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AN EPIPHANY

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A. Born Again

I was really looking forward to the National Association of Developmental Disabilities Council's (NADDC) 1985 Fall Conference in St. Paul, Minnesota. I had written for tickets and made plans to see Garrison Keillor's Prairie Home Companion at the World Theater in downtown St. Paul on Saturday evening October 19, 1985. Oh, I knew the conference would be good. The Minnesota DD Council helped plan it and they ain't no slouch. The conference had the intriguing title "From Values and Vision To Action" and even more intriguing workshop titles: Child Development Services - "Are We Underpampering Child Development Services?" Program Administration Review - "Mirror, Mirror On The Wall;" Empowering Consumers To Make Change - "Return Of Rambo," and best of all "Rejecting Incapacitated Clienthood." But I wanted to meet the man who has riveted my attention with his wonderful stories every Saturday evening these past several years. It's not just that his stories are nostalgic. It's that his stories conjure up a community, and set of values, in which everyone belongs, integration isn't an issue because there is no segregation, everything takes place in homes and natural community settings, everything is family-scale, people care about, and for, each other, people interact with each other and learn from each other, and there aren't really any professionals involved. Nonconformity is tolerated and handled by the community without assigning a label.

You can imagine my great disappointment to learn Garrison

Keillor and his Prairie Home Companion would be on-the-road due to repair work being done to the World Theater. I would have to focus my attention on the conference and be satisfied with a simple radio broadcast.

A conference on values, vision and action in the home state of Prairie Home Companion somehow seemed very appropriate. It was a good conference. I got there Tuesday evening October 15th and worked my way through some important meetings and presentations, but, by Saturday afternoon I was pretty much "conferenced-out" and took a walk with my chairperson to St. Paul Cathedral: a monument to the people of St. Paul. It is a beautiful church and, since I had no plans to go to church Sunday morning, I felt visiting the cathedral could be chalked-up as having satisfied my Christian obligation. It's one value I haven't lost.

My flight wasn't scheduled to leave until Sunday afternoon. I had noticed the conference agenda had one last session at 9:00 a.m., the one titled "Rejecting Incapacitated Clienthood," presented by somebody named John McKnight, and moderated by my colleague from Pennsylvania. I know how poorly attended the last session of a conference can be. I've been one of the presenters. Out of respect for my Minnesota and Pennsylvania colleagues, I decided to attend. Millie Adams, the chairperson of my Council also attended.

It was like going to church. The room was small, more the size of a chapel than a church, and dimly lit. Chairs were set up in a semi-circle- There was no altar, not even a table or podium. Only a few people were there and they sat in the back.

John McKnight was introduced and he quietly began his presentation.

I don't remember how long the presentation lasted but I don't think I moved a muscle. The room remained quite silent, with the silence broken only by late-comers shuffling or rolling in. Soon the room was full and a standing-room-only crowd.

John McKnight challenged every current notion of community service, service providers and professionals. To be told that everything you have done you established to essentially "capture and control" people would tend to bring on silence. Also, I've been in the position of challenging large state institutions and sheltered workshops, but I didn't expect to have challenged what I thought were alternatives. More importantly, I didn't expect to see-the-light about how people not only integrate into communities but participate in neighborhoods.

John's vision was familiar. During my masters program in college, I studied Ivan Illich and Rene Dubos, their theories on the expropriation of health care, education and life in general,¹ but I had never applied those principles to public and private service providers in the disability field. John did that in spades.

Millie's reaction was the same as mine, although hers was compounded by being a public service provider and parent all at the same time. we left that meeting knowing we had to get John McKnight to Connecticut and do something towards implementing his vision.

I know that many of my colleagues knew about John McKnight long ago. (I wonder, however, why more of his vision isn't being

promoted.) It is uncustomary for me to latch onto a guru and to want to practice that guru's doctrine. Even as a Christian, I was born Roman Catholic, married Congregationalist and practice Episcopalian. I haven't had a guru since the radical sixties. This must be what it's like to be "born again."

B. At The Right Place At The Right Time

I am repeatedly amazed at how much the Connecticut DD Council implements as a result of coincidence, happenstance and being at the right place at the right time.

