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News Letter

THE GOVERNOR'S PLANNING COUNCIL ON DEVELOPMENTAL DISABILITIES & THE DEVELOPMENTAL DISABILITIES PLANNING OFFICE OF THE STATE PLANNING AGENCY

Vol. 4, No. 2 State of Minnesota Spring, 1979

1978 Changes in Federal DD Law

— a condensation

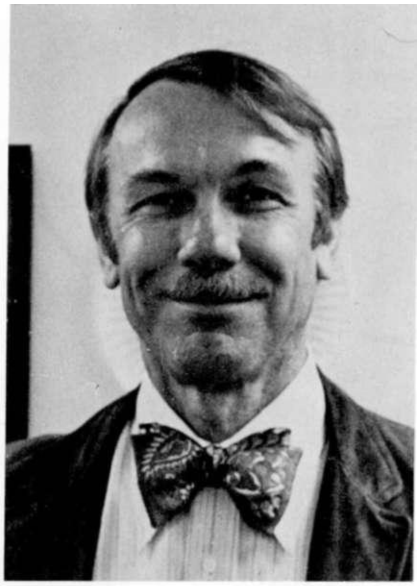
Title V of Public Law 95-602 contains the amendments to the Developmental Disabilities (DD) Services and Facilities Construction Act. The following is a condensation of the important changes which include:

-Authorization of a three year extension of the existing federal DD programs operating in the states;

-Redefining the eligible population (a new definition of developmental disability);

-A shift of emphasis from planning to priority service areas;

-A clarification of the role and change of the composition of state planning councils;



Bruce Balow of Goodhue
New Council Chair
(see Council page 12)

-Increased authorization levels for state protection and advocacy systems;

-Repeal of the National Advisory Council on Services and Facilities of the DD.

The most talked about change in the law is the new definition of DD; therefore, it is examined at some length separately in this newsletter. First, an elaboration of the other changes as listed above.

Three-year extension: Despite the three-year extension of authorization for funding existing DD programs, the states continue to operate under the very well known "continuing resolution" which is funding at the previous fiscal year level (1978).

Members of the DD community are urged to gain support from their congressmen to immediately provide a supplemental appropriation for this fiscal year which ends September 30, 1979.

Priority service areas: State DD agencies are to target expenditures on one of the following four priority service areas:

-Case management: to assist DD persons in gaining access to needed social, medical, educational and other services, including follow along and coordination;

-Child development for prevention, identification and alleviation of DD problems;

-Alternative community living arrangements activities including: in-house, family support, foster care, group living, respite care, and staff training;

-Non-vocational, social development activities to assist persons with DD in their daily living and work tasks.

Amendments to p. 12

Featured In This Issue Is Prominent 1978 Legislation Affecting the DD Community

- Public Law 95-602 1978 Amendments of the 1973 Rehabilitation Act (with a separate article elaborating on "Independent Living")
- Public Law 95-602 1978 Amendments to the Developmental Disabilities Services and Facilities Construction Act (with separate coverage of the implications of the new DD definition)
- State Rule DPW 30, "Cost of Care"
- A profile of State Planning Agency Director, Art Sidner
- A page describing the current composition of the Governor's Planning Council on Development Disabilities

1978 Amendments to Rehab. Act of 1973

On November 6 last year, President Carter signed the Rehabilitation Amendments of 1978. The final bill, with a four-year authorization emphasizes independent living, a new research institute, a new formula for allotment of monies and a number of other important changes.

Changes in the VR program are, of course, of special interest to the developmentally disabled community because of the great number who use these services. This article highlights what appears to be the major changes in this legislation.

At the time of this printing the federal regulations were not available to the states. When they are available they will give direction to the manner by which the state agencies will implement the provisions of the law.

FUNDING

Consumer Price Index

Congress authorized $808 million for basic state grants for FY 1979 and extends authorization through FY 1982. Subsequent increases will be in accordance with the Consumer Price Index, but grants are not to exceed these amounts in millions: 1980 - $880; 1981 - $945; and 1982 - $972.

New formula

In conference committee, Congress reached a compromise on the question of the formula for alloting monies to the states. It was agreed to allow 50% of new funds over the 1978 appropriations level, to be distributed by a formula giving more equal emphasis for relative state per capita income.

Congress yet to act on '79 appropriation

The House Appropriations Committee has yet to decide on the FY 1979 appropriation figure, so state VR agencies are operating under the well known "continuing resolution," i.e., $760 million. If new funds are not appropriated beyond this amount, Minnesota stands to receive about three quarters of a million less for this fiscal year which ends September 30, 1979.

STATE PLAN OF SERVICES

Language of clients

This plan requires a provision to assure that VR agencies will have available, personnel trained in the native language or mode of communication of clients.

Grants to serve Amercian Indians residing on reservations

Requires assurances that VR agencies will provide services to handicapped American Indians. And in Section 130, "The Commissioner...may make grants to the governing bodies of Indian tribes...to pay 90% of the

Accessible facilities

Director cannot delegate final review decision

Number of CAPs no longer limited

NATIONAL INSTITUTE OF HANDICAPPED RESEARCH

DD News Letter is printed in bold type to make it more legible for the visually handicapped readers in our audience.

