

# The Safeguards Letter

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## EARLY ANNOUNCEMENTS – NOT TOO SOON TO START PLANNING

Here are two major learning opportunities in 2007. Although information about these events is still incomplete, it's not too soon for you to start thinking about them and to start to make plans to take part in either or both.

• *Fourth International Conference on Social Role Valorization, May 14-18, 2007 at the Crowne Plaza Hotel, Ottawa, Ontario, Canada.*

Filling valued social roles is an effective way for any of us, including those who have been socially devalued, to have the good things in life. Valued social roles seem to ensure that the person who fills them will experience personal social integration and will take part in society's benefits.

The theme of the 2007 International Conference on Social Role Valorization is "Crafting Valued Social Roles." That theme goes to the very heart of social role valorization. Speakers and workshop presenters will describe how valued social roles can be crafted for vulnerable people of different ages (*from early childhood to old age*), in key life spheres (*education, work, living situation, family and friendship, religion, spirituality, culture, leisure*), and in various service fields (*including developmental disability, child welfare, mental health, early intervention, medicine*). The crafting of valued social roles will be approached on a number of levels such as individual, familial, organizational, and societal and from several perspectives including practice, policy, and research.

For information about the International Conference, visit the web site at <http://www.vrs-srv2007.ca>, or contact Julie Clement at [jclement@instvalor.ca](mailto:jclement@instvalor.ca).

• *Crafting a Coherent Stance on the Sanctity of All Human Life, September 18-22, Catherine Spaulding Retreat & Conference Center, Nazareth, Kentucky (near Bardstown).*

Presented by Susan Thomas, and Associates of the Training Institute of Syracuse University

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.

Details about this 2007 event are still being planned. For more information, contact Joe Osburn, Director, Indiana Safeguards Initiative, at 502-348-1168 or [joeosburn@spitfire.net](mailto:joeosburn@spitfire.net).

#### IN MEMORY OF BENGT NIRJE

Let's take a little time to consider the life and contributions of Bengt Nirje, who died in early April at his home city of Uppsala, Sweden. We remember Bengt Nirje as the author of the very first published treatise about the principle of normalization. That essay, "The Normalization Principle and its Human Management Implications," was, in 1969, part of *Changing Patterns in Residential Services for the Mentally Retarded* edited by Kugel and Wolfensberger and published by the (US) President's Committee on Mental Retardation. Bengt Nirje is a founding father of the normalization principle.

I was only in Bengt Nirje's company once, and even to write that stretches things a bit. I listened to his talk at the conference celebrating the 25<sup>th</sup> anniversary of normalization's publication. The conference was in Ottawa in 1994. Being in Nirje's "company," then, means that I was one of several hundred listeners. I remember noticing that Nirje, like many others I have met, took a circuitous path to the "field" of organizing support for people with disabilities.

Nirje was fascinated with a number of academic interests. During his student days he apparently couldn't make up his mind which department of the university in which to concentrate, so he tried out all that appealed to him. He studied law, philosophy (especially ethics), art history, architecture, and cultural anthropology. He took up literary studies and taught literature to adults in a "folk high school." (Aside: a "folk school" is a popular Scandinavian form of public education for adults that attracted emulation from Myles Horton, the founder of the Highlander Folk School in Tennessee and a teacher to Martin Luther King Jr. among others. Connections like this intrigue me!) Nirje's literary studies were serious enough that he gained a fellowship in 1952 to Yale University. He recalled that his first experience of a US "mental" institution came when he went to interview poet Ezra Pound in Pound's room at St. Elizabeth's Hospital in Washington, DC. (Another aside: at that time more than 7,000 people were housed at St. Elizabeth's, which Nirje described, forty years later, as "... a city of old red barracks with gray, dusty-looking corridors." For Ohioans, that means St. Elizabeth's may have been a larger version of our own "Cambridge Mental Health Center," which is also composed of former military barracks.)

In 1956 Bengt Nirje was recruited by the Swedish Red Cross to work with the Red Cross to assist refugees of the revolution in Hungary. He went to a refugee camp in Austria where he tried to learn and transmit to those seeking help reliable information about where they could go and

what they could do to rebuild their lives. He recalled putting to use his earlier experience with “group dynamics” and what we would now call “community organizing” to help people who had been displaced to move toward their new lives.

...when you are a refugee, you have a past that is gone and does not count in your new country. No one cares about it, no one believes in it, and nobody trusts you. Your past is really gone, and you really know nothing about the future. Your situation is bleak, uncertain, and anonymous. Such a situation can create a very unhealthy climate and dark moods. I also learned how hard it is to live with so many other persons in close quarters, day and night—100 to 160 per room, week after week after week. It means never having a “private space” for oneself for daily recuperation, satisfying daily activities, or meaningful recreation. There is no place for you, your family, and your few belongings. You have to be strong, even if you are competent and not intellectually disabled. But you can become mentally “wounded” and socially handicapped, of that you can be sure! What keeps you going are your dreams, hopes, and desperate expectations of the future.

