A Program Inspection

on

Transition of Developmentally Disabled Young Adults from School to Adult Services

Department of Health and Human Services

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Inspector General

Program Inspections are short-term studies of HHS programs and services conducted at the local service delivery- level. They are not designed to be statistically valid research studies, compliance reviews, audits, program monitoring activities, or traditional program evaluations. Rather, a program inspection consists of gathering current qualitative information from open-ended discussions with clients and service providers. The knowledge gathered is subjective in nature and is intended as a way for senior-level HHS personnel to obtain the views of the people most directly affected by HHS programs. Program Inspection results are meant to be used internally by Department managers as an additional source of information which, - when combined with others, provides a more complete picture of program operations.

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Summary of Findings

The transition from school to adult services for developmentally disabled young adults is an emerging issue in many parts of the United States and will continue to grow. Families that have kept their children at home and received quality services from the public schools have increased optimism about what their DD children can achieve. Parents are now expecting that appropriate community based services will be made available to their adult children.

The public schools have no formal responsibility to plan for services for DD young adults after they leave school and the adult service system usually has no single point of responsibility for case management or coordination.

Gaps in the availability of adult services for DD clients still exist and waiting lists are not uncommon. In some states DD young adults leaving school face competition for services with those being deinstitutionalized. Those DD young adults with behavior problems often face the greatest difficulties in receiving appropriate services.

Debates continue regarding what the adult service delivery system should look like and approaches vary widely. Some states have made significant efforts to put together comprehensive systems to serve their DD population. At the community level, alternative approaches stressing community placement, use of generic services, independent living and competitive employment are being implemented. But these innovative programs often have limited resources compared with segregated special purpose programs such as ICF/MRs and sheltered workshops.

The Department of Health and Human Services makes a substantial contribution each year ($6.62 billion) to support services for the developmentally disabled. A large share of the HHS budget for DD services goes to support institutional care, a needed service for some of the DD population. However, respondents felt that current Federal policy still provides too great an incentive to states and communities to use these services in place of potentially less expensive alternatives.

The Medicaid waiver provisions of the Omnibus Budget Reconciliation Act of 1981 allow states to develop alternative approaches in providing home and community based care. Many states are hopeful that the waiver will help bring about more cost-effective services for a portion of the adult DD population.

Some advocates believe that additional savings can also be achieved through increased reliance on small, community based ICF/MRs and greater use of programs which seek to expand the DD client's potential for independent living and competitive work.

Table of Contents

Page

Introduction

At the request of the Assistant Secretary for Human Development Services, the Office of the Inspector General conducted a program inspection on the transition of developmentally disabled young adults from school to adult services. In some states, this issue has also been referred to as "the aging out process". During September 1983, face to face discussions and telephone conversations were held with 252 respondents in 28 states. Included among the persons contacted were state and local officials, service providers, educators, parents, and other experts.

The purpose of these discussions was to:

Determine the extent of the problem with the transition of developmentally disabled young adults from receiving services in the public schools (mandated under P.L. 94-142) to seeking services from a variety of local, state and Federal programs serving the adult DD population.

Identify program models which have successfully dealt with transition from school and which have improved the adult service delivery system.

Overview

P.L. 94-142, (The Education for All Handicapped Children Act of 1975), requires that public schools provide free appropriate public education for all children between the ages of 5 and 21 regardless of handicap. The Act was adopted within the context of an emerging social policy, reinforced by legislation and court decisions on deinstitutionalization, which sought to expand the opportunities for all handicapped people to function in their own communities at the maximum of their capabilities and in the least restricted surroundings.

In each of the next few years there will be about 90,000 DD students leaving school and seeking adult services of some type. While several states have been dealing actively with the transition problem as an urgent matter, in most places it is seen more as an emerging issue related to the convergence of three factors:

Increased parental expectations for appropriate community services

Fragmented nature of the existing adult service delivery system

Continued limited availability of certain adult services.

III. Discussion of the Issue

A. Transition from School

Responsibility for coordination and delivery of services for developmentally disabled children rests in a single source, the school district. The children served by the public schools may still receive a variety of other health and social services from state DD agencies, other Federally funded efforts, and voluntary programs. But the parents know that until their child either graduates from school or reaches the age of 21 there is at least one centralized source, the public school, to which they may turn and against which they can seek administrative or judicial relief, if they are not satisfied. There are now about 1,120,000 developmentally disabled children and young adults enrolled in special education programs in the public schools. This number has been somewhat increased by the rubella epidemic of 1963 - 1965 which affected over 20,000 children who are currently in the process of making the transition to adult services.

