only have to look at Uncle Dave's life to see the joy and commitment of lifelong supports

from family and friends, as well as needless suffering because of limited resources. We must never forget these lessons. We must remember the institutions and say "never again". We must look to the future and move forward with the highest expectations. Revisionist history is a terrible thing. This essay is an attempt to share my perceptions of how my Uncle's life was shaped by the times he lived in, as well as a tribute to the loving care of his brothers and sisters. It is also meant to honor Uncle Dave's memory. I am sure that my Mom, my Aunts Coletta and Delphina, and my Uncle Al will have different memories of the timing of things and perhaps even why things were done and decisions were made. In that sense this is not just a biography of David Nathal but rather, a way to think about him and his life. It certainly impacted mine! Rest in peace. In memoriam, David J. Nathal.

Mary Beth Pilewski Paul, Westerville, Ohio March 8, 2000

IUST QUOTES

God is at home, we are in the far country.
Annie Dillard, Spirituality of Caring

I'm coming to understand how memories are imposed on the past and also how they get lost. We reach a point where we do not know whether we remember an actual event or an imagined one; we cannot remember whether a significant event actually happened. In studying a photograph, which is documented proof of our presence at an event, we analyze the event as if we had been there, when for the purposes of memory we had not, for it has vanished from the mind.

Bobbie Ann Mason, Clear Springs

A VIEW FROM THE BACK WINDOW

Former Weavers' singer Ronnie Gilbert noted once that, when she had to select songs for a concert, she found herself "pulling out some old ones." That's what I've done this time. I brought this short piece back from the Autumn, 1991 issue of The Safeguards Letter. I revised a couple of things, but not very much. The prices mentioned, for example, are the 1991 versions. I thought that bringing this back might be a bit thought-provoking, even if the practice of doing so may seem a bit lazy.

*To the conversations about choice and empowerment mentioned in the paragraphs that follow has been added the topic of "self-determination". For example, in a recent newsletter published by the American Association on Mental Retardation, Charles Moseley and Thomas Nerney discussed the kinds of organizational changes (in human service culture) that would be necessary if "self-determination" were to become more real for many people with disabilities. I noticed that **income** for people with disabilities was mentioned, but the mention came very late in the article. My re-offering of the following piece is sparked by the notion that income has to be one of the earliest (if not the first) topics in a discussion that is serious about people assuming more valued positions in this particular society. JRP*

"Power to Spend"

Jack R. Pealer, Jr.

There is a great deal of talk these days about ways to bring powerless people into "empowerment"--ways to make "choices" available to those (including people who have disabilities) who have never experienced many. It seems practically impossible to dip into the fountains of knowledge in the human service field--as those fountains are represented by conference programs, professional journals, or edited multi-authored books--without encountering presentations or articles (or presentations converted into articles) about empowerment or choice. I think that this is, in general, a healthy development. I just want those (including myself) who talk about such things to be as clear as they can be about what they are saying. In that vein, I'm going to fuss a bit about one aspect--a most important one, I think--of the choice/empowerment issue.

Almost twenty years ago, my friends Sandra Landis and John Winnenberg led a group of people into thinking and working carefully to try to bring about "the good life" for some adults with disabilities who lived in group homes in New Lexington, Ohio. A part of this work involved elevating to prominence the close relationship between people: a) "making choices" and b) having "disposable income" to use. At about the same time (early 1980's) I was studying the earnings of people with disabilities who worked in various "sheltered workshops" in southeastern Ohio. I was finding that people in those workshops were earning a mean annual wage (total earnings divided by the total number of workers) that was less than 10% of what it cost to keep people in the sheltered workshops. (*It's about the same now.* JRP)

Involvement in these activities--the New Lexington work and the earnings-study--should have made me appreciate the causal connection between income and choice. If one has little or no income, then one's choices must be limited, if not non-existent. I have tested this notion a bit by applying it to myself. I recorded, as best I could, the choices or decisions that I made in one day. It happened to be a Saturday in early October of 1991. I then reviewed my record and jotted down the relationship (if any) of each decision to the spending of money. Some of the things I chose or decided about on that day were:

- To get up and read the Saturday morning newspaper at 8:00 a.m. The Chillicothe *Gazette* costs \$9.75 per month, for home-delivery six days a week.
- What to have for breakfast. My choices were determined by a trip I had made to the local Big Bear supermarket the previous week--in my own, mostly paid-for automobile. At the market I wrote a check for about \$100.00 for two-weeks groceries.
- To go the hardware store or K-Mart for some "stuff" I needed for home-repair or home-improvement (on a home with a \$45,000+ mortgage we were able to get twelve years ago). This "stuff" included two brass porch lamps, some paint, and oil-base stain for the new front porch floor.
- To watch the Ohio State football game on television--ESPN cable, which is part of a "package" from the cable system that costs an extra \$10 or so each month.
- To rent a video ("Cinema Paradiso"--recommended) for Saturday evening, which meant another car-trip (car loan, gasoline, insurance, etc.) and spending \$2.65 for the video.
- To order by long-distance phone (OK, it was an "800" number, but I still have to rent the use of the phone line) two pair of corduroys from L.L. Bean. The only way one can phone-order is by using a credit card, of which I have too many.

Now, this is still a pretty typical autumn Saturday for me--house repairs and OSU football, and I'm willing to believe that it would be typical of lots of my neighbors and fellow-citizens of this part of the world. I'm sure that I didn't recall, much less record, all of the decisions I made. But, of those I did remember and write down, most could not have occurred without my (easy) access to cash or to credit (the promise of future cash).

I remember that, some years ago, one way of explaining the "principle of normalization" included the idea that efforts be directed toward ensuring that people who have been socially devalued experience "life conditions at least as good" as those experienced by typical citizens. "Social role valorization" extended this idea, so that what is called for is the use of valued or desirable methods or tools in order to make more socially valued roles-in-life available to people. If I'm going to decide how someone else is going to be helped, a reliable guide to my decision-making is my sense of what I understand to be "good" or desirable for me. I think that it's "good" for me to have a major hand in choosing things that affect my life. I've built a case, above, that a large part of my power to make choices rests in my power to purchase.

To go back where I started, "choice" and "empowerment" are ideas still on many lips these days. So, what is it that's important to do, if we really want people with disabilities (or other poor people) to gain a measure of real control over what happens to them? Providing people with information--about the choices that may be available to them--is important. Making sure that people who are inexperienced at choosing things have enough time to learn how to do so--that's vital. But, getting **income** to people may be the most important thing of all. And that has turned out to be a hard thing to do. Even the best "vocational" programs for people with severe disabilities that I know of have raised their ratio of workers' earnings to program costs only to about .33; in other words, the program expends about three times as much money for operations as is earned by those who are helped by the program. John McKnight has reminded us that the world of "helping" others, financed by public funds, has become a zero-sum game in which "... the basic competition for the limited funds available for the 'disadvantaged' is between the human service system and cash income for labeled people."¹ In such competition, we know who always wins. And yet, if we look at what we say we want for people (i.e., choice, empowerment) and we look at how we spend our Saturdays or many of the other days of our present lives, we will know that getting people money to spend could be the most helpful thing we could do.

A relevant cartoon appeared in the *New Yorker* a few years ago. It pictures a man sitting in a chair in the office of a bank official. Presumably in response to the banker's question, the man observes: "I've heard a lot about money, and now I'd like to try some." It's certain, in this world of billboards, radio ads and TV commercials (and especially at this time of year) that people with disabilities and others who are poor have heard a lot about money.

Jack Pealer

About THE SAFEGUARDS LETTER

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

¹ "Do No Harm: A Policymaker's Guide for Evaluating Human Services and Their Alternatives"

THE SAFEGUARDS LETTER

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BACK AGAIN

Surprise! OHIO SAFEGUARDS has not entirely disappeared. Here we are, back again. It's good (for me, anyway) to be sending this issue out to our long-time readers. Once in a while someone mentions to me that they enjoyed receiving *The Safeguards Letter*. Sometimes people actually say that they miss it. So, we're trying again.

This issue of *The Letter* is being mailed to everyone on the mailing list, which may take some doing because some readers have surely moved since the last issue came out two years ago. This and subsequent issues of *The Letter* will, moreover, be available on the web, at www.ohiosafeguards.org. We will continue to send issues through the U.S. Mail to readers who want a mailed copy, but we'd be happy (for cost reasons) if readers who could receive *The Letter* via the internet would be willing to do so. Here's what we'd like willing readers to do:

- Tell us whether you're willing to read *The Letter* on-line. It will be a "PDF" document, and you'll need free Acrobat Reader software to read it. You can, of course, feel free to print your own paper copy of *The Letter* if you want to do so.
- Send us your e-mail address. We will build a list and send you a message to let you know when a new issue of *The Letter* is available on the web. You can send your e-mail address through the mail (to the return address on the back page), or you can send it via e-mail to jackjr158@earthlink.net.

Eventually, we expect to post selected back issues of *The Letter* on the web site as well. We hope that you remember some of them and enjoy catching up with them. We also hope, of course, to find new readers through the internet—and, perhaps, receive some interesting responses to *The Letter* in the bargain.

Welcome back to you, our readers. We hope that you welcome us back as well.

Jack Pealer

THE MIRAGE OF PERMANENCY:
Orchard Hill as an ICF/MR. Wisconsin
Coalition for Advocacy

(Editor's Note: Once before, in the summer of 1991, we offered our readers the chance to consider this article, which originally appeared in the Newsletter of the Wisconsin Coalition on Advocacy in July, 1981. The article is now 22 years old-old enough to drink liquor in Ohio. It's still worth reading. We have re-printed it now because we think it speaks to some recent and impending issues.

For example, the Board of Supervisors of Fairfax

County, Virginia recently approved re-zoning of a property so that a church could build a 70 space "respite center" for families with children who have developmental disabilities. Apparently, supporters believe that "respite" will remain the mission of such a center, despite more than 100 years of history that would tell us otherwise—part of that history being Orchard Hill.

Also, for example, tension looms across the country between those in communities who view sheltered workshops as useful, meaningful places where adults with disabilities can work and those who reject the workshops in favor of efforts to

help people be employed on "real jobs" (as many self-advocates describe them). The story of Orchard Hill reveals that one source of this tension is the expectation that a setting-like Orchard Hill or the workshop-will be able to deliver something-like family living or good work-that is actually ruled out by these organizations' very structure and financing patterns.

Anyway, here, again, is the story of Orchard Hill.) JRP

Once regarded as an innovative residential setting when it opened in 1973, Orchard Hill is now in turmoil deeply torn between parents' expectations, the needs of adult residents, and the funding and licensing requirements of the federal and state governments. This case study reveals how the parents' efforts to help their developmentally disabled family members have become perverted by the requirements of the system.

When the state was developing community residences to deinstitutionalize the State Centers, a group of parents, most of whose developmentally disabled family members lived at home, joined together to develop an alternative to a large, impersonal institution. Reasoning that an institution would have greater longevity than an eight-person group home, the parents tried to combine the permanency and security of an institution with the "intimacy" of a group home.

It was most important to the parents that Orchard Hill be a permanent home where their developmentally disabled family members would always be well protected even after the parents were no longer alive. Permanency also meant that the residents would be able to enjoy the security of living in the same place with the same people and avoid the trauma of moving from place to place when professionals determined that their needs had changed. The parents believed that their developmentally disabled family members needed continuity in their personal relationships and lots of tender loving care.

Orchard Hill was designed to provide a comfortable atmosphere where

residents could relax under the protective eye of a house parent. Acting *in loco parentis*, the house parents were expected to provide warmth and caring, to accommodate almost any behavior no matter how inappropriate, and to treat the residents as the parents directed. The parents expected developmental training to be minimal at Orchard Hill in order to preserve a home-like atmosphere. In addition to houseparents, the original programming staff at Orchard Hill consisted of two activity therapists, two dance therapists, and a social worker and nurse. It was also expected that all residents at Orchard Hill would participate in day activities away from Orchard Hill at sheltered workshops or day activity centers or even competitive employment in the community. This separation of residential and day programming functions is recommended from a normalization perspective but is usually violated in most large ICF/MRs. Orchard Hill may have opted for off-site day programming because the parent group which formed Orchard Hill, called Retardation Facilities Development Foundation (RFDF), was actually an offshoot of Madison Association for Retarded Citizens, which operates sheltered workshops and day service centers for developmentally disabled persons in Madison.

To accomplish their vision of a permanent home, the parents conducted a massive fund-raising drive over a two-year period which raised 40 percent of the capital from Health, Education, and Welfare (HEW), 40 percent from a low-interest loan, and 20 percent from private contributions to Orchard Hill. Many parents contributed to Orchard Hill with the expectation that their developmentally disabled family member would be assured of a permanent place at Orchard Hill. The parents also hoped to maintain their control over the direction of Orchard Hill through a strong parent-dominated Board of Directors.

The parents' desire for a loosely structured program at Orchard Hill encountered some difficulties from the beginning, but these were subordinated to the overriding purpose of maintaining Orchard Hill's permanency. As a condition for accepting funds RFDF was obligated to fill a certain percentage of the beds within

the first year of operation. With the founding parents able to fill less than one-half of the places, it became necessary to recruit people with many different needs to live at Orchard Hill. These people with diverse needs, ranging in age from 20-66 years, had to fit into the structure which had already been determined. The parents' vision of "intimacy" at Orchard Hill took the form of eight separate cottages, each supervised by a live-in house parent. The original plan had been for eight residents to live in each cottage, but this number was enlarged to twelve in order to ensure that sufficient money would be generated to cover operating expenses. Most Orchard Hill residents have limited contact with non-disabled people other than staff, and approximately one-half of the residents attended a sheltered workshop located just behind the residential facility.

When Orchard Hill was opened in 1973, Medicaid was the only funding source available for its operating costs and so Orchard Hill was certified as an ICF/MR. At that time Aid to Disabled Persons (*Ed., forerunner to SSI*) was too small, the state had not yet created the Special Living Arrangements supplement, and the 51 Boards (*Ed., county agencies focusing on developmental disabilities*) had not been established in the counties to fund residential services.

As a Medicaid-funded facility, Orchard Hill has always been subjected to annual surveys and Independent Professional Reviews (IPRs) by the Division of Health (DOH) surveyors in the Department of Health and Social Services (DHSS). But the federal government did not circulate the ICF/MR standards until 1974, and the requirements for compliance remained unclear. Lacking expertise in developmental disabilities programming, the DOH survey teams were primarily involved with monitoring physical standards. Located on a sprawling ten-acre campus with an apple orchard that gives Orchard Hill its name, the DOH surveyors observed that Orchard Hill's modern cottages were clean and in compliance with physical standards, and that the residents were away for day programming every weekday. The laxity of the DOH in enforcing programming standards may also have reflected pressure to use Medicaid

funding whenever possible because it cost Wisconsin only 42 cents on the dollar to keep people in Medicaid-funded facilities. With thousands of people with developmental disabilities placed in nursing homes in Wisconsin without special programming, Orchard Hill may have looked like a model residential facility.

It is difficult to probe all of the reasons that the Division of Health altered its enforcement practices. Certainly, the revised ICF/MR guidelines released by the federal government in 1977 provided a clearer basis for enforcing the federal requirements for "active treatment" in an ICF/MR facility.

Through the IPR process, the DOH surveyors have been expected to review the treatment plan for each Medicaid-funded resident in a health care facility and to reclassify the level of care as a resident's needs change. The IPR team consisting of a nurse and a social worker might even determine that the needs of the resident cannot be met in the health care facility in which the person is residing. At Orchard Hill, a few residents have been transferred to nursing homes when it was determined that they needed more medical care than Orchard Hill was licensed to provide as a residential care facility and then as a community-based residential facility (CBRF). When certain behavioral problems came to the attention of DOH, Orchard Hill hired a part-time psychologist consultant to work with a few of the residents. These decisions to adopt a limited active treatment program were supported by some of the most active members of the Board of Directors whose family members needed the most supervision. But many other parents, with a long-standing distrust of institutions, continued to view treatment programs as incompatible with a permanent home.

In 1980 the RFDF Board decided to hire a new administrator whose expertise was in health services and fiscal management rather than in developmental programming. Orchard Hill was experiencing financial problems related to the new ICF/MR formula which the Department of Health and Social Services introduced in 1978-79, and the DOH was beginning to question whether Orchard

Hill's program was fulfilling the requirements of active treatment.

In order to accommodate the ICF/MR standards, the new administrator began developing programming changes and hired a professional staff which would begin to develop individualized case plans for all Orchard Hill residents. As required by the ICF/MR standards, these professional staff have begun performing multi-disciplinary assessments and addressing developmental objectives. The new administration has also begun to introduce a behavior modification program to correct inappropriate individual behavior in a way that some parents and advocates regard as dehumanizing.

At the insistence of the RFDF Board of Directors, the introduction of a behavior management program was confined to one cottage where residents with behavioral problems have been concentrated. Although the Orchard Hill administration claims that the behavioral management program has not been implemented yet, staffing in the behavioral management cottage has been beefed up to 2-3 staff at one time who function on a shift basis compared to one live-in house parent in the other cottages. The concentration of twelve residents with behavioral problems into one cottage, however, has accentuated certain interaction problems among residents, increased staff burn-out, and generated rumors about inappropriate behavior treatment approaches. Three residents have already been removed by the DOH for needing more care that Orchard Hill can provide. The parents of these residents question the authority of the IPR process and are furious with the attitude of the new Orchard Hill administrator that certain residents do not belong at Orchard Hill.

In the last IPR process, Orchard Hill was found deficient for not having individualized plans of care and treatment for eighty-four residents. These problems are not new but have existed since Orchard Hill opened eight years ago. As if to emphasize the qualitative nature of this change, for the first time DOH has decertified two Orchard Hill residents from Medicaid reimbursement for not needing the intensive care that an ICF/MR is supposed to provide. In addition, the IPR

process has identified another fifteen residents who could be transferred to less restrictive settings in the community if appropriate services could be provided.

