MOVING FASTER TOWARDS THE BEGINNING

A Draft Paper to open a dialog

by Sidney Blanchard

"Those who can not remember the past are condemned to repeat it."
George Santayana (1863-1952)

Community Access Unlimited is a private not-for-profit established in 1979 dedicated to helping people with developmental, emotional, physical social challenges, (disabilities), and those who fall through the cracks of the social service system (prior are all part of "disabilities" broadly defined), become productive, independent citizens living real lives integrated into a real community. That to achieve these ends there must be a community inclusive social movement that achieves these goals. This social movement is necessary to create the political leverage to affect the currently dysfunctional distribution of resources and to reinforce specific practice and policy norms that benefit all citizens. This all-inclusive social movement needs to be based on fundamental values/beliefs approaches of:

1. Community integration
2. Holistic interactions as equally valued members of a social activist movement
3. Equal treatment as citizens
4. Equally valued as members of a social activist movement
5. Choice and self-determination

These approaches for achievement are:

1. The empowerment of people with disabilities to locate, develop, obtain, or capture the necessary resources for individual uses as well as for building a community support system.
2. The development of a culture and politics based on equality and full citizenship for all people.
3. Framing issues, policies, and practices holistically and not in the medical model or through segregation terms.
4. The organizing of people and groups into a mutually supportive and caring neighborhood and community at large.
5. Building customized personal support systems one person at a time; yet integrated into a unified movement.

A basic premise underlining this approach assumes that the social movement function requires organizational structures i.e. non-profit agencies, which are the unified fiscal point of resources and power. Organizations that join this movement must be represented by leadership who share these values. The approach also assumes the organic integration of theory and practices i.e. values/beliefs/approaches that influence the development of a social movement and services. This approach also assumes that the tension of competing interests is real and that consumers require real power (collective empowerment not individual empowerment) in order to have meaningful participation "at the table". Resources to meet the

needs of all the various groups is to be found in the Community as well as by capturing resources from government, corporations, and Foundations.

Critically mega-trends over the past two decades in economics (international, national and local); political; social; cultural; demographics; class; and education raise a number of questions which challenge the basic premise of this framework of government for change and practice. These questions include:

1. The privatization/outsourcing and the consequences for non-profits. The current and future role of not-for-profits in the social service arena;

2. The redefinition of the dynamics and the Social Contract between the Welfare State and citizens needs,

3. What are the influences and consequences of the increasing deficit financing of the Federal budget and the Welfare State? What does the future look like assuming current mega-trends persist over the next decade? The next several decades? Is it positive for people with "disabilities"?

4. How are innovative programs addressing the tension between agency culture that focuses on the individual and individual problem solving versus the need for collective forms of practice, action, and agency culture to create new forms of problem solving? What is the bottom line between the needs of people with "disabilities" and the social contract? For whom does the social contract exist? What/who are the vying camps of interests within society?

5. Is there a need for a social movement, and what should it look like? Its organizational structure? Locus of power/resources/control?

THE PRIVATIZATION/OUTSOURCING AND CONSEQUENCES FOR NON-PROFITS

Over the past decade, not-for-profits have become the focal point of attacks from government, family members, and self-advocate groups in the 'disabilities' fields. The attacks have focused on professionalization of agencies and staff in the social service field. This dismissal of professional initiatives whatever its form tends to ignore the denigration and marginalization of agencies and professional work life through various forms of disinvestments. This critique of professional although having some legitimacy reinforces the present trend regarding privatization and disinvestments. It ultimately would further degrade the quality and scope of services provided in the public sphere, offer diminished subsidies to private helpers and render service users atomized and powerless. One might liken this tendency of social services to the home school movement in education.

Local community organizations are being decimated. Professionalism is being converted to volunteers or unpaid relatives, or "neighbors". Individuals and families are being offered the 'entitlement' of middle class lifestyles using public funds, without public oversight in terms of the use of funds or licensing/quality assurances; at the very time availability of funds is shrinking.

The fields of social services and the disciplines of political, economic, and social analysis rarely if ever talk among themselves or with each other. Ever increasing specialization has led to increasing gaps in knowledge both between and within academic disciplines. Yet the removal of non-profits in their day-to-day practice in attempting to address or reverse these trends is striking. To the contrary the recent history of not-for-profit social services is in part marked by responsiveness to dominant trend even if it is not in their self-interest. More to the point a body of work demonstrates that

> "The dominant political economy and historical events of each era help shape and profoundly influence almost all aspects of society, including social investment. Developments affect and are in turn affected by national electoral politics, social struggles, the nature of social welfare, and even community based efforts. In more liberal or public eras, the model asserts, the social welfare state expands, activism on the left increases, as does social investment for reform-oriented service programs. In more private eras, conservative policymakers dominate, corporate prerogatives are asserted with greater openness and are less challenged, right-wing movements gain currency, social welfare systems become increasingly privatized and timid, which reduces both interest in and funding for organizations."

