

The Safeguards Letter

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BACK AGAIN

Surprise! OHIO SAFEGUARDS has not entirely disappeared. Here we are, back again. It's good (for me, anyway) to be sending this issue out to our long-time readers. Once in a while someone mentions to me that they enjoyed receiving *The Safeguards Letter*. Sometimes people actually say that they miss it. So, we're trying again.

This issue of *The Letter* is being mailed to everyone on the mailing list, which may take some doing because some readers have surely moved since the last issue came out two years ago. This and subsequent issues of *The Letter* will, moreover, be available on the web, at www.ohiosafeguards.org. We will continue to send issues through the U.S. Mail to readers who want a mailed copy, but we'd be happy (for cost reasons) if readers who could receive *The Letter* via the internet would be willing to do so. Here's what we'd like willing readers to do:

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

Eventually, we expect to post selected back issues of *The Letter* on the web site as well. We hope that you remember some of them and enjoy catching up with them. We also hope, of course, to find new readers through the internet – and, perhaps, receive some interesting responses to *The Letter* in the bargain.

Welcome back to you, our readers. We hope that you welcome us back as well.

Jack Pealer

THE MIRAGE OF PERMANENCY:
Orchard Hill as an ICF/MR.

Wisconsin Coalition for Advocacy

(Editor's Note: Once before, in the summer of 1991, we offered our readers the chance to consider this article, which originally appeared in the Newsletter of the Wisconsin Coalition on Advocacy in July, 1981. The article is now 22 years old-old enough to drink liquor in Ohio. It's still worth reading. We have re-printed it now because we think it speaks to some recent and impending issues.

For example, the Board of Supervisors of Fairfax County, Virginia recently approved re-zoning of a property so that a church could build a 70 space "respite center" for families with children who have developmental disabilities. Apparently, supporters believe that "respite" will remain the mission of such a center, despite more than 100 years of history that would tell us otherwise-part of that history being Orchard Hill.

Also, for example, tension looms across the country between those in communities who view sheltered workshops as useful, meaningful places where adults with disabilities can work and those who reject the workshops in favor of efforts to help people be employed on "real jobs" (as many self-advocates describe them). The story of Orchard Hill reveals that one source of this tension is the expectation that a setting-like Orchard Hill or the workshop-will be able to deliver something-like family living or good work-that is actually ruled out by these organizations' very structure and financing patterns.

Anyway, here, again, is the story of Orchard Hill.) JRP

Once regarded as an innovative residential setting when it opened in 1973, Orchard Hill is now in turmoil deeply torn between parents' expectations, the needs of adult residents, and the funding and licensing requirements of the federal and state governments. This case study reveals how the parents' efforts to help their developmentally disabled family members

have become perverted by the requirements of the system.

When the state was developing community residences to deinstitutionalize the State Centers, a group of parents, most of whose developmentally disabled family members lived at home, joined together to develop an alternative to a large, impersonal institution. Reasoning that an institution would have greater longevity than an eight-person group home, the parents tried to combine the permanency and security of an institution with the "intimacy" of a group home.

It was most important to the parents that Orchard Hill be a permanent home where their developmentally disabled family members would always be well protected even after the parents were no longer alive. Permanency also meant that the residents would be able to enjoy the security of living in the same place with the same people and avoid the trauma of moving from place to place when professionals determined that their needs had changed. The parents believed that their developmentally disabled family members needed continuity in their personal relationships and lots of tender loving care.

