

Newsletter

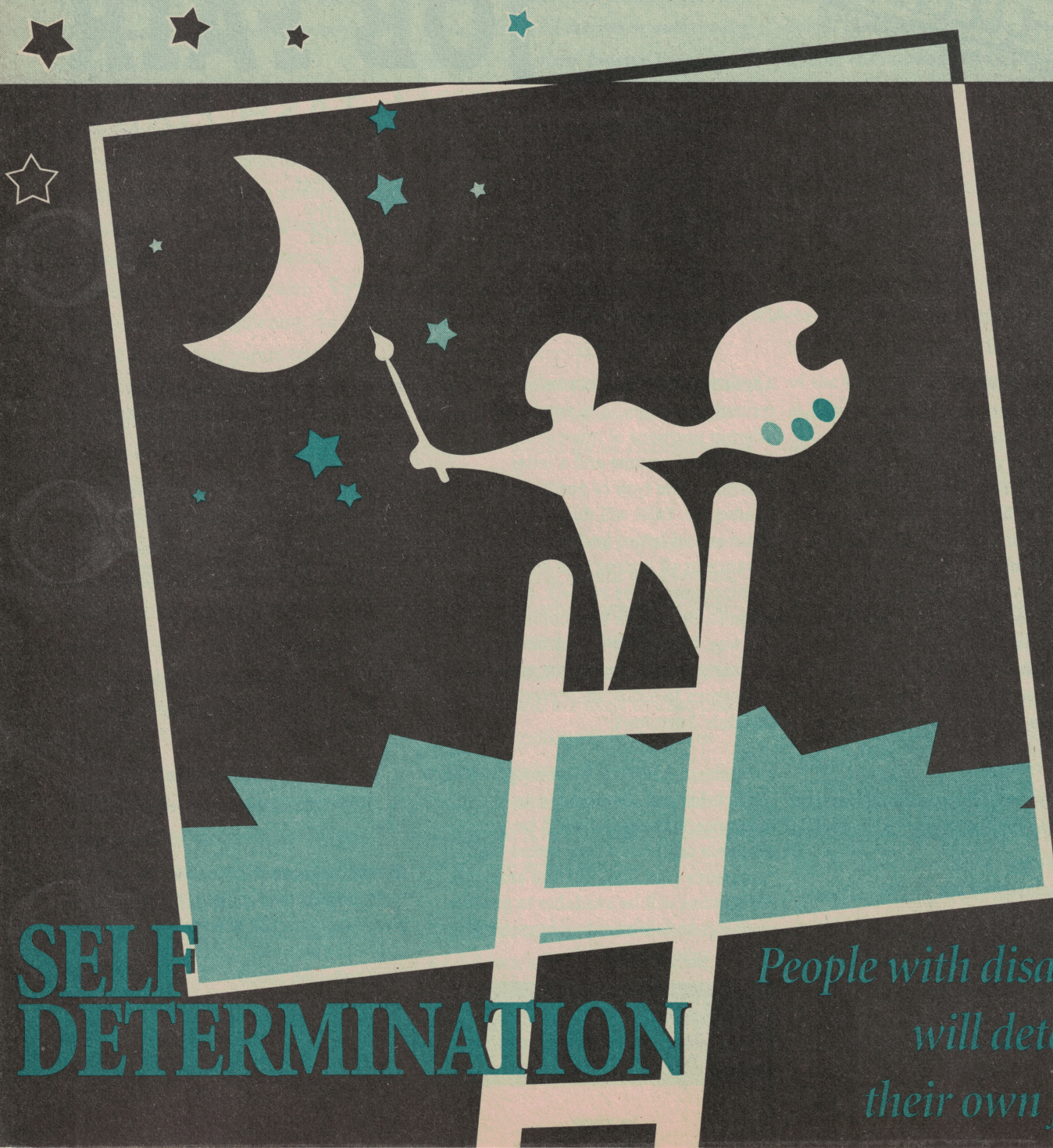
Inside: Civil Rights Report, IDEA Testimony, Conference Information

 TASH THE ASSOCIATION FOR PERSONS WITH SEVERE HANDICAPS

VOLUME 21

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SELF DETERMINATION

*People with disabilities
will determine
their own futures*

NEW HAMPSHIRE SELF DETERMINATION PROJECT

An Affirmation
of Community:
A Revolution
of Vision & Goals

*Brought to you by Sally Barrs, Chuck
Beauregard, Micky Beauregard, Peter
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INTRODUCTION

The following pages comprise a set of principles and strategies that we assumed, and stories that sustain us, in order for the Keene, New Hampshire region to redefine what community could be for persons with disabilities. With the help of the Robert Wood Johnson Foundation and the State of New Hampshire, Bureau of Developmental Disabilities, Monadnock Developmental Services, Inc. (MDS) set out to discover what it would take to move authority for planning one's life — with control over the resources necessary to secure adequate support — for 45 individuals initially targeted for this project.

