

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

JUST 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"