Number Thirteen March, 1990

AN EXPERIMENT

Readers of The Safeguards Letter may notice a difference this time in the appearance of the Letter. Last fall, OHIO SAFEGUARDS was able to purchase a "Macintosh" computer, and this is the editor's first experience at trying to publish the Letter using this new tool. It hasn't been easy. If you look closely, you'll see that the pages have been numbered using the faithful old typewriter. Other final touches (before walking down to the printer's shop) have been added in the same way. No doubt the "software documentation" (as they call it) tells me, somewhere, how to do these things in a few easy keystrokes, but I haven't found that page yet.

Please let us know what you think about this experiment. Is the type easier or harder to read. Which "look" to the Letter do you like better--or do you have ideas about another "look" that would be worth a try as well? We'd love to hear from you!

PASS WORKSHOP "IN THE WORKS"

OHIO SAFEGUARDS is making plans for the 1990 offering of the workshop entitled "An Introduction to the Role of Values in Services, through the Use of PASS 3." Dates and the location for this workshop have not yet been finalized, but we expect that it will be in the late summer or early fall somewhere in the Cleveland area. OHIO SAFEGUARDS is working in partnership with the North Central Region of the Ohio Interagency Training Network, at Case Western Reserve University, to offer this workshop. We hope that a more-detailed announcement about the workshopwill be able to be released soon.

People who plan to attend the PASS workshop will explore some of the ways that our society usually responds to people who are viewed as "different"--especially the ways we act through organized helping forms or "human services". The workshop will help participants learn about human service procedures that affect the dignity, growth, and rights of people who receive services. This workshop is designed for anyone who is interested in developing, delivering, or monitoring/evaluating services in order to improve their responsiveness to people who use them.

Readers interested in making sure that they receive a flyer announcing details about the PASS workshop can contact:

OHIO SAFEGUARDS
P.O. Box 1943, Chillicothe, Ohio 45601
(614) 773-6191

or

North Central Training Network
Office of Comm. Health, CWRU
2119 Abington, Cleveland, Ohio
(216) 368-3660

Additions to the OHIO SAFEGUARDS Library

The library continues to collect new items. Since the last issue of the Letter was published, we have added the following books.

Erikson, Kai T. Everything in Its Path: Destruction of Community in the Buffalo Creek Flood. New York: Simon & Schuster, 1976.

This is a book about the loss of community that resulted from a disaster that was in small part "natural" and in larger part man-made--the sudden flood of the Buffalo Creek valley in West Virginia in February, 1972. Erikson's story focuses, as well, on the compounding of the disaster by the reaction of agencies that were intending to help. The result of both the event and its aftermath has been that a formerly close-knit community made up of several identifiable neighborhoods is simply gone. Much of the book is in the words of Buffalo Creek valley residents, who spoke to the author when he was working with a law firm that sought compensation from the mining interests whose malfeasance led to the disaster in the first place.

Olsen, Tillie. Yonnondio From the Thirties. New York: Dell Publishing Co., 1974.

This novel (or fragment of an unfinished and never-to-be-finished larger novel) was originally written by Tillie Olsen in the 1930's and then "lost"--in Ms. Olsen's life as a mother, homemaker, and worker--for many years. It was finally rescued and published in 1974. In prose-poetic language, Yonnondio takes readers through a part of the life of an impoverished family in the 30's, as they struggle from a western mining town through farming (briefly) on the Great Plains to existence in the slaughterhouse neighborhood of a city like Omaha. It is a sometimes hard-to-read story of the relentless effects of poverty on mothers, fathers, and especially children.

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About THE SAFEGUARDS LETTER

The Safeguards Letter is a quarterly (approximately) 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, P.O. Box 1943, Chillicothe, Ohio 45601. We welcome our readers' ideas and reactions

CALLING ABOUT A DREAM

The phone rang while I was putting the groceries away. I often regard the phone as an annoyance, and I knew right away that was my attitude about this call. My groceries had already been in my car for hours. I wanted to get them taken care of, now. How can it take me so long to do such a simple task? I was puzzled as I heard the operator's voice tell the caller, "Go ahead, sir." Not collect, and not female. Then I heard Bill's voice. "Sandy, are you there?"

He's been in Tampa working the fairs. He'd already lost $2.10 in the phones before we got connected. He had worked out something with the operator to get it back when we finished our call. He said he had seven more dollars in quarters. I could tell he was celebrating something. He'd made a decision, a big one. He wants to move to Tampa by the end of this year. Not because of the warm weather, but because he's found an Army recruiter who said "Maybe." Maybe there's a way for Bill to get into military service. "Maybe" is closer to "yes" than anything any recruiting official has ever said to Bill.

Bill asked me if I remembered how long he'd been dreaming about getting a "job" with the military. We agreed that it had been a long time. As best I can recall that dream was alive when we met, when he was seventeen. Next year he'll celebrate his 30th. "I was honest with him. I told him about where I grew up, my speech, a bad education, my time with the law, and my age, and my slow learning. But I have to live in Florida, for six months. So maybe in about a year. He said it wasn't guaranteed."

I didn't know what to say, and ended up telling him I thought he sure seemed happy about it, and that it sure seemed like a lot to think about. I told him I'd look forward to talking about it when he got back to Ohio. That won't be our first conversation about Bill and the Army. Because Bill and I see the military and military service from pretty different points-of-view, it nearly always makes for a lively discussion. For Bill the Army has been his career of choice. One of his older brothers was in the service. There's the uniform, and the weapons, and the authority. It's respectable, and secure. It's been a long time dream.

I've never seen the military in those positive ways. Given my preference for non-violent theory and practice and my political views about power and oppression, there don't seem to be any benefits. The military is more like a nightmare than a dream to me. But the phone call from Bill that day reminded me of several things that seem important. The "interruption" I was annoyed about turned out to be a conversation with a long-time friend. I'm determined to begin to think about the phone more as my friend Jane Morgan does. She often answers her phone by saying, "I hope this is good news!"

Bill's call was a reminder that dreams last a long time and that some dreams take a very long time to become real--or to be let go of. He reminded me, too, that one of the gifts in this life is sharing good news about a dream with someone you trust will understand just how important the news is.

I don't know what's going to happen. I guess it's possible that some day next year I'll attend the end-of-boot-camp event. I do know that we'll continue to celebrate our friendship, because fidelity in our friendship is a dream we both have.

Sandra Landis

E.I. Blues.

Jack Pealer

Frankly, I'm getting a little nervous about some aspects of the "early intervention" movement. It's terrific to see so many people who understand the importance of early attention to the learning of young children who have developmental difficulties. But---recently I've been seeing signs, within this movement, of surging professionalism such as that which afflicts so much else in human services (witness: "infant psychiatry" as a new specialty), of increasing complexity in organizations that are being set up (collaboratively, of course), and of the construction--with state bond money--of "centers" where young children could be bused for "needed services." Haven't we been this way before?

I thought that one way I could express myself about all this would be to re-state some things that I first wrote six years ago, in a short essay in The Greffsun Letter (the predecessor to The Safeguards Letter). So, here goes--from February, 1984:

We have been reminded lots of times that human beings tend to think in binary terms. One favorite pair of images is that of light and darkness. I want to borrow that imagery to share a few thoughts about what we in human services are increasingly urged to do for young children with disabilities. If Burton Blatt can write about the "dark side of the mirror", and George Lucas about the "dark side of the force," then I'll risk the indulgence of the "dark side of early intervention."

First, though, I ought to look at the "light" side. What are the things that we human service workers increasingly see as desirable and necessary for young children? What do we know about growth and learning that makes most of us anxious or even frantic about the need to start early in trying to affect the development of a child with a handicapping condition? I want to summarize the reasons for our anxiety by inserting two paragraphs from The Tangled Wing by Melvin Konner:

> In a stunning experiment on experience and the brain, rat pups were raised in rich or poor environments. The favored pups, selected at random, grew up in a world full of toys and other pups. A control group grew up under ordinary laboratory conditions. A third group was impoverished; even the relatively low level of stimulation available in the ordinary laboratory was withheld from them.
>
> These different conditions stamped differences in the brain. In the visual part of the brain, where patterns taken from the eye are converted into usable thought, those same pyramidal cells so crucial to higher mental life appeared changed under the cold eye of the microscope. Not changed in their basic placement or overall structure, but in the finer aspects of structure the impact of experience was evident. Animals raised in a rich environment had more small branches far out along the main trunks of the dendrites... more spines could be counted for each unit of length in the rats that had stimulation during growth. (pp. 60-61)

Rat pups are not human infants, and the same experiments worked on rat pups will not, we hope, be deliberately tried on human babies. But, what if the inference I draw from the above quote is right? It seems possible that the human brain and nervous system are analogous to our muscles--if not used, especially at an early age, they may "atrophy" (the analogy is not exact). So, what we human service workers worry about, with good reason, is the likelihood that systematic deprivation of human babies will bring about irreversible differences in the structure and functioning of those babies' brains. And our worrying about this leads us to consider certain kinds of responses--services--in the hope and expectation that we can help babies avoid or minimize loss of brain functioning. In other words, as we usually put it, we want to help children "grow to the maximum of their potential." It's good that we know what we do about the growth of young children. It's right that we, sometimes desperately, try everything we can think of to assist that growth. This is the "light" side of early intervention.

The trouble is that many of us--the same people who are worrying so much about kids--are human service workers. We're pretty powerful folks, as it turns out! Being powerful and authoritative people we routinely seek out answers or solutions that are consistent with the sources of our authority: human service organizations, agencies, and professional credentials. And the usual response that we've learned (from these sources) to make to almost anything that worries us (as the potentially underdeveloped brains of young children worry us) is the discovery of <u>categories</u> of children who fit into <u>programs</u> we devise. In other words, a typical response is: early **labeling** and early **schooling**. These are offered despite all that we know about the social effects of labels and despite our growing suspicion that schools may not be the best way to assist the learning of <u>any</u> child. These usual responses reveal the "dark" side of early intervention. *And, in 1990, if we establish "centers" built with "MR/DD" money, do we think that all our talk--our language--about integration will prevent these places from the strong possibility that they'll segregate some children? Our talk can change like the wind in the night. Buildings will be around for a long time.*

Six (*now twelve*) years ago in Wisconsin I visited a program that gave me my first insight into this sort of thing. I was "floating" with a PASS team that was performing a practicum assessment of an early childhood program where children with disabilities and children without disabilities were, supposedly, grouped together. I arrived at the program during the team's interview with program administrators, and I listened as one administrator complained about the lack of cooperation she experienced from the parents--and particularly about those parents' "lack of acceptance" of their children's disabilities. This is a common sort of complaint from human service workers: if you don't agree with my view of what the problem is and how it should be solved (or even whether there is a problem), then it will be hard to get help from me. What the program administrator was saying--about young children--was that she couldn't help very much until the parents caved in to her point-of-view about the children's capabilities or potentials. The implication for families was: we can help your child best if you will limit your expectations for her/him to what we expect of "retarded" behavior!

Don't we know what such expectations produce? Can't we recognize that such giving-in to limited expectations is equivalent to starting young children on a long downward spiral? It seems to me that considerable credit is due to those parents at the Wisconsin program who were "uncooperative" and who wouldn't accept such a future for their children. They seem to have had a sense about the long-term danger of segregated "help" and early myopic judgments about their children. Somehow, they were aware of the "dark" side of early intervention. They were heroes to me then, and other parents like them remain heroes to me now.

<u>ORWELL "DOWN AND OUT"</u>

Sandra Landis

Have you been looking for an easy to read, relevant critique of western culture's social and spiritual policies? If so, pick up a copy of George Orwell's <u>Down and Out in Paris and London</u>. There's a copy (spotted at a used book sale) available in the OHIO SAFEGUARDS library. Ordinarily it might be kind of hard to find because it was published in 1933.

Mr. Orwell's topic is poverty. The narrative is of Orwell's experiences of what in the 90's we call the "working poor/homeless" person, and, although the experiences occurred in

1930 and 1931, the scene is a familiar, contemporary one. Some things, like being frightened, cold, and hungry, just don't change very much.

The fact that Mr. Orwell spent time on the streets and highways of France and England prior to writing this "report" lend chilling correctness to his closing words:

> "My story ends here. It is a fairly trivial story, and I can only hope that it has been interesting in the same way as a travel diary is interesting. I can say, 'Here is the world that awaits you if you are ever penniless.' Some day I want to explore that world more thoroughly. I should like to know people like Mario and Paddy and Bill the moocher, not from casual encounters, but intimately; I should like to understand what really goes on in the souls of plongeurs and tramps and Embankment sleepers. At present I do not feel that I have seen more than the fringe of poverty"
>
> Still, I can point to one or two things I have definitely learned by being hard up. I shall never again think that all tramps are drunken scoundrels, nor expect a beggar to be grateful when I give him a penny, nor be surprised if men out of work lack energy, nor subscribe to the Salvation Army, nor pawn my clothes, nor refuse a handbill, nor enjoy a meal at a smart restaurant. That is a beginning."

JUST QUOTES

After all, the future is quite meaningless and unimportant unless, sooner or later, it is going to become the present.

Alan Watts, Wisdom and Insecurity

Burnout comes when you are worrying about profits.

Ray Bradbury, Interview

CONTRIBUTIONS STILL WELCOME

Over the past few months we have been fortunate to receive a number of contributions of money from our readers. These contributions have been and will be used to pay the costs of publishing and distributing The Safeguards Letter. If any other readers wish to contribute, to offset the Letter's printing and mailing costs, we'd welcome the help. You can contact us at :

The Safeguards Letter
P.O. Box 1943
Chillicothe, Ohio 45601

A VIEW FROM CHILLICOTHE "Being a Board Member"

For six years I was a member of the Board of public agency in the town where I live. I served two terms--the most allowed by the law--between 1984 and 1989. I've been away from the Board for a few months now, and I think enough time has passed that it is OK for me to try to collect my thoughts about being a Board member.

The agency that I helped to govern is the one, in our town, that organizes and delivers help to people who are called mentally retarded or developmentally disabled. In some ways the Board's purpose doesn't matter so much, with regard to my feelings about my functioning as a member of it. I suspect that many Boards have similar characteristics or act in similar ways. The reason I mention the purpose is because "developmental disability" is something I'm supposed to know a lot about. I've worked for almost twenty years in organizations that have to do with developmental disability. This is not so much a comment on the Board as it is "background" on the experience that I brought to Board membership.

That's important because I assumed, on becoming a member of this particular Board, that I would be able to bring what I know to bear, with some effectiveness, on the problems that face the organization the Board governs. I assumed that having experience with "developmental disability" would help me better understand the Board's work. I assumed that my "expertise" would somehow automatically result in my understanding clearly what was happening in the organization. It didn't turn out that way. For six years I went to meetings once a month. I served on various committees. I read, thoroughly, all the papers that were mailed to me about the Board's business. I visited the programs and took part in some educational or planning events that the organization's staff arranged. I met the legal requirements for "in-service training" for Board members. And, more than six years later, I think I understand the organization only slightly better than I did when I took my oath of office in January, 1984.

Take the budget (please!), for example. The Board I served on could not get control of the growth of its budget. The Board, like Congress, could not slow down the pace of increases in levels of spending, even when the members of the Board understood the likely future consequences of those increases. The Board's chief executive officer worked hard analyzing the past pattern of budget-expansion and shared his analysis with the Board. Committees met and studied the financial situation. The Board devoted significant meeting time to discussing finance and even passed a resolution (like Gramm-Rudman) that stated its commitment to restraint in the growth of the budget. A few months later the same Board (with me as Chair) approved a new budget with an 8-10% increase--about the same rate as that which we had deplored and voted to avoid. I don't think this happened because Board members were cynical nor because they lacked the courage to make harder decisions. I think it happened at least partly because the organization we "governed" is so complicated--so many people doing so many things--that it is very hard to understand. Each Board member devotes a good bit of time to the duties of membership. But even that perhaps substantial contribution of time and attention is not enough for someone to know, to understand what is going on, or to relate that understanding to a decision like a vote on a budget. I often got the feeling that I was helping make decisions in the dark with winds swirling around me. I don't mean to fault anyone--not my fellow Board members (who worked faithfully) and certainly not the organization's staff. Even with my experience, I didn't--and, in the time I was able to give to the Board I couldn't--know enough to act more wisely than I did.

Another thought. The results of a survey, conducted by the National Center for Education Information, were summarized in the Chillicothe Gazette on February 28, 1989. The study surveyed presidents of public school boards across the United States. Among the reported findings was that "... the longer people have been on school boards, the more co-opted they are by the system and the more resistant to any changes in it.... Generally, board presidents who have been members of their boards for short times were found to want changes in numerous areas of education. Those who have been on their boards 10 years or more, 26 percent of the total, are more resistant to changes." My inference from these findings is that there is something about Board membership that makes me less worthy of being <u>trusted</u> by people who use the organization's services, because I've become caught up in supporting the organization's purposes, perhaps at the expense of those who use services. The longer I was a Board member, the more likely it may have been that forces like group identity, loyalty to the group's work, and (conscious or unconscious) adherence to the group's customs or traditions had the effect of dulling my sense of what would have been different and better directions to take. So, there's a <u>dis</u>advantage in experience, sometimes. Columnist Ellen Goodman remarked, in a recent column, that we "... may have to learn once again that ideal public service is, by definition, temporary."

Would I try Board membership again? Probably, if the chance comes along. As I have, for the last several years, gone about the business of "evaluating" the performance of various human service organizations, I've often found myself talking about Boards. I've been saying things like: Boards represent an organization's connection to the future; Boards are a point-of-stability as human service workers come and go in an organization; Boards serve as a link between an organization and its community and the citizenry thereof--a link to local values and interests. Boards, in summary, are the rocks on which things rest, in organizations that are trying to bring about changed lives for people. After some experience as a Board member, I now have more difficulty in saying and believing those confident assertions about Boards. It turns out that Boards have all the frailties and make all the mistakes that should be expected of groups of humans. But--and this seems important--the failure of Boards to reach the ideals we set for them doesn't make them less necessary. Until some other forms of governance are invented, organizations will need good Boards, for all the reasons stated above, even though those reasons sometimes sound hollow to me now. And good Boards, of course, require good members.

Jack Pealer

The Safeguards Letter

A Publication of OHIO SAFEGUARDS

Number Fourteen June, 1990

CLEVELAND PASS WORKSHOP SCHEDULED

OHIO SAFEGUARDS and the North Central Region of the DD Training Network announce the scheduling of "An Introduction to the Role of Values in Human Services, through the Use of PASS 3." This workshop, which has been offered annually in Ohio by OHIO SAFEGUARDS for several years, will take place between Sunday, October 28 and Friday, November 2, 1990 at the Christian Life Center in Cleveland, Ohio. Complete details about the workshop will be announced in flyers issued by OHIO SAFEGUARDS and the North Central Training Network in early July. Fees for the workshop are expected to be in the range of $225-$260 per person, including lodging, meals, and materials.

The title of the workshop describes both its intent and its main emphasis. Those who come to the workshop can expect to be immersed in readings, lectures, discussions, and a practicum visit to a human service agency. All of these activities focus on helping participants learn how the values and beliefs of both human-service agencies and of the culture in which we live shape the assistance people who are in need receive. Those values have, as a consequence, powerful influence on the kinds of lives that people in need are enabled to live.

Most participants in past PASS 3 workshops have found them enriching, stimulating, and (yes!) all-consuming. Some people count their first PASS workshop as a high point in their careers. Registration for the workshop can be accomplished using the form that will accompany the descriptive flyer. Those interested in attending are urged to register as quickly as possible following receipt of the flyer, because only 25 participants will be enrolled. If you want to be sure to get a flyer, please contact OHIO SAFEGUARDS at P.O. Box 1943, Chillicothe, Ohio 45601 (phone: 614/773-6191).

SUBSCRIBE TO TIPS!

TIPS stands for "Training Institute Publication Series" and is published every two months by the Training Institute for Human Service Planning, Leadership, and Change Agentry at Syracuse University. TIPS is edited by Dr. Wolf Wolfensberger, who is the Director of the Training Institute. TIPS is unique. It contains articles, reviews, commentary related to the Training Institute's mission, which currently has to do (as the TIPS editorial policy states) "...with reading the 'signs of the times,' and interpreting their meaning for human services." To quote further from the editorial policy: "We assume that subscribers are people who lead hard lives struggling against great odds, and are aware of many shortcomings in human services. Thus, we try to inject levity into TIPS so as to make subscribers' lives more bearable (or less unbearable, as the case may be), even if not deleriously joyful. In fact, the 'signs of the times' are depressing, and thus some TIPS content is in need of occasional levitation."

In fact, the "signs of the times" as reported by TIPS are serious and sobering. Readers are likely to be enlightened, more than occasionally depressed, and not infrequently outraged. TIPS is, though, one of those publications that is likely to be read as soon as it arrives--no leaving this on the desk for a few days or weeks--because it always includes ideas and opinions that instruct and challenge. Subscriptions to TIPS can be had for $25 a year ($27 U.S. in Canada and $30 U.S. overseas) from:

TIPS Editor, S.U. Training Institute
805 South Crouse Avenue
Syracuse, New York 13244-2280

WE LEARN TO THROW A PARTY!

Originally we said that, at the end of our "DD" project, we'd have a conference to tell people about what we learned. But we didn't really want to do that. Along the way somewhere we decided that we wanted to have a party. And, on May 18, at the Holiday Inn in downtown Columbus, that's what we did.

Since April, 1987, OHIO SAFEGUARDS has been trying to help people and organizations around Ohio learn about "designing individualized services" for people with developmental disabilities. We have both sponsored and conducted lots of training events. We have consulted, about how to focus assistance around each person who needs or wants it, with a number of agencies that try to help people with disabilities . Most important, we have been allowed to enter into the lives of a few people with disabilities and into the lives of their families. It has been a privilege for us to have been permitted to try to help these folks make and carry out actions that result in changes for the better in their lives. We learned from them and hope that they benefited by our work.

We wanted to say "thanks" to these friends that we had made, and we wanted to have a way to allow others whom we know (who are interested in the work we've been doing) to meet and get acquainted with them as well. A party seemed like a natural thing.

But OHIO SAFEGUARDS (and, particularly, the two planners of this party, Landis and Pealer) has almost no "track record" with party-giving. So, we were worried. What if nobody came? Worse yet, what if people came but refused to talk to each other...stood around, bored and silent? Well, we needn't have been concerned. The evening was lovely. The Holiday Inn did a great job with the food, the drinks and the room. The members of the Women's Music Club of Columbus devoted themselves to offering us more than two hours of beautiful string quartet music. Some folks who came to the party thinking they only liked rock and roll learned a bit about Haydn and Pachelbel. And the people who came--all of them--made the gathering a success. We watched in some amazement, gradually becoming convinced that people really were having a good time.

So, we learned about how to throw a party. Get likable people together at the same place and time, add some food and music (helpful, but probably not necessary), and let the people enjoy each other. It was a great way to bring three years of work to a close. We recommend it to other groups that are trying to figure out an appropriate end to some endeavor they think has been important.

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COPIES OF REPORTS AVAILABLE

OHIO SAFEGUARDS' initial "DD Project", entitled "Training for Designers of Individualized Services", is almost complete now (see the note on our party elsewhere in this issue). Part of what we've been doing to wind the project's work down is writing. We've thought and talked with people about several written "products" that might issue from the work that's been done, and, so far, two items have emerged. They are:

> *"Personal Histories: Suggestions for Studying and Recording Them."* As the title indicates, this short (seven pages) paper contains suggestions about how to explore and record the personal history of someone--e.g., someone who has a disability--whom we're helping to plan. The paper was originally developed in response to discussions with people who assume "planning assistant" roles (Case Manager, Service Planner, etc.) in the lives of people with disabilities. We have intended, in this paper, to reply to questions about why the recording of someone's personal history is important and about what kinds of activities help in creating useful records.
>
> *"What Have We Noticed as We've Tried to Assist People One Person at a Time?"* This thirteen-page report is a summary of the ideas expressed during a one-day discussion on "individualization" of responses to people with disabilities that was held by OHIO SAFEGUARDS on January 26, 1990. Those who attended and took part in the discussion were folks who have experience trying to develop "individualized" plans that really are centered in the personal situation of each person who has disabilities. "For real" personalized planning has meant a number of changes--changes in the lives of individuals, changes in the organizations that those people are part of, and changes in communities that the people and organizations inhabit.

A limited number of copies of these reports are available from OHIO SAFEGUARDS. If you think you'd like to read either or both of them, just contact us (in writing, please), and we'll send you copies--as long as they last. When, or if, other items like this are issued (several ideas are in process) we'll let you know.

JUST QUOTES

But what greater torture than to do useless work, like one of my granddaughters, who stood before an assembly line in a small factory in Vermont where Timex watch boxes were made. Her job was to dip one half of the box in glue and attach it to the other half. When one remembers that the same box is discarded right after one purchases and removes the watch, it can only be regarded as utterly useless work. Most packaging--more and more elaborate--falls into this category. In *The House of the Dead*, Dostoevski called attention to the torture of useless work. He had suffered it himself during his imprisonment in Siberia.

Dorothy Day
Catholic Worker
February, 1974

---**Personalism**, a philosophy which regards the freedom and dignity of each person as the basis, focus and goal of all metaphysics and morals. In following such wisdom, we move away from a self-centered individualism toward the good of the other. This is to be done by taking personal responsibility for changing conditions, rather than looking to the state or other institutions to provide impersonal "charity."

The Catholic Worker
May, 1990

The eight regular members of this club were high practitioners of history.... No reputation was safe with them, and only by being present every time could they hope to preserve their own. The innocent were thrown to the wolves, the kind made fun of, the old stripped of the dignity that belonged to their years. *They say* was the phrase invariably used when a good name was about to be auctioned off at the block....

If you come upon footprints and blood on the snow, all you have to do is turn and follow the pink trail back into the woods. You may have to walk miles, but eventually you will come to the clearing where hoofprints and footprints, moving in a circle, tell of the premeditated murder of a deer. You can follow a brook to the spring that is its source. But there is no tracing *They say* back to the person who said it originally.

William Maxwell
Time Will Darken It

THE WORLD OF JOHNNY PAUL PENRY

Newborn children are defenseless. They enter this world and are totally dependent upon the "giants" orbiting around them. Of course, everything usually turns out all right--if the big people are good at nourishing and hugging and protecting. But Johnny Paul Penry never knew such an atmosphere, and maybe--just maybe--that's why he needs such a vigorous defense from the world around him today.

According to printed records, Johnny was born in 1956, into a world that was incredibly unkind. Before age five, he had received a broken arm from being thrown to the floor. He suffered repeated bruises, scaldings and abrasions as well as cigarette burns over much of his body. His head still bears scars from being struck by blunt instruments. He was locked in a room for such long periods it became cluttered with his own waste. He was even forced to eat his own excrement by a mother who viciously attacked her son from the day he had been born--while at the same time screaming that she loved him.

When Johnny was two and the Penry family lived in Bacliff, on the Gulf Coast near Houston, neighbors Betty Olney and Billy Johnson spoke of hearing "terrible, terrible screams" starting up every afternoon. "They were horrible screams. Terrified screams.... The screams would just go on and on." Olney and Johnson mustered up the courage to walk into the Penry home and see what was going on. Then they tried to get police and welfare officials to intervene in the Penry household. But Mrs. Penry threatened to sue and the authorities backed away.

Penry's big sister, Trudy, claimed that he was kicked out of school shortly after entering the first grade because "he was crazy in school." She recalled how at school he was so "out of it," he once left his class, went outside and climbed the school flagpole and they had to coax him down. According to Trudy, his family "never let him go unsupervised."

By age ten, Johnny was a jumpy, short-attention-spanned bundle of impulses. He was placed in state diagnostic clinics and institutions. But, being the mental question mark that he was during his adolescent years, he was caromed between three state institutions with his diagnostic labels undergoing modification at each stop. ...Psychologists had tacked IQ numbers ranging from 51 to 63 on him at different times during his institutional career.

Shortly after his discharge from an institution at age 17, he was arrested, convicted and jailed for arson. At 20, he was convicted of rape and sentenced to five years in prison. Parole came early, in August, 1979, at age 23, even though the Texas Rehabilitation Commission report said, "he has very poor coordination between body drives and intellectual control."

He moved in with his father in Livingston, Texas.

Then on the morning of October 25, 1979--just two months after being paroled--he was asked by officers to go with them to the home of 22-year-old Pamela Moseley Carpenter who had been raped and stabbed to death a few hours earlier. Later, when Miranda warnings were read to him, he waived his rights--even though he never really understood what they were. Then, according to officers, they extracted two confessions from him--an early one and another taken after additional police evidence arrived at the police station. The confessions came after Johnny spent eleven hours alone with policemen in an interrogation room with officers writing things down.

Pamela came from one of Livingston's most prestigious families. Her father was a deacon of the church. Her three brothers were high school football stars. Her older brother, Mark Moseley, was the star kicker for the Washington Redskins, later to be named Most Valuable Player of the National Football League. She was known as her brothers' best rooter and once served as co-captain of the high school drill team. National Public Radio's Nina Totenberg summed up the situation: "In East Texas where football is king, Pamela Moseley Carpenter was a princess."

Pamela's death so ripped up the people in 4928-population Livingston, the trial was transferred to Groveton, 40 miles to the northwest. But to East Texans, a forty-mile drive equates with a city dweller's ten-block walk. And so, the courtroom was filled as judgments against Penry clicked down on him with a quick, irreversible, ratchet-like effect: On March 13, 1980, four months and 15 days after the crime, a jury took 65 minutes to determine that he was competent to stand trial. On April 1, the jury took 70 minutes to find the man guilty. The next day, on April 2, the jury met to decide on the sentence--and they took only 46 minutes before voting for the death penalty.

The defense did, however, present the evidence of childhood abuse, brain damage, mental retardation and incompetency to stand trial: (including)

- A portion of an interview with Johnny on National Public Radio on December 27, 1988:

<u>Nina Totenberg</u>: ". . . and so I guess the question I have to ask you--I have to ask you--is why shouldn't you suffer? I mean, they think you did something really awful, Johnny." (Long Pause)

<u>Johnny</u>: "I would say that. . . that if I did do it I. . . didn't know what I was doing. . . and that
. . . uh. . . I didn't know what the suck . . . suckus . . ."

<u>Totenberg:</u> "Circumstances? Circumstances? Is that the word?"

<u>Johnny</u>: "Right. . . " It's doubtful if this was the word he meant.

Anyone listening that day could easily see how Penry spoke in halting speech--so much so that clear messages didn't always transfer back and forth in that interview. And yet, on the same program, when a portion of Johnny's "written" confession was read by a professional narrator, its perfect sentence structure and impeccable delivery led the audience to believe that the defendant had to be a highly-intelligent killer.

The judge, nevertheless, instructed the jury to vote on only three issues: Did he deliberately commit the crime? Was the crime committed without provocation? Will he be dangerous in the future? The jury voted yes on all three. Johnny's execution was ordered. He probably would have been dead by now if the Supreme Court had not intervened.

On June 26, 1989, the Supreme Court handed down two sharply-divided decisions. It voted 5 to 4 that persons with mental retardation could be executed. Then came another 5 to 4 ruling that Johnny Paul Penry must be re-tried because the jury had not been instructed to consider the mitigating factors caused by his mental retardation.

So, with the ball back in the Texas courts, officials faced a decision: They could commute Penry's sentence to life imprisonment with no parole and call it quits. Or they could order a re-trial and go for the death penalty again. They chose the latter.

The decision is understandable. After all, nothing can tear at the social fabric of Livingston, Texas like a murder can. It rips the hearts of the victim's family and friends. It shreds values having to do with trust, security, orderliness, fair play--even the belief that some good can be found in everyone. And so, anguishing people--trying to fix a hole that can never be fully repaired--suddenly see the death penalty as the single neon-lit solution. Its attraction can so blind a community, no one sees any other alternative than to match a death with another death.

Johnny's last trial begins in Huntsville on May 7, 1990. A jury will vote one more time for his life or death. If it votes for execution, a death warrant could eventually be signed. Then Johnny would go to an isolated cell and be submitted to a month-long ritual of intricately detailed activities, each item being clicked off until the final climactic act: a team of correction officials will strap him to a gurney, wheel him into an adjoining chamber and kill him with a lethal injection of chemicals.

But will his death stop the aching in the hearts of Pamela's family and friends? Will it solve the awful riddle--why the State of Texas failed to protect Johnny as a child and now tries so hard to kill him as an adult?

Probably not.

Robert Perske

OHIO DD COUNCIL STUDIES HEALTH INSURANCE

After nearly two years of study and work, the Ohio Developmental Disabilities Planning Council has issued a draft of the "Position Paper" from the Council's Health Insurance Task Force. The Position Paper offers a brief but thorough overview of the present "health insurance" situation in the United States, with particular attention being focused, of course, on the serious problems presented by the current (inadequate) "insurance" scheme to people with disabilities or chronic illnesses. The paper goes on to describe a model for change in health insurance in the United States--a model comparable to that in use in Canada. Through this Position Paper (as its preface states) "...the Task Force calls for a national, publicly financed and administered health insurance system which guarantees adequate health care for all citizens."

This paper is both an excellent summary of current issues in health insurance for all citizens and a reasoned call for change. Insurance is something that most of us prefer neither to talk nor think about. This paper is a guide, though, to helping us do that talking and thinking more fruitfully. Copies of the paper may be obtained (although, possibly, not until after its final editing) from the Ohio Developmental Disabilities Planning Council, 8 East Long Street, 6th Floor, Columbus, Ohio 43215.

A NURSING HOME VOLUNTEER: MY GRAM

Sandra Landis

This year's gift to my parents for their wedding anniversary was a selfish one. I bought myself an airplane ticket! My grandmother makes her home with my folks but is unsettled when staying by herself. My mom had won tickets to Florida. So, I flew east and visited with my grandmother for a week while they vacationed.

I'd looked forward to this visit for quite a while. I had a long list of things I wanted to listen to my gram talk about. She didn't disappoint me; we chatted pretty constantly for a week!

One of the things I wanted to know more about was her ten years' experience as a volunteer in a local nursing home. Until her recent illness, gram had been a faithful volunteer, one full day a week at the same home. She told me lots of stories, but there were two that particularly struck me.

One story was about a woman named Mrs. Kelly. Mrs. Kelly was a resident at the home when gram first started visiting. She never spoke in all the years my gram visited her. Sometimes visits were spent sitting quietly; many times my gram would read aloud. Other visits were spent sharing snacks. Mrs. Kelly had a few visitors, but no regular contact was obvious, at least to my grandmother. What struck me about this story is that Mrs. Kelly was a wealthy, somewhat "famous" person, yet one of her most faithful visitors was my grandmother. "I felt so sorry for her," my grandmother said. "With all her money and acquaintances, she was forgotten and lonely. I would never have wanted to trade places. And she was the mother of Princess Grace."

The other story was about a man who lived at the home for many years. He and another gentleman struck up a relationship and became roommates. They arranged their room to suit them and called it their apartment. Over the course of several months my grandmother noticed a change in disposition in this man. When she spoke at some length with this gentleman, he confided that "incontinence" was a problem. "I mustered up my courage; I'm not used to talking to people, men particularly, about such personal issues. But I was afraid that if he didn't manage this himself, the staff would, by moving him to the bare ward--you know, the place where there are no rugs, where it smells, and the last place people live, here." My grandmother explained products available, how to use them, and where they could be bought. She encouraged him to manage things herself with help from others as he really needed it. Soon afterward, though, the "apartment" was dismantled. The gentleman was moved to the "bare" ward. He died there within a few weeks. My grandmother's opinion? He died because he lost hope--nobody expects to leave that ward, and very few things that make life livable are present there.

When I asked my grandmother if there are things that concern her, she said that being hospitalized frightens her. Being in the hands of strangers is her greatest fear. I doubt that she is alone in that concern, nor do I think it unfounded.

Sandra Landis

A VIEW FROM CHILLICOTHE — End of the Miracle

Things have gone more sour in Massachusetts over the last two years or so. Where once the state's economy--and, as a result its tax collections for public services--was seen as such a "miracle" that its Governor could parlay this success into a run for the Presidency, now things are bleak. The miracle's end has had a predictable effect on publicly-funded services for people with disabilities. That effect is described by Lou Nisenbaum (Fairhaven, Massachusetts) in the Spring, 1990 issue of Community, a newsletter published by the Nemasket Group:

> What has happened to the COMMUNITY MOVEMENT? ... I refer to Massachusetts' involvement with the State Schools' consent decrees that have been the excuse to strip bare the resources of the community for persons with disabilities who are living with their families or alone in the community. Budgets for our institutions (State Schools) for persons labelled mentally retarded continue to expand even as all other budgets in the human services

> have been decimated. Budgets for community services have been drastically cut! (*"De-obligated" is the Massachusetts Department of Mental Retardation's interesting new word. Ed.*) The only expansion in the community is the "Waiting List"!

The miracle has ended. The state of Massachusetts has withdrawn into its own operations. People with disabilities who learned to depend on community "services" have seen that form of assistance shrink, and the likelihood of early growth again is not great.

Ohio, the Governor notwithstanding, has claimed to have effected no miracle. But our tax collections are reasonably healthy, now, and "services" are, thus, in reasonably good shape. There's a disturbing pattern to things, though, that is resonant of the failed Massachusetts situation and its effects on people with disabilities. We read of Ohio's plans to issue bonds (about $30 million worth) to build more institutional (developmental center) buildings. Those buildings will have to be in use for forty years or more--to ensure the repayment of the debt incurred to finance their construction. (Strictly speaking, this isn't true of "community" buildings.) The state announces the publication of a long-term plan that (apparently) fails to mention continuing reductions in institutional services; I must guess that such reductions aren't being planned for.

I wonder. What will happen--to things like "supported work", "family consortia", or "supported living"--if tax collections turn seriously sour in Ohio? Is it reasonable to think that the current experience of "community services" in Massachusetts sets a pattern that could happen here? Would we begin to feel "de-obligation"? Has it already started, but without our recognition yet? There's no way to know, of course, but it seems natural to suspect that the more we continue to allow the state to invest in its institutions, the greater the chances that those institutions will be the first line of defense when trouble comes.

In 1971 Burton Blatt challenged Ohioans--and many who heard him agreed to accept the challenge--to put an end to state institutions within <u>ten years</u>. We didn't make it. Some of us, though, won't rest easier until that challenge is met.

Jack Pealer

The Safeguards Letter

A Publication of OHIO SAFEGUARDS

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OHIO SAFEGUARDS--Annual January Events

It's become a tradition with us. Every January since 1986, OHIO SAFEGUARDS has sponsored an opportunity for folks to spend time with and learn from John O'Brien . We've had three "planning" workshops in Columbus and one in North Canton. In 1989, we sponsored a "Framework for Accomplishment" workshop in Chillicothe. This year we thought we would try something different. So, we've made tentative arrangements with John O'Brien to hold two shorter but related events in Yellow Springs, Ohio during the week of January 28, 1991. The first of these is to be a two-day event (January 28-29) on the general topic of **what it may take to help keep people SAFE in community life**. This event would deal with such issues as: ways by which people with disabilities and others in communities may be "bound together" to achieve greater security (e.g., citizen advocacy, life-sharing, etc.); the idea of a "healed" community as the strongest possible safeguard for a person; and an examination of whether and/or how "professionalism" may be a threat to the safety of socially devalued people.

The second event is to be a one-day session (January 30) on **"Citizen Advocacy--Stories of Citizen Partnership"**. During this day, John O'Brien will present an overview of the idea of citizen advocacy, and people representing various citizen advocacy programs in Ohio will share stories about what citizen advocacy has meant to both individuals and communities in several places across the state.

This description of the two events is deliberately cast in tentative language because all of the details about the events is uncertain (as of mid- November). All of the plans will be complete before the publication of the next (December) edition of the Letter, and those on the OHIO SAFEGUARDS mailing list can expect to receive complete information about these events. We just wanted to give everyone a bit of advance notice, so you can plan how you will spend the last week of January. We hope some of you will spend it with us in Yellow Springs.

TWO POWERFUL WORKSHOPS!

On January 11-14, 1991, Dr. Wolf Wolfensberger will be presenting two workshops at the Mont Marie Conference Center in Holyoke, Massachusetts. That's a bit far for people from the midwest to travel on a "whim" (especially in winter), but these workshops are so uniquely valuable as to make the trip worth consideration. The first one (offered Friday, January 11 through Sunday, January 13) is entitled **"The Growing Threat to the Sanctity of the Lives of Socially Devalued People."** This event focuses on the growing support, in our society, for practices that either kill socially devalued people outright or that hasten their deaths. Dr Wolfensberger and others think that the issues discussed in this workshop are the most urgent ones to be considered today by people concerned with the life of someone who has experienced social devaluation. The second event (offered on Monday, January 14) is **"The History of Human Services"**--a one day presentation that uses more than 300 slides to illustrate how current human services are full of unconscious remnants or distortions of practices that were originally consciously designed and reliant on positive ideas.

Readers who want more information about either or both of these workshops can contact OHIO SAFEGUARDS or (more direct) can call:

Jo Masarelli
Institute for Leadership & Community Development
17 New South Street
Northampton, Massachusetts 01060
(413) 585-0717

LIBRARY ACQUISITIONS

Since the last appearance of the Letter the OHIO SAFEGUARDS library has added three more items. They are:

"The Adventures of a Radical Hillbilly." (VHS videotape) This is the 2-hour tape of an interview of Myles Horton, the founder of Highlander Folk School. The interview was by Bill Moyers, and it was aired on PBS in summer, 1981.

The Long Haul: the Autobiography of Myles Horton. (1990) Myles Horton, who, as founder of the Highlander Folk School (now Highlander Research & Education Center), had much influence over the strengthening of both the labor and civil rights movements, died in early 1990. We are fortunate that he left this book that both describes the events of his life (in his own unmistakable "voice") and testifies about his ideas about how people and communities learn.

Remembering Our Past; Building Our Future. Helen M. Lewis & Suzanna O'Donnell, eds., The Ivanhoe History Project. This is a history of a small community in western Virginia. Ivanhoe was, at one time, a booming town that was the center of a mining (lead, iron, zinc) area. All the mines have been closed for a long time now. This history-book is part of the work of community revitalization. As the editors put it:

> A community is formed from memories, from a shared past; by retelling and reflecting on these memories its members preserve, learn from, and recreate their community for the future.

Any of these items can be borrowed from the library. Interested readers (or viewers) can borrow books or tapes by contacting us at: **P.O. Box 1943, Chillicothe, Ohio 45601**

TEXAS JURY SAYS PENRY COMPETENT.

© Robert Perske

Huntsville, May 16, 1990 -- It took only one hour and 17 minutes today for the jury to decide that Johnny Paul Penry was competent to stand trial for the 1979 rape and murder of Pamela Moseley Carpenter, the sister of former Washington Redskins football star Mark Moseley. The jury members voted quickly even though the defense's description of Penry differed starkly from the prosecution's. It was as if two different persons had been on trial.

Another remarkable contrast: Unlike the January 11, 1989, U.S. Supreme Court hearing, when leaders in the field of mental retardation packed The Court, only the family and hometown friends of the victim filled the courtroom in Texas.

And so, with all of the earlier notoriety wiped away, court-appointed Huntsville lawyer John Wright sat alone, vigorously defending Penry like he did in 1980. Only private investigator Patrick Page--a former executive for a Texas regional mental health/mental retardation agency--moved repeatedly to his side, providing last-minute information and receiving emergency assignments. The hard-working pair will be paid much less money for their efforts than the prosecution. In the first trial the court allotted a meager $400 for investigation by the defense.

At recesses the audience expressed wonderment over Wright's and Page's obvious efficiency. Why did the defense attorney claim his client could not get a fair trial in Huntsville and move for a change of venue? Why does he "keep stringing things out, when we know what has to be done?"

Although everyone appears to be friendly and understanding of others, they discuss Penry as if he were less than human--a piece of trash that needs to be swept from the earth. One relative of the victim has been writing a book on the case, and he explained that he can't get it published until the last chapter is in place--the one describing Johnny Paul Penry's execution.

