

**An Affirmation of Community; A Revolution of  
Vision And Goals  
Creating a Community to Support All People  
Including Those With Disabilities**

**Thomas Nerney, Richard F. Crowley,with Bruce Kappel**

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"Community is not an abstract ideal, but a concrete expression of personal commitment. It is a witness to the essential unity of the human family."

-Faye Svingnen

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## About the Authors

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Richard F. Crowley has been a champion of self-determination for people who have developmental disabilities for thirty years. In a variety of administrative policy-making positions in Oregon, Massachusetts Washington D.C. and currently in New Hampshire, he has implemented human service system reforms which have led the way in transferring power from systems to the individuals they were created to serve. Through his efforts in grant writing ,contract negotiations, administrative leadership and personal advocacy, many initiatives in early intervention, home ownership, employment, family support and self advocacy have been realized. In addition to consulting, he currently serves as the Executive Director of a private, non-profit agency which provides community supports to individuals with a developmental disability and to their families.

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## **PREFACE**

Maybe it is the times, or maybe it is the fact that we have had some time to examine how it is that we interact with and support children and adults with disabilities in communities. Or maybe it is simply that people with disabilities are sick and tired of being controlled by others. Whatever the reason, self-determination has emerged as the agenda of the 90's. As Bob Williams says: "Self-determination is just another word for freedom." Freedom to live with whom you want, freedom to live a productive life, freedom to attend school with your friends and brothers and sisters, freedom to get around your community, freedom to love and reject. . .

The essential questions are: Is it possible to enjoy self-determination without having direct control over one's resources? Is it possible to choose when, in reality, most organizations with missions focused on people with disabilities are unable to directly disperse resources to individuals and their families? And how do we move organizations and public policy to a place where cash subsidies and vouchers are accepted? In the absence of overt public policy sanctioning cash subsidies and vouchers, how do organizations support self-determination? These questions are the foundation of any effort engaged in providing quality services and supports to individuals with disabilities and their families.

Region V, Monadnock Developmental Services, one of New Hampshire's 12 Area Agencies, has been working for many years to implement the set of principles put forth in this monograph. All of the efforts are focusing on creating a context that supports self-determination. They have done, in part, what Burton Blatt referred to as creating a new organization:

"We must create an organization that earlier reformers, were they here today, would join. We must unite, not about specific task orientations but about powerful ideologies, not about special means, but about consensus of humanistic ends, not about silly slogans thoughtlessly chanted but about the infinite perspectives of a complex dilemma; therefore we must band together, as each makes his (her) special commitment to change. We must become new people, no longer underestimating the potentials we have for changing and thus no longer fulfilling the prophecy of no change."

"We know this is the beginning of a long process in which constant examination and evaluation is required. Have no illusions, self-determination is embedded in complex issues such as safety and sexuality; and dilemmas of personal versus society's expectations and preferences, choice versus coercion, and individual versus family expectations. We hope for and will work toward public policy that supports real choice and empowerment. In the meantime, it will be what the people with disabilities and their families have to say about self-determination that will be the final word."

Jan Nisbet, PhD  
University of New Hampshire  
Durham, NH

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# INTRODUCTION

Since 1983, Monadnock Developmental Services, Inc. of Keene, New Hampshire, (one of twelve private non profit regional agencies contracted to develop and manage a locally controlled system of supports for the New Hampshire Division of Mental Health and Developmental Disabilities) has hosted frequent meetings -- both internally and with outside participants -- to determine a truly coherent moral and legal approach to supporting people with disabilities.

In our search to achieve social justice for people with disabilities, we have determined that that there are fundamental flaws in the manner in which this nation has created a system of "community" services that frequently fosters isolation from community. We are painfully aware, that, though well intended, this separation causes people to be perceived as "different". Their quality of life suffers. Their basic human rights may be jeopardized. How, we asked over and over again, can we change this?

Perhaps, we hypothesize, the service delivery system itself is a problem. Perhaps this system gets in the way of supporting people the way in which they wish to live. Perhaps the delivery systems interfere with friendships and relationships, rather than encourage them. Perhaps, we surmised, we need to creatively examine the way in which resources are allocated and controlled. A revolutionary thought? All right, we accept the challenge of revolution. Believing in a person-centered or family-centered system of supports means more than just changing the language or "shifting the paradigm" -- we will begin a social revolution and a fundamental restructuring of the system.