The journey is ongoing. The struggles occur daily. Only gradually do we gain experience in figuring out how a service system might shift control from professionals to those who require various supports. Only over time will we know just what a "human service system" must become in order to allow individuals with disabilities and families with the assistance of friends — ordinary community members, in fact — to determine their own futures and their own relationship, if at all, to the "human service system."

MDS has committed itself to move these principles to all those in need of support. They apply to families as well as individuals, to early intervention as well as supported employment. New Hampshire is actively considering moving the Self-Determination principles statewide. With block grants and managed care looming on the horizon, the important questions for us concern our ability to shape future legislation, regulation and practice. This project has been operating within a block grant funding stream with individual capitation rates set initially at 75% to 90% of current service costs — a typical "managed care" system. (Capitation rates are for planning purposes and circles are not restricted to these ceilings when they cannot be met.)

Our experience thus far leads us to believe that block grants and managed care principles are not the problem. The real issue is whether or not we can construct a set of operating principles within these coming structures that truly lead to personal freedom and responsibility for folks with disabilities — a far more responsive and cost effective system that is not seduced by greed and the erosion of real choice. Can we replace the current all or nothing system of "total care"? Can we design a method for allowing Self-Determination rather than provider control of resources? Is the coming revolution in funding a nightmare or an opportunity for fundamental change in the way supports are now provided?

*Thomas Nerney
July, 1995*



SIMPLE TRUTHS

Simple Truth #1: All communities have as members people with disabilities. They are people of worth and value. They belong to families and neighborhoods. They are citizens, fellow workers, customers, parishioners. They are one of us.

Simple Truth #2: Members of our families, our churches, our neighborhoods, people with disabilities who are our friends, our co-workers, our customers, are unwittingly being harmed.

Simple Truth #3: Despite our best efforts, this harm is fundamental. It often requires individuals to live in isolation from the large community. It requires that the funding for services and supports they require be out of their control, under the control of a system.

This harm is not gentle. This harm is not benign. It precipitates active isolation from fellow citizens and the benefits of community. It means that some of "us" become "them." And "they" often go to school in different places and in different ways than other neighborhood kids. "They" frequently are told where to live and with whom. "They" are not truly respected for their capabilities. Their requests and suggestions are minimized by professionals who may mean well. "They" are prevented from dreaming about what the future may hold, because "they" do not control the future.

Simple Truth #4: Not long ago, you may have used the word "consumer" rather than "they." In truth "they" are not

consumers. Consumers are people who know what they want, seek out the best quality for the best price, and choose the best response to a defined need. The fact is, service systems for people with disabilities have too often acted as if people are commodities.

Simple Truth #5: We work at jobs that are valued and we pay taxes. We have true friendships. We've been joined in common causes by families, friends and professionals to determine our own destinies. We've taken the best we can all contribute to make a decent life within our communities.

Simple Truth #6: Let the secret be known — without intent, we have been unwitting parties to the systematic isolation of people with disabilities and their families. We have, of course, not set out to harm. We have not plotted to keep people with disabilities from enjoying the richness of life and citizenship in community. And yet we've designed and worked within a system that grave potential to cause hurt and isolation. The service delivery system in this country sets up barriers to full inclusion. The system is fundamentally flawed and must be restructured or completely rebuilt.

Simple Truth #7: We have assembled in files reams of paper, often authored by professionals, that purport to tell other professionals about the "person with a disability" — paper that pretends to know the person! We now know that these voluminous written descriptions do not tell the real story. They focus on what is "wrong" with a person, their level of "dysfunction" and their need for clinical intervention. This process itself is pathological. Only people with disabilities and their intimates are able to tell the true stories in a humane and positive manner.

Simple Truth #8: We have forced many individuals with disabilities and their families to compromise important life decisions in order to meet the

RON

Ron has been very clear over the past several years about wanting to move, feeling the group home was too constricting. Prior to living in the group home, he had lived an everyday life with his family. His parents, becoming elderly, could not longer support Ron to the extent he needed. He moved into a situation with paid staff and two strangers which was a big change. It became clear to Ron that this was not something he wanted. Nothing happened until one of the members of the group home died. Suddenly the funding for the group home was significantly less, causing people to seriously consider how to help Ron get to a place where he wanted to be. He was clear that he wanted to live in a house with a family, and that the house have a large yard so that he could have a garden and maybe some animals. Ron was given the choice between renting a home and inviting someone to live with him, or to move in with Kathy and her two teenage children in their country home. Ron chose to move to the country, where he is taking significant control over many aspects of his life. Kathy makes a concerted effort to listen to Ron's desires, including the time that Ron wants to be able to spend alone in the house. Ron decided that he wanted to try spending two hours alone in the house a day, a decision that was respected by Kathy and Ron's case manager. In the future, Ron will be taking control over paying for his supports and will be saving his earnings to buy a fishing boat. In addition, Ron will be authorizing payment in advance for any supports he receives by September 1995.

organizational requirements of human service agencies.

