

Social Security Advisory Board  
Discussion Forum on the Definition of Disability  
A Response to Berkowitz and Growick

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After listening to everything today, my initial response is that saving money is a good thing, however, more people with disabilities working is a better thing.

All of our current disability programs marginalize people with disabilities. Focus on limited income, limited abilities, etc. interfere with the concept that all people with disabilities have the potential to be productive and employed in our current world. Until we have a system that believes in the capacity of people with disabilities to work at all levels and a system where people with disabilities are integrated into the world of work in normal roles, rather than special or restricted roles, we will continue to have extensive need for income support models such as social security.

The fact that people with disabilities are not working at higher levels is, in my opinion, a systemic issue. Perhaps if we focus on capacity and opportunity from the beginning we can make real changes.

Since 1956, vocational rehabilitation, in some form, has been called for in SSDI policies. However, in reality the Rehabilitation Services Administration (RSA) and the Social Security Administration (SSA) have had a relationship that at its best is antagonistic. We don't play well together. If there is to be any hope of a new disability definition assisting people with disabilities to become productive, then I believe there must be a positive and truly working relationship between the Federal VR Program and Social Security.

Our current disability policy assumes (or forces people to assume) that people will remain on disability income because it is focused on income and not work; because it is so difficult to get on that no one wants to get off and because incentives in Ticket to Work do not begin early enough to move people into vocational rehabilitation activities. The services are offered only after a recipient becomes completely entrenched in the system.

As we develop a new system, it must be one where SSA can be seen in a positive light and not in the role of "Gotcha Officers." You see people simply don't trust what SSA has to say and they don't believe SSA when they offer incentives. SSA must focus on work for the first step of the process and at the center must be truly informed choice.

#### Response to Berkowitz

- 1) Early intervention does matter. The proposal to develop new ways to become involved earlier is important. However, there are responses inside the current "ticket" system that could address some of these issues. A) SSA could change current ticket policies to include 16-18 year olds as ticket recipients and prevent them from entrenchment in the system. B) SSA could include the group of people classified as medical improvement expected (MIE) in the group of people receiving tickets and attempt to prevent their entrenchment in the system. C) When ticket policy was developed, it changed the referral system of denied claimants. SSA could go back to the old system of referring all denied claimants to vocational rehabilitation. This might prevent many individuals from continuing to fight for disability so they could choose to go to work. All three of these steps would cause the focus to be work rather than retaining or obtaining disability funds.
- 2) I agree that a public-private partnership where the Public VR program must compete with other vendors could work. VR does not have the capacity to serve all people. VR will compete well with the people that they can serve. However, I would add that a partnership with Workforce must also be included.
- 3) I disagree that exclusive focus on placement is the answer. Placement activity is only a partial solution. Assistive technology and its potential impact must also be considered. Education and training are also important. We know that education and training directly affect wages. Without considering education, training and assistive technology along with placement, people with disabilities will be relegated to low wage jobs and

poverty or the potential of never meeting substantial gainful activity (SGA).

Response to Growich

- 1) In his discussion regarding return to work, it looks more like a "work first model." This type of model has not met the needs of people with disabilities and likely forces an entire group of people to become deeply entrenched in poverty. If we want people to get off of disability--they will only go for attractive jobs and attractive wages. Consumer choice must be a meaningful part of any return to work effort.
- 2) I would suggest that Dr. Growich assertion regarding public VR and its role is at best, inaccurate. A) For example many state agencies actually provide placement themselves rather than contracting out. Some provide placement for part of there services and contract out for other services. B) VR is not a monopoly, in my own state of Washington there are approximately 900 rehabilitation counselors practicing in some form or another and over 150 community rehabilitation programs, yet there are only 180 VR counselors in the public agencies, hardly a monopoly. C) Order of selection is an issue, but it is a funding issue and could be resolved. Give public VR more money and there will be fewer people on waiting lists (just a note, the COLA for SSA exceeds the entire RSA budget). D) VR is not just measured by quality of life and independence issues, the public VR program is measured by competitive integrated placement and by the wages that our customers are paid.
- 3) Time and cost are not the only measurements that count when considering employment activities. Consumer choice, quality of work, quality of wages, potential for benefits, and job satisfaction are also important *if we want people to stay working and to not remain on disability!*
- 4) Permanent total, temporary total, permanent partial, and temporary partial make a great deal of sense if you truly believe in work as a goal, and

if they are not used as a focus to "hammer" the beneficiary. These definitions are consistent with advancing work. The question really becomes "What is social Security's role?" Is it income replacement...or is it a system that will encourage work and opportunity?

- 5) I agree that public-private partnerships for vocational rehabilitation are needed. It is unrealistic for VR to assume it can serve all people. In the state of Washington, we have enough funds to serve 19,000 people on any given day, perhaps 30,000 in a year's time, but there are 145,000 people who will receive tickets and around 700,000 people of working age with disabilities. However, if the partnerships are to work, Social Security must step up to the plate and assume some of the cost and some of the risk from the beginning, not at the end after everyone else has assumed the risks to try and solve SSA's problem. Sometimes you must look beyond what the actuaries' measure and consider the other possibilities.

Today's meeting has not adequately addressed all of those people with disabilities who are working, but who are "parked" just below where they would lose benefits. If you listen to the consumers, they don't believe current incentives make it safe to try working at a higher level. It is simply an issue of trust. This must be addressed by Social Security.

If you want real incentives, incentives that people will trust, make Medicaid and Medicare permanent, regardless of income or return to work. People will feel much safer if their insurance is absolutely protected.

Finally, what if we all believed in cool jobs with benefits? What if we all believed in work? What if SSA's role was only income until the cool job was stabilized and insurance continued until it wasn't needed? What if RSA and SSA were partners in the possibilities rather than adversaries? What if...?