DISCOVERING COMMUNITY:
Learning from Innovations in Services to People with Mental Retardation

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Introduction

The past twenty years have seen many changes in the location, focus and sponsorship of services to people with mental retardation. Large and increasing government expenditures have resulted in substantial growth in the number and variety of available services and service providers.

Like any complex social change this can be explained as the expression of positive and negative trends. Positive forces which are often identified include: increasing numbers of well organised advocates dissatisfied with institutional living conditions; improving skill in asserting the need for changes in terms of service user's legal rights; growing expectations of the power of developmental interventions;and heightened consciousness of service values. The shadow side of these changes has been shaped by the relative shortage of desirable service options, the expansion of new forms of social control (Estes, 1982), the commodification of people with handicaps, and and the increasing professional'ization and bureaucratization of responsibility for people with handicaps.

"Community" is a central, ambiguous word in discussions of these changes. Sometimes it means that a program or a person is located in a settlement rather than within an institution ("We are moving into the community, but we can only serve a few community clients.") Sometimes it paints out the direction of a program's effort ("The community diagnostic clinic is at the state instituition.") Sometimes it denotes sponsorship by a local agency instead of a state authority ("We are shifting funds to community providers.") Sometimes it defines people who are not service providers or recipients ("The community isn't ready; they need public education.") Sometimes it describes the desired quality of personal relationships within a service program ("Our facility itself is a community.")

The debates, plans and practices that give rise to these meanings of "community" outline the context for this chapter. Within these meanings, we will look for still another sense of community. Larger scale changes in service sponsorship and program location create opportunities for new relationships among people. Growth in number and kinds of services provides the occasion for development of the competency to make better use of available resources.

Developmental I doesn't necessarily nillow growth The recent experience to a large number of people with mental retardation is better described as movement from one land of institution to another than as community integration. Many community alternatives perpetuate undesirable practices such as deprivation of purposeful activity, isolation from ordinary places and people. crowding. lack of choices and failure to provide for individualization. Some settings are outright abusive and challenge people with mental retardation to adapt to bizarre environments for example, see Bercovicci. 1983; Goode. 1983; Landesman-Dwyer, 1984). These are differences from state operated institutions that make little human difference. There is much to learn from these failures and much to be done to overcome their bad effects (see Shadish, 1984). While acknowledging these failures, this chapter focuses on what we can discover about community from the dilemmas and accomplishments of some currently successful mental retardation services.

Tins paper focuses on a set of small scale issues that emerge in service programs where the Question is not whether to support people in community settings but how to develop the competence to do it.Pol icy debates over the place of conqreqate institutions in a desirable future are far from finished. Powerful interest groups are in conflict over who should be segregated and how segregating facilities should be financed (see U.S. Senate. 1984). The outcome of debate on such big issues is vitally important, but this chapter won't attempt to win the point. Instead, some policy issues are framed by the experience of these innovators.

The problems and the possiblities in our current situation are well described by two people who use resdential services. They were interviewed during a needs assessment conducted for the California Council on Developmental Disabilities by members of People First of Sacramento, an advocacy group whose members are or have been mental retardation service users.

> "The last place I lived. when I came back from being away one time they told me they wanted my stuff out...and basically they said it was because they weren't being paid enough. So ever since I left home I had to worry about somebody being paid to take care of me and that's still the way it is. So that's why a job is so important to me, because I'd like to get into a situation where I can say, "Wow, I did something for myself. The state didn't do something for me. They didn't make sure I lived. I made sure I lived."

"... But the difficult thing was it seemed like wherever I tried to go people wanted me for the money instead of myself. They didn't want me for my individuality but because they knew they were going to get paid to take care of me... And the last time I just got fed up and when I found out about the independent living program, I said, 'I'm going to learn those skills!'... At first I thought it would be the same with them. But they didn't want me just for the money and they did give me all the support that they could so I could move out on my own and really believe in myself that I could make it."

(People First of Sacramento". 1984)

The Sense of Community

This paper explores the meaning of community which emerges from the work of innovators who aim to renew and strengthen the relationships between people with mental retardation and the patterns of ordinary life. Following Sarason (1974), we will explore some of the effects of mental retardation services on the sense of community. This is "the sense that one Cis3 part of a readily available, mutually supportive network of relationships....(p. 1)"

Community cannot be manufactured; it is not a commodity or the reliable outcome of any professional activity. It arises when valued personal involvements with a network of others gives rise to purposeful action and celebration.