These developments have undermined the parents' dream of a permanent home for their developmentally disabled family members. Many parents fear that Medicaid requirements threaten to transform the residential nature of Orchard Hill into a medical treatment center. Recognizing that some residents may need more supervision than others, a split has begun to emerge among parents. Parents whose family members appear to function well at Orchard Hill are beginning to question whether other residents, who cannot adjust to the loosely structured program, actually belong there. Other parents remember that Orchard Hill was supposed to be a permanent home for all residents and that forcing some residents to leave now may jeopardize the permanency of all residents as their needs change. Many parents have never believed that their developmentally disabled family members could ever function in a less restrictive community setting. Confronted by a new professional staff which is trained in developmental programming, many parents are angry at the staff's emphasis on independent living skills. Some parents fear that developmental training for their developmentally disabled family members could jeopardize the parents' dream of permanency for them at Orchard Hill while others question the type of training the residents are receiving. Some developmentally disabled residents have been blocked by the parents and guardians from moving out of Orchard Hill into the community. One Orchard Hill resident was overheard telling another, *"I wouldn't mind living in the community, but it would kill my mother."*

At a recent Orchard Hill parents' meeting, many parents expressed the view that their developmentally disabled family members could never live in the community. A heated exchange ensued when a middle-aged other bravely stood up and announced that she hoped her daughter would be able to live in the community. Amid jeers and rebukes an older parent shouted out, *"It is easy for you to say that because you are young enough to help your child*

if she fails in the community." At the bottom of parents' fears is the widely-held perception that the community service system cannot provide the security of an institution. Many parents feel betrayed by the RFDF Board for not having informed them about how precarious dependency on Medicaid could be even though there was no alternative funding source for a facility of the size of Orchard Hill.

The RFDF Board is suspicious of the state and federal governments for changing the rules by which Orchard Hill has been regulated over the last eight years. The new Orchard Hill administration is trying to implement the current ICF/MR guidelines and is frustrated by the apparent assumption of the Board of Directors that the Orchard Hill administration should continue to serve as a buffer between the state and federal funding and licensing requirements and the parents' original expectations for Orchard Hill. Looking at this residential program in turmoil, many advocates wonder why residents who can function well at Orchard Hill wouldn't be able to develop better in a smaller, more socially integrative home in the community; they also wonder whether the residents who

need more supervision will need a more individualized program than can be provided in a twelve-person cottage. In the background the debate simmers about whether it is cheaper to warehouse people in institutions or to provide opportunities for personal development in smaller integrative residences in the community.

In many ways Orchard Hill was built to meet the needs of the parents rather than the residents. But the form it has taken has been shaped by the requirements of funding and licensing and by the lack of sufficient resources in the community service system. These external forces continue to constrain the options of the parents and the current Orchard Hill administration. The real tragedy of Orchard Hill is not that parents value permanency over developmental training but that the long-term support system in Wisconsin fails to guarantee permanent support for developmentally disabled persons in their own homes in the community.

July, 1981 "WCA Newsletter",

About THE SAFEGUARDS LETTER

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

JUST QUOTES

*(Note: Ivan Illich died on December 2, 2002 in Bremen, Germany. I didn't know of this until I read about it in **The Catholic Worker**. The news—and it was certainly news because Illich was and is one of the most-read thinkers in the world—did not make it to our local papers. In observance of Illich's death, I'm including a few quotes from his difficult essays. JRP)*

How should I distinguish the acquisition of education from the fact that people have always known many things, have had many competencies and, therefore, have learned something? So I then came to define education as learning under the assumption of scarcity, learning under the assumption that the means for acquiring something called knowledge are scarce.

In Cayley, David (ed.) *Ivan Illich in Conversation* (1992)

Gravediggers did not become members of a profession by calling themselves morticians, by obtaining college credentials, by raising their incomes, or by getting rid of the odor attached to their trade by electing one of themselves president of the Lions Club. Morticians formed a profession, a dominant and disabling one, when they acquired the muscle to have the police stop your burial if you are not embalmed and boxed by them.

Toward a History of Needs (1978)

I went to Jacques (Maritain), whose imaginative Thomism meant very much for me.... As I was sitting there with him—he had a teacup in his hand and was shaking when I talked to him about the question which bothered me, that in his whole philosophy, I didn't find any access to the concept of planning. And he asked me if this was a different, an English word for accounting. I told him no, and if it was for engineering. I said no. And then at a certain moment he said to me, "Ah! Je comprend, mon cher ami, maintenant je comprend." Now I finally understand. "C'ette une nouvelle espèce du péché de presumption." It's a new species of the sin of presumption, planning.

Part Moon, Part Traveling Salesman (1991)

The compulsion to do good is an innate American trait. Only North Americans seem to believe that they always should, may, and actually can choose somebody with whom to share their blessings. Ultimately, this attitude leads to bombing people into the acceptance of gifts....

Rich nations now benevolently impose a strait jacket of traffic jams, hospital confinements, and classrooms on the poor nations, and by international agreement call this "development"....

This is the moment to bring home to the people of the United States the fact that the way of life they have chosen is not viable enough to be shared.

A Celebration of Awareness (1971)

MORE JUST QUOTES

A tourist focuses in on a most idyllic picture: a man in simple clothes dozing in a fishing boat that has been pulled out of the waves that come rolling up the sandy beach. The camera clicks, the fisherman awakens. The tourist offers him a cigarette and launches into a conversation: "The weather is great, there is plenty of fish, why are you lying around instead of going out and catching more?"

The fisherman replies: "Because I caught enough this morning."

"But just imagine," the tourist says, "you would go out there three or four times a day, bringing home three or four times as much fish! You know what could happen?" The fisherman shakes his head. "After about a year you could buy yourself a motor-boat," says the tourist. "After two years you could buy a second one, and after three years you could have a cutter or two. And just think! One day you might be able to build a freezing plant or a smoke house, you might eventually even get your own helicopter for tracing shoals of fish and guiding your fleet of cutters, or you could acquire your own trucks to ship your fish to the capital, and then...."

"And then?" asks the fisherman.

"And then," the tourist continues triumphantly, "you could be calmly sitting at the beachside, dozing in the sun and looking at the beautiful ocean!" The fisherman looks at the tourist: "But that is exactly what I was doing before you came along!"

From Heinrich Boll, quoted by Wolfgang Sachs in *Resurgence* (Issue 196)

KEEPING THE BALANCE

David and Faye Wetherow

As parents of children with disabilities, one of the vulnerabilities we face is the prospect of personal isolation, a thinning out of relationships to the point where our family's circle (and ultimately that of our child) narrows down to service providers and "others like us"—other families who have children who live with disabilities.

This "narrowing" stems from four sources:

- It is an unhappy fact of contemporary North American life that people remain uncomfortable with disability in general. And people may be particularly uncomfortable when someone close to them is "struck by" a disability. We "don't know what to say;" we "don't want to interfere;" and we are afraid that if we open up communication we will touch a thread of sorrow that may be uncontrollable.

Fear is the mind's reaction against the inherent generosity of the heart.
Because the heart knows no bounds to its giving, the mind feels called upon
to define limits. --Ram Dass

- Because our society is uncomfortable, the *family* is likely to feel uncomfortable about the prospect of "being a burden" to family friends; we become reluctant to "impose," to ask our friends to extend practical assistance.
- The family may feel itself overwhelmed in terms of time, energy, and attention by the child's specific needs and the new demands of engaging with "the system." As any parent can tell you, caring for a young child seems to take up all of your time. Caring for a child with a significant disability is likely to be even more demanding, and the parents may find themselves with disability-related appointments, meetings, support group gatherings, and so on.
- Finally, in North America, family and community ties are fragmented at the best of times. Our society prides itself on being highly mobile, independent, ready to "move on" at the slightest whim or to relocate quickly in a search for solutions to economic, social, or family problems.

However (and this is a big however)...

➤ If it is true that the quality of our child's life (and his family's life) will be greatly enhanced by the presence of a large circle of people who know him, love him, aren't afraid to touch him or to be touched by him, and know that they will be part of his future and he will be part of their future, forever...

➤ If it is true that our child's opportunities will be greatly enhanced by long-term, thoughtful, on-purpose connections with many "civilians"—people whose lives are anchored in the larger world, the broader cultural, economic, congregational, and social environment...

➤ If it is true that our child's development can be greatly enhanced by loving and enduring connections to other children and adults who help us define our identity—who shape our understanding, expectations, hopes, social expressions, etc....

Then it is important to focus *at least* as much of our effort, thinking, learning, and personal action in the direction of the "boundary with community" as we invest in the "boundary with the service system."

What does this mean, in practice?

If we pay close attention, we may discover that this is not only a place of hospitality; it is a place of abundance. The congregation of a small church touches dozens, perhaps hundreds of other “places” in our community. Harry goes to work at the tractor plant. Tom prints the local newspaper. Laurie’s father is a member of a group that rebuilds antique airplanes. Lillian is connected with the Swedish Cultural Society. Jack plays a great bluegrass banjo and has dozens of good friends in the music community.

If these friends understand that one of the gifts they can offer is to look for our child’s gifts, delights, and interests, and to introduce him to people whom they already know and trust, and build bridges to the places where those interests will be welcomed and celebrated, we discover that we live in an abundance of connections. Far too often, though, we turn Harry, and Tom, and Lillian into fund-raisers for the service system, or we recruit them into volunteer roles that are mere reflections of traditional “service” roles and ask them to leave their real identities at the door. We move from abundance to scarcity.

Our friend John McKnight has shared some ways of helping us recognize some of the sweet places in our communities. John reminds us to look for places...

Where people come together by consent, rather than by control; where relationships are centered on affiliation, instead of exchange;
Where people are always identifying, inviting, and mobilizing one another’s gifts;
Where the culture shows up in the form of stories, rather than data;
And where “we hear people singing” because people are *making* music, rather than consuming musing, *making* art rather than consuming art.

The reality is that even with children who do not live with disabilities, the family isn’t “big enough” to do everything alone. Our highly mobile, fragmented society is living with the consequences of fragmentation, as families become more and more separated from extended family, friends, congregational life, and community life. This is a *far* more pressing reality when a child lives with a disability—the family just isn’t “big” enough. We may try to fill the gap with “services,” but the truth is that our sons and daughters need the ongoing commitment, support, devotion, and connections that can be offered by true friends, and that can never really be “delivered” by formal services.

Wendell Berry reminds us:

We hear again the voices out of our cultural tradition telling us that to have community people don’t need a “community center” or “recreational facilities” or any of the rest of the paraphernalia of “community improvement” that is always for sale. Instead, they need to love each other, trust each other, and help each other. That is hard. All of us know that no community is going to do these things easily or perfectly, and yet we know there is more hope in that difficulty and imperfection than in all the neat instructions for getting big and getting rich that have come out of the universities and...corporations in the past fifty years.

-- Wendell Berry, Home Economics

A final note... We are not saying that services are “bad,” misguided, or irrelevant. We are simply saying that they cannot be a sufficient foundation for a good life. We need to do everything we can—which means taking action—to keep our lives in balance, our relationships in balance, and our hearts in balance. Remembering to pay close attention to the shoreline with community and having the courage to call upon the bonds of friendship can play a big role in helping us keep that balance. Peace!

David and Faye Wetherow share their lives with an adopted daughter who has complex mobility and communication challenges. They have long been involved in innovative service development, PATH and creative facilitation training, and community building. They can be contacted at: 911 Terrien Way, Parksville, BC V9P1T2, phone: 250-248-2531, e-mail: wetherow@communityworks.info, web: <http://www.communityworks.info>

View from the Back Window

"June 23, 1953"

I called him Bamp. That was short for Bampoo, which is the sort of name you get when you allow your first grandchild to change your name. As far as I knew, though, he didn't mind.

Today it's been fifty years since he died. It turns out that he was one of my great teachers although in a way that he surely couldn't have wished for.

Fifty years! I can't say I remember it like yesterday. I was not yet ten. It was a thoroughly other world in 1953. Ike was President. Ohio was celebrating its "Sesqui-centennial." But I do remember the date Bamp died, because I told myself on that day that I would never forget. And, most years since, I have not forgotten.

Bamp was my mother's father. He and my grandmother-and other relatives from time to time-lived in a not-so-big house at 151 Arthur Avenue in Mansfield, Ohio. I was born a few blocks from there. My mother and I lived there too because my father was away in the Army (1941-46), and he could only come home once in a while. Bamp mowed the grass; there wasn't much because the lot was small. He trimmed the privet hedge. I seem to recall that he messed about in the detached garage--a dark space lined on the inside with all of the old Ohio license plates he had bought for years. Then, you got entirely new plates every year.

Somewhere I have a photo of him. It must have been taken in the summer because he is wearing a straw hat. Often, in the summer, I wear a straw hat, in honor of both my grandfathers. I remember that Bamp was not tall but seemed a big man anyway. He was quiet. I cannot recall the sound of his voice. When I think about him now, I wonder whether he might have been shy and, therefore, somewhat lonely at times.

He worked for Bissman & Company, a wholesale grocery company. He traveled regular routes across north central Ohio and sold groceries to local stores. A&P and Kroger represented the enemy--threatening to smaller local merchants. I have a packet of letters that Bamp wrote to me, and later to me and my sister. They are all written on the stationery from the American Hotel in Wooster, Ohio. Wooster is just 35 miles from Mansfield, so his sales route must have been a busy one that required a once-a-week out-of-town stay at such close distance. Several of the letters inform me that he had to stop writing "now" so that he could walk across the street to the railroad station to post the letter. That way it would be delivered on the next day.

About once or twice a summer, when I was 6 or 7, I went with Bamp on one of his routes. It was always the same one--east from Mansfield into eastern Ashland County where we made stops in the villages of Redhaw, Polk, and Nankin. The last stop on the route was in Savannah--a slightly larger town--and from there the highway led straight back home to Mansfield. In each place we stopped at a small grocery (or maybe more than one) that had a gasoline pump out front--in those days it was either Sohio or the sign of the flying red horse (Mobilgas). In a dark rear corner in a store in one of the towns (let's say it was Nankin) was a deep cool ice chest. I could reach down deep to pull out an orange or grape "Whistle" or maybe a 7-UP. We would drive off toward the next town but would pull over along the gravel highway near a patch of woods. We would get out the sandwiches my grandmother had prepared--ham salad, in my recollection--and eat lunch and drink cool soda by the side of the road. Perfection of this memory requires that there were cows in the field across the road--a field with wild day lilies growing along the fencerow. I can't vouch for these last details.

Lessons about love were written in those letters from the American Hotel and were given without words in the lunches along the road between Nankin and Savannah. I had other lessons, though, that were learned through Bamp's illness and death.

In 1951 or 1952 Grandma and Bamp sold their home and most of their furniture in Mansfield, and they came to live with us in our house in Columbus. I've never known why. Did Bamp lose his

job at Bissman's? If so, did they lose their income? Was their Social Security insufficient to let them keep their home? Was Bamp sick? In any case, they came to live with us, which was no bad thing for my sister and me.

Except that Bamp did get sick. Some time in the spring of 1953, he had a stroke. He lost much of his memory right away, and he sometimes shouted, raged, and struck out at people around him. Remember, I said he was a big man. Within a short time, he was moved away to a large, old-seeming house on North High Street, close to the office of our dentist.

That house was my first experience with the idea of the nursing home. Along the sidewalk from the nursing home's porch to the street was a pair of life-size stone lions. When we went to visit, I often sat on top of one of the lions. I didn't go inside very much. Maybe I was afraid. Some of the people—there were lots of them in beds in various corners of the rooms—were confused, shouted, looked lost. The smell—so familiar now but simply scary then—mingled urine, sweat, and Pine Sol. Mostly, I didn't understand. Why was Bamp here? Why was he in pajamas all the time? Why did people treat him this way? Why didn't he come home?

He died on June 23, 1953. In my memory, I swore (as seriously as an almost-ten-year-old can swear) not to forget the date. I was so angry at that place, which, if it hadn't caused his death, so clearly contributed to it, in my thinking. And, whether—or not—I swore an oath, I haven't forgotten the date. And now it's been fifty years.

My lesson—my conviction through the experience of Bamp's death—made it easy for me to be convinced about the truth of Wolf Wolfensberger's prose and talk about the creation of deviancy and about the "wounds" of devalued people. When I read and later heard those ideas, the ground for my learning had already been prepared. And that learning has now affected me and my work for more than half of my life. What I felt on June 23, 1953 has, in that way, stayed fresh through the length—and the brevity—of fifty years.

Jack Pealer

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The Safeguards Letter

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ONCE AGAIN!

Welcome to late winter and early spring, 2004. This issue of *The Letter* is being mailed to everyone on the mailing list who did not tell us that they would read *The Letter* electronically. This and subsequent issues of *The Letter* are available on the web, at www.ohiosafeguards.org. As promised, we'll keep sending issues through the U.S. Mail to readers who want a mailed copy. We'd be very happy (for cost reasons) if readers who could receive *The Letter* via the Internet would be willing to do so. If you haven't already notified us and you're willing to try out the electronic version, in lieu of a mailed copy, here's what you can do:

- Tell us whether you're willing to read *The Letter* on-line. It will be a "PDF" document, and you'll need free Acrobat Reader software to read it. You can, of course, feel free to print your own paper copy of *The Letter* if you want to do so.
- Send us your e-mail address. We will build a list and send you a message to let you know when a new issue of *The Letter* is available on the web. You can send your e-mail address through the mail (to the return address on the back page), or you can send it via e-mail to jackjr158@earthlink.net.

We have posted some back issues of *The Letter* on the web site as well, and more will be posted over the next few months. We hope that you remember some of them and enjoy catching up with them. We also hope, of course, to find new readers through the Internet—and, perhaps, receive some interesting responses to *The Letter* in the bargain.

As the weather turns warmer, at least in northern North America, we wish you time in the sun and a great garden in 2004.

Jack Pealer

IN MEMORY, JEROME METZEL

Notice came last week of Jerome Metzel's death in Cleveland. He was 89 years old. In 1992, Mr. Metzel was willing to be interviewed by OHIO SAFEGUARDS. He was one of several pioneers of supports for people with mental retardation in Ohio who shared their stories with us as we prepared a booklet called *The Community Living Paper* for the Developmental Disabilities Council.

I remember talking with Mr. Metzel over lunch at Tower Place in downtown Cleveland. It turns out that I still have the notes from the interview. Here is how we summarized his recollections in *The Community Living Paper*.

Jerome Metzel remembers the beginning of workshops in Cleveland. He recalls that an Episcopal minister at the Trinity Episcopal Church in downtown

Cleveland was interested in arranging employment for adults with mental retardation and had started a small work program at the church. It happened that this minister was also a participant in an athletics group at Cleveland's Central YMCA, right across Prospect Avenue from the church. Other members of the athletics group were businessmen (factory owners or managers, etc.) in Cleveland's industrial near east side. The minister convinced some of the businessmen to come across the street to see what adults with mental retardation could do, and some of these visits produced contract work for the fledgling work program.