In 1993, the Robert Wood Johnson Foundation awarded a three year grant to Monadnock Developmental Services, Inc. to assist us in framing an approach to our overriding question: How would a system of supports look if people with disabilities and their circle of friends, or network, were truly in charge of their own needs, if they truly achieved self-determination?

This manuscript serves as our plan for the revolution. It is a call to action and an illustration of the depth of change required if we are truly to become responsive to people with disabilities. This revolution is an affirmation of community -- it must succeed if our communities are ever to acknowledge and rectify decades of separation, stigma and isolation forced on this population and frequently their families as well. This effort represents the culmination of more than three years of thinking, preparation and partial demonstration. Many individuals at the national, state, and local levels have been instrumental in clarifying issues and sharpening the vision included in this call for an affirmation of community. Together with one of the authors, Bruce Kappel, Consultant to the Connecticut Developmental Disabilities Council focus group discussed these principles and articulated a similar vision.

We are privileged to be part of a state system that encourages self-determination and is seeking ways in which people with disabilities are truly welcomed into their communities. Though significant accomplishments have been made in New Hampshire regarding self-determination and inclusion, much remains to be accomplished before we can profess achievement of truly inclusive communities. In 1991, the New Hampshire Division of Mental Health and Developmental Services published "New Decade, New Decisions" in which they said:

"Not only is New Hampshire committed to supporting people and families where they live and according to their needs and choices, but the state also has the foresight, technology and expertise to establish a system conducive to its

values and has committed resources to supporting its progress in the decade ahead.

We cannot allow this progress to wane in the ebb and flow of relatively seasonal economic changes. The cost effectiveness of New Hampshire's services to its people has been shown time and again to be adaptable, responsive and a `best buy' for the tax dollar."

Now, four years later, we continue those precepts. Our principles are firmly rooted in the cause of self-determination. We must truly understand the importance of community and recognize that all too often the present system actually severs any hope of community relationships and connections for people with disabilities and their families.

We embark on a journey of change, recognizing that changes are often accomplished one person at a time. There is no map to guide us in anticipating the difficulties and obstacles that may surface. This is a journey that will ultimately challenge our very concept of the meaning of community.

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The authors would like to acknowledge the contributions of Ellen Cummings, Gail Connelly, Alan Greene, Brian Remer, Chris LaBarge, Doreen Rosimos, Robin Kenney, the Board of Directors, the Family Support staff, the Family Support Council, Case Managers (Personal Agents) and the Individual Service Options staff of Monadnock Developmental Services, Inc. We are also privileged to have the wise counsel of staff of the Institute on Disability/UAP located at the University of New Hampshire, under the direction of Jan Nisbet and Richard LePore, Consultant. The staff of State of New Hampshire Division of Mental Health and Developmental Services, under the leadership of Donald L. Shumway and Rich Crocker, has made possible the articulation of a vision profoundly grounded in community life and community association. Many others throughout New Hampshire and the country have also contributed to this vision. To all of you, we express our gratitude.

The real leaders of this revolution, however, are seldom acknowledged. Jack, Bev, Kevin and Harold are several of the guiding forces who challenged us and provided the insight necessary for professionals and advocates to finally understand the deep need for choice, relationships and community. Ann, David, Toni, Michael, Robert, Priscilla, Sandra, Joe, Julie, Ron and many other friends taught us that we could no longer be part of a system that controlled peoples' lives and which resulted in such a stunning lack of freedom, all in the name of assistance and caring. Thomas Nerney, Director Richard F. Crowley New Hampshire's Self-Determination Project Executive Director A Robert Wood Johnson Foundation Project Monadnock Developmental Services, Inc.

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# Chapter 1 Simple Truths and Choices

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*"When people with a disability are separated from community, they are perceived as different, their quality of life is called into question, and their basic human rights become endangered. When people are controlled by systems, they are at risk of exploitation, victimization, and disempowerment. When the system of services extends beyond a certain stage and impinges on self-determination and community, increased personal suffering and social dissolution sets in."*

Interrobust VI, Connecticut  
April, 1993

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- **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 larger 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 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. The system is a money-generator that restricts choices and creativity. The system's "consumers" can unintentionally become exploited, victimized and stripped of their power. "They" are essentially bought and sold.

- **Simple Truth #5:**

There are people who have shown us what being one of "us" can mean. We go to school with other kids in our own neighborhoods. We (and our families) have fought for what we want and need. We have found ways to live in houses with people of our own choosing. 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 has 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 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.

