# The Safeguards \_\_Letter\_\_

DECEMBER, 1986

a publication of OHIO SAFEGUARDS • P.O. Box 1943 • Chillicothe, Ohio 45601

#### REMEMBER?

A few years ago, for a few months, a modest publication, The Greffsun Letter, existed. The idea behind the letter was to promote affiliation among people who are interested in and thoughtful about those who live outside the sphere of respected community membership that most of us experience on a day-to-day basis. The publication was well received and supported by a number of people. The Letter "died" when the organizer could not regularly meet the demands of even a limited publication in terms of copy and production. The idea didn't die, though, and the interest in a publication has persisted in the minds of a number of people.

OHIO SAFEGUARDS has emerged as the likely association of people to support such a renewed effort. OHIO SAFEGUARDS is a voluntary, not-for-profit organization based in Ohio. In terms of ideology and purpose, OHIO SAFEGUARDS resembles the Normalization Safeguards Project in Massachusetts. To those who risked supporting The Letter, an appeal is made to risk again by supporting the SAFEGUARDS publication. This support could best be offered by writing down stories, ideas, reflections, and/or articles and making them available for print in this new publication. Additional support would be welcomed via subscribing to the publication and encouraging others to read and subscribe. All those who subscribed to The Greffsun Letter will be sent a year's worth of the new publication, at no cost, to replace the issues of The Letter that were promised but never published.

To those of you who continue to be interested in the issues that are likely to be addressed in <a href="#">The Safeguards Letter</a> but who were not earlier subscribers, an invitation to subscribe is issued. Please send inquiries to: Jack Pealer, President, OHIO SAFEGUARDS, P.O. Box 1943, Chillicothe, Ohio 45601.

Sandra Landis

#### A REPEAT OF A POPULAR FAVORITE

Last January, OHIO SAFEGUARDS sponsored a workshop about planning in human services entitled "Design for Accomplishment." The presenters at this workshop were John O'Brien and Connie Lyle of Atlanta, Georgia—two individuals with international experience at assisting organizations seek brighter futures for people with disabilities. Many of the participants in that workshop were trustees of OHIO SAFEGUARDS.

The workshop was so well received and thought to be so valuable to the participants that a repeat has been scheduled for January, 1987. "Design for Accomplishment" will be offered on January 26-29, 1987 at the Fawcett Center for Tomorrow (The Ohio State University). This year, participation is open to any interested persons. The fee is \$200.00. People are encouraged to attend in groups, all members of which live in the same community. To register, contact Jack Pealer at OHIO SAFEGUARDS or phone Jack at (614) 773.3360.

#### About OHIO SAFEGUARDS

OHIO SAFEGUARDS is a voluntary association of people who are concerned about the often-hurtful life experiences of those in our communities who find themselves in the role of "receivers" of human services--people who have disabilities, people who have experienced serious problems in living, and other people who have been devalued by the larger society that surrounds them. The associates of OHIO SAFEGUARDS are committed to complicated but necessary changes in their communities and, therefore, in the human services that are a part of those communities. These changes mostly involve reminding and recalling our communities to act on those deeply held values and principles that make communities satisfying for ALL of their members--values like: tolerance, cooperation, and equal participation in community life by all members. OHIO SAFE-GUARDS was founded on the idea that the "principle of social role valorization" (formerly known as the principle of normalization) offers the best guidance about how changes in community and human-service-agency life can be planned and carried out. A major mission of OHIO SAFEGUARDS, then, is to provide systematic instruction about social role valorization to people (mostly those involved with human services) who know little about this important principle. This instruction is offered through publications (like this newsletter), through the personal work-lives of OHIO SAFEGUARDS' associates, and through formal occasions for teaching (i.e., workshops and seminars).

The members of the OHIO SAFEGUARDS Board of Trustees are:

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Questions about the mission or activities of OHIO SAFEGUARDS can be directed to any of the trustees. Additional information can be obtained by writing to OHIO SAFEGUARDS at P.O. Box 1943, Chillicothe, Ohio 45601.

## ONE RESIDENTIAL AGENCY'S POSITION ABOUT "GROWTH"

(One of OHIO SAFEGUARDS' trustees, John Winnenberg, is also Executive-Director of Residential, Inc. in New Lexington, Ohio. John shared with <a href="The Safeguards Letter">The Safeguards Letter</a> a recently-considered Residential, Inc. policy regarding agency growth and its relationship to the ability of the agency to carry out its mission. We thought that this statement ought to be made available to our readers, because of its unusual attention to serious matters. John agreed that we could reproduce it here.)

I. Growth in Numbers Served. As a part of Residential Inc.'s guided self-evaluation in the Spring of 1983, the organization made a commitment regarding its intention not to grow in numbers of persons served in the coming years. This decision was made in light of the realization that the organization was indeed committed for a lifetime to nearly all of the 24 people being served. Additionally, many of the 24 people considered the people paid to work at Residential, Inc. as their only source of personal support. Coming to acknowledge that Residential, Inc. was indeed "surrogate family" to at least 20 people was an influencing factor in deciding not to let the "family" get much larger.

Over 3 years later, the commitment to not grow in numbers continues to trouble many persons outside the organization who are concerned about the need for "more residential services" in Perry County and in Ohio. In an effort to clarify its policy, Residential, Inc. submitted the following statements to the Perry County Board of MR/DD, which they adopted in their County Plan for FY-87:

We continue to be dedicated to a "no growth in numbers" policy. We feel this is important if we are to continue to improve upon the quality of support we render to the twenty-five people to whom we've committed ourselves. Our posture toward serving additional Perry Countians is as follows:

- a) 1st Priority Attempt to support other individuals or a newly formed organization to extend commitments to new people. We will be happy to assist them in getting started. We would suggest that they help locate persons in areas outside of New Lexington since there is already the potential for 104 people to live here in licensed situations.
- b) 2nd Priority Requests to serve additional people will be considered by our organization on a case by case basis. If we would agree to serve someone it is likely that we would help establish them in an individualized setting (i.e., their own place or a non-handicapped person's or family's place with unpaid roommates and paid assistance preferable).
- c) 3rd Priority If requested or desired by current consumers of our services, we would consider serving persons who would share already established and licensed homes with them. It would clearly have to be in their best interest.

Residential, Inc. wishes to re-emphasize its commitment to the above "no growth" policy and make the following statement regarding pressure being applied by the Ohio Department of Mental Retardation/Developmental Disabilities to fill to capacity the homes they helped pay for:

We will negotiate with the Ohio Department of Mental Retardation/Developmental Disabilities in good faith regarding the use or sale of the properties which they participated in purchasing. However, we will be guided by our "no growth" in numbers policy statement during these negotiations.

John Winnenberg

## A VIEW FROM CHILLICOTHE: "A Weekend with H.H. Goddard," Part I

Several months ago, while I was preparing a talk on the idea of "needs" in human services, I spent a weekend reading several books by Henry Herbert Goddard (1866-1957). You might say that this is a peculiar way to spend a weekend, and I'd be inclined to agree. But Goddard, who is best known as a pioneer in intelligence testing in the United States and as a leading voice of the eugenics movement, seemed a perfect example of a point I wanted to illustrate in my talk—that much of what happens in human services—if not in life at large—results from the seemingly logical extension of certain often—unexamined assumptions. In other words, I wanted people to think about the possibility that what we do in human services is powerfully influenced or even determined by what we unconsciously believe—mostly about the people with whom we work. H.H. Goddard's work offers an illustration of that idea—one that is of particular importance to those of us who work with people who are described as mentally retarded.

I also wanted to spend some time reading Goddard's work out of a sense of fairness. My previous encounters with H.H. Goddard have been through the writing of Wolf Wolfensberger (The Origin and Nature of our Institutional Models, 1975) and Stephen Gould (The Mismeasure of Man, 1981), and these books made me very suspicious of Goddard's work. I wanted to read the originals to try to find out whether my earlier accusations against Goddard (derived mainly from Gould) were justified.

That they were justified was my main conclusion by the Sunday evening of the weekend I spent with Goddard's books. As well, I was much more impressed with how well H. H. Goddard "works" as an example of the idea that unexamined assumptions have often led to strange, unusual, and even abusive ways of offering assistnace to people in need. The remainder of this essay, in this issue of the <u>Letter</u> and the next, will be devoted to an examination of how that idea is confirmed in the writing of H.H. Goddard.

In 1921, Dodd, Mead & Company published what was apparently to be Henry Goddard's textbook on psychology. Goddard was, from 1922 through 1938 a Professor of Clinical Psychology at The Ohio State University. The title of this textbook was Psychology of the Normal and Subnormal, and in its preface, Goddard explained that his conclusions about psychology derived, in large part, from his many years of study of "feebleminded" (a scientific term of the time) persons. Goddard wrote:

These feeble minds were so simple that it was relatively easy to follow the various processes. It was not so easy to work it altogether into a complete picture. Indeed there are many  $\underline{\text{lacunae}}$  (missing spots in our understanding. JRP) which it has been necessary to bridge by more or less bald assumptions. In making these assumptions, we have constantly kept in mind one rule, namely, never to assume anything that was inconsistent with known facts.  $(p.\ x)$ 

By the time this book appeared, it was clear that, for H.H. Goddard, the "known facts" about human beings included the "fact" that the laws of inheritance applicable to pea-plants, as discovered by Gregor Mendel, were applicable in identical fashion to people. For Goddard, moreover, it was a "fact" that feeblemindedness in people and height in pea-plants were analogous phenomena—both were "unit characters" like the things that produce eye-color and hair-color in people. In his most famous book, The Kallikak Family (1912), Goddard poses this issue: "Does this same law (i.e., that Mendel discovered in pea-plants) apply to human beings?... Our own studies lead us to believe that it also applies to the case of feeblemindedness.... We do not know that feeblemindedness is a 'unit character,'".... But on the same page (p. 111) Goddard stated his assumption that feeblemindedness is like hair color or the height of pea-plants. He did this, he said, "for the sake of simplifying our illustration." Elsewhere in The Kallikak Family Goddard observes of his research subjects:

They (the Kallikaks) were feeble-minded, and no amount of education or good environment can change a feeble-minded individual into a normal one, any more than it can change a red-haired stock into a black-haired stock. (p. 53)

It is important to understand what happened here. Goddard made a major "bald assumption"— that feeblemindedness was like hair color — to cover <u>lacunae</u> or gaps in available information. He then proceeded to draw inferences from this nowestablished "fact" about what ought (or ought not) to be done about feeblemindedness, which was, of course, viewed as an undesirable characteristic of people. Two additional quotes from <u>The Kallikak Family</u> should be sufficient to show the outline of the service response that Goddard believed was called for:

A glance sufficed to establish his mentality, which was low. The whole family was a living demonstration of the futility of trying to make desirable citizens from defective stock through making and efforcing compulsory education laws.... The laws of the country will not permit children ten years old to marry. Why should they permit it when the mentality is only ten? (p. 78)

From all this the one caution follows. At best, sterilization is not likely to be a final solution of this problem. We may, and indeed I believe must, use it as a help, as something that will contribute toward the solution, until we can get segregation thoroughly established. (p. 115)

One of the pleasures, if you can call it that, of reading H.H. Goddard lies in its straightforwardness. There is rarely any doubt about what he meant to say.

For Goddard, then, the problem of feeblemindedness, which was caused by the transmission of a "bad" characteristic, presents two major difficulties: 1) identification of feebleminded people, and 2) taking care of them after they are found. The first of these difficulties could, Goddard thought, be surmounted by the widespread use of Binet's "intellignece test." The second could then be addressed by preventing the procreative activity of people found to be carriers of the "bad" unit character. This could be done through either sterilization or sexual segregation. The principal response Goddard proposed for feeblemindedness was colonization of identified people, which, he said, "is not by any means as hopeless a plan as it may seem to those who look only at the immediate increase in the tax rate." (The Kallikak Family, p. 105) Assumptions about people yielded, for H.H. Goddard, certain conclusions about what people needed—they needed colonies. (Part 2 in next edition of The Safeguards Letter.)

Jack Pealer

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Non-Profit Organization
U.S. Postage
PAID
Chillicothe, Ohio 45601
Permit No. 72

# The Safeguards Letter

NUMBER <u>TWO</u>

MARCH, 1987

a publication of OHIO SAFEGUARDS • P.O. Box 1943 • Chillicothe, Ohio 45601

#### SUBSCRIPTIONS TO THE SAFEGUARDS LETTER

Since we issued the first edition of the Letter we have received a number of inquiries about subscriptions. Those inquiries have an easy answer. People or organizations that want to be assured of receiving one year's set of issues should send \$12.00 to OHIO SAFEGUARDS, P.O. Box 1943, Chillicothe, Ohio 45601. The check should be accompanied by a note indicating that it is for a subscription to the <u>Letter</u> (otherwise, we're likely to treat it as a donation and send you a thank-you note). As noted in Issue #1 of the Letter, former subscribers of The Greffsun Letter will automatically be registered as subscribers for one year of The Safeguards Letter. Any other questions about receiving The Safeguards Letter can be directed to:

> Jack Pealer, Editor OHIO SAFEGUARDS P.O. Box 1943 Chillicothe, Ohio 45601

#### WRITERS ENCOURAGED!!

OHIO SAFEGUARDS wants to encourage the readers of The Safeguards Letter to submit items that they have written for publication in the Letter. If you have something to offer to other readers—a story to tell, an issue you're concerned about, a review of a book you've read, etc.—you can send it to us and we'll try to get it in the Letter. Space is limited, so please be as succinct as possible. Submissions will be subject to our editing, but the main thing we're

concerned about is that what we publish be as clear and respectful as possible about the lives and aspirations of people who receive human services.

We'll try to remember to mention, in each issue, the deadline for submissions to the next issue. (The deadline for the June issue is May 15.) We will identify in the Letter the author of each item that is printed. We hope that our readers will "flood" us with interesting news, observations, and suggestions. Send your "manuscripts" to:

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

#### UPCOMING EVENTS

April 20-21, 1987 -- Columbus
"Citizen Advocacy: Enriching
Community Life for Citizens with
and without Disabilities"

Presenter: Connie Lyle, Atlanta, GA.

Contact: Donna Bookman,

Family Advocacy--Perry Co.

(614) 342-4980

May 22, 1987 -- Wooster
"How to Prevent & Reduce the Abuse of
Technologies in Human Services,
Using Behavior Modification as an
Example."

Presenter: Susan Thomas,

Training Inst.--Syracuse U.

Contact: Ernie Fischer

(216) 263–0862

A commitment to assist a person toward positive behavior change must be a long-term one, and the process must be subject to constant re-evaluation. There are many proposed approaches to achieving behavior change. The best ones focus on the context in which the person lives, and they manage not to blame either the individual or her/his caregivers. I'd like to offer a perspective on disabling behaviors (and on the people who "have" them) against which to measure the value of the many theories about behavior change.

Young people experience frequent "hurts"—from the bumps and scrapes of exuberance and curiousity to physical and psychological abuse inflicted by adults. The range of possibilities for harm to young people, who are relatively powerless in the society, is so great that it has touched us all. The degree to which we have survived these hurts to become rational and productive adults is the degree to which we have encountered contradictory messages along the way. The message that says, "If I run too fast, I'll fall and cut my knee," can be offset by the adult who responds, "Give it a try, and I'll be here to help if you need me." The message that says, "I must not be very smart because groun—ups don't listen to me," can be contradicted (if we're lucky) by the message from an adult who asks our advice and does listen to what we have to say.

When there are enough contradictions to balance the hurts, we can more clearly evaluate new hurts as they happen. We can respond creatively and positively. We are less likely to say, "I'm not (fast/good/smart) enough...," and more likely to say, "Something around me is not working right, so I'll try to fix it."

It is safe to assume that people with developmental disabilities have received some messages like the ones most of us have heard when we were young. People with disabilities, however, tend to receive (through their life-experience) other kinds of messages as well:

\*"Promised events won't happen."

\*"Privacy doesn't exist."

\*"Personal possessions—if I have any—will disappear."

\*I'm living here today, but I may not be tomorrow; If I'm to move, someone else will decide and teld me when it's time to pack."

\*Important people will come and go, and, once gone, they certainly won't keep in touch."

\*My displays of strong emotion lead to my being restrained, one way or another."

Someone who wants to help a person with disabilities achieve behavior change needs to figure out what particular distressful messages are operating, and how to contradict them. It is not a contradiction of a hurtful message to move a person with disabilities from an institution to a group home without her/his consent. It is not a contradiction that paid staff are the only non-disabled contacts often available to a person or that the "average staff turnover rate" is one year. It is not a contradiction of a hurtful message when "outbursts" are responded to with drugs.

Contradictions occur when there is respect and negotiation—when a safe place is provided to express "outrageous" emotions. Contradictions occur when time is allowed for safety to be felt, and when new hurts (because they won't stop coming) can receive the full attention of a friend who remains confident that they can be surmounted.

Given enough safety and support, it is within the capability of each person to unload old hurts and adopt new responses to current situations. In spite of our own doubts and fears (about their "pitiful history," their "low functioning level," or their "prognosis" for change without medications) people with disabilities will, given enough contradicting messages, take the lead toward their own brighter futures. I believe that providing enough of these kinds of "contradictions" to prevailing messages is critical to helping us begin to think about assisting citizens who are said to have disabling behaviors.

(Deb Schmieding is associated with HAVAR, Inc.—an organization in southeast Ohio that tries to offer good homes to adults who have developmental disabilities.)

#### ON "BEING OF USE"

Sandra Landis

Recently, I read <u>Ciderhouse Rules</u> by John Irving. This popular book was entertaining. As well, it prompted me to think again about the idea of "being of use." Mr. Irving's characters offer examples of the fact that the decisions a person makes about what constitutes his/her "being of use" in this world can effect a life-defining course of action. Although that sounds a bit dramatic, I tend to agree. I was reminded of my own preoccupation with the idea of "being useful" a few years ago and the changes I've realized in my own life resulting from decisions I made then.

Several years ago, I made the decision to retire from my brief stint as a full time employee. Over the years I had pretty successfully avoided full time employment as my sons were growing up. I had been fortunate enough to find part time work that was satisfying to me and that fit our schedules. There came the time, though, when I felt compelled to "earn" some traditional credentials as a full-time administrator.

I took a job that kept me pretty busy in that role for about four years. I learned a lot about what it takes to manage the work of an organization. I also learned a lot about organizations and the dynamics that influence the decisions, actions, and values of organizations. I came to understand that organizations, even though they're composed of people, don't have the same capacity to act as human beings do.

I was able to think about my tenure in that job as a useful but painful practicum. My graduate education had focused on organization theory and management principles. I had thought a lot about and had studied change strategies and theories as well. The four years I spent trying to put these theories and principles to work and watching most of my efforts fail helped clarify for me the context in which purposeful, focused change can happen. It also strengthened my understanding about how vulnerable this context is.

In short, I learned a bit more about what undermines and defeats change efforts, and what supports and sustains such efforts. I was finally accepting the limits of organizations and discovering the enormous capacity of human communities.

So, my job ended, and I decided to retire! I'd reached the conclusion that it would probably make a lot more sense for me to reframe the way I thought about useful work for a while than to seek another job. I tried to set aside the thoughts

about how much money I needed to earn and what kinds of positions were currently available in the local job market.

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

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

What kinds of changes do I now attribute to this thinking about "being of good use" that I did a few years ago? I left the city and now live in the country. I left the single "lifestyle" and married. I stopped renting a house and began purchasing a home. I don't look for jobs. I try to create useful work to engage in with others. I continue to find this "being of good use" thinking a helpful way to look at myself in this world.

#### OHIO SAFEGUARDS RECEIVES D.D. GRANT

On February 26, 1987 OHIO SAFEGUARDS was notified by ODMR/DD that our proposal to conduct a project during 1987-88 entitled "Training for Designers of Individualized Services" was approved. As noted in the proposal's "summary" the purpose of the project is "...to strengthen local planning and service competency by engaging local planners in developing and carrying out individual plans of service in a context where the quality standard for service is that which we hold for ourselves and those we care for." The project, funded in the amount of \$50,000, will begin with at least 4 regional workshops about personalized planning in Ohio. There will then be a process for selection of two agencies with which OHIO SAFEGUARDS will establish a "tutorial" relationship during the summer and autumn. Project staff will work with those agencies to try to develop and carry out service-plans for just a few people. There will be more information about the project in later editions of The Safeguards Letter.

#### PUBLICATIONS AVAILABLE

OHIO SAFEGUARDS will send, for the cost of copying and mailing, copies of the following reports to interested readers. We offer these items because we think that they deal with issues that are central to OHIO SAFEGUARDS' mission:

"Sports and Relationships." (14 pp.)
-suggestions about the use of
sports as a vehicle to improve
the relationship-lives of people.
-cost: \$2.00

"Forming Circles." (52 pp.)
-PASS assessment report dealing
with organizing community residential services to support
richer lives for people
-cost: \$5.70

"Family Advocacy PASS Report" (42 pp.)
-deals with "mission" and "identity"
in an advocacy agency
-cost: \$4.70

Write to us at P.O. Box 1943, Chillicothe, Ohio 45601, for copies of these items.

## A VIEW FROM CHILLICOTHE: "A Weekend with H.H.Goddard," Part 2

In the previous issue of <u>The Safeguards Letter</u> I described the first major assumption that I discovered when reading many of the works of Henry Herbert Goddard (1866-1957)—the assumption that feeblemindedness was heritable in just the same way that hair or eye color is. Now, I want to finish the story, beginning with Goddard's second assumption about feeblemindedness; this second assumption has to do with people's personal responsibility for their individual actions. Goddard believed that <u>responsibility for one's actions correlated perfectly with intelligence</u>. As he put it in his 1916 book entitled <u>Feeble-mindedness</u>: <u>Its Causes and Consequences</u>:

...there are all grades of responsibility, from zero to the highest; or, there are all grades of intelligence from practically none up to that of the genius or the most gifted. Responsibility varies according to the intelligence. (p.2)

A part of Goddard's argument for segregation of feebleminded people had to do with his notion of their responsibility. In The Kallikak Family, he wrote: "We must separate, as sharply as possible, those persons who are weak-minded, and therefore irresponsible, from intelligent criminals." We have to understand that Goddard was taking what would have likely been seen as a liberal or progressive position from the point-of-view of criminology. He argued that:

- 1. Feebleminded people didn't know and <u>couldn't</u> know the difference between right and wrong.
- 2. Such people were, therefore, more likely to commit crimes (see the quotes below).
- 3. But, although they committed crimes, feebleminded people didn't know these were crimes, and they should not be held accountable for their actions.
- 4. They should, however, be removed from the presence of society and of "ordinary criminals" and maintained in separate places, most likely for the rest of their lives. Otherwise, how could they be prevented from committing additional crimes?

Apparently in order to buttress this point-of-view Goddard wrote a book (published in 1915) entitled The Criminal Imbecile: An Analysis of Three Remarkable Murder Cases. As the title indicates, the book is an examination of three prominent murder trials of the time, one of which Goddard evidently "examined" solely through newspaper reports. In all three instances, Goddard concluded that the "cause" of murder was the unrecognized feeblemindedness of the perpetrator. The peroration for The Criminal Imbecile contains the following observations:

...these few considerations seem sufficient to make it of the highest probability that persons of a mental age under twelve years, like the normal boys and girls of the same age, do not know and cannot be expected to know the quality of their acts. And this is sufficient because the law requires no more than a reasonable doubt, and there certainly is a very reasonable doubt as to whether such persons know the quality of an act of murder and know that it is wrong. (p. 99)

After all, what we want is protection for society. We cannot have innocent people killed in accordance with the whim of the irresponsible. These imbeciles have killed innocent members of society. What shall the living do to prevent these particular persons from repeating the crime and to prevent other imbeciles from ever committing such a crime? (p. 100)

All of them could have been recognized as mental defectives long before they arrived at the age when they committed crime.... Careful examination, such as is now possible, would have revealed the fact that they were potential criminals.... If we wish to save our teachers from the possibility of being murdered by their pupils or our daughters from being killed by their wooers or business men from being struck down by the blows of feebleminded boys, we must be on the watch for symptoms of feeble-mindedness in our school children. When such symptoms are discovered, we must watch and guard such persons as carefully as we do cases of leprosy or any other malignant disease. (p. 105)

Is it any wonder that reasonable people would not want such social evildoers lurking—let alone living—in their neighborhoods?

Again, the answer to this kind of problem, for H.H. Goddard, was "careful examination" (i.e., testing) of people and separation of those found to be feeble—minded/irresponsible/dangerous from the rest of the citizenry. Goddard asserted that: "Not until we take care of this class and see to it that their lives are guided by intelligent people, shall we remove these sores from our social life." (The Kallikak Family, p. 71) Colonies of feebleminded people were the principal appropriate response to widespread social ills, and the establishment of such colonies was viewed by Goddard as the humane, enlightened, and progressive thing to do. It was even incumbent on society:

While we say that the child of ten year mentality is feeble-minded this does not mean, as has been said, that he cannot function in any environment. It does mean that as society is now constituted in most civilized countries, he cannot function in the ordinary group; but he could function in a simpler one. Since he is in the minority and the majority has made the environment what it is, it would seem to be incumbent upon the majority to provide a special environment for this defective individual, with the expectation that in that special environment he would be normal—that is to say, he would be able to adapt himself and to function satisfactorily. This expectation has been abundantly fulfilled wherever it has been tried. (Feeblemindedness: Its Causes and Consequences, p. 574)

Not only was segregation the  $\underline{\text{right}}$  thing to do, according to Goddard, it was also in perfect harmony with American social ideals:

Democracy, then, means that the people rule by <u>selecting</u> the wisest, most intelligent and most human to tell them what to do to be happy. Thus Democracy is a method for arriving at a truly benevolent aristocracy....