Orchard Hill was designed to provide a comfortable atmosphere where residents could relax under the protective eye of a house parent. Acting *in loco parentis*, the house parents were expected to provide warmth and caring, to accommodate almost any behavior no matter how inappropriate, and to treat the residents as the parents directed. The parents expected developmental training to be minimal at Orchard Hill in order to preserve a home-like atmosphere. In addition to houseparents, the original programming staff at Orchard Hill consisted of two activity therapists, two dance therapists, and a social worker and nurse. It was also expected that all residents at Orchard Hill would participate in day activities away from Orchard Hill at

sheltered workshops or day activity centers or even competitive employment in the community. This separation of residential and day programming functions is recommended from a normalization perspective but is usually violated in most large ICF/MRs. Orchard Hill may have opted for off-site day programming because the parent group which formed Orchard Hill, called Retardation Facilities Development Foundation (RFDF), was actually an offshoot of Madison Association for Retarded Citizens, which operates sheltered workshops and day service centers for developmentally disabled persons in Madison.

To accomplish their vision of a permanent home, the parents conducted a massive fund-raising drive over a two-year period which raised 40 percent of the capital from Health, Education, and Welfare (HEW), 40 percent from a low-interest loan, and 20 percent from private contributions to Orchard Hill. Many parents contributed to Orchard Hill with the expectation that their developmentally disabled family member would be assured of a permanent place at Orchard Hill. The parents also hoped to maintain their control over the direction of Orchard Hill through a strong parent-dominated Board of Directors.

The parents' desire for a loosely structured program at Orchard Hill encountered some difficulties from the beginning, but these were subordinated to the overriding purpose of maintaining Orchard Hill's permanency. As a condition for accepting funds RFDF was obligated to fill a certain percentage of the beds within the first year of operation. With the founding parents able to fill less than one-half of the places, it became necessary to recruit people with many different needs to live at Orchard Hill. These people with diverse needs, ranging in age from 20-66 years, had to fit into the structure which had already been determined. The parents' vision of "intimacy" at Orchard Hill took the form of eight separate cottages, each supervised by a live-in house parent. The

original plan had been for eight residents to live in each cottage, but this number was enlarged to twelve in order to ensure that sufficient money would be generated to cover operating expenses. Most Orchard Hill residents have limited contact with non-disabled people other than staff, and approximately one-half of the residents attended a sheltered workshop located just behind the residential facility.

When Orchard Hill was opened in 1973, Medicaid was the only funding source available for its operating costs and so Orchard Hill was certified as an ICF/MR. At that time Aid to Disabled Persons (*Ed., forerunner to SSI*) was too small, the state had not yet created the Special Living Arrangements supplement, and the 51 Boards (*Ed., county agencies focusing on developmental disabilities*) had not been established in the counties to fund residential services.

As a Medicaid-funded facility, Orchard Hill has always been subjected to annual surveys and Independent Professional Reviews (IPRs) by the Division of Health (DOH) surveyors in the Department of Health and Social Services (DHSS). But the federal government did not circulate the ICF/MR standards until 1974, and the requirements for compliance remained unclear. Lacking expertise in developmental disabilities programming, the DOH survey teams were primarily involved with monitoring physical standards. Located on a sprawling ten-acre campus with an apple orchard that gives Orchard Hill its name, the DOH surveyors observed that Orchard Hill's modern cottages were clean and in compliance with physical standards, and that the residents were away for day programming every weekday. The laxity of the DOH in enforcing programming standards may also have reflected pressure to use Medicaid funding whenever possible because it cost Wisconsin only 42 cents on the dollar to keep people in Medicaid-funded facilities. With thousands of people with developmental disabilities placed in nursing

homes in Wisconsin without special programming, Orchard Hill may have looked like a model residential facility.

It is difficult to probe all of the reasons that the Division of Health altered its enforcement practices. Certainly, the revised ICF/MR guidelines released by the federal government in 1977 provided a clearer basis for enforcing the federal requirements for "active treatment" in an ICF/MR facility.