Social services might be described as having entered "the perfect storm" that includes a convergence of:

- Demographics of increasing numbers of people with disabilities; the increase in the elderly population; and an increase in the number of people in poverty
- A shrinking and increasingly underpaid social service workforce;
- The Federal initiative to dramatically shrink Domestic spending;

- Deficit spending/privitazation and managed care service systems as a fix.

In a track called Filthy Lucre: Creating Better Value in Long Term Supports (2001), Thomas Nerney discusses consequences if current Mega-Trends continue.

"The future interests of individuals with developmental disabilities as well as all other disabilities are inextricably linked with one of the greatest cultural, social and economic changes in American History: *the aging of America*. The issue of how resources are allocated in the future is directly related to the very adequacy of those resources.

As the demographics of this country inexorably change from 12.5% of the population over age 65 to 20% over the age of 65, we can accurately predict the following crises:

- The competition for scarce Medicaid resources will increase dramatically. The fastest growing population of those who are aging will be those most in need of assistance - those over the age of 85.

- While the vast majority of assistance to this aging population is given freely from family members today (over 80% and mostly by adult female children), within twenty years this cohort of adult children will diminish significantly. As the population of older Americans doubles the population of adult female children increases by only 7%. This will exacerbate the problem of increasing significantly the pool of potential direct support workers. This "double bind" is described by Mary Ann Wilner:

  > Since women in this age group provide the vast majority of both paid direct-care services and family care, this care gap in the United States will increasingly become a double bind: families who cannot care for their older members by themselves will find relatively fewer paid staff available when they turn to the formal system for assistance. (Wilner, M. A., 2001)

- The current pool of direct support workers is shrinking in dramatic fashion as a result of inadequate wages and lack of status across all human services. It already constitutes a national crisis.

- Even if the public support dollars were to increase significantly to keep pace with the growing population of those requiring some assistance, there is little hope under the present system that an adequate and trained or interested workforce could be developed.

- Within the field of developmental disabilities alone, demographic projections indicate that within twenty years the more than 500,000 individuals with a developmental disability currently living at home with an aging caregiver will more than double. Aging caregivers are caught between their own aged parents and their adult children with disabilities—an excruciating double bind.

As America ages the competition for scarce resources, especially under the Medicaid program, is going to increase dramatically. This dilemma has the potential for dwarfing the twin crises in Medicare and Social Security.

In the face of this crisis two problems remain intractable: the near total impoverishment of individuals with disabilities within this system of long term care and the low wages and attendant difficulty in attracting and keeping a workforce to support individuals with disabilities. The first problem results in increased isolation and loneliness of individuals with disabilities, rising costs associated with supporting these same individuals, and increased dependency on a system constructed with all the attributes of a massive welfare system. The second problem raises the specter of tens of thousands of Americans in need of support as they age or become disabled without the *workforce* or the *resources* to provide those supports."

Given the current Federal Policy of dramatic cutbacks and, instability of the Welfare State and more specifically in the field of disabilities social services, the question of survival of these not-for-profits is at question.

THE REDEFINITION OF THE DYNAMICS AND THE SOCIAL CONTRACT BETWEEN THE WELFARE STATE AND ITS "CITIZENS" NEEDS

THE SOCIAL CONTRACT IN AMERICA HAS HISTORICALLY BEEN HELD BY DIFFERENCT CAMPS WITH DIFFERENT PURPOSES.

One needs only to look at the 'founding fathers' that held States' Rights' of Jefferson and the ruling gentry of slave holders versus the Federalist of Alexander Hamilton of a unified National Government for Capitalists and Merchants. The Bill of Rights was added later as Amendments to solidify why the masses fought for liberty. It took the Civil War with the casualties of over 650,000 Americans to settle that Social Contract conflict between the leading economic factions. Preservation of the Union and abolition of slavery were the rallying cry for the majority of Northern citizens. The use of the newly energized Federal Government as a social change agent was thwarted in 1877 with the great compromise that resulted in the election of Rutherford B. Hayes as President. Civil Rights, the Vote, and social equality were removed from the public table.

The Progressive Movement culminated in the use of the Federal Government for some social reforms regarding Monopolies and labor unrest that reintegrated a restless population into the mainstream political process.

Under F.D.R's Presidency the Federal Government was used as a toll for addressing social grievances. 'Reform in order to preserve'. The 'New Deal' explicitly addressed a temporary shift in the Social Contract. However, during WW II, in order to expedite War production, labor and reforms for the non-wealthy American took a back seat. Economic good times prevailed for many in post-war America, yet President Eisenhower warned upon leaving office of the 'Military-Industrial Complex' as a threat to America.

The Presidency of LBJ brought the 'Great Society' of social reforms with the ever-strengthening Federal Government led by the empowered 'Executive of State'. The 'Guns and Butter' approach offered something for many sectors of society. With the addressing of civil rights, the vote, and the public discussion of social equality, came a re-energizing of the right wing and the political re-alignment of the Southern voting machine.

