“True individual freedom cannot exist without economic security and independence.”

Franklin Delano Roosevelt

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“Never impose on others what you would not choose for yourself.”

Confucius,

Our Lives Without Limits
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➢ **Description**

This toolkit will help self-advocates and their allies to advocate for Real Jobs for Real Pay. Also known as CIE (CIE). CIE stands for Competitive Integrated Employment. It covers what we thought were good ideas. It covers best practices.

The information in this toolkit can be used to speak up:

- In your towns and cities,
- In your state, and
- In our country.

Now I will tell you about the Values I used in writing this toolkit. These are the core values that the self-advocacy movement believes. They are supported by research and lived experience.

People with developmental disabilities have a right to work in jobs in the community. Along with being paid the same wage as people without disabilities for the same kind of work.

I believe that the fears about closing workshops can be reduced if we promote self-advocacy.

I believe that everyone deserves equal pay for equal work.

I believe in Employment First. Work will be the most important service for all working age people with developmental disabilities. Sheltered Workshops are **NOT** a thing of the past. There are many Sheltered Workshops. We will provide information about Sheltered Workshops and Real jobs. This will help you make decisions about jobs for people with disabilities.
Let’s Talk About Sheltered Workshops:

- What are sheltered workshops?
- How are people paid in sheltered workshops?
- How do sheltered workshops impact the lives of people with developmental disabilities?
- How much do Sheltered Workshops cost?

What is a Sheltered Workshop?

Sheltered workshops are places that only people with disabilities work. They are segregated from the rest of the community. This means we are separated from everyone else.

Sheltered workshops get special permission, so they do not have to follow minimum wage laws. Workers with disabilities in sheltered workshops could be paid as little as one cent or less an hour. Sheltered workshops are usually piece work and a person is paid based on their speed. This is why pay is so low. Piece work is doing stuff like stuff envelopes or putting boxes together.

Timeline Of Disability Employment Rules In United States

- 1837 - First Sheltered Workshop created at Perkins School for the Blind.
- 1933 - Congress passed the National Recovery Act. It was the first law about wages for workers in the United States. The act did not address wages for workers with disabilities in sheltered workshops.
• 1933 - An Executive Order by President Roosevelt gave employers the option of paying sub-minimum wage. But each employer could set the wage and there was no set wage for all workshop employees.
• 1934 - The Administrator for the National Recovery Act issued an executive order that gave sheltered workshops an exemption to paying minimum wage to their workers with disabilities.
• 1935 - The Supreme Court said the National Recovery Act was illegal.
• 1938 - Congress passed the National Fair Labor Standards Act. The first minimum wage in the United States was $.25 per hour. The new law said employers could pay people with disabilities no less than $.19 per hour. People with disabilities had to earn at least 75% of what other workers earned.
• 1966 - The rate went to $.50 an hour to disabled workers if non-disabled workers were paid $1.00 an hour.
• 1994 - Legislative hearings found this system was not fair. Nothing was done about it!
• 1999 - Supreme Court ruled that segregation of people with disabilities is against the law. The Americans with Disabilities Act says this includes where you work.
• 2012 - Disability Rights of Oregon filed a lawsuit saying the state was not providing job services in the most inclusive settings. Inclusive means people with and without disabilities working together.
• Today - 75 out of 100 people with significant disabilities are still paid unfair wages. They work in sheltered workshops.
How Are People Paid In Sheltered Workshops?

What is a wage?

A wage is the amount of money someone is paid for the work they do.

A minimum wage is the lowest amount of money per hour that someone can be paid. There is a federal minimum wage. Federal means that the law or program was created by the United States government. It's not just for one state. The Federal minimum wage is $7.25 an hour. Some states and cities have passed laws raising it from $10-15 an hour.

What is Sub-Minimum Wage?

Sub-minimum wage is when people make less than the minimum wage. This could be based on piece work or how fast someone works. In the 1930’s Congress passed a law which allowed people with disabilities to be paid below minimum wage (Sub-Minimum Wage). This law is called the Fair Labor Standards Act. The specific part of the law is called Section 14(c).

In 1994 legislative hearings found this system was not equal and unfair, but…. Nothing was done about it!

Today 75 out of 100 people with significant disabilities are still paid unfair wages. They work in sheltered workshops. Sadly, many people with intellectual and developmental disabilities who work in sheltered workshops are paid less than $1 a day!
How do Sheltered Workshops impact people with disabilities?

- People think they are safe at sheltered workshops. This isn’t always true.
- Many people are afraid to leave the workshop. What will their new job look like? How will they see their friends?
- These are a one size fits all programs. They do not match people’s strengths or interests.
- Poor working conditions.
- Segregation can hide abuse.

