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ABSTRACT

The study followed up 196 patients of all ages with severe muscular impairment who had been provided with several types of mobility aids (powered wheelchairs, Castor Carts, buggies) over a 3 year period. Of the 138 respondents, 49 were interviewed in their home environment by the evaluation team. A point system was used to quantify the daily use aspects of equipment use, change in life style through equipment use, and reasons for nonuse of the prescribed equipment. Eighty-one percent of the devices were found to be in working condition and 50% of them were being used an average of 9 hours per day at the time of the study. Twenty-two percent of the devices had been outgrown and the average life span per device was 30.0 months. Since the average cost per device was $1,650.00, the cost per day for use of the device through its life span was $1.50. It was concluded that the assistive devices enabled many persons with severe motor impairment to achieve educational and employment opportunities and that the overall cost benefit ratio appeared to be satisfactory. Appended are definitions used in the study, demographic data, equipment pictures, and an assessment form. (Author/DB)

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Resear funded by National Institute of Handicapped Research

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ABSTRACT

As part of a clincial evaluation effort this is a retrospective follow-up study of 196 patients with severe muscular impairment who had been provided with several types of mobility aids (powered wheelchairs, Castor Carts, buggies) which required a variety of controls and/or interfaces for their use. The study participants were provided the equipment by the Rehabilitation Engineering Center over a three year period (May 19[illegible]–May 1978).

The study technique consisted of making contact with all study participants (196). Seventy percent (13[illegible]) responded, and of this group ~~64%~~ 36% (49) were interviewed in their home environment by an evaluation team. Demographic characteristics of the nonrespondent, the questionnaire group and those given home visits were comparable.

A point system was used to quantitate the daily use aspect of equipment use, change in life style through equipment use and reasons for nonuse of the prescribed equipment. Eighty-one percent of the devices were found to be in working condition and 50% of them were being used an average of nine hours per day at the time of the study. Twenty-two percent of the devices had been outgrown and the average life span per device was 30.9 months. Since the average cost per device was $1,650.00, the cost per day for use of the device through its life span was $[illegible]. Although the psychosocial values and changes in life style which [illegible] an ability to enlarge environmental horizons are somewhat intangible, assistive devices do enable many persons with severe motor impairment to achieve educational and employment opportunities, and the overall cost-benefit ratio appears to be satisfactory.

ACKNOWLEDGMENTS

We wish to express our gratitude to the many people who contributed their time and expertise during the conduct of this study. Particular thanks are accorded to Dr. Eugene Bleck and Mr. Maurice LeBlanc for their guidance and support; to Dr. Chester Swinyard who periodically reviewed our progress; to the Research Advisory Committee for their direction; and to the staff at the Rehabilitation Engineering Center for their assistance.

We would especially like to thank the people who participated in the study for their cooperation and the invaluable information they shared with us; and their families, teachers and therapists who welcomed us into their homes and schools.

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LIST [illegible] LES

The Rehabilitation Engineering Center Children's Hospital at Stanford, has been providing direct services to disabled children and adults since November, 1974. In October, 1978 the Center received a federal rehabilitation engineering center grant to carry out research and development, focusing on a core area of controls and interfaces for communication aids and other assistive devices. As part of this grant, the Center has the responsibility to conduct clinical evaluations of potentially useful controls and interfaces for aids and systems developed at our Center and other places. In order to develop a clinical evaluation model that could be used prospectively in the evaluation of new items, it was decided by the advisory committee and the grant participants to conduct a retrospective study, taking advantage of the Center's service delivery history to broaden the elements of clinical evaluation beyond technical and engineering specifications. It was felt this would provide an important input in planning comprehensive services, research activities and clinical evaluations.

Since seating and mobility devices for severely physically disabled individuals have been a primary area of service delivery at the Center from its inception, it was decided to focus the follow-up study on people who had been evaluated at the Rehabilitation Engineering Center (REC) and for whom the recommendation had included a major mobility device with a significant control and/or interface in the system.

An advisory committee was established to oversee the research activities of the REC. In an attempt to define the parameters of evaluation needs (technical, functional, medical and psychosocial), the commitee suggested a four person team: a physician with experience in pediatric rehabilitation; a rehabilitation engineer with experience in seating and

mobility; a medical social worker with pediatrics experience; and an occupational therapist with background in equipment evaluation. They suggested that at least one of the members also be a disabled consumer.

The team was brought together. The physician, rehab. engineer, and social worker were each assigned at 20% F.T.E. and the O.T.R., who also functioned as team coordinator at 50% F.T.E. The research committee was available for consultation.

Research Advisory Committee:

Eugene E. Bleck, M.D., Chief of Orthopedic Services, Children's Hospital at Stanford

Maurice LeBlanc, C.P., Director, Rehabilitation Engineering Center, Children's Hospital at Stanford

Chester A. Swinyard, M.D., Professor Emeritus, Stanford Medical School

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Rationale for Study

It has been the impression of rehabilitation engineers, physicians, and therapists that provision of assistive devices must satisfy technical performance requirements and must also consider the client's lifestyle, physical environment, interaction with family, friends and fellow workers, and the effect on the client's self-image. The benefit of an assistive device is, therefore, both objective and subjective: objective in terms of professional assessment of optimal technical and functional performance, and subjective in terms of the client's satisfaction with the device in home and work surroundings on a day-to-day basis. In this context, the initial assessment of the client's requirements for an assistive device must consider both technical and psychosocial aspects.

