

The Safeguards Letter

A Publication of OHIO SAFEGUARDS

Number Thirty-nine

Spring 2007

IMPORTANT UPCOMING WORKSHOP - MARK YOUR CALENDARS!

*"Crafting a Coherent Stance on the Sanctity of All Human Life," September 17-21, 2007
Catherine Spaulding Retreat & Conference Center, Nazareth, Kentucky (near Bardstown).*

Presented by Susan Thomas, and Associates of the Training Institute of Syracuse University. **Wolf Wolfensberger will present a part of this workshop.** This event is intended for (a) those who perceive that there is a gathering momentum in the world that works toward "deathmaking;" and (b) those who are uncomfortable with a pick and choose approach that objects to some deathmakings but endorses others, and who would like the work toward a more **coherent** position on the sanctity of human life.

This event attempts to accomplish four aims:

- a. Awaken people to the reality that there is growing support in our society for various forms of deathmaking of people who are impaired, elderly, or devalued for any reason. Deathmaking includes any practices that outright kill people, greatly hasten death, or lead other people to act so as to bring about a person's or group's death. Many practices that participants see all the time, and may even participate in, will be shown to contribute to deathmaking.
- b. Orient participants to the disguises and interpretations that are given to deathmaking so as to make it less obvious and less repugnant.
- c. Elucidate the societal dynamics and values that have been leading to these developments.
- d. Help people to see the validity – indeed, the necessity – of a coherent moral stance in defense of all human life, to see what such a stance would entail, and to work toward such a stance.

Special topic: issues of the withholding, withdrawal, and refusal of medical treatment.

For more information, contact Joe Osburn, Director, Safeguards Initiative, at 502-348-1168 or joeosburn@spitfire.net .

AN EFFORT WORTH KNOWING ABOUT: VISIONARIES & VOICES

Visionaries & Voices is a non-profit studio/gallery located in Cincinnati, Ohio and created specifically for artists with disabilities to grow both personally and professionally. V & V assumes that artists with disabilities are valued members of the community and believes they must have opportunities for artistic success and creative growth in an atmosphere of mutual respect, inspiration, and joy. Visionaries & Voices values a world in which artists with disabilities not only create and share their works of art but also are given the chance to show the community at large what it means to be creative and alive without limits.

In 2000, Visionaries & Voices started as a grass-roots effort among Cincinnati area social-workers who were astounded by the art created by people with disabilities in their homes. The early supporters made connections with local galleries to showcase the works, and those shows created enough momentum to help establish a studio-gallery specifically for the artists. On August 1, 2003, Visionaries & Voices opened its doors at Essex Studios in Walnut Hills near downtown Cincinnati. Essex Studios houses close to 100 professional artists, and people who learn or practice their art at V & V make connections with those professionals just by having the studio there. Currently, the studio-coordinator opens the studio every weekday and assists artists with disabilities in purchasing art supplies, learning new techniques, and marketing their works. Over 30 volunteers help out in various ways. United Cerebral Palsy of Greater Cincinnati has partnered with V&V since its inception, and the studio has a small amount of specialized equipment that people with physical handicaps can use to explore their creativity, sometimes for the first time in their lives.

Since coming together, Visionaries & Voices has helped over 300 artists with disabilities create, frame, market and sell their works. It has also introduced the artists' powerful contributions to local culture through exhibits at galleries and arts centers, and through workshops at local libraries and schools. Artists at V & V have developed relationships with artists who are not labeled and who collaborate with V&V artists on paintings, sculptures, public arts projects, and other projects throughout the community.

Give V & V a call if you're interested or for a tour (513) 861-4333. Our address: 2515 Essex Place, Studio # 172, Cincinnati, Ohio 45206. Our web-site: www.visionariesandvoices.com.

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). We welcome our readers' ideas and reactions.

FUNDS TO SUPPORT PUBLICATION

For many years we have not recorded "subscriptions" to *The Safeguards Letter*—and we're not about to start doing that now. Instead of having subscribers we have had financial supporters. Those have been people who saw some value in the publication of *The Letter* and who sent small donations of money to keep it going. The donations have paid for printing and mailing costs. Because we have started to make *The Letter* available on the internet, such costs are reduced. We don't expect, though, that we will entirely stop sending print copies to readers who do not use computers or who really prefer to have *The Letter* come on paper in their mailboxes. It costs about \$150.00 per issue to mail the *Letter* to those who do not or cannot receive it on-line.

