



# **Why Employment Matters: A Resource Guide by and for Self- Advocates Interested in Pursuing Competitive, Integrated Employment**

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## Purpose

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The following guide is designed for Independent Living Centers, the Developmental Disabilities Network, and Traumatic Brain Injury State Partnership Programs to disseminate as an informational resource to individuals with significant disabilities and their families to encourage self-advocates to pursue competitive integrated employment. It is especially helpful for supporting the transition of individuals with disabilities from sheltered workshops or segregated day settings to a job in the community making competitive wages. It is also an excellent resource for youth and young adults transitioning out of the educational system and into the workforce and community living. The premise of the document is that no one is too disabled to live and work in the community, and as such, federally funded disability grant entities should be promoting and encouraging competitive integrated employment (CIE) as a priority goal and achievable outcome for all individuals with disabilities.

## About the Author

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Nicole LeBlanc is the Self Advocate Engagement Advisor with TASH as part of the AoD Disability Employment TA Center, where she provides research and technical assistance on models for incorporating self-advocacy engagement into strategies for advancing employment outcomes for individuals with disabilities and promoting systems-change efforts.



# Why Employment Matters

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## ***A Guide by and for Self-Advocates Interested in Pursuing Competitive, Integrated Employment***

*“True individual freedom cannot exist without economic security and independence.”—Franklin Delano Roosevelt*

### ***Welcome to a Conversation about Work***

So, you’re considering employment? Awesome! Your future is already looking brighter, because you know the value that work has to your life and making the commitment to pursue employment is the first major step! So, congratulations on taking the first step towards pursuing employment. Work is a critical aspect of being a part of American society and gives us all a purpose and makes us more self-sufficient, independent, and responsible.



When you were growing up, you likely saw one or both of your parents going to work every day. Some of them worked traditional office hours during weekdays from Monday-Friday. Others worked part-time at nights or on the weekends. Some of our older family members may have had more than one job. Others may have volunteered in addition to working for pay. Regardless of where you grew up in America, one of the first observations you made about people was likely what they did for a living and what their occupation was: a teacher, a doctor, a police officer, a grocery store owner, a bus driver, a waiter, a farmer, a construction worker...the list goes on and on.

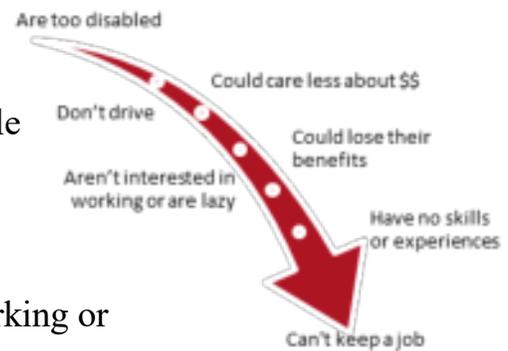


One of the first questions we are asked when we go to school as young children is, “What do you want to be when you grow up?” One child may say they want to be a firefighter. Another one wants to be a chef. Another one says they want to be a pilot. But no child ever says, “I want to sit at home and do nothing all day.” And no child (or adult) would ever say, “I want to go and work isolated from other people in society, doing things I’m not interested in, and not earn any money for my time.” And yet, this is the outcome all too often of people with disabilities who are told they cannot work for a myriad of reasons.



## ***Dangerous Myths about People with Disabilities and Work***

People with disabilities hear a lot of things about having a disability that simply are not true about their perceived limitations. Some uneducated people believe that people with disabilities cannot work because they mistakenly believe that people with disabilities are too disabled, have no interest in working or are lazy, have no skills or experiences that could be transferred into a job, don't care about money, could lose their benefits if they work, or couldn't keep a job in the long-term. But these are just myths, and they could not be farther from the truth! Most people with disabilities want to work, and when given the opportunity to work in competitive integrated employment, typically end up thriving!



## ***People with Disabilities – We're Just Like Everyone Else!***

Just like celebrities, people with disabilities are also like everyone else – we want to work, live independently, have loving friendships and social relationships, and do things we enjoy doing during our free time. We want to be healthy and happy. And to do this, we absolutely will need to get a job to take care of our basic needs and help us accomplish other important personal goals. When you are first considering employment, it can be quite overwhelming and intimidating. Here are some great messages to repeat to yourself daily as you begin your journey to pursue employment.



