

# COMMON Sense

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## Self-Determination: *From New Initiative to Business as Usual*

Charles Moseley, Director  
National Program Office on Self-Determination  
April, 2001

This is an interesting time for the National Program on Self-Determination. The grants from the Robert Wood Johnson Foundation that supported the state system change initiatives will draw to a close in the next couple of months. Many states have earmarked funding to keep the initiative going or, in several cases, to expand it. This is a good time to take stock of what has been accomplished over the past few years and to reflect on our efforts to move the concepts of self-determination from the status of

“new initiative” to that of “business as usual.” Actually, that is probably not the right term. I think

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that what many of us are worried about these days is that what has been called self-determination will slip down the slope of innovation into the tangle of business as it is currently conducted – state driven and provider controlled.

It is clear that significant progress has been made. It is also clear that our efforts to change

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**Self-Determination, continued from page 1**

the way supports are offered to people with disabilities continue to face a number of very serious challenges. The shift to a self-directed system of supports requires a broad-based commitment and bureaucratic flexibility that is as unique as it is difficult to implement. In contrast to the changes we have put our system through in the past, self-determination does not involve a straightforward transition from one type of service model to another, institution to group home, day activity program to workshop, for example. Self-determination is not a type of service, but an approach to structuring the way supports are made available to the people who need them. It rests on the recognition that people with disabilities should not be forced to give up their basic civil rights in order to obtain support. Although there are several structural elements that are associated with successful self-determination initiatives, it has become very clear that the end result - individual control - is as much a function of the process a state uses to change its system and its values regarding people with disabilities as the nature of the individual components that are put into place. The reason for this is that self-determination requires changes in the fundamental building blocks of the system itself. Regardless of where a state starts in the process, when the authority for controlling and managing funds is shifted to the people receiving support, the state very soon finds itself in the position of changing several key aspects of its service system, including:

- ★ The relationship between the individual receiving support and the state with respect to the development of individual and state budgets, strategic planning and policy direction, quality assessment and provider certification.
- ★ The role of state government in the process of fund allocation.
- ★ The relationship the state has with self-advocacy groups, provider agencies, people receiving support, families and schools.
- ★ The process of allocating and accounting for funds provided for supports.
- ★ The roles and responsibilities of staff of state, provider and generic support organizations.
- ★ The process of program, support and service evaluation.

- ★ The structure and functioning of the Medicaid program.

**Defining Self-Determination**

It is through the process of change, working individually in each state, that a common understanding of the definition of self-determination develops. As changes are made in existing funding structures, personnel practices and power relationships, people associated with the disability system in each state, county or individual community learn the extent to which the basic principles of freedom, authority, support, responsibility and empowerment are seen as fundamental concepts that are integral to the operation of the system. For example, although virtually all of the RWJ project states ascribe to the notion that certain programmatic elements are central to self-determination (individual budget, control over decision making, person-centered planning, independent support brokerage and fiscal intermediary), there are considerable differences from one state to another regarding the extent to which each of these elements is actually implemented. Each state has a slightly different operational definition of self-determination. The following examples reveal the extent of some of the differences between states:

In one state to be considered to be living a "self-determined life" an individual must:

- ★ have an individual budget,
- ★ control *all* of the supports he or she receives and
- ★ receive funding through a fiscal intermediary.

A second state, by contrast, considers someone to be "self-determining" if he or she:

- ★ has an individual budget,
- ★ actively manages the budget,
- ★ controls *some* or *all* of the supports received,
- ★ receives the assistance of a support broker employed by themselves as the employer of record, or by a service providing agency, and
- ★ receives funding through a fiscal intermediary, or an agency/governmental entity that *does not* provide services, or an agency/governmental entity that *does* provide services.

A third state views the question of whether a person is living a self-determined life to be primarily a subjective decision of the individual and as such may vary from one person to another. In this state the majority of the people receiving support have had an individual budget for a long time. A person is considered to be "self-determining" if he or she:

- ★ controls *all* or *some* of the decisions regarding the supports received (whether or not the individual has an individual budget),
- ★ receives assistance from a support broker *employed by the state* (which does not provide services) or by the *individual*, and
- ★ has a plan of care that is funded through an independent fiscal intermediary or through an agency that does not provide services.

A fourth state considers a person to be "self-determining" if he or she:

- ★ has an individual budget,
- ★ actively manages his or her individual budget,
- ★ has a support broker that he or she hires and supervises, and
- ★ receives funding through a fiscal intermediary.

The variability between operational definitions raises several questions. For example, can a person be considered to be "self-determining" if he or she has authority over the budget but chooses to give the responsibility for managing it to another? Can a person be considered to be in charge of his or her supports if the support broker works for the service provider? Can people be thought of as directing their own services if they want to control some but not all of the people who come into their lives? There are, of course, countless variations and possibilities that an individual might choose within the context of self-determination. The challenge is to design a system that is capable of tolerating a wide array of changing support options. While most of the variations between states appear to reflect a system in transition, rather than a watering down of the concept of individual control, some do represent a compromise in the basic principles of the approach itself.

## Choice and Control

Last year, I attended a compelling conference put on by a state to mark the progress people had made in their efforts to incorporate the principles of self-determination into the system at large. The title of the gathering was, "With Choices, Life Changes," and presentations highlighted the power of individually controlled supports, the importance of family involvement and the impact of flexible funding alternatives. People involved in self-determination from neighboring states brought examples of new approaches they were using to enable individuals to control the decisions that affect their lives.

The presentations demonstrated that self-determination is more than just an expansion of the choices available, but the title of the conference has stuck with me as a constant reminder that the goal of this effort is not to create a broadened menu of set service alternatives, but rather to stimulate, by shifting control to the individual, the ongoing development of new options for support that are defined by the consumer. The goal is to enable individuals to decide the role that support providers will play in their lives; to move from the position of *participant* in a planning process to that of *director* of the plan. Choice is a given, a non-negotiable means to enable a person to achieve independence and control, but it is not an end to itself. The criteria for self-determination is not met by a person "choosing" to live in an institution or "choosing" to live in situations that place him or her at risk, or that do not meet basic standards for health and safety.

The process of changing the service delivery system to incorporate principles of self-determination is threatened on two sides. The first being the tendency in times of system change to expand the operational definition of the objective, self-direction in this case, to incorporate an increasingly large set of support alternatives, broadening to the point that the concept is rendered functionally meaningless. The second threat is the situation that occurs when the process of system change ends before reaching its goal; when activities become stuck along the path to self-determination, as people settle for expanded

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**Self-Determination**, *continued from page 3*

choice rather than control, for a recognition that conflicts of interest exist, rather than removing the conflicts directly, and for increasing involvement of people with disabilities, but withholding from them the power to decide issues. I talked to a person in state government a few months ago who wanted the self-determination project to succeed, but expressed concern that the initiative would never get out of the development phase. He said, "Its good, but so far with many of the people so many compromises have had to be made in the process, I wonder if we will be able to achieve it in the long run." A person receiving support added these comments, "To be honest, I would tell them that if they are going to do this (self-determination) they had better be ready for the long haul, because it will be a struggle. Its not like, boom, its done."

**Self-Advocacy**

Self-determination is based on the presumption that everyone in society is equally valuable and that people with disabilities have a right to enjoy the same freedom and opportunities for participation as other community members. The new initiatives have strengthened the efforts of people receiving support to organize and assume more controlling and influential roles in the development of policy at the local and state levels. In virtually all of the project states, significant increases are occurring in the involvement of individuals with disabilities on governing boards, advisory committees and quality assessment teams. People receiving services are taking a more active part in the decisions that are being made at all levels, and are making their message clear:

- ★ People want jobs and the respect that comes with being a contributing member of society.
- ★ People want transportation, but they want to be the ones who decide where to go.
- ★ People want to spend time with others, but they want to choose their own friends, their own room-mates.
- ★ Families want help. But they don't want someone else telling them what to do, or what they are able to do, especially in their own homes.

- ★ People want support, assistance, training and someone to be there when they need them. They do not want to be controlled, judged, managed, or abandoned.
- ★ People want and expect their perspective to be included in the decisions that are made regarding the supports they receive.

Individuals receiving support are speaking out as they take a more active role in decision-making. Last summer I met with a small group of self advocates and some of the staff who give them support to talk about how things are different when they choose the services they want and control the how the dollars are spent. The question went around the room with each person describing how he or she redirected the direction of support s/he was receiving. Jeff said he was planning to purchase a computer and hoped to find a job he could do at home. Ted was working with the people he lived with to acquire a van to enable him to go out more. Ann wanted to open her own business. When it became his turn, Charlie, who had been sitting quietly through everyone's comments, announced with a broad grin, "I'm in control. I didn't like what my case manager was doing and I fired her. I got a new one now and things are running just fine." He pointed to his new broker sitting nearby. Charlie was clearly delighted with his decision and expressed annoyance that his original service provider refused to change the package of supports he was originally offered.

But not everyone has experienced the success they hoped for. At a recent meeting I attended of self-advocates from states across the country, people acknowledged that progress had been made, but felt that there was still a long way to go. The system is not yet at a place where those receiving support are actively and substantively involved in key decisions regarding supports. After some discussion the comments of one self-advocate seemed to sum up the opinions of the others: "in my state we do have more choice, but not really more control."

Over the past several years self-advocacy groups have struggled to the secure funding necessary to organize and conduct business. Some states, provid-

ers and developmental disability advocacy organizations have declined to offer financial support, citing fears that the funding would compromise the group's independence. While one can applaud the values upon which the sentiment is based, this concern has not prevented states from allowing providers to include the membership costs of their professional associations as legitimate Medicaid reimbursable business expenses. Nor has it prevented states and agencies from providing grants to parent groups and advocacy organizations for training, public awareness, and other activities in order to keep them viable and involved in the system. People with disabilities need to be afforded the same respect, access and economic support that is routinely made available to other groups.

### **What Has Changed?**

The process of change does not travel in a straight line. Rather, it consists of a growing pattern of successes informed by the failures that occur along the way. In this context, it is important to identify the victories as well as the battles. The picture of self-determination varies with each state and organization. Some have moved ahead rapidly, others have taken a more cautious approach. About half of the project states, including New Hampshire, Utah, Vermont, Michigan, and Maryland, introduced self-determination as a part of a system-wide restructuring effort, while others, Massachusetts, Oregon, Wisconsin, and Ohio, for example, are evaluating different approaches through pilot programs. Change is taking place at different levels and in different forms, depending on the state and the organization.

- ★ Systems are being restructured to promote flexibility, choice of providers, and independent support brokerage.
- ★ Funding is being targeted directly to individuals, enabling people to select the provider of their choice or hire their own support staff, bypassing the existing system altogether.
- ★ Medicaid waivers are being rewritten to increase flexibility and support the development of individual budgets.

- ★ Fiscal intermediary organizations are being developed to increase the capacity of systems to support individuals who wish to hire their own staff, and to address the administrative, tax and liability issues that can place organizations at risk.
- ★ The Health Care Financing Administration is providing support to states that are interested in expanding consumer-directed service alternatives. The system change grants recently announced by HCFA are a \$70 million commitment to the further development of individually controlled community supports.