In talking about the services provided by the schools and what occurs at the time of transition, respondents noted:

> Parents now have much greater incentives to keep their children at home during their school age years. The array of available school services varies in quality and quantity by school district, but often includes everything from special classes and pre-vocational training to physical and occupational therapy, psychiatric counseling, and special programs for children with speech, hearing, or mobility problems. Where school districts are unable to provide or obtain appropriate services, they may contract with private residential facilities out of the district and sometimes out of state, although this is the exception rather than the rule.
>
> Each developmentally disabled child in the public schools has a yearly individualized education program (IEP) which details his or her special needs and presents specific steps which will be taken to meet a series of achievement goals. These written plans are available to parents, who are encouraged to participate in the planning process and to carry out activities at home to supplement the school program. By working closely with the schools and by seeing their children progress (often beyond their earlier expectations) many parents develop a growing optimism about what their child may someday achieve and the degree of independence that may be possible.
>
> The schools have no formal responsibility for developing a program of services for the child after he or she leaves school or for assisting the parent in making contact with other case managers or adult service providers. Some educators explained that their day to day resources were so limited and mandated school responsibilities so great, that someone else would have to coordinate transition.

In many places, parents and families of developmentally disabled children face a time of crisis when their children turn 21 and are no longer eligible for public school services. *Many* of the parents rejected the option of institutionalizing their child at an early age and instead worked to raise their child's level of independence and integration within the "normal" community. But these parents now find few appropriate non-institutional models available for their grown children. Their other children leave high school and go to work or on to further education. Parents ask the same questions about their developmentally disabled children as they do about their normal children: Where will they live? What will they do? How will they obtain support services?

Perhaps the most necessary (and often most lacking) services at transition are case management and vocational evaluation. These were seen by respondents as particularly critical because they present the family with a full range of options in relation to the DD young adult's potential. If the family does not have case management services available or an accurate thoughtful evaluation, the client may be placed in an inappropriate setting or tracked into a dead end option which can limit his or her hopes for a full and independent life.

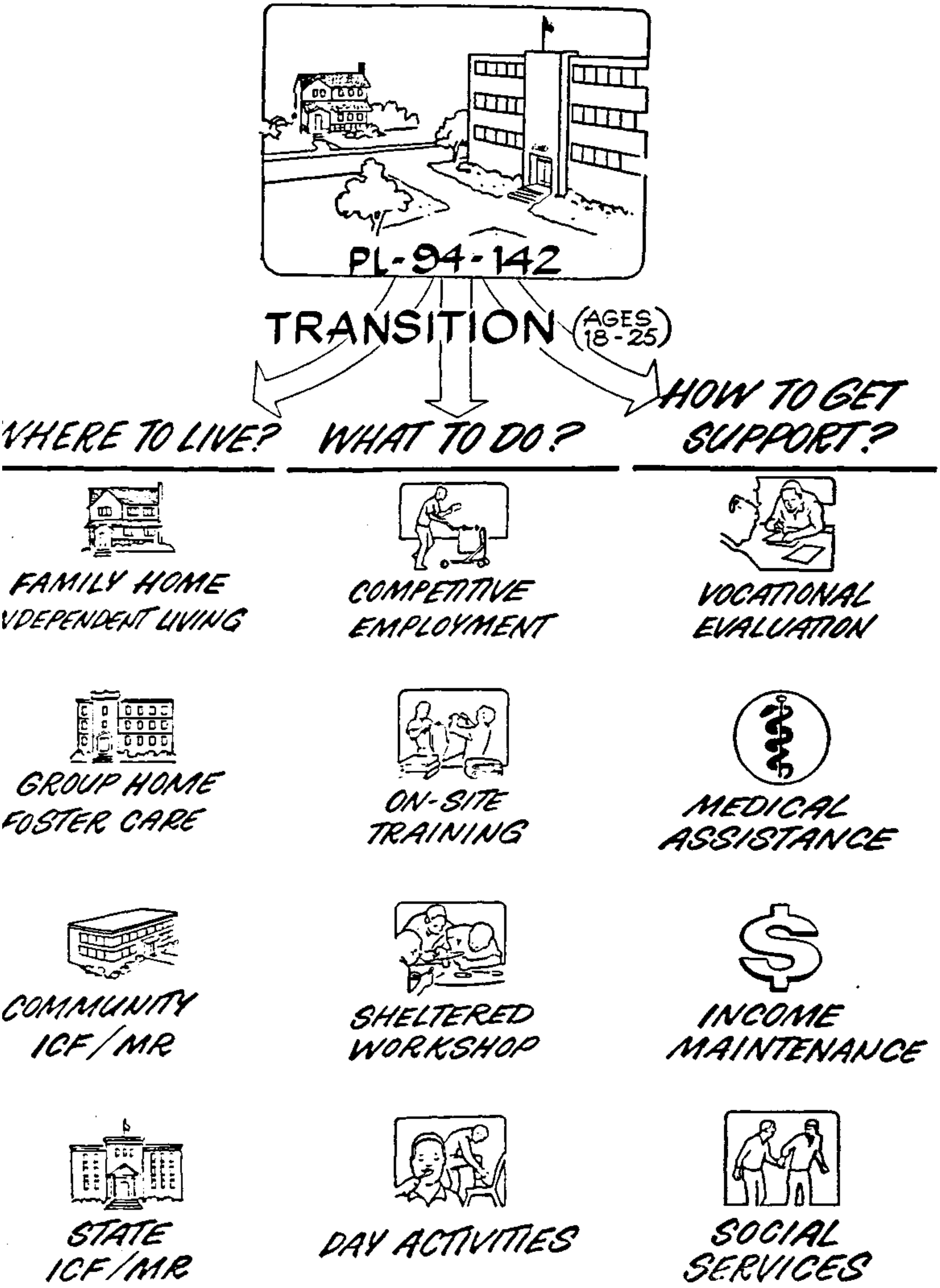
Increasing numbers of parents are asking not only "where can I place my child?" but "what is the best and fullest life that my child can live?" Quality services and individualized packages of services are more and more in demand. In this context, some of their concern about transition issues reflects society's progress in serving the developmentally disabled because parents are not willing to settle for just any service.