## Figure 1. Messages of Positivity – You are a Talented and Valuable Contributor to Society!

- I want to work, and be a productive member of society.
- There are many skills, talents and experiences that I can bring into a job.
- What I don't know, I can learn. I can overcome any barriers that may come my way when looking for employment.
- I am responsible and would be a great asset to any organization.
- Working will give me more money to afford to do things I want to do and an opportunity meet different people.
- Working will give me the opportunity to meet new people and make friends different from me.
- I can find ways to overcome any barriers to getting a job.

"Real Jobs for Real Pay," is the plain language way of saying Competitive Integrated Employment, a core value of the self-advocacy movement. Many self-advocates and self-advocacy groups have spent years advocating for closing down sheltered workshops and ending the practice of paying workers with disabilities subminimum wage (Section 14(c) of the [Fair Labor Standards Act](#)). We truly believe that inclusion and work is a civil right. All people with disabilities have the right to live and work in the community without fear of discrimination. Employment is at the heart of true inclusion and is a great way to see us for our abilities, not just our deficits. [Engaging in the workforce](#) can go a long way in supporting us to eliminate negative attitudes about the disability community that we can't work or give back. When the general public sees people with disabilities working and contributing to society, it changes people's expectations and perceptions about what it means to be disabled. And employers who employ us know first-hand our potential: They know that employees with disabilities come with high motivation, high productivity, and we stay longer.



By working, we also help reduce the need to rely on public benefits like SSI. Disability employment plays a significant role in growing a base of taxpayers. Employment also plays a role in the social determinants of health. People who have meaningful work have better health outcomes. Having a job gives us a mission in life. Everyone has talents and strengths, and it is up to us, with the support of family members and providers, to help develop and use our powers to make a difference in this world. Building a career is a team effort. Employment is at the heart of being person-centered. As providers and families, we can support youth and adults with disabilities to develop skills and hobbies that may turn into a job. Teaching work ethic and the concept of money by giving kids an allowance when they are young will also benefit them as they grow. As the saying goes, “With Rights come Responsibilities.”

Lastly, we must challenge ourselves as advocates, providers, and family members to not aim for jobs but to dream big by looking at careers. Another good thing to remember as we advance our movement of *Real Jobs for Real Pay* is that we are not saying everyone must work 40 hours a week. Part-time employment with robust wrap-around supports is a great way to support self-advocates in building a meaningful day in the community. Accessing and being a part of the economic mainstream is a civil rights issue.



## *The Role of Peer Support and Self Advocacy in Employment*

[Peer support](#) plays a significant role in the [employment success](#) of people with developmental disabilities. [Peer support groups](#) allow self-advocates to get help in



areas that range from job hunting to solving job-related issues that may come up. As states move towards closing sheltered workshops and changing their business models, peer support is critical. Peer-to-peer connections can support families by

eliminating their fears when it comes to real jobs for real pay.

Peer-to-peer connection reduces social isolation and allows individuals with disabilities to get advice from people who will be truthful with them and “tell it like it is.” Access to info from people who have similar experiences with you and can be open with you is at the heart of the disability rights movement. In Vermont, self-advocates use a curriculum called [“Hire Up”](#) in peer support groups to support self-advocates who are unemployed or under-employed. Establishing strong personal networks with other self-advocates is a good strategy for addressing loneliness that may occur during times when you are in between jobs or transitioning into competitive integrated employment for the first time.



### **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 the 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 to live with a disability. I say that because as a kid, I always wished I were "normal." I felt that way because I could never fit in and got teased. The way I look at it, I feel like I suffered from "Low Expectation Syndrome" and "The Disability Double Standard." Peer support can go a long way in relieving the fears about the impact of work on benefits.

