

Parent Advocacy for Disabled  
Children and the Disability  
Rights Movement:  
Similar Movements,  
Different Trajectories

by

Nora Ellen Groce

PONPO Working Paper No. 237  
and  
ISPS Working Paper No. 2237

November 1996

\*\*\*\*\*

Nora Ellen Groce, Ph.D., Yale School of Public Health, Division of Health  
Policy, Laboratory of Epidemiology and Public Health, P.O. Box 208034,  
60 College Street, New Haven, CT 06520-8034.

\*\*\*\*\*

In the interest of fullest possible circulation of information and ideas, the  
Program on Non-Profit Organizations and the Institution for Social and Policy  
Studies reproduce and distribute each Working Paper at the request of the  
author(s) affiliated with PONPO or ISPS. Papers are not formally reviewed, and  
the views are those of the author(s).

A list of PONPO Working Papers can be obtained from PONPO, Yale University, 409  
Prospect Street, New Haven, CT 06511. A list of ISPS publications is available  
on request from ISPS, P.O. Box 208209 (77 Prospect Street), New Haven, CT 06520-  
8209.

Extracts of more than one hundred words may not be reproduced from this Working  
Paper without the permission of the author.

Program on Non-Profit Organizations  
Institution for Social and Policy Studies  
Yale University

Parent Advocacy for Disabled Children and the Disability Rights  
Movement: Similar Movements, Different Trajectories

Nora Ellen Groce, Ph.D  
Yale School of Public Health  
Division of Health Policy

DRAFT: Please do not quote without permission of author.

The author wishes to thank the Yale University Program on Non-  
Profit Organizations for the Mini-Fellowship Award that  
funded the research and writing of this paper.

## Abstract

This is a study about two disability oriented advocacy movements, the Parent Advocacy Movement and the Disability Rights Movement. This particular study is not intended to be an in-depth examination of these individual movements, which have been studied elsewhere, but rather a discussion of why these two movements, so similar in their historic roots, common agendas, and "target audience" maintain so great a distance from one another. Why are prominent leaders, major initiatives and leading organizations in one movement often unknown to members of the other? Why, despite obvious overlaps in interest and agendas, should divisions between them be maintained even down to the smallest, local chapters. This is all the more striking because these are not two single organizations with a national or regional leadership making hierarchial decisions that must be followed down the line, but literally hundreds of organizations, small and large - that fall into one camp or the other (parent-based or adult-disabled). It is furthermore rare to come across a member of either one of these groups, who regularly crosses from one to the other and back again. There is not one, but a series of reasons that seem to account for this bifurcation of time, attention and networking. A consideration of these might provide some insight into the larger issue of why and how movements grow and develop over time and among constituencies.

## Introduction:

Social advocacy movements are composed of social and professional networks that are able to reach some type consensus, define an agenda for action and pursue certain courses of action, while ignoring or choosing not to follow others. Social movements, as a growing body of literature demonstrates, are often 'ideas whose time have come.' But the 'coming' is the end-product of a complex series of historical, demographic, political and economic issues, often brought to a point of crisis by individual leaders and a specific set of circumstances.

In discussing advocacy, we frequently begin with a unifying social issue - discrimination against a minority or improved education for children and then move on to discuss particular organizations within this larger framework. In such studies there is usually an assumption made that although differences may arise in the style, membership and immediate targets selected by subgroups or organizations within the larger movement, these differences are less important in the grand scheme of things than the unifying changes they are working to bring about.

Both the parent advocacy and the disability rights movement seek to bring about improvements in the lives of Americans with disabilities. They frequently work on the same social and legislative agendas, and not infrequently utilize the same community resources. Indeed, there are some individuals who are prominent in both movements, although they rarely bring the two

spheres together even in their own activities. These two broad movements have helped to set policy for many of the 43 million Americans who live with one or more types of disabling conditions.

In this study, I seek to better understand why these two national non-profit movements with virtually identical goals and several million participants, so infrequently work together on issues of mutual concern. Effective in themselves, they continue to build and federate internally without beginning to explore the common ground they share. Indeed, they frequently seem to know little about each other.

In part - but only in part - the answer may be historical. In part, the answer may reflect fundamental disagreements as to who is to make decisions for the individual with disability. In part the lack of greater collaboration may also be organizational in nature, reflecting the fact that once certain networks have been established, members are more likely to utilize familiar paths and rely on already established organizations, than to try to explore new ones. In fact, it is likely that there is not one, but several factors that in sum, have proved decisive in determining the present configuration of these two movements.

I will argue here that the parents movement and the disability rights movement, may serve as case studies to shed more light on why certain movements remain distinct from one another despite what seem to be unifying goals. It is important that we better understand where they come from and where they are going, both to develop a clearer idea of disability advocacy in America and on a

broader scale, to better understand how historical precedents, internal politics and external pressures may shape substructures within movements.

The following discussion reflects on-going research and the findings are based on a series of open-ended interviews held with twenty leaders and thirty-five rank and file members in both the disability rights and the parent movement, over the past year. A representative sample of leaders were selected based on organizational affiliation, regional representation and prominence within the movement. A representative sample of grass-root members was also selected and interviewed using the same criteria for organizational variation and regional representation. (1) The use of those at both the leadership and grassroots levels it is hoped, provides a better understanding of what these movements mean to their participants and what these participants understand about the corresponding movement. At this point, some of these findings raise more questions than they answer, but it is felt that these are questions that are well worth considering.

Background:

Both the parent advocacy movement and the disability rights movement are consumer driven movements which arose after World War II, spurred on by opposition to the then unquestioned (and still not uncommon) clinical model of disability, which placed decision making largely in the hands of medical and social service 'experts.' According to the then widely held assumption, parents of disabled children were simply too emotionally involved in the

welfare of their child to be trusted to make important decisions without professional guidance. Individuals with disability themselves were rarely included in any decision making as it was commonly agreed within professional circles that they were unable to view their conditions with enough detachment to make rational decisions in their own best interests (Shapiro:1993).

The parent advocacy and disability rights movements are not in themselves unified groups. Rather the terms are used to refer to two movements composed of thousands of local and hundreds of regional and state associations, primarily organized and lead by non-professional individuals at the community level. Some groups rally around a specific disabling condition (cerebral palsy, mental retardation, and so forth); some organize around issues of delivery of specific services - education, transportation, rehabilitation services. Others broadly advocate general disability rights or provide a variety of services for their specific cliental.

No matter what the reason for a specific disability-based organization, almost invariability they have historically fallen into one of two camps. The first group of organizations identify in some manner with the interests, activities and advocacy approaches found in the parent led, family based parent movement. These organizations address issues of individuals with disability as a member of a family group. The second group of organizations, led by adults with disability, look to the disability rights movement, which places a strong emphasis on civil rights and self-advocacy, but pays relatively little attention to the individual

with disability as part of a larger family unit.

In the following sections, I will first describe both the parent advocacy movement and the disability rights movement in some detail and then go on to explore the ways in which the two groups articulate (or fail to articulate), with one another.

#### The Parent Advocacy Movement:

The parent advocacy movement, composed of parents of significantly disabled children began in the late 1940s. Parents with children having all types of disabilities are represented, but the largest group within the movement, particularly in its early years, were parents of mentally retarded children or multiply handicapped children who had some form of retardation in addition to other impairments. It was this large group of parents of retarded children that provided the bulk of the early leadership in the movement.

