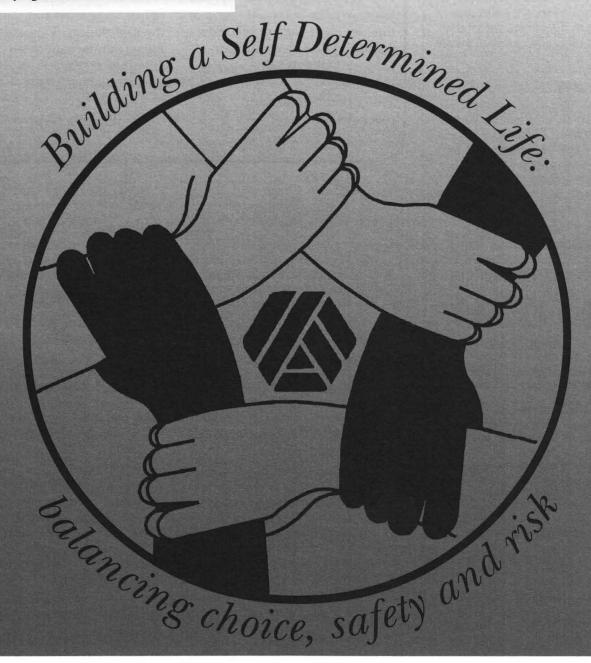
# Equity, Quality and Social Justice for People with Disabilities

### **Inside This Issue**

- What is choice really about?
- Balancing safety and risk
- Living a self determined life
- **Increasing Consumer Control through** The Ticket to Work Act
- **Future Planning**
- **Developing Personal Networks**



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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.

### MISSION STATEMENT



Stretching the boundaries of what is possible;

Building communities in which no one is segregated and everyone belongs;

Forging new alliances that embrace diversity;

Advocating for opportunities and rights;

Eradicating injustices and inequities;

Supporting research and disseminating knowledge and information;

Promoting inclusive education;

Supporting progressive legislation and litigation; and,

Promoting excellence in services.

#### From the Editor

With few exceptions, change occurs at various stages of most peoples' personal and/or professional lives. If we are fortunate, these rites of passage will be positive, sustaining experiences that help us to achieve growth and fulfillment as we gain new perspectives, develop greater abilities, and establish broader relationships.

So, too, has TASH's newsletter undergone various transformations over the years. At one time an eight-page publication produced on newsprint, this issue of TASH's news magazine introduces both a new name, TASH Connections, and a new cover design.

What will not change is TASH's continued commitment to provide its members with informative, thoughtprovoking and inspiring articles, resources and connections.

We appreciate the time many of you have taken to share your opinions about the content of the newsletter, and we invite you to continue to share your perspective about the issues covered in TASH Connections.

Let us know what you think of the new design. Your comments may be sent to my attention at <pnewton@tash.org>.

Priscilla Newton





### WHOM DO I CONTACT??



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From the Executive Director BY NANCY WEISS

ver the past ten years there have been important changes in the way people with disabilities and their families choose to obtain supports.

way of broader implementation of self-directed supports.

While we are committed to assuring that people have the right to self-directed supports, we need also to identify the skills a person needs to participate fully in the self-determination environment. Young people with disabilities are going to emerge from federally mandated educational programs into support systems that offer opportunities to decide:

- Where and with whom they are going to live.
- What kind of work they will do,
- Who will provide the supports needed for success, and

sweep a floor; we understand far less about how to teach someone to make and keep friends.

Unfortunately, the latter skill has direct implications for the richness of life, while the former is probably completely irrelevant. A critical analysis of both the supports a person needs to successfully navigate the new opportunities made accessible by the move toward self-determination and the best ways to teach meaningful skills is needed.

Few would argue that the changes toward more self-directed supports have been welcomed, have been too long in coming, and do not yet go far enough. But with these changes have come new

challenges for people with disabilities, family members and people providing support. Some of these challenges are openly discussed by self-advocates, family members, and people who work in the disability field, but many are not being openly addressed.

When there was an assumption that professionals knew what was best, individuals with disabilities

and their families often relinquished decision-making to the "experts." The selection of a course of action in a given situation, while often counter to the desires of the individual or family, was none-the-less, easily determined. In moving toward a system that is respectful of the individual and his or her family, we have created a support environment in which the best course of action is often unclear.

There is strong agreement that an individual with disabilities has a right to make his or her own decisions, but family members and people providing support confront situations regularly in which the choices an individual makes are discomforting or even potentially dangerous. What is the "right" response when an individual's choices are not benign?

Continued on page 7

We are moving away from	We are moving toward
Professionals and others routinely making decisions on behalf of people with disabilities	People with disabilities want and need to make their own daily decisions as well as set their own course for the future
People being supported to participate in more inclusive living, learning and work environments only after there has been a professional assessment of readiness	People with disabilities want and need opportunities to participate fully in inclusive home, school and work communities
Focusing on fostering independence through teaching basic educational, daily living, and work skills	Relationship building, and achievement of personal aspirations and quality of life, as it is defined by the person with a disability, are much more important than mastering basic skills

Even though there is clarity amongst people with disabilities, family members, and support providers that these more individualized approaches are better in a multitude of ways, true individualized supports are difficult to achieve. Making the move from more traditional services to more progressive supports presents challenges for organizations, managers, direct support staff, family members, and for people with disabilities themselves.

To say that the changes described above have had positive impact on the lives of people with disabilities is an understatement; indeed, for many it has meant the difference between meaningful lives and segregated existences. There are a number of challenges that are inherent to a conversion to individualized approaches. The failure to address some of these challenges is standing in the

• What they will do in their spare time toward building relationships, supports, and community involvement.

There is a need for greater focus on what people need to know to make these decisions and how best to teach these skills. Certainly, I am not advocating a return to a continuum-based approach that requires an individual to prove success at one level before being allowed to move to the next. However, there are skills that will be helpful to people with disabilities, family members and professionals alike in navigating the realities of progressive service systems.

We are much more likely to teach skills that we can task-analyze into small teachable steps than we are to teach those skills we have trouble understanding how we ourselves learned. We know all about how to teach someone to

"Whoever controls the media—the images—controls the culture." Allen Ginsberg

# "Imaging the Future"

2001 TASH Conference Anaheim, California November 14-17, 2001

BY DENISE MARSHALL, TASH, Director of Meetings and Information Resources

t the meeting last December in Miami, members of the TASH Conference Committee were brainstorming about possible themes for the 2001 meeting. Suddenly the door opened, and 25-30 TASH members joined the meeting with enthusiasm and focus. "The next conference needs to be about what creates positive images of people with disabilities! The conference will be in Anaheim next year, with the proximity of this location to Disney and Hollywood, now is the time!" And so, it is.

Daniel Keplinger, about whom the Academy Award winning film *King Gimp*, and the stunning and powerful Cingular advertisement released during the January 2001 Super Bowl were made, has agreed to speak at the opening general session of the 2001 TASH Conference.

"I think Cingular showed courage to do something really differ ent and something significant about the importance of selfexpression. What I especially liked was the message of the com mercial and that I, as an artist, had been cast to symbolize selfexpression. Too often the media depicts people with disabilities as a disability, not a person. The Cingular ad, however, is about me as an artist and that's who I am. It's about the intensity and force of my painting and the freedom it gives me to soar. It's about the beauty of self-expression.

At Parkville High School, an artist was born and the artist was me. Art is what made my identity. In art, I could finally express more of myself. Art came from emotion very deep inside of me,



Painting by Dan Keplinger

saying what I had never said before, taking me in a new direction as far as I could go and then to a new place. With painting, I could express myself clearly without any body interpreting for me. I am so connected with painting. The headstick is my only hand, although it has no fingers and it's slow, it gets the paint on the canvas. The minute my headstick goes on, I don't hear

#### **2001 TASH ANNUAL CONFERENCE**

### 2001 TASH Annual Conference "Imaging the Future"

Continued from page 4

other people in the room, everything is filtered out creating a state of purity possible only through art. I am confined by my physical being, my movement and my speech. When I taste freedom it is intoxication. Art gives me a freedom - a way to communicate."

~ Dan Keplinger

Throughout his life, in words and actions, Dan has embodied the values of TASH. We are pleased that he will be joining us in Anaheim, helping to shape an incredibly powerful dialogue about the role of media and advertising in changing the images of people with disabilities.

Energy, enthusiasm, and daring will characterize the TASH conference this fall. As many of you read last month - the conference was to be held at the Anaheim Hilton, however, that property does not meet the intent of the ADA. TASH stood by our commitment to full access for all and in TASH style, we held out ground and insisted that all means all. When the hotel could not comply, we pulled out of the contract and successfully negotiated with the Hilton to release us without penalty.

TASH is very pleased to announce that the conference will remain in Southern California. It will be held at the Marriott Anaheim and the Anaheim Convention Center. Cal-TASH, the California Chapter of TASH, will be co-sponsoring the conference in lieu of holding a conference of their own. Opportunities to be innovative abound!

We have long understood that greatest obstacles faced by people with disabilities and their families are imposed by society. Advertising and media are just one of the ways images are formed. Understanding the influence that evokes positive images and attitudes toward people with disabilities is critical to effecting social change. Words, stories, movies, pictures, ads, articles, cartoons, books, and everyday interactions in the community are used to prove or disprove the beliefs that shape systems.

