Toward Opportunity

Commission on Independent Living Report

January 1987

Dear Members of the Maine Legislature:

I am pleased to provide you with *"Toward Opportunity,"* a report of vital importance to Maine's disabled citizens recently completed by the Independent Living Commission. *"Toward Opportunity"* embodies a series of new initiatives which, if implemented collectively, will assist these citizens throughout Maine. Each of the seven initiatives is designed to enhance the individual's ability to live independently in the community and become as self sufficient as possible.

Through a series of interviews with experts in the field and a 2-day think tank, the Commission has learned that presently many assistance programs overemphasize income support and underemphasize initiative for equal opportunity. It has become clearly evident through the Commission's research that a substantial amount of the financial resources currently being expended on behalf of disabled citizens are being channelled into institutional environments.

Rather than attempt to reverse or solve every problem confronting disabled citizens, Commission members agreed to make a limited number of policy recommendations that would increase independent living opportunities. These recommendations are tailored to assist disabled citizens in achieving integrated employment at levels their abilities will allow. Given the state's current labor shortage and accelerating economic growth, the time is right to tap this valuable resource of potentially productive disabled citizens.

Purpose of the Commission

The State Legislature created the Maine Commission on the Role of State Government in Providing Independent Living Opportunities and Services to Persons With Disabilities (hereafter referred to as the Commission) in 1985. The Commission's charge was to:

> "examine the entire range of services provided to persons with disabilites in this State, explore possible new opportunities to promote independent living by persons with disabilities, and, based upon its findings, establish priorities and recommendations for legislative action with particular attention to the following areas:

1. How independent living opportunities for citizens with disabilities can be expanded and enhanced at little or no cost to taxpayers;

2. How financial resources currently available to the State for providing services to persons with disabilities may be redistributed so that programs which foster self-determination, independent living and economic productivity can be maximized, as well as become more flexible to meet changing individual needs;

3. How combined private and public sector initiatives can stimulate economic development through the creation of independent living opportunities that focus on removing financial disincentives to citizens with disabilities in this State and thus reduce long-term tax supported dependency; and

4. How the various roles of State Government, private rehabilitation service agencies and consumer advocacy groups can be defined, clarified or modified to provide the most appropriate assistance and support without duplication or conflict while developing a true partnership."

I believe it is truly noteworthy that the majority of Commission members represents a wide range of disabilities. This composition is responsible for the Commission's recommendations which are sensitive to the individual needs of disabled citizens. In contrast to earlier federal disability initiatives which were highly categorical, these recommendations have less restrictive eligibility criteria. The extraordinary costs associated with independent living require the development of innovative resources which are responsive to the individual's desire to contribute and basic need to exercise control over his destiny. These recommendations are based on that philosophy.

In closing, the Independent Living Commission is recommending that these policy initiatives, all of which require legislative action, be introduced in the 113th legislative session through omnibus legislation entitled:

> "An Act to Promote the Creation and Expansion of Independent Living Opportunities for Maine's Citizens With Disabilities."

I hope you will assist us in passing this very important legislation.

Sincerely,

Steve Tremblay

Steven C. Tremblay, Chair
Independent Living Commission

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The Population with Disabilities

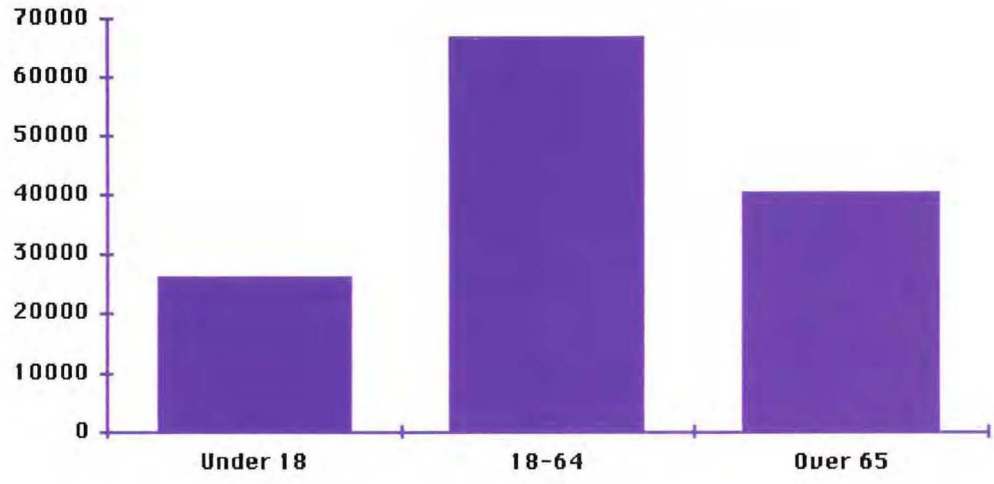
Various estimates place the number of Maine citizens with disabilities between 100,000 and 150,000 persons. A precise and reliable overall figure is not currently available due to different operational definitions of disability, divergent sources of data, and inconsistent survey methodologies, which together make it impossible to aggregate much of the data that are available.

Most existing studies of the disabled population employ one of two major approaches, each of which has its own shortcomings and limitations. The health conditions approach usually tends to produce very large numbers of "disabilities," because of the inclusion of individuals with health problems that would not normally result in their classification as disabled or handicapped. These figures include large numbers of various types of circulatory conditions, respiratory conditions, digestive conditions and skin and musculoskeletal conditions, not typically categorized as disabilities. Because of its focus on the medically oriented notions of health, the health conditions approach also does not provide adequate data on such conditions as learning disabilities and mental conditions.

The other major approach to disability data — the work disability approach — is also problematic. Such studies focus on individuals' reports that they have a condition that prevents them from working or limits their ability to work. These studies have their own shortcomings, however. They underestimate the numbers of people at lower age ranges — the 16 to 24 age group, for example — some of whom are not ready to join the work force and for whom the self-identification as either work disabled or not is often meaningless. They also skew the population counted. Persons who are out of work or who are not seeking work have psychological motives for reporting themselves as having a work disability, whether or not they truly have a disability. Independent disabled persons with a strong work history and who are currently employed, on the other hand, will often refuse to categorize themselves as having a work disability, even if they have a significant disabling condition such as blindness or paralysis. For these reasons, work disability studies tend to underestimate the total number of people with disabilities, and to overestimate the unemployment and nonparticipation in the labor force rates of people with disabilities.