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## Chapter 2: A Vision of What Can Be

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*"In our every deliberation we must consider the impact of our decisions on the next seven generations."*

The Great Law of the Six Nations

Iroquois Confederacy

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The founders of our nation conceived of a community of liberty, justice and equality. This nation was designed so that each citizen, sometimes after long legal battles, contributed to the common good and therefore having a say in the destiny of the community. 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.

To the cornerstones of life, liberty and the pursuit of happiness, we add the following: 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.

When we do not encounter people with disabilities in everyday life, we will wonder what happened. If someone with a disability is missing, it will not be "one of them" who is missing, but a person with a name and face -- a friend. We acknowledge that there are some disabilities which, by their very nature -- are invisible

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.

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## The Vision

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- **Community Life**

People with disabilities are vital and integral members of our community. They will be supported

as members of the community, rather than clients of programs or consumers of services.

- **Self-Determination**

People with disabilities will determine their own futures, with appropriate assistance from families and friends.

- **Community Capacity**

Communities and citizens will see themselves as competent and willing to become involved in the lives of people with disabilities.

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. Have you heard (or used) the term "servicing clients"? This terminology captures the spirit of a system designed for its own ends. 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. We will not pay for supports that isolate them. We will pay only for supports which do good and are delivered in our communities. 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 and as well as in control of the funding for these supports. This means that the individual decides what is in his/her best interest. 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.

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## Chapter 3 NEW GOALS FOR A NEW FUTURE

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*"Never doubt that a small group of thoughtful committed citizens can change the world; indeed, it's the only thing that ever has."*

--Margaret Mead

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There exists no doubt that we have the capacity to re-make ourselves into this new kind of 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 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 for 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 (as several states have successfully done). 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 for 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 challenges Harold who spent most of his life in an institution. Jack uses 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, a home, 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 there 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, whose beliefs were rooted in the myths of an institutional model, felt it would be harmful. That was her life! Attempts to provide community options were offered. 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. She was seen rolling in the leaves on her front lawn with her mom and support staff not long after leaving the nursing home.

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.

The second component of inclusive education focuses on education for democracy. A central ingredient of a quality education will be education for citizenship, equality, and full participation in democratic community life.

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 of ensuring 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 have a job. And it means that when work is done, it is valued. People with disabilities must not become an under-class 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.

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# NEW GOALS FOR A NEW FUTURE

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- **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. 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.

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## Chapter 4 PRINCIPLES FOR ACTION

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*"This ain't no dress rehearsal."*

--Anon

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

### ● **Principle #1: Self-Determination And Control**

Self-determination and control is, as careful readers know, a core principle of this revolution. In whatever form specific supports take, the principle is that individuals must have the authority, power and resources to control their own destinies. This includes the recognized 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 concept that clearly attempts to move 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 control 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. It is important to point out that self-determination also means that individuals with disabilities will take responsibility for their decisions.

Within our revolution of forming a new concept of community, we envision a change in the way public funding is accomplished as well. The use of public and privately donated dollars places a grave responsibility upon each individual and his/her circle or networks. While no restrictions should be set on how the dollars are spent to assist someone, there is clearly a responsibility to limit these dollars to

activities which will be life enhancing and increase the ability of a person to participate in work, leisure and other community activities.

Public dollars must be spent efficiently -- we say, then, that dollars spent on custodial or non-community environments and supports are inherently suspect. The notion of economic efficiency is central to self-determination; thus, one way to address this issue of 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, the old paradigm of 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 individuals. Dollars should be spent only for supports, services or goods that are delivered -- the system we seek to change actually spends dollars in anticipation of their deliverance.

- **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 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.

The positive prevailing principle is that individuals have the power and funds to make and act on their choices. When individuals have the power to make choices, they accept that with choice comes responsibility. Receiving public funds mandates such responsibility, and also places emphasis on the responsible expenditure of such funds.

- **Principle #4: Contribution**

Contribution to the economic life of the community as well as one's own support is a principle 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. It is far better for people who care about their own futures to make such determinations than to leave such decisions to those who do not care or have a conflict of interest. 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.

## **LIMITS ON THE USE OF PUBLIC FUNDS WOULD INCLUDE:**

- The choice should do no harm.
- The option should be available to all.
- The choice should not require the participation of other people with disabilities, thus creating an imposed segregated environment.
- The choice should not create a negative, devaluing image of people with disabilities.

