TASH

CONNECTIONS

Equity, Opportunity and Inclusion for People with Disabilities since 1975

Inside This Issue

Customizing Employment Opportunities for People with Disabilities

TASH MISSION

TASK supports the inclusion and full participation of children and adults with disabilities in all aspects of rheir communities as determined by personalized visions of quality of life.

TASH's focus is on those people with disabilities who:

- **Are most at risk for being excluded from the mainstream of society**
- **Are perceived by traditional service systems as being most challenging;**
- **Are most likely to have their rights abridged;**
- **Are most likely to be at risk for living, working, playing, and/or learning in segregated environments;**
- **Are least likely to have the tools and opportunities necessary to advocate on dieir own behalf;**
- **Historically have been labeled as having severe disabilities; and,**
- **Are most likely to need on-going, individualized supports in order to participate in inclusive communities and enjoy a quality of life similar to that available to all citizens.**

TASH accomplishes this through:
- **Creadng opportunities for collaboration among families, self-advocates, professionals, policymakers and other advocates;**
- **Advocaongfor equity, opportunities, social justice, and rights;**
- **Disseminating krKwkdgcandmfbtmation;**
- **Supporr&jfGradBerice th research that translates to excellence in practice;**
- **# Promc«agindividualized, quality supports;**
- **Working toward the elimination of institutions, other congregate living settings, segregated schools/classrooms, sheltered work environments, and other segregated services and toward replacing these with quality, individualized, inclusive supports;**
- **Supporting legislation, litigation and public policy consistent with TASH's mission; and,**
- **Promoting communities in which no one is segregated and everyone belongs.**

TASH (formerly The Association for Persons with Severe Handicaps) is an international advocacy association of people with disabilities, their family members, other advocates and people who work in the disability field. **TASH** actively promotes the full inclusion and participation of persons with disabilities in all aspects of life. To receive an information packet, contact: **TASH**, 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204 or phone (410) 828-8274, ext. 8 or e-mail: info@tash.org.

■ For issues of policy, chapter or committee support, or general concerns and suggestions, call: Nancy Weiss, Executive Director, at (410) 828-TASH, Ext. 101, e-mail:nweiss@tash.org

■ For information on conferences, regional workshops, or technical assistance, call: Denise Marshall, Director of Meetings and Technical Assistance, at (410) 828-TASH, Ext. 103, e-mail:dmarsh@tash.org

■ For questions about the 2002 Annual TASH Conference, call: Kelly Nelson, Conference Coordinator, at (410) 828-TASH, Ext. 105, e-mail:knelson@tash.org

■ For questions about membership, conference registration or exhibiting, call: Rose Holsey, Director of Operations and Member Services, (410) 828-TASH, Ext. 100 or rholsey@tash.org

■ For information on governmental affairs, call: Jamie Ruppmann, Director of Governmental Relations, at (410) 828-TASH, Ext. 104, e-mail: jruppmann@tash.org

■ For information on newsletter submissions and advertising, marketing and promotions, or permission to reprint, call: Priscilla Newton, Director of Marketing, at (410) 828-TASH, Ext. 102, e-mail:pnewton@tash.org

■ For information on Research and Practice for Persons with Severe Disabilities (a publication of TASH), call: Fredda Brown, Editor-in-Chief, at (718) 997-5243, e-mail: fbrowncuny@aol.com

■ Don't forget to visit TASH's web site at http://www.tash.org

From the Executive Director
BY NANCY WEISS

Another Tragedy ...

At age nine Matthew Goodman went to live at the Haddonfield, New Jersey campus of Bancroft, a residential school for children with autism. There his mother, Janice Roach, family believed that Matthew would receive a good education and appropriate therapy. He lived in an apartment on the Bancroft campus for four years. He had some behavior problems, but a former teacher at Bancroft described Matthew as funny, social, and easily redirected when he got upset. He loved school and social events. He played games, teased, made up stories, watched videos and was always ready to go for a walk.

During the summer of 2000 Matthew developed a staph infection. He needed intravenous (IV) antibiotics. He was hospitalized in a community hospital and restrained for two months so that he wouldn't pull out the IV. He was terribly upset and begged for the restraints to be removed. When the hospital staff did remove the restraints for short periods he was so distraught he would pick at his skin and tear at his ear. When he returned to Bancroft, the staff there asked his parents for permission to put him in their medical unit for just two weeks and to put arm splints on him during this time so that he wouldn't pull at his ear to allow his ear to heal.

The restraints were never eliminated. Matthew would beg to have them off, but staff told his mother that they thought he would injure himself if they took them off. They added medication to sedate him, then more medication, then leg restraints and, finally, a helmet with a face guard. His mother was frantic. Against the protests of his parents, Matthew was made to wear these restraints almost all of the time. They came off only after he was asleep. Staff told his mother that the restraints needed to be on all of the time because if they were to take the restraints on and off, Matthew might perceive them as a punishment.

Matthew in restraints at Bancroft.

Matthew was no longer taken to school, saw no friends, enjoyed no recreation, went on no more walks, and was offered no activities or programming. This was the readiness model taken to absurdity. It seemed as if Bancroft had no way of viewing Matthew's behavior as anything other than a response internal to who he was; no ability to view his behavior as a response to what little life he was offered. Until Matthew demonstrated that he no longer needed the restraints, they would stay on. And as long as they stayed on, the behaviors for which they were prescribed could do nothing but get worse.

Matthew's parents hired consultants who understood the relationship between behavior and environment. They came to Bancroft and spent time with Matthew. They recommended positive behavioral interventions that they were confident would be effective. All of them were clear that the restraints needed to come off. No changes were made to Matthew's services in response to these recommendations. The State of Pennsylvania was paying Bancroft $350,000 a year and for this almost $ 1,000/day,

Matthew was kept drugged and restrained on the floor for months on end.

This independent, funny, charming kid now had to be fed and toileted. The mother of another resident on the same unit said that she saw Matthew at least weekly for six months and was shocked to learn later that he was ambulatory. She never saw him walk or speak. She said, "on those rare occasions when he was awake, Matt would reach out his hand to me and try to talk as though pleading for help." She said that she couldn't get the image out of her mind of the affectionate, outgoing boy Matthew must once have been.

Matthew's mother visited him regularly. Often she was told that they had added another medication or upped the dosage of one he was on. Eventually, he spent his days lying on the floor, drugged and unresponsive. He couldn't lift his head. His mother was on the phone for hours every day desperately trying to find another place Matthew could go and begging with the funding agencies in Pennsylvania to authorize funds for a different kind of service. She told everyone she spoke with that Matthew was dying; that the restraints were going to kill him. She was dismissed as an overly emotional mother. Once people heard that this was a kid who was in restraints all day, no program wanted to take him.

Finally, Matthew's mother found a program willing to take him in Florida. The people from the Florida program who visited him were horrified at what they saw and assured his mother that there would be no restraints in their program. Matthews mother arranged private air transportation through a charitable organization and with relief, scheduled his departure from Bancroft for just a few days later.

On Sunday, February 3rd of this year, Matthew's mother went to Bancroft to tell Matthew that it wouldn't be long now. She had found a place where he could go. He would be leaving on Thursday, just four days later. Matthew's mother laid down next to Matthew on the floor with her face next to

ANOTHER TRAGEDY...
Continued from page 3

his. She held his face, caged in his helmet, and promised him that life would be better and the restraints that he hated so much would soon be a thing of the past. She urged him to hang in there for just a few more days.

But Matthew didn't get the days he needed. Just three days later, the day before Matthew was to leave Bancroft, Matthew's mother got a call from a nurse on the unit at Bancroft who said, "I'm sorry to have to tell you this, but we can't find any vital signs." His mother asked what hospital they were at, ready to run out the door and meet them. The nurse told her that they were not at a hospital. Matthew's mother said to call her right away from whatever hospital he was taken to — she would meet them there. She waited for a call. The Bancroft staff never called 911. They took time to pack an overnight bag with clothes for Matthew. Staff carried him to the agency van. They then drove over 50 miles, past 5 other hospitals with emergency rooms, to an out-of-state hospital in Philadelphia. When they arrived at the hospital Matthew was still alive but he was in shock. He was unconscious but still wearing the ever-present restraints. He died the next day from sepsis (a toxic condition resulting from the spread of bacteria), pneumonia and acute respiratory distress. He had been in restraints for sixteen months.

The state investigation found numerous violations related to Bancroft's failure to follow Matthew's behavior plan. It was also found that Matthew's psychologist who prescribed the restraints was, in fact, not licensed or certified as a psychologist. He was a psychologist in title only. The school was fined $100,000, less than a third of what they had been paid to care for Matthew over the past year, and they continue to operate. They were just granted a full license to continue operations.

Restraints and seclusion are not treatment. Rather, they represent the failure of effective treatment. While it is sometimes necessary to physically intervene briefly when someone is at imminent risk of hurting him/herself or others, when physical intervention is needed the very next questions we should be asking are:

• What is frustrating this person?
• What would he change about his life?
• Does she have a life that is meaningful to her?
• Can she tell us what she wants or needs, and are we listening?

Dangerous or disruptive behavior can be reduced by making people's lives better — by enhancing, rather than sacrificing self-esteem, relationships with others, and human dignity. The use of seclusion and restraint results in psychological harm, diminished self-image, loss of dignity, and too often, serious injury or death. Post-traumatic stress disorder is increasingly being diagnosed among persons who have been subjected to the systematic use of seclusion and restraint. These procedures are used far too often for the purposes of control, as a punishment, in place of quality programming, as a substitute for adequate skilled staff, or to take the place of a life that's worth living. We fool ourselves into believing that such procedures are a necessary or conscionable part of treatment.

There are no federal regulations or legislation preventing the kind of abuse Matthew suffered. The Federal government has no reporting requirements for deaths or injuries while in seclusion or restraint for public or private school programs, camps, or agencies serving adults with disabilities.

Matthew's mother and other advocates are working to pass a law in New Jersey that would make restraint, other than brief physical intervention for safety, illegal. She is fighting to assure that Matthew's death was not in vain. She is hoping that, as a result of this tragedy, laws will be passed that will protect others from similarly inhumane and dangerous interventions.

What can you do?

••• Learn more about Matthew's Law, the law being introduced in New Jersey to make the use of aversive techniques and the inappropri-

Matthew Goodman

ate use of restraint illegal. See the website for Matthew's Law at <http://matthewslaw.bravepages.com>

• Share the website with publications, listserves and other information resources.

• IN NEW JERSEY: Contact your state assemblypersons and senators, telling them to support A2855, "Matthew's Law limiting the use of restraints." Tell them that the other two restraint bills proposed on the same day as Matthew's Law do not come close to addressing the problem.

ACROSS THE COUNTRY: Contact the bill's sponsor, Assemblyman Eric Munoz, M.D., at the address or e-mail on the web site. Tell him of your support and thank him for caring about this important issue. If you have a story to tell about the damage done by restraint use or about the efficacy of positive approaches, please tell it! It is vital that we counteract misleading information from restraint-dependant programs that are telling the New Jersey legislators that restraint is a necessary part of many people's treatment.

* Consider starting a similar effort in your state. Call TASH at 1-800-482-8274 for support.

Faculty Position In Early Intervention
Louis de la Parte Florida Mental Health Institute
DEPARTMENT OF CHILD AND FAMILY STUDIES - Division of Applied Research and Educational Support

Research Assistant Professor/Research Associate Professor

This position is a grant-funded, 12-month faculty position for an early intervention research and demonstration project focused on providing positive behavior support to young children and their families in the Part C service delivery system. This position will coordinate the daily activities of project staff and direct project activities. This position will work in collaboration with a research leadership team (Glen Dunlap, Lise Fox) and project personnel from related research and training projects including the OSEP-funded Center for Evidence-based Practice: Young Children with Challenging Behavior. Additional responsibilities with this position will include conducting research, grant development, writing for publication, workshop and conference presentations, and maintaining familiarity with current research in early intervention for young children with challenging behavior and positive behavior support.

This position is within the Division of Applied Research and Educational Support. The Division of Applied Research and Education Support (DARES) is directed by Dr. Glen Dunlap and houses over 20 externally funded projects in the areas of disabilities, early intervention, autism, family support, and positive behavior support with an annual operating budget of approximately $8 million. The Division employs over 100 faculty and staff who are actively involved in research and program development efforts to improve the lives of children and families who face challenges due to developmental disabilities, challenging behavior, or poverty

Minimum qualifications: Doctorate in special education, **early** childhood education, child development, psychology, communication disorders or related field. Knowledge of intervention approaches in social-emotional development and experience working with young children with developmental delays.

Preferred qualifications: Experience in program leadership of early intervention research, demonstration, or community programs. Experience in infant mental health or positive behavior support. Experience in staff supervision, providing training and technical assistance to early educators and families, working collaboratively with families and outside agencies, professional workshop and conference presentations, writing grant proposals, writing for publication, and conducting research.

Note: Individuals hired for these positions will be required to undergo a fingerprint and background check.

Application Deadline: December 13, 2002. When applying for the position, please specify Position #11827

Mail, fax, or electronically transmit cover letter, vita, and a list of three references to: Patricia White, FMHI-USF/MHC2113A, 13301 Bruce B. Downs Blvd., Tampa, FL 33612-3899, Fax: (813) 974-6115, E-mail: pwhite@fmhi.usf.edu

The University of South Florida is an Affirmative Action/Equal Opportunity/Equal Access Employer. For disability accommodations, please call: (813) 974-4612; TDD 974-2218.

Early Childhood Special Education

The University of Wisconsin Oshkosh College of Education and Human Services has an open position in Early Childhood Special Education (Position 11 1a.0203, Assistant/Associate Professor, tenure-track, academic year).

Responsibilities include teaching undergraduate and graduate courses in a collaborative program for early childhood special education and early childhood elementary education, supervision of related field experiences, professional development, research, scholarly activities, and service. A doctorate in Special Education or a related area (dissertation written prior to September 2, 2003, with a defense scheduled no later than December, 2003) is required. Prior experience teaching young children with disabilities is essential. Review of applications will begin on January 10, 2003 and continue until position is filled.

