

# The Safeguards Letter

A Publication of OHIO SAFEGUARDS

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## TWO UPCOMING WORKSHOPS OFFERED BY THE WEST VIRGINIA DEVELOPMENTAL DISABILITIES COUNCIL

### **PASSING, March 9-14, 2008**

This workshop **may only be attended** by those who have previously attended either a Social Role Valorization or SRV-10 workshop, as it is a training on the practical application of Social Role Valorization (SRV). PASSING is an instrument for evaluating the quality of any human service according to how well it implements SRV theory. As with SRV workshops, it is a very intense training for those who are interested in learning more about SRV by visiting and analyzing two human service settings using the 42 rating tools in the PASSING manual. For most participants, it helps provide further understanding and clarification of the issues raised in an SRV workshop by actually observing, through the eyes of the service recipient as much as possible, a daily routine.

### **SRV-10 - A Revised Conceptualization of Social Role Valorization, Including 10 Related Themes: A High-Order Concept for Addressing the Plight of Socially Devalued People, & For Structuring Human Services**

This workshop provides an introduction to Social Role Valorization (SRV), using the core themes developed by Dr. Wolf Wolfensberger, considered to be one of the most influential thinkers in the field of mental retardation in the world. Dr. Wolfensberger's work helped lay the foundation for many current human service trends, including integration, safeguarding of individual rights, and the deinstitutionalization movement.

The locations of these events—in West Virginia, of course—have not yet been announced. If you have questions, please contact **Linda Higgs** either via this e-mail address ([lindahiggs@wvdhhr.org](mailto:lindahiggs@wvdhhr.org)), or by phone at 304-558-4884.

## CONCLUSION: IT WAS THE WORST DAY OF MY LIFE: A NEW LOOK AT THE OLD PROBLEM OF HELPING FAMILIES AFTER THE IDENTIFICATION OF DISABILITY IN A CHILD.

Diane Hannum and Leah Holden (formerly with The Arc of Ohio)

*(This is the third installment of a response by Diane Hannum and Leah Holden to the notion that families whose children are linked with the possibility of disability endure a "grieving" process as they come to terms with that possibility. I thought it was time that essay, written more than fifteen years ago, be re-issued. JRP)*

### **What helps?**

We must begin with an accurate description of the crisis families are experiencing, if we wish to avoid confusion about how to help. It is not that parents of children who have just been diagnosed have experienced the death of a loved one, even a fantasized loved one. If we assume, as Ken Moses does, that families have experienced a loss related directly to their child's impairment,

and that their difficulties are emotional in nature, we can easily end up on the wrong track.

111 Individuals who have lost a loved one are living through a crisis -- the crisis of grieving. Parents of children who have been diagnosed with a disabling condition are living through a crisis, but it is a different kind of crisis. If a child has a life-threatening or terminal condition, then grief is certainly an accurate term. But if a child is not expected to die but is expected to have physical impairments or

intellectual limitations or chronic health problems, then the challenge for the family is adapting to the child's limitations and recognizing the child's gifts, in the midst of a society that is likely to value this child less than others. This is the nature of the identification crisis.

I think possibly my own survival is probably the most surprising of all, simply based on the fact of all these horrible things that were told to me in the beginning. It certainly sounded like insurmountable problems that we were facing. How were we ever going to get through them, emotionally, financially, physically? I had two other children at the time. I have had another child since Jamie, so that gives me four kids, and it certainly does provide for a very busy lifestyle. But as time goes on, Jamie of course simply became a part of our family. She was just another member of the family. Really quite honestly did not take up any more time than the others when I thought about it, because they all had their certain demands, their wants, their needs. But as far as time actually spent with her, no. And we have all survived, possibly because we didn't know any better. It just happened.