Nirje’s work with the Red Cross and later with the United Nations High Commission for Refugees (UNHCR) led to his employment, in 1961, by the Swedish association supporting children with cerebral palsy. He eventually became the ombudsman and director of that association, made contact with leaders of other similar efforts in other parts of the world, and was in a position to write the initial essay on normalization later in the 1960’s. I suspect, from his remarks about refugees quoted above, that his earlier experience with people who had been displaced from their homes by war quickened his insight into the lives of people who lived in mental institutions. In many ways the normalization principle depicts the reverse image of institutional life. Part of the inception of the principle probably arose from the refugee camps set up to accommodate those who were oppressed and whose lives were devastated in Hungary.

In memoriam, Bengt Nirje.

Jack Pealer

*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.

### JUST QUOTES

What, do you imagine that I would take so much trouble and so much pleasure in writing, do you think I would keep so persistently to my task, if I were not preparing— with a rather shaky hand—a labyrinth into which I can venture, ... in which I can lose myself and appear at last to eyes that I will never have to meet again? I am no doubt not the only one who writes in order to have no face. Do not ask who I am and do not ask me to remain the same: leave it to our

bureaucrats and our police to see that our papers are in order. At least spare us their morality when we write.

Michel Foucault  
*The Archaeology of Knowledge*

Each person, big or small, has a role to play in the world. As we start to really get to know others, as we begin to listen to each other's stories, things begin to change. We no longer judge each other according to concepts of power and knowledge or according to group identity, but according to these personal, heart-to-heart encounters. We begin the movement from exclusion to inclusion, from fear to trust, from closedness to openness, from judgement and prejudice to forgiveness and understanding. It is a movement of the heart. We begin to see each other as brothers and sisters in humanity. We are no longer governed by fear, but by faith, hope, and love.

Jean Vanier  
*Becoming Human*

At the end of my present term, of which two years are yet to come, I propose to retire from public life, and to close my days on my patrimony of Monticello,... I have the consolation too of having added nothing to my private fortune, during my public service, and of retiring with hands as clean as they are empty.

Thomas Jefferson  
Letter to Monsieur Le Comte Diodati  
March 29, 1807

MR. MXYZPTLK REPORTS THAT MOST DISABLED AMERICANS HAVE JOBS Rob McInnes

*(Editor's Note: A longer version of this article was published by Rob McInnes in the May 2006 issue of the online publication Diversity World. This excerpt is re-published here with permission from Diversity World. JRP)*

Mr. Mxyzptlk is an odd character from Superman lore. From another dimension, this character is a mischievous practical joker who uses his powers to warp "reality" on earth and create mayhem. As I read earlier today, his main claim to fame is his "topsy-turvy magical, nightmarish alterations of reality." His only weaknesses are that he cannot stand being ridiculed and, if tricked into saying or spelling his name backwards (Kltpzyxm), he is involuntarily sent back to his home dimension for a minimum of 90 days.

On May 12, 2006 the U.S. Census Bureau issued a press release entitled "More than 50 Million Americans Report Some Level of Disability". Summarizing topical highlights from information collected in the 2002 census, it provides information on employment, educational achievement, computer usage, prevalence of mobility impairments, etc. Here are some of the employment-related findings:

- Approximately 51.2 million people said they had a disability; for 32.5 million of them, the disability was severe.
- About 56 percent of people ages 21 to 64 who had a disability were employed at some

point in the one-year period prior to the interview. People with a severe disability status reported the lowest employment rate (42 percent). This compared with the employment rates of people with a nonsevere disability (82 percent) and those with no reported disability (88 percent).

- 32 percent of people ages 25 to 64 with a nonsevere disability and 22 percent with a severe disability were college graduates. The corresponding rate for those without a disability was 43 percent.
- Among adults ages 16 to 64, 11.8 million or 6 percent reported the presence of a condition that makes it difficult to remain employed or find a job.
- Median earnings for people with no disability were \$25,000, compared with \$22,000 for people with a nonsevere disability and \$12,800 for those with a severe disability.

Based on this press release, a writer for the Associated Press immediately produced an article entitled "Most Disabled Americans Have Jobs" that was picked up by major newspapers across the country. The result? A little mayhem within the disability community! Here at Diversity World, I quickly received several emails - all questioning the validity of the data. One reader wrote: "Are they (the government) trying to convince all of the fine American people the disabled are working despite their disability? All the people I know and some professional people think the opposite."