What about the cost of sheltered workshops?

- Sheltered workshops cost a lot to run. Some states pay as much as $50 million a year for a Sheltered Workshop.
- They usually cost more than integrated employment.
- The amount of support needs to stay the same
- Since people never leave, the cost of sheltered workshops never goes down.
- Workers only make money when the workshop has a real contract.

What Are The Arguments Against Closing Sheltered Workshops?

Many people are against closing sheltered workshops.

✓ Views from families and caregivers:
  - The sheltered workshop gives caregivers respite during the day.
  - Parents wouldn't be able to keep their jobs, if their son or daughter did not have a place to go during the day.
  - Respite Care helps to keep people out of institutions.
✓ **Views about people with disabilities:**
  - The person will just sit on the couch, watch TV, or play video games all day.
  - Finding a job for everyone with a disability is not possible.
  - People simply don’t have the ability to work out there.
  - They will have to go to a segregated day program. They are often worse than being in a sheltered workshop.
  - People will lose all their benefits, (Social Security, Medicaid, food stamps, fuel assistance, Section 8 housing, etc.)
  - People will lose social connections.

✓ **Views about Sheltered Workshops:**
  - They will close without notice
  - Providers who run sheltered workshops will go out of business.
  - They give people long term placements.
  - Closing them may take away the choice to work in a safe environment.

Here is a quote about Sheltered Workshops from a Super Ally: “We are shaking the building and bricks are starting to fall off, but the structure still stands.”

*Curt Decker, Executive Director of National Disability Rights Network.*

➢ **What You Will Learn About Competitive Integrated Employment:**
  - What is Competitive Integrated Employment?
  - Why is Competitive Integrated Employment important?
  - What are the barriers to employment?
• What is the Employment First Policy?
• What are the benefits of Integrated Employment?

What is Competitive Integrated Employment?
Competitive Integrated Employment is work that is done by people with disabilities:
• in settings in the community,
• alongside people without disabilities, and
• paid at or above minimum wage.

Why is Competitive Integrated Employment important?

Read through these quotes from self-advocates about working in the community. Pick the ones that you can relate to.

1. “Involvement in the economy is a civil rights issue.” Example. Money to buy stuff or budget.
2. “It’s about dignity and respect, not just self-confidence but getting others to see our abilities.”
3. “The expectations of the disability community are to live in the community, have jobs or be self-employed. We also pay taxes just like the rest of the world.”
4. “We all need jobs. Everyone has a purpose in life.”
5. “Many people with disabilities want jobs just like everyone else. Jobs get you out of the house. You meet people and make money.”
6. “Gives you a purpose and makes you more self-sufficient and responsible.”
7. “Beyond what is in our laws, working gives me a real purpose. At work, I feel like I fit in.”
8. “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. “

9. “We need to promote presuming competence! 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.” The words “promote presuming competence” are saying we should believe in people and what they can do and let them tell us what they need help with.

10. I’m sick and tired of professionals trying to put me in sheltered workshops. Olmstead says people with disabilities have a right to work in the community. This is ridiculous!” Olmstead is a legal decision that says people with disabilities have a right to live and work in the community with everyone else.

**What are the barriers to employment? Self-advocates speak out:**

- “There is a myth out there that if you receive aid you can’t get a job. This 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 right to close a sheltered workshop by moving people into day programs. The goal is to support people to work in real jobs.”
• “Family members are scared about their adult children 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!”
• “People in sheltered workshops are afraid they will lose their friends.

What is the Employment First Policy?

Employment First is the belief that all people with disabilities should have opportunities to work in integrated settings. The idea is that work be the first and most important service for all working age people with DD. Employment First stresses that it is important to develop jobs based on a person’s strengths. It encourages us to go after our dreams, take risks and get out of our comfort zone.

What are the benefits of Integrated Employment?

Research says:
• We can pay our own way in the community, and not rely on public benefits all the time.
• It saves the government money in public benefits.

In Vermont real jobs for real pay saved taxpayers about $9,000,000 in Social Security benefits.
• Cost of integrated employment goes down as the worker gains independence.
• People in real jobs for real pay often earn higher wages per hour.
• We expect a self-employed person with a disability will make as much money as people without disabilities self-employed in the same kind of jobs.
  • It boosts the economy by $141+billion
  • Medicaid money used for employment services will improve the worker’s income even after benefits are cut.

➢ What Can We Do?
You learned about Competitive Integrated Employment. And you know why we want to close sheltered workshops. Now it is time to do something about it! You can make changes locally, in your state, or nationally.

How to work locally?
Start with yourself, your own team, agency, town or city.

  Suggestion #1: Work with your team to become more self-determined. Make it one of your goals.