The Ronal Reagan Revolution seen in historical context is the prevailing by one group in the Social Contract. Fitzgerald, the herald of the new wave, stated in 1988 that 'Privatization upholds the fundamental economics principles on which America was founded, even as it redefines the nature of political debate in this Country". Peter Drucker, in The Age of Discontinuity (1968), states that "Government should spend more time governing and less time providing, should either purchase services from the private sector or, simply, stop providing".

The 'Reagan Revolution' continues today. The Federal Government, that is the President, Congress, and the Supreme Court consciously move to reduce the tax burden on the Upper Middle and Upper Classes as well as to unleash corporations from rules and regulations seen as impediments to profit.

As the Federal Assistance Monitor (2005) states, 'Programs providing healthcare, child support and other social services are bearing a disproportionate share of the cuts, while programs such as highway aid pretty much are being left alone, despite representing billions of dollars in guaranteed spending. In the

areas of family policy, Marriage strengthening, abstinence education, prevention programs utilizing testing in areas ranging from drug abuse to AIDS-these stand a good chance of receiving additional funding, through existing programs, not new initiatives."

Where programs are funded, the Federal Executive branch simply need not spend. Where there are unexpected costs such as hurricane relief or overruns in defense spending the President requests Congress to rescind already appropriated funding. These rescissions have generally targeted domestic programs.

Currently we are watching the next budget process involve cutting 'people programs' lock stepped with the cuts in taxes for the more economically privileged in society.

This is the current state of the Social Contract, again re-negotiated.

WHAT ARE THE INFLUENCES AND CONSEQUENCES OF INCREASING DEFICIT FINANCING OF THE FEDERAL BUDGET AND THE WELFARE STATE?

What are the current Mega-Trends? What does the future look like assuming current mega-trends persist over the next decade? The next several decades? Is it positive for people with "disabilities?"

In the book, Costs and Outcomes of Community Services for people with Intellectual Disabilities, it is observed that "The human service system in America is moving toward the idea of self-determination in all areas of service delivery. Trends in many fields, notably developmental disabilities and aging (via the Cash & Counseling demonstrations), support this movement toward service recipients and their allies having direct control over the money used to support them, as well as the types of service and assistance they can purchase with that money. The results in Michigan show not only that self-determination is a fiscally conservative approach to service delivery but also that participants in self-determination perceive themselves as having more choice, less professional domination, and higher overall quality in their lives."

"The concept of self-determination is the field of developmental disabilities is simple: If people (and their freely chosen allies) gain control, their lives will improve, and costs will not increase. Another element inherent in the concept of self-determination is that the service-planning teams should be de-professionalized and should increase the involvement of unpaid friends, family, and community volunteers."

At the National Alliance Conference, DC, 09/05, one observer stated that "Medicaid trumps everything from this point on." Just look at the Oregon Model: Generic case management system with one system manager. There is a consolidation of DD and Aging with Medicaid in order to:

- Contain Medicaid spending
- Control Provider Agencies
- Continue the movement to consolidate all levels of management

The current dilemma and the "schools of thought" were well articulated in the seminal work by Randall Fitzgerald in his book, When Government Goes private: Successful Alternatives to Public Services, 1988, which states, "By carving out a new role for itself, that of a service facilitator rather than sole provider, government might lend flexibility and creativity to service delivery mechanisms while simultaneously encouraging the formation of attitudes and values that enhance neighborhood and individual self-sufficiency. The challenge remains to advance these goals without sacrificing the sense of community that binds us as a nation." "A realization has dawned that, irrespective of political party or ideology, privatization may afford public officials a less painful, more palatable budget remedy than raising taxes or cutting services. Fiscal reality demands that we use our understanding of human nature to restructure public-service institutions to utilize the strengths of the private sector. We cannot afford to be any less distrustful of the monopoly privileges of government than we already are of corporate monopolies that periodically evolve in the marketplace. Each kind of monopoly can thwart cost efficiency, stifle innovation, and suffocate the spirit of human enterprise."

"Privatization diminishes neither the concept of community for society nor the sense of public purpose of a program, argues Ted Kolderie of the Hubert Humprey Institute, because the use of non-

governmental producers in no way lessens the social commitment to a program – only government can reduce that commitment as a matter of policy."

Fitzgerald also states that when "critics of privatization, when practical arguments fail generally elevate their criticisms to a loftier plane. Editors of *The Nation* magazine have described privatization as a social project of the far right that orders private values over communal ones, sanctifies greed, and sacrifices civic virtue in the pursuit of self-interest. In perhaps the strangest and least relevant criticism of all, *The Progressive* magazine in 1986 editorialized that the "cult" of privatization was "a scandal and a disgrace…what is happening now reflects a shameful decline in human values…It is in the name of privatization that old people are paying more for medical services, that farmers are losing their land, that children are being shortchanged of education, and that scholars are learning that the world's mightiest nation can no longer afford to keep evening hours at the world's greatest library."

