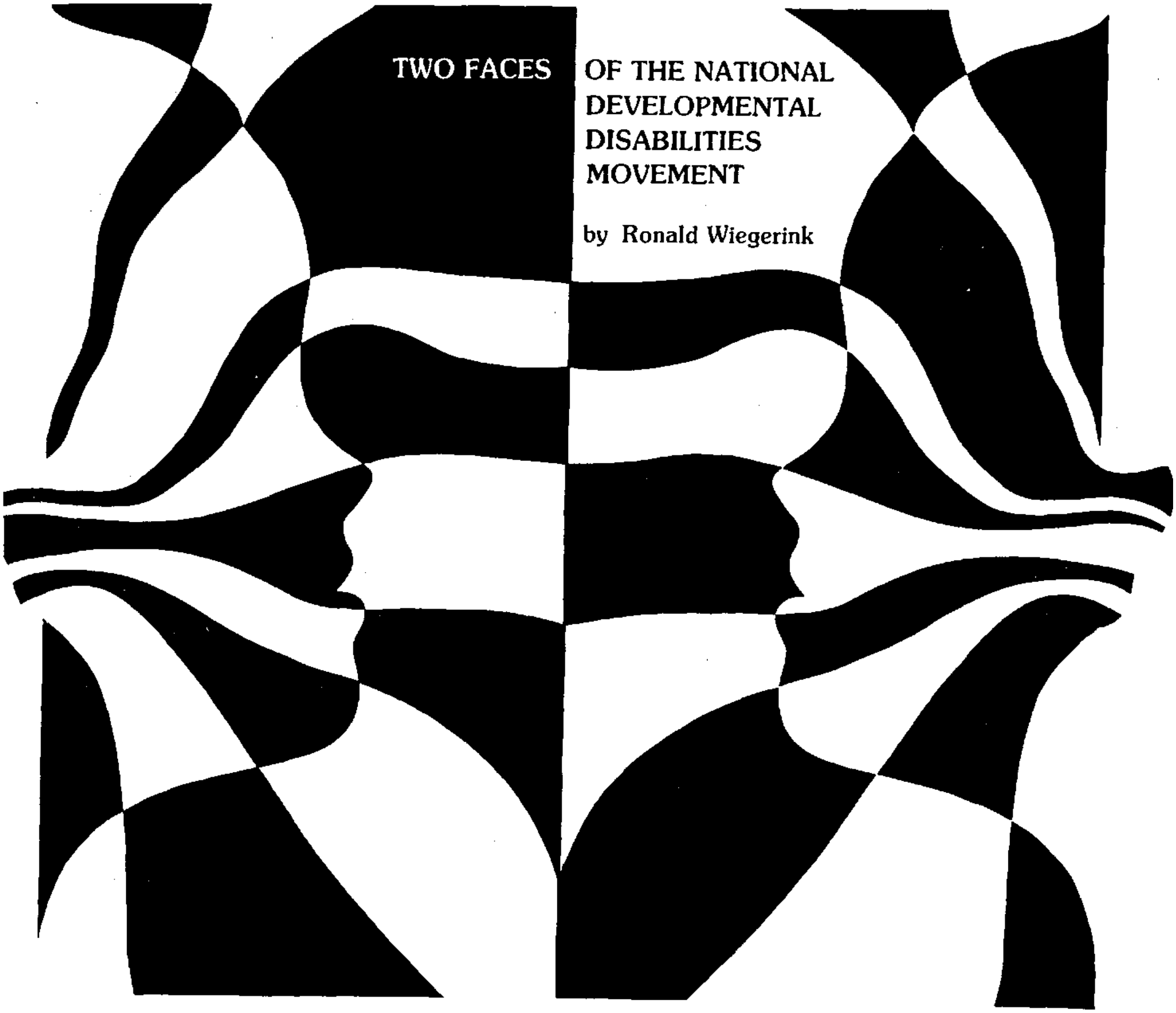
themes & issues

A Series of Topical Papers on Developmental Disabilities



TWO FACES OF THE NATIONAL DEVELOPMENTAL DISABILITIES MOVEMENT

by Ronald Wiegerink

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Introduction

The Developmentally Disabled Assistance and Bill of Rights Act of 1975 has extended and amended the original 1970 legislation. Signed into law October 4, 1975, by President Ford, this Act provides the legal framework for what has become known as the Developmental Disabilities movement, an advocacy movement working to assure developmentally disabled citizens their human rights and the services commensurate with their needs.

