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CP [Cerebral Palsy] Research Foundation Conference '77

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Some Guiding Principles for the Manager of Housing for Handicapped Persons

1. Here, management does not know all the answers, most especially the design problems of elevators, entries, parking, and service processes, such as recreation and shopping.
2. Handicapped persons are whole persons who happen to be functioning under unusual circumstances, and therefore have special physical and emotional needs.
3. Functional capacity, not medical diagnosis, is the manager's key to analyzing adaptation of each person to the housing unit.
4. Therefore, adaptation to the unit must be individual, without preconception, and valid suggestions for that adaptation can come from any source.
5. Persons with one kind of handicap can often assist others with a different kind.
6. Handicapped persons often have special food preparation, bathing, therapy and exercise needs.
7. Housing is a key part, but only a part of a complex of movement and activity by handicapped persons.
8. Employment may be a critical element in continued residency for some, but this may require income waivers.
9. Handicapped persons need all the standard building and community services of subsidized and assisted housing, plus others deriving from individual handicaps.
10. Housing for handicapped persons should be viewed as an intermediate step toward the true goal of full integration of the handicapped into all housing and the community at large. Such housing, therefore, may be seen as a testing ground for integrated, accessible and usable housing everywhere, and information learned must be promptly communicated to planning and building, architecture and industrial design, government and social research.

Morton Leads- Feb. 1977

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CHART II (continued)
SERVICES PROVIDED HANDICAPPED BY FEDERAL PROGRAMS

	Home and Money Management	Food Shelter, Clothing	\$250 Home Repair	Income	Lab and X-Rays	Skilled Nursing Home	Extended Care	Outpatient Services	Physician	Escort Services
Developmental Disabilities Act 1975										
Rehabilitation Act 1973										
Social Services, Title XX, Social Security Act										
Disability Insurance, Social Security										
Vocational Rehabilitation Services, Social Security				X						
Social Services, Public Assistance	X									
Maintenance, Public Assistance		X	X							
Supplemental Social Security				X						
Medicare						X			X	
Medicaid				X	X			X		
Special Transportation Assistance										
Services for Older People									X	X
Model Projects for Older People									X	
Nutrition Program for Older People										

SUMMARY OF FEDERAL PROGRAMS PROVIDING SERVICES TO HANDICAPPED

Program	Services Provided	Financing	Eligibility	Local Contact	Federal Administration
Developmental Disabilities Act 1975	A wide variety of remedial services; also facilities construction	70 percent federal (80 percent in poverty area)	Developmentally disabled; may be mental or physical	State Developmental Disabilities Council	Developmental Disabilities Office of Human Development, HEW
Rehabilitation Act 1973	A variety of guidance, training, other services to help handicapped become employable; also facilities construction	80 percent federal	Moderate and severely handicapped, mental or physical	State Vocational Rehabilitation Agency	Rehabilitation Services Administration, HEW
Social Services Program, Title XX, Social Security Act	A wide variety of social and other services to prevent institutional care	75 percent federal	People with incomes 80 percent of median; also recipients of Aid to Families with Dependent Children, Social Security Income, Medicaid	State department of public welfare or local human resources office	Public Services Administration, Social and Rehabilitation Services, HEW
Disability Insurance-- Social Security	To replace part of income lost because of a physical or mental impairment that prevents a person from working	Direct monthly SSI benefits: \$97.80 for single to \$719 for family	Disabled workers eligible for Social Security who have rehabilitation potential	HEW Regional Office	Rehabilitation Services Administration, HEW

CHART III (continued)

Program	Services Provided	Financing	Eligibility	Local Contact	Federal Administration
Vocational Rehabilitation Services for Social Security Disability Beneficiaries	Direct payments for rehabilitation services to help disabled return to gainful employment	Direct monthly payments	Disabled workers eligible for Social Security who have rehabilitation potential	HEW Regional Office	Rehabilitation Services Administration, HEW
Supplemental Security Income	To provide supplemental income to elderly and to blind or disabled of any age	Direct monthly payments	Based on income for single, less than \$146 a month; \$219 for couples	Nearest Social Security Office	Bureau of Supplemental Security Income, Social Security Administration, HEW
Medicaid	To pay for medical care for financially needy persons	Federal share--from 50 percent to 83 percent	Certain financially needy persons	State department of public welfare or human resources local office	Medical Services Administration, Social and Rehabilitative Services, HEW
Services for Older People, Title III, Older Americans Act	A wide range of social and related services	75 percent to 90 percent federal grant to states	All Older persons	State Office on Aging; Area Offices on Aging, HEW	Administration on Aging, Office of Human Development, HEW
Model Projects on Aging, Section 308, Older Americans Act	Model projects to expand or improve social services or otherwise promote the well-being of older persons	Federal share all or part of cost of project	Public or nonprofit agency	State Office on Aging	Administration on Aging, Office of Human Development, HEW (applications must be submitted to Washington)

Program	Services Provided	Financing	Eligibility	Local Contact	Federal Administration
Nutrition Programs for Elderly, Title VII, Older Americans Act	To provide elderly, especially low income, with nutritionally sound meals	90 per-cent federal	The elderly, including elderly handicapped	State Office on Aging, Area Offices on Aging	Administration on Aging, Office of Human Development, HEW
Specialized Transportation Services	To provide special transportation services meeting special needs of handicapped	100 per-cent federal grants	Handicapped and disabled	Governor's office	Urban Mass Transportation Administration, Department of Transportation

Presentation on:

The Principles of Service Delivery

Workshop on the general theme:

Environmental Barriers to
the Physically Disabled

February 6, 7, and 8, 1977

Holiday Inn Plaza
Wichita, Kansas

Author:

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No nation in the world, has proclaimed the concept of the equality of all human beings in such a way or to such an extent, than has my friendly neighbour, the United States of America. Declaring over 200 year ago that "all men are created equal", the value of equality of human beings became the very essence of the fabric of American society.

As a Canadian, who was fortunate to do graduate study at an American University, I was taught the valuable lesson of the importance of history. Through the history of Black Americans, we have much to learn and much to apply in our deliberations today and tomorrow.

In the beginning, as slaves, Black Americans were unequal to White Americans and were separated out from white living quarters. Thus the words unequal and separate would characterize the first phase of the history of Black Americans.

By 1865, almost 100 years after the Declaration of Independence, and with their freedom being declared, Black Americans became equal in the eyes of the law; but they remained socially unequal and separate.

In the next century, and principally after World War II, Black Americans rejected their equal but separate legal status, and they rejected their unequal and separate social status. Their Civil Rights Movement has achieved equality and integration for the most part in law, but there remains resistance to full social integration and equality in many of our communities today.

Thus, we learn that the process of achieving social equality and integration for Black Americans, while not yet achieved, is:

first, unequal and separate, second, equal and separate, and finally, equal and integrated, with the social achievement always

following the laws of the land.

The population of people with physical disabilities is, like the Black American population, a heterogeneous minority group. In my view, people with physical disabilities, are in the first phase of their history towards achieving their civil rights. They are, for the most part, socially unequal and separate.

Let us learn from the 200 year history of the struggle of Black Americans to achieve equality and integration.

Let us resolve to eliminate the intermediate steps.

Let us strive now and achieve immediately the opportunities for full equality and social integration of people with physical disabilities.

One of the major barriers to integrating persons with physical disabilities into our communities is their dependence upon others for physical help in some of their daily living activities. A second barrier to community integration is that this needed physical assistance is most frequently and typically found in nursing homes, chronic care hospitals, homes for the aged, or other institutions separated out from the mainstream of community life. Thus, many "graduates" of rehabilitation programs may quickly begin lives of isolation and dependency even though individuals may possess good educational and vocational potential and have been equipped with skills and devices for self help. If the rehabilitation goal of active, productive living is to be achieved, and if we are to achieve an equal quality of life for disabled people, then we must ensure their integration into the community through the availability of a range of accessible living, accommodation, together with a broad range of supportive services such as attendant care and transportation,

key elements in successful integration.

With social equality and integration as our immediate targets, I now want to present two basic principles to act as the basis for all our deliberations, including the aspect of support services related to shelter or housing.

The first of these is fairness or justice. What is a fair approach to support services? I submit to you that physically disabled people in need of physical support services want to and should pay for the ordinary costs of living. This is fair and just. I further submit that physically disabled people should not have to pay for any extraordinary costs of living occasioned by an inability to perform physical functions for themselves. To be burdened with extraordinary costs of living associated with physical disabilities would be unfair and unjust. As an illustration of what is ordinary and what is extraordinary, let us for a moment look at the "Case Study of Heidi" which is available to you. Heidi, now 28 years of age, has been a quadriplegic since she broke her neck in a diving accident 5 years ago. Dependent on her motorized wheelchair for mobility, she is nevertheless employed in a hospital earning \$19,500.00 per year. Her major extraordinary costs of living are (See Appendix B)

1) Van transportation to and from work	-	\$2,640.00
2) Transportation for recreation	-	324.00
3) Housekeeping and Meal Preparation	-	4,080.00
4) Physical Care Services	-	1,200.00

The total of Heidi's extraordinary costs of living were \$8,603.51, all of which was also taxable as earnings.

Her ordinary or usual costs of living, contained in Appendix C were calculated at \$5,668.16 per year. You will note from Appendix F Table I, that Heidi had to earn \$19,000 per year just to break even; she could not save any money; and she could take only one vacation per year, and that was restricted to the city in which she lived. Based on today's costs, Heidi would have to earn over \$22,000.00 per year in Metropolitan Toronto, a municipality of over 2 1/8 million people, just to survive.

A second feature under the principle of Justice, is that disabled people must have significant involvement in the planning and management of any enterprise concerning them. Planning with disabled people is fair, where with is the operational word. Aside from what is fair, planning for someone else is foolish and usually results in under or non-utilization as well as unhappiness and the misuse of finances.

The third basic principle for our deliberations and planning is freedom - freedom to interact on an equal basis with one's fellow human beings, freedom to choose where to live and in what kind of accommodation on the same basis as any other citizen; freedom to take risks that involve one oneself; freedom to make one's own decisions; freedom to be responsible and accountable for one's actions and behaviour; freedom to enjoy privacy and with the assurance that others will not betray matters of confidentiality, freedom from control by others, and freedom to assert and do for oneself as much as possible. I might better have said the principle of freedom within limits since each one of us has limits imposed on us in any culture for the protection and well being of all peoples as well as individuals. But, let the limits imposed be applied with equality and fairness for all.

With our targets of social equality and the opportunity for social integration firmly in view, and with our basic principles of justice and freedom as our means of achieving our objectives, what is our task ahead?

Obviously we must decide what we mean by support services related to housing. We should attempt to delineate between physical support services and other kinds such as recreation and transportation. We should deal effectively with what are essential and what are non-essential support services, recognizing that non-essential support services might occasionally become essential because of temporary circumstances. e.g. escort service for emergency banking. We should look at the needs of staff for privacy, for duties and responsibilities. We should take a fresh view of the training needs of staff and not be hide bound with the traditional view of nursing or therapy as being the obvious backgrounds of choice. But above all, we should try to delineate the needs of the populations we are talking about. This must be the first step.

ECONOMICS OF SUPPORT SERVICES

- One experience as a Demonstration Project for the Ontario Government.

The Clarendon Foundation (Cheshire Homes) Inc. at 21a Vaughan Road, Toronto, Ontario, Canada, has been operating a Demonstration Project for 1½ years (see attached sheet) to prove that:

- (1) Many severely disabled people in need of physical support services associated with accessible accommodation of their choice, can live with a better quality of life and in good health, outside of institutional settings such as chronic care hospitals.
- (2) The delivery of essential and other physical support services on a 24 hour basis permits
 - (a) choice of accommodation
 - (b) integration within community life
 - (c) gainful employment, training, and education
 - (d) the Province of Ontario to assess the actual costs of these services separate from the ordinary costs of living such as food, shelter, and clothing which are paid for by the tenants.

Our experience to date with maximum occupancy reveals that our average per diem cost for all support services is \$19.52 per tenant based on 13 tenants. Comparing this to chronic care and extended care hospital costs, we learn that:

- (a) our costs (including food, shelter and clothing) are less than 50% of these institutions whose average per diem cost is about \$55.00 per occupant;
- (b) the number of hours of care given to our tenants is at least 15% more on an average than that given in such hospitals; and
- (c) our tenants are all enjoying productive lives vocationally, socially, and recreationally in ordinary apartment living of their choice.

Our next step, the extension of support services on a wider basis, has already begun with no increase in costs.

INFORMATION RE CLARENDON

Question - What is the Clarendon Foundation and who do they serve?

Answer - Clarendon Foundation (Cheshire Homes) Inc. is a non-profit Corporation which was established in 1974 for the purpose of providing accommodation and support services to severely handicapped adults who are either employed or in training to become employed.

The Foundation is currently operating a pilot project in cooperation with the Ontario Housing Corporation and the Ministry of Community and Social Services at 21a Vaughan Road in downtown Toronto for a maximum of 13 tenants who are housed in 5 apartments plus communal dining and laundry facilities.

All tenants require at least two of the support services offered which are personal care, meal preparation and serving, laundry and housekeeping (light and heavy) in order to function day to day as a student or employee in their chosen field.

Support services are carried out by a staff of 6 full-time attendants, 1 housekeeper, 1 part-time cleaner and 1 part-time Co-ordinator. Services are available on a 24 hour a day basis and are given on the basis of physical inability to perform a function for oneself. Each tenant signs a Service Contract with the Foundation outlining the conditions of the services. There are no fees charged to the tenant for these services; however, tenants are required to pay all normal costs of living such as food, cleaning supplies, etc. The costs for these services are paid for by the Ontario Government.

Through agreement with the Ontario Housing Corporation rent is geared to income and cannot exceed the market value of the space occupied by any tenant. Each tenant has a one year sub-lease with the Foundation under the same general rules and regulations which are in effect in most apartment buildings in Toronto.

CASE STUDY OF HEIDI

The information in the profile is based on a real person but the name has been changed to maintain confidentiality. She is one of more than twenty such disabled young adults who graduate from one rehabilitation centre alone in the Province of Ontario each year.

Heidi, now 28 years of age, has been a quadriplegic since she broke her neck in a diving accident 5 years ago. She is permanently confined to a wheelchair which is motorized (Cost - \$1,500.00) as she cannot push herself in a regular wheelchair. This chair[†] is usually reliable but every few months a problem with the motor or electric wires develops which requires the services of an electrician (\$15.00), the expense of a van to take the broken chair to and from the repair shop (\$12.00) and extra hours of duty from her attendant who must then accompany her throughout the day to provide her with substitute mobility (\$15.00). Two 12-volt batteries provide the power for the wheelchair. Fortunately, these are usually reliable for a 2 to 3 year period but, when they need replacing, this represents an unexpected expense (\$35.00).

Heidi has a university degree and is employed in a hospital (\$19,500.00 per year salary). She chose to accept the hospital job as it was close to her apartment and to the Van Transportation services she requires because of her wheelchair. The shorter distance between work and her place of residence was a definite factor in reducing the already highly expensive wheelchair Van Transportation costs (\$2,640.00).

Heidi was obliged to rent in a modern apartment building because she required a residence without stairs and steps and with an elevator. Because she requires a live-in housekeeper (\$4,920.00)* to assist her with all activities such as housekeeping, cooking, washing, dressing, etc., she requires a two bedroom unit to afford her housekeeper-attendant some privacy (\$2,760.00)**. Even at that, the apartment required some carpentry modifications such as having the bathroom door widened and having a ramp made so she could get over the door sill onto the balcony (\$200.00). Heidi's housekeeper is paid to help her get up and dressed in the morning and to get to bed at night. She does housekeeping and shopping errands as well as providing breakfast and cooking supper. She has the hours between 11:00 a.m. and 4:00 p.m. to herself as Heidi eats lunch in the cafeteria at work (\$240.00). On the weekends, the housekeeper is off and a friend of Heidi's comes in (\$40.00 a weekend).

