# Safeguards Letter

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# People with Disabilities and their Money

Jack Pealer

*It's an old story that people with disabilities (perhaps most people with so-called "intellectual" disabilities) are likely to be poor. The guaranteed income for a 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.1 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.*

*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 |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Yes | | | | | | | | X | | | | |
| Partial* | X | X | | | X | | | | X | | | X |
| No | | | X | X | | X | X | | | X | X | |

*"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.

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

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

- 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.*

- *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."2 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.*

- *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.*

- *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?*

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

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

*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.*