### Some Articles by Sandra Landis

#### Cabin Fever Day

Safeguarda Letter

(This is the third chapter in the story of our community building efforts that began in December 1950, Other chapters were tilled "Storie Soup" and "Stir It Up" and were incluin earlier editions of The Safeguards Letter.)

Whiter unfived in earmest and right on schedule this year, a few days before Christmas. The weeks earlier than that we had hossed a tuncheon in Shawnee to celebrate the end of our Phasia I work. We had a butlet of wonderful homeonobad foods, a nice crowd for lunch of

coming year, and a beautiful day for touring the rehabilitated buildings.

We acknowledged that we'd come up a bit short. Of the lifteen thousand dollars we'd known we'd have to rules through domaions and contributions we'd received \$0,500. To

was a short list of unlinished work that was part of Phase I that remained to be do exterior pointing, some interior trim in the library, and sinal plumbing connections library. We celebrated, released with people who had helped, encouraged newcon

completed before Christmus and that the spart of gift graing might help solve our deticit problem.

Nearly all of our worst feere about the work did not come true. Three buildings

Nearly all of our worst fears about the work did not come true. Three buildings shape were now stable, much impresented in appearance, and at least partially occupied. No one had been high lob, we didn't have any labor disputes the villares severament bud occoperated.

inproved in appearance, and at least particuly occupied. No one rejob, we didn't have any labor disputee, the village government had o patiently, tenants and cooperating groups were making payments on time, and people were pleased about the improvemen

psyments on time, and people were pleased about the improveme district. All the new plate glace was intest, and meterials and supp stonige with minimal security effort on our part.

osecration uncreon we had received notification of a modest grant to support a few months: work in 1994. We were en year with a few of the challengies unresolved but were grateful that we field enoug should for little white answers.

The Phase I celebration was followed, in about ten days, by the holidays and the first bitzants of 1993-94. As the snow fell and the temperatures dropped, I realized how t

#### Holding a Place in Line

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

I have some clear childhood memories of standing in line. We used to have to stans at the nume's cutice in solhoot to get our poids shots, and my brother always faithed stood in line before every recess and lunch period in elementary school. We even a line to weak to the bothroom. And on Saturdays, at one ofclook, my brothers and I w

One memory has to do with being yanised out of line. Our family was traveling outple of days in New Orleans. We walked ground a section of the city with lob

Now I alaund in the at the grocery store, cornelines or resenzants and the print shop the with the folian that there is another line—of human experience—that I am always a and that I intrusence in small ways. The distinction between Exercity conding in the a figuratively holding a piace as the time of human experience became much observed.

Twenty eld: weeks seemed like earthey't too long at time for anyone to just extend in this, a cond bearn to third hood all it into the earnes, as presenting a place for a useful rivel a that like. While I was three, when would i stand for? During the sint occupie of weeks! a whether do they people was learned the ordinate, it is continue in the like or mallow or any whether do they people was learned the ordinate, it is continued in the like or as whether do people was the significant of the significant of the like ordinate is significant to several and fall of their conclusions. On the people or like like the time to read active to two samed collidates, i.

Total or their week are a commence on the standards are dependence, depotation of an interface of thought decide deligible their. I decided up interesting standards impossing and interesting people and and hearings constructing stortion. I conference, as well, that may choke to be a chewrist upposed in the well-and to design and because it was confidenced upon the dependence. I delight a local of times to thick white it was standing them, and there were a lot of these in section and sed decided and out. At the finite is the stight to figure on their could begin to do used work without hearing a job or position. I resented to seem enough to bit was all export may be understand to do used the country of the country of

## Another Poet of Stone Soup

Another Poet of Stone Sou Sandra Landis

seemer on the store in whites, but this one was different. It served as a symbol work we have began, our briest betch of stones out. You may know the story at soup. I hope that my short retelling here sketches the real thing, I suggest that y yourself and mad the whole story about no armsone you like.