There are two faces to the Developmental Disabilities (DD) movement. From the optimistic side, the DD movement is a step in the right direction. From the cynical side, the movement is, at best, a necessary diversion in a struggle for survival.

Optimistic advocates see the Developmental Disabilities movement in the light of its goals: (I) to expand services for severely handicapped people; (2) to reduce duplication in services and resources; (3) to increase gap-filling services; (4) to marshall generic resources and services to aid developmentally disabled people; (5) to develop a consortium of state agency personnel, services providers and consumers or consumer representatives in the comprehensive planning of services; and (7) to provide access for consumers to decision-making that determines what they receive and when. These are necessary goals if the rights of developmentally disabled people are to be realized and services designed to meet their needs.

The cynics see the Developmental Disabilities movement as an inexpensive method of buying off advocates for handicapped and disabled people. The DD program gives each state and territory a small amount of money to conduct an overwhelming task. It establishes a foreign body, the Developmental Disabilities Council, in each state among existing state agencies. The Council is designed to coordinate disparate state and Federal agencies and programs. Though the Federal government cannot coordinate its own agencies' efforts, it directs a small body of people to attempt coordination at the state level. The DD program is constantly subjected to changing and ambiguous regulations, guidelines, and requests. Consumer groups are reduced to fighting over crumbs on the table, while deals are made under the table, and millions of Federal dollars go to other, less desirable causes.

Some Problems

As we begin to implement the new legislation, program conflicts have reached an impasse, and the DD movement is fighting for its integrity. Many state DD

Councils have had to struggle for their very existance. Some have been disbanded, reappointed, and disbanded again, primarily for political reasons. Is it possible that these Councils, made up of state agency heads, prominent professionals, service providers, and consumers were engaged in such objectionable activities - on behalf of disabled people - that they needed to be publicly reprimanded and disbanded? Unlikely. More to the point, they were beginning to establish goals, to define objectives, and to mobilize resources, becoming potent forces on behalf of handicapped people. Perhaps detractors consider such forces dangerous in a time of short monies and human resources.

Some Councils have also been immobilized in other ways: Councils have had to work without staff or with staff whose loyalties lay elsewhere; most Councils have had to borrow their staff from the state administering agency. This has often led to conflict of interest and divided loyalties for the assigned staff and has made interagency coordination a difficult, if not impossible task. Where there is a dedicated staff, too often manpower is inadequate to fulfill Council responsibilities. That is, time and skill for comprehensive planning, understanding of developmentally disabled people and their needs, and knowledge of essential political and legislative tasks are in short supply.

Because some DD Councils have often had difficulty in developing their organizational goals, structures, and resources, they have spent their time acting as mini-agencies passing out service grants from minuscule formula grant funds. As a result, the major responsibilities of comprehensive planning, carefully selected gap-filling activities, provision of access to resources, program development, and policy monitoring were neglected. The service grant-giving activities have often led to squabbles among Council members and conflicts with state agencies, which have a responsibility to inspect service delivery systems. These conflicts have been counter productive to DD Councils' goals of coordination and cooperation.

In some instances, DD Councils have been co-opted by their administering agencies. Various strategies have been used, but the result is usually the same: the administering agency prepares the state plan, sets the priorities, divides the monies into administrative support services and service grants, and in the eleventh hour, seeks the rubber stamp approval of the DD Councils. Councils in this position do not meet often enough to organize resistance to this type of approach. Too often, this modus operandi results in stagnation and apathy; the Council fails to exercise any advocacy function adequately, let alone its legitimate planning function.