Having a disabled child, in that era, particularly one with mental retardation was still considered a shameful condition by many, a reflection of "weakness", "bad blood", "poor genes," a manifestation of parental sins or of incest with a close family member (Groce:1993). Parents with such children were encouraged to allow them to die. If the children lived, the medical community recommended that they be institutionalized (Trent:1994).

Newborns with obvious signs of mental retardation or other forms of disability, were often discharged directly from the hospital to the nursery of an institution. Indeed this was



encouraged by physicians who were concerned that if not institutionalized from the outset, parents would begin to bond, making future separation harder still. Older children were often removed from home and family as soon as they began to show significant intellectual deficits or developmental delays. Thousands of children were institutionalized before the age of five.

In the 1940's, a combination of factors promoted some parents to begin to rethink the option of institutionalization. Given the post-War climate, the rethinking of long-accepted beliefs may have been inevitable. Eugenic theories, which had dominated much of the discussion of disability for the preceding half century, had been soundly discredited by their association with Nazi Germany (Gallagher:1990). The belief that children who were born disabled would quickly die was also reexamined, as new drugs, particularly antibiotics, made it likely that infants sent to institutions would live for years, instead of being quickly carried off by medical complications or by the infectious diseases, such as tuberculosis, that had been so common in the back wards of the institutions and chronic care hospitals.

The institutionalization of children did not disappear overnight, (Center on Human Policy:1979). Indeed, between 1950 and 1968, institutions for disabled children and adults with disabilities grew at a faster rate than at any other period in American History (Trent:1994). In earlier times, children with disability had regularly been all but abandoned in such

institutions from birth. It was not usual for parents to inform siblings and close relatives that a new baby or young child had died, when in reality, the child had been sent to a public or private institution for the mentally retarded or multiply handicapped. (2)

In increasing numbers however, parents were refusing to allow their children to be institutionalized at birth (Dybwad:1990). In going against the then routine medical advice, parents were openly confronting physicians, family and society. This shift in thinking was not brought about by medicine alone. Although the fact that many disabled children could anticipate surviving infancy forced a re-examination of institutionalization, there were larger socio-economic issues that also contributed to the change in accepted practice. The trend towards more nuclear family structures and the post-war housing boom made it possible for many young couples to establish household of their own, allowing them the room and the right to make independent decisions about the care of their child.

Parents who elected to keep their disabled child at home were soon forced to confront a new set of issues. How were they going to socialize and educate their children? Even the most basic of social services were missing and little was available in the realm of home based medical care or physical therapy (Mackie:1969). Most importantly, few early childhood pre-school programs existed. As the tide of baby-boom children began to reach kindergarten age in

the early 1950s, the parents movement crystallized. Its first unifying target was education.

Keeping a disabled child at home put the parents at odds not only with prevailing medical opinion, but also with prevailing educational norms. The American public school system acknowledged virtually no responsibility for children whose performance on standardized tests fell below certain minimums or who were unable to perform certain routine tasks (Mackie:1969). For example, physically disabled children in New York state were unable to attend public schools in the 1940s and 1950s unless they could eat a sandwich by themselves, toilet themselves and perform other routine self-care chores. Even children who scored exceptionally well on intelligence tests were denied an education if they did not meet these criteria. The needs, indeed the very existence of disabled children, particularly those with mental retardation, was not acknowledged or addressed by any regional or national teaching organization (Groce:1993).

This had not always been the case. Near the turn of the century, the development of intelligence testing led to the identification of large numbers of mildly to moderately retarded children (Shapiro:1993). Research in Europe had already established that many of these children would flourish in special education settings (Dybwad:1990). Following the European lead, special classes for mentally retarded children were begun in Providence in 1896, and in Springfield, Chicago, Boston and New York before 1900 (Mackie:1969). Others followed, despite the fact

that most educators felt the responsibility of educating the disabled child did not belong to the public school system. With such an attitude, it is not surprising that special education programs were the first to go when the Depression began to squeeze school budgets. The 'higher functioning' disabled children were sent to languish in the back of the regular classroom, while those children who were more severely impaired were simply sent home or institutionalized.

By the late 1940s, few programs for disabled children remained. New Jersey, for example, despite sizeable increases in overall population, had more children in public school special education classes in 1918 than in 1950 (Groce:1993). Most large school districts had separate schools or separate programs for disabled children. These programs generally offered a notably bad education (Walker:1985; Phillips:1990). School districts often used their special education programs as holding tanks for any child who was "different." Many school based programs stopped at the end of elementary school, after which time, teachers were sent to individual childrens' homes for a hour or two of instruction each week. Diplomas given upon graduation were rarely full high school diplomas, allowing children little chance of continuing on to higher education. Smaller school districts often had even fewer options and none for the retarded and multiply handicapped child (Mackie:1969). Deaf and blind children were educated in entirely separate facilities, often located hundreds of miles from their homes, where children as young as six were routinely sent to live

for months at a time.

In the late 1940's, a small groups of parents began to try to locate spare rooms in church basements or community meeting halls in which to hold classes for their disabled children a few hours each day. These local efforts brought parents together within school districts. Soon these parents began to come together on a regional and state-wide basis to compare notes and lobby for more funding.

In 1950, the first national convention of parents of retarded children was held in Minneapolis. There, a nation wide group, the National Association of Retarded Children, (NARC) was organized. It would later change its name to the Association for Retarded Citizens (ARC). From its inception, NARC distinguished itself by its uncompromisingly grassroots stance and its emphasis on consumer advocacy. NARC proved to be a tremendous success. By 1956, it had well over 50,000 members, with branches in every state, dealing with legislation, parent education and the training of professionals (Dybwad:1990).

The success of parents with mentally retarded children spurred other parents with children who shared particular diagnoses, to come forward and organize regional and national support groups using a similar format. For example, United Cerebral Palsy was founded in 1948, the Muscular Dystrophy Association in 1950.

#### Identifying Agendas

Through the 1950s, these early parent groups had success as

greater numbers of mentally retarded and physically disabled children were brought into the public education system. Educational issues, however, proved to be only the start.

By comparing their experiences, parents quickly became aware that medical professionals often knew little about specific disabilities beyond their ability to diagnose them. Information about how children with specific disabling conditions would grow and develop over the course of time was scarce. How such children might function in adulthood was scarcer still. Institutionalization had meant that from the mid-19th century on, most significantly disabled children had grown to adulthood in institutionalized settings and continued to live within that milieu. In these institutions, chronically underfunded and understaffed, little attempt was made to socialize or educate the patients. Many children were never toilet trained, nor taught how to feed or dress themselves. Rarely spoken to, still more rarely held, few received any sort of individual attention by staff members. Although older children with less severe disabilities were trained to do certain activities (particularly activities that would provide free labor for the institution, such as laundry or the growing vegetables), more severely disabled children were given neither training nor education (Trent:1994). Because of this, almost no one knew how such individuals would fare in a family or community setting. Anxious to learn what the future would hold, parent groups began to fund research and training of physicians, psychologists, therapists and special educators.

At first, reflecting the times in which they lived, parent advocates rarely questioned the basic medical model of disability. Disability was a condition to be prevented, cured or overcome. Individuals with disability, within this model, were considered sick or in frail health, and in need of regular medical supervision. With enough medical research, prevention would someday be a reality; a cure would someday be found. Buoyant faith in science and technology, in particular American science and technology, lead parents to identify strongly with the sympathetic medical experts. Had not a vaccine for polio just been found? Weren't antibiotics preventing thousands of children annually from becoming blind, deaf or otherwise disabled? A better and healthier life for children already living with disabilities was on the horizon.