If we believe that community, involvement in mutually supportive relationships, is vital to living well, there is much to concern us in our present practice. A study of the social relationships of a respresetative sample of people with mental retardation in residential care reports that about 83V. of the residents of community operated facilities operated and about 967. of the residents of state operated facilities have no social contact with non-handicapped peers. About 427. of the residents of community facilities and about 637. of the residents of state facilies are reported as having no personal friends or special relationships (Hill, Rotegard & Bruininks, 1984). Analysis (Flynn, 1984) of the consistency of 205 community residential programs with the principle of normalization demonstrates that programs are present in communities (they achieve a mean score of 607. on items related to the location and characteristics of the setting) but that their residents are not well supported to participate in community life (they acheive a mean score of less than 40% on items that measure program quality).

Human service programs can't produce a sense of community. But they can influence its emergence.

- Community depends on a broad network of personal relationships. Programs that segregate people on the basis of differences like mental retardation stunt the growth of personal networks. Programs that promote new personal relationships for people with mental retardation across the boundaries of prejudice discover community.

- Community is based on people's common desires for decent housing, good work, opportunities to learn, mutual support in difficult times, friendship, intimacy, and celebration. Services that transform these ordinary desires into commodities that can only be properly supplied to handicapped people by professionals encourage passivity and and create a scarcity of "appropriate" professional resources (Illich, 1980: McKnight. 1979). Programs that recognize ability in many community members --including people with mental retardation and their families-- and distribute information, authority, and tools widely build community competence.

- Community depends on people's ability to use conflicts with one another to learn forgiveness and restitution and to seek the best balance among conflicting purposes. My membership in community is more than support for me; it is also a legitimate claim by others on my time and energies (see Christie. 1977 and Vanier, 1982). Programs that try to insulate people from conflicts by rationalizing them away or silencing or exiling the people who occasion the conflict undermine the emergence of the sense of community. Programs that trust people's ability to learn from their conflicts promote development.

The sense of community provides a guide for programatic efforts. Those who are serious about building community find themselves engaged with three related themes: the search for new relationships between people with mental retardation and non—handicapped others: the search for right use of authority. information, and tools: and the search for productive conflicts.

The Management Dilemma

Human service planners and providers who value community are entangled in the management dilemma: we desire community but we can't produce it as the reliable outcome of a professionally controlled process. Most of our images of a managed process include authority, standardization, and definitehess. We couldn't require mutually supportive relationships, even if we had the authority to order them. Dispersing information, authority, and tools increases the variety of ends and means that people choose rather than standardizing them. Engaging the many cross-boundary conflicts that arise from community increases uncertainty about the nature and timing of outcomes.

The dilemma is compounded by the often implicit assumption that human services should be managed as if they were factories. For illustration these assumptions can be cartooned like this: Administrators are accountable for the routine implementation of cost beneficial policies which will solve handicapped people's problems because they embody an expert knowledge of the best solutions. Service recipients are planned for as input to a continuum of services through which they flow until they are output as salved problems. Service providers proceed from a multi-discipiinary assessment to write and implement a comprehensive individual program plan. There are two primary limits on satisfactory outcomes: poor management and scarcity of resources. Mangers are not effective because they lack the training, the authority, or the will to get things done. Insufficient funds are allocated to give everyone in need access to the solution to their problem. There has not yet been enouah scientific research to identify reliable solutions to every problem. There are too few adequately trained professional problem salvers available. People outside the service system ("the community") should pay for the system's preferred solutions and cooperate in their implementation. When the community neglects its responsibilities it is resistent; the community then becomes the client of professional public educators and attitude changers.

These assumptions lead to actions that detract from community. They are also a poor description of the current situation.

- People don't flow smoothly through the service continuum to independence (Bellamy, 1982; Schalock, 1983).
- Even in small, adequately resourced,well managed demonstration projects a bit less than forty per cent of the six month goals defined in individual plans are accomplished (Humphries, 1984).

- At the state of the art. available technical help is unpredictably effective. That is, available technology can reliably assist people with all levels of disability to do many things that would have seemed impossible less than a generation ago. But the effects of such assistance on people's life experience and extent of future reliance on funded services can't be predicted.