The truest democracy is found in an institution for the feeble-minded and it is an aristocracy-a rule by the best. (Psychology of the Normal and Subnormal, pp. 237-238)

The phrase, "Ideas have consequences," is one that comes up frequently during PASS workshops. Trainers try to help learners understand what that means in human services. Henry Goddard's ideas—that feeblemindedness was a thing transmittable

through inheritance like hair color, and that feebleminded people could never be held accountable for their actions—had the consequence of providing intellectual ammunition for increasing separation and abuse of people with mental retardation. Assumptions or beliefs about what people are like often yield conclusions about what people "need"; these conclusions are the ground we stand on when we try to decide about what our response to people is going to be. H.H. Goddard offers us an example of what happens when the original assumptions are incorrect. His were, as even he began to understand later in his life. But his books were published by then—by mainline publishers—and they could not be recalled. The titles still appear on reading lists in the "mental retardation field." Unguided students may still find Goddard's arguments plausible; they are certainly consistent with an unsavory side of our national character.

The upshot of all this is not that we shouldn't make assumptions about people. We  $\underline{\text{have}}$  to do that—first because we can't avoid it and secondly because it is part of our responsibility as human service workers and as citizens to make decisions based on what we think is right for other people. The point to be gained from spending a weekend with H.H. Goddard, it seems to me, is that we have to be very careful about the  $\underline{\text{kind}}$  of assumptions we make. "Ideas have consequences" means that, if we want the consequences to be good for people, the ideas have to be good ones as well.

Jack Pealer

### INDIVIDUALIZED ASSISTANCE TO PEOPLE IN THEIR LIVING SITUATIONS

John Winnenberg

(Editor's Note: In the December issue of the <u>Letter</u>, John Winnenberg allowed us to reproduce Residential, Inc.'s "no-growth" policy statement. The paragraphs that follow are an extension of that policy.)

After opening and operating "good group homes" in the late 70's are early 80's, Residential, Inc. came to realize that the future we were building for people was rather questionable. We were asking unrelated adults to share homes with 1) other people in need, 2) who were people they didn't choose to live with, 3) in large numbers (4 to 8). It was an idea that certainly improved upon large institutional living, but was a far cry from the quality of life to which most people aspire. More importantly, our experience was telling us that "group living" was a very stressful way of life for all parties involved.

We set about assisting people who were skilled in making a home for themselves to do so. We are very proud of the fact that 9 of the people we now serve and another 8 people who were former consumers of our service do now make private homes for themselves. Yet another 16 people still live in the less than desirable group situations described above. We have made the commitment of "family" to these people, and we believe that if we are to honor it, we must be about making solutions for them to live like other people like to live.

We believe that people should have tthe opportunity to: 1) be surrounded by people who are strong and nurturing; 2) have a choice about who they live with, preferably people they care about; and 3) not be asked to live with large groups of unrelated, incompatible people in one household for years to come.

Operationally this means that Residential, Inc.'s policy regarding the service it offers includes the following guidelines:

\*we will continue to match the people we serve to individual "Service Planners" on a one to one basis for the individual planning of brighter futures for people...a strong emphasis will be placed on developing strong circles of support for each person to whom we have made commitments.

\*the homes we sponsor for people at 125 S. Jackson Street and 405 Mill Street in New Lexington will not continue to operate as "group homes" even if this means the divesture of the organization's assets in these properties to satisfy the desires of the Ohio Department of MR/DD to operate "group homes."

\*the organization will work to reduce the number of people we serve at the group residences at 657 Mill St. and 659 Mill St. from 4 to 3 persons each in the coming year. We are committed to seeing that the remaining 6 persons at those residences are afforded the three opportunities outlined above.

Residential, Inc. fully acknowledges that there are many people in need of support via the county and state programs designed for people who are developmentally disabled. We wish that the grouping of these people in living settings was not a pragmatic reality in our society, but we realize that it is. We hope to stand as an example of an organization that has mustered all of its energy to respond to people's needs as individuals and not as groups. We don't expect everyone to follow our example, but we do ask that it is respected and supported by others as one option that ought to be available to people in need.

OHIO SAFEGUARDS
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# The Safeguards Letter

NUMBER THREE

<u>JUNE</u>, <u>1987</u>

a publication of OHIO SAFEGUARDS • P.O. Box 1943 • Chillicothe, Ohio 45601

"TRAINING FOR DESIGNERS OF INDIVIDUALIZED SERVICES" -- OHIO SAFEGUARDS' DD PROJECT

"Individualization of services" has been the philosophical, legal, and (to some extent) procedural ground on which developmental disabilities service—agencies have stood for more than 15 years now. Since the enactment of P.I. 94-142, the development of "ICF-MR" regulations by the Federal government, and the appearance of the Federal developmental disabilities program, agencies have operated on the assumption that tailoring service—responses to the assessed needs of each person with a disability was the right and necessary way to organize themselves.

Or so we have said. In recent years many in the "DD field" have noticed that the practice of individual program planning seems not to live up to the promise. A number of recurring problems seem to intrude:

- \*not enough time for service
  workers to do the kind of
  planning they would like and
  still do other parts of their
  jobs;
- \*<u>so</u> <u>many people</u> to respond to all at once;
- \*lack of confidence is people who have disabilities, in the communities where services occur, and, apparent...
- \*limits in the capacity of specific agencies or systems to respond differently to diverse individuals—thus, limits in service variety.

Within the past few years a small number of individuals and organizations have been struggling with issues like these. Ideas and procedures have been developed that allow for a reaffirmation of the value and possibility of truly personal services for individuals with disabilities and that permit a slow but steady attack on the attitudinal and organizational barriers that often stand in the way of individualization. OHIO SAFEGUARDS has received funds from the Ohio Developmental Disabilities Planning Council to try to share with others around Ohio some of these ideas about how really personal responses to the needs of people with disabilities can be both designed and put into effect. This sharing will take two forms.

FIRST...

OHIO SAFEGUARDS has scheduled four meetings (one in each "corner" of Ohio) during July, 1987. We invite people who are concerned about the current status of personalized/individualized program planning to attend one of these meetings to hear from us and discuss with us ways by which personalized planning efforts can be better than they are now. At these meetings, we'll cover such topics as:

\*why personalized responses are necessary (a review of the lifeexperiences of people with disabilities)

\*the possibility of accomplishing good things for people with disabilities through personalized service designs

\*examples of how individuals and agencies have made personalized planning work. (cont. on p. 2)

(Cont. from p. 1)

These meetings (training sessions) will be held on the dates and places listed below:

Wednesday, July 8 Holiday Inn (Holidome)

I-70, East (Airport exit)

Zanesville, Ohio

Thursday, July 9 Holiday Inn Conference Center

I-76 and St. Rt. 43

Kent, Ohio

Tuesday, July 14 Holiday Inn

I-75 and U.S. 224 Findlay; Ohio

Wednesday, July 15 Bergamo Center

4435 E. Patterson Rd. (off U.S. 35, east)

Dayton, Ohio

The meetings are being organized and will be conducted by Sandra Landis and Jack Pealer, OHIO SAFEGUARDS' consultants on this project. Each meeting will run from 9:30 a.m. until 4:00 p.m. Those who want to attend one of the meetings should notify OHIO SAFEGUARDS at P.O. Box 1943, Chillicothe, Ohio 45601. There is no charge for attending one of these meetings.

SECOND...

The grant from the Developmental Disabilities Council will allow OHIO SAFEGUARDS to establish longer-term working relationships with two agencies in Ohio that want to work hard on improving their responsiveness to the personal situations of the people with disabilities whom they are assisting. We envision these working relationships to be consultative and tutorial in nature. We expect that the project consultants (Sandy Landis and Jack Pealer) will spend considerable amounts of time working directly with consumers, staff and boards of selected agencies during the late summer, fall, and winter of 1987-88. A small part of the agenda at the meetings in Zanesville, Kent, Findlay, and Dayton will be devoted to describing these longer-term working relationships in greater detail. More information about this project is available from either Jack Pealer (614/773-3360) or Sandy Landis (614/347-4126).

#### THE 53 MILLION DOLLAR ERROR...

Sandra Landis

Several years ago, I was enrolled in a graduate program in management and administration. One of the courses I took then was economics. I'd always been both a bit resistant to and somewhat fascinated by discussions about the subject. The course helped confirm both of my intuitions. Recently I've had occasion to think again about some of the things I learned then, particularly the ideas about costbenefit analysis and "opportunity costs."

For a few years we've been working to phase out the use of two group residences in our community. Gradually we have assisted people to move out into their own places, reducing the number of people who lived in one house from eight to six to five. Then, two brothers living in the house decided that they'd like to make a home for themselves. That would mean that only three persons would remain, and they were in various

(53 Million Dollar Error, cont.) stages of planning for their own homes. It seemed a good time to decide about how the house could best be used, now that its days as a "stop" on the route out of the state institutions were numbered.

We felt that the best circumstance would be that the equity and the control of the use of the property remain in our community for purposes of promoting, supporting, and advocating lives of good quality in this community for persons with disabilities. We suggested that the residential-support agency move its office to the building's first floor. We thought that the second floor could easily be modified into an attractive apartment to let. Given the size of the first floor, we also felt that a mid-size meeting room for use/rental by community groups could easily become a part of the house's use. We suggested that income from the apartment and group meeting room be deposited in the organization's Housing Fund. In this way, money realized from the use of the building could continue to assist in purchasing permanent, private housing forpersons served by the organization. We also felt that several people might be employed parttime as caretakers and caterers.

Several parts of the suggestion for use of the house have become sources of heated controversy. As this controversy continues, resolution of this local problem has taken on "precedent-setting" proportions. We've dubbed it the 53 million dollar error—not altogether facetiously. Fifty—three million dollars is the amount of money the funding organization committed to building and/or renovating places in communities for people with disabilities to live. The funds were committed and raised (via the sale of bonds) some ten years ago, with a "payback" schedule of forty years. In some cases, like the one described above, more money was put into purchase or renovation than could be generated by sale of the property at a later time.

All financial estimates about these properties were based on the assumption that the property would be sued constantly for forty years to house the maximum number of persons with disabilities allowed by law. Naturally a suggestion that the house no longer serve as temporary housing for people leaving large institutions constituted a breach of agreement in the minds of the fiscal thinkers, given that the "fiscal philosophy" remains as it was ten and more years ago.

In 1977 we had no examples of community residential programs serving individuals in their own leased or purchased homes. Virtually no money had been spent learning about the best ways to help people re-connect themselves with community life. No one had talked about life-long commitments to the people we brought home. As we learned about these possibilities, the thought of constantly filling houses up with people who needed "familial affiliation" for the rest of their lives lost our support. Our family was already very large, and our community is poor.

This change in community and service organization understanding and capacity has altered our thinking about how the capital investment in community property made in the 1970's can be preserved and used constructively in the next thirty or more years. Fortunately, whoever drafted the contract language developed for the agreements about purchase, use, and payback of "capital-assisted" projects included a phrase allowing that appropriate use of the property would be determined by the organization issuing the funds, and that the organization could be reasonable in its determination of such appropriate use.

So the decision makers struggle with questions of cost-benefit and opportunity costs, I think. How will they measure "opportunity costs" of a policy of never ever eliminating large group residences? How will they define the cost-benefit of a policy that allows capital investments in community properties to be re-invested in homes of

choice by the people who will live in them? I remember thinking that economic decisions seem entirely dependent on ideology—upon what the deciders think is right or valuable. Ten years doesn't seem to soon to re—examine policy regarding community investments. A 53 million dollar error? We'll know soon.

## A PERHAPS-TIMELY QUOTE, RECOLLECTED BY THE EDITOR...

"The familiar last line in T.S. Eliot's <u>Wasteland</u> 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.

If CBR had been allowed to govern history, Socrates would have become a baby-sitter; Galileo and Giordano Bruno, court jesters; Columbus a Venetian gondolier; John Milton a maker of limericks; Jefferson a tax collector; Edison, inventor of rubber stamps, and Einstein a uranium prospector. What was common to them all was a respect for abstractions and a willingness to submit

their ideas to the verdict of later generations.

...The great leaps are still the surest way to higher ground. Exactly what will happen on that ground is uncertain except for one controlling fact: We will become aware of yet higher stations and will enlarge our awareness of what it is that we do not know. And we will discover something even more important than answers. We will discover new questions. If progress is what is left over after we meet a supposedly impossible problem, then the stage will have been set for progress."

from

Norman Cousins "The Fallacy of Cost-Benefit Ratio" Saturday Review, April 14, 1979

# REMINDERS: ABOUT SUBSCRIPTIONS AND WRITTEN "OFFERINGS"

Our announcement about subscriptions in the last issue of The Letter brought responses from such diverse places as Toledo, Ohio; Springfield, Massachusetts; and Burlington, Vermont. We are grateful for these subscribers' interest in our publication and for their trust that their investment will be worth while. One subscriber noted that: "One of these days when I have some time I would also like to contribute to The Letter. For now I will make a financial contribution and look forward to being inspired by others." When that subscriber reads this edition, she will discover just how easy it is to send a contribution of writing.

For others who are reading this and who have neither subscribed nor submitted written items for <u>The Letter</u> we offer this reminder:

\*subscriptions are \$12.00 per year (at least four issues); and

\*written offerings from readers are welcome. The submission deadline for the September issue is August 15.

Either requests to subscribe or offerings of writing can be sent to:

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

A VIEW FROM CHILLICOTHE: "Items that Belong Together" Jack R. Pealer, Jr.

ITEM: Over the past few years I have fallen into the habit of occasionally scanning a widely-distributed magazine entitled <a href="Hospital & Community Psychiatry">Hospital & Community Psychiatry</a>. Sometimes I do this just to look at the pictures—a practice I recommend to others. The June, 1984 edition of this magazine (which is published by the American Psychiatric Association) features a number of articles about the relationship between people with (so-called) mental illnesses and the criminal justice system. The lead editorial in this issue was by H. Richard Lamb, M.D. and is titled: "Keeping the Mentally Ill out of Jail." Some quotes:

\*"Legal restrictions on involuntary hospitalization have also made the jail the only avenue of asylum for many of the acutely mentally ill. Further our clinical judgment tells us that a number of the chronically mentally ill need locked residential care. Deinstitutionalization is not for everyone."

\*"The need for more mental health services in jails is apparent."

\*"We must take a stand for involuntary treatment, both acute and ongoing. Such intervention should not be limited to those who can be proven to be dangerous but should be extended to gravely disabled persons who are too disorganized to avail themselves of vitally needed care."

Skimming further through <u>Hospital & Community Psychiatry</u> I discovered that Dr. Lamb, who is a professor of psychiatry at the University of Southern California School of Medicine, also appeared twice on the published program of the 1984 "Institute on Hospital & Community Psychiatry." Dr. Lamb chaired a panel on "The Homeless Mentally Ill" and helped teach a mini-course about "Writing for Publication in Psychiatric Journals."

ITEM: Victor Nekipelov was arrested in July, 1973 in the town of Kameshkovo, Vladimir Province, U.S.S.R. He was accused of writing slanderous poetry, giving a copy of a newsletter to a friend, and drafting an outline of an unwritten slanderous book. In order that the authorities could try to figure out why he did these things, Nekipelov received a tentative diagnosis of "sluggish schizophrenia" and was sent to the Serbsky Institute in Moscow for two months' observation and treatment. He has written about his time there in a book, Institute of Fools. Presumably, Nekipelov was viewed by mental health professionals as a gravely disabled person who was too disorganized to avail himself, on his own, of vitally needed care.

ITEM: Data contained in another article in the June, 1984 edition of <a href="Hospital & Community Psychiatry">Hospital & Community Psychiatry</a> indicate that local police officers exert a powerful influence over the decision about whether a citizen should be involuntarily committed to a psychiatric hospital. A study of referrals to "mental health" services in two metropolitan counties in the state of Washington revealed, for example, that when police officers assisted families in referring a family member to "mental health" services, the number of resulting involuntary commitments increased by 51.5%. Police were most likely to be called when violence occurred or was threatened, when someone's behavior was seen as bizarre, when an institution (e.g., hospital) requested police assistance, or when someone had a "cognitive or volitional impairment."

ITEM: Just a few months ago an ad for a new movie appeared in my local newspaper. Produced by "RFI" (Rugged Films, Inc.--I'm not joking) the film is entitled <u>Basket Case</u>. According to the copy in the advertisement, the film is about "the tenant is room 7 (who) is very small, very twisted, and very mad." The advertisement—a

box ad that takes up about 1/8 of the newspaper page--promised moviegoers "free surgical masks to keep the blood off your face." A photograph in the ad shows the top half of someone's face, and the person is staring ("wild-eyed," I presume) between the slats of a wicker or venetian blind. The ad announced, in small print at the bottom, that "no one under 17" will be admitted and that there is a second feature entitled <u>Gates to Hell</u>.

For some reason the above items seem to me to belong together, like the links in a chain or the intersections in a network. Somebody thinks that somebody else acts "crazy." Maybe they learned what crazy means from listening to their parents, from other people around them, from hearing stories. Or, maybe they learned by going to the movies or even just reading the local paper. Regardless, they know "crazy" when they see it. "Crazy" is dangerous. So, the police may be called and then. . . .

Maybe it's just me. Two years ago I had occasion to fly into and out of New York City. It seemed ominous to be that from the plane I could see the Statue of Liberty all wrapped up-wrapped in what I knew to be scaffolding but what looked, from a thousand feet up, for all the world like restraints.

Jack Pealer

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# The Safeguards Letter

SEPTEMBER, 1987

a publication of OHIO SAFEGUARDS • P.O. Box 1943 • Chillicothe, Ohio 45601

# $\frac{\texttt{NEW}}{\texttt{NOW}} \; \frac{\texttt{MONOGRAPH}}{\texttt{NOW}} \; \underbrace{\texttt{BY}} \; \underbrace{\texttt{WOLF}} \; \underbrace{\texttt{WOLFENSBERGER}}$

Dr. Wolfensberger's new monograph has a title that is likely to be uncomfortable for potential readers: The New Genocide of Handicapped and Afflicted People. The title and subject matter of this work were apparently too discomforting to publishers as well, because it became necessary for Dr. Wolfensberger to publish the monograph privately. According to Syracuse University's flyer announcing the monograph:

"This 120-page monograph, published in 1987, addresses the subject of the increasing practice of 'deathmaking' of societally devalued people. 'Deathmaking' refers to the many ways--direct and indirect, overt and subtle, simple and complex, immediate or slow-in which people's lives are abbreviated by the actions of others. This monograph presents the case that such deathmaking: is widespread in Western society today; takes many forms; is carried out in both direct and indirect ways; is concealed, disguised, and interpreted so as not to be reconnized for what it is; is highly legitimized; ;and is taking a terrible toll not only on its victims but also on perpetrators and society."

Copies are available from the Training Institute, Syracuse University, 805 S. Crouse Avenue, Syracuse, New York 13244—phone 315/423—4264. The price is \$9.50. People should get it and read it!

# "DESIGN" WORKSHOP AGAIN SCHEDULED IN JANUARY

For the third year in a row, OHIO SAFEGUARDS will sponsor a 4-day workshop on "planning." The workshop's title is "Design for Accomplishment," and the presenters will again be John O'Brien and Connie Lyle of Responsive Systems Associates, Atlanta, Georgia. The workshop will take place January 18-21, 1988 at Fawcett Center for Tomorrow, on the Ohio State University campus in Columbus.

This workshop is about "planning," but it is not necessarily about procedures that aim at making human services agencies work more smoothly or efficiently. Some beliefs that lie behind the ideas offered in this workshop are:

- a) that a real purpose of a human service is to help a community support valued community membership for all its citizens, including those who have been rejected for some reason like "disability;"
- b) that "effective services" are those that discover and rely on connections between individual people (who have experienced social rejection) and the communities of which those people are a part;
- c) that communities and services

  learn to be effective through
  careful attention to the circumstances of socially-devalued
  individuals and through action
  carried out by community members
  with strong social ties to each
  individual.

(continued on page two)

#### "RESOURCES" FOR PEOPLE INTERESTED IN HEALTHIER COMMUNITIES

Over the years the members of OHIO SAFEGUARDS have become aware (often by accident) of other organizations around the country that work—in most cases harder and for a lot longer than we have—for improvements in the lives of communities. These are not, necessarily, groups that focus their effort on people with disabilities; their focus is usually broader—i.e., on assisting people who are poor and, thereby, who endure all sorts of other indignities and hurts. Often these organizations offer workshops or seminars, publish newsletters about their work, and make available book—lists, either as recommendations or as an opportunity to purchase otherwise hard—to—find materials. When we run across these organizations, we want to share information about them with our readers who are concerned about the quality of the life experienced in their own communities. Three organizations that we've found out about are:

Community Service, Inc., 114 E. Whiteman Street, P.O. Box 243, Yellow Springs, Ohio 45387 (513) 767-2161). Founded in 1940 by Arthur Morgan, former President of Antioch College and first Chairman of the Tennessee Valley Authority, Community Service, Inc. is a "center where ideas and practices concerning community are appraised, developed, and circulated." (from the organization's brochure) This association focuses its efforts on work that intends to strengthen the <a href="mailto:small">small</a> community as a vital, essential part of human life on earth. Community Service, Inc. publishes a newsletter, sponsors conferences, offers consultation, and both publishes and offers for sale books about its area-of-interest.

Highlander Research and Education Center, Route 3, Box 370, New Market, Tennessee 37820 (615) 933-3443. For 55 years, Highlander Center has been working to stimulate and support the education of poor people about how to use their own experiences to find their way out of the problems that afflicted their lives. Led by Myles Horton, Highlander has been deeply involved in labor organization in the mines and mills of the mid-South, in supporting the effort of Southern black people to achieve recognition of their civil rights, and in assisting residents of Appalachian communities to reclaim control over their land and their communities' lives. Myles Horton has stated his belief that the job of the teacher in educating people toward social change is "...to get them talking about those problems, to raise and sharpen questions, and to trust people to come up with the answers." Highlander continues to offer a place where poor people can come together to work on their problems, leadership for such work, and resources related to the Highlasnder mission (books, newsletter, rental films and videotapes, etc.).

(continued on page 3)

#### About THE SAFEGUARDS LETTER

The Safeguards Letter is a quarterly (March, June, September, December) 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.

#### "DESIGN" WORKSHOP (continued)

As in previous years, we think that this workshop "works" best for people who plan to attend as part of a group of participants representing a community. These groups are, then, already prepared to take part in and benefit from the small-group exercises that make up an important part of the week work. Watch for fliers about this workshop If you want to be sure to get a flier, just contact OHIO SAFEGUARDS at P.O. Box 1943, Chillicothe, Ohio 45601. We'll ensure that you're on the mailing list.

#### "RESOURCES" (continued)

Institute for Community Economics, 151 Montague City Road, Greenfield, Mass. 01301 (413) 774-7956. The Institute's main interests are housing and land-use in communities where poor people live. The Institute has worked for several years assisting people whose tenure in the places where they've made their homes has been threatened by such forces as speculation, "gentrification," and inflationary land-values. Two major activities of the Institute have been: 1) the development of the concept of a "community land trust"—a vehicle that enables communities to set aside property from the speculative amrket to protect its value to its users (often poor people); and 2) leadership in the establishment of community-development or community-investment loan-funds that become sources of otherwise-unavailable capital for threatened people and communities. The Institute operates with an all-volunteer staff. It also publishes a quarterly newsletter reporting on its work.

In future issues of <u>The Safeguards</u> <u>Letter</u> we'll try to introduce you to other groups/organizations that we think deserve your attention. If you know of such organizations that we haven't heard about yet, please send the information on to us so that we can share it with others.

### A "FIRST" FOR OHIO SAFEGUARDS

Those of us who have formed the association known as OHIO SAFEGUARDS tend to agree about the idea that it's useful to try things out—to experiment. We also agree that it is important to analyze what happens when and after new things are tried. It was in part because of that agreement about the value of experimentation that OHIO SAFEGUARDS responded, last winter, to a "request-for-proposals" by the Ohio Developmental Disabilities Planning Council.

The request invited ideas about how the individual planning process (for people with developmental disabilities) and the people who are involved in developing plans might be influenced, so that the resulting services responses would be "more home-centered." "Home-centered" is one way of expressing ideas that presume that an individually tailored service response would enhance a person's efforts to enjoy the quality of day-to-day experiences that most of us aspire to in our own lives. Because the ideas about useful planning and individual accomplishments in quality living seemed to fit with OHIO SAFEGUARDS's interest in promoting these kinds of things across the state, we decided to "try out" the sponsorship of a funded project.