This year the conference committee has identified interest in presentations that address this theme of images. Proposals may be submitted on topics that demonstrate stories and strategies that have changed images, attitudes, systems, and empowered people to realize the full inclusion of people with disabilities in their home communities. Be a part of shaping the conference by submitting to do a presentation, or encouraging friends and colleagues to be at this exciting gathering. For questions and guidelines about presenting visit our website at <a href="http://www.tash.org">http://www.tash.org</a> or call Kelly Nelson at extension 105, 1-800-482-TASH (8274) or 410-828-8274.

For more information about Dan Keplinger, visit his website at <a href="http://users.erols.com/kinggimp/">http://users.erols.com/kinggimp/></a>





### **IDEA Full Funding Act Introduced**

Representative Charles Bass (R-N.H.) will be reintroducing a bill to make mandatory the full funding of IDEA 97. The Mandatory IDEA Full Funding Act sets a five year timeline to provide the full authorized level of funding for Part B (assistance to states) set by Congress 25 years ago. What makes this bill different from the previous bills and "resolutions" is that the funding will be mandatory — no longer subject to "such sums as appropriated" by the Congress, but guided by the following percentages of the average current per-pupil expenditure in public elementary and secondary schools:

20% for fiscal year 2002; 25% for fiscal year 2003; 30% for fiscal year 2004; 35% for fiscal year 2005 and, in 2006, state education agencies and local school districts can expect funding levels to reach the authorized 40% and remain at that level for each subsequent fiscal year.

A large number of education organizations including the American Association of School Administrators (AASA) and the National Education Association (NEA) have supported this language in the past and are expected to enthusiastically

endorse this bill when it is reintroduced in the next few weeks. The AASA has made mandatory funding of IDEA an organizational priority and will make a "major push all through September 2001" to get the proposal passed.



### Supreme court issues decision in Garrett

The Supreme Court handed down its decision in the Board of Trustees of the University of Alabama v. Garrett et al case on February 21, 2001. In a 5-4 decision, the Supreme Court held that "Suits in federal court by state employees to recover money damages by reason of the State's failure to comply with Title I of the ADA are barred by the Eleventh Amendment" (which grants states "sovereignty" making them "immune" from certain types of judicial actions). Simply put, this means that people with disabilities cannot sue their states for money under Title I of the ADA.

In a forceful dissent, Justice Breyer, joined by Justices Stevens, Souter and Ginsburg argued that the Court was taking away the authority of Congress to "sponsor and support" the 14th Amendment guaranteeing "equal protections under the law." Further, Justice Breyer took issue with the statements of the majority of the Court that "the legislative record of the ADA . . . simply fails to show that Congress did in fact identify a pattern of irrational state discrimination in employment against the disabled." In doing so, he appended the dissent with over 35 pages of State-by-State examples of discriminatory actions presented in response to 13 Congressional hearings and field hearings held in every state by the Task Force on the Rights and Empowerment of Americans with Disabilities, attended by more the 30,000 people.

If there is a positive "side" to the Garrett decision, it is that Justice Rehnquist wrote a very narrow opinion, applying only to money damages and to Title I of the ADA concerned with employment. Individuals with disabilities can file discriminations suits and request "injunctive relief." This means that successful lawsuits can require that employers fix the problems, restore employees to their former positions, and provide the accommodations necessary for successful employment. In addition, people can still recover attorneys' fees if they prevail.

So, what are we to think? First, the ADA is NOT dead. This was a limited decision, primarily about money and pertaining specifically to Title I of the ADA. Nonetheless, important remedies were taken away from individuals seeking to secure their civil rights. Outrageous, too, is the idea that what the Congress sees and hears is somehow not "enough," and that the idea opined in the majority opinion that there is not "evidence" of systematic discrimination in employment is refuted by the appalling unemployment rates of people with disabilities.

In his January 3 "New Freedom Initiative" proposal President George W. Bush stated "Because of the ADA, discrimination against a person with a disability is not just unkind or cruel or wrong: it is an infringement of federal law, and a violation of civil rights. But the banning of discrimination is just the beginning of full participation in our society. Though progress has been made in the last decade, too many barriers remain. Too many Americans with disabilities remain trapped in bureaucracies of dependence and are denied the tools and access necessary for success. My Administration is committed to tearing down these barriers." Today the Supreme Court has erected a new barrier for the President to overcome WITH us as we seek the full participation that he has pledged to support.



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### GOVERNMENTAL AFFAIRS UPDATE

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### The Family Opportunity Act of 2001

The Family Opportunity Act of 2001 was reintroduced on February 8, 2001. Sponsored by Senators Kennedy and Grassley and Congressmen Waxman and Sessions. The goal of the Family Opportunity Act is to give more children with disabilities access to a broad range of health care services and supports. The vehicle to achieving this is to give parents the option of buying into Medicaid and paying on a sliding scale basis. This Medicaid buy-in is important because it is designed to offer a very broad range of services. The bill will allow states to offer Medicaid benefits to middle-income families of children with disabilities for the first time (middle income is defined as 300% of poverty, which is \$51,150 for a family of four in most places). The Family Opportunity Act does not mandate that states provide this option; it allows them to offer the "buy-in." Medicaid is a state-administered program, with the federal government providing "matching" funds and oversight.

To sign up for the Government Relations listserve or for information about specific policy issues or legislation, contact Jamie Ruppmann, Director of Governmental Relations, at (410) 828-8274, ext. 104 (voice); (410) 828-1306 (TDD); or (410) 828-6706 (fax).

### From the Executive Director

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Take, for example, a support person who privately wonders whether it is wise to allow an individual with frequent grand mal seizures to travel back and forth from work unaccompanied; what should the role of family members and support staff be when a person chooses to continue to smoke in the face of life threatening emphysema; to have unprotected sex with an individual known to have AIDS; to make him/herself vulnerable by walking through dangerous parts of the city late at night; or to ride a bicycle with no regard for safety? When, if ever, is it appropriate to intervene or to even propose a plan that is counter to an individual's choices? How imminent must the risk be?

Some people feel that it would not be right to intervene in situations such as those described above under any circumstances, citing the fact that people without disabilities have the right to make choices, and often do make choices, that are unwise. Others would feel it their responsibility to assure safety and well-being. What is absolutely true is that the best decisions will be made when people are able to engage in an open discussion that takes into account the varied points of view of all stakeholders.

Robert Perske discussed the importance of risk taking as far back as 1972. In the ensuing years, the importance of allowing, even purposefully incorporating, opportunities for risk-taking has become well-accepted practice, but people also value safety and success. When the values for safety and risk conflict, decision making becomes complex. Sometimes each stakeholder in a situation is clear about his/her own values but those beliefs conflict with those held by others.

A young woman's parents, for example, may support their daughter's decision to leave her group home for an apartment of her own, while staff may have genuine concerns that she will not be successful. Just as often, values conflicts occur within, rather than among, individual stakeholders. That is, any or all of the individuals participating in this discussion of living environments (including the young woman herself) may at once value the move toward independence.

while fearing the consequences of this important step.

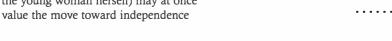
Even in the most progressive agencies one can observe person-centered planning meetings at which all participants are nodding their agreement to a proposed plan while privately, many may worry that they are alone in the concerns they harbor. Reluctant to be viewed as less than progressive or politically incorrect, such doubts are not voiced. Support staff are likely to be influenced by the anticipated responses of others, including co-workers, supervisors, neighbors, or funding agencies. Family members may have difficulty viewing their son or daughter as a person who is maturing and changing or, conversely, may know a much more competent side of the individual than staff are able to perceive. The individual him or herself may be cognizant of both the risks and benefits of a given course of action.

It must be the goal of progressive organizations to develop cultures that promote open discussion and a sense of safety for all team members to express themselves candidly. When values conflict, the challenge to both individuals and organizations is to weigh the strength of one person's belief against those held by all stakeholders. Open discussion about beliefs and concerns is critical. Environments in which every participant feels safe to voice concerns, including those concerns that may seem out-of-sync with progressive approaches, allow each stakeholder to balance his or her own point of view with the viewpoint of the individual and the positions of other stakeholders.

Without losing sight of the fact that an individual's choices are to be respected, organizations must find ways to encourage decision-making processes that value and encourage an open exchange of ideas. By focusing on the skills needed to determine one's own future and by encouraging open discourse on values conflicts that arise, we will have accomplished much toward assuring quality individualized supports for greater numbers of people with disabilities.

#### Reference:

Perske, R. (1972). The dignity of risk and the mentally retarded. Mental Retardation, 10 (1), 24-26.



he concept of "choice" is discussed frequently in the field of developmental disabilities these days. Yet the concept means different things to different people, and is used to justify radically different visions of the place of people with developmental disabilities in society. This article presents some thoughts on the concept of choice.

#### Why is choice important?

Historically, people with disabilities and their families were offered few, if any, choices in their lives. Families of children labeled with severe disabilities had two options: to place their children in institutions or keep them at home with no publicly funded assistance or education. Adults labeled with severe disabilities could be placed in public institutions or live in the community with no services or supports.

With the establishment of a federally guaranteed right to education and the expansion of community services, the options available to people with disabilities and their families slowly started to expand. Nevertheless, many people continue to be denied the opportunity to make choices about the most basic aspects of their lives.

#### What is choice really about?

In my view, choice means that people with disabilities, regardless of the severity of the disability, should be able to enjoy the same choices and options available to other people in society. A public commitment to choice means that public funds and programs should support people in making these choices and selecting these options. It does not mean that public funds and programs should support lifestyle choices and living conditions other people do not enjoy.

