Some Articles by Sandra Landis

Cabin Fever Day

Safeguards Letter #24 Spring 1994

(This is the third chapter in the story of our community building efforts that began in December 1980, Other chapters were titled "Store Soup" and "Stir it Up" and were in in earlier editions of The Sufeguards Letter.)

Winter arrived in earnest and right on schedule this year, a few days before Christmas. weeks earlier than that we had basted a tuncheon in Shawnes to celebrate the end of a Place al work. We had a builted of wonderful homecooked foods, a rice crowd for fundabout this popule a plante brookers active some proposition and applications for

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

We acknowledged that we'd come up a bit short. Of the lifteen thousand dollars we'd innow we'd have to mise through derestine and contributions we'd received \$6,500.

enery ail of our wast fears about the work did not come true. Three buildings in very bad hape were now stable, much sproved in appearance, and at least partially occupied. No one had been injured on the

you, we don't have any approximately an expression professity; terminate and occupanting struge were marking professity; terminate and occupanting struge were marking programment on time, and people were pleased about the improvements in the Markinston. All this new plants claims wire interest marketims and supplies had been stonege with minimal security effort on our part.

Our over now vicines were near, but priety ordered heat womes. The dray before the oslebinistion turbrieson we had neashed notification of a modest grant to support a few months: work in 1994. We were ending to year with a few of the challenges unreceived but were grateful that we had enough to bit solve for in that the while anamed.

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

Holding a Place in Line

Safeguards Letter #20 Spring 1992 Holding a Place in Line Sandra Lendie

I have some clear childhood memories of standing in line. We used to have to stand, at the numer's allow in sohool to get our pollo shots, and my brother always fainted. I stood in line before every recess and lunch period in elementary school. We even at line to wait to the bethroom. And on Sattadays, at one obtack, my brothers and I wo

One manner has to do with haling senting of the Cur family was travaling, shall occupie of days in New Orlaws. We waited around a section of the city with lots of and a wonderful bakery that made French ontillers. I stepped army to the water four

Now I stand in lite at the grocery store, correlines at restrumnts and the print shop. I also the with the Idea that there is another lite—of human experience—that I am always a part of and that I influence in small eyes, in distinction between literally swarings in the and resumment of the I influence in small eyes, in distinction observed influently experience in the literal continuous many in the literal continuous experience became much observed could not be exemplicated to store for the literal continuous distinctions and the literal continuous exemptions are stored to the form the correlations of the literal continuous exemptions are stored to the literal continuous exemptions. The liter

Twenty size weeks assemed like earthey't too long at time for ungonee to just about in like, as also the bean to third house it is that other seems, on presentine passing for useful in that like. While I were there, what would stemd for During the size couple of weeks i weathful of their people and learned the readiles. It blooks for mill be a running a weathful of their people and learned the readiles. It blooks for mill be a running and still others would prike. One people and learned the readiles. It blooks for read storted so made challenges you price. One people also leave to see the time for read storted or some challenges. It societies to be one of the "lock people in the eye and be shownful "people. There didn't to decided to be one of the "lock people in the eye and be shownful "people. There didn't to decided to be one of the "lock people in the eye and be shownful "people. There didn't to the societies to be one of the "lock people in the eye and be shownful "people. There didn't to the people and the storte of the societies of the societi

found there were a difference in the etunding-th-dise experience, departing on horilocated there were a difference in the etunding-th-dise experience, departing people and heading earn structure, storius, I cardierascuci, as well, that my chockes to be a chemistic person in the wedientilely-seary on exclusive lives are being that a south of any structure person in the wesidentilely-seary on the consumer lives are being that any consumer that experience. I did the storius of the consumer that we desire the consumer that are south of the structure of the structure of the consumer that the structure of the consumer that the structure of the

Another Poet of Stone Soup

Another Poet of Stone Sou

Last winter a small pot of simmering water eat on our wood stove. We usually have steamer on the store in white, but this one was different. It served as a symbol work we have begun, our letest betch of stone soup. You may know the story alo soup. I hope that my short refelling here sketches the real thins, I suggest that you

It eleans that come sociates found themselves in a place whose they were not known well without food but very hungs. They set about extinct a rise, finding a role, Silling it will have adding a few problets for something to sit; and talking about asoup, after both and the role and the role of the role of

This is one of the weye we've come to visualize our work here of home. We've decided to "begin to make soon," to nourish an enselvee and others. We are partially arrest that we with menger ingredients that by themselvee will not nourish anyone very well. We see out work as ensemble others by inetialls then to help make steel, and entire the sour. How at the soup is doesn't dispend very much on any one particular ingredient. Usually it's the variety of lagredients in small amounts simmered and tended for a long time that makes best soup.