Work began in late April of this year. Jack Pealer and I, who are acting as "consultants" on the project, have visited many places and talked to many people in Ohio who are interested in exploring ways of personalizing service responses to people with disabilities. We've had the opportunity to talk with more than 200 people over the course of four 1-day seminars. We've thought about what we've encountered in this effort so far, and we've formed some early impressions.

One of these impressions is that there are quite a few people interested in the ideas central to "social role valorization." Another is that people attending the seminars around the state thought that devoting a day to thinking about the many problems confronting people with disabilities and their associates, the constraints that influence service response and quality, and the possibilities for change that exist in the midst of all that is both useful and somewhat helpful.

#### A "FIRST" (continued)

Perhaps the strongest impression we've formed is that there is a substantial amount of unhappiness with the way things are going now. Despite mandates for "individualized plans" and "coordinated I-blank-P's," people involved don't seem to think that those plans make much difference or effect very much change in people's day-to-day experience.

During the seminar sessions that we conducted this summer, we offered invitations for people/groups to work with us on a more extended basis. Eleven organizations from across Ohio responded, and we visited and talked more extensively with most of them. We have selected two organizations (Fulton County Board of MR/DD, and Park West Court Apartments, Columbus) and will begin this month to develop consultation plans with each of them. We hope to begin work with a third organization later in the fall. Our intention is to reflect frequently about what we decide to try out and what we see happening as a result of these efforts. We'll be continuing to share our impressions and observations about this first OHIO SAFEGUARDS "project" as the year and the work progress.

Sandra Landis

#### OHIO SAFEGUARDS TELEPHONE NUMBER

One early result of carrying out a "Developmental Disabilities" project is that, for the first time, OHIO SAFEGUARDS has its own telephone. This will probably last as long as the project does, but readers who have questions, comments, or ideas that they want to share with OHIO SAFEGUARDS can contact us at:

(614) 773-6191

There is an answering device, so you can leave a message if no one is there.

#### NEW OFFICERS FOR OHIO SAFEGUARDS

At the OHIO SAFEGUARDS Board of Trustees meeting on September 11, new officers were elected for two-year terms with the association. Those elected are:

President----Sandra Landis Vice-President---John Winnenberg Secretary & Treasurer----Jack Pealer

# NEW POLICY ON PAYMENT FOR THE SAFEGUARDS LETTER

The OHIO SAFEGUARDS Board of Trustees has adopted a new policy regarding how the Letter is to be paid for. Because we see the publication of the Letter as an essent part of OHIO SAFEGUARDS's mission, we have decided to finance the Letter through voluntary contributions rather than through a "subscription" plan. The trustees decided to encourage each other to contribute an annual amount (to the best of each person's ability) to support the publication of the Letter. Contributions from others for this purpose will be encouraged and welcomed as well. Those individuals and organizations that have sent OHIO SAFEGUARDS funds for subscriptions to the Letter can be assured that they will receive full value for their money; they will be guaranteed at least one year's set of issues of the Letter. Questions about the new policy can be directed to:

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

#### A VIEW FROM CHILLICOTHE

"Visiting Inside the Wire"

On Saturday, March 28, 1987, I went to prison for a couple of hours. It was "open house" day at the new "correctional facility" just north of Chillicothe. The facility was about to receive its first guests. I could write about a lot of the things I saw and took notes about on that afternoon, but in this small space I want to focus on two things. I want to describe some features of a place that is, apparently, the latest thing in prisons, and I want to share with you some of the "public language" used to interpret these features to citizens who took the time to come for a visit.

If you haven't seen it, Ross Correctional Institution is easy to find. Just drive north from Chillicothe on Route 104. You'll first pass the older prison (Chillicothe Correctional Institute) on your right; then, you'll find the new prison on the left side of the road, immediately across from the Mound City National Monument. (If you're new to the area or are just passing through, you might want to make a short visit to Mound City, a set of earthworks built by, so-called, prehistoric people. If you do, you may notice that, as you walk out to look at the earthworks you'll pass a large sign that describes Mound City as a "necropolis", a city of death. Interesting—and right across from the new correctional institute.)

Ross Correctional Institution, or "RCI" as it has already become locally known, is a new-style prison. Among other things that means that some of the "professional" staff of the institution (especially the Case Managers) have their offices in the "housing units" rather than in the administration building. As well, the facility has no exterior wall—merely a double ring of fencing topped with ribbon wire. Despite its newness and its espousal of current language in its "philosophy", there are many things that seem quite traditionally prison—like about RCI.

The institution has been designed to accommodate 1,000 male prisoners. There are to be 500 people on the north end, which is described as "medium security," and 500 others on the south or "minimum security" end. I was told by my tour guide (one of the new Case Managers) that an "invisible line" divides the two halves of the institution, and, indeed, they appear to be mirror images of each other. When it is full, as it probably is by now, RCI will have about 325 full-time staff members, half of whom are "security" personnel. By and large, security is maintained by watching the prisoners, and the watchers have plenty of high-tech assistance to accomplish their task: video cameras in many areas with monitors at all security locations; remote, electronic controls over all cell-locks and other locks as well (not to worry-there is a way to lock all areas at once in the event of a power failure); an external fence equipped not only with ribbon wire but also with an electronic "perimeter detection system" that somehow uses microwaves. I thought of my oven. I also noticed that the "commissary," where prisoners might go to buy snacks or other personal items, has its products (and its staff) displayed behind a wall of shatterproof glass. One might make one's purchases via an intercom system. There is a special "Disciplinary Control" area where prisoners who prove troublesome may be housed. This area has cells with "pass-through" doors for food. It also features an outdoor recreation space (by regulation, every prisoner has to have 2 hours of outdoor exercise each week). This outdoor space is about 30 feet by 12 feet with a concrete floor and concrete walls 15 feet high, topped by chain link fencing. It reminded me of the outdoor space at the Public Gaol in Williamsburg, Virginia (built in 1701)--about the same dimensions with about the same height of wall. So much for the new style.

I wouldn't want to spend an 8-hour shift as a staff member at RCI, let alone live there. Everything, from the intake area to the housing units and dining areas, was grim—forbidding—to me. Not everyone in my tour group would have agreed with that judgment, I think. Maybe that's because some of the members of the group had read the literature handed out by the institution as part of the grand opening ceremony. Here, in part, is what the prison's official philosophy statement says:

The intent of (the facility's) design is to provide a more normalized environment which would contribute to the control of behavior and improve inmate moral (sic). We also feel that inmates will develop a higher level of self-esteem when they are subjected to the more relaxed atmosphere that they will experience here at the Ross Correctional Institution. It is our hope that living in this type of environment will reduce the shock of re-integrating back into the mainstream of society upon an inmates (sic) release and help them adapt more readily to a normal life. An emphasis will be placed on replicating the "outside" work environment while providing relevant programming designed to assist re-entry to a more productive civilian life. (Emphasis added. JRP)

This is the "public" language—the language used to tell the people who paid for the place the official version of what's going on inside. Do they sound like the same places? Does a building housing 125 men who are under regular surveillance, that is grouped with seven other like buildings and sourrounded with an electronic fence sound like a "relaxed atmosphere"? It's hard for me to see how a place that requires you to be strip—searched every time your visitors leave would help you to "develop a higher level of self—esteem." The only place this is more "normalizing" than is a place like the old Ohio Penitentiary (and not by much). That the language of normalization or social role valorization (integration, relevant programming) can so easily be used to obscure truth gives me pause. Actually, it shocked me at the time. But this example of the probably unconscious but still real distortion of essential ideas reminds me that trying to say clearly what I mean (instead of treating ideas like formulae) is the first effective defense against distortion. The second and more important defense, of course, is working hard to live out the truth of the ideas I express. That's the only way by which the ideas either acquire or retain meaning.

Jack Pealer

OHIO SAFEGUARDS P.O. Box 1943 Chillicothe, Ohio 45601

Non-Profit Organization
U.S. Postage
PAID
Chillicothe, Ohio 45601
Permit No. 72

NUMBER FIVE

JANUARY, 1988

a publication of OHIO SAFEGUARDS • P.O. Box 1943 • Chillicothe, Ohio 45601

#### APOLOGIES...HAPPY NEW YEAR ANYWAY!

This is the fifth issue of The Safe-guards Letter. That means we've finished one year of publication—a milestone that's important to us. As perceptive readers will have noticed, though, we've started a bit late. We had intended to publish this issue before Christmas so we could offer the compliments of the season to all our readers. But, things kept getting in the way. We're going to get back on schedule in March, and we'll try not to let it happen again. In the meantime, we think that this issue introduces lots of ideas and opportunities for the next few months.

And, we hope you had a happy holiday season. We offer best wishes to all our reades for the new year that (mostly) still lies before us.

# ITEMS OFF THE A.P. WIRE (VIA THE LOCAL NEWSPAPER)

Markham, Illinois—"A second mistrial was declared for a man accused of murdering his newborn son by slamming the baby's head against the delivery room floor."

When prosecutors indicated they would seek a third trial, on a charge of premeditated murder, the defense attorney labeled their actions "an obscenity" and

said the new trial represented "cruel
and unusual punishment." That looks like
\* an attempt to divert attention away from

\* an attempt to divert attention away from what is genuinely obscene, cruel, and (we hope) unusual in this instance.

Media, Pennsylvania—A judge sentenced a mother to five years' probation and 750 hours of community work for killing her

 $2\frac{1}{2}$  year old "brain-damaged" son. The woman's attorneys argued that "the dis-

(cont. p. 2)

#### ANNOUNCEMENTS OF UPCOMING EVENTS

1) The Community Way—An Evening with John McKnight. On Tuesday, March 8, 1988
OHIO SAFEGUARDS will offer an opportunity to listen to and talk with John McKnight,
Professor of Communication Studies and Urban Affairs at Northwestern University.
Mr. McKnight has an international reputation as a teacher and writer about the
regeneration of neighborhood and community life and the obstacles posed for that
regeneration by continued growth of human service structures.

This gathering will occur in the auditorium of the Franklin Park Conservatory and Garden Center located in Franklin Park, off East Broad Street, in Columbus. The gathering will last from 7:00 until 9:00 p.m. There will be no charge for attending the gathering. Specific notices about the gathering will be mailed out

by OHIO SAFEGUARDS around February 1.

2) Introduction to Normalization through the Use of PASS. OHIO SAFEGUARDS' next PASS workshop has been scheduled for April 10-15, 1988. This workshop, which is being co-sponsored by Advancing the Developmentally Disabled of Montgomery and Greene Counties, will take place at Bergamo Center near Dayton, Ohio. Bergamo is a retreat and conference located in the southeast part of the Dayton area.

#### ANNOUNCEMENTS OF EVENTS (continued)

We hope that the cost of this workshop will not exceed \$200, including lodging. Again, specific announcements will be forthcoming soon.

- 3) Workshop and Practicum on Designing Model Coherent Services, March 15-18, 1988, Laconia, New Hampshire. This workshop is described as a "crash course" on how to construct a social role-valorizing, model coherent human service. The workshop will be sponsored by the New Hampshire Alliance for Community Living and will be led by Susan Thomas and Darcy Miller, associates of the Training Institute for Human Service Planning, Leadership, and Change Agentry (Syracuse University). For information, contact the Alliance for Community Living: Dave Yerter at (603) 924-9783, or the Training Institute: (315) 423-4264.
- 4) Social Advocacies on Behalf of Devalued People, Especially in Light of Contemporary Realities, May 20, 1988, WOOSTER, OHIO. This workshop, to be presented by Dr. Wolf Wolfensberger, examines the idea of "social advocacy" and differentiates it from other activities—both good and bad—with which it might be confused. The workshop explains why real social advocacy is always under attack, how to prepare for such attacks, and how to safeguard advocacy against both attack and perversion. The workshop fee is \$50.00 (including lunch). Contact: Ernie Fischer, Residential Support Services, 337 W. North Street, Wooster, Ohio 44691, (216) 263-0862.

## About THE SAFEGUARDS LETTER

The <u>Safeguards Letter</u> is a quarterly (March, June, September, December) 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 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.

## $\underline{A.P.}$ WIRE (continued)

traught woman shot (her son) in frustration over the boy's failure to respond to a controversial and exhausting therapy known as patterning."

How can we reconcile such events with the presumed value our society places on love for and care of its children? Might we have to modify the statement-of-value to include only children who are "perfect", whatever that means? Or, might we have to begin to question whether we sometimes regard children as little different from our other beloved and cared-for possessions?

Jack Pealer

#### THOUGHTS ON SEIZING THE OPPORTUNITY FOR RAPID DE-INSTITUTIONALIZATION

(Editor's Note. A friend from Western Canada wrote to Michael Kendrick, Director of the Normalization Safeguards Project in Massachusetts, about whether to work furiously to cahieve rapid de-institutionalization in his area. Michael replied and distributed a few copies of his reply. We received one and thought that his ideas would be of interest to our readers. These ideas are presented below with Michael's permission. JRP)

I wish to add some clarity to my position on this as you seem surprised by some of my comments during a recent telephone call. It prompted me to go back and try to think it through a bit more. On other occasions and contexts I've critically remarked about how rapid deinstitutionalization tends overall to lead to poor quality community living arrangements. This is particularly true if large numbers are involved and where "formula" community services are installed. Smaller numbers, far-seeing service leaders and advocates, prior experience and so on can all minimize the inherent dangers in that complex of human activities we call deinstitutionalization.

It's a difficult position that leaders find themselves in when they see an opportunity to get people out of institutions. First, they have no confidence in institutions and know what it will mean for the people if they don't get out. Secondly, they may realize that getting people out may well put them into less than ideal community living arrangements. Further, they might quite rightly suspect that these situations may actually worsen rather than improve. Obviously, most choose to suffer with the limitations of community living rather than those of institutions. Many, of course, take this decision but then fumble the design, management and safeguarding of community living, thereby exacerbating an already difficult situation. In time, less than idealistic persons are asked to lead community services and may start from the position that today's level of quality is optimal (or all that's possible)—thereby negating or diluting the ideals and hopes of those who originally sacrificed to get people out of institutions.

It seems to me that there is reality, in many jurisdictions, to the fear that governments and communities tire of reform. One cannot expect constant openness to change. In some cases the period between reforms may be centuries. Certainly the gap between the "moral treatment" period of the last century in mental health and its successor in this era (the social role valorization movement) has been many decades. The tide goes out, and it is far easier to keep systems than to change them. Consequently, I tend to support those who conscionably try to maximize these opportunities (for change).

The challenge to me is more in how one exploits these opportunities. I can well imagine (and have seen) some pretty irresponsible, short-sighted, romantic and ill advised community service development schemes. Most underestimate how complicated these reforms will be, how virtuous they or their communities are, how they'll not repeat the mistakes of the past and so on.

A good attitude would be one where one is clear about who one is ultimately loyal to, about how difficult it is, about how susceptible to failure all systems are, about maintaining a long term view, about the acceptance of limitations, hardships and sacrifice, the cultivation of positive values, abundance of mercy and so on.

In some instances this could even mean a refusal to start more deinstitutionalization. One could seek approval in principle for it but recognize that the implementive capacity of the system is finite. Under such conditions one can elect to bring the machinery of deinstitutionalization into place when one has confidence that

#### RAPID DE-INSTITUTIONALIZATION (continued)

it won't lead to dumping. In this way I'm arguing for embracing the struggle of distinguishing between optimal, bad, and "least worst" forms of community service development. Not all forms of service development are inherently good just because people get out of the institution.

A good defensible service development strategy may be chosen even if its features include some short term shortcomings in service quality. In fact, the presence of multitudes of problems in community services is unavoidable—there is absolutely no other way to do it if it hasn't been done before. Each problem must be met and addressed. Skipping over these will only mean trouble later, as the "quick-fixes" come undone. I actually see value in people being unable to master community service development—it may discipline them to question their assumptions. One can't elect to get people out of institutions and not have these problems—they all stem from the decision to construct something which hadn't existed before. The real question is the quality of one's strategies in facing these inevitabilities. Some will do better than others and vice versa. Then it will be clearer as to what we must try for. Many of these lessons are now obvious.

Michael Kendrick

REGENERATION Sandra Landis

During my years as a human service worker, I've had a few fortunate experiences. I define a fortunate experience as one where I can earn my living in the place where I live, work with people who learn by acting (as they analyze what they do), and be with people who are guided by vivid aspirations. It's working with people who live cheerfully and hopefully from day to day, who choose methods of negotiation not coercion, and who regard presence and respect privacy.

One of these times has been my involvement with the work some people in Perry County, Ohio have engaged in for the past several years.

I was invited to guide the work that the people who made up Residential, Inc. wanted to do. Our goal was to focus on trying to figure out useful ways to be in good service to some individuals and to our community at large. We began with a serious look at ourselves—as people and as an organization. We spent several months talking together, listening to everyone we could who was associated, and writing some clear statements about our current circumstances, conditions, and roles.

Out of all that thinking and talking, writing and listening came our statements about mission and aspirations. They were very simple. We considered the people we had welcomed home as "family." We saw our mission as standing with and assisting our family members as they created their own space with us in the good life of Perry County. When we identified those aspirations four years ago, I didn't have a familiar, "big-picture" name to describe what it was we were setting out to do. I think, now, that I would title the big picture of our intentions then (and now) as "regeneration."

Regeneration ideas focus on thinking about a particular group or community effort as an opportunity to learn more about itself and recognize the unused or underused resources within the people and the place. The knowledge derived through this cooperative self-examination and reflection expands the group or organization's capacity

#### REGENERATION (continued)

to put to use these newly recognized resources to influence the quality of daily experience in small and big ways.

Ideas about self-examination, reflection, cooperation, and increasing the capacity and autonomy within individual people and in the organization were ones that became our framework for making decisions and carrying out our work. Our appreciation of our connections with the larger community of people, associations, and places began to grow within the first year of this new effort within Residential, Inc. Now the focus is more than ever directed toward actively affiliating with individuals and groups that are here in each of our many "communities."

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

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

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

Out assumption remains that policies that promote including people in the life of our communities rather than excluding them from it tend to improve the quality of experience for all community members. We wanted the voices of our family members to be strengthened, and that meant strengthening our own voices, as well as finding new voices to join with us. Our intent was to stand with and assist a relatively small group of people and to influence useful change in our community policy and values. Over the years that intent has helped us learn a great deal about ourselves, our community, and the barriers that stand in some people's way as they dare to dream about the good life that so many of us know.

We described this good life in simple terms: our home-life and personal well-being; the quality and variety of our relationships with others; our financial security and "wealth-of-life" potential; our opportunities for continued education and useful learning; and the building of our social image, reputation and roles. We agreed that, together, these characteristics help define the satisfaction and comfort levels in each of our lives. We set out to encourage and support vivid personal dreams. We would try to back up these dreams with hard work and help from people who could share in this work in meaningful small and big ways.

Some people have acquired a good bit of security and satisfaction in just a few years. For others the progress has been much slower. A couple of people seem to have been stopped in their tracks by circumstances that are currently beyond their, and our control. We're working on those things.

As we look ahead to the next few years, we see the people affiliated and the

#### REGENERATION (continued)

organization playing different roles in supporting people's accomplishments in day-to-day living. One effort will probably include the organization divesting itself of its involvement in selecting, maintaining, and financing people's homes. This means participating in the development of a local housing agent to offer such assistance. The people we're concerned about and others in our community interested in assuring that good, secure housing is available to people who don't have a lot of money will provide leadership to this effort, separate from Residential, Inc.

A second effort will involve the organization in sponsoring a grant effort that will fund some leadership costs relative to the housing work and will pay for some leadership work in creating finance and business supports in our community. These efforts would also be independent of Residential, Inc.

Our third strategy is to redouble efforts within Residential, Inc. to shift the planning, support, and assistance authority, as much as possible, for as many people as possible, to voluntary efforts. We've come to think of this as helping build circles of support and friendship networks with people over time. If we are successful, Residential would become the back-up, locally supported organization available to assist people and their friends over time.

One of those who says things that inspire us is John McKnight. He has said that "Human service is the secular thief of hospitality." We would like to retreat a bit so that we can support our community's capacity to welcome its own and share its best.

Sandra Landis

#### DIRECTION SERVICE

Donna Owens and Ron Lawrence

(Editor's Note. Donna Owens and Ron Lawrence are members of the Board of Trustees of OHIO SAFEGUARDS. For the last several years they have also worked on the "National DIRECTION Service Assistance Project—an activity of The National Parent CHAIN, Coalitions for Handicapped Americans Information Network. We asked Donna and Ron to explain to us and to our readers what DIRECTION Service means. JRP)

For a great many families, finding the right "mix" of services for their member with a disability is a time-consuming, frustrating process. It can be like finding one's way through a maze.

Even once the right services are obtained, service consumers and their families may not know how to deal effectively with professionals and may lack knowledge of their rights and the importance of their opinions and desires regarding those services. DIRECTION Service is a program designed to address these problems.

Simply stated, DIRECTION Services is a one-stop source of information, referral

and personal help for people with disabilities and their families—to gain access to the services and supports they need. It emphasizes not only the needs of an individual with a disability, but the potential service needs of the total family unit. Ideally, DIRECTION serves people with all disabilities, of all ages. It uses a large data base (usually computerized) of local, regional, and state programs, resources, and supports that is regularly up-dated.

With this information, a DIRECTION Service worker helps an individual and his/her family sort through what is available and make decisions about what services are needed and where they can

### TRECTION SERVICE (continued)

best obtained. The DIRECTION Service worker provides the needed level of support—no more, no less—to access these services. And, in this process, individuals/families gain knowledge and savvy to become their own "case managers."

In one sense, the process can be seen as helping people manage the service system, rather than being managed by it.

Follow-up also is an important component of DIRECTION Service. The level of intensity and personal involvement in follow-up also varies according to the complexity of needs and the individual's/family's ability to use the service system effectively. Whatever level of intensity this follow-up takes, it includes a series of check-points to determine satisfaction with services received, whether the services obtained are still correctly meeting needs, or possible additional needs for help.

DIRECTION Service can be particularly helpful at transition points in a person's life, e.g., when someone enters school, when someone graduates and enters the world of work, etc. In Eugene, Oregon, DIRECTION workers often accompany parents to "Individual Education Plan" meetings, to offer support and/or advocacy. In the Spanish Harlem section of New York City poverty is severe, and people seeking help from DIRECTION Service are faced with significant cultural and language differences. There, DIRECTION workers often may need to attend to basic life needs before pursuing specialized services or adaptive equipment. DIRECTION Service also may need to provide interpreter services for non-English-speaking people.

In rural Warrensburg, Missouri, the head of a DIRECTION Service center sees her dission simply: "We find things for people, whether it's a service, information, equipment or emotional support." In this sparsely populated area, much of the work is done by phone. In Ohio, DIRECTION Service centers are operating or being planned in Cincinnati, Akron, Youngstown, Wapakoneta, Toledo, and Hillsboro. The Ohio Coalition for the Education of Handicapped Children is spearheading DIRECTION development throughout the state.

The National DIRECTION Service Assistance Project, located in Worthington, Ohio, provides assistance for DIRECTION development and currently is working in 12 states. For more information, readers should contact:

National DIRECTION Service Assistance Project. 90 E. Wilson Bridge Road, Suite 297 Worthington, Ohio 43085 (614) 431-1911

Donna Owens, Ron Lawrence

REMEMBER: OHIO SAFEGUARDS HAS A TELEPHONE NOW! You can call us at (614) 773-6191. Leave a message if no one but the machine answers.

Jack R. Pealer, Jr.

What follows is a kind of personal confession, I guess. It also raises some questions that I've been thinking about for a while, and I'd appreciate it a lot if those readers who have thoughts about these matters would share them with me.

The word, community, is a powerful word, it seems. Whether used as a noun (we're interested in helping people with disabilities move into the community") or as a modifier ("this is a perfect community development idea..."), "community" carries with it feelings so strong and clear that, most of the time, no other explanation of what we mean seems to be required. Part of this complex of feelings is, I think, the notion that community, or anything with the word "community" in its title—like community services—always involves a nostalgic sort of perpetual closeness. If we call any group of people a community, then they'll get along better. If we describe anything we do as a community—based effort, then it will work out harmoniously because community is better (automatically) than its opposite, whatever that is. Community is warm and fuzzy, like an electric teddy bear.

Garrison Keillor's Lake Wobegon is, on first glance, that kind of place. Reading or, especially, listening to the stories of people in that town provokes recognition, laughter, and, often, a feeling of warmth and well-being. That's why the radio show and Mr. Keillor's books have been so popular. Re-listening or re-reading, though, can reveal an underside of Lake Wobegon that's a bit disquieting—another slant on the stories that is, I think, one of the real reasons for their effect on those of us who listen or read. In Lake Wobegon, as in any community, people rub against one another. They come into contact—contact that's sometimes warming but that sometimes as well produces sparks. It's part of Garrison Keillor's art that he can recall to us the sparks, the tensions, the conflicts that are part of "community" and still leave us with the feeling that community is what we've been seeking.