Neither Millie nor I knew how we could get John McKnight to Connecticut. Not only didn't we have the funds, we didn't know how to be effective. we realized we already had a few grant projects in the genre of McKnight: two projects were helping Connecticut's citizens with disabilities do grass-roots organizing around the state, another was a contract with a person with mental retardation, and a mentor for that person, to organize people with mental retardation around the state to be self-advocates, a third was a project with a Town to integrate kids with disabilities into the town's recreation programs and a fourth was a grant with our University Affiliated Program to train service providers (e.g.. realtors, law enforcement personnel, chambers of commerce, clergy). Money couldn't be taken from these projects. Besides, these projects were products of our process of planning. But a fellow named E. F. Schumacher says some interesting things about planning that I've always kept in mind while planning with the DD Council.

According to Schumacher, planning is how we use power deliberately and consciously, looking some distance ahead. In

doing our planning, we consider what other people are likely to do, we do a certain amount of forecasting. Forecasting is quite straightforward as long as that which has to be forecast is, in fact, forecastable. Unfortunately, the matters we try to forecast very often are dependent upon the individual decisions of single persons or small groups of persons - like DD Councils. In such cases forecasts are little more than "inspired guesses." The Connecticut DD Council recognizes that much of what it decides is based on the power of judgment and those decisions are the best guesses of what might happen within a range of reasonable probability. In other words, our state plan can be altered by anyone with a better idea, the surprising results of any of our grantees or even the established plans of other agencies wielding power. when the DD Council is confronted with the need to change, it tends to "stop, look and listen" rather than say "look it up in the state plan."

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I stumbled upon one of these situations not long after coming back from Minnesota. Our small project on generic training with our University Affiliated Program was yielding some surprisingly good results, particularly with realtors, chambers of commerce and law enforcement officials. However, Connecticut, heavily influenced by religion, seemed a natural for an intense Council effort to influence support for people with developmental disabilities by religious institutions.

I arranged a meeting with George Ducharme, Northspring Consultants. George is a former director of a regional program for the Department of Mental Retardation (our Administering Agency). In that capacity, he worked with three churches to form

a community service agency called MARCH, Incorporated. The DD Council financed its birth. George now is the Director of the Office for People with Disabilities of the Roman Catholic Archdiocese of Hartford and very interested in working with churches, synagogues, temples and mosques. I wanted to talk about putting a contract out on the clergy, not that the Council had any money this year, but to get it in next year's state plan.

George was excited. With arms flailing, he began to project what might be possible with the Archdiocese and bringing to Connecticut Canada's Jean Vanier L'Arche community. Somewhere during the conversation, I mentioned John McKnight, and our wish to bring him to Connecticut. Well, talk about saying the right thing at the right time. George was also looking for resources to bring John to Connecticut. Not only John McKnight but also someone named David Wetherou, from Canada, and his ideas about cooperatives. In addition, George thought they could be linked up with a woman named Beth Mount from Atlanta, Georgia and Tucson, Arizona, who was already on contract with our Department of Mental Retardation, to do some graphical, positive futures planning. George envisioned a series in which John the philosopher, would be followed by David Wetherou the practitioner and Beth Mount the positive futures planner. With the seed planted, we ended that meeting both in search of finances (\$15,000). While we didn't focus specifically on clergy, we knew religious communities would be very much a part of the McKnight, Wetherou and Mount approach.

A short time later, another grantee surprised us. Not everything we do works. We had to shut-down a bad project. The

good news was we could re-distribute the funds. Re-distribution of funds is the job of the DD Council's Executive Committee. While most of the funds went to projects we could not afford to fund at the beginning of our year, Millie and I were able to convince the Committee to use some of the funds to bring McKnight, Wetherou and Mount to Connecticut. The coincidence that Millie's daughter was the subject of one of Beth Mount's positive futures planning sessions with DMR didn't hurt our sales pitch. We only got half the funds we needed but we got the understanding that the project could carryover into the second year. This allowed us to plan for the second half of the funding in next year's state plan. By planning the series of conferences to take place in September, October and November, we were able to cover half the costs in one fiscal year and half the costs in the second fiscal year. We were off and running! I called George and told him it was a "go." To top things off, John McKnight happened to be appearing in Holyoke, Massachusetts. George attended that meeting, made his acquaintance and began laying the groundwork for the conferences.