So, this little section of *The Letter* is an appeal to donors to send small contributions and to be, therefore, supporters of *The Letter*. If everyone who receives *The Safeguards Letter* were to send just a small amount, all of a year's costs for printing and mailing would be met. Also, donors receive the gratitude of OHIO SAFEGUARDS. If you want to contribute, you can send your donation (it's tax-deductible) to: OHIO SAFEGUARDS, 3421 Dawn Drive, Hamilton, OH 45011.

JUST QUOTES

One limitation of programs created under the traditional program structure is that they require intensive government monitoring, which in turn requires that government agencies, rather than individual program recipients, make crucial decisions about program design and execution.

Jason Hardy & Arthur Lyons

"Assessing the Independent Living Needs of People with Disabilities in Ohio,"
1997

People think of standards—criteria—as being clear rules against which random experience is measured, thereby helping randomness to seem less vexing and oppressive, like a foul line in baseball or the manual of arms or the rules of admiralty. And in general I don't believe the idea of standards is bad as long as they stay as supple as the experience to be measured.

Richard Ford, "A Sea of Stories"

New York Times Book Review, 10-21-1990

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)

(Not long ago I heard, once again, some professional workers talking with each other about the "grief process" presumably experienced by family members when they first find out that a child of the family might have a condition leading to a disability. I've known many families and have never doubted that the point of first identification sparked strong feelings. But I and others have always objected to the death imagery inherent in the use of the metaphor of "grief" to describe those feelings. More than fifteen years ago, Diane Hannum and Leah Holden, then associated with The Arc of Ohio, addressed the first identification issue in a sensitive and sensible essay. I thought it was time that essay was re-issued. So, it's offered here and—because of its length—in the next two issues of The Letter. Jack Pealer)

Family First is a parent-to-parent program of information and support developed and sponsored by the Arc of Ohio. The curriculum was originally written in 1983-4 with a grant from the Ohio Developmental Disabilities Planning Council. Since then it received funding from the Ohio Children's Trust Fund, the Ohio Department of Health and local United Ways and foundations. It has become a part of Ohio's Family Information Network, a parent-to-parent effort in early intervention, funded under Part H of P.L. 99-457. Arc-Ohio currently receives funding for Family First from the Ohio Council of the Knights of Columbus. Most of the parent quotes in this paper are taken from the 1991 videotape series, "On This Journey Together," produced by The Arc of Ohio and the Ohio Department of Mental Retardation and Developmental Disabilities.

Over the past decade, we have had opportunities to travel across Ohio, talking with and learning from parents of children of various ages and diagnoses in urban, suburban and rural

communities. One of the most persistent and controversial topics we have discussed with parents and professionals is how to interpret the experiences of parents whose child has just been diagnosed with a disabling condition. The interpretation put forth most often is that they are "going through the grief process." Family First has never included material about "the grief process," although many people pressured us to do so. We encourage people, instead, to help families understand their experiences in terms of crisis. This paper explains why we recommend this way of thinking about what happens to families when they are told, "Something is wrong with your child."

We didn't find out anything was wrong with Lacie until she was six months old. I kept on telling my doctor that she threw up all the time, and then my mother kept on saying she didn't think she could see, and so we kept on telling him. He finally said, "We'll send you to Children's Hospital in Columbus." We went to the

Handicap Clinic. They looked her over, and they laid everything right out on us and just told us how it was. It was the worst day of my life. But we picked up and moved on.

--- Kathleen Cannon

They diagnosed the CMV two and a half, three months after Lindsay was born, but there was no real way to tell exactly the totality of the damage. We thought she had colic for six to eight months, and we found out then that she was having seizures. ... Nobody really knows how much damage was caused. We really have no idea what she's going to be able to do or what she can't do. We think by now we've got the medical problems basically diagnosed. So we just kind of live with it day by day.

--- Carl Habekost

The first week was kind of a blur. I don't remember very much about it. I remember before we got the actual diagnosis hearing people a couple of times say the word "retarded" and I can remember wondering to myself -- Trevor was so sick in neonatal intensive care and so small -- I couldn't figure out how they could possibly know that he was mentally retarded, and Down Syndrome never dawned on me till they gave me the diagnosis.

--- Diane Hannum

Sarah's my oldest. She was born supposedly normal. Her Apgars were all normal. She was a whiny baby. I would always complain that she cried too much and whined too much, and they would always tell me they thought she had colic, but they wanted to see her again. I'd come back in and they'd check her, but they could not find anything wrong. By the time she was five and a half to six months old, she started doing a quick jerk with her head. It looked like she was startled. I didn't know what it was. Finally I took her in to the doctor, and he put her into the hospital the next day. He thought it might be seizure. As soon as I put her in the hospital they got a lot worse... We had

already gone through a lot of tests. [The resident] was in checking her, doing some routine checks. I had never met him before. I asked, "Do you know the results or have you heard anything they have come up with?" He said, "She has infantile spasm, and she has an 80 to 90% chance of being retarded. And then he just left. Then I was there by myself and thought to myself, "No, this is not right. I've got to talk to somebody else. He's crazy." About ten minutes later my mother called on the phone to see how things were going, and I went out in the hall and told her what he told me. As soon as I said it out loud, I fell apart there in the middle of the hallway, made a big scene. They had to haul me away with a box of Kleenex.... It was like she was retarded. So it was a shock...

