

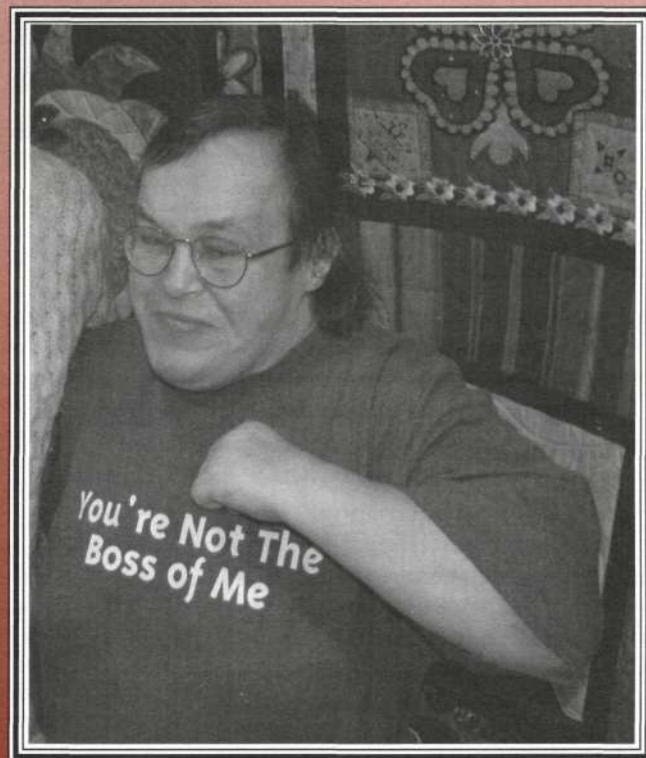
TASH CONNECTIONS

Equity, Opportunity and Inclusion for People with Disabilities since 1975

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- The Funding and Supports System of the Future
- The Slow Pace of Organizational Change from Congregate Services to Individualized Supports
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Re-thinking the System of Long-Term Care



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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.

TASH MISSION

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

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

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

TASH accomplishes this through:

- Creating opportunities for collaboration among families, self-advocates, professionals, policymakers and other advocates;
- Advocating for equity, opportunities, social justice, and rights;
- Disseminating knowledge and information;
- Supporting excellence in research that translates to excellence in practice;
- Promoting individualized, quality supports;
- Working toward the elimination of institutions, other congregate living settings, segregated schools/classrooms, sheltered work environments, and other segregated services and toward replacing these with quality, individualized, inclusive supports;
- Supporting legislation, litigation and public policy consistent with TASH's mission; and,
- Promoting communities in which no one is segregated and everyone belongs.



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From the Executive Director
BY NANCY WEISS

CLOSING THE LAST BASTIONS OF OPPRESSION

As in most states, advocates in Maryland, the home of TASH's central office, continue our fight to see institutions become a thing of the past. Recently, Maryland's State Department of Health and Mental Hygiene was asked to identify one of the four remaining state institutions for closure. The 150-year-old Rosewood Center was identified as a prime candidate for closure — and disability advocates were cheering.

But not everyone was celebrating the impending death of this behemoth. Earlier this month a rally was held — about 200 people took part in the rally, fighting to keep Rosewood open. Some of the protestors were family members of Rosewood residents; more than half were employees and union members interested in assuring that their jobs remained secure. None were Rosewood residents expressing their own views on what the future should be for this institution.

Concurrent with the rally to keep Rosewood open, advocates with and without disabilities, including a number of representatives of the Mid-Atlantic Chapter of TASH (MASH) held a counter-rally, raising our voices against those who want to see Rosewood remain. The motivation of these advocates was purely and simply civil rights - and they made clear the following compelling facts:

- Across the country, individuals with disabilities as severe and health care needs as complex as the individuals continuing to reside at Rosewood, are being well supported in the community. Nine states have closed all of their state institutions and are providing quality supports to all of their citizens with disabilities, even those with complex medical needs, with a range of services in the community.

- The movement toward community living started over thirty years ago and research is unequivocal regarding which type of support results in better lives. People with disabilities living in the community experience improved quality of life in areas such as: opportunities for integration and social participation, contact with friends and relatives, participation in employment, opportunities for choice-making and self-determination, quality and duration of services received, protection from abuse and neglect, and other indicators of a quality life.

- There is no other example in this country of people being locked up and segregated from society — except for prisoners incarcerated for their crimes. It is not reasonable to deny people the right to real lives in the real world when the success of community supports has been demonstrated across Maryland and nationally.

- The current cost of housing one person at Rosewood is \$137, 595 per year (Maryland Developmental Disabilities Administration FY 2004 budget). The average cost to support a person in a community setting in Maryland is \$40,000. Understandably, each individual's cost is determined by his/her needs, and the cost of supporting some of the people still incarcerated at Rosewood is likely to be much higher than this average cost.

Closing Rosewood and supporting people in the community, however, is not an issue of cost — it is an issue of human rights and social justice. It is not acceptable to segregate people in institutions when experience and research prove that all people, including people with intensive needs, can live full and meaningful lives in the community.

Following the pro-institutional rally and the counter-rally on the Rosewood closing, TASH advocates received a letter from a Rosewood employee. She criticized the advocates who demonstrated in support of Rosewood's closure for taking advantage of the people with disabilities who participated in the rally and using them as pawns. Her correspondence said in part, 'I would like to express my disgust at your exhibition Monday night at the Rosewood Center by using the people you serve as hecklers. If these people were institutionalized and mistreated, then they *do* have a right to express their opinion. But I think you need to ask yourself a serious ethical question if you are going to promote and support your members in such a manner. Specifically, how much of their expression is truly their own opinion and how much of it is yours? The lack of respect for others with opposing views was disgraceful.'

My response to her follows:

In some ways, your message gets to the very heart of the matter — whether a person meeting or seeing a person with a significant disability assumes competence, or presumes incompetence. That is, whether people make assumptions that are limiting, or open themselves to the possibility that this person, regardless of appearance, is a thinking, feeling person who has opinions and a voice.

As a person working in this field, I know that you understand that just because someone appears to have a significant disability, or because someone doesn't use speech to communicate, doesn't mean that the person doesn't have something to say. The people

It is one of our country's greatest shame that we continue to keep people in institutions, and an even greater disgrace that we try to convince ourselves and others that this removal from society and denial of rights is in the best interest of the people still in these places. It is time to end this era of segregation and begin one characterized by valuing and including all members of our communities.

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Closing the Last Bastions of Oppression

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with disabilities who were at the meeting Monday night organized and motivated that effort. It was us professionals who were along on their ride, not the other way around.

Though many of the people who have disabilities who participated in the protest may have appeared to you to be "too disabled" to have opinions about the continuation of institutions, you greatly underestimate them when you make this assumption. All of the close-Rosewood advocates at the rally, both those with and those without disabilities, were there because in their hearts they abhor the notion that people with disabilities will continue to be locked away, have their rights abridged (often by people who underestimate their capacity), and be segregated from the rest of society and the richness real lives offer.

You say that if these people were institutionalized and mistreated, then they do have a right to express their opinion.' Many of the people who participated in the counter-demonstration have spent years in institutions and they, and many other of the participants, have been mistreated — they know first-hand what the life-limiting environment of an institution does to the human soul.

However, the people who have lived in institutions are not the only people who have a right to protest. It is a tenet of American society that all people have a right to express outrage over treatment they see as wrong. Surely you would not say that only those people who had been victim to slavery or racial segregation should have a right to participate in civil rights demonstrations?

One of the beauties of this American life is that people who have not been direct victims of abuse feel for, and raise their voices along with those who have. The ten-foot hand-lettered sign that one of the young women who participated in the rally labored to make

read, 'No More Institution for My Brothers and Sisters.' No one told her to make that sign. No one told her what was in her heart. She wrote on behalf of the thousands of people still locked away at places like Rosewood, across Maryland and across the country, whom she thinks of as her brothers and sisters in this fight for freedom.

You make a mistake if you assume that the people with disabilities who participated in the rally were there as pawns of the disability professionals who were present. Nothing could be further from the truth. Assuming some of them may be willing, I would like to invite you to meet personally with some of these individuals. Not all of them use their voice to communicate, but I guarantee that if you spend time with them, you will come away convinced that the professionals who were at the rally were not 'using' people with disabilities to accomplish an agenda that they don't embrace with equal fervor. In suggesting that professionals were using people to accomplish their own goals, you vastly underestimate the power, influence, and dedication of the people with disabilities who organized the counter-rally.

I'm sorry you found the performance of the counter-demonstrators disgusting or were distressed by our heckling and lack of respect. I personally thought we were quite moderate considering the passion of those present and in the face of the injustice being promoted. These are true activists — if you'd ever seen them in action you'd be congratulating them for their restraint.

If I were to raise any questions about the people who were, or weren't, present at the rally, they would be these:

- My first question would be about the 100 or so employees who were there and the very vocal position of the union (AFSCME). I was taken aback when one speaker asked for a show of hands of people who were family members of Rosewood residents and only a quarter or so of those present raised their hands. The rest of the participants, I realized then, were employees. I suppose some employees may be fighting to keep Rosewood

open because they truly believe it is what is best for the residents, but one got the very strong impression that most of the employees were there for their own interests, not those of the residents. The message of the union (and that of many of the politicians) was very clearly concern over the possibility of lost jobs. As Delegate Jon Cardin said in a recent letter, "while jobs are important, lives are more important." It is indefensible to keep a portion of our citizenry locked up so that others can keep their jobs.

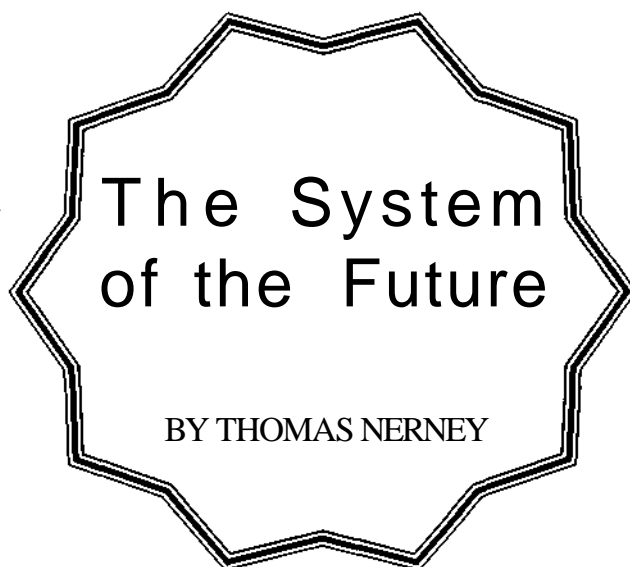
- My second question is, if so many of the people who live at Rosewood love the place, choose to live there, and don't want to move — where were they? You'd think at least a few residents who really want to see the place stay open might have been at the rally (because I don't believe that they are 'too disabled to have an opinion'). Not one Rosewood resident was present, and we haven't heard directly from any residents since.

A saying amongst advocates with disabilities is "Nothing About Me Without Me." Lots of people are happy to speak for and about the residents. One group even calls itself 'Voice of the Retarded' — although not one person with a cognitive disability sits on their board or is represented among their leaders. No Rosewood resident was there to speak on his/her own behalf and say, 'this is where I want to be.' To me, that absence speaks volumes — about both the residents and those who were there supposedly speaking for them.