### ***Importance of High Expectations among Family Members***

Family expectations play a significant role in the employment outcomes of adults with developmental disabilities. It is vital to start the conversation about employment when students are young. If you are a parent of an individual with a significant disability, supporting your child to explore various hobbies that may one day turn into a career is a good start. Disability is not a one-size-fits-all approach. Everyone experiences disability differently. Numerous studies show that self-advocates who come from families with high expectations are more likely to have better outcomes in employment and independent living. Setting the bar high is a great way to teach people with disabilities the importance of budgeting, paying one's way for things like food, rent internet, massages, co-pays, conferences, recreation, and maintaining the exact expectations for us compared to those in the non-disabled world. But, do so by providing us with the right support and accommodations to achieve these outcomes.



Another essential concept to focus on during the transition years is the dignity of risk, and that requires parents to let go a little bit and not be overly protective. All people with disabilities have a right to take risks and get out of their comfort zone. Failure can sometimes be a blessing in disguise. A good example of where youth and young adults need to be given other opportunities is around employment. Being in a sheltered workshop is being sheltered from the world, and thus, it is so important that young people be given the chance to transition out of sheltered work and into other opportunities to work and contribute to the generic workforce. How will we know what is out there and understand what our choices are? Segregation does not protect us -- it stunts our growth and typically benefits only those who want to minimize all risks and decrease their own anxieties. However, in reality, keeping people with disabilities in facility-based programs and not encouraging them to get out there and be a part of their communities is only producing a false sense of safety. Studies show that families who have [high expectations](#) when their son or daughters are young have [better outcomes](#) in the long run. Knowing this success, we must change the post-high school landscape.

In other words, if you are a person with a significant disability, try not to be discouraged by people who think you cannot work. And let's get you from a "maybe" on whether or not to work, to an "absolutely"! After all, we need money to pay for our basic needs like rent, food, health care, and fun. So not working really



isn't an option for most of us – we want to build skills to pay our bills and be our own person.



**Figure 2. Testimonials about the Importance of Work from Self-Advocates**

**What People with Disabilities are Saying about the Impact of Employment in their Lives**

- “It is more than just about the values; it is about 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 am better off working versus just sitting on the couch and collecting SSI.”
- “Beyond what is in our laws, working gives me a real purpose. At work, I feel like I fit in.”

## ***Financial Independence, Employment, and Optimal Self-Sufficiency***

As a society, we expect that adults will work after high school—our jobs and what we do for a living shape our identity. Paying one’s way is a big part of our culture, and it impacts how we look at various groups of people. When people with disabilities work, it busts the myth that we are lazy and taking money from taxpayers. Another significant benefit of



disability employment is that it allows us to rely less on public assistance. For example, in Vermont, employment for people with disabilities saved taxpayers \$9,000,000 in SSI benefits. More information is in the following [Disability Employment Policy 101 guide](#).

## ***Employment and True Inclusion***

Employment is at the heart of true inclusion in our society. Our jobs and what we do for a living defines much of our world today. A diverse workforce is a successful workforce. Creating a culture that values the diversity of all kinds, especially that of people with disabilities, is key to innovation and growth as a business. More resources are available on the following [blog post](#).)



## ***Employment Impact on Benefits and Work incentives***



Access to benefit counselors and peers who have used work incentives to plan and lessen the impact of employment on SSI - Supplemental Security Income or SSDI- Social Security Disability Insurance is vital to the employment success for people with developmental disabilities and their families.

Fear of losing benefits is one of the most significant barriers that families and some providers use to prevent people with disabilities from working. It is vital to include benefit counselors and other peers with lived experience in using work incentives to relieve the stress and anxiety that come with the fear of losing SSI, SSDI, and other public benefits. As many of us know, balancing work and keeping services is like a full-time job.

It is important to remember that your son or daughter will always be better off by working rather than just sitting on the couch collecting an SSI/SSDI check. The earlier we engage families and support staff with benefits counseling, the better off we will be. Lastly, advocating policy makers at the federal level can help eliminate work disincentives that keep individuals with disabilities trapped in poverty. An example of this is the SSDI cash cliff, where if you go over the limit of \$1310 as a nonblind person after all impairment-related work expenses get accounted for, you lose the entire SSDI Check. Unlike in SSI, where your benefits go down \$1 for every \$2 you earn.



## ***Employment in Era of COVID19***

In the spring of 2020, the world we live in was turned upside down by the COVID-19 pandemic. COVID has shown that we can do many jobs from home. Before COVID-19, teleworking was an accommodation that companies often denied many workers with



disabilities. Because of COVID-19, everyone is working from home, which will hopefully start to level the playing field for employment for people with disabilities.