Experts needed to learn more about social as well as medical aspects of disability. Initially, even basic statistics and information, such as how many disabled children lived at home, what services they needed and with what issues their families had to contend in a community setting, were lacking. In the early 1950s, only 14 universities in the country had any sort of training program for special educators. Nationally the number of doctorates in Special Education awarded annually averaged about 11 (Groce:1993) Physical therapists, occupational therapists and vocational rehabilitation specialists were in short supply, with only a handful of programs around the country training practitioners in these fields.

Parent groups turned to federal funding sources, private foundations and the general public to raise money. They proved to be highly successful. Between 1950 and 1980, at the behest of parent groups, the public and private funding that poured into research, training and programming increased many fold. Funding, much of it provided by the Department of Health, Education and Welfare, established over 100 new college and university programs that turned out rehabilitation therapists, special educators, and vocational rehabilitation specialists by the thousands (Mackie:1969; Walker:1985; Berkowitz:1987).

It was the parent groups that had devoted the time, energy and money to campaigning for better research, more educators and better programs. Their relationships to professional groups, such as physicians, educators and social service providers, was complex. Parent advocacy groups amassed a considerable amount of expertise on the individuals they served. While advocates were often more knowledgeable about medical, social and psychological issues, the then-contemporary belief in "experts" made it impossible to circumvent the professionals who served as gatekeepers. Hence, parents and parent groups formed strong links with specialists (Ferguson and Ferguson:1987; Hamre-Nietupski:1991), insisting that more monies be made available for the training and hiring of sympathetic professionals and research. Over the years, a strong and congenial collaboration developed between professional experts and many of the parent groups who were willing to confront established systems to ensure that these experts were well provided



for (Dybwad:1990). The close bonds that often developed would prove disconcerting for young adults with disabilities when the disability rights movement began to coalesce in the 1970s and 1980s, as will be discussed below.

#### Leadership: Competition Within

While progress was being made, it would be misleading to assume all parent groups within the movement were consistently in agreement. There was general consensus when it came to lobbying legislative bodies to draft inclusive laws. Changes in social security and other support mechanisms that allowed families more autonomy and choice, tended to receive unified support.

However because of the structure of the voluntary associations themselves, there was also a good deal of competition between groups. There were a proliferation of groups. Hundreds appeared, many of which were quite small, others were tied together through state, regional and national councils or organizations. These groups had been founded to answer the needs of children and families with specific medical or genetic diagnoses. These groups were dedicated first and foremost to funding research, promoting awareness and providing families with support for issues that pertained to these specific diagnoses.

Such intense concentration on a disease by disease basis lead to significant medical advances for specific diseases and conditions, but from an organizational perspective, also worked against the growth of a more cohesive movement. Hundreds of small

parent-led, diagnosis-specific voluntary organizations were formed (Shapiro:1993). The sheer number of these voluntary organizations is uniquely American. Although some nations, such as England, had a long history of private voluntary organizations carrying out social work or medical research as a supplement to more centralized government planning, most European nations would develop centralized or closely coordinated governmental or semi-governmental approaches for programming and planning for the needs of their citizens with disability. In the United States, however, no centralized or coordinated national approach to disability developed, (although funding through a variety of legislative acts and federal programs for certain services, were established).

Private voluntary organizations seem to have had, from the beginning, a much stronger voice in directing local and national policy and molding public attitudes towards disability. Whether a more centralized system would have been developed by the Federal government, had these organizations not already become so well established in the late 1940s and early 1950s, is an interesting question, and takes on more of a chicken-and-egg argument than can be adequately reviewed here. What is clear is that in the years following World War II, these private efforts filled a vacuum and no single coordinated government 'safety net' or service structure for American children or adults with disabilities developed. Rather, there was pressure on each parent group to justify why the particular disability for which they sought programmatic and research funding was important.

The population's heavy reliance on these parent-led voluntary organizations rather than on a more unified Federal role, has had wide repercussions. Most specifically, it helped to create a system that was from the outset, highly competitive in the following ways:

1) Because so many groups arose requesting assistance, the hunt for funds soon became competitive. As many groups seemed to be requesting funds for what, in the eyes of the general public, sounded like similar goals, organizations were soon put into the untenable position of having to justify to the public why their cause (and not that of another organization) was 'most worthy.' This, many began to do by portraying the individual "suffering" from the particular disease or disability for which funds were requested in the most pathetic terms in order to convince donors that the group requesting funds is the neediest (Phillips:1990). While some of these appeals raised a great deal of money, the portrayal of disabled children and adults with disability as pathetic, dependent objects of charity further reinforced stereotypes (Louis Harris Poll:1991). The Jerry Lewis Muscular Dystrophy Telethon, has been a prominent example of this type of competitive charity (Johnson:1992). Some groups have downplayed this aspect of their traditional fund raising approach in recent years, and a number, such as The Association of Retarded Citizens and United Cerebral Palsy, have done much to redefine and clarify earlier campaigns that stressed suffering and cure. In fairness, many of the groups that used such fund raising campaigns were doing

little more than mirroring the then-current social attitudes towards disability. Yet some campaigns, for example those that featured the beautiful poster children struggling to walk across stage as a narrator provides a heart rendering account of their ordeal, did more than simply reinforce societal expectations. Such campaigns gave a face and name to disability and firmly wedded the idea of eradication or full rehabilitation to the American ideals of hard work, perseverance and the rewards of virtue.

2) Furthermore, because these organizations and their constituents were dependent on voluntary contributions from the general public for much of their programming, the system as it arose, encouraged fierce programmatic competition between organizations. This resulted in two developments that substantially slowed the development of a more unified movement. Organizations competing for charitable contributions and scarce state and federal funds, needed tangible local programs in order to justify the need for present and future donations. This frequently led many organizations to fund visible services, while underfunding or ignoring those services that might be of greater value to individuals with disability and their families, but that had little glamour or visibility from a fund raising point of view. In many parts of the country, particularly large urban areas, this also led to an extensive duplication of services, overseen by a duplication of professional and administrative staff (Scott:1969). Hence a large portion of the funds obtained by these organizations went - and continues to go, not into direct services for disabled

populations, but into redundant services and administrative overhead.

In sum, structural competition built into the very foundation of the parent advocacy movement has meant that an enormous amount of the movement's energy has been focused inward, prompting individuals and organizations to focus on efforts to secure a home base rather than on broadening their horizons with the time and energy to explore how disability issues fit into broader medical, social and legal agendas. This is not to say that there has not been attention to broader issues, but much energy has been sapped by the need for attention to competitive fund raising. All this would have further ramifications with the rise of disability rights groups in the 1970s and 80s.

#### Patterns of Individual Involvement

While analysis of organizations and movements tend to occur at a level of abstraction that implies individual experiences, ideas and motivations are secondary to the movement as a whole, a study of the parent advocacy movement also discloses, a striking and reoccurring pattern of competition for individual leadership. This pattern has had strong repercussions within the parent movement itself and can explain some linkages - or lack of linkages between the parent and the disability rights movement.

Although both fathers and mothers would play a great role in the parent movement in the 1950s and 1960s, because far fewer mothers worked, (and mothers of young, sick or disabled children in

particular were expected to stay home), the voluntary membership tended to be heavily female. Participation in the movement from the outset tended to be largely white and middle-class, (parents who could afford the time to volunteer), although there is a great deal of diversity within the movement as to regional, ethnic background and religious affiliation.