I must confess that the conflict that accompanies community is something I've never sought. I've never sought conflict of any kind; it has always been something to be avoided and feared. When I was in high school, I wanted to play football badly (which was just how I did play it) but could not bring myself to block anyone or tackle anyone very hard. I haven't been in a fight since about the third grade. It's not just physical conflict, however, that discomforts me. About twenty years ago I served for a time on the church council at the church I then belonged to. I remember the debates over such essential issues as whether to floodlight the flagpole in front of the church building as a memorial to soldiers who'd served in Vietnam. Though I had strong feelings about the matter, I took no part in the debates. Later, on several occasions in my professional career, the issue of where people with disabilities were to be "allowed" to live became an item of public political contention in communities where I lived and worked. There were several zoning hearings or city council meetings to be faced. I always wanted not to go, or, if I went and had to speak, I tried to be so rationally convincing that emotion wouldn't take hold. I've always been frightened by angry arguments.

So I have trouble with the idea that one of the major accompaniments to this notion of "community," to which I'm so attracted, is conflict. And there's more. If I want my community (wherever or whatever it is) to change, it seems that I may have to do more that just endure tension and conflict. I may, in fact, have to provoke it sometimes. The great artists of social change all understood that. As witnesses, I think of Martin Luther King and the Memphis garbage-workers, Myles

prton helping organize mill-workers in Virginia and North Carolina, Saul Alinsky and the packing houses in Chicago, and Mohandas Gandhi walking to the shores of the Indian Ocean to make salt. These were actions taken to supr or sharpen conflict, not to dull it or smooth it over. They were meant to bring tension to a head, so that out of the resulting confusion fundamental change could occur.

So, what courses are open to one who has been a habitual conflict-avoider—one who wants his community to change so that it is more inclusive of people who have been previously rejected and excluded—but one who brings to the change—situation mainly the experience of having been a manager? (Thomas Peters pointed out once that modern business and business schools promote conflict—resolution as a major skill of managers—that good managers are ones who "make good charts and smooth over problems.") If conflict is an inevitable part of community change, because it's one result of people rubbing up against one another, how can I come to be comfortable with it, let alone embrace or promote it? Is is possible for a career administrator to change his spots? I don't know the answers to these questions, but, over the past months, it has become more clear to me that it is important to find out what the answers are.

Jack Pealer



#### PLEASE NOTE:

"The Community Way," John McKnight, March 8, 7:00 p.m., Columbus Introduction to Normalization through PASS, April 10-15, 1988, Dayton Overview of Social Advocacy, Wolf Wolfensberger, May 20, Wooster

DETAILS INSIDE

OHIO SAFEGUARDS P.O. Box 1943 Chillicothe, Ohio 45601 Non-Profit Organization U.S. Postage PAID Chillicothe, Ohio 45601 Permit No. 72

# The Safeguards \_\_Letter\_\_

MAY, 1988

a publication of OHIO SAFEGUARDS • P.O. Box 1943 • Chillicothe, Ohio 45601

#### WE GET LETTERS...

My questions about "Embracing Conflict" in the last issue of The Letter provoked more responses than anything else in the short history of this publication. Apparently my fears are common ones, which leads me to think that all of us who are afraid of a fight had better find a way to get un-afraid. If we don't, the changes we want are even further from realization. I want to reproduce here just three of the written responses I received. Perhaps they'll help in trying to extend the conversation.

You broach a very important issue with your piece. I...want to encourage you to pursue it further. Its implications for personal decision making are challenging... in a time of numbing vacuousness.

Your commentary written several months ago, on backing away from confrontation was very well received. I circulated it to all PASS participants and received a number of calls. It struck a common vein.

Your question of community is a much more expansive one than these little personal recollections. Yet, they are the best way to convey my answer to your question of conflict as a means for change. Obviously, change is necessary. My response is twofold. Initially, you mustn't be afraid to be the only one who takes a different stance. If it works you know you were right in

your action. If it fails it means that you need to examine the situation further, at a personal level and with the help of others... No matter how you land, at least you're there. After you've landed, you can't be afraid to face rejection or even to have those you rally care about leave you behind... Even when I'm not sure if someone will stay by me, I will still act on my beliefs. Chances are the others just aren't as strong as you to take action.

Thanks to those who wrote. Others out there: feel free to write as well, if you have something to say about "embracing conflict."

Jack Pealer

#### DICKENS NOTES ECONOMIC TREND

In his speaking and writing, Dr. Wolf Wolfensberger has commented much about the emergence of a "post-primary-production" economy, wherein the sector that makes goods (e.g., farming, manufacturing) has declined to a small minority while "servicers" now occupy the majority sector. Charles Dickens noted something related to this more than 100 years ago, in his novel <u>Bleak House</u>:

"The one great principle of the English law is, to make business for vitself. There is no other principle distinctly, certainly, and consistently maintained through all its narrow turnings. Viewed by this light it becomes a coherent scheme and not the monstrous maze the laity

# GOOD NEWS! SOMEONE DOES THE RIGHT THING FOR THE RIGHT REASONS.

Sometimes we get so confused about the decisions we have to make--not only about which way to choose but about the reasons why one choice might be preferred over another. When we're enmeshed in questions about what to do or why, it may be useful to consider an example like the following one. The story is from the Paris daily, Le Monde, as re-published in the Manchester <u>Guardian Weekly</u> (May 15, 1988).

The French mathematician Alexandre Grothendieck...has just declined the Crafoord Prize awarded to him by Sweden's Royal Academy of Sciences. The prize, worth Skr 270,000 (approximately \$280,000. Ed.) ...has been awarded since 1982 to research workers in mathematics, earth sciences, astronomy, and biology.

In a letter to the permanent secretary on one Swedish academy, Grothendieck gave the following reasons for declining the prize:

- 1) "My pay as a professor and even my pension when I retire in October are more than enough for my material needs and the needs of those I have to support. I therefore do not need money. As for the prize awarded for some of my fundamental research, I am convinced that the only decisive test of the richness of ideas or a new vision is the test of time...by what (ideas) produce and not by honours.
- 2) "I notice moreover that the eminent research workers to whom illustrious prizes...are awarded are all of such a social status that they are already quite well off materially and enjoy a scientific prestige as well as the authority and prerogatives which accompany it. But is it not obvious that overabundance for some can only be achieved at the expense of the necessary for others?
- 3) "The work which has earned for me the Royal Academy's kindly attention goes back 25 years to a period when I was part of the scientific community and shared in large part its spirit and values. I quit this community in 1970 and, without repudiating my passion for research, in my mind I moved further and further away from the community of scientists.

Now in the past two decades, the ethics of the scientific profession... have become so degraded that wholesale plundering of ideas (and particularly at the expense of those in no position to defend themselves) has become almost the general rule among scientists....

Under the circumstances, agreeing to play along with the practice of granting prizes and rewards would also be endorsing a spirit and a development in the scientific world that I see as deeply unhealthy and moreover bound to disappear in the near future, for it is so suicidal spiritually as well as intellectually and materially.

It is this third reason which in my view is by far the most serious.... I have no doubt that before the end of the century totally unforeseen upheavals are going to radically transform our very notions of 'science,' its prime objectives and the spirit in which scientific work is done..."

The <u>Safeguards Letter</u> possibly skirts the boundary of copyright law in reproducing parts of this story from <u>Le Monde</u>. The example, however,—of someone making a clear choice for well thought-out reasons—was too fine to ignore.

#### AN OBSTACLE TO COMMUNITY

I often rely on analogies to better understand, and then associate, ideas that I'm currently thinking about or discovering. One of the analogies I'm thinking about now involves the ideas about community that are represented by John McKnight's and Robert Rodale's and others' work, and the concept of usury that I've learned about as I've been studying land trusts and housing cooperative organizations.

Usury means making money from money: interest, and other fees or charges on the use of money. The idea of usury is important if one's thinking about how to keep the cost of land and housing within the means of all citizens who wish to "own" land or homes. That's because it is the cost of the money to finance land or home purchases, and the speculation on the increasing value of a particular piece of land or property, that excludes many citizens from purchasing property. The customary usury fees are high and continue over a long period of time. The fees are paid to banks, private corporations, mortgage companies, etc.

Recently, the cooperative efforts of some "socially conscious" investors have helped organize usury-free (or, very low return) funds to finance housing and land trust operations in various communities throughout the world. In this way the shared money is invested with people who don't have extra money to pay usual usury fees, and who want the land they "own" to grow very little in cash value. Then some places will be there for people in the future.

I've learned to think about community as a source of the capacity for empowerment that grows from a group of people's shared devotion to and action toward a commonly held aspiration. If I'm interested in supporting and nourishing this capacity, then I want to see the money and other resources we pool as a society used to build community, not to diminish it. In this analogy, <u>bureaucracy</u> is the "usury fee" charged for the distribution of commonly-pooled resources. Bureaucracy, its structure and inherent self-perpetuating tendencies, is an expensive and ineffective method for seeing that our pooled resources really help people to live more securely.

Can you imagine ever entering into a perpetually increasing (i.e., in rate) mortgage agreement? In a world of limited resources, if the bureaucracy constantly consumes more, the capacity to invest in empowerment-organizing will decline. Bureaucracy has been described as "the thief of our culture's democratic future." This suggests to me that the choices we wought to concern ourselves with, if we influence or control or accept part of this "usury fee" are the choices that reduce investments in bureaucratic methods and re-direct the shared resources in ways that increase the capacity to empower through citizenship.

Sandra Landis

## DICKENS NOTES ECONOMIC TREND (Continued)

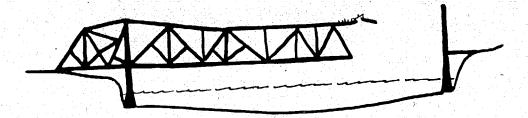
are apt to think of it. Let them but once clearly perceive that its grand principle is to make business for itself at their expense, and surely they will cease to grumble."

from <u>Bleak</u> House

# A TALE OF TWO BRIDGES

The railroad bridge across the St. Lawrence River at Quebec City, when it was built in the early twentieth century, was the longest cantilever bridge in the world. A cantilever bridge is the type of bridge formed from a complicated series of triangular steel girders, a big black framework above the roadbed. Remarkably, an early moving picture was taken of stages in its construction, and by chance the movie was being filmed as the bridge collapsed into the St. Lawrence, with the loss of life of dozens of ironworkers. In the movie it can be seen that the bridge was being built out from one pier or support, all the way across the river, to reach the opposite pier. The builders started from one side and had gotten more than halfway across to the other when the bridge collapsed. The bridge was rebuild, lessons learned, and it still carries the railroad across the wide river.

# Quebec, 1913



The original bridge across the Niagara Gorge, built about 1848 by Charles Ellet and John Roebling, is of an entirely different design. It is a suspension bridge, the archetypal style of bridge design with the sweeping curve of cable above the roadbed, the cable hung from two high supports, the roadbed hung from that cable. The Niagara bridge, built to carry the railroad between Canada and the U.S., was one of the first major suspension bridges, and the challenge of construction at that site made it a model with world-wide impact.

The biggest challenge was to get the cable, which would support the weight, across the gorge. In building a suspension bridge, that's the first step in linking the two sides. To build the Brooklyn Bridge, for instance, the first thing Roebling had to do after the two support towers were underway, was to get the cable across the river. With the Brooklyn Bridge that was easy: carry it on the ferry. But with the Niagara Bridge, given the steep cliffs and the swirling waters, a boat could not carry the cable. It was this challenge that led many engineers to doubt whether such a bridge could be built.

Ellet solved the problem in this way: he held a kite-flying contest. The winner, a boy from Niagara Falls, Ontario, won the opportunity to fly a kite one windy day across the gorge on a long, silk thread. On a windy enough day, that part was easy; the real skill came then in getting the kite to come down into the arms of Ellet and his colleagues who were waiting in Niagara Falls, New York. The work crew in New York then tied strong twine to the silk thread and gave a signal. The work crew in Ontario pulled the doubled line back across the gorge. The Ontario crew then tied a single strand of steel wire to the twine, signalled, and saw the wire pulled back across; and the process was repeated over several months until that silk thread had become a steel cable strong enough to carry the roadbed and two railroad lines across the Niagara Gorge.

#### RETA BLOCKERS (Continued)

wifen they know they are headed for stressful situations. My doctor said, "You'll get used to them and you'd be surprised at the number of people who take them all the time."

I found most of the forementioned surprising, if not downright shocking. My experience was memorable. My buddy, Becky, was visiting the evening I took the first one. Within the first hour, I was damn glad she was there. Not because she's a nurse, but because she could have taken me to a hospital, which was where I thought we'd be going before the evening was over.

Beta blockers initially altered my state of mind. It felt like I'd taken mescaline. That means (because I feel pretty certain you likely never did) (That's right. JRP) that the commonplace seems intensified. I felt very uncertain with doing normal things (driving, going to a restaurant). Food tastes too intense. Food texture is intensified; the grain of a french fry is unpleasant. The bite of hamburger seems to have doubled in size since you put it in your mouth. Swallowing it seems impossible. The intensity diminished on the second day, but hunger or appetite is gone. I lost any desire to eat anything for several days and had to force myself to eat after the fourth day. I lost 10 pounds.

I found I couldn't concentrate—couldn't read and retain information. I couldn't conceptualize an idea and articulate with ease. I was reportedly jovial and spacey, but felt drugged, slow and suppressed. Someone told me that I said: "I've enjoyed having lunch with you, but call me next week and tell me what we talked about"—a remark that, in some contexts might cause professional suicide. It's good I made it to understanding colleague. Meetings I normally chaired seemed impossible, so others alled in for me.

Most of all, I was slowed down. I couldn't physically move as fast as I did normally. I'd feel like I was walking at a rapid (normal) pace and realize my sister was 60 feet ahead of me and I couldn't catch up. I believed I couldn't lift and carry my 20-pound nephew without feeling drained and overextended. Beta blockers are supposed to slow one down, and they do it superbly. But they make you feel pretty uncomfortable at the same time.

By the sixth day I was beginning to feel more confident and normal. My clarity of mind was returning and I didn't feel as muddled as before. I knew I was still moving slowly and on the drug, but I could function pretty well. The feeling of suppression lessened, but I could think and my emotional well being felt intact.

I was never happier than when the doctor said the beta blockers were a temporary measure and not a permanent feature of continued treatment. People may function on them "all the time," but they are not for me. Becky's daughter described them well; they are like life underwater.

Carl King maintains that if you really want to know what a medication is like, you should take it once. I think his point is a good one. We ask people to function on medication all the time and we have no idea of the sacrifice we are asking them to make. Then we're surprised when they stop taking the medication. If my "side-effects" hadn't diminished and I had spent that week at the office, rather than on leave, I don't think I would have retained my job.

I didn't intend to write you an epistle! Hope it helps you understand.

# THE "COMMUNITY LIFE NEWS": WHO AND WHY?

(Editor's Note. John Winnenberg, the Vice-President of OHIO SAFEGUARDS, is trying to help build community where he lives by giving his area—southern Perry County, Ohio—a formal means of communication, in the form of a monthly newspaper called Community Life News. John gave us permission to re-print his first "Comment" column, entitled "Who We Are, Why We Are Here." JRP)

When I was growing up in Corning in the 1960's, I often borrowed my mother's Smith Burroughs typewriter to publish the "Winnenberg Times" and send it out to our relatives across the state and country who had left the area to find "opportunity" in more prosperous areas. I reported on floods that would hit downtown Corning and of Walter Harrop's death.

My brother and I delivered the Columbus <u>Dispatch</u> and the <u>C-J</u> at that time. We also arose early on Sunday morning to stuff the circulars in the Sunday papers at my father's store. I spent several quarters in college studying journalism after being inspired by Ruth Burgess as editor of the <u>Miller Star</u> and <u>Miller Memories</u>. So, I guess you could say that I grew up with newsprint in my blood.

I've had the opportunity to go to school with people from all over the southern part of Perry County. I've lived in Corning and Shawnee and taught school for one year in New Straitsville. Home, to me, like for many of us, is anywhere south of Bristol Hill on State Route 93 and as soon as I hit the Moxie Short Cut coming south on State Route 13.

A lot has happened in these hills in the 33 years I've been alive. Much of it has not been encouraging when you think of the overall quality of life for many of our citizens. One thing that hasn't changed, though, is my secret desire to see my hometown, southern Perry County, thrive again. It's a desire that I know that many of you share. I don't imagine it will even be like it was, nor should we try to make it that way. But, I can imagine us being a bit more prosperous, a bit more caring, and a bit more active in community life than we have been in recent years. As a matter of fact, I think that is already happening. The Community Life News just wants to capture that spirit and help it along.

Much like the "Winnenberg Times," the <u>Community Life News</u> will be family operated. Many members of my family will be helping with the work. It should be noted, though, that I don't limit my definition of family to blood relatives. I'm expecting that my family of friends, neighbors, and associates will also get involved. Don't hesitate to call if you want to help, have a suggestion, or a story. Thanks for reading!

#### John Winnenberg

(Note: For subscriptions, at a rate of \$10 per year, contact Community Life News, P.O. Box 6, Shawnee, Ohio 43782)

# A VIEW FROM CHILLICOTHE: Left-over from "Civics" Class.

Mr. Burgoon might be happy. At least I hope he is. Mr. Burgoon was my "Civics" teacher in my senior year at old North High School in Columbus. "Civics" was more

formally known as either "Problems of Democracy" or "Principles of Democracy" (I forget which—and it probably depended on which party was then in control of the Board of Education). As I recall, the purpose of "Civics" or "P.O.D." was to confirm students' previously acquired understanding of how our nation and its communities govern themselves, so that those who were soon to "enter the world" would be fully prepared to assume citizenship. For many, "Civics" was the final formal lesson about our political institutions.

I guess I took this lesson well—maybe too well. Despite an acquired—and often reasonable—cynicism about the workings of "the system," I've kept a good bit of respect for (some would say "naivete about") public institutions, as I assume, Mr. Burgoon was trying to teach me. Five years ago, when I was appointed to the local Board of Mental Retardation and Developmental Disabilities (my first public office), I had to be sworn—in by a local judge. My recitation of the oath—of—office and the apparent look on my face (of seriousness? of terror?) when I took the oath made the judge pause. He said later that it was rare for anyone to recite the oath with such purposefulness. My sense was less about "purpose" than about simple awe at my first experience at being a public official. I guess I looked serious because I believed the ideas that I had learned about in "Civics" class.

But—to the point of all this. Lately it seems as though there has been a tendency, both in me and in others I know, to reject the notion that public structures can effectively respond to the problems or situations of socially—devalued people. So many of us have both watched and taken part in actions of service agencies that further <a href="hurt">hurt</a> people that we begin to turn away from agency—work and from the idea that the public sector even offers the possibility of help. On the surface of things, that turning—away seems a reasonable thing to do.

But it's only a reasonable thing if I can forget the things I learned about in Mr. Burgoon's class. He tried to teach us that the social and political institutions we created are indeed <u>ours</u>, even though, as I've also learned, those same institutions seem often to acquire lives of their own. If these institutions are our creations, I'm still "naive" enough to believe that we can change them to suit our purposes.

People with disabilities or people who are socially excluded for other reasons still often need large-scale assistance so that they can more fully take part in whatever good life the society has to offer. I can't believe that we have so corrupted ourselves (yet) that we are unable, as citizens, to set aside some of our common wealth to provide the help that some of our fellow citizens need. No doubt we've done this badly much of the time. There have been many errors—probably more than successes. We have to do things much better. But, give up on "public helping?" Give up on the notion of formally exercising our common responsibility for some of our own members? Not yet, I think, because giving up on organizing ourselves right is, as far as I can tell, further loosening the glue that binds us together at all.

Jack Pealer

# The Safeguards \_\_Letter\_\_

OCTOBER, 1988

a publication of OHIO SAFEGUARDS • P.O. Box 1943 • Chillicothe, Ohio 45601

# A BIG IDEA, AND A SMALL BEGINNING....

OHIO SAFEGUARDS celebrates five years of life this fall. Our efforts and accomplishments so far have been small but persistent. As I think ahead to the next five years, I've developed a vision of what life in the association might look like then. The predominant image that I see is something I've begun to talk about as a "safehouse." I'll try to explain.

I am convinced more and more about the importance of creating and sustaining small examples of the est communities we can envision. Oo, I see the association and its friends creating a small example of building community and safeguarding our hopes and dreams for people in need by sharing time and space together.

The safehouse I envision would be located in the Columbus area and would serve two main purposes. It would be the permanent, secure residence for someone who needs a home, and it would serve as a place of welcome and reflection for OHIO SAFEGUARDS members and friends. Perhaps the person(s) who make this house their home would have some caretaking role, our small library would have a place to grow into, and there would be space for people to meet, or rest, or read. I imagine that we would select a property and a neighborhood that could benefit from owners and residents who are interested in maintaining the property in good repair, and who

would not participate in the speculative real estate market. Clearly the property would need to lend itself to two separately defined spaces: perhaps a duplex, or a small house with a second structure (garage-apartment type of arrangement).

Those people to whom I've talked about this support the idea, and then ask, but how? I usually respond by saying, "Agree to participate!" Some of them have. Participating means one (or both) of two things: pledging time to the project; pledging money to it.

Please consider this your first opportunity to comment on the idea of a safehouse, or even a chance to make a pledge toward its accomplishment. Within a few weeks a more detailed description of opportunities to participate will be sent to OHIO SAFEGUARDS' Trustees. Other readers of The Safeguards Letter who also want copies of that description should contact OHIO SAFEGUARDS at P.O. Box 1943, Chillicothe, Ohio 45601. We hope to hear your reactions to our idea soon.

Sandra Landis

#### PLEASE WRITE!

Sometimes it seems like The Safeguards
Letter enters a lost world after it leaves
the Chillicothe Post Office. We know, thoug
that's not true. In this issue we specifically ask for a response from you. Please
write something on the "reader response"
sheet, and let us know how we're doing.

## OHIO SAFEGUARDS Library: A Beginning

Within the past few months, OHIO SAFEGUARDS has begun to collect books and other materials relevant to the organization's mission of fostering richer community life with people who have been rejected and devalued. The items described below are the initial acquisitions. These materials may be borrowed; contact OHIO SAFEGUARDS at P.O. Box 1943, Chillicothe, Ohio 45601. We'll probably ask borrowers to reimburse the cost of mailing the materials.

"Paulo Freire at Highlander Center, December, 1987." (video, VHS format). This is a tape of a retreat/planning session for community-educators from poor communities, held at Highlander Center in Tennessee in December, 1987. Both Myles Horton (founder of Highlander Center) and Paulo Freire (author of Pedagogy of the Oppressed) were present to offer reflections and comments.

The Production of Houses. Christopher Alexander with Howard Davis, Julio Martinez, Don Corner. This book tells a story of putting theories into practice. The text and photographs explain the Mexicali project, an experimental effort that resulted in the planning and building of low cost, efficient, pleasant homes with substantial participation by the families who would later reside in them. The larger theme of the book is that of control of decisions. "If we are to put this situation right, to bring our production systems into order, we must therefore concentrate on this human problem of the distribution of control. What we must find is a system of production which is capable of giving detailed, careful attention to all the particulars which are needed to make each house 'just right' at its own level, at its own scale, and which is yet at the same time efficient enough, replicable enough, and simple enough so that it can be carried out on an enormous scale, and at a very low cost."

<u>Democracy in America</u> (Vol 2). Alexis de Tocqueville. In this second volume of the best-known book about "America" written by a European, de Tocqueville describes and reflects on the utility and necessity, in a democratic society, for "public associations." These associations serve both as means to grapple with community difficulties and as entities to "combat the effects of individualism" in the life of a democracy.

Man and Woman He Made Them. Jean Vanier. The founder of L'Arche is one of the great demonstrators of communal life involving people with disabilities and people without. Based on his experience in community, M. Vanier, in this book, reflects on the sources and meaning of human sexuality.

<u>Under the Eye of the Clock:</u> <u>The Autobiography of Christopher Nolan</u>. Christopher Nolan is a young Irish writer who also happens to live with physically-disabling conditions. This book—his second—is his (so far) life—story, approached in a third—person fashion, i.e., told as if it had happened to a fictional character. Watch for a review of this book in a forthcoming edition of <u>The Safeguards Letter</u>.

#### WE'D LIKE TO HEAR FROM YOU....

This issue of <u>The Safeguards Letter</u> is the seventh one that we've produced. It seems as though, after the first six, we ought to ask our readers about their feelings, opinions, etc. regarding the <u>Letter</u>. So, this page is our "reader response form." We'd appreciate it if you would take the time to think a bit about the questions below, write a response (short or lengthy, as you choose), and mail the form back to us. Please send your completed form to:

Editor, <u>The Safeguards Letter</u> P.O. Box 1943 Chillicothe, Ohio 45601

What (if anything) do you like <u>best</u> about <u>The Safeguards</u> <u>Letter</u>? For example, is there some feature that you especially look forward to?

What about The Safeguards Letter do you find least useful/helpful/interesting?

What suggestions do you have about changes or improvements in The Safeguards Letter (different features, other writers, etc.)?

OHIO SAFEGUARDS has begun to assemble a "resource library" of books and audio-visual materials about improvements in community life and the place of previously-displaced people in communities. Do you have ideas about materials we should consider including in that library?