It esems that some socializes found themselves in a place whose they were not known well without food but very furnings. They set about southing one, furnings and positive film who adding a few pubbles for something to sit, and taiking about acoup. They continued to builtadding a few pubbles for something to sit; and taiking about acoup. They continued to builtabout acoup, act the pot, and the orbit for aroman, and took with passesser, by about the oughthey were marking. What they were doing appeared to be in white to others. They taiked wit most who came by 500 on enough, some people began to think about the soup. Famy

This is one of the ways we've comes to visualities our work have at home. We've decided highly to make a coay," no nouthful horselved and others. We are putally amone that we with measure happellants that by themselves will not noutsit anywer very well. We see work as ensuring others by invitant them to help make, send, and ensity the sours, then the coay is docen't depend very much an amy one particular ingredient. Usually it's the yearley of ingredients in armal commans intermed and tended for a long time that much

Hy friends John and Stephen, and I, have begun a areast consideration. It's name deson the areas in our community where we the "Sunday Creek (Associates), White starting with some lideas, some hope, some energy, and some time. Our supinition is to be a revisibility our little part of the world. We shirk that the ording over time with our neighbboth do and stanulate interesting work and business enterprise, to maintain and impro our trames and the incesses stock in our result, and to participate all account authorities the to be written and quality of our public tile will interest the land of commanity we'll as

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

#### In Response to this Call to Cponscience

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

The preparation for war and the violent invasion of Kuwak and imp by the United States and other nations has brought many people to a sobering time. To me and others this time is yet another call to consolence. Consolence is simply defined by Webster as "... a time of reflection with sensitive regard for fairness or justice." This particular call to consolence has resulted in my understandir that i shall.

As I begin to speak about the reflection and decisions that come from this call to consolence I speak humbly. Only at this late date is my voice becoming truly a public one; it lacks the

#### 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 -a 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 damantic, I tend to agree, I was reminded of my own precoupstion with the idea of "being useful" a few years ato and the chanses I've resitzed 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 a evoided 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-

I took a job that kept me pretty busy in that role for about four years ... I learne a lot about what it takes to manage the work of an organization. I also learner a lot about-organizations and the dynamics that influence the decision@ 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 oduration had focused on organization through a management principles. I had thought a lot about and had studied chan strategies and theories as well. The four years I sport trying to put these theories and principles to work and watching most of my efforts fall help clarify for me the context in which purposeful, focused change can happ also strengthened my understanding about how vulnerable this context in short; I learned a bit more about what. undermines and defeats chang

#### Hidden Children

#### Hidden Children

This summer has offered me several occasions to think about children. children locked intrinselby and children who are unknown to me. Memorial Day was quite a seglining for our aummer. Pry younger on graduated from high school. Pry youngers brother, his wife a heart daughtern, amen to wist and outbeate with au. It was the first wist to not home by those title grids. For several days, I got to watch and play with my nicces, who are three an one and a half stream of so.

I Aure, I spent a week in Atlanta se a member of an evaluation team. The organization sixtod promotes children citizen advocacy and other personal forms of advocacy with object to promote a children citizen advocacy and other personal forms of advocacy with copies in Occapita who cere decreased an extensi advocation. Here the aware that at least of advocacy week or a decreased and the series of a control to the advocacy occursor and the series of a control to the control to the advocacy occursor. I begin to this is doubt the children beach forms. I resident detail did now whether children in Otho were being responded to it the same way. I know there it can be a form and the children and the children in Otho whether children in Otho were being responded to it the same way. I know there it can be a form and the children in the other children in Otho institutions, I exement because it was the many children grow up in Otho institutions, I exement because my first view.

in July, I was invited by a young mother to visit with her and her children in south-satern Orio. It is youngest is two and a half, and he had just entired a preschool program sensity church. If do visit not was exhibited to meet her take son, in he had just finished a switchming with the other children in his class. And the program is the class and the program of the control of the control

In early August, I began the work of organizing practicum altos for an upcoming PASS course. I saw this as a partext opportunity to learn a bit more about how children in Ohk are being responded to by organizations and programs. I almed to recruit two programs earns children for the PASS course.