### What are some important choices that people should be able to make?

All people should be able to make decisions over various aspects of their



lives. For adults, major choices include decisions about:

- In which communities and neighborhoods to live
- Whether to live alone or with others and, in the case of the latter, the specific person or persons with whom to live
- Friendships and participation in community activities and associations
- From whom and how to receive personal assistance and support
- Sexuality and sexual relations
- Where to work
- Medical treatment and therapeutic interventions

Choices about these matters determine the degree to which people can make decisions about day-to-day things such as:

- Meals and mealtime routines
- Bedtime routines
- How to spend leisure time
- Dress and personal appearance

### What public policies and approaches are consistent with choice?

Public policies and service approaches should maximize personal control and choice. The following are some current approaches consistent with this principle:

- Individualized funding. Sometimes referred to as "self-determination" or "cash and counseling," individualized funding provides individuals with funds to arrange for their services and supports. A fiscal intermediary and service coordinator may be used to assist people in managing funds allocated to them.
- Person-directed personal assistance. Under this approach, people are able to select, hire, supervise, and, if necessary, fire their support staff or personal assistants.
- Person-centered planning. This is a planning approach designed to identify people's capacities, needs, and desires.
- Home of Your Own. This involves innovative financing schemes to enable people with disabilities to own their own homes as opposed to living in agency operated facilities.
- Family-centered support services. For children, in particular, families should control the services offered to them.

People without disabilities can make poor choices. Some people pursue unhealthy lifestyles or spend their money unwisely. Disability is not a reason for depriving any person from making the same choices other people have the right to make.

### Are all people capable of making choices?

All people should be presumed competent to make choices about their lives. Some people, however, may be limited in their ability to express their decisions. In these instances, every effort must be made to ascertain their preferences and choices by people who know them well. Surrogates — parents, family members, and guardians — will sometimes need to

### On Choice

Continued from page 8

make decisions on peoples' behalf when it is impossible to determine what they want. The choices that surrogates make in such circumstances should be limited to the range of choices and opportunities available to people without disabilities.

### What about people who make bad choices?

People with or without disabilities can make bad choices. Some people pursue unhealthy lifestyles or spend their money poorly. Disability is not a reason for depriving any person from making the same choices other people have the right to make. Nor is disability a reason for supporting people with disabilities to make decisions (e.g., physician-assisted suicide) that persons without disabilities are not entitled to make.

Family members, friends, and loved ones can and do influence the behavior of others. The strongest safeguard of the well-being of any person is to be involved in caring relationships in which people influence each other in non-coercive and non-manipulative ways.

Choice should never be used to justify neglect, poverty, or an absence of realistic options. People do not choose to go hungry or be homeless. To people who might make bad lifestyle or spending decisions, we should be magnanimous.



### How has the concept of choice been misused?

Increasingly, choice is used by some individuals and groups as a justification for the continued institutionalization of some people with developmental disabilities. What is usually meant by this is that parents and family members should have the option of deciding where and how their sons and daughters with disabilities should live. Although family members can play an important role in supporting people with developmental disabilities, they are not entitled to substitute their own interests and wishes for those of people with disabilities. The condemnation of institutions by organized self-advocacy groups testifies to the fact that people with developmental disabilities do not wish to be put away.

The phrase "one size fits all" is sometimes quoted by proponents of institutions to characterize the policy of community inclusion. Yet, it is the institution — with well-documented patterns of "block treatment" and rigidity of routines — that epitomizes "one size fits all." In the community, there is unlimited variety and opportunity to pursue lifestyles based on individual needs and preferences.

Any adult has the right to decide with whom to associate. Some groups have chosen to segregate themselves from the wider society based on religious, ethnic, and other grounds. Some parents choose to send their nondisabled children to boarding schools where they can be with students of similar ethnic, religious, or economic backgrounds. In a democratic society people have the right to choose segregation — to associate with only those persons presumed to be exactly like themselves. But society has no responsibility to subsidize segregation. Public policy toward people with disabilities should support opportunities to make the same choices other people make — nothing more and nothing less.

THE FOLLOWING BULLETINS
AND FACT SHEETS RELATED TO
CHOICE ARE AVAILABLE FROM
THE CENTER ON
HUMAN POLICY:

Policy Bulletin on Safeguards (1993) addresses how safety can be increased by strengthening community and improving the assistance people receive. It also discusses the paradox of regulations. (18 pages)

Fact Sheet on Self-Advocacy (1999) by Mair Hall briefly defines what self-advocacy is, provides a brief history of the Self-Advocacy/People First Movement, and includes a brief list of resources. (2 pages)

Fact Sheet: Summary of Self-Determination (1998) by Michael J. Kennedy and Lori Lewin summarizes what self-determination is and is not, the principles of self-determination, the values supported by self-determination, and a call for changes in the system in order for self-determination to truly succeed. (2 pages)

Fact Sheet: In Support of Families and Their Children (2000) by Nancy Rosenau discusses why children belong in families and how to assure families for all children. (2 pages)

Feature Issue on Institution Closure (Winter 1995/96) edited by Mary F. Hayden, K. Charlie Lakin, and Steve Taylor contains national information as well as a variety of articles on closing institutions written from the perspectives of self-advocates, professionals, parents, researchers, and policy makers. This bulletin was published through the Impact series of the Institute on Community Integration at the University of Minnesota in cooperation with the Center on Human Policy.

### On Choice

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Center on Human Policy.

Fact Sheet: What is "Permanency"? (2000) by Nancy Rosenau describes the importance of permanency for children and discusses strategies to support and implement it. (2 pages)

Fact Sheet: The Community Imperative (2000) In 1979, the Center on Human Policy at Syracuse University wrote The Community Imperative, a declaration supporting the right of all people with disabilities to community living. The Center has reissued The Community Imperative in 2000 and invites endorsements from individuals and organizations.

### Internet Resources Related to Choice

Advocating Change Together http://www.selfadvocacy.com/

Self Advocates Becoming Empowered http://www.sabeusa.org/

National Program Office on Self-Determination http://www.self-determination.org/

Center on Human Policy http://www.soeweb.syr.edu/thechp/

National Home of Your Own Alliance http://alliance.unh.edu/

Institute on Community Integration, University of Minnesota http://ici.umn.edu/

Steven J. Taylor, Ph.D. is Director of the Center on Human Policy at Syracuse University. Questions or comments regarding this article may be directed to Dr. Taylor by e-mail at <staylo01@mailbox.syr.edu>

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Education in Italy: 《
An Inclusive Approach

May 16-June 11, 2001 Syracuse University

Why study inclusive education in Italy? United Nations observers cite Italy's programs as the most inclusive in the world. There are site visits to schools in Rome, Florence, Bologna, Parma, and a rural village near Naples; guest lecturers from local, regional and national levels.

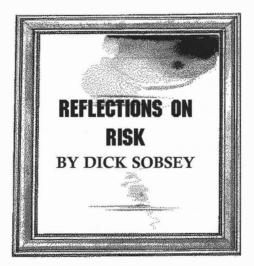
Time is planned for enriching cultural experiences involving the history, art, and architecture in Rome, Florence, Venice, Parma, Pompeii, and Orvieto.

Write or call Dr. Carol Berrigan, Seminar Director, of Syracuse University for more program information at: Center on Human Policy, Syracuse University, 805 S. Crouse Avenue, Syracuse, NY 13244-2280; Phone: (315) 443-3851; E-mail:

How does the latest rulemaking and legislation coming out of Capitol Hill affect you and your family? How can you join with others to make a difference and ensure that your voice is heard?

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or about thirty years now, I've been thinking about the risks and how to manage them. I remember one of the things that made me start thinking about different kinds of risk a long time ago. It was an article by Bob Perske (1972) about the dignity of legitimate risk. I'm not sure now if that was the first time I read something by Perske that made me think and rethink things, but it was certainly not the last. His work over the years has had wonderful impact on a lot of us, making us look at things from a slightly different perspective, making us think a little differently and, more importantly, making us feel differently about things.

I had been working in a large institution for a long time then. One of the main reasons that people ended up there was that someone wanted to protect them from the outside world. I have no doubt that there really were some risks that they were spared by being "put away," but there were a lot of other risks that increased. Hepatitis, a wide variety of parasites and other communicable diseases were common. In the crowded and understaffed dining halls, people choked to death because they learned to stuff food in their mouths as quickly as they could before it was stolen by another resident or taken away by staff. Everyone was neglected. Most were assaulted, and many were sexually abused.

I thought of one young man who had recently died there. Another resident of the institution had gotten a small jar of peanut butter. It was his most precious possession, and he kept it in his shirt so it would not be stolen. One day, the glass jar slipped out and smashed on the floor. As the former owner of the peanut butter stood in shock, Mark, as I'll call him here, deftly scooped up the mixture of broken glass and peanut butter, and he ate it. Of course, eating broken glass is never a good idea but broken glass mixed with peanut butter is a lot worse. Mark seemed to be recovering, but suddenly died a couple of weeks later. I felt sad about it, but reading that article, tears of grief turned to tears of rage. I wanted a gravestone for Mark that said, "Dead at 24. Protected from the risks of a normal life."

Since then, I think a lot about risk. In the middle of writing the paragraph above, my son's school called to say, "David got hit in the face by a soccer ball, and he's bleeding from his nose and mouth." By the time my wife, Louise, and I got to the school, David seemed fine, and most of the blood had been cleaned up. David's disability makes it hard for him to protect himself when playing with other kids. Nevertheless, David is in the game. The boy who kicked the ball is a friend of David's. He comes over to play at our house from time to time. So are most of the other kids who were playing soccer that day.