What is Self-determination?
Self-determination is control in your life to make decisions. Research says that people with disabilities who have meaningful employment in the community:
  • Are healthier,
• Have better quality of life outcomes,
• Make more money, and
• Are more self-determined.

**Suggestion #2** Get involved in self-advocacy. Here is a toolkit about starting a self-advocacy group [https://goo.gl/7wsT5X](https://goo.gl/7wsT5X). If you already belong to a group think of ways to be more active.

**What is self-advocacy?**
Self-advocacy is a person standing up for what she or he needs and wants. Teaching people self-advocacy skills will help them maintain the relationships they had with their peers in the workshop.

**The Role of Self Advocacy in Changing Sheltered Workshops to Employment programs**
The best way to reduce fears when moving to a real job is to support a strong self-advocacy network. One thing I have learned from being involved in the self-advocacy movement is that it's important for people with DD to have access to peer to peer connections. Getting support from others with disabilities.

Peer to peer connections:
• help reduce social isolation, being lonely
• allow us to be proud of who we are,
• Is a great place to get support from people who know how to “tell it like it is.”

While getting advice from staff is nice. The information they give us can sometimes be too biased or sugar coated.
Here is a perfect example of how self-advocacy can help people better themselves is by hosting weekly peer run employment support groups. (http://www.gmsavt.org/hire-up.lesson-plans/)

This is something that Green Mountain Self Advocates did several years ago, with money from Vocational Rehabilitation. They hired a presenter and created a training with activities called “Hire Up.”

Nicole’s personal note about peer-run employment groups: I benefited from taking employment classes taught by self-advocates who had a job. I took a peer-run class during a challenging period in my life. I was dealing with debt and struggling to find work. I was healing from emotional trauma I experienced when at a job corps program. I was harassed and that was painful. Self-Advocacy changed my outlook on what it means live with a disability. I say that because as a kid I always wished I was “Normal.” I felt that way because I could never fit in and got teased. 

The way I look at it I feel I suffered from “Low Expectation Syndrome “and “The Disability Double Standard.”

The disability double standard is that it’s ok for those without disabilities to fail. However, it’s not okay for people with disabilities to fail. A great thing about self-advocacy is that it helps us with problem solving. We also learn to cope better with challenges in the work world. Examples of this are dealing with harassment and bullying on the job. Along with discrimination, and other barriers to successful workforce inclusion. These are the things that get in the way of us being successful. Example of this is making fun of you or your disability. Not giving people fair shots at doing jobs.
**Suggestion #3** Encourage your family members to support high expectations for you. Or the person you support.

**Family Expectations My View**

Families play a big role in the employment rate of kids and adults with I/DD. It’s important that families discuss employment before kids leave the school system. It is important that parents set the bar high when it comes to employment. Along with having typical expectation of paying for one's basic bills, (rent, food, fun, transit, internet, massage, co-pays).

“Being in a sheltered workshop is being sheltered from the world”. How will we know what is out there and know what our choices really are? “It stunts our growth”. “It seems to only benefit those who want to minimize all risks and protect us. “However, in reality it's a false sense of safety.”

Families can support self-advocates in creating a meaningful day for people not working. Supporting your son or daughter to develop hobbies and interests. For example:

- take college classes,
- join a local club,
- gym membership,
- Hiking and so much more

The goal is involvement in community activities alongside those without disabilities.
Suggestion #4 Advocate to close Sheltered Workshops. You will need a plan and some arguments to begin this process.

Arguments for Closing Sheltered Workshops

• Read through the arguments and highlight the ones that you think are important.

• Beliefs about disability and working are old and need to be fixed.
• “Being in a sheltered workshop is being sheltered from the world.”
• Supported Employment is believing in the person with disabilities. Match their interest and skills with the job. Find the employer to match job duties to a person’s strengths.
• The employer is the customer and the job seeker is a customer. When we think how they both benefit, we are more supportive.
• If done the right way there is a job for each person regardless of severity of disability.
• People working real jobs, making real money generally live better than if they were just collecting SSI or getting sub-minimum wage.
• For Families that used sheltered workshops as respite. We can help them to think of work in a new way. Real pay and real support on the job make it possible for them to return to work or take a break.
• If the person with a disability works part time they can pay for community activities, “I pick what I do with my time not what others pick for me”.
• People moving from sheltered workshops to supported employment will get better paying jobs in the community.
• Sheltered workshops and sub-minimum wage fails to help people become self-supporting.

• Research shows that change can be difficult for the person and the agency. A survey showed that people with disabilities are happier that they have real jobs. The work programs say they have better relationships with employers and the community. That agency staff are more positive.