Simple Truth #9: We have a choice. We could let the isolation continue, but now that we know the simple truths, the harm would continue with intent. Or, we can start a revolution — a revolution to design community mutual support and common cause — a revolution for self-determination.

A VISION OF WHAT CAN BE

The founders of our nation conceived of a community of liberty, justice and equality. After more than 200 years, that vision continues to be the cornerstone of the community we are still in the process of creating. And today, we envision a community where people

with disabilities join us as valued friends and citizens.

Community Life — people with developmental disabilities are vital and integral members of our community.

Young people with disabilities grow up with their natural (or surrogate) families and other children in their own neighborhoods. Young people with disabilities attend the same schools and classrooms as the other kids in the neighborhood. Children grow up knowing that disabilities are part of human life, not the grounds for disappearing from community life.

We will interact with, bump into, get to know and be friends with people with disabilities in all of the places and occasions where we spend our time. No one will be missing. In our churches, service clubs, sports teams, places of work, breakfast clubs, fall fairs and shopping malls, we will find ourselves in the presence of and getting to know people with disabilities.

People with disabilities will live with us, learn with us, love with us, and experience joy with us. They will not be forced to live with others because they share a "label." We will build an inclusive community where all people are invited, welcomed, and expected to become one of us. Tolerance is not the issue — membership and belonging are.

Support — people with disabilities will be supported as members of the community, rather than as clients of programs or consumers of services.

There are those who view people with disabilities as people with problems which must be "fixed." We've even created an array of "special" places where these "problems" can be addressed. In these special places, people with disabilities are treated, cared for, and trained for eventual life in the community. The real problem is "eventual" often means never. This is no secret, and throughout New Hampshire and other places in the country we are witnessing an increasing number of individuals and families who are rejecting the current human delivery system because of its limitations.

Think about this: To be admitted to these "special" places, people must be deemed eligible and able to benefit from the "program." Before you can get support for what you want to do, you'll need to demonstrate to the system that you can "benefit" from what the system wants you to do. People with disabilities (and their families) can only ask for what others decide is useful for them.

BONNIE

Bonnie is a woman living in a small town of her choice. The paid staff in her life who were there to help her "access the community" were not members of her community and were barriers to her forming connections to people in town. She fired one staff member, and actually ended up stating "No more staff" and getting rid of the agency that was supporting her. Bonnie wanted to hire a friend to support her. Her friend happened to be a longstanding member of Bonnie's home community who had vast contacts among residents and business people. Initially, the case manager was greatly involved with Bonnie and her friend. They pulled together a group of people from the town as well as former staff, and formed a circle of friends. This circle of friends is so strong that the case manager is feeling that she should back out of their meetings and offer support from behind the scenes. Bonnie's costs went down markedly due to these changes. Bonnie and her friend are now building connections in town, such as joining church committees, participating in local fundraising activities, and planning possible future business opportunities. Bonnie creates her own file and paperwork to meet the service system's certification requirements. This has perplexed the State Office, and Bonnie has yet to receive verification that she is funded. Bonnie receives cash and is able to pay for any supports that she needs.

People with disabilities do not need technicians, mechanics and other professionals to "fix" problems and "service" them like machinery. People with disabilities need support that respects them as individuals and citizens. Support focuses on assisting people to get on with their lives, not become separate from it.

A focus on support means assisting people to make and act on their own choices, not limiting them to the narrow choices of the system. In a community concerned with supporting, rather than "servicing," people will pay great attention to the value of the dollar. Rather than giving over their lives to the system and enduring an entire package of life defining services, people with

disabilities will get what they need, and pay for only what they get.

Self-Determination — people with disabilities will determine their own futures, with appropriate assistance from families and friends.

There are two basic components to our vision of self-determination. The first deals with the fundamental purpose of education in American society — to foster citizenship and participation in democracy. The American system of education is required to assist in the preparation of good citizens; nurturing the gifts and talents of our young people and instilling a desire to be contributing members of the community. In schools, we seek to create a sense of community among

our youth. Citizens educated for democracy know that they have choices, and they make those choices not only in their own interest, but in the best interest of the community as well.

Our vision of an inclusive community requires that people with disabilities be educated for citizenship and interdependence, too. Today's system of education prepares people with disabilities to be dependent and excluded. We know that people who are educated to make contributions to society strive to make a difference. And we also know that children who are educated to see themselves in need of repair do not see themselves as contributors.

The second basic component of our vision of self-determination focuses on empowerment. Adults develop their own capacity and competency for self-determination. The American education system assists children in developing their own capacities and competencies. But developing this empowerment is not enough — we must ensure that people have the opportunity to act on their competencies. Public policy must permit and support a wide range of choice.

We envision a system that is essentially controlled by people with disabilities because they have the resources, capacities and power to make their own choices and act on those choices. Such a system assumes that people will act in responsible ways because they have a vital and vested interest in their own lives and communities.