Through the IPR process, the DOH surveyors have been expected to review the treatment plan for each Medicaid-funded resident in a health care facility and to reclassify the level of care as a resident's needs change. The IPR team consisting of a nurse and a social worker might even determine that the needs of the resident cannot be met in the health care facility in which the person is residing. At Orchard Hill, a few residents have been transferred to nursing homes when it was determined that they needed more medical care than Orchard Hill was licensed to provide as a residential care facility and then as a community-based residential facility (CBRF). When certain behavioral problems came to the attention of DOH, Orchard Hill hired a part-time psychologist consultant to work with a few of the residents. These decisions to adopt a limited active treatment program were supported by some of the most active members of the Board of Directors whose family members needed the most supervision. But many other parents, with a long-standing distrust of institutions, continued to view treatment programs as incompatible with a permanent home.

In 1980 the RFDF Board decided to hire a new administrator whose expertise was in health services and fiscal management rather than in developmental programming. Orchard Hill was experiencing financial problems related to the new ICF/MR formula which the Department of Health and Social Services introduced in 1978-79, and the DOH was beginning to question whether Orchard

Hill's program was fulfilling the requirements of active treatment.

In order to accommodate the ICF/MR standards, the new administrator began developing programming changes and hired a professional staff which would begin to develop individualized case plans for all Orchard Hill residents. As required by the ICF/MR standards, these professional staff have begun performing multi-disciplinary assessments and addressing developmental objectives. The new administration has also begun to introduce a behavior modification program to correct inappropriate individual behavior in a way that some parents and advocates regard as dehumanizing.

At the insistence of the RFDF Board of Directors, the introduction of a behavior management program was confined to one cottage where residents with behavioral problems have been concentrated. Although the Orchard Hill administration claims that the behavioral management program has not been implemented yet, staffing in the behavioral management cottage has been beefed up to 2-3 staff at one time who function on a shift basis compared to one live-in house parent in the other cottages. The concentration of twelve residents with behavioral problems into one cottage, however, has accentuated certain interaction problems among residents, increased staff burn-out, and generated rumors about inappropriate behavior treatment approaches. Three residents have already been removed by the DOH for needing more care that Orchard Hill can provide. The parents of these residents question the authority of the IPR process and are furious with the attitude of the new Orchard Hill administrator that certain residents do not belong at Orchard Hill.

In the last IPR process, Orchard Hill was found deficient for not having individualized plans of care and treatment for eighty-four residents. These problems are not new but have existed since Orchard Hill opened eight years ago. As if to

emphasize the qualitative nature of this change, for the first time DOH has decertified two Orchard Hill residents from Medicaid reimbursement for not needing the intensive care that an ICF/MR is supposed to provide. In addition, the IPR process has identified another fifteen residents who could be transferred to less restrictive settings in the community if appropriate services could be provided.

These developments have undermined the parents' dream of a permanent home for their developmentally disabled family members. Many parents fear that Medicaid requirements threaten to transform the residential nature of Orchard Hill into a medical treatment center. Recognizing that some residents may need more supervision than others, a split has begun to emerge among parents. Parents whose family members appear to function well at Orchard Hill are beginning to question whether other residents, who cannot adjust to the loosely structured program, actually belong there. Other parents remember that Orchard Hill was supposed to be a permanent home for all residents and that forcing some residents to leave now may jeopardize the permanency of all residents as their needs change. Many parents have never believed that their developmentally disabled family members could ever function in a less restrictive community setting. Confronted by a new professional staff which is trained in developmental programming, many parents are angry at the staff's emphasis on independent living skills. Some parents fear that developmental training for their developmentally disabled family members could jeopardize the parents' dream of permanency for them at Orchard Hill while others question the type of training the residents are receiving. Some developmentally disabled residents have been blocked by the parents and guardians from moving out of Orchard Hill into the community. One Orchard Hill resident was overheard telling another, *"I wouldn't mind living in the community, but it would kill my mother."*

At a recent Orchard Hill parents' meeting, many parents expressed the view that their developmentally disabled family members could never live in the community. A heated exchange ensued when a middle-aged other bravely stood up and announced that she hoped her daughter would be able to live in the community. Amid jeers and rebukes an older parent shouted out, *"It is easy for you to say that because you are young enough to help your child if she fails in the community."* At the bottom of parents' fears is the widely-held perception that the community service system cannot provide the security of an institution. Many parents feel betrayed by the RFDF Board for not having informed them about how precarious dependency on Medicaid could be even though there was no alternative funding source for a facility of the size of Orchard Hill.