The value of coincidence, happenstance and being at the right place at the right time cannot be overlooked. It happened that new leadership and philosophy in our Administering Agency was happening at the same time we discovered John McKnight. It was coincidence that this new leadership brought Beth Mount to Connecticut (she is now living in Connecticut) and that the daughter of the DD Council's Chairperson experienced positive futures planning. It just happened that George Ducharme had some ideas about tying John' together with Beth and adding David. And

all of this was in the right place at the right time when funding became available.

There is one other aspect of this story that is coincidence that should also be mentioned here. I will discuss its implications later in this chapter.

John McKnight discusses the importance of one's associations. In one of my associations, I am on the Vestry of Christ Church Episcopal (John, by the way, has been on the governing board of St. Luke's Episcopal Church in Evanston, Illinois) serving as Chair of our Social Justice Committee. As the name implies, we are an activist group, sometimes revolutionary. I hired George Ducharme as a consultant to help us focus our efforts. One of our concerns has been poverty and hunger, particularly in Third World Countries. In doing church work with OxFam America, I discovered incredible parallels between effective "development" of Third world countries and the "development" of community services for people with developmental disabilities. Beth Mount makes reference to the future of Third World countries in her work.

We are also making our church wheelchair accessible, not because I am Chair of the Committee (I have not used my professional position to influence my church) and not because our parish priest has a child with Down's Syndrome (he has not used his personal experience to influence his church), but because a private institution for people with severe and multiple physical disabilities has opened in our community and we want to be in a position to do something about getting those people out and into our church. My Committee was thinking McKnight like and they

didn't know it.

Most recently, however, my ability to keep church and state and private and professional separate has become more difficult. I am negotiating a contract with Beth to work with a parishioner who has had a son in a mental health institution for twenty three (23) years, Beth was at the right place at the right time.

C. Provocation

Knowing what we wanted to do when and why. was a whole lot easier than knowing where, how» and for whom.

George tells a wonderful story about the wheelchair accessibility of the Newington Knights of Columbus Hall. All I want to add is that the selection of the K of C Hall for this conference was deliberate. It didn't start out that way. George spent several hours trying to find hotel/motel meeting space on short notice. At one point he had secured a hotel, only to have the hotel call and back out of the commitment. We definitely did not want to use a facility belonging to a provider agency in the disability field - that would have been walking into the lion's den. Maybe we would have to use a banquet hall type restaurant. It dawned on us, however, that a series of conferences on developing natural community supports should take place in a natural community center. Finding one that was wheelchair accessible was the trick. George tried several churches but, for various reasons, he was unsuccessful. During all this searching and deliberation, George had mentioned the K of C Hall but we knew it wasn't wheelchair accessible. George had some experience with this K of C, however, and he thought he would see if they could do something about their inaccessibility.

Obviously, he was successful. His story about that success is a demonstration of the power of natural community support groups. The DD Council played only a nurturing role.

Many years ago, the use of DD funds for construction was removed from the DD Act. The K of C, however, needed to construct wheelchair accessibility. Where there's a will etcetera...We found the rent of the K of C Hall, with their associated Michael's Catering Service, was inexpensive when compared to any hotel, motel or restaurant. With the suggestion that our rent be raised to offset some of the cost of their construction, Voila! we had wheelchair accessibility and still at a cost below any commercial meeting center.

From time to time, the DD Council does something I know is going to raise the eyebrows of state bureaucracy. A contract with a private, religious group was one of those times. I prepared a memo for the commissioner of our Administering Agency, and all his deputies (one of whom is a DD Council member) and attached it to the contract with the K of C. In this memo I explained the philosophical reasons for not holding our conferences in state facilities, private facilities in the disability field, restaurants, motels or hotels. I also pointed out the contract was cheaper than any of the commercial establishments. If the philosophy didn't sell them, I know I had them by their budgets. I don't know whether my memo stayed attached to the contract all the way through state bureaucracy. I only know the contract was approved. (I had trouble paying the bill not because it was a contract with a religious group but because of my own stupidity and state bureaucracy. For some

unknown reason, the DD Council and Northspring Consultants split the contracts for these conferences. We paid the rent and food services. Northspring paid the professional services. Northspring paid its bills instantly. Our bills got screwed up in the bureaucracy of the State Comptroller. I publicly chastised the Comptroller and apologized to the K of C. Ironically, this incident pointed out the need to empower natural community support groups. They pay their debts on time. I only hope the K of C does not associate people with developmental disabilities with agencies that don't pay their bills on time. I won't split contracts anymore.)

