“To Work or Not to Work?”... may be a question asked by parents and guardians as they begin to think about their sons and daughters going to work. This Q & A on Customized Employment addresses concerns that family members may have and provides answers to address the concerns. Please visit Virginia Commonwealth University’s Disability and Rehabilitation Research Project (DRRP) on Customized Employment at [https://drrp.vcurrtc.org/] for more information on customized employment.

Question: How do I know if my son/daughter with a disability is ready to work in the community?

Answer: If your son or daughter wants to work, customized employment may help him / her achieve that goal. A key aspect to customized employment is finding a job that matches the job seeker’s interests and skills. Using this approach, a representative, usually referred to as an employment specialist, works closely with your son or daughter to negotiate a specific position that uses the person’s talents to meet the needs of a business. The goal is not just to locate any job, but a job specifically negotiated that capitalizes on the job seeker’s interests and abilities. If your son or daughter wants to work, then it may be time to try customized employment as a way to support him or her in finding a job.

Question: I am not familiar with customized employment where can I find these services?

Answer: Customized employment is a service that can be funded by Vocational Rehabilitation (VR) Agencies. A person with a disability has to apply for VR services, be found eligible, and develop an Individualized Plan for Employment (IPE) with a VR counselor. Customized employment could then be identified as a service for the person to achieve his or her employment goal. The VR counselor would authorize payment for an agency, sometimes referred to as a Community Rehabilitation Program (CRP), to provide the services. If your son or daughter is not connected to a VR counselor, you should contact the VR agency in your state for more information. Contact information is located at the end of this Q & A.

Question: But, my son/daughter does not have the skills to meet the demands of a job in a business and needs training. Doesn’t he or she need training first?

Answer: People with significant disabilities may not transfer skills learned in one environment to another, which may make you think he or she can’t work. One of the reasons is that it is difficult to simulate the features of a job in a setting that does not have coworkers and the demands of a real job. For instance, your son / daughter may be in a training program to learn how to work in an office. The participants in the program take turns completing tasks such as sorting mail, delivering messages, and folding letters and stuffing envelopes. However, position descriptions change from business to business. The way that one office prepares and delivers mail can be very different from another. The time spent learning the tasks in the training program could be best spent learning the job duties after your son / daughter becomes employed. In other words, he or she learns on the job! It is also important to consider if the skill being taught in the training program represents an employment goal of your child. Sometimes, training programs are not individualized to what each person wants to do. Instead the training tries to select activities that may represent potential jobs in the future. A person might learn how to do these tasks but never use them because there are no jobs available. Or the person simply doesn’t want the type of job that he or she received training on.

Question: I don’t think my son/daughter should be alone in a community job. Wouldn’t working in a business be unsafe?

Answer: It is only natural for you to be concerned about your sons or daughter’s welfare. Looking for a place to work also includes making sure the person is “safe.” First, “safe” needs to be defined in relationship to your son’s / daughter’s support needs. For example, a person who has a history of walking out of any
Question: How would my son/daughter learn the skills in the workplace?

Answer: Key to the negotiation process is the employer’s willingness to support whatever your son / daughter needs to become successful at work. For example, sometimes a job applicant with a disability will need more skills training than the employer is able to provide. In such a case, the employment specialist will go to work with the individual and provide additional on-the-job training. Or perhaps, the person may need a modification in a company’s policy that would allow him / her to work a flexible schedule. Workplace supports vary from individual to individual and are negotiated specifically to meet the needs of the person in a customized job. At the end of the process, when the job is confirmed, the result is a custom made position for your son / daughter.

Question: I don’t know what kind of job my son/daughter would like. How do you know?

Answer: A very important feature of customized employment is to spend time with the person who wants to work; usually referred to as “discovery.” An employment specialist will spend time getting to know your son / daughter as well as you, family members, and the people in his or her life. The first recommended step is to visit at your home talking about what the person likes to do as well as observing. In addition, an employment specialist will spend time with him / her in the community doing familiar activities, talking with family members, meeting with friends who know your son / daughter well, and so forth. The time will be spent “discovering” his / her interests, abilities, and support needs.

There still may be uncertainty about what your son / daughter might like to do and the skills that he would bring to the job. If this happens, several types of jobs will be identified that seem to match your son / daughter’s expressed work interests. The employment specialist may ask if you know employers in your network that match his or her employment goals. Then, the person can tour these types of businesses to observe as well as “shadow” a coworker. During a work experience, your son or daughter will have the opportunity to observe and sometimes try different job duties to more specifically identify his / her work preferences and interests. This information will be used to customize a job on your son’s / daughter’s behalf.

The employment specialist may conduct what is called an informational interview with employers to learn more about the business and specific needs of the company. When an employer is identified that has opportunities matching your son / daughter’s specific interests and needs, the job negotiation process begins. A proposal will be prepared for the employer’s consideration that will highlight your son’s / daughter’s abilities and how he / she can bring value to the business. Once a proposal has been made and both the job applicant and employer agree to the proposal, a work start date may be negotiated.

Question: How will my son/daughter get to work? The community rehabilitation program provides door-to-door transportation service?