The book Settlement Houses Under Siege: The Struggle to Sustain Community Organizations in New York City (2002), describes how "contemporary government contracting with nonprofit agencies promotes a corporate or business approach to the provision of services. Agencies efficiency, productivity, and outputs receive greater and greater attention. Activity that can be quantified and analyzed in terms of cost per unit gets priority. The intention is to create analogs of corporate measures of productivity in the nonprofit world. The resulting conflict for nonprofit social service agencies, however, is not only that such structural constraints limit an agency's service provision and autonomy but also they do not even consider the qualitative demands and process requirements of forming relationships with community residents. Agencies are being required by contract to do more with fewer resources. Consequently, encounters between coworkers and consumers are increasingly rushed, circumscribed, and harried."

"The decline of community or communal networks represents yet another environmental stressor for nonprofit social service agencies. Social capital is most easily understood as the breadth and depth of social networks and communal capacity. In the past the stock of a community's social capital was perhaps most visible in the daily, informal contacts between residents. The decline of a neighborhood's social capital often translates into spiraling breakdowns in education, physical safety, health, and childcare. The contemporary ethos of privatization expects nonprofit social service agencies to address these strains as problems of individuals, not of the collective. This growing crisis of community and its translation into intensifying and expanding individual needs represents yet another claim on the often limited resources of nonprofit agencies in a privatized, corporate driven context."

"Problems of social service agencies can be traced to internal organizational dynamics. Centralization of administrative authority, monopolization of expertise by professionals, systematic distancing of agencies from the community, and an emphasis of tasks over processes are but a few aspects of agencies' internal choices that can limit their contribution to the development of individual and collective resources."

"Agency infrastructure and staff benefits and salaries are systematically underfinanced in government contracting. The gulf between levels of funding and agency needs requires that administrators cut corners or juggle finding streams to make do with less. For instance, part-time less educated staff may replace more expensive full-time, certified counterparts. Furthermore, limited reimbursements for agency infrastructure and overhead costs may result in a more decayed physical plant, limited staff access to phones, and broken photocopy machines that cannot be replaced. Individually, these contract demands and constraints tend to estrange both workers and consumers for the agency and each other."

"The intensifying demands and narrowed practice options of contracts promote a proleterianization of service work that conflicts with the building of relationships and community. The actual underpinnings of social services increasingly impair agencies' capacity to build relationships. Increased demands, less flexible structures for defining tasks and activities, and diminished supports restrict service encounters. Workers simply have less and less time to carry out expansive, increasingly proscribed responsibilities. Relatedly, the inventive energy, commitment to service work, attachment to agency, and reflective space necessary to promote membership relationships are less and less available. If staff is not cared for within agencies, if the structures that overburden and constrain service work are not transformed, their capacity to create communal experiences for consumers will be significantly limited."

"Workers have to experience the agency as a community before they can internalize and recreate such a possibility for others. This is, of course, a difficult task for agency leadership presently struggling to meet new service quotas or demands. The expansive requirements of contracting and the diminished supports for institutional maintenance create pressures to centralize administrative decision-making and make it more efficient. Greater emphasis on hierarchy or centralization of authority minimizes inclusiveness and reciprocity between administrators and their staff. These tendencies exacerbate the estrangement of staff from agency life. The service worker, like the client, is treated as a receptacle, to be filled with directives. Such circumstances only permit shallow relationships with the leadership of the agency as well as with day-to-day work requirements. Centralized decision making, detached, "efficient" service provision mark encounters between staff and consumers. This cycle is self-reinforcing and ultimately bobs social service work of any possibility of promoting layers of membership relationships or social networks. This is increasingly the reality of service work in our contemporary political economy and a fundamental obstacle to effective practice."

"The effectiveness of social change initiatives depends as much on residents having better resources and information as on strong networks of social solidarity. Only by struggling to integrate individual social services, community building, and social change initiatives can nonprofit social service agencies contribute to arresting and reversing the decline of very poor communities. Community building may well be the most important social service work of the next generation. At least it must be understood as integral to effective social service provision. Yet, the very structure of government contracting limits the capacity of not-for-profit agencies to engage in such work. The intersection between government contracting, the shifting meaning of social services, and the centrality of community building remains relatively under-explored."

The drive to reduce social services and the drive to reduce government participation and responsibility in the general welfare of the citizens creates a movement towards the solidification of a permanent economically poor, undereducated, defenseless, and powerless underclass. The social service practices today in the disability, youth services, and anti-poverty fields, led by the acute care and mental health model of managed care, while proclaiming self-determination and empowerment as the emancipation for all, truly play the role of the Pied Piper to the ultimate decline in resources, and supports for the majority.

