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THE DEVELOPMENTAL DISABILITIES PLANNING COUNCIL

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Dr. Colleen Wieck
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Dear Colleen:

Here is the paper that I talked to you about. I would be very appreciative if you could look it over and tell me what you think.

I am asking you the favor of reading it because you will both know the relevance, if any, of this for our colleagues, and that I can depend upon you to tell me the blunt truth. If it doesn't make sense, tell me. If it seems like it might be worth sharing through the National Association of Developmental Disabilities Councils, I might send a copy to Susan Ames-Zierman.

I apologize for sending you something so lengthy, but perhaps this will explain what I have been up to here.

Warmly,

A handwritten signature in dark ink, appearing to read 'David'.

David B. Schwartz
Executive Director

DRAFT III
3/6/86

RE-VISIONING DEVELOPMENTAL DISABILITIES COUNCILS:

NEW OPPORTUNITIES IN THE MIDDLE KINGDOM

David B. Schwartz
Executive Director
Pennsylvania Developmental Disabilities Planning Council
January, 1986

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"If the misery of the poor be not
caused by the laws of nature, but
by our institutions, great is our sin."

-Charles Darwin
Voyage of the Beagle

I. The New Conceptual Revolution in Developmental Disabilities

"Perhaps we need to distinguish between what we believe and what we will end up doing that violates our belief; and between the weaknesses of two imperfect, fallen helping forms: the formal organized helping form will almost certainly deteriorate to perversion and abuse; the informal human helping is more apt to terminate and be unstable. What drives us to insist that stability is worth more than the benefits of informality, and more worth the risk of deterioration to abuse than the risk of discontinuity?"

-Wolf Wolfensberger

Some mornings in the wintertime I stop to drive out the cold with a warm breakfast at the counter of the Alva Restaurant, a little family-owned place across from the train station in Harrisburg. Like most diners it is a community center of sorts. Each morning finds the same people trading the same banter back and forth. Over to the side of the counter a special table is reserved for the railroad workers' coffee break. You get the impression that trainmen have been drinking coffee there since the Alva was founded in 1916, and it is probably true.

Every Tuesday morning at ten a long table is set up in the restaurant's dining room. A group of fifteen or twenty men, all obviously retired, filter in and spend an hour or so talking over coffee and a danish. Finally, one day, I got curious and asked the cashier who they were. They turned out to be retired trainmen. Having come to the Alva together for so many working years, they had continued to unite their old work crews once a week at the old place. They saw their old friends, and they got out of the house. Their warmth and ease with each other was readily apparent.

A sociologist might refer to these trainmen's Tuesday mornings as an example of an "informal associational group." All that this would mean is that it was an example of the countless, semi-structured groups that serve as associational "glues" to hold society together, bonding us around various purposes with each other.

If one did a study of the effect of the Alva group upon the member's lives, you would undoubtedly discover greatly significant results. In our culture retired people are subject to great loss of meaning in their lives, and consequently to increased risk of depression and probably physical decline. Yet the Alva "geriatric program" requires no funds, no professional supervision, no requests for proposals to be mailed out and reviewed. In fact, the professionally-supervised "adult activity centers" across town seem and are empty and juvenile by comparison.

Finishing up my coffee, I muse on the fact that my task at the office today is to develop formal program funding in the State for not dissimilar needs. The biggest problem of persons with developmental disabilities is their exclusion from the common life of neighborhoods and communities. People in the developmental disability field have tried, with some success, to remedy this problem in a variety of ways. Yet all of us, including Developmental Disabilities Councils, try to accomplish this with the conventional means of human service programs. Is there a limitation inherent in what we do? Or is there another way that we can approach our work? How can we, I reflect on my way to my office, help to develop something with our millions of dollars that is as useful to people with developmental disabilities as the Alva trainmen's group is to them?

A. Background to the New Paradigm Shift: Stages of Service Evolution

There is a conceptual revolution taking place today in human services. This revolution is especially visible in the developmental disabilities field, because it currently remains at the forefront of new approaches to service. By the time allied fields like mental health adopt a developmental disability model like group homes, the cutting edge of developmental disabilities has dropped it and has moved to something better. It is reasonable to expect that, for the present, the initiation of new developments in human service thought will often be observed here.

The conceptual revolution which is taking place may ultimately prove to be equal in historical importance to that which caused the prevailing view of our society to turn away from institutions during the past few decades. Once we saw institutions as "the answer." Finally we saw and recognized their obvious and overwhelming flaws, discomfiting knowledge that we had long repressed. More recently we viewed such community service programs as group homes, day programs, and sheltered workshops as "the answer." After all, was this not the realization of the goal of the pioneers of the mental retardation parents¹ movement? Yet this approach, too, we are finally starting to acknowledge, has started to show its limitations, and even its tragic failures.

To understand the meaning of the current situation, it is helpful to view the history which brought us to this point in the development of services as composed of four stages. Simplified, these might be called: 1) pre-institutional, 2) institutional, 3) first institutional "alternatives," and 4) community services on a neighborhood scale.

1. Pre-institutional: Prior to the development of formal human service forms, people were rarely completely segregated out of their communities. This is not to say that treatment was humane, or that it was not, which is a very complex historical issue in itself. From very small settings grew small institutions such as workhouses and poorhouses. These led, by the eighteenth century, to what David Rothman calls "The Discovery of the Asylum".
2. Institutional: the flowering of the institutional form: By the mid-1800's institution-building in this country began in earnest. This paved the way for the dramatic expansion of mental retardation institutions, spurred by the eugenics scare in the early part of this century. By mid-century, confinement of children with developmental disabilities in massive institutions, many at birth, had become the norm. Integration of such persons with the larger society had reached its nadir.
3. The first institutional alternatives: The early parent-run day activity programs in church basements were a huge leap back into the "community" but these were an exception. The prevailing forms of "community-based care" were almost completely institutionally-based in character if not in location. State institutions were still built; they were just newer, closer to town, smaller, and more campus-like in architecture.

The tentative nature of the early transition to community-based services can be seen rather clearly in the form of New York's Elmira Psychiatric Center, built in the 1960's to express the new "community mental health" philosophy. One of the first new state facilities to be located in a downtown residential neighborhood, the award-winning building presents an outward variegated face of interconnected, small brick complexes that fade, Escher-like, into the matching brick of a surrounding low-

income housing complex. Entering the front walk, on the other hand, brings one into a courtyard bounded by three flat "hospital ward" faces and a row of "community" shops facing inward - although the real community's shops are only blocks away. Externally a modern housing development, internally an institution, Elmira Psychiatric Center is the concrete expression of a human service ideology with one foot still planted firmly in the old way of doing things, the other lightly trying the new ground outside the walls.