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## Chapter 5: CONDITIONS FOR SUCCESS

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*"It's about keeping the dream alive -- by continually reflecting, listening, dreaming , growing. It's about tolerating rapid change. Whatever we think is complete will need fixing. Enjoy the journey -- don't fight it."*

-- Marsha Forest, Jack Pierpoint and Judith Snow  
The Inclusion Papers, 1992

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Each person with a disability needs a support network -- large or small -- whose leadership agrees to meet on a regular basis. This is the successor to the old paradigm or concept of a "team." This circle is made up of individuals who are there at the behest and with the encouragement of the person with a disability. Members of these circles, or networks, share important common values. They understand that the focus of the circle is to help the person make decisions about important life choices. When the circle surrounding the individual is truly invited and unique, dreams can begin to incorporate every person's input. Families, for example would have major effects on their children's dreams and plans. Members of circles or networks share their own vision of a positive future for the individual. The process of developing a dream begins at once.

It is ever evolving and rooted in the following principles:

- A positive view of the person served.
- The possibility for real change.
- System impediments or barriers can be removed.
- The obligation of professionals is to remove the barriers.
- The obligation of professionals is to serve - not dictate.

Virtually every person and organization now in the human service system will see substantial changes in their roles and responsibilities. For example:

The person served moves from passive recipient of "services" to active procurer of supports with assistance when necessary from invited intimates. When this occurs the paradigm will have truly shifted.

Human service agencies will be lean and creative, and not be reimbursed according to congregate rate setting, which is the mechanism that virtually all human service agencies use today to build their budgets and employ personnel. The agencies will vary in size from one person to several individuals or more. Agencies in our new community will be asked by circles or networks to provide discrete or unique supports to an individual based on an individually negotiated amount of money (which may include a fee for management and administration). We assume, then, that some protections need to be built into the system annually to ensure financial viability of cooperating provider agencies when individuals choose to contract with them.

Agencies of the future may:

Accept personnel that come with the contract for support or service At the request of the circle or

network, search for the right person(s) to provide the support(s) Be asked to act as a "pass- through" or conduit for dollars that need to be legally logged Provide any combination of the above that makes sense for the person who is being supported.

Circles or networks will become the primary mechanism for planning supports with regard to leisure, living and working arrangements. The person needing these supports is at the center of this process and is also given the controlling voice and decision. In fact, one of the jobs of the circle or network is to make sure that all the individual's desires are attempted to be met.

Selecting members of each circle or network is critical to the long-term success of this new approach. These are not professional circles or networks. In fact, these circles are "de-professionalized" and draw from a wider group of family, friends, and neighbors chosen by the individual. Professional staff who have so dominated the lives of these individuals will still play an important role, because more often than not, they are invited to join. But in a new community, if they participate, they do so as friends of the individual. The work of each circle or network is ongoing.

It has several dimensions:

- Ensuring self-determination.
- Planning and budgeting.
- Quality assurance.
- Assisting in brokering or arranging necessary supports.
- Making concrete the dreams of the person served.

The old concept of team meetings changes, as well, in important ways. All key members of each circle need to understand the reasons for the circle and be available to participate in ways that are meaningful to both themselves and who invited them. Sessions should be informal and allow enough time for everyone to relax and understand their roles. A group of friends, family and neighbors so chosen might very well decide to meet over coffee or a meal.

It is important to realize that major changes in a person's life may take years of preparation. This will vary depending on present circumstances and needs. A working circle or network must be based on real relationships and demands a quality investment of time.

Planning, an historic component of traditional teams, is also changed dramatically. Circles now have the added function -- and the responsibility and authority -- of budgeting dollars allocated to meet the needs of the individual on an annual basis. This does not mean that circle members need be fiscal experts. In fact, it would be wise and necessary for personal agents to review both potential allocations and individual proposed budgets before and after the circle's decisions are made. This will ensure that only those supports not otherwise available are purchased and all areas of need are addressed.

The circle must function as an ongoing evaluation of the supports and their delivery. Quality assurance stems from having circle members not only knowing the individual, but staying in contact. While this is an informal process, it has the potential of ferreting out problems early on. A personal agent should be the point of contact for any areas where questions arise.

Self-determination can and must be assured by the responsive functioning of the circle. Each member is participating because, first, she/he was invited and because she/he can assist in communicating as well as developing dreams, as well as ensure that long range dreams and everyday preferences are translated into a real plan.

Services or Supports may be sought from:

- Family members when appropriate.
- Friends and acquaintances when appropriate.
- Generic agencies willing to accept individual contracts and/or search for the right person(s).
- Human service agencies willing to accept individual contracts and/or search for the right person(s).