Measurement of benefit has been difficult to document. A review of the literature indicated that clinical evaluation of rehabilitation equipment is either not being carried out, or does not appear in print. A search of the NARIC database resulted in just ten items. Only three were related to evaluation. The keyword "Wheelchair-evaluation" is in fact not even in their dictionary. Other written material on wheelchair evaluation refers primarily to technical and engineering specifications. The available data on English devices is not generally applicable to the American market.

References were found indicating the <u>need</u> for evaluative material. Cost and time factors, especially describing device life span and use factors were also not available. Nor was any information found concerning the psychosocial aspects of using or assessing assistive devices. A selected

reading list was compiled of useful source material. However, from the literature search conducted, there appears to be no similar study reported to date.

Effective evaluation of devices, therefore, is a major gap in the rehabilitation engineering service delivery system. Clinical evaluation begins with the initial assessment procedure, follows along through provision of the device and continues through a follow-up process which documents technical performance and client satisfaction. Clinical evaluation is therefore a crucial component in research utilization.

Study Objectives

This clinical research study is an attempt to determine if: 1) it is possible to define and document the benefits of assistive devices; 2) it is possible to relate benefit to cost; and 3) it may be possible to develop an initial assessment procedure that identifies accurately both technical and psychosocial requirements of the client. An additional objective was to identify economic aspects related to provision of devices: costs, source of funds, time sequences from requests for funds to authorization to payment, and financial obstacles to provision.

The first step in the study was the development of definitions and criteria of measurement of benefit, effectiveness, goals in provision of devices and client satisfaction.

Effectiveness was defined as the overall success of the device and was measured by two criteria:

1) Utility--was the device being used, and to what extent? Included in this criterion were safety, reliability, durability, comfort, appearance and mechanical performance.

2) Goal attainment--was the device meeting its prescribed goals? Goals were defined as:

   a) Management--those directed toward care, comfort and maintenance of health of the client; and protection, support and optimal function of the caretaker related to activities with the client.

   b) Motor--those directed toward improving and/or maintaining current motor function or fostering new motor abilities.

The third area investigated was client satisfaction, defined as the extent to which the device was meeting the consumer's expectations. This was measured in two ways:

1) Objectively during team evaluation in the client's home or school, by observation and interpretation of client/family responses; and

2) By a questionnaire administered separately by the team social worker (John Preston, Jr., MSW, pp. 47 - 58). (The questionnaire will be discussed in a separate section; however the responses to the questionnaire corroborated the team evaluation.)

When the three criteria of <u>utility</u>, <u>goal attainment</u> and <u>client satisfaction</u> were all scored as satisfactory, the device was of optimum <u>benefit</u>.

OPTIMUM BENEFIT = Effectiveness (Utility + Goal Attainment) + Client Satisfaction

Each device seen by the team was given a score, based on a three-point system related to meeting the criteria established.

Points were assigned on the basis of:

1) Utility: one point assigned if

   a) device is currently used, or

   b) device was used in the past, but discontinued because it was either:

      i) outgrown

      ii) requirements changed

      iii) psychosocially unacceptable

2) Satisfaction: one point assigned if device fully met expectations when used.

3) Goal attainment: one point assigned if stated goal has been attained, either an increase or improvement.

Points were cumulative, with a range of 0 to 3. No points were subtracted; each category was scored zero points or one point.

The scores were defined as:

0 = Inappropriate, did not meet any needs

1 = Limited, met few needs

2 = Less than optimal, met most but not all needs

3 = Optimal, met all needs for which it was recommended

Table 1

Note: Each team member developed a form to assess, respectively, engineering, functional, medical and psychosocial components of the evaluation. The forms used in evaluation are available upon request to Sandra Enders, Rehabilitation Engineering Center, Children's Hospital at Stanford.

A. UTILITY

1. DEVICE IS CURRENTLY USED: YES NO
2. IF YES: HOW LONG: _____ MONTHS
3. FREQUENCY: _____ HOURS/DAY
4. IF NO: WAS IT EVER USED: YES NO
   IF YES: HOW LONG: _____ MONTHS
   WHY DISCONTINUED: INAPPROPRIATE RECOMMENDATION
   MECHANICAL MALFUNCTION
   REQUIREMENTS CHANGED
   OUTGROWN
   PSYCHOSOCIAL
   USE SCORE: 0 1

B. EXPECTATIONS/SATISFACTION

1. DEVICE ADEQUATELY MET EXPECTATIONS WHEN USED:
   FULLY PARTIALLY NO
2. EXPECTATIONS WERE NOT MET BECAUSE:
   DISTANCE FROM REC ONE OF A KIND UNPREDICTABILITY
   LACK OF SUPPORT PERSONNEL OTHER (list)
   DEVICE MALFUNCTION
   EXPECTATION SCORE: 0 1

C. GOAL ATTAINMENT: (match to stated goal)

1. MANAGEMENT ASSISTANCE: INCREASE DECREASE NO CHANGE
2. IMPROVE MOTOR ABILITY:
   IMPROVEMENT IN FUNCTION NEW FUNCTIONAL ABILITIES
   IMPROVED POSITION NO CHANGE
   LOWERED ABILITY TO FUNCTION LOSS OF ABILITY
   POSITION NOT AS SATISFACTORY AS BEFORE DEVICE

3. IMPROVE COMMUNICATION ABILITY:
   INCREASE DECREASE NO CHANGE
   GOAL ATTAINMENT SCORE: 0 1

DEVICE SCORE

TOTAL SCORE: 0 1 2 3

Scale:

0 = Inappropriate (did not meet any needs)

1 = Limited (met few needs)

2 = Less than optimal (met most but not all needs)

3 = Optimal (met all needs for which it was recommended)

TABLE 1. POINT ASSIGNMENT
(Point could be given for any circled item)

Study Population

After reviewing REC charts and records, 196 people were found to meet the criteria of: 1) evaluation at the REC between May, 1975 and May, 1978; and 2) recommendation made which included a major mobility device with a significant control and/or interface in the system.