- Administrators are not at the apex of a simple hierarchy. Policy decisions are seldom implemented as written. Changes must be negotiated with many constituent groups, often including people in subordiante positions.

The managerial dilemma can't be resolved just by collecting more resources, amassing greater authority, doing more research, drawing better blueprints, and kicking more behinds. As Kanter (19S3) paints out. not even factory managers can successfully run their enterprises mechanistically. Even less could they do so if they accepted the complexities of managing human services. Pursuing "more of the same" seems to tighten the bind imposed by the managerial dilemma.

There does not seem to be an honorable way to resign from the managerial dilemma. It's a romantic notion to suggest that if specialized providers and bureaucrats just went away all would be well for mentally retarded people. We don't just have services; we are a serviced culture. Many people with mental retardation benefit from well thought out assistance and suffer from commonly held prejudices. People don't make mutually supportive relationships with those they see as appropriately belonging to the other world of 24 hour clienthood. In modern times, before there were specialized institutions there were almshouses and jails. After the mental retardation service system left the lives of some mildly and moderately handicapped people, they found themselves in such atypical settings as nursing homes, state mental hospitals, and jails (Haywood, 1981). Trying to "put it back the way it was before there were services" offers room for much conversation and little action.

The way to live with the managerial dilemma may be to learn through it. Exploring in action what it means to want what can't be manufactured increases understanding of the real limits of professionalized service and the real possibilities of enabling mutually supportive human action. Personal knowledge of people whose deficiencies don't disappear in the face of our best efforts clarifies the meaning and opportunities for service. Thinking deeply about the seldom challenged assumptions that shape the present can give us a better way to face the future (see Minneapolis Citizen's League, 1984). Such learning challenges us to revise our mental maps to allow more room for ignorance, uncertainty, error, and paradox. Negotiating these revisions increases stress, conflict, and opportunity (McCaskey, 1982).

Learning Our Way Through

Within trends measured in billions of dollars of public expenditure, tens - thousands of people with mental retardation. and thousands of service programs, there are many small patterns of significant change. The importance of these changes does not lie in the numbers of people they effect but in the issues they define and the possibilities they create. If they are influential it will not be because they have discovered the answers but because they have changed the ways to put the questions.

Two Kinds of Change

Human service organizations can be said to change in two distinct ways. One kind of change (first order change) happens within a system without changing the system's basic structure, assumptions. and values. A program that improves its efficiency in using staff time to achieve its defined mission is changing this way. People detect and correct errors defined by existing values. They learn how to do the same thing better. The other kind of change (second order change) changes the system's structure, assumptions, and values. A program that changes its mission and design based on a new appreciation of people's possibilities is changing in this way. People not only change how they do things, they change what they attend to and how they evaluate situations. They learn how to do new things. (See Schon, 1983: Seidman, 1984). Finding a faster, easier way to dig the hole you are standing in is a first order change. Reconsidering where or whether to dig is a second order change.

Note that the distinction between these types of change is not the size or the planfuless of the change or the quality of the outcome but its nature. First order changes -—such as the United States' continuing rebuilding of its institutional system— can be extensively planned, very large and consume massive amounts of money. Second order changes -—like Jean Vanier's decision to share his life with two handicapped men, which led to in the development of the L'Arche movement— can be very small and unplanned, especially at inception. One kind of change isn't necessarily better than the other. First order changes can produce many benefits and second order changes can lead to disasters. Second order change doesn't create a problem free environment so much as it reorganizes the kinds of problems people attend to.

Ackoff (1974) observes. "The failures of society and its institutions derive more from their failure to face the right problems than from their failure to solve the problems they face." The management dilemma creates a context that calls for us to face new problems. Actions based on more of the same or trying to move things back to a desirable past are unlikely to be satisfying. We will consider three examples of second order changes. None is the answer to all our questions. Each represents an illuminating shift in a common pattern of assumptions about service to people with mental retardation.