After the individual has stated his/her preferences, circles will have the option to begin bargaining and soliciting support from a variety of sources. In other words, circles can decide to do the brokering themselves or engage someone to do the brokering for them. In most cases, a contract will be developed to be managed by an individual or an organization. Since funding will be assigned to the individual based on availability of funds and past use of services, not all supports will be (or should be) purchased. The circle will assist in procuring non-paid supports whenever possible. In other words, obtaining is even more important than purchasing. Those things most important in a person's life -- relationships, friendships, and associations with others in their community-- cannot be purchased.

However, we realize that many supports must of necessity be purchased and, especially at the beginning of this process, the responsibility for securing at least some of these supports from friends, acquaintances and valued community members becomes paramount. If the most important things in a person's life cannot be purchased, then each plan should over time include more and more natural supports from those making personal commitments to the individual with a disability.

In the past, team plans accented skill development, behavioral changes and personal compliance with rules of the human service system. In the new communities, circles deal in reality based dreams and goals that stipulate the relationships desired, the personal and intimate friendships desired and the associations with other community members and organizations. The role of the circle is to spend the necessary time assisting in making these connections.

Circle meetings are not annual events. Depending on how a person's life is progressing, the circle needs to meet more or less frequently. The role of the case managers will be redefined for advocacy and personal agency.

The skills needed in the Personal Agent role:

- Ability to be a strong advocate and leader
- Ability to communicate and listen to person served
- Ability to negotiate and assist in brokering supports
- Ability to assist in finding circle or network members with the person served
- Ability to enhance communication among circle or network members
- Ability to assess important quality of life dimensions
- And most important, the ability and skills with facilitating a circle or futures planning process.

If the person served could be thought of as the President of the circle then personal agent is the CEO responsible for increasing communication, eliciting information, problem solving, assisting in building the network, and making suggestions and recommendations.

Personal agents/case managers will take on a dramatically changed role. Their responsibility and authority will substantially increase as it becomes their role to communicate and resolve any difficulties

the circle has identified. Agencies or individuals who are not responsive to the circle's concerns can lose their contract. While facilitating a circle of invited participants, personal agents will have the authority (with the concurrence of the individual and the circle) to enter into contractual arrangements. They become the linchpin of the entire system as they communicate the interests of the person served at every level.

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# Chapter 6: STRATEGIES TO ACHIEVE THE GOALS AND HONOR THE PRINCIPLES

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*"Self-determination is a ten dollar word for choice -- it is another word for freedom- - a life filled with rising expectations, dignity, responsibility, and opportunity -- a chance to live the American dream."*

-- Bob Williams, Commissioner,  
Administration on Developmental Disabilities,  
U.S. Dept. of Health and Human Services

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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 fund waivers and options for home and community supports.
- Abolish congregate care rates.
- Initiate individual budgets.
- Invest saved money in supporting those currently without support and stabilize the community support infrastructure.
- Promote inclusion in local community associations.
- End involuntary segregation models.

### **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.

This strategy is consistent with the intent of inclusion and personal directed support. The mere use of Federal dollars is not the point. Most states already take advantage of a number of Federal funding programs. What must be accomplished in direct collaboration with the states and the Federal government is the immediate implementation of an innovative, revolutionary and highly discretionary Medicaid waiver authority.

### **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 means that the designated local, regional or state authority negotiates with individuals based on their needs. Individual budgets means 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.

## **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 and students in regular education.
- Assist people with disabilities to invest in their own housing.
- Reinvest rehabilitation resources into employment support.

"More troubling, nearly 40 years after *Brown v. Board of Education*, the U.S. Supreme Court's landmark ruling, Americans continue to pay for and send their children to classrooms that are often separate and unequal."

--Joseph Shapiro

U.S. News & World Report

(Dec. 19, 1993)

Reinvest special education resources. While inclusive education calls for the abolition of special education as a separate system, we propose transferring all special education resources and students to the regular system. At the same time, though, we must maintain all procedural rights and safeguards -- abolish the special education bureaucracy and re-invest in the regular school system. Isn't all education special?

An immediate consequence of such actions 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. This approach would be assisted greatly if Federal and state regulations would permit individuals to accumulate enough funds to make down payments on houses. Currently, individuals often are required to spend their savings on things they do not need, just to keep their bank balances below a mandated level in order to be eligible for needed supports. This mandate makes no sense, ultimately causes wasteful expenditures, is a disincentive to accumulate equity and therefore stymies self-determination. As in other areas, a home ownership strategy will require affirmative action and a commitment to develop the capacities within our communities. It requires a commitment to assist individuals and families to use existing as well as newly-developed opportunities.