Forty-nine persons, 25% of the total study population (36% of those directly contacted) were interviewed in person by the multidisciplinary team. As the intent of the study was to determine the effectiveness and satisfaction of the devices in the community, the interviewed group was visited by the team in the environment where they used their equipment most frequently: home, school or work.

Firsthand information was obtained on an additional eighty-nine people through mail questionnaires, telephone contact or visits to the REC. Altogether there was direct feedback on 70% of the people in the study

Visited	49	70% - Direct Contact with Client or Family
Other Contact	81	
Deceased	8	30% - Demographic Information Only
No Response	46	
Lost to Study	12	
TOTAL	196	

TABLE 2. ANALYSIS OF STUDY POPULATION (n=196)

Demographic data was collected on all 196 study participants from medical records, REC charts and patient accounting files. Comparison of ten different variables showed that the visited sample was representative of the entire population (Table 3).

Sex
Age
Diagnosis
Total Body Involvement
Speech Deficit
Mental Ability
Living Situation
Distance from Rehab. Eng. Center
Funding Source
Goal

TABLE 3. VARIABLES COMPARED IN POPULATION STUDIED (n=196)

It also showed that the group we had direct information about was essentially identical to the nonresponding group. Therefore, the information obtained through the 49 personal interviews in the field could be generalized to the entire population of 196. (See Appendix for additional population comparison data.)

A.	SEX	Male	57%	
		Female	43%	
B.	AGE	0 to 5 years	14%	
		6 to 18 years	55%	Under 18 - 69%
		19 to 35 years	24%	
		Over 35 years	7%	Over 18 - 31%
C.	DIAGNOSIS	Cerebral Palsy	58%	
		Neuromuscular	14%	
		Spina Bifida	7%	
		Spinal Cord Injury	3%	
		Osteogenesis Imperfecta	3%	
		Other (Table 5) Conditions	15%	
D.	DEGREE OF BODY INVOLVEMENT[1]			
		Nonambulatory - severe	60%	
		Nonambulatory - moderate	17%	
		Nonambulatory - minimal	11%	
		Other	10%	
		Unknown	2%	
E.	SPEECH DEFICIT	Speech deficit present	52%	
		No speech deficit	36%	
		Unknown	12%	
F.	MENTAL ABILITY	Normal or near normal	52%	
		Mildly retarded	16%	
		Severely retarded	25%	
		Unknown	7%	
G.	LIVING SITUATION	At home	77%	
		Foster home	9%	
		Institution	13%	
		Unknown	1%	

[1]Definitions:

Severe - poor head control, poor trunk control, often severe spinal curvature, virtually no use of hands.

Moderate - fair head control, poor trunk control, moderate use of hands.

Minimal - good head control, fair trunk control, somewhat unstable in sitting position.

Other - has some ambulation

TABLE 4. DEMOGRAPHIC DESCRIPTION OF THE STUDY POPULATION (n=196)

TABLE 4. DEMOGRAPHIC DESCRIPTION OF THE STUD' POPULATION (n=196) (continued)

H. DISTANCE FROM REHABILITATION ENGINEERING CENTER

Less than 5 miles	(15 minutes)	3%
5 - 14 miles	(30 minutes)	10%
15 - 29 miles	(45 minutes)	17%
30 - 49 miles	(1 hour)	10%
40 - 80 miles	(over 1 hour)	15%
Over 80 miles	(over 2 hours)	35%

I. FUNDING SOURCE[2]	Private Funds	31%
	Mixed Private & Public	20%
	Public Funds	47%
	Other Funds	1%

[2]Definitions:

Private - not controlled by public sector legislation, includes private insurance, self payment Muscular Dystrophy Association, etc.

Public - controlled by public sector legislation, includes MEDI-CAL, Regional Center, California Children's Services, etc.

These figures represent the percentage of people covered by these funding sources

Developmental Disabilities:		11
Lumbar/sacral agenesis	3	
Arthrogryposis multiple/congenital (multiple cong. contractures)	2	
Mucopolysaccharidosis IV (Morquio Syndrome)	1	
Lesch-Nyhan Syndrome	2	
Bilateral hip dislocation	1	
Bilateral Legg-Perthes Disease	1	
Hydrocephalus, A-V malformation	1	
Disabilities following infection:		4
Poliomyelitis	3	
Meningitis	1	
Post-Accident Disabilities:		4
Near drowning	3	
Head injury	1	
Co-Existing Conditions:		3
Juvenile Rheumatoid Arthritis with Down's Syndrome	1	
Juvenile Rheumatoid Arthritis with severe mental retardation	1	
Spinal cord injury with anoxic encephalopathy	1	
Disability as Complication of Pre-existing Disease:		3
Spinal cord injury - Hemophilia	1	
Spinal cord injury - Neurofibromatosis	1	
Sickle cell disease with CVA (quad.)	1	
CNS Progressive Disease:		2
Spongy degeneration of brain (Canavan's Disease)	1	
Cerebral Sclerosis I (Pelizaeus-Merzbacher Disease)	1	
Malignancy:		1
Osteosarcoma	1	
	Total:	28