That was in 1958. Lots more people in Cleveland have found good work to do since that beginning. We're grateful we were able to learn from Mr. Metzger's memory. Our sympathy goes to his family.

Jack Pealer

DISCERNING ACTUAL LEVELS OF SUBSTANTIVE EMPOWERMENT

(Note: Reprinted, with permission, from *Planet Advocacy*, Issue Number 7, March 2004, pp.6-7.)

There is often a desire upon the part of people involved in services to take steps to ensure that the recipients of services are "empowered." Being able to translate this into practical action, which makes a difference at the level of substance, is often more difficult than many might expect. This is because there is often a lack of precision as to what something like "empowerment" should mean. This is why it is helpful to start with measures of empowerment that are relatively straightforward.

One way to achieve this is to start with the simple test of whether a person who is assisted by services is actually being enabled to make a significant difference, *through their own actions*, on the character of the service they are receiving. More precisely, of the many important decisions taken that result in the actual design and operation of the services they ultimately receive, how many of these were made *by the person*, and how many were made *by others, on behalf of the person*.

In order to evaluate this question, one would need to be able to identify what the major decisions are that most affect the actual substance of what the person ultimately receives, i.e. their service. For instance, given that staff account for as much as 85 % of the total costs of service, the degree to which a given service user has decisive "say so" over who are the staff that enter their life in service roles, might be one of these "key" decisions that should be focused on. By paying a good deal of attention to who is making the actual decisions about services, it becomes possible to distinguish, to an illuminating degree, who is actually empowered on matters of substance, and who is not. This is not all there is to empowerment, but it is central enough a vantage point on the exercise of authority and power that it could certainly not be dismissed as being trivial, immaterial or irrelevant.

It is useful to take this question and convert this standard of "the degree of authoritative decision-making carried by the person" into a continuum from low to high, as this helps clarify the extent to which "empowerment" could be considered a matter of degree, rather than to have it be a simple "yes" or "no" variable. This then requires that there be some manner of scaling of the levels of authoritative personal decision-making into a spectrum

from low to high. If the scale is too refined, it would potentially become a matter of hair splitting about increments of empowerment, whereas if it were too simple it might be much too blunt in capturing the nuances. So, it may be useful to start with a simple six level scale, with each level adding a greater degree of empowerment, at least as measured by the authoritative decision-making standard. What follows is an easy to use version of this.

Level One: The person does not make any substantive decisions about his/her service.

Level Two: The person does not make any substantive decisions about her/his service, *but* the person is routinely informed about the decisions others will be making on his/her behalf.

Level Three: The person is routinely asked to give advice, (i.e. is consulted), by the *actual decision-makers*, about his/her personal service decisions.

Level Four: The person begins to routinely personally make *a significant minority* of the substantive decisions that constitute her/his personal service. A *significant minority*, in statistical terms, might range from 25%-45% of key decisions.

Level Five: The person routinely begins to personally make *a significant majority* of the substantive decisions that constitute his/her personal service. A *significant majority*, in statistical terms, might range from 55%-90% of key decisions.

Level Six: The person is routinely making the vast majority of key decisions. The person simply does not any longer believe that she/he has a meaningful empowerment issue.

It is all too common that most people will never see services, or service systems, that rise much above a level two or three. In fact, most people have never seen a level four or higher service, though these do exist, and are relatively easy to establish and maintain, despite the suggestion that such routine levels of empowerment would be utopian. What makes many people confused is that the empowerment rhetoric used by services makes it seem as if people have much more authority and power than they actually do. This is most obvious in the case of user involvement efforts, where “involvement” or “participation” is largely in regard to comparatively trivial issues, whereas the really authoritative decision-making still remains with people other than the person.

This simple exercise can do much to clarify the actual relationship of service users to the substantive decision-making that affects their lives and services. It can also be helpful for the formation of alternative models of service design and operation decision-making that can leave service users more empowered, in both a practical and substantive way. So, even as a speculative exercise, it can be beneficial in giving more concreteness to aspirations about “empowerment”

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About THE SAFEGUARDS LETTER

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

JUST QUOTES

There is no such thing as a person who is "nobody very much." Everybody is an agonist in one of Fate's time-worn games on the earth, and winning or losing is not what it seems to be in the judgement of others, but as judged by the player himself.

Robertson Davies
Murther and Walking Spirits

"The best thing in the world for being sad," replied Merlyn, ... "is to learn something. That is the only thing that never fails. You may grow old and trembling in your anatomies, you may lie awake at night listening to the disorder in your veins, ... you may see the world around you devastated by evil lunatics, or know your honor trampled in the sewers of baser minds. There is only one thing for it then—to learn. Learn why the world wags and what wags it. That is the only thing which the mind can never exhaust, never alienate, never be tortured by, never fear or distrust, and never dream of regretting. Learning is the thing for you."

T. H. White
The Once and Future King

A corporation, essentially, is a pile of money to which a number of persons have sold their moral allegiance.

Wendell Berry
"The Total Economy"

To some people peace merely means the liberty to exploit other people without fear of retaliation or interference. To others peace means the freedom to rob others without interruption. To still others it means the leisure to devour the goods of the earth without being compelled to interrupt their pleasures to feed those whom their greed is starving. And to practically everybody peace simply means the absence of any physical violence that might cast a shadow over lives devoted to the satisfaction of their animal appetites for comfort and pleasure....

...instead of hating the people you think are warmongers, hate the appetites and the disorder in your own soul, which are the causes of war. If you live peace, then hate injustice, hate tyranny, hate greed-but hate these things in yourself, not in another.

Thomas Merton
"The Root of War"
The Catholic Worker (1961 and 2003)

WE GET LETTERS

From close to home:

I just read the latest issue and the View from the Back Window sparked some memories of my own "Bamps". My paternal grandfather, whom I never got to know (since he died before I was born), was also a grocer, (as was Jack's grandpa). But, what really struck a chord were memories of my maternal grandfather, who also came to live with us for a little while, (which I enjoyed **immensely**). I was about 14 yrs old at the time and had friends over often to hang out in the basement and listen to music. They also enjoyed him, especially when he pulled out his mandolin and started strumming. Often, the party ended up being right there in the family room with Grandpa, and people never would make it downstairs. At some point, he had to go to a TB sanatorium. I remember visiting him there and what a sight that was! Dark, dreary, cold and sterile hallways with a bunch of people sitting in their robes..., or less, just looking so pitiful. At some point later, he had the "privilege" of moving to a nursing home, called Rosedale Manor, which looked similar to the TB Sanatorium, but was a bit more cheery. Fortunately, (if my memory serves me right) he later got the opportunity (he was on a waiting list) to move into his own apartment in a Senior high-rise, which I believe, is where he died. He absolutely loved that apartment and there's no wonder why!! I believe he died a happy man there. Had he **had** to end his days at Rosedale, it would've been different.

I do think all these images have stuck with me during my 38 yrs, and are definitely the reason I got into the human service field. At about the same time Grandpa lived with us, is when I had to sign up for a Service program my sophomore year in high school. Since my first interest, Redwood school, (the MRDD program) was filled with volunteers, I chose to volunteer at a nursing home. I really enjoyed spending time with the "old folks" and listening to their stories. Later that same year, Grandpa died and I remember telling my mom how much I loved listening to Grandpa's stories while he lived with us and with a slight roll of her eyes, she just laughed. (I think I was the only one).

Now, I understand where she was coming from....I'm having a hard time listening to her stories...for the "umpteenth" time.

Thanks for sharing this with me!

Margie Fussinger
Fairfield, Ohio

From farther away:

Jack,

Enjoyed reading your "view from the back window". Beautiful story. It is strange how things get in our consciousness when we are young and lurk there waiting to impact our thinking.

For me it was less Wolf who pointed me towards the "truth" (although his work had an enormous impact on me) and more Jean Vanier. About the time I discovered Normalization I went to a conference where Vanier was speaking.

He was not really "famous" yet. We had a L'Arche community in Winnipeg and I had visited it but did not really "get it." I recall this strange looking and very thin tall man getting up and telling a story about a man who had lived his life in an institution. I recall the words "deeply rejected"..."given up"..."alone". He then said that he thought life was about erecting or taking down the barriers between ourselves and poor and wounded people. The barriers could be

things like comfort, success, security. I remember sitting there and the gospels finally made sense to me. I remember the work I was trying to do finally coming into focus.

I confess at this point in my life feeling somewhat alienated from that work. I did give it a fair run--lived in community in the inner city in Winnipeg, Atlanta, and Lancaster, Pennsylvania (constant threat of Amish break-ins and having black clothing stolen). Somehow raising our children drew us more and more into the mainstream of North American life and away from solidarity with poor folks. Daniel Berrigan was once asked: "what is the most oppressive institution in society"? He said, "the family". He said it demanded as much or more conformity than corporations and the military.

On good days I feel my "teaching" is an extension of the "work". I am a guide. I point students away from the lies of professionalized service and toward community membership. On bad days I feel a third string quarterback...on the sidelines...sending in decoy signals...and clutching a clip-board. Somehow close but not part of the action (I was actually the second string quarterback in high school! The Notre Dame Hounds! Got into a game once against the St.Louis Crusaders in Moose Jaw, Saskatchewan. It was the third quarter and we had a 52-0 lead. I ran the offense for the rest of the game and we won 52-0!). At some level I want back in the action.

Anyway...sorry this is so long and rambling but your story resonated with me. Now to class!!

Take Care, Bob Jones

(Bob is a long-time friend and is currently an instructor in the Disability and Community Support Program at Red River College in Winnipeg.)

A VIEW FROM THE BACK WINDOW

"Savage Discovery"

The title of the article caught my attention: "Childhood Functional Status, Family Stressors, and Psychological Adjustment Among School-aged Children with Disabilities in the United States." I'll call it CFSFSPAASCDUS for short. I lapsed into a satiric mood almost immediately after seeing that title. I wanted a copy, and Kathy Hulgín from Miami University was good enough to get one for me through an inter-library arrangement. The article was published in the July, 2003 issue of the *Archives of Pediatrics and Adolescent Medicine*, a publication of the American Medical Association. Its authors are, respectively, from the Harvard University School of Medicine and the Bloomberg School of Public Health at Johns Hopkins University.

If I had a premonition about CFSFSPAASCDUS, it was strengthened after my first reading. The article reviews statistics from the National Health Interview Surveys about children with disabilities, concludes that those children and their families have big problems getting along in the world today, and suggests that improving the health care (and especially the mental health care) of all of these family members would be a route toward improvement. I wanted, initially, to read CFSFSPAASCDUS because terms like "psychosocial functioning" – or, more alarming, "psychological morbidity" – tend to raise the hair on the back of my neck. (By the way, to borrow a technique that is a cliché, I looked in my Random House dictionary to find meanings for "morbidity." The main meaning is "suggesting an unhealthy mental state." A secondary meaning has to do with suggesting things "gruesome or grisly.") After that first reading, I also wanted to say something about the usefulness of mental health services as a response to children's or families' difficulties with the world.

But, I've been trying to curb what I see, in myself, as more-than-occasional quick trigger cynicism. It was time to back off, read some more, and think more carefully about what CFSFSPAASCDUS is trying to say. Its status as a response to the demand for publication in peer-reviewed journals, felt by faculty members in universities, isn't unlike the status of things I write all the time as a function of some sort of organizational requirement. And, the authors' use of statistics is quite conventional.

It turns out that, in 1994 and 1995, the National Health Interview Survey added a "disability supplement" to its national surveys about the health of the citizens of the United States. To carry out this supplement, surveyors used another instrument called PARS ("Personal Adjustment and Roles Skills") that is presumed to yield conclusions about the adjustment of children to their surroundings. These supplemental interviews were conducted with a few thousand families across the United States. The results produced statistical portraits that have been interpreted, I guess, as carriers of important information about the lives of children with disabilities and their families across the nation. Researchers have been mining this data ever since, and CFSFSPAASCDUS is but one small example of that kind of excavation. When I say that the authors' use of statistics is conventional, I mean that it is quite within a pattern of use of the National Health Interview Survey results. I have seen several other similar examples.

And who could argue with the authors' plea that the lives of children with disabilities and their families would be better if doctors and nurses paid more and better attention to care of the health of those children and families? The last paragraph of CFSFSPAASCDUS says:

...it appears that the medical community can have a major impact by finding ways to assess and address the needs of individual family members. Promoting the health and functioning of each family member reduces the stressors on the family as a whole, which can potentially create a salutary family environment.

Who wouldn't want that? For as long as I can remember, folks interested in the well-being of people with disabilities have been working to get better health care for those people. One way of looking at CFSFSPAASCDUS, therefore, is to regard it as one more small, almost innocuous, contribution to the effort toward better health for an under-served segment of the population.

So why was I still discomfited with CFSFSPAASCDUS? Even when I try to lay cynicism aside and to judge the likely small impact of this article, I return to a question about what's to be made of this piece of writing and others like it. Here's what I think. At least four problems underlie CFSFSPAASCDUS. These problems escape the purview of the authors, who, in a sense, cannot be held responsible for their failure to take the problems into account.

The four problems are:

1. Arguments like those advanced in CFSFSPAASCDUS rely on the reification of supposed facts about the lives of many people on the basis of a small sample of people believed to have similar experiences and characteristics. This reliance on inference from a small group to a larger population is often carried out without acknowledgement by researchers, for example, that the inference might be a weak one. So, what might be small jumps in thinking can turn into large generalizations about whole assemblies of people, and those generalizations shape, among other things, the ways societies spend their money. Now, I don't know of easy ways, other than the exercise of social science, to inform public decisions about how we are to help children and families. I would just appreciate clarity about the misleading nature of some of the science we often find ourselves using to support our opinions.

2. As I mentioned already, CFSFSPAASCDUS proposes support of “health and mental care needs of all members of the family” as a way of “reducing major stressors” on families. This will make their lives better. When I first worked in southeast Ohio, nearly thirty years ago, I was invited to a “planning-luncheon” held by a local mental health agency. The agency presented many charts, graphs, and photos – and a volume of data – to demonstrate the oppression of many local citizens by weak educations, unemployment, substance abuse, and poverty. The agency then promoted large increases in “mental health services” (counseling, psychotherapy, psychopharmacology, etc.) as the right responses to its oppressed community. People without jobs or incomes were going to be counseled to feel better about it. The answer didn’t fit with the problem. The same thing seems true of the answers proposed in CFSFSPAASCDUS.

3. CFSFSPAASCDUS and other studies like it seem designed to avoid a deeper examination of reasons why children with disabilities: might not have learned some of the things they are expected to learn, might have difficulty interacting with others, or might sometimes be hostile. There is no discussion of the conditions of life that might lie behind families’ low incomes or their work, sleep, or marital difficulties. Nowhere in CFSFSPAASCDUS is there description or analysis of the possible effects of systematic rejection by others, isolation from others, or dependence (often on relentlessly low-quality services) on children and families. And this absence leads me to ...

4. ...the sense that my initial reaction about an article like CFSFSPAASCDUS (felt even in its title) derives from the perhaps-unconscious tone of victim-blaming about it. William Ryan (*Blaming the Victim*, 1970) described victim-blaming like this:

The new ideology attributes defect and inadequacy to the malignant nature of poverty, injustice, slum life, and racial difficulties. The stigma that marks the victim and accounts for his victimization is an acquired stigma, a stigma of social, rather than genetic, origin. But the stigma, the defect, the fatal difference--though derived in the past from environmental forces--is still located *within* the victim, inside his skin. With such an elegant formulation, the humanitarian can have it both ways. He can, all at the same time, concentrate his charitable interest on the defects of the victim, condemn the vague social and environmental stresses that produced the defect (some time ago), and ignore the continuing effect of victimizing social forces (right now). It is a brilliant ideology for justifying a perverse form of social action designed to change, not society, as one might expect, but rather society's victim. (pp. 7-8)

About half of the text of CFSFSPAASCDUS is a description of the difficulties experienced by children and families in the sample selected from the National Health Interview Surveys. Though no statement about who’s at fault for those difficulties exists, little doubt can exist that the descriptions fit Ryan’s definition (“fatal difference... *within* the victim”).

I’m not so foolish that I would believe that drinking Miller Lite beer will make me irresistible to super-models. That’s the message, though, that I’m supposed to take from the close association between the beer and the actors in Miller Lite commercials. Neither am I so foolish as to confuse correlation with causation. I’m not so sure, though, that lots of people are clear about that distinction. I don’t have to believe that the people who write research papers overtly blame people with disabilities for the problems that they experience. But there is an implication about who is to be blamed in the close association (the correlations) between people and problems, especially when the association is offered absent other explanations about forces

behind people's difficulties. I doubt that anyone can read CFSFSPAASCDUS without catching the impression that it's the disabling condition, which lies in the person, that's at fault.

Another word appropriate to medicine that labels processes that lie beneath the data examined in CFSFSPAASCDUS is "diagnosis." Yet another such word, more familiar in non-medical contexts, is "assessment." William Ryan suggests another term. For him, a synonym for blaming the victim is "savage discovery."

Jack Pealer

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VITAL LEARNING OPPORTUNITIES

Here are several upcoming opportunities for readers to consider some vital learning. These events respond to the deepest and most crucial issues that, today, face those interested in the well-being of societally devalued people.

August 25-September 1, Blue Mountain Lake, NY (Minnowbrook Conference Center), 2004
Northeast Summer Inclusion Institute: Moving Inclusion from a Good Idea to Everyday Life. Directed by Jack Pearpoint, John O'Brien, Mike Green, and Jan Fitzgerald. From the description: "This workshop is for the thinkers and doers – those who know there are no easy answers...join a group of highly motivated individuals who are seeking new ways of thinking and acting."

Contact: The Adirondack Arc, 518-891-6565, ext. 114 (Les Parker)

September 13-15, Pittsburgh, PA (Holiday Inn, East). **Introduction to Social Role Valorization.** Taught by Darcy Elks. This is an overview of the principle of social role valorization and its applications in the lives of people who have been societally devalued. Participation in a workshop like this is a prerequisite for PASSING training.

Contact: Elizabeth Neuville, Keystone Institute, 717-541-8248

October 25-29, Andover, MA (Franciscan Center). **Crafting a Coherent Moral Stance on the Sanctity of All Human Life, Especially in Light of Contemporary Society's Legitimization & Practice of "Deathmaking" of Unwanted & Devalued People.** Presented by Wolf Wolfensberger and associates. The title quite clearly says what this event is about.