The competency trial centered on two questions: Was Penry too retarded to understand the court proceedings? Was he capable of helping his lawyer prepare a defense? Highlights in the defense:

- Three death row inmates described how they and a few others had created a circle of protection around Penry. "I've never known a man in my life that wanted to have friends more than Johnny did," said James Vanderbilt. Penry was so childlike, Vanderbilt and others functioned like "babysitters." Harvey Earvin explained how Penry's hunger for acceptance had set him up for ruthless exploitations until the circle decided to protect him. James Beathard testified how the circle even tried to keep him away from reporters "who could lead Johnny and get him to say almost anything they wanted to hear."
- Attorney Curtis Mason described his relationship with Penry while defending him in the Supreme Court. "I talked to him as best I could in one-syllable words," Mason said. Then (after a while) Johnny would ask a question and I saw he didn't understand anything I had been telling him." Mason showed how most of the psychological reports placed Penry in I.Q. ranges between 50 and the low 60's. He stated unequivocally that Penry was unable to consult with his lawyer in preparing the case and the defendant did not know what was going on in the proceedings. "I didn't rely on him for anything," Mason said.
- Death row psychologist George Wheat, receiving a subpoena and testifying against his will, strengthened the defense by describing his contacts with Penry during the past nine years. He cited a series of incidents showing how "Johnny doesn't compute things like a normal person does." When asked to rank Penry's intellectual functioning along with the other 300-plus inmates on death row, he said, "We have some with I.Q. 160. But Penry is at the other end with three others. Two of these are smarter than he is. He is in the running for low man."

The prosecution began its case with rapid-fire interrogations of four death row guards:
Prosecution: "Have you observed Johnny Paul Penry?"
Guard: "Yes, sir."
"Have you talked to him personally?"
"Yes, sir."
"Did he ever say anything that's crazy, like going to Mars or something?"
"No, sir."
"Is he oriented to time and place?"
"Yes, sir."
"Have you had any trouble understanding him?"
"No, sir."
"Have you seen him communicate with his attorney?"
"Yes, sir."
"Do you think he has a reasonable understanding of the trial?"
"Yes, sir."
"Do you think he understands the proceedings?"
"Yes, sir."
"Do you think he has a basic understanding of right and wrong?"
"Yes, sir."
"Do you think he can control his own actions?"
"Yes, sir."

And so it went with each guard, with small variations in the questions. Anyone leaning in favor of Penry would have felt the prosecution's case was weak--until the last two witnesses:

- Dr. Walter Quijano, a psychologist is private practice, took 45 minutes to present his academic accomplishments and to explain exactly what a forensic psychologist does. He did it with such wit and stage presence, I found myself wondering if we had anyone in the field of mental retardation who could match this guy. Then, he launched into his findings. Penry was "an anti-social personality" with all the symptoms. He was faking mental retardation ("All inmates test up or test down according to the situation."). He found no remorse. Quijano found him self-centered, manipulative, vicious and dangerous. He placed Penry in the "mild to dull normal range," basing it on finding a verbal I.Q. of 72 in an early Wechsler Intelligence Scale for Children ("This high number shows his potential"). When defense attorney Wright asked him to comment on George Wheat's intellectual ranking of Penry, he responded, "I don't dispute it but I don't believe it." When Wright asked him if maybe Penry was merely trying to appear normal, he replied, "That is true. But we don't have to be retarded to want to look better than we are. That's why we wear clothes." But doesn't he seem like an outcast among outcasts seeking approval? "He didn't seem different to me." But what about all the abuse he suffered? "There is such a thing as negative grace," Quijano said, "and good things can come out of abuse."

Quijano was asked to tell the court what happened when he and both lawyers got up to leave after Penry's psychological examination. Penry had asked Quijano, "What do you think of me?" Quijano said that as a psychologist and as a Christian, he had to reply honestly, "Johnny you are a good person, but you have done wrong things."

•Dr. Fred Fason, a Houston psychiatrist in private practice, also recited a lengthy list of academic accomplishments, including better than 1,000 competency examinations over a span of 17 years. He also placed Mr. Penry in an I.Q. range between "mild and dull normal." His overall diagnosis was three-pronged: "antisocial personality, sociopathy and psychopathic personality--anti-social type." His opinions came after a three-minute and a 20-minute examination. He also felt Penry was faking retardation. Part of this view stemmed from Penry calling John Wright his "attorney" when most people use the less-sophisticated term lawyer.

Judge Joe Ned Dean set May 22 for empaneling a new jury for the capital trial. People leaving the courtroom talked about how the defense would surely "drag that trial out," too. They felt sure, however, that once the jury gets the case "things will work fast."

Robert Perske

About THE SAFEGUARDS LETTER

The Safeguards Letter is a quarterly (approximately) 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, P.O. Box 1943, Chillicothe, Ohio 45601. We welcome our readers' ideas and reactions.

JUST QUOTES

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.

Ivan Illich
A Celebration of Awareness

Civilisation is hooped together, brought
Under a rule, under the semblance of peace
By manifold illusion; but man's life is thought,
And he, despite his terror, cannot cease
Ravening through century after century,
Ravening, raging, and uprooting that he may come
Into the desolation of reality:
Egypt and Greece good-bye, and good-bye, Rome!
Hermits upon Mount Meru or Everest,
Caverned in night under the drifted snow,
Or where that snow and winter's dreadful blast
Beat down upon their naked bodies, know
That day brings round the night, that before dawn
His glory and his monuments are gone.

W.B. Yeats (from "Supernatural Songs", 1935)

SURPLUS VALUE

The merchant calls it profit
and winks the other eye;
the banker calls it interest
and heaves a cheerful sigh;
the landlord calls it rent
as he tucks it in his bag;
but the honest old burglar,
he simply calls it swag.

from *The Catholic Worker*,
June-July, 1990

THE GIFT OF RECEIVING HELP

I find fascinating the ways and times that people reveal their gifts. I learned some time ago that part of the beauty in recognizing gifts lies in our inherent inability as human beings to predict them. Regardless of how well or how long I've shared time with someone else, I can't guess someone else's gifts. Our time together reveals them.

Some people display their gifts often throughout their lifetime. When this happens in people I know, I try to learn from each opportunity that I notice. But, as carefully as I think I'm watching, I'm still overwhelmed and grateful each time a gift is revealed to me.

Jeff is my son. Last Sunday he ran his first Marathon race. He performed better than he had hoped. His time qualified him to run in the Boston Marathon next year. It was a moment of personal victory for him. He'd accomplished something he'd been preparing, for a long time, to do.

During Jeff's running career I've experienced periods of anxiety about what he was doing to his body and periods of pride about the obvious discipline and perseverance that a long-distance runner displays. My feelings last Sunday were mostly those of pride.

As we visited over dinner the night before the race I asked Jeff what it was he did to keep the concentration it must take to endure such a long race. He said he'd think about that and let me know. After the race we talked again. What he had to say put into perspective both my feelings of pride in his accomplishment and my own pride in his discipline--of course, his mother must have had some influence over the development of such fine character!

What Jeff talked about was the help he got along the way. "I was feeling pretty bad between 22 and 23 miles. I had never run that far before. I started talking to the man running near me. He talked to me, encouraged me, gave me a couple of aspirins. He told me I could make it, that my pace was good enough. I don't know whether I would have made it if he hadn't helped me."

One of the gifts Jeff has displayed from very early in his life is his ability to ask for help when he needs it. He prepares himself. He works hard at things, and he keeps focused on his goal. But, invariably, a time comes when he needs some help. He recognizes that and, with humility, he seeks the help he needs from others around him. And, when he's accomplished what he set out to do, he accounts for the help he got from others. As we stand with people who have been hurt and rejected--whether we are members of someone's family, or friends, or service workers--we too might be better sustained for the long course if we were to act from a posture of needing and recognizing the help we ask for and get from others. That might be more supportive, and more honest, than a posture of pride in our accomplishments or our simple endurance.

Sandra Landis

A VIEW FROM CHILLICOTHE Our First "DD" Project--A Final Summary

Between April 1, 1987 and June 30, 1990, OHIO SAFEGUARDS carried out a project, funded by the Ohio Developmental Disabilities Council, entitled "Training for Designers of Individualized Services." It was our purpose during the three years of project work to try to influence the lives of people with developmental disabilities by influencing the content of the plans that organizations and groups made for, about, or (we hoped) with those people, one person at a time. We had two general strategies for doing this work. First, we tried to establish working relationships (consultation) with a few interested organizations and/or families involved with people who have disabilities. In each organization or family we introduced ideas about personalized planning and design of help and, in many instances, demonstrated those ideas by conducting extensive planning sessions that were to lead to real changes in a person's life. We coupled this attention to individuals, and a focus on small things within the life of a person and her supporters, with attention to how the changes necessary for a better life for the individual would affect the organization(s) that tried to help that individual. We wanted people to know that a commitment to personalized planning would mean a commitment to organizational stress and change. It's this latter point that, more often than change in a person's life, proved to be a stumbling block. Organizations change with more difficulty than do people.

Our second strategy was that of offering what we came to call "educational events"--for agency staff, for members of families, for interested others, and for people with disabilities. These events had several purposes. First, we hoped to "spread the word" more widely about the ideas we brought to the work of this project; this was part of our way of trying to recruit organizations or community groups toward interest in the consultation we had to offer. Second, these events offered us a chance to collect, for a brief time, some of those we were working with and give them some exposure to more-advanced ideas than we could discuss during the consultation time. So, some participants in our work got a chance to meet, hear from, and interact with John O'Brien, Connie Lyle, John McKnight, and Susan Thomas.

We've been able to hang around several organizations and communities during the past three years. We've had the privilege of having been welcomed into the lives of some people with disabilities--even though we could get to know these people just a little bit. One result of all this activity is that we have some bits of advice (which we don't have space to detail here) for others who get serious about individualization--about designing really personal responses to the situations of people with disabilities. That advice includes:

1) Beware of "model procedures." For example, the processes we've sometimes used have been labeled with the term "Personal Futures Planning." Labeling a process this way tends to convince others that "it" is something magic. We want not to talk much about "Personal Futures Planning." We want to talk instead about ways of planning that honor the experience and aspirations of each person with disabilities and those others who care about that one person. The strength of what we've tried to do is in the seriousness with which each person is treated, one person at a time, and our willingness to re-organize our agency-lives around that person.

2) Changing things one person at a time is SLOW. People should not look at these ideas as ones that will ever lead to a revolution in social services. The work is hard. The process of supporting leaders to help with change, one person at a time, is a long-term one. There are no guarantees.

3) We want to say this one more time. Two "prerequisites" for starting to assist people one person at a time are: a) developing a thorough understanding of the **personal history** of the person who is the focus of your efforts, and b) ensuring that the people who have power to make decisions about a person's life are folks who have a demonstrated **personal commitment** to this one person.

4) The question of whether someone who wants to change an organization and its response pattern one person at a time ought better to start at the "bottom" (people with disabilities and their direct assistants, if the agency shape is that of the usual hierarchy) or at the "top" is a useful question. We haven't enough experience to suggest that one strategy always works better than

the other, but we do know, from our work on this project, that things will go more smoothly if the leadership of an organization or several organizations at least gives sanction to the work. In at least one organization, our work proceeded further than it might have been expected to, because the agency director and other lead staff were committed to trying personalized planning. In another instance, our work with an organization came to an end following a wholesale leadership change. It looks like it's not necessary to start at the top, but it's helpful if leaders in an organization offer at least some level of affirmation for individualization.

5) Personalizing service responses to people one person at a time almost inevitably calls for organizations that are small and flexible. It's hard, though, for an organization that helps people with developmental disabilities and is seen as successful at it to remain small. The fiscal and political pressures in the direction of growth are enormous, and we witnessed the effects of those pressures in several of the organizations we worked with. Failure to control growth probably means that personalization will fail as well.

6) Finally, we've talked for three years (probably longer) about the barriers--the disincentives--that the human service system puts in the way of individuals who aspire to their own version of "the good life." Those are still there. People still can't own very much. People are still prevented from enjoying relationships with others. People still don't have work that's satisfying and remunerative. Personalized design of services won't make these problems go away, but careful attention to the situation of each person, with the help of the person and those others who know her best, can (we've seen) make a difference. This sort of change works best one person at a time.

The Safeguards Letter

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JANUARY IN SPRINGFIELD AND YELLOW SPRINGS!

OHIO SAFEGUARDS is sponsoring its annual January educational events with John O'Brien, and this year they are taking place in Springfield and Yellow Springs, Ohio--the latter a town where "community" has been an explicit value for a long time! The specific "workshops" to be held are:

*January 28-29 -- Helping People Be **Safe** in Community.* "Safety" seems, these days, to be an increasingly elusive experience for all of us. It is, of course, especially elusive for people who are especially vulnerable--people who have disabilities, people who are sick, people who have lived long lives--people who, in summary, find themselves carrying labels affixed by society's organized helpers, the human service agencies. This two-day event is designed to help participants think together about the question:

> What shall/must we DO, in response to the fact that our fellow-citizens are likely to be HURT?

Some of the issues that are likely to be considered, as we think about this large question, are:

- What is the meaning, for us, of the ways we describe what happens to someone (e.g., "exploitation", "abuse", "neglect"?
- How might vulnerable people and others in a community be bound together in order to achieve greater security for all?
- How might "Professionalism" be a help or a threat to the safety of vulnerable people?
- What can we rely on as useful responses to the vulnerability of some of our fellow-citizens?

The event will include both talks about these and other issues by the "presenters" and ample opportunities for participants to reflect on important questions and discuss those with the presenters and with each other. This event will take place at the Holiday Inn, South, I-70 and State Route 72, Springfield, Ohio. We look forward to a rich two-days!

January 30 - Citizen Advocacy: Stories of Citizen Partnership. Citizen Advocacy is an often misunderstood and neglected way to help people with disabilities and people without disabilities enjoy richer lives together in communities. Citizen Advocacy also offers vulnerable people sources of protection and support that cannot be provided by formal human service agencies. Citizen Advocacy is a way that communities can become more responsive to people in need because it allows those people to reclaim the portion of citizenship that is often forfeited when people receive service from paid experts.

This event, which will take place at the Society of Friends Meeting House in Yellow Springs, Ohio, will introduce the idea of Citizen Advocacy and of the basic principles that seem to make Citizen Advocacy "work" better in communities. This introduction will be presented by **John O'Brien**, of Atlanta, Georgia. Mr. O'Brien is the co-author of "C.A.P.E. (Citizen Advocacy Program Evaluation)" and author of "Learning from Citizen Advocacy Programs"--two publications that offer the clearest explanation of the idea of Citizen Advocacy. Mr. O'Brien is also a member of the Board of Directors of the Georgia Advocacy Office, a statewide "Protection and Advocacy" agency that relies mainly on Citizen Advocacy as its operating method.

Citizen Advocacy will be further introduced through "Story-telling." People representing several Ohio Citizen Advocacy programs will share with participants stories that illustrate what Citizen Advocacy has meant both to individuals and to communities across Ohio. There will also be plenty of time during the event for questions and for sharing of thoughts about how new Citizen Advocacy programs might be started in new places around the state. Participants in this event will be challenged to develop, for their communities, a vision of the future that includes Citizen Advocacy!

People interested in registering to participate in either or both of these events can do so by contacting OHIO SAFEGUARDS (614/ 773-6191). The fee for the January 28-29 event is $60.00, and the fee for the January 30 day on Citizen Advocacy is $5.00. Those interested in coming to all three days can register for a combined price of $65.00.

SERVICE BROKERAGE SANITY & INSANITY

Wolf Wolfensberger

(Editor's Note: This piece appeared originally in TIPS--Training Institute Publication Series--Vol 10, No. 2, August, 1990. It is here reprinted with the permission of the author.)

While we have instituted a perversion alert mechanism, we have not (as yet) instituted a craze alert, though the idea certainly beckons. One difficulty with such a thing would be that virtually everything being done in human services nowadays is based on crazes, and a good part of TIPS would thus be nothing but one craze alert after another.

The service brokerage concept began to be promoted during the 1980's, first out of British Columbia (Canada). It is a poorly conceived, poorly described, but euphorically promoted scheme that we would put into the category of administrative-fiscal enabling mechanisms, as well as into the craze category.

In essence, it strikes us as yet another desperate scheme to try to squeeze some functionality out of an imperial service system that simply no longer is functional; and like so many of the schemes that are in the coordinative/managerial domain (as is this one), it would add yet another layer of bureaucracy and functionaries (in addition to case manager, advocate, individual program plan-makers* , the service itself, etc.) onto the service system, namely, supposedly independent brokerage service agencies.

Of course, the concept of service brokerage itself is an old one. After all the entire California mental health and mental retardation service system has been based on a form of brokerage concepts since the 1960's. Ideas like these keep appearing in cycles, each cycle taking on a few variations that are purported to overcome previous shortcomings or problems. But what is relatively novel about this scheme is that the service brokerage function would be supposedly independent of the service system in order to be accountable primarily to clients (the promotional literature says "controlled by the consumer") rather than the service system, though it is difficult to see how it can be a great deal so as long as it is publicly funded.

The brokerage would be provided by an agency that employs brokers and economists sophisticated about service costs. The literature promoting service brokerage also assumes that all advocacy is or needs to be unpaid, and that brokers cannot be advocates because they are paid. This is not correct in that there are several major types of paid advocacy, legal aid and (legislative) ombudsman systems being merely two obvious examples. In fact, many kinds of paid advocacy may have more independence from the service empire than the paid broker would, except for the relatively rare cases where clients have enough independent private money to hire their own brokers themselves.

The broker scheme also stipulates that brokers only pursue what clients want. Little is said about what should happen when clients are not competent to "want." Apparently, the broker would then be responsible to the family--but it is not clear what happens when there is no family, except that "networks" are mentioned as alternates. Nor is it clear what a broker is to do if client, family or "network" want things that are insane, destructive, or evil, or even what to do if the "network" is divided on an issue. Are brokers to be hired guns, so neutralized in their own opinions and moralities as to pursue a person's suicide, or a person's killing, on demand of his/her family or "network"?

Things get even more problematic when one learns that a broker should organize a "network" where there is none, and become a community organizer if need be. If a broker has to

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* In the documents explaining brokerage, individual program plans are mysteriously distinguished from "general service plans."

organize a network for someone who has no one, how and by whom did the broker become recruited in the first place?

The funds for the services requested via the broker would come (in the form of "credit") from the brokerage agency that, in turn, is supposed to have gotten it from a "funding body." This is really no more than money being allocated to clients rather than to service providers--long a darling concept of conservatives and laissez-faire market ideologues. But even this presupposes that some authority decides who is to be eligible for how much credit, or what limits there are to the purposes to which funds (credit) are allocated.

The brokerage literature says that brokers are to be paid by "an organization directly controlled by the people using the brokerage service." To be an option for more than people who are rich or have a lot of friends with money to donate, brokerage would ultimately have to be paid by public money, which in almost all cases means government--the same people who fund almost all the services being brokered.

Reading the brokerage promotion literature, one finds described a broker paragon of knowledge, skill and wisdom--who will do what s/he is told. Yet in today's service context, one can hardly even find people with the most basic modicum of common sense, and mastery related to service is not only extremely rare, but not even considered a legitimate concept any more. Thus, the more one reflects on the brokerage scheme, the more impractical it can be seen to be--by those who have enough wits to qualify as brokers as described.

Because of its historical baggage, the brokerage promoters do not like the idea of "follow-up" after a service arrangement has been made and they thus use euphemisms such as "remaining generally informed," "maintaining active involvement," and "continuing to liaize." Come on, you can't have it both ways, as CBS-TV commentator Andy Rooney would say.

Brokerage or client-funding schemes are well-known to negate any service system planning, as we have always pointed out. This scheme too would remove its funders from any planning process. True, such planning is largely a joke anyway in the service system today, but there is a difference between delegitimizing planning altogether, versus recognizing the widespread failure to plan the at least theoretically plannable. Thus, the government is expected to pay multi-billion dollars without a say where it goes?

The scheme is unfortunately suffused with language and slogans that obscure rather than clarify how it would function. And as Michael Kendrick has pointed out, much like other brokerage concepts, this one assumes that the needed services of a proper quality are somewhere out there, and can thus be obtained or purchased. But we believe that the best that brokerage functionaries can be expected to accomplish is to negotiate some form of "least worst" arrangements for their clients, and that, as we said, at the cost of another layer of bureaucratism and people to deal with, which means that by contributing to yet further complexity, a brokerage scheme would also, and indirectly, contribute to yet further quality decline.

An inkling that this scheme cannot possibly be a very good idea derives from the fact that the idea has spread like wildfire, among many people, and has already been pushed toward implementation in part of Australia, even before its functionality or limits have been demonstrated--in Canada or elsewhere; and there have been workshops on it in England.

What adds hope but also confusion to the brokerage concept is that in the province of Alberta, a scheme has grown in recent years that calls itself brokerage, but is apparently very different from the one described in the brokerage literature, as sketched above. As it was described to us, anybody in Alberta can set up as a broker, and therefore, brokers are mostly people with human service backgrounds who are free-lancing. Usually in close consultation with, and with the approval of, a mentally handicapped person's parents or guardians, a broker writes a proposal for some kind of service program for that person that will cost money. The proposal is then submitted to the government. If approved, monthly checks are sent to the client (which usually means the client's parents or guardian), and this money is used to purchase the service at issue. The proposal has to be resubmitted, or a new one submitted, every few months, which of course means a great deal of work for the brokers. How are the brokers being paid? They only get paid if their proposal gets funded, and they get a fee that was written into the agreement to begin with. Thus, it is difficult to claim that the broker is truly independent since the broker's livelihood depends on writing successful proposals, whereas a truly independent party might deem that alternatives other than those requested by parents, guardians or the handicapped person are superior, or would be offered. After all, parents and guardians have sometimes wanted their family member institutionalized or made dead, and if such "services" were brokerable, brokers would undoubtedly make money off them. It is almost impossible to get correct descriptions--much less analysis--of issues such as these in the brokerage literature and debate.

The whole problem of course is much more complicated when a mentally handicapped person is involved, because then, the additional layer of another responsible agent on behalf of the person comes into play. This would of course not be the case where a person is handicapped but mentally quite competent.

We are informed that in Alberta, it is theoretically possible for people to by-pass brokerage and submit their proposals to government directly, but apparently too few people are or feel qualified to do so. Perhaps they do not even have an incentive to do so because the brokers do all the work, and insofar as the broker fee is built into the agreement, there is no incentive for them to try to save the government money.

According to Aldred Neufeldt, there were about 170 retarded adults in Calgary, Alberta alone who were "individually funded" as of Spring 1990 by the provincial government, apparently most or all of them via brokerage.

At least the way it works in Alberta, the arrangement does give handicapped people a great many individualizing and more social role-valorizing options, because they can use the money to make their own private arrangements, thereby either bypassing the service system altogether, or retaining enough control over their service so as to command some respect from service providers. For instance, if one needed personal attendant care at home, or let us say a companion to assist with community activities, one could hire suitable people on one's own initiative, whereas under the normal service system arrangement, one would have to go through intermediate agencies such as home health care ones.

For people who can use services which are thusly available (which probably would not always be the case), the additional layer of processes and costs introduced by the brokerage system would be offset--and probably more than offset--by the bypassing of the service agency system and its costliness.

We have several conclusions to offer.

1. Brokerage as practiced in Alberta seems to have much more promise than the way it is proposed in the major brokerage documents. Among the benefits that one could expect especially from an Alberta-type brokerage scheme are the design of more individualizing and more creative options on behalf of specific persons. After all, there are innumerable misfits between what people need and what agencies offer, and to the degree that a suitable individual arrangement is in fact implementable via money, brokerage may provide a dramatic shortcut and facilitation.

2. Brokerage should never be prematurely trumpeted as a major systemic solution, or be implemented suddenly on a grand scale. Instead, it should be implemented gradually under close scrutiny, with ongoing discussion of its strength and weaknesses. The main brokerage model seems to need even more precautions than the Alberta one.

3. Brokerage models have a much better chance of being adopted (ignoring for a moment whether successfully or not) under governmental systems where there is a great deal of discretion for case-to-case decision-making. In turn, this means that it is more feasible under Canadian and perhaps other governmental forms with relatively powerful and unilateral decision-making capabilities which often work as much against as for people in need of service. The largely rights-based objectifying way in which public processes are structured in the US makes it difficult to envision that the brokerage model could work there.

4. Ultimately, brokerage can only obtain whatever funders (usually government) are willing to fund.

5. People are apt to mistakenly equate clinical problem-solving with service brokerage--that is, some mechanism of making available a service that a person says he or she want, and/or providing a person with the money to purchase the service that he or she needs. Of course, providing a person with needed service may indeed solve his/her problems, but this is not at all the same as examining and analyzing the sources of a person's clinical problems, and trying to identify and devise service measures that might address these.

Strangely enough, there are some handicapped groups opposed to brokerage because they believe that brokerage just might meet the needs of handicapped persons, and "…satisfied individuals…see no reason to develop a powerful collective voice through strong organizations of our own." (VIA, Spring, 1990)

Wolf Wolfensberger

About THE SAFEGUARDS LETTER

The Safeguards Letter is a quarterly (approximately) 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, P.O. Box 1943, Chillicothe, Ohio 45601. We welcome our readers' ideas and reactions.

SUPPORT FOR *THE SAFEGUARDS LETTER*

This is our annual appeal for donations of money to pay for *The Safeguards Letter*. Regular readers know that there is no "subscription fee" for the *Letter*. The trustees of OHIO SAFEGUARDS agreed more than three years ago that the *Letter* would not be paid for by "subscriptions" but by the voluntary contributions of interested individuals and organizations. This decision saves OHIO SAFEGUARDS from the task of maintaining subscription lists. More important, though, the decision places the responsibility for the future of the *Letter* where it ought to be--in the hands of its readers. For the past three years the intermittent contributions we've received have made it possible for the *Letter* to reach about 400 readers four times a year. Any readers who want to contribute (it's tax-deductible) may send their contributions to: *The Safeguards Letter*, P.O. Box 1943, Chillicothe, Ohio 45601. All money received will be used for the printing and mailing costs of the *Letter*. We thank you for your continued loyalty as readers.

TEXAS JURY HEARS MITIGATING CIRCUMSTANCES ; VOTES FOR PENRY'S DEATH AGAIN

Robert Perske

Huntsville, July 17, 1990 -- The retrial of Johnny Paul Penry ended today when a jury once again voted his death for the murder of a Livingston, Texas woman eleven years ago. Around 9:30 on the morning of October 25, 1979, Pamela Moseley Carpenter, 22, was raped and fatally stabbed with a scissors in her home. By 6:05 p.m. the police had received a confession from 23-year-old Penry. Since Penry couldn't read or write, the first of two confessions was typed and read to him. He signed it. Five months and six days later, the jury voted the first death penalty.

In 1988, Penry was 13 hours away from execution when the U.S. Supreme Court intervened because he had mental retardation. In 1989, the Supreme Court voted (5 to 4) that a person with retardation can be executed. But it also ruled (5 to 4) that the Texas jury had not been instructed to consider <u>mitigating circumstances</u>. Therefore, the punishment phase of the case had to be retried. Texas responded with a complete trial (including competency, guilt-or-innocence, and punishment phases) as required by its law.

Much needs to be said about the retrial, but only <u>highlights on mitigation are reported here.</u>

<u>The Defense's Evidence of Child Abuse</u>. Written records, two sisters, a brother, three aunts, a next-door neighbor, and a former baby sitter provided the jury with a picture of incredible torture. When Penry was eight months old, his mother returned from a mental hospital and began at least five years of vicious attacks--with fists, fingernails, boards, mop sticks, belt buckles, extension cords, burning cigarettes. A neighbor reported how on summer afternoons she heard Penry at age 2 screaming "terrible, terrible screams," begging his mother to stop. The mother addressed him as "the little bastard," "the little nut," "Blackie Carbon". (Unlike the rest of the family, Penry's hair is coal black and relatives admitted he had been conceived by a man other than the family father.) When he was four, his mother scalded him in the kitchen sink. He still has the scars. She burned his skin with cigarettes. She kept him locked up in a room--often without food--for long periods. When he couldn't get out to the toilet, he defecated on the floor. His mother sometimes made his eat it. At other times, after he had urinated in the toilet, she dipped some into a cup and made him drink it. Once she tried to drown Penry in the bathtub. Another time she took a butcher knife and threatened to cut his penis off for wetting his bed. The relatives claimed they knew Penry had been singled out as a special target, but they were afraid to do anything because they feared the mother too.

<u>The Defense's Evidence of Mental Retardation and Brain Impairment.</u> Dr. Randall Price, a Dallas clinical psychologist and a neuropsychologist, served as the defense's only expert witness. He spent 11 hours testing Penry. Using nine of ten tests from the Halstead Reitan Battery, he found brain impairment in all except one. Using the Wechsler Adult Intelligence Scale, Penry had a verbal I.Q. of 63, a performance I.Q. of 66 and a full scale I.Q. of 63. He administered tests on faking and found Penry to be working as hard as he could. Price examined a massive pile of medical records (especially from the University of Texas Medical Branch at Galveston, Austin State Hospital, Rusk State Hospital, and Mexia State School), focusing only on evaluations, not treatment records....

The defense presented a large "blowup" photograph of a single page from a reading test administered to Penry when he was 15 and living at Mexia State School. It contained pictures of a dog, door, airplane, hen and hat. Penry had been asked to underline one right word out of five after each picture. He did underline "dog" and "airplane" correctly. But he underlined "flag" for the hat, "drum" for the hen, and "dress" for the door. The defense used the blowup to dramatize that Penry could not read or write.

Coupled with his brain impairment and mental retardation, Penry was described as a confused, short-attention-spanned man who was prey to mixed-up impulses, a man who couldn't think as well as he talked, one who worked hard to please others.

His physique and distinctive face--not unlike those of movie stars--didn't help. During a break in the trial, one observer said out loud, "He doesn't look retarded to me. He doesn't even drool."

During the trial, Penry sat quietly, often drawing on pieces of paper provided by his attorneys. Even when angry fingers were pointed at him and harsh accusations were made, he didn't seem to respond. At breaks, Penry would stand with his hands clasped and survey the audience, looking into faces. He was quick to smile and nod anytime a rare person nodded to him.

<u>The Prosecution's Attempts to Disconnect Mitigating Circumstances from the Crime</u>. Price's findings of brain impairment were challenged because nothing visible to the eye could be found--no holes, no tumors, no lesions or infarctions. The prosecution presented to the jury their own electroencephalograms and brain scans on Penry, showing no observable physical damage either.

They criticized Price for reading only the records on evaluation and not treatment. Then they kept him on the stand for five hours, going over every record to see what he had read and what he hadn't. Since many of the records were of the old-style medical type that mostly contained problems and critical incident reports (e.g., scuffling, running away, pencil and scissor poking, fire-setting, youthful homosexual interactions) all were thrown into the face of Price to show the jury that Penry really had an antisocial personality disorder and he was faking mental retardation.

The officers who had read Penry his Miranda Warnings and received the confessions told the jury that they didn't know Penry was retarded. He only seemed to be slow.

Five prison guards told the jury about Penry's infractions in prison--most taking place in the early years of his incarceration--lunging at others with boards having jagged edges, making two "shanks" (toothbrush handles melted around razor blades). They also told the jury they had conversed with Penry and he understood them. Each said he could read and write--even though no sample of his writing was ever presented.

Dr. Fred Fason, a Houston psychiatrist in private practice, focused on the two highest I.Q. scores (Performance I.Q.'s of 74 and 72). He told the jury that these represented Penry's highest potential. "You cannot do better on I.Q. test scores than what you are capable of doing," he said. "It's like an athlete. You cannot run the 100-yard dash faster than what you're capable of. You can run it slower, however." For this reason, Fason felt Penry tended toward the "dull normal" range.

Dr. Walter Quijamo, the former chief psychologist for the Texas prison system, told jurors he didn't feel Penry was truly retarded. He played down the I.Q. measurements and brain impairment tests of Dr. Price. He criticized Price for failing to test for adaptive behavior. (Neither side really tested for adaptive behavior and the American Association on Mental Retardation's diagnostic and classification system--that includes adaptive behavior--was not mentioned once.

He also claimed that Price erred by not administering the Minnesota Multiphasic Personality Inventory (MMPI), a test that examined the propensities of people. Quijamo told the jury that Penry didn't have "academic smarts"; he had "street smarts".

Quijamo went on to claim that Penry was an antisocial personality who possessed every symptom listed in the American Psychiatric Association's *Diagnostic and Statistical Manual III* (e.g., grossly selfish, callous, irresponsible, unable to feel remorse and to learn from experience and punishment)--the very same symptoms attributed to highly-intelligent serial killers like Ted Bundy.

When the defense recited a litany of abuse Penry suffered as a child, Quijamo responded that as a child in the Philippine Islands he suffered abuse from an alcoholic father that may have been worse than Penry's. Although he did not elaborate, he said, "The abuse made me very determined not to become like my father."

Dr. Stanton E Samenow, a Falls Church, Virginia psychologist, co-author of the 1500-page, three volume *The Criminal Mind* and author of *Children and Crime* and *Before It's Too Late,* told the jury that people probably don't turn to crime because of something outside themselves. Crime instead resides within the individual. Therefore, Samenow rejected every defense argument that child abuse could be linked to Penry's criminal conduct. After reading records for 20 hours and making no examination, he told the jury that Penry was a criminal personality "in the extreme sense."

Robert Perske

THANKS VERY MUCH!

During 1990, OHIO SAFEGUARDS has received contributions in support of The Safeguards Letter from the following individuals:

Mary Brandstetter, Fairborn, Ohio
Danette Addison, Dayton, Ohio
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John McKnight, Chicago, Illinois
Robert & Betty Swanseen,
    Linwood, New Jersey
Jo Krippenstapel, Cranston, R.I.
Anne James, Ostrander, Ohio

Our thanks to one and all!

JUST QUOTES

I come, in conclusion, to the difference between "projecting" the future and making a promise. The "projecting" of "futurologists" *uses* the future as the safest possible context for whatever is desired; it binds one only to selfish interest. But making a promise binds one *to someone else's future*. If the promise is serious enough, one is brought to it by love, and in awe and fear. Fear, awe, and love bind us to no selfish aims, but to each other.

Wendell Berry
"Standing by Words"

Often even the most high-minded organizations have little regard for the community around them. I described the situation facetiously at a national meeting of voluntary organizations recently by saying: "A voluntary group may be profoundly and high-mindedly committed to care of the terminally ill and never notice that the community of which it is a part is itself terminally ill."

John Gardner, "Building Community." *Kettering Review,* Fall, 1989

REMEMBERING ROBERT RODALE

In recent years the word "regeneration" has come to mean a great deal to me. As I understand it, the word stands for the belief that people and communities can improve their circumstances by focusing on the capacities and resources available in a given area. Regeneration implies a certain energy and good spirit, as well as hopeful, creative work by a given group or community.

It was this idea of regeneration that first brought Robert Rodale's life and work squarely to my attention. Although Mr. Rodale had been associated with the Rodale Institute and Press since 1949, my familiarity with his work was casual. I could only remotely relate to the initiatives that represented his work in my mind--the publishing of *Prevention* and *Organic Gardening* magazines. Some time in the mid-eighties, I was introduced to the Rodale Institute's work around this idea of regeneration. I think that the impact of these ideas will continue to influence my life and work as long as I live.

Like many others, I feel a sense of gratitude toward the Rodale Institute and Bob Rodale. I found myself envisioning ways that we might prevail on Mr. Rodale to visit southern Perry County. His ideas seem perfectly matched for the challenge we face here. I didn't think that Mr. Rodale would fix anything; it was more an idea of affirming his ideas in the place I live and work. It was a way of saying, "Yes, Mr. Rodale, we understand that this is a place where there is much opportunity for rediscovering capacities in our people and our place. There is much we can do."

In September, Robert Rodale died in an auto accident in Moscow. Since that time I have read several articles written as tributes to this gentle man and his ideas and dreams. His death, and the response to his death by his family and associates has offered yet another useful piece of learning, for each of these tributes I have read convey a very powerful message of hope.

The leadership of the Rodale Institute will continue through the efforts of Ardath Rodale and John Haberern. The comments that follow were published in the "Partner Report" from Rodale Institute, Fall, 1990:

> "We can do nothing less than follow in the footsteps of a man who walked the earth planting hope. If you want to remember Bob, plant a tree nearby, and let us know!" says John Haberern.
>
> "Many of you may never have met Bob personally. Even so, you can know him through his heartbeat--what he believed in--the message to care for all people and nature. I know that there are even greater challenges that will come our way from the seeds that he planted. Our sadness is immeasurable, but his love sustains us to carry on and do the best job that we can do. We all need each other. I reach out to all of you." These are the comments of Ardath Rodale.

The tragedy of Robert Rodale's deathseems to have been overpowered by the strength of the love and hope that surrounded the man in his life and his work. Even in death he reminds me that love and hope do not fail. Mr. Rodale continues to offer a fine example of the regenerative spirit.

Sandra Landis

A VIEW FROM CHILLICOTHE Why I Show No Orange Ribbons

Unfortunately, by the time you read this, events may make moot the thoughts I'm sharing with you. Nevertheless, I thought I'd record some of the reasons why I've resisted the offers made to me, since August 2, to display orange ribbons at my house, on my car, or on my person.

The ribbons are, of course, intended to show my "support" for United States soldiers in the Middle East. Their display is a symbolic act, and I believe deeply in the effectiveness of symbolic communication. A big question about the use of symbols, however, is whether the user is fully conscious of both the meaning of the symbol itself and of what it is that the symbol means to communicate. In the case of orange ribbons, I'm puzzled about the exact meaning of the object (a ribbon, the color orange). I'm even more unsure, though, about what the display of ribbons is supposed to say.

Is it supposed to say, simply, that I "support" our troops? In one of the most tangible senses of "support," I support them. I pay my full share (I guess) of federal taxes--a big part of which go to the military. So far, I haven't acted to withdraw that "support"--something that would be difficult to do, indeed. Is the ribbon display supposed to indicate that I wish no ill to the individual soldiers who have been sent to the desert? Well, certainly I wish/hope that no harm comes to them--some of them are my fellow citizens of this small town. In fact, I hope that all the rest of them (as of this writing, 97 of them have already died, without shots being fired) come home soon.

My refusal of orange ribbons rests, I think, in my feeling that a display of them is intended, by someone, to indicate my total and unquestioning agreement with (allegience to?) the policies that have resulted in some Chillicotheans ending up in the Saudi Arabian desert. I don't want to display some sort of symbol that seems to say that I agree that the biggest "enemy" of my country is a ruler of a poor country half a world away (despotic and dangerous though he might be). There are other "enemies" whom our current leaders do not wish to engage so aggressively. Wendell Berry has asked, for example:

> Who are the enemies of this country? This is a question dangerous to instituted government when people begin to ask it for themselves. Many who have seen forests clear-cut on steep slopes, who have observed the work of the strip miners, who have watched as corporations advance their claims on private property "in the public interest," are asking that question already. Many more are going to ask. ("Property, Patriotism, and National Defense")

I don't have any orange ribbons because I don't wish to indicate my support for some things that may not be worth supporting or defending, especially at the cost of the life of one of my neighbors. Ivan Illich has characterized life in the United States as "…not viable enough to be shared." Is "defense" of Kuwait really a defense of my home--or is it, instead, just an attempt to extend, for a few more months or years, a style of living in which I and my fellow-citizens have grown lazy, slothful (or "slipshod", as my high school Latin teacher used to describe it)? Is that enough for others to die for? What right do I have to such a "defense"? How can "patriotism" be defined as the blind acquiescence to such motives? Again, Wendell Berry offers a pertinent thought:

> That a nation should purchase at an exorbitant price and then rely upon a form of defense inescapably fatal to itself is, of course, absurd; that good citizenship should be defined as willing acceptance of such a form of defense can only be ruinous of the political health of the nation. ("Property, Patriotism, and National Defense")

Some will say, of course, that a failure to show orange ribbons means that I don't "love my country." But, anyone who knows me knows that's wrong. I love this piece of ground that I've lived and gardened on for twelve years. I love this smelly little town I've lived in since 1976. I love the state where I've been all my life. I learned the lessons of my high school civics class; I even believed (and still believe) them. I don't, however, have confidence in the quarter-truths of the current leaders of my country's government. I refuse the shallow patriotism of unquestioning allegience; such allegience is not really an "American" tradition anyway.

I'll say it again. I want the best for my fellow citizens who are in the military. The best would be for them to come home soon and for none of them to die. Maybe, when that happens, I'll cover myself with orange ribbons. But--not until then.

Jack Pealer

Remember:

Helping People Be SAFE in Community,
January 28-29, Springfield, Ohio
&
Citizen Advocacy: Stories of Citizen Partnership,
January 30, Yellow Springs, Ohio

The Safeguards Letter

A Publication of OHIO SAFEGUARDS

NUMBER SEVENTEEN MARCH, 1991

WOLF WOLFENSBERGER IN CINCINNATI

On April 19 and 20, 1991, Wolf Wolfensberger and Susan Thomas, from the Training Institute for Human Service Planning, Leadership, and Change Agentry at Syracuse University, will be presenting two one-day seminars in Cincinnati. These seminars are sponsored by RHMR, Inc. and The Manuel D. and Rhoda Mayerson Foundation of Cincinnati. The events will take place at "The Phoenix", 812 Race Street, near downtown Cincinnati.

On the first day, Friday, Aptil 19, Dr. Wolfensberger and Ms. Thomas will be presenting ideas about "Social Advocacies on Behalf of Societally Disadvantaged People". The seminar offers a synopsis of key issues to be considered in the arena of "advocacy" and differentiates social advocacy from other things with which it might be confused. The discussion will focus on why social advocacy is especially needed today and will examine a number of specific advocacy forms: agency advocacy, "ombudsmanship", citizen advocacy, and others. The seminar also touches on the special roles that voluntary associations concerned with devalued groups can play. It explains that real social advocacy will always be under attack, what the most common forms and sources of subversion are, and how to safeguard advocacy.

Dr. Wolfensberger and Ms. Thomas will spend Saturday, April 20, offering "Reflections on Human Service Developments since the 1950's: What is Still the Same, What has Gotten Better, What has Gotten Worse, and What Lies Ahead". From Dr. Wolfensberger's more than 30 years of experience as a participant, leader, and critic of human services, he will trace service developments from the abysmal conditions that prevailed prior to the reforms that started in the 1950's, up to the present day. On three occasions during the day there will be a panel of others with long experiences in human services who will respond to the various parts of the presentation.

People who are interested in either or both of these seminars should contact John Romer, at RHMR, Inc., 3030 West Fork Road, Cincinnati, Ohio 45211 (phone: 513/661-4111). The fee for the seminars is $55.00 for each day or $95.00 for both days. This fee includes lunch, on both days. We urge folks who read this *Letter*, and who could get to Cincinnati for these days, to take advantage of the chance to hear about these ideas directly from Wolf Wolfensberger!

NEW MONOGRAPH ON "SOCIAL ROLE VALORIZATION" AVAILABLE

Wolf Wolfensberger has also announced the publication of a new monograph entitled: "A Brief Introduction to Social Role Valorization as a High-order Construct for Structuring Human Services". This monograph offers an intermediate-length (50 pages--shorter than the PASSING Manual but longer than other article-length explanations available so far) overview of the idea and implications of social role valorization. The monograph would be useful for people who want a better understanding of "social role valorization"(as formulated by Dr. Wolfensberger in 1983 as the successor to "normalization") but who are unable to attend an introductory workshop on the topic. It is specifically not intended that the monograph be interpreted as an "easy substitute" for the more complete interpretation of social role valorization offered at introductory workshops or PASSING training

The monograph is available, at a cost of $5.00 (+ 1.50 shipping), from the Training Institute, Syracuse University, 805 S. Crouse Avenue, Syracuse, New York, 13244. Order forms, for individual or quantity orders, are available from the Training Institute or from OHIO SAFEGUARDS.