This system involves individuals (and, where appropriate, their families and friends) who are in control of the supports they need as well as in control of the funding for these supports. This means that one individual does not require the congregation of others with

disabilities in order to receive support. The decision of one individual or family does not restrict the choices available to others.

Community Capacity — communities and ordinary citizens will see themselves as competent and willing to become involved in the lives of people with disabilities.

One of the grievous problems of today's system is that it causes people and communities to see people with disabilities as the sole domain of professionals. Because people with disabilities are strangers to many, it is thought that special training, considerable patience, and clinical certification are required.

Our vision is that the citizens and communities will realize that they have the capacity to befriend, care about, work alongside, and learn with and

from people with disabilities. Our shared sense of competency will mean a willingness and desire to work together to create an inclusive community.

NEW GOALS FOR A NEW FUTURE

There exists no doubt that we have the capacity to create the new community we envision. However, small steps, a few at a time, will not do it. We need a revolutionary shift in what we do and the principles on which we choose to act. As a community, we need to set and achieve six specific goals. Together, they represent a quantum leap.

GOAL #1:

Self-determined personal support — Each individual with a disability has the authority to plan for his or her own future and oversee the implementation of those plans.

This is the core principle underlying our vision. With assistance from a personal agent and/or others invited to

PATTI

Patti has been living in group homes for the past 17 years, and her housemates in her most recent group home situation were people with whom she could not even communicate. Her frustration and resulting behavior made it difficult for some of the people in her life to envision her living in any sort of lifeshare. But it has finally happened. Patti and some long time friends of hers decided that they wanted to move in to a house together. Patti got to choose some of the characteristics of the home they would move into. It took six months, but they finally found a wonderful home. Once the lease was signed, Patti really began to shine. She has been more articulate about her feelings and is standing up for herself more. She even asked one of her bosses for a raise — and got it! In addition to a new living situation, Patti is meeting a lot of new people, going out dancing, making the local karaoke circuit and is back playing softball with her former team, activities that always seemed difficult to arrange when paid staff had to coordinate the lives of a group of people. Patti will be authorizing payment in advance for any supports she receives by September 1995.

SELF DETERMINATION

participate, individuals determine what they need in terms of support, then negotiate funding for support.

Self-determination and control translates into people with a disability having control over budgets which are individually negotiated. We envision a self-determined personal support system which provides for flexible funding mechanisms for individuals of all ages. For young people under the age of majority, funds for out-of-school support would flow to their parents, as the family supports their child to develop and enter adult life. As young people become adults, funds would flow directly to them as being responsible for their own requirements. For example, rather than relying on a traditional agency, a person might choose to use their funds to hire a personal assistant to help with the tasks of daily living — getting out of bed, bathing, dressing, eating, etc. In other words, “whatever it takes” is another fundamental principle. No limits would be placed on the use of funds. Individuals could choose to purchase traditional services from existing providers or personally hire support workers. Funds may be used for support or adaptive equipment or to fix the car — whatever it takes to assist individuals to be part of the community.

GOAL #2:

Housing for inclusion — People with disabilities will live in homes in which they have tenure (ownership or lease) and control over the environment.

People with disabilities have the right to the safety and security of their own homes. They must have the right to decide where they live and with whom.

This goal is straightforward. People who now receive traditional residential “services” have no tenure. The service provider, region, or state authorities frequently decide who lives where, with whom, and how long. When people with negatively valued labels are

grouped together, they are isolated and often involuntarily “placed.” In contrast, our community’s goal is to support people where they choose to live, while supporting their efforts to be recognized as essential and valued contributors within their communities.

This goal means that people with disabilities will live in the typical housing of our communities, existing, renovated, or newly built. The issue becomes one of having financial access to housing rather than meeting the admission criteria of human service agencies. Support to people living in typical housing will be arranged under their self-determined personal support system.

GOAL #3:

Elimination of the congregate model — This will ensure that all individuals have the opportunity to live in the community in voluntary association with whom they choose.

This goal is more than just closing institutions. It ensures that individuals now living in institutions or “residential facilities” have the opportunity to live among us, with appropriate supports. Any involuntary congregation of individuals should not be among the range of “service options” available. The reason for this is simple and yet compelling — such congregate housing becomes another form of institutionalization and isolates the individuals from mainstream society. Public policy cannot support the continuation of services which cause this type of harm.

Ending involuntary association has an additional positive benefit — it may free funds currently dedicated to congregate “placements” to be used to community homes. For example, Jack and Harold were “placed” in a two person home in a residential neighborhood. This was a traditional, three shift, residential program with support staff. However, both Jack and Harold expressed a desire to live with a

family. Both chose families with whom they had a previous relationship. Today, both men are part of a community and family life that, in the past, neither had the opportunity to choose. Their individual support needs are varied. The use of crutches, age and medical issues challenge Harold who spent most of his life in an institution. Jack has a wheelchair, has seizures, and periodically needs psychiatric support. Both men have been isolated from their communities because the traditional system worked against inclusion and self-determination.