TABLE 5. DIAGNOSIS--OTHER LESS COMMON CONDITIONS

A. SCOLIOSIS	Present	86%
	Absent	8%
	Unknown	6%
B. CONTRACTURES	Present	90%
	Absent	6%
	Unknown	4%
C. SEIZURES	Yes - Controlled	12%
	Yes - Uncontrolled	14%
	No	47%
	Unknown	27%
D. VISUAL DEFICIT	Yes	25%
	No	63%
	Unknown	12%
E. HEARING DEFICIT	Yes	10%
	No	67%
	Unknown	23%
F. ACCESSIBILITY OF LIVING SITUATION[1]		
	High Access	51%
	Medium Access	10%
	Low Access	14%
	Unknown	25%
G. FAMILY TYPE[2]	Active	39%
	Intermediate	31%
	Passive	12%
	Unknown	2%
	Not Applicable	16%

Definitions:

[1]Accessibility — Low - steps, impossible to independently enter/exit, and/or major parts of house inaccessible independently.
Medium - enter/exit possible independently, and major parts of house accessible.
High - completely accessible and usable, including bathroom, bedroom and eating area.

[2]Family Type — Active - knowledgeable and precisely describe their wants and needs.
Intermediate - between active and passive.
Passive - delegate all decisions to professionals.

TABLE 6. ADDITIONAL DATA--FROM THOSE INTERVIEWED (n=49)

	Number
A. DEVICE	
Manual wheelchair - attendant propelled	4
Electric wheelchair - National	6
Electric wheelchair - Abec	12
Electric wheelchair - Everest & Jennings	3
Caster cart - Manual	4
McLaren buggy	8
Other	2
B. CONTROLLER AND/OR INTERFACE	
Hand control	24
Head control	3
Spatial repositioning of control	9
Joystick	15
Modified joystick	8
Slot control	3
Speed/acceleration limiter	8
Orthopedic seat insert (031)	35
Tray	19
Helmet	2
Other	13
C. REASONS FOR RECOMMENDATION	
Reduce pain	12
Increase sitting time	35
Improve sitting stability	33
Improve upper extremity use	25
Prevent tissue trauma	9
Control scoliosis	15
Energy conservation	8
Prevent deformity	11
Increase independence	33
Increase community participation	33
Improve psychosocial situation	24
Increase communication skills	6
Portability	22
Increase range/distance	19
Provide physical protection	2
Prevent discomfort	3
Other	4

Each device recommended could and usually did have more than one reason for selection. (n=49)

TABLE 7. DEVICES UNDER INVESTIGATION

Results

Seventy-nine percent of the devices optimally or close to optimally achieved their objectives (Score = 2 or 3). This 79% was composed of 50% still using the original device and 29% who had outgrown the original device and were using another technical aid.

Twenty-one percent met the objectives only to a limited degree or not at all (Score = 0 or 1). For each less than optimal rating, a judgement was made whether there was an alternative available at the time of evaluation. In 71% of these cases, the answer was 'no'. (Table 8.)

Optimal or close to optimal (Score 2 or 3)	79%
Limited or not at all (Score 0 or 1)	21%

(No alternative available: 71%)

TABLE 8. GOAL ATTAINMENT SCORES (n=49)

Current device status was evaluated on 44 clients who had received their equipment from the Rehab. Engineering Center. (Table 9.)

Being used		50%
Not used - outgrown		23%
Not used - other		27%
(Deceased	n= 1)	
(Mechanical prob.	n= 7)	
(Psych. prob.	n= 4)	
	n=12 (27%)	

TABLE 9. CURRENT DEVICE STATUS (n=44)

From questionnaire returns and chart review, an analysis of devices not used for reasons other than being outgrown was made, and the results are shown in Table 10.

Deceased	7
Mechanical problems	12
Psychological problems	5
Change in physical status	2
	26 (17%)

TABLE 10. DEVICES NOT USED--REASON OTHER THAN OUTGROWN--TOTAL STUDY GROUP (n=196)

If those who had died were excluded from both the visited group and the total group, 'mechanical problems' accounted for almost two-thirds of the reasons devices were not used. (Table 11.)

	Visited Group	Total Group
Mechanical problems	64% (7/11)	63% (12/19)
Psychological problems	36% (4/11)	26% (5/19)
Change in physical status	0% (0/11)	11% (2/19)

TABLE 11. DEVICES NOT USED--REASON OTHER THAN OUTGROWN--VISITED AND TOTAL GROUPS (Deceased excluded)

Implications of these findings will be discussed in a later section of this paper.

In the total group reviewed, 39 devices were found to be 'not received,' although an initial evaluation had been carried out at the REC. (Table 12.)

Reasons for non-receipt:	N	Total Group %
Lack of funding	15	38
Received elsewhere	13	33
Physical status changed	2	5
Change in recommendation	1	3
Family decision	1	3
Unknown	7	18
	39	100% (20% of total group)

TABLE 12. DEVICES KNOWN TO BE "NOT RECEIVED FROM REC"--REASONS FOR NON-RECEIPT

It is discouraging to note that almost 2/5 of the devices were not received due to lack of funding. If the same percentage is applied to the 'unknown' group (and this is probably an underestimate), the total 'lack of funding' group rises to 46%, or almost half of the devices not received.

Cost and Time Factors

One objective of the study involved the economic and service delivery aspects of rehabilitation equipment. Therefore, cost and time factors for all 196 study participants were reviewed and analyzed. (All of the cost information indicates the payment of the completed device. This is an initial delivery cost and does not include the cost of initial evaluation, repairs, or modifications that may have been made to some devices later.)