IN RESPONSE TO THIS CALL TO CONSCIENCE

Sandra Landis

The preparation for war and the violent invasion of Kuwait and Iraq by the United States and other nations has brought many people to a sobering time. To me and others this time is yet another call to conscience. Conscience is simply defined by Webster as "…a time of reflection with 'sensitive regard for fairness or justice'." This particular call to conscience has resulted in my understanding that I shall begin to live a more public life. My hope is that I might, with others, learn to live more publicly in a way that contributes to a more peaceful world.

As I begin to speak about the reflection and decisions that come from this call to conscience I speak humbly. Only at this late date is my voice becoming truly a public one; it lacks the strength and stamina that comes from frequent practice. It is singular; it does not yet share in a common song with other voices. I don't know if such a song exists, for I have just begun to listen for it. What I can now speak about is influenced most by where it comes from inside of me. I have not sought a way to render judgments of conscience that are simultaneously influenced by anger/despair/fear/prejudice and hope. I have little confidence that I could accomplish that.

I believe that the perspectives I adopt in making judgments characterize those judgments. I assume that speaking with conscience presumes that I select the most useful response I can generate. My responses fall far short of being sensitive when they come from the perspective of anger/despair/fear/prejudice. I tend to think that this is the situation for many, perhaps all human beings.

For me, hope seems the more useful perspective to adopt. This means that I can't rely on feelings that are incompatible with hope to guide my thinking. Those are feelings to be put aside, subordinated, and replaced. My private experience is a source of help to me as I seek useful examples of situations guided by hope. I live day-to-day in the world of family and friends, a neighborhood, and an emerging larger community. This private life is in many ways a peace-seeking, peace-enjoying one. I have confidence that the ideas that help me live peacefully with others as family and neighbor can help guide my decisions about what is just or fair in a public context as well. I want to bring with me to a more public life, and to decisions of a public concern, that which serves me well in my private life.

To accomplish living in day-to-day peace as families and friends it seems that we "put aside" those things which do or are intended to do harm. We live at our best when we put aside power strategies and the attitudes of oppression. We continue to learn about and adopt attitudes of respect and negotiation, particularly at times of hurt, confusion, and misunderstanding. We don't ask people to do things we cannot or would not do. We exist in a context of commitment to work things out. We avoid blaming or distancing a dissonant voice. We acknowledge conflict, but we do not initiate force. Although we may risk being victims of violence, we do not regard violence as a strategy for getting along. We negotiate trust among us, and we learn to extend trust more fully to one another as we grow in confidence.

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

DEFENDANTS WITH MENTAL RETARDATION NEED INTERVENERS WHO UNDERSTAND THEM

When policemen arrest persons with retardation, confusing things happen. Officers recite something to them about "waving at my rights," as a Texan with retardation recalled. Then, with the click of handcuffs, they are taken away from everything that had been safe and familiar to them. They are placed in rooms where investigators work them to exhaustion, trying to "get something out of them." Because persons with retardation want so much to be accepted by others, they often try hard to give the investigators what they want--even though it will be used against them later. No matter whether they are guilty or innocent, they open themselves us to investigators in ways Ted Bundy, Jean Harris and Claus Von Bulow would have never even thought of doing.

Friends and helpers can be concerned, but when they encounter the imposing facade of the criminal justice system and its magical language, they feel intimidated and back off. They are somehow led to feel they're not needed anymore.

Nothing may be further from the truth, says Dolores Norley. This Florida mother of a son with retardation, a professor of communication, a lawyer and a police trainer, believes that "the best interveners will always be people who have actually worked with persons having retardation."

Norley, since the early 1950's, has taught at police academies, logged many hours riding in patrol cars (especially in Chicago), voluntarily visited numerous prisoners with retardation in their cells, written training manuals for officers, attorneys and judges, and helped to develop laws that protect persons with retardation.

The following are selected excerpts from her speeches and papers.

* * * * * * * * * *

The criminal justice system is a confusing place. That's partly true because the system itself doesn't know what it is about:

- It is torn between rehabilitating, punishing and deterring people. One court can act like John Wayne, another like Mother Theresa--for the same crime. One judge can have the spite of a vigilante, another the wisdom and intellect of Justice Brandeis.
- It's not always rational. Tom Wicker, a former editor of the New York *Times*, held himself responsible for the deaths of many prisoners in the Attica prison uprising. In *A Time to Die*, he describes how prisoners asked him to represent them in the mediation sessions. And so, he went to the meetings and openly discussed critical situations with the authorities. Later, after many of the prisoners were killed, he blamed himself for assuming the system was rational. It was not.
- Sentencing practices can be arbitrary, discriminatory and generally unprincipled--often governed by the subjectivity of the judge and influenced by the current vacillating public feeling about any one given offense.
- It is far easier to get into the system than to get out. Chalk this fact up to all the egos and territories that get involved.
- Some system members, nevertheless, are educable. More often than not, they are eager to do right, to learn about the people they are dealing with, and to be inventive in their jobs when they have the right guidance and persuasion.

When persons with retardation enter the system it is not just a crisis, it is usually a disaster. In all of my years in this field I have never seen one of these persons improved by imprisonment.

Excepting those arrested for murder, rape and child abuse, the system usually would like to spit out people having retardation. But it doesn't know how. The police, attorneys and judges have set things they must do--even if the person with retardation doesn't fit the usual criminal mold. That's professionalism.

Psychiatrists are dear to the heart of the courts. The courts were long ago intimidated into accepting them as the authority for practically everything. We as never before need educational and psychological evaluators who have lived with and understand persons with retardation.

Finding a person incompetent to stand trial may not always be a good thing. It could lead to a lifetime of incarceration in an institution and thereby deny him or her a chance to be proven innocent.

The biggest hurdle is the diffidence of those who regularly work with people having retardation. It is easy to blame the system for being insensitive. Then we become intimidated by them and don't try to advocate. Court liaison work is exactly like any other form of advocacy. The rules are identical: Do your homework. Know the problem better than they do. Know some of the solutions. Realize that some folks inside of the system are frustrated and they will welcome you and your expertise.

<u>The first step is educating the police and the courts</u>. I do everything I can to organize programs for training the police, lawyers and judges--even getting them to carry wallet cards that list helpful hints and the local disability agencies on call to them. In my experience, officers who can recognize and delineate disabilities become ambassadors and have been amazingly helpful in avoiding inappropriate arrests. Community level judges, if approached, will often welcome conferences with local people on possibilities for special programming.

<u>Those who work with persons having retardation need educating, too</u>. An example: A teenager with retardation went to his teacher at school to ask if a recent activity (fondling the genitalia of a young boy) was okay. The teacher sent him to the counselor. The counselor called the police. The young man was given 30 years in the penitentiary (even though rapists in Florida only average five years). The judge did it because he had suddenly become horrified by the current mushrooming of sex act cases.

When other prisoners saw the young man as a potential sex object, he requested protective custody. That amounted to being in absolute isolation--no radio, no reading material (he can't read anyway), no exercise, no meals outside his cell. At the time, he was 18 and flabby. When we tried to get him into a sex offender program he was refused because "he has less than normal intelligence."

When I visited, the guards put handcuffs on him and two armed guards stood outside his cell door. Handcuffs are rough when you are wiping away tears.

Whether he is a case of true pedophilia or a case of situational sex play, we may never know. Soon he may either go mad with the isolation, or become so desperate he will be willing to go on the compound and accept the protection of a "lover."

<u>We must train more of us in the field to be assertive interveners</u>. Judges will change. Prosecutors and public defenders will go on to cushy jobs in big firms. Only the advocates will remain constant. We must get to parole boards with facts about retardation as well.

Almost always, I work as an intervener with no status. But I am always welcomed. It works because the courts are desperately looking for any help they can get.

Recently, I went into a court and introduced myself as a person with no status--except for thirty-three years of experience in the field of retardation. The judge said, "Thank God! Do you have a card? I have a few other cases I want to talk to you about."

<u>Early diversion is crucial</u>. Persons with retardation need to be helped out of the criminal justice system and placed into alternative arrangements as early as possible. We need to pay heavy attention to first appearances, preliminary hearings and arraignments. Sentencing hearings are important, too. If we can offer alternative programs, many courts will jump at the chance to try them.

<u>But we need the alternatives</u>. The sad fact: Nine out of ten times it is the lack of alternatives--not the nastiness of the court--which sends our people to miserable incarceration where they are the prime victims of others there. We must create alternative programs.

* * * * * * * * * *

Item: Norley has developed succinct, easy-to-understand guidelines for criminal justice personnel in Florida. For a free copy, send a SASE (self-addressed-and-stamped envelope) to Dolores Norley, 529 Sans Souci Avenue, Deland, Florida 32720.

Item: Johnny Lee Wilson, a shy, likable young man with retardation, remains in prison for murder (even though another man has admitted to the killing). Some political leaders new admit unofficially that Wilson is innocent, but they fear it'll take five years before the Missouri legal system orders Wilson's release. Kids in Doyle Catholic Secondary School, Cambridge, Ontario, (a school noted for building circles of friends around all of their "educationally challenged" students) think that's too long. They have decided to send letters of hope to Wilson (#160230, P.O. Box 900, Jefferson City, MO. 65102). At the same time, however, they sent photocopies to Governor John Ashcroft (P.O. Box 720, Jefferson City, MO., 65102), Attorney-General William Webster (P.O. Box 899, Jefferson City, MO., 65102) and St. Louis Post-Dispatch reporter Terry Ganey (P.O. Box 266, Jefferson City, MO., 65102). Anyone needing information on Wilson can get it by sending a SASE to Perske (159 Hollow Tree Ridge Road, Darien, Conn. 06820).

Robert Perske

OHIO SAFEGUARDS Library: A Complete Listing, as of March 1, 1991

Adams, Frank. Unearthing Seeds of Fire: The Idea of Highlander. (1975).

*"Adventures of a Radical Hillbilly." (video-tape). Myles Horton, interviewed by Bill Moyers (1981).

Alexander, Christopher. (with Howard Davis, Julio Martinez, Don Corner) The Production of Houses. (1985).

Brown, Cynthia Stokes (ed.). Ready from Within: Septima Clark and the Civil Rights Movement. (1986).

*Bryan, Frank., and McClaughry, John. The Vermont Papers: Recreating Democracy on a Human Scale. (1989).

*Coles, Robert. Dorothy Day: A Radical Devotion. (1987).

Day, Dorothy. The Long Loneliness. (1952).

de Toqueville, Alexis. Democracy in America, Vol 2. (1840).

Dunbar, Anthony. Against the Grain: Southern Radicals and Prophets, 1929-1959. (1981).

Erikson, Kai T. Everything in Its Path: Destruction of Community in the Buffalo Creek Flood. (1976).

Freire, Paulo. Pedagogy of the Oppressed. (1970).

Gaventa, John. Power and Powerlessness: Quiescence and Rebellion in an Appalachian Valley. (1980).

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Illich, Ivan., Zola, Irving Kenneth., McKnight, John., Caplan, Jonathan., and Sahiken, Harley. Disabling Professions. (1977).

*Ivanhoe History Project. Remembering Our Past; Building Our Future. (Helen M. Lewis & Suzanna O'Donnell, eds.) (1990).

Moyers, Bill., and Horton, Myles. "Adventures of a Radical Hillbilly." (1982).

Myerhoff, Barbara. Number Our Days. (1978).

Nearing, Helen and Scott. Living the Good Life: How to Live Sanely and Simply in a Troubled World. (1954).

Nolan, Christopher. Under the Eye of the Clock: The Autobiography of Christopher Nolan. (1988).

*O'Brien, John, and Forest, Marcia (with Judith Snow, Jack Pearpoint, and David Hasbury). Action for Inclusion: How to Improve Schools by Welcoming Children with Special Needs into Regular Classrooms. Toronto: Inclusion Press/Centre for Integrated Education, 1989.

Olsen, Tillie. Yonnondio From the Thirties. (1974).

Orwell, George. Down and Out in Paris and London. (1931).

Paulo Freire at Highlander Center, December 5, 1987." (videotape).

Peavey, Fran. Heart Politics. (1986).

Perske, Robert., and Perske, Martha. Circles of Friends: People with Disabilities and Their Friends Enrich the Lives of One Another. (1988).

Shelley, Hugh and Mary Lou. Love is Two Plastic Straws. (1985).

Vanier, Jean. Man and Woman He Made Them. (1985).

'Walking on Air." (videotape)

Wyman, David S. The Abandonment of the Jews: America and the Holocaust, 1941-1945. (1984).

* = new listings since last listing (March, 1990)

Requests to borrow books or other materials should be sent to OHIO SAFEGUARDS, P.O. Box 1943, Chillicothe, Ohio 45601. You may also phone (614) 773-6191. We'll ask you to pay return postage costs.

JUST QUOTES

"On Being Asked to Write a Poem Against the War in Vietnam"

Well I have and in fact
more than one and I'll
tell you this too

I wrote one against
Algeria that nightmare
and another against

Korea and another
against the one
I was in

and I don't remember
how many against
the three

when I was a boy
Abyssinia Spain and
Harlan County

and not one
breath was restored
to one

shattered throat
mans womans or childs
not one not

one
but death went on and on
never looking aside

except now and then like a child
with a furtive half-smile
to make sure I was noticing.

Hayden Carruth

More and more it has seemed to me that the idea of an individual, the idea that there is someone to be known, separate from the relationships, is simply an error.

Mary Catharine Bateson, "With a Daughter's Eye"

Some time ago I was with Wes Jackson, wandering among the experimental plots at his home and workplace, the Land Institute in Salina, Kansas. We stopped by one plot that had been planted in various densities of population. Wes pointed to a Maximilian sunflower growing alone, apart from the others and said, "There is a plant that has 'realized its full potential as an individual.'" And clearly it had: It had grown very tall; it had put out many long branches heavily laden with blossoms--and the branches had broken off, for they had grown too long and too heavy. The plant had indeed realized its full potential as an individual, but it had failed as a Maximilian sunflower. We could say that its full potential as an individual was this failure It had failed because it had lived outside an important part of its definition, which consists of both its individuality and its community. A part of its properly realizable potential lay in its community, not in itself.

Wendell Berry, "Men and Women in Search of Common Ground"

(For devotees of McKnight's "John Deere and the Bereavement Counselor"): Les Parker reports from New York State that St. Lawrence University is offering a special workshop entitled: **"Self-Care for Bereavement Care-Giver Co-Dependent Syndrome"**. Sounds like everything one could "need" all at once.

ADDITIONS TO OHIO SAFEGUARDS' LIBRARY

Three new books have been added to the library in the past few weeks. These, like all other materials in the library, are available for borrowing by contacting OHIO SAFEGUARDS at P.O. Box 1943, Chillicothe, Ohio 45601. The new additions are:

Bryan, Frank. , and McClaughry, John. *The Vermont Papers: Recreating Democracy on a Human Scale*. Post Mills, Vermont: Chelsea Green Publishing Co., 1989. *The Vermont Papers* is a set of proposals for changes in the form of political life for an American state--Vermont--and, by implication, for other parts of the nation. These proposals are rooted in the notion that a fundamental issue in the current malaise affecting public life is the size/scale at which we both define and then attempt to solve "problems." The authors state that the book was written--the proposals made--because "We take democracy seriously."

Coles, Robert. *Dorothy Day: A Radical Devotion*. Reading, MA: Addison-Wesley Publishing Company, Inc., 1987. Robert Coles is best known for his book-series, Children of Crisis. Dr. Coles was a friend to Dorothy Day from the early 1950's (when Coles, then a medical student, worked in a Catholic Worker soup kitchen) through the time of her death in 1980. He wrote this boigraphy based on his conversations with her over those thirty years and on tape-recorded interviews.

Horton, Myles., and Friere, Paulo. *We Make the Road by Walking: Conversations on Education and Social Change*. Philadelphia: Temple University Press, 1990. Myles Horton and Paulo Freire got together in December, 1987 at Highlander Center in Tennessee to "talk a book." (OHIO SAFEGUARDS also has in its library a video-tape of part of that process.) This is the result of that conversation--a distillation of the thoughts and ideas of two of America's (in the real, larger sense) best-known educators of oppressed people about the connections between adult-learning and change in the life-experience of the learners and the behavior of the culture.

About THE SAFEGUARDS LETTER

The Safeguards Letter is a quarterly (approximately) 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, P.O. Box 1943, Chillicothe, Ohio 45601. We welcome our readers' ideas and reactions.

I've been thinking lately about whether "common sense" is a tool that's useful to those of us who want to help people with disabilities live richer lives. It seems that it should be. After all, most of the richness that we're trying to enable people to experience is found, we say, in the varied patterns and textures of that locus of our existence we call "community." And, community is the place that runs on "common-sense" principles. Communities, by definition, function well when their lives are governed by commonly agreed upon ideas--common expectations and experiences. Shouldn't that mean that this "common sense" that supports communities will also support those community members who have disabilities?

Well, sometimes "yes", but more often "no". Let's look at the "yes" examples first. In the past several years, I've often found myself in the role of "facilitator" (or "writer-on-the-wall") at meetings where someone with disabilities and her family and friends were trying to describe a better future life and, then, to figure out how that life would happen. The remarkable thing about these meetings is that, in general, the people who come to them really listen (sometimes for the first time) to the person who is the meeting's focus. Participants really work to understand the interests and wants of that person and then try to have a vision that captures those interests. Most often the vision and the plan that results issues from what I would call "common sense." That is, the ideas that develop are usually self-evidently rational for <u>this</u> person at <u>this</u> time in her life. "Common sense" is the process at work when people understand that someone with disabilities a) can't stand living in a big group any more, or b) won't be helped by coming to a sheltered workshop every day, or c) needs a personal relationship that <u>lasts</u> with one (or more) other person(s). In this context, common sense is what leads planners toward the sort of plain inferences that have sometimes resulted in big changes in the lives of some people who have disabilities. So, at least one kind of "common sense" (the kind that the *Oxford English Dictionary* defines as "…the plain wisdom which is every man's inheritance.") does offer support to people with disabilities.

But, there are other definitions of "common sense", and these offer us less comfort. For example, the *OED* also defines common sense as "…the general sense, feeling, or judgment of a community". The idea here is that communities tend to develop some ideas that are held in common, including ideas about themselves (who "we" are) and about other people (who "not us" is). It is this version of common sense that actually attacks the potential membership of people with disabilities in their communities. For more than twenty years, Wolf Wolfensberger has described the "common sense" of communities with regard to people who are judged to be "not us"; this description has taken the form of a catalogue of "common negative social roles imposed on societally devalued people." (See: *The Principle of Normalization in Human Services, Origin and Nature of our Institutional Models,* or *A Brief Introduction to Social Role Valorization*). Among the roles described in this catalogue are those of "sub-human/animal" and "burden of charity." "Common sense" as community judgment is what led me and other officials of a community where I once lived to decide that the sensible place where (only) children with disabilities should be educated was at a location seven miles from town, adjacent to the county poor farm and animal shelter. Another social role described by Wolfensberger is that of "menace/object of dread." "Common sense" as the general feeling of a community is what has led countless citizens of neighborhoods across North America to abandon civility and oppose, sometimes with violence, the residence of people with disabilities in their neighborhoods.

A few days ago, I sat working in the office of a school devoted to the education of (only) children with disabilities. A car pulled up outside and a man got out. He lifted from the back seat a cardboard box, and he carried the box inside the school. Coming into the office, he explained that he was from the local ("community") American Legion or Elks or VFW (I forget which). His group had sponsored an Easter party the previous Sunday (actually a week before Easter) for "the children." They had candy left over. Would <u>these</u> children like to have it? The candy was accepted, and he returned to his car and drove away. Now, it's possible that he drove past several other schools on his way to deliver the left-over candy. There are other schools in our town. But something--something that I'd call his "common sense" (the general judgment of our community) about <u>difference</u> and the exclusion that communities say must accompany it--caused him to choose <u>this</u> school and <u>these</u> children.

Why am I going on about this? I'm doing so because I want to think carefully about the extent to which "common sense"--mine and that of my fellow citizens--can be trusted, as a tool that will help people with disabilities. And, I conclude that I'm of two minds about it. On the one hand, if I'm trying to assist just one person whom I know fairly well and if I'm doing so in conjunction with others who also know and care about that person, I think that my "common sense" can be trusted, much of the time. When the "plain wisdom" that I and my fellow citizens possess is informed by personal knowledge of and identification with theperson we're trying to assist, common sense is a useful guide. On the other hand, it seems likely that when I'm considering how to "help" a group (or a "batch", as Erving Goffman called such collectivities) of people with disabilities--when I'm making decisions about organized services for them--common sense or the "general community judgment" about them will not often be useful. As a matter of fact, given the history of organized services, which, after all, emanate from communities, the community sense about people who are seen as "not us" is likely to be harmful. It's not to be trusted.

But, organized human services exist, and they will for a long time to come. For as far ahead as I can see, it's probable that our communities will use organized services as implements to try to help groups of people. This probability, coupled with the untrustworthiness of "common sense", means that those who are really interested in better lives for people who use services have to work hard at developing and teaching sets of ideas about how human services can better be organized. The necessity for human service workers (who,after all, grew up learning the general judgments of their communities about people with disabilities, as those judgments were expressed in places like segregated schools) to learn about ideas like "social role valorization" has never been greater! And that's the reason why we who are involved with OHIO SAFEGUARDS keep doing the things we're doing. We offer our workshops and we write the things we do precisely because these things fight against common sense.

Jack Pealer

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The Safeguards Letter

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THE MIRAGE OF PERMANENCY: Orchard Hill as an ICF/MR.

Wisconsin Coalition for Advocacy

(*Editor's Note: Occasionally we still hear of proposals to remedy the "residential problem" for people with developmental disabilities through the construction of large self-contained facilities or "villages" where only people with disabilities will live. Whenever I hear about such proposals, I recall the following article, which was originally published in the Newsletter of the Wisconsin Coalition for Advocacy in July, 1981. It still seems pertinent--especially as a cautionary tale about the expectations that might be attached to "village"-type developments. The article is reprinted here with the permission of the Wisconsin Coalition for Advocacy, 16 N. Carroll St., Suite 300, Madison, Wisconsin 53703. 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 fe w 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 partents, 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 fo 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 lthe 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 announded 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.

"WCA Newsletter", July, 1981

About THE SAFEGUARDS LETTER

The Safeguards Letter is a quarterly (approximately) 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, P.O. Box 1943, Chillicothe, Ohio 45601. We welcome our readers' ideas and reactions.

ANOTHER POT OF STONE SOUP

Last winter a small pot of simmering water sat on our wood stove. We usually have a steamer on the stove in winter, but this one was different. It served as a symbol of some work we have begun, our latest batch of stone soup. You may know the story about stone soup. I hope that my short retelling here sketches the real thing. I suggest that you treat yourself and read the whole story aloud to someone you like.

It seems that some soldiers found themselves in a place where they were not known well, without food but very hungry. They set about starting a fire, finding a pot, filling it with water, adding a few pebbles for something to stir, and talking about soup. They continued to talk about soup, stir the pot, sniff the air for aromas, and talk with passers-by about the soup they were making. What they were doing appeared to be inviting to others. They talked with most who came by. Soon enough, some people began to think about the soup. Many brought something to add to it. As ingredients were added, and simmered, and stirred, the anticipation grew. When it was time, the people shared a meal of nourishing soup.

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

My friends John and Stephen, and I, have begun a small organization. It's name describes the area in our community where we live--Sunday Creek (Associates). We're starting out with some ideas, some hope, some energy, and some time. Our aspiration is to be a part of revitalizing our little part of the world. We think that working over time with our neighbors to both do and stimulate interesting work and business enterprise, to maintain and improve our homes and the housing stock in our area, and to participate in social activities that add to the variety and quality of our public life will influence the kind of community we'll spend our lives in.

Each of us has come to realize that we want to work at home, in the midst of the collection of people and places that make up Southern Perry County, Ohio. Together we came to realize that now was as likely a time to begin as any. If we waited until there was some security in the work, either financial or social, it is likely that we would live many more years thinking about the work but not doing it.

We have spent some time learning about organizing, managing, and sustaining useful work. For a while we looked at this information mostly as stuff to share with other people, so they'd get organized. Slowly we've figured out that it's not necessarily other people getting organized that is the place to begin. Our first step was to understand that we are a few of the soup-starters!

Being "of" the soup-starters is different from being "observers", or even "consultants to" the soup-starters. It seems to us that many successful soup-starters adopt, singly and collectively, a policy of "living in the world as if it could be" as much as possible, where they are. And so, we've begun to live in our future a bit, now! We've begun to tell people about our interest in working at home and figuring out how that might happen in conjunction with things other people want to be a part of community life here. We're beginning to talk with other people about how our communities might be more interesting and self-reliant. We are practicing asking for and welcoming help others can contribute.

Already our stone soup has the benefit of others' ingredients. People have developed ideas and brought them into the conversations. Small organizations and groups of people have added ideas and energy. Some have pledged small amounts of money. Bigger organizations are considering our requests for help. A small group of people has committed some time to help us as Board members. Our little pot of soup has several small but especially savory ingredients in it, even at this early stage. I celebrated when they were added and celebrate again every time the pot bubbles these interesting aromas. I feel hopeful again. There is one such ingredient I particularly like.

We have a friend who's very talented in several ways. Dik's a map-maker, a model-builder, a train enthusiast, and a history student. We've talked about what life was like here a hundred years ago and what life is like now. We've talked about ways of preserving in people's minds some important stories, scenes, and lessons of life here during the early part of this century. From these talks the idea of a Southern Perry County Museum got dropped into the soup pot. Dik is really intrigued and interested in taking on this project. So is the Shawnee Historic Preservation and Business Development Committee, the Tecumseh Theater Corporation, and Sunday Creek Associates. The museum will include models of four of our little communities at the turn of the century, complete with railroads, brick factory, coal mine, and Main Street shops. There will also be displays of collections of photos, products produced, and other items. Lots of people have ideas, items, and stories to contribute. One group has undertaken sponsorship of the museum as its project for the next few years. The museum isn't a reality yet, but it is the focus of some people's energy now. There's a clear image of what can be. We hope to have the Museum doors open by the end of this year. We hope that even a "museum in process" will engage more people in this effort.

Even with this interesting ingredient, our soup is far from being very nourishing to very many now. We're trying to be faithful tenders of the watery stuff. Already we wonder what will keep us tending the pot for a long time. Most of the answer will come from people who join us as soup-makers themselves. Meanwhile, we stay at our task today, and expect to be at it tomorrow. I think we already know that what will keep us here is nothing abstract or mystical. In large part it is our hunger for community life to be more "as it could be," one day at a time, starting with what we have now.

Sandra Landis

SUMMER LEARNING

When an intentional learning experience works well, it tends to stand out in memory. I recall very well my high school physics teacher demonstrating wave theory with a Slinky stretched out in the hall. I also remember Wade Hitzing putting together the "hear it--try it--flub it--try it again--keep thinking" mode (shortened, at some point, to "SBP") and Les Parker elucidating a lively enthusiasm for ambiguity.

The McGill Summer Institute in Integrated Education stands out in memory as well--two weeks of opportunity for discussion, thought, reading, and otherwise poking about at notions of universal inclusion (combined with enough free time to spend a fortune in restaurants). The assembled faculty (in 1990: George Flynn, Jay Klein, Evie Lusthaus, Jan Nisbet, Jack Pearpoint, Judith Snow, Susan and William Stainback, Marsha Forest, Herb Lovett, John McKnight, John O'Brien and Gordon Porter) are clearly charting a course for profound changes in the way we think about the accessibility and hospitality of our schools, workplaces, and neighborhoods. They are knowledgeable, articulate, and enthusiastic. Then, too, an international array of participants makes for richness from which each can forge his or her own sort of leadership. The topics for consideration were: inclusion in schools; strategies for assisting folks with "challenging behavior"; recognizing and tapping the potential of neighborhoods; new ways to think about housing; and others.

I came away with information, but, more than that, I learned a great deal about community, because I was able to participate in the creation of a new one. More information about the Summer Institute (think 1992!) is available by calling (514) 398-4242.

Debbie Schmieding

JUST QUOTES

Government, like dress, is the badge of lost innocence; the palaces of kings are built on the ruins of the bowers of paradise.

Thomas Paine, "Common Sense"

War against an external foe is a most excellent means of distracting the populace from grievances at home.

Niccolo Machiavelli, *The Prince*

"Dancing at Whitsun" -- John Austin Roberts

It's fifty long springtimes since she was a bride,
But still you may see her at each Whitsuntide
In a dress of white linen and ribbons of green,
As green as her memories of loving.

The feet that were nimble tread carefully now,
As gentle a measure as age do allow,
Through groves of white blossoms by fields of young corn,
Where once she was pledged to her true love.

The fields they stand empty. The hedges grow free--
No young men to tend them, or pastures go see.
They are gone where the forests of oak trees before
Have gone--to be wasted in battle.

Down from the green farmlands, and from their loved ones
Marched husbands and brothers and fathers and sons.
There's a fine roll of honor where the maple once stood;
And the ladies go dancing at Whitsun.

There's a straight row of houses, in these latter days,
All covering the downs where the sheep used to graze.
There's a field of red poppies, a wreath from the Queen,
But the ladies remember at Whitsun.

And the ladies go dancing at Whitsun.

(As sung by Jean Redpath)

A VIEW FROM CHILLICOTHE "The Real Heroes" Jack R. Pealer, Jr.

On several occasions during the past few months the President of the United States has advised the nation's citizens to "…remember who the real heroes are." Aptly enough, this advice has come at times when the President was speaking to championship athletes--welcoming winning teams to The White House--that sort of thing. His advice is appropriate then because he contrasts the work and sacrifice of "real heroes" with the athletes' own (very real) work and sacrifice. He pronounces heroism a different thing than athletic glory.

Since I first heard the President talk about this, I've given some thought to the notion of "heroes"--who they are, why others should admire them, what causes someone to become one. I'd guess that most descriptions of a "hero" would include a person's willingness to accept and undertake risk--even risk of losing life--in pursuit of higher aims or goals. A hero would be someone who would act, without regard for personal cost (although not, necessarily, without considering or even regretting that cost) to defend otherwise defenseless people, to suppress tyranny, or, maybe, to preserve the rights and interests of fellow citizens.

I decided that I'm willing to accept the President's advice about remembering the real heroes. I'm willing to make a bargain with him. I'll acknowledge and remember the real heroes he's thinking about, if he'll acknowledge and remember some of mine. His heroes right now, of course, are the soldiers and sailors who carried out the events collectively called "Desert Storm". Those people did swallow the risk attached to the actions they took. Some probably swallowed hard. Believing their political leaders, those people offered their energies and their own futures so that they could defend national ideals and preserve a way-of-life that is important to them and to those they care about. The fact that the effort has (so far) been less costly to the U.S. citizenry than expected does not discount the willingness of the soldiers and sailors to risk. No one (at least no one who is willing to say so) knew, at the outset of the Persian Gulf affray, that virtually all of the U.S. personnel would come home safely. Most citizens expected "our cost" to be much higher.

As far as I can tell, their willingness to risk their futures at his command is what made ordinary citizens into "real heroes" for the President. I understand that and accept the logic of his designation. I insist, though, that, even on the terms that I described above (willingness to endanger their lives in defense of an ideal), there are other "real heroes" in the land. I'm not sure how readily the President would agree to acknowledge the heroism of some of the people I have in mind as candidates for the label of "real hero".

On April 8, 1991, Thomas Adams spent several hours (before he was arrested) chained to a rail car in the freight yards of CSX Corporation (formerly the Chesapeake & Ohio Railway) near Toledo, Ohio. Rail yards are dangerous places. Being chained to a freight-car puts one at serious risk of personal harm. Mr. Adams chained himself to the car so that he could call attention to the transportation of poisonous waste across state lines to dumping-areas of which residents in those areas were unaware. The train to which Mr. Adams affixed himself was carrying more than 2,000 tons of soil contaminated by an earlier train accident in Michigan. Mr. Adams said that he acted because: "This is not just an environmental issue; it's a moral and ethical issue.... We believe that … people have a right to know what kind of wastes are being transported through their communities, and where they plan to dump these wastes." (Chillicothe *Gazette*, 4/27/91)

It seems to me that Thomas Adams consciously acted in a way that put his safety, and maybe his life, at risk, so that he could defend cherished principles: freedom of communities and their citizens from harm, and the right of citizens to knowledge of danger affecting their personal well-being. It looks like this action could qualify Mr. Adams as a "real hero".

Bobby Person, a black man, worked for years as a guard in a North Carolina state prison. According to Morris Dees of the Southern Poverty Law Center, in 1983 Mr. Person applied to take a promotional examination. No black man had ever done so in that prison. When Mr. Person made his application, he came to the attention of the Ku Klux Klan. Mr. Person risked his life in a late-night confrontation with klansmen in front of his home (with his children looking on) and continues to risk his future because he was willing to be a plaintiff in a civil lawsuit against the local Klan. (The lawsuit, incidentally, had to do with the klansmen's acquisition of military supplies stolen from the army by soldiers at Ft. Bragg, North Carolina.) The lawsuit was successful, but Mr. Person has not yet been promoted on his job. He accepted the risks to his life, though, because he wanted to attack a tyrannical organization, and he wanted to preserve ideals like fair treatment and the opportunity to bring a better life to his family. Bobby Person acted like a "real hero".

No parade has been held, or scheduled, for Thomas Adams or Bobby Person, as far as I know. I would guess that they don't care very much about that. Instead, they cared enough about certain principles--keeping the land "clean" or resisting vicious threats to family and future--to volunteer for risk to their own lives. The President says that we should "remember who the real heroes are." I agree, as long as we're willing to remember <u>all</u> of them.

Jack Pealer

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APOLOGY FROM THE EDITOR.

Those who pay attention to such things will have noticed that it's been some time since an edition of *The Safeguards Letter* came their way. After nearly five years of this relatively infrequent--and therefore almost painless--editing and publishing responsibility, I've learned that it's the constancy of the task that is one of its major challenges. After a while I wonder whether I've run out of things to say. I wonder whether the "View from Chillicothe" has become obscured.

One way out of the "late-issue" situation is to give in and offer a "double issue" at a later time. That is (if the "double" is truly twice the size of a regular single issue) a perfectly honorable response, but one that then presents the subsequent problem of how to beg, borrow, or steal enough "copy" for something twice as long as the issue I've already found myself late in issuing. I've decided, therefore, to get this issue prepared, printed, and mailed to you as quickly as I can, and, then, to get back to something that resembles a normal schedule with the "winter" issue. This apology is, then, for having succumbed to **sloth**--the one of the seven deadly sins that (along with pride) applies most directly to writers. I'll try, at least, to avoid that one of the seven in the future. In the meantime, let me offer to all of you wishes for a holiday season filled with peace and renewal.

Jack Pealer

JOHN O'BRIEN SPEAKS ABOUT SERVICE QUALITY

On Tuesday, January 28, 1992, OHIO SAFEGUARDS will offer a one-day presentation by John O'Brien entitled "Perspective on Service Quality: Valued Experiences for People with Disabilities and Service Accomplishments." This workshop will be offered from 8:30 a.m. until 5:00 p.m. at the Hamiltonian Hotel in Hamilton, Ohio. The workshop will take place while OHIO SAFEGUARDS and Mr. O'Brien are in the midst of another, week-long training session entitled "Framework for Accomplishment" (for information about "Framework" please contact OHIO SAFEGUARDS).

Using slides and stories from his international experience with services for people with disabilities, Mr. O'Brien will help workshop participants to begin to think about constructive ways to organize human service resources in their own communities. The workshop will include descriptions of five essential accomplishments for which human service workers can choose to be accountable. Each accomplishment supports desirable experiences for people with disabilities and challenges communities to respond to people with disabilities in more competent ways.

Those who want to register for "Perspective on Service Quality" can contact OHIO SAFEGUARDS at P.O. Box 1943, Chillicothe, Ohio 45601 (Phone: 614/773-6191). The fee for the workshop is $15.00.

JUST A QUOTE

There are two classes of moralists: those who seek to improve the quality of other people's lives, and those who are content to improve their own lives. There are professors of morality, and there are practitioners of it; the categories tend to be exclusive. Nothing is so terrifying as a demonstration of principle. Emerson preached Nature; Thoreau embraced nature; it is Thoreau, of course, who ultimately strikes us as dangerous.

Paul Gruchow, in "
Our Sustainable Table", edited
by Robert Clark

A CHALLENGE FOR ANYONE WHO CARES ABOUT PERSONS WITH RETARDATION AND OTHER DEVELOPMENTAL DISABILITIES.

Robert Perske

Some years ago--on the Tuesday before Easter, in a small Midwest town--a 13-year-old boy was murdered. On that day, the victim, Jonathan Brooks*, attended his junior high school's first baseball game. After the game he failed to come home for supper. A patrolman found his body the next morning in a wooded strip of land that bordered the diamond. He had been battered about the head with a blunt object.

The home team catcher testified that he saw Jonathan during the game, sitting in the bleachers behind home plate. "Jonathan was making fun of the way I was throwing the ball," the catcher said. "He just kept on kidding me. You know, it was all in fun."

More important, however, the catcher said that Jonathan was sitting with a man, "and you could tell they were having a serious conversation." He described the man as five-feet-ten to six feet tall, 175-185 pounds, neat with red curly hair and freckles. Judging the man to be in his early twenties, the catcher thought he might be a teacher from the visiting team's school.

The man who sat with Jonathan Brooks at the game has never come forward. His identity remains a mystery today.

On Thursday, two days after the death, at 7:30 p.m., a detective went to the home of 20-year-old Sammy Rafter, a young man with a slight build and mental disabilities. The officer asked the parents for permission to take Sammy to headquarters and enlist his aid in solving the crime. The parents, puzzled by the request but seeing Sammy jump at the chance to help, let him go.

Just after midnight, the police charged Sammy with murder.

Later, Sammy told his parents how proud he was to have helped the officers solve the case. "He acted as if he had suddenly been made a member of the department," his father said.

Still later, at a bond hearing, the chief state's attorney said the evidence against Sammy was "overwhelming."

But during the trial the state based its case only on what Sammy had told officers that Thursday evening. Sammy had waived all rights to have an attorney present during the interrogation, and he felt no need to remain silent. An officer claimed he had typed Sammy's final description of the killing and that Sammy had signed it.

Defense attorneys argued that Sammy--who possesses an inordinate desire to please people who represent power and prestige--had been "led into saying what he said to the officers."

The defense showed that numerous lab routines failed to turn up even one item of physical evidence that connected Sammy to the crime--not a single hair for fiber or footprint or finger print or human cell. A parade of clinicians described the many disabilities of this five-feet-seven, 140 pound man, who also has a speech impediment, tousled hair and gangling walk. They explained his short attention span, thinking disorders, fantasies of greatness--his significant impairments in learning and judgment and memory. One expert, describing his impaired central nervous system, claimed that Sammy lacked the strength to deliver the brutal blows the victim received. Repeatedly, the defense underscored the young man's unabashed eagerness to please the police--to be accepted by them.

As arguments came to a close, both sides called for "justice." But one excruciating contradiction stood out: A brother, aunt, and uncle swore that Sammy had been home puttering in his room when the

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* Due to approaching parole deliberations, pseudonyms are being used.

crime was committed. On the other hand, three officers claimed that only the killer could have known what Sammy had told them on that fateful Thursday evening.

The jury deliberated for three days--then announced a deadlock, but the judge refused to release the jurors. Two hours later, the jury reached a verdict: guilty of second-degree manslaughter. Rejoicing prosecutors told reporters, "the system works," but the defense lawyers insisted that the state had convicted the wrong man.

Today, Sammy lives in a Midwest state penitentiary where he needs round-the-clock protection from other prisoners. His parents--who once had been active, well-liked leaders in community affairs--now keep a low profile. They used up their life savings in the legal defense of their son. And since the order of things in our society shows little concern for "criminals' families," the Rafters must anguish alone behind closed doors. In their seclusion they probably fail to notice that other parents of sons with disabilities suffer the same lonely fate.

* * * * * *

Today, most folks in that town have forgotten all the finer details of the case. Nobody debates Sammy's innocence or guilt in the town's diners and barber shops anymore. Only broad-brush memories of the case remain: Jonathan Brooks was murdered. The cops arrested Sammy Rafter. He received a trial. The jury found him guilty. The judge passed sentence. The cops must have been right.

Even so, I still give in; to repeated urges to take out all my clipped-and-mounted newspaper articles on the case and read them one more time. Then, one more time, I wonder how a network of committed workers and volunteer advocates <u>who understand and care about people with disabilities</u> might have helped.

I even daydream about sitting in a bar when a man with curly red hair, freckles, and a tongue loosened by five martinis suddenly spills his guts about what he did at suppertime on a Tuesday before Easter, some years ago

Robert Perske

(Robert Perske's recent book, *Unequal Justice?* [Abingdon Press, $10.95} --about persons with disabilities who encounter the criminal justice system--came off the presses on October 1. It can be purchased in bookstores or by calling 800-672-1789.)

<u>About THE SAFEGUARDS LETTER</u>

<u>The Safeguards Letter</u> is a quarterly (approximately) publication of OHIO SAFEGUARDS. The <u>Letter</u> 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 <u>The Safeguards Letter</u> is under OHIO SAFEGUARDS' copyright (©) unless otherwise attributed. Letters, ideas, and items for publication in the <u>Letter</u> can be sent to: Editor, <u>The Safeguards Letter</u>, P.O. Box 1943, Chillicothe, Ohio 45601. We welcome our readers' ideas and reactions.

JUST QUOTES

I became increasingly aware what happened when the good was replaced by values, how the transformation of the good into values, of commitment to decision, of question to problem, in that moment reflects an incorporation of the speaker into a sphere of scarcity, a perception that our thoughts and our ideas, our time are scarce means which can be used for either of two or several alternative ends, that value reflects this transition. And I wouldn't dare any more, in an anthropological reflection on the way of life of people, to speak about their values. I would rather ask the aesthetic question about the shape in which we perceive the good, the sound in which we address it, the feelings with which we respond to it. For me, the discourse on values is sadly subjective, sadly detached from nature.

Ivan Illich, in "Part Moon Part Travelling Salesman" (CBC Interview, 1989)

… it is unjust to expect that opportunities for people with severe disabilities should depend on heroic efforts to outwit segregating policies and work around misdirected professional practice.

Connie and John O'Brien, 1991

ABOUT *THE WHOLE COMMUNITY CATALOG*

Those of us who care about the vitality of our communities and about the place of people with disabilities as members of them will probably want to know about--and possibly carry around with us--*The Whole Community Catalog*. The *Catalog* --to be published in 1992 by Communitas, Inc., Manchester, Connecticut--will be like an idea-generating conversation-in-print among folks who are active at trying to make community life better in the places where they are. Late in the summer of 1991 Communitas published and distributed "An Introduction to the Whole Community Catalog". In this 19-page Introduction, David Wetherow described the aim of the *Catalog* as follows:

> A major shift in vision is underway--from a vision of someone who is "perfectly well serviced" to a vision of someone who is well-loved and held at the heart of community.
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> Each time a shift of this magnitude has occurred, ithas involved "re-visioning" four elements:
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> 1. The people whom we call disabled, their identities, needs, and the gifts they have to offer,
>
> 2. The community, and its willingness and capacity to offer hospitality and to accommodate differences,
>
> 3. Ourselves and our families (our own identities, needs and gifts), and
>
> 4. The nature of our collective responsibility for vulnerable people.
>
> *The Whole Community Catalog* is intended to reflect and support this movement towards full community inclusion. It is designed to provide access to tools and ideas, and to facilitate connections between the people who share this journey.

In the tradition of the Whole Earth Catalog from the late 1960's, *The Whole Community Catalog* will contain ideas and tools submitted by subscribers/readers about how to make "community that includes people who have previously been rejected" work better. The "tools" will be things like: books to read and learn from, other sorts of "media" (films, videos, recordings, etc.), workshops to attend, "networks" to join, and other examples of things that work. Communitas, Inc.'s "Introduction to the Whole Community Catalog" contains both reviews of a few of these tools and an open invitation for readers to send in items that have been useful to them, so that these can be shared with others.