With the place out of the way, we could focus on the who. It seemed contradictory to have service providers dictate invitations to other service providers to a series of conferences on empowering communities and neighborhoods. It was less important for service providers to hear this message than it was for key actors in communities and neighborhoods. Service providers are dependent upon support from people in communities. If we could influence these people, they would influence the service providers. At the same time, these people had no idea we were trying to recognize and support their role, so we couldn't appeal to them directly and expect a good response. The solution was to think small and practice empowerment. The people most likely to know who were key actors in their neighborhood were on the DD Council - people with disabilities and parents. We, therefore, shaped the conference around these people and gave them the power to determine who should attend.

Every DD Council ' member who was a person with a disability

or a parent was asked to generate a list of relatives, neighbors, friends or associates they believed should attend our conferences. At the same time, we used the Connecticut State Registry, and our computers, to develop a list of first selectmen and mayors and major generic service agencies (Kiwanis, Women's Clubs). A student intern was assigned to help Council members generate a list of invitations. By the time we were finished, we had several hundred names with a good mix of people with disabilities and parents, people from communities and neighborhoods and provider agencies. We used the Council members' lists first with our office-generated list as fallback to fill in for people who declined the invitation. The invitation was sent under Millie's signature but every letter had a penned note stating the invitation was being sent by so-and-so, their neighbor. (Staff actually penned the notes, but Council members agreed to putting their names in the notes.)

Response was slow and we did have to use our fallback list. We were prepared for 200 people but we had to settle for 100 to 150. We were not disturbed by the returns. We realized this was a new idea, unfamiliar to community people and somewhat threatening to service providers. In fact, we limited the participation of service providers and turned down several of their requests to participate. Even with this policy of limited participation, service providers amounted to slightly more than one-third of our audience. The best news was the good number of community people who participated.

The conferences went very well, and I'll touch on some

sidelights (not highlights) later. In other chapters, George tells you about some of the people who participated and John, David and Beth tell you about their vision. We captured it all on videotape. The video people, by the way, were from our Administering Agency and are jokingly referred to as WIDMR. The K of C Hall was especially fitting for John's church-like style of presentation and that feeling of being "born again." The Knights stayed up late and got up early to have the hall ready for us and the cooking was homestyle as well as abundant.

There are several other nice touches worth mentioning that enhanced a sense of neighbor, small and personal. First, George met John, David and Beth at the airport and each stayed in his home with his family. I hosted a beer and pizza session at my church with David Wetherou for a small group of people from the area. Finally, following both David's and Beth's presentations (John had to catch a plane), the Executive Director of our Protection and Advocacy Office invited David, Beth, and a few others over to his house for a beer. These little touches of hospitality are what neighbors are all about and we all gained a little more by getting to know each other better through the stories we shared. There is also now a hard core of people serving as "provocateurs."

D. Aid That Works

There is much to learn (or re-learn) both directly and

indirectly from John, David and Beth. You can teach yourself directly by reading their work and listening to what they have to say. While you are doing that, learn indirectly by making some associations with other things you have read and done as a professional and personally. You may experience some simple revelations. I want to share a few sidelights about John, David and Beth's presentations that are having as much of an impact as their direct teachings on what we are doing in Connecticut.

John McKnight, an urban philosopher, friend of Ivan Illich, another philosopher, speaks in the same vein as Rene Dubos, yet another philosopher, and E. F. Schumacher, an economist. They all talk about a conflict of attitudes (values) and they profess a return to certain basic "truths." In all genuine traditions of mankind, these "truths" have been stated in religious terms. Schumacher makes a particular point about values in the Christian tradition and he weaves in values from Hindu and Buddhist traditions. David talks about the unique identity and mission of a church community and the values threaded through the stories told by Garrison Keillor on The Prairie HOME Companion radio show, stories very much influenced by religious institutions in the mythical town of Lake Wobegon. James Lundeen's Christmas, The Christmas Story Re-told, he and Choir, Pastor Ingqvist's Trip to Orlando, Gospel Birds, Our Lady of Perpetual Responsibility Church, etc.) David went so far as to pay tribute to the show by naming his housing cooperative the Prairie Housing Cooperative.

