

## Editorial

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# Facilitating integrated employment outcomes for individuals with significant disabilities: Parents' perspective

Our daughter, Nancy, is considered by test in the bottom 10% of all those with autism, and has had, during her lifetime up until now, severe behavior problems, yet she has been employed full time with full benefits for nearly 12 years. As the parents of a young woman with such a significant disability, we are often asked how this is possible. In fact, we have traveled all across the country providing training and advice to parents, school professionals, as well as Community Rehabilitation Programs on how to facilitate employment for individuals with significant disabilities.

Nancy has a one-to-one job coach/behavior support specialist for which she uses all of her income to pay for most of the cost of this support. This is accomplished without any new funds by utilizing existing resources. Nancy has used Social Security work incentives, including both a PASS and an IRWE. She currently contributes between 15–20% to her total budget from working as well as pays Local, State, and Federal taxes. More importantly, after the initial cost of her job search, the cost of supporting Nancy in an integrated community job is about half of what it would be to have her in a sheltered workshop. Certainly, she would not have the dignity of life that she currently experiences in the community.

The fight today for individuals with disabilities to have the opportunity for inclusive employment must be fought along many fronts including policy, funding, training, education, business participation, marketing, and civil rights. We think that the likelihood of convincing all sheltered workshops that they should convert to community employment, while possible, will take far too long and must be encouraged by diverting the federal, state, and local dollars from sheltered to

community uses. This will require a variety of tactics including pursuing legal redress for those who are denied their civil rights in choosing to live, work, and recreate in the community.

One of the primary concerns that most people have, whether they are parents or supported employment workers, is that people with disabilities can only work 20 hours a week or lose their benefits. This is a misconception if Social Security work incentives are utilized. Another misconception is that natural supports will always be the answer to allowing the employment of people with disabilities to be affordable. Some individuals with disabilities have complex support needs and may require ongoing supports that, with the right kind of job, they can mostly pay for themselves. This approach requires that we rethink our values of making sure individuals with disabilities retain as much of their earnings as possible. In many cases, it is better to have the individual with disabilities pay as much as they can for their work related supports, lowering their countable income and improving their retention of other benefits or maximizing the amount of them. Another important issue in deciding to work or not is Medicaid eligibility. This is so, not only because of medical coverage, but also because of residential Medicaid, often the most important revenue stream if the person has a significant disability and intensive staff support needs. Clearly, a number of important initiatives are still needed at the federal, state, and local policy levels.

1. *Decouple SSI/SSDI financial support from Medicaid and Medicare eligibility and use.* Those over the normal retirement age now are allowed to work and not lose their benefits; people with disabilities should be allowed to do so as well.

Taking all people with disabilities off of SSI and SSDI is not the answer to the funding shortfalls of these systems. Allow people with disabilities to return the money that they receive from SSI/SSDI to the taxpayers by becoming taxpayers themselves!

2. *Stop allowing any taxpayer money from any tax level from going to segregated rather than integrated outcomes.* Do this by defining integrated versus segregated outcomes as one-person placements based on striving for maximum employment for all individuals with disabilities. Require CRPs to report on these integrated outcomes for every student coming out of the public school from some starting point that would be defined.
3. *Use the courts to demand and enforce access to funding.* CRPs now control the money and channel most potential individuals into segregated outcomes, not based on client choice but on economic convenience of the service provider. APSE, The Network on Employment can help with this by identifying lawyers in each state who can lead class action suits under the Olmstead criteria.
4. *Actively promote self-employment for people with disabilities and true choice by providing within the One Stops the professional network to do competent business and benefit planning to support people with disabilities who wish to pursue this employment outcome.* Get the Small Business Association involved to support these plans and make startup capital readily available at affordable rates.
5. *Improve the knowledge and the helpfulness of the local Social Security offices in assisting people with disabilities to write and utilize Social Security Work Incentives.* If parents and individuals with disabilities can't get meaningful help from the people who oversee and promote these tools, they soon get discouraged and give in to the sheltered workshop as the place to go.
6. *Change our focus from reducing the cost of a person with disabilities to society in total to one where it is more important as to who pays, rather than the total cost.* If the individual with disabilities doesn't work, then taxpayers ultimately pay the whole bill. If the person with disabilities works, then they pay part of the cost for their support and the taxpayer ultimately benefits, even if the cost of the supports that the individual needs is no lower. However, if the person works, the total cost will be lower!
7. *Make schools accountable for post high-school employment outcomes.* Do not allow a custodial, pass along model. Schools often engage in meaningless pre-vocational activities and when parents ask for training for real work, they are told by schools that they are not "employment agencies."
8. *Mandate that service providers who receive federal money to provide services be required partners and participants with the schools in creating integrated versus segregated outcomes through the IEP process.* This should include Vocational Rehabilitation, who should be required to participate in transition at age 14 minimum. In our travels, we see very uneven VR support. Rehabilitation counselors often say that they can't or won't help until the student graduates, or they can only fund 80 hours of job coaching maximum.
9. *Parents must also be trained to be the "Quarterback" or at least the continuing "Coach" of their family member as they work to actualize their adult dreams.* Parents and individuals with disabilities, who have been fully integrated during school, do not want segregated lives. They choose segregated lives, because they are not trained on how to avoid it or given access to the money to purchase and direct the needed supports for such a life.

In the marketing arena, we must become better salespeople of the economic and other values to individuals with disabilities of integrated versus segregated outcomes. Once and for all, we need to do the financial studies that show over time that integrated employment is more cost effective for the taxpayer than segregated employment when all information is taken into account and delineated in financial form. Use this information to sway state and local legislators to shift their funding preference from segregated to integrated employment outcomes.

We must address and challenge the supposed advantages of sheltered life versus integrated life. These supposed advantages for sheltered settings are safety, vocational readiness training and choice. After 40+ years of the operation of segregated settings, we know that people are no safer and usually less so than in community settings. There is a great myth of vocational readiness preparation in sheltered settings since fewer than 2% are ever prepared and enter into community employment. Individuals and their families are not going to choose segregation over integration in adult life unless their only alternative is returning to live with

their families without any work or going to a sheltered workshop.

In closing, our daughter has been working for nearly 12 years now. Her individual plan calls for her to be staffed 24/7 for 365 days per year. In the hours between 8–4 p.m., she could go to a sheltered workshop, sit in a “behavior classroom” with a helmet on her head, and require 2/1 staffing. Instead, she goes to work at union scale with full benefits, has a full time job coach/behavior support specialist that she pays most of the cost herself and has an overall budget that is lower than the alternative. Nancy, through her work earnings, is the number two source of funding for her budget! SSDI funding is the smallest source. Our daughter’s revenue support is divided as follows:

- a) Medicaid residential waiver – 58%
- b) Nancy’s net “work” earnings – 16%
- c) MRDD employment support – 14%
- d) MRDD “Cost to Live” support – 6%
- e) SSDI payments – 6%

Which choice is better? Which choice makes more economic sense? Which choice provides the greatest dignity and happiness to our daughter? There is no other choice!

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