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ABSTRACT

This newsletter issue provides rehabilitation professionals with various information pieces concerning consumer leadership in supported employment of people with disabilities. First, a chart lists five questions concerning self advocacy and supported employment, and provides consumer responses to the questions. A second item describes participatory action research at the Rehabilitation Research and Training Center on Supported Employment (Virginia), especially consumer monitoring of supported employment and development of the Vocational Integration Index. Other items are a list of principles of communication from a consumer perspective, a list of 10 consumer rights related to self advocacy issues, and guidelines for professionals working with constituents to facilitate self advocacy. (DB)

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RRTC

*"Improving Supported Employment Outcomes
for Individuals with Developmental and Other
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REHABILITATION RESEARCH AND TRAINING CENTER AT VIRGINIA COMMONWEALTH UNIVERSITY

Consumer Leadership in Supported Employment

There are hundreds of thousands of people with a variety of disabilities who are speaking for themselves. They are voicing their concerns and needs; and, yes, even angers and frustrations at a society which has forgotten them. With the advent of consumer rights, greater emphasis on the individual's involvement in planning and decision making, and the passage of the Americans with Disabilities Act (ADA); many professionals, consumers, and families are wondering what this means for supported employment. Are ADA and supported employment compatible? Do consumer advocates and Centers for Independent Living have issues with supported employment programs? In short, how does the welcomed trend toward consumer involvement relate to supported employment? We at Virginia Commonwealth University's Rehabilitation Research and Training Center on Supported Employment have asked ourselves these very questions and find the two directions highly consistent and parallel with the mutual goal of inclusiveness and integration into the community.

It may be beneficial to go back in time and take a look at how supported employment began. That is, take a look at how and why supported employment emerged as a service alternative for people with disabilities. As we have said on numerous occasions, a new concept does not arise unless there is a need for it. Supported employment emerged, because there were thousands upon thousands of people with severe mental disabilities who were viewed as incapable of working by most service providers and, for that matter, advocates. Their options in life were to be in day programs, adult activity centers, sheltered workshops, to stay at home, or, perhaps, even live in institutions. In the mid to late 1970's, a number of professionals began to experiment with different ways of providing services. The reason for this experimentation was primarily to meet



Consumers meet to discuss self-advocacy issues.

a need. The need was for people to realize competitive employment, earn a decent wage, and have an opportunity to develop a real work history.

Supported employment was developed to give consumers choices in the labor force. This service model focuses on consumer interest and provides an opportunity for individuals to identify a job, specify the working conditions, determine the wage level, select the job location, and decide the hours that they will work. With 72,000 people currently employed using supported employment, it is clear that more and more individuals with severe disabilities are asserting their rights and

going to work for the first time.

Supported employment will not succeed without consumer involvement. Supported employment programs cannot be effective and will not flourish without consumer and family participation, support, involvement, and a willingness to take the necessary risks that are inherent in any competitive employment position. The early consumers that entered the work force in the late 1970's and early 1980's were pioneers. They took the risk of losing their safe spots in adult day programs to enter competitive employment. In most states, there were limited support systems to help replace them if they failed.

The roots of supported employment are deeply entwined in consumer interests, choice, and inclusion. These roots are what has made supported employment one of the most popular and sustainable programs in the United States even in the face of one of the more severe recessions that this country has seen. We hope that you find useful the information provided in this newsletter on some of the issues related to consumer leadership in supported employment.

Paul Wehman, Director RRTC

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Consumers Speak Out

Dear Reader:

We are a group of individuals working on our self-advocacy skills. It is our hope that the information provided in this table will be helpful to a broad group of individuals. In addition, we hope that professionals will work with us to eliminate the barriers and facilitate the self-advocacy process.

