### Some Articles by Sandra Landis

#### Cabin Fever Day

Safeguards Letter #24 Spring 1994 Cabin Fever Day

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

Winter arrived in earnest and right on schedule this year, a few days before Christmas. Tw weeks earlier than that we had hosted a luncheon in Shawnee to celebrate the end of our

We acknowledged that we'd, come up a bit short. Of the fifteen thousand doldars we'd shown we'd have to raise through closelstons and constitutions we'd revealed \$8,000. There exterior painting, some interior tim in the bitary, and final plumbing connections in the library. We celebrated, relaxed with people who had helped, encouraged newcomes to consider becoming involved. We hoped that most of the unfinished projects would be.

Nearly all of our worst fears about the work did not come true. Three buildings in very but shape seen own stable, much improved in appearance, and at feast partially occupied. No one had been injured on the lob, we didn't have any tabor disjource, the village government had cooperated with us patiently, feanants and cooperating groups were making, anyments on time, and people were pleased about the improvements in the Main Street payments on time, and people were pleased about the improvements in the Main Street payments on time, and people were pleased about the improvements in the Main Street payments on time.

storage with minimal security effort on our part.

Our cash flow worries were real, but pretty closely held worries. The day before the

notification of a modest grant to support a few months' work in 1994. We were ending the year with a few of the challenges unresolved but were grateful that we had enough to keep going for a little while anyway.

The Phase I celebration was followed, in about ten days, by the holidays and blizzards of 1993-94. As the snow fell and the temperatures dropped, I realize the period to be proposed the results and beautiful that the result is a significant that the proposed the results and the results and the results and the results and the results are the results and the results and the results are the results and the results are the results and the results and the results are the r

#### Holding a Place in Line

Safeguards Letter
#20 Spring 1992
Holding a Place In Line
Sandra Landis

have some clear childhood memories of standing in line. We used to have to sta t the nurse's office in school to get our polio shots, and my brother slways faint tood in line before every recess and lunch period in elementary school. We eve ne to walk to the hathroom. And no Saturdays at non schools why hothlers and

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

Now I stand in line at the grocery store, sometimes at restaurants and the print shop, I also the with the idea that there is another line—of human experience—that I am always a part of and that I influence in small ways. The distinction between literally standing in line and figuratively holding a place in the line of human experience became much clearer about ten years ago when I showed up at the unemployment office. Hay I never be requested to stand in a line that long again. I startched about the respective of the stand in a line that long again. I startched about the respective of the standing the standing of the standing that the standing the standing the standing that the standing the standing that the stan

Twenty-six weeks seemed like entirely too long a time for anyone to just stand in line, so I soon began to this shoult it in that other sense, as preserving a place for a useful rise in that line. While I was there, what would I stand for 2 During the first couple of tweeks I watched other people and learned the routines. It looked nor the like a number of people had already filled the expert roles. Others had become the silent observers and still others the voice! cytinc. On pean on chose to use the time to read stories to two small children I decided to be one of the Took people in the eye and be cheenful! people. There didn't seem to be many people representing that position.

I found there was a affirence, learning on how it was a suffigence, depending on how it would not be useful to the support of the surface of

#### Another Poet of Stone Soup

Another Poet of Stone Soup

Last winter a small pot of simmering water sat on our wood stove. We usually have a steamer on the stove in winter, but this one was different. It served as a symbol of so work we have begun, our latest batch of stone soup. You may know the story about s soup. I hope that my short retelling here sketches the real thing.! Suggest that you tr

It seems that some soldiers found themselves in a place where they were not known well, without food but very hungh. They set about starting a fire, finding a pot, litting it with water, adding a few pebbles for something to sit, and talking about soup. They continued to talk about soup, sit the pot, sniff the air for aromas, and talk with passers -by about the soup they were making. What they were doing appeared to be inviting to others. They talked with most who came by Soon enough, some people begand to think about the soup. Many brought something to add to it. As ingredients were added, and simmered, and stirred, the articlination serve. When it was time the nonless haven a meel of mourishing sound.

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

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

Each of us has come to realize that we want to work at home, in the midst of the collect of people and places that make up Southern Perry County, Ohio. Together we came to

#### In Response to this Call to Cponscience

The Safeguards Letter A Publication of OHIO SAFEGUARDS NUMBER SEVENTEEN MARCH, 1991 IN RESPONSE TO THIS CALL TO

CONSCIENCE Sandra Landis

The preparation for war and the violent invasion of Kuwait and Iraq by the United States and other nations has brought many people to a sobering time. To

other nations has brought many people to a sobering time. To me and others this time is yet another call to conscience. Conscience is simply defined by Webster as "... a time of reflection with 'sensitive regard for fairness or justice!" This particular call to conscience has resulted in my understanding that I shall

begin to live a more public life. My hope is that I might, with others, learn to live more publicly in a way that contributes to a more peaceful world.