B. Adult Service Delivery System

The adult service delivery system which DD young adults and their parents must confront at the time of transition is complex, diffuse and often uncoordinated. There continue to be gaps in the availability of necessary and appropriate services, with waiting lists for many services that are in place. Although the outreach efforts of service providers vary considerably, parents still have the primary responsibility to seek out appropriate alternatives and negotiate their children's eligibility. As one respondent put it, "Its up to the parents to go shag for services".

It is estimated that almost 80% of the DD population live at home but many of these are school aged children and young adults under 21. As DD young adults grow older, parents seek alternative living arrangements, day activities or work opportunities and appropriate support activities such as income maintenance (SSI/SSDI), medical assistance (Medicaid), case management, transportation, etc. (See Figure 1 on next page.) Options for living arrangements include

FIGURE 1


PL-94-142
TRANSITION (AGES 18-25)
VHERE TO LIVE?
WHAT TO DO?
HOW TO GET SUPPORT?
FAMILY HOME
VDEPENDENT LIVING
COMPETITIVE EMPLOYMENT
VOCATIONAL EVALUATION
GROUP HOME
FOSTER CARE
ON-SITE TRAINING
MEDICAL ASSISTANCE
COMMUNITY ICF/MR
SHELTERED WORKSHOP
INCOME MAINTENANCE
STATE ICF/MR
DAY ACTIVITIES
SOCIAL SERVICES

staying at home, semi-independent living, group homes, adult foster care, nursing homes, ICF/MRs and state institutions. Day and work activities include achievement centers, sheltered workshops, on site training, and competitive employment. Under optimal conditions, a tailor-made package of living arrangements, day and work activities and support services is put together by a parent or local agency case manager. But where services are lacking or parents do not have full knowledge about available options, the outcome may be less satisfactory.

Overall comments made about this intertwined package of where to live, what to do, and how to obtain support services included:

tony respondents in the study observed that DD clients are often evaluated and classified into the eligibility categories of available programs instead of receiving a package of services appropriate to meet their individual and particular needs.

Vocational Rehabilitation programs constitute the largest potential source of evaluation services. Comments on these services varied considerably from severe criticism (e.g., employability criteria) to praise for some recent innovative practices.

There is often competition for available services between young adults who have lived at home and persons being discharged from state institutions. Some state agencies put pressure on providers to serve the deinstitutionalized clients first.

Developmentally disabled young adults with emotional and behavior problems are reported to be the most difficult to serve.

Parents seeking a richer, more independent life for their grown children sometimes must make serious, difficult choices between independence and longer term security for their DD child. This choice is made necessary because some of the most innovative, integrated service delivery programs do not have the assured funding base provided to established institutions or Intermediate Care Facilities for the Mentally Retarded (ICF/MRs).

Examples of Program Models

States and communities are attempting to address the interrelated issues of transition and adult services in varying ways. Particular solutions depend on such factors as available financial resources, general social philosophy, existence of local centers of innovation and expertise, and strength of local advocacy or parents organizations. While an innovative approach which works well in one situation may not be appropriate or acceptable to people in another, it is possible to identify some program models which respondents consider worthy of replication. A brief overview of a few of these programs (discussed at further length in Appendix 1) illustrates the range of approaches which have been adopted to deal with the transition from school and the adult service delivery system.

Transition from School

Several programs are focusing directly on transition mechanisms and are experimenting with ways to improve the link between high school and adult services.