Churches, synagogues, temples and mosques have become very important as natural community support networks for people with developmental disabilities. We are not trying to turn religious

institutions into social service agencies nor are we riding the wave of religious fundamentalism sweeping much of the country. (Even "yuppies" got religion.) We have simply (re)discovered "that old time religion" integrates people into community better than most social service agencies. The religious practice or denomination is unimportant. Jean Vanier communities are Roman Catholic in France, Protestant and Jewish in North America and Muslim and Animist in Africa. what religion has is, first, a doctrine of person that fosters a sense of respect and an honoring of each person with his or her gifts. Second, religion has a doctrine of community that facilitates the importance of friendships, ties and bonds with others. Third, religion has a doctrine of transformation where people feel and receive acceptance, love and affirmation for who they are, not for who they might, could, or should be.³ In Connecticut, we intend to use this power with people who have developmental disabilities.

Beth Mount credits her "interactive planning" process to the work that has been done to assist planning in Third World countries. Schumacher, Illich and Dubos also draw upon experience with Third World countries. Why not the developmental disabilities field? Can it be that we have more to learn from the development of effective aid programs in Third World countries than we can learn from professional seminars on project management, or seminars by trade associations in the disability field? Let's take a look.

A British government white paper on overseas development some years ago stated the aims of foreign aid as follows:

To do what lies within our power to help the developing countries to provide their people with the material opportunities for using their talents, of living a full and happy life and steadily improving their lot (Schumacher, 1973 : 163).

Substitute the name of any agency in the disability field for "developing countries" and we have the mission of philanthropic organizations and public and private agencies that give grants. After all, a grant is aid.

The similarity between aid for "developing" Third World countries and grants for developing services for people with developmental disabilities is striking. Poor people in Third World countries and people with developmental disabilities are both disenfranchised. Aid to developing countries goes into the big cities, largely bypassing eighty-five percent of the poor population, (Schumacher, 1973 : 164), while many grants in the disability field serve "the cream of the crop" bypassing people most in need, people with developmental disabilities. Rich nations benevolently impose a straightjacket of traffic jams, hospital confinements, and classrooms on the poor nations, and by international agreement call this development (Schumacher, 1973: 164). Agencies in the disability field create meaningless, monotonous work in sheltered workshops, and put large numbers of de-valued people in one huge institution, and call these development. Finally, both poverty and disability have been professionalized.

In my role as Chairperson of the Social Justice Committee of Christ Church Episcopal, I used some materials from Oxfam America, an international agency that funds self-development projects and disaster relief in Third World countries. In return

I received a 1985 special report from Oxfam America entitled "Aid That Works" that I have since used as a guide with our DD grant programs. It is appropriate for philanthropic and grant-giving agencies to take advice from Oxfam America, and how aid works in Third World countries, to effectively develop natural community support networks for people with developmental disabilities. According to Oxfam America:

"Aid works when:

1. It results in concrete material improvement in the lives of very poor people....

2. It encourages and re-enforces community life. If...sharing resources is a goal of true development, then aid needs to encourage building the community. After cooperatives are a pragmatic form of social and economic organization compatible with village needs and values....

3. It results in individual and group empowerment....The power of working together...is demonstrating that...groups can command the attention of government....

4. It effectively promotes self-reliance....

5. It spins off wider results, beyond the project itself. Aid that works should inspire others to join the exemplary self-help project, to carry it or to start something of their own....

6. It is efficient and of a manageable scale at the small community level!...Disbursing smallish sums of money and other resources, including appropriate technology, to enterprising-groups at the grass roots...is one of the most daunting tasks for all...development agencies....