It is one of our country's greatest shames that we continue to keep people in institutions and an even greater disgrace that we try to convince ourselves and others that this removal from society and denial of rights is in the best interest of the people still in these places. It is time to end this era of segregation and begin one characterized by valuing and including all members of our communities. We would welcome your participation in this quest."



The time has come to fundamentally restructure human services for individuals with developmental disabilities. After a decade of systems change projects directed at moving control of resources to individuals with disabilities and their close family and allies, enough experience has been accumulated to begin fashioning what human services ought to look like in this century. This means that at a minimum the Federal Medicaid program and the Social Security income programs need to be changed in ways that will remove irrational prohibitions on living, working and truly being part of one's community.



- the development of fiscal intermediaries where public dollars for one's support would be deposited;
- the creation of highly personal and unique individual budgets that would translate the person with a disability's life goals into line items in an approved budget; and,
- the availability of truly independent and competent support coordination in order to provide assistance — free of conflicts of interest — to persons with disabilities and family members.

The structural changes have always been viewed as tools to carry out the essential foundation of self-determination.

The current crisis in the Medicaid program, along with other crises that are reaching epidemic proportions (see the section titled *The Perfect Storm* later in this article), can be a time of retrenchment and loss of supports and services; or, it can be an opportunity to forge a new and cost effective system based on the principles of self-determination.

The Meaning of Self-Determination

Just about a decade ago a small group of people with disabilities, family members and professionals set out on a new path to reform the system of support for individuals with cognitive and intellectual disabilities. These fundamental changes were predicated on the almost total loss of elementary freedoms experienced by individuals served by the human service system, as well as the enforced poverty and consequent harmful side effects experienced by these same individuals. This movement was named "self-determination" in

order to capture both the personal and political dimensions of this effort.

The original principles included:

Freedom: the restoration of those decisions that go to the heart of leading rich and varied lives in the community. These include deciding where and with whom to live, how to create income, and establishing important community and personal relationships.

Authority: the ability to personally control (with appropriate assistance) a targeted amount of long-term care dollars.

Support: the arrangement of these resources in ways that are unique and built on the individual preferences of the person with a disability.

Responsibility: the use of these public resources in ways that are wise and cost effective.

Confirmation: the recognition that individuals with disabilities must be part of the public policy changes necessary to implement self-determination, and recognition that families and individuals with disabilities must be included in all re-design issues.

The structural reforms necessary to carry out these changes include:

What endures as the goal of self-determination is simply the ability of a person with a disability to craft a meaningful life in the community, overcome the destructive effects of enforced poverty, and experience deep and lasting relationships.

The Perfect Storm

The system of supports and services to individuals with developmental disabilities has been relentlessly moving from institutions to the community over the past two decades. This must continue since resource re-allocation will become one of the few ways left to finance the supports needed by those who today remain on waiting lists.

However, as the demographics cited on the following page illustrates, the time may come when the hard analysis will involve the community system itself. What are the most expensive options, what are the outcomes for individuals served in these options, and can we justify morally and ethically expenditures for certain parts of the system at the high end when tens of thousands remain without support at all? This may become the moral equivalent of the institutional-community argument all over again with much higher stakes this time.

The demographics of this population so clearly indicate that what we have witnessed

What endures as the goal of self-determination is simply the ability of a person with a disability to craft a meaningful life in the community, overcome the destructive effects of enforced poverty, and experience deep and lasting relationships.

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The System of the Future

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These three storms — increasingly scarce Medicaid resources, the demographics of the developmental disabilities and elderly populations, and the shrinking workforce — will very soon converge to create the perfect storm and rock the entire developmental disability system.

to date with the waiting list, unserved and partially served populations is simply the tip of the iceberg. During fiscal year 2000 almost 672,994 individuals with developmental disabilities lived at home with a family caregiver over the age of 60. That same year almost 928,000 individuals nationally lived at home with a family caregiver between the ages of 41 and 59 years. This represents 35% of all those living at home and means that the states will have an even larger group coming behind the 672,000 currently living with an aging care giver at home today. (Braddock, 2002)

When the increased competition for scarce Medicaid resources — especially for a rapidly aging population — is factored in, the crisis will only deepen. The fastest growing segment today among the elderly population is those over the age of 85. As the population of America ages and eventually moves from 12.5% to 20% of the entire population, the group of adult children who today account for 80% of their support, only increases by 7% (Nemey, 2001)

Together with a quickly shrinking workforce, it is clear that business as usual will no longer suffice. While short-term monetary increases are necessary to keep the current system from collapsing, longer term re-thinking of the

system of long-term care is necessary today. Each of these three storms — increasingly scarce Medicaid resources, the demographics of the developmental disabilities and elderly populations, and the shrinking workforce — will very soon converge to create the perfect storm and rock the entire developmental disability system.

This is not to suggest that self-determination can ever hope to carry this burden. Self-determination is not a magic bullet, and it requires careful and thoughtful re-design of the present system. However, it remains one of the few advances in the field of disability to demonstrate cost efficiency as well as increased quality. (Conroy, 2000; Conroy, 2002)

The Federal Medicaid Act and the Social Security SSI/SSDI Program

The implementation of self-determination has been slowed and sometimes stymied by irrational aspects of both Medicaid and SSI/SSDI (Supplemental Security Income/Social Security Disability Insurance). There are prohibitions on room and board charges under Medicaid Waiver programs, but in virtually no county in the United States is anyone who receives SSI able to afford to live modestly and eat. The eligibility requirements of both programs force those who cannot jeopardize essential benefits to remain totally impoverished on a personal basis. Housing is often prohibitive and transportation unavailable. It is truly difficult to craft a meaningful life based on the principles of self-determination within the restrictions of these two programs.

These recommendations for a Freedom Initiative grow out of the Center for Self-Determination's work with a small public/private think tank in Washington, DC hosted by the President's Committee on Mental Retardation and The Office on Disability in the Department of Health and Human Services. It is part of an effort to design the "system of the future" — one responsive to individuals and families and more cost effective than the present system.

SSI and SSDI

The intersection of the SSI/SSDI and Medicaid Waiver programs pose substantial problems for individuals with disabilities who rely on both. Supplemental Security Income (Title XVI of the Social Security Act) provides base cash income of \$530 a month. In 32 states, eligibility for SSI based on limited income and disability automatically makes one eligible for Medicaid.

Some individuals become eligible for SSDI (Social Security Disability Insurance or Title 11 of the Social Security Act). This generates cash income based on having insured status as a worker or a child of a worker. The benefit under SSDI is an all or nothing proposition. If one becomes eligible, then the full cash benefit is calculated and the individual becomes eligible after 24 months for Medicare medical coverage, parts A and B.

The problem for individuals with intellectual or cognitive disabilities historically has been reluctance to "jeopardize" either one of these benefits by working and producing enough income to reduce or eliminate eligibility for these programs. The Social Security Administration has been aware of and attempted to address this problem since 1994.

Under the SSDI program, work incentives now include:

- ✓trial work periods;
- ✓continued eligibility up to "substantial gainful employment";
- ✓an extended period of eligibility;
- ✓"impairment" related work expenses;
- ✓extended coverage or purchase of Medicare; and
- ✓subsidy allowances.

Under the SSI program, work incentives include:

- ✓continued SSI eligibility even when earnings exceed "substantial gainful employment";
- ✓continued Medicaid coverage;
- ✓"impairment" related work expenses;
- ✓PASS (Plans to Achieve Self Support) Plans; and
- ✓student-earned income exclusions.

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The System of the Future

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Under both programs, the maximum allowable income from "substantial gainful employment" is \$810. Although this amount is much higher if a person is blind, the standards for increasing income, while reducing or eliminating benefits, remain complex for most individuals. This has led once again to the creation of a new job — not for people with disabilities, but for professionals — called "benefits counseling."

By all accounts these modifications to the SSI/SSDI programs are not working. More individuals with disabilities are entering non-work programs today than enter the world of work and competitive or supported employment. Many who are enrolled in supported employment programs still earn below minimum wage and often work in segregated environments. Not much more than 6% of individuals with developmental disabilities "work" based on a simple standard of 20 hours or more per week at minimum wage or higher.

In virtually all counties and SMSA's (standard metropolitan statistical areas) throughout the United States, SSI income is not enough to purchase food and rent an apartment.

Medicaid Waivers

Medicaid Waiver programs for individuals with disabilities cover support costs associated with living in community settings (though often in human service environments) and attending day, vocational or work programs. Unlike the Medicaid institutional program, to which it is an alternative, Medicaid Waivers are prohibited from covering the cost of room and board. Human service providers and people with disabilities are then forced to use most or all of their SSI or SSDI income for room and board costs.

This frequency leads to congregate living arrangements in order to cover the costs of room and board, and great caution in promoting anything that would jeopardize these payments. For those living at home

where the family is categorized as low income, these SSI and SSDI payments become very important for the financial stability of the family, and family members will often counsel against the person working.

In addition to the general reluctance to jeopardize one's own cash income, service providers join the group of those who frequently do not want to risk the steady income associated with monthly SSI and SSDI room and board payments for wages that may fluctuate or not cover the costs of room and board.

Not adequately understanding the complex Social Security rules for working can also put individuals at risk of having to pay back income mistakenly accepted.

Self-Determination

At its heart self-determination has been historically based on a set of principles that included control of the financial resources necessary for one's support. Freedom and responsibility have become the hallmarks of this movement. However, the control of resources has always been viewed as a tool, not the goal, of self-determination.

The goal of self-determination has remained "crafting a meaningful life deeply imbedded in one's community." Understanding that a meaningful life of necessity includes those aspirations that are universal to all human beings — the exercise of ordinary freedom, the chance to earn income and become a productive member of society and engage in deep and personal relationships — are now the criteria with which we evaluate the systems change associated with self-determination.

Only by addressing directly the systemic problems in both the SSI/SSDI and Medicaid Waiver programs will the forced impoverishment of individuals be adequately addressed, regular housing opportunities made available, and the ordinary freedoms associated with American citizenship be obtainable for those with developmental disabilities.

The following recommendations combine a waiver of some of the current rules under the

SSI/SSDI program with an experimental 1115 waiver under the Medicaid program. (A fallback position that does not achieve all of these recommendations would be to use The Independence Plus Template for 1915 (c) Waivers).

The underlying assumption of this approach is the achievement of better economic and housing outcomes for individuals with disabilities with no increase in federal or state payments. These combined waivers simply provide incentives to work and live in ordinary ways — ways experienced by members of the community who do not have disabilities. They assume that any individual can generate private income based on creative job approaches, or the development of a microenterprise that the person may receive assistance in managing. Part of this assumption rests on the acknowledgement that we simply have to find more cost-effective supports without hurting individuals with disabilities. Because so few individuals with disabilities are working, we simply don't know the contribution many could make to the costs of long-term care.

Another assumption is that those enrolled in the 1115 Medicaid Waiver will automatically be enrolled in the SSI/SSDI Waiver governing income and asset limitations. This would position a state on the cusp of true system change by creating an additional SSI/SSDI Waiver that will work seamlessly with the Medicaid 1115 Waiver. Further possibilities exist if Vocational Rehabilitation and The Ticket to Work were to be legislatively reformed along the principles of self-determination.