The most reliable estimates on disability in Maine available are obtained from a variety of sources including the 1980 Census of Population, the National Center for Health Statistics, the 1981-85 Annual Report of the U.S. Education Department and the 1984 Report on Disability published by the Mathematica Policy Research Institute. These sources shed the following information:

Total Maine Population: 1.1 million
# of Persons with Disabilities: 134,059 (11.6%)



Number of 18-64 year olds with disabilities in Maine:
66,850 or 10.3% of all 18-64 year olds in the State

* (40,679 over 65 disabled persons, or 25% of the 160,583 senior citizens in the State as of 1980.)

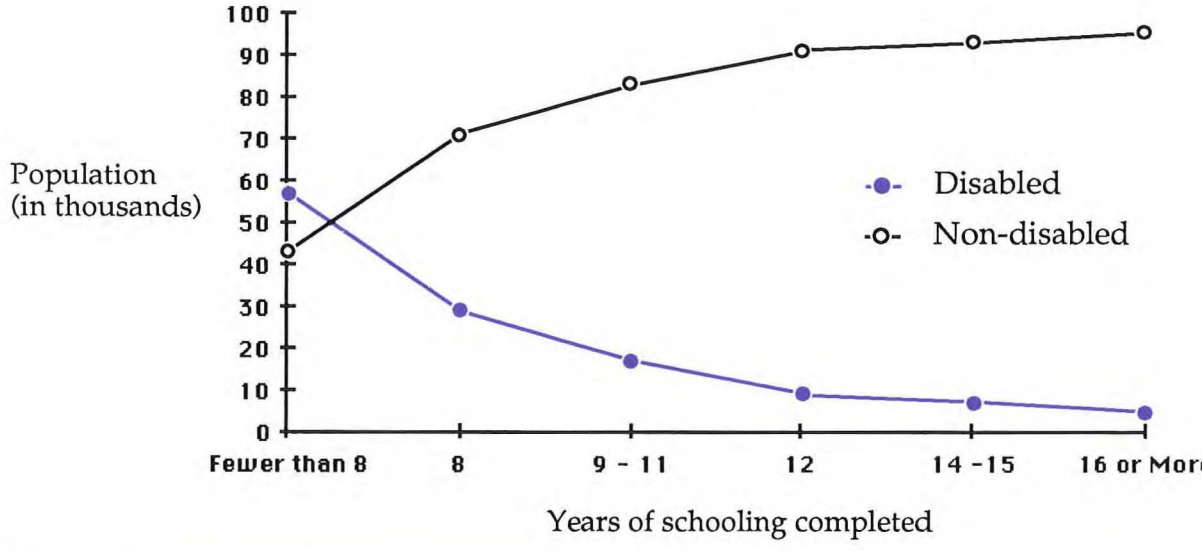
A relatively small group of Maine citizens under 18 years of age is disabled. Of these 307,000 residents, about 8.69 % or 26,440, are handicapped according to the State education agency. There is a discrepancy here. We expected 4% of school attendees to be disabled, not 8.6%. The underlying reason for this discrepancy is that the State education agency counts as disabled children with learning disabilities who are unlikely to be disabled when it comes to work. In other words, the definitions are different.

Census figures also indicate some correlation between work disability and poverty. Of persons of working age reporting the presence of a working disability, 20.1% or one in every five have family incomes that are below the Federal poverty threshold. This is more than double the 9.1% rate of the general population which has a family income below the poverty line.

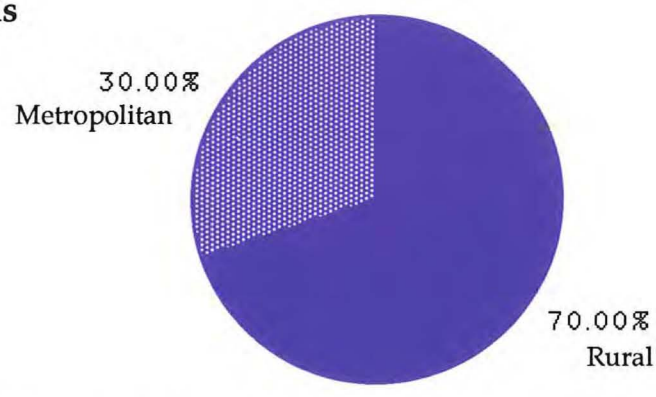
Education Attainment of Maine 18-64 Year Olds Who Are Disabled

Total #; 66,850

Years Completed	*Number*	*Percent*
Fewer than 8	8,676	13.0
8	9,651	14.4
9-11	13,940	20.9
12	23,324	34.9
14-15	7,366	11.0
16 or more	3,893	5.8
	66,850	100



Geographical Distribution of Maine 18-64 Year Olds Who Are Disabled



Only 30% of all disabled 18-64 year olds live in metropolitan areas like Bangor or Portland; 70% live in rural areas.

Introduction to Case Studies

The statistics and data presented in this report are helpful in gaining a general understanding of the population with disabilities in Maine and the nation. However, a distancing occurs when decisions are made based primarily on numbers. The human element recedes into the background. Our concern is for real people with disabilities. The following case studies highlight the statistics in a very personal way.

Case Sample 1

John Doe is 18 years old, lives in Farmington and is graduating from high school in June. He is nonverbal and quadriplegic as a result of cerebral palsy. He uses a motorized wheelchair for his primary means of mobility. John's ambition is to attend USM to study accounting. He has never lived on his own or, for that matter, used Personal Care Assistance services, which are currently unavailable due to a shortage of funds. His method of communication is not functional for going to school or living independently. His family, which is of moderate means, cannot afford to purchase a more sophisticated communication device which costs about $2,500.

In spite of these obstacles, John's ambition to live independently and become employed are of paramount importance to him. Up until now his parents have been his PCA's, fulfilling his social and transportation needs by taking him on infrequent shopping expeditions. They cannot afford a wheelchair lift equipped van. He wants desperately to break away from this cycle of dependency and become self-sufficient which he knows is possible if certain resources such as PCA, adaptive equipment and accessible transportation were made available. John currently qualifies for and receives SSDI, SSI, Medicaid, special education, vocational rehabilitation services, and food stamps. He is tired and frustrated with having so many caseworkers and longs for the day he can live on his own. But, he still wonders how he will manage to find an accessible apartment, access personal assistance, afford his own lift equipped van and acquire health insurance when he becomes employed.