The RFDF Board is suspicious of the state and federal governments for changing the rules by which Orchard Hill has been regulated over the last eight years. The new Orchard Hill administration is trying to implement the current ICF/MR guidelines and is frustrated by the apparent assumption of the Board of Directors that the Orchard Hill administration should continue to serve as a buffer between the state and federal funding and licensing requirements and the parents' original expectations for Orchard Hill. Looking at this residential program in turmoil, many advocates wonder why residents who can function well at Orchard Hill wouldn't be able to develop better in a smaller, more socially integrative home in the community; they also wonder whether the residents who need more supervision will need a more individualized program than can be provided in a twelve-person cottage. In the background the debate simmers about whether it is cheaper to warehouse people in institutions or to provide opportunities for personal development in smaller integrative residences in the community.

In many ways Orchard Hill was built to meet the needs of the parents rather than the residents. But the form it has taken has been shaped by the requirements of funding and licensing and by the lack of sufficient resources in the community service system. These external forces continue to constrain the options of the parents and the current Orchard Hill administration. The real tragedy of Orchard

Hill is not that parents value permanency over developmental training but that the long-term support system in Wisconsin fails to guarantee permanent support for developmentally disabled persons in their own homes in the community.

"WCA Newsletter",
July, 1981

About THE SAFEGUARDS LETTER

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

JUST QUOTES

*(Note: Ivan Illich died on December 2, 2002 in Bremen, Germany. I didn't know of this until I read about it in **The Catholic Worker**. The news – and it was certainly news because Illich was and is one of the most-read thinkers in the world – did not make it to our local papers. In observance of Illich's death, I'm including a few quotes from his difficult essays. JRP)*

How should I distinguish the acquisition of education from the fact that people have always known many things, have had many competencies and, therefore, have learned something? So I then came to define education as learning under the assumption of scarcity, learning under the assumption that the means for acquiring something called knowledge are scarce.

In Cayley, David (ed.) *Ivan Illich in Conversation* (1992)

Gravediggers did not become members of a profession by calling themselves morticians, by obtaining college credentials, by raising their incomes, or by getting rid of the odor attached to their trade by electing one of themselves president of the Lions Club. Morticians formed a profession, a dominant and disabling one, when they acquired the muscle to have the police stop your burial if you are not embalmed and boxed by them.

Toward a History of Needs (1978)

I went to Jacques (Maritain), whose imaginative Thomism meant very much for me.... As I was sitting there with him – he had a teacup in his hand and was shaking when I talked to him about

the question which bothered me, that in his whole philosophy, I didn't find any access to the concept of planning. And he asked me if this was a different, an English word for accounting. I told him no, and if it was for engineering. I said no. And then at a certain moment he said to me, "Ah! Je comprend, mon cher ami, maintenant je comprend." Now I finally understand. "C'ette une nouvelle espèce du péché de presumption." It's a new species of the sin of presumption, planning.

Part Moon, Part Traveling Salesman (1991)

The compulsion to do good is an innate American trait. Only North Americans seem to believe that they always should, may, and actually can choose somebody with whom to share their blessings. Ultimately, this attitude leads to bombing people into the acceptance of gifts....

Rich nations now benevolently impose a strait jacket of traffic jams, hospital confinements, and classrooms on the poor nations, and by international agreement call this "development"....

This is the moment to bring home to the people of the United States the fact that the way of life they have chosen is not viable enough to be shared.

