### Some Articles by Sandra Landis

Cabin Fever Day

In Response to this Call to Conscience

Safeguards Letter 524 Spring 1994 Cabin Fever Day

(This is the third chapter in the story of our community building efforts that began in December 1930, Other chapters were titled "Store Soup" and "Stir it Up" and were incit in earlier cellions of The Safeguards Letter;)

Phase I work. We had a build of wanderful bornecocked floods, a rise crewel for land book of 150 people, a simple broother boding some cooragibithments and explantance from coming year, and a beautiful day for truthing the reinhibilitated buildings. We acknowledged that we'd come up a bit short. Of the fifteen thousand dollars we'd rowns wo'd how to rules through donotdons and contributions we'd modered \$6,500. To

isonome with flower to make through distinctions and contributions will import a first produce the E.St. The was a short list of unstrainable with or this way part of Primary Entra reminished to be done and activate pointing, some intended to the in the Bilman; and Sinsi planning connections in the Bilman; We calculated, willowed Well people with on and begind, encouraged invescomen to consider bencoming involved. We hoped that more of the unstrainable projects would be consider bencoming involved. We hoped that more of the unstrainable projects would be considered bencoming involved.

Nearly set of our worst fever about the work did not come trus. Three buildings in very bud shape ween now rebulbs, much happe with a specialistic much improved in appearance, and at least partially occupied. No one had been highered on the job, we didn'th have any indoor deputes the whilesy governants had cooperated within the preferring themate and cooperating groups were market; permates on time, and people were divised alrout the improvements in the Main Street.

Our coen now victness were near, but prietly occeeny heat womes. The any before the celebration but prieson who all societies of the months: work in 1994. We were ending year with a few of the challengies unresolved but were grateful that we had enough to solve for a little white annower.

going to a state wine anywey.

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

### 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 stand is at the numer's office in solvool to get our pollo shots, and my brother always feinted. We stood in line before every recess and lunch period in elementary school. We even the line to wait to the bethroom. And on Sattadays, at one o'clock, my brothers and I wou

One memory has to do with balan yenhad out of line. Our family was baseline to ocupie of days in New Orleans. We walked around a section of the city with lots and a wonderful balan that made French publics, I stepped away to the water f

Now I stend in line at the grocery store, correlines at resonants and the print shop, I the with the idea that there is unother line—of human seperimor—that I am always a peand that I influence in annual ways. The distinction between Beartally sendings in the and figurathely holding a place in the line of human experience become much observe sole years up with all showed up at the unemployment of lost. Mey I never a expensed to

Teenty-sic weeks seemed like earthwijs too loan a time for anyone to just etend in like, es soon beam to third hood like it had not be ease, as a presenting a place for a suither that like without men them, what would island for Touring the list couple of reseals! I want to the like the likeway liked the like pear Toules. Other and become the salient between and like other localized to be one of the "lock pearing his to the own all the like the cooling his day of the "lock pearing his his to ge and the honder!" people. There didn't cooling to be one of the "lock people his to so own all the like his decidated to be one of the "lock people his to ge and the honder!" people. There didn't cooling the lock of the "lock people his to ge and the honder!" people. There didn't a collection to be one of the "lock people his to ge and the honder!" people. There didn't a collection to be one of the "lock people his to ge and the honder!" people. There didn't a support the lock people his pe

I found there were an offerender on the electrical period and expensions, depotantic on horse! thought about being them a landed up meeting some interesting people and heading som managing stortes. I cardevestout, as well, that my cholves to be a chemistry people in the well entirelyed yeary on behouse let more offered that if would not repeat the expensions. I did in a lot of time to think while let we stording them, and there were a lot of things i needed to a lot of time to think while let we stording them, and there were a lot of things i needed to which which while let a lot of them to think the let we have a lot of things i needed to let a lot of them to think while let we stording them, and there were a lot of things i needed to let be a lot of them to think while let we stord them the lot of the let were a lot of things in the let be a lot of them to the let will. Whether the were a lot of things i needed to the let a lot of the let be a lot of the let were a lot of the let be let be a lot of them to the latest them the let be a lot of the let be the let be a lot of the let be the let be a lot of the let be the let be a lot of the let be the let be a lot of the lot of the let be a lot of the let be a lot of the let be a lo

## Another Poet of Stone Soup

Another Poet of Stone Sou Sandra Landis

seems on a since por a summering weeks dut on who a sover to seem on the stoye in whites, but this one was different. It served as a symbol of work we have begun, our letest batch of stone soup. You may know the story abox soup. I hope that my short retelling here sketches the real thing. I suggest that you yourself and most the whole story about an acrosome you like.

it eleans trate down is occased routin transassives in a place whose tray were not known well without food but very hungs. They sel about esturing a rise, finding a not, Silling it will have adding a few probbles for something to sit; and talking about aoup, they continued to bit about aoup, after the pot, and the orthor norman, and talking about aoup. They continued to be harded to be inviting to others. They talked will most who came by. Soon enrough, soone people began to this about the soup. Hamp brought considerate to add to it. As ingradients were added, and stimment, and stimmel the sound to the sound the sound the sound to the sound to the sound to the sound to the sound the sound to the sound to the sound to the sound to the sound the sound to the sound the sound to the sound the sound to the sound the sound to the sound the sound to the sound the sound to the sound tound to the sound to the sound to the sound to the sound to the so

This is one of the weye we've come to visualize our work here at home. We've decided to Teigh to make aou," to nourish an interelvee and others. We are partially answer that we set with meager ingredients that by themselvee will not nourish anyone very well. We see out work are existing to draw by relating them to help a mote, seed, and enjoy the secure. Here, so the soup is doesn't depend very much on any one particular ingredient. Usually it's the variety of lagoridents in simul amounts simmered and tended for a long time that makes best soup.