As an advocate, the COVID crisis could result in an opportunity to get more people with disabilities professional work from home jobs. There is more to the world than the four common categories where people with disabilities are often encouraged to seek employment; the food, janitorial, floral or laundry folding service industries. As teleworking and flexible work arrangements become more common, we must develop best practices on workforce inclusion. While working from home is convenient, it can also be isolating for many folks. For others, there is a lot of flexibility and advantages to working from one's home. Now is also a great time to look at how we can increase the number of individuals who can back-fill jobs in industries with high demand where labor supply is low. There are lots of job opportunities, as well as opportunities for individuals with disabilities who are interested in becoming entrepreneurs to own their businesses through self-employment ventures. For the long-term, it will be critical for us to shift our focus to the growing impact of automatization of jobs on the disability community. An example of this is how some retail stores no longer have baggers and have moved towards self-checkout or cashiers bagging to save money.



## ***Getting Started: How do I start to pursue a job?***

Local schools or vocational programs must offer job training and career exploration during the transition years to support you in finding your strengths and talents.

Having transition talks from an early age will help Vocational Rehabilitation-(VR) counselors and job development staff support you in finding employment. Signing up for Vocational Rehabilitation, supported employment services at a disability provider agency, or a one-stop is a significant first step. Job development is a paid service you can access either via VR or Ticket to Work. Ticket to Work is through Social Security. The Social Security Administration (SSA) will pay your employment network based on progress towards job goals. (Here is a [short video](#) on the Ticket to Work program for individuals interested in learning more.)

It is also a good idea to work with your family or support team to begin the process of job shadowing, community exploration, informational interviews, explore job training programs, classes at community colleges, and job tryouts. This



process will support you to gain a more extensive network and learn your strengths, weaknesses, likes, and dislikes. Networking plays a big role in employment, “Over 80% of folks say their network has helped them find work.” Here are some [webpage with tips](#) for self-advocates to consider around professional networking.



## Appendix A: Pursuing Employment: Key Considerations & Questions

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Here is a list of common questions that people with disabilities and their families have when an individual is considering whether or not to pursue employment. We have developed some responses in hopes that good information will help alleviate any concerns you have and encourage you to go after your employment goals!

### ***1. How will work affect my benefits? (Examples of benefits may include SSI, SSDI, Medicaid, Medicare, Food Stamps, Section 8, etc.)***

There are numerous work incentives and ways to save money to lessen the impact on public benefits. For example, if you get SSDI and have a job coach, or extra support provided by the employer, SSA will only count half of your gross earnings when factoring in the Substantial Gainful Activity Limit of \$1,310 for non-blind folks. Some states also have [matched savings accounts](#) () that allow you to save money in a special account matched by states so that people can save for things like college education, home ownership and start or expand a business. We recommend that as you begin to look at jobs in the community, you schedule an appointment with a benefits counselor at your local independent living center, vocational rehabilitation office, disability provider agency, or a community work incentives coordinator (CWIC) through the Work Incentives Planning and Assistance (WIPA) Program. A CWIC can provide individual counseling to beneficiaries seeking employment and intensive follow-up services to ensure that they are using the work incentives appropriately. CWICS provide confidential services to people with disabilities who receive Supplemental Security Income (SSI) and/or Social Security Disability Income (SSDI). CWICs educate beneficiaries on how employment will



affect their public benefits such as SSI, SSDI, Medicare, Medicaid, subsidized housing, and food stamps.

CWICs are funded through the Social Security Administration grant called WIPA. CWICs are not SSA employees. However, they do serve SSI and SSDI beneficiaries, including young adults who are transitioning from school to work.

CWICs can help:

- provide in-depth counseling about benefits and the effect of work on those benefits;
- conduct outreach efforts to beneficiaries of SSI and SSDI (and their families) who are potentially eligible to participate in federal or state Work Incentives programs; and
- work in cooperation with federal, state, and private agencies and nonprofit organizations that serve SSI and SSDI beneficiaries with disabilities.

For more information on how to find and contact a local CWIC in your community, call (866) 497-9443.

