

McFadden, D., & Burke, E.P. (1991). Developmental disabilities and the new paradigm: Directions for the 1990s. *Mental Retardation*. 29. iii-vi.

Developmental Disabilities and the New Paradigm: Directions for the 1990s

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There has been considerable attention focused during the past decade on defining the respective roles of federal, state, and local governments as well as nongovernmental entities in providing resources and service initiatives to persons in need. Editorial pages have been crowded with terms such as federalism, local control, deregulation, federal-state partnership, and the like. All of these terms have been used to describe the debate regarding the organization and distribution of power and resources, the optimal "locus of control" in social affairs.

Recently here in Washington, a new conceptual framework has emerged and in some ways, has synthesized many of the elements of this debate: the so called "new paradigm." Simply put, the new paradigm envisions a social order wherein most important decisions are made at the local level, the role of the federal government is diminished in operational aspects of service delivery, and, in the ideal, people are empowered to develop their own solutions to issues affecting their lives.

It is not surprising that new paradigm thinking has caused some concern among advocates for human services and education, who have often sought assistance from federal sources when such assistance was not available at the local or state level. This is, of course, quite true in the field of developmental disabilities, wherein our most recent history is filled with examples of the federal initiatives and interventions in major areas. Beginning in 1963 with the passage of the Mental Retardation Facilities and Construction Act, the field has witnessed a steady stream of federal legislative initiatives, such as the Developmental Disabilities Act, the Rehabilitation Act, the Education for All Handicapped Children Act, and, most recently, the Americans With Disabilities Act. These legislative initiatives and others have provided national level attention to the needs and capabilities of persons with developmental disabilities and have led to fundamental changes in the types of opportunities available and the quality of life experienced by these people and their families. In all of these initiatives, Congress has found that there is a major national interest in expanding rights and access to resources for people with developmental disabilities. Today, there are very few individuals with developmental disabilities whose lives have not been affected by federal initiatives and funding programs.

At first glance, it may seem that new paradigm thinking would be in opposition or contradiction to the recent history of our field. However, upon a more careful analysis there is a remarkable consistency between the local empowerment ethos

that characterizes new paradigm thinking and the individual and family focus emphasized in most recent federal legislation. During the past decade in particular, virtually all major federal policy initiatives have included, indeed mandated, a focus on the individual and family, the "I" embodied in Individual Education Programs, Individual Habilitation Plans, Individual Work Rehabilitation Plans, and Individual Family Support Plans. These Federal laws are abundantly clear in their intent: People with disabilities and their families should be decision makers in every aspect of service delivery, from original design to final evaluation. Thus, although there is obviously a compelling national interest in guaranteeing rights and ensuring opportunity, there is also a recognition of the overarching need to respect and promote individual control of services and supports.

Beyond the legislative area, best practices in the field have reinforced the key role of individual, family, and community involvement and control in designing support services. Tens of thousands of individuals have moved out of large congregate institutions into small community residences. This has been accompanied by significant shifts from reliance upon segregated educational settings to typical public schools and from reliance on sheltered workshops to the development of individual supported employment situations. All of these practices have moved the field away from an almost dictatorial situation in which professionals knew what was "best" for people and into a situation in which consumers are guaranteed involvement in decisions affecting their lives. Other examples of this move toward individual, family, and community empowerment include practices such as "circles of support," citizen advocacy programs, and the mandatory presence of consumers on various decision making bodies, such as state developmental disabilities councils. Some of the most thought provoking and visionary thinking involves a transfer of decision making authority from large organizational units and professionals to local communities. A leading proponent of this school of ideology, John McKnight, has advised human service professionals to "do no harm" and sees the re-establishment of inclusive communities as essential to our collective future well-being (McKnight, 1989).

In a recent article in the Washington Post, Daniel Osborne advised incoming Washington, DC, Mayor Sharon Pratt Dixon on how to turn the besieged city government around. Many of his ideas bear a striking resemblance to those that have been advanced in our field recently. Among Osborne's suggestions are: "use government more to steer than to row, whenever possible, inject competition into public service, let people choose among service providers, don't just spend money, invest it and measure your return, decentralize authority, and push control of services out of the bureaucracy and into the community." (Osborne, 1990, pp.19-23, 38-41). Osborne's ideas are both refreshing and challenging in their intent to re-direct a troubled organization toward effectively addressing the needs of a constituency it has failed to properly serve, precisely the situation our field has struggled with for so many years.

There is, of course, a lingering suspicion among critics of new paradigm thinking

that such thinking signals an attempt to abrogate the federal government's responsibility in the social service area. Osborne (1990) recognized this danger and stated, "That is why we need this other half of the equation: the empowerment of communities. To complement the efficiency and effectiveness of market mechanisms, we need the warmth and caring of families and neighborhoods and other social groupings" (p.43). Although the possibility for regression exists, it is incumbent upon us as advocates to ensure that the many victories we have achieved remain intact, that our agenda for equality and increased opportunity go forward, and that we seize upon the many positive opportunities this new thinking affords us to empower people and create inclusive, and therefore higher quality, communities.