Contact: Jack Yates, 508-946-9718

November 14-19, Shrewsbury, MA (Calvary Retreat Center). **SRV Practicum Using PASSING (Program Analysis of Service Systems' Implementation of Normalization Goals).** Led by associates of the SRV Implementation Project. This workshop engages participants in teams, in a hands-on experience, to develop understanding of the impact of services on the lives of their recipients, to assess quality, and to help with service design.

Contact: Jack Yates, 508-946-9718

Each event listed above offers the most challenging kind of experience available as "training" or "continuing education" in human services. Any of these events would be worth serious consideration.

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. We have not used a subscription-system because of the extra work of maintaining it – expirations, billings, and so forth.

Instead of having subscribers we have had financial supporters. These have been people who saw some value in the publication of *The Letter* and who sent small donations of money to keep it going. Those donations have paid for printing and mailing costs. Because we have started to make *The Letter* available on the internet, those 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.

So, this little section of this edition of *The Letter* is an appeal to donors to send small contributions and to be, therefore, supporters of *The Letter*. If everyone who receives or is notified about *The Safeguards Letter* were to send between \$5 and \$10, 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, if that matters) to: OHIO SAFEGUARDS, 3421 Dawn Drive, Hamilton, OH 45011.

RICH IN THINGS, POOR IN TIME:

Wolfgang Sachs

A tourist focuses in on a most idyllic picture: a man in simple clothes dozing in a fishing boat that has been pulled out of the waves which come rolling up the sandy beach. The camera clicks, the fisherman awakens. The tourist offers him a cigarette and launches into a conversation: "The weather is great, there is plenty of fish, why are you lying around instead of going out and catching more?"

The fisherman replies: "Because I caught enough this morning."

"But just imagine," the tourist says, "you would go out there three or four times a day, bringing home three or four times as much fish! You know what could happen?" The fisherman shakes his head. "After about a year you could buy yourself a motor-boat," says the tourist. "After two years you could buy a second one, and after three years you could have a cutter or two. And just think! One day you might be able to build a freezing plant or a smoke house, you might eventually even get your own helicopter for tracing shoals of fish and guiding your fleet of cutters, or you could acquire your own trucks to ship your fish to the capital, and then..."

"And then?" asks the fisherman.

"And then," the tourist continues triumphantly, "you could be calmly sitting at the beachside, dozing in the sun and looking at the beautiful ocean!" The fisherman looks at the tourist: "But that is exactly what I was doing before you came along!"

The story – told by writer Heinrich Boll – plays upon the hopes and fears of the rich. The tourist, upon seeing the lazy fisherman dozing in the sun, remembers his fears of becoming poor, of getting stuck in a situation in which he has no options. At the same time, he instinctively projects the hope of the rich upon the poor. Without thinking twice, he outlines a road map to expand productivity. And at the end, holds out a promise that is supposed to give meaning to all these efforts: achieving freedom from one's labour and gaining mastery over time.

What makes the anecdote so puzzling is the circular structure of the story; the rich strive to arrive where the poor began. A paradox is offered, which throws up a set of unsettling questions for the affluent. Why all the pains and efforts of development, if the rich attain only what the poor seem to have all along? Or, worse, how come that the rich, despite all the hustle and bustle, appear never even to reach the state enjoyed by the poor? For if the tale of development consists in progressively acquiring a wealth

of goods to attain a wealth of time, then rich societies today have evidently missed the mark. What went wrong?

In remembrance of time.

As is often noted, the economy of time is at the core of any economic action. From Arkwright's Spinning Jenny to Bill Gates' web browser Explorer we know that most the technology employed for the pursuit of progress is used in the belief that doing more things faster is better than doing few things slower. Indeed, the ability to save time has always been the hallmark of productivity revolutions, which have transformed patterns of production and consumption over the last 200 years.

From the very start, far-sighted men and women saw the reign of freedom rising at the horizon, a realm where toil would finally cease, vastly increasing the ability of people to engage in activities of their own liking. Hunting in the morning, fishing in the afternoon, raising animals in the evening, engaging in literary criticism after dinner. This imaginary day was an ideal not just of the young Karl Marx. But what happened to this utopia? Where has all the time gone?

The use of the automobile can serve as a case in point. From the outset, it was hailed as the ultimate time-saver, dramatically shortening the time it takes to reach a desired destination. But contrary to popular belief, drivers do not spend less time than non-drivers in moving from one place to the other. They travel to more distant destinations. The power of speed is converted to more kilometers on the road. And time saved is reinvested into longer distances. As a consequence, the average German citizen today travels 15,000 km a year as opposed to only 2,000 km in 1950.

Across many sectors—from transport to communications, from production to entertainment—time saved is constantly transformed into greater distances, more appointments, larger outputs and increasing

activity. The hours saved are eaten up by new growth. And, after a while, this expansion generates new pressure for time-saving devices—starting the cycle all over again.

Gigantic gains in productivity have by no means been converted into less work and more time. On the contrary, they have, for the most part, been transformed into new rounds of output and commodities. It is evident that everyone could afford to spend much less time for all kinds of daily chores if levels of aspiration had not also changed. It is the relentless expansion in output and aspirations that continues to eat up each generation of productivity gains. The utopia of affluence has undercut the utopia of liberation.

Why is there never enough?

The fisherman in our story would be amazed at the never-ending urge for more in already rich societies. After all, he was satisfied with his morning catch and could then afford to rest. The issue is one that has been examined before: John Maynard Keynes, one of the master thinkers of twentieth-century economics, wondered if an exceedingly successful economy would not at some point reach a state of saturation. In his "Essays in Persuasion" he speculated that the imperative of productivity might lose significance under conditions of affluence, as abundance makes it less and less important to allocate means optimally. But rich societies still fail to conform to that expectation. They are hooked upon the principle of non-saturation. Why do they ignore the notion of "enough?"

What matters in such a society is the symbolic power of goods and services; they are less than ever simply vehicles of utility; they serve an expressive function. What counts is what goods say, not what they do. In modern societies goods are means of communication. They constitute a system of "signs" through which a purchaser makes statements about him- or herself. While in the old days goods informed about social

status, today they signal allegiance to a particular lifestyle.

Many products have by now been perfected and cannot be developed any further; new buyers can be found only when these goods offer more symbolic capital. Cars that cannot become faster and more comfortable are designed to be technological wonders. Watches that cannot show the time more accurately take on a sportive flair when they become diving watches. Television sets whose images cannot become clearer take on a cinematic effect with wider screens. Designers and advertisers are continually offering consumers new thrills and new identities, while the product's utility is taken for granted.

In such a context, the relationship between consumer and product is shaped mainly by imagination, which is infinitely malleable. Feelings and meanings are anything but stable; their plasticity and ease of obsolescence can be exploited by designers in an unending variety of ways. Imagination, in effect, is an inexhaustible fuel for maintaining a growing supply of goods and services. And for that reason, the expectation that rich societies should one day reach a level of saturation has not come about; when commodities become cultural symbols, there is no end to economic expansion.

Frugality and well-being

Beyond a certain threshold, things can become the thieves of time. Goods have to be chosen, bought, set up, used, experienced, maintained, tidied away, dusted, repaired, stored and disposed of. Likewise, appointments have to be sought, co-ordinated, agreed upon, put into the diary, maintained, assessed and followed up. Even the most beautiful of objects and the most valuable of interactions gnaw away at our time – the most restricted of all resources. The number of possibilities – goods, services, events – has exploded in affluent societies, but the day in its conservative way continues to be just

twenty-four hours long. Scarcity of time is the nemesis of affluence. The rich may have plenty of things, but are poor in time. In fact, in a multi-option society people do not suffer from a lack but from an excess of opportunities. While well-being is threatened by a shortage of means in the first case, it is threatened by a confusion about goals in the second. The proliferation of options makes it increasingly difficult to know what one wants, to decide what one does not want, and to cherish what one has.

Human well-being has two dimensions: the material and the non-material. Anyone who buys food and prepares dinner has the material satisfaction of filling his or her stomach, and the non-material satisfaction of having enjoyed cooking a particular cuisine or partaking in good company. This non-material satisfaction requires attention, which means time. The full value of goods and services can only be experienced when they are given attention; they have to be properly used, adequately enjoyed and carefully cultivated. Having too many things makes time for non-material pleasure shrink; an over abundance of options can easily diminish full satisfaction. So poverty of time degrades the richness of goods. In other words, there is a limit to material satisfaction beyond which overall satisfaction is bound to decrease. Frugality, therefore, is a key to well-being.

Indeed, it is often the inability to exercise a certain degree of frugality that is at the core of the problem of time. The art of living requires a sense for the right measure. Less can definitely be more. The modern consumer society continually squanders the wealth of time. In an age of exploding options the ability to focus, which implies the sovereignty of saying no, becomes an important ingredient in creating a richer life. Without that ability, the lament of dramatist Odon von Horvath may become the universal apology: "I am really an entirely different person; it's just that I never get around to showing it."

It goes without saying that without a wealth of time, there is bound to be less generosity, less compassion, less dedication and less freedom—a sort of modernized poverty which the fisherman innately understood, and the tourist only reluctantly became aware of.

Wolfgang Sachs is with the Wuppertal Institute for Climate, Environment and Energy in Germany. His most recent book is *Planet Dialectics: Explorations in Environment and Development*. He has taught at Schumacher College and been a Schumacher Lecturer.

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About THE SAFEGUARDS LETTER

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WE GET LETTERS

Jack, "Savage Discovery" is timely reading for me on several levels. On a very basic level, it captures the tension that exists for me between different kinds of knowing. In professional and policy circles, knowing is about measurement, scientific proof and documentable outcomes, which often take great liberties (as you note) in inferring cause or correlation.

But the older I get, the more I aim to rediscover and reclaim an intuitive way of knowing. Margaret Guenther, a woman who became an Episcopal priest later in life, wrote in *Toward Holy Ground: Spiritual Directions for the Second Half of Life*: "In the second half of life we begin to let go of the kind of knowing dedicated to the pursuit of the demonstrable, definable and provable. The amassing of data becomes just one more form of acquisition. And we begin to take for granted the knowing that expresses itself in useful competence. To offer a homely example: after decades in the kitchen, I 'know' cooking the way I know my native language. My hands know when bread dough has been kneaded sufficiently, and my ears know the 'whistle' of a perfectly sautéed mushroom. Cookbooks have become recreational or possibly inspirational reading to me; but the real 'knowing' of food preparation resides somewhere deep inside me."

I can't translate into numbers all that I've learned and absorbed by knowing people who are labeled or challenged in some way, but that's the knowledge that I trust the most, the knowledge that gives me a headache or some other bodily reaction if I act in ways inconsistent with it. Yet, it is the least valued (actually devalued) way of knowing. To get myself on the same page with policymakers, to speak in ways that they can hear me, I'm forever looking for the "facts" that "document" what I already know.

I think Ryan's observations on victim-blaming (especially the liberal, bleeding heart variety) are sobering, because it is something that I am capable of doing myself when not being thoughtful enough.

Julie Pratt
Charleston, WV

JUST QUOTES

We have lived by the assumption that what was good for us would be good for the world. And this has been based on the even flimsier assumption that we could know with any certainty what was good even for us. We have fulfilled the danger of this by making our personal pride and greed the standard of our behavior toward the world – to the incalculable disadvantage of the world and every living thing in it. And now, perhaps very close to too late, our great error has become clear. It is not only our own creativity – our own capacity for life – that is stifled by our arrogant assumption; the creation itself is stifled.

We have been wrong. We must change our lives, so that it will be possible to live by the contrary assumption that what is good for the world will be good for us.

Wendell Berry
“A Native Hill”

... questions will be asked about us by our descendents, to whom we bequeath an impoverished planet. They will demand to know how we could have been party to such waste and ruin. They will have good reason to curse our memory.

Scott Russell Sanders
“Staying Put” (*Orion*, Winter 1992)

I lost a world the other day.
Has anybody found?
You'll know it by the row of stars
Around its forehead bound.

A rich man might not notice it;
Yet to my frugal eye
Of more esteem than ducats.
Oh, find it, sir, for me!

Emily Dickinson

I've heard it said that within our deathly culture, the most revolutionary thing anyone can do is follow one's heart. I would add that once you've begun to do that, the most moral and revolutionary thing you can do is help others find their hearts. Time is short. It's short for our planet, and it is even shorter for all of those students whose lives are slipping away from them with every awful tick of the clock on the classroom wall. There is much work to be done. What are we waiting for?

Derrick Jensen
“Reading, Writing, Revolution”
Orion, March/April 2004

JUST ONE MORE MEDICAID APPEAL

Joe Osburn

This is a transcript of a letter written by Mrs. Mary Goolsby, the grandmother of, David Cave, a very severely handicapped little boy. Mrs. Goolsby was appealing a Medicaid decision to deny in-home health and nursing care.

Mary Goolsby
1635 Walton St.
Anderson, Indiana
November 9, 1987

To whom it may concern:

I want to appeal the decision made by medicaid for nursing for my severely handicapped grandson who is in my care. We asked for eight hours a day five to seven days a week. And was given ten hours a week only for the month of November, 1987. David was born with severe cerebral Palsy, he also has seizures and obstructive apnea. David has a trach. And is fed by a G-tube. David can do nothing for his self. He is in pampers and will be all his life. I have three children of my own who are being neglected because all of my time is consumed with David's care; also I am unable to give any time to my other grandchild. I don't have any transportation and I have to take a city bus anywhere I go. With the hours given me I can't go pay bills, or take the kids to the doctor or get groceries or anything. Plus to keep my own sanity I need at least an hour or two during each day for my self. I can't hire just a regular babysitter because he needs someone that knows how to change his trach or G-tube and suction him when needed. This is an example of a regular days schedule with David.

6AM	give valium and actifed
7AM	give breathing treatment
8AM	disconnect Kangaroo pump
815AM	send him to preschool
1145AM	give Reglan
12NOON	give breathing treatment, dilantin, klonopin, Valium, actifed and augmentin
1215PM	feed him through G-tube
145PM	give Reglan
215PM	feed him through G-tube
430PM	give Reglan
5PM	feed him and give breathing treatment
6PM	give Valium, actifed, augmentin
730PM	give Reglan, prepare Kangaroo pump for night feeding
8PM	start pump
10PM	give breathing treatment
12midnite	give dilantin, Klonopin, valium, and augmentin

So as you can see I need some help. Ten hours a week is not enough. I have other responsibilities also. But on this schedule there is no time for anything else. Also between all of this he has to be given a bath, trach changed, G-tube dressing changed and be suctioned when ever needed. Plus I try to give him some exercises. So I would appreciate it if you could reconsider your decision and give me nursing care for eight hours a day, seven days a week.

Thank you

Mary Goolsby

Even though Mary was merely relating the facts of the matter to Medicaid--to which I can attest--her request was denied.
Joe Osburn

A VIEW FROM THE BACK WINDOW

“Schools, Arrrrgh!”

I’ve been thinking about why I should keep on worrying about schools – special education, IDEA, IEP’s, and all that. For more than 30 years lots of people I know have worked very hard to make good educations available to students with disabilities. At the same time, some schools keep on doing things like this:

Cleveland Plain Dealer, May 6, 2004. Scott Kendis, who developed a brain tumor when he was 6 and has endured years of health problems as a result, has waited a long time for a slow, 50-foot walk across an auditorium stage to get his high school diploma.

But the Beachwood School District will not let Scott graduate, even though the Ohio Department of Education has ruled that he is entitled to march with his senior class. *(The district is arguing with Scott and his family over who should pay for an additional year of vocational education. The state says the district should pay. Apparently the district is using Scott’s wish to take part in graduation as a weapon in this dispute. JRP)*

The district...came up with another compromise: letting Scott graduate if his parents pay \$10,000 for the extra year of education....

Scott said he wants to graduate in June because he knows the senior class. He said he does not know students in the lower classes.

Siegel (*Scott’s attorney*) said, “All that everyone wants if for this child to walk 50 feet across the stage. It doesn’t cost them a penny.”

Recently, my personal inclination has been to give up on the schooling problem. I’ve been an appreciative reader of Ivan Illich (*Deschooling Society*) and, while I understand the present impracticability of eliminating schooling (which is, after all, a distinct concept from learning or even education), I remain entranced by the vision of doing so. But...

I’ve also been devoted for a long time to practice that has been called, sequentially, “mainstreaming,” “integration,” and “inclusion.” I know that those are not the same things, but we’ve only found that out through time and experience. I don’t think that the similar devotion that many people share has happened because schools are wonderful places for children to be. Some are, but many are not. I also don’t think that many are supporters of inclusion because teachers are universally skilled and understanding conduits for knowledge. Many teachers are, but some are not.

I presume that most people who support inclusion do so because the schools are the places in our communities where the other kids are. We appreciate that children learn best from and with other children. And, students with disabilities, therefore, simply belong with other students. As Inclusion Press puts it: “Together We’re Better. All Means All. Inclusion Means WITH – not just

IN." Being together is not only essential to mutual learning. It's also the foundation of future community life. As people, of all sorts, come to know one another, they make ways to live with each other more effectively.

So far, so good. So, what do we do about those maddening schools—those administrators, those rules, those policies, those lawyers, those state bureaucrats, those legislators, those folks who use a high school graduation ceremony as a bargaining chip?

Some time ago, a teacher made me read a book by Michael Lipsky. The title is *Street-Level Bureaucracy: Dilemmas of the Individual in Public Service* (NY: Russell Sage Foundation, 1980). Michael Lipsky describes the intersection between public service agencies (e.g., schools) as represented by their most direct workers (e.g., teachers, building principals, auxiliary personnel) and those he calls "clients" (e.g., the students at schools and their families). He defines "street-level bureaucrats" as: "public service workers who interact directly with citizens in the course of their jobs, and who have substantial discretion in the execution of their work...." (p. 3)

In summarizing his argument, Lipsky writes:

I argue that the decisions of street-level bureaucrats, the routines they establish, and the devices they invent to cope with uncertainties and work pressures, effectively *become* (*emphasis in original*) the public policies they carry out. I argue that public policy is not best understood as made in legislatures or top-floor suites of high-ranking administrators, because in important ways it is actually made in the crowded offices and daily encounters of street-level workers. I point out that policy conflict is not only expressed as the contention of interest groups but is also located in the struggles between individual workers and citizens who challenge or submit to client-processing....