David has had no more and probably a lot fewer cuts, scrapes, bruises, bloody noses than most ten-year-olds I know. So



the risk of playing with other kids is a normal risk. Furthermore, it is a risk that David chooses to take. As parents there may be times when we have to step in because the risk is too high. When the risks are reasonable, however, why not let David make his own decision?

Louise and I would like to keep him perfectly safe, but the risks associated with being in the game are actually a lot less than the costs of keeping him out of it. He can get hurt playing with other kids, but that risk does not justify the cost of giving up his chance to have friends. About 150 years ago, one authority on risk management summed it up as follows: "Tis better to have loved and lost than never to have loved at all." (Tennyson, 1850).

A lot of the risk that people seem concerned about these days is the risk for abuse and exploitation. I've been one of the agitators that have been worrying people about this. I've spent a lot of the last 15 years trying to get people to see that violence is a huge problem for people with disabilities, so I am not going to trivialize it now. Nevertheless, I do need to say that misguided attempts to protect people can do more harm than good. I suggest two tests to determine whether protection strategies are appropriate. First, identify to what degree the risk is controllable and how much difference the prevention strategy is likely to make. Second, consider the cost to the individual who is being protected, particularly social and emotional costs.

For parents and family members who are horrified to learn that children with disabilities are more than three times as likely to be abused as other children, it is important to think about two kinds of potential abuse -- intrafamilial and extrafamilial. Intrafamilial risk is the most controllable. Many children with disabilities are abused by members of their own families, most often parents.

### REFLECTIONS ON RISK

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The "good" side of this sad fact is that we actually have a lot more control over this. If, as a parent or family member, we can honestly feel secure that our child and loved ones are safe with us and reasonably secure that he or she is safe with the rest of our family, we immediately remove a large slice of that increased risk.

Restricting people from doing what they want in order to keep them safe is disempowering. This does not mean that restricting an individual's choices is always the wrong thing to do, but in my opinion many use it much too often. It should be used only when the stakes are high, harm is likely, and there is no empowering or even less intrusive strategy available.

If some of us are not 100% sure that our child or loved one is safe with us, the most important thing we can do is to get the help we need. If anyone is suffering from depression, has anger management problems, or is having difficulty coping with stress, he or she needs to deal with those issues.

There are also reasonable strategies for minimizing risk for abuse from external sources. Choose caregivers and programs carefully. Use agencies that check police records and screen staff carefully. Ask agencies about their policies. Avoid agencies and programs that isolate you from your child.

For example, if a day care has no unobstructed windows, makes you ring a buzzer to get in, then keeps you in the office while your child is brought to you, it is probably time to get your child out of there. Parents and families should have a way to see what things are like when visitors are unexpected. Of course,

this does not mean that there is no security to keep strangers from entering, but security is not an excuse for isolation.

In considering the cost of violence prevention strategies, think about whether strategies empower or disempower the people who they are supposed to protect. Better communication and sex education, facilitating appropriate social and sexual relationships, and empowering people to chose and reject where they go and who they go with are all strategies that can keep people safer.

Restricting people from doing what they want in order to keep them safe is disempowering. This does not mean that restricting an individual's choices is always the wrong thing to do, but in my opinion many use it much too often. It should be used only when the stakes are high, harm is likely, and there is no empowering or even less intrusive strategy available.

For example, we would not allow our son to go out to the store by himself because there is good reason to believe he would be in serious danger. For now, that restriction is justified. If he can learn to keep himself safe, however, that would replace a restrictive strategy for protection with an empowering one. Risk can also be categorized by its political impact. There has been a lot of discussion of the relative risks of institutional placement and community alternatives. Some researchers have suggested that deinstitutionalization has been accompanied by neglect, abuse, and increased death rates. Others have argued that this analysis is biased and that the risks are actually much higher in institutions. Service providers and parents also have politicized risks at times. A social worker once told me about a group home they found where former residents of a large institution were kept in chains and abused. While they got the residents out, they did not report the abuse because they felt that the publicity would slow down the move

to the community, which they believed was more important. The father of a young man who lived in an institution once told me that his son had been abused there, but he would not report it because he strongly believed that the institution was the best place for his son. In his words, he "did not want to drive another nail in the coffin" of the institution. In my opinion, both of these individuals are making a serious mistake. The moment we agree not to confront the problems of abuse and neglect because confronting the problem conflicts with some greater goal, we have accepted abuse as a permanent reality.

Risk in these arguments becomes a political pawn for a much broader agenda. As a researcher, I will tell you that I still believe that the risk of violence and neglect is higher in isolated institutions. I also need to say: (a) the comparisons are difficult to make in a completely objective way; (b) there are good arguments made on both sides; and (c) deinstitutionalization, in itself, has not and will not solve the abuse and neglect problem. The more important concern, in my view, is that politicizing the issue of risk for or against community living is wrong. Both sides need to pay more attention to solving the problem and less attention to whose agenda is served.

The living conditions in some group homes and other community-based living alternatives have been horrible (e.g., Horwitz & Boo, 2000). No one should have to live under those conditions. The concerns raised about death rates and other problems (e.g., Strauss & Kastner, 1996) among people returning to the community should not be simply ignored or repudiated by advocates for community living. People have a right to life in the community AND they have a right to decent living conditions. No one should have to choose one or the other, and realizing the promise of community living does not mean just being a little better than an institution.

#### REFLECTIONS ON RISK

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A hundred years ago W.E.B. DuBois (1901-1969) wrote eloquently about the hardships faced by former slaves returning to the community. The problems that he identified were significant ones, and some people tried to use DuBois' work to argue that abolition had been a mistake. DuBois did not let himself be drawn into the argument of whether emancipation might have done more harm than good. He did not ignore the problems to avoid the argument.

Instead, DuBois insisted that all people had a right to their freedom and a had right to decent living conditions. In much the same way, we need to face the risks of abuse and neglect in community settings squarely. We need to continue to push for community living, but we also need to push just as hard for quality services that keep people safe.

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TASH Newsletter, FEBRUARY 2001

### Self Determination

BY LIZ OBERMAYER

am a person with a developmental disability and like most people with a developmental disability, I usually was told what, when or how to do something. Sometimes I wasn't even given a choice. This went on for years and years. Parents and professionals didn't think anything of it, and people with developmental disabilities didn't know any better, because that's how life was. Other people made all kinds of choices for us, ranging from where to live to as simple a matter as what to

That is until my friends and I learned about something that people have been calling self determination. Self determination is a very simple concept, I think. People with disabilities are just saying that we should be able to control our lives just like anyone else does. That means simple decisions like what to wear or eat or where to live, to more complicated tasks like controlling our own resources.

Parents and professionals usually will say that we shouldn't be able to control or make decisions for our lives because we can't make responsible and good choices. My argument to this is that all people can learn from events or decisions that may not turn out as planned. Another argument could be that I am sure not every decision or choice my parents or someone made would turn out to be a good or a responsible choice.

Self determination has changed my life for the better because for the first time, I am learning about what it means to control my life. As I have understood the concept, there are four main points to self determination. They are freedom, authority, support and responsibility. I will now describe how each concept effects my life and the live of my friends:

Freedom: In my opinion, this is the most important principle because for such a long time people with disabilities were not allowed to live a free life even though our country is based on this fundamental right. Most of the time people lived in an institution or a controlled environment. For the past couple of years, I have lived in a world where I make the decisions and I can make choices for myself.

I also have the freedom to come and go wherever I want, and make the decision whether I want to tell someone where I am going. I refuse to go back to a world where I am controlled. My friends also enjoy the same kind of freedom I enjoy.

Authority: When I looked up the word "authority" in the dictionary, it says something like the power to influence a command or thought. To me it means, I have the authority or power over my life and I have the final say over things. My friends and I struggle everyday to get the authority over our lives because I think some people without disabilities don't see us having the capability of having the authority over our own lives.

For example, when I was moving from Massachusetts to the Maryland area, my parents helped me get my apartment. We saw two apartments and then when it came down to making the final decision, I made it all by myself, based on what I wanted. This wasn't the case when I moved to Boston from a controlled environment.

Support: This is my favorite principle of all because I think everyone, regardless if you have a disability or not, needs some kind of support. When I no longer required paid support, I formed a circle of support. I like calling it a circle of friends. The reason why I call it that is because I would like to get my support from my friends, not from people who just support me because they have to. I think if people don't get support then people, regardless of disability or not, won't have happy and productive lives.

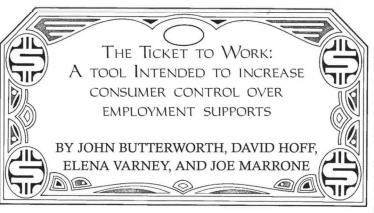
My circle is a circle that I give support to just as much as they support me. I worry

sometimes that people with disabilities take advantage of people who support them. I mean sometimes people with disabilities will expect people without disabilities to help and they don't offer anything in return. This is fine if the person is getting paid to help you, like used to be the case with me, however now it's not. Sometimes all I can do is to listen to my friends' problems, but there are other times I can do more. I like knowing that I am making my friends feel better because it makes me feel like it's a true friendship. My friend, Nancy Ward, once said that support should "go both ways."

Responsibility: This principle is also one of the important principles of the self determination movement. I also enjoy talking about this one. A lot of people without disabilities will often complain that people with disabilities don't want to take responsibility for their own life. They say that people with disabilities would like all the rights and privileges that go along with living and working in the community, however when it comes to taking responsibility to live or work in the community, that's another story.