Back to Mr. Mxyzptlk... I wonder if maybe he has a sizeable army of researchers and reporters who are secretly manipulating all of the data and research that focus on disability and employment - mischievously creating "topsy-turvy magical... alterations of reality". One thing is certain. No one but a seasoned researcher can really understand how to interpret the various facts and figures that are bandied about.

In the April 2004 issue of this newsletter, I wrote an article called "Being Myth-Informed About Employment And Disability" - basically debunking some of the urban legends that abound in this area. One of these is the notion that there is an over 70% unemployment rate for people with disabilities. As borne out by the Census Bureau's press release, it is closer to the truth to simply say that people with disabilities are 2.25 times as likely to be unemployed as their non-disabled counterparts.

Let's take a closer look at this report's assertion that people with disabilities have an employment rate of 56%. This, of course, is the statement that gave birth to the "Most Disabled Americans Have Jobs" pronouncement.

64% of the people subsumed under the term "Disabled Americans" are folks who have severe disabilities. For these 32.5 million Americans the employment rate is only 42%. That means that 13.7 million severely disabled Americans are considered employed. Does that mean that they "have jobs" as we are being led to believe? Not really. Apparently, being classified as "employed" only means that they reported SOME employment in the twelve months prior to the survey.

What we learn from further analysis of the Census data is that of those who were considered "employed", only about 40% had uninterrupted year-round employment - and roughly three-quarters of those folks had full-time jobs while the rest were employed only part-time. While I

haven't seen a statistical analysis, I would speculate that the remaining 60% of "employed" people with severe disabilities have only a very fragmented and sporadic array of part-time, temporary contract employment experiences in their work histories.

Yes, it seems that only 12.8% of people with severe disabilities had full-time, year round employment to report - in contrast to 52.6% of the non-disabled population. Put another way, we could say that people without disabilities have a four times stronger likelihood of having steady full-time employment than do people with severe disabilities.

Well there is just one look at a bit of the quantitative data available on employment for people with disabilities. While it is entirely another can of worms, I am still anxious to see some research findings on the qualitative dimension. What can research tell us about the underemployment of people with disabilities? Quantitative data like this always raises questions for me about the nature of the jobs that people are engaged in - the extent to which they are working in positions that really draw on their best interests, skills and talents - and the extent to which those same interests, skills and talents are wasted as people with disabilities are hired into jobs that don't recognize their full potential in the workplace. But, like I said, that is another can of worms. In the meantime...

"Most Disabled Americans Have Jobs"... I don't think so! Springing that headline on the public was inexcusably misleading. Talk about "topsy-turvy magical... alterations of reality"! How many researchers and reporters are doing Mr. Mxyzptk's bidding? How do you say "researcher" and "reporter" backwards? Maybe we can get them to go away.

Rob McInnes, Diversity World - [www.diversityworld.com](http://www.diversityworld.com)

#### A VIEW FROM THE BACK WINDOW

#### People with Disabilities and their Money

It's an old story that people with disabilities (perhaps most people with so-called "intellectual" disabilities) are likely to be poor. The guaranteed income for a US citizen who can demonstrate disability is still less than \$600 per month – the maximum Supplemental Security Income payment. Many people who receive such income have to pay almost all of it (or perhaps more than all of it) for their rent and other basic living expenses.<sup>1</sup> Sometimes these payments are made to or through the agencies that provide at-home support. The people who make those payments get to retain a small portion of their income as "personal allowance," but the expense of this allowance is under close scrutiny by human service workers. In effect, that small personal allowance is the person's disposable income. In many places in the US the average annual earnings (excluding fringe benefit costs) for human service workers are four or five times the amount of an individual's annual total of SSI payments. Relatively few people with disabilities have regular full-time employment, giving the lie to the headlines derived from recent census data – see Rob McInnes' article elsewhere in this issue. And, at least partly because of a long lag between increases in the US minimum wage, the income gap between those people with disabilities who do have jobs and other citizens continues to grow wider. People with disabilities don't have much opportunity to acquire wealth. It is an old story.

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<sup>1</sup> Sometimes human service systems cover the difference between someone's income and their cost to live.

There's another story being repeated all the time about people with disabilities and their money. The outcome of this other story is that the people whose lives are overseen by human service agencies are kept almost completely away from possible uses of that limited amount of money available to them. Here's some evidence.

I get a chance to read all the reports that are written following visits to the homes and work (or other service) locations used by people with disabilities in our community. My colleagues make those visits, which are required by state regulations so that we can assure the quality of support that's offered. Visitors talk not only with people who use supports but also with members of their families, with workers who offer direct support, and with service coordinators. Among the questions posed to these folks are questions about money or wealth:

- How does the person manage her money?
- Does the person have control over his money?
- Are others (family, service coordinators, etc.) satisfied with the ways that the person's finances are handled?