The primarily institutional identity of virtually all of the initial "community-based" service settings in human services, and especially in mental health and mental retardation, can be readily observed in enterprises of this period, most of which continue to operate today. The federal community mental health centers act of 1963, for instance, was a key pivotal event announcing a conceptual change, or "paradigm shift" between institutional and community thought. Yet these community mental health facilities were quickly observed to fall far short of a community ideal. As Seymour Sarason went so far as to observe, after noting that such centers had increased the readmission rate to state hospitals by over four hundred percent in Connecticut:

"The community mental health center virtually guarantees the continued existence of the state hospital even though its initial rationale was opposed to that of the state hospital ! It could hardly have been otherwise because these centers were conceived within the same traditions of professional practice and theory - the same nomenclature, administrative hierarchical structure, professional preciousness, and professional responsibility - that are the basis for the state hospitals."

Almost all of the "community" services that we thought so innovative only fifteen years ago betray this same "institutional" character from today's perspective. They tend to have a monolithic character which "sticks out of," and may even displace, true community enterprises.

Ultimately, even the initial parent-run day "community" programs were absorbed into the developing movement to establish "professional" sheltered workshops - those same "pioneering" settings which are under attack as "institutions in the community" today.

4. Community Services on a neighborhood scale: The first "small" group homes or "hostels" symbolized a smaller paradigm shift from the essentially institutional approach described above and the more "neighborhood-scale" approach practiced today. At first these homes were still rather large. Small convents abandoned by shrinking religious orders not infrequently were drafted into service as the first ones. To the change agents of the early '70s, a "family" of fifteen or twenty was small - in comparison to the hundreds or thousands of "beds" in the institutions from which these people had been liberated.

Yet as this new model of service evolved, size began to shrink even further as we strove for true family and neighborhood scale. Pennsylvania made an early mark on history by establishing a state-wide group home program for no more than three or four people each. It is instructive to note that this is still the smallest-unit state program in the country today, thirteen years later.

Over the past decade, immense progress in service-building has been made. Recent dreams of "comprehensive mental retardation service systems" are nearing reality in many places. In Pennsylvania parents may find early intervention and education, family support, employment training, and group home living opportunities. As the original group-home residents age, special "aging" programs are created to anticipate needs. Cannot it be finally said that we are approaching realization of the ideal of community services?

Yet while we continue to build and expand our community service system, a sense of disquiet seems to be growing among thinkers in the field. The sheltered workshops we started barely fifteen years ago are starting to look like places of confinement. People who are supposedly preparing for eventual work "outside" them prepare forever. Group homes are abandoning family staff models in favor of hospital-like shifts. Staff turnover in some group home programs exceeds 90% per year. Studies are showing that chemical control of people with mental retardation has paradoxically become more prevalent in some group homes than in many institutions. In mental health, critics are seizing upon the obvious failure of deinstitutionalization through "dumping" as an opportunity to return to an institutional model, paralleling an increasing sentiment for the massive incarceration of criminals.

Faced with such obvious problems, it is apparent that the original plan for community service systems has not been realized, despite our obvious gains. These problems, in fact, may signal a failure in our entire conception of the work. Such "cracks" in a paradigm, or conceptual form, often appear when the existing one is exhausted and a new one is at hand.

B. The New Paradigm

"It will only be one generation between the time the bereavement counselor arrives and the community of mourners disappears. The counselor's new tool will cut through the social fabric, throwing aside kinship, care, neighborly obligations and community ways of coming together and going on. Like John Deere's plow, the tools of bereavement counseling will create a desert where a community once flourished.

"And finally, even the bereavement counselor will see the impossibility of restoring hope in clients once they are genuinely alone with nothing but a service for consolation."

-John McKnight

"My real-life organizing experience, I freely confess, leaves me convinced that nothing can be done to solve social problems by conventional means. Virtually every conventional response will actually make things worse."

-Byron Kennard

1. Report of the Citizen's League

In 1984 the Citizen's League of Minneapolis, Minnesota, issued a report that might symbolize a turning point in our approach to community service. In meeting the Crisis in Institutional Care, they did something which took almost everyone by surprise: they criticized current "progressive" community "alternatives" in mental retardation, mental health, elderly, drug and alcohol abuse, and juvenile offender fields all at one time. They felt that they all had something in common: they didn't go far enough. They said, for instance, that a group home was likely to be "only slightly less restrictive" than an institution. This made a lot of people upset, but the Citizen's League had a lot of evidence to back up their analysis.

"Too often," they stated, "community care unnecessarily fosters the same kind of dependency on professionals that is characteristic of institutional settings. Rarely is the person enabled or encouraged to be more self-sufficient, to return home or to receive care by family and friends rather than by paid

professionals." "It is ironic," they noted, "that there are more retarded people in residential placements today than there were in the 1960's."

Based upon these findings, they made a series of recommendations for providing community services to all groups in a different way. Primary among them was to get over the idea that assistance for any problem must involve a residential placement (what "providers" call a "bed") to get access to services. It was time, they thought, to get over the idea that nursing homes, half-way houses, and group homes are the only way to support people with special needs in a community. In making their recommendations, they recognized the inherent limitations of the formal ways that we have traditionally provided services, even "community-based" ones. More informal approaches, they reasoned, might be better fitted for human needs.

2. The Empire and the Middle Kingdom

John McKnight of Northwestern University has an interesting way to help people to penetrate the differences between formal, organized helping forms and informal ones. In brief, he proposes that one might conceive of the world of services as being composed of two camps. The first of these he calls "the empire;" the second "the middle kingdom." He explained the difference between the two in a provocative talk before the National Association of Developmental Disabilities Councils at their annual conference in 1985.

What is the Empire?

Sneak into the offices of any service provider and rummage through their files, he advised. If you come up with an organizational chart that shows many people taking orders from one person, you know exactly where you are. You are in the empire. Go and sit at the Alva trainmen's coffee hour. Can you draw a comparable diagram? In the middle kingdom such diagrams have no meaning.

Summarizing McKnight's thesis is not possible here, and readers are urged to read his work directly. Yet an important insight to be gained from it is that the vast bulk of what we consider to be our service system is inextricably part of a formal service "empire." Although formal service structures are usually consciously erected to achieve humanitarian goals, they tend to fall prey to predictable and unfortunate tendencies. The most serious of these is that they tend to displace the kinds of indigenous, natural supports which bond society together. That is why it is necessary for someone like the Citizen's League to finally come along and point out that we are not using families and communities enough. How could such displacement have happened? A few years ago families were all that our society had. Somehow our new professionally-based system has pushed them out.

At the end of a logical progression in the erection of formal services, we are left with a system originally erected to help people that has often become the biggest obstacle to their freedom. Professional services have become an industry important to the economy, and industries need things that families and neighborhoods do not. Industries need raw materials. Writes McKnight:

"Removing the mask of love shows us the face of servicers who need income, and an economic system that needs growth. Within this framework, the client is less a person in need than a person who is needed. In business terms, the client is less the consumer than the raw material for the servicing system...His essential function is to meet the needs of servicers, the servicing system and the national economy. The central political issue becomes the servicers' capacity to manufacture needs in order to expand the economy of the servicing system."

While this is a strong statement, there is now considerable evidence to show that this dynamic is becoming a significant one in the shaping of organized caring in our society as we continue the progression from a primary-production to a service-based economy.