A Celebration of Awareness (1971)

MORE JUST QUOTES

A tourist focuses in on a most idyllic picture: a man in simple clothes dozing in a fishing boat that has been pulled out of the waves that come rolling up the sandy beach. The camera clicks, the fisherman awakens. The tourist offers him a cigarette and launches into a conversation: "The weather is great, there is plenty of fish, why are you lying around instead of going out and catching more?"

The fisherman replies: "Because I caught enough this morning."

"But just imagine," the tourist says, "you would go out there three or four times a day, bringing home three or four times as much fish! You know what could happen?" The fisherman shakes his head. "After about a year you could buy yourself a motor-boat," says the tourist. "After two years you could buy a second one, and after three years you could have a cutter or two. And just think! One day you might be able to build a freezing plant or a smoke house, you might eventually even get your own helicopter for tracing shoals of fish and guiding your fleet of cutters, or you could acquire your own trucks to ship your fish to the capital, and then...."

"And then?" asks the fisherman.

"And then," the tourist continues triumphantly, "you could be calmly sitting at the beachside, dozing in the sun and looking at the beautiful ocean!" The fisherman looks at the tourist: "But that is exactly what I was doing before you came along!"

From Heinrich Boll, quoted by Wolfgang Sachs in *Resurgence* (Issue 196)

KEEPING THE BALANCE

David and Faye Wetherow

As parents of children with disabilities, one of the vulnerabilities we face is the prospect of personal isolation, a thinning out of relationships to the point where our family's circle (and ultimately that of our child) narrows down to service providers and "others like us" – other families who have children who live with disabilities.

This "narrowing" stems from four sources:

- It is an unhappy fact of contemporary North American life that people remain uncomfortable with disability in general. And people may be particularly uncomfortable when someone close to them is "struck by" a disability. We "don't know what to say;" we "don't want to interfere;" and we are afraid that if we open up communication we will touch a thread of sorrow that may be uncontrollable.

Fear is the mind's reaction against the inherent generosity of the heart.
Because the heart knows no bounds to its giving, the mind feels called upon
to define limits. --Ram Dass

- Because our society is uncomfortable, the *family* is likely to feel uncomfortable about the prospect of "being a burden" to family friends; we become reluctant to "impose," to ask our friends to extend practical assistance.
- The family may feel itself overwhelmed in terms of time, energy, and attention by the child's specific needs and the new demands of engaging with "the system." As any parent can tell you, caring for a young child seems to take up all of your time. Caring for a child with a significant disability is likely to be even more demanding, and the parents may find themselves with disability-related appointments, meetings, support group gatherings, and so on.
- Finally, in North America, family and community ties are fragmented at the best of times. Our society prides itself on being highly mobile, independent, ready to "move on" at the slightest whim or to relocate quickly in a search for solutions to economic, social, or family problems.

However (and this is a big however)...

►If it is true that the quality of our child's life (and his family's life) will be greatly enhanced by the presence of a large circle of people who know him, love him, aren't afraid to touch him or to be touched by him, and know that they will be part of his future and he will be part of their future, forever...

►If it is true that our child's opportunities will be greatly enhanced by long-term, thoughtful, on-purpose connections with many "civilians" – people whose lives are anchored in the larger world, the broader cultural, economic, congregational, and social environment...

►If it is true that our child's development can be greatly enhanced by loving and enduring connections to other children and adults who help us define our identity – who shape our understanding, expectations, hopes, social expressions, etc....

Then it is important to focus *at least* as much of our effort, thinking, learning, and personal action in the direction of the “boundary with community” as we invest in the “boundary with the service system.”

What does this mean, in practice?

Working on “the boundary with community” doesn’t mean excursions to McDonalds. It means an intentional pattern of invitation, conversation, deep listening, dreaming together, reflection, sometimes repentance and forgiveness, and always celebration.