• Competitive Integrated Employment costs less money than segregated models. It also costs less compared to other community support options. Especially for people with significant disabilities.

• When the only job experience a person has is working in a sheltered workshop they may need more help when going to an integrated setting. When they are just getting started they may not make as much money. When a person learns the job, they will make better money.

• The workers who have not been in the workshop program at all expect to work for money, not sub-minimum wage in segregated settings.

• When you do the math, people with disabilities make out better working in real jobs for real pay. Instead of just collecting an SSI check. (See page 44 SSI Benefit Exercise)

• Exploiting workers with disabilities is wrong and inhumane. This means taking advantage of us and treating us badly.

• Models that pay based on output are old school. No one is really 110% productive every day.
• Sheltered Workshops are a conflict of interest. This is because that they serve as the employer and provider of service. Their mission is at odds with the needs of the business. As a result, they have no reason to lose the most hard-working people. Along with raising their payroll cost. Sub-minimum wage is not consistent with human dignity and rights protection. It goes against our civil rights.

• Sheltered workshops follow a Place and Train model. People are in a workshop to receive training, but they do not get skills needed for real jobs. This model is very outdated.

• There is an argument that people will miss their friends when they leave the workshop. Help 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. By doing people with disabilities can make connections and do fun things with friends.

In Vermont when we closed our sheltered workshops, we had benefit counselors. They showed people how much they can make over 10 years at minimum wage or higher.

**Example**

**Suggestion #5** Advocate with your agency for CIE (Real Jobs Real Pay)

**Suggestion #6** Advocate with your agency to adopt an Employment First Policies.

**Suggestion #7** You can promote workers with disabilities to employers. The benefits below may help you build your case.
Benefits of Hiring People with Disabilities

Read the benefits and highlight the ones that you can relate to.

- We come with strong motivation. We are dependable. We produce at a high level.
- Our work ethic helps to boost business morale and promote an inclusive culture.
- Business revenue can increase. (Money the company gets.) By doing this you will also grow your customer base among the disability community.
- We make great team players, because we are so used to working with others.
- Lower staff turnover that leads to lower hiring and training cost.
- Most supports don't cost that much.
- It shows off a commitment to true inclusion.
- Tax Incentives. (Money back from government when they hire us)
- It can grow your customer base.
- Diversity is great for business.
- We are eager to succeed.
- It's the Right thing to do. For example, 75% of businesses rate workers with disabilities good to very good on performance reviews or evaluations.
What can you do at the State level?

**Suggestion #1. We can write or talk to our State legislators. We can give them these ideas too:**

- Stop the use of state dollars being spent on segregated workplaces.
- Change state contract options, so they can’t be used in segregated job sites or pay sub-minimum wage.
- Stop giving out 14C certificates that pay workers with disabilities below minimum wage.
- Look at the 3 states that have already gotten rid of sub-minimum wage.
- Expand Benefits Counseling.

**Or you can promote the following suggestions at the State level:**

- Increase state funding for Person-Centered Planning for employment. Along with job supports job carving, and self-employment.
- Make state government a model employer
- Reward disability provider agencies to hire people with I/DD.
- Expand Medicaid Buy-In programs. Eliminate asset limits and resource tests. (Money you can save or have in the bank)
- Create an Independent Advocate on CIE.
• Develop a game plan in your state to address Employment issues for adults with disabilities.
• Develop an “Employment First Committee.”
• Create a provider payment model that favors integrated settings over segregated ones. (Provider X would get more money for an integrated work setting and a less money for a segregated work setting.)
• Expand access to job carving services.
• Increase Medicaid match for supported employment in community settings. Cut the Medicaid match for pre-vocational services.

Sample letter that you can use to write to your legislator

(Month) (Day) (Year)
The Honorable (First name) (Last name)
(Room Number), State Capitol, State (Zip Code)
RE: (state the topic or include the bill number, author and subject if you are writing to support or oppose a particular legislative bill)

Dear (Representative/Senator) (Last name):

My name is (your first and last name) and I am a (self-advocate, family member/service provider/advocate/community member) who lives in your district. (State why you support or oppose the bill or other issue here. State clearly three of the strongest points that support your position.