The Freedom Initiative SSI Waiver Provision 1

- Participants take less of a reduction as earnings increase
- Waiver participants cash benefits are reduced only after they have achieved a minimum of \$500 a month or \$1 reduction for every \$4-7 of earned income

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The System of the Future

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- The current system removes \$ 1 for every \$2 earned
- Participants keep much more of their earnings
- No additional cost to state or federal government
- Potential for contribution increases, and individuals who are employed pay into the Social Security Trust Fund

Provision 2

- Certain types of unearned income receive a \$1 reduction for every \$4-7 of unearned income (also see provision 3)
- Under the current system, cash benefits are reduced \$ 1 for every \$ 1 of unearned income
- Unearned income can come from workers compensation, unemployment insurance, private disability insurance, state disability payments and private gifts and donations
- This also encourages family members to save for their adult children with disabilities.

Provision 3

- Participants can save up to \$10,000 per year of both earned and unearned income in a Freedom Account without affecting benefits
- Interest and dividends are not counted as assets
- Freedom Accounts can become Individual Development Accounts or matched savings accounts
- Freedom Accounts can then be targeted for highly desirable personal goals including e.g., microenterprise development and expansion, down payments on homes and transportation,

and additional training and educational opportunities as well as technology.

- Types of Freedom accounts can be checking accounts, savings accounts, certificates of deposit, money market and mutual funds
- Freedom Accounts would be allowed even when the person is enrolled in an employer's retirement plan which would also be exempt from being counted as an asset
- Freedom Accounts would allow family members to contribute to their children's future much as they do for their adult children without disabilities

Provision 4

- Medical Continuing Disability Reviews (CDR) would be suspended for two groups enrolled in the dual waivers: Medical Improvement not Expected (MINE) and Medical Improvement Possible (MIP)
- CDR'S are not suspended for those who are classified as Medical Improvement Expected (MIE)
- This provision addresses those who almost never leave the SSI rolls

There are a myriad of issues that would have to be addressed in accepting enrollment into this waiver, including the effect on other benefits like food stamps and Section 8 housing certificates as well as anyone with a PASS plan. The proposal would also give those dis-enrolling — or when the waiver terminates — up to 24 months to "spend down."

It is also possible for fiscal intermediaries to accept the reporting requirements under this waiver as well as the 1115 one. Together with a small research component the results can be tracked and disseminated on a regular basis.

The Second Waiver

The 1115 demonstration waiver authority with the population of individuals with developmental disabilities has rarely been used. This opportunity, now streamlined by

CMS under the Independence Plus Waiver template, would allow a state to "waive" existing Medicaid provisions that hinder meaningful lives for individuals with disabilities. As self-determination is implemented under this waiver, the essential "tools" of self-determination are implemented:

- Fiscal Intermediaries
- Informed and Independent Support Coordination
- Individual Budgets

The 1115 waiver can then accent those issues most problematic for individuals with disabilities and complement the Social Security waiver by addressing some of the issues associated with forced impoverishment by featuring the following exemptions:

- Waive the prohibition on room and board in order to make typical housing more available to individuals with developmental disabilities
- Waive the prohibition on purchasing transportation, including for those individuals who cannot drive but need to control the means of transportation to live meaningful lives
- Waive any exclusions to paying employers directly for co-worker support, training costs, transportation or temporary wage supplementation
- Waive all prohibitions on qualified Medicaid providers except where appropriate for normal criminal and other background checks. Allow individuals to contract with faith based groups, as well
- Waive any real or perceived prohibitions on allowing individuals to capitalize very small microenterprises up to \$ 1500 annually

Vocational Rehabilitation and The Ticket to Work

Both programs need to be made accessible as cash grants instead of services or vouchers. Self-Determination reaches farther than the Ticket by allowing an individual to hire

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What's Taking So Long?

The Slow Pace of Organizational Change from Congregate Services to Individualized and Integrated Supports

BY PAT ROGAN and PAM WALKER

It is nearly the year 2004. The disabilities support field has demonstrations of thousands and thousands of individuals over the past two decades who are engaged in meaningful supported employment and supported living. People with very high support needs are living, working, and actively participating in their local communities. Research has shown that quality of life outcomes are better for those in supported employment and typical community living settings compared to their counterparts in segregated day and residential services.

Despite this growing body of evidence supporting integrated and individualized outcomes, most people with developmental disabilities remain in congregate, segregated day services and many remain in congregate living situations.

Most agencies have chosen to add supported employment and supported living to their continuum of services, providing both integrated and segregated services. A relatively small number of organizations have undertaken the process of change from facility-based to community-based services. Fewer agencies have been able to accomplish an overall organizational shift from totally facility-based services to individualized community-based supports. Why is this? Why has true systems change been so slow to occur? If some organizations can do it, why can't or won't other

and develop work skills, and so on.

An emerging body of research, however, indicates that organizational change has been a worthwhile undertaking in terms of positive quality of life outcomes. Researchers are now beginning to discover why some organizations have chosen to undertake the changeover process, why only some succeed, what barriers they encounter, what strategies are most successful in helping them make the change, and what outcomes they achieve. We will endeavor to describe key elements of the change process, highlight challenges that organizations face, and offer recommendations for moving toward true systems change.

Why and How Some Organizations Have Done It

To understand why and how some organizations have shifted (and continue to change), we must look to those that have taken it upon themselves to let go of their outdated practices and move into challenging, yet exciting, directions. Although federal and state policies and funding have clearly influenced local practices (both positively and negatively), the impetus for change has typically not come from "above." It is clear from numerous studies of organizational change that the process has been primarily driven by strong values and leaders within the organizations.

The process of organizational change is complex, difficult, and rewarding. It involves a period of operating dual systems (the old and the new) simultaneously, changing staff attitudes and skills, marketing a new organizational image, interfacing with businesses, assisting people with disabilities to pursue their dreams

Barriers to Organizational Change

Certainly, numerous barriers to change exist. Perhaps these barriers are viewed by some as insurmountable and not worth tackling. The following list highlights the issues that organizations have reported to be most significant.

- Operating two programs at the same time during the change process involves finding adequate resources and working through conflicting values.
- Negotiating contradicting policies
- Assisting existing staff to develop the necessary attitudes and skills (e.g., move from "taking care of" individuals to supporting them to become more self-determined)
- Assisting other stakeholders to believe in the abilities of the people being served
- Making ends meet within the restricted funding systems
- Hiring, training, and supporting new staff that may turnover at a fairly high rate
- Developing new procedures related to decentralization (e.g., communication, staff scheduling and supervision, transportation)
- Reorganizing staff to provide dispersed and individualized supports in the community
- Revising job descriptions to better reflect roles, responsibilities, and expectations
- Finding ways to support people with significant needs across all settings and activities
- Maintaining a "safety net" for people as they changed jobs, lost jobs, or increased their work hours

Strategies for Organizational Change

Despite these many barriers to organizational change and to providing individualized services and supports, many organizations

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have successfully shifted to totally community-based services. Among numerous factors these organizations attributed to their success, all reported leadership as the single most important element. While leadership most often came from the Executive Director/CEO and top-level managers, it was essential that leadership ultimately filter throughout the staff in order for the change efforts to be successful (e.g., via participatory management and shared decision making).

Other strategies that have proven effective include:

- ☐ Articulating a clear mission, vision, and values among staff and other stakeholders
- ☐ Involving key stakeholders from the start in the planning and decision making process in order to get buy-in
- ☐ Listening to and acting on the desires of people with disabilities and their families
- ☐ Using individualized, person-centered planning approaches and a "one person at a time" process
- ☐ Hiring, training, and supporting a quality staff
- ☐ Promoting a learning organization that embraces change and is willing to take risks
- ☐ Securing high quality jobs and typical, desirable homes
- ☐ Terminating facility admissions and backfilling after people leave
- ☐ Accessing external consultants to help guide the change
- ☐ Working to flatten the organizational structure with most staff providing direct services

☐ Using a team structure to support staff and meet the needs of individuals

☐ Changing job descriptions from specialists to generalists

☐ Changing the agency's image through marketing and public relations

☐ Sharing success stories

☐ Building business and other community partnerships

- Divesting in buildings and equipment

☐ Redirecting existing funds to community services and pursuing flexible and alternative sources of funds

☐ Connecting with others undergoing changeover

Outcomes as a Result of Organizational Change

Feedback from one organization typified the outcomes reported by many others: "opportunities and outcomes for people with disabilities" reflected "significant growth" as a result of their change, including increased status and improved connections with members of the community. Over 90% of individuals in the Rogan, Held, and Rinne (2002) study reported being happier. Individual growth, both personal and professional, has been the norm. Individuals report earning more money, gaining more skills and a sense of self-confidence and self-esteem, acquiring newfound independence, job satisfaction, making new acquaintances and friendships, building positive connections in their communities, renewing their dreams and visions for the future, and an overall better quality of life.

In addition to positive growth among individuals receiving services, organizations also reported improved quality of their management practices, services, staff growth and overall satisfaction, community and employer relations, and cost efficiency. Better services encompassed giving individuals more choice, focusing on their strengths and abilities, more community connections, and

more responsive services. Respondents in the Rogan, Held, and Rinne (2002) study revealed that the new way of doing business resulted in "feeling better," "a strong sense of purpose/mission among staff and board members," "people were in charge of their own lives," "more positive organizational structure and culture," "funding sources offered support and respect," and "organizations were generally more efficient."

Discussion and Recommendations

These pioneering service providers have demonstrated that multiple barriers can be overcome, full organizational change is possible, and people with disabilities, including those with high support needs, can be successfully supported to live and work in the community. It is important to recognize that the organizations that have undertaken the changeover process share many common characteristics with others organizations nationally. Most started with a full hierarchical continuum of services. They began with the same underpaid, undereducated employees we find in many such environments, and the same top heavy, hierarchical organizational structure that has been the standard for so long. The attitudinal, educational, practical, regulatory, legislative, and fiscal issues described by these organizations as difficult, but surmountable, are the same issues given by other organizations as reasons for not undertaking the changeover process.

Many agencies have managed to make the change, reporting new ways of doing business that result in more positive outcomes for the individuals with disabilities they support, the staff who support them, and the communities in which they are situated. What it is that sets these organizations apart from the rest of the nation? Why haven't most organizations moved in this direction? How can others be persuaded and supported to let go of outdated practices and embrace innovation? The following recommendations are offered as a means of elevating the dialogue and moving the issue of organizational change to the "front burner."

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❶ **Shift the funding.** Money talks. Although Medicaid Waivers and individual budgets have served to promote individualized services, these funding structures are, for the most part, neither sufficient nor widespread. Funding for community living and day services must be earmarked for the community, with gradual shifts mandated over a reasonable period of time, with fiscal incentives for accomplishing desired outcomes.

❷ **Provide extensive, intensive training and technical assistance.** There is currently no funded, ongoing source of expertise about organizational change that is available on a large-scale basis. Just as the federal government has funded many other national training and technical assistance, a National Center for Community Services and Organizational Change should be funded.

❸ **Reward innovation.** Organizations that are leading the way, have taken risks, and are demonstrating "what it should look like" deserve recognition, rewards, and opportunities to network with others via conferences and other forums. Such organizations should be showcased and supported to continue their innovation so that others can learn from them.