Case Sample 2

"A" is a 27 year old man in Augusta. He has been diagnosed both as schizophrenic and as depressed; the doctors aren't really sure, but he seems to stabilize best on a combination of antipsychotic and antidepressant medication. He is a graduate of Colby College; and before he had his breakdown, he planned to go to graduate school to study engineering. He is currently unemployed and lives in a shabby rooming house where he has a room with a hot plate, a sink and a bed. The bathroom, down the hall, is shared by another seven people. He maintains this standard of living on $350/month, paid by Social Security. He doesn't go out much because he has been assaulted twice by some young toughs that hang around his building where they come to buy and use drugs. He has also been robbed on occasion. "No big deal, really," he says, since there was so little to be taken. But the sense of violation lingers.

"A"'s recent history is very similar to the many hundreds of chronically mentally ill persons who live in this State. "A" stays at the Augusta Mental Health Institute when things get so bad that he can't take care of himself. He is usually discharged with little notice when the overcrowding on the wards gets too great. "A" once held a job with Clean Sweep, a contract labor company that employs the mentally ill. Within a year, he had worked himself up to a supervisory position. He was making so much money that he was no longer eligible for Social Security. He took pride in this, believing that he was somehow "cured" and wouldn't need it again. He was living in a full-sized apartment with a roommate — there were only four apartments in the whole building. He bought himself a 10 speed and a stereo from K-Mart. But his illness became cyclical, the voices and delusions returned, and he ended up in the hospital again. This time he was discharged at a time when Social Security was "cracking down" on eligibility requirements. It took him two years of reapplication and appeal before he finally received benefits again. He would like to work again. He knows how much it enhanced his self-esteem, but he doesn't dare take the chance of losing his Social Security. It is his safety net, so he chooses not to work.

"A" has the same needs as everyone for decent, safe, and affordable housing, for social contact, for leisure and recreation, for education, for employment. There are agencies and state programs that provide these services, but each have different requirements for entry. Some require referral by a mental health professional. All require lengthy forms, interviews about the applicant's personal life performed by strangers. For a person with a thought disorder, it is almost impossible to ferret out the different programs, go through the entire application procedure, coordinate the flow of paper work from one agency to a hospital to a case manager to another agency, ad infinitum.

The present system of care is flawed by complexity. It is extremely hard to access. There are disincentives to working in the social insurance system. Most of the housing available to mentally ill persons is substandard, low-income housing. There is not sufficient enforcement of the housing codes. There is overcrowding and the environment is often dangerous. There is no centralized information source for these people to tell them of the available resources. There is no uniformity of admissions criteria. There are no

personal service attendants to help the mentally ill build a network of services. Accessibility means accessing the system of support, not building ramps. The mentally ill need a flexible form of social security that allows them to work when they are able but to have an income when they are not.

The process of rehabilitation of the chronically mentally ill person is lengthy, with many relapses. They have the same needs as any other person, with or without a handicap. They have a right, as human beings, to have those needs met.

Commission's Policy Recommendations

1	**Create a central information system**	Impact - Assist every disabled citizen Cost - $30,000 startup funding
2	**Create a single entry point for services**	Impact - Assist every disabled citizen Cost - $35,000
3	**Create Medicaid Buy in health insurance program**	Impact - Assist 60 disabled citizens annually for 5 years to become employed or 300 persons Cost - $120,000 annually for 5 years or $600,000
4	**Create adaptive equipment loan program thru FAME**	Impact - Assist 1,000 disabled citizens at any one time Cost - $5,000,000 (Revolving Loan Fund; General Obligation Bond)
5	**Expand MSHA new housing initiatives and home accessible loan programs**	Impact - Assist 200 disabled citizens at any one time Cost - $1,000,000 (Revolving Loan Fund; Real Estate Transfer Tax)
6	**Consolidate architectural barrier laws and 504 enforcement**	Impact - Assist every disabled citizen Cost - $35,000
7	**Make comprehensive personal assistance services available**	Impact - Assist 100 disabled citizens this year and 10,000 over time Cost - $1,000,000 this year and subsequent formula based annual appropriations

Central Information System

Problem:

There is no central information system (CIS) available to citizens with disabilities resulting in their having less than comprehensive information on disability resources.

Overview:

Information and custom data services are experiencing tremendous growth and should become common tools used by a large portion of our population by the 1990's. Our lives are affected today by computer data bases, whether we realize it or not. None of us use banking services, purchase consumer goods, are admitted into a hospital or dial the telephone without being in contact with computer information systems. It is not unreasonable to forecast that computer terminals will, one day, be as accessible as pay telephones are today and that the equipment will become affordable for the general population. No investments of time and energy in this area of interest will be wasted...these investments will pay back tenfold because they are investments in people and information, not investments in computer equipment.

Computer information systems or bulletin board services represent especially powerful tools for disabled consumers and groups providing products and services to them. Some of the ways in which the information system can work for these individuals and groups are as follows:

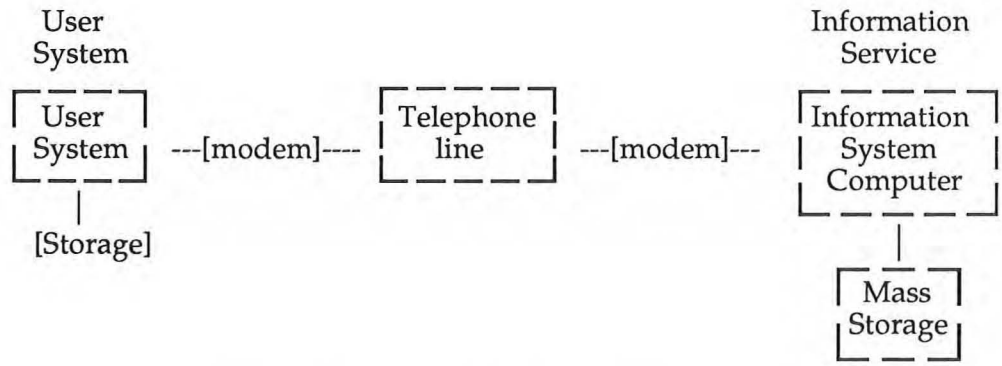
- Electronic mail
- On-line consumer assistance
- Information on adaptive equipment and medical supplies
- Updated information on accessiblity codes
- Consumer hot lines
- Accessibility listings for housing, motels, restaurants, etc.
- Resource banks or clearing house
- Direct mail order of disability products
- Equipment "for sale" board
- Personal care attendant pools
- Eligibility guidelines for services
- On-line legislation updates
- Consumer discussion forums
- On-line referrals
- On-line disability newsletters
- Direct connection of other states' Independent Living Centers
- Access to other existing data bases