-- Include a personal story. Tell why the issue is important to you. Tell how it affects you, your family member and your community.
-- Tell your representative how you want her or him to vote on this issue.
-- Ask for a response.
-- Be sure to include your name and address on both your letter and envelope.
Sincerely, SIGN YOUR NAME
   Print your name
   Street address
   City, State, Zip code

Sample Telephone Call To A Senator

This is how a call might go:

✓ Hello, Senator (senator's last name) office.
✓ Hi, this is (Insert Name) and I live in (City). I’d like to speak to the staffer who works on (YOUR ISSUE).
✓ Hold on please while I check if that person is available. (pause) I’m sorry, (___________) isn’t available right now. Can I take a message?
✓ Yes, I’m calling about (STATE YOUR MESSAGE).
✓ Thanks for your message. Can I get your full name, address, and telephone number?
✓ (Full Name), Address, City, State, Zip, Telephone #.
✓ Thank you. I will pass along your message to the Senator.
✓ Thank you.
✓ Write out your script. Practice it until you are comfortable
✓ **Suggestion #2** You can help pass legislation to realize the dream of real jobs for real pay. You start with an idea and find a Senator or Representative to work with you. It helps to know how the legislative process works. We will look at that now.
How a Bill Becomes Law

1. Laws start off as ideas from politicians, businesses, advocates, and members of the public. This is where you come in. You have an idea, find a Senator or Representative to write it with you.

2. A Bill is proposed

3. Bill is it introduced by a Senator or Representative

4. The bill goes to the right committee. Ex. Health Education Labor & Pensions, human services or the money committee.

5. The bill gets Reported.

6. The Bill is debated

7. The Bill it is voted on

8. The bill is sent to the Senate.

9. After it is approved by the Senate it is then sent to the Governor or the President to be signed into law or vetoed.

10. Bill Becomes Law

Key Points to Remember!

It is very important that the bill you are backing have bipartisan support. That is support from Democrats, Republicans and Independents.

The Affordable Care Act Repeal fight in 2017 taught us that no legislation is good legislation unless it has bipartisan support. The Affordable Care Act is a law that expands Medicaid, It requires
everyone to have health insurance or pay a fine. In addition, it also makes discrimination against those with pre-existing conditions illegal. Some examples of preexisting conditions are autism and diabetes. The GOP thought they could repeal the ACA because it was a partisan bill. It was supported by the Democrats.

As it turned out the GOP did not get enough votes to repeal it. Repeal means to take back or eliminate.

In the past people with disabilities benefited more from Legislation that was supported by all parties. That includes the Democrats, Republicans and Independents.

**Suggestion #3** Advocate for more opportunities in Post-secondary education and LEND programs to support adults with intellectual and developmental disabilities in gaining meaningful careers. LEND stands for Leadership Education and Neurodevelopmental disabilities. This might help people to move out of jobs in the Food, Filth, Flowers, and Filing areas.

**Suggestion #4** Advocate with your agency, DD Council and Vocational Rehabilitation to support a peer mentoring curriculum.

**Example** Maine self-advocates who have been successful mentor adults trying to get out of the sheltered workshop.

**Suggestion #5** Advocate for Competitive Integrated Employment at the State level.
You may be asked to testify at the State House. It's important to share about yourself.

- Tell your story on why it's important for people with disabilities to have real jobs for real pay. Example: It allows us to pay for our basic needs. (Examples: Food, Rent, Transportation, Health-care, Education, Entertainment, Massages, Vacations etc.).
- It helps to bust the myth that people with disabilities are “Takers” from the Taxpayers. “We are all givers and takers, we give as much as we take”. This quote comes from VT self-advocates.
- Talk about your struggles, hopes dreams and what real jobs for real pay would allow you to do.
- Share your struggles as worker, job seeker, and being discriminated against etc.
- Share your strengths and tell people about your Dream Job. If you have one.
- Say that It's beyond the Place then Train model of just sticking any person with intellectual and developmental disabilities in any job.
- Say that how when given the right supports the sky's the limit.

**Suggestion #6.** Advocate to fully Fund the Vocational Rehabilitation Program. It has been underfunded for years. As a result, there are wait lists and long delays for people with disabilities needing services.
What can you do Nationally?

**Suggestion #1** We can write or talk to our Senators and Representatives in Washington. Look at the sample letter used at the State level.

**Suggestion #2** We can work with national disability rights organizations to educate policymakers on these topics.

**Here are a few links to national organizations for you to explore:**

- [https://www.aucd.org/template/index.cfm](https://www.aucd.org/template/index.cfm)
- [https://www.thearc.org](https://www.thearc.org)
- [https://nacdd.org](https://nacdd.org)

**Suggestion #3** We can join action alerts, online newsletters for national groups. You can find websites for these organizations listed on the CCD website- [http://www.c-c-d.org](http://www.c-c-d.org).

**Issues to work on nationally (taken from Segregated and Exploited, NCD employment report).**

- Adopt a national paid leave benefit that gives workers paid time off for illness and disability like health issues.
- Expand Earned Income Tax Credit for single workers.
- Adopt a Disabled Worker tax credit This would offset the cost of living with a disability. It will allow us to work more.
- Fully fund Para-transit and Public Transit.