The organized human services empire is prone as well to living out an unspoken and usually unconscious role as a control mechanism for removing and isolating deviant people from society. Evidence for this latter point abounds in history; in mental retardation we need only look so far as the eugenics scare of sixty or seventy years ago for a particularly pointed example. While most of us recognize such clear examples of this counter-productive dynamic in history, they are necessarily harder to see - in the present. It is very difficult for most people to accept that negative and unconscious forces in human action are never abolished, but tend to resurface, although perhaps in more subtle form. Just as Samuel Gridley Howe warned against institutions in the midst of the last century's unbounded enthusiasm for them as progressive solutions to social problems, McKnight, Wolfensberger, Blatt, Szasz, and many others caution us in this one.

Whether or not institutions are inherently controlling might be argued, that they provide fertile ground in which control over inmates flourishes, there can be no argument. This statement can be extended to group homes as well, the Citizen's League points out to our discomfort. This should not come as a surprise if we remember Sarason's description of community mental health centers as, at bottom, cut from the same cloth as state hospitals. Both are inherently of what McKnight terms the "empire."

The Middle Kingdom

The middle kingdom is where people live. Every community is full of organizations which show more of the characteristics of "networks" than of institutions. It is through these "informal associational groups" that human communities primarily work. Thinking of my small town in upstate New York, I can think in a minute of many groups with varying degrees of informality:

- the volunteer fire department
- the volunteer ambulance service
- farmer's associations
- one-time groups of neighbors who pitch in to help ill farmers with work
- the local tavern card group
- the coffee group at the corner store/post office
- the volunteer library association
- a philosophical study group

Increasingly we are beginning to see the power of such groups harnessed again to support people with disabilities. In Winnipeg, Dave Wetherow has been tapping into housing cooperatives to include and support people with severe disabilities. In western Massachusetts groups of people are forming a few unpaid "social security" groups to surround people who are especially needy with enough support to live outside institutions. Here and there Citizen Advocacy organizations still thrive, linking unpaid neighbors with people with special needs for purposes of assistance and perhaps even friendship.

In Pennsylvania, a group called AHEDD, Inc., has been promoting a concept called the VINE, for Volunteer Interview Network of Employers. While traditional rehabilitation service organizations grind their way through laborious work-preparation, assessment, and placement procedures, AHEDD goes directly to employers. They form a volunteer network of top executives willing merely to give occasional "practice interviews" to people with mental retardation to try out their interview skills. Somehow during this "practice" a lot of people get offered jobs. Soon they have co-workers to have lunch with in the company cafeteria, like everybody else.

In New Jersey several years ago a group pioneered a radical community support program that dispensed with group homes. Instead of providing "beds" or services they specialized in cultivating what the Massachusetts folks would recognize as their "social security groups," but composed here of sympathetic landlords, employers, neighbors, and bank tellers, identified and encouraged by the staff. They succeeded in large measure, apparently, in running a human

service "program" for some years in which the professional staff were barely visible. Unfortunately, we understand, after accepting state funding this posture predictably began to change, to the point that the same agency is now contemplating undertaking a building drive to build larger offices for its social workers. The empire, we must remember, always displaces the middle kingdom.

B. The Application of the New Paradigm to Developmental Disabilities Councils

Developmental Disabilities Councils have historically been *very* energetic in building and expanding community service systems. This was clearly the job to be done when the transition from the institutional to the community paradigm was of foremost importance. Today a new paradigm is emerging. We have begun to see that the group homes and other professionalized services that we once viewed as a goal are really but way-stations on our way to true community integration. Councils' attention should now be on the "middle kingdom." Our particular challenge today is not how to expand the community service system but how to counter it with something completely different by nature. We are moving from the familiar world of structured services into trying to "culture" caring within the subtle fabric of human relationships. This is very difficult to do, because the kingdom is an ephemeral one, different from the reassuringly concrete entities that we are used to erecting.

1. Obstacles

In trying to support the "middle kingdom," Developmental Disabilities Councils tend to encounter three primary obstacles. The first of these pertains to the degree to which we can bring ourselves to trust the "middle kingdom," while the second two relate to aspects of the "empire" which arise on both sides of the Request for Proposal (RFP) ritual.

a. Are we really willing to trust the "middle kingdom?"

Trying to support informal helping forms rather than the formal structures to which we are accustomed entails a radical reorientation in our way of doing business as planners and funders. With each decision we have an opportunity to discover how far we have been able to move towards accepting this "new paradigm" of service described earlier. In Pennsylvania, for instance, the development of attendant care services for persons with physical disabilities is finally entering a period of significant growth, and pilot programs are being established. The development of these pilots has understandably precipitated a significant conflict over models. On one side home health care providers and their various licensed professionals press for a traditional professionally controlled, agency-based model. Advocacy organizations composed of or representing persons with disabilities, on the other hand, press for a system which is under the personal control of the person being served. The key issue boils down to whether attendants are hired by persons with disabilities, or whether they are hired by agencies.

In the attendant care situation, there is a clear delineation between an "empire" vs. a "middle kingdom" based approach. Predictably, following McKnight's thesis, one finds the health care industry opposed to the ultimate control by persons with physical disabilities over their own care. This has given rise to such curiosities as the opposition of nurses to the simple giving

of medication by lay attendants under the supervision of their disabled employers. Fortunately in this situation the Council in Pennsylvania is on record as uniformly advocating a user-controlled, "middle kingdom" approach.

In the family support situation, in Pennsylvania and elsewhere, the story has been somewhat different. In theory many Councils strongly uphold family support subsidies. Family support programs, by offering support to families to keep their children with disabilities at home, are an exact parallel to attendant care services. Both are signs of the new emerging paradigm. In Pennsylvania there has been enthusiastic support for the establishment of family subsidies. Yet once advocates and planners sat down to design the system, true trust in the "middle kingdom" became hard to achieve. Just as in attendant care, one has a potential outcome on one side of the theoretical spectrum of service design in which cash is simply given to families to spend as they wish. On the other, services are funded to and dispensed by provider organizations. Yet, even among advocates, there has been great difficulty in becoming comfortable with the idea of simply getting cash to families. What happens, the question is always asked, if the money is misspent? How much, one might counter, do you really trust families over agencies?

Michigan has a true cash subsidy family support system. Checks simply go each month to each identified family in the state who has a severely disabled child at home. There are no audits and no receipts. Wonderful stories of family ingenuity have emerged from their experience. One family, who hadn't had a vacation in the 28 years since their daughter's birth, saved all their monthly checks and went to Reno. If that is what is necessary for those parents to care for their child for another 28 years, the program designers said, then fine! But such an expense could never survive the necessary audit in an "empire" controlled system, no matter how seemingly benevolent. How does one write a voucher for a trip to Reno?