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 revisibilizing 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 mac, and to participate all socials rachines at the level of the contract of the properties of the social contraction of the level of the little of the social social social social social social to the variety and quality of our public tile will antercome his find of commanity we'll as

Each of us has come to realize that we want to work at home, in the midst of the coll of people and places that make up Southem Perry County, Ohio. Together we came t In Response to this Call to Cponscience

The Safeguards Letter A Publication of OHIC SAFEGUARDS NUMBER SEVENTEEN MARCH, 1991 IN RESPONSE TO THIS CALL TO CONSCIENCE Sandre Landis

has becaused in the training and the control of the

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

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 preoccupation with the idea of "being useful" a few years aco and the chanses I've resilized 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-

time 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 learne 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 each a buse or boles do.

I was able to think about my tonure in that job as a useful but painful pre-tri-um. My graduate reducation had focused on organization theory an management principles. I had thought a lot about and had studied changs 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 helps clarify for me the context in which purposeful, focused changs can happe also strengthened my understanding about how vulnerable this context is in short; I learned a bit more about what. undermines and defeats changs

Hidden Children

Hidden Children

This summer has offered me several occasions to think about children -children i known criterately and children who are unknown to me. Memorial Day was qu'ille a beginning tool you aummer. My owigare one graduated from high echoe. My youngest bother, has with their disaptions, carrier to wide and calebrate with us. It was the first wide to our bone by the their disaptions, carrier to wide and calebrate with us. It was the first wide to our bone by

in June, I spent a week in Atlanta as a member of an evaluation train. The organization visited promotes children citizen advocacy and other personal forms of advocacy with people in Groupis who are described as having a developmental disability, threat the new that at least a doorn youngstorn in Georgia had been admixted to attain instituted during the past year. I begin to think about the children back frome. I resided that I dis trow whether children in Ohio were being responded to in the same way. I know there been a time when many children grow up in Ohio institutions, I remembered my first visit.

in July, Iwas Invited by a young mother to visit with ther and her children in southeastern from, it is younger to two und in his, and he had just enterined a preschool program at a meanty-church. I did visit ned was designed to meet her little oon, it is had just finished with mining with or other children in his class. First he youngest in the class and the only with mining the control of the label resident who are designed to the control of the control of the control of the control of the label resident who can be designed to the control of the control of the control of the label resident who can be control of the control of the control of the control of the label resident who can be that this is still a very rare search. By limite of most children who and half year olds with Down syndroms is they're climbing or being little of once to bus with other children who can be med seabilities to be transported to the special school.

In early Auguet, I began the work of organizing practicum eites for an upcoming PASS course. I saw this as a perfect opportunity to Isam a bit more about how children in Ohio are being responded to by organizations and programs. I almost to recruit two programs to earne children for the PASS course.

I brainstormed a short list of programs for children that I thought would accommodat PASS team and that would offer examples of what was going on for idde in Ohlo in 198 Then I began to make calls to people i know who were associated with these programs was sufficiently encouraged by my initial calls to proceed in regulfing two programs for the programs of the process of the programs of the proceed in the programs of the process of the process of the programs of the process of the process of the process of the programs of the process of the

About Natural Consequences

Safeguards Letter #10, July 1989 About natural consequences

I've been thinking about the idea of natural consequences lately. Ply thoughts have got focused there, so I've lictemed to several public discussions about supporting people wit disabilities in more independent lifestyles. In these discussions, using "natural consequences" has been suggested sea very 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 reperience and current situation, Both the current situation and phistory of pools who are labeled as poor, old, handicapped, neglected, Third World, a are radically different from those that many others of us enjoy.

is probably what people with disabilities will experience in a similar situation.

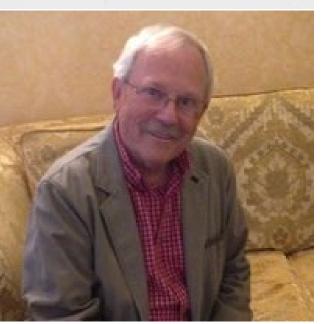
I hear no acknowledgement of nor accounting for the difference in personal vulnerability that nearly slawaye exists between you or me and someone who has disabilities, who is poor or old or inexperienced. It seems to me that we've learned that being labeled by others increases a person's vulnerability. We've also learned that neural consequences impact a person's line and experience in proportion to one's state of personal security and vulnerability. Some people got far more than their share of natural consequences, and the consequences they experience are usually much graver.

I am always a bit aurprised, and then dismayed, 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 when seem to have a particularly difficult time keeping my thinking straight about the difficult in undersability is in the area of finances. I we always considered managing money a necessary chore. For example, much of the time I think of myself as a perpetual cas shortage manager. It seems that I spend quite a bit of my time thinking about how it our little system operating. I begin to think about people who make a lot of money, we seem to have money to threw away, or people who have a lot of money to invest, it is thinking that I know what it's like not to have much money. I hink that I can letted.