The book The Forgotten Generation: The Status and Challenges of Adults with Mild Cognitive Limitations (2001), describes individuals who may have fulfilled the criteria for a diagnosis of mild mental retardation at some time in their lives. Some of the challenges addressed were:

1. An increasingly complex, information-based and technologically demanding society presents substantial and growing challenges, particularly in areas related to reading, arithmetic, processing abstract information, and using technology.

2. In an increasingly complex, more hurried, and less “neighborly” society, people who require support to negotiate social, commercial and governmental settings and circumstances find access to needed supports more difficult to obtain.

3. The barrier to social, commercial, and government settings and circumstances caused by disability-based limitations in reading, arithmetic, use of technology, and ability to gain access to information are as significant as physical and sensory barriers but are less likely to be accommodated.

4. Changes in public policies affecting low-income, unemployed, homeless, and other disenfranchised groups have had a substantial and disproportionate effect on individuals with cognitive limitations.

5. As previously existing programs of social support are being redesigned and downsized, people with cognitive limitations are made more vulnerable by their difficulty in securing knowledge of and access to these new programs and the time lag they experience between loss of previous supports and access to new programs is typically prolonged.

6. Most individuals with mild cognitive limitations desire that their needs be accommodated outside of service systems that bear stigma and will go to substantial lengths and disadvantage to avoid that stigma.

7. The vast majority of people with mild cognitive limitations define their needs in terms of basic income, housing, and other necessities and not in terms of their ability to gain access to a formal system of service. However, in the absence of involvement with such formal systems, few people are able to obtain access to stable and knowledgeable advocates.

8. Individuals with mild cognitive limitations are particularly vulnerable to secondary disabilities as a result of poor quality of health services, absence of preventive health care, and lack of protection from injury at work or at home or as a result of violence.

9. People with mild cognitive limitations are particularly vulnerable to secondary disabilities as a result of limited access to and quality of mental health services and as a result of the preventable effects of stress, loneliness, anxiety, and depression.

10. Individuals with mild cognitive limitations are particularly likely to be victims of crime, violence, and maltreatment because of inadequate preparation for independent living, lack of attention to their needs, tendencies towards errors of judgment, acquiescence to perceived authority, and exploitation of their vulnerability by others.

11. In an increasingly complex society, individuals with mild cognitive limitations are restricted in their employment opportunities by limited academic skills and higher rates of school dropout. They are restricted further by the movement toward higher performance criteria for high school graduation.

In the Youth Service field the book, Uncertain Futures: Foster Youth in Transition to adulthood (2003) discussed the plight of the nearly 500,000 children and youth who are currently in out-of-home placement. Of this number, 30% to 35% are adolescents. Each year, 25,000 to 30,000 young people approximately 18 years old emancipate from care. Once emancipated, the majority struggles for economic survival. Many transfer from one dependency system to another, including public aid, food stamps, housing subsidies, and other societal supports. Studies are consistent in documenting low educational attainment, unemployment, early parenting, and high rates of homelessness. The inescapable conclusion is that their potential for self-sufficiency and independence is low. Experts are concerned that a foster-care underclass is evolving.

These are young people with disabilities – mental, emotional, and physical – are represented in the foster care population. Many with a disability classification do not remain in kinship or relative homes on a long-term basis.

“Approximately 20% of all children in foster care are classified by a Child Study Team as handicapped. Despite an extensive literature on children and youth with disabilities, little attention has been devoted to foster youth classified as disabled.”

“Beyond appealing for the development of a Continuum of Care System, best practices in youth services calls for wraparound services as social capital.”

“Wraparound program require a dramatic shift in philosophy – one that moves from a categorical, uncoordinated ‘one-service-at-a-time’ approach to a community-based, team approach for service delivery.

Criteria for Wraparound Plan

Conditions considered essential in providing wraparound services are:

1. Service must be community-based, with emphasis on interagency cooperation.

2. A team approach is essential. Wraparound teams of five to seven members should include nonprofessionals and professionals. Most team members should be nonprofessionals (i.e., natural-system people), preferably including parents and family members.

3. The service must focus on an individualized service plan.

4. The team must designate a team coordinator who takes responsibility for activating the plan.

5. The team implements the plan and periodically reviews its progress.”

“As youth transition into their communities, contacts with former agency staff may taper off, workers leave jobs, and connections with foster caregivers may be disrupted. It is essential that foster wards connect with individuals who are not employees of the placement system. At some point, “natural system” connections must fill the gap. It is important to link foster wards with citizens who represent a cross-section of the community in which youth will live and work. It is in the best interest of all foster wards to gain experience in building a natural system network for themselves. (Independent-living plans should

describe efforts to develop a transitional network.) Although there are no hard and fast rules as to what resources should be available, it is possible to identify several resources that can be decisive in helping youth move toward economic self-sufficiency such as wraparound services, subsidies for housing, education, medical/health care, and citizen mentors."