How A Central Information System Would Work

The typical information system or bulletin board service (BBS) provides data that can be accessed by users. The system is usually built around the following equipment:

- Computer system
- Modem (or modems)
- Mass storage device (for data storage)
- Telecommunications software
- Telephone line (or lines)

The consumer (utilizing a computer terminal, a modem connected to a telephone line and a telecommunications program) "dials" the number of the information service and, after a series of "logging on" activities, is permitted to use utilities and acquire data stored by the information service, sometimes referred to as the "host" system. In many systems, privileged users are allowed to contribute information to the data base, creating a powerful "information sharing" environment. It is, really, the "information sharing" by users that makes the BBS so powerful and attractive to prospective users.



For instance, if a disabled consumer in Presque Isle requires certain information or data residing in a file called "user.data" on the "host" or Central Information System (for example, a listing of hotels in Portland with wheelchair accessible rooms), he would probably take the following steps:

- Turn on his computer and modem
- "Boot up" or run the modem software
- Dial the number of the service
- Log on the information system using a password
- Tell the information system to "download" the file, "user.data"
- Set his system to receive and capture the file
- Tell the information system to send (the file)
- Log off the information system (disconnecting from the phone line)

In most cases, these steps are automated, allowing the user or his or her family to use "menu selections" to accomplish the task of "downloading" the information that is required. Essentially, the same process is followed if the user is transmitting or "uploading" information. In this situation the user transmits the data as opposed to receiving it, and data is written to instead of

copied from the information system's mass storage device. All of this information transmission can be either accessed or provided by a disabled consumer using a small personal computer and modem from his or her home or apartment or office. Such a system is now available for a few hundred dollars.

Characteristics

Capable of serving a large user base; comprehensive file transfer capability and detailed data libraries. Users able to upload large files freely.

Central Information System and Cost

In general, any computer system, equipped with a modem can support an information system or bulletin board service. Systems vary with respect to speed, power, number of user connections allowed at one time and storage capability. Our experience with the disabled community indicates a medium level system would be required to support a statewide disability central information system. Such a system would include the following:

- 8 bit or 16 bit micro processor (8 to 12 mhz)
- Telecommunications (BBS) software
- Hard disk storage (40 to 80 megabytes)
- Tape backup
- 1200/2400/4800 baud modem

Policy Recommendation:

The Maine Legislature should appropriate $30,000 in start up money to establish a community based Central Information System, controlled and operated by citizens with disabilities or an organization governed by a majority of citizens with disabilities. The CIS would be maintained through revenues derived from the following sources:

- Subscriptions
- Connect time charges
- Donations
- Sponsorships
- Consulting
- Sale or user listings
- Surcharges
- Mail order services

The CIS could potentially offer assistance to every disabled citizen in Maine.

Cost: $30,000 (start-up)

Coordination Enhancement: The single entry point application system

Problem:

There are no fewer than thirty-five federally and state supported programs available to assist citizens with disabilities. The forms of assistance include income support (SSDI, SSI, etc), medical benefits (Medicare, Medicaid, etc.) and a variety of services intended to promote the individual's quality of life. However well intended this comprehensive system may seem to be, many disabled citizens do not acquire the full range of benefits they are entitled to. This is due to the many applications which must be completed, each of which has different eligibility guidelines and its own caseworker to deal with. Furthermore, the programs are administered from different physical locations requiring the applicant to have a means of transportation available if he or she is to apply on site.

In reality, the programs that should serve as path towards well being and independence, in many cases, wind up being obstacles too great for the average disabled consumer to overcome.

Overview:

As federal and state programs seek to promote independence and equal opportunities for people with disabilities, there is an important need that services and programs be coordinated. "Coordinated services" describes the ideal results of a wide range of interactions among persons active in policy and program development. Although these interactions take place every day, their purpose, frequency, and effectiveness vary greatly from community to community, state to state, and from program to program. In the Commission's public forums and through the participation of nearly one hundred disabled consumers at its Independent Living Think Tank conducted in 1986, Commission members heard from disabled people around the state who declared that many programs do not mesh well with other available services, and that too often the service delivery system exhibits gaps, inconsistencies, and inequities. It is clear, however, that there is no single or simple solution to the need for better coordinated services. The Commission believes that mechanisms should be in place throughout the service delivery system that consistently and purposefully attempt to improve the linkages among the policy makers and programs that serve disabled people. Examples of these efforts locally include the Family Services Integration Demonstration Electronic Resource Directory Project and the Select Committee on Transition's Integrated Service Projects.

Policy Recommendations:

1) The Commission recommends the creation of a single entry point application process which will enable disabled individuals to apply for the full

range of supports and services available to them from one location in their communities. The development of this process should, by requirement and design, substantively involve people with disabilities in the planning process in conjunction with department and agency representatives currently involved in administering these programs. The Governor and Maine Legislature should jointly designate one individual to be responsible for coordinating this effort and offer their support with adequate resources to accomplish this goal. Furthermore, this effort should be integrated with existing planning mechanisms such as the Developmental Disabilities Council, the Bureau of Rehabilitation's Consumer Advisory Councils and the Interdepartmental Coordinating Council. Modest costs are associated with this recommendation which should lead to improved communications, more integrated services, and better informed policy discussion. When completed, this Single Entry Point Application Process should be integrated within the Central Information System to provide disabled consumers or their families the convenience of applying for services from their homes with the aid of a personal computer.