* Live-in Housekeeper's Salaries (for cooking and cleaning) range between \$200.00 and \$250.00 per month, plus room and board - according to Miss JOSEPH of Canada Manpower, Dec. 9, 1974 (Telephone: 363-5931, Local 317) Board has been calculated at \$85.00 per month. Heidi pays \$100.00 per month more to her live-in housekeeper for dressing and bathing duties on a special arrangement to avoid the twice daily costs of \$9.00 charged by the Victorian Order of Nurses on a sliding scale for such services (\$6,570.00 per year).

** Using rental figures of \$230.00 a month for a two bedroom apartment as opposed to \$200.00 a month rental for a one bedroom apartment.

Specialized nursing care is required from a registered nurse twice a week. As this visiting service only operates during regular working hours, Heidi must make up the two hours of working time she loses on Wednesday mornings in order to get this care.

Buying clothes (\$500.00) represents a major expense as nearly all of the clothes must go to a dressmaker for alterations for easier getting on and off (\$100.00). Hairdressing is a necessity for Heidi as she cannot lean forward over a bathroom sink and only the hairdresser sinks are at the right height to provide the backward reclining position which can accommodate her neck (\$260.00).

Generally speaking, Heidi has few problems with illness. To maintain her good health however, she must take the drug "Furidantin" daily the year round (\$240.00). In addition, to reduce the spasm in her arms and legs, she must take "Valium" daily (\$88.00). Drug bills are therefore high although she is covered by an Extended Health Care Plan which covers the cost each year after \$50.00 deductible. Equipment costs, in addition to her motorized wheelchair, represent an expense as she requires a manual lightweight adult wheelchair with removable arms (\$362.00), a Hoyer lift (\$392.00) and a bathtub clamp (\$179.00) in order to utilize the lift safely for transfers between wheelchair and bathtub.

Heidi is covered by regular medical insurance (\$51.12 a year) so medical attention is not a problem, although the 10% she must pay of the physician's bill is higher than the norm as she cannot get to the local physician's upstairs office and house calls must be made rather than office visits.

Regular visits to a dentist (\$25.00) are not within her budget as she has to travel downtown in the wheelchair Van (\$12.00) in order to visit a dentist in a modern office building which has no stairs or other architectural barriers.

Heidi's grocery costs are not more excessive than anyone else's who has to provide for two people (\$1,920.00). However, she seldom can afford to entertain people for supper or a party (\$50.00). Neither can she permit herself the luxury of going to a movie or play, or even going to another person's house due to the transportation charge (\$12.00), plus the cost of the entertainment itself (\$5.00). Household sundries, unusual expenses subscriptions, etc., also add to her already excessive expenses and, of course, we have not even considered the initial cost outlay for furnishings (\$2,000.00).

Although Heidi is permitted a \$1,706.00 basic personal exemption and a \$1,066.00 disability deduction (1974), her income tax still represents a major loss of income (\$4,905.00) due to Heidi's relatively high annual salary (\$19,500.00).

Considering all the expenses outlined above, daily as well as unexpected costs, it is quite probable that Heidi will have no margin of financial security at the end of a year.

Heidi, as a well educated, well motivated, ambitious woman, is much admired within her community for her courage, determination and pleasant attitudes in the face of such a permanent disability. What her neighbours should be admiring (but don't because they have no knowledge of it) is her courage in maintaining such a slender insecure hold on an overwhelmingly, costly, complex arrangement for independent living. Heidi must live with the ever lurking knowledge that it is only a slender thread of happenstance which keeps her from the one alternate life-style available to such as she - i.e., confinement to an institution where she would be subjected to institutional rules and regulations, loss of privacy and freedom, loss of employment and salary, and demoralizing dependence on the limited annual income (\$876.00)* which disabled people are allowed to keep from provincial assistance in such circumstances. Instead of supporting herself and others through tax payments (\$5,127.20), Heidi's care would be costing others not less than \$6,351.00 per year**.

Heidi is, in fact, one of the few fortunate persons who have been able to mesh all her problems into a workable solution - i.e. accommodation, care services, transportation, employment, etc.. If one part of this puzzle does not fit - she is then likely to require the services of a nursing home or extended care facility and her job is no longer possible.

* The allowable costs set by the Province of Ontario are \$11.00 per day (\$4,015.00 per annum) for a residential care person and \$15.00 per day (\$5,475.00 per annum) for an extended care person in a 61 bed residence in Toronto providing some supportive care. (These allowable costs prevail in approved Nursing Homes as well.) Each single, disabled resident may receive family benefits assistance from the Province of either \$225.00 (ambulatory allowance) or \$238.77 (wheelchair user allowance) per month. Of these amounts, each resident contributes \$5.75 per day for care, room and board and is thus allowed to keep \$53.00 a month for his/her comfort. The wheelchair user is allowed to keep an additional \$20.00 a month for transportation costs (\$12.00 a return trip by van transportation). Thus, the total cost to the Province for some supportive assistance is between \$4,651.00 and \$6,351.00 per year per resident. Heidi's cost to the Province for these would be \$6,351.00 per annum in this residence or in a nursing home. If Heidi had to stay in an extended care facility, the Province would pay an average of \$37.96 per day, or \$13,855.40 per year.

** "Ontario Hospital Compilation", published by the Ontario Hospital Association and reporting for the period January to June, 1974, revealed that the median per diem cost for patient care was \$37.96 for the 16 participating hospitals providing extended care facilities (the range was from \$56.82 to \$29.77.). The reporting hospitals were classified as public, chronic, extended care, convalescent and rehabilitation.

APPENDIX B

EXTRAORDINARY COSTS OF LIVING FOR A SINGLE PERSON BECAUSE OF DISABILITIES

(a)	<u>TRANSPORTATION - @ \$12.00* per day return trip</u>	\$2,964.00
(i)	To and from Work @ 220 days	\$2,640.00
(ii)	Social, Cultural, Religious, Recreational (based on 1 outing every 2 weeks within Toronto and 1 vacation each year in Toronto)	324.00
* On December 9, 1974, the cost was \$12.00 per return trip with the cost assured of rising to \$14.00 by the end of the month. The Toronto Transit Commission's Pilot Project for 46 working handicapped is scheduled to begin February 5, 1975.		
(b)	<u>HOUSEKEEPING AND MEAL PREPARATION*</u>	\$4,080.00
(i)	Live-in Housekeeper at \$225.00 per month	\$2,700.00
(ii)	Board for Housekeeper @ \$85.00 per month	1,020.00
(iii)	Difference in Cost between 2 bedroom and 1 bedroom apartment @ \$30.00 per month	360.00
* Live-in Housekeeper Salary (for cooking and cleaning) ranges between \$200.00 and \$250.00 per month, plus room and board (Source of Information: Miss Joosen, Canada Manpower, Telephone: 363-5931, Ext. 317, December 9, 1974)		
(c)	<u>PHYSICAL CARE SERVICES</u>	\$1,200.00
(i.e., dressing, bathing @\$9.00 a visit, twice a day based on fees of Victorian Order of Nurses, or \$6,70.00 per year - used alternative of persuading Housekeeper for another \$100.00 per month.		
(d)	<u>DISABILITY INSURANCE PLAN @ \$12.27 every 4 weeks</u>	\$ 159.51
(Based on Ontario Hospital Association Plan)		
(e)	<u>PURCHASE AND MAINTENANCE OF AIDS AND APPLIANCES NOT COVERED UNDER THE EXTENDED HEALTH CARE PLAN</u>	\$ 200.00
		<u>\$8,603.51</u>

USUAL COSTS OF LIVING

(a)	Purchasing, Maintenance, Dry Cleaning, and Alterations of clothing	\$ 750.00
(b)	One-bedroom apartment, rental and hydro at \$200.00	2,400.00
(c)	Board (using \$20.00 per week and \$30.00 per week during 3 week annual vacation)	1,070.00
(d)	Annual vacation and entertainment during year	300.00
(e)	Group Insurance at \$2.00 per week	104.00
(f)	Telephone at \$8.56 per month (party line) - varies depending upon the need for a push button phone with speaker amplifier	102.72
(g)	Savings for unforeseen and Emergency Expenses (at 5% of annual salary)	500.00
(h)	Unemployment Insurance of \$8,320.00 (maximum insurable income)	83.20
(i)	Extended Health Care Insurance for Company Groups at \$0.85 per month (based on Ontario Blue Cross Plan)	10.32
(j)	Ontario Hospital Insurance Plan at \$4.26 per month (plus \$1.25 per month for Semi-Private Coverage)	51.12
(k)	Hairdressing at \$5.00 per week	260.00
(l)	Incidental Expenses (Magazines, writing supplies, soap, toothpaste, library membership, etc.)	120.00
		\$5,663.16

APPENDIX D

COMPARATIVE COSTS OF INSTITUTIONS PER YEAR PER PATIENT

NURSING HOMES

	<u>AMBULATORY PERSON</u>	<u>WHEELCHAIR USER</u>
Room, Board and Care	\$4,927.50 ¹	\$4,927.50 ¹
GAINS INCOME COST TO PROVINCE	\$ 696.00 ²	\$ 876.00 ²
Total Public Assistance	\$5,623.50	\$5,803.50

1. These figures are based on a maximum allowed per diem cost per patient of \$13.50. There is no per diem ceiling under the Homes for Retarded Persons Act as opposed to the Homes for the Aged, The Charitable Institutions, or the Children's Institutions Acts.
2. Effective May 1, 1975, single recipients of GAINS will be paid \$2,887.92 per year instead of \$2,766.00 annually. The increase actually is paid to a Nursing Home leaving \$696.00 per year for an ambulatory resident and \$876.00 per year for a wheelchair user for "comfort" and "transportation". (Under the Guaranteed Annual Income System, a single recipient in a nursing home is allowed to keep \$43.00 per month for comfort and a monthly transportation allowance of \$15.00 per month or \$30.00 per month).

EXTENDED CARE HOSPITALS³

	<u>LOWEST</u>	<u>MEDIAN</u>	<u>HIGHEST</u>
Room, Board and Care	\$10,866.05	\$13,855.40	\$20,739.30

3. Cost figures obtained from the Ontario Hospital Associations' "Ontario Hospital Compilations" publication reporting for the period January to June 1974.

APPENDIX E

DEDUCTIONS AND EXEMPTIONS

1.	<u>DEDUCTIONS</u>		\$ 861.20
(i)	Canada Pension Plan	\$ 101.20	
(ii)	Registered Pension Fund Contributions	\$ 700.00	
(iii)	Annual Union, Professional or like dues	\$ 60.00	
2.	<u>PERSONAL EXEMPTIONS</u>		\$2,772.00
(i)	Basic Personal	\$1,706.00	
(ii)	Disability Deduction (confined full-time to a wheelchair)*	\$1,066.00	
3.	<u>CHARITABLE DONATIONS</u>		\$ 100.00
4.	<u>TOTAL DEDUCTIONS</u>		\$3,733.20

* As opposed to claiming deductions for a full-time attendant as medical expenses where attendant must be a registered nurse prescribed by a physician.

APPENDIX F

COMPARATIVE INCOMES FOR HEIDI LIVING INDEPENDENTLY

TABLE 1

1. Gross Income	\$10,000.00	\$14,000.00	\$17,000.00	\$19,000.00	\$19,500.00
2. Extraordinary Costs of Living	8,603.51	8,603.51	8,603.51	8,603.51	8,603.51
3. Effective Gross Income	1,396.49	5,396.49	8,396.49	10,396.49	10,896.49
4. Taxable Income	6,266.80	10,266.80	13,266.80	15,266.80	15,766.80
5. Total Income Tax Payable (1974 Rates)	1,465.60	2,757.60	3,889.20	4,685.70	4,905.00
6. Effective Net Income (after taxes)	- 69.11	2,638.89	4,507.29	5,710.79	5,991.49
7. Ordinary Costs of Living	5,668.16	5,668.16	5,668.16	5,668.16	5,668.16
8. Surplus or Debt	-5,737.27	-3,029.27	-1,160.87	42.63	323.33

Attitudinal Barriers in Environmental Design for the Disabled

"Normal people, attempting to empathise with disabled people, make assumptions about how people with disabilities behave or ought to behave, which do not at all correspond with how they actually do behave. These assumptions are probably at least as prevalent among architects as they are anywhere else..."

Selwyn Goldsmith: Designing for the Disabled

For the past eight years I have observed the environment, both animate and inanimate, from a lower vantage point in the wheelchair. I have observed it both as a human being, and as a design professional.

I come to my work as an environmental designer for the disabled because I am trained as an architect and am myself a paraplegic. I am therefore daily sensitive to and conscious of how the environment presents itself to me, and how people react towards my existence in it.

My professional specialization has been in the field of housing, because I am drawn to this human shelter which forms a basic foundations to which each individual relates, physically and psychologically, and which contributes such an important core to the sense of human belonging and worth. I have therefore turned to the problem of housing for the disabled, and I have done so with strong feelings about what disabled people truly desire. The goals of the disabled are encompassed in the principles of "normalization" and involve the will to freedom, equality, social integration and choice.

Integrated Housing

My major experience in the implementation of normalization is through a demonstration project of integrated housing for severely physically disabled persons. My associates and I have been engaged in developing and coordinating resources which would allow quadriplegics to live independantly in the community, in individual subsidized apartment units in standard housing projects, with at-home support services when required.

Because our concept was, and still is, somewhat avant-garde in the Canadian context, we have had to cross many attitudinal barriers in discussing the functional feasibility, psychological desirability and economic validity of such a proposal. First we had to convince the many bureaucrats, planners and designers that even severely physically disabled persons did not wish to or need to live in "special" environments particularly conceived for them, and that they were prepared to accept certain inconveniences, risks and uncertainties in order to enjoy a relatively "normal" life-style, according to their choice.

Not only did we encounter great skepticism and fear on the parts of administrators and programmers, who tend to be over-cautious and over-protective, but we also encountered strong resistance from architects and designers. These people, from what little they knew of the topic, were reluctant to accept the integrated concept, fearing that the requirements for accommodating the physically disabled would involve undesirably specialized demands and result in excessive costs.

The truth of the fact is that the objectives of "normalization" are quite the opposite. We have tried to demonstrate, and have had success in this, that physically disabled persons can live in independent housing units which are barrier-free, require a minimum of design modifications, and involve negligible additional expense. Instead of relying on special built-in features, we emphasize the roles of occupational therapists and industrial designers to teach specific types of manouvers and develop simple adaptations and equipment which will increase individual functioning.

This type of housing has the advantage that: 1) it can be provided anywhere; 2) it is well within the design scope of any architect; 3) it can accommodate the able-bodied with equal ease; 4) it in no way stigmatizes the unit or its occupant; and 5) it enables the disabled tenants to learn to adapt to almost "normal" accommodations, so

that they develop coping mechanisms that enable them to function, as independantly as possible, in other barrier-free situations.

These are all essential aspects of the normalizing process. So far we have found few short-comings in this type of approach, and we have noted an improved self-image of the residents because they are pleased that they are coping and living in a standard fashion. Their personal environment and independant life-style, whatever its accompanying problems and responsibilities, is building initiative to try more and to do better. The residents themselves are amazed at their growing strengths and abilities to manage physically, emotionally and financially. All are proud of their progress and achievements, and have a high self-esteem.

We too are proud and happy with this demonstration, because it provides us with experimental ground on which to study various aspects of normalization. In our experience to-date, we have encountered quite a discrepancy between what the able-bodied population, even that part working on behalf of the disabled, see as the optimum solution for the disabled, and what the disabled really aspire to for themselves. Normalization seems to have different parameters for the two groups, and it will be our goal for the future to reconcile them and find a happy medium.