HOW ARE INNOVATIVE PROGRAMS ADDRESSING THE TENSION BETWEEN AGENCY CULTURE THAT FOCUSES ON THE INDIVIDUAL AND INDIVIDUAL PROBLEM SOLVING VERSUS THE NEED FOR COLLECTIVE FORMS OF PRACTICE, ACTION, AND AGENCY CULTURE TO CREATE NEW FORMS OF PROBLEM SOLVING?

What is the bottom line between the needs of people with "disabilities" and the social contract? For whom does the social contract exist? What/who are the vying camps of interests within society?

The fields of Youth Services and Mental Health Services are decades behind Disability Services as to the model of services design. In many aspects, these fields are rushing to catch up to the Continuum of Care Model that the disability field is quickly abandoning. Within the disability field, the field of physical disabilities has been the vanguard.

In the book, Creating Individual Supports for People with Developmental Disabilities: A Mandate for Change at Many Levels by Bradley, Ashbaugh, Blaney (1994), the field of disability services is viewed historically as a series of changes in paradigms with:

- “**The ERA of Institutionalization** (thru mid 1970’s): Norms were dependence, segregation, and medical model of separating the sick and vulnerable from the rest of society.

- **The ERA of Deinstitutionalization and Community Development** (began mid 1970’s): Creation of group homes, sheltered workshops physically integrated in the community but provision of specialization services in socially segregated settings.

- **The ERA of Community Membership** (began mid 1980’s): Functional supports to enhance inclusion and quality of life defined by physical and social integration. This Era came about due to the crisis in funding institutions; specialized community facilities (Sheltered Workshops, Group Homes) with this crisis came the growing demand for supportive services.

The values associated with community membership, when realized, will totally alter the power relationships between providers and people with developmental disabilities and their families. They will make the person the subject rather than the objective of intervention and tie success to quality of life rather than the completion of a treatment regimen. In other words, they will undo professional hegemony forever, which is why this particular period of transition is so threatening. These threatening values are listed below:

- Individualization
- Consumer choice and self-determination
- Community connections
- Integration and inclusion
- Emphasis on families
- Real lives in real homes”

However, since 1994 the issue of Community Membership and self-determination has faded to become the wolf in sheep’s clothing of managed care.

Many champions of the “individual with disabilities” have morphed into family-centered models. The more advanced elements sense that their dreams could become their nightmares.

Smull and Danehey (1994) talks about “Increasing Quality while Reducing Costs.” “Family-Centered efforts must be supported and the transition to adult services seen as moving from being family-centered to being person-centered.” Can this be expected to occur? Or do families have different goals than their adult children? “As choice becomes more and more trendy an idea, the service system must guard against its perversions. The term normalization lent itself to the perversion of ‘normal’ consequences”. “Choice does not remove our responsibility to remain engaged”

“If families are supported, the request for more costly, out-of-home services will be deferred.” “Community associations can be built on the foundations of those already present built by the families who have spent years in the community.”

Over the past two decades, birthed from the civil rights movement by people with physical disabilities, a new paradigm called “self-determination” has grown. This new paradigm grew up concurrently with the movement of privatization.

Tom Nerney, in the paper, Lost Lives: Why We Need a New Approach to Quality (2004), wrote that "The failure of our federal statutes and regulations to adequately address the issue of the common humanity of individuals with disabilities has resulted in the substitution of human services and human service environments and programs for real life and high purpose. Individuals with disabilities have become human service subjects within a system of long-term supports that has no expectations that common life goals based on universal human aspirations can add great depth to the notion of addressing the health and welfare of individuals with disabilities."

"The promise of self-determination from its inception was rooted in increased quality, increased power for individuals with disabilities, increases status within the community for these same individuals and, at the policy and organizational distribution of public funds."

Self-determination was not some form of rugged individualism but rather recognition of our inter-connectedness and shared vulnerability. This included loneliness, isolation and the powerlessness experienced when public dollars are out of control of individuals with disabilities and families."

"There are major points of agreement on the need to shift control of a targeted amount of resources directly to the person with a disability/family. There is a new awareness of the role responsibility plays with this freedom to choose providers and services as well."

"At its heart the self-determination movement was committed to obtaining better value for the dollars currently expended."

In 2001, President George W. Bush announced the New Freedom Initiative for People With Disabilities. It promised to tear down the remaining barriers to full integration into American life that many of this Nation’s 54 million citizens with disabilities still face. For social services, the largest driving economic force is Medicaid. Under the U.S. Department of Health and Human Services, the Centers for Medicare and Medicaid Services is the Federal driver of the Federal and State direction in the numerous social service fields.

Under the Social Security Act, Section 1915 and Section 1115 allows for Waivers from certain standard Medicaid rules in order to develop, at the minimum, Federal cost neutral and preferably cost saving new service delivery methods. These methods utilize managed care methods with capitated levels of support.