2) The Governor and Maine Legislature should keep intact the Independent Living Commission, making funds available as needed for the purpose of examining major policy issues affecting disabled citizens. The retention of this Commission is important because it examines problems from a cross disability perspective and is independent of any one state agency. This unique composition and objective enable the Commission to advocate for the purposeful interaction of all parties involved in policy decisions that affect services to people with disabilities. The Commission pledges to maintain its information base with consumer organizations locally, statewide and around the country and to strengthen interaction on issues with policy actors, private organizations, the Legislature and the Governor.

Disspend.87 AN OVERVIEW OF DISABILITY SERVICES AND ESTIMATED SPENDING (MAINE 1987) (From 1986 Maine Human Social Services Report and other state sources.)

Department and Bureau or Program	Federal	State	Other	Total
Human Services				
Alcohol and Substance Abuse	$1,740,598	$2,479,444	$2,422,167	$6,642,209
Purchased Services				
- Services to Blind	$0	$56,000	$0	$56,000
- Services to Deaf	$0	$39,000	$0	$39,000
Bureau of Social Services				
- Handicapped Crippled Children	$823,826	$579,000	$0	$1,402,826
Bureau of Rehabilitation				
- Vocational Services	$7,878,400	$2,059,200	$530,000	$10,467,600
Special Physical Characteristics Services				
- Medical Eye Care	$0	$451,000	$0	$451,000
- Telecommunication Devices	$0	$43,556	$0	$43,556
- Personal Care Assistance	$0	$1,174,000	$0	$1,174,000
- Independent Living	$605,000	$256,850	$200,000	$1,061,850
- Hearing/Speech Impaired Services	$444,264	$111,066	$0	$555,330
- Divisions of Eye Care	$578,093	$736,070	$0	$1,314,163
Bureau of Medical Services				
- Durable Medical Equipment	$1,625,142	$$790,550	$0	$2,415,692
- Waivers for Elderly, Physically Disabled, and Mentally Retarded	$6,942,350	$2,981,758	$0	$9,924,108
	$20,637,673	$11,757,494	$3,152,167	$35,547,334

Department and Bureau or Program	Federal	State	Other	Total
Mental Health and Mental Retardation				
Bureau of Mental Health				
- Augusta Mental Health Institute	$20,122	$17,193,971	$827,717	$18,041,810
- Bangor Mental Health Institute	$43,372	$15,621,940	$177,138	$15,842,450
- Community Services	$1,329,431	$8,107,084	$0	$9,436,515
Bureau of Mental Retardation				
- Aroostook Residential Center	$0	$599,713	$683	$600,396
- Pineland Center	$9,804	$18,025,061	$102,189	$18,137,054
- Community Services	$98,000	$14,060,087	$936,000	$15,094,087
Bureau of Children With Special Needs				
- Military/Naval Chilren's Home	$0	$361,786	$0	$361,786
- Elizabeth Levinson Center	$13,490	$1,536,753	$0	$1,550,243
- Community Services	$1,394,467	$4,840,443	$0	$6,234,910
Development Disabilities Council	$309,705	$0	$0	$309,705
Alcohol and Substance Abuse	$0	$0	$154,000	$154,000
- AMHI, BMHI, & CMHI - Outpatient Community Services	$0	$0	$138,000	$138,000
	$3,218,391	$80,346,838	$2,335,727	$85,900,956
Transportation				
Elderly and Handicapped Services	$2,330,910	$400,000	$0	$2,730,910
Education and Cultural Services				
Preschool Handicapped Services	$414,955	$1,123,689	$0	$1,538,644
PL 94 - 142	$7,407,391	$0	$0	$7,407,391
State Special Education	$0	$433,412	$0	$433,412
	$7,822,346	$1,123,689	$0	$8,946,035

Department and Bureau or Program	Federal	State	Other	Total
Labor				
JPTA	$11,307,640	$0	$0	$11,307,640
Maine State Housing Authority				
Home Accessibility Loan Program	$0	$0	$250,000	$250,000
Division of Community Services				
Head Start	$0	$2,000,000	$0	$2,000,000
Social Security				
SSDI	$108,820,000	$0	$0	$108,820,000
SSI	$12,142,500	$12,142,500	$0	$24,285,000
	$120,962,500	$12,142,500	$0	$133,105,000
Grand Total Expenditure	$166,279,460	$107,770,521	$5,737,894	$279,787,875

Health Insurance

Problem:

Many persons with disabilities and chronic illness are denied affordable health insurance because of their pre-existing conditions. Many of these individuals are also unable to take advantage of employment opportunities due to Social Security regulations which deny eligibility for Medicare and Medicaid to persons with the ability to work.

Overview:

For a variety of reasons, some of which can be attributable to societal attitudes, many people with disabilities or chronic illness may find themselves without Medicaid or other health insurance. Individuals entering or returning to the competitive job market run the risk of losing their Medicare and Medicaid insurance (if dually covered) before being fully covered by employer insurance plans.

It is not just people with disabilities who are at risk because of the lack of or inadequate health insurance. In 1986 the Joint Committees on Appropriations and Financial Affairs and Human Resources of the Maine Legislature presented a report to the legislature entitled, "Health Insurance Coverage in Maine: An Analysis of the Problems, Its Effects and Potential Solutions." That report states that approximately 13-15% of the population between the ages of 18 and 64 lack health insurance coverage, hospitalization, or other basic medical services. A portion of people with disabilities are included in that figure.

The Commission commends the above mentioned report to the legislature, however, it offers the following selected findings to support its own recommendations which are specifically tailored to disabled citizens.

- Many people with disabilites do not have access to affordable and adequate health care.
- Many people with disabilities are squeezed between Social Security regulations which deny eligibility for Medicare and Medicaid to persons with the ability to work.
- Many employers (especially small employers, employers in the service sector or retail trade, low wage employers, and employers with part-time or seasonal employees) do not contribute to the health insurance coverage of their employees or their dependents.
- Standard group insurance policies do not generally cover ongoing maintenance needs such as personal attendants, prescription drugs, durable medical equipment (purchase and repair), disposable medical supplies, and occuptional or physical therapy.
- Insurance companies are not required to provide health insurance coverage to persons with physical or mental pre-existing conditions, and may reject them outright, exclude treatment for certain pre-existing conditions, or charge a higher premium which may not be affordable.
- High risk pools which are promoted by the private insurance industry have not been able to provide adequate coverage at an affordable cost to most persons with pre-existing conditions who are denied

access to private insurance.
- Many persons with disabilities are discouraged from employment because they would lack access to health care coverage, and many employed persons with disabilites are required to spend an unreasonable out-of-pocket percentage of their income for health insurance.