## ***2. How will I be supported at the job, and how will I be transported there?***

As you prepare to enter the world of work, it is important that you think through what team of supports you need. On that list, you should consider a job developer, VR counselor and long-term job coach. If you qualify for vocational rehabilitation, you have access to supports for a short period of time (typically, 90 days), with extended services for up to two years if needed. If you are eligible to receive services through a Medicaid HCBS waiver, you can request job coaching services that can be paid for with waiver funding. A Plan to Achieve Self-Support (PASS)



plan can also pay for job coaching. This [SSA webpage](#) has more information on how to start a PASS plan.

### ***3. What work incentives are out there to reduce the impact of getting less SSI or SSDI?***

There are SSI subsidies and student-earned income exclusion for people under 22 that allows us to exclude income from earnings in the amount of \$1,930 a month. The SSDI subsidy allows you to keep your full SSDI if you have a job coach or special conditions that are offered as accommodations by the employer. Examples include extra breaks, fewer or easier tasks, lower quality standards, less hours, special transportation, special equipment, and lower production standards. Also, most (but not all) states have a program called Medicaid Buy-In, that allows you to keep Medicaid by paying a nominal membership fee and allows you to earn and save more without fear of losing your health care insurance coverage.

### ***4. How can Vocational Rehabilitation support me towards my employment goals, and what can they pay for?***

VR can support you by paying for things like business attire for interviews and work, assistive technology, health restoration, transportation, college classes, job training, job search assistance, benefits counseling, and referrals to employment networks (like disability provider agencies for job development).

### ***5. What is Medicaid Buy-In?***

Medicaid Buy-In is a state program that allows disabled workers to keep their Medicaid. It has a higher asset limit than regular Medicaid. You pay a small premium, depending on work earnings and income in some states.



## ***6. How do you deal with discrimination in employment?***

Because you have a disability, you are entitled to a reasonable accommodation. If for any reason you are being denied a reasonable accommodation or are being discriminated against because of your disability, there are steps you can take to defend yourself. First, you may consider filing an internal complaint. Your employer may be willing to reconsider its decision once you have explained your rights. Filing a complaint within your employer serves two important purposes: It gives them an opportunity to correct the problem. Even if your own manager or supervisor doesn't take the problem seriously, the human resources department or higher management might. Filing an internal complaint gives an employer another opportunity to do the right thing.

If your employer doesn't handle your complaint to your satisfaction, you may consider filing a charge of discrimination with the federal Equal Employment Opportunity Commission (EEOC) or your state's anti-discrimination agency. You must file a charge to preserve your right to sue for disability discrimination in the future. There are time limits for filing a charge. In states that have their own law prohibiting disability discrimination, you must file your charge within 300 days of the discriminatory action or decision. In states without a disability discrimination law, you must file within 180 days.

## ***7. What is “Ticket to Work”? How do I find out if I am eligible for a Ticket?***

The Ticket to Work program is a free program for people with disabilities on SSI, SSDI who want to try working or return to work. The program offers more choice when looking for services, supporting to enter, re-enter, and staying in the workforce. The goals of the program are to reduce or eliminate reliance on SSI,



SSDI whenever possible. It also supports our financial independence. Under this program, you work with a VR counselor to pick an employment network that will help you with job hunting and work goals. An Employment Network is an Independent Living Center like Independence Now or a disability provider agency like SEEC. Some Ticket-to-Work programs will pay you support payments to work if you achieve certain outcomes. More information is available on the following [webpage](#).

***8. How do you get benefits counseling, and does it cost anything?***

Benefits counseling is free to each person. It is often paid for by Vocational Rehabilitation or Ticket to Work, Social Security.

***9. If I start a job and realize I need some extra or different supports or accommodations to do my best work, how do I talk to my supervisor about this?***

Ask to set up a meeting to discuss your concerns. If you have a job developer or job coach, ask them for support in doing this. Figuring out your support needs is a good step. VR can offer extended services if you have a new need. Anytime you have a new need, VR can and should reopen your case.