Where Do We Look for Security?
Re-orienting Service to Children and Families

For many years in Kingston. Ontario. like most places in North America, children whose situation is described with terms - like "medically fragile" and "severly. multiply handicapped" either lived with their families or lived in an institution. By t981. The Kingston and District Association for the Mentally Retarded (KDAMR) had created another choice in the form of two group homes which each had room for five children who were institutionalized because of their complex needs. Setting up the homes to provide a good program for the children. insure parental support for their son or daughter's move out of the institution, and gain the necessary sanctions and funding was a major accomplishment. The homes operated successfully until November, 1982 when most of KDAMR's employees began a strike which lasted seven months.

This emergency became the occasion for intense learning for the children and their families and KDAMR staff. Each child went home with a family for the duration of the strike: five rejoined their natural families and five lived with other families. It was a time of worry and stress. It was also a fluid time. In cooperation with the Provincial Ministry of Community and Social Services, per—diem funds which had been frozen into buildings and routine staffing flowed into new supports. Two supervisors and three (later six) staff assisted families at home and recruited neighbors to help. The two supervisors also shared their own homes with two of the children.

When the strike was over, some of the children's parents wanted to continue to develop a new kind of family life. Previous arrangements faced families with a hard boundary: a child is either in residential care, perhaps with occasional visits home and parent participation in some decisions, or at home, perhaps with occasional respite and other family support services. Residential care promised security at the cost of separating families and children. Though different from the institution in many ways, KDAMR's group homes provided "more of the same" along this critical dimension.

The strike threatened the promise of security and offered a different way to be a family. Families can have an integrity that includes both the central place in raising their children and participation in intensive, flexible relationships that offer a variety of supports. Like other family forms that don't fit within the boundaries of "mother and father and two children in one house" it's hard to find words for what those who learned through the KDAMR strike have come to want. Like other service forms that don't fit the pattern of "this per-diem for that bed to meet those determined needs" its challenging to find ways to provide resources for and manage necessary assistance.

Five children returned to live in one of the group homes. Five children and their families joined three full time and four part time staff whose stated mission is "to provide as much support as needed to Angela, Matthew, Greg, Gary, and Michael, so that they can be with their families as much as possible." As of February 1984, Angela lives in what used to be the group home and spends most weekends with her family. The other children live with their families. Staff share responsibility with the chil-drens parents for varying amounts of practical assistance, in-struction, care for both handicapped and non-handicapped chil-dren, and support for friendships with non—handicapped peers.

Efforts to transform the Mowat Sreet group home aren't fol-lowing a blueprint. Development follows it's participants learning the application of basic principles, including these three committments (from KDAMR, 1984):

- Parents who have had to dis-integrate their families (send a child to an institution), should be able to experiment with bringing their child home, with support, and without burning the bridge of the group home they left behind.

- Above all else, children should not have to choose bet-ween receiving the special assistance and teaching that their handicap requires; and the love, affection, per-sonal security and opportunities that family life offers.

- Support and assistance must be flexible to respond to changing family circumstances and requirements. Flexibility is the ability to instantly shift between natural family life, associate family life, and group home life without discontinuity of relationships.

In reflection on the changes Fillmore (1984), summarized some of the differences between past and present efforts like this:

	TREATMENT WORLDVIEW	MOWAT WORLDVIEW
What's the problem?	-Child's handicap: medical fragility. -Parental inability.	-Discrmination. -Lack of supports. -Consequent in-ability to cope.
Where is the problem?	-In the child. -In the family.	-In environment.
What is the solution?	-Classify. -Place in special environment.	Support as needed to help families stay together.
Who is in charge?	-Professionals	-Familes with help from support staff.

This amounts to a new perspective on people and service (see DeJong, 1979) which is shared by a growing number of families and a growing part of the organization that serves them and their children. Effort is focused by personal knowledge and flexible, action. Their response to an emergency gives a different form to the desire for security and appropriate assistance: security isn't represented only by a building but by a growing network of people who earn trust by their actions. It seems reasonable now to take the risk that this apparently fragile arrangement may be stronger in the long run than bricks and mortar.

Whether the benefits are worth the risk depends partly on the ability of the people who are directly learning new meanings for family, support, and service and partly on the capacity of the larger service system to invest its resources flexibly, without destroying local initiative.

What's My Job?
Redirecting an Agency

Perhaps the most common image of a community residence for people with mental retardation is of a group home. There are debates about who can be suitably housed in a group home, how they might best be financed, who should sponsor and staff them, how large or small they should be, and where they should be located. But underlying these important differences in policy and practice are some common assumptions.