This allows people with disabilities to accept jobs that aren't located in their hometown. [https://goo.gl/tLubeH](https://goo.gl/tLubeH)
• Stop all federal money used in segregated job placements.
• Stop companies from paying workers with disabilities below minimum wage.
• Get rid of federal rules or laws that send kids from the classroom to sub-minimum wage jobs.
• Congress should give more money to hire and train more benefit counselors.
• Federal government should give money to expand peer support programs for families and self-advocates. Focused on moving from segregated to real work settings.
• DOL Secretary should issue a ban on issuing 14c certificates.

Here’s some other ideas to share with policy-makers in D.C.

Suggestions to Promote Real jobs for Real Pay.
• Encourage employers to hire people with disabilities, by giving them money back (called; tax incentives) when they pay us fair wages.
• Require under IDEA (special education law) that all transition plans focus on pre-employment job skills like social skills training, Examples of this are internships, job shadowing, etc.
• Develop a transition coordinator role at high schools. As part of Rehab Act reauthorization.
• Require states to pay long term job support for 3 years.
• Medicaid should pay for people with disabilities to move from segregated settings to real jobs.
• Require states that move to managed care to show how they will keep access to employment services.
If you are not interested in changing laws and policy. Here are some strategies for building support for Real Jobs For Real Pay:

- Ask the Federal Government to create rules and guidance on integrated employment and make plans for funding it.
- Collect reports on Integrated Employment outcomes.
- Create a task force with a focus on expanding real jobs for real pay. Come up with ideas on how to increase financial independence for people with disabilities.
- Educate lawmakers on the need to fund employment services.
- Promote Transition Programs from school to work.
- Fund and support early work experiences for youth.
- Encourage family support and high expectations for children.
- Advocate for accessible education and training programs

Other Advocacy Ideas to Eliminate Barriers and Promote Real Jobs for Real Pay

- Raise the Supplemental Security Income asset limit. People could have up to $10,000 in the bank instead of $2,000 before losing Social security benefits.
- Develop a Medicaid Buy In program to give you a grace period between jobs before losing Medicaid benefits. Medicaid Buy In allows you to work and save more. It allows you to have more than $2,000 in the bank before you lose Medicaid.
- Develop an online calculator to show how work impacts benefits.
- People with disabilities should be eligible for Medicaid waiver services regardless of income, eligibility, or employer paid healthcare.
• Expand Medicaid Buy In to all states for those, without employer-based health insurance regardless of income or assets.
• Hire more benefit counselors.

Author's Reflection

It seems that we are at a crossroads as a nation in terms of expectations for people with disabilities. Many of us who were brought up as part of the “ADA Generation expect to work in integrated settings regardless of the severity of our disabilities. However, there are many people out there that say community living is for some but not all. They say we should have a choice between segregated settings and integrated ones. They believe that we are taking away that choice by closing sheltered workshops and other segregated settings. It is important that we stop these ideas.

➢ Workforce Innovation and Opportunity Act - WIOA

What is WIOA?
In 2014 Congress passed WIOA. It replaced the Rehabilitation Act of 1973. WIOA is one of the biggest packages of reform to job training and employment services in more than 15 years. This will help all people including those with disabilities. It will allow us to overcome the challenges faced in getting jobs.

Key policy changes, under Workforce Innovation Opportunity Act:

• 50% of States’ supported employment money must be used for youth with the most significant disabilities.
• Every state is required to spend 15% of its Vocational Rehabilitation money on pre-employment transition services. This is money to be spent on young people leaving high school.

• Limits the use of Sub-Minimum wage for youth with disabilities. Businesses may not pay sub-minimum wage unless the person has gotten counseling by a state agency. It is done in a way that allows for independent decision making and informed choice. Businesses now have hoops to jump through before paying someone with a disability subminimum wage.

• **Changes in the definition of Competitive Integrated Employment.** It now says that “individuals with disabilities including people with most significant disabilities are capable of getting real jobs for real pay. With the right supports of course.

• **Customized employment** is an integrated setting with or without job coaching.

• **Supportive Employment** must be in an integrated setting. People must be working towards a real job.

Some advocates are afraid that the rules that give guidance for carrying out real jobs for real pay under WIOA will be weakened or eliminated.

**Why is this a problem?**

This is a big problem because the rules on Competitive Integrated Employment give clear examples to states about what is and isn’t considered an integrated employment setting. The rules basically give the Workforce Innovation Opportunity Act teeth. Without these rules in place
many of us fear we could go backwards. As a disability community, our big dream is to move to a world where all people with disabilities can achieve the goal of meaningful employment in the community. Real jobs for Real pay are at the heart of supporting self-advocates to reach this goal.