priminatornice is entor use or programs for trainers make 1 montpy when the continuous excensions PASS team and that would offer examples of what was going on for lides in Ohio in 1 Then I began to make calle to people I know who were associated with these progra was sufficiently encouraged by my initial calls to proceed in resulting two program school accorded hildren, one protects operated, the other operated through a local by

#### **About Natural Consequences**

Safeguards Letter #10, July 1989 bout natural consequences

The been thinking about the idea of natural consequences lately. My thoughts have gotten focused them, a leve listenant to exwert 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 he heard.

natural consequences fail 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, hendicapped, neglected, Third World, etc., are radically different from those that many others of us eqloy.

What I find troubling in these conversations about heighing people with disabilities to live more independent litestyles is that the helpers act as though the natural consequences or 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 someone who has disabilities, who is poor or old or invogenenced. It seems to me that two be larned 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 ausprised, and then diamayed, at how difficult it is to keep that understanding alive in my mind se I live my day to day life. One place in my life where I ceem to have a particularly difficult thre keeping my thinking streight about the differer in valuerability is in the area of finances. I've always considered managing money a necessary chore. For example, much of the time! think of myed it as a perpetual cash chortage manager. It exeme that spend quite a bit of my time thinking, about how to ke our little system operating, I begin to think about people who make a lot of money, who even to have money to throw www.or people who have a lot of money to have the complete that I know what it's like not to have much money. I think that I can identify with compress the lower.

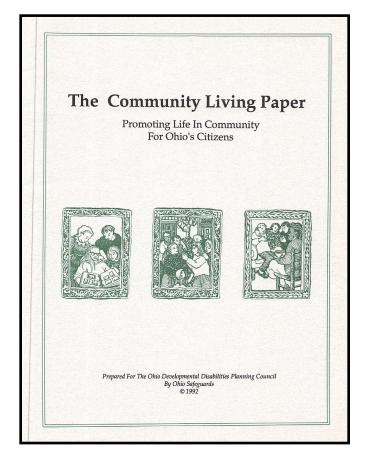
# Safeguards Letter\_\_

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# The Complete Collection of Safeguards Letters - 1986- 2021



A remarkable policy proposal developed by Safeguards in 1992.

They advocated for a "Life in the Community" for persons with developmental disabilities.

Theor Vision is even more relevant today.

# Some Articles by Jack Pealer

# People with Disabilities and Their Money

#38 Summer 2016

People with Disabilities and their Mond

Jack Pealer

It's an old story that people with disabilities (parhape most people with ac-called irrelateductor (desabilities) are likely to be poor. The guaranteed income for a US distan who can demonstrate disability is still isses than \$600 per month—the maximum Supplemental Becurity Income payment. Many people with necesive such income have to pay altrost all of (it's parhape more than all of it for their nert and other basic living expenses. I Sometimes these payments are made to or through the agencies that provide at-home support. The people with or miss trose payments get to resint a small portion of their income as presonal allowance, but the expense of this allowance is under close sorutiny by human service workers, in affect, that small personal allowance is the person's disposable income. In many places in the US the exercise annual sermings (soutiding finings benefit costs) for human service workers are from or the times the monuter of an individual's annual total of SSI payments. Reliablely few people with disabilities have negular full-time employment. Selfwat the its to the headlines delived from resonat consus data—see Rob Mcinaries "article sleewhere in this issue. And, at least partly because of a long last between increases in the US maintain was, the income gap between those people with disabilities who on have does and other cliticase continues to grow wider. People with disabilities do not we much

There's another story being repeated all the time about people with disabilities and i money. The outcome of this other story is that the people whose lives are overseen it human service agencies are kept aimost completely army from possible uses of tha limited amount of money reniable to them. Here's some evidence.