--- Diane Frazee

There was a time a couple of years ago that I was in deep depression over it, and I couldn't get over it. All of a sudden one day I looked at him and said, "He is a beautiful child. I can't sit back here and do this." I had family members telling me, "Why don't you sit down with him with flash cards, the way you did with [you other son]?" It could not be done. I had to find other ways. I have to do what I have to do for him. My goals are still the same for him. I want the best education for him possible. That's what I have to go with. That's what brought me out of it. I stopped thinking about, "Was it that time I got permission from the doctor to get drunk when I was six months pregnant with him? Was it those aspirins I took when I had a cold? Was it this? Was it that?" I stopped thinking like that. I had to. It could have been anything. It could have been genes. But I don't worry about that any more. I worry about him.

--- 222Melissa Smith

I've really filled my life with people that are positive, that see the capacities instead of the deficits. Probably when I'm down the most, I

look to other people to give me those words of encouragement.

--- Cindy Norwood22

What is it that families of children identified as having a delay or a disability really need? What helps?

•Family members say over and over that they want good current information about their child's condition. They want to be told about their child's condition in a way that is respectful of them and of their child's worth. They want plain English (or another native language.)

We were young [when Joey was born} and the doctors acted like they really didn't think we were going to understand what they were telling us, so they wouldn't tell us. We had to go around them to find out. It got to the point where, when he was six months old, we just told them, "Look, this is our baby, and we want to know. Don't not tell us, if we ask a question. Give us a straight answer." That changed 2a lot, because I think after we did that, they started looking at us as people.

--- Beth Scott

There's been a thousand times that we'd have to say, "We really don't understand what you're saying," and sometimes they would get pencil and paper out and draw us pictures and explain to us what they meant. We still might not have known what some of the words meant, but we knew what he was talking about then.

--- Earl Scott

The thing that strikes me about some of that initial labeling or diagnosis was that it was never really followed with much opportunity to get information... I was just told, "We really expect her to die," and not all the details of it. Many, many months and even years later I found out more about some of the conditions, but that information was never really shared. It was always assumed that somebody else told me. The other thing was that there was not a lot of follow up to ask questions. Pretty typically when they would say something -- doctors, nurses -- they'd just kind of drop the bomb and walk out. Not very often did they say, "You might have some questions about this. Why don't we set up a time next week to talk," or something like that. The struggling feeling that I would have after that

was, "What does this mean? Where's a book? How can I read about it?" Things like that. And some of the new technology created new labels or disabilities for my daughter.<sup>3</sup> There weren't books about it. So those resource people, those doctors and nurses, didn't follow through very often.

--- Cindy Norwood

We had an adult neurologist treating her at first, and they were just up against a wall. They could not control her seizures. They didn't know what to do. There were getting nowhere. They called in a pediatric neurologist, which they should have done in the first place... He took one look at her and said, "Oh yes, I know what this is and I know what we're going to do, and this is what we're going to try." It was about two weeks after she had been in the hospital, and I think it was the first time I ate a full dinner in two weeks, because I felt good, because somebody actually knew something they were going to try.

--- Ann-Marie Satterthwaite

Initially Jamie was not diagnosed until she was two months old, which is not a long time. She was still in the hospital. There were lots of hints that there was brain damage, there might be this, there might be that, but nothing real clear. Then of course the day came where they were going to run the big test that would tell us whether or not there was brain damage. The doctor called me at home. It was not handled very well, but it was explained that there was definitely brain damage. I remember feeling very unsure about calling my husband at work. "How do I tell him? What's his reaction going to be?" It was frightening. I finally did call him at work and said, "There is definitely brain damage." He says, "Okay, now we can get off the tightrope. I just feel like I've been walking a tightrope. I didn't know whether to get off or not, but now we know. The evidence is in, and now we can deal with it." We were ready to move forward. That's really all I needed to hear. Okay, he's right, we've got our answer. It wasn't the one we really wanted, but we've got an answer, so let's go with it.

--- Diane Frazee

Learning professional language was a gradual thing, a process of osmosis, one acronym at a time, one huge word at a time. I literally had to go to the library. I finally got smart and said,

"Excuse me, would you explain that?" In the early years it was literally a matter of stopping them and asking, "What does ARC mean?" Alphabet soup, it was a constant sea of alphabet soup.... It took years. Each new year there was new jargon, and I'm learning every day... I have since then decided that on my tombstone I would just have acronyms, and anyone who would see it would scratch their head and wonder what it was I did in life.