Rhonda

Genny

James

Tasha

<u>Interview Questions</u>	<u>Consumers Talk About Self Advocacy and Supported Employment</u>
1. What does the word advocacy mean to you?	Self-advocacy means stirring up things a little bit to get what is rightfully yours. Go to people who will support you and have knowledge about a situation. We then can ban together to educate the people who do not have the awareness that we have.
2. What advice would you give to a person interested in supported employment services?	Don't be afraid to express your opinions and ask questions! I got so excited about finally having a job that I didn't question what an enclave was or what "piece work" meant. Be sure you understand what is happening and advocate for the best possible job!
3. What advice would you give to professionals to ensure consumer involvement in supported employment?	<p>Communication is the key issue. Know your consumers and make sure you don't make any major decisions without their consent. Individuals should guide the process, and the professionals should facilitate and give information that will enable the individual to make a good decision.</p> <p>Gain a more holistic view of the person and an appreciation for us as individuals. A better knowledge of a person's likes and dislikes will make it easier for you to provide incentives and avoid unsatisfying experiences. Interacting with us outside of the job or rehabilitation setting such as going out for a meal, movie, sporting event, or visiting at home is a valuable way of establishing a stronger rapport and learning about the total person.</p>
4. How have you benefited from supported employment?	<p>I've really changed. I've gotten more responsibility and people look up to me. I used to be really shy, but now I help out my coworkers. At first, I thought people would treat me like a charity case but no! If you make a mistake, you know straight up.</p> <p>Supported employment has really given me self-respect. Now I can do things for myself and feel like I am contributing rather than always having someone take care of me. I've also gained alot of friends including my employment specialist and all the coworkers on my jobsite.</p>
5. What do you see as the "roadblocks" to self-advocacy in supported employment?	<p><u>S</u>o much red tape that it is hard to get anything done. The process is often slow and people get burned out from having to fight all the time. I also think that consumers do not understand or know their rights or entitlements.</p> <p>The biggest roadblock is that people with disabilities don't see themselves as equals or that what they do can make a difference. Attitude plays a key role in removing barriers I know that I am just like anybody else. I just happen to use a wheelchair.</p>

Participatory Action Research

Participatory Action Research at the Rehabilitation Research and Training Center on Supported Employment

The words applied research can conjure up a picture of a group of researchers working isolated in their "ivory towers." These experts design a study or project, gather data, interpret findings, and write up results complete with a set of recommendations for a target group of individuals. Recently, the Virginia Commonwealth University's Rehabilitation Research and Training Center on Supported Employment (VCU-RRTC) has focused its efforts on an alternative research strategy known as **Participatory Action Research (PAR)**. Using the premise of PAR, persons with disabilities actively participate with VCU-RRTC staff members to plan and complete cooperative research projects. Consumers are now dynamically involved in identifying possible research topics, conducting research interviews and observations, and presenting results.

VCU-RRTC's use of Participatory Action Research has already had a tremendous positive effect on the Center's research program. First, consumer involvement has affected our choice of research studies. Some potential research topics have been rejected and others selected because persons with disabilities felt that they were potentially more relevant to their immediate needs. Second, we feel direct consumer involvement has shortened the time it takes to translate research results into information that is useful to persons with disabilities and service providers. The following two examples will demonstrate how VCU-RRTC is using PAR to incorporate persons with disabilities as active members of its research team.

Consumer Monitoring of Supported Employment

The **Consumer Satisfaction Survey** is an instrument developed by and for individuals with disabilities. The purpose of the instrument is to provide consumers, their families, and advocates with a tool that can be used to evaluate a worker's supported employment situation as well as give important feedback to direct service providers. The questions on the survey focus on assessing an individual's satisfaction with supported employment services and evaluating his/her degree of choice throughout the supported employment process.