Give priority to the use and adaptation (if necessary) 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 recognize that some people may wish to rent. Our strategy for the new community must ensure that individuals have financial access to rental housing and that accessible units are available within the rental housing stock. Housing can be considered available when people can live where they want, when they want, at a price they can afford, and in a unit which has physical access.

As well as education and housing, we must 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 envelopes 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**

- Physical accessibility
- Transportation - the final frontier

Over the last few decades, we have made considerable advances in making our communities physically accessible to all people. Unfortunately, though our contemporary standards of accessibility do not work. Why? First, existing standards are not designed to meet the needs of people with more significant disabilities. Second, existing standards are not routinely and systematically enforced.

Existing standards are often stated in terms which meet some arbitrary standard condition -- for example the slope of wheelchair ramps assumes wheelchairs of standard dimensions powered by individuals of a given level of strength. The fact is, wheelchairs can be electrically powered and of considerable weight and people who use wheelchairs have quite different levels of strength. 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. This will include the wide applicability to citizens in all kinds of situations, and does not tolerate practices which make places inaccessible. For example, public attitude will not tolerate wide scale negligence in such critical areas as elevator safety. It follows then that we must develop the same level of intolerance when our communities are not safe for our fellow citizens with disabilities.

The success of our efforts in this area will depend on focused training for architects, business people, public officials, and inspectors. It may also require the development of enforcement and review agencies far more effective than existing ones.

We believe that transportation is the final frontier. While physical accessibility is often seen in terms of access to buildings, transportation is also a dimension of accessibility. For people with mobility problems, transportation is a critical issue, if not the most critical. 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.

In areas where there is no effective, efficient, affordable and accessible public transportation (rural or urban), the transportation system supportive of inclusion must rely on personal means. Public and private sector partnerships, for instance, could create a fleet of vehicles which individuals could lease for short and long periods of time. One component of the fleet could be the existing accessible vehicles already funded by public dollars. Such a fleet could be managed by a transportation authority, or through an extensive network of car/truck leasing agents already dispersed throughout each state. Individuals may wish to own their own vehicles and trade or barter with others to use them when they wish.

To make such a system possible, automobile insurance practices will have to change. Today, insurance is discriminatory if one does not drive one's own vehicle and relies on a personal care attendant to drive. Similarly, families whose children have disabilities must often pay very high premiums on their personal vehicles.

## **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.

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## Chapter 7 A NEW WAY OF LOOKING AT SUPPORTS

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*"The process asks much of us. The initial focus is on us, not on changing the other person. However, as we begin to change and draw more closely to the marginalized people, our task is to bring others along to form circles of friends and change reality."*

-- John McGee

Beyond Gentle Teaching, 1992

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There are a range of topics that need delineation within our new community. By taking responsibility for themselves and their budgets, people with disabilities must also recognize that others are also important in the process of decision-making. They must know that there are basic freedoms that must be made available to them in order to achieve true self determination.

### 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. This results in fiscal co-dependency which is a major barrier to self-determination. Individual budgets allow for free movement and free association.

The entire foundation for traditional rate setting is grounded in the congregation of persons with disabilities, in determining "average" agency costs and in allocating the amount thus determined with the full expectation that all the dollars will be spent.

We know also that surrounding individuals only with paid staff is the most effective way to cut individuals off from family, friends and community. For those who have been in the system for a long time, many do not have family and many do not have a single, true, unpaid friend in their lives. As we realize the enormity of what we have done, we need also to recognize the value of current paid staff and agencies. With some certainty we can predict that the possibility of freely given relationships will, at least for the time being, more likely come from the pool of current and past paid staff. We have to

recognize the important commitment that existing staff and agencies have to individuals currently being supported. At the same time we must redouble our efforts to introduce individuals to regular community members and organizations.

For young persons living at home we need to see the family as the major decision makers and accord them the same rights to family self-determination. As their children grow older, authority and power should shift to the person served with the assistance of family and friends.

We need to keep several principles in mind as individual budget are developed to support self determination:

## **The necessity for dreaming first**

A coherent futures -plan for each individual should be constructed. This does not mean that everything must be immediately attainable. For many individuals, especially those currently without friends, this process may take years. Real futures -plans are never ending and always evolving.

## **View dollars as an investment not a lifetime public commitment**

In the past we essentially treated people with disabilities as commodities -- bought and sold within the scope of congregate budgets which have been set through "rates" negotiated with agencies. Now, individuals will gain control over their own destinies. They will get to choose who will provide a particular support they may need. In the past we thought of these individuals who provided these "supports" as providing "supervision" or "coverage".