Applicants should submit a letter of application specifying position number, resume, statement of teaching philosophy, transcripts, and three current letters of recommendation to: Dr. Michael Ford, Associate Dean, College of Education and Human Services, University of Wisconsin Oshkosh, Oshkosh, WI 54901. *The University of Wisconsin Oshkosh is an Affirmative Action/Equal Opportunity Institution.*

UNFINISHED BUSINESS

Lawmakers Negotiate Family Opportunity Act

Negotiations over the Family Opportunity Act (S 321), a bill that would permit middle income families with children who have significant disabilities to buy into the Medicaid program continuing. Rep. Pete Sessions (R-Texas) en meeting with House and Senate staff to try to reconcile the current version of the "Family Opportunity Act of 2002" with several measures supported by House Energy Commerce Chair Billy Tauzin (R-

Under the Senate bill, children with disabilities in families with incomes up to 250% of the federal poverty level, or $45,000 for a family of four would be eligible to receive Medicaid benefits. Current income eligibility limits are 133% of the poverty level for children younger than age 6 and 100% of the poverty level for children ages 6 to 18. The bill would give states the option of changing those eligibility qualifications for children with disabilities. It is estimated that about 200,000 additional children with disabilities would be eligible for coverage under the expansion. Rep. Tauzin supports a

change in the bill that would provide states the option of offering coverage through either their Medicaid or CHIP (Children's Health Insurance Program) programs. It is hoped that Senate and House discussions will result in a compromise that will mean the Family Opportunity Act will be passed in the House when Congress returns after the just-concluded mid-term elections.

Proposals to Amend IDEA *are* Introduced in Congress

Several bills have been introduced in the House of Representatives. Representative Patrick Kennedy of Rhode Island introduced the "Early Intervention Improvement Act" (H.R. 5076) and the "Reducing Special Education through Prevention Act" (H.R. 5352) in September. The Early Intervention Improvement Act is aimed at ensuring that all children under the age of 3 years who are involved in a "substantiated case of child abuse and neglect" are referred to Child Find for assessment and, if necessary, early intervention services. In addition, the bill targets an additional group of infants and toddlers who may be at risk of developmental delay or disability by virtue of their "family condition" which could include diagnosed serious maternal depression, confirmed parental substance abuse, or documented family violence.

TASH has expressed concerns about the wording of the additional "at risk" category as well as the assumptions about the capacity of both current Child Find and early intervention providers and state mental health systems to diagnose and treat mental illness in infants and toddlers who may be referred to them.

The Reducing Special Education Through Prevention Act proposes to improve school-based interventions for students who may develop emotional or behavioral disorders. Specifically, the proposal amends Part D of the IDEA to allow a state or local education agency to apply for a three-year grant to implement programs, strategies and services

designed to reduce the number of youngsters who require the provision of special education and related services for "emotional disturbances."

The IDEA Paperwork Reduction Act of 2002 was introduced by Representative Ric Keller of Florida. This bill has several provisions aimed at "relieving teachers, administrators and related service providers from excessive paperwork burden" and to "reduce time spent by teachers on non-instructional activities." The bill proposes a set of "strategic proposals that are aimed at achieving its purpose:

•• Requiring the Secretary of Education to develop and disseminate "streamlined" models of documents for Individual Education Program (IEP) development, procedural safeguard notices, and prior written notice provisions to parents and guardians

• Permitting states to let their local school divisions, with the informed and written consent of parents, to develop a 3-year IEP which will contain three year goals, some coinciding with what is called "natural transition points" for the student, as well as annual goals for measuring progress in the general curriculum. Further, a "comprehensive review and revision" of the IEP would only occur at those "natural transition points" rather than annually.

• Increasing emphasis on whether or not a student receiving special education services and supports is making satisfactory progress towards achieving the three-year goals (as measured by the annual goals, possibly).

••• Grant waivers of unspecified "paperwork requirements" for 4 years to no more than ten states for the purpose of demonstrating "effectiveness" of various proposals in reducing "paperwork" and non-instructional time spent by teachers in compliance with IDEA.

In addition, the bill gives local school officials "discretion" about whether any member of the IEP team can be "excused from meetings unless the parents or guardians object. The bill continues in this manner, leading TASH to wonder how much "burden" is

UNFINISHED BUSINESS

Continued from page 6

going to be relieved by the micro-managing of every interaction between families and school personnel in planning educational supports and services and in protecting the civil rights of students with disabilities. And, of course, TASH strenuously opposes any proposal that would "strip down" those rights and fail to fully inform parents and students of their procedural safeguards.

This bill is significant because the co-sponsors are Representative John A. Boehner (Ohio), who is Chairman of the House Committee on Education and the Workforce, and Representative Mike Castle, who chairs the Subcommittee on Education Reform, which has jurisdiction over special education programs. TASH members are urged to make note of the House Education and Workforce Committee web site: www.edworkforce.house.gov. Comments about changes to IDEA are still being solicited and taken. In addition, the web site is an accurate and timely source of information about education issues moving through the Congress.

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## TASH Continues to Oppose use of Restraints, Seclusion and Abuse

TASH Executive Director, Nancy Weiss along with Pat Amos of the Family Alliance to Stop Abuse and Neglect, New Jersey TASH members and 200 advocates rallied at the New Jersey State House on Monday, October 7. Speakers included Janice Roach, mother of Matthew Goodman, who died on February 6 of this year. Matthew was being "treated" at the Bancroft School. Prior to his death, Matthew spent literally months in physical arm restraints and a helmet with a darkened visor

restricting his vision (see Nancy Weiss's article beginning on page 3).

New Jersey Assemblyman Dr. Eric Munoz has introduced legislation that would severely restrict the us of restraints in facilities for children and adults with developmental disabilities and traumatic brain injury to a narrowly defined set of emergency only circumstances. Under this law, restraints and seclusion could not longer be written into IEPs and Individual Habilitation Plans as "treatment."

For further information and updates about Matthew's Law visit http://matthewslaw.bravepages.com. To help TASH in our fight against abuse and restraint of children and adults with disabilities, contact Nancy Weiss (nweiss@tash.org)or Jamie Ruppmann (jruppmann@tash.org).

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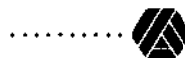
TASH in Action! Is your vote important? Are you registered? How does TASH decide what issues to support and what issues to oppose? What's happening with MiCASSA, and when is the Congress going to do something about housing and people with disabilities?

These questions and more will be answered if you drop by the TASH in Action! exhibit at next month's annual conference in Boston. Talk with Governmental Relations staff and members who are interested and knowledgeable about policy issues that effect the live of people with disabilities. For conference information, including a registration form, visit <www.tash.org>

JUST ADDED!

Research to Educational Practice: A Conference within the Conference for Present and Future Teachers and Practitioners

Sheraton Boston and Hynes Convention Center
Saturday, December 14th
9:00 am - 3:30 pm

Special Saturday Only registration fee:

$59.00 for TASH members
$89.00 for non-members
This special Conference within the Conference is open to all full conference registrants at no additional charge. To register for the Conference within the Conference, use the registration form located on the TASH web site at <www.tash.org/2002conference/regonline.htm>, and select the "Saturday Only" category.

At the 2002 TASH Annual Conference, the Saturday Conference within the Conference features a series of dynamic sessions focused on practical, day-to-day strategies for translating current research knowledge into educational practices that enrich the lives of students with significant disabilities and their families.

Sessions will afford participants the opportunity to hear about the most progressive practices directly from nationally known authors in the field. Featured presenters:

Rick Albin - Positive Behavioral Support
Glen Dunlap - Positive Behavioral Supports
Mary Falvey - Curriculum and Instruction
Chris Kliewer - Literacy and Communication
Diane Ryndak - Curriculum and Instruction
Marti Snell - Curriculum and Instruction
and more!

Participants will have the opportunity to select sessions from one of three strands: Communication and I.iteracy, Curriculum and Instruction, and Positive Behavioral Supports. Lunchtime will include a poster session in which graduate students will display the results of their research and other innovative projects focusing on students labeled with severe disabilities.

For an updated listing of conference sessions, accommodation, travel, child care, and other information, as well as the conference registration form, please visit www.tash.org/2002conference

Employment Strand and Sessions

*T*he following represents a partial listing of the employment related sessions scheduled throughout the upcoming TASH Annual Conference.

This year's conference, "Our Quest: Opportunity, Equality, Justice" is scheduled December 11-14 2002 (preconference workshops on December 10, 2002) in Boston, Massachusetts at the Sheraton Boston and the Hynes Convention Center.

For a listing of sessions in other topic areas, including strands, exhibits, and special events, please visit www.tash.org/2002conference. Please note that this is a preliminary schedule that is subject to change.

Employment Strand

Thursday and Friday
Convention Center Rooms 201 and 202
Strand Coordinator: John Butterworth
This strand features sessions that cover all the important issues related to the employment of people with disabilities. Sessions covering policy, systems, and personal perspectives will be held on both days in Room 201. Those sessions focusing on practice will be held in Room 202.

Wednesday, December 11, 2002
10:00 am-4:00 pm Pre-Conference Session
The Ticket To Work: What Are The Opportunities?
Speakers: David Hoff, Elena Varney
The Ticket to Work, which is currently being introduced by the Social Security Administration, provides a potential opportunity for people with disabilities to have increased choice regarding services that will help them find and keep a job. Attendees at this workshop will learn about the Ticket program, the opportunities and challenges it presents, and ideas for utilizing it to enhance individual opportunities and empowerment.

Thursday 10:15am-l:15pm
Pushing the Employment Agenda: State Perspectives
Speakers: John Butterworth, Allison Cohen, Dana Scott Gilmore, Deborah Metzel
This session will focus on the factors that contribute to high performance in integrated employment among states. Research findings will be presented, followed by a panel of stakeholders from several states who have been directly involved in facilitating systems-level change.

Status Quo, Stigma in Employment
Speaker: Sarah Berger
What are your stigmas in hiring persons with mental illness? This interactive workshop will test your marketing, personal perceptions, and accommodations skills.

Thursday, December 12, **2002**
11:30 am— 12:30 pm
Opportunity, Equality and Justice: Maine's Systems Change Efforts in Employment Supports
Speakers: Deborah A. Gilmer, Alan Kurtz, Kathy Son, Lenny Berry, James Meehan, Brenda Harvey, Mel Gleason
This panel presentation will share information on a number of systems change initiatives undertaken in Maine to build the capacity of community rehabilitation agencies to implement a new vision of employment supports, including curriculum development, a number of statewide staff development activities and policy change.

The Right Person for the Job: Developing Business Capacity to Include Employees with Autism
Speakers: Bud Cooney, David Hagner
This session will present findings from a one-year project developed to improve the capacity of employers successfully include employees with autism. The essential components for success reported by 14 employers along with a training module developed for potential and current employers of persons with autism will be presented.

Thursday.December 12, 2002
2:15 pm — 3:15 pm
Integration of People with Disabilities into One-Stop Systems: A National Progress Report
Speakers: David Hoff, Sheila Fesko, Lora Brugnaro, Allison Cohen
One of the newer strategies for meeting employment needs of people with disabilities is use of One-Stop Centers. Is the generic workforce development system really working for people with disabilities? This session will look at current progress and future trends.

Social Security Benefits: Making Sense of the Maze
Speaker: Elena Varney
As people with disabilities seek employment, the impact of income on Social Security Benefits in often a major concern. This session will cover: the differences between SSI and SSDI; how employment impacts benefits; work incentives available; and tips for dealing with SSA.

Thursday. December 12, 2002
3:30 pm-4:30 pm
Incorporating Social Security Work Incentives in Transition Planning
Speaker: Ellen Condon
Social Security Work Incentives are an effective resource in Transition Planning. Student case studies which illustrate the utilization of work incentives to promote choice and consumer controlled supports will be shared along with strategies developed by schools and communities to access these resources.

Thursday. December 12, 2002
4:45 pm-5:45 pm
Closing Up Shop: It's the Process, Not the Product, That Counts
Speakers: Paul Dickin, Phil Smith, Bryan Dague, Mike Moody, Alan Bushey, Paul Bakeman
Come learn about what it was like to close down the last sheltered workshop in Vermont! Self-advocates, family members, staff, and other stakeholders will describe an ongoing process of conversion of a small, family-centered agency.

You Can Get There From Here: Finding Your Way After High School
Speakers: Beth- Anne Dabek, Erica Sandelin
The journey from high school to adult life can be both challenging and exciting. Come learn what students from five urban high schools in Massachusetts are doing to pursue their dreams of working and recreating in their communities.

Friday, December 13, 2002
8:00 am-10:15 am
Promoting Meaningful Daytimes: Strategies and Issues
Speakers: Pam Walker, Patricia Rogan, Elizabeth Obermayer, Jeffrey L. Strully, Jennie Todd
Despite great strides toward integrated employment, many adults remain in segregated settings or bored and isolated at home. This presentation discusses support for a wide variety of daytime pursuits, including: paid and volunteer work, post-secondary education, and community connections.

Friday, December 13, 2002
10:30 am-11:30 am
Do What You Love....Love What You Do
Speakers: Ken Renaud, Joshua Joyal, Delia Boro, Paula Ortega, Charlotte Testa

Employment Strand and Sessions

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This session looks at the PAL Employment Information Network, an initiative that is comprised of individuals with disabilities who are successfully employed. We will demonstrate how these individuals play an important role in the transition process by sharing their personal success stories with high school students with disabilities and by serving as mentors. They encourage the students to choose jobs that utilize their talents and skills.

When Existing Jobs Don't Fit: Job Creation for People with Significant Barriers to Employment
Speakers: Melanie Jordan, Kimberly O'Neil

"Pre-existing" job openings often do not meet the needs of individuals with significant disabilities. This interactive session will offer practical information, strategies, and many examples and success stories related to creating and restructuring jobs to meet distinct interests and needs.

Friday, December 13, 2002
11:45 am-1:30 pm
TASH Town Meeting
Speakers: Martin Gerry, Social Security Administration, Stephanie Lee, OSEP, Judith Heumann, The World Bank, Anne C. Smith, Zuhy Sayeed and other leaders will join Jamie Ruppmann, TASH Director of Governmental Relations, to discuss the current state of the states in disability policy.