Parameters of "normalization"

Many of the attitudinal barriers which we encounter among architects and designers are based on pre-conceptions and lack of understanding about what disabled people truly want or need. The most damaging and wide-spread in that disabled people have to, or prefer to, function, live, work, recreate, etc. in special environments that are specifically designed to accommodate the handicapped, and that consequently are segregated, different, and apart from normal people and normal environments.

This is a great myth! Disabled people are not a breed apart! They are persons like everyone else, albeit with some physical limitations, but these can be accommodated in an uncomplicated fashion by the elimination of thoughtlessly-built barriers, by promotion of good industrial design, and by developments of simple adaptive apparatus for severe situations.

Uncertain of what a wheelchair really implies in terms of functioning, or what other physical limitations mean in terms of individual manouverability, designers tend to over-compensate in various exaggerated and unnecessary ways. Often they over-design in terms of size and provide unreasonably large spaces or complex features where standard dimensions and equipment, properly applied, would have sufficed and been more desirable. Or designers become so engrossed with ergonomic elements of the physical aids and manouvers, that they design over-specialized facilities that are oriented more to accommodating the physical limitations than to catering to the human being behind those limitations. Often, too, in order to increase some aspect of safety or manouverability, architects incorporate more barriers and problems than they actually eliminate. Or they are so unsensitive to the disabled as living, feeling people, that in an effort to eliminate any mistakes they create anonymous, undefined and sterile spaces which alienate and diminish human beings.

Double-ended adaptation

The total life experience, for everyone, is the continual adaptation to and interaction between man and environment. Unrealistic performance standards and exaggerated design solutions develop attitudes which reinforce barriers against the acceptance and integration of the disabled minority in the social milieu. Disabled persons are generally prepared to compromise and to adapt to environments that are basically accessible and have no gross functionality obstacles. The direction toward barrier-free environments is the reasonable approach towards achieving such ends.

In order to make room for the physically disabled and to accommodate them comfortably side-by-side with the able-bodied, society has to make primary and major modifications in its attitudes and values, along with secondary and minor modifications in the built environment. It has to provide a greater opportunity to the disabled minority to adapt and to give shape to the normal environment, so as to eliminate a divided society where individuals are expected to function only in spaces and in a manner assigned to them. Maybe the reluctance to embrace barrier-free design stems from the fact that somewhere in the back of their conscious, the able-bodied are willing to let the disabled advance only so far, and no further.

Now is the time for myths about the disabled to be replaced by truth and reality. A personal physical limitation does require adaptive aids and occasional simple help to achieve effective functioning. However, over-compensation and excessive design criteria produce an atmosphere that is uncomfortable for everyone concerned. It builds barriers that interfere with the acceptance of the disabled as valid and useful citizens, and it further restricts the personal expression, human potential and self-actualization of individuals who are thus doubly deprived.

Patricia Falta, B. Arch., M. Arch.
Montreal, Quebec, Canada
January 28, 1977

PROLOGUE

"Some men see things as they are and ask why;
I dream of things as they could be
and ask why not."

- Robert F. Kennedy

WHY not? Why not integrated living?

What is INTEGRATED LIVING?

Simple. It is living in environments that are not segregated, separate, apart, restricted, different.

For whom? For everybody. For you, me, young, old, black, white, rich, poor, able-bodied, DISABLED.

Where?? EVERYWHERE. There where all the others live, in the housing they enjoy, in the neighbourhoods they create.

Whereever one BELONGS!

Why??? Because this is an age of expanding awareness. Integration for all. Equality. First-class citizenship. LIBERATION.

What is so difficult about accepting the physically disabled in our midst? Seeing them as human beings like others, with similar aspirations, needs and ambitions, but with physical maneuverability problems and limitations?

Other people have limitations, albeit less obvious ones. Sometimes much more debilitating ones.

Can we not stress the many similarities rather than the few differences? Can we not accommodate those extra physical needs in as natural a manner as possible? Do we have to focus on a wheelchair or other physical aid as the primary defining characteristic of that being?

"Make no assumptions!"

- Sondra Diamond, psychologist

Let ME be me. A person who is part of a family,
wants to love, to help, to share, to contribute.
Inside of my body, I am the same human being as you.

Let me AMONG you. To work by your side, laugh and cry
with you, stumble and succeed as you do, to face the
challenges of living.

Living beside YOU.
In your communities, your buildings, your homes.

Why NOT?

Why not change your attitudes to focus on the ABILITIES,
not the dis-ability.

"Don't do me no favours..."

Don't make my decisions for me, deprive me of my
responsibilities, over-protect me, patronize me.
Don't imprison the real me in your fearful perception of me.

Give me FREEDOMS such as you enjoy, and struggle with.

Psychological freedom - to develop and express myself,
to be stimulated, to be motivated.

Social freedom - to be exposed to people and to activity,
to choose my style, my way.

Economic freedom - to be given opportunities, to work as
you do, to be productive in my way.

Do you realize that I value INDEPENDANCE as much as you do?

"You are a child of the universe,
no less that the trees and the stars
You have a right to be here."

- Max Ehrmann

quero falta
1975

ALTERNATE HOUSING

"Alternate" housing for physically disabled persons implies non-institutional housing; housing that is "normalized", that is integrated both physically and socially into the regular housing-provision systems and structures, and which encourages its residents to interact with equal efforts and freedoms within the community. In the case of severely physically disabled persons, such housing must provide accessibility, functionality and economic feasibility. When necessary, it must also be supplemented by adequate, permanent personal help and by special-use equipment and technical aids where possible. Alternate housing includes living in private homes, in apartments, and in communes or cooperatives.

The Quebec experience with alternate housing is in the field of apartment living. For more than two years Projet Normalisation has been functioning in Montreal, working to promote the concept of integrated housing and to implement the provisions of the components required for independant apartment living for young severely physically disabled adults. To achieve these ends, Projet Normalisation has used the vehicle of a three-year demonstration project which has the support of the federal and provincial social welfare authorities.

The efforts of the demonstration project are mainly coordinative. To the various agencies which are responsible for providing the housing and the service component in the province, the project presents them with the immediate need of the disabled, and advocates that they expand the resources within the various existing resource delivery systems to include also the needs of physically handicapped persons. Projet Normalisation further helps the authorities to define these needs and provide the appropriate resource allocation.

Such an approach has proven successful in opening doors for negotiations for two reasons. First, because as a pilot demonstration project it does not directly threaten to disrupt the existing delivery systems, and does not demand a total initial commitment-to-the-cause on the part of those who are willing to cooperate with us. It offers a trial and error method, open to changes and modifications along the way, and can even encompass failure and rejection.

Second, the project gains a certain status because it is couched in the methods of a pseudo-scientific research program: it is thoroughly documented along each step of the way, closely monitored by the federal and provincial governments, and professionally evaluated as to efforts, efficiencies and effects.

Since it is a demonstration project, the principles and practicalities of integration in terms of independent apartment living can be gradually and comprehensively explored as a pilot experience. The many individuals and agencies involved are continually assessing feedback, both as to method and result, and there is constant review and evaluation of what has been accomplished before a further step is proposed.

The project has now been more than two years in progress, and has given concrete results which provide positive feedback and form real precedents on which to develop future work. As a sequence to the initial stage, the majority of the agencies with which we have collaborated no longer regard the project as a "demonstration". They have convinced themselves that the objectives which we had set forth are feasible and desirable, and they have adopted policies and budgets to include the requirements of integrated housing within their mandates. Thus the pilot project has offered an acceptable means to experiment with new approaches, and existing systems are now being permanently adapted to include the needs of physically disabled persons.

One of the objectives of Projet Normalisation specifically stipulated that young quadraplegic adults should be integrated in independant apartments, and many of them are presently living on their own. Their apartments are mainly located in social housing projects which are rented at a rent geared to income scale. The initial furnishings for the residents have been paid by the Social Affairs Department, and the personal services, as individually necessitated, are provided on a home-visit basis and fully subsidized by Social Affairs. Each of the individuals are happy and proud to be on their own, "chez moi" as they say. They ask for various amounts of personal services, from none at all to a fair amount, but in addition to this type of "formal" help, they depend on other social contacts which they have made and which give them a great sense of personhood - and we are happy for it!

The majority of the units that have so far been handicap-modified are located in Senior Citizens' housing. We had feared that placing young disabled adults into such an environment would be only partially integrative, and therefore only semi-normalizing, but the experience to date seems to erase that fear. The majority of the disabled inhabitants have arranged active lives of their own, and therefore are not deeply conscious of their surrounding neighbours. Thus they are very little affected by the fact the senior citizen residents have different socio-psychological attitudes and needs than their own. The young residents are mainly satisfied with the buildings and apartments as such, and their sense of having a normal life-style is not at all diminished.

The modified units are in high-rise buildings of six to nine floors each, one modified apartment per floor. This arrangement works well, both in terms of design layout as well as of dispersal of the disabled throughout the building. The problem of fire safety has been brought up often. The operative response is that the building administrators and the disabled tenants work in close cooperation with the fire de-

partments, which all keep on file in what buildings and on what floors disabled persons live, whether they are elderly or young adult tenants. In addition, special fire department "invalid" decals are placed in the window of each handicap unit for easy identification, so that in case of fire emergency the firemen would rescue the tenants there first.

The local municipal housing planners, architects and administrators are not unduly worried about fire safety, because they feel assured that their buildings are increasingly more fire-proof, for better safety of all tenants. In case of emergency, they prefer that all tenants use the balconies as escape locations to get out of the smoke. In the handicap units, the balconies are made wheelchair-accessible, and smoke detectors are installed in all apartments.

As regards other modifications in the handicap-adapted units, we have asked for only slight changes and additions, for two reasons.

First, it is easier to convince the architects and administrators that if only minor changes are necessary, this implies little additional work and minimal extra cost. It is easier for the authorities to accept our basic request and it alleviates their fears that they will commit themselves to creating "special facilities" and undesirably different apartments which would be inconvenient for the able-bodied, if such were the need. Basically, therefore, the request is only for simple removal of accessibility and functionality barriers. These constitute minimal design criteria which are well within the scope of every architect and which contribute a negligible cost increment.

Second, we try to encourage the disabled tenants to adapt to an almost "normal" apartment unit, so that they will develop coping mechanisms that will enable them to function, as independantly as possible, in other standard accommodation situations. This forms an important

part of the normalizing process. Instead of relying on special built-in features, we emphasize the help of an occupational therapist to develop simple adaptations and teach specific types of manouvers to increase individual functioning.

So far, we have found no major short-comings in this type of approach, and we have noted an improved self-image of the residents because they are pleased that they are living and coping in a standard fashion. They are also finding that they gradually come to do more and more for themselves, and are amazed by their own increased abilities and strengths. Though originally many feared the responsibility of having to deal with financial independence and its problems, they are all managing well, whether they receive study grants, welfare, salaries or other income. All are proud of their achievements and life-style, and as a result they have a high self-esteem.

In the orientation of the demonstration project, Projet Normalisation has continually resisted the desire to satisfy, in a band-aid fashion, the immediate needs of the disabled population because it is our belief that "special" housing solutions are too often only one-shot deals and provide only short-term relief.

In its stead, the objectives of Projet Normalisation have been to implant long-term, government supported solutions to the housing and service needs of the disabled, so that a natural availability of these resources will be assured in the future for all who require them. These kind of objectives demand a more difficult and time-consuming process, because they require the cooperation of the many authorities which have jurisdiction over the many different requirements that make up "integrated housing". We do not accept that the representatives of the public sector ignore their responsibilities vis à vis the disabled portion of the total population which they are mandated to serve.

But in conclusion, it is important again to focus attention on the disabled individuals themselves. The success of Projet Normalisation is its emphasis in stressing that the creation of integrated housing resources puts the responsibility of living on the individuals themselves. It is up to them to utilize those measures which have been provided for their use. This method of helping disabled persons help themselves must be the ultimate goal of all those who are truly working on behalf of the disabled population.

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February 22, 1977

Mr. Lex Frieden
New Option Research Director
Texas Institute for Rehabilitation
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Houston, Texas 77030

Dear Mr. Frieden:

On behalf of the Cerebral Palsy Research Foundation of Kansas, we would like to take this opportunity to thank you for your participation in our recent Environmental Barriers Workshop. From all indications, the conference was a great success. This success was, in no small part, due to the active participation of persons like yourself. The interaction of those persons affiliated with diverse segments of the rehabilitation movement was gratifying to see and resulted in a workshop which was worth the great amount of effort expended in planning and organizing it. You are to be commended for your active and provocative participation. Thanks again.

Sincerely,

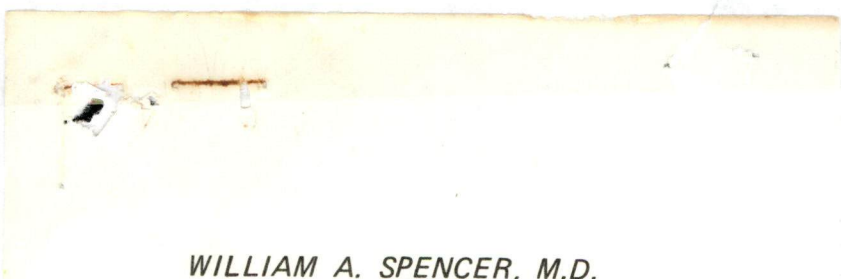
A handwritten signature in dark ink, reading "John H. Leslie, Jr.", written over the typed name.

John H. Leslie, Jr., Ph.D.
Co-Director, Rehabilitation Engineering Center
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A handwritten signature in dark ink, reading "John F. Jonas, Jr.", written over the typed name.

John F. Jonas, Jr.
Co-Director, Rehabilitation Engineering Center
Cerebral Palsy Research Foundation of Kansas, Inc.

JHL/mm



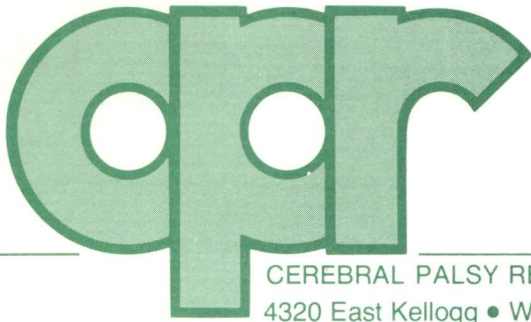
*WILLIAM A. SPENCER, M.D.
Houston, Texas*

12/30/76

Lex - Dr. Spencer thought you would be
a good person to be involved in this
activity - if you have the time and interest.

If you think you would like to participate,
I suggest you write them (with registration
or whatever they require) and tell them
that he asked you to participate in his
stead.

Nelda Montgomery



Daniel M. Carney
Deryl K. Schuster
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4320 East Kellogg • Wichita, Kansas 67218 • (316) 683-5627 • 1 (800) 362-2860

December 22, 1976

Dr. William A. Spencer, Project Director
Rehabilitation Engineering Center
Texas Institute for Rehabilitation and Research
1333 Moursund Avenue
Houston, Texas 77025

*Let
Zander*

Dear Dr. Spencer:

The Cerebral Palsy Research Foundation of Kansas in cooperation with the College of Engineering of Wichita State University has been selected by the Rehabilitation Services Administration to conduct a workshop on the general theme "Environmental Barriers to the Disabled."

This event will be held on February 6, 7, and 8 at the Holiday Inn Plaza in Wichita, Kansas.

The workshop will focus on the following barriers as they relate to the physically disabled.

1. Service Delivery System
2. Vocational and Employment
3. Architectural
4. Educational
5. Transportation
6. Attitudinal
7. Recreational

Specifically, the conference will deal with the development of strategies relative to the creation of a meaningful lifestyle for the severely physically disabled through rehabilitation engineering. It will attempt to integrate the seven elements listed above with the medical restoration research being conducted at the other REC's. Additionally, it is anticipated that the workshop will serve to broaden the area of responsibility of the rehabilitation engineer to include those matters which, up to now, have only received cursory attention. The enclosed diagram attempts to explain, in a pictorial fashion, the goals and objectives of the workshop.