-- Ann-Marie Satterthwaite

Aric was a 30-week baby, so he was ten weeks premature. I had spent the week before in the hospital and we were able to keep labor from coming for another week. He was born at 3 pounds 5 ounces, beautiful little boy... He wasn't breathing when he was born, so they immediately took him over to the NICU at Children's, where he spent six and a half weeks. It was relatively uneventful... When we took him home, we were told we had a healthy, normal, happy, healthy baby. Go home and enjoy peewee football, little League baseball, and live happily ever after. We knew that because of his prematurity he was going to be delayed. ... So he was slow in development. Even with the give time that we were allotted, we noticed he wasn't holding his head up, and he didn't seem to be trying to crawl or pull himself up. None of the developmental stages that I was looking for.... At nine months we went in again for his checkup through neonatal follow up, and a doctor walked in and just blurted out to us that he was severely cerebral palsied, severely mentally retarded, he would never speak, he would never eat, that we should find a nice institution and put him in it. And he turned around and walked out the door.

That was our introduction to the world of disabilities. --- Tina Murray

Why do parents who have just learned that their child has a disability experience shock, denial, anger and depression? They are responding in understandable, human ways to a particular crisis -- the identification crisis.

If we understand that families experience this crisis in a society which still devalues and segregates individuals who have disabilities (and, often, their families), I think it is fair to understand the identification crisis as a "degradation ceremony."¹ This is a sociological term that refers to the process of transforming someone's identity into something looked on as lower and less worthy. The new identity, in this case a "disabled" identity, is not just added on to the person's existing identity. The person's identity is transformed to account for their history as well as for future actions.

¹ Harold Garfinkel (1956) "Conditions of Successful Degradation Ceremonies." The American Journal of Sociology. 61: 420-24 (March).

We didn't find out she had Down Syndrome until she had open-heart surgery. She was a normal kid until she was six months old. She had open-heart surgery at five and a half months, and then she "caught" Down Syndrome.

--- Ray Thomas

By characterizing her label as a diagnosis like any other diagnosis, say, of measles or the flu, this father whittles away at the power of the label to redefine who his daughter really is. He refuses to permit -- even looking back on it -- his daughter's degradation ceremony. But he knows well, as do other parents, that a label of Down Syndrome or cerebral palsy or autism is still a likely first step on a path to segregated educational programs, social and recreational opportunities and ultimately residences and places of work. Without sustained, effective action on the child's behalf, usually led by the parents, a life of devaluation, exclusion and loneliness is still the most likely result of the attachment of such a label.

One mother reported that most of the pain she endured came from hearing over and over all the things her daughter Samantha would never do, and professionals using the label of Down Syndrome over and over. When she

spoke of a positive future for Samantha and how things could be different, she was told, "You're lucky to have any services at all," and early intervention staff discussed how she hadn't "accepted" Samantha's disability.

Some crises occur routinely to most people as they progress through the life cycle. Some depend on the existence of unusual situations. Situational crises bring individuals and families face-to-face with circumstances they did not expect or predict, and which they may believe themselves unprepared to face.

I have a friend who had young children of her own and used to volunteer to watch Eric and Kelsey while I took Trevor to therapy. She was a big help. Later on, when she told me she was expecting her third child, she confided that she had always been fearful of having a child with a disability like mental retardation, but since knowing Trevor, she wasn't afraid any more.

--- Diane Hannum

Crises challenge a person's ability to cope with new demands. Unlike wars, earthquakes and other events that affect groups of people, some situational crises single out individuals. The experience of having a child identified as having a delay or disability is one of these. We know that one of the most common experiences for parents is isolation, the feeling of being all alone, the sense that "no one has gone through what I am going through."

I think the things I used to focus on that made us unique don't seem to hold water any more. I really found I kept saying, "We're different, we're different." I think every family is different. It would be a pretty boring world if we were all the same. I used to say my daughter's needs are more complex. All those things tended to draw me back and added to that feeling of isolation, but when I focused on what I had in common, the love I have for my daughter I find in every parent, we all share that.