Although the original members of the parent movement are now in their 70s and 80s and their children in their 30s, 40s and 50s, the pattern for those new to the movement remains fairly stable. Not all parents of disabled children became involved in the movement. Parents who became involved initially tend to do so as an outgrowth of their children's specific needs. Parents with a disabled newborn or newly diagnosed disabled child are usually referred to these groups, in earlier times by friends and relatives who had heard something about them through the media or through the grapevine, today increasingly, by medical professionals or early education programs as well.

Often young parents with a newly diagnosed child will contact an organization seeking a specific piece of information or a referral to a health care professional, a pre-school program or a local support group. For most parents, particularly those whose needs were quickly addressed, active involvement in parent organizations goes little beyond this point. Many become dues paying members of organizations such as Association of Retarded Citizens or United Cerebral Palsy, but only a small sub-set go on to participate on a more extensive level.

For those who have extensive involvement, a common pattern is that a parent begins as a volunteer with parent-to-parent responsibilities as a public speaker at a local PTA meeting or community affair. They share the experiences of their child and their immediate family in dealing with issues involved with raising a disabled child, and their stories are almost invariably first-hand, eye-witness testimony to the joys and setbacks they have experienced.

Some parents find these volunteer activities very rewarding. For them, there seems to be a formative period - some parents are increasingly called, or seek out the opportunity, to speak to other parents and to professional audiences. As they become known for their ability share their family's experiences, they are invited to join various local boards of directors, task forces, advisory groups and committees.

Fund raising, the work involved in lobbying elected officials, school administrators and health professionals, takes a great deal of time, good organizational skills and a real commitment of energy. Often the next step for the advocate is to accept a part-time position as a staff member in a funded project related in some way to their child's specific disability. Such projects are generally sponsored by a non-profit organization or academic center. Although many start out as part-time workers, they often taken full-time and then administrative positions. Wickham-Searle (1993) provides an interesting discussion of this process. As increasing numbers of governmental and private granting agency

insist that disability programs be 'family-centered', increasing numbers of parents have become actively involved in such projects in an official or oversight capacity.

The professionalization of the parent advocate role has often improved services and programs as individuals who are well acquainted with disability issues are allowed a voice in decision that shape programs and policy. But this unfolding role has also brought with it problems in certain organizations.

Although there are a number of volunteers functioning on the local level, there are relatively few funded positions for part or full-time parent advocates. In a number of cases, when one individual or a small handful of individuals obtain a funded position and are put in the role of decision makers there is the possibility of individuals amassing a great deal of power. It is these now "professional" advocates who are regularly called upon to address public officials, represent the organization in public forums and decide state and regional priorities. Severing on councils and steering committees with community leaders and public officials, these semi-professional advocates can grow to wield a great deal of personal power and influence. They gain the personal connections which allow them to get the head of the board of education, the mayor or the governor on the phone. They can convince the local Senator to introduce legislation on their behalf. With such a power based these individuals have often drifted far from their volunteer roots, becoming professional advocates whose loyalties were at times divided between grassroots



citizenry and the agencies, hospitals or university centers that pay their salaries.

In fact, there appears to be an inherent friction between some long established, professionalize advocates who now think about global policy issues and worry about large grants to fund centers and young parents, who seek a voice in specific sets of services and policies. In my interviews, several full time advocates dismissed such new parents as knowing little and not yet having earned the right to have a voice in decision making for organizations or the movement. The amount of power wielded by 'professional' parent advocates differs markedly, depending on the specific organization, sets of circumstances and the personalities involved. In some cases, mild friction between established advocates and parents of disabled children who are not active in advocacy but want some say in the services and educational programs available for their child, has been resolved to the benefit of all.

At its worst, competition within the ranks of long-established advocacy groups as to who speaks for the families, had led to non-productive and often vicious rivalries. Professional parent advocates often represent the agencies, academic institutions or hospital centers for which they work in the highly competitive field of fund raising and policy making. Grants and contract monies now often amount to hundreds of thousands of dollars. At stake are not only issues of money and politics but also issues of personal power and influence. A parent advocate is accountable in such situations first to his or her employer and only after that to

the constituency she or she is employed to represent.

What is striking is that, despite these underlying issues of money and power, even in the largest and most aggressive of organizations, the role of the funded parent advocate is usually to present themselves as an a-political voice, there to fight for the best interests of the child. The testimony they give before state and federal legislators is often little different from the talks given before the local PTA meeting many years before.

Some professional parent advocates deal with this role well and thoughtfully. Others use the role poorly and as a platform for their own ideas or interests, or that of organizations in which they are employed. A number of parent advocates seem to return to school for degrees in social work, administration or policy studies after a certain amount of time (Wickham-Searle:1993), in part because of the need to better understand how what they seek to do ties in with broader policies and group needs. Some professional advocates however, continue to rely on their own background and experiences. This is not necessarily bad, but such individual advocacy is an arena with few checks or balances. At its worse, individuals who become professional advocates have been known to blatantly misuse the power organizations invest in them, squandering precious time, energy and influence as one individual or group of advocates seeks to overshadow or discredit another. In such cases, the amount of attention given to in-fighting within the movement has narrowed the vision of many and contributed to the gulf between this movement and the disability rights groups, as

will be noted below.

### Moving in to the 1990s: Broadening the Focus

The parents movement has broadened its focus as the initial group of founding parents and their children have moved through the life cycle. By the early 1970s, the fight for school rights was transformed to the fight for programs that provided disabled teenagers transitional programs from school to the work place. Soon thereafter, the issue became the establishment of community based group homes, and adequate health care and social services for adults with disability (Center for Human Policy:1979). Maintaining the middle-aged adult with disability in the community has been a key issue for over a decade. Within the past several years, there have been an increasing number of conferences, publications and workshops on aging and disability, with particular focus on conservatorship for aging disabled adults as now elderly parents begin to worry about the fate of their adult disabled children after they are gone (Zola:1993).

There are today hundreds of parent groups, each attempting to call attention to and foster research on a specific medical condition. A quick review of such important parent directed publications as The Exceptional Child will disclose page after page of queries, facts and editorials, as concerned parents seek to learn and reach others for support and advocacy. Jointly, they all seek to improve the lives of their disabled children by stressing changes in the law, in social services, in the educational system

and in the public's perception of disability in general and their own child's specific condition in particular.

In an on-going discussion marked by consensus and debate, collaboration and strenuous disagreement, fractional alignments and realignments that have involved thousands of families, professionals and organizations, there is one significant voice missing. That is the voice of the children, in whose name the entire movement was undertaken. Infants and children must have concerned adults speak on their behalf. But what of those thousands of children, now grown to adulthood, whose parents have been part of this movement? Where are their voices in the organizations that have been established to serve them? Their absence is striking. The movement, based on assisting a family unit, does not disarticulate the family as the child grows into his or her adolescent and young adult years. A consistency throughout has been parent control. Perhaps it was this lack of space in which to grow that helped spur another movement, one that simply circumvented much of the well-established parent advocacy dialogue. This was the disability rights movement.

#### The Disability Rights Movement

The disability rights movement traces its early history to the late 1950s and early 1960s. Although both the parent advocacy movement and the disability rights movement may be seen as offshoots of the broader consumers movement in medicine that was developing during these decades, from the outset, the disability

rights movement was distinct from the parent advocacy movement. It was founded by young disabled adults intent on staking their own place in the decision making process (Levy:1988; Shapiro:1993).