Portions of *DD News Letter* are read over the Talking Book Radio Network, which serves Minnesotans who are blind or have multiple handicaps.

costs of vocational rehabilitation services for handicapped American Indians residing on such reservations."

Facilities used in connection with the delivery VR services will comply with the Architectual Barriers Act of 1968.

INDIVIDUALIZED WRITTEN REHABILITATION PROGRAM (IWRP)

"The Director...shall establish procedures for the review of determinations made by the rehabilitation counselor...upon the request of a handicapped individual...such procedures shall include a requirement that the final decision concerning the review of any such determination be made in writing by the Director." The Director may not delegate his responsibility.

CLIENT ASSISTANCE PROJECTS (CAPs)

The previous legislation limited the number of CAPs to 20 "in geographically dispersed regions." This numerical restriction has been removed. More money has been authorized, and the scope of purpose and remedies to be pursued expanded.

Establishment of:

1. NATIONAL INSTITUTE OF HANDICAPPED RESEARCH (NIHR)
   INTERAGENCY COMMITTEE ON HANDICAPPED RESEARCH
3. NATIONAL COUNCIL ON THE HANDICAPPED

This newly established institute will administer all research and its dissemination with respect to handicapped individuals; this includes existing RSA research and existing training activities previously conducted by Research and Training centers (R&T).

Independent of RSA

NIHR will operate independent to, but as coequal with RSA; its director to be appointed directly by the president.

INTER-AGENCY COMMITTEE ON HANDICAPPED RESEARCH

NASA included

This is a coordinating body with no direct administrative authority. Its purpose, as established by the "Institute," is to promote coordination and cooperation among federal departments and agencies conducting rehabilitation research, including such governmental agencies as the National Aeronautics and Space Administration (NASA) and the National Science Foundation.

NATIONAL COUNCIL ON THE HANDICAPPED

This newly established body is appointed by the president and is representative of handicapped individuals to serve as a policy setting council.

Sets policy for NIHR

Its fifteen members will set general policies for and review conduct of the NIHR.

and RSA

And the Council will advise the HEW commissioner on policies and conduct of the RSA.

Grant funding

In Minnesota, the agency that could apply for a grant for this new progam is the State Services for the Blind. Separate funding is from the authorization designated for Comprehensive Services for Independent Living, but not in an amount in excess of 10% of the amount made available for the national independent living program for all disabled. Funds would go to those states that submit grants which are then approved by the Commissioner of RSA.

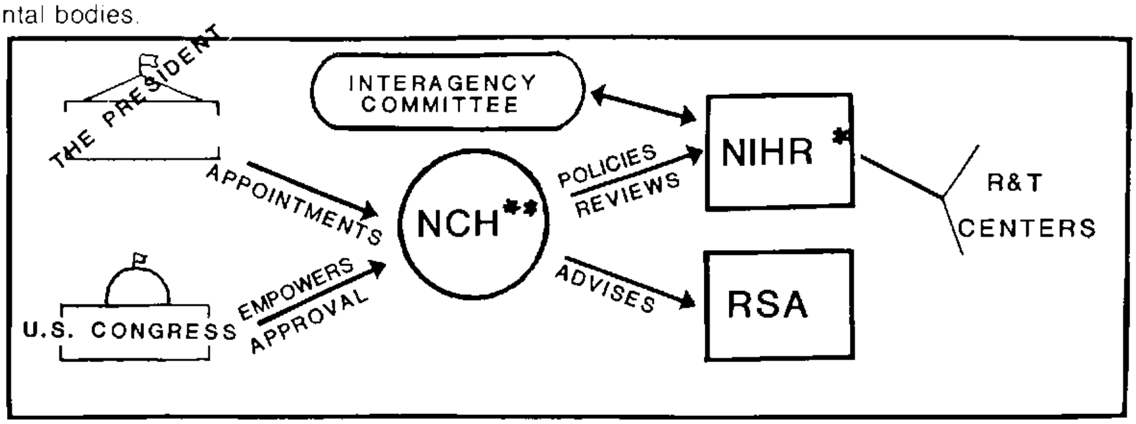
U.S. Dept. of Labor to enter into agreements and pay employment costs

Pilot Community Service Employment Programs (CSEPP), administered by the U.S. Department of Labor, provides jobs to DVR referred clients; Labor Dept. will make agreements with public and private employers and will pay up to 90% of the costs.

COMPREHENSIVE SERVICES FOR INDEPENDENT LIVING AND NEW CENTERS FOR INDEPENDENT LIVING

(See pp. 4 & 5)

Organizational arrangement showing the inter-relationship of the NCH with NIHR, RSA, and other governmental bodies.



