

A Purpose in Life: Why Employment First Matters to Self-Advocates

By Self-Advocates Becoming Empowered
and Green Mountain Self-Advocates

INTRODUCTION

We are seeing a bad employment pattern. Research is saying that the number of people working in sheltered workshops is going down but the number of people working in the community is not getting any bigger. Why? Because instead of working in community employment, many people are moving into day programs. This is not the direction we want to be going in. We need to bring the numbers of people working in the community up! Even though there are new laws limiting the use of sheltered workshops, it is so sad to know that some youth are still placed in sheltered workshops when they could have so many other options. We can do better.



Explore Work Curriculum

This great resource was created with and for self-advocates in Florida to learn more about employment. Working together they are discovering what it means to work in the community.

The curriculum covers 4 topics:

- » Why people work
- » How people decide what kind of job they want
- » Working with VR and other state agencies that can help you find and maintain work
- » Advocating for yourself



You can get a copy at: www.employmentfirstfl.org/explore-work-curriculum

Involvement in our economy is a really important part of true inclusion and a civil rights issue. It's all about dignity and respect. It's not just about building self-confidence but also getting people to see our abilities to work. We should live in the community, have a job or be self-employed, and pay taxes.

Being in a sheltered workshop is being sheltered from the world. How will you know what is out there and know what your choices really are?

It stunts your growth – it seems to only benefit those who want to minimize all risks and protect you. But it really is a false sense of safety. The evidence says that including people with disabilities in supported employment is better. So, shouldn't we be moving speedily towards this model?

The Employment First movement has given a giant boost forward for people with disabilities to have real jobs with real pay. In the spirit of "Nothing About Us Without Us," Self-Advocates Becoming Empowered (SABE) asked leaders in the self-advocacy movement to describe Employment First efforts in their states and how it has changed their lives. We spoke with 21 peer leaders from 18 states and asked, "What does Employment First mean?"

It is important to mention that Employment First as a policy is not well known by self-advocates. Most people could not say if there was an Employment First initiative in their state. However, peer leaders strongly agree that employment should be first in their lives. We repeatedly heard comments like those shared

Striving For Justice In Rhode Island

By Andrew Whalen, Advocates in Action



Employment First, I define it like this... Anybody who wants to work should be able to do so or should have a chance to do so.

In the past, jobs for people with intellectual and developmental disabilities were few and far between. They simply did not exist. There has been a lack of funding. A couple of decades ago, Rhode Island was on the path to being the most inclusive state in the country. But, then there were cuts and more cuts.

Please see "Striving for Justice" on page 8

“Employment First means that above all else, people with disabilities, people of all abilities, need to have a purpose in life. We all have amazing potential to pursue a purpose in life if given the opportunity. Employment first is about making that your top-tier goal in life and really striving to get a job and be a part of your community.”

JOHN FENLEY, PEOPLE FIRST OF NEW HAMPSHIRE



by John Fenley, president of People First of New Hampshire. He said, “I have never heard of an Employment First policy. I haven’t heard of the model, Employment First per se, but I definitely know the basic “gist” of why it’s so important to pursue employment.”

The only peer leader we interviewed who could describe Employment First policies was Clint Perrin from Self-Advocacy Association of New York State. He said, “It should mean that employment should be one of the first options given to people



but in the state of New York people don’t really know what that is... What self-

advocates say it is and what other people say it is, is different, vastly different things. Professionals say it is there but there is not anything in writing. They say it is available but not really.”

This paper shares perspectives from peer leaders on employment and why it needs to be first in our lives. Peer leaders described a desire to work in real jobs for real pay because it gives them a purpose, makes them feel included, and provides independence and self-determination. Employment is seen as an opportunity enjoyed by all citizens and must be extended to people with disabilities. Despite the positive beliefs about employment, large obstacles still block the path converting sheltered workshops into community employment supports.

THEME #1

People with intellectual or developmental disabilities want to work in real jobs for real pay for many reasons.

"Help someone get a job so they don't sit on their butt doing nothing. In my mind, I want to see everybody get a job. I don't think someone should say 'no.' I have a job. I work for Speaking Up for Us and I love it. It is the best job and I want to stick with it for the rest of my life."

"We all need jobs. Everyone has a purpose in life. Many people with disabilities want to have jobs just like everyone else. Jobs get you out of the house. You meet and communicate with people and make money."

- **"I am the oldest. I have a brother and a sister and they do not have disabilities. My siblings don't have the option of not working so why should I. We all need money to pay for our basic needs like rent, food, health care, fun stuff, etc."**
- **"We like to help other people."**
- **"We enjoy the people we work with. It makes you feel important and part of a group."**
- **"But beyond values, do the math. Even though sometimes I feel like I am going bonkers staying on top of all the rules for SSDI and Medicaid, I've done the math and I make out better working versus just sitting on the couch and collecting SSI."**
- **"Somebody has to pay the rent and bill."**
- **"I need to make sure my daughter has a roof over her head."**
- **"Gives you a purpose and makes you more self-sufficient and responsible."**
- **"Beyond what is in our laws, working gives me a real purpose. At work, I feel like I fit in."**



THEME #2

People with disabilities want equal rights to employment opportunities

- "I can do this, let me have a chance."
- "So, for me, equality means I have the same opportunities and expectations of every other citizen. The only difference is that under the ADA I have the right to receive accommodations to support me to work."
- "We should be able to get paid for real jobs and real pay."
- "We want to use our earned money to do things out in the community like everyone else: movies, out to eat, sporting events, travel and visit other places, camping, fishing, and hiking."
- "We are human just like everyone else. We deserve opportunities like everyone else."
- "People with disabilities who are in sheltered workshops don't have access to work-related benefits like health insurance or 401(k)s."
- "Freedom to make our choices for what we want: jobs."
- "An important value for persons with disabilities is to have real jobs with real pay. A real job is when you work in the community alongside persons without disabilities."