The items included on the consumer satisfaction survey were identified by individuals with disabilities who are currently working or who have previously received supported employment services. A Consumer Focus Group was formed by 10 individuals with a disability including mental retardation, mental illness, brain injury, mental illness, cerebral palsy, or other physical disabilities. The participants identified the major issues in supported employment, the barriers, and the issues related to quality service implementation. A validation study to assess the revised instrument's validity and reliability currently is underway. The survey will be administered by personal interview to 120 individuals across several disability areas to evaluate its effectiveness at measuring job satisfaction, service quality, and consumer empowerment in supported employment.

Benefits of The Consumer Satisfaction Survey

A tool for consumers, family members, and advocates to

- monitor supported employment;
- provide direct input for service delivery and program development;
- plan vocational goals, make informed choices, and evaluate career opportunities.

An instrument for program directors, direct service providers, and policy makers to

- evaluate the quality and effectiveness of supported employment services from the perspective of its participants.

The Vocational Integration Index: A Guide for Rehabilitation Professionals, Special Educators, and Consumers

The guiding philosophy behind supported employment has been the belief that individuals with severe disabilities can and should be working in regular community businesses alongside nonhandicapped coworkers. The Vocational Integration Index is the first instrument designed to assess how integrated supported employment consumers are in their employment situations and was developed with the assistance of individuals with disabilities. The Index provides consumers, family members, supported employment personnel, rehabilitation counselors, and educators with an easy-to-use tool. It will help make job placement decisions that are compatible with an individual's personal and social interests and preferences. The Index which can be purchased through Andover Publishers has been statistically validated and found to be a sensitive and reliable instrument.

Benefits of the Vocational Integration Index

- Provides consumers with a tool for comparing employment situations and choosing jobs that are rewarding and personally satisfying.
- Provides direct service personnel with stringent criteria for assessing vocational integration opportunities during job development, placement, and follow-along.
- Provides consumers, families, advocates, program managers, direct service providers, and policy makers with a guide for determining the effectiveness and quality of a supported employment program.

Consumers Speak Out

The Art of Communication

— by Liz Perry-Varner

I am a consumer and a firm believer in consumer empowerment. The first step in the empowerment process is feeling comfortable with your own disability. Until we reach some level of comfort with who we are, we will not be able to make anyone else feel comfortable, especially those who are not consumers. A beginning point for reaching this level of comfort and ultimate empowerment begins with language. The following are some important points related to the art of communicating.

Guiding Principles

- We are individuals first and foremost.
- As individuals, we have unique abilities, likes, dislikes, and characteristics.
- View us in a holistic way, as a person who happens to have a disability as well as many other abilities.
- We rarely suffer from our disabilities, nor are we handicapped or disabled.
- Disabilities can be handicapping, but people are never handicapped.
- We must put a stop to the use of self-depreciating language and encourage others to do the same.
- Labels can be much more debilitating than the disabilities themselves!

Remember!

As long as it is thought that we are inferior or that our disabilities are contagious, language will be abused. After we educate ourselves, we must begin to educate people without disabilities.

Keys to Consumer Empowerment

— by Ed Turner

What are the keys to a successful consumer empowerment movement?

- Effective Leaders
- Good Communication
- A Purpose for Being
- A Solid Funding Base

Commitment, unselfishness, and strong motivation are qualities every effective leader should possess in order to inspire the organization to achieve its goals and purposes. Good leadership must involve the membership in the decision-making process so the whole organization will have an investment in all decisions. Decisions made by a select few breed distrust and may lead to apathy among the general membership. Periodic surveys of the general membership are helpful in sustaining interest and enables the leadership to assess the feelings of their members on issues being addressed by the organization.

Communication is a vital link between an organization's leadership and individual members. A newsletter sent to the local organizations on a frequent basis, or regular phone calls made to presidents of local chapters are essential in keeping information flowing in both directions. Keeping local chapters apprised of state level activities and keeping up on local concerns build a cohesive consumer movement.