--- Nancy Ray

Every child's different. There's not a book on each one of these children telling you what's going to happen. There's no guidelines. You have to set them as you go. It's worked out real well for us just staying active with the other parents that are members of these [support] groups, because little bits and pieces you put together for your own book.

--- Denise Habekost

- Rather than lumping a parent's feelings together and calling them grief, or being satisfied when we can determine the stage a parent has reached, we ought to be listening and learning what that parent is feeling and experiencing, in that parent's terms, without preconceived ideas or judgments.

What would have helped during the days, weeks and months following my son's diagnosis? First, it would have been helpful if people had seen what I was going through, and helped me to see it as a crisis, rather than as grief. I've lived through my share of crises, but no one helped me see that the things I had learned from previous crises could get me through this one. It would have been helpful if someone had paid attention to what I was feeling. While judgments were abundant, careful, empathic, respectful, nonjudgmental listening was in short supply. My feelings were often categorized, but they were not often heard and understood.

--- Diane Hannum

- Parents often want to know about other parents who have lived through similar circumstances, the living proof that this crisis can be weathered.

Other parents definitely help, talking to other parents that have the same problem. The fact that you feel like you're not all alone in the situation. And then you listen to what they might hope for for their child, and you get

other ideas of what you should expect or might expect... It helps as soon as you can to be with other parents that have the same problem, just to realize you're not alone, because initially you feel like you're the only person in the world that this has happened to, and it's awful. Just to talk and share your experiences and also get other ideas of help and other places to go or other things to do. That would be the major, major things I would suggest, that helped.

--- Ann-Marie Satterthwaite

When Trevor was small, before he was six months old, I met the other mothers whose children were in the early intervention program. At one point, Trevor and two little girls were singled out by the staff as needing to learn sign language, because the [segregated] County Board of Mental Retardation School used total communication, and Trevor, Samantha and Stephanie would eventually be attending that school. Fortunately, Trevor's, Ssamantha's and Stephanie's mothers had different ideas. We began to talk together, to phone each other and to visit one another's homes. And we shared our dreams for our children. June and I also started an independent parent group. Currently Trevor attends a regular preschool where he is fully included. So does Samantha, and she also takes ballet class and does very well. (This is because an early intervention professional told June, "Your daughter will never be a ballerina.") Stephanie attended Head Start and last fall went to regular kindergarten. And of course, when they were infants, we were unrealistic, were in denial and didn't accept our children's disabilities.

--- Diane Hannum

Knowing that they're there, that you're not alone, it's so important to know there are people out there that you can reach out to and can help you, just for support sometimes. You think, "Oh my God, I'm at my wit's end. I don't know what I'm going to do." Not thinking that you're totally crazy.

--- Denise Habekost

- Family-centered early intervention, based on partnerships between the family and professionals and community members, when it is available, helps greatly.

The first year of Trevor's life, he and I drove

over 30,000 miles. He was evaluated and therapied from top to bottom. The merit of Trevor having the opportunity to spend time at home with a two-year-old sister and a four-year-old brother in a normal environment was not something that was acknowledged as valuable. The early intervention professional encouraged me to take Trevor's brother and sister to a sitter so they wouldn't be there when she made home visits. As his mother I was seen as an extension of the early intervention program.

--- Diane Hannum

- Perhaps even more important than the presence of paid service workers and formal programs, especially in the long run, is the family's ability to maintain its place in the community, surrounded by supportive people.

I do think what works universally for everybody is having other people. It's not necessarily having other people who happen to have a child with a disability, but just from the very beginning sharing this information with your family and your friends, whoever makes up your own little group. I know I was guilty of this, because Jamie had so many special needs medically that I thought it was impossible for my neighbors and my friends to learn all of the care that went along with Jamie. I don't know who I thought I was, that I was so brilliant that I could learn all of this and nobody else could, but nevertheless as time went on I did loosen up enough that I did allow others to take care of family and to learn about Jamie.