It is also important to note the progress that is being made in the development of opportunities for self-direction of services in the aging and physical disability communities. Through the "Cash and Counseling" and "Independent Choices" initiatives, for example, individuals are accessing cash to pay for the supports they need through their state's Medicaid 1115 Model Demonstration waiver. In addition, people with physical disabilities have gained considerable experience with consumer-direction over the past several years through the Participant-Directed Attendant Care programs in the various states. It would clearly be in the best interests of everyone if the knowledge gained from these different efforts could be brought together for the purpose of identifying key common factors that are present in successful programs.

### **Provider Involvement**

One of the exciting things we have seen is the actions of service providers who have embraced self-determination as an opportunity to restructure the way they do business. Many organizational leaders see this approach as a credible alternative to the traditional structures they have had to stretch over the years in order to provide the kind of supports people request. Administrators and direct support staff alike have observed that self-determination offers them the opportunity to accomplish the goals that originally brought them into the field. I recently spoke with the executive director of a large agency in a metropolitan state who put it this way: "Over the past ten years I

**Self-Determination**, *continued from page 5*

have built the agency up, developed workshops and ICFs, and opened more programs to serve people because I thought that that was the right thing to do. Now, I am not so sure. I think it might be time for a change. I have about ten years to go before I retire and I am thinking that it might be time to take it apart, to set up a more enduring, flexible system of support for people."

But taking it all apart and putting it back together is no easy matter. Another director I spoke with from a large agency in the mid-west tempered his enthusiasm for self-determination with the necessity of dealing with existing bricks and mortar. "I would jump into it (self-determination) in a second," he said, "if I wasn't worried I would loose my shirt in the process." While some resistance to system change is natural and expected, it needs to be recognized that effective transition involves a careful analysis of the mechanisms by which current programs and individuals are financed with an eye to the structure planned for the future. Over the past several years states actively supported service providers to develop new programs, many times guaranteeing the costs of construction and program development, underwriting mortgages, floating bonds to secure funding and obligating dollars to organizations for extended periods of time. Changing the infrastructure to a network of community-based support options requires the same commitment from states that accompanied the deinstitutionalization efforts over the past decade.

### **The Challenge**

Today's challenge is over how we will carry self-determination forward and how effectively states will apply what has been learned in the demonstration projects to the existing system. When pilot projects fail to have a lasting impact it is because the traditional system has not been able to incorporate the new ideas, concepts and innovations that were successful in the demonstration (Schorr, 1999). What happens is that the system just keeps on rolling. Critical policy barriers are not addressed and the ideas of the pilot become co-opted, redefined and recast into the terms and procedures of traditional service system.

Successful incorporation of the principles of self-determination into a system requires a comprehensive reassessment of the purpose and goals of services, of the structure and practice of support delivery and of the roles and responsibilities of the stakeholders. It cannot be achieved by a technical fix, although changing the way we do business is a part of it. It will not happen where people have the attitude that tinkering with the waiver or developing a fiscal intermediary alone is all that needs to take place. It is crucial that strong leadership be provided at this time to the projects to ensure that the important lessons learned over the past five years are extended into the system at large. In fact, a characteristic of projects that are effectively making a difference in people's lives is the presence of clear direction. Where system change is successful, the evidence of positive leadership is conspicuous and extends to all levels. In state offices, provider agencies and local communities where people are controlling their support systems the level of commitment is clear, and extends in a bright line from the central office in state government to an individual's circle of support. The attitudes are the same, the mission is the same and the language is the same.

It has been said that the test of leadership is the ability to enable a group to address its worst fears. As I mentioned above, many fear that the momentum that has kept states moving forward toward "consumer" control of services will slow as system leaders turn their efforts to address other emerging issues. The challenge that confronts us is the need to stay focused on the hard components of system change.

A system designed to foster self-determination must be able to support an individual in a manner that does not compromise his or her ability to freely chose among different alternatives. Support brokers need to be independent of service provision and able to act solely on behalf of the individual without any conflict of interest. A survey of projects conducted last summer revealed that although virtually all of the states offer people the option of selecting their own support broker, the vast majority of brokers still work for provider agencies, county or state governments. Approaches to the evaluation of the quality and appropriateness of supports received must reconcile

the need to respect individual autonomy with Medicaid requirements to assure health and welfare. States should fund the development of sound, non-traditional alternatives for individual support, employment and community living including purchasing alliances, consumer-run organizations, and (non-Medicaid) cash payment systems. Finally, self-determination must be

an alternative that is open to people with even the most intensive need for support. We can't afford to leave anyone behind. ■

Schorr, L. (1997). *Common Purpose: Strengthening Families and Neighborhoods to Rebuild America*. New York: Anchor Books.

## Thoughts on Self-Determination

by Judith Snow

I was searching on the Internet the other day and I found that the phrase 'self-determination' brought up a large number of articles on political sovereignty for colonized nations and for aboriginal groups. This got me thinking again about the way we use these words when we talk about and plan for people who are labeled 'disabled'.

Most groups in the world gained their distinctive identity because they have a definite geographical or ecological boundary, or because they share a culture. In my country, Canada, there are aboriginal groups who descend from people who lived as prairie hunters or woodland gatherers or tundra dwellers. Today they are fighting for their sovereignty—their right to decide for themselves how to use their own resources, solve their own problems and conduct their own business, education and government. Also, the people who are descendants of settlers from France are also fighting for their self-determination in Canada—their sovereignty. They have remained a distinct group in the broader Canadian population because their language is still strong and vital, able to be used in everyday affairs of business and politics. French speaking people live mostly in the province of Quebec, so this group also has a geographic location and definition.

Are people who have been classified as disabled such a group? I don't think so. Rather than being

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naturally a separate group, we acquire our 'disability' identity, everywhere among people. We share every geography, ecology, language and culture with all human beings.

The term 'self-determination' is used in a different way when we think of people who are labeled disabled. For us, self-determination is defined—not as sovereignty—but as Freedom, Authority, Support and Responsibility. Advocates of self-determination for people who are called disabled view these principles as the

cornerstones that are required for a person to live a life of full participation in society.

Ever since I first heard the words 'self-determination' used in relationship to people who are considered disabled I have not liked this term. Don't get me wrong. I work everyday to help make it possible for everyone to live in their own communities, choose their own homes and lifestyles, receive good incomes, be respected, have friends and loved ones, and make the contributions they want to through employment or in other ways that make sense to them.

It's just that people who have great lives are not independent and not self-determined—no matter whether they are labeled able or disabled. All human life is made possible through relationship. Everything

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we know, everything we choose, everything we learn or do is in some way connected to other human beings. It is not more distinctions that lead to vibrant lives of contribution, it is a better quality of relationship and cooperation. Independence does not lead to sovereignty in one's own life—the right sort of relationship does!

The more powerful and fulfilled a person is, the better the quality of her or his relationships with other people. Powerful people influence and are influenced by thousands of other people. People listen to them and respect them—they themselves also listen to and respect many others. People who are fulfilled make choices based on knowledge and support garnered in a vast array of relationships—personal and public, paid and unpaid, intimate and casual.

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In other words, a good way to stay poor, isolated and unable to have a fulfilling life is to keep trying to be independent!

'Disability' is really a lie. 'Disability' is the idea that some people, because their bodies or minds or emotions function in ways that are unusual, are somehow unable to live fully as human

beings. The truth is that every human being has some ordinary ways of being and some unusual ways. Everyone suffers sometimes and has burdens and sometimes burdens others. Everyone also has times of joy, sometimes gives something to someone else, and has the possibility of creating opportunity for others in the world. Paradoxically the most common thing about people is that everyone has unique ways of being himself or herself.

In our world the disability label is used as a way to set people apart from society. In other words, 'disability' is a term used as an excuse to deny us the sort of relationships and cooperation that would allow us to take our full place alongside other citizens in a diverse community.

There really is no lack of money or resources. And although there is always room for learning better ways to support people, we really do know basically how to include everyone together in one world. The question is: "Will we?"

The question: "Will we?" is not a question of personal independence and self-determination. It is a question of relationship and politics. We are all citizens, regardless of ability. How are people who are called disabled going to take their full place in the world? We all need to take a part in answering this question.

A mistaken sense that self-determination is the concern of one individual has often led to more of the same old thing. Those





who don't understand or want full participation everywhere can easily dress up segregation and oppression as choice. Too often, for example, a person is offered a 'choice' between a group home, isolated living in an agency-owned apartment or living as a paying guest in someone else's family. Choosing between options that are designed to keep you small is not real citizenship, whether or not it is self-determination.

Advocates, family members and those of us who are labeled 'disabled' must seek a deeper vision. We are human and society must reflect our human reality as much as it reflects the human reality of those who imagine their abilities are perfect and permanent. We must imagine a society where our unique and our ordinary

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contributions are opportunities for everyone and where we fundamentally belong. Such a society is the birthright of all people.

In the long run perhaps it doesn't really matter whether advocates continue to use words such as 'independent' and 'self-

determination'. What matters, I believe, is that we continue to spread the vision that all abilities are needed in community to make the world complete and whole. Let us continue to work to make this vision real. ■

*Judith Snow, MA., is a social inventor and an advocate for inclusion—communities that welcome participation from a wide diversity of people. She is a founding member of the Centre for Integrated Education and Community. She consults and presents workshops about personal assistance, support circle building, family support and inclusive education. Her goal is to foster understanding about how people with disabilities can fully participate in communities everywhere. Judith does this work out of a background of being labeled disabled herself.*

## Remembering Natalie – *Some Things I Learned Along the Way*

by Brian Salisbury

I vividly recall the day in 1986 when I was called in to my employer's office and told that the (then) ministry for Human Resources had asked our agency to plan for living arrangements on behalf of Natalie Vetter. This 12-year-old girl, who I came to know as Nat, had some very complex medical needs due to a degenerative neurological disorder and was

living temporarily in a Children's Health Care Center. Her family was anxious for her to live in the community with the supports she needed, and through some very effective advocacy, had obtained a commitment from the government to provide her with the resources and supports to do just that. What the government didn't know was 'how' this might be accomplished.

For this reason, (and unbeknownst to the family) the government had approached our agency make the plans. Thus began a lengthy working relationship with Nat and her family that had a profound impact on my development as a broker.

I would be dishonest if I didn't say that I thought I knew every-

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thing there was to know about being a broker. After all, I'd worked in this role for more than a year and assisted numerous people to move from a large provincial institution to their own homes in the community! I realize now how mistaken I was - I had a great deal to learn. Indeed, the important lessons I would learn over my next 10



**Natalie Vetter**

years as a broker would be because of my work with Nat. This was due in large part to the fact that Nat's disability, and her changing needs, required me to constantly think in creative ways to identify new ways to support her.