2. Councils must operate in the "empire."

Councils operate by Federal law as a part of state government. Each must have an "administering agency" which handles its funds. This means that Requests for Proposals (RFP's), contracts, and other mechanisms for disseminating money must follow a standard governmental format. Since government is certainly of the "empire," its mechanisms, including the ones which DD Councils must use, are of the "empire" as well. While a standard RFP process may have evolved to ensure that no fraud exists in putting out a bid to erect a government building, or to buy a fleet of automobiles, this formal system makes it extremely difficult for Councils to get funds to other than "empire" groups. Most small informal organizations do not have the sophistication to write a competitive proposal - and paradoxically, this is often their very strength. As Byron Kennard wrote:

"Here is the awful irony we are facing: The only efforts that the system will permit are those firmly rooted in the old assumptions. An example: When the government, after years of prodding by citizen groups, finally began to support solar energy development, it set things up so that most of the grants, contracts, and subsidies went to big institutions and corporations. Now, it so happens, big institutions and corporations do not really believe in solar energy, nor do they understand how to develop it. By its *very* nature, solar energy is best applied in decentralized ways. By their *very* nature, centralized institutions cannot comprehend decentralization. Handing over the control of solar energy's development to big companies is like asking elitists to promote the values of populists, never the twain shall meet. But big institutions and corporations mouth the assumptions recognized and trusted by the system. They are as comfortable as an old shoe so they get the financial support.

"New efforts rooted in fresh assumptions will be opposed and even repressed by the prevailing system simply because this system is programmed less to learn than to endure. Accordingly, it learns poorly but endures well."

Everything Councils touch tends to turn formal, tends to turn into the "empire" by virtue of the necessity of working through state government.

3. Proposers are the "empire."

Even when a concerted effort is made to transcend the numerous hurdles of the RFP process to make it possible for something imaginative to take place on the local level, success is far from assured. Again, for example, the Pennsylvania Council issued an RFP to stimulate the adoption of children with disabilities into permanent homes. As with most new ideas, it was dismissed as impractical by many professionals in the relevant field.

We knew that, as usual, what we needed to do was to find a couple of "visionaries" who believed that it could be done despite prevalent social opinion. We were prepared for anything unconventional, any new way which would help children get homes. Various ideas discussed internally included such "far-out" approaches as paying bonuses to caseworkers who arranged successful adoptions, with annualized bonuses for each year the child stayed successfully in their new homes. When the proposals came in, however, the Council was disappointed. There was not one single example in any of the submissions of the kind of "inspired lunacy" which makes for creative social change. Most were the kind of professional grants written by standard child care agencies, and all called for social workers in one way or another to trudge through the standard extensive procedures for placing adoptive children which are the *very* obstacles to their successful placement right now.

2. Possible Solutions

In Pennsylvania we have been experimenting with ways to overcome, or at least minimize, these obstacles to effectiveness. These possible solutions fall under three headings and might be termed Education, Strategic Funding, and Developing Safeguards.

Education

"Today public policy is smothered in facts but devoid of wisdom."

-Byron Kennard

"The unheard declarations of the mind decide the noisy journeys of the feet."

-Paul Brunton

Education is a catch-all term and a solution that is prescribed as often as aspirin and with approximately as much thought. Developmental Disabilities Councils fund a lot of "education," usually of two types. One form is technical training of the variety commonly used to develop or improve specific staff skills, such as shaping the behavior of their "clients." The other is usually termed "public education," a heading under which is subsumed a wide variety of public exhortations promoting acceptance of persons with developmental disabilities (and, on the other hand, prevention of such conditions) in leaflets or in public service announcements. Both of these forms have their place, although neither are what we are referring to here. Rather, we are referring to what is sometimes termed value-based education.

The first obstacle to DD Council effectiveness, as noted, is difficulty in fully supporting what we referred to as the "middle kingdom." To be able to put one's faith in informal and perhaps unstable helping forms requires a dramatic reorientation, a "working-through" of key ideas pertaining to one's approach to helping.

Changing one's conceptions in a major way is frequently an uncomfortable process. It requires that one be "ripe" for the new point of view. With the proper readiness, however, exposure to educational opportunities which help participants to inculcate a well-thought-out philosophy has proven to be the

surest and most effective way to guide the long-term development of service approaches. The primary tradition of value-based education in the developmental disabilities field, (and the only comprehensive one) has been developed around the philosophy of normalization (now termed "social role valorization"), primarily as developed by Wolf Wolfensberger. Most progressive community service approaches in the mental retardation field in this country and several others were shaped to some extent by the philosophy promoted by this one individual, directly or indirectly, through thousands of training events.

The "normalization" field is a much broader one today than when Wolfensberger started, as his students and colleagues have gone on to evolve a variety of very different approaches to promoting understanding of the insights which normalization expresses. The principle of normalization is well-known, if not always accurately understood, within the developmental disability field, so it should not be necessary to discuss what it means here. Assuming this, one can move to consider the implications of action which helps people to change and refine their philosophies or, more simply stated, the way that they see the world.

A philosophy (in this case the philosophy of service called "normalization" or "social role valorization") can serve to provide a seed-thought from which all others, and hence all action, is derived. Thus a deep, internalized understanding of "social role valorization" is predictive of a logically-related series of behaviors. These range from the way that one relates to a person with a disability to the form in which one designs a state-wide service system. A person who understands the key thought behind social role valorization will thus predictably promote a number of thematic service approaches which might otherwise seem to be independent phenomena. If he or she sets up community residences they will tend to be family-sized rather than larger. If they

develop vocational opportunities they will tend to be industry-integrated rather than sheltered. If they develop protection and safeguard systems they will tend to emphasize the unpaid involvement of people: with each other rather than exclusively relying on professional intervention or legal action.

Ultimately the thrust of social role valorization is squarely towards work in what McKnight calls the middle kingdom. Work on the development of people's understanding of this philosophy, therefore, may be expected to lead to an increased belief that work within the middle kingdom, rather than the "empire," is most likely to bring about long-term improvement in the lives of persons with developmental disabilities. A series of value-based educational workshops on a state-wide level is the most important component in a campaign to help people learn to trust the informal associational world of the middle kingdom, and to see the ultimate value of such trust. It can help them to recognize the inherent limitations of our traditional, professionalized, "empire" based interventions. To the degree that Developmental Disabilities Councils can internalize such a value-system, they will express it in uncompromising advocacy for policies, programs, and funding plans that express faith in people rather than agencies, relationships instead of social workers, and families instead of institutions or group homes.

An-Experiment in Pennsylvania

Conscious of the ultimate dependence of all of our efforts on a productive ideology, the Pennsylvania Council created a Developmental Disabilities Institute to develop a state-wide series of programs to work in this key area. While a considerable portion of the Institute's efforts will be aimed at those who are rendering services directly, important emphasis will also be placed upon helping policy-makers to examine philosophical and practical issues underlying their future-oriented work. Of prime attention within this latter group will be the Council itself, a group which is charged with promoting progressive and even visionary social policy for person's with developmental disabilities. It will be primarily through value-based educational opportunities that Developmental Disabilities Councils will come closer to trusting the middle kingdom and begin to increasingly see it as its most important field of action. Five years from now, when a family cash subsidy system is proposed for something else, it will be instructive to see on what side of the issue Council sentiment will fall.