* *NIHR and RSA are agencies within and responsible to HEW*

** *NCH is located with HEW but receives its authority directly from the President's office and Congress*

Comprehensive Services for Independent Living (IL)

Possibly the most talked about of inclusions in the 1978 Amendments to the Rehabilitation Act is Title VII - "Comprehensive Services for Independent Living."

Section 781 states:

"The purpose of this title is to authorize grants (supplementary to grants for vocational rehabilitation services under Title I) to assist states in providing comprehensive services for independent living designed to meet the current and future needs of individuals whose disabilities are so severe that they do not presently have the potential for employment but may benefit from vocational rehabilitation services which will enable them to live and function independently."

It is the intention of this article to summarize the definition, historical development, IL projects and centers, and testimony, as legislation was being developed in the House Sub-Committee on Select Education. Also reviewed are current activities of the Minnesota Division of Vocational Rehabilitation task force on IL.

Title VII of the 1978 Amendments states, "Independent Living means any appropriate vocational rehabilitation service...and any other service that will enhance the ability of a handicapped individual to live independently and function within his family and community and, if appropriate, secure and maintain appropriate employment."

Title VII, IL services lists are broad. On the periphery they include child development and preventive services at pre-school age.

In 1959, federal vocational rehabilitation (VR) legislation was proposed asking for services to severely disabled who may not have a specific job objective. This would add a dimension to the VR program which traditionally required a specific job goal as an outcome of services.

In 1961, legislation was introduced containing the title, "Independent Living Rehabilitation Services." Such services as mobility and personal adjustment training were listed with a suggested appropriation figure of $25 million.

None of these proposed legislations with IL provisions passed until 1972. Its conclusion was a pocket veto - the reason given being the IL measure would divert the vocational rehabilitation program from its basic objectives and dilute VR resources.

In 1973, Congress made changes in the bill which compromised the 1972 IL component by providing a "Study of Comprehensive Service Needs." This proved to be the springboard for development of a national policy on services for the severely handicapped. Services for the severely handicapped were prioritized. The focus was to be on "major life activities."

Persons with severe disabilities said the time had arrived for increased services because medical (e.g., prosthetics, orthodics, communications) and rehabilitation technological advances opened up new opportunities beyond health and residential care.

The physically disabled were very active and well represented. Their testimony was heard. They voiced needs not limited to the physically disabled, but open to all disability categories.

The Comprehensive Service Needs Study showed that the needs of those with severe limitations differ widely from the less handicapped; thus the existing rehabilitative programs were insufficient.

Five demonstration programs were funded by RSA to gather information so that specific delivery system issues could be addressed.

In Seattle they looked at physically disabled clients' special staff relationship needs. In New York a project examined coordination and case management aspects of a potential IL program for clients with neuromuscular diseases which were progressive. Out West in Utah and Texas they tested the Vocational Rehabilitation Agency's potential to be a responsible provider of IL programs. In Berkeley, California, the Center for Independent Living (CIL), a consumer self-help organization, was studied to observe ways and means used by the severely handicapped themselves in pursuing a com-

People doing what they want

prehensive rehabilitation program.

During the 1950s states began "mainstreaming persons" housed in public institutions. Often, it was simply the act of discharging the institutionalized resident to a community based, custodial program - usually a board and care type facility. Deinstitutional trends generated greater aspirations for community services to this population.

Hearings regarding needed changes in the VR program before the Brademas Sub-Committee took place in January in Berkeley, California and later in April, Washington, D.C. Testimony based on the Berkeley CIL program, similar programs, and the demonstration projects began to pour in.*

...On their own!

General support came from Robert Humphreys, RSA Commissioner, and from Joseph A. Califano, Jr., HEW Secretary.

On April 12, 1978, in the Bradema's committee, Humphreys stated that the time has come for IL. Later he said that such services would be provided on a *limited scale.*

One person who had received services from the CIL in Berkeley testified, "CIL has made a great difference in the quality of my life and in making it much easier for me to live independently."

There were other consumers who testified in this fashion. The staff and clients of the Berkeley CIL played a major role if not *the* major role in providing testimony to the Brademas sub-committee.

Existing IL programs and projects in the nation range from established programs like Berkeley CIL to experimental types found in Eugene, Oregon and Madison, Wisconsin to see what severely and profoundly retarded, institutionalized residents can do in real work activities.

In Minnesota, Courage Center of Golden Valley has IL services ranging from residential facilities to pre-school activities. Recently during an IL seminar conducted there, visitors from Berkeley's CIL and from RSA's regional offices in Chicago expressed their feeling that Courage Center's IL services were outstanding.

Persons responsible for planning new IL programs, now required under the law, know that business of the first order is to find out what is already in place and to explore how to assess their effectiveness and how to tie the pieces together into some kind of coordinated IL effort.

The agency in Minnesota charged with spearheading the IL plan, to be submitted to RSA, is the State Division of Vocation Rehabilitation. This IL task force, formed earlier this year, is holding meetings and sub-task force meetings to answer basic questions such as:

Who of the severely disabled will be eligible and of those who will be priority? Will it be those who have *never* received basic rehabilitation services? Is there an age limit - pre-school age, working age?