Do you want to continue t	o receive <u>The Saleguards Letter?</u> (We don't want to
send you something that f	itsfor youthe category of "nuisance" mail.)
Ye	s. Please continue sending me the <u>Letter</u> .
No	. Please remove me from your mailing list.
V	
Your name and address	
	·

Do you know of someone else who, in your judgment, would like to receive  $\underline{\text{The}}$   $\underline{\text{Safeguards}}$   $\underline{\text{Letter}}$ ? If you give us their name and address we'll send them a sample copy.

Thanks very much for taking the time to fill out this form. OHIO SAFEGUARDS believes in evaluation. We'd better; we teach it in many of our workshops. So we value your opinion about the <u>Letter</u>.

# A VIEW FROM CHILLICOTHE: Housewarmings

I've been to three "housewarmings" in the past three months. One woman had just moved into her new apartment after years of living exclusively with other people—most of whom she didn't know. Her friends and supporters helped her host a celebration of her new—and her own—place. There were 30 or so people. There was lots of food. There were housewarming gifts—kitchen supplies, "hosting" supplies, appliances—that sort of thing. It was a beautiful early summer evening. "Life is better now" was one thing this woman said to her friend, as she thought about her new place. Maybe not perfect—but better.

On another warm afternoon two days later, two people who are married to each other celebrated their new life with many friends. These people had both lived more than sixty years but never had places they could call their own. Now they do. The man said, repeatedly and with more than just a touch of amazement, "I'm living like a rich man now." They have a small apartment in a tall building where most of the other tenants are also age sixty or older. People gathered that afternoon at the place where they used to live to give them what some called a housewarming but what at least one friend (who formerly lived in Southeast Ohio) called a "pounding"—meaning that the couple received "a pound of this...a pound of that." They were "pounded" with cans of beans, jars of peanut butter, packages of cleaning products, and all the sort of stuff that runs up grocery bills. There was cake and lemonade. Old friends were greeted and new ones perhaps made. We even saw a video—tape (we're never out of touch with technology) of the couple in their new place. It was a satisfying two hours.

Two months later—again on a warm day—I went to a gathering for a friend in the first apartment he's ever had on his own. He moved back to Ohio from a residential community in another state and is trying to make a life on his own in the area where he lived as a child. The people who are trying to help him in that effort gathered to celebrate his new place, which is probably not exactly the kind of place he had in mind. It represents, however, a big step toward the life he's dreamed about. The highlight of the afternoot was the visit of the person who was this man's major helper (continued, p. 6)

# About THE SAFEGUARDS LETTER

The Safeguards Letter is a quarterly publication of OHIO SAFE GUARDS. 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: Jack Pealer, Editor, The Safeguards Letter, P.O. Box 1943, Chillicothe, Ohio 45601. We welcome our readers' ideas and reactions.

# DUBIOUS GOOD NEWS

Heard on a July 8 news report, National Public Radio: "'The United States doesn' have a monopoly on drought,' reports an official of the U.S. Dept. of Agriculture. 'There are drought conditions in the USSR, China, India, and Argentina as well. This means that the United States will not lost its share of the world grain market. It won't affect our competitive position.'"

Well, that's a relief. I was afraid they were going to report that some of our adversaries or arms—length allies were going to get the jump on us in the race to feed people who are hungry. Housewarmings (continued)

at his former place of residence. She drove several hundred miles to be with him on this occasion, and he greeted her with a big welcoming poster on the door. He was wearing a T-shirt with a greeting for her imprinted on it—a shirt he had ordered specially from a stand at the county fair the week before the gathering.

There must be other times in people's lives that are occasions for parties like these. On each occasion I thought, what happens after the housewarming and its excitement are over? What will it be like when the novelty of the place wears off? Could we, maybe, think about anniversary-celebrations for the relationship between a person and her or his place? How about "job-warmings?" Most of the people with disabilities whom I know haven't had real jobs either. Could we think of gifts that would help someone do their work better or enjoy it more? Aren't there lots of possibilities?

Jack Pealer

OHIO SAFEGUARDS P.O. Box 1943 Chillicothe, Ohio 45601 Non-Profit Organization U.S. Postage PAID Chillicothe, Ohio 45601 Permit No. 72 NUMBER EIGHT

# The Safeguards Letter\_\_\_

DECEMBER, 1988

a publication of OHIO SAFEGUARDS • P.O. Box 1943 • Chillicothe, Ohio 45601

#### "FRAMEWORK FOR ACCOMPLISHMENT" WORKSHOP

"Making and carrying out plans for better future lives for people with disabilities" is both a cornerstone for the "developmental disabilities" field and a theme of the work conducted by OHIO SAFEGUARDS for the Ohio Developmental Disabilities Planning Council.

In January, 1989, OHIO SAFEGUARDS will offer a workshop that gives participants (not more than 20) the chance 1) to learn new ideas that will help people with disabilities and their families make plans for themselves, nd, equally important, 2) to try out ways of connecting action for individual changes with constructive actions for change in human service organizations and in communities. The workshop is called "Framework for Accomplishment." It will take place at the Holiday Inn, Chillicothe, Ohio (and in other locations in Chillicothe that will be visited by participants) from Sunday, January 22 through Friday, January 27. The workshop will be directed by John O'Brien of Responsive Systems Associates, Atlanta, Georgia. The fee for the workshop is \$100.00. and participants can register by contacting OHIO SAFEGUARDS at P.O. Box 1943, Chillicothe, Ohio 45601 (phone 614/773-6191).

"Framework" is one of the few learning experiences that focuses on the connections between personal and organizational change. We welcome those of you who are interested in exploring those connections in the real (believe me, very real) community of Chillicothe.

#### ONE-DAY WORKSHOP ON "SERVICE QUALITY"

People who are not participating in the "Framework for Accomplishment" workshop in January may consider coming to "Perspective on Service Quality: Valued Experiences for People with Disabilities and Service Accomplishments." This one-day workshop will be presented from 8:30 a.m. to 5:00 p.m. on Tuesday, January 24, 1989. John O'Brien, of Responsive Systems Associates will present the workshop, which will take place at the Holiday Inn in Chillicothe.

"Perspective on Service Quality" will stimulate those who attend 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.

If you want to register for "Perspective on Service Quality" you can contact OHIO SAFEGUARDS at P.O. Box 1943, Chillicothe, Ohio 45601 (phone: 614/773-6191). The fee for the workshop is \$20.00.

#### IT'S EASY TO WRITE!

You may notice some contributions to this edition of the <u>Letter</u> by readers. It's easy. Just send your ideas to us at P.O. Box 1943, Chillicothe, Ohio 45601. We'll fit them into the <u>Letter</u> as soon as we can.

# A WORKING CONFERENCE ON "DESIGNING PERSONALIZED HELP"

The idea that what we choose to do, in human services, ought to be determined by the experiences and preferences of <u>each person</u> to <u>or with whom things are done</u> is so fundamental to what we <u>say</u> about our work that it might be regarded as one of our "core values." It's like people in church saying their creed—or, to be more up—to—date, like a politician reciting the Pledge of Allegience. You can't swing a cat (only try this with a toy, stuffed one) in a human service without hitting someone who's talking about "individualized services" oriented to "each person's needs."

And it's right that it should be that way. Trying to orient our work around each person we contact is necessary if we're going to have any chance of safeguarding the hopes and the dignity of that person. The difficulty, in human service agencies where more than one person is helped, is in the doing. How can we really respond personally?

As readers of The Safeguards Letter know, since the spring of 1987 OHIO SAFEGUARDS has conducted a project, sponsored by the Ohio Developmental Disabilities Planning Council, intended to support the efforts of people and organizations that plan for lifestyle changes for people with disabilities. We've come to think about this work as an effort to help people with disabilities "get home," that is, to help people live their lives in places where they're welcomed and among people by whom they're appreciated. We've spent time visiting many people in various places in Ohio, and we've grown increasingly aware of how few people with disabilities are accomplishing this kind to good life. The history of devaluation and segregation, when combined with current service practices, presents an almost overhwelming barrier, in many places.

Yet, efforts for change are underway, and they're succeeding in some places, with some people. The places where these efforts are being engineered are places where someone—or several people—has devoted time, energy, and resources to a different life for a particular person, despite the barriers encountered. Because these things that are happening are exciting and because the efforts they're due to are small and fragile, we thought there was a good deal to be gained by bringing together some of the "engineers" of these efforts. We wanted both to learn from them and to allow them to share (experiences, stories, strategies, etc.) with each other. We also thought that this assembly might produce a useful "position statement" about issues involved in devising real personal help and support for people with disabilities ans sustaining that help over time.

(continued, p. 3)

#### 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

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The Safeguards Letter is now printed on 100% recycled paper.

# WORKING CONFERENCE (continued)

So, we invited about 45 people whose interest and experience were known to us to come to Burr Oak State Park, near Glouster, Ohio, for two days in early November. We met and talked and listened; and we had the help of John O'Brien to ask reasonable questions, listen thoughtfully to what people said, and keep a record of the conversation. We talked about: "what happens when we work to develop the personalized help necessary for someone to be a valued member of their community?" Our conversations focused on such questions as:

\*What works to create good experiences for people?

\*What disappoints us as we make these efforts?

\*What <u>supports</u> us in this work—especially when it takes a long time or we're unsuccessful?

The record of our discussion at Burr Oak is being translated into a document—one that will probably be a hybrid of "report" and "collected reflections." We expect to finish work on this document early in the new year, and we're willing to share it with anyone who is interested in designing personal help for people with disabilities. Let us know if you'd like a copy.

Sandra Landis Jack Pealer

# HISTORY OF HUMAN SERVICES WORKSHOP

A long absent "treat" is in store for Ohioans who are interested in better service to people in need. On Monday, April 10, OHIO SAFEGUARDS--together with the Central Ohio Region of the Ohio Interagency Training Network--is sponsoring a one-day presentation on the history of human services. This presentation, which was developed by Dr. Wolf Wolfensberger, will by offered by Susan Thomas, Dr. Wolfensberger's associate, and the Training Coordinator at the Training Institute for Human Service Planning, Leadership, and Change Agentry at Syracuse University. The vital information presented at this workshop and documented by many slides has not been offered in Ohio since 1982. The workshop will take place at the Fawcett Center for Tomorrow on the campus of The Ohio State University in Columbus. Descriptive flyers and registration forms will be available in February. Any readers with an interest in history or who are curious about the origin of many human service practices should mark April 10 on eir calendars.

#### OHIO SAFEGUARDS' LIBRARY NEWS

We announced the beginnings of the library in the October issue of The Letter, and response has been gratifying so far. There have been two or three books loaned, other requests for materials, and a number of suggestions about other books that we might consider acquiring. We thank our readers for this response and hope that the library proves useful.

We recently received another book:

Pedagogy of the Oppressed. Paulo Freire. Written during his enforced exile from Brazil, this book contains a summary of Paulo Freire's theories about the power of learning to transform both individual lives (of poor people) and the cultures that contain those lives. This book, although it is difficult reading at times, is crucial to the understanding of anyone who wants to support/assist personal change that leads individuals (e.g., with disabilities) to struggle to change the structures of society that have oppressed them.

## THINKING ABOUT MY HEROES

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

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

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

I think it was a conversation with my grandmother that helped me start to figure it out. My grandmother celebrated her 90th birthday last July. Earlier in the year I had asked Big Gram if she knew of Dorothy Day. I was reading a biography sbout Ms. Day, was intrigued by the knowledge that Ms. Day and my grandmother were born about the same time, and was interested in hearing my grandmother's opinion of Ms. Day and her work. As I recall, my grandmother's response to me was, "I don't know of this Dorothy Day you've asked me about. But if it is as you say, that she was of the poor and loved God, then I would suppose that many of our days would have much in common. The tasks are simple ones, to be willingly done."

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

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

Sandra Landis

#### BEING HANDICAPPED

(Editor's Note: Steve Dorsey is President of the Delaware County, Pa., chapter of "Speaking for Ourselves," an advocacy organization of people with disabilities. This article, used with Mr. Dorsey's permission, was presented to the Speaking for Ourselves National Conference, Valley Forge, Pennsylvania in June, 1985. JRP)

When I was a small child, I didn't understand why I couldn't do all the things other children did. That is when I first learned the word "handicapped." The doctor told my mother I would never walk. We talked about it at the time and we decided to work hard, very hard, to help me walk. This was accomplished with strong support

# BEING HANDICAPPED (Continued)

from my family. My mom had to spend long hours with me and very little time with my sisters, but they were nice about it. We shared a lot of love.

My personal frustrations were many. I had to have someone push me in my wheel-chair to and from school, help me in the bathroom, help me take a bath, help me with my food, etc., all the things healthy people take for granted. I felt hurt when children and some adults laughed at me.

Now most of the time I need help getting on and off the trolley and bus because the steps are so high, but so do old people. I wish they could change those steps so either the old people or people like me won't have to ask for help all the time. I'm glad for the handicapped parking and the ramps we need. It's just one less frustration we have to put up with. Any small thing you can do to help us have an easier life we appreciate. Try to put yourself in our place and you will soon feel what we do. Any little thing helps, believe me.

It could have been very difficult to accept my handicap, but with the help and support of the people who care it can be a lot easier. Some people accept their handicap with a lot of anger, but I have found that anger takes up a lot of time that could be put to better use. Others accept their handicap by asking someone always to do everything for them: then they become dependent. So, parents, make us do for ourselves so we can feel useful to our family, friends, and our community. If our own family doesn't accept our handicap, how can we?

I know there are a lot of things I can't do, but there are also a lot of things I can do, like camping, swimming, hiking, and even skiing. I have done some of these things and have had a great time. All it takes is determination and places to go, but most of all it takes other people who understand us, help us, but not  $\underline{do}$  for us, to take us to these places.

We can go as far as you allow us to go. We can go as far as we allow ourselves to go. So, if we work together, who knows how far we can travel together? We need and want jobs to provide for ourselves and also for our personal pride. Just because we don't walk straight on the outside does not mean we cannot stand tall on the inside.

Steve Dorsey Folcroft, Pennsylvania

# REFLECTING ON THE DEATH AND LIFE OF LEONARD MILLER

"If a proposed reform is truly significant, it is unlikely that the reformers will live to see its achievement."

--Wolf Wolfensberger, 1977

Leonard's death prompted me to think first about Leonard as a human being, as one who dies. His funeral in Sharon was the first one for my son, Nicholas, age 4, so it was the occasion for going early to the cemetery and talking about death, about people dying, and about the death of this man whom Nicholas had only met once or twice. It was the occasion for thinking about and trying to explain to Nicholas

#### LEONARD MILLER (Continued)

why there are funerals and why he should try to remain quiet there, and it was the occasion for thinking about and trying to explain to Nicholas how and why people die. Now those questions won't ever go away, for either of us. Thinking about Leonard as a human being, too, included for me thinking about the death of a man about my own age, and thinking about the first of the normalization training movement in our area to die. In the series of meetings which founded the Center for Training, Development, and Renewal, even when the size of a given meeting dwindled to four or five, one of them would be Leonard, getting there any way he could. This was the first, and not the last, funeral of a comrade for me.

Leonard's death prompted me to think, as well, about his life and his life work, about Leonard as a member of an oppressed group and as an activist on behalf of that group. The rabbi who delivered Leonard's eulogy in Sharon, and I am sure many eulogies and reflections we will hear or read, have focussed on that contribution and dedication, on Leonard's calling to assert the rights of the group into which he had been cast in his life.

Leonard's death, and his life, prompted me also to think about Leonard as a Jew, and myself as a Jew. The rabbi spoke of Leonard's attendance at Sabbath services, and his steady service to the Jewish Community Center in its activities, and he spoke of Leonard not only as a good man but as a good Jew. Leonard's fidelity to his Jewishness was manifest, one might say, not only in his affiliations in Taunton, but also in his service as an activist on behalf of justice, in his life's work seen not as aiming toward the liberation and empowerment of a particular group but as aiming toward building justice and community in our world. I believe the essence of being a member of a "chosen people" is not that Jews may have been chosen by God, but that Jews have indeed been "chosen" by history to play roles of moral responsibility for justice and for community. In this way, too, Leonard Miller was a good Jew: by taking history seriously and by acting, in his time and place, on the responsibility which that implies. The fact that Leonard did not live to see the achievement of justice and community does not diminish his contribution, and the fact that none of us will live to see that achievement does not diminish the worth of his example to us.

Ĵack Yates Brockton, Massachusetts January, 1988

# A VIEW FROM CHILLICOTHE: Wendell Berry's A Place on Earth

Someone said to me not long ago that it's rare to read a review of an old book. Well, this isn't exactly a review. It's more like the sharing of an appreciation. And the book isn't exactly old. It's Wendell Berry's novel A Place on Earth, which was originally published in 1967 and then revised and re-issued in 1983 by North Point Press. (It's also rare for a writer to find a publisher willing to issue a revision. Wendell Berry notes in the preface that this is an instance where "improved literary judgment can save trees." Most of his revisions were cuts from the original.) I've wanted for some time to write something about this book, so, here's a brief essay about a novel that's reached the age of twenty-one, or five, if you prefer.

A <u>Place on Earth</u> is, I think, a <u>biographical</u> sketch of a particular time in the life of a community. It's a story about people who are <u>at home</u> but who are living in their own awareness of how their home (their place on earth) is threatened both

by the ways they live in that place and by events happening far from that place. The story happens during World War 2.

The main character is the town. There are human characters, to be sure; community doesn't exist without people. The lives of the people in this community (Port William, Kentucky) are closely observed, treated with respect by the writer. Even the people who aren't likable are gently presented. The book is written almost entirely in the present tense, so we readers get a sense of immediacy about the events in the story. We're carried through the experience of the place and the people who live there. It's a vivid way to learn something about the nature of community.

Now, I have to be careful. I respect Wendell Berry's writing. I want neither to over-analyze nor over-interpret. Let me pose this definition, then: "community" can be defined as "people living together in a place." If that's accurate (it's certainly simple-minded enough), then  $\Lambda$  Place on Earth seems to me to be about the wedding of the definition's two parts (the people, the place).

It's about the importance—even the necessity—of continuity in a place to the very idea of community. The people in this book, the members of the Port William community, have an intimate knowledge of the place where they live. Of Mat Feltner, a middle—aged (I think) farmer who is a major thinker of the book's thoughts, it is noted that "...waking from death, (he) would have known in an instant the place, the time of year, the time of day." (p. 33) There is much observation about place—observation of the weather, of the way the clouds cast shadows on the river valley, of the look and sound of rain on windows, of the still noisiness of a small town late on a spring night. As most of the people in Port William are farmers or members of farm—families, there is much comment about their relationship to the land:

For as always it was finally the land that they spoke of, fascinated as they have been all their lives by what has happened to it, their own ties to it, the wife of their race, more lovely and bountiful and kind than they have usually deserved, more demanding than they have often been able to bear. (p. 298)

But, the Port William members who populate this book are as concerned about their care for their place as they are with simple continuity in it. Mat Feltner describes to his daughter-in-law, Hannah, a conversation he had with his son (and her husband) who is missing-in-action:

And I told him that a man's life is always dealing with permanence—that the most dangerous kind of irresponsibility is to think of your doings as temporary.... What you do on the earth, the earth makes permanent. (. 176)

The other part of the definition of community that I proposed above—the part about "people living together"—is the other "pole" of this book. There is a tendency, among those of us who talk a lot about "community" and its attractiveness these days, to sound sometimes like we're describing some place where problems have vanished, where all tears have been dried. Wendell Berry doesn't make that mistake. Port William isn't a place where everybody's perfect. It's a place where people rub up against one another, and, as most of us know, there's both pleasure and pain in that. Much of the pain in these people's lives is caused by vacancy—by the fact of people who are important (to each other and to the community) becoming absent—lost. Mat Feltner's son, Virgil, is missing—in—action. Gideon and Ida Crop's daughter is lost in a sudden flood that sweeps away the bridge to their home. Each loss is like a rent in the fabric of the membership—a tear that even the finding or re-finding of some lost ones cannot fully repair:

...since Mat came to tell him that the baby (Virgil and Hannah's daughter) was born, he has thought of the absence of Virgil. And he stays now because of that, sitting in that vacancy, though he knows he cannot fit or fill it. (p. 227)

The war and its capacity for creating lostness is like an undercurrent in the story. Reminders of it are regular—from letters to absent men, temporary soldiers, to the news on the radio, which the men in the general store card—game use as a finish to their time together each day. Virgil Feltner's "missing" status—his lostness to the community—remains throughout the book. Near the end of the book, the town's celebration (bonfire, music, and whiskey) over the end of the war is set against the funeral of someone who was damaged by an earlier conflict. It's as though the joy over the end of one kind of vacancy—making has to be sobered by a sign that both finding and losing—both joy and sorrow—are essential to community. A community is people living together in a place. In Port William each member is important. No one goes unmissed.

Sometimes I want to go there. Maybe you do too.

Jack Pealer

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P.O. Box 1943
Chillicothe, Ohio 45601

Non-Profit Organization U.S. Postage PAID Chillicothe, Ohio 45601 Permit No. 72 NUMBER NINE

# The Safeguards Letter

MARCH, 1989

a publication of OHIO SAFEGUARDS • P.O. Box 1943 • Chillicothe, Ohio 45601

## HISTORY WORKSHOP -- A RARE OPPORTUNITY

Not everyone likes history, but everyone is probably affected by it. That's as accurate an observation in the realm of human services as in any other area of human endeavor. On April 10, OHIO SAFEGUARDS (with the help of the Ohio Developmental Disabilities Planning Council and the Central Ohio Training Consortium) is offering an opportunity for people interested in helping others to learn something of the history of organized helping in western society. The workshop—the full title is "An Interpreted Pictorial Presentation on the History of Human Services, with Emphasis on the Origins of Some of our Major Service Patterns and Practices, and Some Universal Lessons Which Can be Learned from this History"—will take place at the Fawcett Center for Tomorrow, The Ohio State University, in Columbus, from 8:00 a.m. until 5:00 p.m. (Monday, April 10).

This presentation was developed by Dr. Wolf Wolfensberger of Syracuse University. In developing it, Dr. Wolfensberger used hundreds of slides that he has taken or gathered over the past 25 or so years. The workshop was last presented in Ohio in January, 1982, when more than 300 people assembled to hear and learn from it at Ohio University in Athens. This time, Dr. Wolfensberger will not be present. The workshop will, however, be presented by his long-time colleague and associate, Ms. Susan Thomas. Ms. Thomas is the Training Coordinator at the Training Institute for Human Service Planning, Leadership, and Change Agentry at Syracuse University.

The information presented and insight to be gained through this workshop is probably unavailable through any other forum. As Dr. Wolfensberger put it, in his description of this event:

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.

The basic fee for the workshop is \$50.00. If there are three or more people who come from the same organization, the fee is \$35.00 per person. The fee is also \$35.00 for primary consumers of human services and/or members of their families. To register, contact OHIO SAFEGUARDS at P.O. Box 1943, Chillicothe, Ohio 45601 (phone: 614/773-6191).

We hope that many of our readers plan to join us for this rare opportunity to learn from our own past.

## IT AIN'T OVER TILL IT'S OVER

Sandra Landis

One of the skills I've acquired during my sons' growing up years is conversing on a basic but (at least to them) convincing level about sports. I've even learned how to conduct myself on a golf course. In fact, Gregg credits me, in part, for teaching him how to hit a pretty good seven—iron shot. This learning about sports has helped me maintain some credibility with them from time to time over the years. And, I've learned some things. That's why I know that the title I selected is a Yogi Berra quote.

Gregg ended a conversation we'd had a few weeks ago by winking at me, repeating the quip, and asking me who was famous for saying it. We had started talking about the trips we're planning to college campuses this spring, as he makes a decision about where to go to school next year. As we talked about when we'd go where, I began to think about when he was five and had just begun to go to school....

During the first week of kindergarten I got a call at home from the school secretary. Gregg did not want to stay. In fact, he had left. Could I come? Now? On my way to the school I thought about the fact that I had chosen this school for him. His brother was there. Maybe he just missed being at home.

When I saw his face, I knew that it wasn't just "separation anxiety" at work. There was conviction in that boy's eyes. He had crawled out of the window of his ground floor classroom. He said he was escaping. "That lady doesn't like children, and I'm not going back in." We began discussing, commiserating about, and negotiating our way through his compulsory education that morning on the curb. It felt like my role in his required schooling career was charted that day. I had expected to be his encourager and supporter, a back-up to the pro's, so to speak. That day convinced me that I would also need to be his confidente and, sometimes, his representative. And, a helluva negotiator. My task seemed to be to create some space for the peaceful coexistence of my child and the world of public education.

There was much more at stake here than I had anticipated. In less than a week of schooling, Gregg's sensibilities had been offended, his teacher had been frustrated, and Gregg had decided that school was a place he didn't want to belong.

Through the years, I think Gregg's judgments about most of his teachers and their respective attitudes toward children have been pretty accurate. I think he was right about the first one. Fortunately, most teachers he's met have ranked higher on his list of people who gain his respect. He's been able to accomplish enough space to get through his required thirteen years of schooling.

So, our conversation a few weeks ago was the beginning of a celebration that for a long time I wasn't sure we'd ever have. I told Gregg that. He reminded me that high school graduation is no big deal these days. For some folks, maybe. But his graduating from high school with his spirit, dignity, and integrity intact and committing himself to continue to learn in a formal setting seems like a very big deal to me. That's when he winked and said, "Just remember, mom, it ain't over till it's over. There's three or four more years to go."

