

The Safeguards Letter

A Publication of OHIO SAFEGUARDS

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ONCE AGAIN!

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

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

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

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

Jack Pealer

IN MEMORY, JEROME METZEL

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

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

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

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

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

Jack Pealer

DISCERNING ACTUAL LEVELS OF SUBSTANTIVE EMPOWERMENT

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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About THE SAFEGUARDS LETTER

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

JUST QUOTES

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

Robertson Davies
Murther and Walking Spirits

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

T. H. White
The Once and Future King

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

Wendell Berry
"The Total Economy"

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

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

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

WE GET LETTERS

From close to home:

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

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

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

Thanks for sharing this with me!

Margie Fussinger
Fairfield, Ohio

From farther away:

Jack,

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

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

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

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

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

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

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

Take Care, Bob Jones

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

A VIEW FROM THE BACK WINDOW

"Savage Discovery"

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

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

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

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

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

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

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

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

The four problems are:

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

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

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

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

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

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

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

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

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

Jack Pealer

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