To get a copy of the "Introduction" (if any are still available) or to order a copy of the 96-page "Premiere Edition" of *The Whole Community Catalog* (price of the "Premiere Edition" = $15), readers should write to:

The Whole Community Catalog
c/o Communitas, Inc.
185 Pine Street -- #002
Manchester, CN 06045

THE GIFT

Anthony Cronshaw

(Editor's Note. "The Gift" originally appeared as two articles in *All People*--the journal of Church Action on Disability in Exeter, England. The articles were combined and adapted in *Speak Out*, a publication of The Community and Mental Handicap Educational and Research Association, also in England. "The Gift" is here reproduced with permission.)

One Tuesday my wife visited the Consultant Obstetrician and we learned that the child which she had carried for six months and for whom we had such high hopes, had been discovered to have spina bifida and hydrocephalus. We wept. We wept together. It was our child, conceived out of our love for each other. We wept for ourselves. Gradually, however, we began to see that the child was a gift from God. The child would be gifted by God. The child was not our child alone, but God's

The initial medical advice was very negative and gave little or no hope: myelomeningocoele, hydrocephalus, probably not able to walk, almost certainly incontinent, quite probably an intellectual cabbage, more likely than not to have respiratory problems. In short, quality of life extremely poor; perhaps we ought to induce it now. No! Notice our child had become an "it". We were deeply hurt--not by God's gift of a child with special needs, but by the medical mind which could not see that the whole of God's creation was to be respected and nurtured. We limped into the future in the knowledge that things would never be the same again.

On a hot summer evening, surrounded by a medical world which we had come to regard with suspicion and anxiety, we gave birth to a son. We called him Jacob, which means "protected by God."

They came: paediatricians, neuro-surgeons, uro-surgeons, physiotherapists, health visitors, social workers, orthopaedic surgeons, genetic consultants, medical officers, psychologists. All wise men, all with their professional insights into what was best for Jacob. Few realising that if they had anything at all to offer it had to be offered in the form of a partnership with parents, in the child's interests. A partnership of equals. Inside the fortress which my wife and I had constructed out of our relationship we viewed our experiences. Looking at each other with knowing looks, not daring to speak, not wishing to share our joy with the scoffing masses who surrounded us. They stared at God's gift to us all from the point of view of an imperial reality which proclaimed that this child had no right to be alive; he would be a burden on society; he would be an impediment to the provision of cost-effective, value-for-money health service which could solve once and for all the problem of handicap.

In fact, we met one medical practitioner with whom it was possible to form a partnership. Out of some inner empathy he perceived what it is to be the parent of one whose care has been entrusted to you. He was delighted to be of service to the family. The tissue of the myelomeningocoele had survived the process of birth, there was good leg movement and the hydrocephalus was not too advanced. The doctor referred us to a neuro-surgeon and she offered her gifts. And afterwards, behold there came a multitude: "Oh, isn't he lovely. What's his name?"

Jacob. And those who saw became gifted with the imagination of an alternative reality.

<u>A VIEW FROM CHILLICOTHE</u> "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.

A few 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 <u>in</u> the sheltered workshops.

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 <u>must</u> be limited, if not non-existent.

Recently, I 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. 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 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 the things being most talked about 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 labelled people."* 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 year or two 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 <u>about</u> 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 <u>lot</u> about money.

Jack Pealer

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

The Safeguards Letter

A Publication of OHIO SAFEGUARDS

NUMBER TWENTY SPRING, 1992

WOLF WOLFENSBERGER IN CLEVELAND. PLEASE MARK YOUR CALENDAR!

OHIO SAFEGUARDS is working with ARC/Cuyahoga County and possibly with other organizations to present a unique learning opportunity. On November 16 and 17, 1992, in the Cleveland area, Dr. Wolf Wolfensberger and his associate Susan Thomas will offer two separate but related workshops about the history of human services in general and developments in the field of disability in particular.

Not everyone likes the study of history, but everyone is affected by history. This "everyone" includes people who are connected to human services--those who use services, those who provide them, those who manage them, and those who are concerned about the expenditure of tax money to support services. On Monday, November 16, Dr. Wolfensberger and Ms. Thomas will present a survey of the history of human services in the western world. The full title of this workshop is *"A One-Day Presentation on the History of Human Services, with Emphasis on the Origins of Some of our Major Contemporary Service Patterns, & Some Universal Lessons for the Planning & Structuring of Our Services which can be Learned from this History."* The presentation features several hundred slides that Dr. Wolfensberger has taken or accumulated over the last 30 years. The information presented and the insight to be gained through this workshop is probably unavailable through any other forum. Dr. Wolfensberger's description of the workshop notes:

> The material presented has relevance to every human service worker, from those on the direct clinical level to those at the highest planning levels. This includes service professionals and non-professionals, clinicians, advocates, volunteers, administrators, planners, theorists, and analysts. Attendance at the presentation can help anyone gain a better understanding of the service challenges that they are up against, some of the dangers that lurk everywhere, and what sorts of service patterns to strive for.

Dr. Wolfensberger and Ms. Thomas will spend Tuesday, November 17, offering *"Reflections on Human Service Developments since the 1950's: What is Still the Same, What has Gotten Better, What has Gotten Worse, and What Lies Ahead"*. From Dr. Wolfensberger's more than 30 years of experience as a participant, leader, and critic of human services, he will trace service developments from the abysmal conditions that prevailed prior to the reforms that started in the 1950's, up to the present day. This presentation:

- explains the ideas that gave rise to the deplorable pre-1950's conditions and that, in part, still linger today;
- inventories the major positive changes that have taken place in services since then, as well as some of the things that have NOT changed (or that may actually have gotten worse); and
- explains some of the overarching challenges that Dr. Wolfensberger perceives to lie ahead to confront people with disabilities and their allies in the future.

On three occasions during the day there will be a panel of other people, from northeastern Ohio, with long experiences in human services who will respond to the various parts of the presentation.

We do not know right now exactly where these workshops will be held, except that they will be in the Cleveland area. We are uncertain about how much it will cost to attend either or both of the events. We are trying to find funds to cover part of the cost so that the registration fee can be kept as low as possible, so that lots of people can afford to come. By the time the next edition of *The Safeguards Letter* appears, we will be able to supply further details. Now, we wanted readers to know about these events, mark their calendars, and plan to attend.

HOLDING A PLACE IN LINE

Sandra Landis

I have some clear childhood memories of standing in line. We used to have to stand in line at the nurse's office in school to get our polio shots, and my brother always fainted. We stood in line before every recess and lunch period in elementary school. We even stood in line to walk to the bathroom. And on Saturdays, at one o'clock, my brothers and I would stand in line to buy our tickets for the kids' matinee.

One memory has to do with being yanked out of line. Our family was traveling, visiting for a couple of days in New Orleans. We walked around a section of the city with lots of shops and a wonderful bakery that made French crullers. I stepped away to the water fountain, into line behind two grownups. A woman I didn't know grabbed me by the back of the neck, pulled me out of line, and directed me to the fountain marked WHITE.

Now I stand in line at the grocery store, sometimes at restaurants and the print shop. I also live with the idea that there is another line--of human experience--that I am always a part of and that I influence in small ways. The distinction between literally standing in line and figuratively holding a place in the line of human experience became much clearer about ten years ago when I showed up at the unemployment office. May I never be requested to stand in a line that long again. It stretched ahead for twenty-six weeks.

Twenty-six weeks seemed like entirely too long a time for anyone to just stand in line, so I soon began to think about it in that other sense, as preserving a place for a useful role in that line. While I was there, what would I stand for? During the first couple of weeks I watched other people and learned the routines. It looked to me like a number of people had already filled the expert roles. Others had become the silent observers and still others the vocal cynics. One person chose to use the time to read stories to two small children. I decided to be one of the "look people in the eye and be cheerful" people. There didn't seem to be many people representing that position.

I found there was a difference in the standing-in-line experience, depending on how I thought about being there. I ended up meeting some interesting people and hearing some amazing stories. I understood, as well, that my choice to be a cheerful person in line was a relatively easy one because I was certain that I would not repeat this experience. I did have a lot of time to think while I was standing there, and there were a lot of things I needed to make decisions about. At the time I was trying to figure out how I could begin to do useful work without having a job or position. I wanted to earn enough to live and support my sons but not generate much tax liability. Uncertainty seemed to dominate my attempts to begin my future. Standing in that line was a concrete example of what I seemed to be facing in lots of other areas of my life. Just as I wanted to choose something to stand for and preserve a place for in that temporary line, I wanted my life's activity to preserve a small place for living and working hopefully in the uncertainty that surrounds all of us humans.

When I noticed that cheerful persons seemed a minority in line, it seemed clear that there was room for one more. Why not be that one, especially if I were only going to be around for one twenty-six week stint? In the same way, with only one lifetime, why not continue to choose hope? As far as I could tell the scarcity of cheerfulness in the unemployment line paralleled a scarcity of hope in the lives of many people outside that place.

There was another feeling too. When I looked at the worn, cracked seats on the chairs or at the tiled floor where the pattern had been worn away, I knew that people had been there long before me. I imagined that some of them had come to stand in line and some of them had come to hold a place. Though I would never know them, I felt that I had colleagues in the same activity. Even though we had stood in line on different days, in different years, we were contemporaries, sharing a common experience or performing a common task. This identification with people as sharing "of the same time" experiences with me is a notion that I've happily taken license with ever since. It's been a way of expanding my sense of the present, approaching what John O'Brien calls the "200 year present". By beginning to describe the present in terms of common activity and interest and by stretching my sense of the present through relations with others, I experienced an immediate growth in my circle of allies and intimates. This expanded idea of what constitutes the present has put me in closer touch with my heroes.

I realized that I was just one of many who had stood through a common experience, and I understood that someone before me had also chosen to bring cheerfulness to the line. Because someone did that, keeping the expectation alive, there was a chance for me to do the same when I showed up. There was a connection through activity that I only recognized because of circumstance. Ordinary people decide about the roles they will fill or the ideas they will stand for; thereby, they preserve those roles and ideas in the places where life takes them. Only the particulars limit their influence. Sometimes the decisions of ordinary people in particular situations turn those people into heroes.

I continue to live with these ideas and keep finding work to do that I regard as consistent with keeping a place open for hope, through activity. I've become more practiced at acknowledging small acts of heroism in others, and in myself. I have noticed that my expectations about heroic activity have increased. And, through the happy coincidence of circumstance and opportunity I live now in what I think of as collegial association with a few of my longtime heroes. This is of great comfort to me, and it happened so easily.

I have read Myles Horton's autobiography, *The Long Haul*. Myles became one of my heroes on the day when I met him. As a young man, Myles had developed a simple, clear idea about how people learn useful things. Then he spent his life creating opportunities for that to happen. When he was trying to figure out what direction to take in his work, Myles visited Chicago and spent some time with Jane Addams. They met early in his life and relatively late in hers. Myles admired Ms. Addams' ideas about democracy and leadership within democracy. These ideas, she claimed, were influenced by her father, who, in turn, believed his ideas to have been influenced by Abraham Lincoln. As I read this, I felt closer to understanding why Jane Addams and Abraham Lincoln have been my heroes for a long time. And for the first time I had an appreciation that Ms. Addams, Mr. Lincoln, Mr. Horton, and I are "of the same time". What a wonderful comfort to affiliate with these people through a chain of ideas, activity, experience, and personal relationship (however casual)! This connection buoys my spirit and strengthens my resolve to act and work to preserve a small space for hope through what I do.

Associating freely with heroes has been a faithful reminder to me that my task can't be to "fix problems". Sometimes I have forgotten that, and those are discouraging times. My task is merely to hold a place for hopeful activity in the midst of painful dilemmas and realities--like the oppression and violence that are part of living in this time. The task is to keep the ideas alive as long as alternatives remain. The luxury of living in the extended present is that I am in the company of heroes--the ones I've known and the ones I haven't yet met.

Sandra Landis

MY VISION OF INCLUSION

Debbie Schmieding

My vision of inclusion has me at the center--the responsibility and the benefit. In truth, I work for inclusion not for the poor labelled souls, or for my children or for my neighbors. I do it for myself. My vision involves putting aside fear, timidity, fatigue, and helplessness, for the sake of my own safety and for the richness of my relationships and the depth of my perspective.

Martin Niemöller made an acute and timeless observation, just so that **I** could hold it up to the light and paraphrase it this way:

> They came for the Jews, and I stood in front and said "We are all Jews. You may not take us, but you may join us."
>
> They came for gay men and lesbians, and I stood in front and said, "We are all gays. You may not take us, but you may join us."
>
> They came for the angry people, yelling and banging their heads, and I stood in front and said, "We are all angry. You may not take us, but you may join us."
>
> They came for the people with slurred speech and jerking limbs, and I stood in front and said, "We are all inarticulate. You may not take us, but you may join us."
>
> I had to say these things because by the time they would have come for me, there weren't any of "them" left.

This is my vision of inclusion.

Debbie Schmieding

About THE SAFEGUARDS LETTER

The Safeguards Letter is a quarterly (approximately) 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, P.O. Box 1943, Chillicothe, Ohio 45601. We welcome our readers' ideas and reactions.

PASS WORKSHOP (TENTATIVELY SCHEDULED)

OHIO SAFEGUARDS has begun the planning for its next presentation of "An Introduction to the Role of Values in Human Services, through the Use of PASS 3." This workshop, which has been offered regularly in Ohio by OHIO SAFEGUARDS for several years, has been tentatively scheduled to take place between Sunday, November 29 and Friday, December 4, 1992, in Chillicothe, Ohio. Complete details about the workshop will be announced in flyers issued by OHIO SAFEGUARDS within the next three months. Fees for the workshop are expected to be in the range of $200-$250 per person, not including lodging and meals.

The title of the workshop describes both its intent and its main emphasis. Those who come to the workshop can expect to be immersed in readings, lectures, discussions, and a practicum visit to a human service agency. All of these activities focus on helping participants learn how the values and beliefs of both human-service agencies and of the culture in which we live shape the assistance people who are in need receive. Those values have, as a consequence, powerful influence on the kinds of lives that people in need are enabled to live.

Most participants in past PASS 3 workshops have found them enriching, stimulating, and (yes!) all-consuming. Some people count their first PASS workshop as a high point in their careers. Registration for the workshop can be accomplished using the form that will accompany the descriptive flyer. Those interested in attending are urged to register as quickly as possible following receipt of the flyer, because only 25 participants will be enrolled. If you want to be sure to get a flyer, please contact OHIO SAFEGUARDS at P.O. Box 1943, Chillicothe, Ohio 45601 (phone: 614/773-6191).

SUPPORT FOR *THE SAFEGUARDS LETTER*

This is our annual appeal for donations of money to pay for *The Safeguards Letter*. Regular readers know that there is no "subscription fee" for the *Letter*. The trustees of OHIO SAFEGUARDS agreed more than four years ago that the *Letter* would not be paid for by "subscriptions" but by the voluntary contributions of interested individuals and organizations. This decision saves OHIO SAFEGUARDS from the task of maintaining subscription lists. More important, though, the decision places the responsibility for the future of the *Letter* where it ought to be--in the hands of its readers. For the past three years the intermittent contributions we've received have made it possible for the *Letter* to reach about 400 readers four times a year. Any readers who want to contribute (it's tax-deductible) may send their contributions to: *The Safeguards Letter*, P.O. Box 1943, Chillicothe, Ohio 45601. All money received will be used for the printing and mailing costs of the *Letter*. We thank you for your continued loyalty as readers.

JUST QUOTES…

…being human, whatever that is, is something we have to survive, as there's no prospect of rescue. And, since madness and misery seem to be an inescapable risk of having our particular sort of constitution, the measures that we take to deal with them had better take account of the fact that we don't, and perhaps never will, know what sort of things we are.

Jonathan Miller
"Madness" (on PBS)

Like a Rabbi or a Mullah, you avoided putting forward theories and told stories instead. All your life you have spoken and written like one who knows that arguments can end merely in conclusions and only stories make sense.

Ivan Illich, to Leopold Kohr
Preface, *The Breakdown of Nations*

UNEQUAL JUSTICE?, by ROBERT PERSKE: A REVIEW

Between 1838 and 1840 a Boston woman (a writer of children's books and a school teacher) named Dorothea Dix traveled through the state of Massachusetts, visiting jails, almshouses, and houses of correction. In January 1843, Dorothea Dix summarized what she had seen in an address--a "Memorial to the Legislature of Massachusetts". Over the past several years a Connecticut writer (who has also written books suitable for children) has traveled around the United States, again visiting people in prisons. Robert Perske has had no opportunity to speak to a legislature yet (as far as I know), but he has reported some of what he has learned in his new book: *Unequal Justice?* (Nashville: Abingdon Press, 1991).

Dorothea Dix described her purpose this way:

> About two years since leisure afforded opportunity and duty prompted me to visit several prisons and almshouses in the vicinity of this metropolis.... Every new investigation has given depth to the conviction that it is only by decided, prompt, and vigorous legislation the evils to which I refer, and which I shall proceed more fully to illustrate, can be remedied. I shall be obliged to speak with great plainness, and to reveal many things revolting to the taste.... But truth is the highest consideration. *I tell what I have seen*--painful and shocking as the details often are--that from them you may feel more deeply the imperative obligation which lies upon you to prevent the possibility of a repetition or continuance of such outrages upon humanity.
> (Memorial to the Legislature of Massachusetts, January 1843)

Robert Perske describes what happened to him like this:

> Every now and then, people with mental retardation or other developmental disabilities are arrested for crimes they did or did not commit.
>
> Perhaps we have known of such a person--as a customer or co-worker or student or client or patient or parishioner, or even as our own neighbor. And we may have felt a momentary sadness about the arrest, but we usually assume that an arrested person did commit the crime. After all, most of us want to believe that police officers are righteous officials who don't make mistakes. So, we watch at a distance....
>
> A decade ago, however--after the surprise arrest of such a person near one of my former neighborhoods--something within me suddenly refused to ever let it go so easily again. Now one question whirls around in my consciousness every time something like that happens:
>
> > *Did that person receive equal justice?* Whether guilty or innocent, did the system treat that person as other citizens are treated when charged with the same crime?

Unequal Justice? is a report of Bob Perske's attempts to come to grips with that question. The question mark in the title is important. Perske insists on <u>not</u> treating the situation of people with severe disabilities who are accused of "capital" crimes as "a problem". Problems imply solutions. Despite pain ("…something within me…") and obvious anger, Perske refuses to offer answers. In the last chapter, "A Final Thought", he notes that: "This book ends with more questions raised than answered." This restraint, which must have been hard for the writer to maintain, is the book's greatest strength. When asked to think about it, most anyone can come up with a few grand ideas about how to make the criminal justice system work better. Perske invites us to consider such things, but he does so by telling stories. He calls the book "…my flashlight, turned on for you and beaming its light into a few dark corners…." The light lets us see what's there and, seeing, begin to make judgments for ourselves.

What I saw in Perske's stories coalesces around three sub-questions of Perske's larger question (*Did that person receive equal justice?*). I kept being led to think about: a) lawyers' games; b) police officers' points-of-view of about disability and about their role in our communities; and c) the status of <u>confessions</u> as evidence in criminal trials. First, the lawyers. Perske takes us into a number of court rooms where people with disabilities get caught up in a process they do not understand. Many of the people who became defendants didn't even know that the game of "adversary" was being played. It's not a game with which many of them were familiar. Friends and helpers of people with mental retardation have often noticed how anxious many such people are to <u>please</u> others who are around them. Pleasing your opponent (whom you do not recognize as such) is no way to come out ahead in "adversary", as Perske illustrates.

Then there are the police. I wonder about what police officers think their job is when they investigate a crime. Some of the stories Perske tells hint that some police officers think it's their job just to find someone who can be convicted in court. Is that why, in several of the cases, the police seem intent on searching out someone with mental retardation? Is it because police officers know that arrests of such people will raise the odds of a conviction? Or do police officers share with many other members of our communities a set of beliefs about people with disabilities (i.e., that such people are dangerous, etc.) -- beliefs that might predispose the officers to think that such a vicious act must have been done by one of "those people"? One possible conclusion from the stories in *Unequal Justice?* is that, just as people with disabilities are increasingly being taught to be cautious around (and, thus, to fear) "strangers", perhaps it is worth considering similar teaching about the trustworthiness of the police. But this idea is one that occurred to me. It's in the nature of a "solution", and that's not what Robert Perske offers. He offers a flashlight.

And, what about confessions? The cases described in *Unequal Justice?* share a pattern. A crime is committed. Police find and arrest someone with mental retardation. Under police interrogation, the person arrested confesses to the crime. No evidence other than the confession seems to be offered at the trial. The defendant is convicted--quickly--and is sentenced to a long imprisonment or, often, to death. These stories force us to consider whether statements such as these confessions--statements that lead to such drastic results as life-imprisonment or death--should be capable of being regarded as evidence of guilt. I wondered whether there ought to be a prohibition of the use, as evidence, of confessions obtained from a person with mental retardation without a defense lawyer present. But, again, that's my solution-seeking, not Perske's. He tells his stories, shines his light; and, though he cannot always conceal (nor should he) that he is aghast at the sight, he just shows us what's there.

What's there, as well, is at least one story that warms us. One community, Munnsville, in upstate New York, also felt "something within" when one of its members stood accused of murdering his brother. The story of the trial of Adelbert Ward follows the pattern of many of the other cases with one difference. Mr. Ward was well-known to others in his community, and, despite the vigorous action of police and prosecutors, the community would not believe that he was guilty. The community raised funds for his bond and for his defense. Adelbert Ward was acquitted and went back to live on the farm with his other brothers. This may have been made possible by Munnsville's recognition of him--as a person and as one of "their own." Perhaps Munnsville can serve as an example for other places, including the place where I live.

Unequal Justice? will be a surprise for readers who pick it up expecting similarities to Robert Perske's other books. This is not *Hope for the Families*, although families of people with disabilities should eventually read it. It isn't about *New Life in the Neighborhood*, although it would be a good addition to a neighborhood library. It certainly isn't *Circles of Friends*. Here, the subjects of Perske's reporting are encircled, but (except for the instance of Adelbert Ward) the circlers are hardly friends. Maybe it should have been called "Circles of Enemies", but that isn't a very good title. Actually, the title is just right. It's a book that raises questions, a book that should start conversations, discussions, and even arguments. OHIO SAFEGUARDS bought five copies when the book was published, and we've given most of them to public libraries. I've also thought about getting copies for our local Public Defender and for the nearby police departments and prosecutors' offices. Others should consider similar plans.

Maybe sometime in the near future, Bob Perske will find an opportunity to tell these and other stories to legislators. Through this book (and possibly others to come) he has already done something more important. He's started to enlighten some dark corners for the rest of us.

Jack Pealer

THANKS VERY MUCH!

During 1991, OHIO SAFEGUARDS received contributions in support of *The Safeguards Letter* from the following individuals:

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Alan Tyne, Colchester, England
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Our thanks to one and all!

THE CHANGES THAT ARE NEEDED FOR PEOPLE TO "GET HOME".

John Winnenberg

I have recently read John O'Brien & Connie Lyle O' Brien's fittingly titled monographs *More Than Just a New Address: Images of Organization for Supported Living* and *Down Stairs That Are Never Your Own*. (Both of these are available from Responsive Systems Associates, 58 Willowick Drive, Lithonia, GA 30038.) I am particularly struck by how far we in North America have come during the past decade in figuring out ways to support people with developmental disabilities to make secure and satisfying homes for themselves in our communities.

Any celebration of progress about this, though, has to be similar to acknowledging the first blades of grass that pop through on a barren piece of strip-mined hillside, the history and future potential of which are to support a forest of century-old hardwoods and a rich variety of wildlife and fauna. It will take generations to reclaim what we suppose to be a natural order. I am sobered by visions of thousands of people trapped behind the doors of "facilities" and controlled by others' wishes, practices, needs and conveniences. These visions are the current reality as we attempt to redefine our culture's response to people who are more reliant on others for help than most.

With the O'Briens' work as a helpful background and having the opportunity to be a part of efforts in my home community to assist people to establish places of their own, I have begun to jot down a simple list that describes for me the successful shift from facility-based to "person-centered" community residential supports. I offer this list with the hope that others might add to it as they learn from their efforts. I also offer it in the conviction that, of all the things it will take to see growing numbers of people with developmental disabilities and those closest to them enjoy life in the midst of our culture, some (if not all, in glorious instances) must and will be done without the efforts of paid services.

Change For People with Disabilities:

- From living in facilities (someone else's home or business) with people you have little choice about . . . to living with people you choose in a place that you can call your own.

- From a situation where you must earn independence in living situations and lifestyle . . . to a situation where your abilities have little to do with your right to make a home that is your own, focused on the choices, needs and desires of you and the people you choose to live with.

- From moving from place to place to get "service" as your needs change. . . to establishing a home and then having "service schemes" change as your needs for assistance change.

- From living in the place owned by someone else, whose idea of what kind of home you want to live in must conform to a wide range of people . . . to owning the furniture you sit and sleep on and choosing a style that fits your taste, age and personality--and if you aren't aware of those subtleties of living, at least having people around you who know you well enough to make the best judgement possible about those sort of things.

- From living in a place where administrators control everything from the menu to the Christmas celebrations . . . to sharing and controlling decisions with the people you choose to live with and have assist you.

- From your life being defined by your deficits and people trying to fix them through a variety of treatment and therapies within the context of your home . . . to being offered the support you need to make a home for yourself, having friends, meeting financial needs, establishing a self-identity and learning within the context of your home.

Change for Organizations

- From services driven by funding sources, rules & regulations, and current fads in the human service world . . . to support based on an individual's plans, dreams and desires--one person at a time.

- From firmly set administrative policies and procedures telling people (workers and residents) how to act in a facility . . . to firmly held principles about the choice, integrity, and inclusion of the individual complemented by flexible policies and procedures that encourage support and back-up to a person's desires and plans.

- From an organizational environment of predictability and uniformity . . . to an environment of managing constant change (and often chaos).

- From organizations driven by top-down management . . . to organizations where power is invested in the person with disabilities, those who assist them daily and others who are close to them (family, friends, etc.)

- From an organizational culture where workers constantly turn over and don't get personally involved . . . to organizations where many workers grow close to individuals and commit significant portions of their life to their assistance.

- From organizations isolated from community life unless soliciting charitable contributions . . . to organizations who are *of* the local community fabric with a consciousness about their efforts representing people with disabilities as valued citizens who live as individuals inclusively in the community.

- From organizations where crisis and error create isolation, fear and blaming . . . to situations where error and crisis are seen as opportunities to learn and grow.

Change for Families & People Who Are Close To People with Disabilities

- From being on the outside looking in . . . to sharing a vision of the future with the person you care about and participating in carrying out that vision with them and with paid assistants when necessary.

- From a perception of being in the way of treatment . . . to participating meaningfully in a person's life.

- From turning over responsibility to professionals . . . to sharing responsibility.

- From attending celebrations and traditions in the person's life . . . to in many instances being the reason for such celebrations while at other times helping to plan and carry them out.

Change For Citizens

- From turning over responsibilities to institutions and facilities . . . to expecting to include people with differences in families, workplaces, neighborhoods, churches, associations and other forms of community life--sometimes with inconvenient and/or expensive accommodation required

John Winnenberg

A VIEW FROM CHILLICOTHE "Of Costs and Benefits" Jack R. Pealer, Jr.

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 <u>do well</u> what an organization intends or hopes to do. Effectiveness is about the relationship between aims and achievement. *Efficiency*, says Korten, comes <u>later</u>; 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

The Safeguards Letter

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IDEAS TOWARD RENEWAL

A Series of Workshops from OHIO SAFEGUARDS

During the autumn and winter of 1992-1993, OHIO SAFEGUARDS is planning a series of educational events (workshops) that are directed at people who want to take roles as leaders in the change or renewal of organized human services. Traditionally, OHIO SAFEGUARDS' events focus on "ideas". This focus is based upon the belief that it is the ideas (values) that citizens and communities hold about people who are helped by human services that have the greatest amount of influence on what human services do and how they do those things. Human service organizations carry within them all of the conscious or (mostly) unconscious values or attitudes of the culture of which they are a part.

We have, therefore, dubbed this series of events: "Ideas Toward Renewal". Those who take part in any of these workshops should not expect quick fixes to problems. Instead, they should expect to wrestle with the powerful ideas that lie behind contemporary human services and, through that process, to begin finding out where to search for both personal and organizational renewal.

The workshops are all separate events. The brief descriptions below include information about the dates, locations, and costs of each event. For more complete descriptions and details, please contact OHIO SAFEGUARDS, at P.O. Box 1943, Chillicothe, OH 45601 (614/773-6191).

Learning from the History of Human Services--November 16 & 17, 1992.

This first pair of workshops offers a look into the history of human services, particularly services for people with mental retardation or other developmental disabilities. We are working with ARC/Cuyahoga County and Irene Ward & Associates to present a unique learning opportunity in Cleveland. Dr. Wolf Wolfensberger and his associate Susan Thomas will offer two separate but related workshops about the history of human services in general and developments in the field of disability in particular.

Monday, November 16. Not everyone likes the study of history, but everyone is affected by history. This "everyone" includes people who are connected to human services--those who use services, those who provide them, those who manage them, and those who are concerned about the expenditure of tax money to support services. On November 16 Dr. Wolfensberger and Ms. Thomas will present a survey of the history of human services in the western world. The full title of this workshop is *"A One-Day Presentation on the History of Human Services, with Emphasis on the Origins of Some of our Major Contemporary Service Patterns, & Some Universal Lessons for the Planning & Structuring of Our Services which can be Learned from this History."* The presentation features several hundred slides that Dr. Wolfensberger has taken or accumulated over the last 30 years. The information presented and the insight to be gained through this workshop is probably unavailable through any other forum. Dr. Wolfensberger's description of the workshop notes:

"The material presented has relevance to every human service worker, from those on the direct clinical level to those at the highest planning levels. This includes service professionals and non-professionals, clinicians, advocates, volunteers, administrators, planners, theorists, and analysts. Attendance at the presentation can help anyone gain a better understanding of the service challenges that they are up against, some of the dangers that lurk everywhere, and what sorts of service patterns to strive for."

Tuesday, November 17. Dr. Wolfensberger and Ms. Thomas will spend November 17 offering *"Reflections on Human Service Developments since the 1950's: What is Still the Same, What has Gotten Better, What has Gotten Worse, and What Lies Ahead"*. From Dr. Wolfensberger's more than 30 years of experience as a participant, leader, and critic of human services, he will trace service developments from the abysmal conditions that prevailed prior to the reforms that started in the 1950's, up to the present day. This presentation:

- explains the ideas that gave rise to the deplorable pre-1950's conditions and that, in part, still linger today;

- inventories the major positive changes that have taken place in services since then, as well as some of the things that have NOT changed (or that may actually have gotten worse); and

- explains some of the overarching challenges that Dr. Wolfensberger perceives to lie ahead to confront people with disabilities and their allies in the future.

On three occasions during the day there will be a panel of other people from northeastern Ohio with long experiences in human services who will respond to the various parts of the presentation.

Both of these events will be held at **Executive Caterers at Landerhaven, 6111 Landerhaven Drive, Mayfield Heights, OH 44124**. Executive Caterers is near the Cedar Road exit from Interstate 271, in Cleveland's eastern suburbs. The **registration fee** for the events: **$50.00** (including lunch) for each day, or **$95.00** (including lunch) for both days. Those who are interested can contact OHIO SAFEGUARDS (614/773-6191) or ARC/Cuyahoga County (216/621-4504) for further information or a registration flyer.

Learning How Values Affect Services Now--November 29--December 4, 1992.

OHIO SAFEGUARDS will offer its next presentation of "*An Introduction to the Role of Values in Human Services, through the Use of PASS 3.*" This workshop, which has been offered regularly in Ohio by OHIO SAFEGUARDS for several years, has been scheduled to take place between Sunday, November 29 and Friday, December 4, 1992 at the **Holiday Inn in Chillicothe, Ohio**. Complete details about the workshop will be announced in flyers issued by OHIO SAFEGUARDS. The registration fee for the workshop is expected to be in the range of $200-$250 per person, not including lodging and meals.

The title of the workshop describes both its intent and its main emphasis. Those who come to the workshop can expect to be immersed in readings, lectures, discussions, and a practicum visit to a human service agency. All of these activities focus on helping participants learn how the values and beliefs of both human-service agencies and of the culture in which we live shape the assistance people who are in need receive. Those values have, as a consequence, powerful influence on the kinds of lives that people in need are enabled to live. Most participants in past PASS 3 workshops have found them enriching, stimulating, and (yes!) all-consuming. Some people count their first PASS workshop as a high point in their careers.

Registration for the workshop can be accomplished using the form that will accompany the descriptive flyer. Those interested in attending are urged to register as quickly as possible following receipt of the flyer, because only 25 participants will be enrolled. If you want to be sure to get a flyer, please contact OHIO SAFEGUARDS.

Thinking Together about Future Service Renewal--January 25-27, 1993

The ninth annual January workshop sponsored by OHIO SAFEGUARDS will be *Design for Accomplishment: A Workshop about Planning*, with John O'Brien of Responsive Systems Associates, Atlanta, GA. This event will take place Monday, January 25 through Wednesday, January 27, 1993, at the Fawcett Center for Tomorrow (OSU), 2400 Olentangy River Road, Columbus, OH 43210. The registration fee for the workshop will be $200.00.

This event is intended for anyone who is involved in or concerned about making plans for how organizations or communities must change so that people with disabilities can be enabled to live richer lives. The workshop's design allows those who attend (people are encouraged to come in groups, representing their communities) to search together for better ways to organize "human service resources" in their own communities. Participants at previous workshops of this kind have included: members of families of people with disabilities, administrators of both state and local organizations, Board members of both public and private agencies, and staff members who offer direct help to people with disabilities (e.g., in finding or keeping jobs, in acquiring or maintaining a home, etc.). This event offers planners (or those interested in the plans that get made) a unique opportunity both to hear about exciting ideas that may affect their organizations or communities and to work together with others at devising ways to apply those ideas "back home".

This workshop has been previously offered in Columbus in 1986, 1987, and 1988, and in Canton in 1990. For more information, or to ensure receipt of a flyer about the workshop, contact OHIO SAFEGUARDS.

BEING YOU AND ME

Nancy Ray

I have put off telling this story for too long. One very snowy weekend at Deer Creek State Lodge changed three young boys' lives forever--not to mention the lives of all the adults who were privileged to be a part of the magical weekend.

Because it was a time of work and fun, the boys were actually brought along to entertain each other. None of us were prepared for the rest. They came together in the most natural of ways, over dinner and introductions and polite conversation. "Gabe, this is Eric. Eric, this is Gabe." "How old are you? Do you like swimming?" "Gabe's ten; he swims like a fish. Would you like to join him after dinner?"

Eric seemed very timid about the water, especially the deep end. Every time Gabe got close, Eric felt compelled to inform me. I let him know that Gabe was a very good swimmer and actually preferred the deeper water. Eric seemed pretty amazed by that and took to keeping a closer eye on Gabe, not out of concern this time, but out of total wonderment.

It wasn't until Saturday afternoon that I learned of Eric's near drowning incident just the year before. No wonder he was so cautious and so concerned about Gabe. As I watched the two play, it seemed that Eric had a plan in mind. A pattern emerged from their parallel play. Gabe would swim up from time to time and allow a game of catch for a few minutes. Eric would follow Gabe across the rope to the deep end and swim from rope to ladder. I'll never forget the determined looks on both their faces. They were both working very hard.

By dinner of the second day, the boys were fast friends. They both wore smiling faces as they sought places together at the same table. They shared special toys, after the meal and during the speaker's talk. A bond had been made that only young boys make.

Now for Brian. Because of the bad weather, Brian did not arrive until just before dinner Saturday night. All through dinner everyone watching could see he couldn't take his eyes off the two guys his age at the other table. Because of a busy schedule, hasty introductions were made. "Brian, this is Eric, and this is Gabe." "Gabe, Eric, this is Brian."

By breakfast on Sunday, Brian was visibly straining to spend time with the other two boys. He had mentioned to his mom what a cool dresser he thought Gabe was. Finally, the three met up and spent the snowy morning sharing toys and food and fun.

This story is only remarkable if you know that Gabe is a child with autism and does very little communicating verbally. Eric is a kid who was afraid of the water and who has epilepsy. Now Brian I'm not totally sure about. Mainly he has eleven-year-oldism, which means he doesn't really care about autism and epilepsy. He thought Gabe was a cool dresser, a cool dude. He thought Eric was a great guy. He had a good time hanging out.

When it was time to go, Eric was announcing how Gabe had taught him how to swim. Gabe was looking both Brian and Eric in the eye and smiling a lot. And Brian had made some new friends.

This story was so long in the telling for me because I can't get past the pain of this thing called friendship not happening every day for Gabe. It really wasn't magic at all. It was three guys being allowed to be: being themselves, being cool, being eleven, being afraid. Given the God-given right to be "just friends." My mind still screams: "Why can't that happen every day?" In school it happens for millions of children all the time. Unless, of course, you have a label and you have to go to special classrooms with other special kids, with special teachers who know special things. It's so special that this education never happens next to kids who don't really care about labels or disabilities, but who care about just being a kid.

My pain is not just for my son. It is also for all the Erics who will never be allowed to know guys like Gabe, who won't be allowed to learn from his abilities. It's for all the Brians who won't be allowed to just hang out and be cool and be a friend just because you want to and you can.

Nancy Ray
Columbus, Ohio

About THE SAFEGUARDS LETTER

The Safeguards Letter is a quarterly (approximately) 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, P.O. Box 1943, Chillicothe, Ohio 45601. We welcome our readers' ideas and reactions.

JUST QUOTES

The laws of the state (Vermont) are designed with classroom attendance in mind, and public-school administrators see their schools as nonprofit eleemosynary institutions which have pupils in custody, not as enterprises accomplishing productive tasks.

Frank Bryan & John McClaughry
The Vermont Papers

The power of the public school to coerce, especially in matters of morals, is of course well recognized. It is one of the reasons why religious training is barred from such schools. For the same reason, I believe that the public school is the last place, not the first, for a psychiatric service.

Thomas Szasz
Ideology and Insanity

BRIEF REVIEW: *The Vermont Papers: Recreating Democracy on a Human Scale*, by Frank Bryan and John McClaughry (Post Mills, Vermont: Chelsea Green Publishing Company, 1989)

If you're interested in the role of government in making the lives of citizens better, this is a book for you. If you've read *Small Is Beautiful* and it set your brain on fire, *The Vermont Papers* is likely to fan the flames. Frank Bryan is a teacher (political science) at the University of Vermont and John McClaughry has been a Vermont state senator. What they've written is a strategic plan--they'd hate the term, and I use it advisedly--about how to "recreate democracy" and reconstitute civic and political life in a particular place. In essence, the guiding strategy that they propose is one that would shift civic authority downward (from the level of the nation and the state) and outward (to units of local governance that are of reasonable size and composition). As they put it:

> This is a book about how Vermont can save its democracy and in so doing demonstrate how the rest of America might learn to recreate its own. It calls for radical change--the most complete restructuring of an American state in two hundred years. Democracy is too precious, and the

> forces aligned against it too powerful, for timid measures. In the words of Ernest Callenbach, "If democracy is such a good idea, the time has come to try it." It is and we shall. We take democracy seriously. (p. 5)

Bryan and McClaughry propose reconstituting Vermont--a state with a population of fewer than 600,000 people (about half the size of Franklin County, Ohio) --as a state that is made up of autonomous units of local government called "shires". Each shire would be made up of one or more towns (currently the most important local government units in New England). Shires would be developed on the basis of geography, local history and tradition, and citizen choice. Nearly all of the current functions of state government would become the responsibility of the shires, and *The Vermont Papers* offers ideas and images about how this radical shift would affect: public finance/taxation, public education, public assistance for people who are poor and/or who have been disadvantaged, land-use, and agriculture.

In my imagination, the ideals described in *The Vermont Papers* can be generalized to other places. Overall, Bryan and McClaughry advocate the development of a polity and mode of governance that: a) appeals to local or regional history and tradition--in Vermont this is the heritage of English patterns (hence the word "shire") and of Vermont's own "Green Mountain Boys"; b) places both the responsibility and the authority for most public functions at the local level; and c) enables citizens to have direct participation in civic life, holding such participation up as a major responsibility of each member of the community. It seems to me that these ideals transfer to any place in the western world. Some of the particulars in Bryan and McClaughry's design for Vermont seem unworkable in places where population is denser (like many Ohio counties) or where local identity or a sense of belongingness is less available as a resource. But this is part of the authors' point. They're writing for Vermont; it would be up to folks in those other places, with other kinds of problems and other traditions, to figure out how democracy would best be structured for them.

The Vermont Papers is valuable because, following in the tradition of E.F. Schumacher, Kirkpatrick Sale (*Human Scale*), and Leopold Kohr (*The Breakdown of Nations*), it offers images of how small-scale thinking might actually work--to help public institutions be more effective and to help a democratic vision to survive.

Jack Pealer

OHIO SAFEGUARDS Library: A Complete Listing, as of September 1, 1992

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Olsen, Tillie. Yonnondio From the Thirties. (1974).

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"Paulo Freire at Highlander Center, December 5, 1987." (videotape).

*Pearpoint, Jack. From Behind the Piano. (1990)

Peavey, Fran. Heart Politics. (1986).

*Perske, Robert. Unequal Justice? (What Can Happen When Persons with Retardation or Other Developmental Disabilities Encounter the Criminal Justice System) (1991).

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*Schwartz, David. Crossing the River: Creating a Conceptual Revolution in Community and Disability. (1992).

Shelley, Hugh and Mary Lou. Love is Two Plastic Straws. (1985).

Vanier, Jean. Man and Woman He Made Them. (1985).

"Walking on Air." (videotape)

*Wetherow, David (ed.). The Whole Community Catalog (Welcoming People with Disabilities into the Heart of Community Life). (1992)

Wyman, David S. The Abandonment of the Jews: America and the Holocaust, 1941-1945. (1984).

* = new acquisition since last listing (March, 1991)

Requests to borrow books or other materials should be sent to OHIO SAFEGUARDS, P.O. Box 1943, Chillicothe, Ohio 45601. You may also phone (614) 773-6191. We'll ask you to pay return postage costs.

THE COMMUNITY LIVING PAPER PUBLISHED

In 1983 the Ohio Developmental Disabilities Planning Council published a series of informational papers called the "Deinstitutionalization Papers". These Papers (the "DI Papers") presented and discussed ideas to guide decisions made by the variety of agencies in Ohio that developed and operated programs in response to the situations of people with developmental disabilities. The DI Papers were widely distributed, well read, and generally helpful to a continuing public deliberation about the quality of services to people with developmental disabilities in Ohio. Nearly ten years later, the Ohio Developmental Disabilities Planning Council decided to publish another informational paper so that there can be another discussion of service quality and current service practice. This new paper, written by OHIO SAFEGUARDS, is called *The Community Living Paper*. It is now available for consideration both by those who are directly interested in people with developmental disabilities and by others who have a stake in improving the lives of all citizens of their communities.

Although there has been much change, since 1983, in the ideas that describe what good supports for people with developmental disabilities might be, Ohioans with such disabilities still find themselves caught up in patterns of response to their needs that are dominated by professionalized human services. Ohio's state institutions are smaller now, but they are still operating and, in the process, consuming a huge share of the state's investment for trying to help people with developmental disabilities. The county-based service system organized around Boards of MR/DD and the affiliates of those Boards has grown dramatically, both in the variety of services and supports offered to people and in the amount of public funds expended to pay for those efforts. Some of this growth has meant vastly enriched lives for some people with developmental disabilities. There have been enough examples of change for some children, adults and families to offer hope that larger-scale improvements for even more people could be on the way. Most people with developmental disabilities in Ohio, though, still do without much of the richness that could be available to them in community life. They are still poor, still undereducated, and still isolated from their neighbors and fellow citizens.