> In the Lane County, Oregon, Transition Project, an individual affiliated with the University of Oregon serves clients from age 16 on, meeting with parents, attending IEP staff meetings, and providing parents with a transition manual. At the beginning of the final school year, the parents, school, and transition project participants complete a comprehensive transition plan.
>
> In the Utica, New York, vocational Occupational Rehabilitation in Special Education (VORSE) project, a Vocational Rehabilitation counselor works in each special education district to a) develop a vocational plan for each child and b) provide summer work experience through CETA (now the Job Training Partnership Act). VORSE, run and operated by the District Office of the State Office of Vocational Rehabilitation, is able to habilitate and place these clients at a cost of $1,200 per job placement, while traditional VR placements are costing $2,000 each.
>
> The Madison, Wisconsin, school district employs a transition teacher and several vocational teachers to facilitate the transition of moderately and severely handicapped students directly from school into non-sheltered work- The schools work closely with Vocational Educational Alternatives (VEA), a habilitation/rehabilitation agency which arranges or provides training, placement, job supervision and other support services at integrated community work sites. Between 1971 and 1978 only one of the schools' 53 severely handicapped graduates went on to a nonsheltered workday environment. As a result of the transition and VEA programs, 35 of the 50 leaving school between 1979 and 1983 have been placed in nonsheltered situations. This turnaround has important cost implications. As of January 1983, it cost $5,251 a year to maintain a Madison School District graduate in a sheltered environment, but only $1,681 ($2,203 if one corrects for the somewhat shorter work-day) under the nonsheltered alternative.

In other cases, partly as a result of the deinstitutionalization movement, states are taking greater responsibility for providing a more comprehensive approach to transition from schools. This sometimes includes some continuing responsibility for system-wide coordination and case management even after the young adult enters the adult service delivery system.

California has established a statewide network of 21 Regional Centers, funded almost entirely from state money, which provide a single point of entry to the adult service system, The centers provide an extensive array of mandated services including social development centers, respite care, recreation programs and workshops. Stress is placed on independent living arrangements and case management. Formal arrangements exist between the Centers and the public schools to ensure transition of the DD young adult, and school IEPs become the first step in further planning for the DD client.

New Jersey has a statewide, state/school-financed day program for school age severely and profoundly mentally retarded children and an adult training program for anyone judged unemployable by VR. Currently they serve 1,000 children and 2,300 adults and have a large fleet of buses to get persons to and from these programs. Every child in day training automatically moves into the adult program, thus assuring that at least for this group there is no loss of service at age 21. In addition, because there is a working relationship between school districts and DMR, school officials have a mechanism for referring any educable or trainable mentally retarded child who does not fit VR employability criteria.

North Dakota had at one time one of the highest rates of institutionalization in the United States. As the result of a court order which required drastic changes in the numbers of persons in institutions, the state increased funding for community based services from $500,000 to $10 million in one year. In order to rationally implement an accelerated program to build facilities and increase local services, a planning process was started involving representatives of Vocational Rehabilitation, Vocational Education, DD, Department of Education and others. A centralized case management system was implemented to monitor and track DD clients leaving state institutions and those in the public schools.

B. Adult Services

Even the best transition program is inadequate if appropriate adult services are unavailable in the community. As noted earlier, parents increasingly are seeking not simply a transition mechanism but a package of adult services comparable in quality to the services provided under P.L. 94-142. Their search is complicated by the fact that service providers and other professionals in the field are still debating what an appropriate coordinated set of services for the , developmentally disabled should look like.

In a number of places around the country, cost effective, usually smaller, programs are emerging which offer alternatives to the traditional service delivery system or which seek, in interesting ways, to make the traditional system work better. These programs place heavy emphasis on independent or semi-independent living, community integration, maximum use of generic services, on the job training and competitive employment. Much of their effort is based on the philosophy of moving the client into the real world, rather than building a sheltered environment, filling it up and building another. Although not all DD clients are able to take full advantage of these opportunities for independence, these programs have a record of often accepting clients others have refused and moving them to levels of achievement that are beyond previous expectations.

In Minnesota there are over 313 community based ICF/MRs, almost all of which have fewer than 15 beds. Residents are encouraged to receive habilitation and other services in Developmental Achievement Centers during the day, rather that having all services provided at the ICF/MR. The average per diem cost at an ICF/MR here is about $67 as compared with $110 at a state hospital. State policy makers are also seeking to reduce cost further and improve community integration by applying for a Medicaid waiver to provide additional semi-independent living services, supervised living arrangements, developmental training homes and in-home family services to persons who would otherwise be placed in an institution. As part of the waiver proposal, the state will seek to limit inappropriate increased demand by targeting a specific number of persons to be served and using objective screening mechanisms to choose these clients.

Options in Community Living, an apartment living and support program in Madison, Wisconsin, helps developmentally disabled clients find an apartment, locate a roommate, move in, and learn to function as independently as possible in this environment. It then finds or provides whatever support services are deemed necessary. While the costs per client vary considerably, the average client cost is $240 a month per person. A client receiving $400 a month in SSI and $240 in Options services would be costing only $640 a month in public money, at a time when small group home placements in Madison are costing $750 to $800 a month (including SSI).

The Boston Center for Independent Living, a private non-profit agency, provides training in health maintenance skills, independent living skills and transition living. At an average cost of $112 per month, the program helps developmentally disabled adults live independently, thereby avoiding more costly alternative arrangements such as group homes or ICF/MRs. With the help of funding from the Administration on Developmental Disabilities of HHS, BCIL is planning a new service, Environmental Support Assistance, to help 12 clients stay in their homes and avoid institutionalization.