Aly friends John and Stephen, and I, have begun a small cognitization. It's name decomted use in our community where who—Sunday Cherk (Associates, I) white starting with some ideas, some hope, some energy, and some time. Our application is to be a reputabilization out tills pear of the sould. We think that whother, over time with our neightboth do and stimulate interesting work and business enterprise, to maintain and improve homes and the housing stock no our exa, and to participate a reaction anothers to to the united year quality of our public tils will interest one high of commantly we it is to the united year quality of our public tils will interest one high of commantly we it.

of people and places that make up Southern Perry County, Chic. Together we came to realize that now was as likely a time to begin as any. If we waited until there was some

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

The preparation for war and the violent invasion of Kuwait 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 conscience. Conscience is simply defined by Webster as "...a time of restection 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.

respect of special consolerors is peak humbly. Only at this late date is my voice becoming truly a public one; it lacks the atwenth and standard the comes from frequent practics, it is singular; it does not yet share in a common song with other voice. I thank broom if aright a probability is the strain in a common song with other voice.

### On "Being of Use"

Sandra Landis

Recently, I read Ciderhouse Rules by John Irving. This popular book was entertaining, As well, it prompted, most othirs tagain 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 damatic, I tend to agree. I was reminded of my own preoccupation with the idea of "being useful" a few years also and the changes 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 swold full time employment as my sons were growing up. I had. Deen 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 learn a lot about what it takes to manage the work of an organization. I also learn a lot about-organizations and the dynamics that influence the decisions? actions, and values of organizations. I came to understand that organization 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. Ny graduate rout enton had for used on organization theory an 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 fall helps clarify for me the controct in which purposeful, focused change can happe also strengthened my understanding about how vulnerable this context is in short; I learned a bit more about what, undermines and defeats change.

### Hidden Children

### Hidden Children

This summer has offered me several occasions to think about children - children i know intrinsicity and children who are unknown to me. Memorial Day was quite a beginning for our intrinsicity and children who are unknown to me. Memorial Day was quite a beginning for our summer. Hy pursuages to one good and from high action (I-P) yoursest brother, his wife a set with their daylifetine, came to vide and carbon the wife to we then set with a consideration of the set of th

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 and the series of a contract of a contract

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 explicitly off owner they fact so on, in the July lat finished a switching with the other children in the class. All the program is the class and the program of the control of the co

In carly August, I began the work of organizing practicum altos for an upcoming PASS course. I saw this as a perfect opportunity to learn a bit more about now children in Ohk are being responded to by organizations and programs. I almod 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

I've been thinking about the idea of natural consequences lately. My thoughts have gotten focused there, a two letterants to exercit public discussions solved usupporting 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 five fread.

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, handicapped, neglected, Third World, etc., are radically different from those that many others of us enjoy.

more independent lifestyles is that the helpers act as though the natural consequences of events sent it 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 situatina situation. Their no acknowledgement of nor accounting for the difference in personal vulnerability

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 old or inexperienced. It exemes to me that two be learned that being labeled by others increases a person's vulnerability. We've also learned that natural consequences impact a person's tile 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 aupyrised, and then diamayed, at how difficult it is to keep that understanding alive in my mind as I live my day to day tife. One place in my live where I seem to have a particularly difficult time keeping my thinking streight about the differer 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 myseet as a perpetual cash obstrate manager, it seems that I 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 seem to have money to throw sway, or people with have a lot of money to lived; it skip thinking that I know what it's like not to have much money. I think that I can identify with

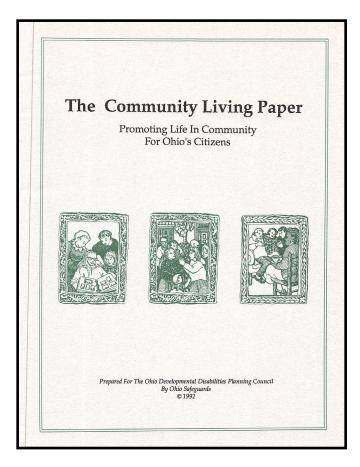
# Safeguards Letter\_\_

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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 Mone
Jack Pealer