Just as there may be a certain percentage of people without disabilities who do not want to work, you will find a segment of people with disabilities who feel the same. However, there are a lot of people with disabilities who do want to contribute to their communities and earn their own living using their own skills and talents. Lots of people with disabilities work at their chosen profession everyday, just as lots of people without disabilities do. And those of us who choose to work and are given the opportunity to work, understand that it is our responsibility to do so if we can.

Last year, we as self-advocates added a fifth principle, Self-Advocacy. We believe that if it wasn't for self



publish final regulations in the Spring of 2001. In the preamble to the regulations for the Ticket to Work, SSA makes it clear that the program has two compatible goals:

NOTE: The information in this article is based on proposed regulations that were published in December, 2000. The final regulations may change some of the details of the Ticket to Work program.

In December 1999, President Clinton signed into law the Ticket to Work and Work Incentives Improvement Act of 1999 (TWWIIA), to enhance the ability of people with disabilities to go to work. This new law does a number of things, including requiring SSA to establish a "Ticket to Work and Self-Sufficiency Program," where individuals receiving Social Security disability benefits (SSI or SSDI) can choose services to assist them in finding and maintaining employment, and reduce their dependence on cash benefit programs.

The Ticket to Work program will be implemented beginning in 2001 on a state-by-state basis. Despite significant concerns about the regulations that have been proposed, the Ticket offers the potential for individuals to have greater control over their employment supports. This article provides an overview of the Ticket program based on the proposed regulations. The TASH Employment Committee encourages individuals and organizations to use the Ticket as a tool for individual and organizational change, and as leverage in redirecting resources to integrated employment.

This summary is based on regulations for the Ticket program that were proposed in December, 2000. The Social Security Administration is expected to

- "To expand the universe of service providers available to beneficiaries with disabilities who are seeking employment services, ..."
- "...To provide beneficiaries with real choices in getting the services they need to obtain, regain, or maintain employment."

### The Ticket to Work Program - What Is It?

The basic idea of the ticket program is to maximize choice by allowing you to select your own employment or rehabilitation provider, and for Social Security to pay that provider based only on a successful outcome. This outcome is defined in the law as successfully getting a person in a job which provides sufficient income that you no longer get a monthly SSI or SSDI check.

The ticket program is being phased in nationally over a three-year period beginning in 2001. The first tickets will be issued in 2001 in the following states: Arizona, New York, Colorado, Oklahoma, Delaware, Oregon, Florida, South Carolina, Illinois, Vermont, Iowa, Wisconsin, Massachusetts. By January 1, 2004, the ticket program will be nationwide.

When the ticket program begins in a state, individuals receiving Social Security disability benefits (SSI - Supplementary Security Income; SSDI - Social Security Disability Insurance) will receive a "ticket" (a paper document). The person with a disability can then use this "ticket" to obtain services to help them find and keep a job. The organiza-

tions providing services under the ticket program are called Employment Networks (EN).

### What types of organizations can be Employment Networks?

A wide range of organizations can be Employment Networks. These include both public and private organizations. State Public Vocational Rehabilitation agencies must be an Employment Network, if they wish to receive any funding from SSA for providing services. Other Employment Networks can include: other state, county and local public agencies (including Mental Health, Developmental Disability/ Mental Retardation agencies), community rehabilitation providers, supported employment agencies, schools, One-Stop Centers, and similar organizations which have traditionally been in the business of helping people find employment. (SSA also expects that some nontraditional entities may wish to become Employment Networks.)

### What is my ticket worth?

The amount paid to an Employment Network is based on a percent of the prior calendar year's national average disability benefits payable under Title II (SSDI) or Title XVI (SSI), and not on the individual's benefit amount. The amounts will be adjusted on an annual basis for cost of living. The charts at the bottom of this page outline the two payment systems as proposed.

Employment Networks receive monthly payments only for those months when the beneficiary does not receive a check from SSA. Therefore, while an EN can receive up to 60 monthly payments, these months may not be consecutive. In fact, under the proposed regulations, these 60 monthly payments could be spread out over up to 14 years from the time an individual first starts receiving services under the ticket program.

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However, if an Employment Network is able to quickly assist you in finding employment, and you work steadily at a job with sufficient income so that you don't receive a social security check, the Employment Network could receive all 60 payments in about 5 years.

The proposed regulations outline two payment systems that an Employment Network must choose from:

- \*Outcome payment system: The Employment Network receives a flat monthly fee for each month (up to 60 months) that the individual does not receive a check from Social Security. (Note: The regulations specify that the individual receive no federal benefit, implying that in states where the state supplements the federal check, the individual could still be receiving that supplement in the form of a check from SSA).
- \* Milestone payment system: The Employment Network receives two "milestone" payments along with a reduced monthly outcome payment for up to 60 months. Both milestones occur after the individual is working at aboveor above substantial gainful activity (SGA), currently \$740/month, but may occur before the individual stops receiving a check from Social Security. The total payments to the EN will be lower than under the outcome payment system (section 411.535).

How much do I have to earn to eliminate my monthly social security check?

#### SSDI

Currently, SSDI checks for individuals stop when you earn more than \$740 per month (\$1170 per month for individuals who are blind), and you have used up all your trial work months (trial work months are months when an SSDI recipient earns over \$530 per month; SSDI recipients can work for 9 trial work months over a rolling five year period without impacting their benefits, and receive checks for 3 more months when the trial work months have been used up).

#### SSI

Unlike SSDI, there is no standard income level where your SSI check is reduced to zero. Instead, the amount varies, depending on the amount of your monthly SSI check from the federal government. The formula to calculate this is: [(Monthly SSI Payment - State Supplement) X 2] + \$85. (Many states add an additional amount to SSI checks, which is called the "state supplement"; under the ticket regulations, only your federal SSI payment has to be reduced to zero for the EN to be paid.) The current average monthly federal SSI cash benefit is \$440, so for evaluating the ticket program, it is reasonable to use a figure of \$965 as an approximate average amount of monthly income where an SSI check would be reduced to zero. However, the required income could be higher, since the maximum SSI benefit for an individual is \$530, requiring an income of \$1150.

### How else will the ticket program help individuals?

Suspension of Continuing Disabilities Reviews while Using the Ticket. SSA conducts continuing disability reviews (CDRs) to determine whether or not you continue to be considered disabled according to SSA's definition and criteria. Social Security benefits end if medical or other evidence shows that you are no longer disabled. SSA must conduct CDRs at least once every 3 years for most recipients. Persons deemed permanently disabled are reviewed less frequently, usually every 5 to 7 years. While participation in the ticket program is voluntary, a major incentive for people with disabilities to use the ticket is that you cannot have a CDR while your ticket is assigned to an Employment Network, (Subpart C).

### The Ticket and Individual Choice and Control

The regulations contain a number of elements so that people with disabilities have choice and control. These include:

- Participation in the ticket program is voluntary.
- If you are dissatisfied with your Employment Network you may assign your ticket to any Employment Network or State Vocational Rehabilitation (VR) agency that is willing to provide services. (Employment Networks have a similar right to decide to no longer provide you services, and no longer accept your ticket.)

Employment Network payments under the outcome system

	Months 1-60	Total payments
SSI	\$176/month	\$10,560
SSDI	\$277/month	\$16,620

Employment Network payments under the Milestone system

Employment Network payments and the Mitestone system								
	Milestone	Milestone	Months	Months 13-	Months 25-	Months 37-	Months 49-	Total
	1	2	1-12	24	36	48	60	Payments
SSI	<u>\$</u> 300	\$600	\$57/mo.	\$141/mo.	<u>\$</u> 150/mo.	\$158/mo.	\$167/mo.	\$8,976
SSDI	\$470	\$940	\$90/mo.	\$222/mo.	\$235/mo.	\$249/mo.	\$263/mo.	\$14,127

Note: Individuals receiving both SSI and SSDI fall under the payment schedule for SSDI recipients.

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- Employment Networks do not get paid, unless they find you a job that pays you a sufficient income so that you no longer receive a social security check.
- An individual work plan (IWP) (or, in the case of a State VR agency, an individualized plan for employment [IPE]) which is agreeable to you, must be developed before you assign your ticket to an Employment Network.
- You and the Employment Network share the responsibility for determining the content of the individual work plan. IWP.
- When you go and talk to an Employment Network about possibly using their services, the EN must provide you with a copy of its most recent annual report, which lists specific information on the results achieved with individuals in the ticket program, to help you decide if the EN is the right one for you.

### What are the concerns about the Ticket program?

- ⊙ The biggest concern is that the ticket program does not by itself provide enough resources to cover the job search and job support needs for an individual with significant support needs. This means that the ticket may be most useful combined with another funding source such as funding from an MR/DD or MH agency. Combining the ticket with the funding from a VR agency is more complicated, since the VR agency functions like an employment network and can take the ticket itself.
- Reassigning the Ticket (and thereby having full control over the source of support services) may be more difficult if you are combining the Ticket with other funding sources to find work.
- For the ticket to have value to an employment network, individuals do

need to be earning a significant wage. Many individuals in supported employment do not reach the wage levels required under the ticket. This is both good news and bad news. The ticket, if it is successful as a program, may provide incentive to service providers to seek better jobs with higher wages and work hours. The bad news is the individual needs to clearly have the goal of reaching that level of work.