Strategic Funding

The second and third obstacles to effectiveness listed earlier pertain to the difficulty of supporting "middle kingdom" concepts in a system dominated by the empire. Councils operate by definition through the empire and those whom they fund tend to fall within the system as well. Thus it is difficult to reach those informal mechanisms, projects, and actors who are where the "action" really is.

The first step of a strategy to try to overcome these obstacles is simple in concept, if sometimes complicated to implement. It involves moving all grant money as far away from state government as possible.

Obviously funding state agencies to produce social change is almost always futile. There is nothing in human services which is more inflexible and conservative than government. Like a huge flywheel, large governmental systems operate largely as huge stabilizers, and it takes a lot of energy to change their spin. Since they are inherently of the empire, state agencies tend to gobble up any new ideas and money that you have to turn out the same old thing that existed before you came upon the scene.

Having eliminated funding to state agencies, one is faced with the two problems detailed earlier. To overcome the first, one must figure out how to thread good ideas through the system so that they emerge as intact as possible into the non-governmental service world. To overcome the second involves reaching beyond that world to the kingdom of informal action which lies past its borders.

Threading good ideas through the system is a technical game. You have to get to know the nuts and bolts of all of the mechanisms by which money is gotten out of the "beast": requests for proposals, contracts, grants, or what-have-you. In Pennsylvania we have an especially baroque bureaucratic labyrinth governing such things and threading it can be quite a challenge, requiring a considerable degree of diplomacy as well as technical expertise. Yet even if relatively successful one can still only get so far in getting money to efforts beyond the conventional ones. This is a reality which must be lived with. There is simply no way to cajole governmental systems into doing certain things. One must, of course, test those limits.

Once you have cleared the last hurdle involved in issuing a request for proposal (RFP), it often becomes discouragingly clear that only a short step from the governmental "empire" has been taken. For by and large the responses one receives, as noted earlier, are rather conventional themselves. The

proposals of large university departments, consulting firms, and provider agencies can be little more progressive than state government itself - and sometimes even less so.

Our tentative experimentation with strategies to overcome this problem has produced mixed results at this point. One strategem which has achieved some measure of success has been drafting RFP's in specific ways to discourage larger, more traditional organizations. For one low-profile, "grassroots" project we even stipulated that the name of the successful contractor could not be used publicly! Limiting allowable administrative costs will often do nicely to separate real advocates from businessmen. Stipulating that the board of an applicant agency must be consumer-dominated also winnows down the field of applicants considerably.

We have also discovered the curious fact that little \$5,000 grants to certain voluntary groups in early informal stages of development, such as self-advocates, often exceed in impact projects funded for ten times the amount to professional groups. Predictably, getting funds to the former through government entails a constant struggle. Often such groups are not incorporated or tax-exempt, and "broker" agencies must be found. There are difficulties in completing specialized RFP's and contracts for unconventional projects, which tend to be held up for scrutiny at *every* stage of the lengthy approval process. Our payment to the self-advocates, for instance, was delayed for nearly a year and almost had to be freed from our administering agencies' hopelessly stalled contractual procedures by a small-claims suit. We have to expect that as we 'continue to reach out to such middle kingdom entities, our conflicts with state procedures will increase.

One possible approach in the future might be to fund a "broker" organization which can issue informal grants to small organizations for us, while preserving an "audit trail" acceptable to state government. This might tend to slow the

tendency of informal groups to become discouragingly formal once government funding has been received.

For the moment, we must continue with the present course: to "reach" as far as possible through the organizations of the "empire" to those "middle kingdom" groups whose identities have become just sufficiently formalized to allow them to the funding table. Our major concern with such organizations will remain that of safeguarding them and the people whom they represent from being drawn too deeply into the world of formal human service. It is this question that we will consider next.

Safeguards

The subject of safeguarding the quality of life of persons with developmental disabilities is one worthy of lengthy discussion in its own right. This is, after all, a prime responsibility of Developmental Disabilities Councils, in close partnership with state protection and advocacy systems. Helping to build a comprehensive and workable system of safeguards is one of the most important tasks on which a Council can focus its attention, for it is with safeguards and not services that quality caring will be maintained, if it is maintained.

The history of the mental retardation system clearly illustrates the way in which informal parents groups start in the middle kingdom, advocating for needed services and, within a few short years, become corporate provider agencies linked inexorably to the human service and state empire. Too often these eventually replicate the same sub-standard services that they were originally erected to correct. This circular pattern has led Wolfensberger, who served as an enthusiastic theoretical architect for many of these service forms,

to write recently that if he were ever to go into a completely "virgin" country, he would erect the service system last - after the safeguards to protect people against them were in place. Thus increasing amounts of our attention in Pennsylvania have been invested in an effort to promote the development of a balanced, multi-component system of personal and systemic safeguards involving personal relationships, voluntary associations, formal and legal protective mechanisms, and state government. While there are many "advocates," coordination and effectiveness are at best now uneven.

One aspect of the safeguards question is how to safeguard the integrity of the organizations that we fund. Once we clear all of the many obstacles in the way of lending support to a nice informal associational group or voluntary association and actually reach them with some funding, we tend to get a discouraging surprise. For the almost immediate reaction of such fledgling groups is to replicate the evolution of their predecessors. Like the trail-blazing Association for Retarded Citizens, they eventually fall prey to professionalization and even become providers of services because "nobody else can do it." It seems that as soon as you find a nice middle kingdom group and give it money, it tends to change into an organization of the empire.

It is really quite essential that attention be paid to this problem for, by continuing to help draft new organizations into the body of the empire, one only extends its eventual dominion over peoples' lives. Since this is a long-term process, however, it is one more likely to be apparent to a Council than to an unsophisticated (their main attraction) voluntary group motivated by immediate and short-term goals.

If Councils are attentive to this tendency of their projects to "drift," there are three things that they can do to slow it. The first, of course, is education, to help those involved in the project to become aware of the

predictable natural evolution of organizations such as their own, and to thus begin to take conscious steps to preserve the strength of their early, more informal stages. The second is to have a multi-level personal advocacy system in place around the proposed effort, the old concept of "watchdogs watching watchdogs." The third is to use the Council's power relating to contract compliance and renewal, as a final resort, to encourage necessary actions.

In Pennsylvania, for example, the Council funded several citizen advocacy programs. The Council hoped to build upon these successful projects to erect a state-wide citizen advocacy component for a comprehensive protection and advocacy schema. In the programs, unpaid "citizen advocates" were matched with persons with developmental disabilities, whose needs they represented as if they were their own. Often such relationships involved long-term friendships for the ordinarily friendless, as well.

After funding one project, the Council began to see a number of signs of "drift." Rather than stressing their identity as primarily a "network," it began to term itself an "agency." The composition of the board was changed to one de-emphasizing "consumer" dominance. The "agency" proposed to have citizen advocates fill out monthly activity reporting forms, listing hours and activities, which strongly resembled professional caseworker reports. All of these signs sent an alert to us that conversion to a professional orientation was underway.