We would appreciate your attendance at this conference. If your schedule does not permit your participation, please bring this matter to the attention of your colleagues who you feel could make a positive contribution by their attendance at the workshop.

Dr. William A. Spencer

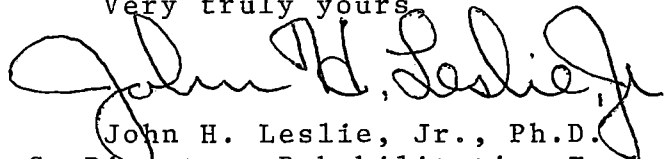
December 22, 1976

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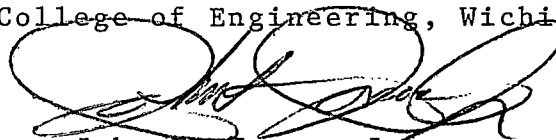
Advanced motel reservations will be made in your name upon receipt of the enclosed conference questionnaire. This questionnaire should be returned no later than January 7, 1977. A copy of flight schedules into and out of Wichita via the major airlines is enclosed for your travel convenience. The cost of travel and subsistence (up to a maximum of \$33.00 per day) will be reimbursed by the Cerebral Palsy Research Foundation of Kansas if this assistance is requested.

We sincerely appreciate your interest in this most meaningful activity and we look forward to your participation with a great deal of anticipation.

Very truly yours,



John H. Leslie, Jr., Ph.D.
Co-Director, Rehabilitation Engineering Center
College of Engineering, Wichita State Univer.



John F. Jonas, Jr.
Co-Director, Rehabilitation Engineering Center
Cerebral Palsy Research Foundation of Kansas,
Inc.

Enclosures: Flight Schedules
Agenda
Diagram
Participant Questionnaire

Note: Limousine service is available from Wichita Mid-Continent Airport to the Holiday Inn Plaza on approximately a 45-minute periodic basis during the day. At evening hours, the schedule varies somewhat but the service is still available.

WORKSHOP AGENDA

TITLE: Environmental Barriers and the Disabled

Sunday, February 6

7:30 p.m.	Registration
8:00 p.m.	Keynote Address
9:00 p.m.	Social Hour (food and drink)

Monday, February 7

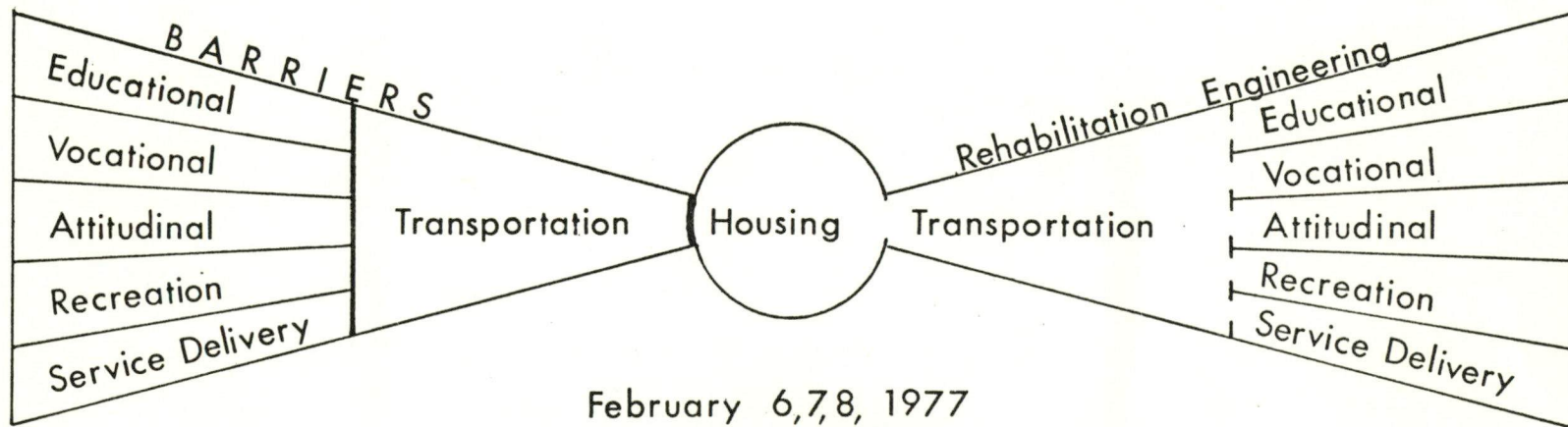
8:00 a.m.	Guest Paper Presentations
9:30 a.m.	Coffee Break
10:00 a.m.	Guest Paper Presentations
11:30 a.m.	Instructions to Workshops
12:00 Noon	Lunch
1:00 p.m.	Workshop Sessions
4:00 p.m.	Free Time
6:00 p.m.	Dinner
7:30 p.m.	Social Activity

Tuesday, February 8

8:30 a.m.	Workshop Presentations
10:00 a.m.	Coffee Break
10:30 a.m.	Workshop Presentations
11:30 a.m.	General Session
12:00 Noon	Lunch
1:00 p.m.	Issues/Answers
2:00 p.m.	Adjournment

CPRFK REC

Environmental Barriers Workshop



February 6,7,8, 1977
Holiday Inn Plaza
Wichita, Kansas

SPONSORS: Cerebral Palsy Research Foundation of Kansas

College of Engineering, Wichita State University

PHONE: 316-683-5627
316-689-3425

after 5, 316-838-8600

REHABILITATION ENGINEERING WORKSHOP
February 6, 7, and 8
Wichita, Kansas

THEME: Environmental Barriers and the Physically Disabled

CO-CHAIRPERSONS: Ms. Pamela J. Cluff, Member of A. W. Cluff
& P. J. Cluff, Architects

Mr. Thomas Moses, General Manager, Reedy Creek
Improvement District (Disneyworld)

Tentative Speakers: The following persons represent the diverse
fields of rehabilitation engineering,
transportation, education, vocational and
employment, housing, recreation, service
delivery, and legislation both from a
public and private viewpoint.

Housing---Mr. Ronald Mace, Barrier Free Environments, Inc.

Transportation---Mr. Ira Laster, Department of Transportation

Education---Dr. Max Mueller, Bureau of Education for the Handicapped

Service Delivery---Dr. Morton Leeds, Department of Housing & Urban
Development

Rehabilitation Engineering---Mr. Douglas Hobson, Rehabilitation
Engineering Center, Memphis State
University

Service Delivery---Ms. Jane I. Staub, MA, Psychologist, Ontario
Crippled Childrens Center

Legislative---Mr. Richard Loux, Former Minority Leader, Kansas
House of Representatives

Recreation---Mr. Ronald Adams, University of Virginia, Therapeutic
Recreation

Aging---Dr. Edward Peizer, Veterans Administration

Economic Analysis---Dr. Allen Schuermann, Wichita State University

Conference Participants: Representatives from all of the
Rehabilitation Engineering Centers supported
by the Rehabilitation Services Administration
of HEW will be in attendance. Also,
persons from local and regional vocational
agencies will be present. Education
representatives will be included as well
as local members of various housing
authorities. The workshop will also be
attended by members of local and state
industrial organizations. The disabled,
themselves, will be active participants in
the conference.

FLIGHT SCHEDULES

CONTINENTAL - to Wichita

<u>From</u>	<u>Leave</u>	<u>Arrive</u>	<u>Flight</u>
Denver	12:15 pm	2:22 pm	24
	4:07 pm	6:14 pm	426
Houston	2:25 pm	4:32 pm	443
Los Angeles	8:25 am	2:22 pm	918/24
	11:55 am	6:14 pm	910/426
Oklahoma City	3:55 pm	4:32 pm	443
Portland	7:55 am	2:22 pm	420/24
	12:00 noon	6:14 pm	426
Seattle	8:45 am	2:22 pm	456/24
	12:00 noon	6:14 pm	908/426

CONTINENTAL - from Wichita

<u>To</u>	<u>Leave</u>	<u>Arrive</u>	<u>Flight</u>
Denver	3:00 pm	3:13 pm	73
	4:55 pm	5:08 pm	443
	8:05 pm	8:18 pm	427
Houston	6:39 pm	8:47 pm	426
Los Angeles	4:55 pm	7:04 pm	443/605
	8:05 pm	11:06 pm	427/43
Miami	6:45 am	12:38 pm	430/954
Oklahoma City	6:45 am	10:57 am	430/291
Portland	4:55 pm	8:03 pm	443
	8:05 pm	10:37 pm	427
Seattle	4:55 pm	8:15 pm	443/989
	4:55 pm	9:00 pm	443
	8:05 pm	11:00 pm	427/431

Note: These suggested flights are representative of those that will allow you to attend the entire workshop. Please schedule accordingly.

January 5, 1977

Mr. John H. Leslie, Jr., Ph.D.
Co-Director, Rehabilitation Engineering Center
Mr. John F. Jonas, Jr.
Co-Director, Rehabilitation Engineering Center
Cerebral Palsy Research Foundation
of Kansas, Inc.
4320 E. Kellogg
Wichita, Kansas 67218

Dear Sirs:

I have been asked by Dr. William A. Spencer, Director of the Rehabilitation Engineering Center here at TIRR to participate in your February workshop on Environmental Barriers to the Disabled. I look forward to this opportunity as I believe rehabilitation engineering may contribute much to alleviating the environmental barriers which those of us who are severely disabled face each day.

My attendant, Mac Brodie, will be traveling with me to the meetings and I would appreciate it if you could arrange for us to have a room with two beds.

I am anxious to meet you and to take part in the conferences you have planned.

Sincerely,

Lex Frieden
New Options Research Director

cc: William A. Spencer, M.D.
Director of TIRR

LF/asm

WELCOME

The Cerebral Palsy Research Foundation Rehabilitation Engineering Center and the College of Engineering at Wichita State University would like to take this opportunity to welcome you to the city of Wichita. Additionally, we are delighted that you could find time in your busy schedules to attend this most important conference.

PURPOSE

This conference entitled, "Environmental Barriers and the Physically Disabled", is designed to determine short term and long term game plans for an integrated approach to the solutions of the problems of the severely disabled through the media of rehabilitation engineering. The theme of the conference is devoted to developing a meaningful lifestyle for the severely disabled, again through rehabilitation engineering.

The scope of the conference is such that we will deal with the following eight aspects of rehabilitation engineering as it relates to the solution of the problems of the severely disabled.

1. Attitudinal Barriers
2. Architectural Barriers
3. Barriers to Effective Transportation
4. Housing and Service Delivery Barriers
5. Vocational or Employment Barriers
6. Barriers to Effective Education
7. Barriers to Meaningful Recreation
8. Barriers Encountered by the Aging

All of the presentations scheduled for Monday morning will address various aspects of the topics as they relate to the disabled population and the rehabilitation engineer.

The presentations are to inform and stimulate your thinking so that you may actively participate in the Monday afternoon workshop groups.

SPONSOR

This conference is being sponsored through a grant from the Rehabilitation Services Administration (RSA). RSA is extremely concerned that a near term and long term rehabilitation engineering strategy be developed to recognize all facets of the problems associated with the severely disabled. It is to this end that this conference is dedicated.

The following pages present a detailed agenda of the conference. All attempts will be made to adhere closely to the agenda and still give the attendees, as well as the speaker, ample opportunity for an appropriate dialogue such that all of us will receive from the conference new ideas that we can apply specifically to our field in dealing with the diverse problems affecting the physically disabled.

STEERING COMMITTEE

Mr. Joseph Traub
Office of Human Development
Department of Health, Education and Welfare
330 C Street, S.W.
Washington, D.C. 20201

Mrs. Pamela Cluff
A.W. Cluff & P.J. Cluff Architects
191 Eglinton Avenue E.
Toronto, Canada M4P 1K1

Mr. Thomas M. Moses
General Manager
Reedy Creek Improvement District
P.O. Box 36
Lake Buena Vista, Florida 32830

Mr. Anthony Staros
Director
Veterans Administration
Prosthetics Center
252 Seventh Avenue
New York, New York 10001

Mr. John F. Jonas, Jr.
Co-Director
Cerebral Palsy Research Foundation
Rehabilitation Engineering Center
P.O. Box 8217
Wichita, Kansas 67208

Dr. John H. Leslie, Jr.
Co-Director
Cerebral Palsy Research Foundation
Rehabilitation Engineering Center
P.O. Box 8217
Wichita, Kansas 67208

REHABILITATION ENGINEERING CENTERS

Dr. James Reswick
Project Director
Rehabilitation Engineering Center
Rancho Los Amigos Hospital
7601 East Imperial Highway
Downey, California 90242
Telephone: 213-922-7167
PGN 23-P-55442/9
Core Area: "Functional Electrical
Stimulation of Paralyzed Nerves
and Muscles"

Dr. Richard Herman
Project Director
Rehabilitation Engineering Center
Kruzen Research Center
Moss Rehabilitation Hospital
12th Street & Tabor Road
Philadelphia, Pennsylvania 19141
Telephone: 215-221-3645
PGN 23-P-55518/3
Core Area: "Neuromuscular Control
Systems"

Dr. William A. Spencer
Project Director
Rehabilitation Engineering Center
Texas Institute for Rehabilitation
and Research
1333 Moursund Avenue
Houston, Texas 77025
Telephone: 713-797-1440
PGN 23-P-57888/6
Core Area: "Effects of Pressure on
Tissue"

Dr. Warren G. Stamp
Project Director
Rehabilitation Engineering Center
University of Virginia
Charlottesville, Virginia 22901
Telephone: 804-924-5551
PGN 23-P-57995/3
Core Area: "Spinal Cord Injury"

Dr. William Berenberg
Project Director
Rehabilitation Engineering Center
Children's Hospital Medical Center
300 Longwood Avenue
Boston, Massachusetts 02115
Telephone: 617-734-6000 Ext. 2866
PGN 23-P-55854/1
Core Area: "Sensory Feedback
Mechanisms"

Dr. Clinton Compere
Project Director
Rehabilitation Engineering Center
Northwestern University
345 East Superior Street
Room 1441
Chicago, Illinois 60611
Telephone: 312-649-8560
PGN 23-P-55898/5
Core Area: "Internal Total Joint
Replacement"

Dr. Paul Bach-y-Rita
Project Director
Rehabilitation Engineering Center
Smith-Kettlewell Institute
of Visual Sciences
2232 Webster Street
San Francisco, California 94115
Telephone: 415-563-2323
PGN 23-P-57590/9
Core Area: "Sensory Aids"

Mr. John F. Jonas, Jr.
Dr. John H. Leslie, Jr.
Project Co-Directors
Rehabilitation Engineering Center
The Cerebral Palsy Research Foundation
of Kansas, Inc.
4320 East Kellogg Street
Wichita, Kansas 67218
Telephone: 316-683-5627
PGN 23-P-57960/7
Core Area: "Vocational Aspects of
Rehabilitation"

SPEAKERS

HOUSING:

Ronald L. Mace, AIA
P.O. Box 3446
Fayetteville, North Carolina 28305

TRANSPORTATION:

Ira Laster
Environmental Program Analyst
Department of Transportation
400 7th Street S.W.
Room 9422
Washington, D.C. 20590

EDUCATION:

Dr. Max W. Mueller
Chief Research Projects Branch
Division of Innovation & Development
U.S. Office of Education
400 Maryland Avenue S.W.
Washington, D.C. 20202

SERVICE DELIVERY:

Ms. Jane I. Staub, M.A.,
Psychologist
Ontario Crippled Children's Center
350 Rumsey Road
Toronto, Ontario M4G 1R8

EMPLOYMENT:

Mr. Rob R. Gregg
Manager
Administrative Engineering
Gates Learjet Corporation
8220 West Harry
Wichita, Kansas 67209

ECONOMIC ANALYSIS:

Dr. Alan Schuermann
Department of Industrial Engineering
Wichita State University
Box 35
Wichita, Kansas 67208

ATTITUDINAL BARRIERS:

Patricia Falta, M.S.
Environmental Designer
2357 MacNeil Road
Montreal, Quebec H3R 2X1

SPEAKERS (cont'd)

RECREATION:

Dr. Julian U. Stein
Consultant
Programs for the Handicapped
American Alliance for Health,
Physical Education & Recreation
120 16th Street N.W.
Washington, D.C. 20036

REHABILITATION
ENGINEERING:

Mr. Douglas Hobson, P.E.
Rehabilitation Engineering Center
1248 LaPaloma Street
Memphis, Tennessee 38114

AGING:

Dr. Edward Peizer
Deputy Director
V.A. Prosthetics Center
252 7th Avenue
New York, New York 10001

LEGISLATIVE:

Mr. Richard C. Loux
Kansas Corporation Commission
4th Floor
State Office Building
Topeka, Kansas 66612

SERVICE DELIVERY:

Dr. Morton Leeds
Program Support Staff
Office of Assisted
HUD Building - Room 6233
451 7th Southwest
Washington, D.C. 20410

VOCATIONAL TRAINING:

Mr. Tom Bergers
Director
Werpenrodd
Vocational Training Center
Hague, Holland

WORKSHOP INSTRUCTIONS

In developing a workshop format, in order to address the many issues associated with the problems of the physically disabled, the following items should be kept uppermost in mind when discussing specific questions included herein.