7. It is channelled through real partnerships with local groups, especially at the village and middle levels of poor societies. It is one thing to acknowledge that paternalism and trickle-down aid have characterized too much of development assistance, it is quite another to have the inter-personal and inter-cultural skills to establish a relationship of equals with grass-roots groups, particularly when we as aid-givers have disproportionate power and material resources. Working through strong and independent-minded groups...who are close to people in villages, is one way to bridge the chasm." 4

Oxfam America suggests aid that works is based on a genuine, ultimately mutually-respecting relationship between people, and

always reinforces the natural yearning for self-respect.

Let's examine Oxfam America's approach further but draw parallels to the disability field.

Concrete materialimprovement in the lives. of VERY POOR people. Some people measure the success of grants in purely material terms: more new housing for people with developmental disabilities, number of jobs pledged or people placed in a job, fewer infant deaths..The quantative approach to learning if grants are working, taken by many grant-giving agencies, puts everything into dollar amounts. Whole bureaus of health planners are hired to decide what will be the value of a service three years from now. There are also social science methods that produce detailed studies of changes in material being or attitudes, by counting the number of people receiving a service or filling out long questionnaires. Of course another way to tell if our grants are working is to measure production. Take any sheltered workshop, for example.

When we visit a program we often wonder at all its material, fantastic complexity and immensity and the knowledge, ingenuity and experience within its walls. However, the program did not spring ready-made out of any person's mind - it came by a process of evolution. It started simple and became complex.

What we cannot see (the immaterial) on our visit is far greater than what we can see (the material). Are project participants increasing their self reliance? Are they true partners in the work of the project? Who participates at meetings? Do the parents speak out? Do only the professionals talk? Do people with developmental disabilities play an

important role? Do they become more and more integrated in their neighborhood? Do neighborhood associations include people with developmental disabilities in their membership? This stuff is beyond Individual Habilitation Plans.

Our tendency is to see and become conscious of only the visible, material disability service and facility and to forget the invisible, immaterial things that *are* making the visible possible and keep it going.

It may be that any failure of our grant projects, or at least our disappointment with the effectiveness of our projects to integrate people into their community, has something to do with our materialistic philosophy which makes us liable to overlook the most important preconditions of success which are generally invisible: empowerment and networking in one's neighborhood. If we do not entirely overlook empowerment and community networking we tend to treat them just as we treat material things - things that can be planned and scheduled and purchased according to some all-comprehensive plan. We tend to think of community networking and empowerment, not in terms of evolution, but in terms of creation. Planners seem to think they can do better than communities, that they can create the most complex things at one throw by a process called planning.

The people at Oxfam America beautifully describe material aid that works and aid that doesn't. I can draw no better parallel than by quoting Oxfam America at length:

"Aid that works is a dialogue: a caring, sharing relationship in which donor and recipient give to and receive from each other a greater sense of their humanity and their human potential...."

Material aid works when it gives a measure of critical support, the small extra margin, for poor people already on the edges of economic existence, helping them and their communities to explore and to take the important risks which growth and development require but which are so difficult for those who are already most vulnerable. Material aid that works tells the poor that others know and care about them as growing, working, struggling human beings. Such aid is a word of human recognition from the donor to the recipient.

In this dialogue, the recipient of aid also speaks words of truth and encouragement to the donor: truth about the hard realities, pains and struggles of life among the world's poor; encouragement at the small but significant successes of poor people changing their communities and fashioning for themselves the better lives they want.

By contrast, aid which fails is like a monologue or a lecture. Aid fails when the donor sees the poor merely as objects of charity, not active, creative people. Aid fails when the donor becomes concerned about flashy, large-scale rapid material results than about the dignity, humanity and growth of aid's recipients. Aid fails when the donor does not listen to the recipient, does not even assume that the recipient also has something to say about his/her world, and something to share about the meaning of life and human development.

Such aid is inefficient in promoting development because *it spends material resources in schemes which may seem wonderful to the donors, the planners, the aid agency, and to everyone else - except the recipients themselves, whose needs and desires for their community may differ from those of the donor" (OXFAM, 1985).

E n c o u r a g e s l i f f i i Most
philanthropic and public and private agencies see their grants as a sharing of resources. Some, like Developmental Disabilities Councils, see their funds as "seed grants" working together with other resources to leverage support for services. The question is whether these resources are building the community or separating people with developmental disabilities from their community.