"Every day I speak up for myself and other people with disabilities. The day that I joined the disability rights movement was the day that I began to have more pride in myself as a person with autism."

-NICOLE LEBLANC



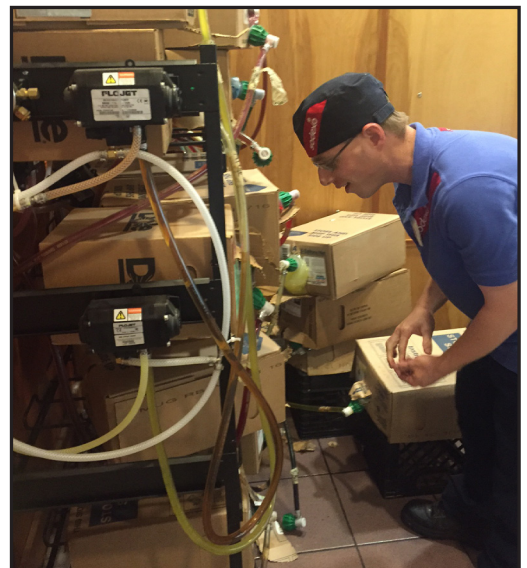
"Real pay is when you are paid what you're worth in a specific job setting, a job that fits your abilities. This never includes being paid a sub-minimum wage."

-MAXWELL BARROWS

THEME #3

Barriers continue to exist to closing sheltered workshops.

- “There’s kind of this myth out there that if you receive aid you can’t get a job which is just not true. In fact, they want you to get a job, they want you to seek employment.”
- “In some group homes, there are no staff working Monday through Friday during the day. If you live there you must leave during the day on weekdays. This makes it impossible to have a part time job or work evenings. People should not lose their home if they do not have a job or place to go during the day.”
- “It is not acceptable to close a sheltered workshop by moving people into day programs. The goal is to support people to work in real jobs.”
- “Get families on board. When family members are scared about their son or daughter about losing their benefits, their fear spills over to their son or daughter. Families are still stopping people from working because they are afraid a person will lose their Social Security or Medicaid benefits.”
- “You need to keep people in jobs, not just find them. You need to be there for folks who lose their jobs and help them find another job. But unemployment is a fact of life!”



- **“As a peer advocate I’ve been visiting day programs and work centers in Arizona for several years. We were hoping they would get smaller and that people would have more community opportunities, I’m sorry to say that is not what I’m seeing. I’m seeing more young people in the day programs. We need to come up with something different to offer youth.”**
- **“There is fear among people in sheltered workshops that they may lose their friends. Well-done conversions to supported employment provide for much better ways to make good social connections. Despite these fears, research shows that the people in sheltered workshops want to work in the community.”**
- **“I hear the argument that people will miss their friends when they leave the workshop. Support them to maintain those relationships by going to the movies, out to eat or shopping with friends. Another way to deal with the loneliness is to develop and support a strong self-advocacy network where people with disabilities can make connections and do fun things with friends.”**

CONCLUSION

Self-advocates across the country want jobs that are meaningful, that allow them to pay their bills and taxes, where they can form social networks, and that give them a sense of purpose. Stirling Peebles from Green Mountain Self-Advocates said, “Employment First means helping young adults with disabilities find adequate employment. Listen to our dreams about having a job. We want to work just like others. Talk to us about jobs, careers when we are young. Help us try out different jobs.”

We heard why it’s important to carve out jobs based on people’s interests. But in addition to converting sheltered workshops, there also needs to be an environment that promotes presuming competence! Nicole Leblanc explains, “It also comes down to dignity of risk and having high expectations. Parents, teachers, and providers must have high expectations for us to have real careers, not just a job.”

Providers were required to do more with less. Then, the Department of Justice came in.

In Rhode Island, people with intellectual and developmental disabilities were not being given a choice following high school. Once they graduated, they were shipped off to segregated employment settings or day programs. The Department of Justice investigated and looked at practices throughout the state. They found that programs in Rhode Island violated the ADA and the Olmstead decision because they were not giving a person with intellectual and developmental disability a choice as to what they would do following high school.

In 2014, the result of the investigation was that Rhode Island had two choices: get sued or enter into a 10-year consent decree to make the changes required by the federal government. Many things must happen to make the system in compliance with the consent decree.

In the past 3 years, Rhode Island has been making progress. Our governor, Gina Raimondo, believes strongly that this should be done. I am on the Employment First Task Force. We come up with ideas and run them by the court monitor. I have attended a court hearing where the state reports back to the judge about progress on the consent decree. Last year, the judge was not happy about the lack of progress but now he is happier.

In an ideal world, people with intellectual and developmental disabilities get the supports they need to get and keep a job. A job that pays well so they can live on their own or as independently as they can.



ThinkWork!
Advancing employment and opportunity for people
with intellectual and developmental disabilities



The Rehabilitation Research and Training Center on Advancing Employment for Individuals with Intellectual and Developmental Disabilities is a project of ThinkWork! at the Institute for Community Inclusion at UMass Boston. ThinkWork! is a resource portal offering data, personal stories, and tools related to improving employment outcomes for people with intellectual and developmental disabilities. The contents of this brief were developed by our partners at Self Advocates Becoming Empowered (SABE) under a grant from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR Grant # 90RT5028-01-00). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). The contents of this brief do not necessarily represent the policy of NIDILRR, ACL, HHS, and you should not assume endorsement by the Federal Government.

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