Today, we see "direct care staff" as instruments to connect folks with other community members. To the extent that a person with a disability needs to have another person present for some or all of the day or evening, this becomes a form of companionship -- not supervision -- a method of ensuring a growing connection with unpaid community members where the possibility of real relationships is present. This leads us to the central connection between money and community:

We have allowed public dollars to be used to create an artificial barrier between a person with a disability and the wider community. Public dollars have unwittingly become an instrument of isolation.

This does not mean that public dollars are unnecessary. It does mean that to the extent a person's life is totally surrounded by paid staff, we have failed. The encouragement of informal supports impacts directly on cost. The reason or motivation for moving to more cost effective individually controlled plans is not to save money! It so happens that full and rich lives suffused with friendships and relationships is extremely cost efficient in many cases.

Another way to think about money has to do with brokering for supports. Persons with many relationships are finally going to have the choice to live, for example, with another freely chosen individual. In the past we have "paid" individuals to do this. Under the new paradigm the person and his/her circle would negotiate with a potential life sharing individual to pay only for the supports that individual needs. This may involve reimbursing a person for health insurance or providing enough dollars to hire someone to provide the extra assistance a person may require. Some individuals and families may request some cash support and reject being part of the human service system. This choice, too, should be respected.

One of the ways individual budgets can be used effectively is by breaking out certain sums of money for one time only "purchases". For example, it is more efficient economically to pay a one time commission of several hundred dollars to assist someone in securing a job and then negotiating directly with an employer for support and job training. Annual expenses can become one time investments.

The entire "system" becomes reorganized to support individual budgets and choice. The human service structure needs to be immediately responsive to individual plans and unique needs. When individual budgets are finalized and are less than what is currently budgeted, some of the difference needs to be set aside as an insurance policy (perhaps 50% to start). Some of these dollars may need to be assigned to other individuals or to someone on the "waiting list". A "pool" of dollars needs always to be available for emergencies, life changes and new investment opportunities. The money negotiated for one person should be seen as an investment for that year and not as a lump sum perpetually available. Each year, or more often as needs and dreams change, individual budgets may also change.

## **Families**

What follows is a passage from Chapter 255 of the 1989 Laws of the of State of New Hampshire, which clearly articulates the commitment this state has made to families with a son or daughter with a disability. By endorsing and actively supporting these principles, we demonstrate a commitment to monitor all legislative mandates for a new vision, a new community. The General Court, in recognition of the findings of the New Hampshire legislative task force to study family support needs, accepts the following principles relative to supporting families who have children with disabilities:

- (a) All children regardless of disability, belong with families.
- (b) Families must receive the support necessary to care for their children at home.
- (c) Family support must focus on the entire family.
- (d) Family support must be sensitive to the unique needs and strengths of individual families.
- (e) Family support must build on existing social networks and natural sources of support.
- (f) Families must have access to appropriate services and needs.
- (g) Family support is needed throughout the lifespan of the individual who is disabled.
- (h) Family support must encourage the integration of people with disabilities into the community.

## **Family-Centered Early Intervention**

A system of family-centered early intervention is fairly complete within the state of New Hampshire and in other states. With a statewide family-centered early intervention network in place, families can be assured of support. However, our vision for a new community recognizes the need to eliminate the needless and often harmful waiting time for services and supports that families experience. We hope that the investment this country is making with Federal and state support will eliminate these obstacles. Our set of outcomes for family-centered early intervention includes meeting the following goals:

Families of at-risk youngsters and those with special needs choose and are connected with the services

and supports they need to function on a day-to-day basis. Families do not have to settle for inadequate or unnecessary supports because that is all that is available. If a particular service or support does not exist, we will have the capacity and flexibility to develop it.

In recognition of the uniqueness and strength of each family, discretionary funds can be accessed by families to cover unusual expenses related to providing a nurturing homelife for their sons and daughters who are at-risk or have special needs. Use of these funds is not abused because they are allocated as part of the state and Federally mandated Individual Family Service Plan developed with each family.

Families of infants and toddlers who are at risk or who have special needs are connected to and support each other through an expanding Parent-to Parent network. More experienced parents help less experienced parents negotiate the trials and tribulations of child-rearing. Siblings are connected with each other and supported on a long-term basis. Support is available to families when they need it during a crisis as well as on an on-going basis.