1. Target groups or elements of the handicapped population should be identified as related to the questions and issues raised in the workshop.
2. The sheer magnitude of the problem should be defined both on the basis of present estimates and on the basis of future projections or trends.
3. Available knowledge should be identified as it relates to research developments affiliated with the physically handicapped in a clinical environment as well as those research developments which affect the physically disabled client as related to his/her home or industrial environment.
4. Gaps in available knowledge as related to the appropriate client population should be identified and, if possible, quantified.
5. Specific areas of fundamental and applied research dealing with environmental barriers for the physically disabled should be identified on both a short range and long range basis and priorities developed as well as funding sources identified and quantified.
6. Information dealing with the broad area of environmental barriers and the physically disabled should be identified and disseminated to user organizations both from an informational point of view and from a training point of view so that professionals can be trained in the field.
7. Service delivery strategies should be developed in order that services resulting from rehabilitation engineering research can be delivered to the user population.

In discussing these issues, it should be realized that all facets of a disabled person's life should be considered, i.e. from infancy through adolescence and adulthood to his senior years.

EXPENSE REPORT

Environmental Barriers Workshop
Wichita, Kansas
February 6, 7, 8, 1977

Name: Lex Frieden
Mailing Address: 9667 Meadowale
Houston, Texas 77063

Expenses

	<u>Breakfast</u>	<u>Lunch</u>	<u>Dinner</u>	<u>Lodging*</u>	<u>Transportation</u>
Sunday (6th)	_____	_____	_____	_____	<u>\$258.00</u>
Monday (7th)	_____	<u>XXXXX</u>	<u>XXXXX</u>	_____	_____
Tuesday (8th)	_____	<u>XXXXX</u>	_____	<u>\$64.63</u>	_____

Other (Please itemize): _____

Total \$362.63

*Attach receipts All expenses include those of my attendant, Mac Brodie.

I certify that the above stated expenses
were incurred by me while traveling to
and from the conference.

Signature: _____

Title: New Options Research Director
Texas Institute for Rehabilitation and Research

Mail to:

Cerebral Palsy Research Foundation
P.O. Box 8217
Wichita, Kansas 67208

Attention: Roger G. Nelson

Rehabilitation Engineering - Thoughts about the Present and Future

Douglas A. Hobson, P. Eng.

I have been asked to discuss the role and contribution of rehabilitation engineering as it relates to service delivery, vocation, architecture, education, transportation, recreation, and societal attitudes -- and do it all in ten minutes. I suppose I could ramble through a series of slides depicting Captain Marvel with his flashing lights and computer print-outs doing all kinds of "far-out" things -- with some of them even benefiting patients; but I do not think that that would serve to impress anyone in this audience. I'm sure that most people in this room have few doubts that the judicious application of science and technology has tremendous potential for enhancing many aspects of the lives of the physically handicapped population.

I would rather spend the short time I have discussing with you some basic issues about the field of rehabilitation engineering most of which are relative to the focus of this workshop. I should say at the onset that some of the views I will be expressing will not entirely be mine, as some will be opinions contributed by others at the recent workshop in Knoxville, (1) or at previous workshops held under the auspices of CPRD. (2) The factual information I have manipulated from several references that I have listed at the end of the paper.

Brief Background

Over the past twenty years a variety of Federal programs have attempted to direct advances in technology to the needs of the physically handicapped population. To date, the greatest successes have been made in the fields

of prosthetics and orthotics. These advances have come largely as a result of the close coordination, consultation, evaluation and dissemination efforts carried out by the formed Committee of Prosthetics Research and Development, of the National Academy of Sciences. A major commitment to research and development in the fields of prosthetics and orthotics by federal agencies such as the Veteran's Administration (VA) and the Rehabilitation Services Administration (RSA), Department of Health, Education and Welfare provided the funding base necessary to achieve these advances. This effort was further supported by the strong prosthetics and orthotics industry that has a well established service delivery system. In general, progress in other areas involving the application of technology to the severely handicapped have not experienced similar successes.

Throughout the 1960's, attempts were made to transfer sophisticated technology ^{developed} by the National Aeronautics and Space Administration (NASA), the computer industry, and other space-age technical spin-offs into the clinical setting. This effort was abandoned after eight years as no significant success was achieved. The major difficulties stemmed from the inability of the involved disciplines to communicate effectively, and from the fact that there was not a mechanism within the clinical environment that could integrate the technology in a manner that was acceptable to patients. A more realistic approach has placed engineers, physicians, and related professionals together in a clinical setting to work directly on patient problems. This approach has been termed rehabilitation engineering, and received a major program commitment by DHEW in FY 1972, and also more recently by the VA.

Specific areas of concern have been delineated for rehabilitation engineering which distinguishes this RSA program from the biomedical engineering program of the National Institutes of Health (NIH). The RSA plan

called for the establishment of a network of rehabilitation engineering centers throughout the country. Since its inception in July 1971, seven rehabilitation engineering centers have been established within complexes that combine medical and engineering resources with a commitment to rehabilitation services, research, and training programs. Each center has been charged with a core-area of research with an obligation to function as a cooperating member of the center network for the purpose of information exchange, evaluation, and education.

Objectives of Rehabilitation Engineering

Rehabilitation engineering is a new and rapidly developing sub-specialty of medical engineering. The field is in a very dynamic state of growth, and at this time no clear picture emerges as to the ultimate scope and boundaries of the field. However, the objectives of rehabilitation engineering are fairly clear and have not changed substantially since its inception in 1971. I wish to present a few definitions to you, the first of which was developed in 1971 at CPRD workshop⁽²⁾ and the second was derived at the recent Knoxville meeting⁽¹⁾.

A) *"Rehabilitation engineering strives to enhance the lives of the physically handicapped through clinical involvement in a total approach to rehabilitation combining medicine, engineering, and related sciences and technology."*

(CPRD-1971)

B) *"Rehabilitation engineering is the application of science and technology to improve the quality of life for the disabled."* (Knoxville - 1976)

I personally prefer the 1971 definition as it contains key words - -

"Clinical involvement" and "total approach to rehabilitation". Rehabilitation

engineering like any other discipline needs a base or nucleus from which to develop. It is my view that the clinical setting is the appropriate environment in which Rehabilitation Engineering should grow its roots, and then develop from that experience to encompass the total rehabilitation process. It will ^{be}_A through a basic commitment to solving patient problems that the field will best develop its identity and strength. And upon this foundation can be based the ongoing justification for a national delivery system, educational programs, research activities, and last but certainly not least - the necessary financial support

Justification

The hallmark of our contemporary society is on the one hand the high and accelerating level of science and technology and on the other, the basic concern for the welfare of the sick and the disabled. The challenge of rehabilitation engineering is to marry the advances of the former with the needs of the latter.

A conservative estimate is that at least 10 million of the country's (3) 20 million physically handicapped can benefit from some form of technology in their daily lives. Prosthetics and Orthotics have been the primary source of technology for the physically handicapped over the years. Recent (4) studies conducted by the Committee on Prosthetics Research and Development indicate that approximately 4 million individuals directly benefit from prosthetic and orthotic services which are provided primarily by the private sector. By deduction, this means that there are approximately 6 million individuals who stand to benefit directly from additional types of technology that are generally unavailable to them.

In many cases it is possible to change a disabled person from a ward

of society to a contributing member thereby providing a direct economic cost/effectiveness measure which justifies rehabilitation engineering.

However, when measures of improved quality of life through reduced dependency and increased life activities are used, rehabilitation engineering, to the extent that it is successful, is totally justified aside from cost. Therefore, it would be totally immoral to decide on the social worth of rehabilitation engineering on the basis of financial cost/effectiveness alone - - although costs must, and always will be, of major concern.

Current Status

At the present time there are seven rehabilitation engineering centers established within the RSA network, and approximately an equal number of clinically based programs functioning within the VA structure. The strength of these programs is their legislated support which provides a stable financial base for both manpower and program development. Each center within the RSA network has adopted a core area of research, and in total there is probably in excess of 150 research projects actively being carried out; with an additional 50 projects being supported as individual research projects. Throughout these projects, there is in excess of 150 engineers, therapists, research scientists, prosthetists, orthotists, and other professionals working on projects "to improve the quality of life for the physically handicapped." It is unfortunate that at this time there are probably less than six engineers working as functioning members of clinic teams, with the direct responsibility for delivery of newly developed, or available technology to solve patient problems - - the stated objective of rehabilitation engineering. Nor do we have an educational process by which individuals can gain the training and experience necessary to perform this fundamental activity. Nor do we have a

clear plan developed for the evolution of a delivery system that is necessary to "package" technology in a manner that is acceptable to consumers.

I do not mean to imply that the present research activities ~~are~~ being conducted under the umbrella of Rehabilitation Engineering ^{lack} the potential for solving many of the problems experienced by the handicapped population -- as many are excellent projects. However, I do mean to imply that a partial shift in emphasis is necessary, which will result in a greater commitment to design and development combined with an ongoing dedication to solve patient problems - if the essence of rehabilitation engineering is to be justified in this decade. The point is, that many of the every day problems experienced by the handicapped population have solutions within the armamentarium of available technology. The challenge that is before us is to identify and modify this technology in a manner that will result in concepts and devices that will offer immediate benefit for the handicapped. Failure of those within the present network to respond to this need for an identifiable clinical component, combined with community outreach activities that can directly benefit those in need, will greatly reduce the effectiveness and basic justification of rehabilitation engineering in the years ahead.

Challenge for the Future

I have outlined in a general way the status of the field, the deficiencies as I see them, and now I would like to conclude by discussing what I feel are our challenges for the future; particularly as they relate to the theme of this workshop.

I am most pleased to say that many positive steps have been taken in the last year or so; that if realized will resolve many of the concerns that have been mentioned above. For example, more emphasis has been placed on

research and development projects that have immediate prospects for patient application. Some of these developments are now finding their way to manufacturing and distribution and are becoming available to others on a national basis. The Knoxville workshop has produced strong recommendations for a pilot education project in rehabilitation engineering, which could form the basis for the development of a national training program that will provide the manpower necessary to get the job done in the years ahead. Plans are underway for the establishment of a number of demonstration service delivery models, complete with identification of potential third-party payment for services.

Now, as we identify new needs and visualize the growth of rehabilitation engineering to encompass community based problems of, home and work environment modifications, transportation problems, recreational needs, architectural attitudes, and education of the handicapped -- my plea is, let's be realistic.

Let's not forget rehabilitation engineering has only been formally recognized for five years; and its foundation is still weak and uncertain, its "bench strength" is lousy, and an organized system to "deliver the goods" is non-existent. Let's not repeat the mistakes of the 1960's by dumping technology on the lives of handicapped with the implication that the onus is on them to be grateful and accept it even if it generates more problems than it solves. Let's not forget that technology as it relates to the needs of the handicapped generally requires some moderating influence; which may be in the form of a clinic team approach, an involved consumer advocate, or a setting in which the consumer himself can make his or her needs and desires clearly understood. As we gaze into the future let's from time to time touch base with the lessons of the past, let's make sure we are working from

an ever strengthening foundation, and move forward to embrace ^{these} new challenges with enthusiasm; and above all with a true concern for those we have pledged to serve.

References

1. Workshop on Rehabilitation Engineering Education (Draft Proceedings):
Held at University of Tennessee, Knoxville, Tennessee, November 3-5,
1976.
2. Rehabilitation Engineering - - A Plan for Continued Progress; CPRD,
1971, and 1974 (draft)
3. Science and Technology in the Service of the Physically Handicapped;
Committee on National Needs for the Rehabilitation of the Physically
Handicapped; Division of Medical Sciences, National Research Council,
1976.
4. Patient Population and Other Estimates of Prosthetics and Orthotics
in the U.S.A.; LeBlanc, M.A.; Orthotics and Prosthetics; September
1973, pages 38-44.
5. Rehabilitation Services Administration. DHEW, R&E Strategy, FY, 1976

Julian U. Stein
Consultant, Programs for the Handicapped
American Alliance for Health, Physical Education, Recreation
1201 16th Street, N. W., Washington, D. C. 20036

Many times problems are approached in terms of obvious symptoms rather than basic causes. Although this process results in elimination of some specific problems, many others are unaffected. Therefore, a dual approach is necessary to result in the most rapid removal of problems and barriers causing less than full participation of impaired, disabled, and handicapped persons in educational, rehabilitation, recreational, social, and vocational activities. These same kinds of problems and barriers limit opportunities and make it extremely difficult for these populations to attain high quality lives worth living.

As individual topics being considered at this workshop are looked at analytically and objectively, it seems that one basic cause permeates them all—attitudinal barriers. Unfortunately too many of us are affiliated with hardened categories that subtly influence our attitudes and ways in which we relate to and interact with impaired, disabled, and handicapped individuals. Limited expectations of what individuals can and cannot do not only affect the general public, generalists in education, and other disciplines represented at this workshop, but parents, and specialists in many of these same disciplines. Obviously persons interested and involved in physical education, recreation, sports, and related activity areas for these populations are not immune from the

¹ Paper presented at workshop on Environmental Barriers and the Physically Disabled sponsored by Cerebral Palsy Research Foundation of Kansas in cooperation with the College of Engineering of Wichita State University at the Holiday Inn Plaza, Wichita, Kansas, held February 6-8, 1977.

influence of this type of negative behavior. It is not the intent or purpose of this presentation to delve into basic causes of problem areas restricting or limiting participation of impaired, disabled, and handicapped persons in recreation programs and leisure activities. Rather various innovative ways in which specific problems, barriers, and inconveniences have been overcome are to be explored. Consideration is to be given to ways individuals with various psychomotor, affective, and cognitive conditions have been able to take part actively in recreation programs and leisure activities. For example:

- . Visually impaired ski cross country, downhill and on water, participate in gymnastics, play golf, skin and scuba dive, wrestle, climb the highest mountains, and run in competitions such as the Boston Marathon.
- . Amputees, paraplegics, and quadraplegics ski, swim, fish, dive, surf, and take part in gymnastics, pool, archery, hockey, weight lifting, football, soccer, karate, basketball, golf, tennis, fencing, track and field.
- . Bedfast individuals dance, take part in dramatic productions, work with clay, paint, attend camps and parties, and swim.