A solid funding base is necessary, because it determines how frequent written communication can be sent out to the membership or if reimbursement can be offered to members traveling to meetings. What type of funding base should be sought is another big issue to be settled. Grants, though solid for a short time, can limit advocacy efforts if the organization disagrees with its source of grant funds. The old hesitance of "being careful not to bite the hand that feeds you" can prevent using effective advocacy techniques. Also, another drawback to grant funding is that these funds can only be used to carry out the purpose of the grant. Using dues to build a solid funding base is unrealistic when 75% of your membership is on fixed incomes. However, members need to be encouraged to pay their fair share, because this will measure their commitment to the organization.

You Have Rights!

Hi! My name is **Victor Hall** and I work for an ARC in North Carolina as the Self Advocacy Coordinator. I became interested in self advocacy issues about five years ago when I got tired of how I and other persons with disabilities were being treated in our society. Now I think that I have one of the best jobs around! I get to travel and remind people with disabilities that they have choices. The goal of my job is to support individuals as they work to become **self-advocates**. I hope that you will take the time to disseminate the following list with people who might be interested.

YOU HAVE RIGHTS!

1. You are a **PERSON, AN INDIVIDUAL, A CITIZEN**. You are not a client, resident, or patient.
2. You have a right to make choices about things that matter in your life (where you work, live, and recreate).
3. You have the right to say **NO**.
4. You have the right to ask questions and get answers from people who are paid to serve you.
5. You have the right to work and get paid a fair wage.
6. You have a right to community employment.
7. You have the right to develop relationships.
8. You have the right to influence the law.
9. You have a right to be part of the community.
10. **YOU HAVE THE RIGHT TO CONTROL WHAT HAPPENS IN YOUR LIFE.**

My Dream Job

Fill in the blank...



These were the remarks made by a group of self-described supported employment consumer advocates.

Who made the following statements?

1. I want to work in sports.

2. I want to make money doing something I enjoy.

3. I want to be my own boss.

4. I want a career that has room for advancement.

5. I want to select my own employment situation.

6. I want to own my own business.

Ten self-advocates volunteered to assist the Virginia Commonwealth University Rehabilitation Research and Training Center on Supported Employment to identify the issues facing consumers in supported employment services. It is the hope of all group members that persons with disabilities are afforded the same employment opportunities as any individual with the same qualifications. Employers, family members, rehabilitation professionals, and the general public must begin to understand that we offer resources to business, industry, and government.

Working With Constituents

For the past two years, the Virginia Department of Rehabilitative Services (DRS) has emphasized working with constituents to define a vision of the future and to enhance current services and partnerships. In a poem by Robert Frost, an individual must choose from two possible paths knowing that the choice will make all the difference. Similarly, the choice to broadly define "Stakeholders" in the department's activities and to seek their counsel and involvement has made a great difference in our approach to issues and opportunities.

Choosing the Path

It has long been my view that enhanced employment and independence for persons with disabilities will require rehabilitation agencies to seek partnerships with consumers, business and industry, local communities, and the ever diversifying non-profit sector. This requires considerable outreach, listening, and communication. For DRS, creating the Action Agenda was the first step along this path.

Every person in the agency had the opportunity to frame the department's future regarding improved client focused service delivery. The Action agenda envisions enhanced coordination and sharing of talents within the agency and joining with other organizations to develop teams and comprehensive services. Staff training, performance expectations, and the agency's organizational structure have been refocused to support this direction.

Involving Stakeholders

The Department's approach to involving stakeholders is intended to encourage both public and private commitment to consumer choice, equality of opportunity, and enhanced services. These goals can be achieved by building a firm foundation at a deliberate and persistent pace. It takes time for diverse groups to recognize common goals and needs and for trust to emerge.

As individuals work toward specific purposes, trust and teamwork may develop. DRS, for example, has included stakeholders on recruitment panels for key departmental positions. Groups such as the Head Injury Council and Employment Service Organizations have participated with DRS staff in defining processes and structures for current and future activities.