Friday, December 13, 2002
1:30pm-2:30pm
Building Community Connections: A Networking Approach for Transition Age Students
Speaker: Colleen O'Mara Condon

This session offers an overview of a workshop on how students can use networking, the most effective job or career search strategy. It will include sample exercises as well as discuss the facilitator's role in empowering students to use their networks.

Optimal Roles of Job Developers and Job Coaches to Promote Natural Supports in the Workplace
Speakers: Carl Cignoni, Brian Patingre, Madonna Trotter

Natural supports are a determinant of success for people with disabilities at work. Many roles job developers and coaches assume either promote or discourage natural supports, often unawares. Participants will examine the optimal roles to promote natural supports.

What is Our Obligation to People Who Do Not Seem to Want to Work
Speakers: Jeannine Burns, Aimee Pavlak, Matt Slosek, Melissa Stefano

People with disabilities may not want to work due to fear of failure, undesirable employment options, no positive work experience, and low expectations. This session will explore these and present strategies to create positive experiences for people to work successfully.

Friday, December 13, 2002
2:45 pm-3:45 pm
Accessing Community Transportation, Inc.-Apeer travel training Self Directed Support Corporation
Speakers: John Susa, Terri Trautman, Connie Susa, Mark Susa

Despite multiple disabilities, Mark Susa is president of a business that teaches others with disabilities how to use public transportation. Learn how his school to career transition and state-funded supports were used to create this self directed support corporation.

One Stop Career Centers: A Resource for All Job Seekers
Speakers: Cynthia Thomas, Pauline Donnelly, Lara Enein Donovan

This session will provide an overview of the One Stop Career Centers and how they can be used by individuals with disabilities seeking employment. Promising practices will be described to provide attendees with a better understanding of the system and what they can do to make it work for them or individuals they support.

Friday, December 13, **2002**
4:00 pm-5:00 pm
It's a Job You Really Wanted, But Now Are You Happy?
Speakers: Bruce M. Menchetti, Elizabeth Haines, Lori Garcia, Renee Llewellyn

In this session you will learn how people with disabilities helped develop a job satisfaction survey to guide employment services. Most importantly, however, you will hear from a self-advocate, as she discusses what is important to her personal job satisfaction.

Sometimes I Get Fired: Co-memoir Eugene Marcus' Supported Work Experiences
Speakers: David Marcus, Eugene Marcus

Join this session as father and son discuss Gene's life experiences in regards to supported work. Using facilitated communication, the presenter will discuss his successes and failures in the work place. Come to this interactive session prepared to ask questions.

Saturday, December 14, 2002
10:00 am-11:00 am
How To File A Winning ADA Employment Discrimination Complaint
Speakers: Kathryn Moss, Tia Nelis, Joy Weeber

Under Title I of the ADA, individuals who have experienced employment discrimination based on a disability may file a complaint. This workshop will teach participants about how to file a winning complaint.

The following Poster Sessions related to employment are scheduled from 8:00-10:00 am on Saturday. December 14. 2002.

Creating Vocational Opportunities for Students with Disabilities
Speakers: Chris Peltier, Laurel Peltier

This multimedia workshop will present various approaches to creating community-based vocational opportunities through collaborations with schools and businesses. This presentation will utilize group exercises to inspire creative thinking about students' careers and will engage the participant for positive action.

It's Not About Jobs, It's About Income
**Speakers:** Darcy Smith, Doreen Rosimos

This presentation will focus on how Doreen Rosimos and Darcy Smith have made the production of INCOME happen across the country. They will discuss case studies, and the importance of engaging the community in your life and enterprise. Combining Joy, Permission and Investment has lead to life altering experiences for many individuals. We will engage you with lively conversation and a different view to bring income into people's lives, no matter the challenges.

Let's Get Working! How to Transform your Vocational Department into Cutting Edge Program Emphasizing Person-Centered Planning
Speakers: Kate Clark, Stan LeRoy, Jo-Ann Bernard

This presentation will highlight the areas that we have developed in our program including assessment and evaluation, job preference inventory, employability skills curriculum, career development, and supported employment. The presentation will include strategies to involve family and friends and the job seeker for future planning within the IEP Vision Statement. It is our hope that individuals who attend our conference will take away multiple resources that they will be able to utilize easily upon conclusion of our presentation.
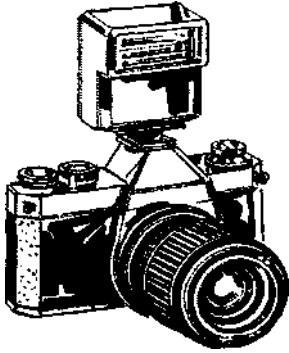
Through Our Lenses

BY ABBY L.W. CROWLEY

A unique program at the Lt. Joseph P. Kennedy Institute in Washington, D.C. is expanding career options for people with developmental disabilities. The U.S. Department of Labor, in its Occupational Outlook Handbook, paints a promising picture of growth in need for people who can operate cameras and process photographs using traditional and digital technologies.

Careers in portrait, commercial, industrial and news photography offer about 161,000 jobs nationwide. The entertainment market, particularly the cable industry and the Internet, has increased the demand for camera operators. The increase in availability of one-hour processing facilities in malls, supermarkets and retail outlets provides an additional 42,000 jobs nationwide.

In most cases, employers prefer applicants for these jobs who have had some experience in the field. Albert "Al" Price, an experienced photographer and a person with many years of experience working with people with developmental disabilities, thought that he could combine his two areas of expertise to develop a new kind of training program within Kennedy Institute's employment services division.

Starting with a $3,000 investment, he purchased ten cameras and 500 rolls of film and started working with a group of eight adults in the basics of 35mm black and white photography in a 16-week, 250-hour program called Through Our Lenses. In the beginning, he had the students' film developed and printed commercially. Their first exhibit, My First Exposure, garnered acclaim and media exposure for the program. This led to donations and grant opportunities to purchase darkroom equipment and supplies. Grants and donations also allowed Mr. Price to take his group to New York City to take pictures and to see the Andy Warhol Perfecting Mankind exhibit at the International Center of Photography.

When you meet Mr. Price, you are immediately struck by his passion and enthusiasm for his program and the participants. His excitement and willingness to "just pick up the phone" and ask for what he needs have been key to the program's success. The Washington Post was a major benefactor, providing photographic equipment. Mr. Price was able to recruit members of The Exposure Group, a Washington-based African-American photography association, to mentor his students. Photographic printing and framing for the exhibit were all donated. For the trip to New York, Amtrak donated train tickets and a company donated a limousine for the day. The program received grants from Kodak and the District of Columbia Arts and Humanities Council. Most recently, the program received a substantial grant from the District of Columbia Youth Investment Trust Corporation. This grant will provide a 2 1/2-month training program for three cohorts often individuals from 14-21 years old. Mr. Price's current ambition is to acquire a photographic print machine so that his students can have hands-on experience that can turn into marketable skills in the one-hour photo processing market.

Mr. Price has taken his training one step further. He has developed a partnership with CVS Pharmacy and has begun to place people in competitive employment in their photo labs. He has plans to develop relationships with other photo labs as well.

Mr. Price is quick to point out that the benefits of building skills in photography are not only in the area of employment. People also have become photography hobbyists and find photography to be an excellent vehicle for making connections with people and for personal expression. He has seen self-esteem and social skills enhanced by involvement with photography. Program participants have also developed an appreciation for photography and art as a result of their involvement.

These new photographers can best describe the value of having access to training in the field of photography. Kelly, age 18 says, "I like using the camera to take photographs of outdoor scenes and people having fun. I like to show off my photographs." Stormy, age 21, who is now competitively employed at a one-hour photo lab, says, "I think I found my talent. I surprised myself because I didn't think I had a talent." And finally, Lisa, age 23, expresses her hopes: "I would like to be a photographer one day for the Washington Post or for the President of the United States." Through Our Lenses has the power to make dreams like these come true.

Making Dreams a Reality:
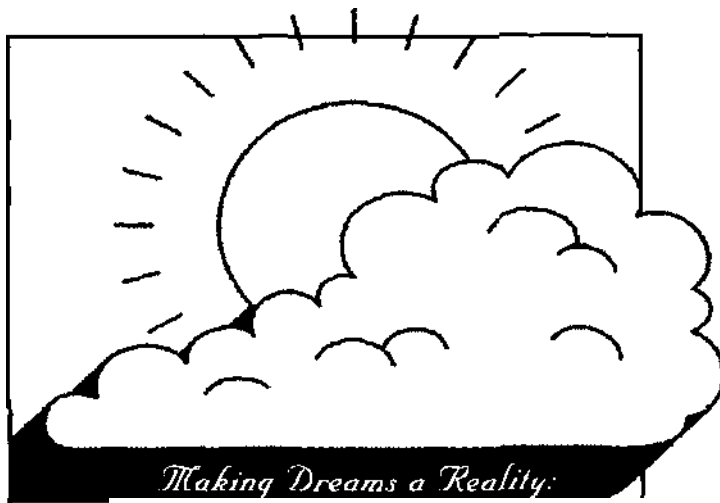
Using Personal Networks to Achieve Goals as You Prepare to Leave High School

BY JAIMIE CIULLA TIMMONS, MAIREAD MOLONEY, DANIELLE DREILINGER, AND JENNIFER SCHUSTER

Introduction

Getting ready to leave high school can be both exciting and stressful. Young adults with disabilities need to figure out what their interests are and develop goals for the future. Decisions need to be made about where the young adult might live, what kind of job he/she might have, or where he/she may continue his/her education. New life options create opportunities for more decision-making.

Although young adults with disabilities may become more independent during this time, the support and encouragement of others remains crucial for success. The Institute for Community Inclusion (ICI) interviewed high school students with disabilities and their parents and/or guardians. ICI asked these families about their plans for the future and how others may have influenced their decisions. In addition, both students and their parents were asked to tell ICI about important decisions they have made as a family, and who they depend on when there is a problem and support may be needed.

Three stories

Many of the students and parents who participated in ICI's study described how they used and depended upon their personal networks — both formal and informal — to figure out what they need and want, and help them discover, reach for, and achieve their personal goals. In addition, these personal networks helped to develop self-determination in the young adult. The three stories that follow illustrate ways that students used personal networks to help them achieve their goals, and sometimes, how they could be better used to make their goals a reality. These examples also illustrate how personal network members can help a young person achieve self-determination.

What is self-determination?

People who have self-determination know what they want and how to get it. They know a lot about themselves and have a clear vision for the future. Self-determined people can make decisions for themselves, and know what they have to do to achieve their goals. They feel independent and in control of their life plans. A self-determined person does not need to know all the answers, but he/she knows that there are a variety of options in life that are available. They understand their own strengths and weaknesses, try to solve problems, and make their own choices. Self-determination is related to self-esteem and confidence because in order to pursue your goals, you need to feel that you can be successful in your endeavors. In addition, self-determined people know how to find help when they need it. This help usually comes from their personal network.

What is a personal network?

A personal network is basically everyone that a person knows. This includes both formal and informal network members. Formal network members are professionals such as school counselors or teachers. Informal network members are people close to you, like your friends, family members, and others you may have met in social organizations, sports teams, religious organizations, or even in your neighborhood.

How can a personal network help to develop self-determination?

Personal networks can guide self-detetmined people as they solve problems and support them when important decisions are made. People from the personal network help teach new skills as goals are achieved. Self-determined people learn to plan and coordinate their lives with help from these important people. Members from the personal network provide more and more opportunities for the self-determined individual to make decisions and learn new skills on his/her own.

(The stories that follow are based on conversations with high school students and their parents and/or guardians. Each student and his/her parent/guardian were interviewed for approximately 45 minutes. A total of nine students and eight parent/guardians (6 mothers, 1 father, and 1 foster mother) were interviewed. Please note that names have been changed to protect their privacy.)

Story 1: "I found what I needed to move forward "

Heather, a recent high school graduate with physical and special health care needs, expected to have a full-time job, live with her boyfriend, and someday have kids. She felt very strongly about the value of work. As she said, "I want to work 100%. I want to work for my money." Heather's mother, however, was concerned that a full-time job would have a negative effect on Heather's Social Security benefits.

> *Self-determined people may not necessarily know exactly what they want at all times, and their visions may change from one day to the next, but they know how to get what they need*

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Despite her mother's concerns, Heather was determined to pursue a full-time job. Throughout high school, Heather's personal network exposed her to a variety of employment opportunities. When she was looking for a summer job, a family friend who worked in landscaping helped her find a job in the business. Her brother introduced her to the auto body field by letting her work on his car. This led Heather to take classes in auto body repair at school to gain more experience.

These experiences gave Heather the knowledge to develop work and career goals. Heather gathered the support she needed from her boyfriend and brother who went with her as she collected job applications, helped her fill them out, and provided encouragement. Heather's brother advocated on her behalf to their mother. "He's the one that's fighting with my mother telling her that I should work." Heather also applied for jobs independently and used school personnel to help her uncover the Department of Vocational Rehabilitation (VR) as an additional resource. She set up an appointment with a VR counselor on her own. All these activities led her to find a job in a field that matched her interests.

Important points:
● Heather's network gives her opportunities to discover her preferences by exposing her to a variety of work experiences.
● Heather chooses to work. Her self-determination is evident in her strong desire to work despite her mother's concern.
● Heather demonstrates self-determination not only by independently finding Vocational Rehabilitation as a resource, but by gathering support from her boyfriend and brother.

• Heather makes substitutions for gaps in her personal network. Because she feels her mother was not supportive, she finds other people (her brother, boyfriend, and school personnel) to help. Positive network members balance out other members who have reservations.
• Heather uses a combination of informal network members (brother and boyfriend) as well as formal network members (school personnel, counselor from VR) to reach her employment goals.
9 Heather's informal network provided both encouragement and specific help (like filling out applications).