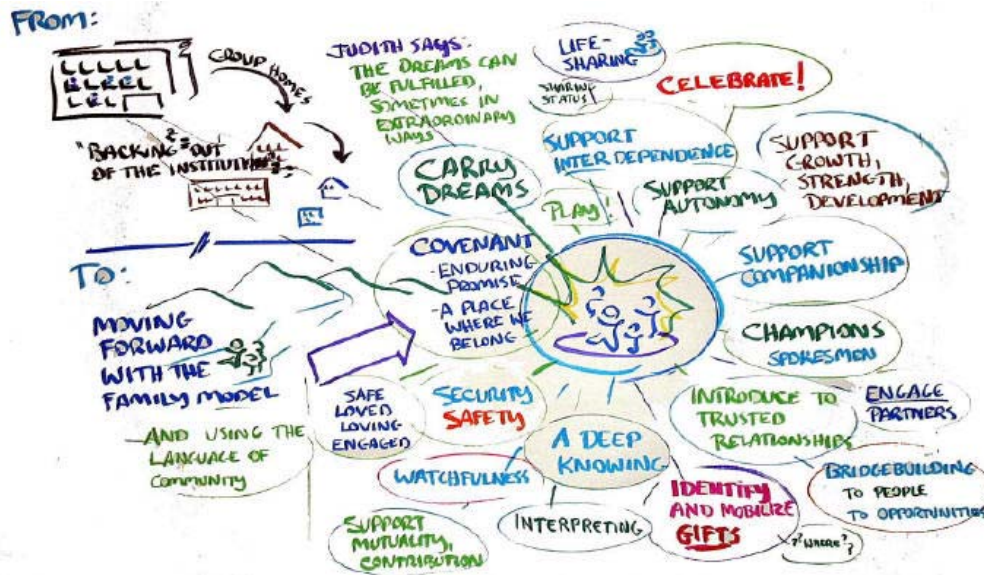
Working on “the boundary with community” doesn’t mean recruiting community members into the world of disability. It means remembering (another form of conversation) that we are all part of a larger world, and that a great community systematically identifies, mobilizes, and celebrates the gifts of *every one* of its members.

It doesn’t mean just yearning for connection. It means taking the difficult step of *asking* for involvement. It means coming to terms with the fact that true friendship is woven of threads of joy and threads of sorrow. And it means taking the even more difficult step of coming to terms with our own self-isolating behavior.

Finally, it means recognizing and consciously resisting the powerful magnetic attraction of formal service systems, especially when professionals and other parents keep sending us the message that “The most important work you can do as a parent is to get skilled at finding services, using services, advocating for services” (a regrettably consistent emphasis in early intervention services, child guidance clinics, diagnostic and treatment centers, advocacy groups, and disability “support” groups).

Of *course*, these conversations are difficult at first. It is difficult to say to our old friends, “I need you more than ever now.” It is difficult to say to our church, “More than ever, we’re called to be community for each other.” The good news is that people are yearning to be *asked*. We’ve so often heard people say, “We wanted to do something, but we didn’t know what to do.”

Some time ago we developed a graphic of a “family pattern” – an intentional pattern of thought and action that, ideally, should be “there” for any child, in any family.



As we begin to navigate the boundary with the community (Faye suggests calling it a shoreline), we make a discovery. Beyond the “sweet places” of friendship and extended family life, there are other places in the community that can be particularly welcoming and fruitful. Think about the places where people feel most deeply valued and deeply “at home” – our churches, synagogues, and mosques, places where a shared culture or a shared passion for justice, for the environment, or creating beauty draw people beyond the usual boundaries of age, economic status, and even disability.

If we pay close attention, we may discover that this is not only a place of hospitality; it is a place of abundance. The congregation of a small church touches dozens, perhaps hundreds of other “places” in our community. Harry goes to work at the tractor plant. Tom prints the local newspaper. Laurie’s father is a member of a group that rebuilds antique airplanes. Lillian is connected with the Swedish Cultural Society. Jack plays a great bluegrass banjo and has dozens of good friends in the music community.