Ideally, and by training, street-level bureaucrats respond to the individual needs or characteristics of the people they serve or confront. In practice, they must deal with clients on a mass basis, since work requirements prohibit individualized service. Teachers should respond to the needs of the individual child; in practice, they must develop techniques to respond to children as a class....

At best, street-level bureaucrats invent benign modes of mass processing that more or less permit them to deal with the public fairly, appropriately, and successfully. At worst, they give in to favoritism, stereotyping, and routinizing—all of which serve private or agency purposes. (xii)

With regard to school inclusion, Lipsky points us, I think toward either despair or hope. It's toward despair if we find ourselves in this position: "On matters of the greatest urgency and moment, such as health care, education, justice, housing, and income, clients passively seek the benign intervention of public agencies when evidence and experience suggest that their hopes will go unrewarded." (Lipsky, xiv) Despair may ensue, for example, when we rely solely on established law, policy, or the opinions of managers without further action on a question so important as how a child will best learn.

Hope might be found, though, in the "crowded offices and daily encounters of street-level workers." If Lipsky is right—if street-level bureaucrats (read: teachers and other school personnel who deal directly with kids and families) do actually make policy through their daily actions with students, then we need to appreciate that fact and we need to intensify our work with them. Policy might be shaped. Some schools or some classrooms might be more

welcoming. Most of us know particular teachers, particular building principals, and maybe even particular “special ed coordinators” who share at least part of our vision about students learning together. We know what a difference those folks can make, when they choose to do so.

If we have to work with schools – because that’s where most of the kids are and all those kids are important to us – then it makes a difference how we do it. It may not make sense to have much confidence in laws or rules or court cases. Instead, we need to focus on the street (or classroom) level people whose daily work shapes potential welcome, sometimes in ignorance or even disregard of laws, rules, or court cases. One of my former supervisors had been and again became a school administrator. Her consistent advice about getting things done in or around schools was “work with the teachers.” Often those people, whose names we know, are capable of at least cooperation and sometimes leadership – capable of agreeing with our ideals and delivering on much of what we want. Michael Lipsky suggests that we had better learn to connect with and influence them.

Jack Pealer

THE SAFEGUARDS LETTER

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REFRAMING LEADERSHIP: A DAY WITH PETER BLOCK

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

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

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

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

NOTES FROM A LECTURE BY THOMAS SZASZ

Wolf Wolfensberger

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

humans. Furthermore, humans do not die from mental illness, while they can die from almost all other kinds of diseases.

Psychiatry is a secular religion and psychiatrists are successors of the medieval priesthood. He points out that while a disease is a fact, diagnosis is only a word or a verbal phrase, and is tremendously subject to ideological and political pressures. Many of the psychiatric diagnoses are merely reformulations of the seven deadly sins, e.g., lust is not “sex addiction”; what was once the deadly sin of anger has become the psychiatric construct of hostility. If it were true that there is such a thing as mental illness, then why would it not be neurologists instead of psychiatrists who would be in charge of it? Also, one is allowed to deny that one has some medical affliction, but things go very ill with one if one denies that one is mentally ill when the shrinks have said that one is. It is terrible to call facilities into which “mentally ill” people are put “hospitals,” when one is allowed to leave any real hospitals, but

mental hospitals are the only ones where one is forcibly detained. To call a place a psychiatric "hospital" if one cannot walk away from it he likened to calling a concentration camp a labor camp. He also noted the irony that one can force people to take psychiatric drugs these days, but cannot force them to take all sorts of other drugs, not even when they have TB. There is also a great irony in that psychiatry has long been invoked to prevent suicides, but is now recruited to help people, including some identified as insane, to commit suicide. The insanity defense is a travesty. For instance, a person who is called schizophrenic can get away with murder

when he claims that God told him to kill his wife, when one would not be equally likely to attribute a claim that God told one to be nice to one's wife as being a symptom of mental illness. He also said that psychiatry is a proselytizing religion in contrast to some religions that are not; and like many proselytizing religions, it is prepared to kill those who resist it. Altogether, he said that the psychiatric cure is worse than the disease.

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

THANKS VERY MUCH!

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.

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

JUST QUOTES

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

Richard John Neuhaus
First Things, March, 1990

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

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

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

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

MOVING HOME

Alan Tyne

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

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

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

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

At the beginning the move is like a game. "We're thinking of moving. It's just an idea—nothing definite." We look at one or two places, get lists from the estate agents. There's a lot of talking and day dreams and so it can go on—almost forever it seems. Sometimes we think about it, and sometimes we don't. Then one day it changes and becomes serious all at once.

We've seen a place we really like; somebody wants our house. The talk is all of dates and times and money and arrangements. We used to have choices, but suddenly we don't any more. Things begin to move to a timetable that we don't control. The further along this path we go, the fewer choices we really have. You only have choices until you've made them. It's a time of gains but also of losses.

We begin to sort through our things—those we'll take and those that will have to go. Our furniture, clothes, books and papers, equipment. There is not room for everything. Moving home is time to make a fresh start. Things we've hung onto "in case we find a use" (but really because we can't bear to be separated from them) are regretfully dumped. Some things will fit just nicely in the new place. Others simply have to go. And so with our relationships—our neighbours, the people in the local shop, maybe people we've worked with—we know we won't see them again. Well, we promise to write (but will we? Do we ever? Isn't it like when we meet people on holiday—we say we'll write, but we don't, or maybe just once...). That way parting is less painful. Already we are beginning to look forward with excitement and just a little bit of fear.

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

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

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

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

your name of the rent-book means that it is your house. That makes it possible to be more in control of your own life.

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

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

"Nobody grows unless somebody loves them."

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

Another kind of person who keeps us safe is an "Ally." An ally is someone who stands by you, even when times are not good. I made a long voyage in a small sailing-boat in the summer. We were many days away from land. At one point there was a storm. We were not in too much danger, but storms are always a worry. During the day we saw a great ship that showed up out of the waves and the rain, and it just kept station with us for about an hour. He couldn't help at all. To come close would have put all our lives in danger, but he just kept a watch—to see that we were all right. And we all felt better because of it. An ally is like the ship—standing by you. Sometimes an ally will speak out for us. Sometimes she will give us the courage to speak out for ourselves. Staff are sometimes allies, but often it needs to be an outsider—someone who can speak freely without fear.

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

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

It's very important of course that we choose the right assistants—not just people we like (sometimes you don't know if you like someone until you've shared some time with them doing something you're both interested in), but people who are good at what we need help with: home making and

community. We've been finding that the best way of knowing about assistants is to go home with them. If you go to their house and smell good cooking, see a home that looks really interesting (I don't mean just clean—anyone can do that), a place with room for a cat, a place you could be comfortable in yourself—then the chances are they'll be a really good assistant. If theirs is the sort of house where people feel happy walking about with no clothes on when they've had a bath, chances are it's the sort of house people feel safe in. When you walk with them around their neighbourhood, if they stop and talk with people they obviously know, offer help when it's needed, are greeted by others, then chances are they'll know about making a way through community life.

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

Finally, Associations help keep people safe—the clubs and societies, groups and classes, informal gatherings which keep us safe by giving us “membership.” By joining, we “belong.” When we belong we have a place. Our place is what keeps us safe.

One of the nice things about John O'Brien's list of people who keep us safe is that they all begin with “A,” which helps us remember: Anchors, Allies, Assistants, and Associations.

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

Alan Tyne

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

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A VIEW FROM THE BACK WINDOW

"Time to Worry?"

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

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

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

When ideas are new, their very freshness compels attention and, often, overcomes opposition. Later, though, opponents may re-group. These opponents sometimes find ways to re-describe their old ideas using the newer language (e.g., institutions portrayed as "community-based" services or even "facility-based supported living"). Opponents also, of course, capitalize on the inevitable failings or weaknesses in the implementation of new ideas to which they are opposed. Those failings are interpreted as evidence that discredits an idea like moral management or

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

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

³ Roy Porter. *Mind-forg'd Manacles*.

normalization. If normalization can be discredited, then other (usually less-dignifying to the service-user) idea-sets can be brought forward or, we might say, dragged out of storage.

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

- One group of British politicians has plans to arrange for "...pupils with disabilities (to be) removed from the mainstream schools and taught separately." (*Guardian*, August 6, 2004) Proponents of this idea argue that integrated education may both damage children with disabilities (because integration has not been well done in British schools) and dilute the quality of education for other students. If these plans are put into practice, many segregated schools would remain open and others could be expected to start.
- A large church in the Virginia suburbs of Washington, DC will build a "respite center" (70 beds) for "children and youth" with developmental disabilities. This center will include such services as lengthy (week-long-they don't say how many consecutive weeks) respite care, group therapies, and even haircuts or styling and dentistry provided by "volunteer professionals." Those who know the history of institutional respite are aware that the proposed center will quickly become a large permanent residence for 70 people and, depending on how much land surrounds it, the base for even more similar "centers" around it.
- The Virginia legislature recently made it much easier to build and operate group homes under the "Intermediate Care" program than to assist people to establish their own homes with useful supports. Now, public service systems in Virginia have a much greater incentive to develop "12-bed" facilities.
- The Illinois Health Facilities Planning Board has approved the construction (and, presumably, the occupation by "clients") of four 10-bed group homes on the grounds of the former Lincoln Developmental Center in central Illinois. Lincoln State School, as it was formerly known, was the site of Jack Dykinga's well-known and Pulitzer Prizewinning photo "Ward of the Lincoln State School" in the Chicago *Sun-Times* in 1970.⁴ Now, there will be a greater chance of history repeating itself.
- Beatrice State Developmental Center (BSDC) in Nebraska still houses 400 people. Now Nebraska's governor wants to look into sending people with disabilities who "need a higher level of attention" to BSDC. "A higher level of attention" apparently means a more-secure location, because this proposal followed an incident when a resident of a "community-based care facility" in Lincoln, NE fatally injured a child.⁵

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

Moral management did not fail; it was abandoned. Normalization has not failed; it hasn't been

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

⁵ *Beatrice Daily Sun*, July 10, 2004

fully tried. As a matter of record, normalization has furnished the intellectual energy behind more than 30 years of improvement in the life-situation of many thousands of people with disabilities. But, normalization presents an ideal that human services and systems seldom reach. And, when our reach falls short, we often react both by blaming the standard (it's too high or it sets us in the wrong direction) and by abandoning the earlier ideal for others that leave us more comfortable with the results we've produced. "Efficiency" (whatever that means), "cost-benefit," and "security" offer such more apparently reachable goals.

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

Jack Pealer

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THE SAFEGUARDS LETTER

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New Year 2005

TINY BITS OF SPRUCE

We went to Cape Breton Island in September. I fell in--I guess I'd have to call it infatuation with the island. We weren't there long enough for me to call it love. We listened to local music and heard or read local stories. I'm an easy mark for stories about loneliness or loss. And, it seemed that every Cape Breton story or song ended with someone looking back, over his shoulder, at the Cape Breton hills as he crossed the Canso Causeway, heading south, heading away.

I bought a small book of stories by Alistair Macleod. The first story in the book is titled: "The Closing Down of Summer." It's about a team of Cape Breton miners who earn their living developing deep mines in places far away, like South Africa. The miners' summer at home is ending. They wait, sunning themselves on a beach on the Gulf of St. Lawrence for the sign that it's time to go again. The sign comes. Then...

...in the legal sense there is no public road that leads to the cliff where our cars now stand. Only vague paths and sheep trails through the burnt-out grass and around the clumps of alders and blueberry bushes and protruding stones and rotted stumps. The resilient young spruce trees scrape against the mufflers and oilpans of our cars and scratch against the doors. Hundreds of miles hence when we stop by the roadsides in Quebec and Ontario we will find small sprigs of this same spruce still wedged within the grillwork of our cars or stuck beneath the headlight bulbs. We will remove them and take them with us to Africa as mementos or talismans or symbols of identity. Much as our Highland ancestors, for centuries, fashioned crude badges of heather or of whortleberries to accompany them on the battlefields of the world.

They took small sprigs of spruce—small bits of home—with them on their hard trip halfway around the world.

I shared this image from Macleod's story with the folks who come to Sebago Lake in Maine every October. I asked people there to consider the small sprigs from home that they carried with them, as mementos, as talismans, perhaps as charms to bring them safely home again. In October I didn't answer my own question very well. I'll try to do better now.

When I open my wallet I find both customary and unusual things. The customary ones are a driver's license, other identity cards, a couple of credit cards, and (usually) a small amount of money. The non-customary things are my sprigs of spruce. Here, among the photos, is a picture of my grandmother. She died 25 years ago. When I was very young she taught me the Lord's Prayer, repeating it with me every night before sleep until I knew it well. She expected a lot of me, and her picture reminds me of that. I hope she's not disappointed.

There, underneath my health insurance card, is a clipping with a quote from Ralph Waldo Emerson (not my favorite writer):

"Write it on your heart that every day is the best day in the year. He only is rich who owns the day, and no one owns the day who allows it to be invaded with worry, fret, and anxiety. Finish every day and be done with it. You have done what you could."

I don't carry Emerson's advice because it's especially effective for me. I worry and fret all the time. I need the advice but can't seem to follow it. I carry the quote because my mother clipped it from a newspaper and gave it to me more than 35 years ago. I think now that she expected I would need this kind of guidance, noticed the clipping, and made a point of giving it to me. I've never been without it since then. When I see the quote, it reminds me of her. That's why I keep it with me.

And, just behind the Emerson clipping is a ticket for the Paris Metro. I've had this ticket since my first visit in Paris in 1987. I think I kept it, in the first place, as a kind of charm—a sign that I'd get to go back again. But now the ticket is simply a reminder of how much my wife Renate loves Paris. So, it's a reminder, as surely as a photo, about her. It's an odd reminder. Unusual, yes, to have a token for transportation thousands of miles away call out about connection and home.

These are my small bits of spruce: a photo, a clipping, a ticket. These are things I'd want with me if I had to go into deep mines in Africa.

At the end of the novel, *No Great Mischief*, Alistair Macleod's narrator reminds both himself and the reader: "All of us are better when we're loved." I hope you will take a minute to pull out and look again at the tiny bits of spruce that you carry always. I hope that you all feel loved. I expect that you are. Happy 2005.

Jack Pealer

SCOTT'S STORY: "I NEED YOU TO KNOW THAT IT'S WORTH IT" MOVING OUT, MOVING ON

"Can you come over and meet with us sometime next week? There's somebody we want to talk to you about." This was a bit of an unusual call. We didn't often hear from the social worker at the local children's institution.

"In a few weeks, we'd like you to meet Scott. He'll be coming home for summer vacation from the School for the Blind in Ontario. Scott's turning twenty-one, so this is his last year at the school, and there's really nothing for him to do here during the day. If he stays here, he'll just end up doing crafts.

"We know you folks have been involved in starting housing cooperatives and other services. Do you think we could work together? Create a way for him to start a new life in the community?"

A couple of weeks later, we met Scott. He'd lived in the children's institution from the time he was a baby. When he was about seven years old, a visitor from a neighbouring Province who worked at the School for the Blind met Scott, and said, "I

don't think this kid is retarded - he's just blind. Why don't you let him come with us, and we'll see how his learning progresses." David Wetherow

You've got to meet Scott to understand why he ended up in the children's institution. He's a pretty unique young man, and he must have been a pretty unusual-looking baby. For one thing, Scott is short. One night, he was listening to a stand-up comedienne talk about what a hick town we lived in: "I come out of my hotel room and across the street there's a store called Mr. Big and Tall. Now who would ever shop at a store called Mr. Big and Tall?" Scott stood up, which meant that he got about four inches shorter, put his hands on his hips, and declared, "I sure as hell wouldn't!"

Scott's arms and legs are short, even for a short guy, and somehow he arrived with no thumbs and some other rather unusual features. He has a little bit of vision in one eye. When Scott was born in the late 60's, the wisdom of the day was to tell his family, "It's not reasonable for you to try to raise this child. We have a place that will give him the care and protection he needs."

I Need You to Know That It's Worth It!

We met Scott and had a series of conversations with him over the next several months. We invited him to tell us about his life, and to tell us how he envisioned his life outside of the institution. We talked about a lot of possibilities - finding an apartment, renting a small house - and talked about the kind of support he would need to make a 'go' of it.

One of the things we had in mind was finding a place where there might be a bit of 'instant community', so we looked at some small downtown housing cooperatives. Scott had told us that he wanted to live downtown, where he could walk to lots of places: "My legs are really short, and I have a hard time getting on buses. I don't want to get stuck inside all the time."

We found a small cooperative apartment building and did some creative 'bridge building' with the manager and a handful of co-op members well before Scott moved in.

Scott figured out that he needed a roommate to help him on a day-to-day basis: "Somebody tall enough to reach inside the cupboards." So we recruited a good candidate from a local human service worker training program. Scott did all the interviewing, and a couple of us 'rode shotgun' on the interviews, helping Scott recognize the places where one can get fooled.

He moved out of the institution in the middle of January, in 30-below weather. On his last night in the institution, he went to the cafeteria for supper with a couple of staff. A few days later, the members of the co-op held a welcoming party, and Scott started in on his new life.

About a month after he moved (it had warmed up to 20-below), Scott was having dinner with Neil, the government community service coordinator who had done a wonderful job of arranging funding and opening doors. Neil asked, "How's it going, Scott?"

Scott said, "Neil, I need to tell you that I'm scared all the time. I'm scared that I'll slip down a snow bank into the street. And when I'm walking across the park that's in

front of the co-op I'm scared that a dog might come up behind me and run me down.

"But Neil, I need you to know that it's worth it!"

How About That Job in Radio?

About a year after Scott moved out of the institution, he became a member of our board of directors. One evening, a new member who happened to be a corporate lawyer was attending his first meeting. Alan walked into the lobby of the building where we had an office on the seventeenth floor, and saw Scott standing by the elevators. Scott was waiting for someone who could see well enough and reach high enough to hit the 17th floor button. Alan took one look at this unusual young man and thought, "I'm not sure I can handle this. I sure hope he isn't getting off at the same floor that I am."

Scott asked Alan to hit the button for 17, and they rode about halfway up in silence. Scott looked up at Alan, waving his small hands in front of his eyes, and said, "Well, what do you think of me so far?" Alan remembers that the ice-cold shell around his heart *cracked*.

Later, during a break in the meeting, Alan and Scott were making small talk and Alan asked Scott what kind of work he did. Scott said, "Well, Alan, I go to this pre-employment training program every day - it's kind of a workshop. I clean and repackage the headphones for one of the airlines. But it's not really what I want to be doing. I don't have any thumbs, and it's hard to do it with just fingers. And my arms are short, so I have to hold the work close to my face, and the cleaning fluid gets in my nose. It's not a good high."