So, what did I learn from Nat on my journey? For a start, that everyone can communicate their dreams and preferences, regardless of the nature or extent of their disability, if only we take the time to truly observe and listen. Also, having an involved network of family and friends is vital. They are there for the long haul, unlike professionals who come and go. Family and friends can play many roles in enabling the person to achieve the quality of life they desire, and in this regard Nat's network certainly worked with me in ways that helped me do my job more effectively.

Nat helped me understand that brokers cannot be decision-makers. Yes, people may need help to put their plan together and to negotiate for funding, but they *must* be free to determine the extent of this assistance. I learned that I could provide quality information and advice, laying the foundation for effective decision-making. And while I could also play a role in helping them understand the ramifications of their decisions, it was ultimately for Nat and her family to decide the road they would travel. This is a lesson I am truly thankful I learned—far too many professionals don't understand what the true helping relationship is supposed to be about.

I learned that without autonomy from the government (funder) and providers, my best efforts to assist them to locate, arrange, and use community services and supports would be compromised. And because Nat controlled the funding to pay for my services, she and her family always called the shots. Without this, my accountability to them would have been token at best. Having funding meant that Nat could access brokerage-planning support when she needed it, for example when her circumstances changed due to deteriorating health, and not because I decided it was time for a change in her life. Nat and her family determined the kinds of professional roles and activities I engaged in, and because I worked for them, I was free to cross all system and organizational boundaries on their behalf to find the best possible ways to meet Nat's needs. I also learned that while good planning can anticipate crises, problems will invariably occur, and the broker must be both informed and available to help everyone to respond in creative ways.

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There were some harder lessons as well. I discovered it was okay to say "I don't know," even though my social work training had subtly, yet nonetheless reinforced the idea that I was somehow the knowledgeable 'expert'. I also learned that if I was to have Nat and her family's confidence, I needed to fully represent their views or the decisions they had made when I was at meetings on their behalf. No guessing

about what might be acceptable to them . . . no acting in their 'best interests'. Being someone's personal agent means following their instructions - always. Fortunately for me, as I got to know Nat and her family, they came to trust me more and extended a great deal of latitude to me when I dealt with others on their behalf.

Nat taught me that being an effective broker was not about me, my needs or my ego. It was about helping her achieve her hopes and dreams. In fact, I came to appreciate that the most gratifying part of my role was that I could be personally empowered by empowering Nat and her family. Part of this was recognizing that I needed to use my knowledge and

skills to enable Nat and her family to become effective advocates, and over time they actually became more confident and skillful and took on more of the roles associated with planning. For me to have acted as the advocate, or the person in charge of this process, would have been patronizing and disempowering.

Although Nat died almost four years ago due to medical complications, I will always remember her warm smile, her infectious laugh, and especially her flirtatious manner. Nat truly made those around her better people. Nat, you taught me a great deal about what being a good broker really involves. Thank you for that, and for giving me the opportunity to share my experience and lessons with others. ■

## A Service Broker Can Make a Difference

*by Arlene Schouten*

My daughter Natalie was one of the first people in British Columbia with a developmental disability to receive individualized funding, along with planning support from an independent service broker. But before I talk about how that experience impacted Natalie's life, and that of our family, I want to tell you a little bit about her. Natalie was a very loving child and had a great sense of humor. She especially loved to tease and flirt with the men in her life (including her broker!). Like many young girls she attended school and girl guides, and loved listening to music, playing with her cats, and going on outings with family and friends. I also remember Natalie as the only one of 5 children who enjoyed doing both her chores and her homework.

While Natalie was in many ways a typical kid, we also began to notice things that most children don't

experience—deteriorating vision, the development of seizures, difficulty communicating and problems with walking (In fact, by the time she was a young adult,

she had deteriorated further in these areas, including losing the ability to eat and control her basic bodily functions.) Although we knew something was wrong, Natalie was not diagnosed with Batten's disease, a rare degenerative brain disorder, until she was eight. By the age of twelve, the disease

had progressed to the point where she required constant support. Like many families facing similar circumstances, we eventually reached the point where we felt we could no longer provide the care she so desperately needed. A contributing factor to this intolerable situation was the fact that there were few services within our community that supported families

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*Difference, continued on page 12*

*Difference, continued from page 11*

to keep their children at home. Our experience with 'homemaker' support was a disaster—it seemed that the workers were either inflexible or needed constant guidance and supervision from us to do their job, adding stress to our already overwhelmed family.

We began consulting with professionals involved in her life to discuss our options. The social worker could only provide support if my husband and I split up, or if we gave our child up to the system. Neither option was acceptable to us. At the same time, we found out that Sunny Hill Hospital, where she had been receiving respite care, would no longer be available to us to provide this support. The only alternative offered to us was Queen Victoria Hospital for Children, a facility that served children with profound physical and mental disabilities, located on Vancouver Island. We were shocked that this was even considered an appropriate place for Natalie. Not only would our access to her be limited because of distance, but we knew that input by families (like the kind we wanted) was virtually unheard of in a hospital setting.

After sitting down as a family and weighing our options, we decided that desperate measures were needed in order to obtain the services and supports Natalie required. Our family was at the point of burnout, and we knew we couldn't continue to provide the often 24-hour-a-day support at home that Natalie needed. Yet, we

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also knew that whatever supports we were able to access, we wanted to continue to have input about her life and to make key decisions with her, and on her behalf where this was necessary. Following a yearlong battle with the government, aided by extensive media coverage, the government finally relented and promised to help us. That support came in the form of a commitment to individualized funding (money allocated to Natalie based on her strengths and needs), along with planning supports from a broker who worked for the Community Living Society. During the interim, however, we agreed that Natalie would be placed in Sunny Hill Children's Hospital until the broker could work with us to develop a plan

identifying the services and supports that she needed to live safely and happily in her community. So, even as the future began to look brighter, we were forced to accept a compromise that we did not really want to make—putting our daughter in an institutional setting—but unfortunately there were no other options available to us as a family.

Unlike the many social workers we had been involved with (up to this point more than 200 different professionals had been involved in our daughter's life!), the broker spent time getting to know Natalie as an individual, and not just in the hospital setting. He took her for walks, or out for lunch. The broker asked her, and us, important questions such as: What made her happy or sad? What did she like or dislike? What motivated her? What were her dreams and goals? What were her strengths? What sorts of things did Natalie and we as a family value? He also spent many hours getting to know us, Natalie's brothers and sisters, as well as friends and other family members in her home community. This was so important because this knowledge served as the basis for our collective understanding of her true needs and for the support plan that was developed.

I clearly remember the first time I met Natalie's broker at the hospital. The professional team, including the social workers, was in attendance and members were ready to provide him with what they thought was the necessary

documentation and medical assessments. Staff thought that without these reports, no one could plan for such an extremely complex person. As he approached, he simply asked, "Before we start, can I meet Natalie?" A somewhat shocked staff member replied, "Oh, she's in the recreation room, but everyone is in the conference room ready to discuss their assessments and to talk about her placement needs." The broker's response was simply, "Well, I appreciate that, but I think it is very important that I at least meet her before we start." I couldn't believe what I had just heard, this guy was sincere, and he was actually going to visit with Natalie and get to know her. And maybe even us! The broker taught me a very important lesson that day. **Never become overwhelmed by the endless assessments and professional opinions, stay focused on who the person is, and never lose sight of the fact that first and foremost, we are talking about people's lives.**

As the broker began working with Natalie to develop her support plan, it became clear to us that members of our family, along with her friends, for the first time were seen as people with something useful to contribute to the process. What was really different though was that the broker regarded my husband and I as the key people supporting our daughter's decision-making. The broker spoke with us at length about the knowledge that our

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family and network could provide him, based on our years of hands-on experience in which we were both her parents and 'support workers'. He listened to us, and respected us as the key people who had a life long commitment to Natalie because of our love and concern for her well-being. This respect and valuing from the broker gave us moral support and made us stronger advocates. It confirmed the vision we had long held for our daughter—that she was someone with gifts and talents, who had a right to live in the community with dignity and support. Unfortunately, in our experience, professionals had all too often told us that Natalie would never reach the developmental milestones that others kids

did. All this did was undermine our confidence and lead us to question ourselves and the vision we had for Natalie. The broker, however, put us in touch with other families who had gone through similar experiences, and this helped us sort out our own thoughts and feelings, while enabling us to ask others who had used individualized funding and a broker about what we should expect.

During the first few months, the broker began helping us to think about the kinds of services and supports that Natalie needed to live in her community. Unfortunately, although the government had committed to provide individualized funding in Natalie's name, existing policy would not allow the same funding to purchase the in-home staff support Natalie required so she could remain with us at home, nor could it be used to support Natalie to actually buy and live in her own home. Because of this, we were forced to think somewhat differently about where and with whom she would live, and what kind of place that would be. On our behalf, the broker began to meet with potential residential service providers. However, after reviewing what they had to offer to Natalie, it was clear to us that these agencies simply could not respond to her complex and unique needs. Neither did these same agencies really want the degree of family involvement we expected. We refused to 'slot' Natalie into an

*Difference, continued on page 14*

**Difference.** *continued from page 13*

available bed in a 'residential program' and instead decided to try and identify an agency that would work with us to create something entirely new for our daughter that would focus on her as an individual first.

With this decision made, the broker negotiated on our behalf with a service provider in our community to develop a home in which Natalie would be the focus and where she would receive the 24-hour support she needed. We also understood the government would not be willing to pay a high amount of money for one person, so we were prepared to make another major compromise and let Natalie live with one other person. However, because this was such a major decision, we demanded the right to determine who this person would be. With the broker's support, we arranged a meeting between Natalie and another girl who was a few years older who was also trying to find a new home. Fortunately for Natalie, they hit it off immediately and it was eventually decided that the two of them shared enough common interests that they could live together to the benefit of both.

While plans for the new home were being developed, which included purchase and renovations, the broker worked with us to ensure that other needed supports were in place. This included things such as: medical equipment purchases; access to a nursing consultant, occupational therapist and a physiotherapist; a new community doctor, and a protocol

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**As planning unfolded, it became clear to us that a factor contributing to the success of the process was that the broker was independent from both the funding body and service providers.**

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with the local hospital should Natalie need to be admitted because of uncontrolled seizures.

As planning unfolded, it became clear to us that a factor contributing to the success of the process was that the broker was independent from both the funding body and service providers. The broker was accountable to Natalie and our family because we determined the roles and activities he engaged in on our behalf. The broker did not have a conflict of interest when thinking about available options or making recommendations, meaning his focus always stayed on our daughter's needs, rather than thinking about what dollars or programs were available. This independence and accountability proved to be critically important in the work he was able to perform with both the

Ministry of Education and Health concerning the school's policy on the special education assistant's (SEAs) job description. Existing policies meant SEAs were only allowed to work in the classroom and were not allowed to perform certain tasks. By documenting how this was not in Natalie's best interest, the broker persuaded both Ministries (Health was paying funding toward the SEA) to allow the SEA to administer her medications at school, pick her up to bring her to school, and accompany her home, supporting her until staff arrived. The Ministries also agreed that the SEA could work at home with Natalie if she could not attend school for health-related reasons.