*Story 2: **Shared goals and a** champions support bring success*
Shantelle, a recent high school graduate with a psychiatric disability, worked part-time while living at home. A large, dependable network of both formal and informal members helped support her as she developed her goals. This included a close friend, teachers, a therapist, and a neighbor who employed her as a babysitter. Shantelle talked to a close friend and teachers about her decisions for a career, and a therapist about more personal problems.

Most importantly, Shantelle has had great support from her mother. They agreed in their hopes and goals for her future. Shantelle said her mother supported her to reach greater independence: "She doesn't suggest anything. She thinks it should be my concern and my issues what I should do. She thinks I am responsible for myself. She lets me make my own decisions...[but] if I don't know if it's a good or bad idea I ask for her opinion." Shantelle's mother confirmed this by saying "if she says she wants to try something I don't stop her.... We let her make her own decisions. The only way you are going to learn is to make the mistake on your own."

The only challenge Shantelle's mother saw that could stand in Shantelle's way was her tendency towards low self-esteem. This motivated her to surround Shantelle with support. Shantelle's mother gained insight through talking to teachers, the family doctor, church members, and even neighbors. "That's what it takes, you know. Keeping that self-esteem up *and saying,* 'We know *you can do* it.'" Shantelle's family and friends were quite proud of her. Shantelle's mother best summed

up her philosophy and optimistic outlook for her daughter when she said, "We're all looking for a bright future for her."

Important points:
● Shantelle's mother supports Shantelle's self-determination by listening and making suggestions, and not making decisions for her. Shantelle's family and friends focus on building her self-esteem and confidence so she can move forward and be more self-determined.
● Shantelle has a large personal network that includes both informal network members (close friend, neighbor, and especially a strong relationship with her mother) and formal network members (teacher and therapist).
● Shantelle uses members from her personal network differently; some she talks to specifically about work (friends and teachers), while others support her more personal concerns (therapist).
● Shantelle's mother uses her own network to learn how to support Shantelle and encourage self-determination.
● Shantelle's mother makes sure not only that she is surrounded by support, but uses her own network as an expansion of support for her daughter.
● Shantelle and her mother are in alignment. This means that they agree, and share high expectations for the future. This alignment and shared goals are crucial in maximizing Shantelle's self-determination.

*Story 3: **On the road to self-determination.***
Carlos, a recent high school graduate with a cognitive disability, had a variety of interests including art and electronics and was very serious about working. However, while he had ideas about careers that would fulfill his interests, he did not know how to achieve his goals. He had high expectations for his future and didn't want to settle for any old job. High school frustrated him because he felt that the work experiences and skills he learned there would not prepare him for the working world: "I am not going to get anywhere with those jobs." Although he advocated to change his situation at IEP meetings, school personnel did not change his program.

Carlos' mother was also disappointed by his school, and supported his advocacy efforts. However, she was concerned that Carlos's

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standards might be too high. "He doesn't want to take any suggestions.... I don't think he understands [that] he doesn't get to pick and choose." She also doubted whether he would be able to pursue the jobs he liked. "It's kind of, like, out of his grasp, but I don't say that."

Carlos and his mother used two formal network members to help him succeed. This included a professional from a private organization and a counselor from the Department of Mental Retardation (DMR). Carlos's mother coordinated these services. Carlos's mother also used his monthly SSI check as a "bank account" to give him experience in using money. However, Carlos's mother reported that they didn't use their own personal network as a resource: "We're it, my husband and I." One result is that, according to Carlos's mother, Carlos relied on her too much.

While Carlos's mother wanted Carlos to be independent, she feared that he would make bad choices if left to his own resources. "I don't think he is mature enough to understand what the big decisions are and how he can handle them." She didn't know how to support him to make good decisions on his own without her making them for him. "I kind of guide him.... I kind of sway him, kind of try to con him into it."

Carlos felt the lack of support. Despite a college course in computers, he didn't feel confident that he could find a job he liked. Carlos felt stuck. "I don't want to be alone... for the rest of my life. And I don't have a good job that I am good at."

Important points:
• Carlos demonstrates self-determination through his strong desire to work, not settling for the limited options offered him by his school program, and self-advocating at school IEP meetings.
• Carlos shows self-awareness in that he had clear interests. Having self-awareness is a

crucial first step to being self-determined.
• Carlos's family helps to develop self-determination by allowing him access to his SSI checks. Carlos's mother uses SSI as a tool to increase independence, learn the value of money, and teach financial planning. However, Carlos's mother is responsible for coordinating the support from his formal network rather than Carlos doing it himself.
• Carlos and his family use formal network members to help him reach his goals. However, Carlos and his mother may not know how useful informal network members such as friends and family could be. A broader range of informal contacts could give Carlos a fuller array of assistance and help him get a clearer focus on his goals, skills, and opportunities.
• There is a lack of alignment between Carlos and his mother. This means they did not agree or share the same expectations for Carlos's future. Although they shared the vision that he would work and live independently in the future, they disagreed about what jobs he is capable of pursuing at that stage. Carlos's mother thought that Carlos was too picky. Carlos, on the other hand, didn't want to waste his time on jobs that didn't match his interests.
• Carlos feels powerless, like he was not "in the driver's seat." This is the opposite of self-determination. Carlos does not see himself as being on a positive path to a **fulfilling** future.

What can Carlos & his family do?
Carlos's mother can begin to give Carlos more responsibility in coordinating the support he receives from formal network members. In addition, while continuing to rely on their formal network members, Carlos and his family could develop their informal network. In this way, Carlos could gain a fuller array of assistance, particularly in areas in which he is is interested, with the addition of the personal knowledge and insight that family, friends, and neighbors can give. Their support could help Carlos get a clearer focus on his goals, skills, and opportunities. How can a family develop their personal network? It may not be as hard as you think!

The families who participated in this study were probably much like your own. They had varying racial/ethnic backgrounds, and the students ranged from freshmen to seniors in high school. The young adults had a wide

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career ideas, and explain your interests. Network members may know about employment opportunities or be helpful in exploring job ideas with you.

• Ask people in your network to introduce you, or refer you, to people they know who *may be helpful to you. This can lead to new* opportunities.

• Don't be afraid to ask more than once.

• Realize that members in your network will play different roles and you will not get the same thing from each member.

• Realize that network members aren't always able to help. There may be times when you ask for help and they are not able to give it to you. This is okay!

• Keep your network updated on your progress. People like to help and it will make them feel good to know that you are working toward your goals.

You are already exercising self-determination just by reaching out to those you know. Remember, a self-determined person knows what he/she wants and can find the support to achieve his/her goals! It's up to you to find this support.

A good network member:
• Thinks of him/herself as a resource.
• Is willing to listen. He/she may offer suggestions or different ways to think about your decision or issue.
• Will make time in their schedule for you.
• Offers encouragement, guidance, and advice when you need it.
• Is a positive role model.
• Should never be someone you feel uncomfortable with or someone who puts you down.
• Is someone you can trust.
• Is someone who is happy to share his/her experience with you.

A good network member supports self-determination by:
• Asking questions but not directing or making decisions.
• Allowing you to experiment with more

responsibility, encouraging you to be more responsible for yourself.
• Allowing you to make mistakes in order to learn from them.
•Offering fewer suggestions to encourage independent decision-making.
• Letting you know that he/she thinks you are capable and support the decisions you make independently.
• Building your ability to gradually handle your own affairs.
• Boosting your self-confidence.

Ideas **for budding independence and self-determination:**

• Schedule an informational interview in an area of interest. Plan and rehearse phone calls and interviews with someone in your network.
• Take responsibility for setting up job interviews and doing job searches. Participate actively in all aspects of your job search.
• Get involved in school meetings. Bring a list of questions and concerns to your IEP meeting. Consider conducting your own IEP meeting with guidance and support from your school personnel. Remember, they are there to help!
• Learn responsibility through household chores, cooking meals, or having a pet. Hard work often produces rewards!
• Experiment with public transportation when you don't have to be anywhere important. This is a good way to be able to eventually get to a job or friend's house without having to rely on others.
• Practice opening and managing a checking or savings account. Having a savings account is a good way to begin saving money for college, a first car, or moving out on your own.
• Share in family bill-paying. This helps to understand the value of groceries, clothing, personal items, or rent.

Figuring out what you want: The first step to self-determination
Start by figuring out what you want for yourself. These should be your dreams, not someone else's dreams for you. Explore different career options. Think about what you are good at and what makes you happy. Think about who you are and create a personal vision statement. Write this statement *down on paper. Remember, a self-determined* person understands his/her own strengths and weaknesses, and knows a lot about him/

herself. Self-determined people may not necessarily know exactly what they want at all times, and their visions may change from one day to the next, but they know how to get what they need.

Going out and getting it: The second step to self-determination
Once you have figured out what you want, it is time to develop clear goals and come up with an action plan. Think about where you would like to see yourself down the road. Again, write down your plan step by step. *Take out your list of network members and* think about how each member might be able to help. Put a star next to the names of those that you feel especially close to, and whom you would be comfortable asking for help. Different people in your network can probably help you in different ways. Be willing to ask for help and be specific. Remember, you don't need to have all the answers. Self-determined people know how to get what they want and know how to find help when they need it. They can define their goals and take initiative in achieving them.

Starting early
Although the students in these stories are recent high school graduates, you and your family should not wait until then to start building these skills. In fact, it is important to build these skills early in high school. The point is... it is never too early to start practicing self-determination and expanding your network! So get started!

Conclusion
Being self-determined is exciting, although making your own choices can be difficult sometimes. Don't be afraid to find and ask for help. Reach out to your personal network and ask them to help you reach your goals. Don't get discouraged if you feel like you don't know what you want, you change your mind, or you've made bad choices in the past. It's okay to make mistakes. Remember you are capable and you can do it!

Acknowledgements

Employment: From Competitive to Customized

BY MICHAEL CALLAHAN

The Americans with Disabilities Act of 1990 (ADA) provides a strong mandate that describes the rights and responsibilities for employers and prospective applicants with disabilities regarding the hiring process and the employment relationship. However, after more than a decade of implementation, there continue to be unmet expectations — outright frustration, some would say — on both sides of this sensitive issue. Employers continue to be cautious about the narrow consideration the ADA requires concerning employee performance, essential job responsibilities and reasonable accommodation. They are not able to ask about issues relating to disability, other than the accommodations necessary to perform essential job responsibilities, during the interview and prior to extending a job offer. On the other hand, many applicants with disabilities are frustrated by their difficulty in meeting arbitrary job descriptions designed for employees without disabilities.

To further confuse the situation, the current thinking within the disability community does not seem to encourage applicants to negotiate tailored job descriptions by presenting an employment proposal that identifies the specific skills that could match specific needs for the employer. Rather, applicants are encouraged to focus almost solely on obtaining employment from the perspective of legal entitlement. The bitter data from the decade of the post-ADA 1990's, a period of our country's strongest economic growth in history, indicates that the number of Americans with disabilities who were employed at the end of this robust decade was fewer than when the Act was signed in 1990 (Houtenville, 2000).

This confused situation seems to leave the people who are supported by an organization such as TASH out of the employment picture altogether. If people with disabilities who are fully able to compete are finding it difficult to become employed, how can we expect employment to become an expected outcome for people who experience significant disabilities?

The answer can be found by examining the nature of the employment relationship between employers and applicants. When framing the ADA, Congress used the concept of "competitive employment." Within the ADA, applicants with disabilities must compete against two apparent issues:

a) the essential responsibilities of the job, as described by the employer, and
b) other applicants, those with and without disabilities, who might also apply for the same job.

Not only must an applicant be able to effectively perform the essential responsibilities of a job for which he/she is applying, he/she must also compete successfully against other qualified applicants.

Many applicants with disabilities indicate they are also competing against a potential employer's fear of the unknown concerning issues relating to disability. While both sides — employers and applicants — have voiced their concerns, the structure of the ADA in its current form represents a compromise with a slant towards civil rights instead of the nature of the employment relationship.

This critical legislation walks a fine line providing "the art of the possible," the promise and usefulness of which will continue to unfold in the years to come. We are likely to find that the ADA is a better piece of civil rights legislation than it is an effective tool to directly advance employment. It is time now to go beyond waiting on case law to decide specific issues. There are other ways for employers and applicants with disabilities to forge relationships, in addition to that of rights and responsibilities. The employment relationship can be unfairly negotiated.

Within the disability field during the 1990s, practitioners revisited the challenge of the 1980s to work with applicants with significant barriers to employment, targeting those not likely to compete effectively even with reasonable accommodation provided by willing employers. It was discovered that if applicants with significant disabilities were represented by job developers who offered a specific employment proposal and, if employers were approached in an open manner using negotiation as opposed to legal entitlement, successful employment relationships could result (Examples: Callahan, 1990, Mast & West, 1995).

We found that people with significant disabilities could become employed using tailored or personalized job descriptions and that employers, by and large, were willing to embrace this concept. However, many in the generic employment and traditional rehabilitation fields felt that this approach did not represent "true" employment. Critics seemed to feel that these individual strategies were a sort of aberration, only useful for persons with the most significant barriers to employment to function in a quasi-employment relationship in a grey area between "real" employment and charity-based volunteer work.

Indeed, the history of TASH has been marked by contentious debates regarding the nature of employment and the strategies necessary to assist people to work, for example, the "Brown & Bellamy" debates of the mid-'80's. Some felt that it was necessary to fundamentally alter the employment relationship, including payment for work performed, in order to assure full access for all persons who might want to work. Others felt that it was important to stay within the traditional boundaries set by employer expectations, typical wages and competition. It is probably fair to say that these critically important

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debates fizzled as the tidal wave of supported employment shifted our focus from policy and theory to the tough reality of keeping persons in jobs defined by the Rehabilitation Act of 1986 — mostly comprised of 20 hours of work per week at or around minimum wage.

However, even as the debate waned, the issue of employment for persons with the most significant impact of disability did not go away. From the beginning of supported employment, observers and researchers scolded practitioners for overlooking those applicants with the highest support needs and those with the most difficulty with competition.

Can the employment relationship be individualized?