- © The requirements for work under the ticket program appear to recognize that it may take time for some individuals to work towards self-sufficiency, possibly with cycles of relapse and remission. While this may sound reasonable from the ticket users perspective, if an individual is able to comply with only the minimum requirements, it may be difficult for the Employment Network to justify the cost of services:
- under the outcome system, the Employment Network will receive no payment until year five (unless an individual on SSDI has previously used up his/her trial work months)
- under the milestone system, the Employment Network would receive only two payments prior to year five
- the Employment Network could potentially have the 60 months of payments spread out over fourteen years from the time the EN first starts working with an individual.
- People with disabilities use work incentives such as Plans for Achieving Self-Support (PASS) or Impairment Related Work Expenses (IRWE) that help people with disabilities pay for items and services related to employment. As a result of these work incentives, part of an individual's income will not impact their social security check. The regulations do not appear to adequately address the impact of work incentives on payments to the Employment Network, effectively increasing the amount an individual would need to earn before the Ticket would pay off for the employment network.

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Note: This is part 1 of a two-part article. Part 2 will appear in the March issue of TASH Connections and will include TASH's concerns and recommendations regarding the Ticket to Work and Work Incentives Improvement Act Proposed Regulations.

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#### **RESOURCE LIST**

For further information on the Ticket to Work and Self-Sufficiency Program and regulations, contact:

Geoffrey Funk, Team Leader, Legislative Implementation Team, Office of Employment Support Programs, Social Security Administration, 6401 Security Boulevard, Baltimore, MD 21235-6401; Voice: (410) 965-9010; TTY: (800) 988-5906; Web site: www.ssa.gov/work

Text of the regulations:

The Ticket to Work and Self-Sufficiency Program: Proposed Rule; Part 411 of Title 20 of the Code of Federal Regulations [20 CFR Part 411]; Federal Register, December 29, 2000. Available on-line at: <a href="http://frwebgate.access.gpo.gov/cgi-bin/getdoc.cgi?dbname="http://frwebgate.access.gpo.gov/cgi-bin/getdoc.g

Related publications available from the Institute for Community Inclusion <a href="https://www.childrenshospital.org/ici/">www.childrenshospital.org/ici/</a> publications/policy.html>

The Proposed Ticket to Work Regulations (Tools for Inclusion, Vol. 9, No 1, January 2001).

Proposed Regulations Implementing the Ticket to Work and Self-Sufficiency Program (Vol. 3, No. 1, February 2001, 12pp.)

The Ticket to Work and Self-Sufficiency Program and Established Under the Ticket to Work and Work Incentives Improvement Act of 1999. (Vol. 2, No. 2, February 2000, 4pp.)

Improvements to the SSDI and SSI Work Incentives and Expanded Availability of Health Care Services to Workers with Disabilities under the Ticket to Work and Work Incentives Improvement Act of 1999. (Vol. 2, No. 1, February 2000, 8pp.)

These publications are available via the ICI web site at <www.childrenshospital.org/ici/publications/policy.html>

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### **Foundations for Freedom:**

## International Perspectives on Self-Determination and Individualized Funding

by Steve Dowson & Brian Salisbury



This enlightening report is based on the First International Conference on Self-Determination and Individualized Funding, Seattle, 2000.

Anew

focusing on the concepts of selfdetermination and individualized funding is now available!

These concepts continue to evolve and take on meaning for greater and greater numbers of people with disabilities and their families.

Throughout this groudbreaking report - one resounding principle rings true - no one but the person with a disability (and for children, the child and his/her family) could possibly know what was best for that person. All over the world people with disabilities are seeking and accepting only those supports that provide what they want and need to realize their own futures.

This 88 page report is an in-depth look at the Declaration formed as part of this conference, and the implications it has for changing the ways systems and communities support people with disabilities. The report was sent to all who attended the conference.

"The writer, Victor Hugo, said that when people dream together, they create a shared future. To Hugo, this meant far more than daydreaming. It meant grappling with the challenges and injustices of life, to create a better tomorrow, a richer world of opportunity for all people.

This has been the critical work of this conference, and it must continue to be the work we all do, each in our own ways, long after we leave here.

The declaration we have just heard outlined must guide our collective efforts. Like all declarations, it is a call to return and recommit to first principles, the fundamental principles of justice and equal opportunity.

We must translate the language of self determination into a far more common and universally understood, language of human freedom, which I believe all people and most governments throughout the world, not only understand, but actively seek to embrace.

We need to recognize, and help everyday people and our governments, recognize that this thing, that some call self determination, is not new. It is ancient. As ancient as the human will to live free."

~taken from Bob Williams' closing address, which followed the presentation of the Declaration. The full speech is included in the report.

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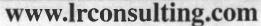
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rindividuals with disabilities are outliving their parents. Advances in medical technology, improved health care availability, higher social expectations and community living have ensured a longer life for our friends and family members with disabilities. In the next decade close to 6 million families in North America will be caring for their aging relatives with a disability.

My daughter, Liz, is a good example. Before she was five years old, she had had two life-saving operations that were not available five years previously. Nowadays, individuals with Down syndrome are living on average into their 60s. Compare this with an average of 9 years of life in the 1920's and 30 years in the 1960's for individuals with Down syndrome.

The immensity of this fact is slowly creeping into our consciousness within the disability community, and will soon command the full attention of government policy makers and even the corporate sector. This demographic trend, however, simply underscores a worry and anxiety that perches on the shoulders of parents the world over from the moment our children are born. "What will happen to my son/daughter with a disability if something should happen to me?" is a constant concern confronting all parents at the best and worst of times.

Thinking about the future is a natural extension of being a parent regardless of the age of our children. As one parent in Australia recently commented, "I need a 'drop dead' plan." And, as we all know, although many of us prefer to ignore it, growing old is not a certainty for any of us.

As more and more individuals enjoy their senior years, pressure is exerted on our systems and institutions to respond. This, in turn, has the benefit of raising awareness on the importance of planning for the future for our sons and daughters with disabilities regardless of their age (or our age, for that matter).

### Creative Responses are Emerging

Fortunately, families everywhere are developing creative responses to what some people have described as "aging anxiety." And the solutions are emerging from the age group one might expect - parents who, in their senior years, are forced to confront their own mortality. These families, many of whom were leaders in the community-based disability movement which emerged after World War II, are not content just to resolve their own future planning challenges. They are passionate about sharing their pioneering efforts with younger families. We will all benefit from their living legacy.

I work for one such group, the Vancouver, Canada-based Planned Lifetime Advocacy Network (PLAN). In 1989 a small group of 15 families, average age 70, came together to help each other answer the stark question, "What will happen to our sons and daughters with disabilities when we die?" They created an organization as a container for their worries, their dreams and their solutions. Little did they know they had stumbled into an area families and caregivers everywhere were struggling with. The content of this article has been distilled from PLAN's experience and direct contact with over 10,000 families in the ensuing years.

From a general perspective, families report three lessons which emerge once they embark on the path of preparing for their own death and planning for the future well being of their relative with a disability. These are worth remembering as you read the 7-step overview presented here.

- 1. The most important consideration is not how long you will live, but how well you will live your life. In other words exploring the dimensions of "a good life" is the key challenge.
- 2. Planning for the future is the best excuse for changing the present.
- 3. Wills, estate planning and trusts are mere utensils, not the meal.

Respecting the choices and preferences of our relatives while at the same time ensuring their safety can be a tough balancing act. Legal guardianship has always juggled autonomy – respecting the choices of individuals with disabilities – with protection. The result, unfortunately, is usually over-protection. However, efforts to change this are underway in many jurisdictions.

### Securing The Future for People with Oisabilities

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### Seven Steps to Creating a Plan for the Future

Fifty per cent of North Americans die without a will. Ninety per cent of the heads of family-run businesses die without a viable estate and succession plan. Clearly, thinking about our own death, let alone preparing for it, is something most of us would prefer to avoid. The added dimension for families who have relatives with disabilities is they must create a plan not just for their own lifetime but also for the lifetime of their relative.

The following seven steps represent the key elements in creating a plan for the future. Each is important and will move you along the path. Taken together they represent a holistic and comprehensive approach to creating a safe and secure future and a good life. You will be able to create a checks and balance system that recognizes the best any of us can do is to be well prepared for the future, not attempt to predict it.

#### Step One:

Clarifying and Sharing Your Vision

As the old saying observes, "If you don't know where you are going any road will get you there." Families have definite dreams and yes, nightmares when they think about the future of their loved ones. We have learned to use both our love and our fears as motivating forces for clarifying our vision for the future. The trick is to release them from our silent consciousness and share them with others who care about our relative with a disability. We often ask families to make two lists, one describing a perfect day in the future, and the other describing their worst nightmare.

We have also learned not to ask, "What program or service do you want for your son/daughter?" That question simply invites program and service answers

which restrict the vision. Instead we ask, "What might a good life be?"
Those answers abound with eloquence and often poetry. Emotional, spiritual and social considerations take precedence and services fade into a supplemental role. Answers to the "good life" question invariably fall into the following categories:

Our vision of a "good life" for our relative with a disability might include:

- a. Being surrounded by friends and family members
- b. Living in a place of one's own
- c. Contributing to one's community
- d. Having one's choices respected
- e. Enjoying financial security

Clarifying a vision for the future would remain an artificial exercise unless one:

- ► Includes your family member with a disability in the process
- Shares the results with other members of the family and your son/daughter's personal network
- ▶ Trusts in the possibilities for the future for your relative
- ▶ Is prepared for a few surprises

#### Step Two:

Nurturing and Consolidating Relationships

Billie Holiday sang it best, "Without friends I ain't got nothin." To be isolated is an enormous tragedy and as Mother Teresa observed, "a most terrible poverty." Loneliness may be the most significant handicap experienced by our friends and family members with disabilities. This loneliness becomes even more disturbing when one contemplates the time when we are gone.