Answer: A critical aspect to customizing a job for your son / daughter will be finding work opportunities at locations where transportation will not present a barrier. Every situation is different. For example, some people may travel to work using public transportation, while others, ride with co-workers, take specialized transportation services, or walk. Today, some individuals with disabilities are using Uber or Lyft just like anyone who needs transportation services.
Part of getting to know your son / daughter will be exploring various transportation options. This information is vital to the strategic plan for customizing a job, since it influences the scheduling requirements and the work location. For instance, your son / daughter may have access to the public bus system, but may not be able to ride the bus alone. In this case, a transportation trainer can teach your son / daughter how to get to and from the job on the bus. Or, another option might be that the place of business is on a friend’s route to and from work. This could become part of the employment negotiation process. For example, employment negotiations may center around a specific work schedule that would allow the person to work a schedule that matches the friend’s daily commute times.

If you are not comfortable with these options, staff can determine if there is a specialized transportation service in the community that can offer door-to-door service. Or, perhaps a college student or senior citizen would like to earn extra money providing transportation. You can be assured that the support needs of your son / daughter will be met so that everyone feels comfortable. He / she will not be left alone until the skills to get to and from work independently have been demonstrated.

**Question:** But, that would cost extra money! How will that impact his/her paycheck?

**Answer:** Your son / daughter would be making at least minimum wage or more based on what other workers earn who are performing similar job duties. The amount would be negotiated with the employer at the time of hire and again during the course of employment for pay raises. In addition, if your son / daughter is receiving social security benefits, he / she may be able to claim an Impairment Related Work Expense (IRWE) for the transportation expense. This is a work incentive designed to assist people with disabilities in paying for expenses that are needed to work. Specialized transportation is one such expense. Basically, a person can deduct the cost of services and items needed to work and reduce the amount of countable income. When Social Security calculates how much a person will receive in the monthly check, an IRWE allows him / her to keep more money than if there were no work expenses. While he / she will not get all of the cost of transportation covered through the work incentive, your son / daughter should have more money available than if not working.

**Question:** Well, that raises another concern? My son/daughter can’t lose Social Security benefits and Medicaid. The reality is that he/she needs the health care coverage.

**Answer:** The answer is to become informed! A Community Work Incentives Coordinator (CWIC) or sometimes referred to as a benefits planner or specialist can explain the basics of how work will impact your son’s / daughter’s monthly benefit check. You also will need more information on work incentives. These incentives were developed to encourage Supplemental Security Income (SSI) recipients and Social Security Disability Insurance (SSDI) beneficiaries to become self-sufficient. The IRWE is just one of the work incentives that can help your son / daughter. Others include the Earned Income Exclusion, PASS (Plan for Achieving Self Support), and Section 1619 (a) and (b).

Under Special SSI Payments for People Who Work: Section 1619 (a) and 1619 (b), a worker can continue to receive Medicaid. Eligibility continues as long as your son / daughter meets the basic eligibility requirements and the income and resources tests. Under 1619 (b), Medicaid coverage continues even when earnings become too high to receive a SSI payment, but there are threshold levels in each state. Some states have eligibility rules for Medicaid that differ from SSA’s. This is information that you will need to discuss with a CWIC to find out exactly how work will impact your son’s / daughter’s benefits. However, he / she can always earn more money working than by just receiving benefits alone. If you still feel unsure after meeting with a representative, talk to other family members who have adult children with disabilities who are working in the community. You can download a booklet produced by the Social Security Administration, The Redbook, which provides more information on how work can impact benefits at https://www.ssa.gov/redbook/.
**Question:** What if my son/daughter loses job? Can he/she go back to the workshop or day activity program?

**Answer:** Negotiating a customized employment opportunity for your son / daughter hopefully will prevent this from happening. Rest assured that staff will work hard to solve any problems that come up during employment and to address any support needs that could lead to job loss. This includes re-negotiations with the employer, if necessary, to further customize your son’s / daughter’s job. But, of course people still lose jobs. If this occurs, staff will work with your son / daughter to find a new customized job in the community. A new position will be negotiated based on what is learned in the first job about his / her interests, work skills, and support needs. Remember, employment specialists are always willing to talk with you whenever you have additional questions!

**Resources**

**Social Security Redbook:**
A copy of the Social Security Redbook can be downloaded from the Social Security Administration’s website https://www.ssa.gov/redbook/. The Redbook provides information on how work can impact benefits.

**Vocational Rehabilitation:**
Each state has a Vocational Rehabilitation (VR) Agency that assists individuals with disabilities achieve their employment goals. A list of state and US territory contacts can be found at the following link: http://www.askearn.org/state-vocational-rehabilitation-agencies/

**Work Incentives Planning & Assistance (WIPA):**
The WIPA program enables Social Security beneficiaries with disabilities to make a successful transition to work. Each WIPA project has Community Work Incentives Coordinators (CWIC) who will provide in-depth counseling about benefits and the effect of work on those benefits. Learn more at https://www.ssa.gov/work/WIPA.html and at: https://choosework.ssa.gov/findhelp/

**Acknowledgments**
The author of this Q & A is Dr. Katherine Inge. If you have questions about this Q & A or about the VCU DRRP on Customized Employment, please contact Dr. Katherine Inge at:

kinge@vcu.edu or 804-828-5956.

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