--- Diane Frazee

- One challenge for all new parents, but perhaps more challenging for parents who have additional roles and responsibilities, is finding time and space to rest and recover from the day-to-day grind.

You think your child is going to get better, and when that doesn't happen, then you need someone. At first you think, "Well, I'll handle it myself," and you just can't do it all by yourself.

--- Denise Habekost

It is important to have a life. It's not always easy, you know, to find something that you find rewarding and give yourself permission to do it. I think that does help. It's learning from

little things that you do with yourself to get yourself out of a hole, if you fall in a hole. It's talking to a friend. I think faith does have a lot to do with it, too.

--- Linda Hasecke

On a bad day, you go shopping -- I do -- or don't get out of bed, which is one of my favorite things to do, or you go to a movie, or you go on vacation. I do whatever I have to do to renew and rejuvenate myself in ways that I enjoy, and I call that "mental health days."

--- Nancy Ray

•We can also be sure to celebrate every life. Too often we are so busy teaching parents to mourn that we forget to join with them in celebrating and affirming the value of each life.

The day Trevor was born I went to the hospital for another stress test, the fourth in two weeks. I was standing at the desk in the maternity ward waiting for a nurse and I could hear a baby being delivered down the hall. I heard someone yell, "It's a girl!" and everyone broke out in cheers and applause. I began to cry. It was my first realization that others were not going to celebrate child's birth. And then there was the absence of "congratulations on your new baby" cards, and the "friends" that didn't come to see him. Everyone would look at Trevor's picture and say, "Oh, how cute." Most four-pound infants who are dehydrated and covered with fecal matter and blood and in stress are not "cute." Trevor was no exception. The first time someone looked at the pictures and said, "Oh, my God!" I could have kissed her. Of all the things that happened, one of the most meaningful for me was a certificate I received from my state legislator, Jack Cera. It said that Trevor was a citizen.

--- Diane Hannum

•We have to celebrate in spite of the disability, not in ignorance of it, because if the child is not celebrated as he/she is, the parents feel the rejection as a palpable part of the identification crisis. Parents want others to celebrate and accept their children as they are. One mother's experience was the silent birth, and the presentation of a little girl who looked very different. Then she was told by everyone, "You have a beautiful, healthy little girl." Cheryl said, "After I took Stephanie home I wanted to die and I wanted her to die. I knew she looked different and I knew she had problems and every

denied it-- my husband, our families, and the doctors. I just wanted someone to agree with me."

My family doesn't accept that Shane and Shaun are deaf. They don't talk about it, but when they do, they're sad. That really pisses me off.

--- Eddie, father of five young children

**Conclusion** In summary, how can we best assist and support families following their child's diagnosis? We can pay attention to each task of managing crisis:

- 1) preserving life and maintaining physical health;
- 2) identifying and expressing feelings related to the crisis;
- 3) understanding the crisis event, clarifying and adjusting personal beliefs, values and goals;<sup>55</sup>
- 4) making needed adjustments in daily patterns of work, play and relationships in light of the crisis event.

That is, we can encourage people to take care of themselves physically, we can encourage them to express their feelings and listen nonjudgmentally when they do, we can help them make sense of their experience and develop personal beliefs that will help them negotiate change, and we can "walk with" them, as they make necessary changes in habits, relationships and patterns of living in response to change.

We can help families understand what they are experiencing as a crisis and help them learn from other crises they and other people have experienced. We can help them see the opportunity as well as the danger in their crisis. We can stop interpreting their experiences as grief.

The stress of having a child with a disability is not something one can "work through," "accept" and then move on, unless of course through "grieving" one comes to accept devaluation and segregation as normal facts of life. On the contrary, it is rejecting devaluation and opposing segregation in all its manifestations that offers hope for families of children with disabilities or chronic illnesses. It is a vision of an inclusive world that offers hope for us all.

