

Part VII: Toward New Service Concepts

Chapter 15

The Free Choice Principle In the  
Care of the Mentally Retarded

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CARE OF THE MENTALLY RETARDED

This presentation is the product of the collective thinking of several members and staff of the Research and Advancement Subcommittee of the President's Committee on Mental Retardation. Patrick Doyle, Matilde Krim, Allan Menefee, George Tarjan, and Donald Stedman (1967) were of particular help in developing this concept. However, I take responsibility for its consequences.

The Medicare Act of 1965 initiated a revolution in medical care for the elderly, and for the indigent and medically indigent. Title V initiated comprehensive care of children; Title XVIII initiated a health insurance program, paid for during younger working years, and utilized after age 65; Title XIX initiated a free choice system of medical care for the poor rather than the previous welfare system which forced many to city and county hospitals for the poor.

I am proposing that we need a Mental Retardation Care Act of 1969, equivalent to the Medicare Act of 1965, making possible the individual selection of programs and facilities by each family of the retarded, so that not only public (state or local) institutions will be providers of care.

The Medicare Act of 1965 provides for reimbursement, on a full cost basis, for expenses in private or public, profit or nonprofit hospitals; in nursing homes, proprietary or nonprofit; and for private physician's services.

What impact has this act had on the users and the purveyors of service? What has been the response of the public and the private health industries to that act?

In less than 2 years of operation, there has been a dramatic shift from city clinics and city hospitals to private physicians and private hospitals even though these latter may be less accessible. Indeed, there has been a rejection of public type care: for the first time, city clinics and city hospitals are experiencing decreases in registration and patient census. Even Cook County Hospital is no longer overflowing. Free choice has moved the consumer away from public medicine. I am told that a neighborhood health project of the Office of Economic Opportunity was rejected by the poor of San Francisco. They are tired of long lines, massive facilities, and impersonal care, and they want a middle-class system of care.

In response to this demand for private services, facilities are being built or altered to provide more acceptable environments for patient care. City hospitals are undergoing face-lifting operations that are transforming the long benches to privatelike clinics.

More pertinent to our argument in mental retardation is this remarkable statistic from the Social Security Administration: in only twenty-one months of operation of the Medicare Act, the number of nursing homes has increased from 1,200 to over 4,000; and while many of these are proprietary, almost all meet accepted standards. Likewise, the Small Business Administration reports that the most common low interest loan which they currently advance is for nursing home construction.

The simultaneous presence of funds to support private care as well as demand by patients for such care has created a burgeoning new industry. In a free enterprise system such as ours, the presence of consumer demand and consumer capability to pay rapidly leads to better facilities and better programs on a competitive basis.

Yet neither new facilities nor new program plans could be operated without professional manpower. What has been the response here? In fact, an enormous number of trained nursing and medical personnel has appeared--almost "out of the woodwork"--because these new facilities are small, very personal, easily accessible in our suburbs or near our population bases, close to the homes of nurses formerly in retirement, close to physicians, to volunteers, close to the homes of families of the beneficiaries.

Let us now contrast extended care for the aged under Title XVIII of the Medicare Act, or acute care for the poor under Title XIX, with the care of the severely and profoundly retarded in most of our states.

Unless parents are indigent or medically indigent (e.g., an income under \$3,100 for a family of four in Maryland), or unless they carry an unusual variety of health insurance, they must bear the full cost of diagnostic and therapeutic studies in the first several months of life of a severely handicapped child. Birth defects are omitted from coverage in many health insurance plans. It is little wonder that young families are wrenched apart with hospital bills that disrupt the future of the normal as well as the affected child.

As the handicapped child grows, opportunity for day care is limited by the tenuous financial situation of private or, sometimes, public agencies. Rarely are young couples able to meet the full cost of even day care. What if care out of the home is needed for the well-being of the child or family? What are the options for the family? For all practical purposes there are no choices. There is only one answer: public care.

Extended care in private facilities for the mentally retarded is almost never covered by private insurance, not even by major medical benefits. The cost of private residential care is geared more to the less severely handicapped, especially those with emotional disturbance, and amounts to four to eight thousand dollars per year. Such costs cannot be met by other than a small segment of our upper class. Not only the lower class, but even the middle class in a sense becomes medically indigent and must turn to public care for the retarded.