❹ **Develop leadership.** It appears that values driven leadership is the single most important ingredient for success. Yet, there are virtually no opportunities for agency personnel to obtain leadership training geared to their needs and interests. State level leadership development efforts should be initiated to sustain and support existing leaders, as well as develop future leaders.

Conclusion

Although the number of organizations in our country that have undertaken organizational change to integrated community services and supports remains small, they have served a critical need in our evolution of service

delivery practices. They have demonstrated a better way and proven that it can be done.

Despite the many real and challenging barriers, they have moved ahead, around, and through the "why not's." These organizations will be the first to say it has not been easy, and the first to say it has been a worthwhile endeavor. There is no valid reason for the slow movement toward community services and our stagnation in an entrenched system of congregation and segregation. We know how. It is past time to move ahead responsibly and responsively by aligning policies, funding, and practices toward quality services and quality lives.

Pam Walker is with the Center on Human Policy at Syracuse University. Pat Rogan is Associate Professor, Indiana University School of Education. Comments about this article may be directed to Ms. Walker at <PmwaUter@sy.edu>

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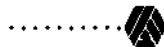
The System of the Future

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anyone including potential employers to assist in job development or job retention. As well, self-determination heralds the development of microenterprises as an alternative for those individuals with disabilities who would prefer self-employment. Utilizing fiscal intermediaries individuals developing personal budgets should be able to incorporate cash grants into their budgets for entering the world of business and commerce with whatever assistance they deem necessary from whom-ever is in a position to assist.

Thomas Nerney is Director of The Center For Self Determination in Ann Arbor, Michigan. The article, The System of the Future, in its entirety, he entire article can be found in its entirety on the Center's web site, <www.self-determination.com>

Comments about this article may be directed to Mr. Nerney at tomnerney@earthlink.net



Our thanks to

Norris Haring

for his continued
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This \$1000 cash award is presented to promote research and scholarly activity in the field of significant disabilities. The award is presented to the author(s) of a study of particular significance that was published in RPSD within the two years prior to the TASH annual conference. The study will have demonstrated scientific merit, and have made an important contribution to the disability field.

TASH is pleased to announce the 2003 awardees:

Mary Fisher and Luanna H. Meyer
for their article

*Development and Social Competence After Two Years for Students
Enrolled in Inclusive and Self Contained Educational Programs
RPSD, Vol. 27(3), p. 165-174*

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Preserving! Quality In Challenging Times*

BY LORI SHEPARD, SCOTT
SHEPARD, and CHERYL
MAYFIELD

Challenging times" are as varied as the people defining them. For some, there are financial difficulties, for others, it is relationship problems or health issues. Some may be worried about the past, the present or the future, but whatever the definition, keeping a deep commitment to people we support a priority will enhance everyone's life.

Outlined in this article are some ideas that should be helpful to anyone involved in adult services. From the person in the center to the administrators on the outer fringes and all the people in between, these suggestions will keep us thinking about what is really important in the lives of people who rely on support staff to insure they have a life of their choosing.

© Keep middle management (and administrators) involved in peoples' lives and out of meetings by both allowing and requiring them to spend time providing direct support to people.

Too often we hear those we support complain that they never get to see their favorite support person anymore because the individual received a promotion into a management or supervisory position. The Catch-22 is that it is difficult for agencies to hold onto competent staff without promoting them to higher positions with more pay and responsibility. But middle-manage-

ment and management positions generally place quality staff farther away from direct support services.

We then find these staff spending much of their time in meetings and/or "problem solving" sessions related to challenges that have come up in peoples lives. When these same staff spend more of their time directly supporting people in their homes, at their jobs and in the community, many of these same issues are identified so that support can be provided before they become a "challenge." The good news about this dilemma is that by simply ensuring that middle management staff continue to provide direct support to people (we suggest a minimum of 50 percent of their actual work schedule), most of the "crisis related meetings" will be prevented.

©Identify and utilize generic resources and varied sources of funding.

Try not to rely on one sole funding source. Try to diversify the sources of your revenue (for example, local and federal grants, sponsorships, start-up funds, other local, state and federal aid programs, fund raising, related services). It's also important to collaborate with others in your community to identify and utilize generic resources. A sample list of generic resources can be found at the end of this article.

©Look for ways to decrease bureaucracy.

Keep the money closest to the people being served.

Don't add more systems, levels of administration or departments between the people being supported and the State or Federal source of funding. Put money into people and services, not buildings and paperwork! Cheryl often reminds us that the people that get her out of

bed each morning are much more valuable to her than a person who sits behind a desk.

©Work with your State Legislators to ensure that federal funds earmarked for services to people with disabilities stay in the system (and are not diverted to the general fund or other uses).

Educate support staff, families, people receiving support, employers, neighbors and co-workers about the political issues. Advocate for individuals and staff. Keep updated on funding sources, budgets, potential cuts and all information that affects people's quality of life. Grassroots efforts work!

©Support legislated "wage pass-through" which insures that increased funding goes directly to direct support workers.

Dollars allotted to direct support people must be used to compensate staff through improved benefits and wages, not administration or overhead. Insure that the people who are supporting individuals and families every day benefit from funding increases.

©Commit to quality before quantity when determining the size of an agency.

While it is difficult to turn away someone who wants, and likely needs, the unique support a particular agency offers, the quality of those services may decline if the agency tries to provide support too many people. A balance needs to be met between having too many people (both support people and people receiving support) and the ability to expand. The top level of management should be able to keep in touch, individually, with each person within the agency on a weekly basis.

©Agencies that are "doing something right" should share their experiences with people interested in providing similar services.

One alternative to increasing the number of people an agency serves is to assist others (including families and people being supported) to create their own support agency. A successful agency can help support additional quality options for people by "mentoring" interested people

.....
● As the demand for individual-
● ized services increases,
● agencies that are "doing
● something right** should
● share their experiences with
● the people they support to
● encourage and empower
● them to create their own
● support agency.
●

Preserving Quality In Challenging Times

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through the process of becoming their own agency. As the demand for individualized services such as supported living, independent living, supported employment and individualized day services increases, the greater the need for more choices in service options.

• Advocate for and assist people receiving support and/or families with the self-vendoring process.
"Self-vendorization" allows a person to be in control of the state or federal monies they are allotted in order to hire, fire, coordinate and pay the people they need to support them. Many states also have a process for parents or siblings to become vendors to coordinate supports for their relative.

Conclusion

The future of adult services is full of opportunities for everyone. Technology, funding, strong circles of support, legislation and education can be combined to support people to live wonderful lives as they see fit. By standing strong in our commitment to support people, we can lead others to take a stand and solidify the foundation that previous stakeholders have built.



Cheryl Mayfield shares her mission as a Board Member of an agency that provides supported living and individualized day services:

1. To ensure that people are listened to and being treated with respect.
2. To ensure that people are receiving adequate supports & services.
3. To keep the agency small, so that the board, administration, and staff can be better in touch with people's lives and see what is going on.
4. I don't want this agency to be the biggest. simply the best as far as quality of services.

5. To provide technical assistance, training & mentoring to interested families and others who wish to start their own agency.

"My dream is that more people will have an agency that is small and responsive to their unique, individual needs. Not just in my state, but for the world."



Resources for People Living in Their Own Homes

HOUSING / UTILITY DISCOUNTS

"Bonding": rental discounts available in some cities for low income tenants

Lifeline rates and discounts: (Gas, Electric, Phone, Water (some), Cable (some - for basic only))

Medical Baseline Discounts: Increased allowance for lowest rate on utilities, based on necessary medical equipment (i.e. power wheelchairs, respirators)

Waived or discounted deposit fees for utilities

Free "411" calls

Adaptive phone equipment, including some emergency calling devices

Call blocking services: (various combinations are possible, at no charge)

HEAP Home Energy Assistance Program; (Once a year assistance w/ utility bills. 1-800-433-4327)

Housing insulation and repair programs, many for tenants as well as home owners

Housing advocates/fair housing councils

Dept. of Housing and Building Safety (various names in various cities): can help get landlords to make needed repairs

Home adaptation providers

Legal Aid, Newcomers Clubs (Welcome wagons)

Police (Evictions, assistance with problem tenants)

FOOD/MEALS

Meals on Wheels, food banks and pantries, food stamps (emergency assistance), WI.C. (Women, Infants and Children), community and church assistance leagues

HEALTH CARE

Free medications: For information, call 1-800-PMA-INFO, ask for Directory of Prescription Drug Patient Assistant Programs, which is free and very detailed.

County health dept., pregnancy help centers, Alcoholics Anonymous (AA), Narcotics Anonymous, etc.

Hospice care, doctor/dentist referral services, home health nursing, "assisted living" providers, "911," non-emergency medical transportation companies, State licensing boards for checking license status, filing complaints, etc.

MENTAL HEALTH SERVICES / CRISIS INTERVENTION

County Department of Mental Health, counseling centers, crisis intervention / PET Teams, battered women's shelters, rape crisis centers, suicide hotlines, support groups around special issues/disability, victims of violent crime assistance programs, church-sponsored counseling services/programs

PARENTING / FAMILY SUPPORT

Pregnancy help centers, Head Start, child-birth preparation classes, parenting classes, child care referral services, adoption/foster care services, Legal Aid, Planned Parenthood

TRANSPORTATION

Para-transit companies, para-transit referral service, discount transit vouchers (offered by the city to residents), driver's training programs, non-emergency medical transportation, carpool/vanpool, Para-transit referral service, taxi service

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RPSD-Connections

RPSD-Connections is focused on bringing the latest research from TASH's journal, *Research and Practice for Persons with Severe Disabilities*, to *Connections* readers. Our goal is to summarize some of the articles that are newly published in RPSD to help keep you abreast of the latest available research and information.

The following article summary was prepared by a graduate student at Queens College, City University of New York. If you would be interested in summarizing an article for publication in this column, please contact the RPSD office at 718-997-5315, or send an e-mail to [<fbrownuncny@aol.com>](mailto:fbrownuncny@aol.com)

Fredda Brown, Editor, and June Downing, Associate Editor, RPSD



Smith, V. M. (2003). "You have to learn who comes with a disability": Students' reflections on service learning experiences with peers labeled with disabilities. *Research and Practice for Persons with Severe Disabilities*, 28, 79-90.

Summary prepared by: Christine Scott, Queens College, City University of New York (graduate student in the Programs in Special Education)

Background

Service learning is the integration between community based student projects and the formal curriculum of a school or particular class, such as in a teacher education program. Service learning assists and prepares students to develop awareness in areas such as multicultural issues, preparatory skills, and disability.

Typically, when preparing teachers in the area of special education, students acquire knowledge through their course work, combined with student teaching experiences. Most student teaching experiences place the student in the role of "teacher" and the person with the disability in the role of "learner."

Within the framework of service learning, however, the student and the person with the

disability come to together on "equal ground." It is anticipated that the students begin to veer away from preconceived notions and develop new insight and understanding towards persons with disabilities.

Purpose

This investigation analyzed the changing perspectives of seven college students who were partnered with an individual with a disability. The intention was to explore ways that the students viewed their service learning experiences and its impact on their previously held opinions and assumptions about people with disabilities.