Funding Sources

Funding data was collected on all 196 study participants. At the time of initial evaluation, a cost estimate was determined for each patient. The records show a total of $320,125 estimated for the 196 devices, or an average of $1,633/device. Information on source of payment was obtained by examining the hospital's patient accounting files for documentation of actual payment receipt. There were 133 cases in which both receipt of device and evidence of payment (or write-off) could be found. These 133 cases were broken down into their funding sources. (Actual dollar amounts are reflected: e.g., if 80% of the total payment was made by an insurance company and 20% was made by the family, the payment figure was divided into the two sources just as it was actually received.) (Table 13.)

Private insurance	$ 58,006	26%	
Self paid	17,534	8%	Private = 39%
Voluntary agencies	10,638	5%	
Medi Cal (TITLE XIX)	59,440	27%	
Regional Centers	27,082	12%	
California Children's Service	13,100	6%	Public = 48%
Champus	4,215	2%	
Dept. of Rehabilitation	1,575	1%	
Uncollectable	29,939	13%	Uncollectable = 13%
TOTAL	$221,529	100%	Total = 100%

TABLE 13. PAYMENT FUNDING SOURCES

The first three sources are then combined to reflect funding sources, i.e., sources not controlled by public legislation. The next five sources are combined to reflect public funding sources; i.e., sources that are controlled by public legislation. When the "uncollectable" figure, which was written off by Children's Hospital at Stanford, and is privately controlled, is added to the private sector sources, the breakdown becomes:

Private Sector Funding	52%
Public Sector Funding	48%

Use Pattern and Costs

In the interviewed group, 50% of the devices received were still being used (n=20). As of January, 1980, these devices had been operating

from six to forty-nine months, with a median of twenty-six months. Current daily use was assessed in the number of hours/day the person sat in the device (n=20). This ranged from 2 to 15 hours/day with an average of 9 hours/day. (Table 14.)

Hours/Day	($) Cost	Months Used (to 1/1/80)
2	$1,409	25
3	1,675	7
3	2,800	37
4	1,400	28
4	450	42
5	3,450	26
7	1,550	12
8	1,325	20
8	1,450	36
10	480	16
12	1,615	12
12	2,050	26
12	2,156	49
12	3,107	38
13	980	25
14	3,250	48
14	3,313	28
14	3,959	21
15	1,821	6
range = 2 to 15 hours/day average = 9 hrs./day	range = $450 to $3,959 average = $2,013	range = 6 to 49 months average = 25 months

TABLE 14. PRESENTLY USED DEVICES--DAILY USE, COST & TIME FACTORS

Months Used	($) Cost	($) Cost/Month	($) Cost/Day*
12	$1,514	$126	$4.21
39	1,610	41	1.38
36	2,596	72	2.40
36	1,650	46	1.53
35	1,000	29	.95
23	500	22	.72
42	275	7	.22
26	300	12	.39
24	525	22	.73
36	2,850	79	2.64

Cost:	range	$ 275 (manual caster cart) $2,850 (OSI, elec w/c, tray, modified control)
	average	$1,282
Lifespan of device:	range	12 to 42 months
	average	30.9 months
Cost/day:	range	$0.22 (manual caster cart) $4.21 (OSI, McLaren buggy, tray--child had unexpected growth spurt)
	average	$1.52

*Based on 360 days/year

TABLE 15. OUTGROWN DEVICES--COST/TIME FACTOR

Since 69% of the study population was under 18 years of age, examination of assessed devices known to be outgrown was used to determine expected lifespan of devices. (Table 15.) Twenty-three percent of the devices received by the interviewed group fell into this category (n=10). The average lifespan of a device was found to be 30.9 months. The range was from 12 to 42 months. These devices ranged from a $275 manual caster cart to a $2,850 system which included an orthopedic seat insert and electric wheelchair, modifications to the electronic controls and a special tray. The average cost per device was $1,282. By dividing the cost of the device by the time it had been used, we calculated a cost/day figure. The range ran from $0.22/day for a manual caster cart to $4.21/day for an orthopedic seat insert in a McLaren buggy with a tray. The average was $1.52/day. (Table 15.)

In overall cost per device, average values were established. Case data was only entered if final payment data was available. For the interviewed group, an average of $1,648 was found. Broken into two components: outgrown: average = $1,282; presently used: average = $2,013.

	Average Cost	Number
Total Study Population	$1,666	133
Total Interviewed Group	$1,648	29
Presently in use	2,013	19
Outgrown	1,282	10

TABLE 16. COST PER DEVICE

Distance Related to Benefit Score

One factor in securing assistive devices is distance from the Center providing them. An investigation into this factor did not appear to

indicate any difference between those clients who traveled over 50 miles and the total group. However, when narrowed to the lowest and highest scores, a trend appeared.

	Subgroup: Over 50 Miles		Total Group
Score 0 + Score 1	n = 4	22%	21%
Score 2 + Score 3	n =14	78%	79%

But when divided into lowest and highest scores, this trend appears:

	Score = 0 (n=6)	Score = 3 (n=27)
under 50 miles	(2/6) 33%	(17/27) 63%
over 50 miles	(4/6) 67%	(10/27) 37%

The numbers are too small for statistical analysis, however.