College, for a person like Gregg, represents a continuation of life in the compulsory education culture. I have mixed feelings about encouraging him to do that. As one of the investors in his education I'd much prefer to arrange a mentorship or tutorial relationship to guide his learning during the next few years. Those kinds of options seem to be rare in this country. I guess he's right, successfully negotiating the public education culture ain't over yet.

# DDITIONS TO THE OHIO SAFEGUARDS LIBRARY

The library continues to grow! To use any of the books or tapes, just write to OHIO SAFEGUARDS, P.O. Box 1943, Chillicothe, Ohio 45601 or call at (614) 773-6191. The following books have been added since the December issue of the Letter was published:

Gaventa, John. <u>Power and Powerlessness</u>: <u>Quiescence and Rebellion in an Appalachian Valley</u>. (Univ. of Illinois Press, 1980).

Observers of victimized groups of people are often amazed at the tolerance shown by such people toward their victimizers or the forces that do them harm. John Gaventa describes such tolerance as "quiescence" and shows its necessity for the maintenance of control by powerful forces over powerless people. The book is an extended case study in the balance between "quiescence" and revolt in a coal-mining valley in southeastern Kentucky/northeastern Tennessee.

Perske, Robert., and Perske; Martha. <u>Circles of Friends</u>. (Nashville: Abingdon Press). This book is subtitled: "People with disabilities and their friends enrich the lives of one another." It is a collection of stories about precisely that topic—stories that continue happening all over North America (and other places too). The stories are told in the Bob Perske style and accompanied by winning illustrations by Martha Perske.

Moyers, Bill., and Horton, Myles. "The Adventures of a Radical Hillbilly."

This is the transcript of a television interview of Myles Horton, founder of the Highlander Folk School in Tennessee, by Bill Moyers. The interview took place in 1981, and it focuses on Highlander's experiences and methods of promoting change through citizen-education. The transcript offers reminders about how long and with what commitment (and with what good humor!) some people in America have been working for fundamental change.

\*Myerhoff, Barbara. Number Our Days. (New York: Simon and Schuster/Touchstone).

Ms. Myerhoff is an anthropologist who studied "the aging process" by spending time with older Jewish people who live in Venice, California. The book records stories about how their culture seems to offer these people strength to face enormous and daily problems, such as poverty, loneliness, inadequate housing, poor health, and physical danger.

# About THE SAFEGUARDS LETTER

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ideas, and items for publication in the Letter can be sent to: Jack Pealer, Editor, The Safeguards Letter, P.O. Box 1943, Chillicothe, Ohio 45601. We welcome our readers' ideas and reactions.

"There comes to be something deeply pleasing to him in the idea of a bridge-not, maybe, the first mark a man makes on the earth, but surely one of the first marks made by a neighborhood...."

Wendell Berry, <u>A Place on Earth</u>

#### LIBRARY ADDITIONS (continued)

Dunbar, Anthony. Against the Grain: Southern Radicals and Prophets, 1929-1959. (Charlottesville: University of Virginia Press):

Some of the origins of the labor and civil rights movements in the American South are explored in this book. The "radicalism" described is specifically Christian; its leaders (many of them) were clergymen and seminary students. In some ways this is a story about early "liberation theology" and some of its outcomes.

\*\*Peavey, Fran. Heart Politics. (San Francisco, New Society Publishers).

Fran Peavey is a comedian. She's also a "networker." And she's a community organizer, ready to do daring things. This book contains stories of some of those things, like trying to save a hotel in San Francisco where older people made their homes, or like traveling around the world carrying a sign that read: "American willing to listen." The book is, as Ms. Peavey says in the introduction, "about how we build connections with people whose lives are different from ours...."

Adams, Frank. <u>Unearthing Seeds of Fire: The Idea of Highlander</u>. (Winston-Salem, John F. Blair, Publisher).

This book is the story of the mission and work of the Highlander Folk School (now the Highlander Research and Education Center). Highlander was founded in 1932 in Tennessee. Its original purpose, according to Mr. Adams, was "educating for a revolution that would basically alter economic and power relationships to the advantage of the poor and powerless...." This book carries the story of that kind of education through its first 40 years.

\*Wyman, David S. <u>The Abandonment of the Jews: America and the Holocaust, 1941-1945</u> (New York: Pantheon Books).

Dr. Wyman recounts the story of the official unwillingness of the United States to offer help to people whom the United States knew were at risk of being systematically killed. Wyman notes: "...the killing was done by people, to other people, while still other people stood by.... Would Americans be more sensitive, less self-centered, more willing to make sacrifices, less afraid of differences now than they were then?"

Illich, Ivan., Zola, Irving K., McKnight, John., Caplan, Jonathan., and Shaiken, Harley. <u>Disabling Professions</u>. (New York: Marion Boyars, Publisher).

As the jacket to this book asks, why do we put so much resource into medicine, education, and the law with so little apparent result? Why do we hold the professions in awe and allow them to set up what are in effect monopolies? The book is a collection of essays pointed toward such questions. Among the collected essays in John McKnight's "Professionalized Service and Disabling Help."

\*\*\*Shelley, Hugh and Mary Lou. Love is Two Plastic Straws. (published by the authors).

Mr. and Mrs. Shelley both are (or were; Mr. Shelley died several years ago)
people who have cerebral palsy. They met and married in Columbus, and both
worked at Columbus State Institute during the 1960's. The book is the story of
their relationship and the contributions they've made to the lives of others
in the Columbus community.

# OHIO SAFEGUARDS Library: A Complete Listing, as of March 1, 1989

- Adams, Frank. Unearthing Seeds of Fire: The Idea of Highlander. (1975)
- Alexander, Christopher. (with Howard Davis, Julio Martinez, Don Corner)
  The Production of Houses. (1985).
- de Toqueville, Alexis. Democracy in America, Vol. 2. (1840).
- Dunbar, Anthony. Against the Grain: Southern Radicals and Prophets, 1929-1959. (1981).
- Freire, Paulo. Pedagogy of the Oppressed. (1970).
- Gaventa, John. Power and Powerlessness: Quiescence and Rebellion in an Appalachian Valley. (1980).
- Highlander Research & Education Center. "Education for Economic Development Series." (manuals and curriculum) (1988).
- Illich, Ivan., Zola, Irving Kenneth., McKnight, John., Caplan, Jonathan., and Shaiken, Harley. <u>Disabling Professions</u>. (1977).
- Moyers, Bill., and Horton, Myles. "Adventures of a Radical Hillbilly." (1982).
- Myerhoff, Barbara. Number Our Days. (1978).
- Nolan, Christopher. <u>Under the Eye of the Clock: The Autobiography of Christopher Nolan</u>. (1988).
- "Paulo Freire at Highlander Center, December 5, 1987." (videotape)
- Peavey, Fran. Heart Politics. (1986).
- Perske, Robert., and Perske, Martha. <u>Circles of Friends: People with Disabilities and Their Friends Enrich the Lives of One Another.</u> (1988).
- 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).

Requests to borrow books 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 postage-costs.

# LIBRARY ADDITIONS (continued)

Economics Education Project, Highlander Center. Education for Economic Development Series. (Highlander Center, 1988)

1) "Claiming What is Ours: An Economics Experience Workbook." This workbook is about making changes in communities and lives through community-based economics education. It focuses on what can be learned from people's stories of economic adaptation, survival, and collective action.

2) "The Jellico Handbook: A Teacher's Guide to Community-based Economics."
This course on community development and the economy is part of the project's materials for use by colleges in community settings. This handbook outlines a ten to sixteen week course on community devleopment.

3) "Workshop on Developing Feasibility Studies for Community-based Business Ventures." The workshop is a laboratory where cooperative action can be developed and implemented. It presents an opportunity for an individual or a group analysis of the local economy to be actively incorporated in the planning for economic ventures.

We have been surprised and gratified by people's donations of books to our library. Donations in the above list include:

\* donated by Jack Yates, Brockton, Massachusetts
\*\* donated by Debbie Schmieding, Athens, Ohio
\*\*\* donated by Jack R. Pealer, Sr., Columbus, Ohio

It's exciting to receive and open a package to discover someone's gift of a well-used and thoroughly underlined book. For a reader and book-lover, giving a book away is a genuine act of sharing. We thank the donors for their confidence in us.

#### ABOUT THE PAPER..

Readers of The Safeguards Letter may have noticed a change in this and the December issue-the paper the Letter is printed upon. We're now using 100% recycled paper. I have this quote from Gandhi posted on the wall above my desk: "The things you do may be very small, but it is very important that you do them." Well, the decision to switch paper was a small one, although maybe bigger than is obvious, in a town where the main industry involves making bond paper from fresh trees. Anyway, we like the new paper. If you'd like to try some recycled paper for personal or office use, we suggest you contact the Earth Care Paper Company, P.O. Box 3335, Madison, Wisconsin 53704. They'll send you a catalog.

# HELPING PEOPLE GET HEALTH INSURANCE

The Ohio Developmental Disabilities Planning Council is trying to find ways to help Ohioans who have disabilities get adequate health insurance. The Council has formed a committee about this, and the committee is seeking people interested in helping out. It is hard for people with disabilities to get coverage under most health insurance policies because of policy language that lets insurance companies avoid people with disabling conditions. If this lack of insurance coverage is coupled with earnings-tests for Medicaid eligibility. it's easy to see the reasons why the decision to get a job can become a hard one for people with disabilities. To help the DD Council in its effort, call the Council at (614) 466-5205 or the committee chairperson, Regina Sweeney, at (216) 321-2844.

#### THE NEXT STEPS... THE "SAFEHOUSE" PROJECT

Sandra Landis

Glouster, Ohio 45732

In the October, 1988 issue of the <u>Letter</u> I wrote some ideas about creating a place of residence for the OHIO SAFEGUARDS library and a home for a caretaker. Since that writing, several people have offered ideas that have helped me continue to think about this endeavor. For example, we received a letter from Helen Zipperlen and Donna Sturgis of Kimberton, Pennsylvania that said (in part):

Although we cannot participate in the local effort towards your "safehouse," we do want to participate fully in the evolution of the idea. We can feel the same kind of idea struggling forth among several groups of people we know.

One of the significant threads is, that instead of simply providing "houses for the handicapped," we enlist each other's interest and work so that each contributes to another's need and in the process a new bit of community is nurtured. We note a frequest ability of people who "need a home" to become hosts to others who need a creative and nurturing place in which to hold converse.

We are most interested in exploring this process of "guests becoming hosts." Without it, we are always in danger of imprisoning each other in permanent "consumer-hood."

Another idea thathas been helpful is the notion that an interested property owner might lend the use of a now vacant property to OHIO SAFEGUARDS. This idea is appealing because we do not have enough funds in hand or pledged to purchase at this time. Finding someone who would lend or lease a property for this use for an extended period of time would ease the task and require less money.

Several things need to happen to move these ideas from a vision to a reality. Those that seem most obvious include: identifying a geographic area to begin looking for possible properties/owners; organizing a pledge campaign to assure financing of lease costs, improvements, and/or renovations; and recruiting people to volunteer their time and ideas to the project.

The "first" next step seems to be to gather interested people together to describe these activities in more detail. Please consider this an invitation for you to gather with others who are interested to listen and talk more about this notion of creating a home with someone in need. The gathering will be held:

Sunday, April 30, 1989.
11 a.m.-2 p.m. (potluck lunch while we work)
Landis/Fountain residence
(off State Route 13 in southern Perry County)

This invitation is extended to any interested persons. Please call me (614/347-4126) or return the form below so that I will know of your interest. We hope to hear from you and see you on the 30th of April.

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	OHIO SAFEGUARDS: 1st "Safehouse" Gathering	
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I a	am interested in helping and will attend on April 30.	
I a	im interested but cannot come on April 30. MAIL TO: Sandy Landis	
T w	vill need a man to find your house	

# A VIEW FROM CHILLICOTHE "Take a Rest from Law-Making?" Jack R. Pealer, Jr.

In 1729 Jonathan Swift doubtless shocked many Englishmen with the publication of his classic satire "A Modest Proposal."\* My proposal is not so drastic as Swift's Neither do I offer it in the same ironic tone as did Swift; nor is my prose so elegant. I'm at least half-to-three-quarters serious. Regardless, I'd guess my proposal may be nearly as shocking to some—why don't those of us interested in better lives for people with disabilities abandon all our contacts with legislatures (local, state, federal) for at least two years?

What would we lose? Well, we would probably endure a relatively-small decline (but a real decline) in the amount of money set aside for services to people with disabilities. It's not likely that the decline would be sharp because departments of government could be depended upon to provide legislatures with plenty of reasons to keep expenditures up. If the rest of us just stayed home, I don't think budgets would suffer much in two years, although their growth would be smaller.

We would also lose many of the ideas (good or bad) that are currently "in the hopper" before city councils, state legislatures, or the Congress. There are two things to be said about this loss (which would be a <u>real</u> loss), however. First, the setback would only be temporary—perhaps not even outside the natural order of things, as changes in law go. How long, after all, have organizations been working to try to change the Medicaid program's effect on people with disabilities? It's possible that a two-year absence on this or other issues would hardly be noticed by Congress or the Federal administration. Second, we may well ask whether some of the new laws we might et are worth having, especially after lots of compromises have been engineered into them. Let me offer an example—a new law, the worth of which is at least debatable.

On December 15, 1988 Ohio's Governor approved an act (Substitute House Bill 403) that has been described as an attempt to address the serious issue of abuse and neglect of adults who have developmental disabilities. The act sets up procedures that resemble those previously used to "combat" child abuse: various human service workers and other personnel required to report suspected harm; a human service agency required to investigate reports (in this case, the investigating agencies will be County Boards of Mental Retardation and Developmental Disabilities); and an array of legal and service actions established to try to make the situation better for a person who may have been hurt. This law takes effect on March 16, 1989. How likely is it that the law will do what its supporters (and others) want? What are likely to be its effects?

One almost-immediate effect will be to increase the personnel requirements of the "case management" sections of County Boards of Mental Retardation and Developmental Disabilities. I'd guess that the County Board of which I'm a member will receive a request for one additional "case manager" within six months (a 25% increase, that will cost a minimum of \$22,000 per year). On the relatively-fixed budget of the Board, that will mean that we'll trade one job-coach or a substantial number of hours of at-home support or almost a year's worth of "family resources" for an abuse-investigating case manager who, of necessity (and no matter how "client-oriented" or hard-working), will end up managing mostly paper. Does this make the law worth having?

Another likely effect will be an <u>absence</u> of noticeable impact on the abuse or neglect of people with disabilities. In 1978, in a monograph entitled "The Limitations of the Law in Human Services," Wolf Wolfensberger reminded us that "...one of the biggest

<sup>\*&</sup>quot;A Modest Proposal for Preventing the Children of Poor People in Ireland from Being a Burden to Their Parents or Country, and for Making Them Beneficial to the Public."

limitations of the law...is its virtually total inability to create constructive human relationships." This observation has surely been borne out in the case of laws governing child abuse. Just within recent days, for example, the United States Supreme Court, in a child abuse case involving a child from Wisconsin (the DeShaney case), observed that the United States Constitution was devised to protect us from the government, not to make the government protect us from each other. It seems unlikely that the provisions of Ohio's Substitute House Bill 403 will magically be more effective than have been the child abuse laws. The child in Wisconsin was horribly hurt—in a state noted for the progressiveness of its human service laws and structures.

It's at least arguable that people with developmental disabilities in Ohio would be as well off if the cost of carrying out this new law were directed elsewhere. And, (and this is really my point) I choose this law just an an example. If this is the kind of change we're getting, could we not do without it for two years? Two years is a lot of breathing space—a lot of thinking time. We could probably put the money we'd save on "influencing legislation" to good alternative use. It would be like the gift of the day when I'm writing this—the gift of a "snow day"—a day off from the routine of February or March. We might get refreshed. We might even be renewed for the times ahead when it becomes necessary to face the lawmakers again.

Jack Pealer

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# The Safeguards \_\_Letter\_\_

JULY, 1989

a publication of OHIO SAFEGUARDS • P.O. Box 1943 • Chillicothe, Ohio 45601

#### TENTH ANNIVERSARY PASS WORKSHOP

OHIO SAFEGUARDS has scheduled "An Introduction to the Role of Values in Services, through the Use of PASS 3" for September 17-22, 1989 at the Ramada Inn, South, Columbus (Grove City), Ohio. Flyers describing this workshop have been mailed to individuals and organizations both within and outside Ohio.

We've noted that the first PASS (Program Analysis of Service Systems) training course also took place in Columbus—in the spring of 1979. We are, therefore, regarding the September workshop as the "Tenth Anniversary" of this kind of training event in the state. Altogether, more than 200 people have participated in the seven workshops that have been held since 1979.

Sharp readers will notice that we have decided to change the title of the workshop. We've done this so that the title will more accurately state our purpose in offering this event. OHIO SAFEGUARDS believes that the values of a culture—those things the culture agrees are desirable and worthy for all its members—are the major determinants of "quality", both in the lives of the culture's members and, by extension, in the forms of help offered to people who experience difficulties.

People who come to the September 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 the Tenth Anniversary PASS Workshop, but who haven't received a descriptive flyer, can contact OHIO SAFEGUARDS at P.O. Box 1943, Chillicothe, Ohio 45601. Phone: (614) 7.73-6191.

## WHAT ABOUT "THE OTHER ECONOMIC SUMMIT"?

OHIO SAFEGUARDS, in conjunction with Community Services, Inc. of Yellow Springs, Ohio, has arranged to sponsor an evening presentation by Mr. Larry Martin, General Coordinator of "The Other Economic Summit," North America Office.

This presentation is scheduled for Thursday, October 19, 1989 in Columbus. The location and time for the event are being arranged. They will be announced in the September, 1989 issue of The Safeguards Letter. We envision the event as one similar to the "Evening with John McKnight" that was held in the spring of 1988.

Mr. Martin and "The Other Economic Summit" are particularly interested in and concerned about our economy and the implications of current systems on the future. A tentative title of his talk is: "The Gross National Waste Product"—how our economy leads to waste and what might be done about it.

(Editor's Note. The follwoing essay was originally printed in a publication titled "Speak Out," published by the Community and Mental Handicap Educational and Research Association — CMHERA — of London, England. Subscriptions to "Speak Out," which focuses on offering evidence for the reality of "deathmaking" in Great Britain, are available, for 10 pounds sterling, from CMHERA, 12a Maddox Street, London W1R 9PL. The following article, taken from a speech by Paul Williams before the Southampton University Debating Society, 20 October, 1988, is reprinted with Mr. Williams' permission.)

In Opposition to the Motion "This House Thinks That Euthanasia Should Be Permitted."

Proponents of euthanasia often claim to be concerned with just one kind of euthanasia—namely easing the process of death for people in great suffering who themselves request release from that suffering, or whose loved ones do so on their behalf. The picture is of an elderly person after a lifetime of contribution to society and great personal fulfillment, being in excruciating pain from cancer and requesting to be relieved by death. The relatives and friends value and love the person so much that they wish to do everything to make the end of the person's life a peaceful and dignified one.

My argument is in three parts:

- that this kind of eithanasia is not in fact the kind that is most talked about, written about, and practised or condoned by families, doctors, lawyers, philosophers, and others;
- 2) that permitting euthanasia in individually prescribed circumstances by doctors or others in consultation with people themselves and their families, has likely consequences for society that are undesirable—in other words, that euthanasia is a social issue not just a private and personal one;
- 3) that the use of death to solve any problem is morally wrong and in particular is a spiritually bankrupt response to the universal human condition of pain and suffering.

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#### About THE SAFEGUARDS LETTER

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

This last argument especially is one of moral belief rather than rational debate, and I suspect that in the last analysis our decisions on this issue, and in particular today our voting on this motion, will be determined by our basic beliefs rather than our being convinced by argument—just as would be the case if we were debating abortion, capital punishment, nuclear weapons and similar issues.

However, even in the application of moral beliefs there is an important place for debate, so let me first examine my proposal that the kind of "cosy" euthanasia—ending the life of a highly valued and loved person to relieve that person's pain, ideally with their consent—is not the only kind of euthanasia that is commonly proposed.

# PPOSITION TO EUTHANASIA (continued)

Euthanasia is commonly proposed for people who are considered an actual or potential burden—to their families, to society or to themselves. In particular, euthanasia has been strongly proposed for handicapped people.

Perhaps the best known example is the book published in Germany in 1920 by a lawyer, Karl Binding, and a doctor, Alfred Hoche, called "Release from the Burden of Life without Value." They argue that the lives of people who are incurably ill and of people with severe mental and physical handicaps are of no value to themselves or to society. Unfortunately, this notion of certain people being of no value combined with extremes of nationalism in Germany to create a climate for mass killing. However, even if it had not had this particular connection and influence, it represents a clear statement of the idea that euthanasia is about relieving a burden on society.

This idea has been frequently resurrected, a recent example being a book by two Australian philosophers, Helga Kuhse and Peter Singer, called "Should the Baby Live?" This advocates euthanasia for newborn handicapped babies with the consent of their parents. They argue that such children often wreak havoc in families and are a severe financial burden in society.

Here we see why euthanasia cannot be regarded as a purely personal and private matter concerned with the suffering of an individual. People who are suffering or are handicapped do place responsibilities—"burdens" if we wish to use that word—on families and on society. Once we accept that suffering is a good reason for causing the death of an in—lividual for the individual's benefit, it is then only a very small step to accepting that a person's death can be caused for the benefit of the person's family or of society.

Many elderly people are in favour of euthanasia for themselves if they were to become seriously ill or disabled, sometimes because they do not wish to suffer pain or debility or loss of dignity themsleves, but often also because they do not wish to be a burden to others. Thus, euthanasia to relieve suffering for the individual is often closely linked with the idea of euthanasia to relieve a responsibility or burden.

Once euthanasia is condoned for individuals it can more easily be considered as a social tool for the management of handicap and suffering and their consequences.

It may seem that this is controllable—surely we can set laws that limit the use of euthanasia so that only clearly good ends result? Unfortunately, this seems unlikely. Nearly all human societies use death as a tool for the management of social threat, inconvenience, or upset. Examples are capital punishment, war and genocide, all of which are distressingly frequent in human history. In an increasingly hedonistic and utilitarian world, suffering and handicap are seen as requiring management and elimination in whatever ways seem possible. The interest of society in euthanasia is not for the good of the suffering individual, but for the perceived good of other people or of society as a whole.

This can be seen clearly in the fact that proponents of euthanasia for people with handicaps often do not confine themselves to cases where the handicap involves obvious pain or distress. Kuhse and Singer, for example, advocate euthanasia for children with Down's Syndrome because of the distress and upset they can cause to families and the cost of providing services for them. Down's Syndrome, however, does not necessarily involve inherent pain or distress for the person themselves.

# OPPOSITION TO EUTHANASIA (continued)

Because Down's Syndrome is perceived by doctors as a medical abnormality, and they encounter families where the birth of such a child has been distressing, many of them tend to see people with Down's Syndrome as of low value and may advocate whatever means are within the law to end the person's life. A few doctors probably practice active euthanasia, certainly on newborn babies with handicaps and on some elderly people. Much more common is withdrawal of treatment for medical complications like a blocked intestine or pneumonia, because that is not clearly perceived as illegal. At the trial of Dr. Leonard Arthur in the early 1980's (he was acquitted of attempted murder of a baby with Down's Syndrome from whom he had withdrawn treatment) Sir Douglas Black, President of the Royal College of Physicians, stated that withdrawal of treatment from handicapped babies was common and most, doctors, including himself, approved of it.

I would argue that any increased legalisation or condoning of euthanasia, even in a very restricted and seemingly benign form, would result in an escalation of such killings, not to relieve the suffering of individuals, but to relieve the perceived burden on others of people who are not valued highly in society. Euthanasia in relation to elderly people would not only be practised more when highly valued people had tremendous pain ended while surrounded by their loving families; it would be practised much more with abandoned, devalued people not necessarily in pain but seen as a burden.

I think that only total and clear prohibition of any form of euthanasia can prevent this.

If we oppose euthanasia, then we are led up some very difficult and challenging moral and philosophical paths. It seems to me that we are led to have a coherent position on the moral wrongness of using any form of death to solve human problems. We have to review our position on war and weapons, on capital punishment, on suicide, and perhaps also on abortion. We have to have a rationale for treating human beings differently to anumals. We have to have an alternative way of reconciling ourselves to problems in the world, and in particular to the existence of pain and suffering, in the knowledge that for at least some problems we have no solutions and perhaps never will. A crucial question to this whole debate is: what is our view of suffering that we cannot control?

These are hard questions, but they are questions that are curcial for the culture and civilisation of mankind. And of course for us individually, we have to acknowledge that we may have to wrestle with these moral dilemmas while faced with a dying loved one in great pain and distress.

To sum up, I believe that using death to manage suffering is a morally and spiritually inadequate response to suffering. It will inevitably result in an increasing use of death to manage perceived "burdens" in society, and that is part of a universal but evil tendency of humans to utilise death as a solution to social problems. We must find other ways if the human race is to survive, hard though that is when we are faced with personal circumstances and dilemmas. You may think that the allowing of private, selective, tightly controlled euthanasia is not of such great social significance, and that the benefits outweigh the dangers. However, I would strongly urge you to oppose this motion as an affirmation of your opposition to this and to any other use of death to solve any of man's problems.