As I begin to speak about the reflection and decisions that come from this call to conscience I speak humbly. Only at th late date is my voice becoming truly a public one; it lacks the strength and stamina that comes from frequent practice. It is singular; it does not yet share in a common song with other

#### On "Being of Use"

On "Being of Use" Sandra Landis

Recently, I read Ciderhouse Rules 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. Jusas reminded for my non-precognisation with the idea of a

Several years ago, I made the decision to retire from my brief stint as a full time employee. Over the years I had pretty s 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 fulltime 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. I 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 beines 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 fielped clarify for me the context in which purposeful, focused change can happen also strengthened my understanding about how vulnerable this context is. In short: I learned a bit more about what, undermines and defeats hange efforts, and what has been a botterior in the efforts.

#### Hidden Children

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 ourges not signatured from high school. My younges to thorthe, his wife and active their daughters, came to visit and celebrate with us. It was the first visit to our home to the their daughters, came to visit and celebrate with us. It was the first visit to our home to the selecting disk in Several days, I cell to watch and play with my nicese, when they are these and make the selection of the several days. I cell to watch and play with my nicese, when they are the selection of the several days. I cell the selection of the several days. I cell the selection of the several days. I cell the selection of the several days are the selection of the several days. I cell the selection of the several days. I cell the selection of the several days are the selection of the several days. I cell the selection of the several days are the several days. I cell the several days are the several days. I cell the several days are the several days. I cell the several days are the several days. I cell the several days are the several days. I cell the several days are the several days. I cell the several days are the several days. I cell the several days are the several days. I cell the several days are the several days are the several days. I cell the several days are the several days. I cell the several days are the several days are the several days are the several days. I cell the several days are the several days are the several days are the several days. I cell the several days are the several days are the several days are the several days are the several days. I cell the several days are the sev

In June, I spent a week in Atlanta as a member of an evaluation team. The organization we visited promotes children 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 Children whether children in Children whether children 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 institution in 1371. I saw all of to fildren that day.

in July, I was invited by a young mother to visit with her and her children in southeastern folicit Her younges it to wand a hair, 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 widcomed into a class of typical youngest by regular teachers. I was very aware, however, of my sense that this is still a very rare event. My image of most other two and a half year olds with Down syndrome is they're climbing or being littled 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 t serve children for the PASS course.

I brainstormed a short list of programs for children that I thought would accommode PASS team and that would offer examples of what was going on for kids in 10 hio in 19 Then I began to make calls to people I know who were associated with these program was sufficiently encouraged by my initial calls to proceed in recruiting two programs school aged children, one privately operated, the other operated through a local put

#### About Natural Consequences

Safeguards Letter #10, July 1989 About natural consequences

I've been thinking about the idea of natural consequences lately. My thoughts have got focused there, as I've listened to several public discussions about supporting people w 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 w

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 pahistory 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 lifestyle is it hat the helpers act as though the natural consequences o 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.

I hear no acknowledgement of nor accounting for the difference in personal vulnerability that nearly always exists between you or me and somenow who has disabilities, who 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 experience in proportion to one's state of personal security and vulnerability. Some people get far more than their share of natural consequences, and the consequences they experience are usually much graver.

I am 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 the difference in vulnerability is in 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 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 that I can identify with someone who is poor.

# The Safeguards Letter\_\_\_\_

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The Complete Collection of Safeguards Letters - 1986- 2021

## Some Articles by Jack Pealer

# People with Disabilities and Their Money

#38 Summer 2016
People with Disabilities and their Money
Jack Pealer

t's an old story that people with disabilities (perhaps most people with so-called 
intellectual" disabilities) are likely to be poor. The guaranteed income for a US citizen who 
and edinantial disability is sill lies stans 860 per month—the maximum Supplemental 
security income payment. Many people who receive such income have to pay almost all of 
(top perhaps more than all of it) for their rent and other basic living expenses. To Sometimes 
hese payments are made to or through the agencies that provide at-home support. The 
seople who make those payments get to retain a small portion of their income as "presonal 
lillowance," but the expense of this allowance is under close scrutiny by human service 
workers. In effect, that small personal allowance is the person's disposable income. In 
nany places in the US the average annual earnings (excluding fringe benefit costs) for 
numan service workers are frour or five times the amount of an individual's annual total of 
SSI payments. Relatively few people with disabilities have regular full-time employment, 
giving the lie to the headlines derived from recent census data—see Rob McInnes' article 
sleswhere in this issue. And, at least partly because of a long lag between increases in the 
Si minimum wage, the income gap between those people with disabilities don't have much 
spoporturity to acquire wealth. It is an old story.

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

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

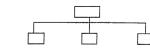
How does the person manage her money?