To help counter this trend the Council is currently developing a training program through its Developmental Disabilities Institute to introduce the board of the association to the key tenets of citizen advocacy, so that the drift might be consciously seen and reversed. Secondly, a consultant knowledgeable in citizen advocacy is being engaged to monitor the development of the group, to assist the board, and to report to the Council on its progress with specific attention to be paid to: how well it is preserving the "middle kingdom"

character essential to its purpose. Finally, if necessary, funding will be discontinued if movement towards a "service agency" model is not halted. There are enough of these already, and it is not the Council's proper task to create more.

II. Three Over-riding Themes: Social Change, Plan Coherence, and Social Witness

In preceding sections we examined a vision of a new pattern, or paradigm, with which Developmental Disabilities Councils can approach their work. We moved to examining obstacles which stand in the way of actualizing this new paradigm, and explored some of the ways in which these obstacles may be overcome or at least minimized. There remain three additional themes relating to the new vision of Developmental Disabilities Councils to explore. These "higher order" themes have emerged from our attempt to understand and implement the purpose of a Developmental Disabilities Council as an organization, and may lend levels of significance beyond its particular mission. These three are: 1) the need to understand how social change takes place, 2) the need to achieve coherence in action to bring about change; and, 3) the need to include symbolic action as a valid expression when other avenues are closed.

Understanding the Mechanism of Social Change

"...novelty emerges only with difficulty, manifested by resistance, against a background provided by expectation."

-Thomas Kuhn

Thomas Kuhn's The Structure of Scientific Revolutions is a landmark work of intellectual history, well-known to scientists but, until recently, virtually unknown to our field. In the past few years, at least two individuals have introduced Kuhn's work to the developmental disabilities field. William McCord, in an unsurpassed 1982 article entitled "From Theory to Reality: Obstacles to the Implementation of the Normalization Principle in Human Services," drew heavily upon Kuhn's concepts. More recently, Bob Perske made a translation of Kuhn's key ideas in several recent workshops, including a planning retreat held for the Pennsylvania Council in 1984.

The attention of Developmental Disabilities Councils is on the future. As "systemic change agents," their specific job is to hasten the development of new approaches to service that will improve the lives of people with developmental disabilities. Strategically applied, their limited resources can be used as "levers" to move large bureaucratic systems in a progressive direction.

As noted earlier, all service approaches are rooted in conceptions of the world and of service held at a particular time. To change services, one must encourage peoples' ideas to change. Here Kuhn's work is enlightening, for he isolates the ways that ideas change in the scientific world, drawing upon a wealth of historical information to illustrate his points. Once it was thought, Kuhn points out, that the sun revolved around the earth. The reconceptualization of a universe in which the earth revolved around the sun constituted one of the difficult and highly-resisted events in intellectual history which Kuhn terms "scientific revolutions." In Perske's translation, once we believed that mentally retarded people spread vice and criminality throughout society on a primarily hereditary basis, so we locked them away in massive institutions so they could not procreate their kind. When the "conceptual revolution" disproving this notion and calling for the integration of

such persons in regular neighborhoods dawned, it occasioned a great struggle in the field. This struggle is still going on.

Kuhn examines with great precision the mechanisms through which such revolutions in thought take place. It is impossible to summarize these adequately in a brief space, and the reader is referred to Kuhn's book and Perske's lectures, if he or she is not already familiar with them. Yet certain simplified ideas can be mentioned at this point. Key among them are the role that anomalies serve as "levers of change."

The revolutionary shift from an old model of thinking (what Kuhn, again, terms a "paradigm") to a new one involves the appearance of new findings, or anomalies, which cannot be explained by the old way of thinking. Such events violate the expectations created by the reigning paradigm.

Some of the most striking "anomalies" in the developmental disabilities field in the past few years have appeared in the vocational area. In this corner of the field so many have appeared due to a number of social, cultural, historical, and political factors that a quite tumultuous conceptual revolution is now definitely underway.

One of the earliest challenges to the old paradigm was the expectation-shattering work of the late Marc Gold. Gold provoked great excitement as well as great resistance by travelling around the country showing how severely retarded people, dismissed as having "no vocational potential" and left to rock on some ward, could be quickly taught to perform such complex tasks as assembling an intricate bicycle brake.

The paradigm-shifting power of Gold's demonstrations was revealed in the fact that it tended to rock not only conceptions of vocational training to the core, but even foundation knowledge of what mental retardation "was." One might simply state that if what the field held to be true about intelligence, IQ,

and the predictive value of diagnostic tests was true, then what Gold was doing should be absolutely impossible. Yet there the evidence was. Gold's violation of the expectations of the old mental retardation paradigm shot a large and fragmenting fissure through it, a fissure later wedged open further by the work of Bellamy and Wehman in supported employment. In a fragment of historical time industry-integrated supported employment programs have advanced to the point that the future of institutional sheltered work (a revolution of its own thirty years ago) has been cast in as grave doubt as the future of institutional sheltered living.

In fulfilling its role as a change agent it is important, Perske tells us, for Councils to spot, nurture, and support such futuristic anomalies in order to help to bring emerging conceptions of service into the world. Councils serve a vital role in this process, for new inventions in society have been shown to virtually always arise from visionaries on the margins of the established system or order. Since new potential challenges to an established paradigm predictably stimulate resistance, such social inventors are always in great need of exactly what Councils are equipped to provide: seed money and legitimatization.

Councils have traditionally been one place in the system where someone with a new idea, like group homes, supported work, or self-advocacy could turn for resources and support to help keep them alive and "take root." An understanding of the mechanisms of change set forth by Kuhn can help Councils to refine their capacity to search out and recognize new ideas with the potential to improve social conditions and services. In this search, which Kennard calls "Stalking the Wild Idea" in a brilliant essay of the same name, it is important to know where to look. Predictably, one finds that such new ideas are almost never found in government, or in established service providers, which are much more likely to be instruments of suppression of anomalies than inventors.

New ideas tend not to flourish at all within the necessarily rigid confines of what we have termed the "empire." In the fluid medium of the middle kingdom, however, new ideas are constantly being born and tried out by people too innocent of socialization by the profession to know that they can't work. It is through finding such anomalies and nurturing them into catalyzing conceptual revolutions that Developmental Disabilities Councils largely find their expression and reason for existence.

2. The need to achieve coherence of action to bring about change

Thoroughly grounded in a productive ideology towards human service, and cognizant of the mechanisms by which concrete expressions of this ideology can be promoted, Councils are faced with the practical necessity of deciding exactly what to do. This is expressed by the construction *every* three years of a state plan for developmental disabilities which outlines through the listing of goals and objectives the precise campaign that the Council intends to follow towards improving the lives of the persons whom they are charged to represent.

Construction of such a plan is a strenuous undertaking, as all those represented on a Council strive to insert their favorite projects. What is frequently the result, unfortunately, is a disconnected, incoherent series of objectives providing funding for fashionable but often insubstantial or even obsolete projects. Such projects and objectives may bear no logical relationship to one another, because they do not arise out of any shared vision of the field and the work to be accomplished. Such state plans reflect a failure to attain a coherence of mission, thus opening the door wide to lower-order influences on planning, including unworkable or irrelevant ideas promoted by

members or contributors in genuine good faith. Implementing plans like this is like firing a shotgun off into the woods. There is a lot of noise and smoke, but very little impact is made.