***10. If I am having problems at work, who can help me address my concerns at work?***

If you have a trusted colleague or mentor, or someone else that helps support you at work, start with talking to them about your challenges and seeking their counsel. You may also consider reaching out to your VR counselor or Job Coach to troubleshoot problems when they arise. Having weekly 1:1 meetings with your supervisor



is also encouraged, especially if you are in a professional job. If you ever have a new need, VR can open your case again.

***11. What are some helpful tips for beginning a job search or starting to pursue a job?***

Take part in information interviewing. Work with a Job Developer, VR counselor, or a friend or family member on developing a resume for yourself. Gather any work samples, like booklets or articles you have written to market your skills. See if there are any Discovery or customized employment programs you can enroll in to help you gain exposure to different types of jobs. Volunteer and participate in internships in your local community at places where you might want to work or have an interest. Take part in job shadowing opportunities, where you observe someone in a job you might wish to have. And most importantly, tell everyone you come across that you are currently looking for a job, tell them what you are interested in, and ask them if they have any ideas or leads of places you could apply. Don't be shy to ask them to introduce you to friends they have in certain industries or sectors you are interested in working as well.

***12. My family is anxious about me getting a job. They think I may fail, could get hurt on the job, may jeopardize my benefits, or that people may not be friendly to me. How do I talk to them, so they understand why work is important to me?***

It can be very difficult to talk to family members about your interest in employment, but it's also a great opportunity for you to work on managing conflict. If your family is concerned about you pursuing a job, ask them to sit down with you to hear the reasons why you are interested in pursuing a job, the types of jobs you are interested in doing, and why it is important to you that they be supportive. Find out what their



concerns are. Think about inviting a person you trust to be there during the conversation to help advocate for you and support you. Finally, be prepared to talk about all the benefits of you working – making money of your own that you can spend on expenses; contributing to your community; making friends and being a part of your community; and learning skills and a trade that can help you pursue other jobs and a career in the future. Also, consider asking your vocational rehabilitation counselor or case manager if they know of any families in a similar situation (where the individual wanted to work but their family wasn't supportive) where the individual went to work and had really positive results. See if they can connect your family members with other family members of individuals who are working to share their positive experiences and feedback. Whatever you do, don't be deterred.

Oftentimes, the people we love the most worry about us and don't want to see us fail or get hurt. But failure is a part of life, and we all fail sometimes. We won't know, however, if we will succeed in employment until we get the opportunity. And even if we have trouble in the beginning, we need to be supported to keep at it and stay committed. Tell your family members you want a chance to contribute to your society and to be independent like everyone else in your family is.

***13. I'm having a lot of trouble finding a job during the COVID pandemic. Are there strategies I should use to help find work during this time?***

Try searching on job websites like Monster.com, Idealist.org, or Indeed.com. Work with a job developer who can work with you remotely on resume development, scheduling informational interviews, and attending virtual career fairs, to name a few. The COVID pandemic has shown that many people can work from home. Tapping into programs that can give people with disabilities access to computers and



tech devices is a good step. Lastly, network and be vigilant in asking people for connections, ideas, and support in pursuing employment.

***14. I have a job but am scared to go to work because I am worried I may catch COVID from the people I work with or come in contact with as part of my job. Do I have rights that protect me from being fired if I cannot go to work during the pandemic? And if not, what should I do to protect myself from COVID?***

Yes, you have rights. Work with your VR counselor or job coach to set up a meeting with your employer about accommodations to protect you from COVID. If it is possible, consider switching shifts to a time that's not so crowded or busy if you work in an environment where there are a lot of people around. Another option could be to see if there is the ability to carve out a role that does not involve being



around lots of people. Lastly, start looking for a job that is remote during COVID. A helpful resource is the following [guide for informed decision-making](#) related to working during the pandemic.

***15. I lost my job because of the lousy economy due to COVID. Now that I am at home without work, I am bored and lonely. What suggestions do you have for me to develop more skills and even get another job during COVID?***

Great question! First and foremost, do not lose hope! We can do many activities from home, such as taking online college classes or attending virtual training programs and conferences. Many businesses are now holding online job fairs to



share your resume while working with a job developer to get a better job. Take advantage of online resume and cover letter workshops. If applicable, make a portfolio of work samples. Attend virtual groups to meet new people and network. Let everyone in your community and network know that you are looking for a new job – the more people who know you are looking for employment, the better.