If these friends understand that one of the gifts they can offer is to look for our child’s gifts, delights, and interests, and to introduce him to people whom they already know and trust, and build bridges to the places where those interests will be welcomed and celebrated, we discover that we live in an abundance of connections. Far too often, though, we turn Harry, and Tom, and Lillian into fund-raisers for the service system, or we recruit them into volunteer roles that are mere reflections of traditional “service” roles and ask them to leave their real identities at the door. We move from abundance to scarcity.

Our friend John McKnight has shared some ways of helping us recognize some of the sweet places in our communities. John reminds us to look for places...

- Where people come together by consent, rather than by control; where relationships are centered on affiliation, instead of exchange;
- Where people are always identifying, inviting, and mobilizing one another’s gifts;
- Where the culture shows up in the form of stories, rather than data;
- And where “we hear people singing” because people are *making* music, rather than consuming musing, *making* art rather than consuming art.

The reality is that even with children who do not live with disabilities, the family isn't "big enough" to do everything alone. Our highly mobile, fragmented society is living with the consequences of fragmentation, as families become more and more separated from extended family, friends, congregational life, and community life. This is a *far* more pressing reality when a child lives with a disability – the family just isn't "big" enough. We may try to fill the gap with "services," but the truth is that our sons and daughters need the ongoing commitment, support, devotion, and connections that can be offered by true friends, and that can never really be "delivered" by formal services.

Wendell Berry reminds us:

We hear again the voices out of our cultural tradition telling us that to have community people don't need a "community center" or "recreational facilities" or any of the rest of the paraphernalia of "community improvement" that is always for sale. Instead, they need to love each other, trust each other, and help each other. That is hard. All of us know that no community is going to do these things easily or perfectly, and et we know there is more hope in that difficulty and imperfection than in all the neat instructions for getting big and getting rich that have come out of the universities and...corporations in the past fifty years.

-- Wendell Berry, Home Economics

A final note... We are not saying that services are "bad," misguided, or irrelevant. We are simply saying that they cannot be a sufficient foundation for a good life. We need to do everything we can – which means taking action – to keep our lives in balance, our relationships in balance, and our hearts in balance. Remembering to pay close attention to the shoreline with community and having the courage to call upon the bonds of friendship can play a big role in helping us keep that balance. Peace!

David and Faye Wetherow share their lives with an adopted daughter who has complex mobility and communication challenges. They have long been involved in innovative service development, PATH and creative facilitation training, and community building. They can be contacted at: 911 Terrien Way, Parksville, BC V9P1T2, phone: 250-248-2531, e-mail: wetherow@communityworks.info, web: <http://www.communityworks.info>

View from the Back Window

"June 23, 1953"

I called him Bamp. That was short for Bampoo, which is the sort of name you get when you allow your first grandchild to change your name. As far as I knew, though, he didn't mind.

Today it's been fifty years since he died. It turns out that he was one of my great teachers although in a way that he surely couldn't have wished for.

Fifty years! I can't say I remember it like yesterday. I was not yet ten. It was a thoroughly other world in 1953. Ike was President. Ohio was celebrating its "Sesqui-centennial." But I do

remember the date Bamp died, because I told myself on that day that I would never forget. And, most years since, I have not forgotten.

Bamp was my mother's father. He and my grandmother-and other relatives from time to time-lived in a not-so-big house at 151 Arthur Avenue in Mansfield, Ohio. I was born a few blocks from there. My mother and I lived there too because my father was away in the Army (1941-46), and he could only come home once in a while. Bamp mowed the grass; there wasn't much because the lot was small. He trimmed the privet hedge. I seem to recall that he messed about in the detached garage--a dark space lined on the inside with all of the old Ohio license plates he had bought for years. Then, you got entirely new plates every year.