Policy Recommendation:

1) Create a Medicaid buy-in program to enable working disabled people to receive Medicaid coverage on a sliding fee basis. This plan would also allow Medicaid to serve as a supplemental insurance (wrap-around or Medigap Policy) when a private plan is inadequate to meet needs. The proposal would be state funded, with major offsets expected from premiums, reductions in entitlements, and increased tax revenues from those individuals who would now be able to work. This plan should also include coverage for additional health needs such as personal assistance services, hearing aid repairs and batteries, telecommunication devices for the deaf, and interpreter services related to medical visits. The program could operate within an existing delivery system (Bureau of Medical Services), rather than require the creation of a new bureaucracy.

For people who cannot be covered by existing insurance plans or mandatory pools, the Medicaid buy-in plan offers a better short-term, incremental strategy than a high risk pool. A Medicaid buy-in plan could be funded by federal and state Medicaid dollars or it could be funded by state revenues only. Wisconsin is considering a state funded pilot buy-in plan for persons with disabilities as part of its state level initiative to close the gap of the uninsured. Among the advantages of a Medicaid buy-in plan are the following:

a. Sliding fee scale maximizes participation among people who could not afford the high cost of high risk pools, thus promoting economies of scale and easing the transition from Medicaid for people on the 1619 program. (Section 1619 of the Social Security Act permits SSI recipients to continue to receive Medicaid coverage while earning above the substantial gainful activity [SGA] level of $300 per month, which originally qualified them as disabled.)

b. Administrative efficiency can be increased by using the Medicaid system for processing claims, negotiating with providers (insurers, hospitals, HMO's and specialty clinics), and purchasing in quantity for durable medical equipment, drugs, etc.

c. Comprehensive benefits modeled after Medicaid recognize ongoing maintenance needs. To avoid a Medicaid stigma that exists in certain states, it may be desirable to promote the buy-in plan as a separate program; and it may also be necessary to include services that are not covered in the regular Medicaid plan.

d. Deficit for health care expenses beyond premiums collected is financed out of federal and/or state revenues — not

assessments on insurance companies which exclude the contributions of self-insured employers.

e. Medicaid buy-in can build on approaches to managed care for other Medicaid clients. Although this is not without problems for the disabled population, the recent experience of the Urban Medical Group in Boston suggests how managed care in an Independent Living Center context can promote cost containment and continuity of care for persons with severe physical disabilities. A high risk pool has less incentive to reduce its costs by managed care because the costs are dispersed among all insurers. From the insurer's point of view, it has the added advantage of raising premiums, limiting benefits, and reducing participation in the high risk pool.

f. Unlike the high risk pool, the Medicaid buy-in creates an incentive for the state to regulate insurers and employers more aggressively to maximize cross-subsidization, discourage dumping, and to utilize managed care.

* Estimated Number of Users	- 300 (Phased in over 5 years)
* Estimated Cost	- $600,000 (Appropriated over 5 years)

* Figures extrapolated from a research project completed by The Cape Organization for Rights of the Disabled, Hyannis, MA, May 26, 1987.

2) The Maine Legislature should encourage the Health Policy Unit of USM's Human Services Development Institute, which is collaborating with the Department of Human Services on the health insurance problem in Maine, to consult with persons with disabilities who are knowledgeable about their health insurance needs and associated problems so these issues are adequately addressed in the Robert Wood Johnson Foundation managed care demonstration project.

Adaptive Equipment Loan Fund for citizens with disabilities

Problem: A variety of technological aids that enhance independence in the home, work place and other environments are unavailable to the low and middle income consumer with a disability due to the high costs of those products, lack of adequate government assistance and the fact that families struck by disability or illness have no savings for such merchandise.

Overview: Modern technology has resulted in numerous types of adaptive equipment designed to enable people with disabilities to live independently. Reduced effort driving systems, environmental control units, communication aids and roll in showers are relatively new products in the consumer marketplace. Due to the limited demand of these products, their costs are unusually high. For example, the estimated costs of some of these products are as follows:

— Van driving system and wheelchair lift for quadriplegic (does not include van price)	$15,000
— Communication aid for nonverbal individual	$4,000
— Roll in shower for individual confined to a wheelchair	$2,000
— Porch lift system or home elevator	$10,000
— Environmental control system for elderly disabled individual	$5,000

Presently, limited financial assistance is available for these products from special education funds and the Bureaus of Medical Services and Rehabilitation. The demand for this type of assistance, however, far exceeds the resources these agencies have available for these aids. There is a desire by most individuals with disabilities to pay for these products themselves if the conditions and terms of borrowing the money needed are affordable to the consumer. Such a loan program could be designed accordingly.

Program Outline of Loan Fund

Purpose

Make loans available to persons with disabilities at affordable rates and terms to acquire equipment designed to assist the borrowers in becoming independent ("adaptive equipment"). Loans should assist people with a variety of disabilities to improve their quality of life, access employment opportunities and either become or continue to be productive members of the community.

Funding

Loans will be funded from a revolving loan fund created with proceeds of a State general obligation bond in the amount of $5,000,000. Money in the fund may be used both for loans and for program expenses.

Administration

The program will be administered by a Board of Directors appointed by the Governor and confirmed by the Legislature. The Board will consist of nine members, at least five of whom must be persons with a range of disabilities. The Board shall also include an experienced consumer lender and a certified public accountant. The Board shall also include the Commissioner of Human Services or his designee and the Treasurer of State or his designee. Members other than ex officio members shall serve four year terms and shall be eligible for reappointment. Members shall be compensated for expenses only. The Board may employ an Executive Director who shall be appointed by the Governor and confirmed by the Legislature, and such staff as may be necessary to administer the program. Or, the Board may contract with a non-profit agency or the Finance Authority of Maine to assist in administration of the program, including local outreach and loan underwriting and delivery. The Board shall prepare an annual report to the Legislature detailing Board activities and fund transactions.

Loan Eligibility

Individuals, profit and non-profit corporations and partnerships will be eligible for loans provided the applicant demonstrates that the loan will assist one or more disabled persons in improving their independence or becoming more productive members of the community. The applicant must also have sufficient access to credit at affordable rates and terms and must have the ability to repay the loan. Individuals are eligible for loans of up to $30,000 for purchase of adaptive equipment for personal use. Other applicants are eligible for loans up to $100,000 for purchase of adaptive equipment for business or public use.