For Councils to have impact it is thus important for them to have carefully focused plans. Good plans, again, must be "grown" from the roots of a solid positive ideology, then "trained" and "pruned" as necessary to achieve a unified logical coherence of statement and action. For the more focused the social campaign, the more likely it is to bring about lasting social change in the end.

Starting only from the normalization-based ideological orientation of the 1984 Developmental Disabilities Act one can create a plan expressing the virtues of "integration, independence, and productivity" in a variety of inter-related ways. The needs of persons of developmental disabilities are quite simple and require no esoteric studies to uncover. They are the same needs that any human has. What differentiates people with developmental disabilities is both the degree of certain needs and the extent to which they often remain unmet.

Pennsylvania, as a "large-allocation" Council, has chosen to work towards the refinement of a multiple-objective, multiple-goal plan, (see Appendix) In idealized theoretical form, this originates with several inter-related assumptions based upon the principle of normalization/social role valorization as noted in the Federal Developmental Disabilities Act. These beliefs are expressed on the practical level by implementation of the plan through two complementary channels, the development of new service approaches, and the development of safeguards. Development of new service approaches is confined to basic general areas, which everyone, disabled or non-disabled, needs: a home and a job. Thus, a fairly complex plan can be seen to be the logical

expression of a small number of goals arising from but one thought. It should be emphasized, however, that Pennsylvania's approach is far from being an attained ideal and is offered rather as one example of an attempt to work out the challenge of plan coherence in realistic action. A variety of other approaches are no doubt possible. The smaller allocation Minnesota Council's plan, comprising only two supporting objectives shows, for example, a much "cleaner" plan logically, and one which appeals to me considerably because of this.

Although plan coherence will tend to arise naturally if a set of shared assumptions is in place, a shared ideology in itself will not prevent other possible objectives which are not in the range of the Council's chosen focus from arising in the planning process. Some of these objectives will be admirable and represent an acute need. In these cases the commitment and discipline of a council to express a coherent campaign of social action will be tested.

Under these conditions a council must deeply consider the tradeoffs and compromises entailed in sacrificing some measure of "sharpness" of the plan which they intend to use as their instrument, as against the advantages of incorporating dissimilar or separate issues. The issue of planning integrity must also be weighed, as the introduction of one "compromise" objective may threaten the integrity of the plan as a whole, as new suggestions for objectives are thrust into the breach opened by straying from agreed-upon higher-order goals. Use of a previously agreed-upon set of standards for plan objectives (see Appendix) may make this process more manageable. The outcome of much of this will, of course, be governed by the maturity of the council as a group, and the ability of individual members to sacrifice personal project favorites to the symmetry of the group product.

3. The need to include symbolic action as a valid expression when other avenues are closed.

It would be an ideal world if Developmental Disabilities Councils could select pressing needs and, guided by a positive ideology, innovative service ideas, and strategic planning could count upon a significant and lasting advance. Unfortunately, even our gains fall prey to universal forces of perversion and seduction as they are, as I phrased it earlier, "dragged into the empire" and institutionalized, bereft of their original essence. Readers are referred to William McCord's article mentioned earlier for a precise examination of the reasons that the expression of a productive ideology through human services has proven to be so universally difficult.

Many problems in our current society, including those affecting persons with developmental disabilities, are probably not amenable to solution. This is because they are manifestations of negative tendencies which are so deeply embedded in the current evolution of our society that no mere program within the conceivable range of governmental or other intervention may be expected to achieve real success. Insofar as every problem is a manifestation of deep societal trends, so do interventions tend, to a greater or lesser extent, to be topical at best.

The vast apparent increase in teenage pregnancy and consequent increased incidence of low birth-weight babies, for example, seem symptomatic of increased sexual activity by teenagers, which seems symptomatic of a larger-scale breakdown in traditional moral strictures within society, which itself is probably an expression of those changes in the view of man toward God and the

universe over the past few centuries best understood by philosophers and theologians. While one cannot expect that such pervasive changes in society can be changed, there is room for common-sense practical action. Making birth control available, and attempting to make it acceptable to high-school children, is an example of one such "symptomatic" intervention, which might well delay the birth of children until the mother is older and better able to bear and care for her child, at least over the short-term. Addressing unemployment among young black fathers might be another productive and common-sense action to take. We cannot at this point, however, be terribly optimistic about the outlook over the long term, and there is very little that we can directly do about it. We must, of course, continue to try.

There remains, in addition, a disquieting number of things about which we can probably do nothing at all that is likely to succeed, even symptomatically. One such example is the current rush of states to convert empty mental retardation institutions to prisons. While this action only affects some persons with developmental disabilities, and those indirectly, it could be charged that those of us in this field who have used the potential for reuse as a strategy to close institutions have a moral obligation to try to prevent the wholesale incarceration of a new "scapegoat" devalued group. By remaining silent, we are accomplices, it might be said, of a trend which is keeping the U.S.'s incarceration rate per population the third highest in the world, right after the Soviet Union and South Africa, no matter what the gains in developmental disabilities deinstitutionalization may have been.

Were a Developmental Disabilities Council to become convinced of the need to take action upon this problem, it would certainly have to do so with the clear understanding from the start that there was probably no hope at all of* affecting the situation. They would also be advised to expect considerable

displeasure on the part of state government and perhaps even advocacy agencies. Yet it might still need to be done.

If a Council were to make a statement opposing the policy of their state in this matter, they would have taken a step away from those kinds of activities in which some kind of outcome is expected. They would, to use another phrase, move from a role as a traditional systemic advocate to that of a witness for social justice. In dispensing with the validity of outcome as a criteria for action, they would have moved to assumption of validity based upon the act itself. Instead of reaping observable social change, such a council would, instead, make a symbolic gesture.

Developmental Disabilities Councils may increasingly find themselves faced with decisions regarding the taking of actions which are largely symbolic, faced with developments in society which exhaust our faith in social/technical solutions. The "Baby Doe" and Philip Becker cases and their kin, which seem to be expressing an increasing tendency to label some disabled children as "non-human," is profoundly disturbing in its implications for persons with disabilities in general. The vigor with which voluntary groups such as the Association for Retarded Citizens sprang to the defense of these children was reassuring evidence of the vitality still remaining in them. It remains quite possible, however, that such groups, including councils, will have to increasingly stand in opposition to such destructive tendencies without making appreciable gain. In one large northeast state, for instance, the beginnings of a strong reversion to institutionalization is currently underway, as plans to erect "community residences" on institutional grounds proceeds on a large scale, and new residential special education expansion is proposed. In other states, new mental retardation institutions are actually to be erected.