Service Delivery Process

Time factors in the service delivery process were examined. Five dates were recorded for each study participant:

Date of Referral
Date of Evaluation
Date of Authorization for Funding
Date of Delivery of Device
Date of Final Payment

In each category, information was reported only if the relevant dates were complete. Therefore, the number of cases reported in each time period is variable. The following intervals were found:

Process Time: This indicates the number of days between referral date and the final payment date.
n = 133
(range = 6 days to 1,127 days) median = 337 days

Provision Time: This indicates the number of days between the initial evaluation date and the day the device was delivered.
n = 135
(range = 0 to 768 days) median = 134 days

Evaluation Date to Authorization Date:
n = 10
(range = 19 days to 410 days) median = 64 days

Authorization Date to Delivery Date:
n = 103
(range = 384 days to 670 days) median = 85 days

Delivery Date to Final Payment Date:
n = 129
(range = 0 to 1,058 days) median = 162 days

Note: In this table, the median figure was calculated since it is less sensitive to extremes in distribution.

TABLE 17. SERVICE DELIVERY PROCESS

Diagnosis	Age at Death
Morquoi Syndrome	72 years
Amytrophic Lateral Sclerosis	62
Friedreich's Ataxia	31
Spinal Cord Injury--Neurofibromatosis	23
Muscular Dystrophy (Duchenne Type)	18
Cerebral Palsy	8
Osteogenesis Imperfecta	2
Congenital Myopathy (type undiagnosed)	2

TABLE 18. DIAGNOSIS AND AGE AT DEATH OF DECEASED IN STUDY GROUP* (n=196)

*Seven clients did not use the recommended device due to death near time of receipt of device. One client used the device for several years before death.

(In addition to the above deaths, two of the interviewed group died subsequent to the team assessment visit: one had post-poliomyelitis disability [age 66 years at time of death], and one had cerebral palsy [age 25 years at time of death]. These two have been included in the study as "living" at the time of evaluation.)

From the viewpoint of cost/benefit in provision of assistive devices, it is worth noting that only three of these ten individuals were under 18 years of age at time of death, and from the diagnoses given, it seems reasonable to assume that the older clients were disabled for some years. This may indicate that disabled persons may enjoy the benefits of assistive devicces for a long period of time. However a longer time period in follow-up would be necessary to demonstrate cost/benefit of devices to individuals over their lifespan. In fact, longer follow-up of cost/benefit of a single device could not be made due to time constraints of this particular study. We were able, however, to determine cost/benefit of outgrown devices. (Table 15.)

DISCUSSION

The results of the study showed that 79% of the devices under investigation optimally or close to optimally achieved their objectives. This compares favorably to the results of a survey for Consumers Union which stated "...39 percent reported that they had purchased special or rehabilitation-related equipment and later found it to be inadequate in terms of effectiveness (utility). The most common types of equipment reportedly ineffective were: wheelchairs, seat pads/cushions, portable lifts, and walkers."[1]

The same study also surveyed mechanical reliability. "...30 percent reported that they had purchased and later not used a piece of special or rehabilitative equipment because it was mechanically unreliable." Our study found 81% of the devices to be mechanically sound.

	CH@S Rehab. Eng. Ctr.	National Survey[1]
Device is ineffective	21%	39%
Device is effective	79%	61%
Device is mechanically unreliable	19%	30%
Device is mechanically reliable	81%	70%

[1]T. B. Grall. 1979. A feasibility study of product testing and reporting for handicapped consumers, p. 67 Consumers Union of United States, Inc.

TABLE 19. NATIONAL SURVEY COMPARISON FIGURES

While these figures indicate a better mechanical performance record for the REC, the review team felt that a 1/5 unreliability record was unacceptable over a long period of time. Since the REC had opened in 1974 and the study dates were 1975-78, some mechanical problems were felt by the rehabilitation engineer to be due to internal problems in getting materials and training new personnel. Of far greater importance, however, was the finding that a number of the interviewed group had not made the REC aware of mechanical problems, and had not returned for necessary repairs or reconstruction. This is a strong argument for regular REC initiated follow-up and education of clients to report malfunction and other problems.

Outcome Measurements

The criteria for assessing device effectiveness and client satisfaction were found to be relevant to observed benefit of the devices in community settings and the documented use time in months and in hours per day. (Tables 8, 14 and 15.) Goal attainment measured against the goals

identified at evaluation was also found to be relevant in observed use of the device in community settings.

Motor function was defined as those activities actively initiated by the person and directed toward task accomplishment. Motor function goals aimed at maintaining and/or improving current motor activities, or fostering new motor activities. These were clearly identified in the assessment records and were possible to document by obser tion.

Management goals were defined as facilitating care and comfort of the client, and protection and optimal function of the caretaker in activities related to the client. These were not clearly identified in assessment records partly because funding was difficult to obtain when management goals were the primary reason for obtaining a technical aid. The function of the disabled person is unlikely to change significantly in this circumstance, although caretaker tolerance, endurance and performance may be significantly improved, with corresponding improvement in atmosphere in home, school or community setting.

MediCal (Title XIX in California) has recognized 'management' as a justification for equipment provision in institutional settings: "if the patient's personal or nursing care will be significantly facilitated through improved positioning or compensation for physical deformities." Policy Statement MBS 78-6 (MediCal)

This policy should be applied in community settings as well, since the maintenance of the disabled individual in the community is less costly and usually preferred by the client and family. Education of third party payment sources may be necessary for the formulation of realistic guidelines for authorization for assistive devices for management goals.

Management and "mothers' backs" are closely related. In the visited group, only two mothers (caretakers) were found who were not experiencing back problems developed while caring for children. At least two mothers were using traction equipment regularly to alleviate pain which had developed while lifting and transferring their disabled children.