A recent example is the Vermont Health Access Plan under a Section 1915 (c) Waiver which will 'substantially expand the state's capitated managed care plan, which heretofore has been restricted to acute and preventive health care services, to include Medicaid-financed services furnished by a variety of other state agencies, including the Department of Children and Families (children's programs and field services), the Division of Economic Services (eligibility determination), the Department of Aging and Independent Living (long-term care and disabilities services), the Department of Education (school-based services), the Department of Health (mental health and substance abuse services, public health services and chronic care services), and the Department of Corrections (probation and parole services), Community Services Reporter, 11/2005.

A new Section 1115 Waiver in Florida sets the future direction, the likely next step in the managed care process. An e-mail from the ARC of Ohio (10/05), announces that, "The Bush administration approved a sweeping Medicaid plan for Florida (Gov. Job Bush sic), that limits spending for many of the 2.2 million beneficiaries there and gives private health plans new freedom to limit benefits." The Waiver allows the state to set a ceiling on spending for each recipient. "Joan Alker, a senior researcher at the Health Policy Institute of Georgetown University said, 'Florida's proposal is one of the most far-reaching and radical proposals we've seen to restructure Medicaid. The federal government and the states now decide which benefits people get. Under the Florida plan, many of those decisions will be made by private health plans, out of public view'."

We see the actual results in the implementation by the Federal Government policy of domestic funding capitation and policy of "dramatic cutbacks in domestic funding." Medicaid driven schemes under the Section 1915 and Section 1115 Waiver and the Independence Plus Initiative encourages states to transfer ever shrinking domestic resources into a managed care system run by huge not-for-profit organizations who administer provider networks so that individual 'customers' may choose, with funds allocated to them, to purchase services. 'Customers', the 'customers' support group, and social service providers are encouraged to build 'social capital' in the communities i.e. find free volunteer supports. Although in the abstract such approach has an ideological logic of individual empowerment for people with disabilities it ultimately serves to further marketize, individualize and commodify services. Equally important a larger collective life for service users embedded in agency and underpinned to some extent by professional expertise is being eviscerated by such a tendency. Ultimately, this is a policy that may atomize and render invisible disability groups. This is hardly an outcome that speaks to a collective or individual empowerment especially when significant others, family, etc. are likely to make decisions for the service users. Ultimately this is a return to 16th century forms of non-institutional care that intensified the marginalization, stigma, and powerlessness of the poor and people with disabilities. Concurrently, in the prior two decades, the movement to close Rooming Homes, Nursing Homes, Institutions, and other large congregate care models have generally subsided, thus perhaps reopening the door for policies of re-institutionalization.

Within the developmental disability field over the past two decades serious questions have arisen about the continuing viability of community residential programs, social service agencies in general, and the

paradox of the growing lack of options that people with disabilities have to chose from concurrent with the expanding movement of services being unbundled and funds being controlled by the “consumer/customer.”

We are seeing the potential demise of local, community based not-for-profits due to cuts in service funding, the inability to hire and retain trained staff, the increasing demands of funders for accountability and increasing reporting requirements and costs, and the continued increase in operations such as utilities, transportation, health coverage, etc. outpacing new revenue. At the same time there is a dramatic growth in the size of certain not-for-profits and the emergence of large for profits in the field. Mergers, acquisitions and price undercutting through a more frequently used bidding process to provide services is changing the nature of social service delivery. Obtaining or developing free or low cost "natural support” is driving down the ability of agencies to compete. It is forcing social service sectors to become drains on community resources rather than developers of community resources.

IS THERE A NEED FOR A SOCIAL MOVEMENT, AND WHAT SHOULD IT LOOK LIKE?

Do we know what the mega tends are and do we know where we want to go? If there is a need for a social movement, its organizational structure? Composition? Locus of power/resources/control?

Bob Gettings stated at the National Alliance Conference, DC, 09/05, that a "New leadership coming in with no experience in the field. Those with experiences in the system are 'financially starved' and reorganized out of the system due to downsizing of government and government supports. With this in mind, what is needed is a Nation-Wide Leadership Institute in Policy and Services that is multi-disciplined, with consumer and professionals. Need early and mid-career term internships; succession planning at all levels of organizations; and need to continue the alliance pf the DD communities."

In order to have a direction for a movement, it is important to establish where things are today, and where things should be tomorrow. Otherwise it is likely that one will have the illusion of movement but discover that after all the efforts we just floated along with the mainstream of the prevailing mega trend.

As Jim Conroy, from the Center for Outcome Analysis, stated in September 2005 at the National Alliance Conference, "There haven't been any really new ideas in the past decade".

As a field we need to begin the discussion. We need to do it now otherwise there will be no need for leadership as there will be no place to which to lead.

We see a mega trend where community resources are being crushed through under funding. The Federal Government cuts back and places the burden on the states. The states capitate Medicaid funding through managed care schemes. Private for-profits and not for profits become the agents of government as the Manager of Comprehensive Provider Networks, (CPN). The CPN contracts with local for profits and not for profits as well as other businesses to be in the network at a negotiated reimbursement rate. The Consumer is given a capitated 'voucher' and must chose a comprehensive provider network from which to purchase their services. As the funding is capitated and usually not enough, the consumer, his/her family, and friends are almost forced to find free support services in the community. The structure of support is often fragile.