It's an old story that people with disabilities (parkaps most people with a -o-alized intellectual indebutities) are likely to be poor. The quaranteed income for a US distant who can demonstrate disability is still isses than \$600 per month—the maximum Supplemental Security income payment. Heavy people who receive such income have to pay atmost acid (if or perhaps more than all of it) for their rark and other besis bring superses. I Sometimes these payments are made to or through the agencies that provide at-home support. The people who makes trace payments get to resein a small portion of their income as presonal allowance, but the expense of this allowance is under close sortifyin 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 (soulding fings benefit costs) for human service workers are from or the thres the monuter of an individual's annual total of SSI posments. Reliability few people with dissolities have regular full-time employment. Selfment the list on the headlines derived from record consus data—see floch forlines' orticle slewwhere in this issue, and, at least purity because of a long larg between increases in the total makes the frome responses to months or the people with disabilities don't have much contentialities are continued to the conditions of the on other than the month recordulation and continued to the continues to grow wides. Recipie with disabilities don't have much constraints.

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.

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 oblinguage make those visits, which are required by state regulations so that we can assure the quality of support that's dirend. 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 mon

### Image for an Organization

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

rearry other organizations, the worker or a precty of groganization, releasity every year, use more other organizations, the agency where it work publishes an official swelsten of its tables of-organization. Tables-of-organization are images or pictures of how a format organization sees itself working. Long ago, it was Workflyfoltensbergs who first made clear to me the customery discrepancy between how an organization envisions itself and how things inside the organization actually work. The day-to-day world often adde lots of equisigly (ines to the "org chart".

in a time when both the organization where I work and lots of other organizations that have tided to offer service to people with developmental disabilities are neconsidering their shapes and functions, in view of the needs or demands of the people some now ungs us to think do as "customers"; it occurred to me that it might be useful to give thought to the images that we use to portray how our organizations either do or are supposed to work, Bellow 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 entage, which can be symbolically cast in shorthand as a "pyramid" (the graphic shorthand that I usually use to stand for a formal organization) has ke origin in the military, with the emphases on chain-of-command, lines of reporting, and at least 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 finished reading a neweletter from a sixte government agency. One article said that it is important to "support evidence-based, high-quality, cost-effective models for intervention services for children with autism and other developments if 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 neelly want to argue with it. I'vits authors may be right, I just want to ary to regare with the disabilities and thinks a bid both what the statement means and thinks a bid both what the statement means and thinks a bid both what the statement means and thinks a bid both what the statement means and thinks a bid both what the statement means and thinks a bid both what the statement means and thinks a bid both with disabilities. Because I've

Twenty or so years ago, the statement by the state might well have called for "models" that were "normalized." It was pretty common then for people to attach the idea of normalization—usually underined and unseptained—to shomest every proposal for any kind of service, at least for people with developmental disabilities. Part of my disconfiort with the current prominence of "evidence-based practice" (FFIP) comes from suspicion that FIIP and its twin "bast practice" are being used today in about the same way that normalization was used in the past—without suplanation or examination. After all, like normalization, "evidence" is

Today, if you want someone to consider your new idea seriously you'd likely describ an exidence-based best practice, But, as was the case with the label of normalizati simple labeling of new proposals as evidence-based lan't enough.

Let's take a look et EBP. To find out its meening I did what many perfectly respects 21 stoantury people do. I used Google to consuit Wikipedia and to find references "treatments that work" et a web-site from Oxford University Press. Here's what Hearned.

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 indicates the WHIGHOUSE of the Committee of the Co

### The Power to Spend

Safeguards Letter #19 Autumn 1991 Power to Spend

There is a great deal of talk these days about ways to bring powerless people into 
"empowerment"—ways to make "choices" unshable to those (including people who have 
disabilities) who have never experienced many it is seems pructically impossible to dip into 
the "fountains of knowledge" in the human service field—se those fountains are represente 
by conference programs, professional journels, or edified multi-authored books—without 
encountering presentations or articles (or presentations converted into articles) about 
encountering presentations or articles (or presentations converted into articles) about 
encountering presentations which in this is, in several, a healthy development. I just want 
those (including myself) who this hout such things to be as older as they can be about 
what they are saying, in that with, I'm going to fiss a bit about one aspect—a most importer 
one. I thin—of the choice-incrowerment issue.

ting and working carefully to by to bring about "the good life" for some adults with biblies who lived in group homes in Hew Leeington, Chio. A part of this work involved siting to prominence the close relationship between people; i "making cholose" and b) ng "disposable income" to use. At about the same time (early 1980's) I was studying the ings of people with dissoluties who worked in verious "shettered workshope" in heastern Chio. I was fixfully that people in those workshope were earning in mean int wage (total earnings divided by the total number of workers) that was less than 10%

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.

recounts, reserve time notion a pix by applying it to impeet, recounts, as braces could, other, holicides of decisions that I made in one dus, it happened to be a Saturday in early October, i then reviewed my record and jotted down the relationship (if mys) of each decision to the spending of money. Some of the things I noise 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.
- \*What to have for breakhast, by onlones were determined by a trip I had made to tool Big Bear supermarket the previous week—In my short, mostly puid-for outomobile. At the market I wrote a check for about \$100,00 for two-weeks groceries.