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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 Mone
Jack Pealer

It'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 13 citizen who and dismostrate disability is all lies shan failod per morth—the maximum Supplannenal Security income payment. Many people who receive such income have to pay atmost all of for perhaps more than all of it for their rest and other basis bring expenses. I Sometimes these payments are made to or through the agencies that provide at-home support. The people who make trose payments get to restin a small portion of their income as "presonal allowence," but the suppose of this allowence is under close sorutiny by human service workers, in effect, that small personal allowence is the person's dispensable income, in many places in the US the evenue annual cernings (evoluting fittings benefit costs) for human service workers are four or live times the amount of an individual's annual total of SSI payments. Reliability few people with dissubilities have regular full. One employment, sheep the list to the headlines derived from recent census data—see the Mointer's unities sheephare in this besue, And, at least partly because of a long large between increase in the US minimum wags, the income gap between those people with dissubilities don't have much

e's another story being repeated all the time about people with dissabilities and their ley. The outcome of this other story is that the people whose lives are overseen by an service agencies are kept almost completely away from possible uses of that ad amount of money ereliable to them. Fiers'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 regulators so that we can assure the quality of support that's direct. 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 abour money or

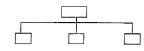
How does the person manage her mon-

Image for an Organization

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

For the past seven years, Tve worked for a pretty big organization. Nearly every year, (illo many other organizations, the assimous where I work publishes an official revision of its sable-of-organization. Tables-of-organization are images or pictures of how a formal organization sees itself working. Long ago, it was Wolffvoltensberger who first made clear to me the customary discrepancy between how an organization envisions fixed and how things inside the organization actually work. The day-to-day world often adds lots of quiesty lines to the "organization".

is time when both the organization where I work and lots of other organizations that have dot to offer organizations, with developmental disabilities are reconsidering their hapes and functions, in view of the needs or demands of the people some now urgs us to interest of a "customers". It occurred to me that it might be useful to light blought of the larger at that we use to portray how our organizations either do or are supposed to work, elow is the customary picture of a formal organization; it is certainly, in simplified form, he picture that we have reliad on when we want an image to depict organizational shape, a far as I know, this particular shape, which can be symbolically cast in shorthand as a organization; the critical profile shorthand that I usually use to stand for a formal organization; has a origin in the millitary, with the emphases on chain-of-command, lines of reporting, and at uset 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

ve just finished reading a neweletter from a state government agency. One article said that 's important to "support evidence-based, high-quality, cost-effective models for nervention

instruversion services for children with autism and other developmental disabilities...." The article furth said that such models are important because they will help up better "coordinate" supports on that statement a bit. I don't really want to again with it. It is authors may be right. I just want to try to regare out what the statement means and thinks a bit about what difference agreement it would make to the ways we try to support people with disabilities. Because I've pondered entire in the Stateguards Letter about "out-affectivences" (Stummer 1992), I'll skip that here. I want to think about what this "evidence-based practice" means.

Twenty or so years also, the esistement by the state might well have called for "incodels" the ware "normalized." It was pretty common than for people to ettain the idea 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 practics" (FIPP) comes from suspicion that FI 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 seaple seam on this they undestand without indicts the time to look

something that people seem to think they understand without taking the time to look oloses. Today, if you want someone to consider your new idea seriously you'll likely describe i an addenna, based heet resorbes. But no lasts the case with the label of normalization.

Let's take a look at EBP. To find out its meening 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 Codord University Press. Here's what I learned.

When people are said to have needs that out for intervention, service, or treatment, there's viten a choice among methods. That's noticeable in the medical, social-service, or "mental teath" arms, EEP is a very to inform choices in those and other fields. EEP indicates (says Williagedia) a preference for service measures (treatments) that have been shown to work by means of emplicial endefance. Most who paid on EFP to halt tham induffer empans and emplical endors service.

The Power to Spend

Safeguards Letter #19 Autumn 1991 Power to Spend

we is a great deal of balk these days about ways to bring powerless people into apowerment "- ways to make "choices" uneitable to those (including people who have abilities) who have never superioroad many; it seems practically impossible to dip hato "fountains of knowledge" in the human service tied—as those fountains are represented porfesence programs, professional journels, or edited multi-authored books—without powerment or choice. I think that this is, in sanema, a healthy development, i just want at they are seying, in that win, I'm point to the se clear as they can be about at they are seying, in that win, I'm point to these as it about one espect—a most important to they are seying, in that win, I'm point to fixes as it about one espect—a most important.

wy yeurs aso, my rhends Sandro Londie and John Winnenberg led a group of people into killing und worlding carefully to try to bring about. "The good life" for earne adults with abilities who leved in group homes in hiew Leatington, Chio, A part of this work involved writing to prominence the close relationship between people; a) "making choices" and a) ing "disposable homen" to use A drouct the same time (early 1980b) I were studying the this of people with disabilities who worked in verifous "shettered workshops" in thesettem Chio. I were studying 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 approximate the anusal connection between income and choice, if one has little or no income, then one's choices must be limited. If not non-waternt.

volces 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 ending of money. Some of the things I chose or decided about on that day were:

- *To get up and read the Saturday morning newspaper at 8:00 a.m. The Chillicothe Gazette costs \$9.75 per month, for home-delivery six days a week.
- toosi Big Bear supermarket the previous week. In my own, mostly poid for automobile. At the market I wrote a check for about \$100.00 for two-weeks groceries.