In addition to usual vocational rehabilitation services, what IL services will be available: attendant care, physical therapy, child development, recreation? (Such services *may,* by law, be provided but are not mandatory).

How much money will the federal and state governments provide?

[At this time, the law authorizes $80 million for fiscal 1979, but as of this writing the Carter budget recommends only $2 million and the House Appropriations Committee has yet to act on an IL appropriation.]

The DVR IL task force, which is composed of representation of all disability categories from public agencies and consumer organizations, intends to develop the IL plan for Minnesota. The final draft of its proposed plan is due later this year.

Federal regulations on requirements of the IL section of 95-602 are due to be published by late June. These, together with the final DVR IL plan, should do much to answer many questions concerned persons have about plans for Independent Living.

In conclusion, it is fair to say that no one would testify against the need for more comprehensive services for independent living for the severely disabled. What has to be done now is to gather correct information for effective planning and coordination of resources and technology already in existence. It appears unlikely that any significant amounts of public funds for IL will be forthcoming in the near future.

**Rep. John Brademas of Indiana, Chairman Sub-Committee on Select Education of the Committee of Education and Labor, U.S. House of Representatives.*

Public Law 95-602, Title V, Section 503 states:

''The term 'developmental disability' means a severe, chronic disability of a person which - is attributable to a mental or physical impairment or combination of mental and physical impairments; is manifested before the person attains age twenty-two; is likely to continue indefinitely; results in substantial functional limitations in three or more of the following areas of major life activity: (i) self-care, (ii) receptive and expressive language, (iii) learning, (iv) mobility, (v) self-direction, (vi) capacity for independent living, and (vii) economic self-sufficiency; and reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are of lifelong or extended duration and are individually planned and coordinated.''

The law stipulates that HEW analyze the impact of the new definition and report its findings to Congress by January 15, 1981. Thus HEW contracted with Morgan Management Systems, Columbia, Maryland, to prepare an interpretation of the new definition. The principal author was Elinor Gollay who in March 1979 completed a paper entitled, ''THE MODIFIED DEFINITION OF DEVELOPMENTAL DISABILITIES: AN INITIAL EXPLORATION.''

To provide the reader with insight into the meaning and implications of the definition, we are presenting below paraphrasing and ''verbatim'' excerpts from the Gollay paper. The author warns that the definition is ambiguous and that her paper is a starting point for exploring issues and implications raised by the definiton - it is not the final say so.

CONCEPT: The underlying concept stresses a pervasive, cumulative and early impact on the person requiring long-term care and integrated services. The population is considered one generally overlooked by human service systems in the past.

ASSUMPTIONS:

1.) Persons with developmental disabilities (DD) experience minimal acquisition of basic skills in all areas (social, educational, personal, etc.) during childhood. Conversely, those whose disability was acquired during adulthood would have acquired much greater skill development.

2.) Results of slower skill acquisition are: ''feelings of failure and frustration;'' segregation from the mainstream, (thus isolation and limitation of life experiences); and a sum total impact in early childhood which is greater than the individual effects of physical-mental impairments.

3.) ''By the very nature of being developmentally disabled, people are likey to be underserved, inappropriately served, or unserved because they are '...frequently considered to be too severely handicapped to benefit from services...' Most programs aimed at independent living have not focused on the needs of the retarted segment of the DD population.''

4.) Persons with DD are often limited in their ability to be self-advocates and may require others to represent them. However, many could, with appropriate support, be self-advocates.

5.) All persons with DD do not have the same level of abilities nor do they share the same kind of limitations. Mental abilities range from high to low, many are mobile, many face serious mobility problems, and many need different services at different times in their lives.

INTENT OF THE DEFINITION: ''...that the concept become less arbitrary in terms of who would be included and who would be excluded...'' And, the definition would be, ''...more clearly focused on the most substantially handicapped population.''

The focus of the prior definition on the most substantially handicapped was ''frequently lost and people were considered to be DD automatically

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ANALYSIS: Gollay's paper proc
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chronicity). She mentions severe emotional disturbances, such as childhood schizophrenia, severe physical impairments such as spina bifida, multiple handicaps such as deaf-blindness and others.

None of the conditions (potentially included disabilities) are included unless the person meets *all* of the criteria listed in the definition.

Most of the additional conditions which could be included have low incidence and prevalence rates, and for those more common the segment meeting the criteria will be quite small.

Few conditions are automatically included or excluded, yet persons whose functional limitations result from social conditions are excluded.

III. AGE OF ONSET: ''...is manifested before the person attains age twenty-two.''

The word ''manifested'' replaces the word ''originates'' and places the burden for inclusion on the observable presence of functional limitations. Origin of disability alone is not determinant of DD.

Also, Gollay indicates that raising the age to 22 (old limit was 18) is not expected to have a major impact on incidence, although it may allow for new numbers of groups such as those with spinal cord injuries.

Excluded are persons whose disability manifests and impacts on people *after* age 22 - even if the nature of their problem is similar to those manifested prior to age 22 (e.g., Huntington's disease).