- An agency acquires and manages the building.
- Staff are employed by the agency.
- Housing is offered along with other services such as instruction, supervision, and personal assistance in a tightly connected package: the residential program. It is not usually possible for a person to refuse services and retain tennancy. Sometimes program regulations call for eviction from a residence if a person stops attending a day service.
- Usually the person with mental retardation contributes only a small part to the program's costs from discretionary income. Most program costs are paid by a third party who may bundle several funding sources together to make up a daily rate per person.
- Reimbursement rates are often justified by a scheme for determining a person's "level of Cneed for care". This frequently results in grouping people with similar needs in the same place and paying more to serve people who are less able. It creates the expectation successful programs will decrease people's need for care and that they will move to new, less costly, arrangements as their assessed level of need changes.
- People often assume that different types of buildings match different degrees of handicaps..The most able people live in apartments. The least able people live in congregate health care facilities. The people in between belong in group homes.
- People are "admitted" to a "bed" as "residents" or "clients" and receive "residential care" or "active treatment" or "programming". At the conclusion of their stay they are "discharged" or "demitted" or "graduated" or "referred or transferred to a more appropriate program."

- An agency. not the people in residence, holds the property's lease, mortgage, or title and owns most of the furni shi ngs.

In a sense. people with mental retardation are guests in someone else's home. guests whose role is to cooperate with the host's program of care and treatment. Adults who need extra assistance and want their own homes face a difficult choice: Either be in a, program and have help or be out of a program with very limited, assi stance.

These" assumptions are expressed in organizational mission statements like these:

> "The ultimate aim of this, program shall be to foster those behaviors that maximize the human qualities of the resident, increase the complexity of hi-s behavior, and enhance his ability to to cope with the residential environment."
>
> "This agency will be a provider of sheltered living and training in basic living skills for persons with a history and who have' a high potential for completely independent living."

A growing number of "agencies are challenging these assumptions in practice. This mission statement captures some of the differences from the typical pattern.

> "The mission of Options in Community Living is to provide support and coordinate services to enable adults with developmental disabilities to live on their own in small, integrated community settings. The agency works with people to heko them make their own choices and reach their own goals, with support available as often and for as long as it is needed."

In 1978 Community Living, an agency which operated group homes for a total of forty to fifty people with mental retardation in Yakima, Washington, turned a routine problem into an opportunity for basic change. A number of serious problems in the physical plant seemed to call for costly repairs. The agency's leadership redefined the situation from "how to fix up our buildings" to "how to use our staff resources to help people have a more self—sufficient life in their own apartments."

This fundamental change required a renegotiation of basic agreements with residents, a number of active parents, staff, and the state Division of Developmental Disabilities. Concerns for people's safety and comfort and a desire to involve residents more in decision making guided the location of affordable apartments the definition of new staff roles and schedules and the focus of resident training during the relatively brief transition peri od.

Those involved remember the months of transition as a time of hope and anxiety. There were high expectations and a great deal of uncertainty. The residents, most of whom are described as moderately mentally retarded, were accustomed to a large group setting with continuous staff presence. Making the transition within the existing budget meant that though there would be staff contact every morning and evening, most people would not be with staff overnight.

These uncertainties led to careful thinking about each individual and each pair of roommates and the invention of a number of aides and routines to insure safety. Staff were readily available on call at all times and slept on people's couches as necessary. The five people who experienced the most difficulty with self direction moved into a staffed house together. All the rest sucessfully made the transition which one person described like this, "I was a resident for a long time. I thought I'd always be. But now I'm a tenant. We have our own place. Some ways it's harder but I like it better."

One day all of the people served by Community Living "needed" to live in a group home. The next day they did not. The first move toward change was made by the agency and its staff. Reorganizing their resources around new assumptions created different opportunities. Committment to the idea that people should have the support they need to live in their own homes set off a new process of learning for everyone.

Some of the effects of change are evident in staff role differences.

Before the change staff spent almost all of their time supervising and doing things for groups of people within the homes and doinq housework. There were well established routines and close oversight by supervisors. Group outings were common but, except for taking people to appointments. it was very rare for staff to go anywhere with one or two residents. Residents had individual plans but movement toward independence was rare even for those who were "ready" because there were no available programs. All residents had training objectves but there was only time to implement a few teaching programs.