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

How does the person manage her mone

#### Image for an Organization

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

mony other organizations, the agency where I work published an official revision of its table—of-organization. Relius—of-organization are images or pictures of how a formal organization sees itself working, Long ago, it was WorfWorleneberger who first made clear to me the customery discrepancy between how an organization carvisions itself and how things inside the organization on actually work. The day-to-day world often adde tots of equipagity lines to the "ong chart".

in a time when both the organization where I work and lots of other organizations that have index to offer service to people with developmental disabilities are meconsidering their shapes and functions, in view of the needs or demands of the people some now ungs 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, selow is the customary picture of a formal organization; it is certainty, in simplified form, the picture that we have relied on when we want an image to depict organizational shape, as far as I know, this particular extens, which can be symbolically cast in aborthand as a pyramid" (the graphic shorthand that I usually use to stand for a formal organization) has to origin in the millitary, with the emphases on chain-of-command, lines of reporting, and at seast theoretical accountability.



futures that we see for the people with whom we work or the new missions for support agencies that those futures may imply. I can think of several reasons why the pyramid doesn't fit.

#### Considering the Evidence

Safeguards Letter #44 Autumn 2008 Considering the Evidence Jack Pealer

I've just initiated reading a neweletter from a siste government agency. One article exist it is improved in the reading a neweletter from a siste government agency. One article exist intervention services for children with autism and other developmental disabilities...... The article furth said that such models are important because they will help us better "coordinate" support in our sease for people with developmental disabilities. I only want to disact gaze on that satement a bit. I don't really want to again with it. It/lis authors may be right, I just want to try to rigare out what the statement means and think a bit about what disabilities. Because I've with it would make to the ways we ny to support people with disabilities. Because I've

Twenty or so years ago, the statement by the state might well have celled for "models" the were "normalized." It was pretty common then for people to etach the kiden of normalization—usually undefined and unexplained—to elmost 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" (FIPI) comes from suspicion that FI and its with "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

someoming (nat people seem to (nink they understand without taking the time to too closes.

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

Let's take a look at EBP. To find out its meening I did what meny perfectly respectate 2 Istonatury 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 oall for intervention, service, or treatment, there's often a choice among methods. Thei's noticeable in the medical, social-service, or "mental health" areas. EMP is a way to inform choices in those and other fields. EMP inflowers by Wildpedhaj a preference for service measures (treatments) that have been shown to work by measure of mentions affected additional. More who need to a EMP in the than feel the support sending.

#### The Power to Spend

Safeguards Letter #19 Autumn 1991 Power to Spend lack Pealer

There is a great deal of tell these days about ways to bring powerless people into 
"empowerment"—mys to make "choloes" unstable to those (including people who have 
ideabilities) who have never experienced many it is seen proudcisely impossible to dip into 
the "fountains of knowledge" in the human service field—se those fountains are represente 
by confevence programs, professional journels, or exfled multi-authored books—without 
encountering presentations or unticles for presentations converted into uniticels about 
encountering presentations or unticles for presentations converted into uniticels about 
encountering presentations or unticles for presentations converted into uniticels about 
encountering myself who talk about such things to be as older set they can be about 
what they are expling, in that weln, I'm going to fuse a bit about one aspect—a most importer

thinking and working carefully to try to bring about "the good like" for some adults with disabilities who lived in group homes in New Leadington, Ohio. A part of this work involved deverating to promisence the close relationship between people. or "making choices" and having "disposable income" to use. At about the same time (early 1980's) I was studying i earnings of people with disabilities who worked in verfous "shettered workshope" in southeastern Choi, I was findfull that people in those workshope wave earning a mean annual wage (total earnings divided by the total number of worksraj that was less than 16

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

receiving, I desired the notion a bit by applying, it or impess, I recorded, as policy rooted, the nhoises or decisions that I made in one due, it happened to be a Sattudy in early Cotober, I then reviewed my record and justed down the relationship (if any) of each decision to the spending of money. Some of the things I choose or decided about on that day were:

- \*To get up and read the Saturday morning newspaper at 8:00 a.m. The Chililoothe Gazette costs \$9,75 per month, for home-delivery six days a week.
- "write: to neve to randomst." my undrives were determined by a trip I had hade to local Big Bear supermarket the previous week.—In my own, mostly poid-for euromobile. At the market I wrote a check for about \$100.00 for two-weeks groceries.