Once Natalie's basic supports and the way they would operate were agreed to, the broker finalized the details of the support plan and gave it to us to review and approve. He emphasized the point that this was Natalie's plan, and that it was our right to change anything we were not comfortable with or disagreed with. This was the very first time that a professional made it clear to us that it was our right, on behalf of our daughter, to question anything. While we changed a few things, I remember that the plan was very comprehensive, yet it presented Natalie as a real person. It clearly spelled out what supports were needed and why, and what costs would be involved. The plan included relevant information from trusted professionals like her neurologist who advised staff

about how to deal with seizures. There was even information listing goals and priorities and suggestions about how the plan should be implemented. Finally, the broker helped us draft a letter that spelled out our 'bottom lines' and covered aspects that were most important to us about how services would operate.

Finally, after almost six months of planning, we asked the broker to negotiate with the government for the required funding. This was a surprisingly straightforward process, and due largely to the plan being well-organized and based on Natalie's needs to live a life of quality in the community. Once the budget was agreed to, the broker (again at our request) began to work directly with the services and supports identified in the plan to enable Natalie to move from the Hospital to her new home which was located less than half an hour from where we lived. The only dampener on what was a day of great celebration was that we knew many of the professionals from whom the broker had sought information believed Natalie's 'condition' meant that she would not live very long in the community.

While I've described the initial roles that Natalie's broker played, he was always available at our request to provide information and advice, or the technical assistance that was necessary when Natalie's needs changed (which they did often) and we needed to rethink how to best support her. We could do this since one of the things we

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did in later budgets was negotiate for money in order to purchase brokerage-planning hours. Sometimes our request for assistance involved only information. For example, we often needed current information about the medical services plan, or the availability and cost of equipment. As a small example of how resourceful the broker could be, I remember when Natalie was first diagnosed we received only a short paragraph from the neurologist on Batten's disease, yet the broker was able to quickly acquire many detailed pages for us. On other occasions we also asked the broker to provide training for new workers, or to attend meetings with professional staff when our work schedules would not allow for this. There were also other, more difficult circumstances under which we

accessed the broker's support. On more than one occasion, for example, we asked the broker to play a mediation and problem-solving role because staff resisted our efforts to make what we believed were positive changes in Natalie's life. For the most part, we were able to resolve these difficulties to everyone's mutual satisfaction and for the first few years, at least, the situation in Nat's original home was relatively stable

Following a change in senior leadership, support workers in the agency focused less on Natalie as a person, and more on their role as professionals who had a right to make decisions for her. And even though we worked diligently with our broker to address this issue, we were unsuccessful in getting staff and management to change their attitude and approach with us. Eventually, when we could no longer tolerate the fact that our involvement in Natalie's life was not welcomed, but was in fact being undermined, we asked the broker to identify a new place for Natalie to live. As I mentioned earlier, because Natalie didn't actually own the home, it was she who had to move! But luckily for us, she had developed a very close relationship with a young female support worker who expressed a willingness to leave the agency and support Nat in a basement suite in her home. In our view, the thought of Nat sharing a home with a young couple and their child seemed a good one. We asked the broker to put all of this informa-

*Difference, continued on page 16*

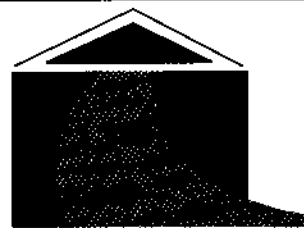
**Difference**, continued from page 15

tion into a new plan and negotiate a new individualized funding contract with the Ministry. Within a month, the plan was approved and Natalie was able to move!

The most difficult phase of our involvement with the broker concerned the last few years of Natalie's life. About two years before Natalie died due to complications associated with Batten's disease, conditions in the basement suite where Natalie was living became so problematic that the entire support network was concerned about her safety. And as was the case previously, an attitude of 'ownership and control' by support staff had developed to the point where we were being treated as intrusive parents when we questioned anything that concerned us. Assisted by the broker, friends and a few professionals we trusted, we literally moved Natalie back home within hours of deciding that this was the right move. By then we knew that our daughter's medical condition was deteriorating significantly, and that she likely had only a year or so to live. You need to understand that by then Natalie had undergone surgery so she could be fed by a G tube in her stomach, and her seizures were often out of control. The broker quickly pulled together a plan that outlined the reasons we wanted her at home, and which clearly identified the costs of the extensive in-home supports Natalie would need. The broker also helped us to locate and negotiate with a service agency that would provide the support staff, but who would let us play a major role in hiring staff, as well as determine how staff would work with our daughter. That plan and budget were approved in fewer than 36 hours because like previous plans, it was based on a true understanding of who Natalie was, what her real needs were, and more importantly, how those needs could be best supported.

It has been four years since Natalie died. Yes, there were many challenges and the process of supporting her was not always easy. However, with the support of her broker, we were able to make sure that everyone involved in our daughter's life respected Natalie's fundamental right to make her own decisions and control her own destiny. Because of this she lived a longer, happier and more fulfilling life. ■

## ADVANCING AFFORDABLE ACCESSIBLE INTEGRATED HOUSING FOR ALL AMERICANS



**CHANCE**

**CENTER FOR HOUSING AND  
NEW COMMUNITY ECONOMICS**

The Institute on Disability at the University of New Hampshire (IOD) is excited to announce the creation of the Center for Housing and New Community Economics (CHANCE).

CHANCE represents an innovative partnership between IOD and ADAPT.

ADAPT and the IOD will collaborate with a broad coalition of people and organizations concerned with housing, economics, personal assistance services, and advocacy, including people with disabilities and families, as well as federal, state, local, and public and private organizations.

CHANCE will:

- ensure that people with disabilities are afforded the opportunity to direct all aspects of their lives, including where they live, how they receive their services and supports, and planning for their economic well being;
- reject mandatory links of housing and personal assistance;
- improve access to integrated, affordable, and accessible housing coordinated with, but separate from, personal assistance and supportive services;
- work toward and advocate for systems change at the local, state, and federal levels, and the collaboration of the public and private sectors;
- encourage the collaboration of the public and private sectors; and
- offer progressive alternatives to approaches that segregate, congregate, and control people with disabilities.

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Web site: [alliance.unh.edu](http://alliance.unh.edu)



# A Virtual Community: *The International E-mail Discussion Group on Self-Determination & Individualized Funding*

by Brian Salisbury and Steve Dowson

Whether you are an advocate on the outside or a leader within services, achieving the transition to a system that truly supports self-determination through individualized funding is hard work. It can also seem a lonely task, even when there is a general willingness to make the move. As real-world complications come up against founding principles, your original vision may start to fade, your certainty weaken. You won't have all the answers that other people expect you to have. Does it matter who pays the service brokers? Can people be the employers of record for their own support staff? Doesn't individualized funding mean uncontrollable spending? Should people be able to spend their funding on anything they want?

Now, thanks to the Internet, you can have access to a community of several hundred people who are driven by the same vision and face the same complications. Here you can get information, advice, sympathy—and occasionally a vigorous but friendly debate. This 'place' is the international e-mail Discussion Group on Self-Determination and Individualized Funding. It was established in 1997 to facilitate discussion on new approaches for allocating public

"The three main elements: Brokerage, individualized funding and personal networks, are intended to work in concert providing a system of checks and balances. This does not however mean that the individual cannot choose to manage their own funds without the broker or their network, simply that the system is in place for them to use if they so choose."

Discussion Group Quote (1997-2001)

money and providing planning assistance designed to enable people with disabilities to exercise greater self-determination.

Initially, discussion was limited because of the small number of participants. However, as more people who were interested in exploring radical system change joined the group, we built the membership to 175 people from North America, Europe, New Zealand and Australia. Although the overall amount of correspondence was generally quite light, there were occasional periods in which a flurry of e-mails was exchanged. For example, an early discussion on the role of unions provoked heated debate, as did

criticism voiced about the effectiveness of self-determination projects funded by the Robert Wood Johnson Foundation to create lasting system change. The suggestion that an individualized funding system should be left to operate like any other consumer market also provoked lively (but still good-humored) exchanges.

In December 2000, this virtual community began a new stage in its life. At the request of Chas Moseley and Jay Klein from the National Program Office on Self-Determination, their four e-mail groups were incorporated into the list that we already moderated. Financial assistance from the National Program Office has ensured that we can sustain our role as moderators for at least another year. Although this merger of two groups of strangers caused some understandable awkwardness at first, it has led to an increase in the number of postings and in the variety of topics.

For readers who are not familiar with e-mail discussion lists, the way they work is simple. If someone on the list sends a message to the e-mail address for the list, it is automatically sent to everyone else on that list. Other people can then choose to send responses in

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**Virtual**, continued from page 17

the same way. The result is like any ordinary round-table discussion, except that it happens more slowly. Some topics cause wide interest, others result in a 'chat' between just three or four people. E-mail discussion groups also develop their own style, conventions and private jokes, but if you subscribe to this list you will not feel as if you've crashed a private party, and in any case you have no obligation to add your 'voice' to the conversation.

There are two topics that are at the heart of the discussion group:

- the different fiscal mechanisms such as individualized funding and direct payments, and their advantages and limitations; and
- the various forms of technical planning support, such as independent service/support brokerage, which people sometimes require in order to identify and meet their community living needs, including managing their supports.

"I think it is absolutely essential, when beginning an undertaking such as brokerage, you start with a VERY clear vision and don't allow the system to rush you into a process. Never underestimate the time needed to consider principles and philosophical foundations. If it's not done prior to the process work beginning, good luck trying to retrieve the initial idea later!"

*Discussion Group Quote (1997-2001)*

"I still find it curious and disturbing how such a simple idea as access to independent (or autonomous) technical/professional planning supports is such a difficult idea to comprehend and accept."

*Discussion Group Quote (1997-2001)*

Other topics include such things as: 1) the roles and rightful powers of the various actors in a demand-driven system; 2) identifying the appropriate balance between the freedom of the individual who requires support to achieve his/her own desired future, and the duty of the State to ensure that public funds are used properly; 3) the ways in which these new funding and personal planning systems may be obstructed or perverted by vested interests, and strategies to avoid or counter such problems; 4) the role of labor unions; 5) how the funding body can effectively macro manage an Individualized Funding budget; 6) how providers can be supported to 'unbundle' their block funded budgets; 7) the appropriate parameters of effective brokerage practice; and 8) how community engagement can be achieved.

The list is not only a forum for discussion. It's also a very useful channel to share information about important developments and alert members of the group about new publications and other resources. For example, Jean Tuller

from the Health Care Financing Administration (HCFA) and the National Program Office recently posted New Tools for Systems Change (<http://groups.yahoo.com/group/directfunding/files/>), a document that outlines some of HCFA's new system change initiatives, while Jay Klein posted materials on the Access Housing 2000 Initiative (<http://alliance.unh.edu/accesshousing2000c.html>).