Jack and Harold have friends, family, homes, go on vacation, have hobbies and are known and contributing members of their respective communities. They have a life! By their choices, they have revealed to us how the traditional system was stifling and confining them. Their contributions to the community are meaningful and they are happy. As a result of achieving self-determination they freed up thousands of dollars annually that were previously needed to support the traditional service system. This was not their intent — it simply happened.

Sandra, 33 years old, was placed in a nursing home in 1977. Through a series of family events, her mother, having no choice, made the decision to place her temporarily. She was labeled “profoundly mentally retarded,” has a history of seizures and has cerebral palsy. Ten years later, Sandra was referred to a community agency to see if there were alternatives to her having to spend 21 hours a day in a crib and three hours a day in a wheelchair. She was rarely allowed out of the facility because the professional staff felt it would be harmful. That was her life!

In 1993 Sandra was finally liberated. Today she lives in a ranch house with her new family. Sandra also enjoys a wonderful relationship with her mother who visits her often.

Today, Sandra has a circle of friends and family, who provide her with activity filled days. Her spirit has been awakened, she is engaging, she expresses joy. She is becoming a known member of her community. She has a life! Sandra and other individuals could have remained in isolation if the opportunity to revolutionize the system and change social policy in New Hampshire had not been supported. Risks, with safeguards must be taken. Because Jack's and Harold's choices were supported, their quality of life has improved and state and Federal funds were reallocated so others could receive support and achieve self-determination. These are examples of social justice and self-determination! What Jack, Harold and Sandra now need is to exercise control over their individually designed supports and funding. To remain free, to remain in truly voluntary relationships, they must have control over the dollars required for their support.

GOAL #4:

Inclusive education means young people with disabilities attend age-appropriate classes with other young people from their neighborhoods.

Inclusive education means doing whatever it takes to confirm that young people with disabilities receive a quality education. Special schools and special classes do not meet the test of inclusion. While there is often confusion about the meaning of the term "integration," the meaning of inclusion is straightforward.

This goal should apply to all educational settings — those for children and adults and those in both public and non-public systems. Students with disabilities should be seen and supported not as members of a special class of learners but as members of a community of students.

GOAL #5:

Equal access to employment — People with disabilities will participate in the

labor force to the same extent as the rest of the community. In many situations, equal access will require that individuals with disabilities be supported for varying lengths of time, to obtain and retain employment and meaningful work in integrated settings with fair pay. It means a commitment to ensure that people with disabilities are supported to make their contributions to the community as workers and taxpayers. It means an opportunity to develop a career, not just a job. And it means that when work is done, it is valued. People with disabilities must not become an underclass of unfairly paid, devalued workers.

To achieve this goal, state and federal disincentives to employment must be removed. Employment should create a context for people contributing to the cost of their support, not impose a penalty for achieving self support.

GOAL #6:

Universal physical accessibility that assures that all people can get into and move about in the places they have a right to be as citizens.

One of the most easily identifiable obstacles to the participation of people with disabilities is lack of physical accessibility. Mobility aids, communication devices and other adaptive technology have made it possible for people with mobility problems to move about with great ease, that is, at least until they come to the front door of an inaccessible building, or try to work in an office with no accessible restroom. Federal legislation such as the Americans with Disabilities Act is a reasonable start to assuring that all people can get inside a building and all of its hallways and rooms.

This is Part I of a two part series on the New Hampshire Self Determination Project to be continued in the September issue.

NEW GOALS FOR A NEW FUTURE SELF-DETERMINED PERSONAL SUPPORT:

Each individual with a disability, with assistance from a personal agent and others the individual invites to participate, has the authority to plan for his or her own future and oversee the implementation of those plans.

HOUSING FOR INCLUSION:

People with disabilities should live in homes (the typical range of dwellings) in which they have tenure (ownership or lease) and control over the environment. People with disabilities have the right to the safety and security of tenure. They should have the right to decide where they live and with whom.

ELIMINATION OF THE CONGREGATE MODEL:

All institutions and congregate settings will end. Individuals will have the opportunity to live in the community in voluntary association with whom they choose.

INCLUSIVE EDUCATION:

Inclusive education means young people with developmental disabilities attend the regular, age-appropriate classes with other young people from their neighborhoods. It means that young people with developmental disabilities receive a quality education. It means doing whatever it takes to ensure that young people receive a quality education.

EQUAL ACCESS TO EMPLOYMENT:

People with disabilities will participate in the labor force to the same extent as the rest of the community.

UNIVERSAL PHYSICAL ACCESSIBILITY:

This will ensure that people can get into and move about in the places they have a right to be as citizens.

Election Issue, UNESCO & Self Determination Part Two

Newsletter



TASH THE ASSOCIATION FOR PERSONS WITH SEVERE HANDICAPS

VOLUME 21

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INCLUSION AROUND THE WORLD



NEW HAMPSHIRE SELF DETERMINATION PROJECT

PART 2

An Affirmation of Community: A Revolution of Vision & Goals

Creating a Community to Support All
People Including Those With Disabilities

Continued from TASH Newsletter Volume 21 No. 7

*Brought to you by Sally Barrs, Chuck
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PRINCIPLES FOR ACTION

Let's look more closely at the principles set forth in the previous *Newsletter*. Many of the goals are particular expressions of a set of principles to guide the future.

