

SOCIAL SECURITY ADMINISTRATION'S TICKET TO WORK AND WORK
INCENTIVES ADVISORY PANEL
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I am pleased to be here this morning to talk briefly to the question "How have individual control of funds and waivers promoted work and asset building strategies for people with disabilities?" I assume this question is meant in the context especially of the Florida Freedom Initiative.

The simple and most direct response is "not at all". That is, controlling the funds does not in and of itself lead to either employment or to asset building. If you peruse the results of most of the services that individuals with disabilities have managed to direct (under Cash and Counseling e.g.) you will see that employment and private asset building have never been part of the foundation for this approach. That is because control of human services (the hiring and firing of direct support personnel e.g.) was always the primary goal. Unless we deliberately address some essential public policy issues, raise serious questions about the purpose of public funding, re-think what we mean by quality in human services and, finally, raise expectations for individuals with disabilities in a publicly funded system, we will never meet the goal of increased employment and asset development.

There are important distinctions that I would like to make up front before getting to a series of recommendations regarding work and asset development. The Florida Freedom initiative grew out of increased understanding that, at least for those individuals served by both Medicaid Waivers and Social Security, there would never be a significant breakthrough unless we created substantial changes to the Medicaid program as well as melded those changes with a waiver on the income and asset side with regard to Social Security benefits. The Social Security Administration has been a crucial partner in creating this new approach.

The first public policy issue I want to put on the table is simply this: by creating a system of deliberate impoverishment for individuals with disabilities in the Medicaid and Social Security programs, we have profoundly affected the lives of individuals with disabilities on a personal level and driven the cost of our long term care system through the roof. The paper in your handouts *The Poverty of Human Services* speaks to these issues especially the notion that impoverishment leads to community isolation, lack of long term relationships and further dependency. How can we speak to "meeting the needs" of individuals with disabilities when we deny to them the tools they need to attain these goals.

Only by re-thinking what we mean by quality in human services and beginning to norm quality on universal human aspirations can we lead the system to acknowledge the

consequences of impoverishment and the high cost of long term care. So the purpose of public funding for those of us committed to self-determination has always been to enable individuals with disabilities to craft a meaningful life in the community, exercising the same freedoms that all Americans treasure, pursuing relationships and community and creating an economic future. Controlling the services is not the issue. Controlling the dollars in order to lead a meaningful life is the issue. So, within what we mean by self-determination, creating an economic future has become paramount. This means that we need to look at new ways to gain employment, new approaches to the development of microenterprises and new approaches to asset and income development. We need to squarely address the possibility of both active and passive income and asset development. We have to stop creating yet another human service alternative to the community and encourage individuals with disabilities to work directly with banks and credit unions, become “banked” and pursue credit, create checking and savings accounts and in all respects behave as other Americans in pursuit of the American Dream.

The present system is neither organized to address this agenda nor prepared to make the significant changes needed to turn this huge ship around. Present unarticulated public policy for those served by both Medicaid Waivers and Social Security benefits is simply this: we don't care whether you work or not. However, if you choose to work we will make it difficult for you and hugely complex. If we move to individual control of the Medicaid Waiver funds we can clearly see that this will be insufficient by itself. The first challenge is to change the very definition of what those Medicaid funds can be used to purchase. We need to create within the Medicaid Waiver program incentives for pursuing work and income production, allow for more creative ways to purchase and give individuals with disabilities a whole new set of tools to become productive.

One of these tools is the unique waiver provided to Florida and another set of new tools are the new things that can be purchased using Medicaid funds. It is only by addressing the intersection of Medicaid and Social Security and creating a dynamic new approach to work that we can begin to forecast a positive change in the employment status of individuals served by both programs. In the last four years there has been a leveling of those employed and an increase in those served in non-employment based day programs. All of the training that we do across the country through the Center for Self-Determination posits the possibility for everyone with a disability to produce income privately. No exceptions. Our individual budget guidebook, *The Promise of Freedom*, demonstrates how with the realignment of current resources, the changing of some rules and regulations and the creation of high expectations all individuals can begin to create some private income.

What do we need to do? Specifically the Social Security Administration:

- Work closer with CMS to help restructure provisions of the Medicaid Waiver Program to align better with the Social Security Waivers of income and asset development
- Promote the use of banks and credit unions especially as natural depositories for individual Medicaid accounts under our Waiver programs

- Recognize the utility of true individual budgets (not just individual allocations) that allow for innovative practices like:
 - Paying employers directly for co-worker support, training and assistance with transportation
 - Using public dollars to capitalize microenterprises
 - Purchasing transportation on a personal basis

- Encourage the payment of outcomes to employment by opening up the world of job development to anyone with an interest in assisting the person and end the monopoly of human service provider-only approaches
- Encourage state Vocational Rehabilitation agencies to earmark funds for the capitalization of microenterprises
- Begin at least 4 or 5 move Waiver demonstrations in counties/regions committed to this new approach under self-determination
- Do analyses of current data on just who is working by hours worked and wages earned. Much of the current data appears to be misleading