Some Progress

Lest this appear too negative, let me point out that ineffective Councils have dwindled in number. In most states, Councils have solved the problems mentioned above and have shifted their focus to planning, advising, monitoring, and advocating. In a number of states, statutory legislation has established the Council and its functions as a permanent body of state government. In other states, executive orders clearly support the Council's role in planning and advocating. There has been a steady trend toward enhancing visibility of Councils in state government. Advisory Councils once assigned to low level divisions within agencies (e.g., the Division of Mental Retardation within the Department of Mental Health) have now become Planning Councils attached to high level Human Resource Departments, or to the Governor's Planning Offices. This upward trend acknowledges and stabilizes the Councils' meaningful role and the importance of the consumers they are attempting to serve.

Numerous Councils have taken direct action in reviewing state legislation and standards as they affect the rights of handicapped people. Some have proposed and monitored legislation and standards, while others have exposed rights guaranteed by law, but not observed. Several Councils have established legislative committees and task forces, and employed legal staff to assist in these activities. Some, with the support of the National Center for Law and the Handicapped at South Bend, Indiana, have acted as "friends of the court" in legal action.

Many DD Councils have assessed Federal legislation in order to gain resources for developmentally disabled people. A number of states have targeted the Supplemental Security Income program and Revenue Sharing as sources of direct support and services for disabled citizens. DD Councils have also influenced Title XX social service plans, assuring inclusion of disabled people. Other resources, such as the Housing and Development Act and the Comprehensive Employment and Training Act (CETA), have proven useful in expanding resources. In all of these efforts, DD resources have been used as seed monies to produce multiple effects.

Perhaps one of the most common activities of the DD program is the emphasis on public awareness. Almost half of the DD Councils across the country have established public awareness as one of their top priorities. These Councils have produced and made available public information programs through radio, television, and newspapers for a variety of targeted audiences. They have held public hearings and forums. They have established hot lines and public information centers. Along with the public awareness efforts of consumer organizations, DD Councils are rapidly introducing the general public to the needs of developmentally disabled people and the resources available for them.

A growing number of Councils see their role of monitor and advocate as one of primary importance. These Councils have established task forces and standing committees to review major service programs, to develop standards and regulations, to review seed grants and granting procedures, to make onsite visits to residential programs, etc. Often, the outcome of these activities is to motivate the Council to advocate for new legislation, new monies, and new forms of coordination and cooperation among agencies and service providers.

To assist in these efforts and others, a number of Councils (twenty-one as of this writing) have established regional mechanisms within their states. These mechanisms range from regional hearings, to committees, to regional Councils with paid staff budgets. The regional mechanisms have been used to assess needs, develop regional plans, give service grants, monitor services and conduct public awareness activities. It appears these mechanisms are very useful and cost-effective and are much needed to give the DD Councils statewide impact.

All Councils have helped to develop gap-filling, innovative services for their states. For example, the North Carolina DD Council has assisted in developing a network of twelve group homes under the auspices of the Methodist Church; Florida has developed a statewide system for assessing the medication needs of epileptic citizens in its state; Rhode Island has developed an interagency early education screening, diagnostic and treatment program; Kentucky has developed a hortotherapy program, providing work for handicapped persons in a network of private or profit greenhouses; and Tennessee has developed a coordination system for one of its service delivery regions which assures interagency communication and identifies gaps in services. In most cases, these and other states have used some of their formula grant monies to pay for direct service projects to fill existing gaps and to develop programs that would eventually be funded by other sources. This seed money approach has been one of the most common and successful methods for developing the role and credibility of DD Councils, while at the same time setting the stage for their involvement in policy issues and decisions.

Conclusion

Fortunately, the Developmental Disabilities Program has gotten a new boost with the passage and signing of the Developmentally Disabled Assistance and Bill of Rights Act of 1975. The Act calls for:

(1) the recognition of autism as a developmental disability;

(2) adequate support staff solely responsible to the Councils;

(3) dividing implementation and planning responsibilities of the Council and administering agencies;

(4) providing funds for establishing advocacy and protective services;

(5) establishing a nationwide evaluation effort;

(6) early screening, diagnosis, and treatment; and

(7) recognition of the rights of developmentally disabled people.

These are only a few of the notable features.

Most important, with the new legislation, the Developmental Disabilities movement is alive and well. It is a movement that is larger than the legislation itself. It is a movement of advocates who work with passion, competence, and discretion to improve the quality of life for handicapped citizens. From any perspective, the DD movement is facing in the right direction.

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