Another, albeit unintended, outcome of the group's exchanges over the years is that they helped to shape the kinds of issues we (as program co-chairs) eventually included in program for the First International Conference on Self-Determination and Individualized Funding that was held in Seattle in July, 2000.

"People hear terms, make assumptions, and rapidly put together something that is really a reflection of what already exists in traditional services—but name it brokerage, individualized funding, microboard, etc. and think they grasp the concept. It's frustrating at best and often scary."

*Discussion Group Quote (1997-2001)*

By the very nature of the topics, discussion can sometimes be fairly technical and abstract. However, the dialogue is generally kept "on the ground" by contributors who speak about their experience of being on the receiving end

of individualized funding arrangements, or their work to develop real alternatives to global/block funding and case management or service coordination. As moderators, we have not yet had to intervene to ensure that discussions remain civil and respectful. Part of the reason is that subscribers to the list are expected and assumed to support a change in service systems in order to bring about a transfer of power. Inclusion, self-determination and self-

"I also hope we won't let borders and geography impact our decisions about where or not to endorse a model of support. Who cares where an idea comes from: if it works we should be glad it's shared."

*Discussion Group Quote (1997-2001)*

advocacy are often mentioned in contributions, and there may be discussion about the meaning of these concepts, but participants who join know from the outset that this forum is not a place to debate their validity.

So, if you would like to participate in the process of promoting meaningful system change and enjoy passionate discussion, you are welcome to join us. To become a list member, all you need to do is send an e-mail to [directfunding-subscribe@yahoogroups.com](mailto:directfunding-subscribe@yahoogroups.com), or you can visit <http://groups.yahoo.com/group/directfunding> for more information.

#### Other Internet resources:

Seattle 2000 Declaration: <http://members.home.net/directfunding/>

Information Resources on Individualized Funding: <http://members.home.net/tsalisbury/>

Steve Dowson and Brian Salisbury are principals in Emprise International Training and Consultancy (<http://www.emprise-international.com>). Emprise is a partnership that assists and promotes the policies, systems, and support services (including individualized funding and service brokerage) required to enable citizens with intellectual impairments and/or other disabilities to achieve self-determination and community inclusion. Emprise works with government, service providers, and with agencies providing technical support services, to help them to define their new roles and develop the skills they require.

"If Direct Funding is going to be a force for positive change in people's lives, then we must focus our efforts on supporting self-advocates and parents to organize and lobby for the kind of implementation they want, and for their control over the structures that support DF and brokerage."

*Discussion Group Quote (1997-2001)*

## Self-Determination Trends in Australia

by Tony Shaddock

I really wanted to write an optimistic, tastefully boastful account of Australia's success in furthering the self-determination of our citizens with disability. But even in the afterglow of the Sydney Olympics, with jingoistic sentiment still high, I could not

write such a story, so I'll apologize now. Sorry, mate!

The six states and two territories that make up the Commonwealth of Australia differ in many ways, including the way they provide supports for people with disabilities. Traditionally, state and

federal governments have provided a large proportion of the funds for 'disability services' and generally speaking, these services have been 'top down' and bureaucratically driven. Although parent, consumer and advocacy groups have been

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**Australia**, continued from page 19

active and influential, they operate with few resources and are often in the invidious position of being part-funded by the very Government Department they are trying to stir.

In Australia, the term self-determination is more likely to be understood politically and mentioned in relation to indigenous people and people from other cultures. Although one sees many good examples of people with disabilities achieving self-determination, it would be misleading to suggest that there is a strong 'self-determination movement' in this country. This is not to say that Australians are unaware of, or unsympathetic to, overseas developments, but merely that many people who are committed to assist people with disabilities to achieve a quality lifestyle have, for historical, local and/or strategic reasons, chosen not to use self-determination as a rallying concept. Furthermore, the Commonwealth, state and territory governments (which steer the legislation and control the resources) do not frame the discussion or the debates in terms of self-determination.

So what are we talking about and doing in Australia? Well, many of the policies and practices that are consistent with self-determination are certainly on the table. For example, the conservative Commonwealth Government is currently engaged in 'welfare reform', and one of its principles "Mutual Obligation" emphasizes the contri-

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*bution and participation of people with disabilities.*

Astute advocates for people with disabilities, such as Eddie Bartnik in Perth Western Australia, realize that in today's political and economic climate, Treasury will listen to 'moral arguments' if they are supported by 'business arguments'. So innovative approaches that are more incremental than revolutionary, that provide data along the way so the initiative is successful on a variety of measures, are gathering support.

One state, Western Australia, is a long way down the track with individualized funding, and has been systematically developing and refining the approach for twenty years. Support coordination ventures are under way in New South Wales. If you can believe the publicity brochures,

person-centered planning is practiced in many places. One of my former students, Melanie Rees, gave me some great examples of how she and her colleagues in Canberra assist people with intellectual disabilities to achieve their aspirations.

In New South Wales, mainly through the work of Trevor Parmenter, Roger Stancliffe and colleagues at the Center for Developmental Disability Studies, many traditional approaches to disability support have been rigorously tested against financial and person-centered benchmarks. At the moment, careful compilation and dissemination of this type of data seems to have more impact than the moral or ideological case for self-determination.

The Victorian Government recently commissioned a research report on power-sharing in the provision of disability supports and Karen Nankervis, one of the authors, told me that power sharing is proposed as a means towards self-determination.

In preparing this article, I sought input from many who are involved on a daily basis with people with disabilities around the country. Tony Spinks, who manages an employment project for workers with high-support needs in Canberra, the nation's capital, told me that self-determination is intimately linked with wage justice and getting incomes above the poverty line.

Michael Bleasedale from New South Wales raised a relevant

point recently in a contribution to the direct-funding discussion group (directfunding@yahoo.com) Michael pointed out how industrial relations traditions and policies in particular countries modify the extent to which initiatives such as self-determination are appropriate or practical. For example, Australian workers are mostly unionized so their industrial organizations are wary of service initiatives that have the potential to exploit workers through 'too flexible' working conditions.

It is an unfortunate reality of Australian life at the moment that many Governments seem to just want to 'manage and contain' rather than to embark on progres-

sive and humane policies that give all citizens a 'fair go'. Some of these governments are re-elected, so they obviously do some of the things that voters want. Australia is also seeing the rise of right-wing minorities that frequently hold the balance of political power. Uncertain economic conditions, the loss of job security, the recent Asian economic crisis and the potential impact of a weakening U.S. economy appear to have made voters more self-interested and less sympathetic to the needs of 'minority groups'.

Self-determination for people with disabilities is a morally correct stance, but it is not a well-understood concept in Australia. (Even in the disability

community, many would not appreciate that self-determination also implies *responsibility* and *contribution*). Australia does not have a nationally funded program to explore and explain self-determination in the Australian context and there is little advocacy for the concept among those who could resource pilot projects. Consequently, although there are some sensible and effective support initiatives being implemented, they are derived from a different philosophical basis, planned within a different political reality and implemented in a culture that traditionally has placed more emphasis on the 'common good' than on individual rights. ■



**A NEW BOOK FOCUSING ON THE CONCEPTS OF SELF-DETERMINATION  
AND INDIVIDUALIZED FUNDING IS NOW AVAILABLE!**



## FOUNDATIONS FOR FREEDOM

**International Perspectives  
on Self-Determination and  
Individualized Funding**

**by Steve Dowson & Brian Salisbury**

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

These concepts continue to evolve and take on meaning for greater numbers of people with disabilities and their families. Throughout this groundbreaking report, one resounding principle rings true: no one but the person with a disability (and for children, the child and his/her family) could possibly know what is best for that person. All over the world people with disabilities seek and accept only those supports that provide what they want and need to realize their own futures.

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

Copies are available for only \$22.95. Discounted price for family members of people with disabilities and self-advocates: \$15.95. To order call 1-800-482-8274 (410-828-8274) or use this link: [http://www.tash.org/publications/foundations\\_for\\_freedom.htm](http://www.tash.org/publications/foundations_for_freedom.htm)

## **It May Be Non-Aversive But Is It Non-Coercive? *The Ethics of Behavior Change in the Modern Age***

*by Nancy Weiss, Executive Director, TASH  
January, 2001*

**The technology of behavior modification is ethically neutral. It can be used by villain or saint. There is nothing in a methodology that determines the values governing its use.  
(B.F. Skinner, 1971)<sup>1</sup>**

I am concerned that those of us who would never use physically or emotionally painful techniques to change the behavior of people we support fail to consider the potential ethical issues inherent in our work. It is as if we believe that if we are not doing work that is by its nature inhumane, we are necessar-

ily acting humanely. There is a vast and dangerous gray space between those practices that we know to be unethical and those that would be truly life affirming.

The late Herb Lovett is credited with coining the term 'positive approaches'. In the spirit in which Lovett intended the term, is impor-

tant to recognize that every approach that does not rely on aversive procedures<sup>2</sup>, is not by default a positive approach. Positive approaches are only those which enhance a person's life – they are characterized by collaboration versus control and focus more on illumination (or under-

standing the meanings and purposes of the behavior from the individual's point of view) than on elimination (or reducing behaviors we perceive to be unacceptable).

There is no question that some people with disabilities have behaviors that are dangerous or seriously disruptive. I am not a person who believes that because all people are to be valued and respected equally that all behaviors are equally acceptable. Some people (both with and without disabilities) exhibit behaviors that interfere with the quality of their own lives and the lives of the people with whom they interact. We have a responsibility to offer supports for people to change behaviors that are dangerous, disruptive or interfere with their ability to achieve goals they have set for themselves. Our responsibility, however, is to do this in ways that value, enhance and include people rather than through the use of methods that are coercive and come dangerously close to revenge.

We Americans have a strongly held ideology that supports the notion that people who work hard and do right should be rewarded (the Puritan work ethic) and those who do wrong need to be punished. The roots of such thinking go back to the very earliest days in this country; the Salem witch trials being a good example. Often when I speak with people who work in residential settings or schools, there is resistance to some of the principles of positive behavioral supports. They say, "So we're just going to let her do whatever she

pleases? There have to be some consequences for her behavior!" It's hard for people to let go of their need to punish behavior they find troublesome.

Many ethical issues in the design and implementation of behavior programs relate to issues of control. Whenever one person tries to change the behavior of another there is an inherent and unavoidable imbalance of power. People with disabilities are often denied opportunities to make basic life choices and are subjected to unreasonable amounts of control as a matter of course.

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There is an unfortunate cycle that operates in schools and programs that seek to control too many aspects of people's lives. The cycle starts with an individual attempting to assert a degree of control over aspects of his/her life that are in the control of others. This is a natural response, characteristic of all people who are made to feel powerless. Having few other options, people in restrictive environments protest the control

by behaving in ways that are challenging. Staffs conclude that additional restrictions that serve to limit self-expression must be needed. Because it sounds more pleasant, people prefer to say "a more structured environment is needed" rather than "we need to apply additional controls or restrictions." In response to the new and improved controls, people can be expected to escalate behaviors in further attempts to assert themselves. This leads caregivers to determine that they were correct in assuming that more "structure" was needed; they now conclude that since behaviors have gotten 'worse,' even more control measures are called for, and the cycle continues. Caregivers rarely emerge victorious from such power struggles. It has always seemed not only unethical but downright illogical to respond to people's desperate attempts to assert some degree of control over their lives by responding with efforts to impose greater and greater amounts of power over them.