The concern that individualized, negotiated employment does not reach the level of "real employment" began to be put to rest early in 2001 when, within a week of her confirmation by Congress as the Secretary of the U.S. Department of Labor (DOL), Elaine Chao suggested in a speech that, "In one sense, the new economy is deconstructing work, with jobs that can't be pigeonholed into a traditional workday or workweek, and corporate structures that, in some cases, are eliminating the need for a workplace altogether. Workers themselves are demanding more autonomy, more freedom, more customization of the terms and conditions of their employment. As we invest in critical job training, we are giving workers the bargaining power they need to custom-design their jobs around their lives-- instead of the other way around."

While skeptics might reasonably argue that her true intent was to weaken the power of labor unions to arbitrarily represent groups of workers, Secretary Chaos remarks, taken at face value, indicate that the strategy that had been working for people with significant disabilities for over a decade has relevance for the broader population. In other words, customized employment is real employment.

During the decade following the passage of the ADA, Congress passed sweeping reform of U.S. labor law in the Workforce Investment Act of 1998. Within this legislation, people with disabilities are welcomed into generic employment services, along with a host of other categorical groups that were consolidated within this sweeping Act. This generic system shares similar issues with employers in addressing the needs of people with disabilities. One solution identified by the U.S. Department of Labor was to use the concept of customized employment.

Even though, conceptually, customized employment represents a relevant approach for both people with disabilities and the general population, it is fair to say that little has been written or discussed about the strategy on a nationwide basis until the summer of 2001. On July 20, 2001, the Federal Register published a solicitation for projects to implement customized employment options within DOL-mandated local workforce boards for people with disabilities who might need such approaches to become successfully employed. Again this year, DOL has issued a solicitation containing the following definition of customized employment that will be used in the proposal for federal funds:

"Customized employment means individualizing the employment relationship between employees and employers in ways that meet the needs of both. It is based on an individualized determination of the strengths, needs, and interests of the person with a disability, and is also designed to meet the specific needs of the employer.

It may include employment developed through job carving, self-employment or entrepreneurial initiatives, or other job development or restructuring strategies that result in job responsibilities being customized and individually negotiated to fit the needs of individuals with a disability.

Customized employment assumes the provision of reasonable accommodations and supports necessary for the individual to perform the functions of a job that is individually negotiated and developed

(Federal Register, June 26, 2002, Vol. 67. No. 123 pp 43154 -43149).

Characteristics of Customized Employment

Possibly the most defining characteristic of customized employment is that it is "real employment" — real employment performed in typical community work settings for typical wages by one person. Customized employment is different from other forms of employment mainly in terms of the unique manner in which the essential responsibilities (ADA, 1990) of the job are negotiated by or on behalf of an applicant and the suggestion that applicants and family members consider allowing job developers to disclose aspects of the person's disability for purposes of negotiation. Other characteristics of customized employment include:

• The job description of an applicant with a disability is customized through voluntary negotiation with an employer.
• Applicants with disabilities often, though not always, use job developers to assist in the negotiation of customized job descriptions.
• The primary focus of the customized job description is on contribution instead of competition.
• Job developers and applicants with disabilities present employers with a proposal to be considered by the employer in a voluntary manner.
• Applicants voluntarily disclose issues concerning their disabilities as a good faith strategy to resolve support and accommodation issues.
• Negotiation is based on a "template strategy" in which an applicant's potential contributions are placed as a template over potential employer needs. Any matches between applicant contribution and employer need might become the component responsibilities of a customized job description.
• Funding for additional applicant support needs, beyond those provided by employers through reasonable accommodations and supports offered to typical employees, might be available through funding sources such as vocational rehabilitation, the workforce system, social and adult services, schools and community organizations.
• While job responsibilities and the conditions of employment that surround the job

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are negotiated, pay is determined by the commensurate wage paid for the traditional job description most similar to the customized job.

The implications for individuals with significant disabilities seem clear. Customized employment offers a strategy from which all people who wish to become employed can become employed. It is our responsibility within TASH to recommit to assuring the provision of the supports, representation, resources and, most importantly, the values necessary to make employment a part of life for all.

Customized Employment for Marci Garvin

Marci is a woman from Ft. Worth, Texas, who experiences the most significant impact of disability in her life. Marci represents almost perfectly an entire group of people in our society for whom the idea of a meaningful life evokes feelings of confusion, complexity and doubt. Even if society were to embrace the notion that Marci should have a life of participation and passion, membership, relevance and the opportunity for contribution, figuring out how to assist her to accomplish this would still be difficult.

As a child of the "94-142" generation, she had access to educational services in a manner that earlier members of her group never dreamed. However, the role of school in the lives of people with the most significant disabilities is often as unclear as the role of adult services in assisting people with such labels to be active participants in our culture. The implied promise of an effective and inclusive education is that if one receives it, as a result there should be some clear benefit in relation to adult life. When Marci reached the age of 21, the path ahead seemed to lead only to an adult day center or to her family's living room. To her parents thinking, this kind of life seemed unfair, boring and unsatisfactory.

While Marci's parents were confused as to what a meaningful life should look like, they felt she needed to make a contribution to her community and be appreciated for that contribution. Some would say that Marci and people like her should simply be appreciated, honored and included in society "for whom they are," without arbitrary or typical expectations. While Marci's parents certainly agreed with the idea of acceptance for their daughter, they wanted far more. They wanted Marci to experience the daily routines, the variety, the ebb and flow of a typical life. Most particularly they wanted Marci to have a job.

But who was this young woman on the cusp of adulthood? In an effort to have that question answered for purposes of receiving adult services, her family had Marci "evaluated" by a well-known vocational evaluator. The results were devastating. Marci was described as functioning as a seven-month-old infant. If this assessment was accurate and meaningful, it was obviously a stretch to imagine that Marci might work for pay in the community. But her parents felt that this view of Marci — this comparative, competitive view — did not have any practical relevance. Instead, with assistance of a handful of supporters who were willing to take a risk, they embraced the idea of discovery.

Discovery allowed Marci's complex life to be explored rather than to be compared to others. It provided a new way of looking at her disability. And it set the foundation for customization of employment. Instead of seeing Marci's life in relation to traditional indicators of success such as skill levels, productivity, independent performance and the like, she could be viewed from the perspective of what works in her life, what moves her to be present, and what kinds of supports might she need to make a contribution. We found that instead of capturing Marci in a two-page assessment report of comparative performance that her complex life could be described in a document the size of a book. Of course, no one wanted to write a book before Marci became employed, so a ten page descriptive profile was used to capture all the information found in discovery.

Marci doesn't speak and the communication she uses is the most subtle imaginable. Since birth, her mother says that Marci has never shown emotion though facial expression. Her body is often in a state of movement and, occasionally, what appears to be agitation. Her mom says that when the external situation is pleasing and meaningful to Marci, she becomes still, attentive, and present. It provides the clearest way for Marci to express choice and preference. Marci rarely interacts in a physical manner with objects and people, but we learned that she does have some control over her right arm, which is less rigid from spasticity than her left. She often moves that arm across the front of her body in a gentle rocking motion from right to left.

The process of discovery was essential to uncover the subtle manner in which Marci expresses her feelings and reacts to the world around her. We were able to determine the environmental conditions that seemed to best fit with Marci, as well as those situations and people she seemed to prefer over others. What was missing from the equation was a way for Marci to contribute in a work place.

In reviewing her school records, it was discovered that teachers had attempted to introduce a saucer-shaped electrical switch to Marci for purposes of turning on a tape recorder for playing music. Marci seems to enjoy the effect of music and this was thought to be a functional task that might lead to other ways for her to control her environment. Hand-over-hand assistance was offered to Marci to first turn on, and then turn off, the tape player. However, that task was quickly discontinued due to what was perceived as resistance on Marci's part. After careful consideration and analysis of this activity by a dedicated support person, a flaw was discovered.

While turning on the tape player is undoubtedly a functional task for those of us who love music, turning it off is not as functionally motivating. The proposed solution involved using a 20-second telephone answering tape with music that Marci seemed to like. She would be assisted to turn the music on, and after twenty seconds the tape would stop and rewind automatically. The next assist would be to turn the music back on.

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This single idea, derived through discovery, was the basis for Marci's job using customized employment as a specialty stapler in the personnel office at the <u>Fort Worth Star Telegram</u>, the daily newspaper for that city. She has been working for over three years in a job in which the hours are set to meet Marci's needs. The switch that Marci turned on, initially to hear the music she liked, operates the stapler. Within a couple of months, the music was no longer needed. She receives commensurate pay for her work and assistance from a job trainer funded by the Medicaid Waiver program in her state. Since starting work, Marci has routinely made more per hour than her support personnel. During the past year, shredding of personnel documents has been added to her responsibilities. This task utilizes a sheet feeder, which Marci operates with her switch, comprised of an old ink-jet printer Velcro taped to the top of the offices auto-feed shredder.

Marci has been employed for six year at the <u>Star Telegraph</u>. This job cracks open the door to the possibility of Marci having a life that approximates the rhythms of those led in her community. Beyond the work place, she needs assistance to first identify and, later, participate in activities that connect her to her community. In the summer of 2001, Marci and her family agreed to participate in a self-determination pilot project in her county. Through this project Marci has begun to participate in community activities outside of work that include receiving personal shopping assistance from the manager of a Bath and Body Works store, picking up her medication at her local pharmacy and having her Ensure nutritional supplement blended in a Starbucks Frappiccino. She also has recently gotten a debit card in her name to make purchases as she shops in her community.

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Using Personal Networks to Achieve Goals as You Prepare to Leave High School
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Inclusion, especially John Butterworth, Sheila Lynch Fesko, Cynthia Zafft, and Rooshey Hasnain.

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Using Personal Networks to Achieve Goals
Continued from previous column

Additional Institute for Community Inclusion resources on this topic

Tools for Inclusion Series
Stories of Success: Using networking and mentoring relationships in career planning for students with disabilities. (February 2001, Vol. 9, No. 1)

Networking: A consumer guide to an effective job search. (January 1999, Vol. 7, No. 1)

Training Manuals
Building a Self-Determined Future For All Youth. (2001)
This manual offers an exciting approach to teaching and learning leadership and self-determination skills. It is divided into twelve curriculum units that are designed to introduce middle and high school students to a broad spectrum of leadership and self-determination skills. The guide is interactive and contains a collection of learning activities and materials that pertain to leadership.

Building Community Connections: Designing a Future That Works. (1996)
This manual serves as a curriculum for a two-day workshop designed to teach individuals with disabilities to utilize their contacts in a job search. Topics covered include: tapping the hidden job market, using networks for career development and job searches, identifying and engaging individuals, keeping in touch with people without becoming a pest, creating a mutually beneficial relationship with potential employers, dealing with disclosure, and using service providers.

Increasing Family and Consumer Choice and Control over Transition and Employment Services through the Utilization of SSA Work Incentives

BY ELLEN CONDON

Poor post-school outcomes for students with disabilities has been a continual cause for concern for educators and policy makers since the 1980's. A 1999 report by the Office of Inspector General for the U.S. Department of Health and Human Services linked poor transition outcomes for youth with disabilities to factors such as lack of employment preparation, transition planning, and lack of services and linkages to agencies prior to high school exit. While waiting lists for adult services averaging 5 years exist nationally (Wehman, 2001), resources which could be used to enhance transition planning, linkages between schools and agencies, and employment outcomes such as Social Security work incentives, remain underutilized.

The Social Security Work Incentive Program, which allows Supplemental Security Income (SSI) recipients to set aside income and resources to fund vocational services and supports, has been in place since 1974. However, the number of individuals accessing this program nationally is minimal. According to the March 2002, quarterly report from Social Security, "SSI Disabled Recipients who Work," 1,649 PASS (Plan for Achieving Support) plans are currently active in the United States, but only 1 PASS plan is in active status for an individual under the age of 18. Ninety-seven (97) PASS plans are active for young adults ages 18-21 years old. According to the Social Security Administration (SSA) in 1999, thirty-six thousand (36,000) people aged 18-24 were receiving SSI and Social Security Disability Insurance (SSDI) benefits concurrently; potentially all 36,000 were eligible for PASS plans.

While PASS plans won't solve all the needs of unserved or underserved people within the disabilities systems, they could make a significant dent in the problem. Work incentives such as PASS plans have been used successfully to bridge the gap in services for students who are exiting school and being placed on adult services waiting lists, and PASS plans have been utilized to enhance transition to employment services for students who are still in school (Condon, 2002). Additionally, money generated by a PASS plan can be leveraged to entice other agencies to come to the table and fund services to support employment for a student as a collaborative investment, where they may have been reluctant to serve as the sole financial support.

Although schools are required by law to assist families in connecting with appropriate agencies and resources as a component of Transition Planning, many school personnel have little information or experience with Social Security benefits or work incentives. Comprehensive surveys of school personnel, school administrators, adult service administrators, and adult service providers in Montana consistently identified that service personnel felt it was their responsibility to refer students and families to SSA, but seldom indicated that they had any involvement, responsibility, or experience in the actual development of an application for SSA benefits or work incentives (Vogelsberg, McGregor, Buck, & Vanek, 2002). Virginia Commonwealth University estimated that only 15% of parents learn of the SSI program through school personnel (cited by Johnson, D. 2002).

In two Model Transition Demonstration projects in Montana, funded by the U.S. Department of Education, Social Security work incentives are being incorporated into transition planning for students with labels of severe disabilities and ongoing support needs. Work incentives can be a valuable resource in transition planning for several reasons. Work incentives are proving to be one avenue for generating financial resources which can support career development and employment for students while they are in school (for students who are eligible) and as they transition to adulthood. In a PASS plan, income or resources can be sheltered and used to support employment preparation at the time the PASS is approved or, saved to purchase future employment supports, services or equipment. This incentive is a viable alternate funding source to pay for supports necessary to obtain or maintain employment for students as they graduate from high school and perhaps placed on waiting lists for adult service agencies.

> Social Security work incentives such as PASS plans can be a valuable transition resource for eligible students with disabilities during school and as they graduate.... The development of PASS plans needs to be thought of as a Needed Transition Service as schools are forming interagency linkages to support the positive outcomes for students with disabilities.