Principle #1: Self Determination and Control

In whatever form specific supports take, the principle of self-determination requires that individuals have the authority, power and resources to control their own destinies. This includes authority to plan their own futures, and directly negotiate for funds which will assist them in realizing their dreams. Only those whom the individual invites, to assist in this planning — family, friends, advocates — will take part in the discussions.

This is a principle that moves real decision-making to the person who is asking for support. For this concept to work, nearly everything that has been put into place by organizations and regulations needs to be fundamentally altered or in some cases renegotiated. This concept applies to those who have the ability to clearly communicate their needs, desires and dreams, as well as those who do not. To be successful, individual attention must be paid to both the myriad of ways that some individuals communicate and the necessity for people who care deeply and respect each of these persons to be an integral part of this communication process.

Most importantly, circles or networks must be composed solely of people whom the person being supported has freely chosen. This will mean, then, that major training in how to facilitate assistance must be offered for those within the circle. Concepts such as maps and circles of friends, to cite only two examples, must become part of the training process.

Self-determination means, essentially, that individuals with disabilities have both the means (funding) and the authority (the planning process) to determine by themselves how they will live their lives — planning days, weeks, months and years with as much detail as they wish. This plan will always be under their con-

trol and able to be changed, as anyone can change the way they plan to live each day.

Self-determination also means that only those who are invited to be part of the circle, or planning process, will be so. It means that individual budgets are developed with choices unlimited as to how each plan will be enacted — the only constraints will be the availability of dollars, the contribution of community members and the creativity of the person's circle.

Public dollars must be spent efficiently. Dollars spent on custodial or non-community environ-

individuals. Dollars should be spent only for supports, services or goods that are delivered.

Principle #2: Whatever It Takes

Whatever it takes is a thinking that represents a radical shift in emphasis. Historically, people have received the support that others have determined is appropriate or within regulations. This has often meant that individuals and families have received help, but not the help they think will be useful. In our new communities, the principle will be to support individuals' and families' decisions about what they need, including decisions that result when individuals and their families work with people and/or organizations (schools, agencies etc.) to decide what supports will make full inclusion possible.

Whatever it takes means that formal services and human service professionals are not the only ones permitted to assist. Whatever it takes may mean repairing an automobile or assisting a mother to return to school to learn a trade that will better help her support her daughter. Whatever it takes places no limits on what is purchased, from whom or where.

Principle #3: Choice and Voluntary Association

Choice and voluntary association will be part and parcel of each person's thinking. In our current community, choice can be a meaningless concept. Individuals with disabilities (and their families) are asked to select from a very narrow range of pre-determined options. For most, this means fitting themselves into the program or service. **True choice means creating the best fit between what an individual needs and what is designed or made available in response to the need(s).**

Choice means the individual makes the choices, not agreeing to something pre-determined by a third party. Choice means that there is neither segregation nor congregation — two ways in which internal exile has been fostered.

The right of voluntary association is central to the principle of choice. Like all citizens, people with disabilities have the right to associate with

PRINCIPLES FOR ACTION

Self Determination and Control

Whatever It Takes

Choice and Voluntary Association

Contribution

Fiscal Conservatism

ments and supports are inherently suspect. Economic efficiency is central to self-determination. One way to achieve economic efficiency is to insist on budgets that are individually designed to provide a personal future that matches that person's unique needs. Individual budgets can easily change each year as circumstances and funding needs change.

In our new community, congregate rate setting will be extinct. Congregate rate setting assumes that expenses will increase each year, and was designed to meet the needs of agencies, not

whom they choose. They have the right to free assembly. No one but they should decide with whom they spend time, or live. No one has the right to exclude others from service clubs, service groups or self-advocacy associations.

Principle #4: Contribution

Contribution to the economic life of the community as well as one's own support is a principal vision of the new community. We envision a community in which people with disabilities have the opportunity and support to enter into gainful employment and accumulate wealth. In this context, of course, it is expected that people who are accumulating wealth will also contribute to the cost of their support. This would be an act of citizenship, not an imposed penalty or disincentive to employment.

Principle #5: Fiscal Conservatism

Fiscal conservatism and fiscal efficiency are hallmarks of a new system of supports and services. The current system dedicates massive amounts of money to services which may go unused or indeed do harm — services which do not respond to the real needs of individuals. Two fundamental shifts in thinking are required. First, decisions about what is important to be funded are left to the individuals who will benefit from the decisions. Second, a system which is

initiated and led by people with disabilities means that **only what is received will be paid for.**

A system defined by the choices of individuals will be far more efficient, for it will rely on individuals (and those close to them) to make good decisions for themselves. The concept of fiscal conservatism takes as a given the need to, wherever possible, considerably reduce the size of the bureaucracy. Fiscal conservatism also means taking advantage of the many funding sources which are consistent with the vision, goals and principles of the revolution. Much greater use of funding should be made available to people with disabilities. One example would be rethinking housing costs — rather than support congregate housing, the money would be better spent to insure guaranteed mortgages for those who wish to purchase a home of their own.