Method

Seven undergraduate students and six students with disabilities, all about the same age, participated in the study. The seven undergraduate students were selected through an interview process. The students were college sophomores, juniors and seniors, between the ages of 19 to 22. The college students' involvement in this study was either directly related to their coursework or was to fulfill a field placement requirement. Four out of the seven students had some limited experiences with people with disabilities. Three out of the seven had no past experiences. One out of the three had stated during his interview that he clearly "avoided them." Six of the students with disabilities came from

within the community, and one came from a neighboring town. The identified disabilities were Down Syndrome, Rett Syndrome, Tourette Syndrome, autism, mental retardation, multiple disabilities, learning disabilities, obsessive-compulsive disorder, and other disabilities. The verbal communication skills of these students varied.

The college student participants completed surveys that addressed their current views and past experiences with people with disabilities, as well as their personal interests and activities in which they typically engage. This information assisted in pairing the student with his/her partner. The college student participants were not given specific "labels" of their peers with disabilities, only information on how the disability impacted their partner.

Participants were told that they would be assisting their partners in learning about "campus life" and, in turn, their partner would be helping them learn about disability related issues. For a given semester, the participant and partner spent two hours per week engaged in various leisure activities. Such activities included working out at the gym, swimming, involvement in sports, listening to music, playing instruments, attending classes, and having meals together.

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RPSD Article Review Sudanis' reflections on service learning experiences with peers labeled with disabilities

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Participants were required to record weekly journal entries reflecting upon their experi-

Results

All seven of the college student participants emerged from this study with new understandings, feelings and overall opinions regarding people with disabilities. Participants initially were stated to be "nervous" and "scared" about meeting and interacting with their partner. Their concerns ranged from "...am I going to say the wrong thing?" to "...how am I going to deal with this?" to "they're (partners) are not going to understand me..." Participants who had partners with limited to no verbal communication skills discovered that there are many other ways to communicate (e.g., facial and body gestures)

that do not involve the spoken word. Participants were noted to have an "eye-opening" understanding — that in many respects, their partners were "just like me."

Many of the participants were glad that they were not given a specific "label" for their partner's disability, feeling that it would have only impeded them from getting to know the person, and instead would have focused them on getting to know only the "disability." All of the participants had similar views and frustrations regarding the use of labels and felt that their partner's identified label clearly did not represent who their partner was. Towards the end of the study, the participants were spending more than the assigned time with their new "friends."

The findings of this study reflected three themes across all the participants. First, participants were in definite favor of having the opportunity to experience the "person" rather than the "classification." Second, there was a newfound understanding that the ability of a person to verbally express him or

herself is not directly connected to what that person understands. Finally, all participants had mixed emotions regarding how others viewed their new friends and their relationships. The participants strongly felt that society, in general, needs to embrace individuals with disabilities as opposed to excluding them.

Summary

There is a genuine need for continued research that will support how biased views can be overturned by a "little bit of knowledge." The participant who initially stated that he "avoided people like that," concluded that ALL students should be required to take a service learning class in this area. It was quite evident that the participants gained an abundance of knowledge which altered and shaped their thinking, attitudes, and perception of people with disabilities.



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OTHER FINANCIAL RESOURCES

Customer service representative at the bank, State Depts. Of Public Social Services, In-Home-Support-Services/ attendant care/personal assistance (for eligible persons who are elderly or have disabilities), A.F.D.C., Food Stamps (Emergency) - for those not getting SSI, W.I.C. (Women, Infants, Children), F.E.M.A. (Federal emergency management agency), BOGG grants pay for registration costs at Community Colleges for people with low income, Debtor's anonymous, Consumer Credit Counseling

CONTINUING EDUCATION

Community colleges: disabled student services (accommodations, tutoring, etc.), literacy programs, driver's training programs, community college, high tech centers; Adult education: colleges, high school, night school/adult ed., Dept. of Parks and Recreation, Classes offered by the city, classes offered by individual businesses (i.e., craft stores, cooking supply stores), YMCA, etc.

MISCELLANEOUS

Centers for Applied Rehab. Technology, computer access center's, supported employment agencies, free fishing licenses (State Dept. of Fish and Game), discount camping fees at most state and federal parks, immigration/refugee services, Independent Living Centers, volunteer bureaus, roommate finders services, senior centers/services, City Hall

WHERE DID WE FIND THESE RESOURCES?

Telephone directories, Regional Center/ State DD Services, City Hall, city newsletters, newspaper/"Life" section, library, Dept. of Rehabilitation, other "providers," friends, radio information lines, local access cable information, local guides (accessibility; recreation; etc.), the United Way publishes a "service agency guide" in most communities (free or small fee), senior centers/senior newspapers.

Compiled by Jennifer Pittam, a Lifetime TASH member, while working with CHOICES.





2003 TASH Conference, "*Possibilities*"

Hilton Chicago - December 10-13

Pre-Conference TASH Tech Workshops

Wednesday, December 10th

10:00 a.m. - 4:00 p.m.

TASH Techs are full-day workshops held on the pre-conference day. These in-depth, practical, and participatory sessions provide a wealth of information on cutting edge topics. Registration for these sessions is separate from the full TASH Conference registration fee. If you plan on attending the full TASH Conference, where there will be over 400 one- or two-hour breakout sessions to choose from over the course of the three-day event, why not add on a day for one of these focused sessions? If you are local, join us for just the day!



T-1 Building Meaningful Daytimes: Organizational Change from Sheltered Programs to Integrated Life in the Community

Facilitated by: Pat Rogan, Jim Meehan, Jeff Strully, Pam Walker, and Mark Vincent

Many adult service organizations are struggling to support adults with disabilities to live self-directed lives in their communities. This session focuses on the complex aspects of organizational change from segregated facilities, including day and residential programs, to integrated, community-based services and supports. This workshop will also address current legislative and practice issues such as WIA/Rehab Act & Ticket to Work, self-employment, and other systems change issues.

T-6 Civil Rights, Self-Determination and Decision Making vs. Guardianship

Facilitated by: Dohn Hoyle, Sally Burton-Hoyle, Kathleen Harris, and Mayer Shevin

Guardianship represents, at best, a removal of fundamental rights and a lifelong diminution of a person's basic control over his or her own life. Guardianship is incompatible with real self-determination and full citizenship, and is therefore incompatible with the principles of TASH. This session will discuss how to support choice and self-determination rather than substitute or "second party" best interest decision-making and is designed for family members, attorneys, care management, agency staff, and long term advocates.

T-7 Learning To Listen Differently: A guide to supporting people in having a life of their own choosing in the community

Facilitated by: Joe Wykowski, Patti Scott, Jay Klein, Judith Snow, and Ed Cohle

Living a full life in the community - owning your own home, having a career, controlling your own resources, having relationships and a full social life - is a dream for most of us and has started to become a reality for many people with disabilities. For those who challenge their friends, families, supporters and allies to think (and take action) differently in order to support them, this is not always the case. How do we learn to listen differently? How do we act on what we learn to provide creative supports?

T-8 Self Determination With and For Individuals with Significant Cognitive Disabilities and Their Families

Facilitated by: John Agosta, Rud Turnbull and other invitees

Join panelists for a lively look at practical ways to achieve self-determination when a person cannot express his/her choices in traditional ways. Can everyone self-determine? How can we learn to truly listen to and understand messages that are unspoken, but nevertheless, clearly conveyed? This session will explore ways that family and individual culture can be honored in the process of developing and sustaining a self-determined vision for quality of life over a person's full lifespan.

Prc-Conference TASH Tech Workshops

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T-9 Achieving True Self-Determination through **Rethinking the Meaning of Quality, Systems Change, and New Funding and Policy Models**

Speakers: Jim Conroy, Ric Crowley, Michael Head, and Others

This session will address the changes in federal and stateside policies that will make self-determination a reality for people with significant disabilities. How will people learn the skills they will need to design and implement individual plans, choose service providers and manage supports, understand and use funding mechanisms? Traditional quality assurance approaches just don't work—learn about new ones that do. With SSI waivers and freedom accounts, meaningful self-determination is starting to be attainable. Join this lively, interactive session to learn how to make self-determination a reality.

T-10 Sexuality: A Collaborative Dialogue About the Issues

Facilitated by: Charles Dukes and Pamela Lamar Dukes

This highly interactive workshop Presenters will facilitate a discussion on the impact of sexuality on all our lives and will address the social aspects of sexuality and those barriers that may bar individuals with disabilities from realizing a personally satisfying sexual life. The session will conclude with collaborative problem solving and solution development.

T-11 Behavior. Theirs and/or Ours! Coping strategies to help us survive-and create positive possible future **with and for folks labeled as "trouble"**

Facilitated by: Jack Pearpoint, Lynda Kahn, Colin Newton, and Derek Wilson

This session will focus on strategies that we can teach and try that focus on OUR behaviors - over which we have more control that policies and budgets.. We will present useful take home tools and techniques to 'get through hard days' and to enlist the talents and capacities of those around us to work out viable, affordable and future positive strategies that will assist in creating full lives with people who are labeled.

T-12 Facilitating Community-based Employment Outcomes

Facilitated by: Katherine Inge, John Buttenvorth

This session will focus on critical steps for organizations expanding community-based employment programs. Issues concerning strategic planning, staff development, funding, and outcome measurements for organizational change will be discussed. Target audience should include program managers, staff, and families and individuals. This pre-conference session is made possible by the Office of Disability Employment Policy, U.S. Department of Labor's cooperative agreement, T-TAP to Virginia Commonwealth University and the Institute for Community Inclusion, University of Massachusetts Boston.

Issues in Adult Services & Supports

TASH is at the forefront of the struggle to ensure that people with disabilities have the supports they need to live in their own homes, making employment a reality, and participate fully in their communities. People with disabilities have a multitude of gifts that contribute to the diversity and strength of communities. Emphasizing each person's unique contributions, including their diverse ethnic and cultural heritages, increases the potential for the individual to connect with others in the community; and reduces the likelihood that people will be segregated or perceived as "clients" rather than as friends, classmates, neighbors or co-workers.

Consult the Sessions Schedule section on TASH's web site <www.tash.org/2003conference/program/index.htm> for tentative session dates and times.

Achieving Real Lives Strand

Strand Coordinator: Nancy Weiss

People with disabilities want real lives, meaningful work and good outcomes; agencies want to provide progressive, person-centered supports — this strand explores the challenges and triumphs of moving from a more traditional agency to a provider of truly progressive individualized supports. Come hear from people who are on the road to better futures as they explore some of the hardest lessons learned and pass on advice and suggestions in our quest to find the joy behind the challenges? This strand focuses on why providing or receiving individualized supports is a wonderful way to spend your life and where it really gets tough. Breakout sessions in this strand include:

Recapturing Person Centered Plans

John W. O'Brien, P. Sue Kullen, Beth Mount, Connie Lyle O'Brien, Michael W. Smull, Mark Vincent

Out-Maneuvering the System: How to Succeed in Providing Progressive Supports Against the Odds

Pam Walker, Patti Scott, Patricia Rogan, Jay F. Klein, Patricia Fratangelo

Finding Allies and Building Alliances: Making it Happen

Deborah A. Gilmer, Ric Crowley, Chester Finn, Debbie Prockner

Ya Can't Give What Ya Don't Get: Personnel Management Styles for Community Supports That Work

Lynne Seagle, Denine C. Hunt, Caroline Schestag, Noal Presley, Tara Asai

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Issues in Adult Services and Supports

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The Challenges (and joys) of Providing Life-Changing Supports

Gail D. Jacob, James L. Dehem, Carole Gothelf, Fredda Rosen

When People's Choices Make Us Uncomfortable

Scott Shepard, Patti Scott, Jose Perez, Joe H. Wykowski

The Management Challenges of Individual Supports

James Meehan, Patricia Fratangelo, Kathleen Hulgin, Laura Broderick

Using Self-Determination Tools to Achieve Flexible Supports

Jacqueline Golden, Tim Quinn, Jean Tuller, Anita Yuskas

Paying Customers Are Not Enough

Dennis Harkins, John W O'Brien

Community Supports Roundtable

Judith Snow

Advocacy

Sessions in this topic area are not organized into a strand. They are scheduled as either a poster session, a one-hour or two-hour breakout session, a pre-conference TASH Tech (extra cost) or a 3-hour Saturday Institute.