The Macomb-Oakland Regional Center (MORC) in Mt. Clemens, an agency of the Michigan Department of Mental Health, has been described as "the institution that became a community system." MORC serves 90% of its 900 clients - most of whom were previously institutionalized - through group homes, foster homes, or semi-independent living situations. By dispersing clients into group homes ($80-$100 per day versus $150 per day in an ICF/MR) and other less costly residential alternatives, MORC provides a more "normalized" environment at a considerably lower public cost.

The Eugene, Oregon, Supportive Employment - Specialized Training Program provides paid, long-term community-based structured employment in electronics, electrical and mechanical benchwork assemblies for severely and profoundly retarded adults. This model STP program, in operation 10 years, has been replicated 14 times in 4 states. A 1980 study of five STP's showed that participants were earning an average of $1.93 an hour, while their counterparts in work activity centers and sheltered workshops earned $.43 and $.58 respectively.

Using the supported work methodology and demonstration funding from the Manpower Research and Development Corporation, the Vera Institute of Justice "Job Path" in New York City seeks to move developmentally disabled young adults from sheltered workshops to competitive employment. The project uses two "account executives" to identify and develop job sites, often with the assistance of a Business-Labor Advisory Council. Then training consultants work with the trainee and on-site supervisor to introduce the trainee to the job. The average training period is about six months and costs $8,000 to $10,000. After one year 70% of Vera trainees were still employed and 83% of those placements were in private sector jobs.

Transition I and II in Barre and Burlington, Vermont are competitive employment projects for the severely handicapped who are mentally retarded and have at least one other disability. Funded by ED/RSA as a 3 year demonstration project, they identify job opportunities, break the job down into its essential components, and then conduct on-the-job training, at a total cost of $7,000 per placement. Over a three-year period, this $7,000 compares favorably with the $15,000 costs of a traditional day/work activity program. Approximately 65% of the placements from Transition Projects will still be on the job three years later, compared with 41.5% of severely disabled RSA Vocational Rehabilitation clients.

Bay State Skills Corp. (BSSC) is a quasi-public state-funded corporation in Boston that awards grants to educational institutions which link up with one or more private firms and, since 1981, jointly train people for jobs in high growth fields. With an initial grant of $500,000 from the state, BSSC began "Supported Work for the Mentally Retarded" — a program providing mentally retarded adults with work in a structured private-sector work environment to develop their skills and work habits to the point where they can work independently in unsubsidized jobs. At a cost of $5,000 per client, the program trains and places clients into competitive employment.

Estimated Federal and State Expenditures for the Developmentally Disabled (See Table 1 and Figure 2)

The combined Federal and state expenditures for services to the developmentally disabled are estimated to be $14.33 billion. Federal expenditures are $6.93 billion (48%) and state expenditures are **$7-40** billion (52%).

The Department of Education administers school programs for DD children with a Federal cost of $200 million and vocational rehabilitation services programs for DD adults with a federal cost of $110 million (together, 5% of all Federal DD costs).

The Department of Health and Human Services administer programs with a Federal cost of $6.62 billion (95% of all Federal DD costs):

HCFA

The Health Care Financing Administration has the largest share of Federal programs serving the developmentally disabled with a total cost of $3.63 billion (52% of all Federal DD costs).

Institutional costs for DD clients constitute 40% of all Federal DD costs while serving only 6% of the DD population. Average state costs for ICF/MRs range from $24 to $167 per day or $8,760 to $60,955 per year.

Most respondents felt that many of the DD clients now placed in expensive institutional care could be served more appropriately in less costly and less restrictive settings, and that a portion of the growing ICF/MR budget should be diverted to alternative levels of care.

Litigation and voluntary efforts aimed at deinstitutionalization are expected to continue to reduce the number of persons in large state institutions. This in turn will put a greater demand on adult service agencies in the community, particularly ICF/MRs.

Under the Omnibus Budget Reconciliation Act of 1981, states now have some authority to develop alternative home and community based service systems for DD clients who would otherwise be placed in institutions. As of October 20, 1983, 31 states had filed a total of

46 multi-purpose or MR/DD waivers, of which 24 had been approved. During the states' third year of using the waiver, states report they will be serving 9,044 ED people at an estimated average cost of $16,500 per annum not including SSI or non-institutional medical costs.

SSA

The Social Security Administration administers income maintenance programs (SSI, SSDI) which amount to $2.3 billion (33% of Federal DP costs).

SSI and SSDI, coupled with Medicaid, food stamps. Title XX and state prograimatic funds, provide the basic means of support for DD clients living at home, independently, in adult foster care, group homes and other non-institutional environments.In a state with a well developed service system the total cost ranges between $22 and $40 per day, or S8,030 to $14,600 per year.

Roughly 30% of the DD population (1.1 million out of 3.7 million) receives SSI/SSDI, which constitutes 33% of federal DD costs.