Over the course of the next decade, we at the Administration on Developmental Disabilities seek to respond effectively to the needs of our constituency -- people with developmental disabilities, their families and communities-- in a manner consistent with the more positive elements of broad social thinking, such as the new paradigm framework and the best practices currently available in our field. Our overall goals are to increase the independence, productivity, and integration of people with developmental disabilities in communities all across our nation. To this end, and in concert with the wisdom provided to us recently by over 10,000 individuals with developmental disabilities and their family members, we will be supporting activities in five key thematic areas.

The first of these areas is Empowerment and Leadership. The Developmental Disabilities Act itself calls for strong consumer involvement in planning, service delivery, evaluation, and advocacy activities. In the 1990s, we will work to underline and reinforce the participation of people with developmental disabilities and their families in decisions affecting their lives through the provision of leadership training. Thus, we are planning to sponsor a Leadership Training Institute for and with people with developmental disabilities that will serve as a national resource for the development of future leadership in this area. We also seek to increase the participation of family members in decision making through a Family Leadership Training approach. It is our belief that decisions that affect the quality of life experienced by people with developmental disabilities and their families are best made in consultation with and participation by the consumers themselves. During the past several years, we have witnessed the development of People First, Partners in Policy Making, and Family Leadership Training programs in many states. We wish to expand these types of activities nationally. Through these initiatives we believe that we will significantly increase the number of informed and articulate spokespeople on both the state and national level.

The second theme we will pursue is Choices and Flexibility. Empowerment and the development of leadership skills are somewhat hollow concepts in the absence of an opportunity to receive individually tailored services that provide the individual and the family with choices. In order to reinforce the empowerment of individuals and families, we will encourage the development of flexible personal and family support programs. Not only are such programs highly individualized and tailored to the

expressed needs of individuals and families --remarkable outcomes in and of themselves-- they are also much more cost effective and efficient in that we avoid providing unnecessary services, services that individuals and families do not want or require, but which are often included as part of the "package deal" provided by agencies. Through empowerment and choice we can go a long way toward significantly increasing consumer satisfaction, the relevance of our services, and our ability to responsibly allocate resources to their maximum benefit.

The third theme might be termed "A Home of Your Own." Activities in this area will involve the development and implementation of creative approaches to consumer-controlled housing: the ownership, leaseholding, or other control of housing by people with developmental disabilities themselves or in cooperation with others or, when desirable, with family members. Various approaches to address the lack of affordable housing have been proposed and sometimes offered in the past few years. Investment tax credits, consumer co-ops, land trusts, and various other strategies have been advanced to address housing needs. We seek to increase housing options and consumer control of these options. In line with the empowerment theme, we also believe that consumers should have a major voice in designing and evaluating home-based supports that might be provided. A person's home is his or her castle. People with developmental disabilities can have castles too.

The fourth theme is Full Community Participation. We may think of this as "turning a house into a home." Our vision is that we will assist people with developmental disabilities to move beyond mere physical presence in our communities and into the full array of social spaces in our communities as full and valued participants. We want to significantly increase the use of generic recreation and leisure opportunities, including participation in on-going sports, civic, and/or church groups, depending on an individual's preferences. We need to expand opportunities for people with developmental disabilities to experience programs such as Outward Bound, to travel, to achieve. We also hope to assist people to experience what we call "Inward Bound," that is, the development of a positive self-image and the confidence that comes with acceptance, achievement, and recognition. People with developmental disabilities need to enjoy all that their communities have to offer. People also should have the opportunity to share their skills and talents within their communities. This, of course, will more readily happen as we achieve inclusion and participation.

Our fifth and final theme is Positive Public Education. Here we will seek to significantly improve the public's perceptions and attitudes concerning people with disabilities. It is true that images and expectations have improved greatly over the past decade. We now live in a nation where we see actors with disabilities on national television programs, in print ads, and on stage. Yet this is still the exception, and not the rule. We live in a culture in which we are constantly bombarded with advertisements and image enhancing media designed to glorify things to wear, things to eat, things to drive. We need to access this imagery stream

and increase the positive portrayal of people with disabilities in order to shape more positive attitudes. Given the history of our field and the way people with disabilities have been regarded in the past, it is clear that we have a long way to go. It is sobering to think that children with disabilities are still being killed because of damaging negative stereotypes. We need to help ordinary people appreciate and value the presence of people with disabilities in our neighborhoods, in our schools, in our workplaces, and in all those thousands of social spaces that make up the tapestry of our life experiences. Thus, we will be making a national-level effort to educate the public on the value and contributions of people with disabilities.

These five themes: Empowerment and Leadership, Choice and Flexibility, A Home of Your Own, Full Community Participation, and Positive Public Education, represent our views about the directions the field should take during this decade. Like new paradigm thinking, they synthesize much of what we have learned in our advocacy and capacity building efforts to date. They also challenge us as advocates, as policy makers, as social engineers -- as human beings -- to consolidate the many gains we have made at the federal level into strategies to massively increase the presence and valued participation of people with developmental disabilities in the lives of all of our local communities. In short, we need to discover in the invisibility of true integration the outcome we have sought for centuries.

References

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