Reflections on Diversity: Disability in Film

Zachary Rossetti, Christine Ashby, Katrina Arndt

Building an Inclusive Community, Effective Collaborations for Social Change

Patricia M. Moore, Rebecca Bialecki

Inclusion is NOT a Gift - It is a Right

Mary Trinkley, Gregory Galluzzo, Beth Dixon, Marion West

Service Learning and Teaching Chicago Public School High School Students about Diversity and the Special Education Field

Patrick Schwarz, Sylvester Rodriguez

Advocacy, Self-Advocacy

Colleen Huston, Patricia Okahashi, Lloyd Thornhill

Wanna Hear a Joke? Identifying and Interrupting Oppressive Remarks and Behaviors

Robin M. Smith, Mara Sapon-Shevin

Nick's Crusade: Grassroots Activism In-Depth

Nicholas Dupree

Aging

Sessions in this topic area are not organized into a strand. They are scheduled as either a poster session, a one-hour or two-hour breakout session, a pre-conference TASH Tech (extra cost) or a 3-hour Saturday Institute.

Retreat and Resilience: Life Experience of Older Women With Intellectual Disabilities

Barbara W. LeRoy, Patricia N. Walsh, Noel Kulik

Communication of End-of-Life Wishes and Person Centered Planning for Persons Who Are Aging and/or Dying

Leigh Ann Kingsbury

Assistive Technology

Sessions in this topic area are not organized into a strand. They are scheduled as either a poster session, a one-hour or two-hour breakout session, a pre-conference TASH Tech (extra cost) or a 3-hour Saturday Institute.

Enhancing Transition Through Assistive Technology

Sandra Alper, Charlotte Mull, Elaine Daack, Steve Noyes, Delann Soenksen

It's Simple! It's Easy! It Works! Low Tech Assistance for All-Learners Plus: An Overview of the Florida Inclusion Network (FIN)

Elizabeth Willis, Kimberlee Oakes, John Venn

Interactive Literacy Learning Experiences for Children with Disabilities and their Siblings

Andrew Cox, Amy Cox, Denise Clark

Assistive Technology Using Technology Appliances to Increase Student Access to the General Curriculum

Debra Bauder, Thomas J. Simmons, Jean Isaacs

Kentucky's Use of Digital Text to Improve the Learning Process for Special Education Students Across the State

Michael Abell Thomas J. Simmons, Debra Bauder

Continuing Our Understanding of Autism: What We are Learning and What We Need to Learn More About Strand

Strand Coordinator: *Jeff Strully*

You can't open a newspaper or magazine without seeing an article on autism spectrum disorder. The rise (640% increase) in autism is alarming. Families, consumers, educators and other human service professionals need the latest information and strategies to support, educate, and serve children and adults with autism. This strand will provide some of the leading experts in helping us to think about, develop effective and efficient strategies and to learn what works and what doesn't work. Come join us and learn together to better support people with autism spectrum disorder by listening to people with autism, their families, and people who have walked with them on their journey.

TASH TECH Pre-Conference Session: Stories, Voices, and Inclusive Schooling: Educating Students with Autism

Paula M. Kluth, Janna Woods, Tyler Fihe

Movement Issues In Autism

Martha Leary, Anne Donnellan

The Ethics and Values of Behavior Change

Larry Douglass

Listening As If It Matters

Mayer Shevin

All Things Considered: Puzzling Support Situations

Martha Leary, Mayer Shevin, Judith Snow, Anne Donnellan, Sue Rubin, Larry Douglass, Peyton Goddard

Autism: A Journey to Understanding

Gail Gillingham Wylies

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Issues in Adult Services and Supports

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Communication

Sessions in this topic area are not organized into a strand. They are scheduled as either a poster session, a one-hour or two-hour breakout session, a pre-conference TASH Tech (extra cost) or a 3-hour Saturday Institute.

Working Toward Independence in Communication

Katrina Arndt, Christine Ashby, Keonhee Kim, Zack Rosetti

Examining Communication Repairs of Young Children with Disabilities who are Nonverbal

James Halle, Erik Drasgow

The Communication Mentors' Project: Building Local Capacity to Raise the Voices of Self-Determination

Rosa McAllister, Mark Reeves, Kathy Dunkleberger, LeeFlad, Barbara Gimino, Stacy Jones, Ann Reeves, Jim George, Anne Kalinoski, Kim Riegel Michelle Wilt

High-tech, Low-tech, & No Tech: Exploring Many Ways to Communicate!

Jennifer McCary, Rosa McAllister, Jeannie Steele

Communication of Children Identified with Autism in Inclusive Classrooms

Keonhee Kim, Qing Shen

There are No Prerequisites for Communication

Martha Snell, Ellin Siegel

Claiming Self- Identity for Individuals with Disabilities

Sheila Foglesong

Typing and Talking: AAC Users Experiences with Using Multiple Methods of Communication

Christi Kasa-Hendrickson, Douglas Biklen, Alicia Broderick, Jamie Burke, Lucy Harrison, Tyler Fihe

Community Living Strand

Strand Coordinators: *Joe Wykotvski and Patti Scott*

Controlling your own resources, hiring and firing your own staff, living in a home of your own, having a circle of friends and living a rich and full life in the community.....all are values shared by the presenters of the Community Living Strand and members of TASH. Join us as we explore how these values and principles are being realized in communities throughout the United States and Canada.

TASH TECH Pre-Conference Session:

Learning to Listen Differently: A Guide to Supporting People in Having a Life of Their Own Choosing in the Community

Joe H. Wykowski, Patti Scott, Judith Snow, Jay F. Klein, Edward Cohle

International Association for Inclusive Citizenship

Judith Snow, Jack Pearpoint, Robert Cutler, Michael Dowling

One Community Integration Project Building Community Relationships - One Person at a Time

Lorraine Sheridan

I Believe! Community Support Workers Talk About the Values that Underlie their Work and How they Put Them Into Action

Fredda Rosen, Beth Mount

Michigan's Personal Assistance Services and Supports: Charting a Path to Self-Directed Community Living

Angela Martin, Sharon Milberger

Privileges of Citizenship

Marilyn Kuna

The Three "R's" of Supported Living: Relationships, Rights & Responsibilities

Scott Shepard, Jose Perez

Supported Living Services: Individual Vendors Forum

Joan Schmidt, Kathleen Campbell

Utilizing Community Connections

Lyle Romer, Leah Preston Ing, Melanie Richardson

Community Living/Housing

Sessions in this topic area are not organized into a strand. They are scheduled as either a poster session, a one-hour or two-hour breakout session, a pre-conference TASH Tech (extra cost) or a 3-hour Saturday Institute.

Home Control and Ownership Through Proper Estate Planning

Theresa M. Varnet

A Decade of Change: The Oklahoma Quality Tracking Project, 1990 to 2000

Amanda Fullerton, James W. Conroy

Good Virus Called Self-Determination

Marilyn Kuna

Advocates and Labor Update: Progression of a Paradigm Shift

James W. Conroy, William Welz

Waisman Center-Sound Response Program

Duane Tempel Chris Patterson, Danielle Lockwood

Creative & Performing Arts

Sessions in this topic area are not organized into a strand. They are scheduled as either a poster session, a one-hour or two-hour breakout session, a pre-conference TASH Tech (extra cost) or a 3-hour Saturday Institute.

Meet the Artist Mave O'Brien

Mave OBrien, Mary OBrien

Opening Doors Through the Arts: An Inclusive Visual and Performing Arts Program for Adults within the Autism Spectrum

Susan Gurry, Anne Larkin

Adaptive Art of Individuals with Disabilities

Jack Brandt

Creative or Performing Arts, Telling My Story

Patricia Okahashi, Lloyd Thornhill

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Marc Gold is being honored at this year's conference as the first recipient of TASH's Legacy Award. Marc was a founder of TASH and a visionary whose "power of expectations" changed the course of history for people with significant disabilities. Marc was one of the pioneers of the field ~ he rejected traditional thinking that dictated that a person's potential was limited by IQ.

Through his groundbreaking work, Marc taught us that when a person's skills were not progressing it was our challenge to find creative approaches to teaching and supporting change. One of Marc's many gifts (in addition to being a great jazz clarinet player) was that he didn't buy into the limiting power of labeling and categorizing people. He believed in all people and their potential for accomplishment. He saw people with disabilities as he saw everyone else - as people with particular challenges for which ways needed to be found to bridge gaps. Marc taught us that there is power in presuming that someone will be able to accomplish something and that by expecting more, more will be accomplished. His work built upon the empowering presumption of ability. He was a person who touched the lives and changed the thinking of many.

Paradigm Shift

A reflection on the contributions of Marc Gold and the implications for improving services today

BY CHARLES J. DURGIN

Introduction

This article highlights the substantial contributions of Dr. Marc Gold. In sharing this information, I would like to stress that he was one of many talented, assertive, and courageous individuals who helped to advance the field of special education. This includes academics and researchers from many different fields of study, family members, practitioners, advocates, and of course those individuals with special needs who still teach and guide us to this day. Clearly, he was one of many people who have made unique and critically important contributions to the field.

Early Experience and Formal Training

Marc Gold has indicated that his educational philosophy is rooted in providing a deep respect for all people, particularly those who have been negatively treated and labeled by society. He reports learning these values from his parents.

His father, who managed a bicycle and key shop in the poverty-stricken Hispanic barrio of East Los Angeles from 1930-1966, was a particularly strong influence. His father set a positive and unwavering example as he worked closely with many people who faced substantial disadvantages and hardships. As it turned out, time in the bike shop also gave Marc the mechanical aptitude to design a variety of training and vocational tasks for persons with significant disabilities (e.g., bike brake assembly, electronic circuit boards, etc.).



After these early years, as Marc became a young adult, the values-based commitment to respecting and helping others was reinforced when he was training to become a special educator at Los Angeles State College.

By the time he was teaching students labeled "retarded" in the Los Angeles City School System he had already developed a solid belief system as well as the drive to give his students the best possible education. He viewed education as a critical pathway to helping these individuals advance their circumstance (i.e., to becoming respected individuals deserving of humane treatment and fair opportunities). He also felt that the role of education and vocational training was to give people with disabilities the best possible opportunities for a productive and satisfying life.

To accomplish these ends, his vision was to

design curricula and instructional methodologies that taught skills which were valued by society. At this relatively young age, Marc already recognized the interconnections between learning, opportunity, systems failures, service gaps, negative biases and social prejudices. This started and fueled a fire inside of him that helped to drive the next steps of his career.