OHDS

The Office of Human Development Services administers programs for the developmentally disabled with a cost of $619 million (9% of Federal DD costs). Included in OHDS programs are Title XX, $500 million; the DD Program, $62 million; AFDC/Foster Care, $50 million; and Head Start (for DD children), $7 million.

OHDS programs provide the Department's primary impetus toward the development and maintenance of community based services. States have used Title XX and DD funds, along with local contributions, to support day activities, case management, respite care, planning, advocacy and other services. AFDC/Foster care funds are used to maintain DD children in family settings outside their natural homes.

To the extent that agencies and programs (outside the education establishment) supported by Federal funds are thinking about the issue of transition, it is OHDS money that in part supports them.

PHS

The Public Health Service administers programs with a cost of $67 million (1% of federal DD costs). This primarily goes for such services as PKU screening, lead content screening and crippled childrens' services provided under the Maternal and Child Health Services Block Grant.

Table 1

Developmental Disabilities Services

Estimated Costs in Millions

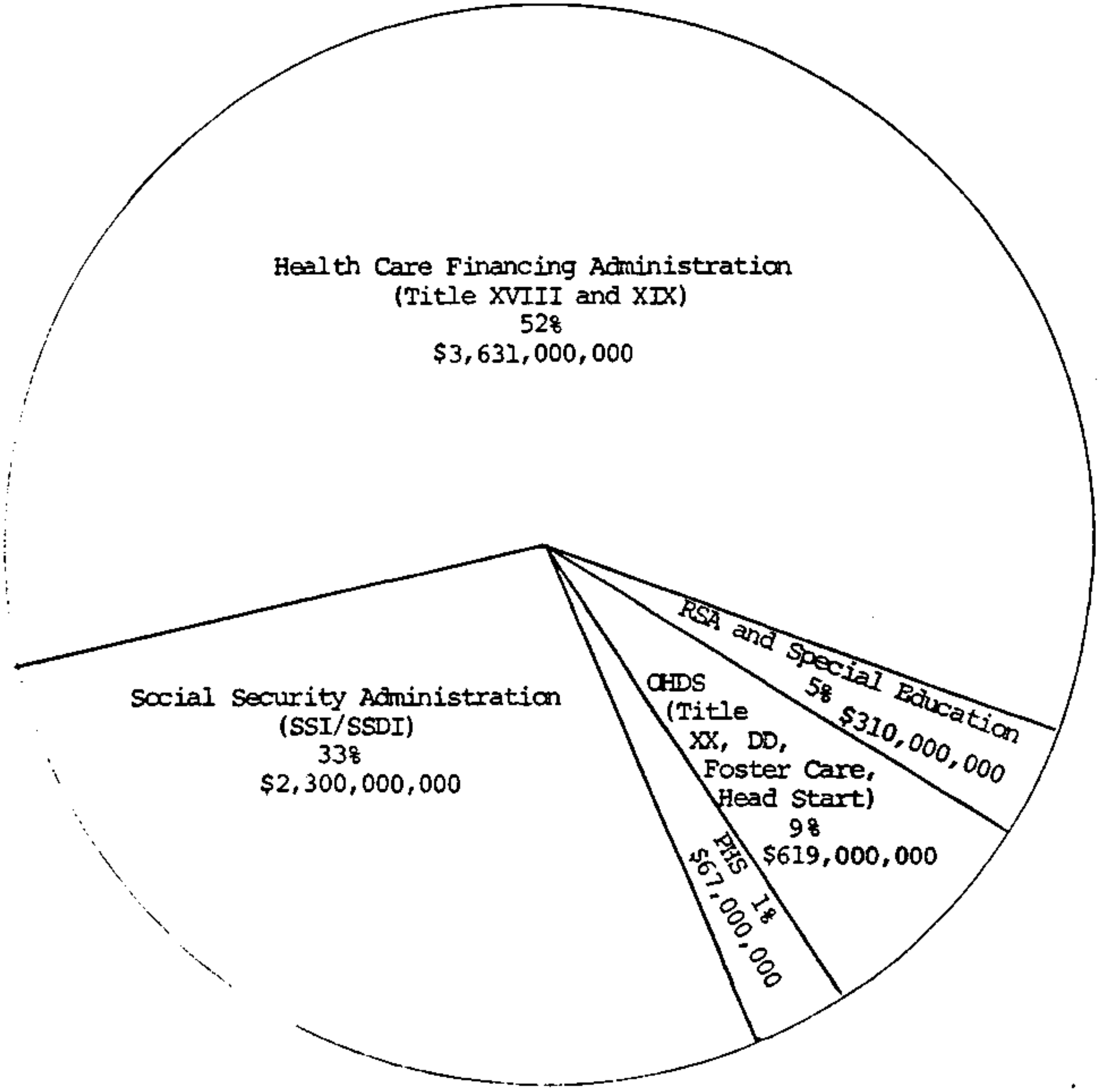
Program	Federal	- State & Local	Total
DHHS			
HCFA			
SNF, ICF,	$ 790	$ 640	$ 1,430
ICF/MR	1,990	1,620	3,610
Non-Institutional MA	701	574	1,275
Medicare	150	0	150
(Total HCFA)	(3,631)	(2,834)	(6,465)
SSA			
SSI, SSDI	2,300	530	2,880
(Total SSA)	(2,300)	(530)	(2,880)
OHDS			
Title XX	500	300	800
DD	62	14	76
AFDC/Foster Care	50	130	180
Head Start	7	0	7
(Total OHDS)	(619)	(444)	(1,063)
PHS			
PHS	67	7	74
(Total PHS)	(67)	(7)	(74)
TOTAL DHHS	$6,617	$3,865	$10,482
ED			
RSA	110	35	145
Special Education	200	1,400	1,600
TOTAL ED	$310	$1,435	$1,745
Other			
Community MR	0	1,200	1,200
State Institutional	0	900	900
TOTAL OTHER	0	$2,100	$ 2,100
TOTAL	$6,927	$7,400	$14,327