As I read a number of reports about these visits recently, I kept track of the answers to questions like those. Below I summarize what I noticed about whether the answers reflect a belief that the person being visited is what we might call an "economic agent." Do people around the person think that she can learn or be trusted to handle money? Here's what people said:

Person >	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	Total ↓
Yes								X								1
Partial*	X	X			X				X			X		X	X	7
No			X	X		X	X			X	X		X			7

\*"Partial" means that the person is believed competent to handle very small amounts of money doled out by human service workers.

I read further that a professional worker involved with a person with a disability was asked: "Does she (the person with a disability) actively participate in financial decisions?" The answer was: "She is able to purchase small things she wants or needs." She could do so, of course, only up to the limit of her personal allowance – around \$60 US per month. Another human service worker responding to the same question about another person simply said: "He doesn't understand money values." Those were the most frequent answers to questions about participation in financial affairs. Even those who know people with disabilities best and spend the most time with them do not see them as economic actors, except (maybe) at the very smallest scale.

I can think of at least five reasons to worry when people are dismissed as economic actors or agents.

1. Like it or not, most of us in this society regard responsibility for taking care of one's money or property as an essential part of being a person. Women's groups have understood that for a long time (see Virginia Woolf, *A Room of One's Own*). Unfortunately, some members of the society measure others' worth entirely according to the others' wealth and skill at manipulating it. Most of us don't use wealth to judge other people quite that baldly. Instead, we've learned unconsciously to attribute

personhood more easily to others who seem able to make clear decisions... to choose about things in their lives. But we live in a time and place when the main tool for choice is money. If you don't have money or are prevented from using what you have, you won't be able to make as many clear choices; so, indirectly, access to and use of funds connects to the worthiness attributed to a person.

2. People you and I know are oppressed both by their low incomes and by laws or rules that make sure that income stays low. For example, should someone who has used long-term supports financed through Medicaid suddenly have a chance to earn more – or perhaps to receive an inheritance – that person will soon find that he's built up a bill (called "patient liability") that others are very determined to collect. A direct support worker in an Ohio community reflected: "It has been hard for me to deal with people's poverty: the state takes everything so some people's parents have disinherited them."<sup>2</sup> That and similar policies further discourage people whose economic prospects are uncertain, and that discouragement further reduces the chances that someone will find a way out of oppression. As workers with poor people have learned, escape from economic imprisonment comes through opportunity – something that's hard to imagine as possible for someone whose very status as an economic agent we deny.
3. Money does matter, personally, to people with disabilities. Sometimes, as we've seen, workers with people who have disabilities deny those people's ability to "understand" how money works. As well, sometimes in the next breath the same workers remark about how some of the same people: a) look forward to pay day, b) ask for the money they receive to be in small denominations so it will look like there is more of it, or c) require guidance about not taking money from others. Are those the kinds of things people who "don't understand money" would do? It seems as though many people may be calling out, in ways we don't understand, for more experience with the economic part of their lives.
4. We don't know as much as we think about people's understanding or potential participation in their personal economies. Much of the history of services for people with so-called intellectual disabilities has reflected assumptions about limitations in the capacity of people to learn and grow. But we've learned. We found out that some people with "autism" could communicate with the help of a touch on the shoulder. We now know that many people with disabilities make great employees and fellow citizens and even greater friends. Given what we've learned, why should we keep on assuming that making financial decisions is somehow out of reach?
5. Those of us who work for pay trying to make life better for people with disabilities are supposed to be expert at teaching and organizing support. Long ago Marc Gold described "mental retardation" as a condition that demands superior teaching and environmental arrangement from society (my paraphrase). The adaptive strategy is not to blame people for their failure to learn; the adaptive strategy is to take responsibility for figuring out how to teach, including how to teach someone about an active economic life.

Wouldn't it be worth a try? Others have thought so. The Highlander Center has long conducted economic education efforts for people who had little experience with money or credit. A housing support organization in Minneapolis has developed a "financial literacy" program for adults with developmental disabilities. Other organizations have sparked the creation of credit unions

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<sup>2</sup> O'Brien, John. "Getting There: Residential, Inc.'s Next Steps." Responsive Systems Associates, 1986

or even smaller loan funds that are governed by people with disabilities and that make both cash and credit available, albeit in small amounts.

We learned from Lou Brown and others about “partial participation.” Partial participation means that people are IN on things. They are enabled or supported to do at least a little (or maybe a lot) more than we initially think they can do. And the learning from partial participation—the outcome—becomes the starting place for next steps. People—all of us—learn to take part in new things by doing so with guidance and direct teaching as it’s needed. If any of us knows how to handle her finances and if we “understand about money” it’s because someone showed us how and offered help as we lived through mistakes and got better. I’ve tried to say why being an economic agent is important to people with disabilities. Like it or don’t, handling money is part of all our lives. Let’s not dismiss this part of the experience of people with disabilities.

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