It doesn't matter how much money we leave in a special needs, discretionary trust, or how well written our will is. Without friends our family member could be cast adrift in a very impersonal service delivery system after we are gone. Readers of TASH Connections

are well acquainted with the social and health benefits of relationships. Supportive social ties reduce the likelihood of illness, aid the healing process, improve our immune system and are the most effective means for ensuring a good and safe life for individuals with disabilities. All other approaches are secondary.

It should go without saying yet it bears repeating: No disability precludes relationship. Parents can often lose sight of this. We have discovered that not only is it important for our family member to be in relationships with several people, but also it is equally important to connect these people with each other. Formalizing these connections into a Personal Network or Circle of Support provides:

- Companionship
- Sharing of responsibility among brothers, sisters, friends and supporters
- Advocacy and monitoring of the formal programs and services your relative receives
- A potential source for executor and trustees
- A vehicle for addressing your hopes and dreams
- Continuity after you are gone

#### Step Three:

Living in a Place of One's Own

The value of home is universal. Our home is our haven, our place of refuge. It



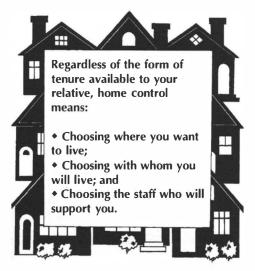
is where our authentic self emerges. Home is where we can truly "be," offering hospitality, relishing privacy, enjoying intimacy. Unfortunately, many people with disabilities live in houses that are essentially organized as places of work for staff; houses devoid of the little things that make a place a home. Group homes for example, excel at providing a place to eat, sleep and be

### Securing The Future for People with Oisabilities

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sheltered. Often they do not reflect the relatedness of people, places and things. They do not nurture relationships among the people who live there, or help them understand their connection with nature or with the everyday things they use.

Getting from "house" to "home" can be challenging for our friends and family members with a disability. One approach is home ownership. The National Home of Your Own Alliance has the best material on accomplishing this dream. There are, however, other means to create control over the housing environment in which your relative chooses to live. These include long-term leasing, co-housing, housing equity coops, and land trusts.



Creating a home cannot be done in isolation from the other steps discussed here. Without the existence of a Personal Network, our sons and daughters will be just as isolated in their own place as anywhere else. Similarly, your will and trust agreement will formalize arrangements for housing tenure and maintenance. For example, a home may be owned by a trust. Step 5 provides

some options for protecting your relative against exploitation and to assist them in making housing-related decisions.

#### Step Four:

Making a Contribution

Each of us has a deep longing to give, to contribute, to offer and to share what is meaningful to us. Unfortunately, this is often an experience denied to our friends and family members with a disability. There are at least two reasons for this tragic oversight: there is no recognition they have something to contribute; and they have little opportunity to make their contribution.

A good life, now and in the future, for our daughters and sons with disabilities means:

- . Believing they have a gift
- Validating their gifts
- Assisting to develop their gifts
- Ensuring their gifts are given

Contribution establishes the valued role of citizen. The next leap forward for the disability community will be made from the base of citizenship. Citizenship is about both rights and obligations and obligation is about contribution. People with disabilities are an underutilized resource in our community and their contribution, whether paid or unpaid, is an important source of "social capital" - the glue that holds our communities and neighborhoods together.

#### Step Five:

Ensuring Choice

Respecting the choices and preferences of our relatives while at the same time ensuring their safety can be a tough balancing act. Legal guardianship has always juggled autonomy — respecting the choices of individuals with disabilities — with protection. The result, unfortunately, is usually over-protection. Efforts to change this are underway in many jurisdictions. These were well-described in Dohn Hoyle and Kathleen Harris's article, *Re-thinking Guardianship*,

Ensuring choices for individuals with disabilities means creating a process for supported or joint decision making. When combined with a Personal Network and individualized funding, there is greater likelihood their choices will not only be heard but heeded.

which appeared in the November 2000 issue of the TASH newsletter.

In general, families would be advised to examine supported decision making as an alternative to formal guardianship. Supported decision making provides a way to respect the unique decision making style of each individual with a disability and to provide support where necessary without depriving the individual of his/her legal decision making rights.

Supported decision making for our relatives and friends with disabilities means:

- They are an active participant
- All methods of communication are taken into consideration
- Their tastes, preferences, intuition, motives and ability to discriminate are respected
- Trusting relationships have as much weight as intellectual ability
- The focus is on abilities
- They are surrounded by caring, knowledgeable and trusting people who are in a relationship with them
- Risks, failures and mistakes are recognized as learning opportunities

Many families and friends are developing a Supported Decision Making Agreement which identifies individuals who are available to assist with decision making in the areas of medical/health; financial; and daily living. These agreements are recognized legally in some jurisdictions and are having the force of moral authority in others.

### Securing The Future for People with Oisabilities

Continued from page 23

Ensuring choices for individuals with disabilities means creating a process for supported or joint decision making. When combined with a Personal Network and individualized funding, there is greater likelihood their choices will not only be heard but heeded.

### Step Six:

Designing a will and estate plan

A will and estate plan is one of three potential sources of wealth for individuals with disabilities. The other two are the income they receive from work and the individualized funding they receive from the government.

A will and estate plan is the means by which parents can leave a share of their wealth to their child with a disability. There are some critical considerations to address, the two most important being:

- 1. Write a will. If you do not have a will, the government will distribute your assets according to a formula they devise. Similarly, they will determine who will care for your minor children and it may not be whom you want.
- 2. Establish a 'special needs' or discretionary trust. These trusts enable individuals with disabilities to receive their share of the estate left on their behalf without jeopardizing the benefits they receive from the government.

The more friends and supporters your relative with a disability has, the greater the possibility of "humanizing" your will and estate plans. For example, if you choose a corporate trustee to manage, invest and disburse money from a trust fund you establish, assuming they are likely to know very little about your family member. We recommend families consider nominating two trustees, at least one who has a personal connection to the family member with a disability. A good source of trustees is

the Personal Network. You can advise your trustees to seek advice from the Personal Network members before spending from a trust. Finally, you can instruct your trustees to check directly with your son or daughter before making any financial decisions.

#### Step Seven:

Securing your plans

If a family has followed the previous steps they have:

- clarified their own thoughts for their relative with a disability and shared with others these hopes and dreams
- developed or formalized a network of support
- built a vision of home and contribution
- developed a supported decision making agreement
- and created a will and estate plan.

These plans by themselves will definitely ensure the safety and well being of your family member with a disability. Nevertheless, more and more families are going one step further. They are creating a new type of organization to provide two main services:

- 1. To assist families of all ages to develop their plans while the parents are still alive
- 2. To monitor and safeguard these plans when the parents become incapacitated or die.

Planned Lifetime Advocacy Network (PLAN) and similar organizations can be used by families to:

- Provide advice to executors and trustees
- Maintain the health of the individual's Personal Network
- Monitor and advocate for improved services and programs
- Oversee supported decision making arrangements
- Keep in regular and direct contact with the individual with disability
- Respect and carry out specific wishes

of the family

• Provide continuity

Typically these organizations are independent of the service delivery system and independent of government funding. This ensures their objectivity and effectiveness as an advocate and monitor. These organizations are family-controlled and directed and become the eyes and ears, arms and legs of the parents after the parents are gone. In many ways, these new groups are revitalizing the family arm of the disability movement. Families are discovering what they already knew — together they are better.

#### Conclusion

The good life paradigm represents a new way of thinking and acting about the life we want for our loved ones with disabilities. In a paradoxical but wonderful manner, a good life framework actually makes a difference now, not only for our relatives with disabilities but also for their parents. In that regard future planning is less about the future and more about peace of mind, now!

Al Etmanski is the Executive Director of the Planned Lifetime Advocacy Network (PLAN). He also serves on the faculty of John McKnight's Asset Based Community Development Institute. He is the author of numerous articles and the books, Safe and Secure - Creating a Personal Future Plan For People with Disabilities and A Good Life - For You and your Relative with a Disability.

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PLAN's web site is <www.PLAN.ca>

#### References:

National Home of Your Own Alliance - <a href="http://alliance.unh.edu">http://alliance.unh.edu</a>



ichael is a ham. He loves being the center of attention. These days he's a far cry from the abrupt, reticent, and withdrawn man of ten years ago. If only his mother could see him now. Her faith in the power of relationships would not be misplaced.

Tonight he is giving a workshop. The copresenters and Michael meet beforehand. The topic is 'Personal Networks - Weaving the Ties That Bind.' They agree on a format. Vickie will assume the role of a television personality and interview Michael.

Michael is excited. A real television-style interview. No detail is too small. It must be authentic, for a man who is precise. It must be Oprah, not Rosie. There must be a microphone. There must be an elevated stage. Everyone agrees. They go along with the illusion.

Seventy-five are in attendance. There is a camera crew from the local community college. The workshop is being taped for distribution.

The moment arrives and Vickie as Oprah turns to ask Michael her first question.

"Hold everything," shouts Michael. "Let's get rid of these extra chairs." The chairs are removed.

Then, nodding to the camera operator, he asks if they have enough light. They do, but thank him for asking. Michael, clearly, is the one in control.

Next comes a sound check. You can never be too sure!

Vickie tries again. By now the audience is into the spirit of the occasion. "Let's go, Rosie," they chant encouragingly. "No, no," interrupts Michael. "Not Rosie but Oprah. Oprah Winfrey." "Yes," says Vickie, "Oprah would like to ask you a question."