Work incentives such as PASS plans can be a source of consumer controlled funds and promote choice and control for families and students who are eligible and utilize them. PASS plans are flexible in what they fund, as long as it supports employment and is written into a plan which is approved by Social Security. PASS plans have been utilized to purchase vehicles, job development services, Vocational Evaluations (or community based alternatives such as the Vocational Profile), transportation, equipment needed to start a small business and many other items or services needed to assist someone become employed, advance employment or in the case of someone who utilizes supported employment services, maintain employment. The restrictions regarding who one can contract

Transition and Employment Services through the Utilization of SSA Work Incentives
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with to provide *sen/ices are* fewer using a PASS plan than if one were using state or federal disability funds, which again increases consumer choice and control. Work incentives such as PASS can be used to bridge the gap between youth and adult life while allowing students and families to choose what they need for supports, services or equipment and whom they would like to provide these services.

Are students really eligible for PASS Plans?

In January of 2002, the amount of wages students were allowed to earn before impacting their SSI checks was increased to $1320/month or a total of $5340/year. This incentive is referred to as the Student Earned Income Exclusion. It is unlikely that students receiving SSI benefits only will become eligible for PASS plans due to their own earnings while still considered a student. However, as soon as they graduate from school, their wages, after the first $85/month (if they only receive SSI), will begin reducing their monthly SSI check, thereby making them eligible for a PASS.

The goal for schools participating in the Montana transition demonstration grants is to graduate students with severe disabilities into paid jobs of at least 20 hours per week, customized for them through an individualized Discovery and Vocational Profile process.

In one Montana school the three graduates involved in the projects were working upon graduation but were placed on waiting lists for employment services from the state Developmental Disabilities agency. All three students require some form of ongoing supports to maintain employment. PASS plans were written for each student sheltering their wages or unearned income to pay for their needed supports. It was essential for each student's Individual Education Plan (IEP) team to organize these supports in the student's Needed Transition Services and link

them to appropriate agencies that could fund and provide these services prior to graduation. PASS plans were written, submitted to the PASS Cadre, and approved in advance of the student graduating, contingent upon their earnings upon graduation.

Student PASS Example *#1:*

When Matt turned 18, his family assisted him to apply for SSI. He was determined eligible to receive the full benefit rate of $545.00/month. Although Matt was working part time while he was still in school, his earnings were not above $5340/year (2002 Student Earned Income Exclusion amount). Since his wages were not reducing his SSI check he would not be eligible for a PASS until he graduated and began earning over $85/month (the earned income exclusion rate). For every $2 exceeding the first $85/month gross earnings, Matt's SSI check would have been reduced by $1 if he did not have a PASS plan in place.

From Matt's high school work experiences, his team knew that he would need intermittent ongoing support to enable him to remain employed. Matt had been referred to Developmental Disabilities Services for employment supports and found to be eligible, but like many young graduates, he was put on a waiting list for these services. As part of his transition planning, Platte High School set the goal to place Matt in a paid job prior to exiting high school. If Matt was working 20 hours per week after graduation, he would be eligible for approximately $200/month in a PASS. (The amount his SSI check would be decreased due to his wages.) The need for a PASS plan was included as a transition service need on his Individual Education Plan (IEP).

Based upon Matt's aptitude and interest in numbers, computers and his abilities to find mistakes, his PASS plan was written with the work goal: to obtain a position within the desk top publishing field. The plan enabled Matt to hire his family to help him get to and from work and hire a person he chose to provide the critical follow-along support for his job and receive computer tutoring to enable him to acquire skills to advance his employment. His plan was written for the period of two years.

To be eligible for a PASS, an individual must have income or resources which decrease their SSI benefits. While it is unlikely for students to have high enough earnings to decrease their SSI, due to the SEIE (Student Earned Income Exclusion) amounts, they may have unearned income *which reduces their* monthly SSI which, in turn, would make them eligible for PASS plans while they are still in school. Sources of unearned income which were utilized for Montana students included: Adoption Subsidies, Survivor's Benefits, and Social Security Disability Insurance, (SSDI) through a retired or disabled parent's SSA account. In these cases, PASS plans began for students as young as age 14. PASS funds were set aside for future support needs or utilized to purchase services, supports, or items necessary to achieve a current Vocational Goal.

Student Pass Example #2:

Ann was a 16 year old sophomore in high school, and she had been receiving only SSI and at the full benefit rate ($545/month in 2002). However, upon the death of her father, Ann began receiving survivor's benefits of $310/month which reduced her SSI check from $545/month to $235/month thereby making her eligible for a PASS.

Her IEP team chose to write a PASS plan which would "shelter" her unearned income. Her monthly SSI check would then remain at the 2002 Federal Benefit Rate (FBR), $545.00 month. She would then use the sheltered $290 month to support the pursuit of her vocational goal.

Ann's team began with the assumption that she could work in the community if she had a position customized to meet her support needs where she could make a contribution. They had been spending time gathering information about who Ann was, what her preferences and interests were in regards to employment, what her support needs were, what job tasks she could perform and what her particular contributions might be to an employer. They had learned that Ann had an exceptional memory for schedules and details and she very readily offered solutions to

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difficulties in juggling transportation or staffing schedules in the classroom. The team identified her vocational goal to obtain a position as a logistics coordinator.

The team chose to write the Plan ending 2 months post graduation with the assumption that they would amend the plan if the goal had changed or what she needed to purchase changed or write an extension if all remained the same. The Plan paid for Job Development, Job coaching and transportation which allowed Ann to augment services provided by the school. Upon graduation the PASS was amended to include sheltering her wages in addition to unearned income for a total of $497/month. The PASS allowed Ann to purchase a wheelchair accessible van, pay for a driver and for follow-along services to support her on her job, and set aside monies for future job coaching or development if needed.

Summary

Social Security Work Incentives such as PASS plans can be a valuable transition resource for eligible students with disabilities during school and as they graduate. Strategies to increase the utilization of PASS plans need to be incorporated into transition planning for students. The development of PASS plans needs to be thought of as a Needed Transition Service as schools are forming interagency linkages to support the positive outcomes for students with disabilities.

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Employment Strand and Sessions

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***Utilizing the** Discrepancy Analysis **Tool to Guarantee the "Perfect" Job** Match*
Speaker: Jennifer Joyce

Job matching is necessary for successful employment and leads to the satisfaction of employees, employers, and funding sources. This workshop describes the process used to determine potential discrepancies and their interventions in order to facilitate the "perfect" job match.
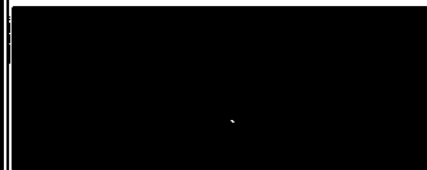
When it comes to employment-related services, within the disability community much attention is paid to public vocational rehabilitation and those services provided and funded by developmental disability and mental health agencies. However, over the last several years, the public employment and training services that are designed to serve anyone needing assistance in finding a job have undergone extensive changes, opening a variety of opportunities for people with disabilities.

In 1998, Congress passed the Workforce Investment Act (WIA), which replaced the Job Training Partnership Act. One of the key principles of WIA is universal access. What this means is that anyone, including people with disabilities, can receive a basic level of services from the workforce development system. Under WIA, services are accessed via One-Stop Career Centers, which operate through a network of centers in each state. Each state is required to have at least one comprehensive center in each major population area.

One-Stop System Overview

One-Stops are sometimes referred to as an agency. This is really a misnomer, since a One-Stop is not a single agency, but rather multiple agencies and partners that have come together to form the One-Stop system. The intent of the One-Stop system under WIA is to provide seamless access to multiple programs and services in one location, making it easier for job seekers and employers to use these services.

A number of federally funded programs are mandated to be partners in the One-Stop system under WIA. The only mandated

The ability to access some services without undergoing an eligibility process, and to receive services in an integrated setting, side-by-side with the general public, are a realization of the types of opportunities for which TASH and similar organizations have long advocated

Workforce Investment Act and One-Stop Career Centers: Opportunities and Ongoing Challenges

By David Hoff

disability partner is the public vocational rehabilitation (VR) system (which also includes public agencies for the blind and visually impaired). As a result, some level of VR services should be available via the One-Stop system. In some cases, the entire local VR office is located at the One-Stop Center, while in others, individual VR staff are based at the One-Stop on a full-time or part-time basis. One-Stops can go beyond the federally mandated partners and form a variety of relationships and partnerships with non-mandated public and private agencies, and many examples of this exist throughout the country.

The services available via the One-Stop system are broken into three categories: core, intensive, and training. Core services provide basic assistance in finding employment. These services tend to be fairly self-directed, or are done in group settings. Intensive services, which typically provide more one-to-one assistance than core, are intended for individuals who have not become successfully employed as a result of core services. Intensive services are provided either at the One-Stop or off-site, possibly through a contract with a service provider. Training services are intended for eligible individuals who have not become successfully employed as a result of core and intensive services, and are provided off-site. Types of training services include occupa-

tional skills training; skills upgrading; and customized training for employers. Training services are provided through Individual Training Accounts which allow an individual to choose to receive training from any approved training provider. While core services are available to anyone, you must meet eligibility requirements for intensive and training services.

The set-up of the One-Stop system varies from state-to-state and even within states. The locally driven nature of the system accounts in part for the differences between One-Stops that are often observed within a state. Local Workforce Investment Boards [LWIBs] appoint the One-Stop operator. Each LWIB is its own incorporated body, and the One-Stop system is set up based on the preferences of the LWIB. While a few less populous states have only one LWIB, most states have multiple LWIBs.

Many One-Stops are free-standing facilities. Others are located within existing public settings, such as community colleges, or government complexes. Some One-Stops use a mall-like concept, with a wide range of programs and services on-site. Others have only the core services available on-site, and act as a referral point for other services based elsewhere. Full service One-Stops have a resource library which typically has a bank of computers for developing resumes, cover letters, and conducting job searches over the internet. The resource library also usually contains publications and information on looking for a job, and papers copies of job listings from local employers. Most full service One-Stops also offer basic workshops (at no charge) on job seeking, interviewing skills, and related topics. In addition, many One-Stops have support groups for job seekers. One-Stops may have many other core services available as well.

In addition to full-service centers, many states (particularly rural ones) also have satellite centers, with more limited services. Satellite centers may be free-standing facilities, but also

Workforce Investment Act and One-Stop Career Centers

may be based in other public settings such as public libraries. In addition, many states offer some services via the internet, and the US Department of Labor also has a variety of internet tools at: www.careeronestop.org

One-Stop Career Centers go by a variety of names depending on the state. The term "One-Stop" may not even be part of the name. Some states use the same name for all centers throughout the state (for example in New Hampshire, all centers are called "New Hampshire Works"), while in other states (such as Massachusetts), the name is different in each local area.

The Opportunities and Realities of the One-Stop System

Given the variety of other service options that already exist, many people with disabilities may wonder why they should even bother investigating services from the One-Stop system. There are several reasons:

•One-Stops can expand the array of service options available. Via the One-Stop system, a person with a disability may become aware of services and opportunities that they did not know previously existed. In particular, there may be many "non-disability specific" services available, which an individual may have previously been unaware of.

••• One-Stops provide the opportunity to receive services in a more efficient fashion. With access to an array of services available at one location, like other One-Stop customers, people with disabilities can avoid going from place to place, having to provide the same information over and over, or needing to make numerous phone calls to get the services they need.

••• One-Stops do not have to be an "either/or" option. Many people with disabilities are using the services of the One-Stop system in addition to other services they are already receiving.

••• The ability to access some services without undergoing an eligibility process, and to receive services in an integrated setting, side-by-side with the general public, are a

realization of the types of opportunities for which TASH and similar organizations have long advocated.

Over the last few years, through a variety of initiatives, the Institute for Community Inclusion has had the opportunity to gather information and conduct site visits with One-Stop systems throughout the United States. Based on this work, and the information gathering of other entities, it is clear that in many areas of the country, One-Stop Career Centers are operating which are truly are a major contrast to the previous employment and training services, providing customer-friendly assistance and access to a wide range of services to meet individual's employment and training needs. Many One-Stops have devoted significant time, energy and resources into building up their capacity to serve people with disabilities, and are able to respond effectively in meeting a variety of customer needs.

• It is clear that the key to properly serving customers with disabilities is an overall focus on quality services for all customers. It has been observed that a general emphasis by the center management on making every customer feel welcome goes a long way towards ensuring that people with disabilities receive the respect and treatment to which they are entitled.

•♭» The initial interaction and intake process that occurs when an individual first enters a One-Stop is crucial. Those One-Stops that have thoroughly analyzed this process to ensure that customer needs are quickly identified and responded to, and have properly trained staff at the front desk to handle a variety of customer needs, are better able to meet the needs of people with disabilities.

••• One-Stops are implementing a variety of universal design and learning strategies to ensure that the services they offer cover a wide range of communication needs and styles, which allows the One-Stop to meet a greater range of customer needs, and reduces the need for accommodations for specific customers and the need to disclose non-apparent disabilities.

• Many One-Stops have dedicated signifi-cant resources to obtaining a wide range of assistive technology to ensure that computer work stations and other One-Stop services are

accessible to a wide range of people with disabilities.

• Public Vocational Rehabilitation is increasingly recognizing the mutual benefits that can result from participating as a partner in the One-Stop system. For instance, VR clients are often participating in various workshops offered to all One-Stop customers, rather then VR spending its resources on its own groups of people in search of employ-ment. Also, many examples exist of VR co-funding services for a consumer with other partners. For example, VR may pay for assessment services, with WIA funds used for provision of training.

• Beyond public VR, the One-Stop system is building a variety of partnerships with other disability entities. In some areas, Public Mental Health agencies are increasing their level of interest and involvement in the One-Stop system with referral mechanisms and collaborative service delivery. With a few exceptions, public Developmental Disability and Mental Retardation (DD/MR) agencies have had limited involvement in the One-Stop system. However, through various demonstration projections interaction is increasing, and some Development Disability Councils are beginning to dedicate resources to enhancing the ability of One-Stops to meet the needs of their clients.