Activism within the disability community was not new. Regional, national and international organizations of deaf and blind people have existed since the 19th century, and these groups frequently took stands that were quite radical for their time and place. Nineteenth century organizations of deaf persons, for example, battled unsuccessfully for decades to keep Sign Languages in the deaf educational curricula (Lane:1984). (By the 1850s, deaf activist John Flourney (1857) had become so enraged at the lack of rights and respect accorded deaf Americans that he campaigned to have Congress allocate lands in the newly opened American West for a commonwealth exclusively for deaf adults and their families). At various times, groups such as disabled veterans and blind adults marshalled considerable monetary and legal backing to ensure that specific programs be established or that particular pieces of legislation be passed (Groce:1993).

The disability rights movement however, had a perspective that marked it as distinct from all preceding efforts. For the first time, individuals who had been divided on the basis of their specific medical "conditions" into distinct constituencies, (and as noted earlier, often placed in the position of vying for what little support existed), began to argue that their shared concerns far outweighed their diagnostic differences (Scotch:1989).

By the 1960s, no matter what type of disability individuals

might have, they now confronted common problems. Their lives were structured and their options defined and often limited by complex medical, legal, and educational bureaucracies; by a social security system not really designed to serve those individuals with disabilities who wanted some measure of independence and self-determination; and by the broader society where prejudice and stereotypes were still widespread (Shaw:1994).

A social movement of individuals with disabilities began to gather both speed and focus in the early 1960s. Those who have documented the movement, regularly point to a core group of physically impaired students who arrived at the Berkeley campus in the early-1960s (Shapiro:1993), the first to live on campus was Ed Roberts, who would become a leader in the movement until his untimely death in 1995. Roberts, whose bout with polio as a teenager left him a significantly impaired wheelchair user, initially convinced University authorities to allow him to attend classes and live in the University infirmary, as no dormitory room was accessible for wheelchairs. Over the following years, several more men with disability joined Roberts and the university eventually established a communal disabled student dormitory.

In 1970, Berkeley established the Physically Disabled Students' Program to coordinate services for these few students. Soon, Berkeley's Disabled Students Program was besieged by individuals with disability who were not students, but who were in need of the information, services and support the students were assembling (Levy:1988). Using the campus based program as a

model, Roberts and a handful of disability advocates established the Berkeley Center for Independent Living in 1972. The Center quickly became a central focus for the individuals with disability nationwide. The Center was further strengthened in the early 1970s when Judy Heumann, an East Coast advocate who had established an early New York based advocacy group, Disabled in Action, came to join the Berkeley group. Heumann's group focused on political action, while the Berkeley group initially concentrated more on providing services. Combining the idea of consumer responsive services with political activism proved to be a fertile cross-pollination of ideas. Soon independent living centers, established on the Berkeley model were being founded across the country, and individuals with disability were becoming increasingly insistent that they be taken seriously (Levy:1988).

The unifying concept behind the new movement was very straightforward: individuals with a disability, so the emerging activists argued, had a right to make decisions on their own behalf. This differed markedly from the medical and rehabilitative model where "experts" made decisions on behalf of an individual with disability. It also differed markedly from the parent movement's model, where parents and family filled the decision making role (Shapiro:1993).

The new movement drew its membership from that large group of adult Americans with a variety of disability conditions who, as adults, had had to settle for a life lives with fewer civil or social rights than their fellow citizens, lives marked by a lack of

work, isolation from family, community and society, and restricted accessibility.

A very early point of contention was who had the right to speak on their behalf. These young activists felt that they should be able to represent themselves. Many established experts and large charitable organizations felt these young advocates were asking too much. Some prominent individual parent activists felt that their role of spokespeople was being overshadowed by a young of young, impatient novices.

#### Knowing One's Place

The 1960s and 1970s were years of great social change across the nation and many groups, questioning basic social inequities and reflecting generational differences in perspective, came forward to demand concrete changes in the status quo. A number of future leaders in the Disability Rights Movement were initially involved in anti-war, Civil Rights and women's rights protests (Levy:1988). Young, idealistic and committed, their initial concern about other social issues gradually led them to question their own status within American society (Shaw:1994; Gallagher:1985).

The experience of these young Americans with disabilities were different from that of any generation of disabled citizens before them. In purely demographic terms, those reaching their 20s and 30s in the 1970s and 1980s were part of the baby boom generation.

Because of the sheer number of children born between 1945 and 1960, as well as the impact of the polio epidemic on this large



pool of children, this group of adults with disability was far larger than any preceding generation . This generation was not only larger, but thanks to the work of the parent advocacy groups in sponsoring medical research and special educational initiatives, this generation was also healthier and better educated than any earlier generation of people with disabilities.

In addition, these young women and men were sophisticated consumers of medical services. Many had spent years in rehabilitation, carefully following the grueling rounds of therapies and exercises that was expected of them by physicians, therapist, special educators, parents and society. Much of their political and organization reality was framed by their first hand experience in the system. They realized that neither the experts nor the older generation necessarily held all the answers to their future.

Questioning the norms lead to questioning the authority that advocated the norms. Why, young people with disabilities asked, should someone with a degree in medicine, physical rehabilitation or special education, be assumed to know more about disability than an individual who had lived with that impairment (Johnson:1992). Why did they have to go to professional 'gatekeepers' for permission for prescriptions to obtain the needed medications, basic equipment or services (Shaw:1994)? Why were they denied the basic right to self-determination (Johnson:1992)? The answer seemed to lay not within themselves, but in those around them. In seeking the answer, they revised the age-old question of 'what is

wrong with me?' by standing it on its head. They asked 'what is wrong with society that it refuses to accept me?' Perhaps the most fundamental achievement of the disability rights movement has been reframing the disability experience from a medical to a civil rights issue (Louis Harris:1991).

Questions were not confined to the experts themselves, but also to the social institutions and organizations established in the proceeding decades. Scrutiny of large organizations working on behalf of those with disability raised disturbing issues. Parents, working in close collaboration with sympathetic professionals had often been very successful in establishing large, well-funded rehabilitation systems, schools, nursing homes and hospitals, vocational rehabilitation facilities, sheltered workshops and medical research facilities all working to prevent, cure or overcome disabling conditions. Some were now multi-million dollar enterprises with professional staffs, prominent boards of directors and a great deal of federal and private grant monies. Although these organizations were in the position of interpreting the disability experience and designing disability policy for American society, very few of these organizations involved individuals with disability in any capacity save that of recipients of services. They were organizations for disabled persons, not organizations of disabled persons. Specialists who were not disabled were asked by groups of consumers with disability to shift from the role of decision maker to that of technical advisor.

The stage was set for conflict with the Disability Rights

Movement, and it was not long in coming. Early attempts by disabled activists to raise issues with established disability organizations were at first met with patronizing responses (Phillips:1990; Levy:1988). Dialogue between young adults with disability and parent/professional groups often became heated.

For the first time, young disability activists openly confronted society. For example, protesting the fact that their taxes went to pay for public transportation systems that were completely inaccessible. Some went from discussion to civil disobedience, with wheelchair users chaining themselves to buses, and taunting authorities to make arrests (Levy:1988). (The fact that even the jails to which they were being brought were inaccessible to wheelchair users only served to further underscore their point).

When Joseph Califano, then the Secretary of Health, Education and Welfare, refused to sign two substantial pieces of disability legislation (PL 49-142 and PL 504) groups of protestors with disabilities took over the Secretary's Washington office for 28 hours, and the HEW regional offices in San Francisco were occupied for 25 days.