Client comfort as an objective may also be overlooked. Study participants repeatedly applauded the comfortableness of the devices. One mother of a non-vocal severely athetoid teenager said: "It's the first time in her whole life she has ever been comfortable!"

In general, management strategies in individuals where this is the realistic long-term emphasis need to be implemented earlier. They should be planned as active intervention to prevent breakdown in caretaker function and subsequent institutionalization of the disabled client.

Severity of Disability (degree of body involvement)

This was one parameter of the study which required definition at the outset. Table 4 contains the concept of disability severity in the study population, and it is evident that 82% were non-ambulatory. Sixty percent of the study population were classified as: non-ambulatory--severe, which was defined as: poor head control, poor trunk control and poor hand use.

In assessment of the visited group and in review of the charts, clients were rated at highest estimated functional level (by the physician and occupational therapist on the team). Hence the category 'non-ambulatory-' 'severe-involvement' meant inability to control head in sitting position, inability to sit without support and inability to use hands for activities of daily living such as self-feeding and personal care (hair combing, washing, toileting).

Discussions of a disabled population frequently focus on the minimally and moderately severely disabled group. When resources are listed and described, they often are aimed at the less severely disabled person. There are fewer resources for the more involved individual, and those which do exist are frequently "one-of-a-kind" solutions. These devices in many cases seem very expensive. However, in the client population reviewed in this study, such assistive devices are viewed by the client and caretaker as necessary to comfort, management and/or performance.

When cost and time factors are considered over the lifespan of a device, the initial purchase price can be viewed more objectively. The study showed an average cost of about $1.50 per day. (Table 15.) Length of time in use was measured in two ways: those devices which were outgrown and replaced (22%), and those devices still in use (50%). For the outgrown devices the average lifespan per device was 30.9 months or two and a half years. (Table 15.) For those still in use the average duration of use was 25 months, or over two years, and the average number of hours used per day was nine. (Table 14.) This is judged to be an excellent "track record" for these assistive devices and demonstrates a satisfactory cost/benefit by the standards and definitions applied.

In view of the severity of involvement of this study population, commercial availability of appropriate assistive devices is unfortunately less likely than for involvement of lesser severity. Many devices are indeed "one-of-a-kind," requiring extensive redesign or modification from commercially available items, or construction from components or basic materials. For some clients nothing really satisfactory is available from any source at the present time. For example, in the visited group, in 21% where goal attainment score was 0 or 1 (Table 8), the rehabilitation

engineer on the study team estimated for 71% of these clients that no alternative was currently available.

The REC as "provider of last resort" tends to bring the problem of distance into the picture. Since 50% of our study group lived more than 50 miles from the Center (Table 14), distance was frequently a complaint of study participants. It is evident that a trend is apparent in the extremes of score, i.e., zero and three, related to distance (page 20). Two-thirds of the devices scoring "zero" lived over 50 miles from the REC. On the other hand, two-thirds of the devices scoring "three" (optimal) were under 50 miles from the REC.

Equipment may require increased effort to "work out the bugs." Return visits to the REC for minor adjustments are more difficult when distance is a factor. Clients who are part of "active families" are more likely to persist until their needs are met, and not all families are "active." In our interviewed group, only 39% were so designated. (Table 6.)

A network of interacting resource centers covering the State of California is one way to minimize distance problems. This would foster interchange of ideas, designs and materials among centers and save travel time for the disabled clients and their families. Another solution to the problem of distance is use of a mobil unit which travels to areas distant from centers and near patients' homes. This is currently under study by the State Department of Rehabilitation and the REC.

Growth and Development Factors

Growth and development are factors synonymous with childhood and should be considered in provision of all assistive devices. Estimates of growth are possible using standard charts of height and weight, and with

medical information about the child. Development can be similarly charted, using standard motor maturity evaluations, psychological assessment and reports from parents, teachers and therapists. Though more difficult to measure in some children than in others, "development" assumes increasing maturation and complexity of adaptive behavior. Ability to use assistive devices depends upon motor capabilitiy, perception, understanding and motivation toward a functional end. Growth and development are factors in all areas.

The "outgrown devices" tabulation (Table 15) revealed average time use of two and a half years, which is a realistic figure for growing children. In the area of prosthetics for children, the duration of use before replacement has been generally accepted as related to growth and development of the child.

It is also important to consider delay in securing authorization for funding of assistive devices for children. An interim period of three months in a child under 3 years should suggest re-evaluation; for older children, a six-month delay should result in review. This is especially important for custom fitted devices such as orthotic body jackets and orthopedic seat inserts, in the opinion of the rehabilitation engineer on the study team.

Compatible Systems

In this study, inquiry was made about compatibility of equipment systems, but awareness of the concept was found to be low. It was our impression that issues of access, transportability, and compatibility must be incorporated into the initial assessment, since they may become critical to acceptance and successful use of the device.

At the most basic level, the shapes of devices must "match" the person, but they must also "match" the environment, e.g., a roll-in shower chair must be able to fit through the door and turn corners when user-occupied; the tiedown in a school bus must haved a suitably sized part on the wheelchair to connect with safely; the new wheelchair should still fit under the dining room table for both functional and psychosocial reasons. In a more sophisticated way, the individual's lifestyle must be taken into account: e.g., does the person engage in wheelchair travel or sports; might younger siblings be likely to catch their fingers in the wheelchair's spokes or chain drive? There are numerous aspects of a person's environment that may need to be included in the selection of any particular piece of equipment.