This pattern of experience of Ohio's citizens with developmental disabilities and their allies parallels, in important ways, the situation faced by many other citizens today. Increasingly, ordinary citizens feel that their incomes are threatened. Citizens are worried that the education their children receive will be insufficient preparation for the future. Many citizens sense that they are cut off from their fellow community members and that they and their neighbors may be powerless to affect the public and civic institutions that have such great impact on their daily lives. Over the last 40 years, the customary answer to the questions posed by such feelings has been "growth". Economic growth would promote income security. And, important for the discussion in *The Community Living Paper*, growth in the scope and array of professional services in arenas such as public education and public services for people with disabilities would alleviate all of the problems that people experience. Such problems were often attributed to the existence of "gaps" in the comprehensive scheme of services.

Now Ohio and the nation are poised at a time when the traditional answer of growth is at least temporarily unavailable. This "temporary" situation could, of course, last longer than experts expect. At the same time, the expectations of people with developmental disabilities and their families and other allies have not declined. Nor should they. Like other citizens with other concerns, people with developmental disabilities hope for lives filled with accomplishment. They both need and want high-quality personal assistance, much of which will have to be paid for and some of which must come from well-trained professionals. They have, however, been promised and, therefore, reasonably expect a voice in designing and overseeing the help that they need.

Robert Bellah and his associates argue that the crisis of confidence in such public services as schools, courts, and services for people with disabilities must be regarded as a civic and moral issue--not a technical problem susceptible to professional problem-solving. Bellah suggests that there is a need for renewal of "a serious public conversation…to strengthen the institutions" that support democratic life in our communities. (Bellah, Robert, et al. *The Good Society*, p. 293.) *The Community Living Paper* proposes that a big part of a way out of the tension between rising expectations on the one hand and difficulties associated with reliance on "growth" on the other lies in increased listening to the voices of people with developmental disabilities and their allies. This listening must be followed by flexible rearrangements in the ways that both human service organizations and communities respond to people's voices, so that people with developmental disabilities have more control over what kinds of help they get, and when and how they get that assistance.

Listening to people who have for so long been voiceless and, therefore, powerless will be a new thing for both communities and human service organizations. If human services and communities do listen to people with developmental disabilities and their allies and then, act on what they hear, there will be great change in both the experience of service agencies and in the life of communities. It is impossible to predict exactly what will happen. *The Community Living Paper* is, however, an attempt both to argue for a greater effort to hear what people with developmental disabilities have to say and to point in some of the directions in which a serious public conversation might lead.

Readers who want a copy of *The Community Living Paper* should send $3.00 (to cover the cost of postage) to OHIO SAFEGUARDS.

SUMMER WENT SO QUICKLY

Sandra Landis

The calendar says that it is the last week of summer, and for the first time in years I don't want summer to end. I want to stretch it into October, then go to the beach and walk in the sand and sun. Some of my enthusiasm for summer this year has to do with the weather. At home we had hot days and cool nights, and very few sweltering combinations of high temperatures and high humidity. I went to sleep listening to the creature symphony going on outside, no fan to distort the sounds of the night. On vacation in the northwest, many rooms had no screens. Depending on the day I could listen to, and smell and see the rain or the sun or the wind. I could even sit on the windowsill and dangle my legs in the night.

It's been a summer of celebrations, some planned and some unexpected. I'd say that the afternoon with the whales was the best spontaneous event! It was the first time I'd been on the water next to Orcas. Two pods met and socialized for a couple hours and revealed themselves quite splendidly. Some twenty or more Orcas offered a vivid, wonderful image of camaraderie and confidence that will stay with me for a long time.

Another, more personal image of camaraderie happened when we celebrated a birthday. These summer months were the last in a year of celebrating the end of a childhood. Our traditional rite of passage, so to speak, involves the creation of a photo album. It is the last of the gifts given at the end of a long childhood, made possible by the love of many people. We celebrated and welcomed Gregg to the expanding camaraderie of community and family life that comes with symbolic sanction of official adulthood--his 21st birthday. He brings a generous spirit, a contributing nature and a hopeful attitude. Our tradition of preserving and protecting the gift of childhood is both affirmed and strengthened by his presence with us now.

Perhaps a part of wanting the summer to last a little longer is the hope of maintaining the sense of clarity and comfort I experienced when I went and visited with my grandmother, shortly after her 94th birthday. A series of accidents and maladies have meant that Gram has lived in a hospital or extended care place for the past year. For most of that time her physical world has been very limited. As her vision diminishes and her mobility is determined by others, even the places she spends most of her time in are virtually anonymous.

I learned, again, that if one's world is limited and essentially controlled by others, it's often the way that the very small things happen that makes for good, or not so good, living.

The Jersey tomatoes were ripe when I was there, and a big one was sitting on Gram's bedside table the day I arrived. We sliced it up when the lunch tray came, and sprinkled a little sugar on it-just the way she likes it. Gram ate mostly tomatoes for lunch that day and talked about the farmer's market she'd bought produce in forty years age. After lunch we wrote some letters to old friends from back home. She kept me pretty busy, just being around to notice and do the little things in the right way. I felt very grateful to my parents, and brothers and sisters-in-laws, and ex-mother-in-law, and nieces and nephew and church members, and friends and neighbors who stand in for me when I am so far away.

I was a little worried before I went to visit; people had told me that Gram seemed confused. I feared that she might be distressed or lonesome. A year in hospitals must be a very long time. Gram is not unused to pain and the idea of death does not trouble her, but she had had great impatience with undue dependency and being away from home. She greeted me with a smile, a sigh, and a "Oh, I am so happy you are finally here."

She is a peaceful woman. Gram explained to me that she is a guest here, that anyone who needs a place can stay. She empathized with the cooks: how difficult it must be to feed so many guests, so often. She asked, at every meal, whether all the guests had enough and had been served before she began her meal. Sometimes there seemed to be many diners, sometimes just a few.

Gram has explained many times, to my parents, that sometimes little children are cold and want to be warmed up, and so she lets them crawl into bed. Sometimes they have kept her awake. And sometimes, when they leave before she wakes, she looks for them and calls after them.

My week went by very quickly; it had been a fine visit. I left, comforted that Gram feels safe in the company of her thoughts. She is living patiently, and in some respects quite energetically, yet is confined in a small, anonymous space. Her memory and experience with others offer her activity that comfort and sustain her now. She lives now, as she always has, as both a guest and a host.

I would like to keep that idea clear in my mind. It seems to fit with the other images of camaraderie that have emerged this summer. Seems like a summer's worth; but then, I won't know for sure till I get to the beach.

Sandra Landis

A VIEW FROM CHILLICOTHE "Inclusion" and School Reform Jack Pealer

I should acknowledge right away that the topic I'm writing about is one that deserves more thought--and more space in print--than I will give it here. Maybe there will be a chance for me to join a more extended conversation about these issues; then that conversation can result in a more thoughtful treatment of them.

For seventeen years now I have believed in and, to some extent, worked to advance the personal social integration of students who have disabilities with other children of similar ages in the public schools. Before 1975, when I went to my first PASS workshop, I didn't know that such a thing might be possible. I was instrumental in the construction of a segregated (for retarded children only) school in the

Ohio county where I worked. Also, I've often told how, when I was young, I learned to be afraid of children who couldn't hear--I think because I lived close to the separate "School for the Deaf" and because I didn't go to school with (and, thus, didn't get to know) any kids who couldn't hear. Now, though, I favor integration--or inclusion, as what I have understood as personal social integration has more recently begun to be called.

It's reasonable to ask why. Do I favor inclusion of children with disabilities in public school buildings and classrooms because they're such great places to be? I do NOT. I remember lots of things about being in school; a good many of them are not pleasant. I have shared my life with a public school teacher for quite a few years; her daily and yearly experience is both grim (at times) and exhausting. No, the schools are not great. There is an enormous amount of room for improvement in the way we teach our children. Why would anyone want kids with disabilities to spend their days and years in these not-great places? Because these places have something that can't be found anywhere else. I want kids with disabilities to go to public schools because, so far, **that's where the other children are**. I'm a member of an organization called S.A.F.E.--Schools Are For Everyone. I think schools are for everyone, or at least they ought to be.

And what's going on in these schools-for-everyone these days? "Reform." School reform is a hot topic on radio talk shows, in universities, and in the newsletters of Chambers of Commerce. It's often mentioned on the so-called "campaign trail". Something about school reform is in the newspaper just about every day. I want to mention just two items from our local newspaper, within the past week, that have to do with "improving" schools.

ITEM: (Chillicothe *Gazette*, September 19, 1992) Chris Whittle, owner of Whittle Communications--a $213 million-dollar-a-year company that sells, among other things, TV commercials in public schools--has started "the Edison Project, a $2.5 billion plan to construct a national system of for-profit schools." The project has attracted the support of the former president of Yale, Dr. Benno Schmidt, who quit Yale to work as the project's chief executive officer. Mr. Whittle describes the difference between schools he proposes and public schools as mostly a matter of process: "The real revolution will be in *how* students are taught, not *what*." The article about Mr. Whittle does not specify how teaching would be different in his schools. Tuition for these schools will be around $5,500 per year, with enough funds being raised by the investors to provide full scholarships for one student in five.

There are lots of questions that have been and could be asked about Mr. Whittle's idea and its potential execution. Right now, I have only one. Will the student bodies of Edison Project schools include (in buildings and classrooms) children with severe disabilities? The newspaper article doesn't say.

ITEM: (Chillicothe *Gazette*, September 17 & 18, 1992) The Superintendent of the Chillicothe City Schools introduced his "dream" to the Board of Education and to about 300 citizens gathered for the school board meeting on September 16. His dream is about the "Chillicothe Academy for Primary Students" (yes, there's already an acronym--CAPS--and a logo for it). This academy would be in a set-aside elementary school building in Chillicothe. Students who attend would be ages 5-8 and would be those who are judged to be "at risk of educational failure." The Superintendent believes that "…improvement in education has to start among elementary children" because "…by the time they reach high school problems that started early are much harder to solve because students' self-concepts have been ruined by continued failure." The academy would feature low teacher-student ratios (no more than 22 kids per classroom, plus lots of volunteers and aides), flexible but challenging school hours including year-round operation, uniforms for students and maybe for teachers, lots of use of computers, and provision of counseling and social services for students' families. Of the State of Ohio Superintendent of Public Instruction, who attended the meeting, it was noted by the newspaper that he "seemed thrilled" by the idea.

There are a lot of questions that could be asked about this dream (and, believe me, they're already being asked). Right now, I have two. Is it expected that the Chillicothe Academy for Primary Students will include, as part of its student body, children with severe disabilities? Will children with severe disabilities still have the opportunity to go to school with students who are NOT judged to be "at risk of educational failure"?

These are only two of thousands of ideas that are floating around about how to change the way we educate our children. My point is this: those of us who are interested in inclusion are, mostly, committed to it because we understand that both children with disabilities and children without have a great deal to gain from contact/association with each other. We want, as I noted above, kids with disabilities in public schools because that's where all of the other kids are--the ones who don't have so much trouble learning to talk or play or learn where Afghanistan is. So far, that's where we'll find the assemblage of kids who mirror our communities, and we want all kids to learn about living in community together. And some of the ideas about school reform, including both of the ones our newspaper recently described, threaten the schools' role as reflections of our communities. Some of these ideas would remove from the neighborhood public schools some of the children with whom students with disabilities most need to be. If we're not careful, we could find ourselves in the nightmare of achieving "inclusion" for students with disabilities but finding that it is inclusion in a public school system that's been gutted of the other students who might have been the best role models.

I think that inclusion is terribly important. It's not, however, the only educational issue that's before the society. Those of us who care a lot about children with disabilities have to be able to see our advocacy of inclusion as a <u>part</u> of what needs to be changed about public education. As well, however, we have to pay close attention to and take part in developing and critiquing other ideas about changes in schools. Otherwise, we run the risk of turning our support for inclusion into an effort that, by default, succeeds in robbing children of opportunities once again.

Jack Pealer

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DESIGN FOR ACCOMPLISHMENT WORKSHOP

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This event is intended for anyone who is involved in or concerned about making plans for how organizations or communities must change so that people with disabilities can be enabled to live richer lives. The workshop's design allows those who attend (people are encouraged to come in groups, representing their communities) to search together for better ways to organize "human service resources" in their own communities. Participants at previous workshops of this kind have included: members of families of people with disabilities, administrators of both state and local organizations, Board members of both public and private agencies, and staff members who offer direct help to people with disabilities (e.g., in finding or keeping jobs, in acquiring or maintaining a home, etc.). This event offers planners (or those interested in the plans that get made) a unique opportunity both to hear about exciting ideas that may affect their organizations or communities and to work together with others at devising ways to apply those ideas "back home".

This workshop has been previously offered in Columbus in 1986, 1987, and 1988, and in Canton in 1990. For more information, or to ensure receipt of a flyer about the workshop, contact OHIO SAFEGUARDS.

ABOUT KNOWLEDGE Alan Tyne

You can, if you wish, believe in "The Truth". Whether individuals really have any choice in the matter of belief is hard to say. We often speak of being "drawn" or "driven" to belief, and that's probably a genuine reflection of our feelings. Many observers suggest the social groups and organisations we adhere to affect the formation of our beliefs--churches, for instance, or "the Academic Community", or political parties often seem to provide a basis for belief in "The Truth". Whether we have choice, belief seems to reflect decisions made to act as if certain things were so. Some decisions we make clearly, some contrarywise, on some we dither, prevaricate, and hold simultaneous and conflicting positions. Thus is the basis of our belief.

You can believe, too, that "The Truth" is organised in what by good fortune, seems to us--Western, 20th century men and women--as a sensible way. Often this is portrayed neatly as a hierarchy, or a kind of tree, but drawn upside down so the big ideas are at the top, and the little ones lower down. Believing that truth is organised like this is again a decision, if not a choice.

The decision that you personally have access to "The Truth" is another belief. In varying degrees, it may reflect arrogance, or simply a current stage in a struggle to comprehend better a small but accessible slice of the universe. To be convinced unswervingly, with no doubts at all, that you have identified clearly the main trunk and branches and have a clear sense of where the many smaller bits go, is probably arrogance. Our paths through life teach us we may each have some good fortune in identifying the twiggy bits near to us, checking them against accumulated experience and that of our friends--those we've come (by whatever process) to respect. We sometimes have a little success too, at spotting some of the connections between things--or, at least, what *seem* like connections…here…now. But the chances that any one of us, or even a decent sized group, might gain access to the whole thing, or that the connections we see here, now, might be all there is to see--these chances really do seem quite small.

Nevertheless, you can if you want discount the probabilities, and lay claim to "Authority". Like the climbers on the mountain, you may choose to pin your own personal flag (or that of the group you adhere to or who helped you the most) there. The outcomes will probably depend a lot on who recognizes your flag.

You may believe instead in truth (No Capitals), and that belief comes in several kinds. One has it that truth consists of the little bit of "The Truth" that we personally in our hazy, incomplete and faulty (that is to say, "human") way have managed to comprehend so far. A second has it that there may or may not be "Truth", and that we will likely never know, for sure. Our quest for understanding will always be bounded by human frailty and will always lead us to be dealing at best, with truth, rather than The Truth. A third belief has it that there is definitely no Truth--and that seems to be about as arrogant as the claim to Authority.

If you are in the business of dealing with truth (of whichever kind), rather than Truth, images of the hierarchical organisation of knowledge are more likely to be seen as simply helpful devices we've invented to help calm our panics when confronted by what seems (honestly) like chaotic information. Knowledge and truth are more likely to be depicted as irregular, unclear, almost certainly untidy and profoundly inconvenient. If the debility that goes with belief in The Truth is likely to be arrogance--claiming an authority not rightfully yours--then the debility that goes with belief in truth is likely to be irresponsibility--denial of any sense or meaning in things, the relativity of everything, the ascendancy of style and transitory fads, the futility of commitment--and so on.

Whilst it's likely none of us will avoid a life full of error, it's probably best for us and others if we work at avoiding error, nonetheless. With effort and some luck, we may avoid excesses both of arrogance and irresponsibility. At the same time, we may aspire to some of the virtues of both beliefs--staunchness and fixity of purpose on the one hand, a willingness to tolerate uncertainty and chaos on the other.

We work in wide and disparate fields, linked by some shared visions and purpose, connected through friendship, locality, networks and associations, formal organisation. As individuals and groups, we make our tracks using the maps of belief we've decided (or are still trying to decide) on. In our discourse with one another the natural scope for rivalry, competition, mean pettiness and other human frailty is often compounded by accidental inaccuracy, failures of understanding, thoughts poorly expressed and communicated.

We can, though, work to avoid some of these, not just for our own ease, but for the sake of the vision and the purpose we *do* share--that those we serve be better served.

- To say, for instance, that someone "Does not tell The Truth", may make a limited kind of sense to people who can see the Capital T's. But it may confuse people who only deal in the truth. People who can see that may think the confusion was on purpose. Thus grows distrust, and a little more elbowroom for mean pettiness to creep in.

- To speak of a "denial of Authority" may make a little sense (again, capital letters and theories of knowledge permitting), but only within the field of discourse bounded and acknowledged by belief in The Truth. Among humble seekers of the truth, it spreads confusion. Seeing that, we may think it was purposefully done; distrust will do its corrosive work.

- To be disdainful of the teaching and learning that grows out of day-to-day struggle with the chaos, irrationality and cupidity of the human service system may encourage more people to keep their hands clean in the Pursuit of Truth. The flight from engagement with practical action and all its awful compromise leaves much truth undiscovered. To characterize all such work, even by default, as irresponsible, is arrogance indeed.

In our sharing of vision and purpose we can afford disagreement (even about the nature of disagreement), but we cannot afford disrespect. We've come to our different decisions about truth or Truth often enough for good and sufficient reasons. It is time to welcome, celebrate, clarify and *respect* the differences, I think.

Alan Tyne
Colchester, England

THANKS VERY MUCH!

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Our thanks to one and all!

SOCIAL ROLE VALORIZATION WORKSHOPS IN INDIANA

The **Indiana Safeguards Initiative** (OHIO SAFEGUARDS' western kin) announces a schedule of workshops that will take place during the spring of 1993. There will be three 3-day introductory workshops on **Social Role Valorization** that will review in depth many of the critical issues concerning th provision of quality human services including public attitudes and community acceptance, physical and social integration, and personal service supports. These workshops will be conducted in a reflective format that allows for much individual and group reflection on devaluation and social role valorization. They are designed to facilitate introspection regarding the manifestations of devaluation and how to address it on a personal, community, agency, ang societal level. The workshops will be led by Darcy Miller Elks of Syracuse, NY and Joe Osburn from the Indiana Safeguards Initiative. These introductory workshops will take place:

March 15-17, 1993, in New Albany, IN
March 19-21, 1993, in Mitchell, IN
May 10-12, 1993 in Indianapolis (Beech Grove)

A five-day workshop on PASSING--a method for evaluating the quality of human services according to social role valorization- derived criteria--will be held in Indianapolis (Beech Grove) between May 31 and June 4, 1993. Persons intending to go to the PASSING workshop must have attended one of the earlier workshops (or equivalent training) as a prerequisite.

For more information about any of these events, contact the Indiana Safeguards Initiative at 2421 Willowbrook Parkway, Indianapolis, IN 46205; phone (317) 254-2065.

REVIEW: *Crossing the River: Creating a Conceptual Revolution in Community and Disability*, by David Schwartz, et al. (Brookline Books, 1992)

On several occasions in my life, after completing a certain book, I can recall saying, either to myself or to others, "I wish I had written that." I'm sure I said it at the end of Wendell Berry's *A Place on Earth*; I think it every time I finish *Lord of the Rings*. That's pure wishful thinking, though. I could never have written either of those favorites, both because I suspect I lack the talent for fiction and because my experience of life has been very different from Berry's or Tolkien's. Of *Crossing the River*, however, I am able not only to say "I wish…"; I can also say "I might have…." What I mean by that is that David Schwartz and his colleagues have written about the field and the period that covers my own professional experience. As I read, I sometimes wondered whether the authors had been involved in some conversations in which I remember taking part. Then I remembered: probably they were. They just had the good sense to write things down, and *Crossing the River* is the helpful result.

As its subtitle indicates, *Crossing the River* is an examination of a major shift (Schwartz calls it a "sea change") in ideas about people with disabilities and what may help them toward full membership in community life. The book relies on an idea borrowed from Thomas Kuhn's *The Structure of Scientific Revolutions*--the concept of the "paradigm shift". Kuhn's book is about how change occurs in the formal sciences, and his carefully wrought terminology cannot be transferred directly into other fields. Schwartz, however, uses the notion of "paradigm shift" metaphorically and, thus, offers a helpful image of the kind of change of which he wishes to speak.

David Schwartz was actively involved (as was I) in the rapid development of "community services" for people with mental retardation/developmental disabilities that were intended to replace and supersede the old-style institutions during the 1970's and early 1980's. He describes the disillusion that accompanied the reluctant discovery that what he (and I) worked so hard for was not "the answer". Schwartz' characterization of the current situation of service-systems for people with developmental disabilities is that the field is weighed down by five issues, which he further describes as "symptoms of … change at work within the field." These are:

1) Widespread abuse and neglect of people with disabilities within the "community services" that were supposed to be better than the institutions that they replaced. This is coupled with administration of psychotropic drugs to people with developmental disabilities at rates that are often higher than the rates in institutions. As Schwartz comments, these things were just not supposed to happen in "community services".

2) A staff "retention and recruitment" crisis. This is not just an issue of high "turnover" rates, although those rates are certainly unacceptably high. Schwartz also examines the meaning of "turnover" from the point-of-view of the people who receive "service"; if the "essence of service" is in the relationship between those who are helping and those who are to be helped, what does staff turnover mean for the quality of the lives of people with disabilities? Schwartz captures the gist of the crisis when he characterizes it as "…a managerial description of settings in which those with the economic freedom to leave consistently do so."

3) Isolation of people with developmental disabilities from community life. Schwartz speculates, for example, that, were there an instrument that--from the sky--tracked the movement of people in and out of a setting but that ignored the presence of professional workers, that instrument would show the homes of many people with developmental disabilities standing by themselves--far away from other people.

4) An increasing clinicalization of the field. The author notices, for example, that the work of assisting people with developmental disabilities has come to be seen as "a field", when that was not true in earlier times. He observes:

> This new social movement ("deinstitutionalization") involved by design the creation of thousands of new settings. These settings, the group homes and fledgling agencies, formed the seeds of communities, called together by vision and opposition. They were, like most new settings from marriage to nations, forges of growth and personal transformation for all involved in them. It was a heady time in social reform.
>
> That heady time is now undeniably past. The new settings and the new "alternative" community system they collectively formed are now riddled with seemingly intractable problems. Task forces on finance, on abuse, on staff recruitment and retention meet urgently. Remedial actions are proposed. Yet underneath such actions lies a sense that the breakdown of our precious new settings is proceeding so rapidly that our efforts, redoubled though they might be, are insufficient and in vain….

5) The "retarding effects" of the service system itself on the lives of those who find themselves reliant on it. People with developmental disabilities are, observes Schwartz, diverted from richer lives by the chronically low expectations of them that are held by "community services". He offers as example the not-uncommon retention of the best-producing workers by sheltered workshops so that contract-quotas can be met.

In the context of a field bedeviled by these five issues, Schwartz and his colleagues A.J. Hildebrand and Sharon Gretz describe and offer vignettes of what they call "a new conceptual revolution". Consciously borrowing from the work of Seymour Sarason and John McKnight (as well as Kuhn), Schwartz proposes (in my words, not his) that "community services" may be an oxymoron. What Sarason calls "the psychological sense of community"--a sense of being a part of things--is unlikely to occur in the context of professionally-managed, bureaucratic systems. The revolution described begins, in small ways, to make real the vision of people with disabilities as citizens and community members. The major example of "revolution" offered in *Crossing the River* is that of a series of projects undertaken in Pennsylvania under the auspices of the Developmental Disabilities Planning Council (of which David Schwartz is the Executive Director). From the Council's point-of-view, the objectives of these projects were: to encourage and legitimize the development of "anomalies"--new ways of doing things; and, to seek diversity of responses to diverse people in diverse places within the state. In essence, according to Schwartz, the projects were intended to try to answer the question: "Would ordinary citizens invite people with disabilities into their families, their communities, and their associational life, if one asked them in the right way? What was the right way to ask?"

When I had finished reading *Crossing the River*, just a few months ago, I had also (along with my friends and colleagues Sandra Landis and John Winnenberg) completed the publication-draft of *The Community Living Paper* for the Ohio DD Planning Council. I remember speaking to Sandy and John about David Schwartz's book--not so much to say "I wish I had…". Instead, my comments leaned a bit toward "…we might have…", but even more in the direction of "I'm glad we read this after we were finished with ours". Otherwise, I might have been discouraged from going on with our work. Why bother, when someone else has done this so well? I congratulate David Schwartz and his colleagues for their accurate description of where we are in this business of trying to help people with disabilities and where, if we work very hard, we may be going. I advise my friends to read *Crossing the River*.

Jack Pealer

THE GARDEN CLUB MUSE

Sandra Landis

This Christmas marks the tenth one here. Only one other time have I spent nine years in the same neighborhood. That was a long time ago, in the place I did much of my growing up. My folks made the decision to move. I recall very little reluctance on my part. We were moving to the shore; I was fifteen, and it all seemed rather exciting to me.

Nearly twenty-five years later, the move to this place began with a couple of invitations from friends. Staying here has been a matter of love, determination, and in some ways, self-preservation. There haven't been many thoughts about leaving, and most of those are dreams about extended vacations, not resettling. Living my future in the place where I've been is a new experience for me.

In the past my ideas about the future have focused mostly on relationships with specific people and work opportunities. As I think about the future now, my thoughts are pretty clearly connected to this place as well. I don't think that I came here with the idea that this would be home for as long as I could imagine, but sometime in the last few years that has happened.

There is a sense of calm and quiet that comes from understanding that change in me. I know that for many years I wondered if feeling "rooted" in a place, like I belonged to a place, was something that I would ever experience. I frequently felt transplanted but not purposefully settled into a place where I would stay. I found the logic of Myles Horton's "bloom where you're planted" idea painfully clear, sound advice. What do you do when it seems you've been planted in a dozen different plots? Just as there are things you learn from living in a variety of places, there are some things you never have a chance to learn if you're not around a place for an extended period of life.

I had a chance to think about all of this a couple of weeks ago, on a blustery day that threatened lots of snow. Despite the weather, four of us were on the way to the winter garden club meeting. Our meeting was outside of the county, at a specialty shop where we would listen to a short talk about winter greens and make a wreath to take home. The travel time passed quickly as I listened to three longtime residents tell stories about people they've known and events they shared in common. It was a bit of a history lesson for me, especially because some stories were about the ridge and valley I live on now.

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

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

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

This season I can finally accept and celebrate my lot as a transplant. I'm grateful I've landed in welcoming territory with sturdy, well-rooted neighbors. And I'm glad to have discovered that there is a place in membership for the listener.

Sandra Landis

BRIEF NOTICE: *You Can't Say You Can't Play*, by Vivian Gussin Paley (Cambridge, MA: Harvard University Press, 1992)

How is the habit of rejection of other people acquired? How is it that people select some other people to be specifically excluded from taking part in games and, by extension, community life? Are there ways to prevent such habits from being acquired by people when they are young? *You Can't Say You Can't Play* is an exploration about such questions by Vivian Gussin Paley, a MacArthur fellow and a kindergarten teacher in the University of Chicago Laboratory Schools.

Ms. Paley introduced a new rule into her kindergarten classroom--a rule designed around the precept that "We must be told, when we are young, what rules to live by. The grown-ups must tell the children… so that myth and morality proclaim the same message while the children are still listening." The rule is: "you can't say you can't play." Rejection of others from playtime (and, later, from acting out parts in stories) is explicitly forbidden. But the introduction of the rule is prepared for by lengthy conversations--debate might be the better word--involving not only the kindergarten students but children in the higher grades as well. Ms. Paley relates the feelings and judgments of the students, both before and after the introduction of the rule, about her attempt to legislate moral behavior. She intersperses these dialogues and her reactions to them with the stories she told her students about Magpie, the magical bird who helps both children and adults learn to accept and care for each other.

You Can't Say You Can't Play looks deceivingly like a "children's book". It has, probably like the best books for children, a tough message: the exclusion or rejection of others is NOT the natural order of things. Rejection is a habit, and, like other habits it can be attacked and broken. Determined, sensitive teachers and other helpers can help children (and maybe older people too?) learn to live in communities that welcome all their members.

Jack Pealer

JUST QUOTES

I believe
That we walk pigmies where we should stand tall
As old Promethean giants, that the power
Of sharing in creative energy
Is written in the fibers of our being.
It does begin to seem as if the answers
Are not all in, as if the explanations
Based upon science and psychology
Remain inadequate. It seems our dreaming
May well excell our waking, that our hopes
Of being and belonging may be nearer
Reality that all our dismal fears.
In fact, the final truth could well be greater
Than our best expectation--we might be
Destined to pass all limitation, break
All bounds of space and time, and where the stars
Are sown like snowdrops in a mountain meadow,
We may walk finally as sons of light.

George Dell, from
"A Sermon in Pentameters", 1961

There is an old Amish quiltmaker who lives near Pfeifer's Station, a crossroads store and village I often frequent. Her immediate family is long gone, and she lives now with somewhat distant relatives who, being nearest of kin, are pledged to care for her. Her quarters are a wee bit of a house connected to the main house by a covered walkway. I make up excuses to visit, pretending to be interested in quilts. I have no idea how old she is, other than ancient.

Around her I feel the kind of otherworldly peace I used to feel around nuns before they decided to dress up and hustle about like the rest of us. Her bedroom is just big enough for a bed and quilting frame; her kitchen is equally tiny. The boys of the family keep the walkway stacked with firewood for her stove. She has her own little garden. Children play on her doorstep.

She has her privacy but is surrounded by living love, not the dutiful professionalism of the old folks' home. And she still earns her way. Quilt buyers come, adding to her waiting list more quilts than her fingers, now slowed by arthritis, can ever catch up with. I love that scene. She still lives in the real world. If she were not Amish, she would have languished in some nursing home and no doubt be dead by now--from sheer boredom if nothing else.

from Gene Logsdon, "Amish Economics"
reprinted in *Community Service Newsletter*, September/October, 1992

A VIEW FROM CHILLICOTHE "French Potatoes and Medicaid Waivers" Jack Pealer

During this past summer I got to ride along on another bus trip through France and England. On the last day that we spent in Normandy, at about 5:00 in the afternoon (rush hour), our bus was approaching St. Malo--the walled seacoast city from which Jacques Cartier launched his explorations of North America in the 17th century. The bus suddenly stopped and took its position in a long line of traffic. When we had moved forward to the next "rotary" we could see something spilled on the roadway. It was a huge pile of **potatoes**. Highway crews with heavy equipment were loading potatoes into dump trucks, to be hauled away. But there was more than one heap. Local potato farmers had brought their produce to the city--not to sell it in the market but to dump it on the roadways at key intersections. We were caught in a protest over a government proposal to reduce farm subsidies. We witnessed what might have been a scheme devised by Alinsky; the Norman farmers might well have read *Reveille for Radicals*.

France has traditionally valued small-scale farming, and this value has, for a long time, been translated into government policies that subsidize growers of vegetables, livestock, grain, etc. The value runs deep, as Louis Bromfield observed:

> The permanence, the continuity of France was not born of weariness and economic defeat, but was a living thing, anchored to the soil, to the very earth itself. Any French peasant, any French workingman with his little plot of ground and his modest home and wages, which by American standards were small, had more permanence, more solidity, more security, than the American workingman or white-collar worker who received, according to French standards, fabulous wages, who rented the home he lived in and was perpetually in debt for his car, his radio, his washing machine.
>
> Sitting there it occurred to me that the high standard of living in America was an illusion, based upon credit and the installment plan, which threw a man and his family into the street and on public relief the moment his factory closed, and he lost his job. It seemed to me that real continuity, real love of one's country, real permanence had to do not with mechanical inventions and high wages but with the earth and man's love of the soil upon which he lived. *(Pleasant Valley)*

The potatoes on the road spoke of the clash between that value--for small farms, personal engagement with the soil--and other values that may sometimes be obscured by such rally-around-able slogans as "free trade". Without the subsidies, the small agriculture of France may be unable to be sustained. Apparently, according to Wendell Berry and others, this is largely true of North American small farming as well (see Berry's "Our Tobacco Problem" in *The Progressive*, May 1992). Thus, something of great value--personal attention to the earth and the growing of food or other goods on it--will be lost. In its place will be what can only be called "collective", impersonal farming that is carried out either by desperate small owners in fief to their bankers or by employees of large agricultural (or agri-business) corporations. Despite my wish to be able to continue drinking French wine occasionally (remember the U.S. government's threatened tariff in early December?), I'm on the side of the potato-dumpers. It makes little sense to me to transform small-scale enterprises that people willingly give their lives to into gigantisms that people must (sometimes) be forced to work for. It makes less sense that we may choose to do this through the mechanism of an international control structure (the GATT court) that is outside of our electoral influence. Tea, anyone?

What I'm mostly quibbling about, though, is the continuing pattern of exchanging small things for large ones--giving up patterns that may be known for ones that are beyond our capacity to understand. Four or five years ago, the state of Ohio started a new way (for state government, anyway) of trying to help people with developmental disabilities find and maintain homes. This new way, which was based on ideas already in practice in places like Madison, WI, Attleboro, MA, and New Lexington, Tiffin, and Wooster, OH was called "supported living". The state had a notion about small-scale and low overhead ways to enable people to have homes of their own--homes of their choice and under their control. These homes would, in a sense, be like French farms--small, personal, and (eventually) beloved.

Then, several things happened, and as they happened valuable possibilities began to be lost. First, the supported living notion began (as it had to, at the time) with money that was a windfall, which meant that the funds to support the program had to be found afresh during the next budget cycle. Second, though the fresh money was found, naught but "continuation" of supported living could be paid for; there was no way to expand this simple idea for other people using state funds. Third, no source of money (other than that for "supported living") was available to be used to help people with disabilities who were in serious trouble (so-called "crises") in Ohio communities. These developments hampered the achievement toward which supported living aimed.

And then the Federal government came to the rescue with the "Medicaid waiver". Imagine, spend a dollar helping someone with disabilities (in an approved way) and you'll get sixty cents back from Washington. Fill out all the papers and assemble all the "packets" in a form that fits requirements that are devised by people you'll never meet--that's the only way that you'll be able to help more people (saying nothing, of course, about the likely raised cost of each "service" that's paid for in this way). It just seems to me that there's an analogy of some sort between what's happened to supported living and what's happened to the French farmers. Follow the experts and buy more land, buy more and bigger tractors; to do a better job, buy more clerks and more powerful computers to handle the paperwork.

And that's saddening. And dangerous. There just has to be room in the world for French potato growers, who love where they are and what they do. There must be a low-tech, low-overhead way to support people with disabilities in homes that they choose and that they can come to love. I'm with the potato-growers. I long for the preservation of supported living in its original form.

Jack Pealer

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A SEASON OF CHANGES

Anyone who has tried to call the OHIO SAFEGUARDS telephone number lately has probably been told by a recorded voice that the number is "no longer in service." Things have been changing for us, and the discontinuation of our office telephone is only one of the signs. Six years ago, we began the first of two projects for the Ohio Developmental Disabilities Council. At that time, we had a phone installed in the office in Jack's house in Chillicothe. That's the number that many of you have dialed over the last few years. We said, in 1987, that we would keep the phone as long as we had some way to pay for it. But now our time as "grants-persons" have come to at least a temporary end. Hence, no more phone!

You can still reach OHIO SAFEGUARDS though. You can write to us at our P.O. Box (#1943) in Chillicothe, or you can call Jack, Sandy, or John directly. The numbers are:

Sandra Landis, President, (614) 347-4126
John Winnenberg, Vice-Pres., (614) 767-2213
Jack Pealer, Secretary-Treasurer, (614) 773-3360

Obviously, we're still busy--publishing *The Letter and* planning for various events to be held later in 1993 or early 1994. OHIO SAFEGUARDS has not changed its mission. It's just that the lives of its three officers have changed over the past few months. There are two articles in this issue of *The Letter* that describe those changes--"Stir It Up" by Sandy and "A View from Chillicothe" by Jack. We're doing different things with much of our time now, but we're still here and still devoted to the same aims that have guided us since we started.

We'd love to hear from readers about these changes. It's just that you can't call us at an office any longer.

PASSING WORKSHOP IN INDIANA

This is just a reminder of our earlier announcement that the Indiana Safeguards Initiative in Indianapolis has scheduled a PASSING ("Program Analysis of Service Systems' Implementation of Normalization Goals") Workshop this spring. The workshop will take place at the Beech Grove Benedictine Center in Beech Grove, IN (a suburb of Indianapolis) from Monday, May 24 through Friday, May 28. These dates are different from dates earlier announced. Those who are interested in participation in the PASSING workshop should directly contact the Indiana Safeguards Initiative at (317) 254-2065.

JUST A QUOTE

It is true, as Romain Rolland said, that literature is useless against reality while being a great consolation to the individual. But it is increasingly clear that the fate of the universe will come to depend more and more on individuals as the bungling of bureaucracy permeates every corner of our existence.

Books are the Grail for what is deepest, more mysterious and least expressible within ourselves. They are our soul's skeleton. If we were to forget that it would prefigure how false and feelingless we could become.

Edna O'Brien, in
"It's a Bad Time Out There for Emotion"
New York Times Book Review, 2/14/93

ON THE NECESSITY OF PORCHES AND THE RECOVERY OF THE PUBLIC VOICE

Mark B. Lapping

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Dialogue has long been recognized as among the most vital elements in the fabric of the democratic process. Nowhere is this a more cherished part of the past reality and folklore of governance than in rural and small-town America. The "town meeting," once part of the structure of many small-town political processes, and a favorite institution of Jefferson, is often seen as the quintessential forum for American public dialogue. It is the arena wherein people come together as a community to debate some of the most essential issues of the day.

Despite its tendency to be romanticized, "town meeting" remains for some a functioning "public voice" where matters as diverse as the efficacy of the Gulf War, declaring a community a nuclear free-zone or establishing a sister city relationship with a Polish town, are as likely to be topics of debate as school finances, road maintenance and stray animal control. Of course, in many places the power of "town meeting" has faded, come under the control and manipulation of the bureaucratic necessities of other levels of government or has proven itself "inadequate" for one reason or another. But even in some of these communities town meeting survives as a metaphor for and the memory of democratic self-rule and the manner in which issues ought to be aired and decisions made.

As a popular institution the town meeting is, as two Vermont commentators have recently noted, "central to the aspirations of every true democrat. Town meeting government asserts the fundamental wisdom of the common person, sanctifies openness, abhors secrecy, holds the human spirit in the highest esteem and is grounded in a fundamental trust that the truth will out in any free debate of citizens assembled."[1]

Many demands from both the "right" and the "left" for the restructuring of civic culture are, essentially, calls for the recreation of the institution--both of an appropriate nature and scale--which can encourage and sustain the quality of dialogue traditionally ascribed to the town meeting.[2]

But town meetings are not enough. We continue to search for additional venues, opportunities and symbols for community discourse and governance. Again working from our agrarian and small town heritage, let me offer another notion that, in a very fundamental way, America needs more "porches," as essayists John Baskin and Garrison Keillor have suggested.[3] Both have identified the porch as the "room and situation" for a kind of neighboring, a place of discussion and for the contact we crave and which democratic culture desperately requires if it is to be sustained.

Writing during the early 1980s Baskin said that "I have long been convinced that any of mankind's problems could be properly brought to bay on a good porch. I even spent an hour the other night scanning the papers for facts about where the president and Mr. Brezhnev were going to sign their arms limitation treaty. When I read the treaty would be signed in Vienna at the Hapsburg Dynasty's Imperial Palace, I spent another hour trying to remember if such a place had any porches." A good and serviceable porch, he continues, "should have railings, so everybody could put their feet up. The feet need to be up during a good problem-solving, as this takes away purchase for bellicosity."

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[1] Frank Bryan and John McClaughry, *The Vermont Papers: Recreating Democracy on a Human Scale*, Post Mills, Vermont: Chelsea Green Publishing, 1989, pp. 53-54.

[2] Kirkpatrick Sale, *Human Scale*, New York: Coward, McCann and Goeghegan, 1980

[3] John Baskin, *In Praise of Practical Fertilizer: Scenes From Chester Township*, New York: W.W. Norton, 1982, pp. 93-95; Garrison Keillor, *We Are Still Married: Stories and Letters*, New York: Viking, 1989, pp. 142-145.

For Garrison Keillor porches came in a number of varieties and designs. "Of useful porches there are many sorts, including the verandah, the breezeway, the back porch, front porch, stoop and now the sun deck, though the verandah is grander than a porch need be, and the sun deck is useful only if you happen to like sun. A useful porch may be large or not, but ordinarily it is defended by screens or large shrubbery. You should be able to walk naked onto a porch and feel only a slight thrill of adventure. It is comfortable, furnished with old stuff. You should be able to spill your coffee anywhere without a trace of remorse." Further, "the porch promotes grace and comfort. It promotes a good conversation simply by virtue of the fact that on a porch there is no need for it. Look at the sorry bunch in the living room standing in little clumps and holding drinks and see how hard they work to keep up a steady dribble of talk. There, silence indicates boredom and unhappiness, and hosts are quick to detect silence and rush over to subdue it into speech. Now look ar our little bunch on the porch. Me and the missus float back and forth on the swing, Mark and Rhonda are collapsed at opposite ends of the couch, Marlene pursues her paperback novel in which an astounding event is about to occur, young Jeb sits at the table gluing struts on his Curtiss biplane. The cats lie on the floor listening to birdies, and I say, 'It's a heck of a deal, ain't it, a heck of a deal.' A golden creamy silence diffuses this happy scene, and only on a porch is it possible."

Porches can be, at one and the same time, intensely private and yet open and communal. Reynolds Price has pointed out that historically "in the slave-owning South and the Puritan-private North, it (the porch) served, for instance, as a vital transition between the uncontrolled out-of-doors and the cherished interior of the home."[4]

Even then, the porch was a middle place, one of connection between the individual and the communal. It was, in a real sense, a zone of connection between the private person and the public person. And, like the town meeting, not everyone is invited onto the porch, though what happens there is subject to a very high degree of visibility. Those who occupy a place on the porch tend to be those with some "membership" in a community, in one way or another.

This, too, is like the town meeting in that the right to speak and vote belongs to those who live within the town and have some form of membership and stewardship responsibility for it. Even governors and senators and perhaps the vice president, can attend and speak at town meetings but only upon invitation and with the concurrence of those to whom the meeting belongs. The parallels continue in that informality is cherished on the porch--it is a place which frustrates pomposity and the too well-turned-out--and one ought to be comfortable and at ease on one's porch or in one's own town. Moreover, town meeting is a rather idiosyncratic institution. It "generates variety, a propensity for doing things different ways, for doing things that were not expected to be done, and in some cases for doing nothing…."[5] Precisely. What an accurate definition of porch behavior and decorum!

In an age and time of growing frustration with public purpose and public process, we should seek to both repair and reinvigorate the public voice through a vigorous program which would see porches brought up to good repair (with some added on in existing communities where too few exist) and which would mandate lots of access for those who might traditionally have had difficulty in coming on board. If the hallmark of small-town life that gave birth to town meeting was that "good fences make for good neighbors," then more good conversation, less shouting, and perhaps a little more neighboring might be achieved by a good porch policy. And if one of government's jobs is to keep up the repair of porch railings and the provision of some good, cold, tart lemonade, then we might really have made a useful start on recovering a public voice.

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[4] Reynolds Price, "The Lost Room," in *Out on the Porch: An Evocation in Words and Pictures*, Chapel Hill, North Carolina: Algonquin Books, 1992, p. 1.

[5] Bryan and McClaughry, p. 54.

About *The Safeguards Letter*

The Safeguards Letter is a quarterly (approximately) 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*, P.O. Box 1943, Chillicothe, Ohio 45601. We welcome our readers' ideas and reactions.