Somewhere I have a photo of him. It must have been taken in the summer because he is wearing a straw hat. Often, in the summer, I wear a straw hat, in honor of both my grandfathers. I remember that Bamp was not tall but seemed a big man anyway. He was quiet. I cannot recall the sound of his voice. When I think about him now, I wonder whether he might have been shy and, therefore, somewhat lonely at times.

He worked for Bissman & Company, a wholesale grocery company. He traveled regular routes across north central Ohio and sold groceries to local stores. A&P and Kroger represented the enemy – threatening to smaller local merchants. I have a packet of letters that Bamp wrote to me, and later to me and my sister. They are all written on the stationery from the American Hotel in Wooster, Ohio. Wooster is just 35 miles from Mansfield, so his sales route must have been a busy one that required a once-a-week out-of-town stay at such close distance. Several of the letters inform me that he had to stop writing “now” so that he could walk across the street to the railroad station to post the letter. That way it would be delivered on the next day.

About once or twice a summer, when I was 6 or 7, I went with Bamp on one of his routes. It was always the same one – east from Mansfield into eastern Ashland County where we made stops in the villages of Redhaw, Polk, and Nankin. The last stop on the route was in Savannah – a slightly larger town--and from there the highway led straight back home to Mansfield. In each place we stopped at a small grocery (or maybe more than one) that had a gasoline pump out front – in those days it was either Sohio or the sign of the flying red horse (Mobilgas). In a dark rear corner in a store in one of the towns (let's say it was Nankin) was a deep cool ice chest. I could reach down deep to pull out an orange or grape “Whistle” or maybe a 7-UP. We would drive off toward the next town but would pull over along the gravel highway near a patch of woods. We would get out the sandwiches my grandmother had prepared – ham salad, in my recollection--and eat lunch and drink cool soda by the side of the road. Perfection of this memory requires that there were cows in the field across the road – a field with wild day lilies growing along the fencerow. I can't vouch for these last details.

Lessons about love were written in those letters from the American Hotel and were given without words in the lunches along the road between Nankin and Savannah. I had other lessons, though, that were learned through Bamp's illness and death.

In 1951 or 1952 Grandma and Bamp sold their home and most of their furniture in Mansfield, and they came to live with us in our house in Columbus. I've never known why. Did Bamp lose his job at Bissman's? If so, did they lose their income? Was their Social Security insufficient to let them keep their home? Was Bamp sick? In any case, they came to live with us, which was no bad thing for my sister and me.

Except that Bamp did get sick. Some time in the spring of 1953, he had a stroke. He lost much of his memory right away, and he sometimes shouted, raged, and struck out at people around him.

Remember, I said he was a big man. Within a short time, he was moved away to a large, old-seeming house on North High Street, close to the office of our dentist.

That house was my first experience with the idea of the nursing home. Along the sidewalk from the nursing home's porch to the street was a pair of life-size stone lions. When we went to visit, I often sat on top of one of the lions. I didn't go inside very much. Maybe I was afraid. Some of the people—there were lots of them in beds in various corners of the rooms—were confused, shouted, looked lost. The smell—so familiar now but simply scary then—mingled urine, sweat, and Pine Sol. Mostly, I didn't understand. Why was Bamp here? Why was he in pajamas all the time? Why did people treat him this way? Why didn't he come home?

He died on June 23, 1953. In my memory, I swore (as seriously as an almost-ten-year-old can swear) not to forget the date. I was so angry at that place, which, if it hadn't caused his death, so clearly contributed to it, in my thinking. And, whether—or not—I swore an oath, I haven't forgotten the date. And now it's been fifty years.

My lesson—my conviction through the experience of Bamp's death—made it easy for me to be convinced about the truth of Wolf Wolfensberger's prose and talk about the creation of deviancy and about the "wounds" of devalued people. When I read and later heard those ideas, the ground for my learning had already been prepared. And that learning has now affected me and my work for more than half of my life. What I felt on June 23, 1953 has, in that way, stayed fresh through the length—and the brevity—of fifty years.

Jack Pealer