It helps, if you're going to prevail in a one-upmanship battle, to convince yourself that such interventions are *necessary* and to detach yourself from the people with whom you work. This depersonalization makes it easier to continue your use of demeaning procedures. Danger abounds here for everyone concerned. Not only are the basic human rights of the people subjected to such approaches threatened, but we also compromise the public's percep-

*Non-Aversion, continued on page 24*

**Non-Aversion**, continued from page 23

tion of all people with disabilities when our treatment implies that these are dangerous, unpredictable people whose extraordinary behaviors need to be controlled through extraordinary means. Ironically, the use of coercive techniques requires avoiding of a personal and caring relationship – when that is the very thing that people with challenging behaviors most need in order to change their behaviors.

Though it can be argued that need is the mother of invention, it is also true that invention is the mother of need. None of us needed cell phones, fax machines or e-mail fifteen years ago – now that they exist many can't live without them. We become addicted to using what we have; what we know. In the same way as we have become addicted to the technology of electronic communication, we have become addicted to the technology of behavior modification. Behavioral techniques are seductive. They seem so clean, logical, well-proven and, in this age of emphasis on good record keeping; so neat to measure and document.

Often the very systems that support people with disabilities encourage over-reliance on behavioral interventions. In architecture, the rule of thumb is 'form follows function'; in human services it is 'form follows funding.' When funding sources and administrators expect quick resolution of unpleasant behaviors, we deliver. We often are so ready to identify the

behavior, isolate its characteristics, measure it, and design a program to reduce it, that we forget to ask the basic questions we would hope someone would seek to answer about us. Such as:

- Who is this person?
- What important needs are unmet for this individual?
- Given a full range of options, what would he/she change about his/her life?



- What *has* changed about this person's life that may not have been consistent with what he/she would have chosen?
- With whom does this individual have meaningful relationships (or as Herb Lovett would have asked, "Who loves this person")?

If we could determine answers to some of these questions, we would have accomplished much toward unlocking the secrets behind the behaviors. If we could offer people more meaningful lives, many difficult behaviors would resolve themselves. Clearly, many people

with disabilities can't easily articulate answers to questions such as the ones above. Likely this is the very reason they resorted to extraordinary behaviors as a means of self-expression in the first place. Often, however, the people who know the person best can come up with some good guesses worthy of further exploration. When family members and the people who spend time with the individual day-to-day are asked to put themselves in the place of the person with disabilities and think about the questions above, much can be learned.

Our first response in encountering a difficult behavior should not be to ask "how can we apply technology to reduce this behavior?" Rather, initial responses should focus on meaningful, collaborative attempts to determine the nature of the distress the person may be communicating through his/her behavior and practical changes to the nature and quality of the person's life.

Not long ago I visited a small group home and talked with Roger and his staff about the behavior program that was in place for him. Staff explained to me that Roger's behavior problem was that he asked questions repeatedly. His behavior program required that he sit in the staff office alone for twenty minutes if he asked the same question more than once. "For example," one staff person told me in a tone of exasperation, "he'll walk in from the day program and he'll say, 'We're going to watch



the game tonight, right?' I'll tell him 'yes'. Ten minutes later, he'll say, 'We're going to watch that game tonight, aren't we?' I'll tell him 'yes' again. The third time, he goes into the office for twenty minutes." Roger understood the mechanics of his behavior program but seemed confused by its necessity. "Why is it so bad to ask questions?" he pondered, "a lot of times they tell me to do something over and over again."

I asked the staff member if he had any thoughts about why Roger might ask questions repeatedly. At first he said that he didn't know. I told the staff member that it was true that we don't know for sure, but, knowing Roger pretty well, I bet he could come up with some good theories. He first suggested that Roger was doing it for attention, but with further discussion, he came up with several other possibilities. He suppositioned that in the past there may not have been follow-through when promises were made so Roger was, in essence, re-confirming the commitment. His second idea was that maybe this was Roger's only way to initiate social contact; maybe, theorized the staff person, Roger wanted to talk, but didn't know any other way to start a conversation. Finally, he suggested that maybe Roger actually found it hard to hold the idea in his mind; that as time went on he really did not remember what had been promised.

I commended the staff person for coming up with three excellent

possibilities and asked the staff person what he thought would happen, if, the *second* time the question was asked, he sat down with Roger and said something like: "Gee, I can tell you're worried about this. I don't want you to worry, because I've given you my word. I want to give you something that might help. I am writing my promise to watch the game with

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**How would life  
change for people  
with disabilities if,  
when we saw people  
acting out to get at-  
tention, we re-  
sponded in loving  
concern rather than  
using controlling ap-  
proaches to treat the  
symptoms of their  
yearnings?**

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you on this piece of paper. I'm going to sign my name. I don't sign my name unless I'm really going to keep a promise. If you get worried again, maybe you could look at this paper and it will help to remind you that I've given my word. If you're still worried after you look at the paper, you can come ask me again. I don't want

you to be worried". How different services would look if we were as motivated toward being humane as we are toward being in charge.

After this conversation I gave some thought to the meaning of the staff person's initial hypothesis – that Roger was asking questions for attention. It's an observation that is often said with a level of disdain, "It's just attention-seeking behavior." What if, rather than seeing the quest for attention as a shortcoming, we were struck by how unfortunate it is that someone would need to act in remarkable ways to get noticed? How would life change for people with disabilities if, when we saw people acting out to get attention, we responded in loving concern rather than using controlling approaches to treat the symptoms of their yearnings?

Joan loved music. Each day when she returned home from school she would sit quietly for awhile listening to her favorite tapes. Her parents met with a psychologist to design a behavior program for Joan's behavior of destroying property. He started by asking her parents to list those things Joan found reinforcing. Music was at the top of the list. It was decided that her parents would hold Joan's cassettes. When Joan had not destroyed anything all day she would be offered her choice of a cassette to listen to for a half-hour before bed. Joan's psychologist was shocked when his program was criticized. "But it's all based on

**Non-Aversion**, continued on page 26

**Non-Aversion**, continued from page 25

positive reinforcement!" he insisted.

A wise person with a developmental disability once said, "I've got it figured out. You better not tell them what you like or they'll make you earn it and you better not tell them what you don't like or they'll use it against you" (Henning, 1991, lecture). Most of us have moved beyond star or token systems but forcing adults to earn privileges that are readily available to most of us raises serious ethical considerations.

Most programs that rely heavily on positive reinforcement are contrived and intrusive. It is not necessary to bribe people to do things they find meaningful or pleasurable. When we are tempted to implement some complex system of positive reinforcement, it is probably a good time to step back and look at the big picture—to ask ourselves if there aren't meaningful changes that could be made in this person's life. The message we should attempt to communicate should not be "I'm in charge and you're not," but rather that the person's preferences, goals and feelings are worthy and deserve to be heard and acted upon.

People with seriously difficult behaviors act not out of choice but because some need is unmet for them. Lovett said, "My experience has been that extreme behavior often comes from not feeling listened to. Just as repressive organizational or political systems lead to aggression and revolution, the most profoundly disturbing

behavior is often found in ... unresponsive service systems."<sup>3</sup>

Laura was in a regular fourth-grade classroom but because of her disabilities her teacher didn't include her in many of the learning activities in which the other

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redirected back to  
her seat and her  
activities, Laura  
would often become  
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materials on the  
floor and  
occasionally even  
pushing and hitting  
the teacher.**

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children participated. The teacher had selected a few activities for Laura that she felt were better suited to Laura's abilities. These included sorting pegs by color, putting together a puzzle, and matching objects to pictures on a grid. Laura showed curiosity about the activities of the other children. Their activities were more interesting and generally of a more active and participatory nature. Laura would often wander around the classroom disrupting the work of the other students. When she was redirected back to her seat and

her activities, Laura would often become upset, throwing her materials on the floor and occasionally even pushing and hitting the teacher. Laura's teacher enlisted the help of the school's behavior specialist to develop a program to encourage Laura to stay in her seat, attend to her work, and to reduce Laura's aggressive behavior. She told the behavior specialist that Laura was non-compliant. The behavior specialist was happy to begin designing a careful system of reinforcement to assist Laura to achieve these behavioral goals.

The ethical questions are clear. Simply because the technology exists to train Laura to be compliant doesn't make it acceptable. Attempting to change behavior to adapt to an inappropriate environment or inappropriate demands is at best ethically suspect. An astute teacher or behavior specialist would recognize Laura's behavior as one of the most objective critiques of service quality that he or she is ever likely to receive. We could save money on hiring expensive consultants to do complex evaluations if we just paid attention to what the people we support tell us.

What if we eliminated the term "non-compliant" from our vocabulary? The term doesn't appear in the dictionary because it is not a word used outside of the disability or health care fields. **We** stand up for ourselves. **We** are assertive and enterprising. Our non-disabled children are spunky and strong-

willed. There isn't a big market for self-help books that tout the skills needed to be more compliant nor do we brag that our children are masterful in their compliance. Only people with disabilities earn labels of 'non-compliant' when they attempt to forge their own destinies. When people do not act in a cooperative way our first question should be whether we are asking them to do something that makes any sense to them. Many of us avoid doing things that we do not find personally fulfilling (think back to the last meeting you missed)—we would rightfully resent a coercive attempt to force us to take part in meaningless activity. The best way to teach cooperation is to provide opportunities to participate in activities that are engaging and fulfilling. All people take pride in mastery and achievement.

Last May the Hartford Courant documented over 150 recent cases in which children or adults with disabilities died while being restrained. In none of these cases was the staff person or teacher motivated by an intent to do harm; all of these procedures were used 'for the person's own good'. The circumstances leading up to these deaths describe a litany of power struggles. One man was restrained when his behavior escalated after he asked to watch television and was told that TV was not allowed during the day; one man became upset after he was denied access to the bathroom; a woman died for the crime of being unwilling to hand

a family photograph over to staff.

While these cases represent the worst imaginable result, power struggles such as these are commonplace. Institutional, community and educational service systems often are designed to restrict freedom of choice. When power is taken from someone it is a natural response for him/her to act almost as one would in self-defense to reassert control. Rather than viewing difficult behaviors as an indication to re-think the necessity for restricting people's right to self-determine, they are often viewed as signaling the need for even more stringent controls. Behaviors escalate further in response, and the cycle goes unbroken, often until tragedy results—if not in loss of life, surely in the unnecessary loss of a life of quality and meaning. It's time to put an end to unethical and coercive practices—not only because they are dehumanizing but because they are unnecessary.