In this regard, Gollay concludes, ''Despite its arbitrariness, this criterion is crucial to limiting the population to those individuals who have had the unique experiences of growing up disabled.''

IV. DURATION: ''...is likely to continue indefinitely.''

The use of the term ''likely'' was purposely stated with ambiguity because some developmentally disabled persons who receive appropriate intervention will have reduced limitations and thus will not have long-term service needs.

V. SUBSTANTIAL FUNCTIONAL LIMITATION: ''...results in substantial functional limitations in three or more of the following areas of major life activity: (i) self-care, (ii) receptive and expressive language, (iii) learning, (iv) mobility, (v) self-direction, (vi) capacity for independent living, and (vii) economic self-sufficiency.''

Remember that substantial functional limitations in three or more of the major life activities are required for DD inclusion.

VI. SERVICE NEED: ''...reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are of lifelong or extended duration and are individually planned and coordinated.''

In short, a person with a developmental disability is likely to need many services throughout life. But each person has a different set of needs appearing at different times.

Gollay's paper concludes with this comment:

''The nature and extent of the implications and ramifications of this new definition have not yet all been identified, and certainly not yet measured. It is apparent that there needs to be considerable effort expended to ensure that the new definition is applied appropriately; under varying conditions, and to ensure that the negative impacts are minimized and the beneficial ones are enhanced.''

Readers who want to request a copy of Gollay's paper may contact:

Kristen Rogge, Evaluation
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Room 2326, Mary E. Switzer Bldg.
330 C. Street, SW
Washington, D.C. 20201

ART SIDNER

— a profile of SPA Director

Art Sidner is Director of the State Planning Agency (SPA) which houses the Developmental Disabilities Planning Office. Mr. Sidner was appointed to the position by Governor Al Quie on February 2, 1979 and assumed duties February 12. The goals which Mr. Sidner seeks for the SPA and the manner in which he pursues them have a direct bearing upon Developmental Disabilities operations.

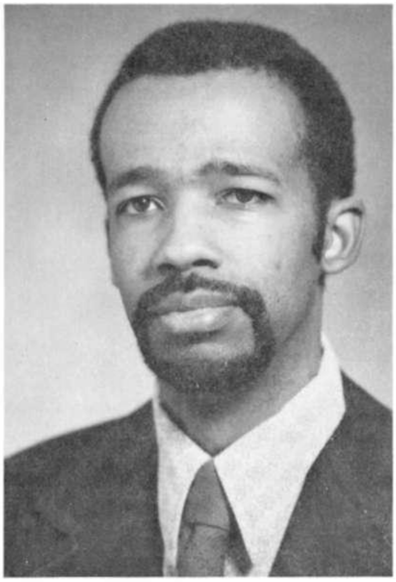
Sidner is a person who thinks keenly about basic human needs. He traces this to his family background in St. Louis, Missouri. His father demonstrated a sincere and warm regard for the well being of people in his work as an x-ray technician in a St. Louis hospital. Daily he tended to patients who often were in pain. His father would return home with thoughts about the people he administered to during the day - injured people from all walks of life, from professional athletes to skid row residents.

Sidner felt within his family a degree of social consciousness and a sense of the pioneering spirit for social change - a desire for poor people to uplift themselves.

Amidst these family surroundings Sidner grew up and pursued his education culminating with Bachelor's and Master's Degrees in mechanical engineering, both received from St. Louis's Washington University.

The engineering field would eventually be new ground to break for Sidner to practice some "pioneering" and to do some human service exploring.

While still in graduate school -summers of 1963 and 1964 -Sidner was employed in a summer "technical employee program" with the 3M Company, St. Paul. This opened the door to his being the first black engineer hired by the 3M Company. He began as a full-time employee there in April of 1965.



Art Sidner

By 1973 he had moved from product development engineer to a "new business" developer. In this assignment he identified new business opportunities for 3M technologies.

By the late 1960s Sidner had read up on and had given considerable thought to the social issues of the times. Social reforms in the areas of minority rights, economic and social change had begun. He wanted to get involved. Sidner saw opportunities through his employment in a large corporation. He felt that his work as a product engineer and new business developer could be orientated to have an influence upon finding solutions to problems indigenous to the poor.

The going was slow, yet he offered ideas and continued to explore business ventures which would generate profits and also appeal to and assist poor people.

Sidner uses the term 'poor' to include people who not only face immediate problems in the materialistic sense, i.e. poverty, but who are behind in their aspirations in other important aspects of life (social, educational, cultural, etc.).

The large business system was slow to adapt itself to socially minded busiess ventures.

Sidner, therefore began to reexamine his career goals. He assessed his vocational interests and identified strengths in artistic and religious areas. He decided to look beyond engineering.

As fortune would have it, while Sidner pondered his future, the Equal Opportunity Affairs Supervisor position opened up at 3M. They offered the job to him and he accepted. He changed careers within the company in December, 1975.