Our dream is to for a world where people with disabilities will not have to choose between employment and healthcare. In order to live and work successfully in the community. We worry that any changes to Medicaid will make it hard to reach this dream.

Again, the dream is that all people with disabilities have real employment options as a pathway to living successfully in the community.
(Administration on Community Living)

➢ Self-Advocates Stories on Real Jobs For Real Pay

Frank Meeuwis
(pronounced May-vis) was born in Pennsylvania. He has lived in Europe. He also graduated high school in Knoxville, Tennessee. At 18 years of age, he got a traumatic brain injury from a car-collision. He was comatose for 2 months and initially unable to speak. He used a wheelchair for eight months and then returned to college. At The University of Tennessee, Frank graduated with both his bachelor’s degrees and a Master of Science in Social Work. Since 2007, he lives in Nashville, where he works as the Director of Quality Improvement and Systems Change at The Arc Tennessee. He continues to volunteer his service as Treasurer for
the Brain Injury Association of Tennessee. He is also on an advisory committee for Nashville’s Mayor. Married since 2009 to his college note-taker, Frank and Mary have a cat and two sons, 7-year old Jack and 3-year old Milo. (2019, February 17. Retrieved from http://disabledparenting.com/author/frank-meeuwis/)

What the ADA Means to Our Family


My brother, Evan, was born with Down syndrome 40 years ago. This was 10 years before ADA passed. Expectations for people with disabilities were very low. Doctors said that Evan would never learn, hold a job, or participate in activities with peers. The best option for him was an institution. My parents refused to listen. They worked hard to make a very different life for Evan. They fought to give Evan the same opportunities as his sisters:

- to participate fully in school,
- to be a valued member of our community, and
- to pursue fulfilling employment.

Evan writes, “after graduation, I started working at the Marcus Jewish Community Center of Atlanta. I have worked there for 18 years in different jobs. I now work in the Health Club. I check the clients in on the computer. I make sure the equipment is in good working order and collect used towels and fold the clean ones. Most of all, I love to talk to the many people who
come to the health club. I know all their names, love greeting them, and enjoy joking with so many people.

My co-workers have become some of my best friends. They help me when I needed some extra help. We eat lunch together and sometimes go out together on the weekends. I have even been the best man at my co-worker’s wedding.

I live in an apartment with a friend I choose as a roommate.

I am able to be an independent man, because I get help from my Medicaid Waiver. My Medicaid Waiver provides me with needed transportation and a terrific job coach. It also gave me someone to help me with independent living skills. I continue to learn new things that make me so proud. I receive SSDI along with my paycheck and a Medicaid Waiver. This allows me to be independent.

I am proud to be a member of the Georgia Council on Developmental Disabilities.

My parents and sisters are happy to see me living my dreams. They tell me that these are their dreams, too.

As you can see, my life is very full. I work, live, and play in the community. My dream is to continue this healthy and useful life.”

CODY DRINKWATER STORY

I graduated from Towson University in 2012. I thought my interest in history would land me a job. I was in for a
surprise. I found that there were no jobs in the field I was interested in. That began my five year look at my life. I tried to find the right type of job/career. I have had a lot of teaching jobs. I learned important skills on the jobs. But none of them were good careers. I found that working in a school caused me lots of anxiety.

An interesting fact about anxiety: Sometimes you don’t realize you have it. Until you experience a moment without it. My anxiety was terrible. I was calling my bosses all the time. I couldn’t cope with the stress of dealing with a lot of people at once. I lost jobs at least three times.

Then my mother helped me to get tested for a disability again. I was tested in the past. I was diagnosed with dyscalculia (a Math disability) and “nonverbal learning disorder”. The new testing said I am on the Autism Spectrum. I could see the full picture now.

Now I set about planning my life again. I took a hard look at my deficits. I applied for DDA services. I got employment counseling from Vocational Rehabilitation. It took me 4 years to find the right job/ career. I volunteered to get experience. That helped me make job connections. I hired a job coach. Finally, I got a job as the Regional Advocacy Specialist at the Eastern Shore Regional Office. It’s an incredibly fulfilling and rewarding job. It’s the first job I’ve had that understands that I have a disability. They are supportive without putting me down.

Finding employment with a disability can be hard. Finding a job when you have an invisible disability like anxiety can make it harder. But, it is possible to manage your disability and find employment. If the supports are in the right place.
I work and have a disability. I know how important it is to work with people who are not disabled. I have worked in two places. I worked as a secretary at the Arc of Washington County. Now I work for DDA as the Western Maryland Regional Advocacy Specialist.

It has not been easy getting a job as a person with a disability. But I did it.