STIR IT UP

Sandra Landis

The title of one of my favorite Bob Marley tunes conveys the spirit of this sequel to "Another Pot of Stone Soup" (in the Summer, 1991 *Safeguards Letter*). "Soup" was about the beginning of some work here at home, a kind of introduction. "Stir It Up" is the first brief chapter.

Before our first winter of work was over, the soup pot had gotten dangerously low and suffered from inattention more than a few times, but we kept it going. Two years have now passed. It feels like we've learned a great deal more than we've accomplished, and we seem to be in a period that calls for tenacity, analysis, adjustment, and vision all at the same time. It's a good thing that the days are now longer. It feels like we need all the daylight we can get.

What we decided to do was operate a local, not-for-profit development corporation in Southern Perry County, where we live. The first project would be in Shawnee, where we could substantially rehabilitate and assist in assuring the occupancy of several vacant Main St. buildings (buildings on the National Register of Historic Properties). This has introduced us to the world of preservationists and the accompanying bureaucracy. Thankfully, getting to know these buildings well has also meant that we've spent a fair amount of time listening to the stories of folks around here. We've met people we hadn't known before, and we're getting to know a lot of people much better. Working on these buildings seemed a modest step, but one that was big enough in scale to generate enough work to make the development and support costs feasible and visible enough to make a noticeable difference in the appearance and activity in the town. We thought the project would also last long enough that it would allow us to become "regulars" in the eyes of those whose help we will need to complete this project and create future work.

The next few months will tell the tale, so to speak. All of the paperwork has been done. All the required permits have been issued. 90% of the money has been secured. Local workers have been identified and materials have been ordered. Work begins this week!

We've set an ambitious schedule. The Grand Opening of the Southern Perry County Museum and Model Rail Exhibit in one rehabilitated commercial space is set for June 26th! (Everyone is welcome!) Two community groups are developing exhibits, planning and working on the rail exhibit, organizing the "Museum Shop", and recruiting people to host the museum and keep the coffee pot filled in the liars' corner.

The Perry County branch library in Shawnee will move up the street into its new, larger space in the newly rehabilitated commercial space in the Tecumseh Theater building in August. Two apartments will be available for lease in July. Two rehabilitated commercial spaces will be ready for occupancy or leasehold improvements by September 1.

There are lots of pressures and tensions. Will the corporate community invest with us and offer the final 10% we need? Will the 30 or so construction jobs pay off for local people? Will the budgets really hold, given our meagre contingency funds? Will the village council extend our scaffolding permit? Can we avoid injury and accident in the process of some scary work? Will the interim sewage system function? Will the mayor have a change of heart? Will we find two commercial tenants in six months? Will people keep the faith with us? Can we keep smiling and take time to celebrate? Will people respect the work and protect the investment, rather than vandalize it?

We understand that this work of development, regeneration, and community strengthening relies on others becoming engaged--investing with us, having a stake in decisions about success and sharing in its gifts. This work has introduced us to a part of the world and our community we knew little about the lending community and the world of finance. We knew that we needed "cheap money"--loans at very low interest and/or financial gifts. We also knew that we needed to acquire money in ways such that the long-term control of property and of what is defined as "successful occupancy" would reside locally. We needed local financial institutions to share the risk with us. We have finally negotiated $87,000 worth of loans at an acceptable interest rate with three local banks. At the same time, we found helping organizations that have "bought down" our rate while assuring lenders their usual rate of return. We have also received two grants, small cash contributions, and pledges of help from the business community.

The work of organizing and managing (which mainly means keeping a record of the work through minutes, reports, bookkeeping, conversations, and otherwise conveying information) is not new, but this context is different than we've experienced. Each of us has, in the past, put our energy and talent to work on behalf of someone else--in human services, it's on behalf of "those who rely on the service"; in architecture, it's on behalf of the client or owner or those commissioning the work. In this new (to us) context we're trying some things out. One is using consensus as a policy and strategy making process. We do this internally (among ourselves or with others whom we pay) and publicly (with our Board and other working groups). It's been interesting, and sometimes difficult. Consensus is a new way of operating for some of us. Conflict is not yet easily resolved. We understand that we have more to learn before that happens and that time together is part of the way we will learn.

We have relied a lot on the modeling/imitation method as we begin to take action in unfamiliar territory. We've looked for good models, and we've found some. Now we're starting to locate more good examples to study and to accept help from as we shape the specifics of successful work. When I think about ways of describing our organizing strategy, what seems most clear is that our focus has been: "What do we need?" And: "Whom shall we ask to help through active participation?" This focus has led to affiliations with: other individuals, voluntary associations, informal groups, not-for-profit corporations, quasi-public organizations, county and local governments, private lending institutions, large foundations and trusts, public utility companies, small and large businesses, "trade associations" and more.

Our idea, we think, has been a simple one. Create a project that reflects a variety of ways for community strengthening and enlist the help we need to do it well. Two years ago, there were three of us beginning this work. Now there are about thirty people locally and a dozen others further away who share the excitement and tension with us regularly. We've chosen a set of problems to deal with, found others who will help, and together have spent some time stirring things up. By summer's end we should have a pretty good idea about what kind of soup we've been stirring all this time.

If you have something you'd like to add to the pot--an idea, a suggestion, a word of hope, or anything else that occurs to you--please contact us: Sunday Creek Associates, Box 109, Shawnee, OH 43782, or (614) 394-1171. We don't have a perfected recipe to share, but we can share what we know about the ingredients that seem most helpful and that give the soup its character and nourishing value. To be continued…

Sandra Landis

JUST QUOTES

I also became aware (in pre-1964 Romania, ed.) that hidden everywhere among us were people feeding on forbidden books. To pick the secret readers out of the crowd became the great game. I studied strangers like maps to try to discover the surreptitious reader in them. Certain of their features seemed to mark them clearly: a certain turn of the mouth, a gaze that pointed inward. I shadowed my secret intellectuals in the street, listened in on them in coffeehouses. I was drunk with the feeling of being part of a secret society. The Cambodian Communists learned to read for "intellectuals" in much the same way in the 1970s. Everyone wearing eyeglasses was murdered. They thought that faces marked by reading, like hands marked by farm work, could be read at a glance. Woe unto the secret reader!

Andrei Codrescu, in *The Disappearance of the Outside*

… If there is a story in Mann Gulch (site of a fatal 1949 forest fire, ed.), it will take something of a storyteller at this date to find it, and it is not easy to imagine what impulses would lead him to search for it. He probably should be an old storyteller, at least old enough to know that the problem of identity is always a problem, not just a problem of youth, and even old enough to know that the nearest anyone can come to finding himself at any given age is to find a story that somehow tells him about himself.

Norman Maclean, in *Young Men and Fire*

25 YEARS OF NORMALIZATION!

OHIO SAFEGUARDS has received word that a major conference is being planned to celebrate the 25th anniversary of the first statement of the principle of normalization. This statement was the chapter entitled "The Normalization Principle and its Human Management Implications" by Bengt Nirje in Kugel and Wolfensberger's 1969 edition of *Changing Patterns in Residential Services for the Mentally Retarded*, published by the U.S. President's Committee on Mental Retardation.

The celebratory international conference bears the title: "Twenty-Five Years of Normalization, Social Role Valorization (SRV), and Social Integration: A Retrospective and Prospective View". It will take place in Ottawa, Ontario, Canada on **May 10-13, 1994**. The conference is being organized by Robert J. Flynn, Ph.D. of the School of Psychology of the University of Ottawa; Bob Flynn is well-known for (among other accomplishments) his research on the results and implications of both PASS and PASSING assessments. The purpose statement from the conference announcement notes:

> The year 1994 will be the 25th anniversary of the first systematic statement of the principle of normalization in the human service literature. In marking this event, the conference will provide an opportunity to analyze and assess what has become an internationally influential approach, including its social science foundations, past and present impact, and future contributions. In bringing together people from different countries, the conference is also intended to promote international collaboration in areas such as training, evaluation, research, and program and policy development.

The conference announcement also included a note about the possibility of submitting applications to conduct "poster sessions" at the conference. The deadline for such applications is November 1, 1993. Early registration for the conference itself may be advisable because no more than 275 registrants will be accepted, on account of space limitations at the conference site (The University of Ottawa). The registration fee is $150.00 Canadian (prior to Jan. 31, 1994) or $175.00 Canadian (after Feb. 1, 1994).

For complete information about this conference, contact:

Robert J. Flynn, Ph.D., "SRV" Conference
School of Psychology, University of Ottawa
11 Marie Curie (Vanier Hall, 6th Floor)
Ottawa, Ontario, Canada K1N 6N5
(613) 564-6875

As well, readers of *The Safeguards Letter* can contact OHIO SAFEGUARDS for copies of the preliminary conference announcement and registration form. This looks like it will be a once-in-a-generation event. We would not want anyone who wants to take part to miss the chance to do so.

A VIEW FROM CHILLICOTHE "Thanks, Mr. LaPointe"

John LaPointe died last week. That's not his real name. I thought about telling you his real name, but I decided that sometimes all of the fussing about "confidentiality" is right. It seems to me that it honors this man more if I don't reveal his name.

I don't know, for sure, how old Mr. LaPointe was. I'd guess that he was in his late 20's. I do know that he could not see, that most likely he could not hear very much, and that he had what we typically call profound mental retardation. He lived, when I met him and for the rest of his life, in a large nursing home, where he had a room of his own. Nurses gave him his meals, visited with him, and took care of some other things that he needed. A teacher from the local developmental services agency came to see him regularly--to talk to him, to see how things were going for him. The teacher tried in whatever ways she could think of to help Mr. LaPointe reach out to be a part of the larger world beyond his room and beyond the nursing home. It is no discredit to that teacher nor to others working to assist Mr. LaPointe that the "reaching out" that people hoped for didn't happen very much. They helped in ways they knew and, perhaps, tried some things that they hadn't known of before. But Mr. LaPointe challenged them with his sheer inability to do most of the things that we usually mean when we talk about someone's "potential" or "capacity".

I met Mr. LaPointe about a year-and-a-half ago. I was making the local arrangements for OHIO SAFEGUARDS' "Framework for Accomplishment" workshop (led by John O'Brien) in the community where Mr. LaPointe lived. One of the agencies that cooperated with the workshop was the "day activity center" for people with severe disabilities, and it was the director of that center who suggested that a workshop participant might meet Mr. LaPointe. After I met him, I had to decide whether spending time (quite a few hours) with Mr. LaPointe, who didn't speak and who moved very little, would be a useful experience for someone coming to the workshop. I thought that it would be. Then, I had to choose--to assign someone to go to meet Mr. LaPointe. I chose the most thoughtful and experienced person (at least as far as I knew) who had signed up for the workshop. She went, sat with Mr. LaPointe, talked to his helpers, and thought about him. She and I had several conversations during the week about how hard it was to think about "accomplishment" in connection with Mr. LaPointe. We didn't think it was impossible--just that it was hard.

Two weeks ago, John LaPointe caught a cold--probably not an unusual thing in a nursing home. The cold turned to pneumonia. And then he died.

Why am I telling you this? Partly because I remember John LaPointe and want others, too, to think about his life. But mostly, I'm telling this because I've taken a new job, and reflecting on John LaPointe's life is one thing I can do that, I think, will help me do this new job better. I've come back to the community where Mr. LaPointe lived to become the "Director of Case Management" for the developmental service agency--the Butler County (Ohio) Board of Mental Retardation and Developmental Disabilities. Most days you can now find me at my desk (phone 513/867-5913) attempting to figure out what "case management" means and how to support people who are trying to do it well. Despite my misgivings about organized human services (these have been reasonably well-chronicled in *The Safeguards Letter)* I have now come back to the heart of a large service agency. I've chosen to do this because I want the chance once again to test the hypothesis that commitment, reason, and will can shape complicated organizations so that they work more effectively to help people.

I've also taken this new job because there are people who need the organized help that human services try to offer. John LaPointe certainly did. He needed someone to help him eat, to help him stay clean, to take part in any sort of activity. He didn't, as far as I can tell, participate very much in the life of his community. To do so, he would have needed help that those around him apparently could not imagine. Is it possible for human services to imagine, then design, then actually offer forms of help that would have made Mr. LaPointe both look and feel like a citizen? I want to try to find out.

I don't think I'm rationalizing about this. (Readers can tell me what <u>they</u> think.) I know that organized human services have enormous weaknesses. Often the way we arrange things to try to help turns out to be harmful to people to whom our "help" has been directed. That's true in the community where I still live; it's true in the communities where I'm now working; it has been true in every community that I've ever visited. Still, all these communities have chosen--at least in part voluntarily--to respond to human needs by setting aside portions of their wealth in common (through taxes) to pay for organized help. The sum of the wealth that's devoted to trying to help some members of a community is quite large. It seems to me that this investment--to pick a voguish word--ought to be well used. It seems that services, in which people in need and citizens in general put some measure of trust, ought to work better than they do. So, I decided to once again try to puzzle out how that could happen in just one place.

And when I started, I again was reminded of John LaPointe. He challenged his community about what citizenship for all of its members means, and he challenged me about what might, for me, constitute useful work. Thanks, Mr. LaPointe.

Jack Pealer

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The Safeguards Letter

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HELLO AGAIN

As the country song goes: "Well, hello there! My, it's been a long time." We won't ask whether you've noticed that *The Letter* hasn't shown up for about a year; we'll just try to slip quietly back into your lives without making a fuss. As we mentioned the last time we wrote, there have been some changes in the lives of those who write and edit *The Letter*. That does not mean, though, that the aims of OHIO SAFEGUARDS have changed or that the purpose of the organization has come to fulfillment. Far from it. Living -- as Sandra Landis and John Winnenberg do--in a community that carries a reputation as "poor" offers continued incentive to try to raise hope for people for whom hope has sometimes been elusive. Hanging around a "case management" office--as Jack Pealer does--gives the daily lie to any notion that the "wounds of devalued people" are unusual occurrences. The mission that OHIO SAFEGUARDS set for itself almost ten years ago will remain sadly unaccomplished for a long time.

But some things about us have changed. The one that you may have noticed most is the place from which *The Letter* is being mailed. It is no longer coming to you from Chillicothe, for the good reason that the editor no longer lives there. *The Letter* now issues from the Hamilton, Ohio Post Office. And PLEASE NOTE that OHIO SAFEGUARDS' new mailing address is: **Post Office Box 18-181, Fairfield, OH 45018**.

Also, we're back to our old ways--no office and no phone. You can contact us best by mail, but if you must reach us more quickly, you can call Jack, Sandra, or John at the following numbers:

Jack -- (513) 887-7515
Sandra--(614) 347-4126
John--(614) 767-2213

It's good to be back. We'll try not to stay away so long the next time.

RON LAWRENCE

I'm sorry that I have to report that Ron Lawrence, a founder and trustee of OHIO SAFEGUARDS, died earlier this spring in Lexington, Kentucky. I met Ron at a PASS Workshop in Kentucky about fifteen years ago. He worked with Kentucky and Ohio agencies that serve people with disabilities and was devoted to seeking greater community membership for the people he tried to assist. He was especially interested in helping Christian congregations become more welcoming to people with disabilities. He extended this commitment in 1991 when he left a position in Columbus and joined the Christian Appalachian Project in Berea, Kentucky.

When OHIO SAFEGUARDS was founded in 1985 Ron agreed to help draft our "Statement of Mission", and it was Ron who insisted that a major part of the statement be: "…an acknowledgment of our unquestionably common need for celebrating the dignity of all human beings." Those are the words of Ron Lawrence. We will miss him.

CASE MANAGEMENT JOURNAL (I)

Edward Conlon wrote an article entitled "To the Potter's Field", which was published in the July 19, 1993, *New Yorker*. The article said, in part:

> Most New Yorkers are spoken for when they die: there is someone to hire an undertaker, to call friends, family, and clergy together to remember the life and observe the body's passage to mausoleum, grave, or urn. But many who die here are strangers to the city: the homeless, luckless, transient, and alone--people without friendships or connections, who cannot inspire memories after death, because they escaped notice when they were alive. Each year, approximately three thousand New Yorkers die unidentified, or without leaving information on next of kin. Their relatives may live in another country, or they may be unable, financially or emotionally, to lay claim to the body. In Manhattan, these dead are zippered into rubberized canvas bags and delivered by truck, with appropriate paperwork, to a morgue near Bellevue Hospital, on First Avenue and Thirtieth Street. In the lobby of that building, there is an inscription, in steel block capitals on rich brown marble, that reads, "TACEANT COLLOQUIA. EFFUGIAT RISUS. HIC LOCUS EST UBI MORS GAUDET SUCCURRERE VITAE." It means "Let conversation cease. Laughter, take flight. This place is where death delights to aid the living."

When someone's life is dominated by human services, every aspect of that life seems to be different--to be touched by the kinds of processes that human services invent and on which human services seem to thrive. One of those aspects connected to a person's life is the response from others to that person's death. Within the past few months, someone who was "on the caseload" at the place where we work died. Below, in edited and disguised form, are the social service notes that describe what happened after the man's death.

5/12/93, 1:20 p.m. Spoke with the office manager who said she got a call from Joan S. (nursing home social worker) at 10:00 a.m., informing us that William R. had died this morning. We are still unaware of how he died. The hospital officials said that the coroner hadn't been in yet and that they will let the nursing home know the cause of death. The office manager called the nursing home to ask them to call us when they find out.

5/12/93, 2:15 p.m. Called the workshop where William worked. The Program Manager there said that he had been sick for the past two weeks. The last time he came to work was 5/6/93.

5/12/93, 3:06 p.m. Telephone call from Mr. Barrett (from Barrett Funeral Home), who said he got a call from the nursing home stating that a funeral home in Cincinnati refused to take William, and asked if he could do it. Mr. Barrett said he could but that he needed to know whether William was to be buried or cremated. Mr. Barrett mentioned that cremation costs less. I told him I would call William's guardian.

5/12/93, 3:13 p.m. Called William's guardian-agency. His guardian was not in the office, but another staffer told me that guardianship ends at the time of death. She said that the nursing home, as William's representative-payee, is responsible for deciding about burial, etc. I left a message to have the guardian call me.

5/12/93, 3:25 p.m. Called the nursing home. Joan S. wasn't there. I spoke with the administrator, who was reluctant to do anything without talking to William's guardian.

5/12/93, 3:36 p.m. I called our agency's attorney. She wasn't in. I left a message.

5/12/93, 3:39 p.m. Telephoned Mr. Barrett of Barrett Funeral Home and told him I've left messages with William's guardian in two places and don't want him to do anything until after we've heard from the guardian. Mr. Barrett explained that the city would pay $500, Medicaid would pay $750, and William's burial account has $220. He needs someone to authorize the services, though.

5/12/93, 6:03 p.m. Spoke to Joan S. and explained what happened with the original funeral home in Cincinnati--they refused to take William for financial reasons and because they would have to come from Cincinnati to pick him up. Joan had called Mr. Barrett. He told Joan he found out the county didn't have any plots, and he hasn't been paid for previous Medicaid burials. I told her that I had spoken with him and there are some plots, though he does need to get authorization for services and for cremation.

5/13/93, 8:44 a.m. Telephoned William's guardian at the guardian-agency. She said that the nursing home is William's payee and that, legally, she cannot do anything, though she would call the funeral home (Barrett). She checked William's file and found that he is Protestant. She does not believe that there is a problem with cremation, but she's calling her supervisor to find out.

5/13/93, 9:23 a.m. Telephoned the Department of Social Services to find out who William's caseworker is. Was placed on hold for 10 minutes, then they asked me to call back in 10 minutes.

5/13/93, 9:45 a.m. Telephoned the Department of Social Services. No answer.

5/13/93, 10:18 a.m. Telephoned the Department of Social Services. William's caseworker is Patricia Scott. I called her number. It was busy.

5/13/93, 10:25 a.m. Telephoned the guardian. She said that the agency's attorney said that the guardian cannot sign anything. The guardian called Mr. Barrett and told him she couldn't do anything. Mr. Barrett said that someone needs to sign so that he can be reimbursed by Medicaid. The guardian said that it's up to the nursing home.

5/13/93, 11;10 a.m. Telephoned the Department of Social Services caseworker. I left her a message.

5/13/93, 11:40 a.m. Received a telephone call from the nursing home. I told them what the guardian had said. They said that their attorney told them they are not responsible. Finally, though, they did agree to call Mr. Barrett and sign papers to authorize cremation and for Mr. Barrett to be reimbursed by Medicaid for the service.

5/13/93, 12:01 p.m. Telephoned Mr. Barrett. He said he talked to the nursing home but said they need to speak with the guardian again and that they will call him back.

5/13/93, 1:21 p.m. Received a call from Mr. Barrett. He said he got a call from the Barkley Funeral Home, who said that the Wheatley Funeral Home in Cincinnati would be handling William's services.

5/13/93, 1:43 p.m. Telephoned the Wheatley Funeral Home and asked who contacted them. The woman who answered was not aware of who called. She said she would have someone contact me to report.

5/13/93, 1:46 p.m. Telephoned Janet Perkins, William's niece. She said that the nursing home called and gave the OK for cremation. Then she heard from the Wheatley Funeral Home who said that they were coming to make arrangements. She did not call them and doesn't know who did.

5/13/93, 1:53 p.m. Telephoned the guardian and explained the situation. She was quite upset and would rather have the arrangements with Barrett. She said that maybe the original funeral home in Cincinnati called Wheatley.

5/13/93, 2:03 p.m. Telephoned the original funeral home (Binder's). They said they spoke to someone at the Dept. of Social Services and to the nursing home and told both agencies to call a local funeral home. They did not call Wheatley.

5/13/93, 2:10 p.m. Telephoned the Dept. of Social Services (not William's caseworker but another staffer). She said she did not call Wheatley.

5/13/93, 3:00 p.m. Received a call from Wheatley Funeral Home. The director said that Janet Perkins (William's niece) had called them. I told him that she said that she had not called there. I said I would re-contact Ms. Perkins.

5/13/93, 3:22 p.m. Telephoned Ms. Perkins. She has since talked to Wheatley and told him that she wants Mr. Barrett to handle the funeral for William.

5/13/93, 3:40 p.m. Received a call from Mr. Barrett. He needs Ms. Perkins to send a fax authorizing cremation or to be somewhere where there's a fax to receive it.

5/13/93, 3:44 p.m. Telephoned Forest Cemetery (Georgene). I told her that Mr. Barrett asked me to call to say we would need their services. She said that $225 would have to be paid up front and that some paperwork would have to be completed to authorize the scattering of William's ashes.

5/13/93, 4:30 p.m. Telephoned Mr. Barrett. He said he called Ms. Perkins and she's trying to locate a fax. He'll let me know more in the morning.

5/14/93, 9:40 a.m. Telephoned the social worker at the nursing home. She said that Mr. Binder from Binder's Funeral Home called her and was angry that we had agreed to the plans with Mr. Barrett. I told her that all details are, as far as I know, all settled. The social worker reported to me the cause of William's death--a massive heart attack.

5/14/93, 1:16 p.m. Called Georgene at Forest Cemetery. I scheduled the services for 1:00 p.m. on May 19. Mr. Barrett will bring William's remains. I will need to call Janet Perkins to see whether she's coming and to sign forms for scattering ashes and to verify correct spelling of William's name.

5/14/93, 1:54 p.m. Called the nursing home social worker and told her that services for William will be at 1:00 p.m. on May 19 at Forest Cemetery. I asked her about a minister (Rev. Schwartz) she had mentioned. She will call him and call me back.

5/14/93, 2:58 p.m. Received a call from Rev. Nutter from St. Luke Methodist Church. He said Rev. Schwartz had called him because he (Rev. Schwartz) could not do the service. Rev. Nutter was willing to fill in.

5/14/93, 3:10 p.m. Telephoned Mr. Barrett and gave him all the information. He will be there at 1:00 on 5/19. He said the cremation cost was $735.

5/19/93, 1:00 p.m. Went to Forest Cemetery for William's funeral service. Many people were present, including people from the workshops where he worked and the social worker from the nursing home. A former instructor gave a eulogy, and another sang a song. Following the service, his remains were scattered in the scattering garden.

5/21/93, 2:25 p.m. Telephoned William's guardian to ask her whether she needed the certificate of cremation. She said that she did need it for the file. I will send her a copy.

Margie Fussinger
Jack Pealer

About THE SAFEGUARDS LETTER

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ETHICAL ISSUES IN PREVENTION AND TREATMENT

Paul Williams

(Paul Williams, a friend in Great Britain, was invited to give a talk at the Annual Conference of the British Institute of Mental Handicap, in Edinburgh, on September 15, 1992. In this and subsequent issues of The Safeguards Letter, we'll tell you what he said. Ed.)

When I was first asked to give this talk, it was under the title, "Community Action", but during recent years I have become more and more conscious that our views and actions in the areas of prevention and treatment of disability have a major bearing on our ability to welcome and include disabled people in our communities. It seems to me that many of our efforts to achieve inclusive communities are in conflict with some of the basic philosophy that appears to underlie modern trends in prevention and treatment. In a nutshell, concepts of community inclusion rest on the *valuing* of people with disabilities, while much prevention and treatment rests on denying that value.

I want to start by illustrating this in relation to Down's syndrome. I am sure that nearly all of us here will know and appreciate the positive achievements and qualities of many people with Down's syndrome. I will quote some examples. One question that it is important for us to consider is whether we think those people have these positive qualities *because* of their Down's syndrome or *despite* it. This may be a key difference between the valuing and the devaluing view.

Twenty-five years ago, what was probably the first book written by a person with Down's syndrome was published in Britain: *The World of Nigel Hunt*. Nigel typed his book himself on his portable typewriter. He has a fascinating way with words, and his book contains some genuine creativity of language and a subtle sense of humor and enjoyment of life. This extract describes an occasion when he travelled alone into London to see the Horse Guards' Parade.

> I sauntered to the Royal Mews and asked where Buckingham Palace is and the man said, "just keep to the left and you will come to it." I asked a man to take me across the road; then down the Mall to Horse Guards' and I borrowed a programme off a Coldstream Guardsman. I asked a policeman when the band will be along and he said, "ten and a half minutes." So, I stood and waited. Then I heard a terrific throb, and my ears were lifted, and with a Biff Biff Bang the band came along, and when they turned the corner up came their Oompahs and the miserable trombones - and blowed me in the middle of nowhere!

My book *We Can Speak for Ourselves* on self-advocacy by people with learning difficulties, features two self-advocacy groups: Project Two in Omaha, Nebraska, in America, and the Avro Social Education Centre Students' Council at Southend, Essex in Britain. In both groups the chairperson was a person with Down's syndrome: Tom Houlihan in Omaha and David Ward in Southend. In the early 1980's, David attended and spoke at a national conference of the National Union of Students, and Tom came to Britain on a visit during which he sometimes travelled unaccompanied.

The people who support Tom in Omaha, where he lives in his own flat and has a part-time job, have explained to him that he has Down's syndrome, and Tom has developed a certain pride in that fact. During his visit to Britain, I took him to meet a family who had a young daughter with Down's syndrome. As soon as we got there, Tom introduced himself by saying, "I hear your daughter has Down's syndrome. I myself have had Down's syndrome ever since I was born, and if there is anything I can tell you I'd by only too pleased to help." Tom doesn't *suffer* from Down's syndrome, he is a *consultant* on it.

On 6th January 1990 the television programme "Jim'll Fix It" featured a young girl with Down's syndrome, Kathryn Kaye, who had been chosen as a model for a Mothercare catalogue. She was described as a "beautiful blonde toddler," "happy," "full of laughter and life," "a credit to any modelling agency," "would brighten up any fashion page or advert."

The first time I met Celeste Hinds, whose story of her struggle to get heart treatment for her Down's syndrome daughter I will recount below, was at a conference when her daughter Maria, had to be taken out for disturbing the audience by laughing so much with enjoyment.

The Spanish author Josep Espinas wrote a book about his 33-year-old daughter Olga who has Down's syndrome. In a review of the book in the *Daily Mail* she is described as "thoughtful," "brave," "funny," "acutely sensitive to the needs of others," "loved and respected," "has taught a great deal to others," "gives freely."

In the July 1990 issue of *Disability Now*, Andy Brindle and Geoffrey Goodall, two young men with Down's syndrome, are shown acting in a performance by a musical theatre group at an international arts festival in Denmark.

In the book *Down's Syndrome: An Introduction for Parents* by Cliff Cunningham, published by Souvenir Press, there is a picture of Mr. Rothwell, a man with Down's syndrome, and his bride on their wedding day.

Amongst us here today, I'm sure we could generate many more such accounts of the positive characteristics and achievements of people with Down's syndrome known to us. How, therefore, can we explain the following?

In 1981 a paediatrician, Dr. Leonard Arthur, was tried and acquitted for the attempted murder of a newborn baby with Down's syndrome. In consultation with the parents, he had ordered the child to be given a sedative drug and no food; the baby died after 69 hours.

Most remarkable in the case was the evidence given in Dr. Arthur's defence by a number of highly respected senior members of the medical profession. Dr. Alistair Campbell, Professor of Child Health at the University of Aberdeen, stated that he had given similar instructions on a number of occasions so that handicapped infants would not survive. Sir Douglas Black, President of the Royal College of Physicians, no less, expressed his view that "it is ethical to put a rejected child with Down's syndrome on a course of management that will result in its death; it is ethical that such a child suffering from Down's syndrome should not survive."

Following Dr. Arthur's trial, the *British Medical Journal* stated in a leading article: "If the child is one of the quarter of newborns with Down's syndrome with congenital defects of the heart or other internal organs, then treatment may reasonably be withheld if that is the consensus reached by the parents and at least two doctors."

This is Celeste Hinds' account of events following the birth of her daughter, Maria:

> When Maria was four months old, she was diagnosed by the Paediatric Cardiologist as having a major heart defect. It was a malformation of the central heart common to 30% of children born with Down's syndrome. From her earliest days she was breathless, even when asleep, and she always had a blueish tinge to her skin.
>
> At that first consultation when her heart problem was diagnosed, the Cardiologist said immediately that it was inoperable. He said nothing could be done to help her. I remember asking him, "not now, not ever?" He said, “no." Each time we saw him after that it was the same, "Inoperable. No surgery."

We eventually sought a second medical opinion at a London hospital. The Cardiologist there agreed with the Cardiologist at our hospital. Maria's heart condition was inoperable, and yes, she would die prematurely. However, wasn't she a lovely child and so bright too, she said, "Now don't you think about the future, just you take her home and enjoy her."

Some weeks later we met someone who asked us if we had heard of the Sick Children's Hospital in Toronto. A friend of hers had taken her child to this hospital, where the child's heart had been successfully operated on, her parents having been told at our local hospital that it was inoperable. We hurried home and rang the hospital. We were put through to the heart surgeon. He was amazed when we told him about Maria. "Haven't you been offered the surgery in your country?" he asked. We told him no, and of the things that had been said to us by the doctors here. "We operate on this defect here routinely each week," he said. "There's no question of us not doing it; if we don't these children die. It is major surgery, but we have a 90% success rate. The defect does occur in normal children as well as in children with Down's syndrome, but in much smaller numbers. Of 100 consecutive operations we do to repair this defect, 80 will be on children with Down's syndrome."

We returned once again to the Cardiologist at our local hospital, feeling hope for the first time. We eagerly told him our news that Maria's heart condition wasn't inoperable; that successful surgery was being done on her heart condition in Canada. Very quietly he said, "You don't want to be asking yourselves where it should be done, but whether it should be done at all." He then told us that they did do the operation at our local hospital, but in the six years he had been there it had only ever been done on normal children.

We asked if Maria could have the operation locally, but the Cardiologist still refused, saying that the risks were too great. When we asked him why these risks were acceptable for normal children he replied, "Oh, it's well worth it with those children; they grow up to work, get married and have families." "But what about Maria and other children like her with Down's syndrome?" we asked. He just shrugged his shoulders.

Celeste Hinds went on to discover that, of nine Paediatric Cardiology departments in Britain, only one is prepared to operate routinely on children with Down's syndrome. As a result, around 300 children with Down's syndrome may be needlessly dying each year. *(To be continued. Ed.)*

<u>CABIN FEVER DAY…</u> Sandra Landis

(This is the third chapter in the story of our community building efforts that began in December 1990. Other chapters were titled "Stone Soup" and "Stir It Up" and were included in earlier editions of *The Safeguards Letter*.)

Winter arrived in earnest and right on schedule this year, a few days before Christmas. Two weeks earlier than that we had hosted a luncheon in Shawnee to celebrate the end of our Phase I work. We had a buffet of wonderful homecooked foods, a nice crowd for lunch of about fifty people, a simple brochure noting some accomplishments and aspirations for the coming year, and a beautiful day for touring the rehabilitated buildings.

We acknowledged that we'd come up a bit short. Of the fifteen thousand dollars we'd known we'd have to raise through donations and contributions we'd received $6,500. There was a short list of unfinished work that was part of Phase I that remained to be done: some exterior painting, some interior trim in the library, and final plumbing connections in the library. We celebrated, relaxed with people who had helped, encouraged newcomers to consider becoming involved. We hoped that most of the unfinished projects would be completed before Christmas and that the spirit of gift giving might help solve our deficit problem.

Nearly all of our worst fears about the work did *not* come true. Three buildings in very bad shape were now stable, much improved in appearance, and at least partially occupied. No one had been injured on the job, we didn't have any labor disputes, the village government had cooperated with us patiently, tenants and cooperating groups were making payments on time, and people were pleased about the improvements in the Main Street district. All the new plate glass was intact, and materials and supplies had been safe during storage with minimal security effort on our part.

Our cash flow worries were real, but pretty closely held worries. The day before the celebration luncheon we had received notification of a modest grant to support a few months' work in 1994. We were ending the year with a few of the challenges unresolved but were grateful that we had enough to keep going for a little while anyway.

The Phase I celebration was followed, in about ten days, by the holidays and the first of the blizzards of 1993-94. As the snow fell and the temperatures dropped, I realized how tired I was, and I welcomed the respite and hoped that others would too.

In the two months that have passed since then we have experienced the most challenging winter in many years. It's the kind of winter that makes persons ask if they really do intend to grow old in this climate and, if so, why? We have "closed" the office for a couple of months, and we are working at home to complete all the paperwork tasks that accompany work that is funded by a variety of sources. We're trying to carefully spend our dollar resources on things other than heat and power. We've conducted a few planning conversations and discussions, stopped in to pick up mail and messages and materials we need to work at home, checked for frozen water pipes, apologized to the library staff for the inconvenience to them of not getting the final plumbing connections in place before the freeze, but generally have been absent from Shawnee on a daily basis. This stretch of time, certainly not planned or even anticipated, has revealed some interesting things.

I admit to having been worried about a number of people. I thought about the fact that kids have been out of school for weeks. I wondered how a limited food budget gets stretched to cover all those extra meals that the kids might usually get at school. I wondered how mothers and dads could deal with the activity levels produced by having young children cooped up inside for so long. I kept thinking about the utility bills mounting up, and what it would take just to keep up with little things like washing dishes for a family of six when the pipes are frozen for days.

When I stopped in Shawnee, whether it was daylight or dark, someone <u>always</u> would appear, with news or ideas to share, questions or plans to discuss, requests for information or help, or just a "hi, stranger, where have you been?" I was both comforted and intrigued. People were obviously thinking and seemed hungry to talk. A solution for some of the distance was the phone, so we've loaned the key to the office to our neighbor so information can get back and forth, despite the weather.

So, what's been happening in Shawnee during this time of winter "isolation"? One group of folks has been tending the roof of the old school building we're hoping to make into a recreation center. The roof is in bad shape and leaks onto the hardwood basketball court floor. Tarps have been put in place and are checked regularly to keep any more damage from occurring. A couple of people have been lobbying village council to set up a payment plan system for water bills and have been helping a few families figure out how to keep services intact through the cold spell. The Preservation Committee had a potluck and planning get-together.

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

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

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

We're going to make it through this fourth winter of Sunday Creek Associates' "pot of stone soup." We're beginning to develop a "sturdier stock" as our ingredients are blended together. I think some maturing has happened; things are beginning to change again. A number of folks are thriving and creating new roles for themselves. More people, including many children, are joining in, drawing on the encouragement and strength that come through active community membership.

Sandra Landis

JUST QUOTES

But then, even in the most insignificant details of our daily life, none of us can be said to constitute a material whole, which is identical for everyone, and need only be turned up like a page in an account book or the record of a will; our social personality is a creation of the thoughts of other people. Even the simple act which we describe as "seeing someone we know" is to some extent an intellectual process. We pack the physical outline of the person we see with all the notions we have already formed about him, and in the total picture of him which we compose in our minds those notions have certainly the principal place. In the end they come to fill out so completely the curve of his cheeks, to follow so exactly the line of his nose, they blend so harmoniously in the sound of his voice as if it were no more than a transparent envelope, that each time we see the face or hear the voice it is these notions which we recognize and to which we listen.

Marcel Proust, *In Search of Lost Time*

Conquest's Law: To anticipate the behavior of an organization, assume it to be controlled by a secret cabal of enemies determined to discredit it.

Robert Conquest, as quoted by George Will

A committee is an activity where minutes are kept, and hours are wasted.

From a business card found in Chillicothe.

A VIEW OVER CHILLICOTHE "Saying Good-bye" Jack R. Pealer, Jr.

(Cynics--a group that usually includes me--should beware. The paragraphs that follow are frankly and intentionally sentimental. JRP)

I guess that I share with lots of others an affection for J.R.R. Tolkien's *The Lord of the Rings*. When I was a student, I learned about a tool of literary analysis called "form criticism", which helps the understanding of literature by requiring an identification, when it's possible and reasonable, of the various "forms" (e.g., a song, a fable, a hymn, etc.) that a writer employs. One of J.R.R. Tolkien's favorite forms in The Lord of the Rings is the "farewell scene". For example, early in the story Frodo Baggins leaves his home to start his great adventure:

> After some time, they crossed the Water, west of Hobbiton, by a narrow plank-bridge. The stream was there no more than a winding black ribbon, bordered with leaning alder-trees. A mile or two further south they hastily crossed the great road from the Brandywine Bridge; they were now in the Tookland and bending southeastwards they made for the Green Hill Country. As they began to climb its first slopes they looked back and saw the lamps of Hobbiton far off twinkling in the gentle valley of the Water. Soon it disappeared in the folds of the darkened land and was followed by Bywater beside its grey pool. When the light of the last farm was far behind, peeping among the trees, Frodo turned and waved a hand in farewell.
>
> "I wonder if I shall ever look down into that valley again," he said quietly.

I'm standing on the east edge of the top of Carlisle Hill, just where the Chillicothe town Christmas star lines up with the center line of Main Street when it's the last three weeks before Christmas. Downtown lies below. The towers of the courthouse, the Carlisle building (where Bob, who has framed, elegantly, most of the pictures in our house, maintains both his shop and his loquaciousness), and St. Mary's Church rise above the other roofs. The house that I love and have lived in for more than fourteen years is just over the edge of the hill on my right. It's evening, so everything below seems quiet--peaceful--though I've lived here long enough to know that isn't always so.

I've spent quite a few hours over more than a few years thinking, reading, and talking with others about "community". I understand that being a part of a community--being a "member", as Wendell Berry has put it--takes time and lots of effort. I realize that I have begun to experience membership here, in this place that lies before me, in the very neighborhood I'm looking over. And tomorrow I'm leaving. Maybe for another adventure. Frodo's question occurs to me.

Another literary form that fits this occasion is what critical readers might call a litany of praise--a list of the admirable or praiseworthy qualities of another. At this moment, to me, Chillicothe seems to be worthy of great praise. I ask you to honor with me:

- Good neighbors like Sandy and Brent, Alberta and Gus, Betsy, Joy and Alan, Dona and Jeff. In the past years it has been comforting to know we can depend on them and challenging to try to live up to the idea that they sometimes count on us.

- 158 West Fifth Street--a place I expect to dream about until I die. There is the front porch--a great place for summer breakfast or for quiet talk on a warm evening. Over there are the gardens I planted and tended, including a spot where the cat who taught me to like cats is buried.

- Doing business with folks I got to know and who got to know me. Sometimes these connections grow beyond simple business relationships. Sometimes they become friendships. I made rounds on foot to the bank, the Post Office, Lightning Print Shop, the public library, Hottinger's Photo, and other places. I'll miss having Sonja give me a haircut and, sometimes, a tension-busting neck rub.

- Places that define a community or that may come to mean "home" to those who are members. For me such places include: the Majestic Theatre (being rescued and restored as the "oldest operating theatre west of the Alleghenies"), Hirsch's Fruit Farm (where, if the aroma were bottled, I'd surely buy a case), the Cross Keys tavern (especially on Thursday nights when the Goosetown Astonishers play Dixieland), the Lucy Webb Hayes Birthplace (just around the corner from home), and Grandview Cemetery (where it's quiet high above the town and where so much of Ohio's early history can be recalled.

You can't, of course, see what I see, remember what I remember, as I stand watching night drop softly in front of me. You may, though, think of a community--an interaction among people and a place--that sparks like sentiments in you. Belonging…membership…being part of things turns out to be so vital, even though we don't often recognize its importance.

There is no clear answer to the question of why I'm now saying good-bye to this place. As I turn into the now-dark, Frodo's question again comes to mind.

Jack Pealer

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"TO THE SUCCESS OF OUR UNSUCCESSFUL DEALS"

Alan Tyne

(Our friend, Alan Tyne, is an ocean sailor. We received a copy of the following talk from Alan at Christmas, 1993. It refers to his voyage from England to St. Petersburg, Estonia and Latvia in the summer of 1993. JRP)

(Being the second part of a speech given at the 26th Annual Dinner of the Wivenhoe and Rowhedge Yacht Owners' Association. The first part was quite traditional--mainly some ribald but friendly comments about the many well known local people present, and some who were sadly not.)

Sailing--especially cruising in small sailing boats--celebrates some very old values and virtues. The value of independence, for instance, not that kind which is claimed through dominance, aggression and competition, but rather through patiently earning the skills and accepting the disciplines of seamanship and navigation. The sense of adventure that urges people to test and understand their own limits, and those of their boats, the seas and the seasons. The spirit of community that binds together a crew, that joins us in clubs and associations, and which we share with those we meet along the way.

The gift that we bring in our small boats is the gift of a visit. In our cruising we reach out and touch the lives of others. Struggling to weather some stormy headland, we don't see the people who stand there and think: "I wonder who they are…where they're coming from…will they make it round. I hope they'll be all right." As we make our way into a strange and distant harbour we're busily thinking, "I wonder what we'll find here--it's good that we've made it." We often forget there are others standing and watching us come in, who are saying, "Thank goodness they're safe. I wonder if they could do with some help. I bet they've a story to tell. I wonder if we'll like them…wonder if they'll like us?"

This summer our cruising took us to people who for many years it had been forbidden to visit, and who had been forbidden to visit us. They did not have much materially, but what they did have they would give without reserve. They were open, generous, and hospitable. They lacked some of the confidence affected by their visitors. They seemed nervous of what others would think of them. They feared rejection by the people who had always been "outsiders". They had been denied opportunities for independence and adventure, and for joining the community of small-boat sailors.

Among the many things they taught us was a toast--a funny-sad thought to accompany the passing of a glass among friends. It was "To the success of our unsuccessful deals"--spoken seriously, but followed with laughter. One man said, "You see, we Russians are really good at being unsuccessful--it is what we are most successful at." As he talked, his meaning grew a little clearer--the nation that defeated Napoleon at the cost of burning cities and a starving population; who were part of the victorious alliance in World War II, at an estimated cost of some 23 millions dead…*millions!*

St. Petersburg itself speaks of a nation famed for striving greatly, but at a cost. Designed as a version of Venice, but more than a thousand miles to the North. The brick-and-plaster architecture which works so well in the warm Mediterranean climate is a disaster 500 miles from the Arctic Circle. Every day the citizens of Saint Petersburg struggle to prevent the gilded fronts of their buildings falling down into the streets, the foundations from sinking slowly into the black ooze of the delta of the Neva.