(<u>Vote:</u> The motion was carried by 57 votes in favor of euthanasia being permitted, with 31 against and about 15 abstentions.)

# JUST QUOTES...

We're trying something that's new (but relatively simple) for us. This segment of the <u>Letter</u> will contain "just quotes"—snippets from elsewhere printed without further comment, except, sometimes, about their context. Readers are invited to send us items they've run across, for sharing in "Just Quotes".

\*Friendship is evanescent in every man's experience, and remembered like heat lightning in past summers. Fair and flitting like a summer cloud; there is always some vapor in the air, not matter how long the drought. There are even April showers.

Thoreau, "A Week on the Concord and Merrimack Rivers"

\*The ideal rides ahead of the real, renewing beyond it, perishing in it—unreachable, surely, but made new over and over again just by hope and by the passage of time; what has not yet failed remains possible. And the ideal, remaining undiminished and perfict, out of reach, makes possible a judgment of failure, and a just grief and sympathy.

Wendell Berry, A Place on Earth

\*...anything that goes through an interagency process is likely to come out oatmeal.

Elizabeth Drew, The New Yorker, June 26, 1989 (commenting on current American foreign policy)

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

Garrison Keillor, January 7, 1984

# UPCOMING EVENTS WORTHY OF YOUR ATTENTION

"Two Inter-related Workshops: <u>Social</u> <u>Advocacies</u> on behalf of societally devalued people, and an introduction to <u>Citizen Advocacy</u>.

These sequential workshops are being held in Coraopolis, Penna. (near Pittsburgh) on October 5-8 (Thursday through Sunday), 1989. The events are

being jointly sponsored by the Commonwealth Institute of Harrisburg, Penna. and by the Training Institute for Human Service Planning, Leadership, and Change Agentry of Syracuse, New York. <u>Dr. Wolf Wolfesnberger</u> will be present to direct these workshops, accompanied by his associate, Susan Thomas.

The first workshop introduces the

(continued, p. 6)

#### UPCOMING EVENTS (continued)

concept of "social advocacy" on behalf of people who are disadvantaged or oppressed, such as those who have handicaps, who are poor, who are members of a devalued minority group. The workshop examines universal reasons why social advocacies on behalf of such groups are always needed, as well as some reasons why certain forms of advocacy are especially needed today. The second workshop is an introduction to one form of social advocacy—Citizen Advocacy. In citizen advocacy, an individual volunteer citizen is recruited and matched with one individual person in need in order to represent the interests of that person. The workshop explains: the history of citizen advocacy and its key elements, the things that make citizen advocacy different from other types of advocacy, and the unique benefits that come from citizen advocacy relationships. Readers interested in these workshops should contact:

Thomas Neuville, or Trini Swalm Commonwealth Institute P.O. Box 5500, Harrisburg, Penna. 17110-5500 (717) 238-5360

"The Sanctity of the Lives of Devalued People." This workshop is being presented by Dr. Wolf Wolfensberger on Friday, December 1 through Sunday, December 3 in Syracuse, New York. The event, which is presented mainly in lecture style with some time for discussion, addresses the largely unrecognized but growing support in our society for various forms of "deathmaking" of people who are impaired, handicapped, or elderly. "Deathmaking" refers to any practices that outright kill people, that greatly hasten their deaths, or that lead others to act against them so as to bring about their deaths. The workshop stresses that people must become aware of such realities and must take strong moral stands to protect and defend the lives of endangered people. For more information about the workshop, readers should contact:

Training Coordinator
Training Institute -- Syracuse University
805 S. Crouse Avenue, Syracuse, New York 13244-2280
(315) 443-4264

#### ABOUT NATURAL CONSEQUENCES . . .

Sandra Landis

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 helping people. I've been troubled by what I 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 aren't 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.

## ATURAL CONSEQUENCES (continued)

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 jilemma 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 his 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, nor 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 though—about 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.

### NATURAL CONSEQUENCES (continued)

The things that help keep the natural consequences I experience manageable are things like: lots of relationships with lots of people, lots of practice, others to help pay for things, others to help do the work that needs to be done, confidence that this is only temporary, and being forgiven for mistakes that I make. In other words, it takes lots of real help to offset the severity of natural consequences. My security comes from this help being there when I need it. Most of the help I get comes from people who know me well. If this same kind of help were present in 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, natural consequences seems a risky helping strategy. In the continued absence of natural supports, "natural consequences" turns out to be just one more way of contributing to people's hurtful experiences.

Sandra Landis

## A VIEW FROM CHILLICOTHE

The Mystery of Making Decisions

In the film "Dead Poets Society" Robin Williams plays the part of a gifted teacher at a private boys school. The teacher's influence on his students leads them toward various personal decisions and actions that they otherwise might have feared taking. These decisions that the boys—young men, actually—make are the points on which the film's plot turns. One student's decision, and the action that issues from it, leads to disaster. A highlight of the film, for me, was a brief scene near the end when the teacher—Robin Williams—is shown sitting in the empty classroom grieving over the terrible event that has happened. In the politics of the story he has been blamed for that event and has lost his job. What makes this moment so right, I think, is that it portrays the teacher recognizing the justice that's in the judgment. He knows—and he is the only one who knows—that he is responsible for what has occurred. He knows just how he did this—by doing his work so well, by being a good teacher, and by offering good advice. We're all so closely tied to each other, the film seems to be saying, that it's hard to know what will happen even if we do the <u>right</u> thing. Making decisions is a mysterious process.

And it's a process that we can't avoid. Especially we can't avoid it if we are, like the character played by Robin Williams, people whose careers involve us in trying to help others—human service workers. That the responsibility for <u>deciding</u> is an inevitable part of the role of human service workers is something that Wolf Wolfensberger has reminded us about for more than twenty years. In the prologue to <u>The Principle of Normalization in Human Services</u>, Dr. Wolfensberger wrote:

("Human management" is) entry of individuals or agencies, acting in societally sanctioned capacities, into the functioning spheres of individuals, families, or larger social systems in order to maintain or change conditions with the intention of benefitting such individuals, their family or other social systems, or society in general. The term "human management," it is hoped, will help to keep us humble and perceptive of what we do and are, and of the part of our functioning that we are often inclined to deny. (p. 2)

# YEW FROM CHILLICOTHE (continued)

I've been a human manager for nearly 19 years. The decisions I've made have ranged from assigning people to transportation routes (with some bus drivers who were known to me to be less-able than others), through arranging that adult workers would go for their "work" each day in the "only building we could find"—a converted turkey hatchery, to (as a board member) influencing and voting on the ways that more than \$2 million will be spent each year in our community to assist people with disabilities. There are thousands of small choices masked by that last decision alone. And I, like the teacher in "Dead Poets Society", can neither avoid making those choices nor evade some responsibility for things those choices lead to. Making decisions is a necessary but perilous process.

But how does the connection between my decision and someone else's action or their life-experience work? Is "accepting responsibility for" my decisions the same as seeing my choices as the "cause" of what happens to someone else? The answer to the latter question turns out, it seems, to be "maybe" or "sometimes"—answers that are insufficient either to work up guilt over or to hide behind. The connection between decisions and actions isn't so simple.

In March of this year I went one evening to a "Distinguished Lecture in Science" at Ohio State University in Columbus. The lecturer was Stephen Jay Gould, whose writing I've admired for a long time, and his topic was "Human Evolution as a Contingent Fact of History." He began with a few words about "contingency," which, as far as I can make it out, refers to an idea about how history works. History is, at least in part, a record of the interaction between people's choices and people's actions. Dr. Gould suggested hat, if we wanted to understand the idea of "contingency," we should either read the econd epilogue to Tolstoy's War and Peace or we whould watch Frank Capra's film It's a Wonderful Life, in which a man gets a chance to see the impact of his life by experiencing a bit of time in his community as it would have been without him. Because I was familiar with the story of George Bailey as played by James Stewart in the Capra movie, I chose Tolstoy.

At the end of <u>War and Peace</u> is Tolstoy's reflection on the question of how the actions of individual persons make other people act in certain ways. This reflection is oriented around the events in the novel—the invasion of Russia by Napoleon's army. I neither presume nor intend to summarize Tolstoy's argument. He does, however, offer an analysis of "power" (decision—making power?), which is the thing offered by historians as the cause of events. What is this power? Does it reside in Napoleon, in his superior intelligence or ability to motivate soldiers? Or, by analogy, does it reside in me, in some magic capacity for choosing the right bus driver for every person? On the other hand, could "power" be situated outside an individual, in an entity like the "will of the people" or "community opinion"? If that were true, how (Tolstoy asks) do we explain the seeming easy changeable—ness of that will or opinion? Is power that fickle?

Tolstoy arrives at the judgment that "power is power...a word the meaning of which is beyond our comprehension," at least by abstract reasoning. We have learned about power (choice-making) by experience, however. And, from the point-of-view of experience, power "is only the dependence existing between the expression of the will of a person and the carrying out of that will by others." Tolstoy points out that, of all the decisions ("commands") that Napoleon issued, the majority were not carried out. Napoleon gave directions intended to lead to an invasion of England. He gave these directions for many years. These came to nothing. I can think of thousands of decisions I've made about things that would have been good and right but that came, in the end, to the same place. Tolstoy observes that "man acts in time, and himself takes part in the event."

#### VIEW FROM CHILLICOTHE (continued)

This is what complicates things. And..."examining in time the relation of commands to events, we find that a command (decision) can never in any case be the cause of the event, but that a certain definite dependence exists between them." So, "power," our experience tells us, is the "relation of the commanding person to those he commands"—the connection between the decided and those affected by the decisions.

This, I think, is complementary to Dr. Wolfensberger's point about "human managers." Dr. Wolfensberger wants those who occupy that role to understand, appreciate, or even to be in awe of the power they hold with regard to others who have disabilities or who are in other kinds of difficulties in their lives. Tolstoy helps human managers and others, however, toward humility about that power. It doesn't reside in something special in me—some artifact of my genetic makeup or education. Neither does it reside, so clearly, in the assembled will of those who appoint me—the human manager—to my post. Rather, power is in the relationship among me, those I try to help, and those who sanction my work. Sometimes the working out of that relationship in time (in history) is mundane, as Tolstoy notes:

When some event takes place, men express their opinions and desires in regard to the event, and as the event proceeds from the <u>combined action of many men</u>, some one of the opinions or desires expressed is at least approximately fulfilled. When one of the opinions expressed is fulfilled, that opinion is connected with the event as the command preceding it. (emphasis added)

What seems important in this mysterious relationship between decisions and actions (commands and events) is, as Dr. Wolfensberger has been reminding us for years, awareness consciousness about the relationship and our daily effects on it.

I'll close this with a story told on the radio by Garrison Keillor, one of our experts at the confusingness of choices, actions, and relationships. As one of his "News from Lake Wobegon" segments, he read a "Letter from Jim," an old friend from Lake Wobegon who had lived away from home for many years. At the close of the "letter," Jim recalls his thoughts as he waits in the front yard of his home to be picked up for a trip to Chicago with a woman who is not his wife:

As I sat on the lawn, looking down the street, I saw that we all depend on each other. I saw that, although I thought my sins could be secret, they would be no more secret than an earthquake. All these houses and all these families—my infidelity will somehow shake them. It will pollute the drinking water. It will make noxious gases come out of the ventilator in the elementary school. When we scream in sneseless anger, blocks away a little girl we do not know spills a bowl of gravy all over a white tablecloth. If I go to Chicago with this woman who is not my wife, somehow the school patrol will forget to guard an intersection and someone's child may be injured. A sixth-grade teacher will think "What the hell" and eliminate South America from geography. Our minister will decide "What the hell, I'm not going to give that sermon on the poor." Somehow my adultery will cause the man in the grocery store to say "to hell with the Health Department. This sausage was good yesterday; it certainly can't be any worse today." I just leave the story there. Anything more I could tell you would just be self—serving, except to say that we depend on each other more than we ever know.

Respect for that dependence we have on each other is the place where the clues to the mystery of making decisions ware to be found.

Jack Pealer

(Tolstoy quotes from the "Modern Library" edition of War and Peace.)

# The Safeguards Letter

a publication of OHIO SAFEGUARDS • P.O. Box 1943 • Chillicothe, Ohio 45601

NUMBER ELEVEN

OCTOBER, 1989

# OHIO SAFEGUÁRDS' ANNUAL LECTURE EVENT: AN EVENING WITH LARRY MARTIN

On October 19, 1989 at 7:00 p.m. at the Leo Yassenoff Jewish Center in Columbus, OHIO SAFEGUARDS will sponsor the second of its annual lecture events. Mr. Larry Martin, General Coordinator of "The Other Economic Summit, North America" will visit Columbus from Washington, D.C. Mr. Martin will offer a presentation entitled "The Gross National Waste Product."

Mr. Martin's presentation will focus issues relating to the economic realities of the waste industry and waste production in North America and on the call for individual and community responses to those realities. Mr. Martin views this period of time as critically important for community builders. It is a time when small, focused efforts that respect the sensibilities of people, the land, and the relationships between them together can have tremendous influence.

Mr. Martin says, "Concern for environmental health, paired with a vigorous initiative on the part of communities to strengthen their local economies through strategies to recover the material value of discards, is a plan for direct action to strengthen the local economy, transform waste into resources, and reduce the causes of environmental deterioration."

Please plan to join us at the Jewish Center on College Avenue in east Columbus at 7:00 p.m. on October 19, 1989. There is no charge for attending this lecture. Please share information about this event with others you know who may be interested.

printed on recycled paper

#### "SANCTITY OF LIFE" WORKSHOP: SECOND NOTICE

We understand that the prospect of traveling to Syracuse, New York (with the world's possibly-worst weather) in early December is not attractive. Nevertheless, we again encourage readers to consider the trip in order to participate in Dr. Wolf Wolfensberger's workshop "The Sanctity of the Lives of Devalued People" on December 1-3. The workshop focuses on the largely unrecognized but growing support in our society for various forms of "deathmaking" of people who are impaired, disabled, or elderly. "Deathmaking" is a term coined by Dr. Wolfensberger to refer to any practices that outright kill people, that greatly hasten their deaths, or that lead others to act against them so as to bring about their deaths. The workshop stresses that people must become aware of such dynamics in our society and must take strong moral stands to protect and defend the lives of endangered people.

Citizens of Ohio should be on special alert about the deathmaking phenomenon. Our legislature has seen introduced and has held hearings on a bill (H.B. 221) that would allow (and, therefore, encourage?) the practice of declaring dead of certain infants born in Ohio hospitals so that these babies organs can be used for transplants. The active consideration of such a law indicates the presence of deathmaking among us.

For more information, or to register for the "Sanctity of Life" workshop, readers can contact:

Training Coordinator
Training Institute - Syracuse University
805 S. Crouse Avenue, Syracuse, N.Y.
13244-2280

(315) 443-4264

#### HIDDEN CHILDREN

Sandra Landis

This summer has offered me several occasions to think about children—children I know intimately and children who are unknown to me. Memorial Day was quite a beginning for our summer. My younger son graduated from high school. My youngest brother, his wife and their daughters came to visit and celebrate with us. It was the first visit to our home by these little girls. For several days I got to watch and play with my nieces, who are three and one—and—a—half years of age.

In June I spent a week in Atlanta as a member of an evaluation team. The organization we visited promotes citizen advocacy and other personal forms of advocacy with people in Georgia who are described as having a developmental disability. I heard the sad news that at least a dozen youngsters in Georgia had been admitted to state institutions during the past year. I began to think about the children back home. I realized that I didn't know whether children in Ohio were being responded to in the same way. I knew there had been a time when many children grew up in Ohio institutions. I remembered my first visit to Columbus State Institute in 1971. I saw a lot of children that day.

In July I was invited by a young mother to visit with her and her children in southeastern Ohio. Her youngest is two-and-a-half, and he had just entered a preschool program at a nearby church. I did visit and was delighted to meet her little son. He had just finished swimming with the other children in his class. He's the youngest in the class and the only child in the class who has a developmental disability. I was pleased that this little one was being welcomed into a class of typical youngsters by the regular teachers. I was very aware, however, of my sense that this is still a very rare event. My image of most other two-year-olds with Down's Syndrome is their climbing, or being lifted, onto a bus with other children who also have disabilities to be transported to the "special" school.

In early August I began the work of organizing practicum sites for an upcoming PASS course. I saw this as a perfect opportunity to learn a bit more about how children in Ohio are being responded to by organizations and programs. I aimed to recruit two programs that served children for the PASS course.

I brainstormed a short list of programs for children that I thought would accommodate a PASS team and that would offer examples of what was going on for kids in Ohio in 1989. Then I began to make calls to people K knew who were associated with these programs. I was sufficiently encouraged by my initial calls to proceed

## About THE SAFEGUARDS LETTER

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(continued, p.3)

JUST QUOTES

"It's not a tragedy when a man dies at the end of his life."

Wendell Berry
The Memory of Old Jack

"Truth strikes us from behind, and in the dark, as well as from before and in broad daylight."

Thoreau, <u>Journal</u>

## HIDDEN CHILDREN (continued)

in recruiting two programs for school-aged children--one privately operated, the other operated through a local public school district. The PASS course took place in late September. Neither school-age program participated. It was not feasible, given the respective administrative constraints operating inside the prospective sponsoring organizations.

The situation in the public school program was interesting and informative. I scheduled a meeting with the two (I thought) administrators involved in a decision about participation in the PASS course. I had already talked with the classroom teacher and a parent in the district who was familiar with the program. Both were enthusiastic about the idea. The two people I met with seemed to think that the idea of participation in PASS had merit. The idea of assessing the quality of the classroom experience from the point-of-view of the students was interesting to them and not something they had thought a lot about.

It turned out, though, that there were just too many people in the way for it to happen, this year anyway. As we sat and talked that day, we discovered that there were eleven people inside the school administrative staff, plus the parents of each student, who would have to say "yes" before a PASS team could visit. The PASS team visit fell under the school's category of RESEARCH and would have been, therefore, covered by the research policy manual. The steps one would take to qualify as an acceptable research event were specified in an eleven-page document. We were able to tentatively set a timetable for working through the process. It seemed that the conversation that day would be the appropriate time to start "establishing credentials with the district" so that a visit by a PASS team would be feasible during the 1990-91 academic year.

I've decided to continue to think about the children here at home and to continue to look for them. With rare exception, my limited search for children this summer has only increased my concern. I know that some children continue to be deliberately hidden from us. Some are hidden by distance and separation, some by layers of bureaucracy. Nearly all are kept strangers to us in our day-to-day life.

Sandra Landis

#### SUPPORT FOR THE SAFEGUARDS LETTER

This is an appeal for donations of money to pay for The Safeguards Letter. Regular readers of the Letter know that, since the first few issues, there has been no "subscription fee" for the Letter. The trustees of OHIO SAFEGUARDS agreed more than two years ago that the Letter would not be funded by "subscriptions" but would be paid for 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 two 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-costs that range from \$300 to \$400 per issue. We thank you for considering us and for your continued loyalty as readers.

#### OTHER UPCOMING EVENTS -- WORTHY OF NOTE

October 19: "The Key to Making Learning Fun and Functional for Students with Severe Disabilities and Teachers"—a workshop presented by Dianne Ferguson of the University of Oregon.

\*Holiday Inn, Ohio Center, Columbus \*sponsored by Ohio Society for Autistic Citizens

\*cost: \$20.00

\*contact: 0.S.A.C.

751 Northwest Blvd. Columbus, Ohio 43212 (614) 294-5784

October 20-21: "Building the Regenerative Community"—the annual conference of Community Services, Inc.

\*resource people:

-Larry Martin, The Other Economic Summit, Washington, D.C. -Liz Cook, Friends of the Earth, Washington, D.C.

-Ron Shegda, New Generation Press, Emmaus, Pennsylvania -Dick Hogan, Village Services,

Wilmington, Ohio \*Glen Helen Outdoor Education Center, Yellow Springs, Ohio

\*cost: \$65.00

\*contact: Community Services
P.O. Box 243
Yellow Springs, O.
45387
(513) 767-2161

November 30, December 1 and 2:"The Inclusive Community: Educating Children with Disabilities in the Regular Catholic School Classroom" —with Marsha Forest, Patrick Mackan, and George Flynn \*The University of Dayton \*cost: \$95 (commuter)—\$115 (shared double)—\$130 (single) contact: Marilyn Bishop, MORES University of Dayton Dayton, Ohio 45469 (513) 229-4325

#### ONCE AGAIN--"DESIGN FOR ACCOMPLISHMENT"

OHIO SAFEGUARDS has again arranged with John O'Brien and Connie Lyle of Atlanta, Georgia for the presentation of "Design for Accomplishment"—a three-day workshop about organizing for positive change and for the valued participation of wounded people in community life. This workshop will take place during the week of January 22, 1990. The location of the workshop is, as yet, undetermined.

Beliefs that underlie this workshop are: 1) that a real purpose of a human service is to help a community support valued membership for all its citizens; 2) that effective services are those that discover and rely on connections between individual people who have experienced social rejection and the communities of which those people are a part; 3) that communities and services learn to be effective through careful attention to the circumstances of socially-devalued individuals and through action carried out by community members with strong social ties to each individual.

As on previous occasions when OHIO SAFEGUARDS has offered this workshop, we think that the workshop "works" best for people who plan to attend as part of a group of participants representing a community. These groups are, then, already prepared to take part in and benefit from the small-group exercises that make up an important part of the three-days' work. Watch for fliers about this workshop! If you want to be sure to get a flier, just contact OHIO SAFEGUARDS at P.O. Box 1943, Chillicothe, Ohio 45601 (614) 773-6191. We'll be sure that you are on the mailing list.

## A VIEW FROM CHILLICOTHE

"Learning about Differences—a Memory"

We (OHIO SAFEGUARDS) just finished another of our regular workshops about the influence of social values on human services. The workshop, which used PASS 3 to organize the participants' work, was really about the effects of the beliefs and attitudes of powerful, valued people (especially human service workers) on the life-experiences of people who are much weaker and more vulnerable.

Spending time with participants at the PASS workshop led me, once again, toward considering how things have gotten to be the way they are. How do I/we learn to think the way I/we do about people who have disabilities or people who have experienced some other difficulty in life? Why couldn't we just as easily have learned to disregard disabling conditions (or skin color, or sex-differences, or whatever) when we decide about the worth of other people?

Part of the answer, of course, is that we could have learned things differently but that we just didn't. Or, at least, I just didn't. I won't speak for you. When I was young I learned some strange things about people with disabilities, and I was not aware until many years later either about the content or the process of that learning. For example, when I was about ten years old I learned something about people who can't hear that, I'll bet, not many other people know.

I learned that people who can't hear can <u>run faster</u> than anyone else. You didn't know that? From the time I was around seven years old until I was sixteen I lived just two blocks from Ohio's State School for the Deaf, which we, of course, called the "Deaf School." In that neighborhood it was common knowledge—at least within the age 7-13 set—that the "deaf kids" were <u>fast</u> and, therefore, vaguely dangerous.

The State School for the Deaf in Columbus is located on land that, until about 1952, was a golf course. A major crosstown street runs past the entrance to the school, which is housed in a campus of one-story buildings located several hundred yards back from the street. Now I know it is only several hundred yards. When I was ten it looked like the school buildings were two miles away across a vast plain that used to be the golf course. That expanse of land was our playground. We played football and baseball there. We played adventure games—pirates, cowboys, etc.—in the heavy shrubbery that lined the school's entrance road. I even remember an exercise in youthful civil engineering—the construction of a dam across a tiny stream after a heavy rain.

But games were interrupted when "they" came out. On many afternoons students from the "Deaf School" would walk, usually in groups, toward the street at the entrance to the school. They were going to catch the bus or to walk to the nearby shopping center. We gave them plenty of distance. You see, we knew there was something funny about them. They made funny movements with their hands, and some of them made odd sounds to each other. And ... they could run. We stayed away because we knew that, if we got too close and they spotted us, they would run after us, catch us, and do odd and unspeakable things to us. When those kids appeared we abandoned the field. We knew better than to hang around.

We just knew. We learned, seemingly, from the air. I can't, even today, tell you how we learned what we knew—except, perhaps, that I understand better now the effects of that distance across the field and the messages about difference that distance and separation carry. I can say that I know no one who was ever harmed, chased, or even approached by any student from the School for the Deaf. As a matter of fact,

## VIEW FROM CHILLICOTHE (continued)

I suspect they were as apprehensive about us as we were about them, and I wonder sometimes what sorts of stories might have been told about me and my friends. What unspeakable acts were we believed capable of committing?

How have things gotten to be the way they are between people with and people without disabilities? It looks like separation, distance, and resultant ignorance have played big parts. And, if that's right, then getting together again (and adopting and carrying out policies that will make that happen) would be the essential step toward change.