Initially when you find out you have a child with a disability, it does hurt, and you do feel pretty raw, and you do feel pretty lonely, but I guess we're here to say you do heal, too, and

that life does go on, and there's quite a wonderful quality to that life, of being able to realize what's really important and what's not so important. I think Jamie and Adam have brought a tremendous amount into our lives and into the lives of our other kids.

--- Linda Hasecke

My dream is that the birth of every child be celebrated -- whether or not that child has Down Syndrome or some other disability. I say this with a heavy heart, because I did not celebrate Amy's birth. What a breach of faith that was! She has had to rise up against all my early misgivings, sadness and disappointment. I worry that she knows somewhere deep inside that in those first few hours after her birth I didn't want her. I wanted the baby who fit my ideas and my standards. Little did I know then that I had been given a gift -- a daughter who would give true meaning to spirit, courage, love and joy. If only I'd known in those first dark hours that our life together would be more ordinary than extraordinary. If only I'd known that this daughter would more than fit my ideals and standards -- she would fit hers which are higher than mine... At 19, Amy is so typical that it's difficult to define her disability and what it means. Certainly, she still needs

support daily in ways other 19-year-olds may not, but her days are full and rich. Amy goes to school, works part-time, saves her money for things like clothes and jewelry, has a boyfriend, goes on dates and is very excited about going to her Junior Prom in a few weeks... It fills me with joy and pride to see her doing these things -- what more could a parent ask for? What more could I have wanted when she was born?

Emily Murgo, "If Only I'd Known," reprinted in the Family Support Bulletin, Spring, 1992, UCPA

People still remark to me that I'm defensive or angry. It always makes me think of Dumbo's mother. She was "crazy" too, until others learned to appreciate her son. That's all I want, too -- for people to appreciate Trevor, just the way he is. And if it doesn't happen, they might have to chain me in a circus wagon, too. Trevor is a gift, as my other children are. He has never been a source of grief, either now or at his birth. I have indeed been through a crisis and have experienced pain, but he was not the source. He has many times been the consolation.

--- Diane Hannum

*The Safeguards Letter* is an occasional publication of OHIO SAFEGUARDS. The *Letter* exists 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 (e-mail: [jackjr441@earthlink.net](mailto:jackjr441@earthlink.net)). We welcome our readers' ideas and reactions.

AN EFFORT WORTH KNOWING: Highlands Nature Sanctuary

The words “wilderness” and “Ohio” haven’t been used meaningfully in the same sentence for a long time, unless that sentence indicates absence. For example: “There isn’t any wilderness left in Ohio.” I’ve been told by historians that, when European settlers first arrived in Ohio, it would have easily been possible for a squirrel living in the forest canopy to walk/jump from one side of the state to the other (of course, there was no “state” then) without touching the ground. Now, Ohio is likely seen as a place with lots of farms (still true), a good many moderate-to-large cities afflicted with air pollution and traffic (also true), and lots of coal-fired power plants that friends to the north and east blame, with justification, for acid rain. Usually if Ohioans seek wilderness they go somewhere else.

But, for the past dozen years or so, at least one group of Ohioans has been trying to change that situation. That group, which organized in 1995 under the name “Highlands Nature Sanctuary,” says:

...wilderness in the East seems to be a dimming possibility. But though it is the 11<sup>th</sup> hour, 59<sup>th</sup> second for wilderness, it is not too late to call it back and give it a place of refuge. It wasn’t by accident that these soils grew one of the richest forests in the world. The deep youthful soils of Ohio, coupled with a relatively mild climate, could enable a relatively quick return of an old-growth forest, if only we could give the forest the simple gift of space and time.... Such a gift doesn’t take magic, scientific studies, or complicated technology...it merely takes money. Land is expensive, but we only have to buy it once.