Rather than seeking ways to control people further we should seek ways to understand them and to communicate to them that we are on their side. You will never go wrong asking, "You seem unhappy—is there anything I can do?" or "You seem to need something—can I help?" When people feel valued and included they are much more likely to behave in ways that do not challenge systems or the people around them. It is not enough to design behavior programs that are non-aversive – defining an approach by what it is

not does little to describe what it is. As family members, advocates, staff, teachers and others who work in the disability field, we have a responsibility to people with disabilities that has little to do with getting them to act in pre-determined ways and much more to do with supporting them to be spirited, self-directed and fulfilled. ■

*Nancy Weiss is the Executive Director of TASH, an international disability advocacy organization devoted to equity, quality and social justice for people with disabilities and their families. In a former life she ran a natural-setting positive behavioral support program for children and adults with severe disabilities. To receive a free information packet about TASH that includes sample publications, send an e-mail that includes your mailing address to [nweiss@tash.org](mailto:nweiss@tash.org) or call (1-800-482-8274, ext. 109).*

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1. Skinner, B.F. (1971). *Beyond freedom and dignity*. New York: Alfred A. Knopf, Inc. p. 150.
2. All aversive techniques have in common the application of physically or emotionally painful stimuli in response to behaviors that are deemed unacceptable. Examples of aversive procedures include electric shock, water spray, visual screening, prolonged restraint/isolation, taste aversives, etc., used as punishment in an effort to decrease the likelihood of a specific behavior reoccurring.
3. Lovett, H. (1996). *Learning to listen*. Baltimore: Paul H. Brookes, Publishing Co. p.6

# Supporting Self-Determination with Integrity

by David and Faye Wetherow

Main Entry: **in-teg-ri-ty**

Etymology: Middle English *integrite*, from Middle French & Latin; Middle French *intégrité*, from Latin *integritat-*, *integritas*, from *integr-*, *integer* entire

Date: 14th century

1 : firm adherence to a code of especially moral or artistic values : **INCORRUPTIBILITY**

2 : an unimpaired condition : **SOUNDNESS**

3 : the quality or state of being complete or undivided : **COMPLETENESS**

## An Evolving Pattern Language

The movement toward self-determination signals a major advance in understanding and practice in 'disability services'. As we celebrate this advance, it might be an especially important time to remember our history and consider what we will carry into the future.

For 200 years, the language of *asylum, protection and special treatment* supported a largely unchallenged pattern of segregation and institutionalization of people with disabilities. For 200 years, we reflexively and systematically stripped people away from the context of family and community life and confined them in segregated settings. Then in the mid 1960s, Burton Blatt and other advocates brought us face to face with the suffering engendered by the institutional 'solution'.

In the mental health field, driven by a portrayal of institutions as anathema, lured by the prospect of cost containment, and encouraged by the promise of new psychotropic drugs, the overly simplistic language of

'deinstitutionalization' contributed to a pattern of abandonment that haunts us to this day. In the field of developmental disabilities, early attempts at 'deinstitutionalization' were implemented using a service pattern that has sometimes been described as "breaking pieces off of the institution and dropping them into the stage setting of the community in the form of segregated programs."

In the early 1970s, Wolf Wolfensberger, Ed Roberts, and other leaders brought us face to face with the impoverishment of these solutions. The new 'pattern languages' of Independent Living and Normalization (now Social Role Valorization) began to emerge, and for two decades helped shape our perceptions and refine our practices. As they struggled with the limitations of segregated 'community' programs, parents and allied professionals in the field of developmental disabilities began to envision new directions and began leading the way toward inclusive education, supported employment, family support, and innovative inclusive housing options.

In the 1980s and '90s, pioneers such as Jack Pearpoint and Marsha Forest, John McKnight, John McGee, Herb Lovett, Judith Snow, John O'Brien, Marc Gold, Jean Vanier and others began creating pattern languages that were richer, more adaptive and more complete. *'Circles of support, inclusion, diversity, gifts and contributions, personal futures planning, mobilizing community capacity, invitation, companionship, community-building, hospitality, citizen advocacy, self-advocacy, covenant relationships, life-sharing, Gentle Teaching, and asset-based community development* all became part of a new working language of allied professionals, men and women with disabilities, family members and advocates.

As the field moved forward with an enhanced language and a richer vision, people began to discover and forge new *structures* that facilitated collaboration, invited new forms of social engagement, and reversed some long-standing patterns of control: *'Home of Your Own' initiatives, co-housing, cooperative, and microboard initiatives, independent planning, individualized*

*funding, and self-determination* all took their place in the working language and generated a wide array of experiments and models.

### **Two Steps Forward, One Step Back**

As positive as these developments were, practitioners sometimes made the mistake of leaving behind important elements of the *complete* pattern. We backed ourselves into dead-ends, struggled with confusing terminologies and a lack of definition (think about the confusion over *mainstreaming*), moved forward with single-path solutions, and neglected some important lessons from the past. The complete pattern sometimes became lost in the rush of excitement over new terms, new forms, and new initiatives.

Just as the overly simplistic language of 'deinstitutionalization' failed to convey the importance of building strong patterns of support in the community, the raw language of *independence* and *empowerment* sometimes failed to convey the importance of interdependence, contribution and engagement. In some instances (especially in the field of services to people with developmental disabilities) an overly simplistic approach to *independent living* led to a lack of essential supports and social isolation. Direction and wholeness—integrity—receded.

### **Self-Determination Out of Context**

When we carry parts of the larger pattern implicitly, rather than remembering to make them ex-

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plicit, we may make the assumption that these desirable directions will automatically be understood and incorporated into daily practice. This is not always a safe assumption. Being reluctant to 'impose' values or direction, some proponents of self-determination may lose sight of the importance of supporting companionship, connection and contribution.

We are beginning to see some indications that the bare language of self-determination—"autonomy, choice, freedom, and responsibility"—may fail to convey the importance of engagement, companionship,

contribution and affiliation. On recent occasions we have heard new practitioners define their roles within self-determination initiatives as simply "helping people with disabilities do what they want." On the surface, these practitioners seem to work under the assumption that 'finally having control' is a sufficient precondition for a good life. In practice, we have sometimes seen this translate into personal isolation or into an endless round of disconnected 'consumer activities'.

*Integrity, continued on page 30*

*Integrity, continued from page 30*

### **Self-Determination with Integrity**

This doesn't have to be the case. A few months ago, we listened as a service coordinator told the story of a man who had lived a tormented life in an institution. He had gained what Herb Lovett used to call a 'severe reputation' for combativeness and challenging behavior. Under the auspices of a self-determination pilot project, he began living in his own home with the support of resourceful companions and assistants, was contributing to his community, and he was *happy*.

The combat had ended; but one thing was clear: this didn't just happen by writing a check. Indeed, this young man now had much more power to express his life's direction, and he was enjoying a degree of respect that had long been missing in his life. But the overall direction was something that emerged in the context of collective wisdom, companionship, perspective and encouragement.

Our friend the service coordinator had been this man's champion for many years, and now with the flexibility that was afforded by the self-determination project, he could fully offer—as a supportive partner—his creativity, his ability to envision a richer life, his skill at inviting and supporting connections, and his sense of a positive, possible future. Money and self-determination was an important condition, but this man's championing played an important role.

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**In a recent workshop, a leader asked, "What are the characteristics of a good facilitator?" One participant said, "A good facilitator doesn't control the direction, but she does ask important questions."**

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### **Balancing Respectful Listening and Facilitation**

In a recent workshop, a leader asked, "What are the characteristics of a good facilitator?" One participant said, "A good facilitator doesn't control the direction, but she does ask important questions."

John McKnight's pattern for Asset-Based Community Development, PATH and related futures planning processes all involve strategic questioning and engagement. They serve as guides for questioning, listening, commitment building, community building, and effectively conveying a new vision.

In *I've Known Rivers: Lives of Loss and Liberation*, Sarah Lawrence-Lightfoot reflects on the role of the listener:

*As I listen to these extraordinary women and men tell their life stories,*

*I play many roles. I am a mirror that reflects back their pain, their fears, and their victories. I am also the inquirer who asks the sometimes difficult questions, who searches for evidence and patterns. I am the companion on the journey, bringing my own story to the encounter, making possible an interpretive collaboration. I am the audience who listens, laughs, weeps, and applauds. I am the spider woman spinning their tales. Occasionally, I am a therapist who offers catharsis, support, and challenge, and who keeps track of emotional minefields. Most absorbing to me is the role of the human archaeologist who uncovers the layers of mask and inhibition in search of a more authentic representation of life experience. [Thanks to John O'Brien for bringing this writing to our attention.]*

There is *direction* in the listening. The direction comes from our willingness, as Judith Snow suggests, to help 'carry the dream' for someone who is vulnerable. It comes from remembering what constitutes a good life, and as our daughter says, it sometimes involves "speaking your truth with authority." It means remembering our history and bringing the *entire* pattern into the dialogue—indicating direction without imposing direction. Working with soundness and completeness.

### **"No, You Have to Be Working There"**

A while ago, we listened to a story told by a mother whose son has a hearing impairment and who also

struggles with a significant movement disorder. Hearing about his interest in music, people found it easy to think in terms of his attending community concerts and Friday night jam sessions at a local bookstore.

At the outset, David had difficulty expressing the possibility of a musical vocation, and he had no connections in the music industry that would have made that a foreseeable direction. Employment counselors had assumed that his interest in music had little relevance to his prospects for employment. But a friend in his church congregation *did* have connections in the industry, and saw the possibility that David's interest in music might 'take off' in the direction of employment.

'Self-Determination' alone might not have generated this new direction. The possibility emerged because someone knew David well, understood how much meaning music had for him, and understood the importance of capturing the thread of his interest and moving in the direction of companionship and contribution. David's friend seemed to have an innate sense of what it takes to create a good life. He had the audacity to carry the dream for his friend, and he exercised his own power of invitation. His understanding of the value of moving from 'activity' to connection and contribution led to a richer place.

Now David works for a company that assembles the cable sets for

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**Supporting self-determination with integrity involves deep listening. It involves vulnerability—an openness to being changed ourselves.**

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the sound systems at large concerts. Most of the time he works in a small factory, cutting cables and installing terminals. He is fully accepted as 'one of the crew'. At concert time, he helps with the final installation of complex sound systems. David has become part of the working music scene in a large nearby urban centre. Last month, as he was about to leave on a three-day trip to help set up a rock concert in the city, his mother (who was starting to feel like she was missing out on the fun) asked, "Can I come?" Her son signed, "No, Mom, you have to be working there."

### **Some Final Reflections**

As we work to support self-determination, we're walking a tight-rope, and not for the first time—remember '*the dignity of risk*'? We need to learn to *create* fruitful conditions without *imposing* conditions, and at the same time to not abandon what we've learned about the value of invita-

tion, connection, contribution and engagement. Supporting self-determination with integrity involves deep listening. It involves vulnerability—an openness to being changed ourselves. It involves a commitment to honour our agreements, and a rigorous commitment to reflect on our experience.

Self-determination is a vibrant, essential element in an expanding pattern language—an element that has long been buried under the cloak of control and patronage—but it is not a whole language. Individualized funding and independent planning has added flexibility, respect and excitement to the equation, but ultimately, moving toward a life that has integrity (in the sense of *completeness*) involves being on the journey with allies who can share a larger picture.