Jack Pealer

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# The Safeguards Letter\_\_

a publication of OHIO SAFEGUARDS • P.O. Box 1943 • Chillicothe, Ohio 45601

NUMBER TWELVE

DECEMBER, 1989

#### "PLANNING" WORKSHOP IN JANUARY

The fifth annual January workshop sponsored by OHIO SAFEGUARDS will be "Design for Accomplishment: A Workshop about Planning," with John O'Brien and Connie Lyle of Responsive Systems Associates, Atlanta, Georgia. The workshop will take place Monday, January 22 through Wednesday, January 24, 1990 at Walsh College in North Canton, Ohio. The fee for registration for the workshop is \$200.00.

This workshop 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 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 agencies, Board members of both public and private organizations, and staff members who offer direct help to people with disabilities (e.g., in finding/keeping jobs, in acquiring or maintaining a home, etc.). The workshop has previously been offered in Columbus in January of 1986, 1987, and 1988.

The workshop offers planners (or those interested in the plans planners will make) 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."

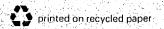
For more information, or to register for the workshop, contact:

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

## SUMMER INSTITUTE IN INTEGRATED EDUCATION, 1990

OHIO SAFEGUARDS has received from McGill University in Montreal a preliminary announcement of the fifth annual Summer Institute in Integrated Education. The Summer Institute, which is a program designed for professionals and parents interested in learning how to bring people with challenging needs into our schools, workplaces, and communities, will, between July 9 and July 20, 1990, offer an array of seven different workshops from which participants can choose. Presenters at these workshops will include: Marsha Forest, Judith Snow, John McKnight, Herb Lovett, Jan Nisbet, John O'Brien, and Jack Pearpoint. The Institute takes place at McGill University in Montreal. Anyone interested in further information about the Institute can write to:

Silvana Pellecchia, Secretary
Summer Institute in Integrated Educ.
Faculty of Education,
McGill University
3700 McTavish Street
Montreal, Quebec H3A 1Y2
CANADA



NUMBER OUR DAYS, by Barbara Myerhoff -- Commentary by Jack Yates (This book is available for borrowing from the OHIO SAFEGUARDS library. Ed.)

So what's this book about? I've given it to some people because they are interested in issues of aging, since it's about elderly people at a senior citizen center. I've given it to other people because they are Jewish, since it's about elderly Jewish people who live in Venice, California. The author is an anthropologist, so the book is also about people, identity, continuity, and community.

A book about being Jewish: "The Kaddish, known as the mourner's prayer, significantly, says nothing about death. It is a prayer about continuity in which the name of the departed may be 'bound up with all the company of righteous Jewish men and women,' with the ancestors and with those who will yet be born. The continuity of remembrance is assured for all the dead by the children's Kaddish prayers."

A book about what it means to be Jewish: Josele, having been beaten up by teenagers on the boardwalk, tells Myerhoff: "Today is not the first time I got beat up. When I was only a boy I was already a revolutionary, working for justice, that's all I cared about. Then the Cossacks beat me up with clubs yelling all the time just like this girl, 'Dirty Jew.' So what has changed? As long as these things happen, I know my work is not finished. Now I go home. I don't keep the Sabbath with prayers. I got my own ways." He chuckled and picked up his cane. "On Fridays the cats on my street get extra rations. Since we got no more beggars in America, we got to do the best with what we have."

A book about people's life work: "Rebekah was about to leave for her Spanish class. She studied Spanish, she explained, because of her work with Mexican migrant laborers. After the calss she would be passing out petitions supporting their strike. I asked her, 'Do you enjoy that work?' She replied, 'Who could enjoy standing in a parking lot on a cold day, arguing with ignorant strangers? You don't do these things to enjoy. It has to be done, that's all.'"

For many readers this will be most of all a book about stories and about histories. Myerhoff conducted an oral history class at the senior center, and the stories of the participants form the heart of the book. So, it is a book, too, about autobiography: "Basha came out of the Center and Abe called to her, 'Basha, how would you like to have the professor make a book from your life?' Basha did not hesitate. 'You got a pencil? You want to get it down right. I begin with my childhood in Poland. Tell me if I go too fast. Naturally, it's a long story.'"

(continued, p.3)

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#### THANKS VERY MUCH!

During 1989, OHIO SAFEGUARDS has received contributions in support of <u>The Safeguards</u>
<u>Letter</u> from the following individuals or organizations:

-Pennsylvania DD Planning Council, Harrisburg
-Beth Mount, New York, New York
-Sandra Landis, Glouster, Ohio
-Mark Friedman, Philadelphia, Pa.
-Carol Minnich, Columbus, Ohio
-Jack Pealer, Sr., Columbus, Ohio
-Don Trites, Wells, Maine
-Habilitation Opportunities, Inc., Cincinnati
-Deb Schmieding, Athens, Ohio

Thanks to one and all!

Commentary: NUMBER OUR DAYS (continued)

And about truth: "Shmuel protested, 'Rebekah, Rebekah, it was all there. You won't make it any different if you say it wasn't there. The hymn, the tsar, the fear, the blood, the beauty, it was all there. It must be kept all together. To take out one part and lose the rest, to try to keep only the good parts, is to make every day the Sabbath. So far, the Messiah has not come. When every day is beautiful, we will be in Paradise.'"

And about the necessity of stories and of histories: Shmuel tells us: "For myself, growing old would be altogether a different thing if that little town was still there. All is ended. So in my life I carry with me everything—all those people, all those places, I carry them around until my shoulders bend. I can see the old rabbi, the workers pulling their wagons, the man carrying his baby tied to his back, walking up from the Vistula, no money, no house, nothing to feed his child. His greatest dream is to have a horse of his own, and in this he will never succeed. So I carry him. If he didn't have a horse, he should have at least the chance to be remaining in the place he lived. Even with all that poverty and suffering, it would be enough if the place remained, even old men like me, ending their days, would find it enough. But when I come back from those stories and remember the way they lived is gone forever, wiped out like you would erase a line of writing, then it means another thing altogether for me to accept leaving this life. If my life goes now, it means nothing. But if my life goes, with my memories, and all that is lost, that is something else to bear."

So I give this book also to all of you, because you are people who may welcome reminders of history and will surely welcome the most powerful stories I have read.

Jack Yates

#### THE END OF 1989

This year, more than most, December has served as a time for me to reflect. I've been unable to escape the notion that somehow, because it's almost "the nineties" this is a very important time. It's the end of the eighties, the start of the last decade in the century. Thoughts of where and how I want to be clelbrating New Year's Eve in 2000 keep popping into my head.

I have recollections of the past three decades, and images that help put those years into some perspective for me. In '59 I was an adolescent, and my boyfriend gave me a golden locket for Christmas that I thought I would ahve forever. By '69 I'd been through high school, college, getting married, and giving birth to my first child. I was concerned about the dilemma my brother and many other young men faced concerning military service and Vietnam. I knew and was uncomfortable with the fact that I escaped the same dilemma personally only because of gender. In '79 I was preparing for a formal dissolution of my marriage and was attempting to create another commitment I could live out. I was investing myself in my human service career. The mistakes others had made left much to be corrected. I thought I had found a place to take my stand and see it through.

In '89 I find myself in a very different place, in the midst of commitments that are evolving through my tenure in the places where I live and spend my time, and through the promises I make with people who are close. My illusions about resolving situations via some career role are gone. My sources of inspiration and hope often come through association with people who have lived longer than I have. As my discomfort with the presence of fallibility in myself and others has eased, I've noticed some gains in stamina in

#### END OF '89 (continued)

myself and those around me. If I were to predict, I'd guess that New Year's Eve 2000 will find me here. And, if my good fortune continues, I'll be celebrating with folks who live hopefully in the midst of fallibility.

Sandra Landis

#### ADDITIONS TO THE OHIO SAFEGUARDS LIBRARY

Three new books have been added to the OHIO SAFEGUARDS library and are now available for borrowing. Interestingly, all three of these books have a common central issue—poverty. All of them are connected to that most (economically) impoverished of all recent periods in history—the 1930's.

Dorothy Day. The Long Loneliness. (New York: Harper & Row, 1981) This is the autobiography of Dorothy Day, the co-founder (with Peter Maurin) of the "Catholic Worker" movement. The book, originally published in 1952, describes Miss Day's early years as a journalist in New York in the 1920's, her conversion to Catholicism that had such momentous consequences for her life, the beginning of the work of the Catholic Workers in 1933, and the struggles of the movement through the Great Depression, the Second World War, and the early postwar period.

Helen and Scott Nearing. Living the Good Life (How to Live Sanely and Simply <u>in a Troubled World</u>.) New York: Schocken Books, 1970. This book was recommended to a trustee of OHIO SAFEGUARDS by John McKnight. Helen and Scott Nearing lived in New York City in 1932 (just a year before the first publication of The Catholic Worker); Scott Nearing ran for Congress, as a Socialist, in 1932. He lost. As the preface to the book puts it: "During the deepest part of the Great Depression, in 1932, we moved from New York City to a farm in the Green Mountains. At the outset we thought of the venture as a personal search for a simple, satisfying life on the land, to be devoted to mutual aid and harmlessness

with an ample margin of leisure in which to do personally constructive and creative work. The society from which we moved had rejected in practice and in principle our pacifism, our vegetarianism, and our collectivism. So thorough was this rejection that, holding such views, we could not teach in the schools, write in the press or speak over the radio, and were thus denied our part in public education. Under these circumstances, where could outcasts from a dying social order live frugally and decently, and at the same time have sufficient leisure and energy to assist in the speedy liquidation of the disintegrating society and to help replace it with a more workable social system?" The book is the Nearings' attempt to answer that question.

George Orwell. Down and Out in Paris and London: New York: Harper & Brothers, 1933. George Orwell found it necessary, for a timm in 1930 and 1931, to live the "down and out" life in both France and England. This book is his description of how life is with nearly no money--life as a dishwasher in Paris restaurants or as a "tramp" on the road in London and rural England. He notes: "...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 hand-bill, nor enjoy a mean at a smart restaurant. That is a beginning."

These books, as well as other materials in the library, may be borrowed by contacting us at P.O. Box 1943, Chillicothe, Ohio 45601— (phone: (614) 773-6191. A complete listing of all library materials will be published in the March, 1990 edition of The Safeguards Letter.

#### CHILDREN HIDDEN ELSEWHERE TOO

(Editor's Note: In October, 1989 Sandra Landis wrote of her experience of trying to arrange for a PASS team to visit a school or other kind of children's program during OHIO SAFEGUARDS September PASS workshop. She told of her frustration and ultimate lack of success and concluded that "nearly all [of the children] are kept strangers to us in our day-to-day life. Her article led to the following response from Great Britain.)

Dear Jack: I recently read a copy of <a href="The Safeguards Letter"><u>Netter Safeguards Letter Safegua</u>

From the details I have of the schools that have been used in the U.K. I would highlight some issues which cause real problems for the young people who depend on these services for help. I'll only be able to mention some of the more significant aspects here.

There was a striking paucity of intensive programes, in spite of this being a fundamental expectation of an educational service. The teachers often used teaching methods which have no proven effectiveness for children with learning difficulties.

There was evidence of limited—token?—integration. Usually children were taken out in groups, rather than individually. Often the community settings were chosen for use at times when few other young people would be present. This meant that their "friendship gaps" were not being offered any real opportunities to be filled. As a consequence of the pupils' general isolation from others of their age, their range of life-enriching experiences was significantly curtailed. This was particularly true of schools which had in—school segregation of pupils, into such groupings as the "special care class."

Many of the schools had settings which projected negative images about their pupils—some heavily laden with images of sickness and hospitalisation; others for pupils in their teens looked remarkably like nursery schools/kindergartens.

Within the schools' philosophies were real contradictions between "hopes for as normal lives as possible" and explicit preparation of the pupils to fit in to the next service provision along. In the U.K. this usually means obtaining a place in a sheltered workshop, attending an Adult Training Centre, or staying at home with parents. There was no evidence of educational staff's awareness that such provision is no longer viewed as adequate by many people who are concerned to provide/seek out real employment and job training opportunities.

There is no doubt that educational services can learn a lot from PASS and PASSING evaluations—particularly about the daily experiences and the possibilities for change in the lives of young people with difficulties. I also know that there is a reservoir of good will among many teachers, both within special schools and regular mainstream schools, waiting to be properly channelled.

In conclusion, I intend coordinating another workshop (PASSING) locally nextyear. I am hopeful that one of my sites, at least, will be a "special" school. I suggest that

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### CHILDREN HIDDEN (continued)

the best way forward is to have a "local initiative" which includes health, social, educational, and voluntary services examining their coordinated efforts. I am also pushing for Head Teachers of "special" schools to attend a PASS workshop, so that they have a clearer understanding of what is involved.

I hope that you find this to be of interest for your publication.

Yours sincerely, Sam Carson 12 St. Monica Grove, Durham ENGLAND

(Mr. Carson is an Educational Psychologist with the schools in Durham, England. Ed.)

#### JUST QUOTES ....

A statistician of international repute (myself, if you want to know) has reckoned that every adult now gets through three times as much in a day as his grandfather; we are not measuring achievement, naturally—only activity. But when it comes to running about, meeting one another, hurrying from town to town, and taking papers in and out of brief-cases, our generation is vastly superior to any of which we have record.

This remarkable increase in activity could not have been achieved without a great deal of hard work, and I think that we owe much to the organizers, heads of speakers' committees, pep and ginger groups, and others who have made it possible. And in order that they may meet frequently and exchange ideas on how to goad the rest of the population into even greater activity I am organizing an international association for them alone, to be called "The Friends of Thrombosis." The emblem of the association will be a small wire wheel with a demented squirrel in it.

Robertson Davies, as Samuel Marchbanks
The Papers of Samuel Marchbanks

(Scrooge) had no further intercourse with Spirits, but lived upon the Total Abstinence Principle, ever afterwards; and it was always said of him that he knew hos to keep Christmas well, if any man alive possessed the knowledge. May that be truly said of us, and all of us! And so, as Tiny Tim observed, God Bless Us, Every One!

Charles Dickens

CITIZEN ADVOCACY PROGRAM EVALUATION (CAPE) IN OHIO

Donna Bookman

An international team gathered in Perry County on November 6-9, 1989 for the first-ever Citizen Advocacy Program Evaluation (CAPE) in Ohio. The team was led by Carolyn Bardwell Wheeler of Louisville, Kentucky. Citizen Advocacy, Inc of New Lexington invited

(continued, p. 7)

## CAPE IN OHIO (continued)

the evaluation after reorganizing the activities and sharpening the focus of the Perry County program toward citizen advocacy exclusively.

Citizen advocacy was conceptualized by Dr. Wolf Wolfensberger in 1966. By definition, citizen advocacy involves: a valued citizen who is unpaid and independent of human services (who) creates a relationship with a person who is at risk of social exclusion and chooses one or several of many ways to understand, respond to, and represent that person's interests as if they were the advocate's own. Citizen advocacy has emerged in the form of over 200 programs which, through their evolution, have developed their own particular variation of the citizen advocacy idea, often misinterpreting or inappropriately implementing the original conceptualization. Because of the recognition of the need for some "standard" against which to measure programs operating under the term "citizen advocacy," CAPE was developed.

CAPE is comprised of 36 ratings divided into three cluster categories—1) adherence to citizen advocacy principles, 2) citizen advocacy office effectiveness, and 3) program continuity and stability. CAPE has two major uses. Through organized external evaluation CAPE helps safeguard the quality of citizen advocacy programs. Board and staff groups may also productively use CAPE for program self-assessment, as a basis for citizen advocacy program planning and design.

Citizen advocacy is not a recent idea in Ohio. Citizen Advocacy, Inc. (formerly Family Advocacy) began in New Lexington in 1982. While citizen advocacy has always been part of this program's mission, much has been learned in recent years about what must be done to achieve greater adherence to the principles and to operate a more effective office. Because our local program has undergone growth and change, we asked for the CAPE evaluation with these questions in mind: 1) Are we on the citizen advocacy track, and, 2) if so, how can we do what we are dong better?

The response of the evaluation team confirmed to the Board and staff of Citizen Advocacy, Inc. that the program is indeed "doing" citizen advocacy. The evaluation called attention to the need for the program to continue to strive toward "crystal clear" focus of our purpose—saying "NO" to things that might draw effort away from citizen advocacy; maintaining clarity of board, staff, and advocate roles; and planning thoughtfully and vigilantly around the issues of protege, advocate, and board recruitment, community embeddedness, and funding. The team recommended that we prepare a BOLD statement about the changes that Citizen Advocacy, Inc. has made.

The experience of being evaluatied was enlightening and powerful for the people involved in citizen advocacy in Perry County. In addition, as is typical with CAPE, team participants—even those very experienced in the use of CAPE as evaluator, evaluated, or leader—reported a deepening of their own knowledge of citizen advocacy. Two Ohioans participated as members of a CAPE team for the first time, thus giving a renewed sense of solidarity to the work of definitively understanding and implementing citizen advocacy in other parts of the state. We hope that this CAPE evaluation will be followed by others in Ohio—to provide valuable opportunities for more people to learn together about citizen advocacy.

#### Donna Bookman

(Ms. Bookman is an OHIO SAFEGUARDS trustee and the Director of Citizen Advocacy, Inc.)

It's the afternoon of Christmas Day as I write this. It's been cold lately, and we've been deep into the "holiday season" for two or three weeks now—both factors that have kept me from traveling so much. That means that I have had more time to just sit and think.

I've been thinking back in time—about fifteen years, to be specific. In June of 1975 I went to my first PASS workshop. It was in New Stanton, Pennsylvania and was sponsored by the Pennsylvania Office of Mental Retardation. At the time, I had little idea what was about to happen to me. Back home, I was the "Superintendent" at the Delaware County Board of Mental Retardation, and the brick walls of the new (segregated) school that Delaware County was building were just starting to show up above the foundation. This was something long anticipated—something we were supposed to be grateful to see, after a number of setbacks that occurred in the process of planning the building.

I drove home from New Stanton knowing that my view of the world had changed. I was exhausted, to be sure—this was in the days of PASS workshops that featured long lecture sessions and two assessments—but I knew, even during that drive, that I wouldn't be able to share any more in the satisfaction others at home were feeling over the progress of the new school building. I left Delaware County just a few months after the building was completed and occupied.

My friend and colleague Sandra Landis attended the same PASS workshop. This was early in the time after we had come to know one another. After we had both gotten some rest and had some time to think about the workshop and what each of us had learned from it, we decided that others in Ohio should have a chance to learn in the same way. We started planning, plotting, scheming—whatever you call it—to have a PASS workshop in Ohio. That workshop happened in 1979 (we're a little slow), and others have followed. Sandy and I, and the other people who have joined with us (some of them as trustees of OHIO SAFEGUARDS), have spent quite a bit of our lives over the past fifteen years stumbling around trying to share some ideas about more dignified experiences for people who have disabilities (or people who have other serious difficulties in their lives).

Why am I thinking so much about this now? It may be because of the old caution about being careful of what one prays for because one might get it. Or, in this instance, I find myself divided between enthusiasm and suspicion while some people with disabilities are apparently starting to get some of the things that I and others have wanted for them for so long. In the past year or two, words or phrases like "integration," "friendships," "community" (either as a noun or as an adjective, as in "community employment"), or "supported living" have become by-words. Recently, an official of state government here in Ohio told me that the state is only interested is adopting new standards for programs that are "quality-of-life" standards. What's going on? Is this evidence of the success we've been waiting for—working toward? Have the multitudes (and their leaders) finally seen the light?

Well, I hope so. I rejoice over the ideas that are being talked about. I want to help take advantage of the opportunities that the presence of such language indicates—to grab the chance to help some people toward greater dignity. So, I'm going to nod knowingly when folks around me wax enthusiastic over "supported living"; I intend to do everything that occurs to me to promote "partnerships" that will help people with difficulties in their lives get jobs and earn greater incomes.

But, I have to do something else too. I have to remember that there have been

## <u>NEW FROM CHILLICOTHE</u> (continued)

earlier enthusiasms—for ideas like "humanization", "community readiness training" (in the institution), "group homes", or "deinstitutionalization" (a word we hardly use any more, as though it expressed an idea that's no longer necessary). These ideas had their day as by—words in my own (about 20—year) memory as a human service worker. Even earlier there were ideas like "asylums", "state schools", and "moral treatment". Each had its time and was later left behind or forgotten. Knowing the faddishness and/or addiction to novelty (only the "new" is "good") that lives within human services, I'm confident that "supported living" too will pass. Either it's my age or it's our time, but it seems to me that the half—life of "new" or fresh language is growing ever shorter.

As well, when I'm tempted to declare even small victories in a fifteen-year (how short a time that is!) struggle, I remember something that a wise man named Wolfensberger haskept reminding us about. To paraphrase him (with a nod toward Joseph Campbell):

abuse wears a thousand faces. Ways of hurting people whom we don't like—and there are lots of folks our society still doesn't like very well—multiply much faster than we can anticipate. Abuse devleops so quickly and so variously that, if we were betting creatures and we wanted to win our bets, we'd wager that the struggle we're in is ultimately a losing one. What this means to me, today anyway, is that it's precisely during the times when things seem to be going the way you wanted when you have to be most alert. It means that apparent success conceals danger.

So, as Christmas and the decade (an artificial interval, to be sure) come to an end, I'm going to be trying to figure out both how to properly celebrate how far we've come since 1975 (a personal watershed for me) and how to renew myself for what's likely to be a longer and harder journey. I expect that many of you out there will be with me or even ahead of me on the path.

Jack Pealer

Contact OHIO SAFEGUARDS for details!

REMEMBER: "DESIGN FOR ACCOMPLISHMENT" -- January 22-24 at Walsh College, Canton

OHIO SAFEGUARDS
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Chillicothe, Ohio 45601

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# The Safeguards Letter\_\_

EXTRA EDITION

SPRING, 1989

a publication of OHIO SAFEGUARDS • P.O. Box 1943 • Chillicothe, Ohio 45601

## AN OPPORTUNITY WE WANTED YOU TO KNOW ABOUT

Over the past years, a number of people who have attempted to act morally and in accord with adaptive principles in human services have come to grief in their human service careers. After they tried to assume an active, rational and moral human service or change agentry role, they were margnalized, rejected—and, in many instances, forced out of their jobs or service involvements. These have been traumatic experiences for many such persons, especially because they were often not fully prepared for the experiences or did not understand (or believe) the extent and subtlety of the disfunctionalities embedded within human services. In order to survive with high moral ideals, with one's integrity intact, and (hopefully) also with some effectiveness within human services, one needs a special balance of world-views, preparation and support.

From May 21 through May 26, 1989, the Syracuse University Training Institute and The Safeguards Project (western Massachusetts) are sponsoring a workshop in Holyoke, Massachusetts that is intended to address part of that need. The workshop is entitled "How to Function with Personal Moral Coherency in a Disfunctional Human Service World," and it has been planned and will be directed by Dr. Wolf Wolfensberger. OHIO SAFEGUARDS is one of eleven other organizations in the United States and Canada listed as "cosponsors" of this workshop. The workshop will explore some of the major values that undelie human services and that must be addressed and, in many cases, challenged by a person who wants to become or remain a moral service worker. The workshop is not, however, intended to provide participants with specific solutions to specific problems. Instead, participants will be exposed to an array of strategies that are universally applicable to any planning project, service operation, voluntary involvement, advocacy relationship, etc.

The workshop is aimed at people who are, or who aspire to be, conscientious moral service workers or citizens playing some human service role at any level or in any profession. It is particularly aimed at those who are, or who aspire to be, agents for bringing about adaptive change.

This workshop will be held at the Mont Marie Conference Center in Holyoke, Massachusetts. The cost of the workshop is \$295.00, and this fee does <u>not</u> include the cost of accommodations or meals. Fee reductions may be available to persons from cosponsoring organizations or areas. We suggest that anyone who has an interest (even a casual one) in attending this seldom-available workshop contact Michael Kendrick, The Safeguards Project, 187 High Street, Holyoke, Massachusetts 01040 (phone 413/536-2401) to ask about costs of attending and about arrangements for accommodations and meals. If you want to give serious thought to the issues this workshop addresses, don't miss this chance to at least inquire about attending. It could be life-changing!

•

I think there is already enough government-legitimated killing going on. Governments are already the major organizers of war. Indeed, it sometimes looks as though war is government's primary function. Another kind of killing of people that's permitted by society right now is also carried out by government—so-called "capital punishment." I think that war and capital punishment are alike in their immorality. I'm sorry that, as a citizen, I'm a participant in both.

It makes no sense to me, then, for government to introduce another form of permitted killing—this time one to be carried out by professionals. There is a bill in the Ohio Legislature (H.B. 221) that will (if it's passed) allow a small number of babies—those born with "anencephaly"—to be literally made dead by declaration so that their organs can be used for transplants. The declaration would involve a definition of "death" that would be different for these few people than it would be for any other citizen of Ohio. The declaration would be made by a physician, who would be protected by the force of the law.

It's sad when a baby is born without most of his/her brain. It confuses us, like many other things about life that seem unfair, unjust, or wrong. But we have this saying about what "two wrongs" don't make... I don't think that authorizing another form of killing will make the sadness go away or reduce our confusion. Another principle of our culture is that it's wrong to use other people. There is already enough government-legitimated killing going on. I'm opposed to H.B. 221, now in hearings before the Ohio Legislature.

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