Alan asked Scott what he really wanted to do. "I've always wanted to be in radio. I worked in the school station when I was at the School for the Blind in Ontario, and did the same thing at Red River Community College after I moved out of the institution. But the rehab people say that I can't see well enough to cue records, and that no thumbs makes it even harder, so I have to do headphones."

Alan said, "You know, Scott, I have a friend who's in the radio business. Maybe I could talk to him and we could see about getting you a job at his station."

"Alan that would be great!"

A month later, at the next board meeting, Scott came up to Alan during one of the breaks and asked, "How about that job in radio?"

Alan realized that he'd dropped the ball, and also realized that his conversation with Scott was a *commitment*. [We had coffee with Scott and Alan last week, and Alan told us that he ducked out of the meeting and called the station manager on the spot!] So the following week, Scott and Alan met with the station manager. The station manager told Scott that people hadn't cued records in his business for years - it was all tapes, CDs and computers now. And he invited Scott to come down to the station the following Monday.

The crew at the radio station taught Scott to record interviews on a portable tape recorder (one of the engineers adapted the microphone so Scott could hang onto it without thumbs). They taught him to edit tape, and Scott's interviews started popping up at four o'clock on Sunday mornings - which, when you think of it, is where everyone starts. On Tuesday and Wednesday mornings, Scott did pre-production work for the program Sunday Report.

Ten years later, Scott is still working part time at the radio station, mostly in customer relations. He's definitely one of the gang, and has done a whole variety of jobs there since he started. It was a great lesson for us in finding someone with connections *in the community*, as opposed to looking to the service system for all the answers.

Evergreen Place

About four years after he moved to the cooperative, Scott told us that he wanted to move closer to Osborne Village, where he'd found one of those places 'where everybody knows your name'. Any Friday night, you could be sure to find Scott at a small Irish pub called The Toad in the Hole. One of the wonderful things about Scott is that he has a

great, rough-around-the-edges singing voice and a passion for the music of Stan Rogers and the Irish Rovers.

Scott gave notice at the cooperative, and moved into Evergreen Place, a high-rise apartment with an indoor swimming pool and a weight room. Scott started swimming *every* afternoon, worked out a new route to the radio station, and began making friends in the building.

By this time, Scott had hired his third roommate - a fellow who played semi-professional football for the local team. Scott had learned (and taught us) a great deal about finding roommates with whom he shared interests, and getting the relationship to move quickly beyond 'taking care of Scott'. The football player brought other football players (and their girlfriends) into Scott's life, and life moved on.

The fourth roommate turned out to be pretty cranky. Scott's words were, "He wasn't there for me." He and Scott got along alright, but he had a pretty strong pattern of keeping other people away. That lasted a bit less than a year, and Scott decided that he wanted to try living 'on his own' - without a roommate.

He waited until it was time to renew his lease, and negotiated for a one-bedroom apartment in the same building. Everything else stayed in place - the Toad in the Hole, swimming every morning, the job at the radio station. Scott traded the support contract with a roommate for some occasional heavy cleaning, made arrangements for some of his meals with Home Care and Meals on Wheels, and got on with the next phase of his life.

We've thought many times about the difficulty that a traditional 'residential service' would have had in keeping up with the changes that Scott wanted to create in his life - three apartments, four sets of roommates, finally working out a way to live alone but not in isolation. Separating the provision of services from housing was one key. *Listening* was another. And working harder on bridge-building than on 'life skills' was a third - it gave us all confidence.

Rise Again

It hasn't always been easy. Scott had some hard work to do with his family, in terms of getting them to accept his independent lifestyle and also in coming to terms with the question that had been haunting him ever since he was a child: "Why didn't you take me home when I was a baby?"

One of Scott's 'standards' at the King's Head, where he now sings with a band called The Tarry Trousers, is a song by Stan Rogers' called The Mary Ellen Carter. He brings the place to its feet at least once every Friday evening when he raises his arms and sings:

Rise again, rise again

Though your heart may be broken

and life about to end.

No matter what you've lost,

be it a home, a love, a friend,

Like the Mary Ellen Carter,

Rise again!

(c) 2003 David and Faye Wetherow
Community Works

About THE SAFEGUARDS LETTER

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

WE GET LETTERS

Jack, I was pleased to get the latest issue of the Safeguards Letter. I was not at all put off by your sobering piece on the possible return to some form of neo-institutionalization in America. I suspect that we are seeing almost the end of the moral impetus of the baby boom generation of leadership on this question, with a great deal of ambiguity about who, (if anyone), will take up the issue subsequently. Reversals and collapses of reforms such as occurred with the Moral Treatment era ought not to surprise even reflexively optimistic Americans. A good friend in Holland just sent me the recent Soros report on institutionalization in Europe. See <http://www.inclusion-europe.org/institutions/MenuTemplateText.asp?lang=EN&level=D&PosMenu=6>. They most certainly face an even more strengthened institutional sector than we do. Perhaps the gloom of BUSH 2 is being unduly influential, but it may help awaken people to the fact that we are poised over an abyss if we are not careful. Thanks again.

Michael Kendrick
Holyoke, MA & Halifax, NS

Good morning Jack. Just finished reading your article about being worried in your latest newsletter. All I have to say about it is "Amen!" There's plenty of worrying to be done it seems.

Linda Higgs
Charleston, WV

I fear you are correct. The quote from Porter made the hair stand up on the back of my neck (if I had hair on my neck it could have happened)... "It was too personal to be permanent". I was talking to George Durner last year sometime about L'arche and he said he could see it at some point either "winding-down" or being perverted. Why? It is too personal!!! It calls for something that is so counter to the sweep of the larger culture (or worse human nature).

Bob Jones
Winnipeg, MB

IUST QUOTES

I am tired of going to the mall following behind Cindy (support worker), watching her try on clothes I can't afford, watching her buy make-up I can't afford and eating pizza because that's what she wants to eat. But I go because I want to get out.

Unidentified woman living in "supported living"
B.W. Leroy, et al. "Retreat and Resilience." *American Journal on Mental Retardation*, Vol. 109, Number 5, September 2004.

A glacier is time incarnate. When we lose a glacier—and we are losing most of them—we lose history, an eye into the past; we lose stories of how living beings evolved, how weather vacillated, why plants and animals died. The retreat and disappearance of glaciers—there are only 160,000 left—means we're burning libraries and damaging the planet, possibly beyond repair. Bit by bit, glacier by glacier, rib by rib, we're living the Fall.

Gretel Erlich, "Chronicles of Ice"
Orion, November/December 2004

When we accept that there are sets of problems for which there are no answers, and that there never will be answers, we create room for mystery and imperfection in life. Mystery and imperfection restore our humanity.... There needs to be space for wonder, gratitude, surrender, grief, and compassion in our institutional lives as well as our personal lives. It transforms what we thought were "problems" into the human condition.

Peter Block
The Answer to How is Yes

A VIEW FROM THE BACK WINDOW

"Belated Thanks to Stephen Jay Gould"

Stephen Jay Gould died suddenly in May 2002. I always wanted to thank him for his teaching and what I learned from it, but I didn't do so then or earlier. So, I'm offering this belated "thank-you" now.

In 1981 the Quality Paperback Book Club offered Gould's then new book *The Mismeasure of Man*. I must have been intrigued by the book's description because I ordered it and, when it came, devoured most of it in just a few hours. Toward the book's end the math--statistics--wore me down, but most of *The Mismeasure of Man* was as exciting as any detective story. Years later, through a happy accident, my wife was able to get me an autographed copy, which I consider the second most valuable book I possess. *The Mismeasure of Man* is a book I've pressed on others since the early 1980's.

In March 1989 Stephen Jay Gould came to Columbus to offer the first in a series of

"Distinguished Research Lectures" at The Ohio State University. Perhaps the biological sciences faculty required or strongly encouraged student attendance. Whatever the reason, Mershon Auditorium (then the largest venue for such lectures at Ohio State) was filled to the back row of the balcony, which was where I found a seat. Gould's topic was: "Human Equality As a Contingent Fact of History," and he argued for equality not as a moral/ethical preference, but as a fact resulting from the working-out of evolutionary history.

In that lecture and through his books and essays, Gould taught me about both the strengths and weakness of science, about the idea of "contingency" as an explanation of how history works, and about evolution.

Science. Gould was interviewed for the TV program *Nova* in 1984. The producers visited the classroom at Harvard where he taught a very popular course about the history of the earth and of life. In an early lecture he said:

Science is a fascinating dialectic. It creates cultures by instigating change through its discoveries. But it also reflects cultures, because it's done by human beings who are enmeshed in the biases and thoughts of their age. They're no different from anybody else. Scientists aren't special. That's one of the main themes of this course. Science leads and provokes change, but science is also embedded in culture, and often reflects the largely unconscious biases of those who do the work.

He went on to identify four such biases in particular. First is the notion of progress—the idea that the world is somehow moving in a way that's favorable to us. Second is the bias of determinism—that things that happen have causes, which are rationally arranged. The third bias is gradualism, which is the notion that change always occurs through slow, almost undetectable steps. And the fourth bias is what Gould calls adaptationism, which is the view that everything somehow fits or works—is logical or well ordered—is there for a reason. Holding these points-of-view, even unconsciously Gould argues, prevents knowledge of possibilities that we had never before considered because we could not even think of them. It's a humbling but liberating view of the role of science.

"Contingency" in history. One of Stephen Jay Gould's frequent invitations to thinking was: "...wind the tape backward." He encouraged us to consider the outcomes of a history that might have flowed from small changes in earlier events. He argued that "history" is the furthest possible thing from our usual notion of a record of planned or influenced activity. In his 1989 book, *Wonderful Life*, Gould wrote:

A historical explanation does not rest on direct deductions from laws of nature, but on an unpredictable sequence of antecedent states, where any major change in any step of the sequence would have altered the final result. This final result is therefore dependent, or contingent, upon everything that came before—the unerasable and determining signature of history.... When we realize that the actual outcome did not have to be, that any alteration in any step along the way would have unleashed a cascade down a different channel, we grasp the causal power of individual events.... Contingency is the affirmation of control by immediate events over destiny, the kingdom lost for want of a horseshoe nail.

Gould reminds us of the example of George Bailey in Frank Capra's "It's a Wonderful Life." When George gets a chance to wind the tape backward, he grasps the influence of seemingly small events on the life of his family, his town, even his world. When, like George Bailey, my wife Renate and I speculate on the chance events that led to our meeting each other and the perhaps-long odds of those events' occurrence, we're thankful that contingency worked out the way it did. As Gould observes in the quote above, this view of how history works frees us to consider and hope for better results from even the smallest of human actions.

Evolution. Gould was the most articulate spokesman for evolution whom I have read. Evolution

is an "imaginative vision" that has proven since Darwin's time to be extremely useful at revealing how biology affects and is affected by surroundings. Gould warned repeatedly about the mistake of some early and not-so-early Darwinists of equating evolution with progress (bias number one). Evolution is just a theory--a remarkably persuasive one--about how organisms change or adapt to the conditions surrounding them. Sometimes these changes occur quite slowly, through long stretches of time; at other times (see *Wonderful Life*) adaptation seems to happen all of a sudden. Evolutionists do not see progress in this. As a matter of fact, *The Mismeasure of Man* (which, in my judgment, should be required reading for folks involved with people who have been accused of "retardation") is a careful historical argument against biological determinism (bias number two), which might be summarized as the view that all of life is a pyramid with humanity (especially often male Caucasian humanity) at its peak. Evolution, as described by Darwin and utilized by most scientists, makes no such claim.

These seem like important things to know or think about. I'm grateful for Stephen Jay Gould and his clear writing and faithful teaching. I just wish I'd had a chance to tell him so.

Jack Pealer

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IMPORTANT WORKSHOP: *Crafting a Coherent Moral Stance On the Sanctity of All Human Life, Especially in Light of Contemporary Society's Legitimization and Practice of "Deathmaking" of Unwanted and Devalued People*

Sunday, October 16, through Thursday, October 20, 2005 at Christ the King Retreat Center, Syracuse, NY

Presented by Dr. Wolf Wolfensberger, Susan Thomas, and Associates of the Training Institute of Syracuse University

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.

Note: this five-day workshop, to include evening sessions, is approved for **54 contact hours** of Continuing Education for Registered Nurses and Licensed Practical Nurses by the Ohio Nurses Association, an accredited approver by the American Nurses Credentialing Center's Commission on Accreditation OBN-001-91. CE contact hours are provided by workshop co-sponsor Family Lives Nursing Services.

Cost of tuition and room and meals is \$650, payable to the Syracuse University Training Institute. Group discounts and flexible tuition for those in need **are available**: call Susan Thomas at 315 / 473 – 2978. Send registration to the Training Institute, Suite 3B1, 800 South Wilbur Avenue, Syracuse NY 13204.

FEELING WELCOME: JOINING OUT OF LONELINESS FOR EACH OTHER. Bruce Anderson

William Stafford, poet and teacher from Oregon, writes that things join “out of loneliness for each other.” At the heart of all community building is the desire to connect citizens with other citizens. These acts of joining, small or large, form the fundamental cure to loneliness. Could those of us strategizing ways to build community make good use of our time by considering what the condition of loneliness means to each of us in our own lives? By joining together, telling our own stories of loneliness, and describing the pathways that guided us through those times, we may locate a collective wisdom we can expand and take back to our work on a larger scale.

Why aren't we talking more about our own loneliness? The stories of times when we have felt disconnected with others take us back to places many of us would choose to forget, if only we could. As part of our organization's community building work, we often ask groups to divide up—in pairs or threes—and have each person tell a story about a time in their life when they felt like they didn't belong. As those stories are shared, many of them told for the first time since the event happened, there is often an initial feeling of darkness and despair. What we have learned, however, is that the darkness is quickly replaced by a feeling of unity and strength as the similarity in the stories is noticed and people begin to remember that the condition of loneliness is part of our common story. We have also learned that each of us has wisdom and unique understanding about loneliness that is useful to share. There is a strength resulting from the telling of these stories that binds people together and increases their commitment to community building action.

Is our unwillingness to “join out of loneliness for each other” because we want to be alone? Not me. I have persistent and haunting memories of each time in my life I have felt lonely...somehow unwanted or unaccepted by others even though I yearned for their touch or their particular nod in my direction. So now, as I consider my own quiet refusal to stand beside those who are lonely, I question the advantage my silence brings me. I get the comfort from not revealing my own stories of loneliness to others who may benefit from hearing them, but also the damaging turbulence that locked up stories bring to my soul. I get the advantage of thinking that my life is put together somehow more completely, and that I need less help than those around me, but also the daily burden of maintaining that false front. I get the “calm before the storm” advantage of delaying facing my own suffering, though not answering that knock at the door creates a deeper dissatisfaction with my own courage.

Sometimes I respond to loneliness by saying “but, in the end, we are alone in the world”. I know when I think or say these words it often comes on the coattail memory of its companion belief—another grim reminder—which begins... “You really can't trust anyone but yourself”. These two half-truths, usually erupting out of some situation in which I did not receive the love or attention I thought I deserved, serve to drive me further into my loneliness by carrying into my psyche the idea that the world is a dangerous and hurtful place. It is that small and afraid voice inside reminding me that when you go out in the world, this is what you can expect. You should have known better. These responses come from a desire to reconcile my feelings of loneliness by pushing them towards hopelessness. Far from courageous introspection, this comfortable hopelessness gives me permission to see loneliness in others and myself and not take action.

William Stafford, in a poem called *A Ritual to Read to Each Other*, reminds us of the deep obligation humans have to stay joined and act when we are a witness to disconnection. He writes about a band of elephants holding each other's tails on the way to the park. “But if one wanders”, he says, “the circus won't find the park. I call it cruel and maybe the root of all cruelty to know what occurs but not recognize the fact.”

Loneliness comes from the unmet desire to feel the presence of another in your life. There is a sadness and disconnection with the world that comes with the feeling of loneliness. Being alone, on the other hand, is not the same as being lonely. Being alone does not, in itself, cause loneliness. Being alone simply states that you are standing by yourself, not in the presence of others. That

you are “going it alone” for the moment, and acting by oneself. Being alone can involve courage, a feeling of wholeness, and a feeling of deep connection to those around you.

What are we doing to help those around us not feel lonely? And what are we doing to encourage those around us to know the power of standing alone? For myself, I know that helping others find ways out of their loneliness has shattered my own illusion that I am not lonely. I struggle with my own feelings of being unwelcome each time I witness another person taking courageous steps towards connectedness with others. As Wendell Berry says, “true social change may stick, not through large heroic acts of defiance, but rather through the small acts each person makes because their conscience and integrity would be shattered if they did otherwise”. The small acts of standing by that we make each day tell more about our desire to cure loneliness than the heroic programs and principles we pledge our allegiance to.

My fear
is in getting to know you.
For in those moments of conversation
when I begin to see you more clearly,
I may discover I am not
the loving person I imagine myself to be.
Not loving. Me. Now I've said it.

My safety
is my silence and quiet refusal
to stand beside you when you need me or I need you.
I hold my breath tightly, silently,
trying to stop love from moving through me,
giving trouble a solid place to stand.
Forgetting that, like water,
love moves through all things.
Like the tides, it washes over dry souls who wait.

If I could have one thing,
just one thing different,
it would be to touch that stone-cold part of my soul
and give it light.

Bruce Anderson

(Bruce Anderson lives in Vashon, WA. He is a partner in “Community Activators,” an organization devoted to “fresh ideas and tools to build welcoming and productive communities.” He says: “In 1985 I was a fisherman in Alaska who, by a string of events that now seem anything but accidental, ended up sitting in front of John O’Brien in a bad motel meeting room with shaggy red carpeting. It was a PASS workshop, and it changed my life.” JRP)

About THE SAFEGUARDS LETTER

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JUST QUOTES

Life accepts only partners, not bosses. We cannot stand outside a system as an objective, distant director. There is no objective ground to stand on anywhere in the entire universe. Our disconnection—our alleged objectivity—is an illusion; and even if we fail to realize this, the system will notice it immediately. Systems work with themselves; if we aren't part of the system, we have no potency. Systems do not accept direction, only provocation.