While some in the parents' movement were sympathetic and supportive about such demonstrations, many of the most prominent members of the parents movement already in their 40s and 50s, were scandalized. The gulf that was perceived to exist between the generations may have been over-exaggerated, but a number of parent advocates interviewed, noted that during that era, it was easy to

summarize the young adults with disability as hot-headed, angry youths, rebelling against authority. To the parents who had worked so long and hard to establish links with the professionals and administrators, open confrontation seemed unnecessary and counter-productive (Groce:1993). Parents had worked for years to establish close ties with sympathetic professionals.

Most parents had not directed their anger towards the experts who they felt held the answer for a better life for their children. Rather it was directed against the institutions - the school districts, the hospitals administrators, the social service bureaucracies , that denied funding to build programs and blocked access to these specialists (Groce:1993).

The disability rights movement participants however, came with a different frame of reference. Coming later on the scene, these activists were forced to contend with a rehabilitative establishment that looked far more ridged and bureaucratic than it had a generation earlier (Johnson:1992).

Distrustful of experts and organizations, some disability advocates began to establish their own organizations (Shapiro:1993). The Berkeley Center was soon joined by a diversity of disability-led organization: dozens of independent living centers, support groups for disabled women, artists with disability, wheelchair users interested in global travel, and so forth (Shaw:1994). These organizations began to federate internally and spread internationally (Groce:1993).

Some, like Disabled People International (DPI), began as

international movements and attracted membership from national groups worldwide. Others were very local in scope, seeing to effect change in one rural or urban area. Unlike the parent movement, where a high proportion of those involved were involved with mentally retarded children, the new disability rights movement was lead almost entirely by individuals who were physical disabled (Levy:1988).

As it grew and developed, many of the goals of the disability rights Movement were striking similar to the parent's movement: greater social acceptance, laws to protect the right to medical and educational services, better support from social security and within the past several years, a growing concern about aging with a disability in the community (Zola:1993).

For many of the Disability Rights people, used to being dismissed as children who lacking the perspective and maturity to understand the issues, (and their place in society), and who would always be in need of continual care and direction, uncompromising demands seemed to be the only way to make their point (Shapiro:1994).

Some organizations and non-disabled experts accepted these challenges and confrontations better than others. For example, what had begun its existence as the National Association of Retarded Children changed its name to The Association of Retarded Citizens, and supported individual choice and self-advocacy initiatives. Some other organizations gave the new ideas lip-service, but avoided making any significant changes at the policy

or administrative levels. Other organizations ignored the changing scene entirely and continued to provide services and fund raise according to the older models.

## Findings

Having set out a short history of the two movements that details their similar but distinct paths of development, what then can be said of the differences between them? the answers are complex because the movements are complex. Nevertheless, significant patterns do emerge. Among the most prominent issue that seem to account for today's gulf between parent advocacy and disability rights seem to be: 1) an underlying philosophical disagreement, based on historical antecedents that help determine what issues have and are being addressed; 2) significant differences in ideas of where the locus of power should lie; and 3) a significant lack of communication between the two movements based in large part on long-established and rarely examined networks that too frequently limit frames of reference. To address each of these in turn:

### 1) Differing Targets

It was not a generational issue alone, nor an issue solely of how to go about achieving change that separated the established parents movement from the fledgling disability rights movement. It was also a question of what targets to go after. The parent movement's primary concern was in changing the system. Parent groups fought to broaden the system, expand programs and change

policies for children and their families, from early intervention to sheltered workshops and adult training programs. Initially few in the parent movement questioned society's basic conceptualization of disability. Rather these parents sought to provide enough education, training and medical care, to enable their children to adapt to society.

The disability rights camp took on a much broader target - the treatment of disability throughout society. Legislation, social services, medical rights, access to transportation and architectural barriers, were all of concern. So were public stereotypes and individual prejudice. If parent advocates tended to look at the individual as the locus of the problem, disability rights activities reversed the issue, questioning society's most basic assumptions about disability.

So for example, even legislation that would seem to have universal appeal to both groups are often prioritized differently. For example, disability rights groups were instrumental in the passage of the Americans with Disabilities Act. The parent movement was notably for its absence on this hotly contested bill, pouring their own attention instead into the Parental Leave Act, which was finally signed into law by President Clinton in 1992.

Certainly all benefit from gains made by the other movement. For example, despite their initial absence in work on the Americans with Disabilities Act, parent groups, as well as organizations large and small, regularly invoke the Act when seeking services, proposing legislation or when coming before the courts. Again,

parent groups never opposed the act. Their attention was simply directed elsewhere. What is striking is the lack of discussion between members of the two groups when such legislation has been under consideration, however.

## 2) The Locus of Power: Who Makes the Decisions

If looking at the 'targets' of these two movements is helpful, looking at the underlying motives can also provide insights. The vast gulf that lies between these two movements may at its heart, lie in the fact that they are designed to serve two different population: non-disabled parents and adults with disability. (It was interesting to note that of all those interviewed for this study, the two parents who most stridently objected to having members of the disability rights movement speak on their behalf, were two women who had become extremely powerful in their home states as professional parent advocates. Hence, the issue of personal sphere of influence, as well as philosophical differences and organizational differences, must be considered part of the mix).

Who decides what is best for those with a disability? Most of the non-disabled parents interviewed felt that no matter what age their child had become (and a number interviewed for this research, had children in their 30s and 40s), the ability to make decisions on key issues in life (where one lives, works, with whom one associates, etc), lies with the parents. This was true no matter what particular type of disability the child in question,



had.

Several parents interviewed conceded that, left to their own devices, their children would make, what they considered to be "appropriate" decisions. A number more (over a third of those interviewed), felt that their child did not have the ability to make such decisions and needed to have strong and continuing parental involvement.

These parents' good intentions is not at issue here, however it is also striking that, for some of these parents, much of their own identity and the identity of their families, have become invested in being parents of a child with a disability. Advocacy on behalf of their child has brought them into social networks and support systems than now make up a substantial portion of their social networks outside of their immediate family and work place.

Some parent advocates drew a very distinct line between the work they undertook and the issues those in the disability rights movement addressed. It was striking how a number of very thoughtful parent advocates seemed to firmly believe that the disability rights issues had little relevance to their own lives or the lives of their children, (even when their children were of an age to benefit from many of the programs initiated by the disability rights groups). These parent advocates were most insistent that the parents and families of individuals (children and adults) with disabilities are the best judges of the needs of those with disability, not disability advocates who had no knowledge of their family's particular situation.

Such comments are illuminating, for they underscore an important issue - the difficulty in transition from child to adult years. Few of the children whose families have been active in the parent advocacy movement seem to have become participants in the disability rights movement. Instead, their activities continue to be centered in the Parent's Advocacy Movement. It might be justly argued that a large number of those in the parent movement have children who were severely to profoundly mentally retarded, and hence, were less likely than other individuals with disability to take part in the disability rights movements, yet a growing number of individuals with intellectual disabilities are participating in the disability rights movement. There are also many individuals with disabilities, parents are part of the parent movement, whose physical, sensory or intellectual impairments do not block their ability to participate in disability rights activities. Yet few of these individuals seem to have made the transition to self-advocacy and independent living. Their identification seems to remain with their parents, in a role of dependent or semi-dependent child, rather than independent adult.

In contrast, while many of the most committed adults who are part of the disability right movement had parents who had fought for services on behalf of their own child, very few seem to have had parents who were themselves involved in broader advocacy. A number of the adults with disability interviewed specifically mentioned that while their parents were sympathetic, few were able to provide the information and guidance they often needed about

disability. A number felt that they had had to learn to speak up for themselves and that this experience was a hard-won victory - one that they now had no intention of relinquishing. They wanted neither parents nor professionals to now speak on their behalf.