STRATEGIES TO ACHIEVE THE GOALS AND HONOR THE PRINCIPLES

What would visions, goals, and principles be without strategies to enact them? They are offered here with a strong commitment to start the revolution of a new community.

STRATEGY # 1: WISER USES OF FUNDS FOR INCLUSION

Fully funded waivers and options for home and community services.

One method to reduce the real costs of supports and maximize Federal funds is to make greater use of Medicaid Home and Community Services waivers and the personal assistance option. Ensuring supports are fully funded will provide an even greater incentive to participating in more effective, quality approaches. Often, these approaches provide higher quality outcomes at lower costs. The waivers, however, should be stripped of all remaining disincentives to self-determination and the law carefully reviewed to determine if new legislation is necessary.

Abolish congregate care rate setting and develop individual budgets. Congregate care rate setting stands in the way of achieving the goals of community life and self-determination. Rate setting, as opposed to individual budgets, limits choice and compels the selection of segregated and congregated options. Most often it means that individuals do not get what they want or need. This in itself is a waste of money but is particularly a waste when what is purchased is more than the individual wants or needs. Individual budgets mean that the designated local, regional or state authority negotiates with individuals based on their needs. Individual budgets mean no predetermination of need based on an individual belonging to a class of people defined by levels and types of disabilities.

Invest saved money in supporting those currently without support. By reducing costs and bureaucracy and maximizing Federal and state funds, there may be a long-term reduction in state and Federal expenditures for the group of people to whom the states are already providing support. These savings should be invested in supporting those who currently receive no support.

INDIVIDUAL BUDGETS

The development of an individual budget based on the unique supports that an individual may need is a first and necessary step toward self determination. The right to free association is fundamental to the concept of determining where and with whom one lives, plays and works. Currently, many people in the system lack the basic freedoms associated with self-determination precisely because their budgets are intimately tied to those of other individuals within a total agency budget. Traditional agency rate setting is grounded in the congregation of persons with disabilities, determining agency costs and allocating the amount thus determined with the full expectation that all the dollars will be spent. This results in fiscal co-dependency which is a major barrier to self-determination. Individual budgets allow for free movement and free association.

Develop incentives to promote inclusion in local community associations. From a community development perspective, our communities and local associations have too little experience in including people with disabilities. To develop such a capacity will require a commitment of time and energy to assist community groups and organizations in welcoming people with disabilities. This is a long term strategy, but one that must be engaged for full inclusion in the new community.

End involuntary or segregated models.

There is a serious imbalance in the range of choices available to people with disabilities. Far too many individuals live in settings not expressly chosen by them and receive only partial support or no support in achieving employment. We find that when given choices, individuals reject the segregated models for opportunities to be in real jobs and homes and become a part of their communities.

**STRATEGY #2
SHIFT THE POWER AND
INFLUENCE**

Involve people with disabilities in policy making.

Replace case management approaches with personal agents and brokerage approaches.

Let us begin the revolution by involving people with disabilities in policy making. Consistent with the principle of self-determination, people with disabilities should be actively and decisively involved and supported to participate in public policy making. People First, a state and locally based and national self-advocacy organization, should be publicly funded and supported. Generic boards and advisory councils should include people with disabilities, and people with disabilities should be hired in government and board level policy making positions.

Another power shift will replace case management approaches with personal

agency or brokerage. Our current thinking about case management is based on traditional services. As funds flow directly to the individual, and the individual exercises control over those funds, the issue shifts to assisting the individual to determine what he/she needs, then purchasing it in the most effective manner. Historically, case management has often meant steering the person into opportunities currently available as well as managing the system's response to the individual. But when individuals have the power to plan and purchase on their own behalf, management roles become far less important than brokerage roles which assist people to invest their resources in the best methods of support. Individuals with disabilities will find that **personal agents act on their behalf, at their discretion, helping sort out the system rather than representing it.**

**STRATEGY #3:
RE-ORIENT MAJOR
COMPONENTS OF THE
SERVICE SYSTEM**

Reinvest special education resources. We propose transferring all special education resources and students to the regular system. At the same time, we must maintain all procedural rights and safeguards.

An immediate consequence of such action would be to reduce the inefficiencies in the current system. Out-of-district placements and separate transportation systems are but two of the examples of costly inefficiencies. One target for reinvestment would be training and supporting teachers, including pre- and in-service training, the use of paraprofessionals, and the creation of a coordinated source of expertise on inclusive education.