Margaret Wheatley and Myron Kellner-Rogers
A Simpler Way

"The big idea of education, from first to last, is the idea of a better place. Not a better place where you are, because you want it to be better and have been to school and learned to make it better, but a better place somewhere else. In order to move up, you have got to move on. I didn't see this at first. And for a while after I knew it, I pretended I didn't. I didn't want it to be true."
(Hannah Coulter considering that her children are all far away.)

Wendell Berry, *Hannah Coulter*

In a life with its fair share of darkness, I have found full-body baptism in the plain and glorious particulars of life to be a powerful antidote to despair. The fact is that the details of our natural surrounds offer infallible fascination and a route out of morosity. In a world deeply flawed by the infantile excesses of our own kind, this is no small potatoes.

Robert Michael Pyle, "Consolation Prize,"
Orion, March-April 2005

Given the constraints imposed by the regulations and service practices that the initiative (i.e., the Robert Wood Johnson self-determination initiative) itself is designed to overcome, it might be said that people with disabilities are being given a chance to participate in a political and social experiment designed to discover how much flexibility and personalized support it is possible to wring out of a hybrid medical system that concurrently, and as a whole, is the object of attempts to control its costs by others who are higher in state and federal bureaucracies.

John O'Brien
"Notes on Complex Change"

AN APPRECIATION: *Waddie Welcome and the Beloved Community*, by Tom Kohler and Susan Earl. (Toronto: Inclusion Press, 2005) Available from Inclusion Press (www.inclusion.com) or Chatham-Savannah Citizen Advocacy, 127 Abercorn Street, Suite 100, Savannah, GA 31401.

Waddie Welcome and the Beloved Community shows and tells the story of a Georgia native and citizen, the town where he lived, and the people whom this Georgian drew together in a common but radical enterprise. In only a minor way is the book about human services; organized agencies appear mostly by default or omission.

Waddie Welcome was born in south Georgia 138 years to the day after the publication of the Declaration of Independence. He was born 88 years exactly after the deaths of John Adams and Thomas Jefferson; he is only one lifetime removed from the founding fathers. Mr. Welcome lived all his life in southeast Georgia—more than 70 years with his immediate family and more than 80 years in Savannah. After Mr. Welcome passed his 80th birthday, people in his neighborhood who knew him and his family worried that remaining family members were unable to take care of him well enough any more. A usual thing to do when people have those worries is to contact local human service agencies, and that's what happened. The outcome of the contact was that Mr. Welcome moved, first to a local nursing home and later, when that home's license was taken away, to another nursing home about 150 miles from Savannah. Mr. Welcome did not agree with those choices, but his disagreement apparently could not be understood. *Waddie Welcome and the*

Here's the first verse of what I thought of as an "I" hymn—a pretty familiar one, sung to the same tune as the official hymn of the U.S. Navy:

□

My hope is built on nothing less
Than Jesus' blood and righteousness;
No merit of my own I claim,
But wholly lean on Jesus' name.
On Christ, the solid rock, I stand;
All other ground is sinking sand.

Four first-person singular pronouns appear in that first verse. □ Those pronouns made me uncomfortable.

I wanted plural pronouns. □ Here are the first two verses of a well-known hymn by Isaac Watts (1674-1748):

O God, our help in ages past,
Our hope for years to come,
Our shelter from the stormy blast,
And our eternal home:

□

Under the shadow of thy throne
Thy saints have dwelt secure;
Sufficient is thine arm alone,
And our defence is sure.

□

See the difference? □ The only singular pronouns are second-person: □ thy, thine. □ All first-person pronouns are plural. □ They are communal, which is what I thought religious and worship life was supposed to be. □ I'll bet I picked Isaac Watts' hymn, more than once. □ But many of the "I" hymns are old favorites. □ We get caught in a struggle between me and us.

□ Another example. □ Not long ago, someone asked me if I had gotten "Sirius." □ That's not misspelled. □ "Sirius" is a company that sells radio receivers and access to many commercial-free satellite radio channels. □ The deal is that you or I can invest \$100 for a receiver and choose a monthly plan, at a price of about \$13 a month. □ If you or I do this, we can listen to radio free of commercial messages, and we can do this in our homes, in our cars, or in other locations where we can take the receivers. □ If I want to, I can listen to Martha Stewart—or even Howard Stern. □ All this comes exclusively to me or to anyone else who buys a radio and pays the monthly fee. □ It's only available to those who pay.

□ Another deal comes my way fairly often. □ I'm regularly offered opportunities to send some money (an amount I get to choose) to any of several "public" radio stations close to where I live. □ If I "invest" (as they say) in public radio, I can listen, almost without commercial messages, to classical, world, folk, or '40's swing music. □ If I want to, I can catch a talk show or hear the news from NPR. □ As the announcers emphasize during pledge-weeks, the side-benefit of public radio seems to be inclusivity. □ Anyone with an FM radio can listen, without paying. □ That means my contribution (it could be \$246 per year—about the same price as Sirius) pays for other people to listen. □ So, the guy in the car next to mine can overhear Beethoven's "Hymn to Joy" or Django Reinhardt playing "Someone to Watch Over Me" on my radio. □ Then, he can smile and turn on the same music, on my dollar. □ My neighbors can hear "Tunes from the Crypt" during the Trick-or-Treat hours on Hallowe'en, and they can turn it on too. □ It would be great to hear the neighborhood echoing with Bernard Herrmann's theme from *Psycho*. □ The innocent chills the kids get, out in the dark, would be just as innocent but maybe a little bit chillier. □ And it would be my small investment in a common enterprise that paid for all the neighbors' listening. □ To me, that seems so much about us, and not just me. □ But, it's so rare. □ It seems to go against our nature. □ We have trouble with a struggle between me and us.

OHIO SAFEGUARDS
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THE SAFEGUARDS LETTER

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EARLY NOTICE: IMPORTANT OPPORTUNITIES TO LEARN

1. MORAL FUNCTIONING IN A DYSFUNCTIONAL WORLD – JUNE 2006

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

Anyone involved in the field of human services (whether through work, volunteer, family connections) has seen first hand many of the problems of services in today's world. These problems may come from economy, laws and regulations, society, etc., and they seem to be mounting, which bodes ill for people dependent on such services. This workshop proposes that human services are inherently limited, dysfunctional, and to some degree unfixable, and that this dysfunctionality manifests itself in pervasive tendencies of service efforts toward decay, disorder, and even violence. Organized agency services especially do not work well over the long run and often end up doing the opposite of the noble purposes they started with or still claim. In the face of this, what is a committed "server" to do? The workshop will first outline these unpleasant realities and the contemporary societal and service dynamics that aggravate them. It will then propose adaptive strategies that may enable workshop participants to (better) perceive the nature of these realities and to achieve a greater degree of moral coherency and integrity in how they live and act, particularly in their service roles.

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

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

DATES: May 14 to 18, 2007

THEME: *Crafting Valued Social Roles*

PLACE: Ottawa, Ontario, Canada

Description: For devalued persons, occupying valued social roles seems to be an effective way of achieving the good life. The theme of the 2007 conference goes to the very heart of Social Role Valorization (SRV). Plenary speakers, discussants and workshop presenters will describe how valued social roles can be crafted for vulnerable people of different ages (*from early childhood to old age*), in key life spheres (*education, work, living situation, family and friendship relations, religion and spirituality and culture and leisure*), and in various service fields (*including mental handicap, child welfare, mental health, early intervention and medicine*). The crafting of valued social roles will be approached on a number of levels such as *individual, familial, organizational and societal* and from several perspectives including practice, policy and research.

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

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

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

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

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

First barrier: Wolfensberger's language. If one has read even a few of his writings, it is easy enough to hear his unique voice. However, I began wincing at each mention of "mentally retarded" or "impaired person". I found myself thinking of all the people I would love to have reading this book along with me, but I know most find these labels offensive and would not be open to reading further. Wolfensberger gives a rationale for his terminology choices on p.2. He has obviously heard every possible critique about this problem, and does not apologize for using what he calls

"traditional and informal idiom(s) that might be used by ordinary citizens."

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

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

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

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

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

I also have imagined a dialogue with Wolfensberger. I would tell him how our own family life has played out some of the perils that he describes. I would tell him that I have indeed found great support from other parents, but not in the way he describes. (On-line communities have been as helpful and compassionate as many flesh-and-blood friends.) The other thing I would tell him is that this book can be very, even extremely, depressing. (He admits this.) He has a fondness for listing all kinds of bad reports. Even when he does have something good to say about a service or strategy, he uses the tongue twisting "least worst" to describe it.

Wolfensberger's solutions to the fears that we parents have? He exhorts us to have *strategies* in place, as there is no such thing as a *solution* to the problems we parents face. On pp. 70-72 he covers societal values and ways people reject our loved ones with disabilities. He then proposes radical steps parents might take to make changes in their own lives. He lists the noblest ways in which parents can rise above their own family's troubles and personal prejudices

and help others. (Sort of a Maslow's Hierarchy of Moral Development of Parents of Children with Disabilities!) An existing, helpful strategy he recommends is "Citizen Advocacy". These are local, volunteer efforts that he proposed and helped establish years ago, but cannot be accessed in every state.

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

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

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

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

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

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

I have both a personal and professional interest in reviewing this monograph by Wolfensberger. On a personal level, I am the father of a son who has significant impairments (that is, Down syndrome and autism). Professionally, as a teacher educator who is hearing impaired, I am interested in the inclusion of children with disabilities in education and in the larger society—albeit, most of my scholarly work concerns children who are deaf or hard of

hearing. I am familiar with Wolfensberger's concept of normalization and his recent rendition—social role valorization. I have even read about Wolfensberger's theological views, which have affected me pervasively, particularly as they pertain to individuals with mental retardation.

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

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

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

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

The third section exemplifies Wolfensberger's earlier point (that is, "depressing thought") about the shortcomings of most parents. Some of the flaws include a discussion of the following ideas: (1) someone else will take care of my child; (2) the 'here-and-now' syndrome (that is, not planning for the future); and (3) my situation is unique (resulting in detachment from others or going it alone), and—my favorite—(4) expecting too much or too little. With a strong emphasis on the errors that parents/caregivers make, this section of the monograph can cause a great deal of disillusion, even for parents who think they are doing the right thing.

retarded and that compelling evidence of this was presented at his trial. □ Leading mental retardation experts testified. □ Their well-supported opinions were based on objective testing of Mr. Atkins, as well as on detailed descriptive information from numerous schoolteachers, family members, and individuals who had been Mr. Atkins' peers growing up. □

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

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

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

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

In Mr. Atkins' case, Dr. Samenow dismissed the relevance of low IQ and relied on Mr. Atkins' own description about his life skills and abilities to conclude that he does not have retardation. □ This is absurd. □ While IQ testing has its limitations, no one working in the field would suggest that it is not the linchpin of a mental retardation assessment. □

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

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

Dr. Samenow does not meet this standard.

Robert Perske

A VIEW FROM THE BACK WINDOW

"A Pledge Not Redeemed"

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

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

In mid-July, this year, the state agency that has responsibility for service to people with developmental disabilities in Ohio quietly announced that a contract had been awarded to a private consulting firm. The contract was/is for a study that "...will examine the role and function of Ohio's developmental centers as an integral part of the state's present residential

service system for people with disabilities.” As far as I can tell, this means two things, neither of them good.

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

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

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

In terms of Human Rights:

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

In terms of education and support services:

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

So:

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

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

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

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

Jack Pealer

OHIO SAFEGUARDS
3421 Dawn Drive
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The Safeguards Letter

A Publication of OHIO SAFEGUARDS

Number Thirty-seven

New Year 2006

LEARNING OPPORTUNITY IN NEARBY WEST VIRGINIA

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

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

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

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

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

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

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

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

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

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

IN MEMORY

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

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

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

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

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

NOTES ON DEINSTITUTIONALIZATION

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Jack Pealer

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

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

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

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

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

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

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

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

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

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

Jack Pealer

JUST QUOTES

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

Christopher Alexander
The Production of Houses

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

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

A VIEW FROM THE BACK WINDOW

"Of Costs and Benefits"

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

From an essay by Norman Cousins in the April 14, 1979 issue of *Saturday Review*:

The familiar last line in T.S. Eliot's *Wasteland* suggests that the world will end not with a bang but with a whimper. I believe Eliot was wrong. The world will end neither with a bang nor a whimper but with strident cries of "cost-benefit ratio" by little men with no poetry in their souls. Their measuring sticks will have been meaningless because they are not big enough to be applied to the things that really count.

In places where I've been or among people I've met lately there's been a lot of talk about cost-effectiveness, cost-efficiency, or cost-benefit ratios. This kind of talk is always around, but it seems to become more prominent in human services in times when money is especially dear. People slip *cost effectiveness/efficiency* into conversations and discussions and, particularly, into their plans for the future. I'm always a little puzzled about what people mean when they use these terms. I am not a close student of economics (either macro or micro), so my thinking about costs and benefits and efficiency, etc. is (like lots of other stuff I write or talk about) absent of the taint of technical knowledge. Perhaps any economists who read this could set me straight.

I am, however, going to presume to think on paper about these ideas, because they seem to me to be a part of a code that carries information about how our communities and our society as a whole respond to people who have disabilities (or to other people who need assistance). First, I'm going to take those terms (cost-benefit, cost-effectiveness, and cost-efficiency) apart. Then, I'll describe what seem, to me, necessary cautions about the application of these terms in programs that try to help people who need assistance.

First, let's think about *cost*. I looked in my faithful *Oxford English Dictionary*, hoping that I might find some obscure Northern Gothic or Old Slovenian root word that would shed new light on the idea of cost. I didn't. The primary definition of the noun, *cost*, is "...that which must be surrendered or given in order to acquire, produce, accomplish, or maintain something." The equivalent verb, says the *OED*, means "...to be acquired or acquirable (at) so much," or "...to necessitate or involve the expenditure of (time, trouble, or the like), loss, sacrifice of (some valued possession), suffering (of some penalty)." So, *cost* is what we think it is. It is what we give in exchange for something we want.

What about *effectiveness*, *efficiency*, and *benefit*? For help with the first two I turned to a 1983 essay by David Korten ("Social Development: Putting People First"), whose ideas about how organizations learn to do new things have been useful to me for several years. *Effectiveness* is the first thing to be aimed at--it means learning to do well what an organization intends or hopes to do. Effectiveness is about the relationship between aims and achievement. *Efficiency*, says Korten, comes later; it involves reducing unnecessary expense of resources (time, money, etc.) so that expansion of activities can be considered. So, an organization trying new things first has to learn to do these things well, and only later can it expect to do them without sloppiness, without waste. *Benefit*, of course, means some good that comes to a person or a group of people--something desirable that happens to or becomes possessed by a person or group.

Cost-effectiveness, *cost-efficiency*, and *cost-benefit* are, then, expressions of relationships that are presumed to exist between:

- what we pay to have something done and its accomplishment (Cost-effectiveness);
- a pared-down, leaner price for getting something done, and its continued accomplishment (Cost-efficiency); and
- what we pay to have something done and the presumed good that its accomplishment yields (Cost-benefit).

Are you with me so far? I'm not sure that I am. But let's go ahead and think about these ideas a bit further, particularly about their application to efforts to help people who may need assistance in order to take full parts in community life.

It looks like there are three problems to be considered when we apply *cost-effectiveness et al* to organized efforts to help.

The idea of *cost* applied to people and their situations. I looked hopefully to the *OED* for a derivation of *cost* that carried with it a sense that the cost of things has a bit of naturalness or inevitability about it. That kind of sense wasn't there, but I think that it's present, at least a little, in the connotations that have gotten attached to *cost*. The *cost* of services or supports for people somehow means to us something a bit more than the amount that we expend for those services and supports. The notion of cost seems to have transferred to the people themselves, and the implication that there are such people as *costly* people leads us in a dangerous direction. There's just a hint of slavery here.

The difficulty of determining the cost of doing things. In human services we have become accustomed to counting *cost* only in terms of money. But, what has to be expended in order to accomplish our aims and to acquire some agreed-upon good for people is not so easily counted that way. It's hard, for example, to figure out how to include in our billing-rates or our unit-of-service fees (these are often believed to be equivalents of *costs*) the value of long-term relationships between the people being helped and those who are doing the helping. But, if we don't account for that value, we are unlikely to be counting the *cost*.

The difficulty of determining what is *effective* and what is a *benefit*. Ronald Conley addressed this difficulty in his 1973 book *The Economics of Mental Retardation*: "The measurement of benefits is one of the unsolved problems in most evaluations of investments in people. Data is scanty. Measuring instruments are imperfect or nonexistent for many benefits. By their very nature, many benefits cannot be expressed in terms that are directly comparable." (p. 258) As Conley pointed out, if we're going to develop and use a ratio between costs (if we can be accurate about those) and benefits, we have to attach a numerical value--a money value--to the achievement of our aims and the good that achievement is supposed to do for people who are to be helped. That can be tricky, as Wolf Wolfensberger noted, in a recent (Feb-April, 1992) edition of *TIPS* (Training Institute Publication Series):

In order to apply cost/yield and risk/benefit analysis to pollution, some kind of value must be placed on human life. This is commonly done by valuing people's lives in terms of their lifelong earning power. One consequence is that a poor person's life is worth less than a rich person's. Therefore, one logical outcome of these kinds of reckonings is that poor people may be exposed to more pollution than rich ones. This is precisely what has been happening in the US where the health costs of siting waste incinerators and landfills have been falling disproportionately on the poor (*Greenpeace*, 9 & 10/89).

So, a conversation about *cost-effectiveness* or *cost-benefit* ought to be a careful conversation. It ought to take account of WHO decides the aims or the presumed benefits of an organization's

actions. If the decider is the organization itself or its supporters, there is a strong possibility that the aims will produce benefits for the organization first; those aims may produce benefits perhaps only incidentally for the people who need help. The instance of institutional residence for people with disabilities seems a good example. The cost of residential institutions (especially state-operated ones) is high. The expenditure of that cost sometimes helps institutions reach aims--compliance with standards of funders--that are important for the organizations themselves. It looks as though these aims, however, have little to do with an experience of what could be called "the good life" by people who live in such places. The ratios of both cost/effectiveness and cost/benefit depend on whose opinion counts when aims are decided upon and the identity of *what's good* is determined. PASS evaluation teams have often noted that the cost/benefit ratio of a service cannot be higher than zero, regardless of the service's cost, if nothing or harmful things are being done to people.

Counting costs and trying to decide whether we are getting what we wanted in exchange for them, whether we're wasting things, and whether we're achieving good --these are valuable and necessary efforts. Let's just think harder about them, so that we don't find ourselves using these activities to add further to the burdens that are carried by some of the members of our communities and our society.