I live in Washington County, Maryland. I have severe vision impairment. I use assistive and adaptive technology along with Braille at school and work. I graduated with an associate degree in General Studies. Along with a certificate as a Paralegal. I helped to start an advocacy group. I got the “Self-Advocate of the Year” award. I also got an award for being successful using technology in the workplace.

I bring my values, compassion, and determination into everything I do. Working with a disability has its challenges for me and my coworkers. People who are not disabled. But it has been a learning experience for all of us. They have learned about:

- Adaptive and assistive technology,
- Braille,
- and how I do things.

When I first started working at Developmental Disabilities Administration, I learned the layout of the building so I could navigate it with my white cane.
as independently as possible. I do need help with tasks that I am unable to do myself. I need help to access transportation. Coworkers read for me if my technology doesn’t work. I am sent a copy of the documents for meetings ahead of time. They are on my tablet or in Braille at the meeting.
➢ ACRONYM DIRECTORY

WIOA - Workforce Innovation Opportunity Act
CIE - Competitive Integrated Employment
IDD - Intellectual & Developmental Disability
SARTAC - Self Advocacy Regional Technical Assistance Center
NDRN - National Disability Rights Network
FAQ - Frequently Asked Questions
LEND - Leadership Education and Neurodevelopmental Disabilities
DC - District of Columbia
AAIDD - American Association of Intellectual Disabilities
NIRA - National Industrial Recovery Act
SSI - Supplemental Security Income
SSDI - Social Security Disability Insurance
FLSA - Fair Labor Standards Act
MFP - Money Follows the Person Program
SSA - Social Security Administration
SE - Supported Employment
FMAP - Federal Medicaid Assistance Percentage
AIDD - Administration on Intellectual & Developmental Disabilities
Resources/Websites Used for Information on Disability Employment and Competitive Integrated Employment Policy

Final Report by Advisory Committee on Increasing CIE for Individuals with Disabilities - September 2016

NDRN Segregated & Exploited Report Jan. 2011

Khemka, Hickson, & Reynolds, 2005; O’Connor & Vallerand, 1994;
Wehmeyer & Schwartz, 1998 http://www.wintac.org/topic-areas/implementation-of-requirements

Other websites with useful information:

- https://www.thinkwork.org/sites/thinkwork.org/files/files/ThinkWork_sabe_14_F.pdf,
• http://www.rootedinrights.org/videos/employment/bottom-dollars/
• https://www.ncd.gov/publications/2012/August232012
• https://vimeo.com/ondemand/bottomdollarsad
• http://wise.unt.edu/content/basic-skills-supported-decision-making-employment
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• https://scholarworks.umb.edu/cgi/viewcontent.cgi?article=1067&context=ici_pubs
• https://researchondisability.org/docs/default-document-library/epm-wioa-webinar-ppt.pdf?sfvrsn=0

Policy Options for Ending Segregated Employment/Sub-Minimum Wage

Link to good guides on Employment


Meet Ed.

- Ed does not have a job.
- He gets $721 a month from SSI this can be different State to State.
- He gets $13 a month as an inheritance from his grandmother.

Let’s do the math- $721+ $13= $734. Ed gets $734 a month total while he is not working.

Ed was afraid he will lose all his benefits if he went to work. His benefits counselor told him that was not true. He trusted her and got a job. Let’s see how it worked out for him.

- Ed’s Grandma still gives him $13 a month this is called unearned income
- Ed earns $450 a month this is called wages.

Now let’s see how Social Security helps Ed and others out while he is working.

Social Security automatically helps Ed since he is working by letting him subtract some benefits from his wages. The benefits are set as follows:

1. **General income exclusion** = $20
2. **Earned income exclusion** = $65
3. **50% or half** of remaining earnings = **Total Countable Earnings**

Ed uses this new **Total Countable Earnings** to see how much of his SSI he can still collect every month.

4. **SSI Federal Rate Total Countable Earnings** = **Total SSI payment**
Below is all the math Ed can do to see how much money he would get a month if he is working. You need to know that Social Security figures this out for you, but I know some of you like to see it for yourself. So here is the math. Let’s compare- $734 while he is not working or $971.50 while he is working! Which do you think is more?

**Countable Income Calculations**

$13  
$20  
$7

Unearned Income from Ed’s grandmother  
Unearned income exclusion  
Countable unearned income

$450  
$65

Gross work earnings  
Earned income exclusion  
then divide by 2 = $192.50 countable earned income

SSI Payment Calculation

$721.00 - $7 - $192.50 = $521.50 is how much he gets from SSI

**An estimate of Ed’s Monthly Income while he is working.**

$450 + $521.50 = $971.50

Wages  
SSI  
Total Income
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