In the period immediately after the change staff spent much more time problem solving with tennants and teaching skills which are functional in their homes. With some people, staff monitored and supervised, and assisted with daily living tasks. Most people needed assistance in learning their way to day programs, exploring more individualized leisure activities, and using local service providers. A great deal of effort went into helping people find their way around their own neighborhood and meet at least one or two of their neighbors- Individual goals are defined more by people's response to real situations and less by checklists and tests. Staff assumed greater responsibi1ites be—

came much more self-directed, organizing their own schedules and developing ways to deal with novel situations.

As time has passed. most people have grown comfortable and competent in their homes and their neighborhoods. And new issues have emerged. Staff are concerned with how to better support, tennant choices, especially in situations which involve some risk, and disagreement between tennants and staff. They are seeking a better balance between teaching new skills, providing support, and letting people get on with their lives. They want to increase the continuity of people's relationships and deal constructively with the fact that a number.of people have very few relationships with non-handicapped people other than staff. They want better working conditions including adequate pay for their considerable responsibi 1 ities.

The reorganization of Community Living has been possible because the agency's leadership has been open to taking on new problems. They have overcome bureaucratic prejudices against uncertainty and error and thereby opened the way for new learning. There has been much negotiation with funders and regulators to maintain the resources for continued development.

The larger system has been responsive to the initiative of Community Living and other agencies seeking to provide a new form of service. The Division of Developmental Disabilities has created a rapidly growing program category called Tennant Support to fund and regulate the growing number of programs committed to assisting people to live in their own houses and apartments (Co>:, Drake, &c Johnson, 1983). Though there are contentious issues between providers and their funders, Washington's Tennant Support program is a good example a how a large system can promote innovation.

Finding a New Base for Assistance
A Redesign

The Prairie Housing Co-Operative (PHC) in Winnipeg, Manitoba, was founded in 1983 to develop new social roles and new' personal relationships while providing its handicapped and non-handicapped members with affordable, congenial housing which is cooperatively owned. Though PHC was founded by people with personal concern for people with devlopmental special needs, it is not a human service but a cooperative based on traditional principles of mutual ownership, mutual effort and support.

As of April 1984, PHC has purchased eighteen units of housing in five separate neighborhoods. The cooperative provides housing for fifty-seven people (including children). Ten members have handicaps; most of the handicapped adults have previously lived in institutions and community residential services.

PHC is organized on a neighborhood basis. Each neighborhood includes several households which share Co—Operative membership and a common concern to provide a circle of unpaid, neighborly support to one or a small number of members with disabilities. PHC does not provide any paid service or support to any of its members. Members who need assistance beyond that given by their circle of neighbors and friends use other community services.

PHC's economic base is the provision of Canada's National Housing Act which provides housing cooperatives the means to get very low interest loans and.allows a rent subsidy for low income members.

The work of PHC's founders is a leading example of the process of redesign. Rather than work within the context of existing service forms to create practices which disclose new assumptions, they have carefully planned and nurtured the development of a new context for relationships and action.

By design, PHC offers people with handicaps new, positive social roles. They are not the clients of their homes but cooperative owners of them. The co-operative form of ownership has a long, positive tradition in Manitoba; it isn't just for people with handicaps. Members with handicaps participate in decision making through general meetings and seats on the govet—ning board. They have opportunities to give and receive personal support among a circle of neighbors

As an organization PHC faces the dilemmas of early success. For instance, people want PHC housing for themselves and their handicapped friends and family members. But the co-operative must stay small to preserve its values. It's members are struggling to decide how much they can grow and at what rate. There are no clear maps to chart a certain course through these questions. Members have an important opportunity to keep learning together.

PHC members face many human difficulties. Living out personal concern for one another can be a joyful experience. It can also be tiring, sad, confusing, and anger provoking. But the nature of their relationships with one another transforms the management dilemma. Members don't face the problems of clienthood among themselves.