Where is this public care located? Usually many miles away, sometimes even across state lines. And what are these public facilities like? Large, old--planned years before our modern concepts of handling the retarded were developed--impersonal, crowded.

Yet these facilities represent a major capital investment for the state: large physical plants, large civil service payrolls, and large commitments which minimize change simply from the enormous inertia of such monolithic systems. Even now, many of these excessively large facilities are being enlarged still further.

With all respect to the efforts of programs aimed at improving existing residential facilities, these are stopgap measures. Only a totally new approach can produce major changes.

What if public institutions do not satisfy parents? What if care is poor? What if distances are too great? What if legislatures limit appropriations?

Now, under our present system, families have no options--no more free choice than the medically indigent 3 years ago--only the "city hospital" for the retarded; some are good, many are bad.

How then can options be developed? How can the free choice principle be applied to long-term as well as acute care? By providing a new basis for reimbursement: insurance, supported on the widest possible base, and designed to meet unexpected and catastrophic financial burdens.

The application of the same principles as those of the Medicare Act to the care of the severely and profoundly handicapped child would make possible, on an insurance basis, payments to families to assist in providing care where families rather than public officials prefer it. Families could then choose facilities and programs, day or residential, which were most acceptable to them, just as with acute medical care.

With consumer demand and consumer capability to pay, a multiplicity and variety of facilities to meet a variety of needs would be created, just as with the Medicare Act. Small size would be inevitable because of limits on local capitalization for such ventures. Small size, intimacy, personal involvement, volunteer and parent participation would result. With demand, new job ladders, new job opportunities would arise close to home, accessible as well as available to the married women and the volunteers, young and old, of urban and suburban society.

Nonprofit and proprietary both could flourish--regulated more by consumer satisfaction and competition, by parent boards and community leaders than by legislative committees or even boards of trustees that "visit" the institution once a year.

How would an infant, child, or adult enter this new system? By application from the family, or an agency acting for the family. Determination of disability would be made by medical, psychological, and other disciplines. Indeed, appropriate study for each child would be guaranteed as a byproduct of this system.

The comprehensiveness and cost of such a program would be dictated by demand. Medical care, medically oriented therapies, nursing, physical therapy, behavior analysis, and the like would be provided under such a Medicare extension. Since education is essential for many of the severely handicapped, the cost of education activities should be borne by state or local educational structures in those cases where such is not provided by the public schools. This principle should be maintained because education is a public responsibility by tradition so firmly rooted that it could not and should not be shaken. Within limits of their income, families would be expected to bear costs to the same extent they would bear costs for a normal child at home. Thus, these three components would combine to meet the total costs of services.

The reasonable cost of such a program nationally would approximate 1.2 billion dollars annually, liberally calculated. Much of this would be a replacement for present expenditures from state and local appropriations. To an employed person it would represent an increment of 0.19 percent of taxable base income, and a similar increment to the employer--a price to pay, not insignificant, not easily bought by politicians, but one that labor unions and middle class will buy.

Indeed, the possibility exists that the cost may be no greater than in the present system despite markedly improved services because of the reduction in overhead that inevitably accompanies massive facilities, massive personnel rosters, with their supervisors and supervisors of supervisors.

To this point I have presented only the positive aspects. Needless to say, there are potential flaws: parents and government exploited by entrepreneurs; government exploited by parents and physicians; parents might not follow adequate counsel; parents may die, leaving the child without guardian. This last problem must be faced realistically, and a surrogate parent, a life manager behind the scenes, must be created instead of the dependence upon the security of isolation in the large institution where the superintendent is the life manager for thousands.

Yes, this is an extension of social security to a different group, but not to a different purpose.

Some may say it is a step down the road to more socialized medicine. To those I would say the present system is the ultimate in socialized medicine: state facilities, state-operated, state-controlled, state-regulated.

There are concerns: there are dangers. California is partly experimenting, but inadequately so, without an adequately broad base of insurance coverage. Canada seems to be moving successfully in this direction.

Sooner or later, parents of the retarded will demand options-- options which they control, not others.

In a free society, sooner or later, free choice is inevitable, even for our least privileged: the retarded. The wise society will act speedily to create a mechanism for this free choice, and bring to parents of the retarded everywhere a new cause, a new involvement, a new opportunity.

#### Reference

Stedman, D. A recipe for improving institutional care: Add a dash of Capitalism. Unpublished position paper for the President's Committee on Mental Retardation, 1967.