Basically adaptations and modifications of facilities, equipment, devices, and materials used in recreation programs and leisure activities are designed for therapeutic, educational, training, instructional, rehabilitation, and recreational purposes. As such three basic organizational patterns need to be considered for these programs and activities --

- . Regular programs or services - individuals who can take part in regular activities, safely, successfully and with personal satisfaction should be guided and encouraged to participate in regular and community programs where they participate with family, friends, peers, and contemporaries.
- . Intermediate or halfway house type programs or services - many individuals have the potential to take part eventually in regular programs but for the immediate present cannot. Something is lacking - confidence, experience, skills, emotional stability, social awareness, intellectual ability, physical condition, overall control, interest. The intermediate or halfway house type program serves to help the individual overcome such problems.

- Special programs or services - some individuals have severe, profound, and multiple conditions so that they need long-range opportunities and experiences in special, segregated, or sheltered programs. Individuals in this group should not be considered permanently confined to special programs and activities- to consider such an approach is inconsistent with concepts advocated throughout this presentation and incorporated in current legislation.

As related to recreation programs and leisure activities, problems, obstacles, and barriers requiring a trans-disciplinary approach transcend housing, transportation, education, facilities, service delivery, and programs including activities, methods, and evaluation. Certainly communication, cooperation, and coordination among individuals representing various disciplines and associations interested and involved in all of these areas are vital. Much is going on in these areas individually and collectively throughout the world. Interaction and exchange stimulated by workshops such as this one are invaluable for promoting more effective and efficient delivery of services. Since most of these topics are being dealt with in other presentations at this workshop, emphasis of this presentation is to be on general factors for developing and producing devices related to facilities, activities, and methods for recreation programs and leisure activities. It seems appropriate to define the many facets of recreation. Recreation is defined as --

Activities engaged in voluntarily during an individual's uncommitted time for personal fulfillment, health and fitness, creative expression and aesthetic appreciation, socialization, enjoyment, pleasure, and fun, and to fulfill leisure skills and interests.

Specific elements in a comprehensive recreation program include --

- Leisure education - a process by which individuals learn about recreation and leisure activities, opportunities, facilities in general and how to use and apply them in their own communities.
- Therapeutic recreation - a special service within the broad area of recreational services that involves a process which utilizes recreation services or progressive intervention in some physical, emotional, and/or social behavior to bring about a desired change in that behavior and to promote growth in that individual.

- . Recreation conducted in community settings - a large majority of impaired, disabled, and handicapped persons can take part in recreation program and leisure activities in their own communities right along with their families, friends, and peers. Basic aims and objectives of programs and activities conducted in these settings are the same for all participants and lead to amusement, diversion, relaxation, and re-creation. However, it should be noted that all programs conducted in community settings may not be of an integrated or mainstreamed nature. Special and intermediate type programs are also appropriate for community settings. The community resources and facilities can be used in many ways to stimulate active participation by these populations in recreation programs and leisure activities.

As an ultimate objective of recreation programs and leisure activities at any of these levels, maximum degrees of independent, self-actualizing behavior is stressed. Many individuals, regardless of type or severity of handicapping condition, simply need minor modifications or adaptations of facilities, equipment, devices, or materials to be able to take part in ongoing recreation programs and leisure activities. However, individuals and groups which are responsible for designing, developing, producing, and distributing such equipment, devices and materials need to be aware of, recognize, and deal with problem areas such as ---

- . Recognizing pros and cons of custom-made and mass produced items.
- . Determining when homemade adaptations are more practical, functional, and feasible than commercial produced items.
- . Obtaining input and involving directly individuals with various handicapping conditions in process of developing and designing facilities, equipment, devices, and materials.
- . Basing adaptations and modifications in these areas on individual needs rather than diagnostic labels or traditional categories.
- . Emphasizing flexibility and adaptability of facilities, equipment, devices, and materials so that individual participant needs can be best and most appropriately met through universal use items.
- . Approaching design of needed items in ways that emphasize simplicity rather than over-sophistication and complexity.
- . Keeping expense of items reasonable so that they are readily available to individuals who need them the most.

- . Recognizing all that has and continues to go on in this field in general and as related to active participation in recreation programs and leisure activities by impaired, disabled, and handicapped persons in particular so that continual rediscovery of the wheel can be eliminated.
- . Developing and maintaining ways by which personnel interested and involved in disciplines and specializations related to rehabilitation engineering have regular and planned opportunities for dialogue to exchange information, communicate ideas, and attack mutual problems.
- . Applying technical know how more effectively in development, refinement, and distribution of equipment, devices, and materials for use in recreation programs and leisure activities.

Architectural barriers, despite federal, state, and some local legislation requiring that all facilities be accessible, and attitudes of many people toward special facility and equipment needs are among greatest and most pressing problems in these areas. Many communities and states still emphasize isolating special populations in special facilities. Groups still superimpose their wishes on special populations whether these approaches and procedures are appropriate or desired by the group. Many facility and equipment modifications are not wanted or needed. On the other hand, basic accessibility still remains a major problem. Simple, commonsense adaptations can make inaccessible facilities functional and usable by even the most severely involved individuals.

Special projects, task force groups, advisory panels, planning committees, and countless groups explore problems of facilities and equipment for special groups. Unfortunately, very few of these groups involve or even ask input from or opinions of those who are to be most directly involved -- consumers and their families. As a result --

- . Some playgrounds designed for severely and profoundly mentally retarded adults can best be used by Marine Commandos!
- . Braille trails go unused by the blind!
- . Totally accessible facilities are found to be far from totally accessible!
- . Countless millions of dollars are used to build special facilities not needed or wanted by the group for which they were designed.

- . People are ripped off unmercifully by guarantees that don't exist and expensive devices that can be obtained free or made inexpensively!
- . Individuals are prostituted by special programs, unique aids, and scientific sounding programs, activities, and devices that are not special, unique, or scientific!

Much extensive equipment and expensive special facilities are unnecessary.

Participants want to take part in programs conducted in facilities that are as little different from those used by their peers and contemporaries as possible.

Basic accessibility is the key to use by even the most severely involved person. Legal, moral, and ethical reasons exist to take this tact and follow this approach. So many of the most practical, functional, and realistic adaptations have been initiated by consumers themselves. Consumers must be involved--professional providers of services, legislators, and decision-makers must listen and heed what consumers say.

In addition to these problem areas, a number of specific facility, equipment, device, and materials needs require consideration, exploration, and development by rehabilitation engineers --

- . Refining wheelchairs for use in specific sports and athletic activities.
- . Developing new and additional equipment, devices, and materials for use in various physical education, recreation, sports, and athletic activities.
- . Developing new and additional equipment, devices, and materials for use with populations consisting of severely and profoundly mentally retarded, and seriously multiple involved individuals.
- . Developing and refining equipment, devices, and materials for aquatic and swimming activities involving pool heaters, solar heating of pools, ways to retain heat in pools, pool resting platforms, improvised ramps, flotation devices, pool design itself, and inexpensive ways to change and heat water quickly and inexpensively.
- . Developing of aquatic activities for use with various populations in regular, intermediate, and special settings.
- . Developing more effective multiple use facilities, equipment, devices, and materials for use in all aspects of physical education, recreation, sports, aquatic camping, outdoor education, and related activity areas involving impaired, disabled, and handicapped participants.

- . Emphasizing facilities, equipment, devices, and materials that enable impaired, disabled and handicapped persons to participate in least restrictive environments--in regular program settings--to the maximum degree possible.
- . Considering ways to eliminate conditions in facilities that accentuate, aggravate and irritate sensory difficulties while at the same time emphasize and make maximum use of sensory abilities of participants.
- . Giving some priority to ways and means of increasing and improving mobility of individuals with various sensory difficulties especially those with severe and multiple conditions so that they can attain more and higher quality opportunities for participation and comprehensive recreation programs and leisure activities.
- . Developing ways that camps and outdoor education recreation facilities--including wilderness areas--can be more effectively and easily used by impaired, disabled, and handicapped persons, especially those with severe and multiple conditions.
- . Exploring ways in which winter activities can be made more available and accessible to these populations, especially those with most severe and multiple conditions.
- . Developing materials for prosthetic devices that will make it possible for individuals with various types and levels of amputations to participate actively in sports such as football.

Mr. Chairman, Ladies and Gentlemen:

On behalf of the Board of the Dutch Society for the Rehabilitation, I thank the College of Engineering, as well as the Cerebral Palsy Research Foundation for the invitation to attend this Conference.

I am the Secretary of this Society which is coordinating various activities in the field of rehabilitation and is promoting the rehabilitation of the handicapped. Members of this umbrella organization are organizations from and for the handicapped. The body is for a large part subscribers by the Dutch government in order to further activities in this field and to obtain a good connection between the 150 member organization.

My daily job is Director of the Vocational Training Center for the Severely Physically Handicapped Youngsters from 12 to 20 years. I have taken a film of 22 minutes from home and if time is available, you will get the opportunity to see what we are doing for them. In our opinion, the best thing is to send every laddie well person to a normal school. However, we have to accent that if the laddie is too severe and there are other problems, for example, nursing, social circumstances, or misbehavior, it is necessary to have a choice for next to the best. Teaching, training, preparing youngsters for their entrance into society we have much experience about the subject we discuss as well as we can obtain a good advancement in the future by teaching our students how they can have more influence in their future lives and/or especially how they can improve their way of life.

How many persons are handicapped in our country? Our government has asked the central bureau to have an investigation and the research was based on a sample of 55,000 persons older than 4 years. We have translated the results to the population of a small town of 100,000 inhabitants older than 4 years.

Of these 100,000 inhabitants, some 8,700 would be handicapped by one or more disturbances. When categorizing these handicaps, the following approximate numbers would ensue:

- 3,900 people would have a disturbance in staying power, mainly caused by a disturbance of heart and lungs. They have, in general, trouble with all sorts of activities like climbing stairs.
- 3,700 people would have a disturbance in leg function. Some 900 of them would not be able to walk at all outside their home, or only with the help of another person.
- 1,400 people would have a disturbance in hearing. Of this group some 540 persons would not hear at all, or only with a special hearing aid.
- 820 people would be blind or partially sighted. Of this group some 290 persons would be blind, or could not move outside the home without a helper or special aids.

These are the main disturbances. There are, however, other disturbances where environmental barriers play an important role, such as those in arm and hand functions, in equilibrium, etc.

These handicaps would have the following repercussions on integration:

2,500 people would have difficulties when visiting public buildings

3,100 people would have difficulties in using public transport. Of this number about 1,400 would not be able to use this at all, and would have to rely on other means of transportation. Some 300 people would, outside their home, have to rely entirely on rolling transport such as a car, (electric) wheelchair, or a special invalid carriage.

This report was published in 1976. In the next few years we can expect a further development in the field of rehabilitation. However, the last 25 years our society, as well as our government, improved the situation for the handicapped.

At the moment, there are building regulations. In 1973 we published an extensive loose-leaf book, which gives the main details of barrier free design in general building, housing and facilities for open-air recreation. The criteria of this publication are accepted by all bodies, such as the government, building societies, architects, etc.

The technical commission of Rehabilitation International has asked us to publish the main part of this book on their behalf. This booklet: "Architectural Facilities for the Disabled" has had a world-wide distribution by ICTA: Fack S-161 03 Bronnma, Sweden.

Up to now the Netherlands has no general "imperative" legislation as regards making building accessible. The municipalities are, however, in the process of taking over the criteria of "barrier free design". These are laid down in the "model building regulations", which were established in 1975 through negotiations between the Society of Municipalities and the Netherlands Society for Rehabilitation. These regulations are "imperative" for public buildings, with the exception of privately owned shops and offices. Rules exist for making the subsidized sport halls, swimming pools and communal centres accessible. There are already some 1,000 fully accessible buildings that have received the international symbol after careful inspection. We have some 120 volunteers who inspect these buildings. These are mostly handicapped people.

Last year some \$10 million was spent on the adaption of public buildings under the scheme of combatting unemployment. Efforts are being made to obtain funds from the government for the carrying out of a complete program of adaptation of existing buildings. Research has been carried out to ascertain the priorities in the demands of the handicapped.

Housing

There is a great demand for housing for the handicapped. The government subsidizes the extra cost, necessary for adaptation. In principle an adapted house should be available for all handicapped who are in need of it. There is, however, still a shortage in this field. The time people have to wait for such a house is often too long. Adaptations are being made to existing houses as well as to new houses. The aim is to obtain a greater "flexibility" in housing, so that necessary adaptations can be more easily attained. Efforts have to be made to build a certain percentage of housing in a form that serves the interests of various groups. As an example of this is given in the type where the ground floors of two standard dwellings are being transformed into one dwelling for a wheelchair-user and his family, and the two first floors into two small flats for single persons or households of two persons. In this way the integration of the handicapped, as well as the single person, is furthered. In this scheme little extra cost is involved if the planning is made from the outset.

The classification of requirements is laid down in the brochure "Housing", which has been written in conjunction with the film of the same title.

The Netherlands has a variety of collective living conditions for the physically handicapped. They vary in size between the internationally well known "Het Dorp" with about 420 inhabitants and the small settlement for about 20 persons. Various experiments are being carried out.

Although there is still a shortage in this field, we believe that the situation in the Netherlands is comparatively fairly advanced. This is also due to the extensive (and expensive) system of social insurance in our country.

Transport

The Dutch railways are cooperating with the Netherlands Society for Rehabilitation, by making stations and trains as accessible as possible. All the main stations have now "leaf-bridges" on wheels, so that a wheelchair-user can ride into the train. The difference in height and distance between the platforms and the trains is about 50 cm.

The Dutch railways provide assistance at most stations to handicapped people who need help. Those handicapped who need an escort on their journey can obtain a special legitimization card, on which the escort receives free transport.

The Dutch railways publish an annual guide in which all facilities are described.

Transport by air is comparatively easy; Schiphol airport is adapted.

The Amsterdam metro, which will be opened in about 9 months, will be fully usable by wheelchair-users.

Buses are not adapted. There are, however, buses for wheelchair-users in use in a number of cities. Most of them are owned by (small) private companies or institutions for the handicapped. Efforts are being made to obtain a system for public transport that should equal the Swedish example.

Under the scheme of social insurance, cars and other means of transport such as (electric) wheelchairs and special carriages are being provided. Allowances are given towards the running of these cars or for the running of privately owned cars.

This pertains to people who need transport for their work or for enabling them to partake in social contact, recreation, etc. A scheme of adapted facilities along the highroads is being established. An annually published map of the relevant restaurants and filling stations that have a toilet for wheelchair-users gives the detailed information on this subject.

There is a fairly large number of fully adapted sport halls and swimming pools. It is felt, however, that a much larger number of handicapped people could partake in sports.

The Netherlands Society for Rehabilitation publishes an annual guide in which all the special camps, holiday accommodation such as hotels, bungalows, tours, etc. are described. There is still a lack of adapted facilities for holidays for the handicapped. It is often not very easy to obtain the correct information.

The Netherlands Society for Rehabilitation has recently concluded an agreement with the main tourist organization (the ANWB, comparable to the British A.A.) to take over the activities in the field of giving information for holiday possibilities for the handicapped, just as they provide it for their non-handicapped members.

Mr. Chairman, Ladies and Gentlemen, I hope that I have given you an idea of our research in the field of rehabilitation. It is difficult to tell within 10 minutes about this large field in the small country. For those persons who are interested, I am likely prepared to give more detailed information later on.

STARTING THE CEREBRAL PALSY
PROGRAM AT GATES LEARJET CORPORATION

R.R. Gregg
2-7-77

On July 11, 1973, Dr. Leslie sent approximately 58 copies of the attachment "A" letter to businesses in the Wichita area. This was, I thought, a very good presentation of the facts. The following reflects what happened to that letter and how the program was started at Gates Learjet Corporation.