--- Cindy Norwood

The identification crisis thrusts parents into the world of human services, some for the first time. They may face confusing decisions about

medical treatment, early intervention or family support, and often these choices must be managed in a language full of jargon and unfamiliar communication patterns.

Parents often find their sense of family and community quickly falling apart. Members of the extended family, friends and neighbors may be no better prepared for the arrival of a child with a disability than the parents, who themselves rarely are prepared to negotiate complex human service and health care systems, which tend to be confusing enough for people who work in them every day.

Jess' condition was one of always being on the balance of life and death, and I think that many people are afraid of facing death or afraid of facing a potential sorrow. My family really withdrew, friends really withdrew. My daughter's medical needs really led to a feeling of isolation, that she was so unique and that our situation was so unique. I really felt very alone and very isolated. It was a very isolating situation, completely. So the way my family responded was first to be there for me at home, but my daughter's first year and a half of life was spent in a hospital, and they didn't very often come down to see her, and some of them not at all. Even when we first brought her home, it was very, very isolating. Family withdrew and a lot of friends withdrew. We relied very heavily on paid service providers, doctors, nurses, social workers in the hospital.

--- Cindy Norwood

I had a "good friend" who called me at the hospital the day after Trevor was born, unaware of anything except that I'd had the baby. She asked how he was doing, and I explained he was in Neonatal Intensive Care. She quickly said she'd call me back. She called, all right -- nine months later. (Guess she'd finally worked through her denial.)

--- Diane Hannum

When I first got LaMar, my life was completely different. I hadn't carried him for nine months, I wasn't expecting a

baby. All my children were grown and off, so my life had changed. You rearrange your life after your children grow up and leave home, then I had to rearrange mine again, because I had another child in the home. I had to limit my activities. My friends that I thought were friends turned out to be acquaintances, because they kind of shied away. LaMar was a very funny-looking little kid when he was young. He had a huge head, big eyes and a little tiny body. He weighed nine pounds at birth, and at six months he was weighing six pounds, something like that, so it was kind of scary, and I guess they really didn't know how to handle it. I probably didn't either, because if they didn't want to be involved, that was okay, I just shut them out. I had no problem with that. I've always been, "If you don't want to be bothered with me, that's okay, that's your problem, it's not mine. But what I didn't realize was that I couldn't do everything for LaMar myself. I needed other people, but I needed people that wanted to be involved with him, not people that were paid to be involved with him.

--- Peggy Miller

Families and their supporters may struggle with learned devaluation of people who have disabilities and the love they feel for their child.

I'm going to admit it, maybe I was like this before we had Lindsay, you see a person with a problem and you want to kind of ignore it, you don't want to face them. It's that kind of thing. I think because we've become so convinced about thinking Lindsay deserves a quality life, because it's easy for people to push children like Lindsay away, under the carpet, so they don't have to deal with it. So as a parent you really have to counteract that. You have to really be an advocate for your child. People don't do it on purpose, but it's just the way society is.

--- Carl Habekost

My feelings about people who were mentally retarded interfered with my

ability to come to an understanding of Trevor having Down Syndrome. I thought it was about the worst possible thing that you could be, and it took me some time to appreciate the fact that Trevor had a whole lot of things going for him, and that it really wasn't as big of a deal as what I thought it was. It gave me a whole different perspective on what quality of life means, and that intelligence doesn't necessarily have a very big bearing on your quality of life. It was kind of a gradual process of coming to appreciate Trevor. I can remember holding him and always thinking: Down Syndrome. Even when I was cuddling him and loving him,

it was, "Trevor had Down Syndrome..." I began to appreciate him more and began to think about Trevor, because Trevor was a wonderful individual who brought a lot of good things into my life, and I quit thinking about Down Syndrome.... I guess there was a certain day when I didn't think about it until later in the day, and when I thought about it later in the day, it occurred to me that I hadn't thought about it earlier in the day. He was about six months old.

--- Diane Hannum

(To be continued in the next issue of The Safeguards Letter)

WOULDN'T YOU OBJECT?