Loan Terms

All loans must be repaid within such terms and at such interest rates as the Board may determine appropriate in accordance with guidelines established by rule making pursuant to the Maine Administrative Procedure Act.

Policy Recommendation:

The Maine Legislature in conjunction with FAME should create a revolving loan fund of $5,000,000 with proceeds of a State general obligation bond which may be used for both loans and program expenses. This loan fund will be capable of assisting one thousand consumers on average in an ongoing manner as the loans are paid back. The importance of this new resource will become more evident as our population ages and individuals with disabilities become more independent as a result of recent new opportunities in education and independent living.

Housing

Problem:

There is an acute shortage of affordable, integrated accessible housing for Maine's citizens with disabilities resulting in barriers to independent living, education, employment and community opportunity.

Overview:

It is essential for people with disabilities to have the opportunity to improve their quality of life whenever possible and in the ways that their nondisabled counterparts do. The availability of a variety of accessible housing options is necessary to provide disabled citizens these opportunities. Yet, very few choices exist for them presently.

The U.S. Department of Housing and Urban Development made available the first accessible apartments in Maine through its 202 loan program in the early 1970's. These subsidized units were developed primarily in elderly complexes and were designed with a single bedroom according to accessibility standards that have long been replaced. Today, there are approximately 119 of these units available statewide. The Maine State Housing Authority has developed 405 additional accessible units. Outside of approximately 325 units developed in rural Maine by the Farmers Home Loan Program and a few scattered accessible apartments in the private sector, there are virtually no more housing options for the rising numbers of disabled citizens who desire to live independently in their communities.

Selected findings by the Commission reveal the following:

- There are presently 750 persons with disabilities on housing authority waiting lists statewide seeking subsidized, accessible housing. This number is expected to exceed 1,000 by 1990.
- Over 80% or 680 of the accessible apartments that are subsidized have a single bedroom, no roll in shower and are located within an elderly complex.
- Most of these units were constructed according to outdated accessibility standards that did not emphasize adaptable design resulting in their being uninhabitable by persons who use motorized wheelchairs.
- Virtually all of Maine's accessible housing stock is in the public sector and thus not available to the growing number of gainfully employed, self-sufficient persons with disabilities.

A related problem exists for persons with mental disabilities. The majority of persons with long-term mental illness are eligible for and receive Supplemental Security Income (SSI) as their sole income source. Annualized, the sum of SSI income is only 75% of the Maine State poverty level. This severely limits the ability of these persons to purchase clean and safe housing. Conservative national estimates identify one-third of all homeless persons as having long-term mental illness.

Policy Recommendations:

The Maine State Housing Authority (MSHA) has initiated a new program that should be expanded and tailored moderately to address more specifically certain housing shortages experienced by citizens with disabilities. This will require the Maine Legislature to retain and continue supporting the real estate transfer tax which provides the Authourity with the financial resources needed to pioneer creative housing solutions.

1) The New Housing Initiatives Program and other state housing initiatives should be tailored to stimulate the development of more housing that incorporates adaptable design criteria, promotes independence and is fully integrated in residential neighborhoods. These initiatives should concern themselves particularly with the needs of persons with mental and physical disabilities

2) Quadruple to $1,000,000 the size of the Environmental Access Grants and Loan Program (EAGL) and raise the income guidelines to enable more applicants to qualify. Whenever appropriate, this program should seek out the assistance of the vocational technical institutes to complete home modifications.

Equal Opportunity and Access

Problem:

Understanding the Maine statutes for making buildings accessible is difficult because of overlapping laws. Enforcement is uneven and remedial actions are rarely taken when violations are discovered. The Section 504 Coordinator position (responsible for ensuring program accessibility to federal recipients) is not housed in the agency that normally responds to claims of discrimination causing further confusion among disabled citizens and design professionals.

Overview:

In 1967 Maine enacted Title 25, Sections 2701-2703, which required publicly-funded new construction to meet accessibility standards. Requirements covering privately-funded accommodations and places of employment were enacted in 1973 as part of the Maine Human Rights Act, Title 5, Sections 4551 et seq. The coverage of these Titles became confusing when subsequent amendments were established setting dollar limits and special standards for renovations and housing.

In the past ten years this "patchwork" legislation has been updated to include the most recent version of the ANSI standard. Although the most recent legislative session finally specified that local code enforcement officers should review compliance in private construction, remedial action is still in the hands of the Maine Human Rights Commission and enforcement for publicly-funded facilities rests with the Bureau of Public Improvements.

To confuse matters more, regulations for Section 504 of the federal Rehabilitation Act of 1973, prohibiting discrimination against handicapped people where federal funds are used, have been in effect since 1977. The thrust of the Act is the requirement that programs, when viewed in their entirety, do not discriminate. The regulations require a recipient of federal funds, such as the State of Maine, to name a 504 Coordinator who responds to consumer complaints and inquiries and oversees implementation of plans to eliminate discrimination on the basis of handicap from all state programs.

The 504 Coordinator is presently housed in the Bureau of Rehabilitation. In Maine, other activities related to handicapped discrimination are carried out by the Human Rights Commission. Thus, this arrangement requires consumers who wish to resolve claims about discrimination in federally-financed State programs to follow two separate paths.

Policy Recommendations:

1) Consolidate Title 25 and Title 5 into one (preferably Title 5) and require them to read in a consistent fashion and have more uniform applicability. Place responsibility for ensuring compliance with the statutes at the local level. Provide penalties for failure to take corrective action.

Sections 4593, 4594-A and 4594-B of Title 5 and Sections 2701, 2702, 2702-A and 2703 of Title 25 should be brought under one heading. Recognizing that the construction statutes previously passed must remain on the books "for the record," a reorganization could eliminate existing confusion. There should be a clear format listing date, dollar amount, type of building and the the applicable standard. The requirements of both titles that relate to the construction of housing should be united under one heading.

2) Provide funds to the Maine Human Rights Commission for oversight of 504 compliance. This would consolidate enforcement of all handicapped discrimination complaints within one agency.