There may be no immediate resolution here, but the feeling that things function at cross purposes here is striking. Parents, worried that strangers with specific and often short-term agendas, will be allowed to make decisions that will affect their children's lives are just as insistent on being heard, as the disability rights advocates who fear that parents and experts will continue to demand the right to represent them in the social and political arenas.

In its most basic form, there is a power struggle here that will need to be addressed with a great deal of careful deliberation. (3)

### 3) Communication Between the Movements

Finally, there was the broad question of how advocacy groups in our society communicate across disciplinary and organizational gulfs. How much awareness does each group have of the other? The question itself is a difficult one, given the diverse nature of membership in the two groups, and the variety of organizations that comprise each movement. Nevertheless, speaking with several dozen knowledgeable individuals from each camp, this author came away with the distinct impression that each of the groups, busy with its own priorities and agendas, spent relatively little time thinking of groups working on similar issues in the other movement. Parent advocates focused specifically on their children's need, had

difficulty discussing expectations for their children's adulthood, except in the most general of terms. Adults with disability, on the whole, had thought little about disabled children. Both movements had an impressive number of conferences, journals, newsletters and other 'grey literature' circulating among their members, as well as strong and long-established social networks that carried and distributed an immense amount of information. Yet conferences and meetings rarely attract individuals outside the already established networks, newsletters and announcements rarely reach them. Hence, even those meetings expressly held for 'an exchange of ideas,' tend to attract the same group of attendees. Speakers tend to find themselves 'preaching to the converted.' Books and newsletter that are standard references in the parent advocacy movement seem to be unknown among disability rights advocates and a number of parent advocates questioned had never heard of major disability rights publications. The Exceptional Parent was largely unknown by the adults with disability, the Disability Rag unknown among parents of disabled children. Leaders of national prominence in the parent advocacy movement pass through crowded reception halls at conferences of disability rights activists virtually unrecognized and vice versa.

Discussion

Given the background, competition for resources and the focus on changing social attitudes towards disability, it would be anticipated that some conflict between parent movement and disability rights groups might arise. Instead the two movements

seem to ignore each other - to go about their particular issues unaware of each other. When pressed to speak on the subject, members of both movements seemed hesitant to speak ill of the other, but members of both movements queried were also very clear on the role the other movement was supposed to play. Parent movement members identified their role as advocating on behalf of disabled children as they moved through the life cycle. Adult members of the disability rights movement were equally clear in stating that they were the individuals and groups primarily responsible for advocating for disability-related issues in society. Members of both groups expressed a conviction that the work they do today will make a difference not only to themselves but to disabled children in the coming generation. A number noted with surprise that those outside the movement, members of the press, the public, public officials and legislators, seem to frequently confuse the various groups and causes.

Several individuals interviewed during the course of this study had a foot in both camps. For example, a hearing son of a deaf parent was keenly aware the interests and concerns of the Deaf Society in which he was raised, and the advocacy in which both his parents were deeply involved. He and his wife had become foster parents of a physically disabled child, and played a major role in the local Cerebral Palsy Association. He often worked with members of both movements on a daily basis, but had rarely introduced parent advocates to deaf rights advocates, and had never mentioned his work on behalf of his foster child to the deaf adults with whom

he and his parents socialized.

This apparent lack of regular communication is regrettable, for each of the movements could benefit from greater interaction. Several areas in particular stand out:

1) Strength through numbers: There is of course, strength in numbers, particularly within democratic forms of government. In many cases, collaboration between organizations from both movements would be of advantage to all involved. With groups within both movements working on very tight budgets, short time schedules and limited volunteer hours, the benefits of collaboration in some arenas should not be overlooked. The diversity of contacts and networks available through collaboration as well as the shared amount of skills the membership of both movements could provide, would add greatly to any individual goal, be it legislative or programmatic. Increased communications, be it between small, local groups or larger regional or national associations, would help identify common arenas where collaborative efforts might be particularly effective.

2) Mentoring - Advocates from the Disability Rights Movement have much they could teach families with young or newly disabled members. Currently, we expect parents with child who has just been identified as being disabled, to immediately become knowledgeable in both anticipating the needs of their own child, and in navigating the immensely complex medical, educational and social service systems set up to serve those needs. Adults with disability have already have had a lifetime to learn how the system

operates. Furthermore, they have mastered hundreds of practical daily living skills - including how to deal with a society that often knows and cares little about disability. Such adults could be of immeasurable assistance to families suddenly faced with the realities of raising a disabled child. Ideally, pairing parents and children with an adult living with a similar disability might be particularly helpful.

3) Cooperation in the Transition into Adulthood: Currently, there are few bridges between childhood and adulthood for Americans with disability. Most of the services for disabled children end at age 18, and a whole new set of services must be put in place (Berkowitz:1987). Many disabled adolescents fall through the cracks and the transition from school or training programs to adulthood is often long, needlessly frustrating and ultimately difficult for both child and family. It is an enormous waste of human potential. Parent groups and adult-centered disability rights groups would do well to collaborate on planning and programming to ensure that individuals in transition and their families are familiar with all the options and opportunities to which young adults with disabilities are now entitled.

3) Organizational Expertise: Most disability rights groups, centers for independent living and a wide array of other advocacy groups that stress self-determination, share one significant problem, not previously mentioned. While small amounts of funding

come from state and federal sources, most of these centers exist on shoestring budgets and the efforts of their voluntary membership. Parent movement groups have a history of successful fund-raising and organization building, as well as significant contacts in the community that might be of real assistance to disability rights groups. A sharing of ideas and contacts however, must be undertaken with the pre-existing understanding that the locus of power and decision making remain firmly in the hands of the disability rights groups and their leadership. Disability led organizations usually have a clear idea of what they want to do. They often lack the funds and connections to change ideas into reality

5) Aging as a Shared Area of Concern: Increasingly, parent organizations have broached the issue of who is to advocate for their children as they move into middle age and old age. Disability-led groups are the ones that increasingly are taking the lead in advocating on behalf of adults with disability who live and work in the community and who, in increasing numbers, can be anticipated to grow old and retire in the community as well. They will be the ones to whom policy makers and society turns on the issue of aging as we move into the 21st century. It would be advantageous for aging parents to join with middle aged disability advocates to ensure that all will eventually be included in policies that reflect the best both movements have to offer. Indeed, collaboration on the issue of aging might be an idea venue in which to test collaborative models between the two movements



that could eventually be expanded to broader collaborative ventures in other arenas.

## Conclusions

This paper was begun with the cautionary statement that the divisions between the two movements examined herein, are as yet poorly understood. What continues to be of interest is the similarities manifested by both movements as they move towards the end of the 20th century. The almost studied indifference and lack of awareness members of each display towards the other, may be coming to an end. As American medical and social service systems change rapidly under the impact of managed health care and as state and federal funding can be anticipated to decrease over the coming decade, many of the independent services and programs offered by dozens of smaller programs, may be forced to more closely collaborate in order to survive. While definite answers as to where the movements have been and where they are going are not yet available, we can at least begin to more closely examine what they are and what they do.

## Footnotes:

1) Interviews were conducted in person and by phone. Thirty, half-hour to hour and a half in length, following a series of questions about the individual's experience, group affiliations, opinions, etc. Representatives of parent advocacy associations as well as parents who remained unaffiliated and parents who had once been

active but were not active in advocacy efforts, were all interviewed.