Jack Pealer

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The Safeguards Letter

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Not-quite Mid-Summer 2006

EARLY ANNOUNCEMENTS—NOT TOO SOON TO START PLANNING

Here are two major learning opportunities in 2007. Although information about these events is still incomplete, it's not too soon for you to start thinking about them and to start to make plans to take part in either or both.

• ***Fourth International Conference on Social Role Valorization, May 14-18, 2007 at the Crowne Plaza Hotel, Ottawa, Ontario, Canada.***

Filling valued social roles is an effective way for any of us, including those who have been socially devalued, to have the good things in life. Valued social roles seem to ensure that the person who fills them will experience personal social integration and will take part in society's benefits.

The theme of the 2007 International Conference on Social Role Valorization is "Crafting Valued Social Roles." That theme goes to the very heart of social role valorization. Speakers and workshop presenters will describe how valued social roles can be crafted for vulnerable people of different ages (*from early childhood to old age*), in key life spheres (*education, work, living situation, family and friendship, religion, spirituality, culture, leisure*), and in various service fields (*including developmental disability, child welfare, mental health, early intervention, medicine*). The crafting of valued social roles will be approached on a number of levels such as individual, familial, organizational, and societal and from several perspectives including practice, policy, and research.

For information about the International Conference, visit the web site at <http://www.vrs-srv2007.ca>, or contact Julie Clement at jclement@instvalor.ca.

• ***Crafting a Coherent Stance on the Sanctity of All Human Life, September 18-22, Catherine Spaulding Retreat & Conference Center, Nazareth, Kentucky (near Bardstown).***

Presented by Susan Thomas, and Associates of the Training Institute of Syracuse University

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.

Details about this 2007 event are still being planned. For more information, contact Joe Osburn, Director, Indiana Safeguards Initiative, at 502-348-1168 or joeosburn@spitfire.net.

IN MEMORY OF BENGT NIRJE

Let's take a little time to consider the life and contributions of Bengt Nirje, who died in early April at his home city of Uppsala, Sweden. We remember Bengt Nirje as the author of the very first published treatise about the principle of normalization. That essay, "The Normalization Principle and its Human Management Implications," was, in 1969, part of *Changing Patterns in Residential Services for the Mentally Retarded* edited by Kugel and Wolfensberger and published by the (US) President's Committee on Mental Retardation. Bengt Nirje is a founding father of the normalization principle.

I was only in Bengt Nirje's company once, and even to write that stretches things a bit. I listened to his talk at the conference celebrating the 25th anniversary of normalization's publication. The conference was in Ottawa in 1994. Being in Nirje's "company," then, means that I was one of several hundred listeners. I remember noticing that Nirje, like many others I have met, took a circuitous path to the "field" of organizing support for people with disabilities.

Nirje was fascinated with a number of academic interests. During his student days he apparently couldn't make up his mind which department of the university in which to concentrate, so he tried out all that appealed to him. He studied law, philosophy (especially ethics), art history, architecture, and cultural anthropology. He took up literary studies and taught literature to adults in a "folk high school." (Aside: a "folk school" is a popular Scandinavian form of public education for adults that attracted emulation from Myles Horton, the founder of the Highlander Folk School in Tennessee and a teacher to Martin Luther King Jr. among others. Connections like this intrigue me!) Nirje's literary studies were serious enough that he gained a fellowship in 1952 to Yale University. He recalled that his first experience of a US "mental" institution came when he went to interview poet Ezra Pound in Pound's room at St. Elizabeth's Hospital in Washington, DC. (Another aside: at that time more than 7,000 people were housed at St. Elizabeth's, which Nirje described, forty years later, as "... a city of old red barracks with gray, dusty-looking corridors." For Ohioans, that means St. Elizabeth's may have been a larger version of our own "Cambridge Mental Health Center," which is also composed of former military barracks.)

In 1956 Bengt Nirje was recruited by the Swedish Red Cross to work with the Red Cross to assist refugees of the revolution in Hungary. He went to a refugee camp in Austria where he tried to learn and transmit to those seeking help reliable information about where they could go and what they could do to rebuild their lives. He recalled putting to use his earlier experience with "group dynamics" and what we would now call "community organizing" to help people who had been displaced to move toward their new lives.

...when you are a refugee, you have a past that is gone and does not count in your new country. No one cares about it, no one believes in it, and nobody trusts you. Your past is really gone, and you really know nothing about the future. Your situation is bleak, uncertain, and anonymous. Such a situation can create a very unhealthy climate and dark moods. I also learned how hard it is to live with so many other persons in close quarters, day and night—100 to 160 per room, week after week after week. It means never having a "private space" for oneself for daily recuperation, satisfying daily activities, or meaningful recreation. There is no place for you, your family, and your few belongings. You

have to be strong, even if you are competent and not intellectually disabled. But you can become mentally “wounded” and socially handicapped, of that you can be sure! What keeps you going are your dreams, hopes, and desperate expectations of the future.

Nirje’s work with the Red Cross and later with the United Nations High Commission for Refugees (UNHCR) led to his employment, in 1961, by the Swedish association supporting children with cerebral palsy. He eventually became the ombudsman and director of that association, made contact with leaders of other similar efforts in other parts of the world, and was in a position to write the initial essay on normalization later in the 1960’s. I suspect, from his remarks about refugees quoted above, that his earlier experience with people who had been displaced from their homes by war quickened his insight into the lives of people who lived in mental institutions. In many ways the normalization principle depicts the reverse image of institutional life. Part of the inception of the principle probably arose from the refugee camps set up to accommodate those who were oppressed and whose lives were devastated in Hungary.

In memoriam, Bengt Nirje.

Jack Pealer

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

What, do you imagine that I would take so much trouble and so much pleasure in writing, do you think I would keep so persistently to my task, if I were not preparing—with a rather shaky hand—a labyrinth into which I can venture, ... in which I can lose myself and appear at last to eyes that I will never have to meet again? I am no doubt not the only one who writes in order to have no face. Do not ask who I am and do not ask me to remain the same: leave it to our bureaucrats and our police to see that our papers are in order. At least spare us their morality when we write.

Michel Foucault
The Archaeology of Knowledge

Each person, big or small, has a role to play in the world. As we start to really get to know others, as we begin to listen to each other’s stories, things begin to change. We no longer judge each other according to concepts of power and knowledge or according to group identity, but according to these personal, heart-to-heart encounters. We begin the movement from exclusion to inclusion, from fear to trust, from closedness to openness, from judgement and prejudice to forgiveness and understanding. It is a movement of the heart. We begin to see each other as brothers and sisters in humanity. We are no longer governed by fear, but by faith, hope, and love.

Jean Vanier
Becoming Human

At the end of my present term, of which two years are yet to come, I propose to retire from public life, and to close my days on my patrimony of Monticello,... I have the consolation too of having

added nothing to my private fortune, during my public service, and of retiring with hands as clean as they are empty.

Thomas Jefferson
Letter to Monsieur Le Comte Diodati
March 29, 1807

MR. MXYZPTLK REPORTS THAT MOST DISABLED AMERICANS HAVE JOBS Rob McInnes

(Editor's Note: A longer version of this article was published by Rob McInnes in the May 2006 issue of the online publication Diversity World. This excerpt is re-published here with permission from Diversity World. JRP)

Mr. Mxyzptlk is an odd character from Superman lore. From another dimension, this character is a mischievous practical joker who uses his powers to warp "reality" on earth and create mayhem. As I read earlier today, his main claim to fame is his "topsy-turvy magical, nightmarish alterations of reality." His only weaknesses are that he cannot stand being ridiculed and, if tricked into saying or spelling his name backwards (Kltpzmx), he is involuntarily sent back to his home dimension for a minimum of 90 days.

On May 12, 2006 the U.S. Census Bureau issued a press release entitled "More than 50 Million Americans Report Some Level of Disability". Summarizing topical highlights from information collected in the 2002 census, it provides information on employment, educational achievement, computer usage, prevalence of mobility impairments, etc. Here are some of the employment-related findings:

- Approximately 51.2 million people said they had a disability; for 32.5 million of them, the disability was severe.
- About 56 percent of people ages 21 to 64 who had a disability were employed at some point in the one-year period prior to the interview. People with a severe disability status reported the lowest employment rate (42 percent). This compared with the employment rates of people with a nonsevere disability (82 percent) and those with no reported disability (88 percent).
- 32 percent of people ages 25 to 64 with a nonsevere disability and 22 percent with a severe disability were college graduates. The corresponding rate for those without a disability was 43 percent.
- Among adults ages 16 to 64, 11.8 million or 6 percent reported the presence of a condition that makes it difficult to remain employed or find a job.
- Median earnings for people with no disability were \$25,000, compared with \$22,000 for people with a nonsevere disability and \$12,800 for those with a severe disability.

Based on this press release, a writer for the Associated Press immediately produced an article entitled "Most Disabled Americans Have Jobs" that was picked up by major newspapers across the country. The result? A little mayhem within the disability community! Here at Diversity World, I quickly received several emails - all questioning the validity of the data. One reader wrote: "Are they (the government) trying to convince all of the fine American people the disabled are working despite their disability? All the people I know and some professional people think the opposite."

Back to Mr. Mxyzptlk... I wonder if maybe he has a sizeable army of researchers and reporters

who are secretly manipulating all of the data and research that focus on disability and employment - mischievously creating "topsy-turvy magical... alterations of reality". One thing is certain. No one but a seasoned researcher can really understand how to interpret the various facts and figures that are bandied about.

In the April 2004 issue of this newsletter, I wrote an article called "Being Myth-Informed About Employment And Disability" - basically debunking some of the urban legends that abound in this area. One of these is the notion that there is an over 70% unemployment rate for people with disabilities. As borne out by the Census Bureau's press release, it is closer to the truth to simply say that people with disabilities are 2.25 times as likely to be unemployed as their non-disabled counterparts.

Let's take a closer look at this report's assertion that people with disabilities have an employment rate of 56%. This, of course, is the statement that gave birth to the "Most Disabled Americans Have Jobs" pronouncement.

64% of the people subsumed under the term "Disabled Americans" are folks who have severe disabilities. For these 32.5 million Americans the employment rate is only 42%. That means that 13.7 million severely disabled Americans are considered employed. Does that mean that they "have jobs" as we are being led to believe? Not really. Apparently, being classified as "employed" only means that they reported SOME employment in the twelve months prior to the survey.

What we learn from further analysis of the Census data is that of those who were considered "employed", only about 40% had uninterrupted year-round employment - and roughly three-quarters of those folks had full-time jobs while the rest were employed only part-time. While I haven't seen a statistical analysis, I would speculate that the remaining 60% of "employed" people with severe disabilities have only a very fragmented and sporadic array of part-time, temporary contract employment experiences in their work histories.

Yes, it seems that only 12.8% of people with severe disabilities had full-time, year round employment to report - in contrast to 52.6% of the non-disabled population. Put another way, we could say that people without disabilities have a four times stronger likelihood of having steady full-time employment than do people with severe disabilities.

Well there is just one look at a bit of the quantitative data available on employment for people with disabilities. While it is entirely another can of worms, I am still anxious to see some research findings on the qualitative dimension. What can research tell us about the underemployment of people with disabilities? Quantitative data like this always raises questions for me about the nature of the jobs that people are engaged in - the extent to which they are working in positions that really draw on their best interests, skills and talents - and the extent to which those same interests, skills and talents are wasted as people with disabilities are hired into jobs that don't recognize their full potential in the workplace. But, like I said, that is another can of worms. In the meantime...

"Most Disabled Americans Have Jobs"... I don't think so! Springing that headline on the public was inexcusably misleading. Talk about "topsy-turvy magical... alterations of reality"! How many researchers and reporters are doing Mr. Mxyzptlk's bidding? How do you say "researcher" and "reporter" backwards? Maybe we can get them to go away.

Rob McInnes, Diversity World - www.diversityworld.com

A VIEW FROM THE BACK WINDOW

People with Disabilities and their Money

It's an old story that people with disabilities (perhaps most people with so-called "intellectual" disabilities) are likely to be poor. The guaranteed income for a US citizen who can demonstrate disability is still less than \$600 per month—the maximum Supplemental Security Income payment. Many people who receive such income have to pay almost all of it (or perhaps more than all of it) for their rent and other basic living expenses.¹ Sometimes these payments are made to or through the agencies that provide at-home support. The people who make those payments get to retain a small portion of their income as "personal allowance," but the expense of this allowance is under close scrutiny by human service workers. In effect, that small personal allowance is the person's disposable income. In many places in the US the average annual earnings (excluding fringe benefit costs) for human service workers are four or five times the amount of an individual's annual total of SSI payments. Relatively few people with disabilities have regular full-time employment, giving the lie to the headlines derived from recent census data—see Rob McInnes' article elsewhere in this issue. And, at least partly because of a long lag between increases in the US minimum wage, the income gap between those people with disabilities who do have jobs and other citizens continues to grow wider. People with disabilities don't have much opportunity to acquire wealth. It is an old story.

There's another story being repeated all the time about people with disabilities and their money. The outcome of this other story is that the people whose lives are overseen by human service agencies are kept almost completely away from possible uses of that limited amount of money available to them. Here's some evidence.

I get a chance to read all the reports that are written following visits to the homes and work (or other service) locations used by people with disabilities in our community. My colleagues make those visits, which are required by state regulations so that we can assure the quality of support that's offered. Visitors talk not only with people who use supports but also with members of their families, with workers who offer direct support, and with service coordinators. Among the questions posed to these folks are questions about money or wealth:

- How does the person manage her money?
- Does the person have control over his money?
- Are others (family, service coordinators, etc.) satisfied with the ways that the person's finances are handled?

As I read a number of reports about these visits recently, I kept track of the answers to questions like those. Below I summarize what I noticed about whether the answers reflect a belief that the person being visited is what we might call an "economic agent." Do people around the person think that she can learn or be trusted to handle money? Here's what people said:

Person >	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	Total ↓
Yes								X								1
Partial*	X	X			X				X			X		X	X	7
No			X	X		X	X			X	X		X			7

*"Partial" means that the person is believed competent to handle very small amounts of money doled out by human service workers.

I read further that a professional worker involved with a person with a disability was asked: "Does she (the person with a disability) actively participate in financial decisions?" The answer was: "She is able to purchase small things she wants or needs." She could do so, of course, only up to the limit of her personal allowance—around \$60 US per month. Another human service worker responding to the same question about another person simply said: "He doesn't

¹ Sometimes human service systems cover the difference between someone's income and their cost to live.

understand money values.” Those were the most frequent answers to questions about participation in financial affairs. Even those who know people with disabilities best and spend the most time with them do not see them as economic actors, except (maybe) at the very smallest scale.

I can think of at least five reasons to worry when people are dismissed as economic actors or agents.

1. Like it or not, most of us in this society regard responsibility for taking care of one's money or property as an essential part of being a person. Women's groups have understood that for a long time (see Virginia Woolf, *A Room of One's Own*). Unfortunately, some members of the society measure others' worth entirely according to the others' wealth and skill at manipulating it. Most of us don't use wealth to judge other people quite that baldly. Instead, we've learned unconsciously to attribute personhood more easily to others who seem able to make clear decisions... to choose about things in their lives. But we live in a time and place when the main tool for choice is money. If you don't have money or are prevented from using what you have, you won't be able to make as many clear choices; so, indirectly, access to and use of funds connects to the worthiness attributed to a person.
2. People you and I know are oppressed both by their low incomes and by laws or rules that make sure that income stays low. For example, should someone who has used long-term supports financed through Medicaid suddenly have a chance to earn more—or perhaps to receive an inheritance—that person will soon find that he's built up a bill (called “patient liability”) that others are very determined to collect. A direct support worker in an Ohio community reflected: “It has been hard for me to deal with people's poverty: the state takes everything so some people's parents have disinherited them.”² That and similar policies further discourage people whose economic prospects are uncertain, and that discouragement further reduces the chances that someone will find a way out of oppression. As workers with poor people have learned, escape from economic imprisonment comes through opportunity—something that's hard to imagine as possible for someone whose very status as an economic agent we deny.
3. Money does matter, personally, to people with disabilities. Sometimes, as we've seen, workers with people who have disabilities deny those people's ability to “understand” how money works. As well, sometimes in the next breath the same workers remark about how some of the same people: a) look forward to pay day, b) ask for the money they receive to be in small denominations so it will look like there is more of it, or c) require guidance about not taking money from others. Are those the kinds of things people who “don't understand money” would do? It seems as though many people may be calling out, in ways we don't understand, for more experience with the economic part of their lives.
4. We don't know as much as we think about people's understanding or potential participation in their personal economies. Much of the history of services for people with so-called intellectual disabilities has reflected assumptions about limitations in the capacity of people to learn and grow. But we've learned. We found out that some people with “autism” could communicate with the help of a touch on the shoulder. We now know that many people with disabilities make great employees and fellow citizens and even greater friends. Given what we've learned, why should we keep on assuming that making financial decisions is somehow out of reach?
5. Those of us who work for pay trying to make life better for people with disabilities are supposed to be expert at teaching and organizing support. Long ago Marc Gold described “mental retardation” as a condition that demands superior teaching and

² O'Brien, John. “Getting There: Residential, Inc.'s Next Steps.” Responsive Systems Associates, 1986

environmental arrangement from society (my paraphrase). The adaptive strategy is not to blame people for their failure to learn; the adaptive strategy is to take responsibility for figuring out how to teach, including how to teach someone about an active economic life.

Wouldn't it be worth a try? Others have thought so. The Highlander Center has long conducted economic education efforts for people who had little experience with money or credit. A housing support organization in Minneapolis has developed a "financial literacy" program for adults with developmental disabilities. Other organizations have sparked the creation of credit unions or even smaller loan funds that are governed by people with disabilities and that make both cash and credit available, albeit in small amounts.

We learned from Lou Brown and others about "partial participation." Partial participation means that people are IN on things. They are enabled or supported to do ~~at least a little (or maybe a lot) more than we initially think they can do. And the learning from partial participation — the outcome — becomes the starting place for next steps. People — all of us — learn to take part in new things by doing so with guidance and direct teaching as it's needed. If any of us knows how to handle her finances and if we "understand about money" it's because someone showed us how and offered help as we lived through mistakes and got better. I've tried to say why being an economic agent is important to people with disabilities. Like it or don't, handling money is part of all our lives. Let's not dismiss this part of the experience of people with disabilities.~~

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