In addition, Major projects have been developed and implemented through highly collaborative efforts. For instance, the Virginia Assistive Technology Systems project operates under a federal grant designed to make assistive technology more accessible and affordable statewide. A council composed of consumers, providers, and staff of state agencies, participate fully in the development of every major initiative.

Pathways to Progress

Success will occur only if a joint vision of the future is developed and shared by persons with disabilities, public policy

makers, employers, and others in the public and private sectors. This can form the basis for effective coalitions for advocacy, development of new opportunities, and coordinated services. The impact of stakeholder involvement is limited only by imagination and the willingness to move forward.

— Susan L. Urofsky, Commissioner
Virginia Department of Rehabilitative Services

The Professional's Role in Facilitating Self-Advocacy

1. Realize that all people have the right to make choices.
2. Get to know people with disabilities as individuals.
3. Speak out against the labeling of any person.
4. Ask questions and listen carefully to be sure that you understand what is being communicated.
5. Encourage individuals to set goals.
6. Propose options for decision making rather than giving your personal opinion.
7. Know both federal and state laws that prohibit discrimination against persons with disabilities.
8. Participate in the information gathering process to determine if there are laws or policies applying to a specific advocacy situation and suggest procedures for resolving or appealing a decision.
9. Encourage individuals to define a problem and delineate facts, feelings, and major and minor issues.
10. Assist in determining expectations and sources of support.

Symposium Update

You Don't Want to Miss Our National Symposium on Supported Employment

What's New?

- Meet with participants of supported employment services.
- View the latest innovations in assistive technology.
- Hear the most recent information on supported employment across all disability areas.
- Participate in topical forums on consumer/professional partnerships.
- Meet international leaders in supported employment.
- Hear Ed Roberts present the key-note address.
- Learn how to TAKE leadership in your community.
- Enjoy a variety of evening entertainment.
- Cruise Norfolk Waterside or visit the Beach.

Remember!!

October 14-16, 1992
RRTC/VCU
Symposium on
Supported
Employment

Meet at Norfolk
Waterside in Virginia
to find out the latest
information on
Supported Employment.

Pat Brown-Glover, Symposium Coordinator
Phone: (804) 367-1851
TDD: (804) 367-2494

Look for a Registration Packet in the Mail. See you in October!!

Virginia Commonwealth University Rehabilitation Research and Training Center on Supported Employment

The Virginia Commonwealth University Rehabilitation Research and Training Center on Supported Employment, funded in 1988 by the National Institute on Disability and Rehabilitation Research, provides research, training, and leadership on supported employment for citizens with developmental and other severe disabilities. Research at the RRTC focuses on supported employment policy analysis, program implementation at the systems and consumer level, and program evaluation issues. The RRTC provides training for rehabilitation counselors, program managers, employment specialists, consumers, educators, employers, parents, and other persons interested in supported employment.

For further information write to VCU-RRTC, VCU Box 2011, Richmond, VA 23284-2011. Specific information regarding this newsletter should be addressed to Ms. Katherine Inge at this same address. Funding for this publication is provided by the U.S. Department of Education, Grant # H-133B80052-91.

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Training Materials

Audiotapes are now available for the Rehabilitation Counselor Desk Top Guide (\$14.95) and the Supported Employment Services for Individuals with Traumatic Brain Injury (\$15.95).

SET NET video library offers videotapes of telecasts on a wide variety of supported employment topics. Guest presenters include over 50 national experts. If you are interested in any of these RRTC products, please contact Teri Blankenship at (804) 367-1851.

NEW

Life Beyond the Classroom: Transition Strategies for Young Adults with Disabilities

by Paul Wehman

Available through: Paul Brookes Publishing Company
P.O. Box 10645
Baltimore, Maryland
(Available 8/92)

Vocational Integration Index

by Wendy Parent, John Kregel, Paul Wehman

Available through: Andover Medical Publishers
125 Main Street
Reading, MA 01867
(Available 4/92)

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