Thankfully public policy is proceeding in a more enlightened direction in Pennsylvania, at least for the present. On a more subtle level, the support of citizen advocacy by the Pennsylvania Council might be interpreted as a milder form of such a symbolic act. For although the avowed goal is to set up self-sustaining programs and the possibility of a state-wide system, it must be recognized that all such efforts are "bucking the current" of prevailing human service values, and thus may not survive very long once specific funding and advocacy for this approach to service expires on the Council level. Yet even if the long-term plan to establish a citizen advocacy system fails, it may still be an important thing to do. For in funding such a project, the Council has an opportunity to make a statement about the neglected importance of unpaid personal relationships as the core of all helping, and as the core of all advocacy, "one person representing the needs of another as if they were his own" in a very uncomplicated way. In supporting such a concept, the Council extends legitimacy and encouragement to a small group of people who show through personal sacrifice their commitment to a personal approach to service, as opposed to the professional/technological approach so popular today.

In remaining attentive to opportunities for selective symbolic action councils may preserve one of their most potent avenues for expressing their values and their commitment to the people whom they represent. They may even, through such a difficult course, help to draw attention to crucial but overlooked issues. Such issues may, like citizen advocacy, help rediscover the "soul of service" from the everyday lives of people in the middle kingdom. They may even, as in "Baby Doe" or "Philip Becker," stand with a child against that which threatens to take away his or her life. Such stands must, even if unsuccessful, occasionally be taken, regardless of consequence.

III. Afterword

Human service organizations are fickle creatures, subject to the whims and fluctuations of a hundred internal and external influences. Among human service organizations Developmental Disabilities Councils tend to be particularly subject to the ills, fallibilities, and instabilities likely to beset creatures of such composite and negotiated design. Not quite governmental bureau, not quite voluntary association, not quite foundation, they have proven as an organizational type to be quite problematic to raise to great effectiveness. There is a certain comraderie among those who, against all of the odds, try to make one work. Yet *every* so often a group of people is successful and a Council is able to accomplish true improvement in the life opportunities of people with developmental disabilities.

Despite their difficulties, however, one thing that Developmental Disabilities Councils are particularly good for is observing trends in human services and thus in society. With their advantageous location ambiguously and indirectly in the midst of everything, and blessed with unequalled opportunities to try out a hundred new ideas, they provide a rare platform from which to observe what works, what doesn't, and perhaps even why.

The developmental disabilities field can be seen, as Seymour Sarason once commented, as "a window through which to view society." Everything that exists in the world of social man exists in the field of social service. We see ourselves and our groups at our best and at our worst through our human service undertakings.

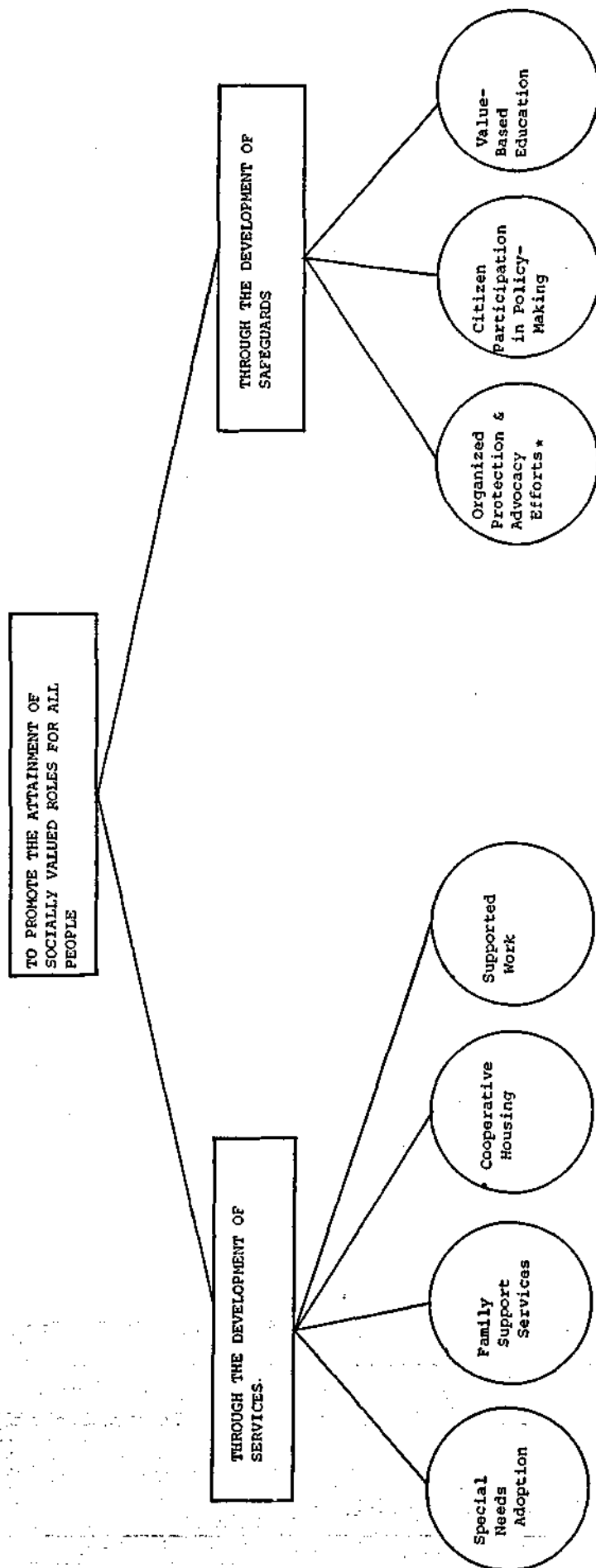
Through our attempts to alleviate human suffering on a societal scale we are brought ultimately to contemplating such universals as suffering, or the ideal of social justice, as integral parts of human existence. We are brought to admit and reflect upon the consistent failure of social programs, even our own, to better conditions on the earth in a lasting way. But we are also continually heartened by the fact that, however imperfect our work, it

serves as evidence of the sincere desire of a number of people to help those who are less fortunate in gaining access to society's opportunities. We are made aware of the fact that in pursuing this work we are, as Byron Kennard once noted, merely eliminating the roadblocks that normally prevent anything worthwhile from happening. It is society itself that is bringing the improvement about.

I have been very fortunate over the past two years to have an opportunity to try to clear away the obstacles from a number of appealing and interesting ideas that wanted to become manifest in social policy in Pennsylvania. Virtually all of these ideas came from the active minds of others with whom I have had the pleasure to associate. It has been a particular interest of mine to try to see a pattern in these ideas, and perhaps to fit them together in a meaningful way. That has been the purpose of this paper.

This essay should thus be understood as an attempt to reason out and set down some of the main themes and insights that we have encountered thus far in the evolution of the Council as a potentially effective instrument of positive social policy. Its primary aim has been to pose a theoretical approach that captures the unifying principles behind our efforts. Perhaps it may be useful in furthering our reflection on and continued understanding of this complex undertaking. Such continued discussion and understanding may, in the final analysis, be the most important, if abstract, product of Developmental Disabilities Councils, once all of today's exciting ideas and model projects have long disappeared.

Pennsylvania Developmental Disabilities Planning Council - 1987-89 Plan Objectives



*Including development of a schema for P&A services, involving the respective roles of personal, case, legal, and systemic advocacy.

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