NOTE: These figures are derived from the latest FY data available. They do not include costs for HUD Section 8 or 202 programs, food stamps, Targeted Job Tax Credits or Job Training Partnership Act (formerly CETA) programs.

FIGURE 2

Estimated Annual Federal Expenditures For DP Services

$6,927,000,000



VI. Cost Implications

The debate now taking place regarding the make up of an appropriate community based DD service delivery system has cost as well as quality implications. It is expected that parents of DD young adults leaving the public schools will continue to make increased demands for appropriate services. But questions remain regarding where to find the money to fund these services. SSI/SSDI and Medicaid are the only entitlement funds available for non-institutionalized DD adults. The cost of additional programs to support these clients (such as day activities, workshops, rehabilitation, case management, respite care, etc.) come primarily from Title XX, Vocational Rehabilitation and other state and local grants. But major increases in these sources are not expected. In addition, the total cost of institutional care in ICF/MRs continues to increase, growing from $602 million in 1976 to over $3.6 billion today. This also places a strain on the ability of many states to put additional funds into non-institutional care.

There are two emerging approaches to the financing and delivery of adult DD services that may help alleviate this situation:

> Increased reliance on smaller community based ICF/MRs and on home and community based care allowed by the Medicaid waiver provisions.
>
> Historically, large state institutions were the primary source of care for the developmentally disabled. Over the last 20 years, the number and proportion of DD clients living in these facilities has steadily declined and there are pressures to reduce this occupancy futher. Many of the people leaving these institutions were moved to community located ICF/MRs. Although somewhat smaller in size, these facilities continued to treat residents as patients according to a medical model of care. HCFA (which administers the ICF/MR program) has issued regulations which some feel have reinforced the medical model approach and kept costs fairly high. Some states have tried to modify this situation by using Medicaid ICF/MR funds to purchase some services for residents in locations outside the actual facility.
>
> A little less than half of the DD persons in private ICF/MRs now live in facilities of 15 beds or less. Advocacy groups and others believe that significant cost savings can be achieved if DD persons leaving state insitituions and many of those in larger private facilities are placed in smaller community based institutions. They support the proposed "Community and Family Living Amendments of 1983" which would, over time, limit the payment of Medicaid ICF/MR and SNF funds to care provided in smaller facilities. Even if this proposed legislation is not passed, these groups will continue to pressure states to make increasing use of smaller ICF/MRs, and to take full advantage of the Medicaid waiver provisions.

The waiver provisions of the Omnibus Reconciliation Act of 1981, which gave states the option of providing alternative home and community based services to DD clients, are beginning to have some impact. Although the numbers of persons now served are relatively small, and include mainly persons being discharged from state facilities, the waivered services provide examples of alternate approaches which can be made available to DD young adults leaving school. In addition, they provide a funding source to begin to build up resources in communities where they have previously been lacking. The actual results of these waiver actions have not yet been well publicized. While most respondents saw these provisions as a good first step in redesigning the service delivery system, others were concerned about the implied temporary nature of a "waiver" and saw the need for the Federal government to make a more permanent commitment to this approach.

Growing use of programs which seek to enhance the DD clients' potential for independent living and competitive work.

The innovative special programs, discussed above and in more detail in Appendix 1, can be viewed as alternatives to the more traditional model which places emphasis on the building and operation of segregated special purpose programs. The advocates of these newer approaches maintain that, in many cases, they can provide better services at less expense by working to place the DD client in already available private living and work environments. Projected cost savings would come from the limited capital investment required to start these programs, the absorption of overhead by already existing organizations, and the expectation that many DD young adults, previously thought unemployable, can eventually attain competitive employment. By placing more persons in these situations, slots can be opened in existing service programs for those clients truly needing a sheltered environment.

There are a number of current Federal incentives which have the potential to encourage or support these approaches. (See Appendix 2 for a fuller description of Federal programs affecting the developmentally disabled.)