Not long after becoming a special education teacher, his talents were recognized by a State education supervisor, Dr. Robert Henderson. Dr. Henderson joined the faculty at University of Illinois at Urbana-Champaign and Marc was invited to enter the doctoral program.

In 1969 Marc Gold received his doctorate in experimental child psychology and special education. Upon completion of his doctoral degree he was hired by the University to conduct research at the Institute for Child Behavior and Development (formerly the Children's Research Center).

If there is one message above all others in Dr. Gold's work that still holds true today, it is to take action to ensure that all people with disabilities are appropriately challenged and that all teachers are fully prepared

As we meet these challenges together, we hopefully will continue to build more systems of care and methods of instruction that both achieve results and inspire others.

A reflection on the contributions of Dr. Marc Gold

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Contributions to the Field

Philosophy, methods, and applications

A primary emphasis of Dr. Gold's work was to develop a technology with three components — philosophical instruction, basic systematic instruction, and rules and guidelines for usage — which could result in persons with severe disabilities performing marketable tasks. Part of Dr. Gold's legacy is working with individuals with significant disabilities who had been given no genuine opportunities to advance their condition and demonstrate how they can learn. Dr. Gold routinely would teach individuals with IQs tested at below 50, and demonstrate a positive learning curve on multi-step tasks after only a few training sessions.

This was revolutionary because the beliefs of the day were that anyone with an IQ below 50 was not worth teaching because they were not believed to be capable of learning. In an excellent overview of his work, Perske (1987) quotes Dr. Gold as saying, "The time has come to train people, not constantly test them, then walk away, leaving them with just a bunch of ugly numbers" (p. vii).

Unfortunately, social conventions and professional practice at this time were to institutionalize the young and old who fit this profile of "mental deficiency." Meyer (1991) reinforces this point about this era stating that "a label signifying a severe disability inevitability led to institutionalization and custodial care" (p. 634).

Dr. Gold's work also showed us how we could become better teachers and significantly increase our professional effectiveness. As a profession we needed to change our beliefs, philosophy of instruction, as well as our teaching methodologies, he insisted. In addition to advocating for ideological and procedural changes, he stressed the importance of introducing content and curricula that would be of value to the students (personally, socially, and materially).

There were many significant barriers — institutional; legislative; limiting approaches on the part of society — beyond the formidable forces of tradition and professional skepticism, with which Dr. Gold and others struggled. Dr. Gold sought to convince others that people other than himself could implement his approaches. His effectiveness both inspired and intimidated others.

For example, it was commonplace for him to consult with state training schools and institutions. He would often start by "walking in cold" if you will, ask to meet the most difficult and challenging student or resident, and invite him or her to work. Dr. Gold would proceed in front of the audience with his trainee in a calm, composed, reassuring, and systematic manner.

Early on people were so taken by his intensity, precision, and results that many felt that only he (or someone else in his stratosphere) could achieve similar outcomes. To dispel this perception, which he understood was critical to advancing the field on a large scale, he conducted hundreds of training sessions that taught staff and family members to use his approach. Interestingly, if you carefully watch his training film *Try Another Way*, you can see what appears to be a deliberate effort to dispel any notion that his teaching technologies are difficult to learn and implement.

At this point some of Dr. Gold's largest contracts were being administered and/or supported by leading disability advocates who by this time had moved into positions of formal authority or influence within various institutions and agencies. One of the most notable was a contract executed under the leadership of Ed Roberts, who had become the head of the California Department of Vocational Rehabilitation.

For Ed Roberts to attain this position was a remarkable turn of events, in that he had been rejected by the agency years earlier when a counselor told him that he was not employable due to the severity of his disability. Ed did have a severe disability stemming from acquiring polio as a teenager, but this did not in any manner limit his drive, talent, or accomplishments. In many ways there is no higher form of praise than to be hired by

individuals who are the most able to judge what services will offer the most value.

Key Contributions

To provide a concise overview of his work, the guiding intervention principles that Dr. Gold frequently discussed appear below. A brief overview of four other key concepts that re-occur in his research follows.

Although these concepts are widely understood and accepted today in societies that have resources devoted to people with disabilities, it is important to remember that many of these principles were just being formulated, conceptualized, and applied early on in Dr. Gold's career. As with all fields of study, many of these concepts evolved from insights and contributions made by others in the field.

Some of the philosophical beliefs which set the foundation for all of Dr. Gold's include (Gold, 1980):

- One can best serve people with severe disabilities by training them to do marketable tasks.
- Persons labeled as having mental retardation respond best to a learning situation based on respect of their human worth and capabilities.
- A lack of learning in any particular situation should first be interpreted as a result of inappropriate or insufficient use of teaching strategies, rather than inability on the part of the learner.
- To this point in its development, testing is, at best, limiting to the person labeled as having mental retardation.
- Labeling is both unfair and counterproductive.

1. Maintaining a Balanced Relationship - Refers to the absolute need for the learner-trainer relationship to be based on mutual respect, thereby recognizing the need for both parties to be able to change and adapt. Both individuals must adjust to each other with

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A reflection on the contributions of Dr. Marc Gold

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respect to the content of the task and the quality of their relationship.

2. Power (Instructional) - Refers to the amount of intervention and direction required by teachers to help the student reach criterion. This concept shifts the burden of responsibility for learning and designing instructional tasks to the instructor. In other words, it's not the learner's inadequacies but the teacher's need to adjust content and methods if one is to achieve results.

3. The Competence-Deviance Hypothesis - Building upon and re-shaping the idiosyncrasy-credits theory of Hollander (1958, 1960), Dr. Gold formulated the competence-deviance hypothesis and applied it to persons with significant disabilities. The premise is that the more competent an individual is, the more deviance will be tolerated in him or her by others. This has two significant implications. First, people with disabilities who differ in appearance, behavior, and/or skill level are at risk of being rejected and may well face a variety of social prejudices and economic disadvantages. Second, it is particularly important for training programs to enhance the competence of persons with disabilities in order to increase society's tolerance of their differences and to give them greater opportunities to live successfully within the community.

4. On Intelligence and Ability - Dr. Gold often stressed that there is a significant difference between intelligence as assessed by IQ tests and trained ability. One does not need to have high intelligence to be trained to perform important tasks. Some tasks require a high degree of intelligence to complete, but other tasks require quality training and a minimum of intelligence to perform. Thus, the instructional challenge is to find valuable tasks that can be broken down into teachable components, and learned when effective teaching is provided.

Personal and professional commentary

Different people remember Dr. Gold in different ways. People with disabilities found

him non-threatening and encouraging. For these individuals there was security, purpose, opportunity, and productivity associated with their contact with him. Family members of people with disabilities found him to offer more than hope. He offered direction, conviction, honesty, time to experiment and explore, persistence to attain results, visions for change, as well as support.

To his credit, the art and science of his work predominantly took place "in the trenches." Although it did not always bring him positive regard, Dr. Gold was an outspoken advocate who was quick to challenge conventions that imposed restrictions on those who were different. In many ways his leadership helped "open the door" for others to question commonly held beliefs as well as service system practices that limited human potential and violated human rights.

Professionals were impressed by Dr. Gold's ability to combine a highly sophisticated yet practical research orientation with a strong ideological belief system. He was able to perform scholarly work that won the respect of academics while at the same time he was leading others on the frontline with heart. He was an unusually charismatic person among an already impressive group of social visionaries.

Dr. Gold's level of intensity, data driven methods, spontaneous demonstrations with the most challenging students, willingness to take risks, and passion to institute reforms exposed our profession to something meaningful, provocative, and exciting. Those who heard him lecture and saw him teach were aware that they were experiencing something profound and that they would never see things quite the same again. His work helped to alter the way in which the capabilities of people with disabilities were conceptualized, how service programs were being designed, and how professionals were trained. Paradigms were shifting. Optimism for a brighter future was growing.

An additional quality that is important to discuss is Dr. Gold's ability to encapsulate problems and identify strategies by using simple phrases. He was a master at creating "sound bites" (as they are known today). Examples include:

- Train don't test
- Don't spend time assessing competence, spend time teaching competence
- Labels are "hanging tools" that make sure individuals function at the same level.

These types of statements provided staff with clear ideas on how best to approach their work. His choice of words immediately elevated the stature of people with significant disabilities and at the same time increased our responsibility to see that their needs and rights were recognized and addressed. This was particularly important in that these individuals were highly vulnerable to the deficit-oriented thinking, the reductive testing-diagnostic methods, as well as the harsh placement practices of the day.

As mentioned earlier, almost all persons with significant disabilities and behavioral challenges were being subjected to prognostications that had a powerful impact on shaping their future without their consent. Additionally, most were being placed and/or institutionalized without the benefit of first receiving quality training opportunities to more carefully assess abilities, interests, and resources. In many ways, while confronting these "high stakes" issues and re-conceptualizing interventions, Dr. Gold and his contemporaries were developing a new language which re-defined human potential and future possibilities. This, in turn, altered how people thought and acted, and in time dramatically altered how people with significant disabilities were viewed, treated, educated, and included.

According to his close friend and associate Robert Perske (1987), Dr. Gold became quite ill in the summer of 1982. He assembled his staff in his home to review the direction of the *Try Another Way* system. After a critical review of the approach and considering other advances in the field, a number of significant modifications and refinements were suggested by the team and ultimately supported by Dr. Gold (Callahan, 1987). This included changes in emphasis such as: pushing for integration as being more important than skill acquisition in training sessions, simplifying

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A reflection on the contributions of Dr. Marc Gold

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and individualizing the process of writing a task analysis, preparing employees at the job site to provide training and support (to decrease the dependency on professional staff), and utilizing employer training resources and approaches where appropriate.

These changes were directly influenced by the innovative approaches championed by Lou Brown and colleagues (1976), who strongly advocated for vocational training to take place in work environments in the real world. Thus, training out of context was being de-emphasized for work related skills. Ultimately, these turning points in the field among others, led to the development of new and progressive models of vocational training and resulted in greater levels of community participation for persons with severe disabilities (Inge, Barcus, Brooke, & Everson, 1995).

A few months after this meeting with his staff, and all too early in his life and career, Dr. Marc Gold died of complications associated with Hodgkin's disease. Although he has passed, the quality of his person and that of his work has not. His work still influences and shapes both the ideological and instructional aspects of many service programs throughout the world.

If there is one message above all else in Dr. Gold's work that still holds true today, it is to take action to ensure that all people with disabilities are appropriately challenged and that all teachers are fully prepared. As we meet these challenges together, we will hopefully continue to build more systems of care and methods of instruction that both achieve results and inspire others. Without question, as we make this happen there will be more room for new paradigm shifts, advances in service quality, and renewed hope for an even brighter future.

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Author's Statement

"This article evolved from a paper that I completed at The Johns Hopkins University for an educational leadership class when I was asked to write about an individual who made a pioneering contribution to the field. When given the assignment, Dr. Marc Gold's name and image came to mind immediately. I had been exposed to his work as a graduate student in the late 1970's.

The assignment led me to a lengthy investigation of Dr. Gold's work through a variety of methods. These included speaking to his former advisor in his doctoral program on a number of occasions, reviewing Dr. Gold's publications, studying some of his training films, interviewing his direct colleagues, listening to trainees as well as persons knowledgeable about his work and the field at that time, reading commentary on his professional contributions, in addition to reviewing some of the literature in the field today.