Probably the greatest "heroic failure" of them all is the Revolution itself. All the great sweep of the socialist vision, trampled beneath the wheels of an oppressive and corrupt bureaucracy, the insatiable demands of the Arms Race!

The other theme in this tragi-comic toast was a more optimistic one. Like sailors everywhere, they had their schemes and their dreams. For one it was to make a trip abroad; for another to build, even to own his own boat; and for others to build a modest washroom and toilet at the side of their decrepit clubhouse. At every turn, these generous, ingenious, hopeful sailors were confronted by officialdom--the same officialdom which throughout the world has as its principal purpose to stifle initiative, regulate adventure and carefully limit the spirit of community. So if they wanted a project approved, they had first to make a quite outrageously grandiose proposal, only to have it turned down--"…isss not perrmissible". Then would begin a process of compromise, trimming a little here, amending there, and at every stage "…isss not possible", until at last, with a show of reluctance they would gain grudging permission for the very project they had wanted from the beginning! Officialdom felt satisfied that it had controlled and regulated, our sailors were rewarded for their courage and tenacity!

So the toast then is at one and the same time both a celebration of our enormous human capacity for making cockups--and the almost unlimited capacity of the human spirit for rising above them!

Please join me and think of those sailors far away as we toast:

"To the success of our unsuccessful deals"

Alan Tyne, December, 1993

About THE SAFEGUARDS LETTER

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WE GET LETTERS

(The following note came from Susan Thomas, Training Coordinator of the Training Institute at Syracuse, in response to "Angel Dance in Ottawa?" in the Summer, 1995 Safeguards Letter.)

Just a short note about your reflections on the Ottawa conference, which appeared in your summer, 1995 Safeguards Letter. I had thought that the two main issues of contention at Ottawa revolved around whether (a) normalization meant rights, and had done so from the beginning; and (b) power and legal rights, not human rights, was the best avenue for devalued people to get their just due. It seemed to me that the first issue was one that could have been resolved just by looking at the historical record, and that this record showed that indeed, normalization had not been originally conceived to mean only rights. Nonetheless, the historical record did not seem to cut any ice. As to the second, I hope it is not seen as splitting hairs to distinguish between human rights and legal ones. These distinctions may not make much difference to your main point that ultimately, the argument comes down to the nature of human nature. Also, maybe I was just out of the loop on this, but I did not realize there was any ongoing debate as to who deserved more credit, only a debate on who was right about the above question. And we certainly think that Nirje deserves much credit, and hope that we conveyed that at the conference, and that he felt and received that message. Susan

JUST QUOTES…

…it was unfortunate that the crows and the man had so little regard for one another. Their use of the hay meadow was nicely symbiotic, although neither party was much interested in the fact. The crows thrived on the abundant insects, which the cattle raiser fostered by fertilizing and mowing the meadow. The mowing maintained a high solar energy budget by excluding woody vegetation that would otherwise shade out the productive grasses. On the other hand, the cattle raiser would get less hay from the meadow if its wireworms, cutworms, and grasshoppers went unmolested. Of course, farmers can sometimes be convinced of the value of crows, but how does one convince a crow of the value of farmers?

David Rains Wallace, *Idle Weeds*

A man isn't old until regrets take the place of dreams. John Barrymore

…we come into the world as wild things and go out the same way, no matter how many boxes of lead or concrete we sheath about our bones (and the faster we consume the resources that eons of creative wildness have left us, the faster will the wild forces of deterioration pull us down). So it is not enough to look back and admire wildness as our heritage, we must look forward to it as well. The elk and panthers devoured by our factories and emporiums are presently being excreted as pariah dogs and sewer rats in our inner cities. We may like the new forms even less than our ancestors liked the old, but the pattern is the same.

David Rains Wallace, *Idle Weeds*

OHIO SAFEGUARDS LIBRARY.

It has been a long time since we reminded readers about our OHIO SAFEGUARDS library. The books and other materials listed below make up the library, and they are available for borrowing. Most of these items have something to do with the mission of OHIO SAFEGUARDS--paying attention to the situation of people who are outside sphere of respected community membership. Some of these materials may be hard to find elsewhere. We hope that readers will use these items. We also hope that the books, tapes, etc. will be sent back to us when folks have finished with them.

Adams, Frank. Unearthing Seeds of Fire: The Idea of Highlander. (1975).

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Alexander, Christopher. (with Howard Davis, Julio Martinez, Don Corner) The Production of Houses. (1985).

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Nearing, Helen and Scott. Living the Good Life: How to Live Sanely and Simply in a Troubled World. (1954).

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Orwell, George. Down and Out in Paris and London. (1931).

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Peavey, Fran. Heart Politics. (1986).

Perske, Robert. Unequal Justice? (What Can Happen When Persons with Retardation or Other Developmental Disabilities Encounter the Criminal Justice System) (1991).

Perske, Robert., and Perske, Martha. Circles of Friends: People with Disabilities and Their Friends Enrich the Lives of One Another. (1988).

Schwartz, David. Crossing the River: Creating a Conceptual Revolution in Community and Disability. (1992).

Shelley, Hugh and Mary Lou. Love is Two Plastic Straws. (1985).

Vanier, Jean. Man and Woman He Made Them. (1985).

"Walking on Air." (videotape)

Wetherow, David (ed.). The Whole Community Catalog (Welcoming People with Disabilities into the Heart of Community Life). (1992)

Wolfensberger, Wolf. The New Genocide of Handicapped and Afflicted People. (1987)

Wyman, David S. The Abandonment of the Jews: America and the Holocaust, 1941-1945. (1984).

Requests to borrow books or other materials should be sent to OHIO SAFEGUARDS, P.O. Box 18-181, Fairfield, Ohio 45018. We'll ask you to pay return postage costs.

ETHICAL ISSUES IN PREVENTION AND TREATMENT (continued)

Paul Williams

(Paul Williams, a friend in Great Britain, was invited to give a talk at the Annual Conference of the British Institute of Mental Handicap, in Edinburgh, on September 15, 1992. In this issue of The Safeguards Letter, we complete our publication of Paul's talk. Ed.)

I will now turn briefly to consider some aspects of what we might term the global politics of prevention. Since the founding of the science of genetics we have hankered after using it to control the quality of our own children and of future generations in general. Again, the power to decide does not lie in the hands of individual women or families - it lies with power groups in society. Between the wars, sterilisation or confinement of people to stop them breeding was proposed for large groups of people, including people with learning difficulties, mentally ill people, gypsies, Jews and black people. Such policies resulted from fascist, racist, elitist and disablist social policy and politics, not from individual choice. Today there is increasing interest in sterilisation of women with learning difficulties, and - in my view - an unhealthy interest in prevention based on genetics and microbiology, which will inevitably lie in the power of the medical profession to operate.

It would be wrong to generalise about the medical profession as a whole, but nor can we assume that all its members have benign motives or beliefs. Doctors led the eugenics movement in Britain and America between the wars, and doctors were prominent in the extermination of handicapped people in Nazi Germany, many of them actively joining the SS. We have already illustrated the general enthusiasm of doctors now to eliminate Down's syndrome.

Enthusiasm of the medical profession for prevention tends to focus much more on techniques that they can control than on working towards remedying the *social* causes of disability. The biggest single cause of disability, including learning difficulties, in the world as a whole, is malnutrition in developing countries. The prevalence of mild mental handicap is known to have a social class bias, almost certainly related to such things as poorer maternity services, greater poverty, poorer diet, less adequate environment and working conditions, and unsatisfactory housing. The politics of prevention should be about these things.

Sensible genetic research into the causes of conditions associated with pain or loss of functioning may be justified, but we must be very careful how such research is allied to views on the undesirability of disability in society, i.e., how such research, and especially the resulting measures of prevention, may threaten the social value of a disabled identity. Attempts to distinguish between the disabled person (to be valued) and his or her disability (not to be valued) are problematic: sometimes the treatment or prevention of the disability inherently involves the identity, the social perception, and even the existence of the person themselves. The main thrust of so-called preventative human genetic research has been to improve our ability to identify disabled people early enough to ensure they are not born.

Can it be argued that genetic engineering holds out hope of preventing disability while not destroying people? This possibility cannot be divorced from the political considerations we have outlined. Here is another quote from Michelle Stanworth's chapter on "The New Eugenics":

> Even if human genetic engineering is a science-fiction possibility at the current stage of development, the concern that it evokes is understandable. There is a worry that the definition of "unfit" will become a mask for prejudice and intolerance; that information about biochemical differences will become translated into judgements about the differential value of persons. That, in short, we will not distinguish finely enough between scientific questions and political ones. More immediately, there is a danger that genetic knowledge will be seen not as *a* tool of human advancement but as *the* tool: that research which might reduce the number of genetic defects will replace

> research to improve the prospects of people with disease or disability; that attempts to reduce genetic variability will be substituted for efforts to create an environment in which the range of human variability can flourish.

Who says that Down's syndrome, or deafness, or even what we call "physical disability" are abnormalities rather than simply variations in our human condition?

A response by some to the concerns I have discussed has been to oppose such developments as embryo research, human genetic engineering, and abortion on the grounds of disability. We must each ask ourselves what our position is on such things. Much that is bad will be done in our names if we are not aware and have not actively expressed opposition.

However, many of you may feel that such blanket opposition is wrong or unnecessary, or you may feel that it ignores reality, that it is rather like saying "Stop the world, I want to get off!" In case you do, I want to suggest five practical strategies that I believe can help to redress the very desperate situation for the people we work with and for:

The first strategy is to be more vocal, persistent and noticed in our proclamation of the humanity of all people with learning difficulties. With our first-hand knowledge of the value of such people, we are specially placed and have a special responsibility to do this. I will illustrate the need by quoting two opposites of the spectrum of beliefs in the humanness of people.

This is a quotation from Peter Singer, an internationally known Australian philosopher who has written extensively in favour of non-treatment of handicapped babies after birth (e.g., in his book *Shall the Baby Live?*):

> Once the religious mumbo-jumbo surrounding the term "human" has been stripped away, we may continue to see normal members of our species as possessing greater capacities of rationality, self-consciousness, communication and so on, than members of any other species. But we will not regard as sacrosanct the life of each and every member of our species, no matter how limited its capacity for intelligent or even conscious life may be. If we compare a severely defective human infant with a non-human animal, a dog or a pig for example, we will often find the non-human to have superior capacities, both actual and potential, for rationality, self-consciousness, communication and anything else that can plausibly be considered morally significant.

Now a quote from Jean Vanier, the founder of the L'Arche movement for life-sharing with people with learning difficulties. It is taken from a chapter entitled "A Wound Deep in Man's Heart" in the book *Mental Handicap: Challenge to the Church* edited by Brian Kelly and Pat McGinley, Brothers of Charity, 1990.

> I've often told this story: it's about a very normal man. As you know, normal people are very sad. When you're normal, you have problems; you're sad when you have problems. I mean family problems, problems about bringing up your children, financial, political and economic problems - endless problems of this kind.
>
> One day Mr. Normal came to see me because he had many problems. Well, there's a lad in our community called Jean-Claude who's very playful and unaffected. Some people call him a mongol, but for me he's Jean-Claude. He's very uninhibited; he likes fun. Perhaps he spends too much time giggling, but anyway he likes fun and he's not too fond of work. We've been living together for fourteen years so we know one another pretty well. I was talking with Mr. Normal when someone knocked. In comes Jean-Claude, chuckling. He shakes hands with me, shakes hands with Mr. Normal and goes off, chuckling. And Mr. Normal turns to me and says, "How sad to see children like that!"

> Well, to make such a remark you have to be dreadfully handicapped! He was so blinded by his projects, his sadness, his tears and his prejudices that he couldn't see Jean-Claude. But beneath Mr. Normal's protective shell there's a child, a weeping child, a frightened child too. Because if he's unable to look at Jean-Claude, it means that somewhere inside him he's afraid. Somewhere, he dares not be himself.

We obviously need to beware of mere sentimentality, but people with learning difficulties generally have a bad press, and we can remedy that with our own stories of their value and their humanness.

The second strategy I would suggest is strong support for self-advocacy, so that people with disabilities can develop a political voice of their own, alongside the better known voices of women and black people.

The third strategy is support for families, especially around the time of birth of a handicapped child. There should also be no expectation of life-long unsupported care by parents. This is where concern for ethical issues in prevention and treatment links with the development of caring inclusive communities. It should be communities, not just parents, who accept responsibility for disabled people.

Fourthly, I would point to the need to work on the competence of disabled people and the contribution they are enabled to make in their community. Many of the speakers at this conference have developed ways of pursuing this aim, and well-known principles such as social role valorisation and the "five accomplishments" provide useful frameworks for support.

Finally, I think we need to develop our philosophical views on suffering. Religious beliefs are helpful here, but even if we do not have these there are key questions that it is important to think about and try to resolve:

- can suffering be eliminated?
- can we control suffering?
- what constitutes an adaptive response to suffering?
- can we relieve suffering without destruction or elimination of suffering people?
- is disability inevitably associated with suffering?
- does suffering have a purpose and benefits?

I believe it is vital for us to think more about the issues I have touched on and to develop strategies that acknowledge and build the value of the people we work with, lest by default and prejudice that value is denied and people are destroyed.

Paul Williams

THANKS VERY MUCH!

During the past year or two OHIO SAFEGUARDS received contributions in support of *The Safeguards Letter* from the following individuals and groups:

Guy Caruso, Wexford, PA
Lisa Talayco, Jamaica Plain, MA
Terri O'Connell, Delaware, OH
Meg Kane, Cincinnati, OH
Debra Jo Pierce, Columbus, OH
Deborah Yenrick, Toledo, OH
Debbie Schmieding, Athens, OH
Celeste Boehm, Huber Heights, OH
Child Advocacy Center, Cincinnati, OH

Our thanks to one and all!

A VIEW OUT THE BACK WINDOW "Meeting Aunt Mary"

The barn still stands, and that is remarkable after the events of more than fifty years. Its actual age is unknown. It stands just a few feet off the highway that leads from the German-Czech border through the Bohemian forest toward Klatovy and eventually to either Pilsen or Prague. The barn, and the farm it once anchored, is just 2 kilometers from the border, but that short a distance made all the difference in the world. My wife Renate's grandparents owned the farm of which the barn is now the sole reminder. I don't know how long the family lived there, but it was long enough for them to have had 10 children, including Renate's mother and including Aunt Mary, whom I was able to meet during our visit to Europe this past summer. Grandfather Ludwig, Aunt Mary's father, was a forest worker--a lumberjack (the Bohemian forest is part of what still is the largest area of forest in central Europe), and Grandmother Rosalia was a mother and homemaker. Because their farm was in an area far from cities and industry, their lives were relatively unaffected by the war that surrounded them between 1938 and 1945.

Aunt Mary was 26 years old in 1945. As a child she did not do well in school and, after a while, she didn't go to school any more. She never learned to read. My wife remembers that she tried to give Aunt Mary reading lessons in exchange for instruction in needlework. Aunt Mary continued to live with her mother and father.

In 1945 the war that was ending arrived at the farm. Everyone who knows of World War II knows that it ended with Europe divided between so-called "western" (U.S.) and "eastern" (U.S.S.R.) spheres of influence. The line between these ran along the German-Czech border--just 2 kilometers west of the barn. Aunt Mary, her parents, and her brothers and sisters fled, before the Russian army could arrive. Other family members didn't go quickly enough or didn't want to flee. For all in the family the border took on an importance it hadn't had before. After Winston Churchill's Fulton, Missouri speech in 1948, that formerly almost inconspicuous border in a thinly populated area became part of the "Iron Curtain". And, neither Aunt Mary nor her mother or father could ever go back to their home--just an easy 45-minute walk from the frontier.

Aunt Mary and her father and mother lived first in refugee camps west of the border. (Renate lived in one of those camps too, but she was too young to be able to now remember anything about it.) Later, for a brief time, the family moved to a city. But they were accustomed to the forest and wanted to return to it. One son located lodgings in a small village about 15 kilometers west of the border, or about 17 kilometers (roughly 10 miles) from what used to be their farm. Aunt Mary, Father Ludwig, Mother Rosalia, and niece Renate moved into these lodgings--one large room upstairs above the barnyard in the village of Langdorf. And, within a few yards of that house, Aunt Mary has stayed for 51 years.

The village has changed much since 1945. Renate remembers it as a place with dirt streets, a well where villagers drew their water, a communal bake-oven by the street, and forest and fields full of berries and mushrooms that were a minute's walk away. Today Langdorf might almost be described as a resort; the open country of fields and forests and the clear water and air draw vacationers from all over central Europe (and from further away, as my visit attests).

Aunt Mary stayed with her parents. She worked around the house and maybe helped others in the village with housework or field work. Apparently she worked in a nearby gästhaus--tavern/restaurant--for many years and was very poorly paid for her work. (Lots of Americans with disabilities know about spending years of effort in "vocational" settings where they receive negligible, though legal, levels of pay.) About fifteen years after the family moved to Langdorf, Aunt Mary's mother died. Then, a few years later, her father also died. Both her mother and father are buried in the churchyard across the street from the house where the family lived. Sometime after the family arrived in the village and Aunt Mary started working at the gästhaus, she met a man who taught her about sex. She had a child--a son. Local custom and pressure caused the father of the child to marry her, but apparently they never lived together and the man eventually went away.

After the deaths of her parents, Aunt Mary was alone with her son. Other family members who were around helped her at times. She kept working at the gästhaus as the years passed. Her son grew to be a man but remained with her. He had a job in a nearby town. He learned about taverns, eventually developed kidney disease, and also died--just two years ago. He is buried in the same churchyard plot as are his grandparents.

We met Aunt Mary at her apartment. It is in the top floor of a multi-family house just down the street from the church. The climb to the top floor is hard, especially the last narrow flight of stairs, so Aunt Mary probably doesn't leave the apartment very often. A neighbor who lives downstairs sees to it that Aunt Mary has plenty of food (and beer--Aunt Mary likes a little beer each day). The owners of the gästhaus now provide her with sausages and other meat at no cost. While we visited, another neighbor cut and stacked firewood for her. The wood was neatly stacked just outside the side door on the ground floor of the house. Neighbors bring wood up to Aunt Mary as she needs it. The three-room flat is nicely furnished. The furnishings include lots of photos and mementos of Aunt Mary's family. There is, as well, a new large-screen television, which attaches to the satellite dish outside on the balcony. Aunt Mary's income comes from her social-insurance pension check from the German government. Another woman--a long-time friend of the family who is married to the village burgermeister (mayor) helps see to it that Aunt Mary's money is wisely used.

Aunt Mary now spends her time fixing her meals, visiting with the neighbors and others who come to offer help or companionship, watching a little TV, taking care of her place, and looking over her memorabilia. Mostly, though, when the weather is good, she seems to like standing on her balcony high above the street. She watches the activity of the village--children coming and going from the school, farmers hauling hay from fields to barns, people going into shops, tourists trying to find their way around. From her balcony, too, she can keep watch over the church and the churchyard where her loved ones lie.

While we visited Aunt Mary, someone suggested that her life was a sad one, and maybe I have portrayed it that way. If I think about Aunt Mary while I'm wearing my human service hat, I see that her life-situation looks like one we would work hard to make available to others. She has a pleasant if simple place to live. She has income that seems adequate to her needs. Apparently, coverage of the cost of health care (if she needs it) is connected to her pension. Most of all, she has "natural supports"--people who help her because they are her neighbors, because they have known her or her family for a long time, because of friendship and care. It may be my imagination, but I think that Aunt Mary fills a role as an elder of the village--that her presence on the balcony is a bit like a blessing and even more like a connection between Langdorf now and some of its past. I don't think that such a life is necessarily sad.

But I wonder. The balcony is high. The air is usually clear. When she looks south and east, sometimes, can Aunt Mary somehow see more than ten miles over the forest? Can she catch a glimpse of the remaining barn beside the road? Does she think of the farm that is no more? And does she wonder what might have been if that curious force called the war had not for so long imposed a barrier that could not be crossed?

Jack Pealer

The Safeguards Letter

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NUMBER TWENTY-SIX SUMMER, 1995

WE'RE NOT ASLEEP; WE'VE JUST BEEN RESTING OUR EYES.

One of our faithful readers corrected me once after I had begun an issue of The Letter with an apology for that issue's delay. I accept correction, but, like most people, I don't usually seek it out. So, I won't make the apology mistake again. I'll just say, "Here we are again." We hope that you remember….

When we left you, we had just printed the first of three parts of a speech by our friend Paul Williams. This issue contains the second part, as well as a couple of short book reviews, a few quotes, and a reflection on the May, 1994 Ottawa Conference on the 25th anniversary of the first publication of the "normalization principle". As always, we invite contrilbutions of writing (letters, poems, plays, whatever) from our readers. The next issue after this one will come out sometime in the autumn. So, sharpen your quills, load your fountain pen, or reorganize the segments on your hard drive. Let's try to stay in closer touch.

OPPORTUNITY IN INDIANAPOLIS

Indianapolis will be the location, in November, 1995, for an important workshop presented by Wolf Wolfensberger and his associate, Susan Thomas. Sponsored by the Indiana Safeguards Initiative, Dr. Wolfensberger will present "How to Function Morally, Coherently and Adaptively as a Human Service Worker in an Imperfectible World of Incoherent and Poorly Adaptive Services." This 7-day workshop is a rare event but one that is likely to affect participants for the remainder of their lives. The workshop is described by Dr. Wolfensberger as follows:

"Powerful disfunctionalities in both the world and human services constantly buffet human service workers and seek to destroy their ideals, their integrity, and their effectiveness. This workshop is intended to help participants understand and cope with these forces while retaining or attaining their personal moral coherency and capacities for genuine service to their follow human beings."

The workshop begins on Saturday, November 4, and ends on Friday, November 10, 1995. It is being held at the St. Vincent Marten House Hotel and Conference Center in Indianapolis. Those who are interested can contact the Indiana Safeguards Initiative at (317) 264-0332.

ETHICAL ISSUES IN PREVENTION AND TREATMENT (continued)

Paul Williams

(Paul Williams, a friend in Great Britain, was invited to give a talk at the Annual Conference of the British Institute of Mental Handicap, in Edinburgh, on September 15, 1992. In this issue of The Safeguards Letter, we continue with Paul's talk. The conclusion of the talk will then follow in the next issue. Ed.)

The following is taken from accounts in the *Daily Telegraph* and the *Independent*, 14th August 1992:

> Routine blood testing of pregnant women could avoid thousands of handicapped children being born each year, researchers say today. Blood screening for Down's syndrome is effective in practice and can readily be integrated into routine antenatal care, say Professor Nicholas Wald and colleagues at St. Bartholomew's Hospital, London, In a three-year trial involving 12,000 women in East London, Professor Wald offered amniocentesis to women where blood tests showed a risk of a Down's pregnancy. Twelve of 25 affected pregnancies were detected, he says in the *British Medical Journal*. Three-quarters of women at risk had an amniocentesis and there was a 90 per cent acceptance of an abortion in those where that test indicated the child would be handicapped.
>
> The researchers have costed their screening method and estimate that it costs £38,000 per Down's baby avoided. The lifetime costs of caring for one Down's child have been estimated at at least £120,000. But the doctors say, "The most important reason for screening, however, is not financial; it is the avoidance of handicap and of distress to the families concerned."

Thus we can see there is a concerted attempt by the medical profession to eliminate Down's syndrome altogether, through prenatal testing and abortion, and to some extent through denial of treatment and care after birth. But surely, we might argue, part of this is simply the development of technology which enables women and families to have a greater choice in the area of reproduction. However, this issue of choice is not as clear-cut as it may appear.

The following is a quote from a chapter entitled "The New Eugenics" by Michelle Stanworth, in the book *Making Connections*, edited by Ann Brechin and Jan Walmsley (Hodder and Stoughton, 1989), which is the Reader for the Open University Course "Mental Handicap - Changing Perspectives":

> A survey of consultant obstetricians in Britain found that 75 per cent of those questioned required women to agree to abortion of an affected foetus before they give amniocentesis. Information that should be a resource for parents becomes, in these cases, an instrument of population control. It is not acceptable that the understandable desire of many women to have as healthy a baby as possible should become a duty, aimed at the welfare of the gene pool rather than that of the parents or the child.

In *Everywoman* magazine, June 1990, Caroline Hearst wrote about the pressures on her to be tested with a view to abortion if handicap was discovered. This is taken from her article, which is entitled "The Right Not to Choose Abortion":

> I was 35 when I became pregnant, and my partner and I were both delighted to be starting a family together. When I went to the doctor I was told that because of my age there was an increased risk of a Down's syndrome baby. I was offered two tests, amniocentesis or chorionic villi testing, that would tell if the foetus had the condition. In fact I did not want them, because I was not willing to have a relatively late termination of my pregnancy, even if I did discover that the foetus I was carrying had Down's syndrome.
>
> I am unhappy at the thought of giving birth to a Down's syndrome child, but that is because of the way the child and we, as the parents, would be treated. It is difficult to get adequate support, and life with and for a mentally handicapped child can be isolated and grim.
>
> At my first hospital appointment the midwife seemed puzzled that I had not had amniocentesis. It was easier to say that I found the risk of miscarriage unacceptable than to explain that I would not want a termination even if I was carrying a handicapped foetus. She then offered me an alphafetoprotein test, which is a test of the mother's blood to see if there is a high probability that the foetus has spina bifida. She assumed that I would have this test, since it is harmless in itself. I had to explain that I didn't really want a termination,

> regardless of the result of the test. I was terribly apologetic because I didn't want to get a reputation as a "difficult patient".
>
> I discussed things with my partner and he said he was not sure he would make the same decision. He said he would find it hard bringing up a child with spina bifida. He agreed that it was pointless to have the test if I wouldn't want to terminate the pregnancy, and he would not put pressure on me to have an abortion if I didn't want one. However, I already felt pressure: if I had a baby with spina bifida because I'd refused a test my partner wanted me to have, I would feel that it was all my fault. That would make it feel like my sole responsibility to look after the child. After all, its father wanted it "prevented", so why should he have to deal with it?
>
> I wished I did not have to make this decision. It seemed that the availability of the test involved an automatic assumption from everybody that I would have it - imposing on me a choice of life or death which I did not want. Because of the test, if our child had spina bifida it would no longer be seen as just an accident of nature, but the result of a wilful decision on my part.
>
> Later, a nurse asked why I had not had my first scan yet. I said I was not having one. She looked horrified and asked why. I explained that nobody had given me a good reason to have a scan. "Patient refused scan" was scrawled on my notes.
>
> In hospitals and doctors' surgeries up and down the land, pregnant women are being offered tests which presuppose our willingness to have abortions - and late ones at that, at 20 weeks and more. I found well-meaning medical personnel assuming that I would want these tests, and I experienced their incredulity, when I declined, as pressure to conform to their expectations.

So technological developments may not simply serve to increase individual choice; they may become tools of medical and social policies that are highly discriminatory in their effects.

Now let us consider another condition that can be identified through amniocentesis and other techniques: being female. In an article in the Observer, 26th January 1992, the head of the All-China Women's Federation, Chen Muhua, described the effects of China's population reduction measures. Since 1979 there has been a policy of allowing only one child per family. Boys are more valued than girls since they potentially carry on the family lineage and provide support for the parents in old age. As a result, millions of girl children have been aborted or killed after birth. This is reflected in census data which show an excess of male children over female of 30 million. It is estimated that by the year 2000 there will be 50 million men unable to find wives.

These facts prompted me to consider the question: Is there any fundamental difference between having Down's syndrome in Britain and being female in China? Are we not witnessing in both cases totally unacceptable oppression and devaluation? I re-looked at the newspaper accounts of the proposal to test the blood of all pregnant women for Down's syndrome as a matter of routine antenatal care, and tried substituting "being female" for "having Down's syndrome":

> Routine blood testing of pregnant women could avoid thousands of female children being born each year, researchers say today. Blood screening for femaleness is effective in practice and can readily be integrated into routine antenatal care, say Professor M. Chauvin and colleagues at St. Macho's Hospital, London, In a three-year trial involving 12,000 women in East London, Professor Chauvin offered amniocentesis to women where blood tests showed a risk of a female child. Around 6,000 affected pregnancies were detected, he says in the *British Medical Journal*. Three-quarters of women at risk had an amniocentesis and there was a 90 per cent acceptance of an abortion in those where that test indicated the child would be female. The researchers have costed their screening method and estimate that it costs only £200 to

> avoid a female child. The lifetime costs of caring for females have been estimated at at least £120,000. But the doctors say, "The most important reason for screening, however, is not financial; it is the avoidance of burden and of distress to the families concerned."

We would surely never condone the abortion of people in Britain simply because they were female. Why then when they are disabled? Surely the answer to a problem of inequality of opportunity and inequality in need for care and dependence lies in equal opportunity policies and provision of adequate services?

However, is it not the case that Down's syndrome and other disabilities are "abnormalities" or "errors of nature", whereas differences in gender or race are natural variations in the human condition, to be welcomed and valued? This is a common view, but it may well be that it is our inability to think clearly about this issue that results in anti-disablism having a much lower profile in our consciousness than anti-sexism or anti-racism. Some physically disabled people, for example Mike Oliver, have begun to argue that, while some aspects of disability can and should be prevented, a disabled identity is one to be valued just like ethnic or gender identity. We must be very careful that any measures of prevention, and even of treatment, do not threaten the personal and social valuing of this identity. Deaf people have also proclaimed the value of their identity, reflected in their own culture and language.

Paul Williams

Richard L. Rubenstein's *The Cunning of History*. An Appreciation.

I always search the sale tables at bookstores. Recently such a search turned up a little book (about 110 pages), the title of which tickled in the back of my mind: *The Cunning of History: The Holocaust and the American Future* by Richard L. Rubenstein. This was indeed a find. Rubenstein's little book--not much more than an extended essay--is a meditation on the meaning of the Nazi experiment at Auschwitz from a vantage point 30 years later (the book was published in 1975). It is also a sober message to western society today about what may lie ahead.

Rubenstein states his purpose as:

> …to point out that the explosive combination of surplus population, finite resources, and the expanding sovereign powers of government suggest that the Nazi extermination program may yet foreshadow other exercises in the politics of total domination by future governments as they face catastrophic population problems arising out of mankind's very success in mastering nature. (p. 86)

Rubenstein comments that it is a mistake to regard what happened at Auschwitz and elsewhere as something as simple as mass execution. Mass executions have occurred often in recorded history. Rubenstein insists that Auschwitz instead represents the first appearance of "a new form of human society"--the necropolis (city/society of the dead). He identifies and discusses four intertwined threads in the history of western society that, in his view, come together to make the creation of such a necropolis possible. These are:

1) Bureaucracy, a form of social organization dominant in the industrial west that substitutes rationality and allegience for personal conscience;

2) The de-enchantment of the world that issues from the insistence by western Christianity (especially Protestantism) on the distance or separation between the deity and the creation;

3) The rise of de-nationalization or statelessness, by bureaucratic definition of various European nations following World War I. People who lived in the wrong places as borders shifted were stripped of citizenship and became officially stateless. This thread

relates directly to Rubenstein's startling observation that Nazi authorities violated no laws by exterminating stateless people, because these were people to whom no laws officially applied.

4) Slavery and its connection to a money economy. Rubenstein comments on the resemblance between slavery in the United States and that practiced in German industry between 1939 and 1945.

5) Corporate, capitalist rationality operative in Nazi Germany (and elsewhere?). Rubenstein notes "…the extent to which the same attitude of impersonal rationality is required to run successfully a large corporation, a death camp slave labor factory and an extermination center." (p. 60)

These threads were not done away with when the death camps were discovered and eliminated in 1945. Forms of each may be recognized today, sometimes in combination; they are reported in our daily news. In his introduction to *The Cunning of History*, William Styron uses another metaphor for the above themes. He describes each as a "sleeping virus in the bloodstream of civilization". Richard Rubenstein deserves credit for his warning about what did, and, therefore, could again happen when these viruses become active and combine.

It's a good idea to check out the sale table.

Jack Pealer

About THE SAFEGUARDS LETTER

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JUST QUOTES

My Uncle Hughie was surprised when I told him that many people who are not suffering from mental illness go to psychiatrists and psychotherapists. "Don't they have friends?" he asked. Friends have to become scarce or unavailable before, as a society, we begin to prefer buying someone to be our confidant for an hour. But that is what we have come to. We are no longer interested in a neighbor who claims that chewing on some leaf relieves headaches. To be taken seriously, our healing procedures must be scarce, distant, and costly.

Joseph Ferry, in "When the World Goes Stop"
Community Service Newsletter, Nov.-Dec., 1993

A committee is an activity where minutes are kept and hours are wasted.
(Found on a business card)

Have we come to thinking that writing difficult books is better than doing a little good?
John O'Brien, OHIO SAFEGUARDS Retreat, January ,1991

The blind willingness to sacrifice people to truth… has always been the danger of an ethics abstracted from life. This willingness links Gandhi to the biblical Abraham, who prepared to sacrifice the life of his son in order to demonstrate the integrity and supremacy of his faith. Both men, in the limitations of their fatherhood, stand in implicit contrast to the woman who comes before Solomon and verifies her motherhood by relinquishing truth in order to save the life of her child. It is the ethics of an adulthood that has become principled at the expense of care that Erikson comes to criticize in his assessment of Gandhi's life.

Carol Gilligan, *In a Different Voice*

There's nothing wrong with teenagers that reasoning won't aggravate.
(Overheard among parents).

A BRIEF REVIEW: Trent, James W., Jr. *Inventing the Feeble Mind: A History of Mental Retardation in the United States.* Berkeley: University of California Press, 1994.

Someday I hope to be able to read a history of the experience of **people** with mental retardation in North America or the western world. This hope will probably be unfulfilled because the lives of those people are largely hidden. Most of the experiences of people with mental retardation have not been recorded, or perhaps even noticed very much. They have, therefore, not come to the attention of most historians. I suspect that it will take either a writer of fiction or a social historian like Philippe Aries or Georges Duby (*A History of Private Life*) to either imagine or uncover the past stories of people whose experience has been obscured.

Good use has been made by James Trent, Jr., however, of some of the records of some formerly hidden lives in his new history of mental retardation (the phenomenon, not the people), *Inventing the Feeble Mind*. If currently-accepted prevalence estimates of mental retardation can be applied backward in time, never was more than a minority of people with mental retardation residing state or private institutions. It was the development and thriving of institutions, however, that defined and shaped the idea that we have come to call "mental retardation", as James Trent so fully describes.

His title reveals his thesis. Mr. Trent alleges that the construction of mental retardation as a field of endeavor was a process that involved deliberate design. Mental retardation shares with other human service fields the curious feature that "it"--the focus of study and work--is something that is defined exclusively by people who do not have "it". So, Mr. Trent's attention to the professional lives of leaders in the mental retardation field makes sense. The lives of the professionals are clear windows on the history of the field.

Inventing the Feeble Mind argues that three themes related to professionalism have influenced the history of mental retardation in the United States.

> …I claim that … state schools became places where care became an effective and integral part of control. Furthermore, superintendents and social welfare agents did not move simply "from care to control," but reshaped the contours of both care and control to ensure their personal privilege and professional legitimacy. Second, I hold that the tendency of elites to shape the meaning of mental retardation around technical, particularistic, and usually psycho-medical themes led to a general ignoring of the maldistribution of resources, status and power so prominent in the lives of intellectually disabled people. Finally, I find that the economic vulnerability of these people and their families, more than the claims made for their intellectual or social limitations, has shaped the kinds of treatment offered them. (p. 5)

There are two ways to see the lives of the people affected by professionals. Look at the photographs made at mental retardation institutions almost from the beginning of those institutions' existence in the United States. Read the letters between institutional staff (especially Superintendents, whose correspondence was more likely to have been preserved) and the families of residents. James Trent had access to substantial collections of both letters and photographs and has used both to develop his thesis. He writes:

> Drawing on methods associated with intellectual and social history and a theoretical framework from social constructionism and critical sociology, I have concentrated my study on the fabrications and the gazes--pitying, fearful, knowing, controlling--of those in control of mental retardation, and on the larger context out of which these constructions emerged. In addition, I have tried to hear the voices of people whose lives were shaped by the gazes and the fabrications, to capture, however incompletely, their responses, and to understand how so much apparent progress could cover so little real change. (p. 2)

I recommend *Inventing the Feeble Mind* both as a history of the forces that shaped efforts to help people with mental retardation and, perhaps more important, as a parable of how professionalism (and allied credentialism) have arisen to have such power over the lives of vulnerable people. James Trent notes:

> There are indeed aspects of the lives of mentally retarded people (and mentally accelerated people too) that require help from other individuals, but by looking at the mentally retarded person, the other, so obsessively, we fail to look at ourselves and examine the "screens of ideology" which shape and direct our obsessive gaze. (p. 6)

Inventing the Feeble Mind is a valuable attempt to help us redirect our gaze.

Jack Pealer

SUPPORT FOR *THE SAFEGUARDS LETTER*

This is our appeal for donations of money to pay for *The Safeguards Letter*. Regular readers know that there is no "subscription fee" for the *Letter*. The trustees of OHIO SAFEGUARDS agreed more than eight years ago that the *Letter* would not be paid for by "subscriptions" but by the voluntary contributions of interested individuals and organizations. This decision saves OHIO SAFEGUARDS from the task of maintaining subscription lists. More important, though, the decision places the responsibility for the future of the *Letter* where it ought to be--in the hands of its readers. For the past several years the intermittent contributions we've received have made it possible for the *Letter* to reach about 300 readers. Any readers who want to contribute (it's tax-deductible) may send their contributions to: *The Safeguards Letter*, P.O. Box 18-181, Fairfield, Ohio 45018. All money received will be used for the printing and mailing costs of the *Letter*. We thank you for your continued loyalty as readers.

A VIEW OUT THE BACK WINDOW

"Angel Dance in Ottawa?"

It has been a year now since the International Conference in Ottawa--the celebration of the 25th anniversary of the initial publication of the "normalization principle" in English. (Normalization was first described in print in an article by Bengt Nirje that appeared in the 1969 book, *Changing Patterns in Residential Services for the Mentally Retarded*, edited by Robert Kugel and Wolf Wolfensberger and published by the U.S. President's Committee on Mental Retardation.)

This was my first international conference. It took place in a truly international city. There was simultaneous translation of all the proceedings from French to English and vice versa. Speakers came from as far away as Australia, Japan, Scandinavia, and Poland; most of the conferees were North

American. The (sole) conference hall was filled with green-covered tables, although I am certain that the coverings were not green baize. I even had some trouble getting past Canadian immigration/customs officials when I arrived at the airport. (I had never before been expected to bring a passport to enter Canada--a sign of the times.) There were just so many romantic spy-movie elements to this event. I had looked forward to it for some time. And my reaction?

How many angels can dance on the head of a pin? The question reflects a popular image of medieval scholasticism, about which I know very little. This question, today, connotes people at esoteric scholarly or monastic conclaves giving their lifetimes to meaningless questions. The angel-dance question often symbolizes out-of-touch thinkers engaging in debate over fundamentally unarguable propositions mostly for the sake of the debate itself.

My raising of the image of the angel-dance points toward my initial reaction to the Ottawa conference. Some part of this first response remains with me. What were these people all about? Couldn't they see that a would-be celebration of a valuable idea--the principle of normalization--and of its effects on the lives of a vast number of people was being trivialized by petty bickering? Yes, I got the chance to spend time with many long-time friends. Yes, it was marvelous to come to a normalization-related event with no responsibility other than to listen and talk with others (and the talk was optional). Why were many of the speakers in this room (there were no "alternate" sessions) wasting everyone's time with wannabe academicism? What had this bombast to do with work to promote change in the lives of people who have endured profound rejection? Why was there so much jabber about "how many angels…?"

It took me a while to catch on. It turned out that at the heart of the conference was an essential disagreement over <u>what people are like</u>--the question that has been called the "nature of humanity" question.

That this was the case--that "what people are like" was the main issue before the conference--was made plain on the conference's last day in an exchange between Wolf Wolfensberger and Bengt Nirje, who were the two towering figures of the conference. Dr. Wolfensberger, while speaking of the future of the ideas of normalization and/or social role valorization, characterized humanity as "sinful", that is, full of sin in the sense meant by the theological term "original sin". In other words, humanity is fallen, corrupt, and "aiming toward death." As he has done so many times, Dr. Wolfensberger described our age as a time when (fallen) humanity lives in a state of "normative insanity", wherein human beings have forgotten about or obscured their own corrupt condition. (I found myself wondering whether 19th century British, 16th century Dutch or 14th century French commentators might have spoken in a similar vein.) In a time when insanity and evil have control of human affairs, the idea of "normalization" (the use of what is culturally typical as a standard for what to make available to people within human services) makes little sense. This was a major reason, said Dr. Wolfensberger, for developing the "social role valorization" formulation. He continued that the corruption of humanity is leading to disintegration of human affairs. And what might once have worked works no longer. For example, reliance on (potentially successful) appeals to "human rights" as the rationale for better social responses to devalued people is tied to the waning economic prosperity of the West. As prosperity declines we may, observed Dr. Wolfensberger, find ourselves foregoing "rights" in order to retain <u>order</u> during times of collapse.

Bengt Nirje strongly took issue with Dr. Wolfensberger's assessment of the state of humanity and the world. He could not, he stated, agree with the expressed world-view. Europe, he observed, does not look like the world Dr. Wolfensberger described. (By Europe he surely meant Scandinavia; he could not have been talking about the Balkans.) Europe, Mr. Nirje said, features a spirit of cooperation and escalating respect for human rights. He believes that the human species is progressing--that we are better (if not exactly perfectible) than we were at earlier times. Thus, normalization as he described it still has a valuable function--to help in the advance toward universal human rights.

A major part of the conference was a sharp academic argument, often carried out by adherents of these two men, about which of them is "right" and about which mentor deserves more credit for the historic development of the idea of "normalization." The question of which is more right deserves attention; the question of who gets more credit does not.

What about resolution of this disagreement? Do I have to choose where or with whom to stand? Wolf Wolfensberger and Bengt Nirje presented themselves like magnetic poles on the question of what people are like. Both are admirable men, tempered by the experience of war. If they are like "poles", how far north or south should I or can I be?

Well, my money is on sin. My life and training as a "Lutheran" (interestingly, many Scandinavians are at least nominally Lutheran too) predisposes me to credit human fallenness and suspect anything that hints at the possibility of unassisted human perfection. But, I also remember that radio listeners once complained to Garrison Keillor (another Lutheran) about a story that he began but did not resolve. His response was something like: "I don't know what their lives are like, but mine is full of irresolution--of unanswered questions." So, finally, I can't decide who--Nirje or Wolfensberger--is "right". I'm glad that I was there for the debate and have had the chance to mull over the question. And, despite some silly moments at the 25th Anniversary of Normalization conference, I've decided that sometimes it's important to argue about the dancing capability of angels.

Jack Pealer

THE SAFEGUARDS LETTER

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RAYMOND LEFT US

The tears came as I put down the phone. Ray Ferguson, our colleague and my friend, was gone. These weren't my first questions, (I won't say what those were) but they occurred to me soon: Whom will I ask about where to find the best audio equipment? Whose judgment can I trust when I'm considering buying another car? Who will tell me about the best places in his beloved Columbus to find really unusual and good wine? On whom else can I count for a hearty (the word absolutely fits) welcome, smile, and gentle ribbing? We miss Raymond as a colleague--as one who became a leader in his field--but I miss him as a presence, with whom I never got to spend enough time. For some reason, which I think I understand, the following poem came to my mind in the first hours after I heard that Raymond had died. Ray, this is for you.

The Wild Swans at Coole
W.B. Yeats

The trees are in their autumn beauty,
The woodland paths are dry,
Under the October twilight the water
Mirrors a still sky;
Upon the brimming water among the stones
Are nine-and-fifty swans.

The nineteenth autumn has come upon me
Since I first made my count;
I saw, before I had well finished,
All suddenly mount
And scatter wheeling in great broken rings
Upon their clamorous wings.

I have looked upon those brilliant creatures,
And now my heart is sore.
All's changed since I, hearing at twilight,
The first time on this shore,
The bell-beat of their wings above my head,
Trod with a lighter tread.