> In some places, Vocational Rehabilitation agencies are beginning to give additional consideration to expanded use of on-site training and habilitation for DD clients.
>
> The Department of Labor administers several programs to provide incentives to industry to train and employ handicapped workers, including the Job Training Partnership Act and the Targeted Jobs Tax Credit program.

The Social Security Administration has authority under Section 505. of the Social Security Disability Amendments of 1980, P.L. 96-265, to develop and carry out experimental projects to determine more effective ways of encouraging SSI and SSDI beneficiaries (including the developmentally disabled) to return to work.

In addition, Section 1619 of the Social Security Act contains provisions for extending Medicaid eligibility for persons no longer receiving SSI benefits, if losing coverage would seriously inhibit continuing employment or if earnings are not great enough to provide a reasonable equivalent of SSI and Medicaid. This availability of Medicaid coverage is particularly important to the DD client because of the frequent incidence of associated medical problems which require adequate health insurance.

Finally, the mainstreaming of adult DD clients requires that all Federal and state generic service programs be truly open to these persons so that they get a full and equal share of the benefits for which they are eligible.

APPENDIX 1

PROGRAM MODELS

Transition Project
Lane County, Oregon, School System

An individual affiliated with the University of Oregon is under contract with the county school district to assist parents of developmentally disabled students with transition plans. Clients are served from age 16 on. While schools are not legally obligated to continue this service beyond age 21, the transition advisor continues to assist program graduates past this age when necessary because Adult Services does not perform this function.

This transition counselor meets with parents at the beginning of each school year (in the home, if necessary), attends Individualized Education Program (IEP) staff meetings, provides parents with a transition manual, and encourages parents to join advocacy groups in order to lobby fox appropriate adult services.

At the beginning of the final school year, the parents, school and transition project participants complete a comprehensive transition plan delineating time lines and assigning responsibility for assuring income support, vocational and residential placement, leisure activity, transportation, medicine, guardianship, long-term care, insurance, and maintenance of family relationships for the young adult.

Vocational Occupational Rehabilitation in Special Education (VORSE)
New York state Office of Vocational Rehabilitation - Utica Office

Vocational Occupational Rehabilitation in Special Education (VORSE) is a demonstration project originally funded by ED/RSA to facilitate the transition of mentally retarded students from high school into competitive employment. It combines VR, vocational education, and special education by putting a VR counselor in each of the BOCES (special multi-county school districts) to develop a vocational plan for each child in special education. They begin planning by age 16 and make the Individual Written Rehabilitation Plan (IWRP) a link to the Individualized Education Program (IEP). Another important component is the summer job experience made possible through CETA (now Job Training Partnership Act). During the summer of 1981, 339 disabled youths were employed, and 156 of these received on-the-job training through "job coach" instructions. As of October 1, 1983, VORSE is fully funded by OVR as a normal component of the Utica office.

VORSE is able to habilitate and place these clients at a cost of $1,200 per job placement, while traditional VR placements are costing $2,000 each.

Madison, Wisconsin School District and Vocational Education Alternatives

For the past three years, the Madison, Wisconsin, school system has employed a transition teacher and several vocational teachers to facilitate the transition of moderately and severely handicapped students from the Madison school system into nonsheltered work.

By the final year of school, most students are at the training site (potentially their post-school work site) on a full-time basis, often on a paid basis. During this final year of school, the vocational teachers and transition teacher work closely with Vocational Education Alternatives (VEA), a new (1980) type of vocational habilitation/rehabilitation agency funded by the County Unified Services Board which in turn receives state and Title XX money. VEA arranges or provides training, placement, job supervision and other support services at integrated community work sites. Although the school's legal responsibilities end when the student leaves school in June, the schools have been paying transition teacher salaries during the summer so they can work with VEA during the student's first few months out of school.

While only one of the school's 53 severely handicapped 1971 - 1978 graduates went on to a nonsheltered workday environment, 35 of the 50 leaving school between 1979 and 1983 have been placed in nonsheltered situations. This turnaround has important cost implications. As of January, 1983, it cost $5,251 a year to maintain a Madison School District graduate in a sheltered environment, but only $1,681 ($2,203 if one corrects for the somewhat shorter work-day) under the nonsheltered alternative.

Options in Community Living Madison, Wisconsin

Options in Community Living is an apartment living and support program for developmentally disabled adults wishing independent or semi-independent community living arrangements. Since 1974, the program has grown to serve 95 clients (77 with a primary or secondary MR diagnosis ranging from mild to severe) in apartments rented on the open market and scattered throughout the city. Options staff help the client find an apartment, locate a roommate, move in, learn to operate the appliances, etc., and then find or provide whatever support services are deemed necessary. This package varies considerably over time and from client to client.

While the costs per client also vary considerably, the average client cost is $240 a month per person, paid by the county's Unified Services Board. A client receiving $400 a month in SSI and $240 in Options services would be costing only $640 a month in public money, at a time when small group home placements in Madison are costing $750 to $800 a month (including SSI).