#### Image for an Organization

Safeguards Letter #28 Autumn 1999 Image for an Organization Jack Pealer

r the past seven years, I've worked for a pretty big organization. Nearly every year, like any other organizations, the agency where I work publishes an official revision of its bele-of-organization. Tables-of-organization are images or pictures of how a formal ganization sees itself working. Long ago, it was WolfWolfensberger who first made clear me the customary discrepancy between how an organization envisions itself and how ngs inside the organization actually work. The day-to-day world often adds lots of uiggly lines to the "org chart".

n a time when both the organization where I work and lots of other organizations that have ried to offer service to people with developmental disabilities are reconsidering their chapes and functions, in view of the needs or demands of the people some now urge us to think of as "customers"; it occurred to me that it might be useful to give thought to the mages that we use to portray how our organizations either do or are supposed to work. Seldow is the customary picture of a formal organization; it is certainly, in simplified form, he picture that we have relied on when we want an image to depict organizational shape. As far as I know, this particular shape, which can be symbolically cast in shorthand as a pyramid" (the graphic shorthand that I usually use to stand for a formal organization) has ts origin in the military, with its emphases on chain-of-command, lines of reporting, and at east theoretical accountability.



think its worth asking ourselves whether this picture of an organization fits either the utures that we see for the people with whom we work or the new missions for suppor agencies that those futures may imply. I can think of several reasons why the pyramid Joesn't fit.

#### Considering the Evidence

Safeguards Letter
#44 Autumn 2008
Considering the Evidence
Jack Pealer

e just finished reading a newsletter from a state government agency. One article said the important to "support evidence-based, high-quality, cost-effective models for ervention

services for children with autism and other developmental disabilities...." The article further said that such models are important because they will help us better "coordinate" supports in our state for people with developmental disabilities. I only want to direct gaze on that statement a bit. I don't really want to argue with it. It/lis authors may be right. I just want to try to figure out what the statement means and think a bit about what difference agreement with it would make to the ways we try to support people with disabilities. Because I've pondered earlier in The Safeguards Letter about "cost-effectiveness" (Summer 1992), I'll skip that here. I want to think about what this "evidence-based practice" means.

I wenty or so years ago, the statement by the state might were have caused for models the were "normalized." It was pretty common then for people to attach the idea of normalization—usually undefined and unexplained—to almost every proposal for any kin of service, at least for people with developmental disabilities. Part of my discomfort with the current prominence of "evidence-based practice" (EBP) comes from suspicion that El and its twin "best practice" are being used today in about the same way that normalization was used in

the past—without explanation or examination. After all, like normalization, "evidence" is something that people seem to think they understand without taking the time to look closer.

Today, if you want someone to consider your new idea seriously you'll likely describe it as an evidence-based best practice. But, as was the case with the label of normalization, simple labeling of new proposals as evidence-based isn't enough.

Let's take a look at EBP. To find out its meaning I did what many perfectly respectable 21stcentury people do. I used Google to consult Wikipedia and to find references to "treatments that work" at a web-site from Oxford University Press. Here's what I learned.

When people are said to have needs that call for intervention, service, or treatment, there's ften a choice among methods. That's noticeable in the medical, social-service, or "menta ealth" arenas. EBP is a way to inform choices in those and other fields. EBP indicates (says //kikjeda) a preference for service measures (treatments) that have been shown to work by neans of empirical evidence. Most who rely on EBP to help them decide among service.

#### The Power to Spend

Safeguards Letter #19 Autumn 1991 Power to Spend

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

wy years ago, my friends Sandra Landis and John Winnenberg led a group of people into king and working carefully to try to bring about "the good life" for some adults with abilities who lived in group homes in New Lexington, Ohio. A part of this work involved vating to prominence the close relationship between people: a) "making choices" and b) ing "disposable income" to use At about the same time (early 1980's) I was studying the rings of people with disabilities who worked in various "sheltered workshops" in theastern Ohio. I was finding that people in those workshops were earning a mean usal wage (total earnings divided by the total number of workers) that was less than 10%

Involvement in these activities—the New Lexington work and the earnings-study—should have made me appreciate the causal connection between income and choice. If one has little or no income, then one's choices must be limited, if not non-existent.

ecently, I tested this notion a bit by applying it to myself. I recorded, as best I could, the holices or decisions that I made in one day. It happened to be a Saturday in early October. I en reviewed my record and jotted down the relationship (if any) of each decision to the hearding of money. Some of the thins's I hose or decided about on that day were:

- \*To get up and read the Saturday morning newspaper at 8:00 a.m. The Chillicothe
   Cazette casts \$9.75 per month, for home-delivery six days a week
- •What to have for breakfast. My choices were determined by a trip I had made to the coll Big Bear supermarket the previous week--in my own, mostly paid-for automobile. At the market I wrote a check for about \$100.00 for two-weeks groceries.