Parents receive training in effective child-rearing practices and obtain specialized information on meeting the unique medical, developmental, or other needs of their child. Child care is available so parents can attend training sessions out of their home. A strong outreach program assures that parents who can't or won't attend training sessions still receive the information they need.

Families that need child care or choose group learning settings for their infants and toddlers use the same high quality programs available to all youngsters in their communities. These generic infant, toddler and preschool programs are attitudinally, programatically, and physically accessible to all youngsters. Tuition will be subsidized for families in need.

Generic early childhood service providers such as day care centers and nursery schools welcome all. Staff members celebrate diversity, are committed to providing individualized services, and have the skills to make the early intervention experience positive and productive. The early intervention specialists will collaborate with these staffs and provide the expertise necessary to support children with needs for more specialized or intensive support.

In these generic early intervention programs, at-risk infants and toddlers and those with identified disabilities learn side-by-side with their non-disabled peers. Because they have typical role models, at-risk infants and toddlers and those with disabilities reach developmental milestones more rapidly and benefit greatly from the language, social, and motor stimulation. Because of this early intervention, the children and their families have the natural supports they need and are less dependent on specialized services as they grow older.

There is no wait list. As soon as it is clear that a child may benefit from family-centered early intervention, a service coordinator will be assigned to assist the family to determine what the child and family need and develop and implement an Individual Family Service Plan. Every child who would benefit from early intervention services will have immediate access to the full configuration of supports needed to maximize that child's development and reduce dependency on publicly funded services.

Related services such as physical, occupational, and speech and language therapies are available to all children who need them. Consistent with best professional practices, these services are integrated with other aspects of the children's lives.

School districts will work cooperatively with those providing family-centered early intervention

supports, and be prepared to continue appropriate interventions and provide ongoing supports to children who are at risk or who have a disability. This will include collaborating with families when these children reach the age at which they are eligible for services through the public school system. There are no breaks in service and smooth transitions occur between children's placement in early childhood settings and their entrance into regular nursery school and kindergarten. Family support staff remain involved with families to support them and advocate on their behalf as they negotiate the public school system.

Necessary purchases of supports or goods are made by the family through allocations from early intervention and family support appropriations.

## The School Years

A fully inclusive educational system must be a given, with all children preparing for adulthood in the same environment -- neighborhood schools. Our new community ensures that all children with disabilities will participate in normal school and community activities as they, like all children, prepare for life as a contributing adult in a democracy.

By supporting families in securing their children's dreams (as well as supporting the families' dreams) we assure ongoing support and technical assistance to families, assist them in understanding the special education statutes and regulations, provide for respite and other forms of support. Within this community no child will be sent "out- of- region or state" to live or be educated because of a disability. As children age, we envision they will receive the experiences necessary to obtain employment or continue their education and continue as productive members of their communities.

We will work to change the definition of special education to mean a system of supports to regular education teachers. All students will attend classes with their non-disabled peers and all students will benefit from the presence of students previously relegated to segregated classrooms or schools. Children with disabilities will grow up in their natural or surrogate families, attending school with other children in their neighborhood, and socializing with their peers. A major goal of this vision, this revolution, is to end the notion of producing "clients of an adult human service system." Rather, our goal is to work with children, their families and their school districts to assist children and adolescents in becoming fully functioning adults with only the necessary supports provided -- supports determined by the individual and his/her family.

## Adult Life

In this vision of community, adults with disabilities will function as autonomously as possible. Case management will become a form of personal agency or advocacy. Residential "services" will become personally-controlled living arrangements. Day "programs" will be individually designed and rely on the notion of work and pay as the mainstay of the day. Employers will become more valued and be able to choose the method of support that best meets their needs as well as the individual's needs.

All living situations will be voluntary. No one will be "placed" with others. And in times when the wishes of an individual with a disability conflict with the wishes of their parents, other responsible family members, friends or guardians, careful, respectful and considerate discussions will be held to reach an accommodation that neither destroys relationships, violates individual rights, nor diminishes individual dreams and hopes for a self-determined future. All parties will willingly accept their

individual responsibilities and support the agreed upon outcomes. It is at this juncture that rights versus responsibilities and the dignity of risk will be the focus of everyone's attention.

"Our challenge is to enable ourselves and others to enter a culture of life, a process that increasingly brings meaning to the human condition, instills hope, and establishes a process toward companionship. Unconditional valuing is the central dimension of this. Our essential role is to express to each person his or her dignity and worth by entering into a relationship based on dialogue .... because we see our own human condition in their alienation and in their longing for justice and companionship."

-- John McGee

Beyond Gentle Teaching, 1992