The traditional language of the Nisga'a Nation of Northern British Columbia includes at least four separate words for the idea of *encouragement*. Every member of the community is reminded that part of their individual responsibility is to offer all four forms of encouragement to friends and family members. One of the words stands as a reminder of the integrity of family and community life—a call to keep the threads of community woven together. The Nisga'a understand that we 'determine' our paths, but they are also always mindful that we also *discover* our paths in the context of companionship and community. ■

# Advancing Affordable, Accessible, and Integrated Housing for All Americans

*by Jay Klein and Bob Kafka*

While the number of people living in institutions and large facilities has decreased, the vast majority of individuals residing “in the community” live in residences owned and controlled by someone else. Housing and personal assistance services are dictated far more often by government and agency preferences than by the needs and desires of persons with disabilities. Current approaches do not assure that people with disabilities are afforded control over, or even a voice in, the most basic decisions regarding where they live, with whom they live, the nature of the assistance they receive, and how they spend their time. The development of community housing and services for people with disabilities has been a major national policy direction for the past 20 years. Unfortunately, the administrative structures supporting community services typically promote congregate and agency-controlled approaches to housing and personal assistance services.

## **ONE RESPONSE: ACCESS HOUSING 2000**

Recognizing the need for dramatic changes in policy and practice, the U.S. Department of Housing and Urban Development (HUD), on December 19, 2000 published a Notice in the Federal Register on Access Housing 2000. The summary states, “This Notice provides information on Access Housing 2000, a proposed national initiative that will assist persons with disabilities to transition from nursing homes into the community by providing improved access to affordable housing and necessary personal assistance and supportive services. HUD is partnering with the U.S. Department of Health and Human Services (HHS) and the Institute on Disability (IOD) at the University of New Hampshire to carry out this initiative. Using Section 8 housing vouchers in conjunction with supportive services available under the Medicaid program, the proposed initiative presents an opportunity to design and implement innovative housing and

supportive service strategies. If successful, these strategies could expand the availability of accessible, affordable housing in the United States, including home ownership opportunities for persons with disabilities, and assure that such individuals receive the assistance and the ongoing supportive services necessary to make a smooth and successful transition to living in the community.”

The Federal Register Notice calls for the IOD to create a center to:

- “(1) Build broad-based partnerships and collaborations in both the public, private, and advocacy sectors;
- (2) conduct outreach to create local coalitions consisting of public, private, and advocacy organizations to build ground-level support for the initiative and to assist in its implementation;
- (3) evaluate the efficacy of the strategies developed during the initiative and the dissemination of best practices;
- (4) conduct research that examines the process for, benefits of, and barriers to the implementation and accomplishment of the objectives of Access Housing 2000;
- (5) examine whether the strategies developed during the initiative can be replicated on a large-scale basis;
- (6) analyze Federal and State policy affecting the implementation of this initiative; and
- (7) develop a means of ensuring that the experience of the initiative receives broad attention and review, e.g. creating a website.”

On March 18, 2001, IOD joined in partnership to announce the creation of the Center for Housing and



New Community Economics (CHANCE). The IOD has a proven record of success with its National Home of Your Alliance, and ADAPT has extensive experience in providing technical assistance with issues affecting people with disabilities on a national basis. CHANCE will implement the core principles of Access Housing 2000, and will embrace and promote a broader scope of ideals. CHANCE's purpose is to offer alternatives to approaches that segregate, congregate, and control people with disabilities. CHANCE will be discussed in greater detail later in this article.

The December 19, 2000 Notice:

- states "Access Housing 2000 is a unique partnership focusing on providing a national coordinated response to the Supreme Court's decision in *Olmstead v. L.C.* (527 U.S. 581 (1999))." Although this is only a small part of their total *Olmstead* response, HUD and HHS must be commended for putting forth an initiative that recognizes the need to provide ongoing personal assistance services (through Nursing Home Transition grants) that are coordinated but not linked with integrated, accessible, and affordable housing (through the allocation of housing vouchers).
- states that HUD informed the public in the August 10, 2000, Federal Register of its intention to use a portion of the remaining unobligated Fiscal Year 2000 funds from two Section 8 voucher programs, set aside for people with disabilities, for Access Housing 2000. HUD did not distribute these 400 vouchers in fiscal year 2000. Soon after the August Notice was published, the IOD, ADAPT, and other groups worked with HUD, HSS, and Congress to utilize fiscal year 2001 fair share vouchers instead of using vouchers that were set aside for people with disabilities. Unfortunately, these efforts were unsuccessful. However, if implemented quickly, Access Housing 2000 has the potential to ensure that, without further delay, people with disabilities who are in nursing homes and have incomes below the poverty line will use the 400 undistributed vouchers.
- states "HUD will make available, through its funding award process, approximately \$2.5 million initially

to fund 400 Section 8 vouchers targeted for use by persons with disabilities and families of children with disabilities who currently reside in nursing homes. Therefore, Access Housing 2000 targets people who reside in nursing homes, who are both old and young and may have physical, cognitive or psychiatric disabilities. The initiative has been designed to reach all categorical groups and ages of people with disabilities.

1990 U.S. Census Bureau figures indicate that 181,270 people younger than 64 years of age live in nursing homes. In the State of the States in Developmental Disabilities 2000 Study Summary, David Braddock, Richard Hemp, Susan Parish, and Mary Rizzolo reported that 35,887 persons with developmental disabilities currently reside in nursing homes. In addition, The Office of Inspector General, Department of Health and Human Services, attempted to identify the number of people between the ages of 22 and 64 with severe mental illness who are nursing facility residents in its report "Younger Nursing Facility Residents with Mental Illness: An Unidentified Population." In the January 2001 report, the Inspector General states that, "Twenty State mental health authorities (SMHAs) reported a total of 40,277 younger nursing facility residents with mental illness. These 20 States report that, on average, 10 percent of a State's nursing facility population is comprised of younger individuals with a primary diagnosis of mental illness, and 20 percent is comprised of younger individuals with a primary or secondary diagnosis of mental illness."

The census bureau reports that in 1990, 4,231 people under the age of 25 lived in nursing homes. This initiative, if allowed to move forward, will afford low-income families the opportunity to use housing vouchers to help establish homes for their children who live in nursing facilities. The housing vouchers, when combined with assistance and ongoing supportive services (which are part of this initiative), will help these children make a smooth and successful transition to living in the community.

*Housing, continued on page 34*

**Housing**, continued from page 30

In addition, the Notice:

- calls for creation of local coalitions consisting of public, private, and advocacy organizations to build ground-level support for the initiative and to assist in its implementation. This required public-private partnership is the initiative's centerpiece. It has the potential of benefiting people with disabilities, who live in a variety of institutional settings, by affecting systems change at local, state, and federal levels.

Seventeen Public Housing Authorities (PHAs) in eleven states enthusiastically asked to be involved in the Access Housing 2000 initiative. These PHAs overwhelmingly stated that they wish to use the vouchers to assist people to obtain integrated, affordable, and accessible housing. Access Housing 2000 is designed to assist PHAs and Medicaid Agencies develop the capacity and collaborations necessary to assure people with disabilities rent or own housing that is coordinated with personal assistance and supportive services.

The initiative is designed to create affordable, accessible, and integrated housing and ensure that people with disabilities are afforded the opportunity to direct all aspects of their lives. The Notice states, "The vouchers will be administered by the selected PHAs and will be used by persons with disabilities to rent apartments in privately-owned buildings, assisted living facilities, or residential facilities, or to eventually own accessible and affordable homes." Therefore, implementers of this initiative will need to provide direction and assistance to ensure that people use the vouchers to rent and own integrated, accessible and affordable homes while directing their services and supports, funding, planning, and coordination activities.

- Access Housing 2000 will increase the supply of housing for people with disabilities by providing the opportunity, over five years, for 2000 people with disabilities to leave nursing homes and rent or own their housing.

## **CHANCE: A BROADER APPROACH**

The approach of CHANCE will be based on a clearly defined set of principles promoted by the IOD, ADAPT, and their collaborators for several years. These principles pertain to both attitudes and practices and will guide all aspects of center activities:

- while people with disabilities need personal assistance services and integrated, accessible, and affordable housing, assistance and housing must not be linked;
- people with disabilities must be afforded the opportunity to direct all aspects of their lives, including their homes and apartments, services and supports, funding, planning, and coordination activities;
- an initiative that succeeds in bringing about integrated, accessible, and affordable housing and personal assistance for people with disabilities will require systems change at the local, state, and federal levels and the collaboration of the public and private sectors;
- supports and services must be provided under auspices that are separate from housing; any resistance and barriers which may impede ability to access personal assistance and support services to live in the community must be overcome;
- replicability is enhanced through sensitivity to state and local issues and practical, intensive support by highly competent experts (including people with disabilities and their families); and
- affordable, accessible, integrated housing must be attainable for all Americans.

The IOD and ADAPT intend to collaborate with a broad array of "like minded" individuals and organizations concerned with housing, personal assistance, and economic equity. CHANCE will bring together numerous private and public national financial institutions, advocacy organizations, federal and state

agencies, foundations, civic and community associations, and others. These collaborators will accomplish the work of CHANCE in partnership with people with disabilities, and families.

The role of collaborators will be to provide information and technical support related to integrated, affordable, and accessible housing coordinated with, but not linked to, personal assistance. This support may include working with housing agencies and lenders; creative finance and alternative underwriting; pre and post-purchase and rental counseling; home selection; and design, renovation, maintenance, and architectural barrier removal for rental and homeownership. Other available assistance will include technical support with accessibility, Nursing Home Transition Grants, the use of Section 8 housing vouchers and other rental assistance in conjunction with innovative services offered through the Medicaid program, and implementation of Olmstead-related activities.

Facilitating broad-based systems change at local, state, and national levels, and fostering partnerships

between public and private agencies and foundations concerned with housing, community living, and economic equity will be a significant focus. CHANCE will work to dramatically increase community capacity—skills, tools and person power—to assist people with disabilities to transition from all types of institutions into the community. CHANCE will promote innovative, field-tested, state-of-the-art strategies (based on real life experiences) to increase the number of people throughout the country who make successful transitions.

Access Housing 2000 is explained by HUD in the December 19, 2000 Federal Register and by HSS in a letter sent to State Medicaid Directors on January 10, 2001 titled "Olmstead Update No: 5." Both of these documents are available for viewing and downloading by clicking on Access Housing 2000 at [alliance.unh.edu](http://alliance.unh.edu)

If you are interested in signing on as a collaborator of CHANCE, log onto the website mentioned above or e-mail Jay Klein at [chance.iod@home.com](mailto:chance.iod@home.com) or Mike Auberger at [chance.adapt@home.com](mailto:chance.adapt@home.com). ■





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300 CENTENNIAL OFFICE BLDG  
658 CEDAR ST  
SAINT PAUL MN 55155-1603