Very often, human services are structured and provided in such a manner as to actually be an obstacle to those they *are* intended to serve. Such situations gave birth to the social role

valorization (normalization) movement. Much has been said, and done, about social role valorization, so there is no need to repeat the work of Wolf wolfensburger, and others, here. It is enough to point out that many of our traditional responses to people who are poor, disabled, elderly or otherwise socially devalued are actually counterproductive. Social role valorization, however, represents a set of positive principles that can be used to help guide the development and delivery of quality human services that are sensitive and responsive to people's needs. It has grown out of values-based convictions about society, people in need, and services to them and it is consistent with a vast body of research, empirical observations and major social theory. Using this approach encourages and reinforces community life because it emphasizes the use of tools, techniques and structures which are positively valued in society in order to enable people who depend on human services to lead culturally valued lives.

Using cooperatives is one way of stressing community values. Cooperatives are born out of community and are owned and operated by the community. Each co-op member is a valued participant. Later in this book, David Wetherow describe how cooperatives have restored "capacity" to people with developmental disabilities, how they have been used to support people in their neighborhoods and how they have contributed to their communities.

Individual and group empowerment. For any years, those of us in the disability field have been committed to a radically equitable access to services, rights and jobs for people with developmental disabilities. We have supported this struggle for

justice through the promotion of self-advocacy - on our terms. It is much more important, and difficult, to deal with its complement: the politics of self-advocacy - on their terms.

Ivan Illich would say that we professionals have expropriated life from people with developmental disabilities.

We have transformed pain, illness, and death from a personal challenge to a technical problem and thereby expropriated the potential of people to deal with their human condition in an autonomous way. The self-advocacy movement is a step to giving it back but we must now deal with what he calls "the politics of conviviality:" the struggle for an equitable distribution of the liberty to generate use-values and for the instrumentation of this liberty through the assignment of an absolute priority to the production of those professional commodities that confer on the least advantaged the greatest power to generate values in use (ILLICH, 1977 : XIX). In other words, the services needed, used and valued by people with developmental disabilities would be created and personally fostered by these people.

Let's look at ourselves through Illich's eyes.

"Let us first face the fact that the bodies of specialists that now dominate the creation, adjudication, and satisfaction of needs are a new kind of cartel...Today's domineering professionals...decide what 'shall be made, for whom, and how it shall be administered...Professionals...tell you what you need. They claim the power to prescribe...A profession... holds power by concession from an elite whose interests it props up...A new kind of health scientist is now much more common. He increasingly deals more with cases than persons; he deals with the breakdown that he can perceive in the case rather than with the complaint of the individual; he protects society's interest rather than the person's. It is no longer the individual professional who imputes a 'need' to the individual client, but a corporate agency that imputes a need to entire classes of people and then claims the mandate to test the complete population in order to identify all who belong to the group of potential patients...They enjoy wide autonomy in creating the diagnostic tools by which they then

catch their clients for treatment...Language...is thus polluted by twisted strands of jargon, each under the control of another profession..." (ILLICH, 1977 : 24-35)

Ten (10) years later a Harvard Business Review article on a study of non-profit and for-profit hospitals echoes Illich:

"While non-profit hospitals receive more social subsidies than for-profits, they do not achieve better social results. They are not more accessible to the uninsured and medically indigent..."

Non-profits...do more to maximize the welfare of the physicians who are their main consumers. These hospitals make large numbers of staff and beds available to the physicians, and they finance these benefits through social subsidies, tax exemptions, and delays in replacing plant and equipment. Today's physicians are subsidized by current taxpayers and future patients...

Non-profit hospitals do not inevitably improve social welfare in their communities..." (HERZLINGER and KRASKER, 1987 / 93).

While this article is about hospitals, the authors make the point that the hospital sector is only part of a larger debate on the appropriate roles for private, non-profit and public organizations and they call for "changing the way the game is played."