Assist people with disabilities to invest in their own housing. Enormous amounts of public funds have been invested in housing in which people with disabilities have no tenure, security or equity, and in which their right to

voluntary association is fundamentally violated. It makes far more sense to assist people to own their own homes, rather than live in houses owned by a state or an agency. The Home of Your Own project has been successfully implemented in New Hampshire and has spread to other states. It makes far more sense to assist people with disabilities to use and adapt existing housing than it does to build large, congregate structures which have little, if any, use as general housing. People with disabilities are trapped yet again when the housing constructed for groups of people cannot be used in another way. It becomes necessary to hold people in those structures to make the investment worthwhile. Does it make sense to invest in bricks and mortar rather than in people's futures?

A number of steps can be taken to construct a sensible strategy. Take advantage of Federal funds for appropriate individual housing (new or renovated) scattered throughout the community. Seek an active program of consultation and collaboration with banks and other sources of investment capital to ensure access to guaranteed mortgages. Low income home ownership could be a reality if banks can feel secure in their investment, if socially responsible businesses can dedicate a portion of their community contributions in this way, and if individuals and families are assisted to invest their personal resources in home ownership. If there is a fundamental recognition that people with disabilities can legitimately aspire to home ownership as other citizens do, this vision will become a reality.

Give priority to the use and adaptation of existing housing stock, coupled with a moratorium on the further development of congregate segregated housing. This will mean appropriate redirection of Federal funds to home ownership for individuals, not the state or agency-owned houses. We accept as a given the need for a commitment to a new Federal/state program for home ownership and tenure. By shifting the emphasis from housing as the location of programs to housing as a place of security and a sense of home, this strategy ties into self-determination — individuals purchasing supports they require to live in their own homes.

We must also reinvest rehabilitation resources into employment support. Our current system of Medicaid, vocational rehabilitation and special education is not resulting in a labor force that includes the talents and contributions of people with disabilities. Many spend their day or part of their day in congregate segregated programs. Others may work, but often set apart. Some who work do not receive a decent wage. Many receive their wages from a human service agency, thus the individual with a disability is not an employee of a business. This model creates only the illusion that a person has a real job and is a valued employee.

Sadly, many of the current models still view people with disabilities as unemployable. This belief is misinformed and contrary to what we know to be possible. For most, the current system and the promises of supported employment have left many under-employed, underpaid, or unemployed. Our new community envelops a strategy that builds on the desires and capabilities of people with disabilities to work, to be paid fair wages, to be taxpayers. Consolidating and re-directing funds currently in the system makes these funds available to individuals based on development of an employment or career plan. Again, this is self-determination. Funds would then be negotiated based on such a plan, and the person with a disability could purchase or hire the support required, if any, to implement their plan. In fact, the person with a disability could pay the employer to train him/her.

This strategy moves from an orientation toward rehabilitation (fixing the problem) to one of participation and contribution. It requires professionals to be gifted in assisting people to navigate the system rather than acting as gatekeepers. It requires professionals to assist people to determine what they need rather than deciding if an individual's plan for the future matches a particular program or service. Using existing and new incentives, professionals assist individuals in dealing directly with employers. This strategy certainly requires the elimination of separate budgets related to employment and significant reductions in the bureaucracy required to administer separate programs.

STRATEGY #4: DEVELOP A CULTURE OF ACCESSIBILITY

Develop a Culture of Accessibility

Physical Accessibility

Transportation - The Final Frontier

We must develop a culture that assumes that accessibility is part of the way we do things. Rather than an add-on or an extra consideration, accessibility must be assumed as a basic consideration. Only then will people with disabilities become part of our community.

Our strategies for the future must include residential and commercial building standards which are realistic and those standards must be implemented and enforced. Public attitude must shift to appreciate the benefits of accessibility and become intolerant to inaccessibility.

For people with mobility problems, transportation is the critical issue. Each person's individual budget should have sufficient funding allocated to ensure control of personal transportation needs, including the purchase of a personal vehicle, if necessary.

Our vision of people with disabilities participating in and contributing to community life

will be difficult to realize if people are not able to move around the community. Self-directed personal support assumes that transportation is an essential component of whatever it takes. If individuals are able to purchase their own transportation, any number of options become possible.

STRATEGY #5 KEEP THE VISION IN FOCUS

People in Relationships

People in Community

None of these strategies will be effective if people with disabilities are not part of our communities. All of these strategies are intended to break through the barriers to having valued relationships, participation and contribution in one's home community. Each is necessary to support people to enter into and sustain relationships and their membership in the community. Each is necessary to support communities to recognize our fellow citizens who have been missing among us for so long.

A consistent theme throughout these strategies is that choice, decision-making and financial resources are in the hands of people with disabilities. One result of this approach is that there will be fewer intermediaries standing as barriers between people with disabilities and other members of their community. Today, a massive service system and bureaucracy stands as a barrier. Our future will be built together — professionals, ordinary citizens, friends, colleagues, co-workers and family members. Professionals will assist people to turn their plans into reality. Community members will continue to work together to build a community and nation in which individuals live quality lives and contribute to the common good.