I must stress that this was not an exhaustive review of the field and the intricacies of its evolution, nor is this my expertise. It was, however, an investigation that brought me closer to Dr. Gold's work and the ideals that he and many others fought for many years ago and still strive for today.

As I had more time to examine his work and reflect upon my formal training, I was reminded how much his work had a strong formative impact in shaping my educational philosophy and professional skills. Going through this process also forced me to critically reflect on our past successes and the significant challenges that we still have before us.

Comments about this article may be directed to Charles Durgin by e-mail at durgin@kennedykrieger.org or by calling (443) 923-7835.



Independent Evaluation of California's Self-Determination Pilot Projects

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Executive Summary

The evidence from nearly three years of study of California's pilot projects on self-determination for people with developmental disabilities supports a positive conclusion: self-determination is highly beneficial to, and extremely welcome to, participants and their families. The evidence also indicates that self-determination is inherently fiscally conservative.

Moreover, California's developmental disabilities service system, as it has evolved under the Lanterman Act, appears to this research team to have more potential for self-determination than any other state. We therefore suggest that self-determination should be supported and expanded in California, with heightened fiscal and programmatic commitment from Sacramento. The evidence supports a policy to move the self-determination initiative to the next level, beyond a small set of "pilot projects," and toward larger scale system efforts.

In this Executive Summary, we sketch in broad outline what we have learned from three small pilot sites of about 30 participants each.

This report required nearly three years of study, in which every participant and every participant's family was visited, interviewed, and surveyed, each year. The primary intent of the evaluation was to answer the fundamental question: "Has this made a difference in the lives of the participants?" In other words, does this new way of providing

supports help people or not? Important additional questions involved how the efforts were designed, how they could be made better, and what it would take to expand this "experiment" to a larger implementation.

1. *Synopsis*

California is the only state thusfar in which a self-determination effort was required by legislation. In 1997, the legislature passed a bill to start self-determination

pilot projects at three of the 21 Regional Centers. Each Regional Center worked with 30 participants and families. An independent evaluator was selected to study the outcomes of this pilot effort. The evaluator visited each participant in each year, and collected information from the person, the family, and support providers.

The evaluation included 30 people and families who wanted to participate, but who had to wait until later to get involved. This group served as a natural "comparison group." The evaluator also conducted extensive focus groups, key informant interviews, and collected individual "stories" during the years of investigation.

The evaluation has produced very positive findings. Individual outcomes show evidence of rapid and significant benefits. Participants and their families really like the self-determination idea and the values that are part of it. They believe their lives have improved because of it. There have been barriers, problems, delays, paperwork, and cases of inflexibility, but despite all challenges, these complaints have been viewed as minor, and the overwhelming consensus is that California should continue and expand this innovation in providing supports to its citizens with developmental disabilities.

Most key informants believe that self-determination is in keeping with the ideals of the law that has structured California's entire developmental services system, the Lanterman Act. In fact, many believe that self-determination is an essential step in moving forward with the vision of the Lanterman Act:

freedom, individual supports, and dignity through partnership.

The evaluator recommends that California now consider expanding its self-determination efforts beyond the "experimental" stage. This will require careful consideration of specialized case management, fiscal intermediary mechanisms, and innovative revisions to the fiscal management process. Given sufficient support, the evidence suggests strongly that California can become a national leader in moving toward the values of self-determination for people with developmental disabili-

2. *Major finding: The Theory of self-determination is Sup*

These three pilots began their work three years ago. They took time to get started. Sites took roughly a year to get up and running with 30 participants each. In the past two years, the efforts have grappled with a constant barrage of barriers, difficulties, and systematic impediments. Nevertheless, great progress has been made, and considerable reason for enthusiasm has been generated.

Normally, a "program evaluation" like the one summarized in this article would extend another year or more, since the pilot sites took a year or more to get online. For a full three years of data on the efforts, we would have to wait another year or more, so that we could see what happened in the lives of the participants over a full three year experience. However, the excitement and enthusiasm for this initiative is apparently so high that an early evaluation report was demanded. An early report can be justified only because the present evaluation team has experience in evaluating self-determination's progress in dozens of other states over the past decade. Without the benefit of this team's history, context, and proven measurement techniques, the present early report would not have been feasible or sensible.

The reason for continued interest and enthusiasm about self-determination in California is probably the same as the reason for the rapid proliferation of the concept all over the country: it feels "right" to all or nearly all stakeholders, from participants to

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the general public. The theory seems to make good common sense, it adheres to fundamental American values, and it is characterized by concern for fiscal conservatism. In its clearest operational form, the theory of self-determination is this:

1. If power shifts (carefully, gradually, responsibly, case-by-case) from paid professionals toward the people and their freely chosen allies,
2. Then lives will improve,
3. And costs will be the same or lower than they would be in the traditional professionally-dominated approach.

Our evaluative work has focused primarily on finding out whether these three parts of the self-determination theory are supported by the evidence. If they are, then it follows that California policy should proceed toward self-determination. Better lives at the same or lower public costs is obviously a win-win proposition that should meet with universal support.

We measured the sharing of power between people (plus allies) and paid professionals by visiting each participant each year, and by collecting a power-measurement scale we developed specifically for our self-determination research during the past decade. The data from the visits show clearly that power has shifted measurably and significantly. On our 100-point scale, power shifted from paid professionals toward people and the allies (usually relatives) by about 5 points. This change was statistically significant, and rather large, considering that less than two years passed between measurements. Thus the first part of the theory has been supported.

The second part of the theory says that improvements in qualities of life will accompany the power shift. We applied measurement scales that have been used for more than two decades in dozens of major studies in the developmental disabilities field, again, via personal visits and data collection with all the participants. To strengthen our scientific

evidence, we also included a study of a "Comparison Group" of people at one of the Regional Centers who did not participate in self-determination.

We found strong evidence to conclude that many qualities of life for participants and families did improve, and none got worse. Moreover, the subjective perceptions of quality of life indicated very strong changes for the better. People and their allies believe they are much better off in the self-determination paradigm than they were in the traditional approach.

The third part of the theory says that self-determination will not cause increases in public costs. The idea underlying this part of the theory is that people and their allies are themselves fiscally conservative, on the whole. Although exceptions do occur, the evidence shows that the great majority of people have purchased just what they need, and no more, when given real choice and control of resources.

Over a three year period of observation, purchase-of-service costs increased for the self-determination participants, but they increased less than for the comparison group of non-participants. Thus, our evidence strongly suggests that the cost-neutrality part of the theory is thus far true in California. The evidence further supports the inference that self-determination has been fiscally conservative, holding back cost increases that might otherwise have occurred.

However, a very large source of assistance for California's developmental services system is Federal funding via the Medicaid Waiver. For the self-determination experiments, the Federal Waiver program was consciously ignored. This was done in the belief that Waiver requirements and restrictions might have artificially limited flexibility by "disallowing" creative uses of public dollars. We found that, in fact, the self-determination participants sharply reduced their Waiver participation over the three years of the pilot projects. This situation must change if self-determination is to continue and expand. Self-determination has been applied in Waiver environments in many other states, and it can surely be done in California. Since the Federal government will pay for more than

50% of California's approved community support costs, it should be obvious that no program that exists outside the Waiver can long survive. Self-determination must be made "Waiver-friendly."

3. Major Finding: California has Unique Potential for 'Self-Determination'

It is very important to note in this Summary that California's developmental services system appears to be uniquely suited to self-determination in several ways.

First and foremost, individual budgets are an innate part of the California's system. Individual budgets are a necessary, although not sufficient, condition for self-determination. Budgeting for developmental disabilities services in traditional service systems has usually been done along a "program funding" model. In this model, money is paid to operate facilities and programs, rather than tying funds to individuals.

California's approach is different. Money really can follow people in California, to a degree that many other states might envy. Thus, the first precondition for self-determination, individual budgeting, poses a major stumbling block in many states, but is relatively easy to achieve in California.

Second, California's legal framework for developmental disabilities services is unique in that the Lanterman Act establishes an entitlement to services. In other states, services are only provided conditional upon available funding, and hence there are very long "waiting lists" in most states. In California, the law mandates that individual needs can and must be addressed. This makes the California system unusually favorable for self-determination.

Third, California's developmental services system is open to the concept of "self-vendorization," in which a person and/or a person's circle of friends can become an authorized provider of services. This can be quite important in the evolution of self-determination, which envisions micro-boards and micro-enterprises as options for support structures. Whereas the largest Federal assistance program, Medicaid, is by its nature

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a "provider payment system," and not a system for providing funds for individual supports, the ease of vendorization in California can be a very significant advantage in making the system responsive to individual needs.

Accompanying these three major advantages in California are several others that are important, but it remains to be seen how important they will become. The *Sanchez v. Johnson* litigation is designed to confront the issue of inequity of wages between institutional and community support workers. The future of community care is inextricably linked to the problem of low wages and high turnover rates. This national labor pool crisis is being addressed by litigation in California and nowhere else.

On a related note, California has made unique progress toward involvement of organized labor in home and community based care systems. The In-Home Supportive Services or IHSS program for elders has been extensively organized by the Service Employees International Union. This is one force that will tend to increase wages for community support workers, a goal that seems to be universally accepted as desirable, although the sources of funds for decent salaries have not been easy to specify. The point is that, in California, the issue is being addressed to an unusual degree, and some progress has been made.

Another contributor to California's unique receptivity to self-determination is its history of powerful judicial actions and decisions that favor individual community supports rather than congregate care and segregation. The *Coffelt v. DDS* experience resulted in the largest and most rapid shift from institutional to community living in history. Now another lawsuit, *People First v. DDS*, has been filed. This new lawsuit can be expected to maintain the pressure on the legislature, DDS, and the Regional Centers to show preference for person-centered support designs rather than congregate models. This too is likely to favor the evolution of self-determination in California.

These unique California qualities, combined with our very positive scientific evidence, lead this evaluation team to conclude that the expansion and extension of self-determination is highly desirable in California. In order for expansion to succeed, however, it must be recognized that those involved in implementing California's self-determination efforts need resources for intensive person-centered planning, intensive case management and service coordination, and intensive fiscal management.

Thus far, the three pilot sites have voluntarily extended resources to test and demonstrate the viability of self-determination. Any expansion will require significant commitment to fund the necessary local efforts. This commitment is necessary during transition from one kind of service system to another. The future system, driven by self-determination, seems likely to be both beneficial and cost-effective, but getting there will require firm leadership and significant resources.

The authors wish to acknowledge and thank the self-determination participants who allowed us into their homes to find out how they were doing. We also thank the three pilot Regional Centers for their cooperation and the DDS Information Services staff for providing the Purchase of Service records. Very special thanks to the Project Coordinators and the Fiscal Department Personnel for the detailed information about their operations. In gratitude, we dedicate our work and this report to people with disabilities and their families.

Comments about the California Self-Determination Pilot Projects Evaluation may be directed to Dr. James Conroy, Center for Outcome Analysis, at <JConroyCOA@aol.com>
The full evaluation report is available at <eoutcome.org>

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Effective Strategies for Teaching Self-Determination and Personal Safety Skills
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