Toward a Way *to* Change
Reflections on The Examples

One image of the way to change assigns initiative to the people at top of the system. In consulation with experts they design a policy and embody it in a law or a regulation or a court order, often they invest in creating and documenting model programs, they find the resources and the authority to implement change, they insure the provision of technical assistance, they monitor performance, evaluate outcomes and revise. None of the three examples of important change that we have just considered developed according to this image. But each seems to have made some room for an increased sense of community. There are some hints of another image to promote constructive change among'their common features:

- Each is small and vulnerable to being dismissed as nice but insignificant in light of the magnitude of the problems we face.

- Each is new and changing. None has proven that it can maintain its unique values beyond the exciting moment of invention.

- Each is the result of local action by a group of leaders who share a common vision of what would be desirable for people with handicaps and their communities. These are not the stories of heroic lone rangers but of small groups that work together to make change.

- The basis of each group's vision is the principle of normalization (Wolfensberger & Glenn, 1975) together with commitment to finding the meaning of these principles in the lives of specific people with handicaps- Each change is to bring about new relationships, choices, and competencies for unique people.

- Each change questions common assumptions and measures of performance. It may implement a system's goals --say for services that restrict people as little as possible— but it does so in a way that is unlikely to be captured by routine monitoring and reporting mechanisms. Indeed, this sort of change is an irritant to established procedures for insuring accountability.

- There is strong initiative in each situation. Ordinary problems are re—framed to create the occasion for fundamental change. The leadership group is active in re-negotiating the terms within which it works to protect and expand the changes they want to make. None of the people in these examples are waiting for direction or permission from above.

- The people who are leading these changes have a claim on the systems they work within. In each situation at least some of the leaders have been successful at the routine work of their system. In all of the examples the quality if not the continued existence of the change depends on the larger system accommodating to the change.

- None of these changes claims to be a blueprint for large scale or a model program for replication. But people in each situation are confident that others can learn from their experience and actively seek the chance to share their discoveries.

- Some of the leaders in each situation have strong ties to a network of people working toward similar changes in other places.

- Leaders in each situation have an acute sense of the risks they are asking people with mental retardation to take. They are less likely to try to reduce risk through pre-planned procedures than through increasing awareness and engagement with problems as they develop.

Some Concluding Thoughts for Us as Policy Makers

Analysis of the kind of change that seems to enhance the sense of community offers policy makers four bits of advice for reflection. This advice is intended those who govern agencies, and local, county, state, and federal levels of government. This seems as necessary as it is presumptuous since all of the systems governors are met as constraints or assistants to many significant developments.

First, there is no substitute for personal knowledge of people with handicaps. The most critical issues in discovering community are better and more easily understood in the context of a personal, neighborly relationship with people and families that live with handicaps than from expert testimony or library research. Community can't be done at a distance. Those who are engaged in building community are personally involved. Those who are distant don't know what can be done no matter how much valuable information they may have about constraints on action.

Second, there are many illuminating small examples of respect for the sense of community in practice. Expert advisers and model builders should search for them and learn from them.

Third, it may be more important to remove disincentives to promoting the sense of community than to try to order its creation. Some disincentives to community can be identified: [1]

- Segregation destroys the web of personal relationships that are community. It should be possible to decrease the rate of investment in segregated settings over time. It is immediately possible for each of us to expand our own relationships to include some people who are vulnerable to exile.

- Policies that encourage hoarding of information, tools and skills need to be re-evaluated. The frequent legal insistence on professional credentials and procedures as necessary for making important judgements is counterproductive. Personal, not professional knowledge, is the foundation of community.

- There are powerful incentives to concentration of authority, which undermines the personal action necessary for community. Instruments for funding and insuring the accountability of expenditures need careful examination to identify and neutralize preverse incentives. We can struggle locally to invent ways to limit the harmful effects of these incentives. Perhaps we can find ways to design them out, as the founders of the Prarie Housing Cooperative have done.

Fourth, it is worthwhile to make room for change. This means recognizing and accommodating to the positive changes that do arise and resisting the pressure to trap their inventors in the management dilemma ("This is wonderful. Can you deliver 500 just like it in Los Angeles next Wednesday?")

Like all advice, this is more fun to give than to take.

Conclusion

Community is precious. We can learn much about its fragility and its strength from taking care to understand the lives of people with mental retardation. We can promote the sense of community if we develop the competence to overcome our habits of segregation, professionalization, and bureaucratization on even the smallest scale. Discovering community means testing the everyday assumptions of the service world through action and ref1ection.

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