Counterresearch on fundamental alternatives to current prepackaged solutions is the element most critically needed. This counterresearch is a good role for DD Councils, albeit difficult. Councils would have to first of all doubt what is obvious to every eye. Second, they would have to persuade those who have the power of decision to act against their own short-run interests or bring pressure on them to do so. And finally, they would have to survive in a world they are attempting to change fundamentally so that colleagues among the privileged minority see the Council as a destroyer of the very ground on which all of us stand (ILLICH, 1977 : 78).

Individual and group empowerment does not mean disregard for the special needs that people manifest at special moments of their lives. It only means that people have a right to live in an environment that is hospitable to them at such high points in their experience (ILLICH, 1977 : 125).

E. With Whom Do You Stand?

Call it coincidence but strange things happen when you start hanging around religious types. In our case, the DD Council just happened to find some money to bring McKnight, Wetherow and Mount to Connecticut and Beth Mount just happened to move to Connecticut. Most recently, the U. S. Congress, and the President, signed a budget bill that channeled considerably more money to the Connecticut DD program than we expected. We felt it would be appropriate to use this "godsend" to further the development of natural support networks in communities and neighborhoods. This objective isn't in our state plan but it will be in our amendments (if we must, in fact, submit amendments).

First, we have contracted with Northspring Consulting to apply John McKnight's "bridgebuilding" model over a three year period in three neighborhoods around Connecticut. Northspring will use some of our funds to produce an edited version of the tapes we made of the McKnight, Wetherow and Mount presentations. These tapes will be used to encourage communities to develop natural support networks for families and individuals in their neighborhoods. Northspring will also bring John and David, and some of the families David works with, to Connecticut to work with and encourage people from neighborhoods.

Related to Northspring's work, we have contracted with Beth to work with six individuals and families over a three year period on positive futures planning. In addition, Beth will be working with individuals or families in Northspring's experimental neighborhoods. The stories that arise from the families Beth works with will be used by the DD Council as indicators of the changes needed in the state's system of services.

Third, the DD Council has set aside funds for any individual, group of people or agency interested in developing cooperatives around any individual or small group of individuals. David Wetherou is expected to provide consultation to these co-operatives. Beth and John may also be available. We know it is a risk. We do not intend to "create" cooperatives but only to stimulate their evolution.

Finally, all DD Council members and staff are going through values-based training.

It should be obvious we are serious about making change.

The DD Council will realize several associated benefits in developing natural community support networks. First, the people Beth and George will be working with are potentially new DD Council members. They are also likely to be thinking "progressively."

Second, Altrusa Clubs, Big Brothers, civic groups, the Druids, Eastern Star, firemen, Girl Scouts, 4H, and others, are a whole new set of "private providers" that might be more important DD Council members than the state and local "society in favor of disabling deficiencies."

Third, there are untold stories to be heard and these new stories will yield what really needs to be changed in the state's system of services.

Finally, from this new approach will evolve yet another new philosophy about people with disabilities and their families. No one knows what that might be, but we look forward to the unknown with enthusiasm.

There is a major risk in taking this new road. Half the DD Council membership are parents or people with disabilities; the other half are provider agencies. It will become not a matter of where you stand but of with whom you stand.

F. POSTSCRIPT TO PAPISTS, PROTESTANTS, HEBREWS AND HEATHENS

The role of religion in my chapter may be too much for some and a surprise to my colleagues. I am not an Evangelist but too many "coincidences" have just sort of happened since embarking in this NEC direction and the writing of this chapter. The day I finished writing this chapter, George happened to stop by my office. We shot the breeze about various projects he was carrying out for us, including a project to assist the Connecticut Traumatic Brain Injury Support Group with setting new priorities. George reported having met with the Support Group's relatively new executive director, a former Roman Catholic Seminarian (like George). This exec happened to be a friend of The Rev. Henri J. M. Nouwen, a reknowned spiritual writer. Henri Nouwen is currently a priest-in-residence at Daybreak, the l'Arche community in Toronto. George and I talked about linking the Support Group exec, Nouwen and Jean Vanier (l'Arche Community) for a future gathering in Connecticut. In that

evening's mail, I received the first edition of a publication I subscribed to just two months ago - The. New Oxford Review, a liberal theological journal. One of the articles in the journal was by Henri Nouwen and was the fourth installment in a series of articles about his reflections while in residence at 1'Arche. Coincidences?

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