••• Community Rehabilitation Providers (CRPs) have developed a broad range of relationships with One-Stop Career Centers. Examples include: assisting consumers they are working with to use the services of the One-Stop system as a supplement to the other services the CRP is providing; job developers using the resources of the One-Stop to identify potential employment opportunities; CRPs using the One-Stop as a satellite office with a desk at the One-Stop; co-teaching of workshops with One-Stop staff; and serving as a vendor for intensive and training services.

••• Full- and part-time benefit planners funded by the Social Security Administration work out of many One-Stop Centers.

• Many One-Stops and LWIBs have developed disability committees and advisory groups to promote ongoing dialogue regard-ing a range of disability issues and to under-take various initiatives.

• Many workforce boards have significantly addressed the needs of people with disabilities

Workforce Investment Act and One-Stop Career Centers

in their planning documents and strategic planning processes.

• There is significant interest in the new Ticket to Work program from Social Security. A few One-Stop Career Centers and Workforce Boards have already become service providers under the Ticket program, and these numbers are expected to expand significantly. Developing the capacity to be a provider under the Ticket to Work, will certainly enhance the overall ability of One-Stops to serve people with disabilities.

• The WIA Non-Discrimination and Equal Opportunity Regulations contain strong protections for people with disabilities. The U.S. Department of Labor is expected to expand its monitoring of enforcement of these regulations over the coming months.

•> One of the major frustrations for people with disabilities and their families is the ability to easily access information regarding services for which they may be eligible. There is increasing recognition that One-Stops provide a framework for addressing this issue. The ideal One-Stop would be one that goes well beyond the mandates of WIA, and provides information on the full range of services that an individual may be eligible for from the array of disability agencies (such as VR, Mental Health, DD/MR) and also non-disability agencies. This would include the ability to obtain assistance regarding Social Security benefits, public health benefits (Medicare/Medicaid) and other supports (such as transportation and housing) all in one location. Although no One-Stop system has been observed that is fulfilling its complete potential in this regard, there is increasing movement by some local One-Stops, to expand their role as an information and referral point for the all the workforce development activity in the community, including those services targeted towards people with disabilities.

• In general, the interest of One-Stop Career Centers and workforce boards in disability issues has grown significantly over the past few years. There is an increasing recognition that people with disabilities are a major population subgroup, which One-Stops must

have the ability to serve. It was particularly gratifying to the author to be at a recent meeting with a One-Stop operator who stated that people with disabilities were under-utilizing the services of the local One-Stop system, and that she wanted to take steps to address this issue. Her interest had nothing to do with any additional funding opportunities, but simply because meeting the needs of people with disabilities was seen as an important part of their fundamental mission as a One-Stop operator.

Ongoing Challenges

Such practices and developments clearly demonstrate that the One-Stop system does indeed have the interest and ability to serve individuals with disabilities in an effective manner. However, these observations are certainly not consistent across the country, or even within different areas of individual states.

While the One-Stop system has made significant progress in meeting the needs of people with disabilities, there is still much to be done. Some One-Stops continue to demonstrate a limited capacity to respond to the needs of people with disabilities, which seems usually to translate into a limited ability to respond to the needs of other customer groups as well. There are still way too many cases of people with disabilities being denied services that are universally accessible to all, not being provided proper accommodations, or being automatically referred to public VR (which is not permitted under WIA). It can be particularly frustrating, given all the attention that is being paid to this issue, if your local One-Stop is still not recognizing and responding effectively to the needs of people with disabilities. Here are some suggestions for people with disabilities, in dealing with concerns with their One-Stop system:

• In cases where you feel you were not treated properly at a One-Stop Career Center, or just feel that the needs of people with disabilities could be better met, you should feel free to ask to meet with the manager, or Equal Opportunity Officer. Every One-Stop is supposed to have an Equal Opportunity Officer, and contact information for this individual is supposed to be prominently displayed.

•Another alternative is to contact the Local Workforce Investment Board, which appoints the One-Stop operator, and has oversight responsibility. LWIBs are required to regularly have public meetings, which may provide a forum for input.

• In advocating with One-Stops and LWIBs, do more than just complain - educate! It is rare that the needs of people with disabilities are not being met because of intentional discrimination. Instead, it is often simply lack of education and awareness regarding disability issues. Offer to assist the One-Stop and LWIB to better serve people with disabilities. Put them in contact with local resources, and the range of technical assistance entities receiving funding to assist One-Stops and LWIBs with disability issues.

• If your state or local area is receiving funding from USDOL to enhance the capacity to serve people with disabilities, you may wish to contact the individual's involved with these initiatives to determine if there are ideas and resources available to improve the One-Stop's ability to serve people with disabilities.

• In cases where, despite your advocacy efforts, the One-Stop and/or LWIB is continuing to not properly meet the needs of people with disabilities, you can contact the U.S. Department of Labor's Civil Rights Center (CRC), which is responsible for ensuring that workforce development services under WIA do not discriminate. Contact information for the CRC is listed in the resource section at the end of this article.

It is important to bear in mind that given their mandate to be universally accessible, One-Stops cannot be all things to all people, and there may be cases where due to limitations on resources, One-Stops are unable to meet all of an individual's employment and training needs. No matter what though, you are entitled to be treated with dignity and respect, to have access to the core services, to be provided reasonable accommodations if needed, and to receive equal consideration for intensive and training services.

Conclusion

If you have yet to go there, visit your local One-Stop Career Center and see what it's all about. If there's room for improvement, don't be silent - advocate! WIA and One-Stops

Workforce Investment Act and One-Stop Career Centers

provide a wonderful venue to prove that integrated service delivery does indeed work, to the benefit of individuals with disabilities and society as a whole. It's important to not let this opportunity slip by.

Resources
For additional information, including details on One-Stop disability initiatives in your state, please contact the National Center on Workforce and Disability/Adult at: 1-888-886-9898 (toll free) or by e-mail: contact@onestops.info; website: www.onestops.info

For information on workforce development services for transition contact the National Collaborative on Workforce and Disabilities/Youth at: 1-877-871-0744 (toll free); e-mail: collaborative@iel.org; website: www.ncwd-youth.info

To find the location of your local One-Stop Career Center, contact America's Service Locator at: www.servicelocator.org, or by calling: 1-877-US-2JOBS

Contact information for most workforce boards can be found at the National Association of Workforce Boards website: www.nawb.org

US Department of Labor, Civil Rights Center - voice: 202-693-6502; e-mail: CivilRightsCenter@dol.gov; web site: www.dol.gov/oasam/programs/crc/crcwelcome.htm

David Hoff is the Project Coordinator for the National Center on Workforce and Disability for Adults, at the Institute for Community Inclusion, U Mass Boston. Voice 617-287-4345; TTY: 617-287-4350; e-mail- david.hoff@umb.edu

PROMISING DEVELOPMENTS IN THE ONE-STOP SYSTEM

Department of Labor Disability Dollars

Many of the promising practices and developments that have occurred within the One-Stop system are in part a result of the extensive funding the U.S. Department of Labor is dedicating to building the capacity of the One-Stop system to meet the needs of people with disabilities. States that have received funding for such purposes through various Department of Labor (DOL) grant initiatives include: Alabama, Alaska, California, Colorado, Connecticut, Florida, Hawaii, Illinois, Iowa, Indiana, Kansas, Kentucky, Louisiana, Maine, Maryland, Massachusetts, Michigan, Minnesota, Missouri, Montana, New Hampshire, New Mexico, New York, North Carolina, Ohio, Oklahoma, Oregon, Pennsylvania, Rhode Island, South Dakota, Tennessee, Texas, Vermont, Virginia, Washington, West Virginia, and Wisconsin.

Some of these initiatives have funded statewide efforts while others are focused on a specific local area within a state. In addition to these efforts, each of the 10 federally funded regional Disability Business Technical Assistance Centers has received funds to work with One-Stop Centers in their region.

It is important for disability advocates to be aware of the activities that are taking place within their state to determine if there are opportunities to become involved and participate in these efforts, to ensure that such efforts are truly building the capacity of the One-Stop system to meet the needs of customers with disabilities, and to learn about promising practices that are occurring for possible replication.

In addition to these various state and regional efforts, the U.S. DOL has funded two national technical assistance centers on workforce development and disability. One of the centers is focused on issues for adults, while the other is focused on issues for youth (contact information for each of these centers can be found in the Resource listing on this page). The bottom line is that literally millions and millions of dollars are being spent to ensure that the One-Stop system can properly serve people with disabilities. The end result should be increasingly greater consistency across the country in the ability of the One-Stop system to the meet the needs of the disability community.

Opportunities for Young People Under WIA

The main focus of this article is on One-Stop Career Centers, which are mainly targeted towards adults. However, One-Stop Career Centers can also be a significant resource for young people with disabilities transitioning from school-to-adult life.

For example, in Massachusetts, One-Stop Career Centers have successfully assisted a number of transitioning students to obtain employment. There are also additional options for young people under WIA, beyond One-Stops. Local Workforce Investment Boards oversee funding for a variety of youth services, which are designed to assist young people in obtaining vocational experience. Individuals with disabilities are eligible for these youth services. In addition, the U.S. Department of Labor has been awarding funds for a variety of demonstration projects focused on youth with disabilities. For additional information, contact the National Collaborative on Workforce and Disabilities for Youth (contact information in the Resource section on this page).

GROWING JOBS IN RURAL COMMUNITIES

BY CARY GRIFFIN
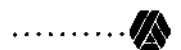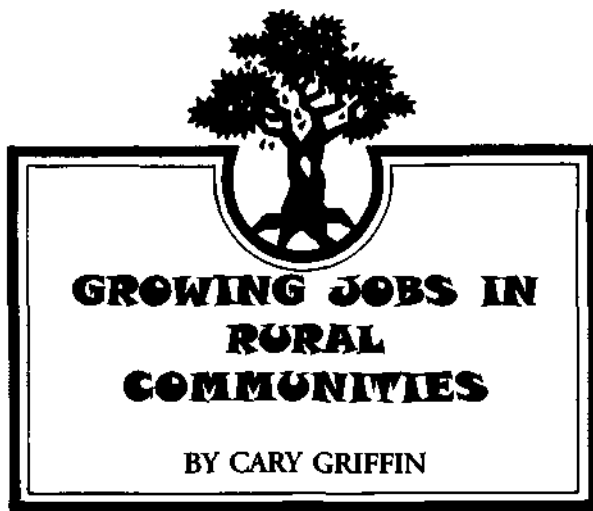
Employment development for transition age youth and adults with significant disabilities is often constrained by reactions to the alleged "job market." Even today, many job developers and employment and transition specialists are taught to review the labor market and test people with disabilities to see if they "fit" within the current economic environment. In areas of high commercial activity, this approach may work well enough to reinforce its premise, but in typical markets (and especially in depressed markets) this just labels individuals with significant disabilities as "unemployable." In rural areas (and urban, too), people get jobs through various networks of association, and by being competitive in the workplace.

Employer and Consumer Control of the Job Discovery Process

The power of networks for the job seeker cannot be overstated. Without "respected other's" representation, the job seeker is just another name on an application. In interviews, job seekers may be just another applicant, except that they also have a disability. Transition/employment specialists and job seekers alike must create networks that include people who influence those who hire.

Typically, people use references such as their former bosses or professors, but many people labeled with severe disabilities have no one of community standing representing them. If transition/employment specialists take action to become known as credible and giving members of their communities, the job

development process gains the respect of employers.

One promising technique for growing jobs involves nurturing community relationships and networks by establishing Active Employment Councils (AECs) or Business Leadership Networks (BLNs). These councils meet monthly and members are required to bring at least one employment lead or "contact."

One or two consumers are asked if they have an interest in exploring employment in the "contacts" business. This contact is then called and given the name of the council member who suggested calling, and an appointment to discuss employment opportunities is made. Sometimes contacts are suppliers to the council member's business, and a natural business relationship already exists that can be leveraged into job development. Often, too, the council members find that they have jobs available in their own companies and can help minimize the red tape and other roadblocks inherent in job hunting. Because business and consumers participate in the council, employment outcomes are the absolute priority for all council activity, mutually beneficial and respectful relationships form that create a force for job development in the community.

When prospecting for Council members, begin incubating the group with a core team of strongly committed employers. School personnel might logically approach the business people on the School Board and enlist their participation.

Critical lessons are being learned through such councils that seem to have universal applicability to all communities. These include:

✔ In order to create employment and act as a representative for people with disabilities, the transition/employment specialist should be well known to the business community, and should have people with disabilities actively

and visibly create business and personal relationships;

✔ Businesses are particularly concerned about the future of students leaving public schools, and many local Chambers of Commerce, service clubs, and city/county governments have committees studying school improvement that welcome contributing committee members and can assist with job development efforts;

✔ Be careful not to overlook the public sector as an employment option. There are government jobs in large cities and in the smallest of communities. Washington State, which has a large rural population, recently announced a state government initiative to hire people with severe disabilities in public sector jobs utilizing supported employment techniques.

Employers understand their workforce and production needs much better than those of us who do not work in those businesses. Employers can assist in job restructuring and on-site training efficiently and more naturally than outside human service or school personnel who typically must learn jobs first, then teach the new worker. In numerous cases, co-workers effectively instructed new workers with disabilities in task performance, while employment specialists offered instructional support and effective teaching/supervision strategies.

Staff at the Rural Institute at the University of Montana develop and create jobs in rather remote sections of the country. Often, no formal jobs exist. The strategy is to look for products or services that are needed and either create a consumer-run enterprise or help established business expand through the use of formal partnership agreements.

Recent business start-ups include a small engine repair business, run as a sole proprietorship but located within another "fix-it shop" in Plains, Montana; a stuffed animal concession at a Nature Center in Red Lodge, Montana, (where the Nature Center receives

GROWING JOBS IN RURAL COMMUNITIES

Continued from page 27

10% on all sales in exchange for housing the business run by a young entrepreneur with serious disabilities), et al. The possibilities are limitless. Active Employment Councils help identify local entrepreneurs and companies willing to develop partnerships and businesses within businesses, and individual members bring priceless expertise and advice concerning local market conditions.