Personal Assistance Services

Problem

The lack of attendant services affects 1.5% or 16,500 individuals in Maine from being as independent or productive as possible. Since the late 1970's Maine has attempted to address this significant problem by funding these services through an array of support systems including Home Based Care, Medicaid Waivers and an alternative long-term care program. Despite these efforts many disabled individuals and elderly persons have been precluded from recieving the assistance they require due to shortage of available funds. Restrictive eligibility criteria, piecemeal attempts to address isolated aspects of the program rather than a comprehensive approach, prohibit individuals from acquiring PCA services. Worker disincentives and a frequent bias toward an unnecessary medical model must also be overcome.

Overview:

The World Institute on Disability (WID) recently completed a fifty state survey to identify the current availability of personal assistance services and published its findings in 1987. Here's what WID discovered upon examination of this problem.

Who Needs Help

1) As a result of functional limitations arising from disability, chronic illness or advanced age, many millions of people need help in getting up, dressing, bathing, moving about, preparing meals, shopping or carrying out any of numerous other activities of daily living. Obtaining this help (otherwise known as attendant services) and/or paying for it, unfortunately, is difficult or impossible for many of these people. A study recently completed by WID indicates in fact that three out of four Americans who need attendant services are not receiving them from publicly funded sources.

2) The Independent Living Movement has long identified the lack of adequate attendant services as one of the most important problems facing disabled people in the U.S. and a major factor inhibiting them from working. The elderly movement, as well, has begun to recognize attendant services as an essential element in a well-functioning system of long-term care. Contributing to this recognition have been several recent studies which show that 15 to 20 percent of the thirty million people over 65 in this country need help in one or more activities of daily living and that almost half of these people report that they do not get as much help as they need.

3) It is commonly thought that people with functional impairments can find relatives or friends to press into service, but this option is often foreclosed by the need to fulfill employment or other responsibilities. So many people scrape by the best they can on their own, frequently at the cost of deteriorating health and premature entrance into an institution.

Selected findings by WID on Maine's need for personal services and what programs are currently available offered up the following:

- Like most other states Maine has followed a piecemeal approach to addressing the need for personal services.
- Only 33% or about 5,000 individuals who need personal services are currently receiving them.
- Many individuals with certain types of disabilties are currently excluded from existing programs. These include hearing and visually impaired individuals who need interpreters and readers, respectively, as well as individuals with mental disabilities who require mentors or environmental support assistants.
- The average hourly wage for personal attendants is below $5.00 an hour, thus making it very difficult to attract people to this kind of employment. Usually, most personal attendants work without benefits as well.
- Certain ages are not served at all by existing programs. For example, individuals with physical disabilities are not eligible for personal attendant services through either the Home Based Care Act or the Medicaid Waiver for Physically Disabled Adults until they become 18 years old.
- Medicaid waivers have had limited success in their intended purpose of providing home services to people who are at risk of institutionalization due to the financial caps and other restrictive guidelines imposed by these programs and the fact they do not allow users to hire their own personal attendants.
- Currently, the Federal Medicaid plan excludes reimbursement for home based services to persons with mental illness and mental retardation. The Maine Home-Based Care Act identifies many home-based services that could significantly assist persons with mental impairments to live more independently at the community level. Funding within the act specifically excludes these persons from receiving needed services. The Maine Commission to Study Overcrowding at state psychiatric institutes recognizes the need for supports of persons with severe mental illness to enable them to function within the community. The availability of home-based services to this population could greatly enhance this objective.
- The largest number of people who need services and are not receiving them are the elderly (an estimated 7,500 individuals).
- There is presently no comprehensive policy to address the incremental salary increases and improvements in benefits needed by personal attendants to ensure improvement in the quality of these services.
- Finally, literature in the field shows that for those people who do not receive publicly funded services, the burden of care usually falls on the shoulders of an unpaid female family member who might otherwise hold a job.

Policy Recommendations:

The Governor and Maine Legislature should adopt a comprehensive strategy immediately to address the increasing demand for personal services by individuals with disabilities and elderly persons.

1) A. The Home Based Care Act should be expanded to make available personal services to elderly and physically disabled persons whose needs are currently unmet. Funds to support the expansion of these services should be derived through an annual appropriation computed by a formula that takes into consideration the size of the state's population, a decent hourly wage and benefit system for personal attendants, the average number of hours of personal services required by individuals in need and the cost of administering these services at the community level.

B. A companion act to the Home Based Care Act should be implemented to address the home based care needs of persons with mental illness or mental retardation who would like to live more independently if a broader range of support services were available.

C. The Bureau of Medical Services should immediately adopt personal assistance services as part of the state Medicaid plan. It should consult with a broad variety of potential consumers including persons with all types of disabilities and the elderly to assist with defining the regulations for governing these services. Such regulations should allow for these personal services to be provided in a manner that allows the consumer to achieve maximum control over his or her life while minimizing the orientation to a medical model whenever possible, which will result in reducing overall costs.

Cost: An estimated $1,000,000 is needed this year to address the current unmet personal services needs of 100 Maine citizens. Additional funding would be needed annually thereafter to provide services to other persons. A formula must be developed to define precisely future funding needs.

2) The newly created Maine Human Development Council and its Targeted Services Sub-committee should direct attention to the current personal care attendant labor shortage and implement strategies to increase the number of attendants. These strategies should include developing competitive wages and benefit compensation, subsidizing transportation, offering career ladder opportunities, and targeting selected chronically unemployed groups such as mildly retarded persons, AFDC mothers and welfare recipients as potential attendants and offering day care assistance.

3) The Governor and Maine Legislature should monitor the actions closely of Maine's Congressional delegation in the areas of catastrophic health insurance and long-term care and ensure that personal services, in addition to hospital and nursing home care, are included for reimbursement. These services are essential to the well being of many disabled individuals and elderly people. The Governor and Maine Legislature should also encourage our congressional delegation to support the federal legislation entitled "Medical Home and Community Quality Service Act of 1987," sponsored by Senator John Chafee, which will restructure Medicaid to better reflect the needs of those with disabilities, promoting their integration into the community.

THE MAINE COMMISSION ON THE ROLE OF STATE GOVERNMENT IN PROVIDING INDEPENDENT LIVING OPPORTUNITIES AND SERVICES TO DISABLED PERSONS
(Ch. 44, Resolves of Maine, 1985)

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