This position opened up new territory and opportunities for finding different solutions on behalf of minority classes. Sidner now intermingled business with human service ventures and became more aware of people projects found in governmental and private agencies.

What Sidner saw from inside the corporation was in interaction between an established large corporation, which liked to operate efficiently, and ethnic and other groups on the outside whom the corporation, presumably, would help become occupationally and materially better off. Both groups would have to come to grips with differing value systems in order for mutually beneficial change to take place.

Over the course of three years, Sidner supervised some innovative equal opportunity activities and saw measurable improvements. He also saw limitations on just how much could be acomplished there. The bigger question remained, "How can minorities become productive on their own right?" The reality was, as Sidner phrased it, "In the neighborhoods and out on the streets. The problems could not be confronted effectively within the corporate walls."

Thus, in 1978 Sidner decided to leave his employer of some 15 years to pursue his social concerns as a private consultant.

The same day that he received Sidner's resignation, a 3M executive received a call from a

Chicago based community organization called "Inroads." The purpose of the call was to gain support from 3M for Inroads, a non-profit organization which assists students with vocational training in the fields of business and engineering. A chapter was to be established in the Twin Cities and a director was needed. The 3M executive was able to suggest a likely candidate for the job - Art Sidner. The very next day Sidner inked his first contract as a private consultant to direct the new chapter of Inroads. Inroads fell in line with Sidner's aspiration to help black people find a way to advance themselves.

Yet another juncture in Sidner's new career was not far off. He had met gubernatorial candidate Al Quie and had discussed his views on social issues and the whole idea of human development. They found much in common.

After candidate Quie was elected Governor he contacted Sidner to invite him to consider working in some capacity with his administration. There were two positions suggested; one with Economic Development and the other with the State Planning Agency. Sidner chose the latter, applied and was hired. Quie felt he found in Sidner a combination of one concerned for people and one with a practical background provided by his engineering and business experience. Sidner's goal was to get to the bottom line of meeting aspiring people's needs in a highly complex, institutionalized society.

Sidner's Goal: "to get to the bottom line of meeting aspiring people's needs in a highly complex, institutionalized society"

Sidner sees three vital elements to consider in approaching the problem of economic development for poor people, namely: psychological education to deal with psychological barriers to development; intermediate technology which provides opportunity for poor people to participate immediately in the productive process; small scale organization which avoids the dehumanizing effects of working in large bureaucratic organizations.

These elements working would allow poor people to be better able to use their own style, their own language, their own tools and methods in a more compatible environment to become productive.

The "intermediate technology" lies somewhere between crude, hand methods of production found on mass production lines and the most advanced "higher" technology found in advanced industrial laboratories. The kind of technology that Sidner sees as intermediate is that which the workers themselves might devise in direct involvement with the owners or managers. Important throughout is maintenance of the proper psychological climate for the expression of achievement motivation. The people must be made to feel like they are on equal footing if they are to participate.

Sidner feels that this scheme of things can be applied to any group endeavor as may exist in the human services field, such as in the area of developmental disabilities. Techniques of super management and paternalistic overseeing should not be the norm.

A tendency of management, and this is found abundantly within government, has been the taking of the role as "manager of the people." "I believe that we have not distinguished clearly between material objectives and the human objectives," stated Sidner. "For example," he said, "we plan well on a technical objective such as rapid-moving, motorized traffic but we miss the boat on the needs of human traffic in the way of pedestrians. And poverty problems are not ones to be solved in the same way as traffic problems."

Sidner has some thoughts about the issue of affirmative action in the recruiting and hiring of persons who happen to have disabilities. "I look first at the person's abilities and their strengths. I want this agency to be a place where people who have a skill can be employed because of that and thus become productive workers. Stress strengths, not weaknesses," Sidner stated.

Sidner is director of an agency in which planning activities cross every conceivable line of operation: urban and rural, human services and physical environment, federal and state, land management and mineral resources, health and demography, economic and political. Whether his influence as director be technical or otherwise, he is open about his view of life: "Individual people though poor and weak, have dignity and value as human beings, made in the image of God, and will respond to being treated as such."

Cost of Care: MN Rule DPW 30 -As amended Sept. 18, 1978

— major medical expenses still a problem

Minnesota Rule Department of Public Welfare (DPW) 30 governs the administration of reimbursement to county welfare and human services boards for the cost of boarding care outside state institutions for children who have mental retardation, epilepsy or emotional handicaps. Rule 30 as *amended* was promulgated (became effective) September 18, 1978. The current Rule 30 has undergone changes over the years related to the intent and content of the statutes.

The Cost of Care Minnesota Statute, 1978, Section 252.27, is entitled, "Cost of Boarding Care Outside of Home or Institution." This is the legal foundation for Rule 30. The Statute, amended by the legislature in 1977 begins, "Whenever any child who is mentally retarded, epileptic or emotionally handicapped is in 24-hour care outside the home and outside the state institutions, in a facility licensed by the commissioner of public welfare, the cost of care shall be paid by the county of financial responsibility..."

