T-TAP
Training and Technical Assistance for Providers
Virginia Commonwealth University & The Institute for Community Inclusion University of Massachusetts Boston
June, 2004

Q & A on Customized Employment: Addressing Parental Concerns

"To Work or Not to Work"... that is a question being asked by many individuals with disabilities and their family members as they begin to think about going to work in their local communities. This fact sheet addresses frequently asked questions by family members and provides answers to dispel the concerns. After reading this, it is hoped that family members will agree that the answer to the question: "To Work or Not to Work" is **"To Work!"**

Q **I have been told that my son/daughter is not ready to work in the community.**

A Customized employment eliminates the need for a person to "get ready" to work. If your son/daughter wants to go to work, then it is time for him/her to go. A key aspect to customizing employment is finding work that matches your son's/daughter's interests and skills. Using this approach, a personal agent or employment specialist works closely with a job seeker to negotiate a specific position that uses the person's talents to match the needs of a business. The goal is not just to locate any job, but a job specifically negotiated that capitalizes on your son's/daughter's interests and abilities.

Q **But, my son/daughter does not have the skills to meet the demands of a real job and needs training.**

A Many people with significant disabilities do not transfer skills learned in one setting such as a workshop to another such as a community business. 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 workplace. 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, typically 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 task in the training program would be better spent in the actual workplace where your son/daughter is employed.

The Office of Disability Employment Policy, U.S. Department of Labor

Virginia Commonwealth University

Institute for Community Inclusion at the University of Massachusetts, Boston

Contributors for this Issue:

Dr. Katherine Inge, Project Director
T-TAP - VCU -- kinge@atlas.vcu.edu

Ms. Pam Targett, Employment Services Director
RRTC on Workplace Supports -- psherron@atlas.vcu.edu

T-TAP is funded by the Department of Labor (DOL), Office of Disability Employment Policy (ODEP) cooperative agreement # E 9-4-2-01217. The contents of this product do not necessarily represent the interpretations or opinions of DOL. Virginia Commonwealth University, is an equal opportunity/affirmative action institution providing access to education and employment without regard to age, race, color, national origin, gender, religion, sexual orientation, veteran's status, political affiliation, or disability. Privacy Policy. If special accommodations or language translation are needed contact Katherine Inge at: kinge@atlas.vcu.edu or Voice (804) 828 - 1851 | TTY (804) 828 - 2494.

Q The workshop is a safe place, and I don't think my son/daughter should be alone in a community job. He/she has never been without the support of the agency's staff.

A Looking for a "safe" place to work is also part of the customized employment process. 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 door at home or the workshop may have a very different safety concern than the person who just lacks community based experiences. In some instances a workplace that limits access to the outside or machinery may be warranted. Another person may just need to have a little extra support from a coworker.

Your safety concerns will be taken into consideration when negotiating work. It is only natural for you to be concerned about your son's or daughter's welfare. For example, part of the negotiations might include arranging for some additional supervision or creating a job where your son/daughter works alongside a coworker who is aware of the support need. Once again, an agent would work closely with an employer to negotiate a job that minimizes your son's/daughter's disability and provides the workplace supports necessary for him/her to be successful.

Q How would my son/daughter learn the skills in the workplace?

A 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, a trainer sometimes called an employment specialist will go to work with the individual and provide additional on-the-job training. Or perhaps, the person needs to use an assistive technology device to get the job done like using a reaching device to pull items off of a high shelf. Another, job applicant 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 tailored specifically to meet the needs of an individual in a customized job. At the end of the process, when the deal is struck, the result is a custom made job for your son/daughter.

Q I don't know what kind of job my son/daughter would like.

A A personal agent or employment specialist will spend time getting to know your son/daughter as well as your family. For instance, an employment specialist may spend time with him/her in the community doing leisure 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.

Occasionally there still may be uncertainty about what your son/daughter might like to do. If this happens several types of jobs will be identified that appear to match your son/daughter's expressed work interests Then, he/she can have a brief work experience, perhaps 3 - 4 hours within each job type, to more specifically identify his/her work preferences and support needs. This information will be used to customize a job on your son's/daughter's behalf.

Now prepared, the personal agent or employment specialist will begin to identify potential places of employment in the local business community. You may even be asked if you know employers in your network that would be willing to support a person with a disability in the workplace. The agent will meet with employers to learn more about the business and specific needs of the company. Whenever an employer has some suitable opportunities that match your son / daughter's specific interests and needs, the job negotiation process will begin.

A good customized job individualizes the employment relationship between employees and employers in ways that meet the needs of both. 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 will be set.

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

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.

Part of getting to know your son/daughter will be exploring various transportation options. This information is vital to the strategic plan for customizing employment, since it influences the scheduling requirements and the work location. For instance, your son/daughter may have access to the public bus system, but lack the skills needed to get to the bus stop and 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, we 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.

But, that would cost extra money. I don't imagine that he / she would be making very much anyway.

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). 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 or working in extended employment options (sheltered workshops).

Well, that raises another serious concern! My son/daughter can't lose Social Security benefits and Medicaid. The reality is that he/she needs the benefits and health care coverage.

The answer is to get informed! You should contact your local Social Security Administration Office to locate a Benefits Planning Assistance and Outreach Specialist. This person can sit down with you to 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. Under Section 1619 (a), your son's/daughter's check could be reduced as low as one cent due to work income, and he/she still 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 Benefits Specialist 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 receive SSI and are working in the community. You can also download a booklet produced by the Social Security Administration, ***The Redbook***, which provides more information and sample calculations on how work can impact benefits at http://www.ssa.gov.

Q My son/daughter has friends in the extended employment program. Going to work would mean losing those friends.

A If the opportunity to make friends is important to your son/daughter, then this along with other key information would be taken into consideration during negotiations with employers. Every workplace culture is different. For instance, some are friendly and others are not. To understand the workplace culture, the person representing your son/daughter would ask the employer questions and look for signs that the workplace is friendly and supportive. For example, employees who appear to be enjoying their jobs may signal a pleasant place to work.

Developing a good fit between a person and the social characteristics of a workplace is as important as learning how to perform a job. Many people with significant disabilities report making new friends at work and an overall, satisfaction with employment. Your son/daughter would have support establishing relationships with coworkers. Social activities that are available to other employees would also be available to him/her. Going to work also does not mean that your son or daughter has to give up friends from the workshop. They can still socialize outside of the workshop setting. Working should expand his/her social opportunities and not limit them.

Q What if my son/daughter loses the job? Can he / she go back to the workshop?

A Negotiating a customized employment opportunity for your son/daughter hopefully will prevent this from happening. Rest assured that we would 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.

If this occurs, staff will work with your son/daughter to find a new 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, our program staff is always willing to talk with you whenever you have additional questions!

Summary

Hopefully this fact sheet has provided information on what parents want to know about customized employment. There are other resources available online at the project's website: http://www.t-tap.org

Please contact us directly for more information on T-TAP.

Dr. Katherine Inge, Project Director, T-TAP - VCU
kinge@atlas.vcu.edu

Dr. John Butterworth, Technical Assistance Coordinator
T-TAP - ICI, University of Massachusetts Boston
John.Butterworth@umb.edu

W. Grant Revell, Training Coordinator, T-TAP - VCU
wgrevell@mail1.vcu.edu