Our copy of the letter was received within a day or two of the July 31, 1973 date. Where it went from early August until August 27th is unknown. On the 27th, it was received by the Vice President of Industrial Relations. He referred the letter to me with the "Rob???" note in the upper left-hand corner. This was not buck-passing but his shorthand requesting recommendations. This was one of many pieces of correspondence received, and my first reaction was to send a negative reply. Why a negative reply?

We were already involved in a maze of programs which included the handicapped. The personnel responsibilities today are so complicated it is no longer possible to perform the function and be assured you can keep your company out of trouble.

For example, you must have the right mixture of people and skills by male and female, minority, majority, veteran, handicapped, disadvantaged, ex-offenders, etc. There is the Affirmative Action program monitored by the Federal Contract Compliance Office with actual performance plus good faith effort plus upward mobility for all groups. In addition, there is support for the United Way, Junior Achievement, bonds, etc.

With all of the programs now under way and reasonably good performance on each, I could recommend against participation and it would be dropped.

Why not send a nice letter, you know the kind, "Good program, keep up the good work, we are not able to participate at this time, am sure others can help....."

The second choice was more difficult. How can we assist this program to get started? Get the facts - go, see, talk.

On September 6, 1973, I went to the University and met with Dr. Leslie, Charles Shute, and Roger Nelson. I was greeted with "We do appreciate your interest. You are the only company of the 58 to respond." Another reaction "Can 57 companies be wrong?"

What I found was a group of people who were meeting a tough problem head on. They were honest in their assessment of the problems, their solutions and time factors involved. They had reasonable suggestions for planned action to compensate for the individual limitations, adjustment and progress in an industrial environment.

There was emphasis on the fact that they did not know all of the answers and needed help to get some of the people on jobs to see how they could perform. I looked at the test devices and the film of an Australian firm which showed the program had very good potential.

The question that had to be answered was, What would be the best approach to start this program?

First, what questions must be answered. The following is a partial list:

1. Identify areas where handicapped can be used.
2. Check on Insurance coverage and potential premium increase, if required. (No significant problem)
3. Check with Health & Safety for their recommendations. (It was negative.)
4. Check with the Union for their cooperation. (They would cooperate.)
5. How could jobs on 2nd floor be made available - no elevators? (Ambulatory only on 2nd floor.)
6. What will happen if they cannot produce as well as other employees in the same classification? Won't others complain if they get the same pay?
7. What will happen to their morale if we are forced into a layoff situation and they are laid off?
8. How will we retrain for another assignment or for upgrading?
9. If machines are modified for the handicapped, what will happen if present employees complain it is more awkward for them to use?
10. How will transportation problem be solved? No public transportation is available to plant area.
11. How will emotional problems be handled?
12. How can supervision be picked that will be sympathetic to the program?

13. On what basis can I recommend the program to assist WSU?

14. Where is the best place to start?

The greatest number of potential jobs were in manufacturing. As a result, the first contact was with the Vice President of Manufacturing. I gave him a detailed description of the proposed program and recommended we try to assist. He readily agreed and requested a meeting on Thursday, April 4, 1973 with his Industrial Engineers, Manufacturing supervisors, and WSU personnel.

There were a series of contacts, and the "Burr Shop" was the area selected. The principal work is removal of sharp edges from parts and material. This is done with power and hand tools.

We requested Dr. Leslie to let us know when he had two candidates. When they were ready, we reviewed the results of their tests. Attachment "B" is a sample. The recommendations of each candidate were also reviewed, and two were selected and started on the job.

Quite early, one individual received a serious hand laceration which required stitches and caused concern about returning to that same job. After a period of time and help from supervision and WSU personnel, the concern was overcome, and they are still on the job today.

Attendance has been normal when compared to others in the same area. Minor injuries have been higher for one than the other. Major injuries have not occurred.

Two additional applicants were selected and entered a sheet metal training class. There were problems in using this approach and they did not make it.

Work contracts are also being given to Center Industries to assist in this part of the program.

I asked the question, why don't we have more people on board from this program? The reason seems to be the same thing that causes the loss of a customer in any business. A call was made by GLC to see about additional candidates, the wrong person answered the phone creating a negative reaction, and as a result, we did not follow up as a company. The end result was a break in communication and a break in the program. This has been discussed and corrective action is to be taken.

It appears to me that it all boils down to how wide and deep is our vision. For those who say 'I can't place these severely handicapped people' ask what would happen if I ran an ad in the paper offering \$1,000 for each placement of a handicapped person in a legitimate position for one year. Payment of the \$1,000 would be monthly for 12 months as long as the person remains employed up to one year.

How many new ways would be developed to effectively place the severely handicapped that we are not now using?



WICHITA STATE UNIVERSITY

COLLEGE OF ENGINEERING
WICHITA, KANSAS 67208DEPARTMENT OF INDUSTRIAL ENGINEERING
(316) 689-3425

SEPT 6th
2 PM.
Room 203
2nd Floor.

July 31, 1973

RECEIVED

AUG 27 1973

Gates Learjet Corp.
8220 West Harry
P.O. Box 1200
Wichita, Kansas 67201

GATES LEARJET CORP.
INDUSTRIAL RELATIONS DEPT.

Dear sir:

The Industrial Engineering Department has recently been engaged in research relative to the employment of severely handicapped persons in an industrial environment. Like you, we have a great concern for the tremendous loss of human resources and capability represented by our handicapped population. We are at a point in time in our research where it has become imperative that we place handicapped persons in an on-going industry in order to validate and verify our experimental procedures. Accordingly, I am writing this letter to determine if your organization would be interested in participating in this research to the extent of providing job opportunities for handicapped people associated with our research endeavors.

I must strongly emphasize two things. (1) The jobs selected for placement of handicapped persons should be legitimate industrial tasks, we do not want any token jobs created expressly for this purpose, these people want to carry their own weight and it is extremely necessary that they do so if our research is to be successful. (2) The people we are dealing with will be severely handicapped. The people with "nice" or minor physical disabilities are being readily placed in industry at the present time. We are dealing with individuals with multiple or severe physical disabilities such as persons with Cerebral Palsy.

Persons selected for consideration for employment will be evaluated relative to their physical capabilities by the diagnostic testing procedures developed through our research efforts. These individuals will also be trained by members of our staff in order that they may be productive at your facility. As new developments emerge from our research we will implement them, if, in our and your opinion, they are beneficial to the people involved as well as economically feasible.

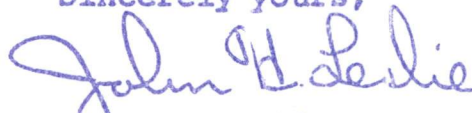
DR LESLIE TO CALL 9-28-73 FOR
PLANT TRIP. P.M.

page two

July 31, 1973

If we are to truly fulfill the idea of the American dream that all individuals should attain the highest social and economic level as their motivation and aspirations will permit, then it becomes imperative that we not forget a group of highly motivated individuals, namely the physically handicapped. We are excited by this research but our efforts will be just as fruitful as the cooperation we receive from industry in placing these people on a self-supporting basis in on-going industry. The enclosed summary sheets indicate the progress of our research so far and some of our goals and objectives for the future. Your participation in this activity will be sincerely appreciated and I personally would welcome the opportunity to discuss the procedural details of handicapped client placement at your facility. Thanking you in advance for your kindness, I remain

Sincerely yours,

A handwritten signature in dark ink, appearing to read "John H. Leslie". The signature is fluid and cursive, with the first name "John" being the most prominent part.

JOHN H. LESLIE, Ph.D.
Associate Professor & Chairman
Industrial Engineering Department
Wichita State University

REMARKS BY IRA LASTER, JR., PROGRAM COORDINATOR, OFFICE OF
ENVIRONMENTAL AFFAIRS, BEFORE THE REHABILITATION ENGINEERING
WORKSHOP ON ENVIRONMENTAL BARRIERS AND THE PHYSICALLY DISABLED
FEBRUARY 7, 1977 -- WICHITA, KANSAS

I. INTRODUCTION

Ladies and gentlemen, I appreciate the opportunity to appear before you today to discuss the question of environmental barriers to the disabled and the activities of the U.S. Department of Transportation in this area.

I am pleased to say that the U.S. Department of Transportation carries out a variety of activities aimed at a reduction in barriers to travel by the disabled, and I shall now describe some of these activities.

II. DOT ACTIVITIES TO REDUCE BARRIERS IN TRANSPORTATION

A. Mass Transportation. First, in the area of mass transportation, section 16(a) of the Urban Mass Transportation Act of 1964, as amended in 1970, declares "the national policy that elderly and handicapped persons have the same right as other persons to utilize mass transportation facilities and services," and it directs "that special efforts shall be made in planning and design of mass transportation facilities and services so that the availability to elderly and handicapped persons of mass transportation which they can effectively utilize will be assured." In an effort to be responsive to this policy, the Urban Mass Transportation Administration (UMTA) carries out the following activities:

1. Planning Assistance

Under section 9 of the Urban Mass Transportation Act of 1964, as amended, UMTA provides 80 percent matching money to approximately 250 metropolitan and 50 State agencies for transportation planning, engineering, designing, and evaluation of urban mass transportation projects. UMTA regulations on "Transportation for Elderly and Handicapped Persons," published on April 30, 1976, state that transportation planning at the local level must include "special efforts" to plan mass transit facilities and services that can effectively be used by elderly and handicapped persons, including wheelchair users. UMTA also requires urbanized areas to budget for and implement specific projects for the elderly and handicapped, including wheelchair users.

2. Operating Assistance

Under section 5 of the UMTA Act of 1964, as amended, UMTA provides matching funds on a 50/50 basis to States and local public bodies (such as a city, county, or regional transit authority) to cover up to 50 percent of the operating costs involved in providing transit service.

Operating costs include such expenses as salaries, administrative expenses, advertising, maintenance, and routine bus replacements. All transit operations receiving section 5 funds may not charge elderly and handicapped persons more than

one-half of the regular fare applied to general transit users during peak hours. This requirement is applicable only in off-peak or non-rush hour periods. For example, if the regular bus fare is 40¢, elderly and handicapped persons would pay only 20¢ a ride during the non-rush hours of 9 a.m. - 3:30 p.m. and 6 p.m. to 6:30 a.m.

3. Capital Assistance

Under section 3 of the UMTA Act of 1964, as amended, funds are made available to public agencies and private operators (through contracts with public agencies) to fund 80 percent of the cost of capital acquisitions including new bus and rail car purchases and construction costs of maintenance facilities, bus garages, new rail lines, etc.

The UMTA regulations on "Transportation for Elderly and Handicapped Persons" require that many vehicle and fixed facilities (stations, terminals, etc.) have features that can make transit use easier for these individuals. The requirements include such things as improved handrails and stanchions, non-slip flooring, lighting in the bus step well, priority seating signs for elderly and handicapped persons, warning strips next to boarding platforms and other hazard warnings in transit-related buildings. In addition to the above requirements, for the currently available transit bus, all newly designed, full-size transit buses advertised for bid and purchased with UMTA grant funds after February 15, 1977, will be required to have front door step risers not exceeding eight inches in height. This is the same accessibility standard now applied to buildings.

In addition, for new design buses advertised for bid and purchased after February 15, 1977, UMTA has required that manufacturers offer, as an option, a wheelchair accessibility package consisting of a level-change mechanism (lift or ramp), sufficient front door and passageway clearances to permit the wheelchair to reach a securement location in the bus and at least one securement device to hold the wheelchair in place. UMTA also requires that all new transit buses to be advertised for bid or purchased with Federal grant funds after February 15, 1977, have effective floor heights of not more than 24 inches. This requires both a lowering of bus floors from the current 34 to 35 inches and incorporation of a "kneeling feature" to lower the front of the bus when it stops. In other words, some combination of kneeling feature and lowered floor height must be capable of producing a net floor height of 24 inches or less.

4. Capital Assistance Program for Private Nonprofit Organizations to Transport Elderly and Handicapped Persons

Under section 16(b)(2) of the UMTA Act of 1964, as amended, UMTA administers a special capital assistance program, known as the "16(b)(2) program," to provide capital grant funds to private nonprofit organizations for the purchase of transportation equipment to provide transportation services to elderly and handicapped persons. About \$21 million was committed to more than 1,000 private nonprofit organizations under this program in fiscal year 1975, and \$22 million was allocated for the fiscal year 1976 program.

5. Research

In order to acquire a better understanding of the problems elderly and handicapped persons encounter in using public transportation and to solve some of those problems, the Department of Transportation conducts and supports a variety of research and development studies and projects.

Some examples of current and planned research activities include:

a. A major national study, entitled Research on the Transportation Problems of the Transportation Handicapped, has been underway since April 1976. This project's objective is to determine the travel requirements of various classifications of handicapped people and to develop multi-modal transportation service alternatives which can cost-effectively satisfy such requirements. The primary emphasis of this national needs study is a market research effort among persons with disabilities who experience difficulty using current transportation systems and facilities.

Although much research has already been undertaken in this area, the Department's Urban Mass Transportation Administration recognizes the need to fill the information void about the nature of the transportation problems of the handicapped. This research study will: (1) describe a national program for improving the mobility of transportation handicapped persons and estimate

the cost of implementing such a program; (2) conduct a cost/benefit analysis and rank the alternative approaches for meeting the transportation needs of the transportation handicapped; (3) develop minimum standards and guidelines for a range of alternative service and equipment improvements; (4) develop a manual for urban transportation planning for the transportation handicapped; (5) develop criteria for selection of representative urban environments where actual operating demonstrations may be designed to evaluate proposed solutions; and (6) recommend operational demonstration projects to be conducted in three urban areas.

b. Another project, the "Small Bus Requirements, Concepts, and Specifications" program, has been initiated to: (1) examine small bus operations and projected desired operations in the United States; (2) establish needed and desired operating features for small buses; (3) determine desirable features for accommodating the special needs of the elderly and handicapped, including wheelchair travelers; (4) produce conceptual small bus designs to meet the operating features; and (5) establish a performance standard for a small bus suitable for mass transit service in the United States.

c. The TRANSBUS program, now nearing completion, provided for the development of three prototypes of new standard 50-passenger city transit buses which are specially equipped with experimental hardware that can readily be used by elderly and handicapped persons, including wheelchair passengers. Extensive testing of the prototypes has been completed but

further research is continuing to achieve the design goal of a 22" floor in full size transit buses.

Information gathered from the TRANSBUS project was utilized in developing the regulations on Transportation for Elderly and Handicapped Persons, issued April 30, 1976.

d. Research is underway for the preliminary design of a wheelchair accessibility package for current model buses. This investigation and design will produce a lift or ramp for production line installation in current design buses. Future research is also anticipated for retrofitting existing buses with lifts and securement devices.

e. Research is also anticipated to determine whether modification of existing escalators is a feasible way to help elderly and handicapped persons change floor-levels in those transit stations where escalators exist. Another area of anticipated research will be to assess the use of inclined elevators in transit stations, such as Stockholm, Sweden. This case study will determine the potential value of the inclined elevator in transit stations in the U.S.

6. Demonstrations

The UMTA Service and Methods Demonstration Program provides funding support to develop, test, and promote innovative and nationally relevant transportation services and methods. Program funds may cover part or all of the project expenses involving capital investments, operations, administration and evaluation. As an example, demonstration projects have

included: testing the viability and effectiveness of user-side subsidies for the elderly and handicapped in Danville, Illinois; starting a large city transport service in Chicago, Illinois that is coordinated with health and social service agencies; and conducting an exemplary demonstration of a comprehensive, transit company operated, special transport system for the elderly and handicapped in Portland, Oregon.