What the Highlands Sanctuary organizers did was figure out ways to buy land, starting with the area around the Rocky Fork Gorge in Highland County, south central Ohio, between the towns of Bainbridge and Hillsboro. Two people who had worked for the Ohio state park system knew of the remaining beauty and comparative isolation of the Gorge. They tried to convince others to preserve the land but found they were more effective after they formed a small non-profit corporation and began systematically attracting others to the dream and the work. The Sanctuary started with a 47-acre purchase in late 1995. Now, in 2007, Highlands Sanctuary has purchased a total of more than 2,000 acres near the Gorge, acquired 500 other acres in what, as naturalists, they call “biological hotspots” along the edge of the Appalachian foothills, and recently led an effort to preserve an ancient Hopewell culture site called “Spruce Hill” near Chillicothe. The latest effort supplements the work of the U.S. National Park Service and its Hopewell Culture National Historic Park.

The ultimate dream is an effort with others to create what they call the “Arc of Appalachia”—an unbroken stretch of preserved forest between Chillicothe in the mid-Scioto valley bending west and south to the Ohio River near Manchester or Aberdeen. They hope to join with groups like the state of Ohio (forestry, parks), The Nature Conservancy, local parks, and other associations so that the possibility of the old-growth Appalachian forest can begin to be revealed. Most of this land will be treated as wilderness, and if the confidence of the Sanctuary founders, members, and volunteers is not misplaced, some day the words “wilderness” and “Ohio” will again belong in a sentence that refers not to absence but to presence.

To learn more about Highlands Nature Sanctuary—and to see the great photographs of budding wilderness—you can visit the Sanctuary web site at [www.highlandssanctuary.org](http://www.highlandssanctuary.org).

JUST QUOTES

We are not interested in reforming the social service system and its institutions. Instead, we want to create a different approach--an approach that relegates the social service system to the background.

Al Etmanski, Preface, *A Good Life*

When ends become subservient to the tools chosen for their sake, the user first feels frustration and finally either abstains from their use or goes mad. Compulsory maddening behavior in Hades was considered the ultimate punishment reserved for blasphemy. Sisyphus was forced to keep rolling a stone uphill, only to see it roll back down. **When maddening behavior becomes the standard of a society, people learn to compete for the right to engage in it.** Envy blinds people and makes them compete for addiction.

Ivan Illich, *Tools for Conviviality*

Just as an article being processed through an industrial plant must be followed by a paper shadow showing what has been done, what is to be done, and who last had responsibility for it, so a human object moving through a system must be followed by a chain of informative receipts detailing what has been done to and by him and who had most recent responsibility for him.

Erving Goffman, *Asylums*, (1961)

History is not an agreed-on fiction but what gets made in a crowded room; what is said isn't what's heard, and what is heard isn't what gets repeated. Civilization is an agreement to keep people from shouting "Fire!" in a crowded theatre, but the moments we call historical occur when there is a fire in a crowded theatre; and then we all try to remember afterward when we heard it, and if we ever really smelled smoke, and who went first, and what they said. The indeterminacy is built into the emotion of the moment. The past is so often unknowable not because it is befogged now but because it was befogged then, too, back when it was still the present.

Adam Gopnik, "Angels and Ages."  
*The New Yorker*, May 28, 2007

It was born of a romantic dream and it was aimed at glory, and glory was out of date, a gauzy wisp of rose-colored filament trailing from a lost world. Victory could no longer be imagined as a bright abstraction, lying like the sunrise at the end of a shining road. It was an ugly juggernaut that would crush and smash many values and many lives into the everlasting mud, and it was the only thing that counted nowadays. The longer the war lasted the more victory was going to cost, and a dazzling cavalry raid would not even be the small change of the final purchase price.

Bruce Catton, *A Stillness at Appomattox* (1953)

A VIEW FROM THE BACK WINDOW

The Governor and the Institutions

On September 1, 1970 I started work as an administrator for the then-called Delaware County (Ohio) Board of Mental Retardation. I knew almost nothing of a technical nature about "mental retardation." I've always thought of that lack of knowledge as a blessing. One of the ways I tried to learn, though, was to visit the institution where some people from the area were in residence. It was then called the Columbus State Institute. I left that visit convinced that no such place should be allowed to exist. No people should be put into such conditions. More than thirty years later the outward appearance of the institutions has changed—they're usually cleaner and more orderly. But, they're still institutions, operating under essentially the same rules that have governed them for many years. They still shouldn't be allowed to continue. That's why I wrote the following letter to Ohio's new governor, after I learned that he has

decided that closing institutions won't be a part of his policy.