Parents whose child had resided in a state institution were relieved, for the most part, of costs of major and every day medical care. When their child left the institutional setting and was placed in a community residential home, many such parents experienced the shocking burden of having responsibility for medical care which could be and often is financially disasterous. Such anticipated major medical costs which could be thrust upon the family would continue as a gnawing concern for many.

The statute addresses itself to the children under age 18.

The current version of DPW Rule 30 and its changes are the subject of this article, but first, a look at the history behind cost of care statutes and rules.

By 1969 the deinstitution movement in Minnesota was in full swing. Impacting this swing was a pressing need for community based residences. These needs were voiced by parents, relatives, foster parents and others close to and interested in the children coming out of institutions or still in the home. The organization which picked up the challenge and lead the effort at the state legislature was the Minnesota Association for Retarded Citizens (Minn. ARC). Minn. ARC recieved a boost when a legislative study made a recommendation that something significant be done for children needing such residences.

Thus the original enabling legislation, from which Rule 30 was developed, came in the form of Statute 252.27 signed into law in 1969.

The intent of State Statute 252.27 was to spur on and encourage county welfare boards to provide assistance to pay the cost for placements in the board and care facilities. Counties facing this new social service and financial challenge would be given a concrete incentive via state reimbursements permitted by law to maintain placement spaces in board and care homes.

The first DPW Rule 30 included the following provisions:

1. determination of parental financial responsibility
2. determination of child financial responsibility
3. provision of temporary care for a diagnostic evaluation
4. individual program planning (IPP)
5. reimbursement requirements for eligible claims
6. establishing one account for cost of care appropriations from the state legislature for mentally retarded/epileptic.

The original statute and corresponding Rule 30 exempted families whose gross income was less than $4,000. Those families required to pay fees faced at the very maximum a fee of $60.

The original statute did not include persons with emotional handicaps. This population was added in amendments of 1971.

The original statute allowed state reimbursements up to 50 percent of the local agency cost.* The last appropriation by the state legislature, Fiscal 1979, supplied enough funds to DPW cost of care to reimburse counties for 53 percent of their claims for those with mental retardation or epilepsy and 10 percent for those with emotional handicaps.

The actual dollar amount that any local welfare agency can recover under Rule 30 is dependent ultimately upon the monies appropriated by the state legislature. (See box showing history of appropriations.)

Medicaid (Title XIX) and GAMC (General Assistance Medical Care) are the federal and county supported alternatives to parents for cost of care eligible children for coverage of all medical cost.

This is generally the way things have been under the cost of care legislation and rules prior to September 18, 1978. What changes have been inserted in Rule 30 as a result of the 1977 amendments to Minnesota Statute 252.27?

1. *Financial Responsibility:* Parents whose gross incomes are less than $11,000 are exempt from paying fees. Previously it

was a base of $4,000. As before, in the temporary rule, it provides a fee schedule based upon the annual gross income adjusted by household size. Now, for example, for a household size of 8 (including the child outside of the home) with a gross income of $17,000 to $18,999 the fee to the parents would be $30 per month.

The maximum fee payable by any parental household or child has been increased from the previous 60 dollar figure to $125 no matter what the income level or size of household may be.

2. *Parental Cooperation:* The rule now makes it clear that parents *"shall* cooperate with the county agency in matters pertinent to their child's eligibility for receipt of benefits..." Third party child reimbursements, such as insurance, shall be paid to the county providing the cost of care.

3. *Medicaid Alternative:* Cost of Care is now an alternative source to parents placing children in an ICFMR residence. ICFMR residences are mandated to use Title XIX (Medicaid). In the past, parents placing in such homes faced stringent restrictions posed by Medicaid regulations requiring them to "spend down" significant amounts for the child's medical costs before medicaid relief was forthcoming. Now the parent, at the time of application, may choose between Rule 30 or Medicaid. If the placing parent faces "spend down" requirements in excess of the cost of care assessment (the maximum fee is $125 per month) then they may choose the lessor.

4. *Temporary Care Clarified:* "Temporary Care" (Respite) has been added to the language of the rule to clarify that reimbursements may be made "...for purposes of diagnostic services or boarding care, of a mentally retarded or epileptic child requiring 24-hour care and treatment, for a temporary period of time not to exceed 90 days within a 12-month period of time."

Sandra Erickson, Division of Social Services, DPW, is responsible for administration of Rule 30 reimbursements and plays a demanding role in answering questions about Cost of Care.

She feels that the new changes in Rule 30 will serve as an incentive for local agencies to keep on maintaining residential facilities in their communities for children covered under the rule. She cautions, though, that dollar amounts of reimbursements from the state DPW are limited by the size of the legislative appropriation and on the basis of each county agency's expenditures.