B. RURAL TRANSPORTATION

1. Demonstrations

a. A program which benefits the handicapped and elderly living in rural areas, although it is not designed specifically for them, is the Rural Highway Public Transportation Demonstration Program, established pursuant to section 147 of the Federal-Aid Highway Act of 1973, as amended, and authorized to begin in fiscal year 1975. Under this program, the Federal Highway Administration has selected for funding 102 demonstration projects in 48 States. The selection and evaluation criteria specifically required consideration for the adaptability of transportation systems to the needs of the elderly and handicapped. The projects selected for funding represent a variety of service strategies including use of "dial-a-ride" systems, taxicabs, small buses, school buses, and automobiles. Most projects will also pool financial assistance from various levels of government.

b. Section 143 of the Federal-Aid Highway Act of 1976 extended

the eligible use of Federal-aid funds available for carpool demonstration projects to include such measures as "providing carpooling" opportunities to the elderly and handicapped. Regulations incorporating this revision were published in the Federal Register on June 26, 1976, and have been made part of the Federal-Aid Highway Program Manual.

C. RAIL TRANSPORTATION

1. Cooperation with Amtrak

In the area of railroad passenger service, the Federal Railroad Administration (FRA) through its Office of Federal Assistance has collaborated with Amtrak in order to sponsor programs and design of special facilities within the railroad industry that will accommodate the handicapped and elderly populations simultaneously. These programs created by Amtrak are fully funded through FRA's Office of Federal Assistance. As of now, new equipment designed for the handicapped and elderly have already been put to use on the turbo liners in upstate New York and on the Am Fleet (operated in the North East Corridor, midwestern and western routes).

D. SAFETY

1. Research

In the area of safety, the National Highway Traffic Safety Administration (NHTSA) is supporting research designed to improve the driver performance and to assist handicapped and elderly drivers. Some of the projects that are being supported

by NHTSA funds include:

- a. Identifying vehicle design deficiencies that might lead to accidents by the handicapped and elderly drivers;
- b. Identifying driver visual limitations of the elderly driving population and treatment requirements for correcting the vision problem;
- c. Development of a supplemental driver manual to inform those over 55 years of age of the possible problems they may encounter and should anticipate to be safe drivers; and
- d. Identifying driver licensing and improvement requirements of older drivers.

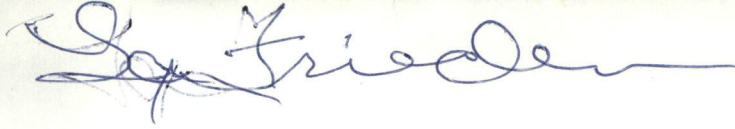
2. Highway Safety Program

Under the State and Community Highway Safety Program of the National Highway Traffic Safety Administration, States are encouraged to plan and execute their own projects to benefit the elderly and handicapped. Through the use of Federal, State, and local funds, States are planning, preparing, and providing programs for the elderly and handicapped in the areas of driver instruction, pedestrian safety, and driver licensing.

The activities that I have described have dealt primarily with the Department of Transportation's efforts to improve access to transportation systems. In carrying out some of these activities, we have, however, relied on rehabilitation engineering, particularly in determining the types of adjustment in hardware that are required to make it accessible to and

usable by individuals with different types of disabilities. We anticipate that rehabilitation engineering will continue to play an important role in the Department's efforts to improve transportation for the physically disabled population.

Thank you for the opportunity to present these remarks. I shall be pleased to respond to questions at the appropriate time.



ECONOMIC BARRIERS TO THE DISABLED

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The economic impact and benefits to be gained from the employment of physically disabled is not fully understood in the United States today. Previous cost-benefit studies have shown that investments in the vocational rehabilitation of physically disabled persons are economically attractive. However, these analyses have usually been performed from the perspective of society in general and not from the disabled individual's viewpoint.

A portion of the research effort at the Cerebral Palsy Research Foundation Rehabilitation Engineering Center is to develop a greater understanding of the cost-benefit relationship by considering three quite different, but closely intertwined viewpoints:

- (1) Governmental
- (2) Industrial
- (3) Disabled individual

The societal impact of investments in rehabilitation of the disabled must reflect the tradeoff between the taxes paid by that rehabilitated individual to the federal, state and local governments; the discontinuance of social welfare

payments when he or she is able to subsist without this aid; and the funds that flow with multiplying force from this worker as he spends his earned dollars; and the investments by our nation in order to effect this rehabilitation.

The industrial viewpoint must consider the economic benefits and associated costs which are incurred by a company when contemplating the employment of the disabled. The company must be provided with a means to intelligently determine the economic effect of government contract incentives, preferential tax treatment for equipment and facility modification, labor mix ratios and equipment and personnel aides for the disabled.

This paper will concentrate of the third viewpoint, that of the disabled individual. The ultimate goal of the research effort, however, will be to analyze all three viewpoints simultaneously in an effort to determine if rehabilitation can be effectively accomplished either with existing or proposed legislation.

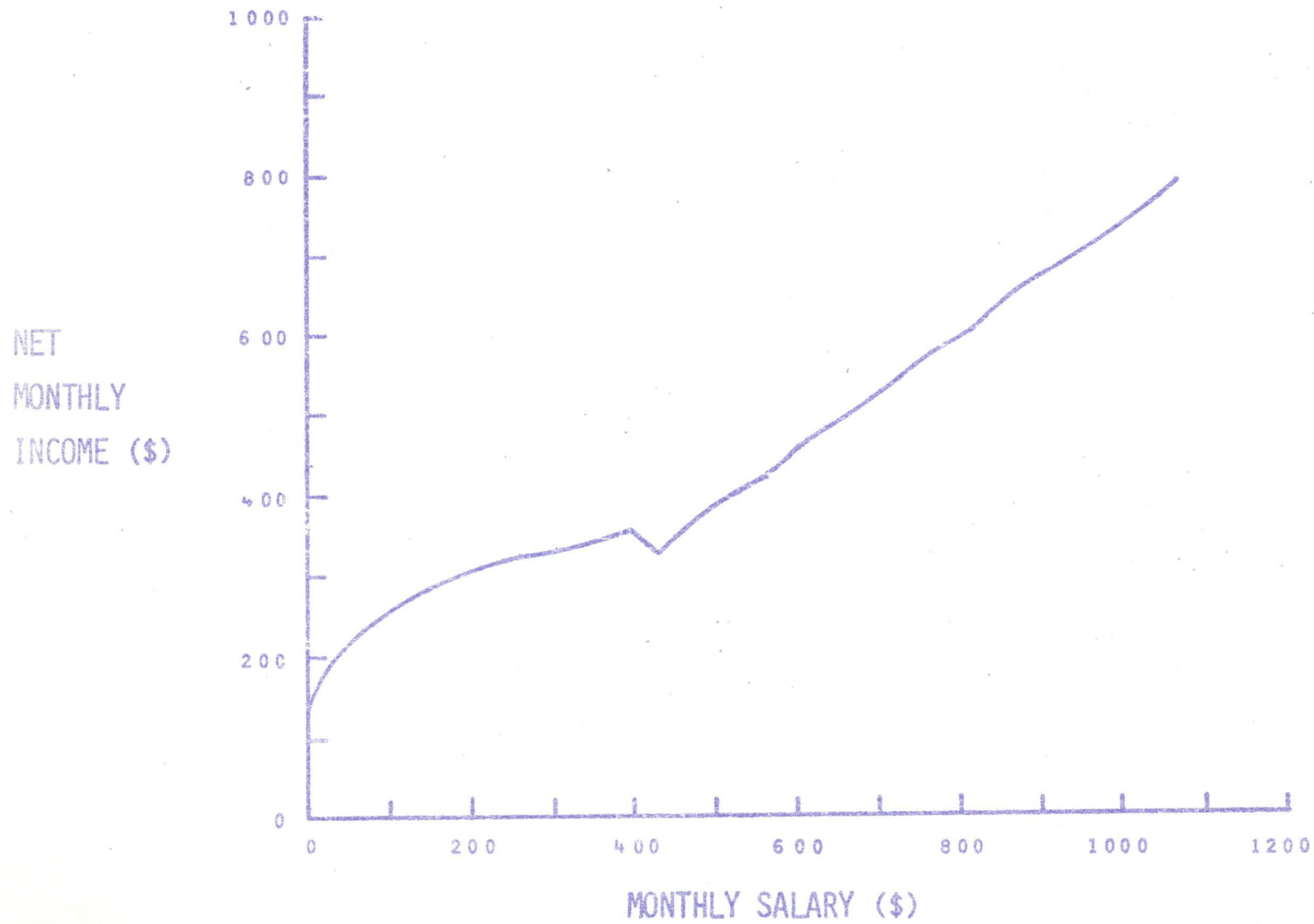
The current analysis does not take all relevant factors into consideration, especially those pertaining to the intangible benefits. The benefit scale measures only earnings capability and does not consider such variables as psychological satisfaction, social improvements and long term vocational growth.

The questions posed by this research include the following:

- (1) Is employment (and rehabilitation) initially economically attractive to the disabled individual?
- (2) Is an employed disabled individual economically motivated to advance?

In order to answer the first question, one must consider the various government programs which impact the employment of the disabled. Some of the major programs which provide support to the disabled individual include the supplemental security income program (SSI) and Medicaid. SSI has introduced a brand new philosophy, since it can quite properly be termed to be a guaranteed-annual-income plan for the disabled. At the present time, SSI provides a guaranteed minimum income of \$167.80 per month. In order to measure the economic impact of this program on the decision of a disabled individual to seek rehabilitation and employment, various "income disregards" must be considered. Thus, the disabled individual is not confronted with an immediate loss of these benefits. Figure 1 indicates the magnitude of net monthly income which the disabled person will realize for a given monthly salary. This figure takes into consideration the Social Security, federal and state income taxes the individual will be paying on his employment earnings. In addition, when the individual reaches an income level where he or she is no longer eligible for SSI payments, (\$420.60 per month) the Medicaid coverage is also no longer provided. This coverage is a grant-in-aid program in which

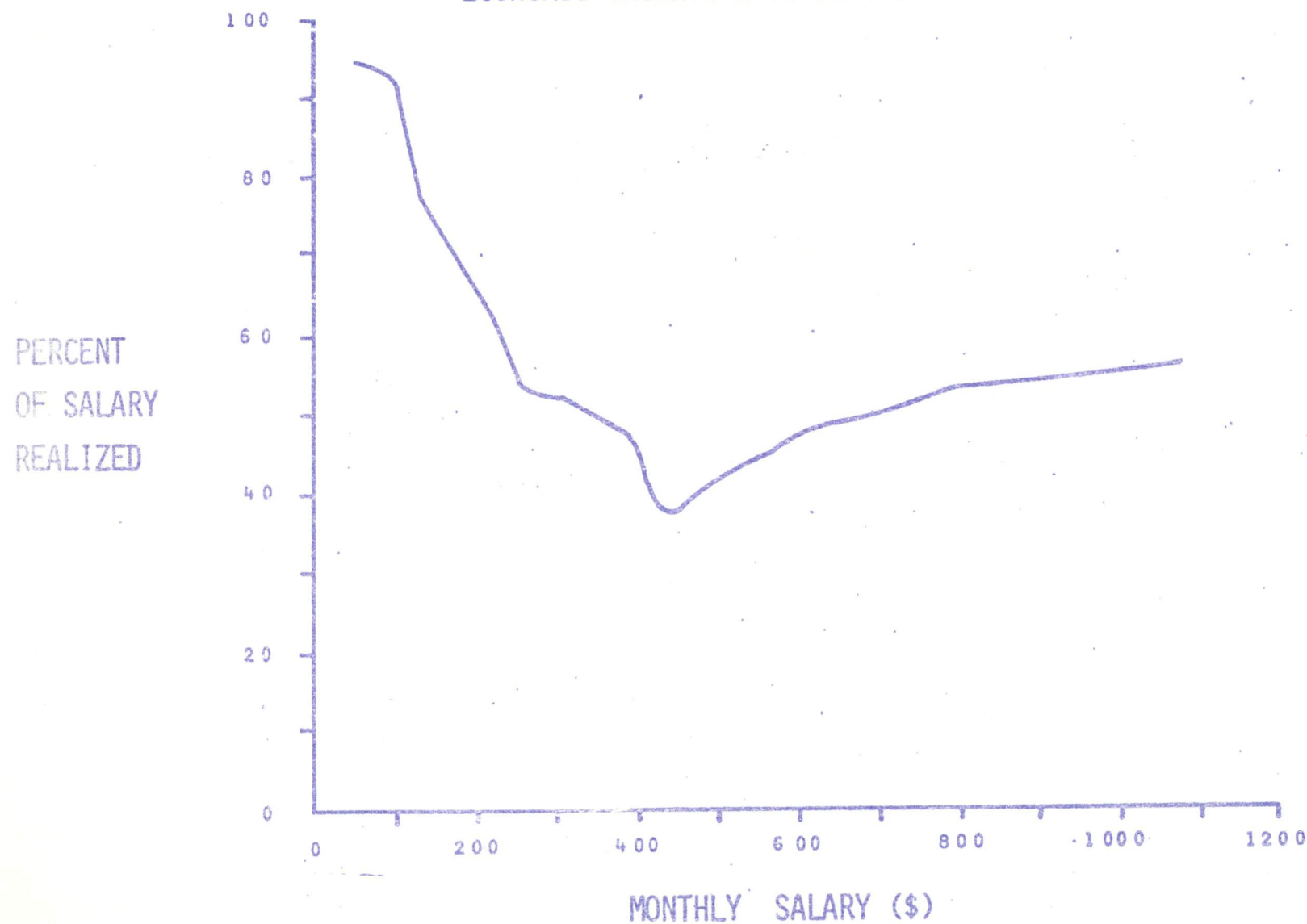
FIGURE 1
NET MONTHLY INCOME



the Federal and State governments share the costs of medical care for people with low income and is authorized under Title XIX of the Social Security Act. The services provided under Medicaid include medicines, doctors' fees, eye examinations and glasses, and intermediate and skilled nursing home care. If these services are no longer provided, the employed disabled individual will need to obtain such coverage from a private carrier. Such coverage could either be a fringe benefit of the employer, a shared cost with the employer, or a cost to be directly absorbed by the individual; figure 1 assumes the cost will be shared with the employer. It would appear that this figure substantiates the economic attractiveness of successful rehabilitation and placement in employment.

However, figures 2 and 3 present this same data in a different format and indicate a potential barrier the disabled individual may face when deciding whether or not to seek rehabilitation and employment. Figure 2 indicates the incentive an unemployed disabled individual perceives in terms of the fraction of his monthly salary that will actually result in an increased level on income. As a consequence of the gradual loss of SSI payments and Medicaid coverage, the fraction of monthly salary the disabled person actually realizes is disarmingly small. Because of the risks associated with the decision to enter rehabilitation and subsequent employment, it is understandable how an individual might view such a move

FIGURE 2
ECONOMIC INCENTIVE TO BECOME EMPLOYED .



with apprehension and reluctance.

Another perspective is the incentive an employed disabled person has to continue his vocational growth in order to increase his income. Figure 3 depicts the fraction of a \$10 per week raise that will result in an increased income level for the individual for various current monthly salaries. As the figure clearly indicates, there is currently little economic incentive for the disabled individual to attempt to improve his employment situation.

The economic benefits to be gained from successful rehabilitation and employment are not necessarily shared equally by the disabled person and society. If our society is to help the disabled individual to actively participate in society, we must lead the way to a better understanding of these factors and promote necessary changes in current legislation.

In addition, similar inequities exist in the governmental and industrial sectors which must be more clearly understood so that intelligent alternatives may be posed. The Cerebral Palsy Research Foundation Rehabilitation Engineering Center is dedicated to the development and dissemination of the data which will result in the successful rehabilitation and employment of the physically disabled.

FIGURE 3

ECONOMIC INCENTIVE FOR A \$10 PER WEEK RAISE