This item is reprinted from Update, published by the International Task Force on Euthanasia and Assisted Suicide, Vol. 20, No. 3, June 2006

Residents of a Zurich apartment complex are gathering signatures to evict Dignitas, the assisted-suicide provider group that uses a fourth-floor flat as the place to end people's lives. Describing it as a "house of horrors," Gloria Sonny, a six-year resident of the complex, said, "This is meant to be a residential flat, but some days you'd think it was a morgue." For many residents, the worst part is seeing these suicidal people in the halls and elevator on their way up to the apartment to die. "The look in their eyes haunts me," Sonny explained, "particularly if they are young." For other occupants, seeing the corpses in body bags propped up in the corner of the communal three-person elevator is the most disturbing. Since the elevator isn't big enough for a coffin, Dignitas uses a body bag to bring the corpse down to a waiting hearse. "Almost every day the bodies of people...are taken down in the lift," Sonny said. Kelvin Leneveu, another resident added, "It's very creepy. The floors are thin and when we hear movements upstairs, we know that means they're up there, and someone's going to die." [*British Medical Journal*, 6/3/06; *Daily Telegraph*, 6/4/06]

A VIEW FROM THE BACK WINDOW

People with Disabilities and their Money (2)

The last time I wrote in this space I shared some worries about people with disabilities and their money. This time I want to expand a bit on one of those worries—a specific result of people's utter dependence on Medicaid as the source of funds to pay for day-to-day living support. That specific result is called "patient liability."

Most Americans living with significant intellectual disabilities receive Medicaid, the dominant and often only payer for key services. Few families, even among the affluent, could provide care without it. So they do what they legally can to maintain eligibility. States recognize these realities by establishing (or tolerating) asset-shielding arrangements. Many families are nonetheless forced to resort to backhanded strategies that create unforeseen complications. Some

nominally disinherit a disabled child, leaving funds to an able-bodied sibling who is honor-bound to help. These arrangements have no legal force, and they create new difficulties. Some able-bodied siblings die or divorce. Others borrow funds intended for their sibling.... When caregivers die, persons with disability face the loss of Medicaid if they inherit assets or if they must cross state lines to establish new living arrangements.

Harold Pollack, "Learning to Walk Slow: America's Partial Policy Success in the Arena of Intellectual Disability." *Journal of Policy History*, Vol. 19, No. 1, 2007

In the late 1970's when I supervised a "District Office" for Ohio's state mental retardation agency, the office would occasionally be visited by agents of Ohio's Bureau of Support, as it was customarily called. Actually the official title was "Section on Reimbursement Services." When I found out that the agents were there to gather information that would help them, in effect, garnish the wealth of the poorest Ohioans (people with disabilities living in institutions or community residences), I tried to have them barred from the office. One phone call from Columbus set me straight. There was to be no interference with that work.

I didn't know that people who lived (and who often were hurt) in the crappy places the state (my employer) made available to them were accumulating bills for the services they used. Foolish and naïve youngster! The practice of placing claims on the meager wealth of poor people has, it turns out, deep historic roots, and it extends down into the present in the process that Medicaid calls "patient liability."

As far as I can tell, patient liability is either the deductible or the co-payment (maybe both) that a patient—an "insured" in customary insurance-talk—has to pay as part of the Medicaid long-term care scheme. Many of us have some kind of health insurance (although many others do not). Users of health insurance have learned that they will have to pay a certain percentage of the cost of medical service and a flat fee (mine happens to be \$25) every time they have appointments with their doctors.

Suppose, though, that I go to my doctor, pay my \$25, and claim \$65 in additional cost for the appointment from my insurance company. Then, a week later, I win \$500 in the lottery (highly unlikely because I don't buy tickets, but that's another story), and those funds go into my bank account. I would not expect my health insurer to send agents to my doctor or to my bank to gather information so that they could recover the \$65 because I had an unexpected financial windfall. But if I were claiming a benefit under a Medicaid "long-term care policy" that's exactly what would happen. As a poor person (I'd have to be poor to qualify for Medicaid in the first place), I would be building up a bill for every day I lived using, say the services of an intermediate care/mental retardation (ICF-MR) program or a Medicaid "waiver." If used such a service and I had even a small windfall, state agents whose job it is to make sure I pay my "patient liability" bill would be likely to find me before I could consider any other use of my money.

Does that sound like an incentive for productive employment for someone who uses a Medicaid waiver to pay for the supports on which she relies? Does it sound like a policy that encourages families to contribute to the economic life of family members who have disabilities? Does "patient liability" enhance people's ability to assume places as respected and productive citizens?

Actually, “patient liability” policies—together with chronic unemployment of people with disabilities—are the engine of perpetual dependency. Although ways to slow that engine (e.g., establishment of a “Medicaid pay-back trust” that defers “patient liability” payments until the life of the trust beneficiary ends) have sometimes worked, those ways are relatively unknown, are hard to use, and consequently are not practically available to most people who use Medicaid to pay the cost of long-term support. What people may really need is either the elimination of policies like “patient liability” (with the resultant savings in the costs-of-collection) or—even better—ways to accomplish long-term support without reliance on the Medicaid system at all.

Jack Pealer

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