Bill Olson, Director of the Home for Creative Living in Windom, Minnesota, expressed disappointment that the medical care coverage under Rule 30 continues to fail as a source of relief to families for the major medical costs their child will have over the long run. (Rule 30 coverage is limited to costs incurred as part of the Individual Program Plan and normally delivered in the facility.) Olson said, "Parents of children currently housed in state institutions where medical costs are covered would postpone placement in the community because of their inability to pay catastrophic medical expenses. (Most parents, Olson feels, are ineligible for Medicaid or General Assistance Medical Care.)

History of State Appropriations for Cost of Care Reimbursements

For Mentally Retarded/ Epilepsy			For Emotionally Disturbed	
Fiscal Year		**Amount**	**Fiscal Year**	**Amount**
1970		$ 650,000	1970	figures
1971		1,900,000	1971	not available
1972		1,100,000	1972	$ 600,000
1973		1,250,000	1973	622,800
1974	biennial	3,196,900	1974	678,200
1975			1975	687,088
1976		2,998,700	1976	1,106,000
1977		3,268,600	1977	1,106,000
1978		3,565,460	1978	1,116,600
1979		3,781,188	1979	1,899,596

Olson points out that the rule continues to place a burden upon the residential staff and the parents to write an Individual Program Plan (IPP) which covers as many medical costs as possible that will be paid by Cost of Care. The county agency case worker is involved in the development of the IPP and is responsible for its final approval.

Regarding DPW Rule 30 changes relating to SSI, Julie Harris, Social Services Worker of Olmsted County, explains it this way. If the child is receiving SSI at the rate of $187 per month, the county will require a fee of $125 and the parents who are consigned the money will pay $30 to the facility for clothing and personal expenses. The residual, in this case $32, according to Social Security Administration rules must be used for special needs of the child and the SSA will monitor such expenditures annually.

It's too early and too difficult to assess the total effect of this newest version of MN. DPW Rule 30. The rule, after all, has only been in effect since September, 1978. The need is for ongoing clarification of what the Statute 252.27 intends to do and just exactly what Rule 30 provides. It is evident that Rule 30 as amended does nothing new to alleviate certain families of large medical expenses they must bear.

DD COUNCIL

The Minnesota Governor's Planning Council on Developmental Disabilities is pleased to inform you that Governor Al Quie has made appointments of new members and re-appointments of several existing members of the Council.

Governor Quie has also appointed Bruce Balow, Ph.D., who has served on the council since February, 1975, the new chairperson. Balow assumed duties on May 2, 1979. He replaces Eunice Davis, M.D., who chaired the Council since December of 1975.

Balow has been active in the field of special education since 1953 when he began as an elementary school reading specialist in Mahtomedi, Minnesota. Since that time he has been involved in many facets of special education including teaching, research, publications, and program directorships. He has served on a number of state and national committees of organizations concerned with special education and the needs of persons with handicaps. Dr. Balow resides in Goodhue, Minnesota.

Listed below is the current membership of the Council:*

NEWLY APPOINTED

Harvey Caldwell
Steven Chough
Tom Emery
Eugene Frey
Judy Graves
Jo Gascoigne
Mary Hinze
Ben Kilgore
Ron Leif
Ray Lundgren
Chet Oden

RE-APPOINTED

Bruce Balow
Dona Caswell
William Messinger
Marijo Olson
Richard Nelson
Glenn Samuelson
Dottie Spencer
Richard Ramberg

ONGOING

Kathleen Berland
Bonnie Ford
Lois Fort
Betty Hubbard
Marvin Tritz
Linda Yates

The Council wishes to express its deep appreciation to the following individuals for their fine service:

Jane Belau
Eunice Davis
Edward Constantine
John Dilley

Barbara Goman
Shirley Held
John Groos
Bernie Klein

Daro Larson
Wes Restad
Lee Schacht
Charles Turnbull

ANDO [illegible]

*All appointments are for three years. Two seats remain to be filled to complete the 27 member council.

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Amendments from p. 1

Additionally, a state may elect another priority area of service, provided it is specified in their state plan.

The law specifies the kinds of service activities which may be included under any given service area, such as outreach and training activities. Plans for activities in those service areas must be developed by FY 1980.

State Councils: The State DD Planning Council is to develop the state plan jointly with the designated agency.

Council membership is shifted to allow for one-half instead of one-third consumers; the remaining is half general public, and state agency representatives.

The consumer half is to be at least one-third persons with DD and one-third immediate relatives or guardians of persons with mental impairments.

NATIONAL ADVISORY COUNCIL REPEALED

At the same time that the DD law repeals the DD Advisory Council, the Rehabilitation Amendments of 1978 provide for a National Council on the Handicapped (NCH). Although the DD community may be represented on the NCH, their is concern for how sufficient DD representation will be.

The law does not specify DD representation.

Copies of P.L. 95-602 may be requested through offices of the Minnesota Congressional Delegation.

DD Newsletter is a publication of the Governor's Planning Council on Developmental Disabilities and the DD Planning Office of the State Planning Agency.

Bruce Balow, Ph.D.
DD Council Chairperson

Marylee Fithian
DD Planning Office Director

Frank Thimmesch
Editor

DD Newsletter welcomes reactions from its readers. (612/296-4018)