At the heart of these councils is Peer Marketing — having an employer influence other employers to hire individuals with disabilities. This is much more powerful and effective than human service or school representatives acting as sole job developers. Employment development benefits from creative professional rehabilitation expertise, but there is a major role to be played by having business folks work face-to-face with people with disabilities in need of employment, and with their peers in the business world.

Hiring people with disabilities is, unfortunately, still viewed as a business risk. Hearing of successful employment from business and workers with disabilities provides powerful support to employers who have not yet hired. Human service roles seem most appropriate in the context of getting these constituents together and providing technical and strategic support until a quality employment relationship has been developed.

Job Carving /Job Creation

The process of breaking down jobs into their key components and reassigning those pieces in more efficient or understandable ways is called job carving. This strategy is a creative extension of job development that results in job restructuring or job creation (i.e., typical work duties are reassigned to one or more workers or a new job is created to address efficiency needs). While full-time employment is certainly a reasonable outcome, job carving is often used with individuals in transition from school-to-work or supported

employment who, for a variety of reasons (including physical disability, cyclical psychiatric illness, medical fragility, available supports, and choice) may not be in the market for full-time employment. Care must be taken not to create jobs that devalue workers with disabilities by physically separating them from other workers or by having them perform tasks that are considered bothersome, dangerous, or unpleasant.

Job carving entails analyzing work duties of specific jobs and identifying specific tasks that could be assigned to employees with severe disabilities who have a proficiency for these tasks and who want to perform these jobs. Job carving can be a useful tactic for helping individuals gain experience in paid situations, and for helping employers reach a new comfort level with employees with disabilities.

Many variables influence job carving. For instance, the marketing approach in job carving is deliberate and businesslike. Transition/employment specialists should approach potential employers as diagnosticians, ready to determine needs and offer solutions to productivity challenges. Another variable is consumer employment objectives. No job development effort can take place without a thorough understanding of the type of work that is suitable and acceptable to a particular individual.

Some examples of rural job carving include:

Clerical Assistant: Duties include photocopying, formatting and copying computer disks, answering phones, assembling documents. Hours: Monday, Wednesday, and Friday, 20 hours per week.

Mail Delivery: Duties include mail, parcel, and message delivery for rural county government offices. Hours: Monday - Friday, 12.5 hours per week.

Pet Groomer: Duties include washing dogs, general animal care. Hours: Monday - Friday, 20 hours per week.

Bank Teller Assistant: Duties include sorting documents, operating coin counter equip-

ment, paper shredding, etc. Hours: Monday - Friday, 15 hours per week.

Taxidermist Assistant: Duties include salting hides, preparation work. Monday - Friday, 20 hours per week.

Seamstress: Duties include guiding material through computerized sewing machine, quality control, packaging, etc. Monday-Friday, 40 hours per week.

Car Wash Attendant: Duties include cleaning wash bays, refilling soap and liquid wax reservoirs, emptying vacuum cleaner bags, policing the grounds. Hours: Monday - Saturday, 22 hours per week.

Grocer's Assistant: Duties include "facing" cans on shelves, arranging produce, unloading delivery trucks, light cleaning, recycling shipping boxes. Hours: Saturday & Sunday, 16 hours per week.

Gas Station Attendant: Duties include: Pumping gasoline, washing windshields, checking oil and fluid levels, washing and detailing vehicles. Hours: Monday - Friday: 30 hours per week.

Farm Hand: Duties include: moving cattle, clearing irrigation ditches, feeding cattle, bucking bales, assorted tasks performed in partnership with the manager. Hours: 7 days per week, 35 hours per week.

Cary Griffin is Director of Special Projects, Rural Institute, University of Montana and Senior Partner, Griffin-Hammis Associates, LLC. For more information on job development. Active Employment Councils, self employment, and community employment in rural areas, please contact Cary Griffin at cgriffin@selway.umt.edu or (406) 243-2454.

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INITIATIVES AT SYRACUSE UNIVERSITY PROMOTING INCLUSIVE POSTSECONDARY EDUCATION

The mission of the Center on Human Policy is to promote the full inclusion of people with disabilities. Historically, the Center has focused on issues such as deinstitutionalization, community living, education, and family support. In the past year, we have focused significant attention on inclusion in postsecondary education. This article describes two initiatives within the School of Education at Syracuse University that promote inclusion in postsecondary education. While the issues raised in these two examples are referenced to Syracuse University, they are applicable to all postsecondary educational settings.

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The Beyond Compliance Coordinating Committee (BCCC)
BY THE BEYOND COMPLIANCE COORDINATING COMMITTEE

The Beyond Compliance Coordinating Committee is a group of students at Syracuse University working to address issues of concern to people with disabilities on campus. BCCC was initiated by graduate students within the Disability Studies Concentration, within the Cultural Foundations of Education Department, School of Education, at Syracuse University. The students brought diverse backgrounds and experiences with disabilities. The commonality of the students' experiences was their commitment to creating

an environment in higher education where students with disabilities would be able to thrive and reach their potential. The group quickly identified that most institutions of higher education look at accommodations for students with disabilities from a compliance mindset. It is common to hear that an institution is committed to compliance with the ADA (Americans with Disabilities Act) and other relevant laws. However, BCCC emphasizes that the ADA is simply a starting point. Mere compliance does not create an environment in which students can reach their full potential. An attitude that goes "beyond compliance" is needed within institutions of higher education. As part of their efforts, they wrote a position statement that reflects key areas of focus for an institution of higher education in order to move "beyond compliance."

The Beyond Compliance Position Statement

1. Reshaping V *ity's conception of disability,.*
Disability is more than just a physical or mental impairment. Accessibility is more than just compliance with federal and state laws. Disability is about the human condition, and the Syracuse University community would be enhanced by a broader conceptualization of disability that calls for inclusion, integration, and equality. Thus, compliance with laws is the starting point, not the bottom line, for the university community, and disability should be included along with race and gender in what is defined as a "minority" on campus.

2. Raising disability consciousness on campus.
Disability is an important aspect of diversity in a university community of scholars, faculty, and students. Inclusion of people with disabilities in the Syracuse University environment provides a learning experience for all and reaffirms the dignity of all human beings. Accordingly, disability should be part and parcel of the university's dialogue on diversity.

3. Hiring faculty and staff members with significant disabilities.
A pioneering university in the areas of disability studies and special education, Syracuse University should reflect its commitment to these disciplines by hiring and

promoting people with significant disabilities as faculty members throughout the university.

4. Creating model accommodations exemplifying the university's commitment to equality of opportunity for students with disabilities.
Students with disabilities are entitled to effective reasonable accommodations and should be included in the decision-making process. Syracuse University should be committed to providing the latest in technological advances that would enhance access for students with disabilities.

For more information about BCCC, contact: Michael Schwartz, at Schwartz@twcny. rr. com

On Campus at Syracuse University
BY VALERIE SMITH

For the past two years, a partnership between Syracuse University's School of Education and the Syracuse City School District has brought several city school students who are between the ages of 18 and 21 and who have a variety of developmental disability labels to the SU campus. These city school students audit classes, work, and socialize every day alongside their university peers. Most people can easily imagine the benefits of this arrangement to the city school students.

For example, city school participants have the opportunity to learn in classes to which they wouldn't otherwise have access, to practice social skills with same-aged peers who don't have disabilities, and to spend each day in the same environments and having similar experiences as their same-aged peers. What is equally important to recognize is that the university community, including students, staff, and faculty, also benefit from having the On Campus students as a daily presence at Syracuse University.

Benefits to SU Community
1. On Campus students add to the diversity at the university. They help us broaden the definition of diversity from the traditional boundaries of ethnicity, religion, and sexual orientation. They provide us with opportunities to learn the value of many kinds of diversity.

INITIATIVES AT SYRACUSE UNIVERSITY PROMOTING INCLUSIVE POSTSECONDARY EDUCATION

Continued from page 29

2. OnCampus students provide the campus community with opportunities to question old ideas about who belongs in higher education. They show us that, given adequate support, they are successful students, friends, and members of the university community. They cause us to examine ideas about social justice and the meaning of disability labels in society.

3. OnCampus students show us the many ways that competent people look, behave, and communicate. They help us develop skills conversing with people who don't speak, or who communicate in unique ways. They help us learn how to develop relationships with people who seem quite different from us. They help us learn that there are many important ways that we are all the same.

4. OnCampus students help faculty think differently about how, and who, they teach. OnCampus students bring the class a variety of adaptations that demonstrate innovative ways to teach all students. They make unique contributions that add to the richness of the course for all students. They demonstrate to faculty that learning, and intelligence, are expressed in many ways.

In connection with OnCampus, a service-learning course was developed. Eugene Marcus was a guest speaker in the course, sharing his experiences as a man with autism. He wrote the following in response to a question from a student about what advice he had for peer supporters of students with disabilities. Eugene now co-teaches this course.

Advice to Peer Supporters
BY EUGENE MARCUS

My friends, thank you for deciding to be supporters, and thank you for being peers and not bosses or role models. Bosses are a dime a dozen in our lives, and role models are people we choose, not ones who choose us. But peers are just what we need.

Peers are people who are in the same boat as we are, and who are our equals. That means people who must follow the same foul rules that we do, and who have ways of coping that we need to know about. Role models are expected to be perfect, but peers can fumble and make mistakes just like we do.

All we need are three things: time, respect, and information. Time is obvious, and the more the better. We mostly have way too much free time. Respect is not so observable as time, but is more important and not easy to establish if it is not there to begin with. My definition of respect is when one person assumes there is just as much chance that I am right as that he is. Good peer support is always from people who are eager to learn and that means people who don't mind being wrong a lot of the time.

The third thing our supporters provide us with is information. So what information do you peer supporters have that we need? My guess is that if you want to find out, we can tell you if you ask us. If that doesn't work, give us some choices. Real support will include lots of stories about you and your friends and your loves and your parents. And real support will help us in ways that will amaze you.

For more information on OnCampus and the service learning course contact Pat English-Sand and Eugene Marcus, 315-443-9683.
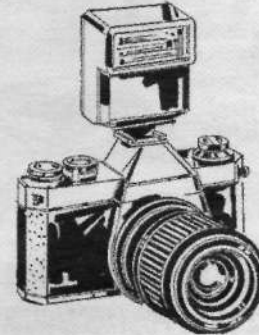
Through Our Lenses
Continued from page 12

TASH is honored to have Mr. Price and several of the Through Our Lenses program participants join us at the upcoming TASH Annual Conference next month.

Mr. Price and his students will be honing their skills by photographing sessions, special events, attendees, and more throughout the conference. If you see them about, feel free to smile and say "cheese!"

Abby L. W. Crowley, EdD., is Director of Professional Development at the Lt. Joseph P. Kennedy Institute in Washington, D.C.

Questions about the Through Our Lenses program may be directed to Ms. Crowley at 202-281-2751 or by e-mail:
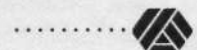*acrowley@kennedyinstitute.org;*

Photo by Ken Stein (1994).

Diane Lipton

Diane J. Lipton
(1945-2002)
Disability Rights Leader

(The following information is provided by the staff and Board of DREDF on behalf of Diane Lipton's family, Jim and Daria Armstrong and Chloe Lipton.)

Diane J Lipton, the Director of the Children with Disabilities Advocacy program at the Disability Rights Education and Defense Fund (DREDF), died in August after at the age of 57 after a two year battle with cancer.

Born in New York City, Lipton was a nationally recognized parent advocate. For nearly two decades as a lawyer fighting for the rights of children with disabilities, as well as a formidable and successful advocate for children and their parents long before she became a lawyer, Diane was a nationally recognized luminary on the front lines fighting to end disability discrimination. Diane started out her career as a teacher and rehabilitation counselor, but came to her true calling as a devoted advocate for the civil rights of children with disabilities in 1979 when her daughter Chloe, who has severe disabilities, was segregated and deprived of her educational rights as a child in the Richmond, California school system.

Diane and a few other parents, with the assistance of the Disability Rights Education and Defense Fund in Berkeley (DREDF), developed a national practice of public policy litigation and technical assistance to end the segregation of children with disabilities across the country. Her local advocacy brought about the closing of all disability-segregated schools in Richmond.

Diane and the parents she organized told the State Commission on Special Education in 1981, "Segregated education is but another form of institutionalization which we view as extremely detrimental to the growth and development of disabled and nondisabled children alike." For over twenty years, Diane never wavered from that conviction, and her professional and personal lives were seamlessly devoted to ensuring the rights of children with disabilities.

Diane's passion for justice drove her through personal sacrifices and professional struggles. She went to law school at night and joined DREDF (the Disability Rights Education and Defense Fund in Berkeley California) in 1979, where she has served as director of the State Bar Trust Fund Program and the Director of Parent and Children's Advocacy services.

Her work on state and federal legislation has had a widespread impact, from protecting the hard-earned rights of parents to participate in their children's educational plans, to ensuring the rights of children with disabilities in juvenile halls to special education.
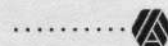
In addition, she spearheaded a number of landmark legal cases which to this day stand out as beacons in the struggle for ensuring the rights of children with disabilities in our nation's schools. She received a number of awards and honors, including two American Jurisprudence Awards, the Distinguished Parent Award from TASH, and as well as honors and awards from the Developmental Disabilities Counsel, and the National Center in Educational Restructuring and Inclusion.

She earned a law degree from Golden Gate University School of Law, San Francisco, California, a M.S. degree in Rehabilitation Counseling from San Francisco State University and a BA. from the University of California, Berkeley.

She is survived by her husband James Armstrong of Richmond California, and daughters Daria Armstrong (Richmond, California), and Chloe Lipton (Emeryville, California).

Diane Lipton and her family request that any donations, addressed attention: "Diane Lipton Memorial Gifts," be made to one of the following two charities:

East Bay Innovations, 440 Grand Avenue, Suite 425, Oakland, California 94610, telephone (510) 832-7126; and/or DREDF, 2212 Sixth Street, Berkeley, California 94710, telephone (510) 644-2555.

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( ) Regular Education Teacher/Administrator

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