Unwearied still, lover by lover,
They paddle in the cold
Companionable streams or climb the air;
Their hearts have not grown old;
Passion or conquest, wander where they will,
Attend upon them still.

But now they drift on the still water,
Mysterious, beautiful;
Among what rushes will they build,
By what lake's edge or pool
Delight men's eyes when I awake some day
To find they have flown away? (1917)

A REVIEW. *NEW VOICES: SELF-ADVOCACY BY PEOPLE WITH DISABILITIES* (Edited by Gunnar Dybwad and Hank Bersani, Jr.). Reviewed by Keith Banner.

Almost at the end of *New Voices: Self Advocacy by People with Disabilities*, a passage appears, excerpted from *The Mouth*, titled "A New Voice," by Bob Kafka. In this passage Kafka states, "You (institution) operators want to pretend it's complicated. You raise a lot of pseudo-issues to disguise the fact that's all about your money and your power."

This statement, and many others in this great handbook for people with and without disabilities on how to organize and stay that way, goes to the core of what self-advocacy seems to be about: the elimination of "pretending" by people in power. The book traces the self-advocacy movement from its humble origins in the seventies to its complicated and varying versions now, in the nineties, all over the world. But even as self-advocacy spreads and gains momentum, its primary function, as is evident in the many essays and interviews in this book, is to bring about great change at the level of everyday life for people with disabilities. As the definition of self-advocacy adopted by the Second Annual North American People First Conference states: (self-advocacy is) "independent groups of people with disabilities working together for justice by helping each other take charge of their lives and fight discrimination."

New Voices focuses mainly on the self-advocates themselves; people such as Nancy Ward, Thomas Holmquist, Elizabeth Broberg, and Barb Goode offer insights into what it means to gather together in order to alter their collective universes. It is incredibly inspiring to witness their stories and histories, as they tell us about what it was like existing in institutions and group homes--sobering accounts of living in a world guarded and isolated just because they were seen to be voiceless and useless by the people in power. Voicelessness, in fact, is the key disability for all these people who eventually found their voices through self-advocacy and the usefulness of helping other people stop the "pretending" by speaking out.

As a whole, *New Voices* is a collection of voices and insights that is not just propaganda for a movement but a rich and rewarding documentation of progress and a developing consciousness that "We are not going to take it any more." This honesty allows the book to be more than mere advertisement and professional jargon, giving it urgency and meaning outside the world of "disability". More important, the book is critical yet still hopeful, as the people question both self-advocacy as a movement and how this movement is put to use around the world. In his essay, "Self-Advocacy at the Crossroads," Bernard J. Carrabello, a survivor of Willowbrook who now works for the New York State Office of Developmental Disabilities, writes, "Advisors (of self-advocacy groups) must be extremely careful to make sure that what is advocated for, is what the self-advocates want and not merely window dressing for an agnecy's need."

This split, between an agency and the people the agency is supposedly helping and supporting, is key to the understanding of what self-advocacy can and must do in people's lives. *New Voices* is a road map directing people how to--and how not to--utilize self-advocacy toward beneficial and necessary goals: stopping the pretending and letting people outside the world of disability politics and disability jargon understand that it is not right that people still "live" in congregated facilities, still "work" in sheltered workshops, and still are given excuses instead of opportunities.

(Keith Banner is a writer who lives in the Cincinnati area. He also works as a case manager with people who have developmental disabilities.)

<u>ABOUT NATURAL CONSEQUENCES</u> Sandra Landis

(Editor's Note: The article that follows was originally printed in *The Safeguards Letter* in July, 1989. It is reprinted here, with Sandy's consent, because the issue it discusses still regularly appears. JRP)

I've been thinking about the idea of natural consequences lately. My thoughts have gotten focused there as I've listened to several public discussions about supporting people with disabilities in more independent lifestyles. In these discussions, "using natural consequences" has been suggested as a way of <u>helping</u> people. I've been troubled by what I've heard.

Natural consequences fall into the category of things I regard as relative--in this case, relative to one's past experience and current situation. Both the current situation and past history of people who are labeled as poor, old, handicapped, neglected, Third World, etc. are radically different from those that many others of us enjoy.

What I find troubling in these conversations about helping people with disabilities to live more independent lifestyles is that the helpers act as though the "natural consequences" of events <u>aren't</u> relative. The assumption is made that what happens to you or me in a situation is probably what people with disabilities will experience in a similar situation.

I hear no acknowledgement of nor accounting for the difference in personal vulnerability that nearly always exists between you or me and someone who has disabilities, is poor, or old, or inexperienced. It seems to me that we've learned that being labeled by others increases a person's vulnerability. We've also learned that "natural consequences" impact a person's life and experiences in proportion to one's state of personal security/vulnerability. Some people get far more than their share of natural consequences, and the consequences they experience are usually much graver.

I am almost always a bit surprised and then dismayed at how difficult it is to keep that understanding alive in my mind as I live my day-to-day life. One place in my life where I seem to have a particularly difficult time keeping my thinking straight about this difference in vulnerability is the area of finances. I've always considered managing money a necessary chore. For example, much of the time I think of myself as a perpetual cash flow shortage manager. It seems that I spend quite a bit of my time thinking so much about how to keep our little system operating. I begin to think about people who make a lot of money, who seem to have money to throw away or people who have a lot of money to invest. I slip into thinking that I know what it's like not to have much money. I think I can identify with someone who is poor.

And then something happens to remind me of my relative prosperity and the real poverty of someone else. I am reminded of the relativity of natural consequences.

Several weeks ago, I got a call from a friend. He wanted some advice about a dilemma he was facing. The month before, he was fired as the maintenance person at the apartment complex where he lived. His job had paid for the apartment, so he had to leave the apartment. He got another job but couldn't get another apartment without cash and references. He'd been working as many hours as he could get scheduled and was "living" at his place of work. That was becoming a problem with his employers and the security people. He'd been told to get a place and a shower, or no more job.

About seven weeks ago I got my most recent paycheck. I'm used to getting one every couple weeks. While I expected a somewhat longer interval between checks this time, I didn't think it would be such a long interval. Since I didn't adequately anticipate the delay and compensate for the resulting lack of cash, I experienced a cash flow crisis. I couldn't pay some of my bills on time, not could I estimate, with any confidence, when I would be able to pay. After getting a pink slip from the bank, I called the banker to explain why I hadn't made the mortgage payment. I blamed it on the bureaucracy and on the purchase of a tractor my spouse had fallen in love with. The banker chuckled, assured me that there was no problem, and asked me to send the payment when I received a check.

In our own ways my friend and I have each experienced the natural consequences of being short of cash. My friend lost his home and his job, and his reputation continues in jeopardy at best. I've been mildly embarrassed, somewhat inconvenienced, and very conscious of my good fortune. Quite a difference!

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

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

Until vulnerable people have in place the natural supports that most of us enjoy, reliance on "natural consequences" seems a risky helping strategy. In the continued absence of natural supports, "natural consequences" turns out to be just more way of contributing to the hurt that people experience.

Sandra Landis

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Teeth

Today in class
we talked about teeth
I had not thought
of them as symbols before.

There are welfare programs
that help pay medical bills
but there are not programs
that pay the dentist
if you are poor.

So the poor wait
in silent desperation and hope that they can
bear the pain until it passes
but sometimes it doesn't pass
and they find themselves
as emergency walk-ins
waiting again
for the dentist
to come and stop the pain

She sat in class
her flushed cheek swollen
and throbbing
with a pain so intense
you could almost hear it beating.
She had three teeth pulled
the other night.
She knows that part
of one pulled tooth
is still there.
She can feel it with her tongue.
She thinks that perhaps
the dentist missed it
because he was in a hurry
and late for a meeting
and two other "emergencies"
were waiting for him.

She remembers
that it didn't seem to hurt
so much last time
and wonders if the dentist's hurry
could be the reason.
I asked her why she
didn't call the clinic that
is down the road
and get something for the pain.
She said that
she was afraid to call them
because she owed them money
from when her kids were sick.
I asked her why then she
didn't call the dentist
who is in another town.
She says that
she has no phone
and it would be a
long distance call
and she has no money
for the call
or for the prescription.

Her teeth could be saved
if she could afford it
but it is too expensive
so she will wait
until the pain comes again
and someday
if she can
she will get dentures
because they are cheaper.

Someone else spoke up
to say that he had
never been to a dentist
in his whole life,
almost sixty years,
and he still had
one tooth.
I wondered to myself
what it would be like
to have just one tooth.
Would none be better?

And I thought about tomorrow
and the dentist
where I will go
in broad daylight
with no emergency
and the latest in equipment
and plush office furniture
and chaise lounges
instead of chairs
and piped-in music
with individual earphones
and an indoor rock garden
with its own waterfall
and picture windows
overlooking the woods.
All of this
to make it easier
to relax.
This dentist
is not for the poor.
You must pay in advance.

The economics of teeth
speaks for
the power to choose
that belongs to the haves
and the waiting for fate
that is the lot of the poor
in a society that
does not recognize
the injustice that exists
in the disparity of
health care.

Rosalie Borman

(Rosalie Borman lives in Cincinnati. She has worked with families in the Virginia and Kentucky mountains. She now works with people who have developmental disabilities.)

JUST QUOTES

For him, that was the bitterest evidence of defeat--the fact that the citizen, the man in the street, so long as he was prosperous, no longer cherished a sense of duty, of honor, of decency. What puzzled him most were the men who somehow in the midst of unscrupulousness assumed a cloak of honor, men of character and wit and ability, who found virtue and credit in sharp dealing. It was not that they were hypocrites, but that, yielding, they came to believe that bargaining and compromise and bad faith were simply a part of the new system and the new political philosophy and must be accepted as such, for the general good, but most of all for the good of business.… He could not understand placing the holy affair of the government upon the level of business, nor could he understand those men who exalted material success as a God.

Louis Bromfield
The Farm (1932)

What does it mean that the 7-Eleven and the emergency room are atmospherically similar? The emergency room is the true domain of necessity, the place where there is no drawing back before the bleeding wound, the broken bone, the last-minute contractions. But a Pop-Tart, a six-pack of Coke in the middle of the night? We have come to believe that convenience is necessity. What begins as slogan, words sprayed on the surface of things--billboards, labels, magazines--becomes visceral, and if we can't find it now we feel a knot of anxiety, frustration. We are thrown back on a world that has its own rhythms, that doesn't immediately bend to meet our yen to eat a candy bar or have a shirt pressed.…

Noelle Oxenhandler "Fall from Grace"
The New Yorker, 6-16-97

"…then God took pity on him, ran down the road and embraced him and took him to his eternal home."
Bill Clarke on Henri Nouwen

VIEW OUT THE BACK WINDOW "A Miscellany (Catching-up on Notes in the File)"

Managed Care Hurts. We've heard a little less about managed-care of Medicaid-funded services for people with developmental disabilities lately. Probably that's because the federal treasury currently seems awash with cash. It's likely, though, that the interest in managed-care approaches will revive when "the economy" is less robust than economists say it is now. Noteworthy for that revival of interest, then, are the results of a study published in the *Journal of the American Medical Association* (September, 1996) that indicate that the health of poor people and older people declines more rapidly when their "care" is "managed". At least, that's what the poor people and older people themselves reported to the researchers during a four-year study. These results don't predict high levels of satisfaction or success for "managed care approaches" among people with disabilities. (Aside: how could the lives of people with disabilities become much more "managed" than service-agencies have already made them?)

How about Some Radium Crunchies? The December 31, 1997 edition of the Boston *Globe* contained a story about the award of $1.85 million to former residents of Walter Fernald State School who were fed "radium-spiked breakfast cereal" in experiments sponsored by M.I.T. and Quaker Oats during the 1940's and 1950's. Interestingly, my local paper--the Hamilton *Journal-News*--carried an AP "brief" about this story on New Year's Day, but the "brief" failed to mention that the "students" at Fernald School were individuals with disabilities.

This story, like the ones of the Tuskegee experiments regarding syphilis and the Willowbrook experimentation about hepatitis B, reminds me that, as dangerous as the life of a person with disabilities is, the danger increases when people with disabilities are gathered together into large groups and situated at a distance from other citizens. It was, perhaps, this sense of danger that prompted People First of Tennessee to sue that state for the release of people with disabilities from the state's "developmental" centers. Fred Boyce, a 57-year old man who lived as a child at Fernald during the time when the M.I.T./Quaker Oats tests took place, was quoted in the *Globe*. "Anytime they put a drug out on the market, they went in and fed things to people--birth-control pills, high-blood pressure pills,... It was very convenient for the drug companies." Having been caught administering potentially lethal (in those days, who knew?) substances to very vulnerable people, academic giant M.I.T. and food giant Quaker Oats (makers of "Mother's Oats") agreed to pay, 40 years later, about $105,000 to each named plaintiff. Not surprisingly, they're having trouble finding all the children who got radium in their cereal 40 years ago.

I don't know how the support laws work in Massachusetts. If, however, a former resident of the Columbus or Orient institutions in Ohio got a similar award, the state would make an early claim on it. The claim would be lawfully enforced. Its purpose would be to re-pay the state for the cost of the "services" the individual received in the very place where she or he might, unknowingly, have received Radium Crunchies.

Starting to be a Grandfather. In a few days, my new, and so far only, grandson will be six months old. The status of "grandfather" always looked like some sort of gift I might get but probably wouldn't deserve. I'm trying to work my way toward being at least a little worthy of it. It's a complication (not an absolute impediment--MasterCard and Delta Airlines help) that Drake (he's named for the English explorer) lives a continent away in California.

I've been lucky to have lots of good demonstrators of the grandfather role (I learned to talk/write that way at PASS workshops), and I've determined to follow explicitly the guidance of several of these. My dad and my great-uncle Earl both showed me, for example, how fly-fishing (or, really, any kind of fishing) could be a medium for sharing trust, companionship, and love. Norman Maclean wrote about that too. So I've resolved to pick up a fly rod again after many years. So far, I've progressed as far as getting some of the equipment, looking longingly at alluring catalogs from Orvis and L.L. Bean, and going to some lectures about fly-fishing at a Cincinnati outdoor sports store. A friend once reported trying to get a camping merit badge from the Boy Scouts by writing a paper about making a camp, in lieu of going out into the woods. My return to fly-fishing has been mostly like that so far, but I vow that by April my casting arm will be stronger and my feet will have been wetted by a stream. I'll keep you posted, if you're interested.

My other model for grandfathering was my other grandfather, whose business was the sale of groceries to small stores in tiny towns in north central Ohio--towns with names like Polk, Redhaw, Nankin, and Savannah. He traveled to these and many other small towns, taking orders for canned goods and other stuff that I can't remember. Once a week or so, he had to stay overnight away from home. When he did that, he wrote letters to me and my sister on the stationery of The American Hotel in Wooster, Ohio and then went right out the same evening and posted the letters at the depot. I know this because I have a stack of those letters, which are mostly about the weather, his daily business (mostly hard), things like animals or trains that he saw along the road, and his affection for us. Remembering those letters, I knew that letter-writing is an important and happy responsibility of a grandfather. I think that Drake received his first letter from me; at least, that was my aim. My intent is that, by the time he can read, there will be an interesting stack of letters to browse through.

But now, this particular view out the back window has to come to an end. I've just realized that it's been two weeks since I wrote to California. Important business awaits.

Jack Pealer

OHIO SAFEGUARDS
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THE SAFEGUARDS LETTER

A Publication of OHIO SAFEGUARDS

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BACK AGAIN

This time it's been more than a year and a half since you've seen a new edition of *The Letter*. Three or four years ago, we changed our promise about how often you'd see this little publication. At the beginning (1986), we said we'd do this four times a year, and we stuck to that for several years with few delays. Then, the lives of those who assemble *The Letter* changed, and the promise became one of an "occasional" publication. Twenty months probably stretches the definition of occasional. But, here we are again. We'll make no new promises about frequency. "Occasional" seems to fit. Promising no more than "occasional" fits with a dilatory quirk in the editor's character (see the "Just Quotes" segment on page 4 for a pinch of the editor's self-criticism). And, as a small benefit to research, the occasional nature of this effort is a regular test of the ability of the US Postal Service to keep track of readers who move, sometimes more than once, between *Letters*. About 220 people receive *The Letter* . If we get no more than about 10 of them returned for inaccurate addresses, either the Postal Service has found you or you've stayed put, and either of those results would be good. Some of us just need to stay put, while others deserve to be found. Anyway, we're back again.

A REVIEW

Gallagher, Hugh Gregory. By Trust Betrayed (Patients, Physicians, and the License to Kill in the Third Reich). Arlington, VA Vandamere Press, 1995.

Those of us who try to understand the forces that keep people with disabilities from full and valued participation in our communities or in our society should be grateful for Hugh Gallagher's readable review of the Nazi program that intended, between 1939 and 1941, to kill Germans (and others) who had disabilities. (Note: Gallagher makes it clear that, although the program officially ended in 1941, it unofficially continued until 1945.) Despite occasional sloppy editing, Gallagher's book clearly surveys the "Aktion T-4" program --from its antecedents in German and American psychology and biology to its denouement at the Nuremberg war-crimes trials.

Gallagher leaves no doubt that Aktion T-4 (the program takes its name from the address of the Berlin building where it had its headquarters--Tiergartenstrasse #4) was a consciously developed program of the Nazi regime. Adolf Hitler personally created this program by means of a "secret" order dated September 1, 1939--the same day as the invasion of Poland and the beginning of war; this order authorized physicians that "persons who, according to human judgment, are incurable can, upon a most careful diagnosis of their condition of sickness, be accorded a mercy death." (Gallagher, p. 16) By 1945, more than 200,000 individuals with physical, mental, and/or emotional disabilities had been collected from their institutions by an efficient bureaucracy, transported to other hospitals or institutions, gassed, and cremated. The efficient bureaucracy then issued fraudulent death certificates and faithfully notified individuals' families of their deaths and cremations. Each family was provided with a package of what was purported to be their loved one's remains from the crematory, although, because the cremations were en masse, no such identification could have been possible. The volume of smoke coming from the chimney of the Hadamar institution (photo following p. 156) is testimony that Aktion T-4 was a large-scale operation.

Gallagher summarizes the involvement of members of various German professions in either carrying out or standing against Aktion T-4. None of the professions (medical, legal, clergy) particularly distinguished itself as a group. Aktion T-4 was, however, primarily a program to be implemented by doctors. Gallagher notes

> It must be pointed out that, while the Nazi period was certainly unfortunate, the errors of the euthanasia program were few; and

> there was no confusion whatever about its purpose. This was a program in which doctors killed their patients. (p. 216)

Gallagher reports on several efforts by local prosecutors and judges in various locations throughout Germany to charge hospital/institutional killers with crimes. Hitler's order, being a secret one, was not published in any government bulletins or law journals, so attorneys and judges were ignorant of the official sanction for Aktion T-4. Once they found out about this sanction, however, most legal professionals cooperated

> Charges against the doctors, brought by relatives of the deceased and by prosecuting attorneys, were ordered quashed. Inquiries and protests were ignored. Cases against untimely dead defendants were dropped. The records of vanished wards of the court were simply filed away. At this wholesale prostitution of justice only one judge is known to have protested. (p. 174)

Christian pastors--both Protestant and Catholic--were, according to Gallagher, the most likely protestors or challengers of Aktion T-4. They seem not to have protested in great numbers, but Gallagher cites several outstanding examples. Pastor Paul Gerhard Braune, an official of the Protestant "Inner Mission" produced and submitted to high military officials an accurate report of the institutional killings, but his report had no effect. Pastor Friedrich von Bodelschwingh, head of the Bethel Mission (a large institution) refused to submit requested information on people living under his care; many fewer of them died. Bishop Clemens August Graf von Galen, bishop of Munster, delivered (and arranged wide dissemination of) a ringing sermon against Aktion T-4 on August 3, 1941; on August 24, 1941 the Aktion T-4 program <u>officially</u> ended, again by means of a secret order issued by Adolf Hitler. One of the benefits of Gallagher's book is the inclusion, as appendices, of both Pastor Braune's report and the Bishop of Munster's August 3, 1941 sermon.

I learned from Hugh Gallagher's book that Aktion T-4, at least at its beginning, had something in common with ideas that I hear discussed in today's news. At its start, the deaths to be delivered by physicians operating under Hitler's order were for <u>Germans only</u>. That is, these deaths were seen as a form of "mercy" that was only to be made available to the more favored members of the class of people who were in hospitals and institutions. This restriction of the privilege of a merciful death faded quickly. Stories in today's news tell of the "mercy" that is available via physician-assisted suicide (the Nazis never thought of that wrinkle) in Oregon and maybe soon in Michigan and other places. Folks like members of "Not Dead Yet" and others who are deeply suspicious of the quality of the "mercy" of a Jack Kevorkian have an ally in Hugh Gallagher, whose book reminds us that, once before, taking the side of euthanasia led to mass death and to the judgment of guilt at Nuremberg.

Jack Pealer

<u>About THE SAFEGUARDS LETTER</u>

<u>The Safeguards Letter</u> is an occasional publication of OHIO SAFEGUARDS. The <u>Letter</u> 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 <u>The Safeguards Letter</u> is under OHIO SAFEGUARDS' copyright (©) unless otherwise attributed. Letters, ideas, and items for publication in the <u>Letter</u> can be sent to Editor, <u>The Safeguards Letter</u>, P.O. Box 18-181, Fairfield, Ohio 45018. We welcome our readers' ideas and reactions.

WE GET LETTERS

February 27, 1998

...I'm writing to tell you how much I enjoyed Sandy's thoughts on natural consequences (the whole letter, actually--all of them really) and to ask your permission to circulate it to a few citizen advocates and other people in our life who I have had similar discussions with or with whom I need to have such discussions....

Eight or ten years ago I was making a road trip from the Athens of America (Columbus, Indiana) with my kid sister. An important objective for me was to visit Malabar Farm (yes, I got to sit on the Bogart-Bacall honeymoon bed). In 1970 I bought my first farm and since neither my wife nor I knew much about farming I went to the library where I learned about Malabar Farm in its post-war restoration period. The farm went the way of sad divorce settlements and college tuitions, but the lessons I learned with Louis Bromfield as my mentor have mostly stuck. Thanks for the quote from *The Farm.*

Chuck Burkhouse, Norristown, PA

I moved and stopped receiving your newsletter. In the craziness of rehabbing a house, I forgot about you for a bit.... I've always enjoyed hearing from you--you provide a much needed voice of feeling and personalization in a field that has become too "professional" and aloof and too forgetful of where we have come from.

I work in a pristine, highly regarded program. A loving mother came to us in tears. An "expert" had told her that the way to solve the problem of her seizuring, profoundly brain-damaged son's biting his gums till they bled was to have all his teeth pulled. I was shocked. All I could see were the toothless faces of all those 30 and 40 year olds coming from the old institutions! I said "if he weren't disabled I know they could help you find another solution--don't accept this. He's only 1 year old!" My professional colleagues couldn't understand my concern. " They are only baby teeth. He'll never talk, etc., etc." I just kept seeing those toothless faces and wondered if this well-meaning "help" was how it all started--that we began to accept "solutions" for "them" that we'd never consider for "us".

A Reader from the Midwest

JUST QUOTES

Long toil and small leisure are part of the heavy price we pay for our North American standard of living. It is reputed to be the highest in the world, and so it should be, for it is bought at an inordinate price.

Robertson Davies
A Voice from the Attic

Education is a great shield against experience. It offers so much, ready-made and all from the best shops, that there's a temptation to miss your own life in pursuing the lives of your betters. It makes you wise in some ways, but it can make you a blindfolded fool in others.... (E)ducation is just as much a barrier between a man and real art as it is in other parts of life.

Robertson Davies
World of Wonders

(These remind me of myself. JRP) He (William Prescott) did not like to work. He had to make bets with his secretary that he would write a certain number of pages or carry out some other resolution. He was always making resolutions, never too old to make them; and he was never old enough to keep them.... (Of William Henry Channing) ...a mystical enthusiast, like Dr. Channing, but without his uncle's will, irresolute, introspective, the victim of innumerable intentions, a talker and taker of notes who longed to be "useful".

VanWyck Brooks, *The Flowering of New England*

YES, SHE KNOWS SHE'S HERE by Nicola Schaefer A Review by Judith Snow

(Note This review has previously been published by Inclusion Press and is reprinted here by permission. Find information about Inclusion Press at http//inclusion.com *or by writing to 24 Thome Crescent, Toronto, ON M6H 2S5 Canada)*

So what's so unusual about a young woman moving out and setting up her own household in the company of four or five friends?!? Why would her mother write a book about it?!?

Catherine Schaefer is the subject of Nicola Schaefer's first book, *Does She Know She's There* and now an update, *Yes, She Knows She's Here.* Catherine has forged ahead in living her life--ordinary in many extraordinary ways. Catherine does not speak in conventional words although she is articulate in her own ways. She doesn't move her body much though she moves people and governments. Catherine has intellectual impairments and her compassion and wisdom are legendary.

Through this book we are treated to the ground breaking work that Catherine, her friends and family have accomplished in buying an ordinary home and setting up a supportive household. In the late 90's, living in one's own home is still controversial in the world of disability, particularly for an individual who doesn't speak in words and who participates with 24 hour per day support from others. Catherine has been on this path for more than eleven years. Along the way she has garnered an ever increasing crowd of close friends, admirers and well-wishers. "Cath" has opened the way for less feisty souls by doing what hadn't yet been done and by continuing to succeed at it in fine style in spite of bureaucratic barriers, her own health challenges and plain old human feelings.

Nicola Schaefer is the mother of this daughter who could easily be rejected by everyone, including her own family. Nicola's buoyant words describe a story of innovation and perseverance that led to her daughter having a fulfilling life as a young woman interdependent and participating fully in her own community. Nicola's tale of the trials and the victories is fascinating and important. She teaches us what it takes to turn an avalanche around.

The story of the policy and technical triumphs is important. So is the tale of Catherine's life in her own home. The recounting of the other family members' progress is intriguing. But the best part of *Yes, She Knows She's Here* is the way Catherine's voice sounds throughout.

I have long admired the mystery of communication that people who don't use words often open up for or ask us to experience. Frequently we hear that " the nonverbal" have a disability--one that is to be ameliorated with therapy and technology. Yes, Catherine tried all that! What shines through this glorious book is the manner in which Catherine has opened up the minds, hearts and spirit of person after person. Through her attentive silence, her joyous laughter and gestures, and her deep appreciation of life lived in the moment in partnership with other people--through simply being herself Catherine has brought happiness, healing and opportunity to countless others.

Thank you, Catherine for being the amazing pioneer that you are! Thank you, Nicola for being the inspiring leader that you are! And thank you for letting Catherine reveal her wisdom and love through your words.

Judith Snow

THE POWER OF ONE

Tom Kohler

Tom Kohler is the long-time Citizen Advocacy Coordinator with Chatham-Savannah Citizen Advocacy, Savannah, GA. This article is reprinted with permission from Vol. Nine, No. One of Citizen Advocacy Forum, P.O. Box 86, Beaver, PA)

It is a Sunday afternoon, a few hours before the Jewish New Year begins. A small group of people of varying ages, races and backgrounds gathers in an interior room at the May Street YMCA.

We have come together to celebrate the 95th birthday of Miss Addie Reeves, a woman whose strength, love and generosity have touched each person in the room.

We are her disciples. Even though we do not all know each other, we are immediately linked because of this woman. She belongs to all of us--by action, involvement and leadership.

Ms. Reeves takes a seat at a table laden with casseroles, and cakes, each made with love and brought for the celebration. Next to her sits Waddie Welcome, a man with piercing eyes. He is the reason many of us have had the privilege of knowing Ms. Reeves. Ms. Reeves and Mr. Welcome have known each other for more than 50 years. Mr Welcome has needed "someone to worry over him" since his mother died 40 years ago, and that is what Ms. Reeves has done.

The program for this day honoring Ms. Reeves is simple. We will share prayers, songs, stories and food. The day starts slowly as many of the members of Ms. Reeves' church are involved in a program at a neighboring church. The group grows from a few to 30 by the time the program begins.

There are prayers and songs. The prayer asks for God's blessing. The song proclaims God's love. The words flow from the heart. Nothing is rehearsed. Two men, one from the church and one from the disciples, stand to praise Ms. Reeves. Each speaks of her kindness, sense of family, outstanding cooking and outstretched hands. As these men tell their stories, little outbreaks of knowing laughter punctuate the room. The master of ceremonies asks for words from others.

A man, a stranger to us, stands. He has heard of this gathering by simple chance. He and his family made sure to come. He lived across the street from Ms. Reeves in Yamacraw Village. She set a place for him at her table every night, a plate and a cup turned over, waiting for him to stop by, turn it upright and share dinner. She is his "second mama." Ms. Reeves would sometimes come get him when his mama was "cutting his behind." He also tells us that Ms. Reeves would dress up in costume every Halloween and "scare the pants off the children." That was more than 40 years ago, and he is now 48.

Another raises her hand. This woman tells how years ago Ms. Reeves took her around to show her how to look after sick people. Over the years, Ms. Reeves has looked after hundreds of people. She does this in many ways over the telephone, calling to check on friends in ill health; by visits; or by moving into a person's home and nursing him or her back to health.

Another woman tells of taking this way of caring into the community and her church. Using Ms. Reeves' example, she started a mission society in her church. Many acts of responsibility and kindness can be traced to Ms. Addie Reeves.

A prayer is offered, the buffet line forms and the food is shared. Two young people, moved by what has been said, speak with Ms. Reeves and Mr. Welcome. They have had enough of seeing Mr. Welcome in his room at the nursing home. They know he needs a place to go. They know he is 82 years old and that his deep cry has been to leave the loveless and careless confines of the nursing home. They offer their home.

The Power of One... over time... by example... in a thousand quiet ways... to live the life of faith and committed action... to do small things with one person... and to allow others to grow braver and stronger by watching. The Power of One.

What a power to do good do we all have? Can we do it as quietly, gently and elegantly as this woman? That is hard to know. Can we do it? That is easier to know.

Tom Kohler

SELF-COMMODIFICATION

(Produced by the Center for Economic Policy Analysis [CEPA] 202 S. State Street, #1302, Chicago, IL 60604 and funded by the Connecticut Council on Developmental Disabilities. Text by Mike Ervin; edited by Jason Hardy and Art Lyons. Reprinted by permission.)

Let us hazard a definition of the word *commodify* 1. To reduce a person to the level of a commodity. 2. To dehumanize.

People with disabilities know all too well what it's like to be commodified. Archaic social policies determine our worthiness according to our economic viability, as if we were commodities. We are institutionalized, segregated, prohibited from taking control of our lives by the cold perception that the return doesn't justify the investment.

People with disabilities have engaged in a lot of self-commodification too. It happens when we attempt to state our political agenda in terms of economic rather than human benefits. It's tempting to try to win policy-makers over to the virtues of deinstitutionalization, inclusion, independent living, and self-determination based on the fact that these are often much more cost-effective than the alternative. We accept our commodity status and try to make it work in our favor. But in the long run, that's a losing strategy. Our humanity must always be the first and foremost justification for our right to serve and be served.

Why do we do it? What makes us, as advocates, self-commodify?

Maybe it's restlessness We want results and we want them bad. We believe if we can win in a concrete battle of numbers, case closed. Nothing left to argue. Change will occur.

Maybe it's embarrassment We're all raised not to be seen as pushy or demanding. We don't want to be too much bother, especially for our own personal needs. The economic forum is much more objective, civilized, and dispassionate.

Maybe it's pragmatism We believe that whereas economic justifications don't always work, the work sometimes. Any advancement is better than none. We take what we can get. Pragmatism sees idealism as the enemy.

Maybe it's the dependency paradigm We feel accepting what's offered, not empowerment, is the answer. What society at large chooses to bestow upon us is all we deserve. We see commodification as our lot.

Maybe it's elitism We believe a fair society is one where people with disabilities who require the least support should compete and win. We are unwilling to champion the rights of other disabled people who have less money, education, family support, or physical and mental ability. We see them as sad casualties. We allow them to be commodified.

Maybe we underestimate the policy-maker We automatically assume all policy-makers are jaded and won't understand if we remind them that we, like everyone, are human beings.

The problem with self-commodification.

It doesn't challenge fear The predominant emotions some people feel toward the reality of disability are fear and pity. Unwilling to cope with these emotions, people commodify us. To refuse to be commodified is to encourage them to overcome their fear.

It falsely assumes rationality prevails The hard fact is, some people have strong incentives to keep people with disabilities powerless. True freedom of choice means less money for owners of institutions because few people would choose to live in institutions.

It's not always true Community supports for some people with severe disabilities will always require large public expenditures. Do these people deserve nothing more than a life of institutionalization because they are not cost-effective?

It breeds poor quality services When cost-effectiveness is the first criterion service providers must meet, cutting corners is encouraged. Neglect spreads. The cheapest public policy is to do nothing at all.

It's the other guy's ballpark Numbers lie. Smart businesspeople and bureaucrats can manipulate statistics to support any position.

It's susceptible to market whim What's cost-effective today may not be tomorrow. So any victory is tenuous.

Our humanity never changes. Policy rooted in human rights never loses its reason for being.

The Price

There is a sharp class dichotomy in the disability community. Life has never been better for some. Their lives are rich and full of opportunity. But many others still find themselves locked in institutions or stifled by paternalistic systems, with no more freedom or opportunity than disabled people of the last century.

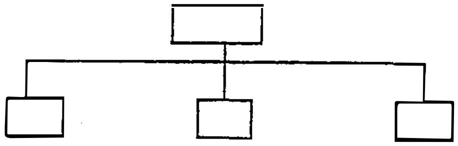
This is not true liberation. True liberation will occur only when we get what we need not because we are cost-effective, but because we are human beings.

Our unified message is clear and simple We, like everyone, deserve the best.

VIEW OUT THE BACK WINDOW "Image for an Organization"

For the past seven years, I've worked for a pretty big organization. Nearly every year, like many other organizations, the agency where I work publishes an official revision of its table-of-organization. Tables-of-organization are images or pictures of how a formal organization sees itself working. Long ago, it was Wolf Wolfensberger who first made clear to me the customary discrepancy between how an organization envisions itself and how things inside the organization actually work. The day-to-day world often adds lots of squiggly lines to the "org chart".

In a time when both the organization where I work and lots of other organizations that have tried to offer service to people with developmental disabilities are reconsidering their shapes and functions, in view of the needs or demands of the people some now urge us to think of as "customers", it occurred to me that it might be useful to give thought to the images that we use to portray how our organizations either do or are supposed to work. Below is the customary picture of a formal organization; it is certainly, in simplified form, the picture that we have relied on when we want an image to depict organizational shape. As far as I know, this particular shape, which can be symbolically cast in shorthand as a "pyramid" (the graphic shorthand that I usually use to stand for a formal organization) has its origin in the military, with its emphases on chain-of-command, lines of reporting, and at least theoretical accountability.



I think its worth asking ourselves whether this picture of an organization fits either the futures that we see for the people with whom we work or the new missions for support agencies that those futures may imply. I can think of several reasons why the pyramid doesn't fit.

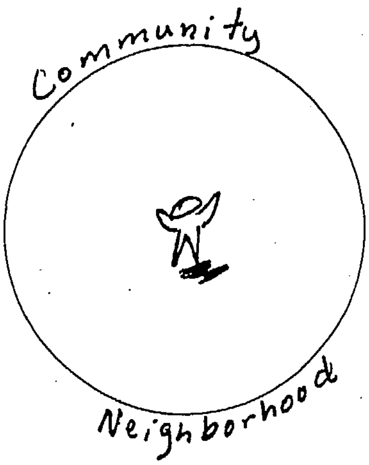
- The usefulness of the image of the organizational pyramid is connected to the assumption that we have control over all of the forces with which we have to deal in order to work toward an organization's goals. Such forces include money in "sufficient" amounts, the uniform performance of workers, the unambiguous response of communities (e.g., employers, schools, social agencies, associations, etc.) to our efforts. Clearly, we do not have such control. Our agencies are part of what organizational thinkers have called a "turbulent environment".

- The organizational pyramid implies that command-and-obedience are the drivers of performance. As organizations grow larger, more complex, and as they work within larger territories (e.g., not just buildings but entire communities), the illusion of command-and-obedience fades. Tolstoy pointed out that command-and-obedience often fails even in a military context; see the postscript to *War and Peace* for his thoughts on the matter. How much less will commanding work in small, spread-out organizations that have the ambition of supporting a variety of people with increasingly personalized responses?

- The pyramid design has the unfortunate effect of pushing the responsibility for really hard choices upwards along the reporting lines. Regardless of whether the "king" of this kind of organization wants to rule, the logic of the design says that the way to get things done is to cause some kind of reaction or distress for the king. The king will then issue the right command so that problems can be resolved. No king (even a smart and very experienced one) has that kind of wisdom.

- The pyramid shape has no logical place within it for a person who uses services or supports. Such a person does not usually appear on the tables-of-organization for social service agencies. The implied place, in many human service organizations, for the person who uses services is at the bottom of the table, beneath the authority of the directly-helping staff members. Newly restated visions for the citizenship and dignity of people with developmental disabilities don't accord well with this image.

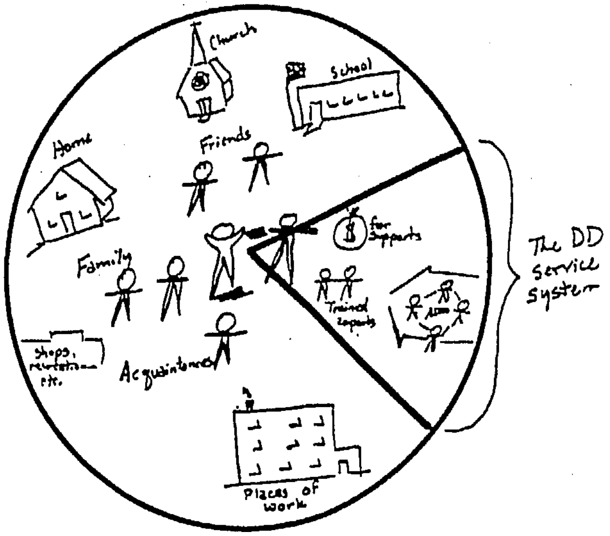
Isn't it time to find other images for our organizations?



For the sake of stimulating thought and maybe argument (not a bad thing), let me propose another image---another shorthand symbol that might, by virtue of its shape, more accurately represent the way that organizations seem to want to assist people who have disabilities. Suppose that we start with a person who has a developmental disability and that person's community. In concert with the missions of many agencies, suppose that we want the person to enjoy full citizenship and participation in the life of her/his community. Suppose that the circle at the left represents the community of which this person is or might become a member.

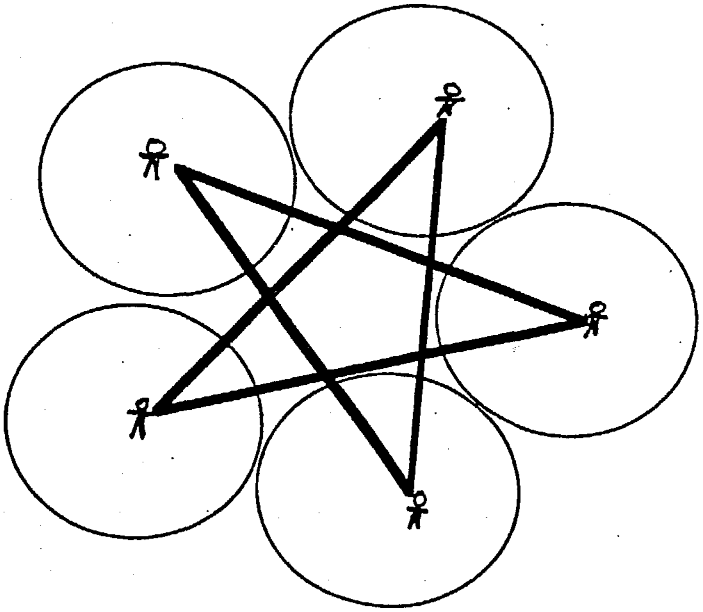
Supportive organizations exist because people with developmental disabilities have had difficulty in managing community life without help. The difference between support organizations now and earlier such organizations established to offer help is that now most supportive organizations say that they want to provide help to people right in the places where the people are--in their homes, within their families, in places of ordinary work, school, etc. So, our supportive organizations are part of the communities that we're trying to affect, and in those communities we try to carry forward relationships of support to certain people who can benefit from such relationships.

Any of our agencies might, then, be seen as a slice or wedge of the community that has a particular interest in a person primarily by virtue of that person's disability. At the tip of that wedge, next to the individual who uses the support that we offer, is another person (or it could be a group) who is that individual's main contact with the work of the agency or system. Call that person standing alongside, oh, a "case manager" or "service coordinator". Or call that person an advocate, or maybe call the person mom or dad or brother Steve or Aunt Phyllis. Whomever we find in the alongside position is a key to organizing supports that the "focus person" may want or need. Maybe we could see the person standing alongside as the chief interpreter to the agency or system of the individual's wants or needs. Let's look at this in a diagram.



I think that the wedge or near-triangle on the right side of this diagram may be thought of as the developmental disabilities service system **particularized** for this specific person. Haven't we promised personally or individually designed supports for people with disabilities for a long time? From inside this wedge flow to the individual the funds that pay for necessary supports, the trained experts who bring their special knowledge and experience to bear, the administrators (accountants, human resource specialists, planners, etc.) who enable things to work . This circle with a wedge may be seen as a close-up, high resolution view of the developmental disabilities system. This is how the system might be portrayed as it applies to just one person.

Suppose that we retreat to the middle distance. How might this developing image of an organization look from a little farther away, when we have more than one individual with disabilities to consider? If we take the depiction of the particularized system above and cluster it with a few other similarly-organized depictions, we might end up with an image like this



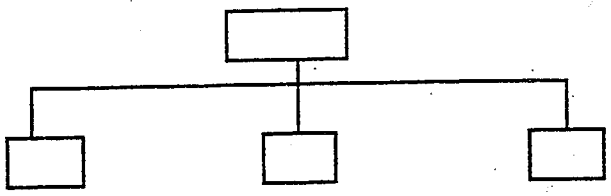
Things start to get complicated when we begin multiplying the number of people to whom a worker or group of workers might have some responsibility. The image of a circle with a demarcated wedge has now, by means of this multiplication, turned into a star. If the function of administration is to enable useful action within each of the circles--that is, within an individual person's life in community--then how will that administration occur? The force that impels decisions can no longer be said to be the receipt and execution of instructions from above. Now the force has become the terms of the agreements reached by individuals and their circles that exist within community. This shift might make us ask

- How do "direction" and "accountability" work in an organization that's a star and not a pyramid? How will people doing administrative or supervisory work know what to do? How will they know whether the things they do are the right things? If they are the right things, how will the doers know how well they are doing them?

- How will the circles connected to the "points" of the star relate to one another? How will I as either a supportive or administrative worker know how to divide my time so that each person assisted by my work unit (this is what the star may represent, as an organizational image) gets a needed or fair response? Note that what's needed and what's fair are not necessarily the same.

- How many points can a star have and still be a star? In other words, how many individuals can a work unit arrange its effort toward while staying coherent and functional? In the image above the star has 5 points. It may be unlikely that any work unit can redesign itself so that it attends to just 5 people. But, how big can a work group get before its identification with the individuals supported gets lost--before it loses touch with the circles and individuals who are its reason for being?

Finally, let me push this image just a bit further. If we were to retreat a greater distance to look at an organization that tries to support hundreds of people with the star, instead of the pyramid, as an organizing image, what we would see is a constellation. We'd see lots of stars, of varying intensities (at least from our point-of-view), arranged in patterns to which we might give names. There are two things that I think are interesting about the image of a constellation. First, the names for them change, according to what people in different places and times have wanted the constellation to represent. In other words, the pattern is interpreted as being one that is useful to "us", for purposes that we have in mind. So should the organization that supports people with disabilities be shaped in congruence with our purposes. Second, I've looked at the night sky quite a bit, and I've never yet seen a constellation that is shaped like this



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