When the Federal government cuts back, the states cut back. The Managing Comprehensive Network Agency (now a multi-million dollar business) cuts back on its reimbursement rates to the providers in the network. The Consumer is allocated through various schemes less 'voucher' dollars either directly or through capitation. Over time wither way the purchasing power is reduced through inflation. The door to services becomes harder to enter. The Gate Keeper to the 'system' through various incentives restricts entrance. This spiral continues unchecked, as there are few if any organizations left to fight back.

Tom Nerney, the Executive Director of the Center for Self-Determination, a Nationally visible group that promotes Self-Determination and the Federal Trends in funding, makes some important observations in an article in TASH Connections, April 2005. As a disclosure, the Center for Self-Determination was established and funded by a large ($123 million per year budget) Comprehensive Provider network Manage, Community Living Services, Inc. of Wayne County, Michigan.

Tom Nerney observes, “In truth, self-determination is suffering from both confusion and compromise. It is difficult to implement in very complex systems that are organized to easily resist the structural changes required. It is labor intensive at the personal and family level. There are hopeful signs of increased understanding that self-determination is not about tinkering with the present system. It is, in fact, a vital restructuring of what we call ‘long term care’ in this country.”

“We are on the brink of a fundamental reordering of the Medicaid program by others. We are witness to the potential collapse of the community system as it has slowly evolved. We look helplessly at the growing lists of those without supports. The central questions of the next decade will be how the system of long-term supports will be organized, who will be served, and finally, what value base will under gird it. For us, today, the issue of just who will determine the answers to these questions remains an open one.

In the face of this unprecedented crisis, the anemic responses of the traditional provider and professional groups are organized around protecting the existing system and praying for increased appropriations. There is no counter offer to governors and federal officials that rests on deeply held values but acknowledges that the present system is besieged by high costs and few positive outcomes. The time has come for a more robust policy analysis”.

“Four competing strategies overlap and have added to both the confusion and the compromises that we have seen in the past decade:

- Provider choice
- Person centered planning
- Self directed services, and
- Self-determination

When some individuals received their allocation many states called that an individual budget. Simply assigning your budget to a provider is nothing more than provider choice. Many simply bought back traditional services.”

“Some states decided to substitute self directed services for self-determination. That is, individuals were allowed to hire and fire key personnel to provide various supports. This approach ignored all of the deep dimensions associated with the necessity of belonging both to the community and to loved ones, as well as the necessity of addressing the personal and social consequences of poverty. It is possible to ‘direct your own supports’ and remain friendless and impoverished.”

“Some have substituted person centered planning for self-determination. This interpretation relies on a very paternalistic view of individuals with disabilities. Without control of the resources the goals of person centered plans remain entirely at the discretion of those who typically provide services and supports. ‘Power sharing’ has become the mantra of some. Unfortunately in these arrangements the ‘power’ can always be withdrawn.”

“Others, still, have simply changed the name of case management to independent support brokering, never addressing the inherent conflicts of interest and the necessity for a whole new set of skills.”

"The Medicaid program is broken and beset with archaic and irrational rules and regulations. Individuals with significant disabilities served by the Medicaid program are inextricably tied to the rising costs of health care and the drag on Medicaid expenditures from institutional arrangements in every state budget. In fact, it can be argued that middle class individuals who protected their assets in order to become Medicaid-eligible for nursing homes are the largest single user group of long term care under Medicaid."

"The time is now to advance a legislative agenda that recognizes that defense of the old system will no longer hold. The consequences of failure here will be the constriction of Medicaid eligibility, a huge increase in the waiting lists for those who need support and, finally, a future of significant cutbacks that will do great harm to what will soon become a minority of those who need support and currently receive it." Tom Nearny then offers a list of 'new agenda items' that basically would accelerate the current Medicaid trends."

"He further states in the article that "What is remarkable about properly implemented self-determination is that it holds out the promise of real freedom, the promise of better value for the dollars (more cost efficient), and the promise of a new policy partnership which recognizes that the primary stakeholders are people with disabilities and their families and allies."

Nerney does not explain who the 'new policy partners' are or whether the current group in charge of the national social contract wish to be partners with Mr. Nerney and the self-determination movement or simply use them as a tool for further 'cuts to the body of domestic spending until it dies'. Nor does Mr. Nerney spell out who are the 'allies'.

However, looking at the historic and actual results of the holders of the current social contract we see that more resources are being eliminated and that there is every reason to believe that there is no intent to better serve people in the long run. It is simply, at best, the re-scattering of an ever-reducing level of crumbs more widely.

And there is no identified mechanism of resistance and roll back. However, historically that too will come. The answer is in front of us; we have yet to open our eyes to see it. That is our current task and duty.