2) Even for those who chose to institutionalize their children, their roles after World War II were significantly different than in earlier decades. Those who choose to place their children in institutions often did not abandoned their children to the system. Unlike earlier eras, many parents tried to keep in close touch with their children, visiting them weekly or monthly, and writing or calling their attendants on a regular basis. (Whether many of these parents had a real understanding of what life was like in a number of this country's institutions is debatable (Rothman and Rothman:1984), but many of these parents did make concerted efforts to do the best they could). A number of these parents also became advocates for their children within the institutional setting, serving on parent advisory groups, and advocacy groups to oversee the care and education delivered in these institutionalized settings. Parents of children who have been institutionalized have reappeared on the national map in the past few years, as advocacy groups and politicians, have sought to close the last remaining institutions. These parents have fought hard to keep the institutions open, arguing that there are not only few other places in which their children can live, and that the institutions are the only secure homes which their children have known. In states such as Connecticut, parents advocating on behalf of institutions have, at least temporarily, stayed the hand of closure.

3) An interesting aside must be added here. An increasing numbers of adults with disability are electing to have children of their own. Much of the current debate is still focused on issues of the decisions involved in becoming parents and the very real social and legal barriers put in place to allow adults with disability to bare or adopt children and to raise them (Asch:1990). A new newsletter, 'Through the Looking Glass' speaks specifically to this. Of those parents with disability who were interviewed during the course of this study, a middle ground was noted. Whether the parent with a disability had a disabled or an able-bodied child, these parents were somewhat less judgmental about the lengths some members of the parent advocacy movement had gone to, to ensure that they were the primary decision makers on behalf of their children. It should be noted that the parents with disability interviewed here all had very young children. As these children grow towards greater independence, their parents' attitudes towards where the locus of decision making lies will be interesting to note. In other words, part of the phenomenon being discussed here may have to do with more universal parent/child issues of separation and intergenerational conflicts, than with disability per se.

#### Bibliography:

Asch, A. 1990. Reproductive Technology and Disability. in S. Cohen and N. Taub (eds). Reproductive Laws for the 1990s. Clifton, NJ: Humana Press.

Berowitz, ED. 1987. Disabled Policy: America's Programs for the Handicapped. Cambridge: Cambridge University Press.

Biklen, D. 1985. Let Our Children Go: An Organizing Manual for

- Advocates and Parents. Syracuse, NY: Human Policy Press.
- Center on Human Policy. 1979. The community imperative: A refutation of all arguments in support of institutionalizing anybody because of mental retardation. Syracuse: The Center on Human Policy.
- Darling, R. 1979. Families Against Society: A Study of Reactions to Children with Birth Defects. Beverly Hills, CA: Sage.
- Des Jardins, C. 1971. How to Organize an Effective Parent/Advocacy Group and Move Bureaucracies. Chicago: Coordinating Council for Handicapped Children.
- Dybwad, RF. 1990. Perspectives on a Parent Movement: The Revolt of Parents of Children with Intellectual Limitations. Brookline, MA: Brookline Books.
- Featherstone, H. 1990. A Difference in the Family: Life with a disabled child. New York: Basic Books.
- Ferguson, PM; Ferguson, DL. 1987. Parents and Professionals. In P. Knoblock (Ed.) Understanding Exceptional Children and Youth. Boston: Little, brown. 1987. Pp. 346-391.
- Flourney, J. 1857. Scheme for a Commonwealth of the Deaf and Dumb. American Annals of the Deaf and Dumb. 1856:8:118-125.
- Gallagher, H. 1985. FDR's Splendid Deception. New York: Dodd, Mead.
- Gallagher, H. 1990. By Trust Betrayed: Patients, Physicians and the Right to Kill in the Third Reich. New York: Henry Holt and Co.
- Gliedman, J.; Roth, W. 1980. The Unexpected Minority: Handicapped Children in America. New York: Harcourt Brace Jovanovich.
- Goffman, E. 1963. Stigma: Notes on the Management of Spoiled Identity. New York: Touchstone.
- Groce, NE. 1993. The United States Role in International Disability Activities. New York: Rehabilitation International.
- Hamre-Nietupski, S.; L. Krajewski; J. Nietupski; et al. Parent/Professional Partnerships in Advocacy: Developing Integrated Options with Resistive Systems. Journal of the Association of Persons with Severe Handicaps 1991:13:4:251-259.
- Harris, L. 1991. Public Attitudes Toward People with Disabilities. Conducted for the National Organization on Disability by Louis Harris and Associates, Inc, New York.

International League of Societies for the Mentally Handicapped. From Charity to Rights. 1968. 4th International Congress, Jerusalem, 1968. Brussels: International League of Societies for the Mentally Handicapped.

Johnson, M. ed. 1992. People with Disabilities Explain It All for You. Louisville, KY: The Avocado Press.

Kingsley, J.; Levitz, M. 1994. Count Us In: Growing Up with Downs Syndrome. San Diego: Harvest.

Lane, H. 1984. When the Mind Hears: A History of the Deaf. New York: Random House.

Levy, CW. 1988 A People's History of the Independent Living Movement. Lawrence, Kansas: Research and Training Center on Independent Living, University of Kansas.

Lipsky, DK. 1985. A Parental Perspective on Stress and Coping. American Journal of Orthopsychiatry. 55:614-617.

Mackie, R. 1969. Special Education in the U.S.: Statistics, 1948-1966. New York: Teachers College, Columbia University Press.

National Research and Training Center on Families of Adults with Disabilities. 1995. Through the Looking Glass: Parenting with A Disability. Berkeley, CA.

Rothman, D.; Rothman, S. 1984. The Willowbrook Wars. New York: Harper and Row.

Phillips, MJ. 1990. Damaged Goods: Oral Narratives of the Experience of Disability in American Culture. Social Science and Medicine. 30:8-14.

Scotch, RK. 1984. From Good Will to Civil Rights: Transforming Federal Disability Policy. Philadelphia: Temple University Press.

Scott, R. 1969. The Making of Blind Men: A Study of Adult Socialization. New York: Russell Sage Foundation.

Shapiro, J. 1993. No Pity: People with Disabilities Forging a New Civil Rights Movement. NY: Random House.

Shaw, B. ed. 1994. The Ragged Edge: The Disability Experience from the Pages of the First Fifteen Years of the Disability Rag. Louisville, KY: Avocado Press.

Taylor, S.; Bogdan, R.; Racino, JA. Life in the Community: Case Studies of Organizations Supporting People with Disabilities.

Trent, JW. 1994. Inventing the Feeble Mind: A History of Mental

Retardation in the United States. Berkeley: University of California Press.

Turnbull, HR.; Turnbull, AP. 1985. Parents Speak Out: Then and Now (2nd ed.). Columbus, OH: Charles E. Merrill.

Walker, ML. 1985. Beyond Bureaucracy: Mary Elizabeth Switzer and Rehabilitation. New York: University Press of America.

West, J. ed. 1991. The Americans with Disability Act: From Policy to Practice. New York: Milbank Memorial Fund.

Wickham-Searl, P. 1993. Mothers with a Mission. In P. Ferguson and S. Taylor. Interpreting Disability. New York: Columbia. 1993

Wikler, L, Wasow, M.; Hatfield, E. 1983. Seeking Strengths in Families of Developmentally Disabled Children. Social Work 28:313-315.

Zola, IK. ed. 1982. Ordinary Lives: Voices of Disability & Disease. Cambridge, MA: Applewood Books.

Zola, I. 1993. "The Parent Advocacy Movement Moves On" Disability Studies Quarterly. 13:4-12.