"Wait a minute," says Michael forgiving her indiscretion, "You've got to start properly." "Lights, camera, action," announces Vickie, clapping her hands to simulate take seven. "And now, here's Michael."

Everyone is finally satisfied, particularly Mcihael. The interview can begin. He handles the preliminary questions with



# You Can Count on Us

BY VICKIE CAMMACK

aplomb. Next comes a more personal question.

"Tell me, Michael, what does your network do for you?" "They give me hope, love and encouragement which I really need now that my mother is dead and gone up to heaven." You could hear a pin drop. It was worth the wait.

Michael's mother. Marie was a courier de bois. This is a French term for the early Canadian explorers who cut, punched and hacked trails through our country's dense forests. In Marie's case she was blazing a trail to the future. She knew her health was declining. She quickly cut through the details of wills, estates, trusts and lawyers. She then found herself alone on the precipice with Michael. There was a large summit ahead of them. She knew Michael would be alone in the world without her. It was at this point that she and Michael decided to actively create a personal network or circle of support for Michael. The story at the beginning of this article illustrates the discoveries of their final journey together. Marie has passed away and Michael certainly misses her. But as Michael says so poignantly, he has a network of people to give him love, encouragement and support.

Michael's comments begin to illustrate what personal networks mean for the people at the center of them, especially when their parents die. I work for PLAN (Planned Lifetime Advocacy Network). We support individuals with disabilities and their families to take the trek to the future. Early on in our work with Marie, Michael, and our other founding pioneers, we realized there would be no future, or at least not a future anyone wanted, if friends and family were not a part of it. We also realized that the vast majority of folks who were coming to us were, like Michael, very isolated, especially in terms of friendship.

We determined that actively and strategically facilitating relationships had to be a key element of preparing for the future. We also learned very quickly that of course, friendships are key elements of having a life in the present. In fact, many of the folks at the center of PLAN's personal networks would equate getting a network with, in today's vernacular, getting a life.

At PLAN we like to focus on the future by thinking about what constitutes a good life. Personal networks contribute to what virtually all us of would call a good life in five very compelling ways. Clearly, as Michael states above, having a group of friends and supporters provides the emotional support and encouragement that each of us needs. Personal networks also provide practical, hands-on assistance with the tasks of daily living. Perhaps less well known, however, is that personal networks play a crucial role in the health, the wealth and ultimately in the citizenship of people with disabilities in our communities.

The following paragraphs illustrate how personal networks make a difference in each of these five areas now and in the future.

#### **Emotional Support**

This is probably the area most us of think of when it comes to friends and families. Most of us cannot imagine

### You Can Count on Us

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life without our friends to share our joys with when times are good and to lean on when times are tough. PLAN's personal networks have been great sources of encouragement for the people at the center of the networks. There is nothing like having a group of people who believe in you when it comes to gathering up the courage to take on a new challenge. Our networks have been bolsters for folks bracing themselves to start a new job, go back to school, or even to simply meet a new person. The emotional support of network members has been the catalyst that has liberated folks to see themselves as competent and capable of achieving their dreams.

We also have seen our networks walk with people through traumas such as substance abuse, episodic mental illness and personal loss. For example, when George's mother became ill with cancer his network knew he would need a lot of support in preparing for her death. They collaborated with George to create a video of his mother's life. When she did pass away this amazing group of men and women adopted the motto 'never alone.' And, indeed, George was never alone for the first month after his mother's passing. A few months after his mother's death George was able to

The contributions of people who have been labeled as disabled have never been more needed. Providing the opportunities for these contributions to be made by ensuring that a personal network of friends is there to receive them is one of the most profound legacies a future plan can create.

say, "My mother has died and I miss her. But with the help of my network I'm doing o.k."

#### Practical Assistance

Most families in preparing for the future are acutely aware of the innumerable things, small and large, they do on behalf of their relative. These can range from filing income tax returns to buying the best-fitting brand of underwear. It is often these personal details that families are the most uncomfortable leaving to individuals who are paid to support their relative. Personal network members at PLAN provide a vast array of practical support to their friends.

Network members are the ones who notice if the coat is getting threadbare and make a quick trip to the mall. They help write holiday cards, make sure the neighbors are happy, and that the doctor's instructions are followed. They have even been known to clean the toaster and take the cat to the vet. In short, while we all know a personal network can never replace families, they are the next best thing.

#### Staying Healthy

One of the issues families are most concerned about in thinking about the future is the health of their relative. Painstaking and important work is often done by a family to make sure all the details of medical treatment over the years are documented and shared. Clearly having a network member in the know is critical to communicating with the medical establishment to ensure the best treatment is received.

There is, however, another often overlooked role that personal networks play in safeguarding the health of the person at the center. There is a burgeoning field of research called pycho-neuro-immunology. This field explores the mind-body connection in health. The results of this research are conclusively pouring in. When we have a supportive social network we all live longer, get sick less often and heal more rapidly if we do

become ill. The old maxim holds true: a good friend is the medicine of life. Ensuring there are involved friends and loved ones is a crucial task for any family worried about their relative's health in the future.

### Wealth and Social Capital

Planning for the future always involves some discussion about financial resources. Certainly having adequate income is a critical element in anyone's future. What we have discovered at PLAN though, is that money alone can't buy happiness or success. Of course, we knew this when we began our work, but initially the seductive power of finance had us thinking that wills and estates were the most important things to be addressed in future planning. They seemed so concrete and practical and, frankly, easy in comparison with the intangible world of relationships. Interestingly, the concept of social capital has recently emerged and it is beginning to put value on the often difficult-to-measure assets of relationships.

Social capital is both the number of relationships we have and the trust, reciprocity, and shared values in those relationships. Our supply of social capital directly impacts our choices and opportunities. Research about social capital is finding among other things, that when we have a good stock of it our job prospects increase, our ability to learn is improved, and our safety is enhanced.

Alternatively, when individuals or groups are found to be lacking in social capital their locus of control is diminished and clientele-ism increases. Social capital could be considered the most important source of wealth a person with a disability has. Creating a personal network represents a strategic and focused way for families and individuals to increase their social capital.

### You Can Count on Us

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### Contribution Equals Citizenship

It is fair to say that the term citizenship does not often come up when working with families and individuals to plan for the future. Instead, they use phrases like doing something meaningful, having a reason to get up, being valued, and making a contribution. When you think about it, aren't giving, contributing, and making a difference all at the very heart of citizenship? At PLAN we believe contribution equals citizenship.

People with disabilities, along with other marginalized groups, have made enormous strides in securing their rights in the past two decades. The battles won, the laws passed, and the policies written have all been extremely important on the road to citizenship. Perhaps for people with disabilities, they represent the first half of the road. It is the other half of the path to citizenship — not rights but obligations or contributions — that needs to be traveled now.

Relationships are the ticket to the contribution side of the journey to citizenship. As seen above, social capital can certainly help to secure employment if that is the main path to contribution. But there are many other unique and crucial contributions that people with disabilities can make.

Time and again network members tell us that their friendship with the person at the center of the network contributes to them seeing their own life as more meaningful. They say things like, "Her presence grounds me. It is a real gift since I get so caught in the doings of life." And, "He reminds me that we all have needs for each other that we don't even realize." Network members use words like inspiration, courage, and creativity when they are speaking about what they receive from their relationships with people with disabilities.



Someone once said a vocation is where our deep gladness and the world's deep hunger meet. Surely most of us are hungry for meaning in our lives, surrounded as we are by today's culture of individualism and greed. The contributions of people who have been labeled as disabled have never been more needed. Providing the opportunities for these contributions to be made by ensuring that a personal network of friends is there to receive them is one of the most profound legacies a future plan can create.

For the people at the center of a personal network, contribution of their unique gifts equals the living of a life of meaning. For the rest of us, the privilege of receiving these gifts equals an opportunity to become our most human.

Vickie Cammack is a co-founder of PLAN and the Executive Director of PLAN Institute for Citizenship and Disability. She developed and directs PLAN's Personal Network Program and assists communities internationally in their efforts to develop similar organiztions. She is coauthor of "Safe and Secure - Six Steps to Creating a Personal Future Plan for People with Disabilities." She can be reached at vcammack@plan.ca

### Living A Self Determined Life

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advocacy or self advocates, we wouldn't have self determination. I worry sometimes that professionals want people to gain self determination so bad, they forget to include us in the self determination process.

A lot people without disabilities will often say that self determination can only be achieved by the "chosen few." What I think they mean by that is that my friends and I can achieve self determination because we have jobs in the community and we are "smart enough" to handle our own lives. However, people think that people who use wheelchairs or have "severe" disabilities can't ever gain self determination.

I would argue this point because I have seen people gaining self determination for themselves. I have a friend who has a "severe" disability and he needs 24-hour support. He lives in his own home. He also makes his own decisions with support from his family and friends.

I am really enjoying my life. I believe without self determination I couldn't do as much as I am doing today with my life. I also believe that people are truly happier with their lives than they were 40 or 50 years ago when they lived in institutions, or even 10 years ago when many lived in group homes where they were controlled by others.





### TASH NEWSLETTER

Policy Statement

It is TASH's mission to eliminate physical and social obstacles that prevent equity, diversity and quality of life for children and adults with disabilities.

Items in this Newsletter do not necessarily reflect attitudes held by individual members or the Association as a whole. TASH reserves the right to exercise editorial judgement in selection of materials.

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