Dear Governor Strickland: I've worked for 37 years with Ohioans who have developmental disabilities and with their families. Right now I am employed by the Butler County Board of MRDD. The opinions I express in this letter, however, should not be interpreted as those of my employer nor of any other group of which I'm a member. The opinions are my own. I just want to offer what journalists usually call full disclosure.

On May 30, 2007 the Director of the Ohio Department of Mental Retardation and Developmental Disabilities announced, in a departmental newsletter, that "we are not closing any Developmental Centers." He went on to describe ways that the Department intends to "spotlight" or enhance the work of the ten "developmental centers." The decision to reverse Ohio's earlier direction about state institutions for people with developmental disabilities is a big one, and I assume that you approved it. So, I'm writing to you about that decision.

It's the wrong decision. Residence in an institution has at least three bad effects on people with disabilities.

First, institutional living clusters large groups of people physically away from other citizens and the community places where citizens make their lives together. If you're living in an institution there's practically no chance that you will go to school, go to work, go shopping, or have fun in the same places where other citizens do those things. By definition, institutions are separate worlds.

Second, institutions portray the people who live in them as very different from ordinary citizens. That may not be the intent of an institution, but happens all the same. The fact of the collection together in a separate place of a large group of labeled people carries messages about difference and, more worrisome, messages about potential dangerousness. Difference and implied or inferred threat are poor bases for identification or relationship. Like it or not, most people are reluctant to offer friendship easily to others with whom they think they can't easily identify. And, it's relationship—not rules or inspectors—that offers people with disabilities the greatest chance for safe and vital life experiences. Institutions prevent relationships between the people who live there and ordinary citizens who might welcome those people into their lives.

Third, the institutions don't live up to the euphemistic titles they've operated under for the past twenty years—"developmental centers." Learning works best when people try out new things in contexts that are challenging and when the learners are in the company of skilled others as guides or models. Hardly any such conditions exist in institutions. That means they offer very low levels of "developmental" support. One of the best known and most powerful ways that people learn—new skills and abilities, for example—is imitation of others who perform the to-be-learned skill or ability very well. The grouping that institutions enforce means that the "models"—those whom we'd want people to learn from—are simply unavailable in sufficient numbers, and no amount of "programming" can overcome that deficiency. Institutions are, then, by their very nature actually anti-developmental, if "development" is taken to mean the acquisition of skills and roles that promote close relationships with others and a richer life in community for the learner.

You can find a better policy about how Ohio should support people with developmental disabilities by turning from a reliance on institutions and by committing the state to live up to "The Community Imperative," originally drafted by the Center on Human Policy at Syracuse University in 1979. That statement says:

***In the domain of Human Rights:***

- *All people have fundamental moral and constitutional rights.*

- *These rights must not be abrogated merely because a person has a mental or physical disability.*
- *Among these fundamental rights is the right to community living.*

***In the domain of Educational Programming and Human Services:***

- *All people, as human beings, are inherently valuable.*
- *All people can grow and develop.*
- *All people are entitled to conditions which foster their development.*
- *Such conditions are optimally provided in community settings.*

***Therefore:***

***In fulfillment of fundamental human rights and in securing optimum developmental opportunities, all people, regardless of the severity of their disabilities, are entitled to community living.***

Continued reliance on institutions to try to support Ohioans with developmental disabilities says that we lack confidence in the ability of Ohio's communities to be good places to live for all their citizens. I don't think that's something we really want to say. Why not presume communities' competence? Why not turn away from an outdated service form that isolates some people and maintains them in poverty and ignorance? Why not bring people home?

Sincerely,  
Jack R. Pealer Jr., Hamilton, Ohio

I doubt that this letter will have much effect, although of course I got a reply. Maybe someone else out there would like to try.

Jack Pealer

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