Options

People need adequate information to make intelligent decisions when there are options in these areas. They also need to be told when there are no real options, given the existing state of device design. The assessment process can become an education process for the entire group. The consumer and family should become active participants in the decision making. In some cases, the best decision may even be to forego a device if it isn't capable of meeting basic requirements; or to settle for less than optimal if the more complex system would be difficult to maintain locally. These are decisions that can only be made when options are fully understood.

Every device has limitations as well as assets, adn these must be considered. Not infrequently, the client must make a choice and achieve a group of functional advantages at the sacrifice of activities which seem to be of lesser value.

A Team Approach to Assessment

In providing technical aids, a "match" is required between the person, the device and the environment in which it must work. Knowledge in the following two areas are needed in assessment:

1) Knowledge of the impairments, functional abilities and performance needs of the individual.
2) Knowledge of the mechanical possibilities, materials and construction of the device.

Professional training in both areas is uncommon; ideally, two professionals with appropriate training are required to provide clinical, environmental and mechanical assessment and recommendation of an appropriate device. These decisions also require input from client and family members.

Where indicated, medical assessment may be needed, and/or psychosocial assessment, and these professionals should then be added to the core team.

Core Team	Expanded Team
	add
Client/family	Physician
Rehab Engineer	and/or
Therapist (OT or PT)	Social Worker or Psychologist

Indications for Assessment by Expanded Team

1. Medical assessment needed
2. Lack of consensus among referral sources
3. Requirement for multiple pieces of equipment
4. Unclear mental ability status
5. Discrepancies in background/medical information
6. Undesignated psychosocial factor: this area needs more study
7. Decision of core team

It is important to encourage an active mode of participation by the consumer, family and others involved. They must be part of the team, and feel a sense of control in the decision making. There is a reciprocal responsibility on the part of professionals: they must learn not only to listen to the client/family but also to be able to deal with the emotional reactions that active participation may elicit.

When working with a severely disabled population, it is necessary for the technical staff to be trained in interaction skills; and/or have a resource person (e.g. a social worker) who can assist in these areas. Working with people with extraordinary needs is very rewarding, but can also lead to feeling overwhelmed and frustrated when one is not able to "solve" everything with available technology.

Service Delivery

The information collected about the service delivery process (Table 17.) may be useful to other facilities delivering rehabilitation engineering services. In this study, process time (date of referral to date of payment) usually took more than a year; "delivery to final payment" usually took five to seven months. If the provision system cannot absorb the expenses involved in delayed payment, there will most likely be increasing financial problems.

"Authorization to delivery" time was a little less than 3 months. This time has been shortened by development of working relationships with manufacturers, suppliers and distributors, and by maintenance of adequate inventories.

The average time was 2 to 3 months between evaluation and authorization. For service providers, this time interval represents another complication, especially with young children, and this problem has been previously discussed.

As the time cannot realistically be expected to shorten, and construction cannot be started prior to funding authorization, professionals considering children for referral should be encouraged to recommend assistive devices as early as seems feasible. Professionals should also be aware of problems and delays in funding procedures, so that when assistive devices are being considered, the family has time and opportunity to explore possible funding sources.

In summary, this clinical research study has investigated a number of issues:

1) benefits of assistive devices as measured by utilization, goal attainment and client satisfaction (optimal results);
2) reasons for non-receipt and/or non-acceptance of assistive devices (suboptimal results);
3) cost and time factors: duration of use in months and hours per day, and cost per device and per day of use;
4) effectiveness of team evaluation in the assessment process; and
5) service delivery factors.

It is hoped that the study demonstrates that: 1) it is possible to define and document the benefit of assistive devices; and 2) it is possible to relate benefit to cost.

A prototype assessment form is attached. This is being client-tested at the Rehabilitation Engineering Center. It is hoped that both technical and psychosocial requirements of the client can be accurately assessed with this form and with the aid of a core team. The study group would welcome comments and suggestions regarding the form.

SUMMARY AND RECOMMENDATIONS

Summary

The Rehabilitation Engineering Center is a regional resource center, providing technical aids and services to disabled individuals and their families. The seating and mobility devices recommended and fabricated here tend to be more individualized than the average off-the-shelf aids available through local vendors. In addition, these devices are generally used by the more severely disabled person.

In assessing overall effectiveness of these technical aids, it was found that 79% of the devices optimally, or close to optimally, achieved their objectives; while 21% met them only to a limited degree or not at all.

The provision of an effective device correlated 100% with a perceived lifestyle change in the disabled consumer and/or family. Other psychosocial factors were identified as needing further study.

Technical performance was found in 81% of the devices to be satisfactory. This compares favorably to the results of a recent national survey which stated that "30% of those polled discontinued using a rehabilitation product because of lack of product reliability, usually attributed to a mechanical design problem."

Fifty percent of the devices are still being used; and the average number of hours used per day was found to be nine. Twenty-two percent of the devices had been outgrown; and the average life span per device was 30.9 months.

The average cost per device was approximately $1,650. The average cost per day of use of the device was $1.50. Private funding sources accounted for 52% of monetary reimbursements, and public funding sources for 48%.

An assessment tool was developed which would assist the team in matching the disabled person's needs and priorities with the environmental parameters, and with the device requirements. It is being evaluated clinically at the Center and is included in this paper for comment and suggestions from other Rehabilitation Engineering Centers.

Recommendations:

1. Evaluation of an individual for an assistive device should be related to: a) functional needs; b) psychosocial factors, and; c) the environment in which it will be used. Evaluation forms should be available to document that such factors were considered.

2. A team approach is indicated; the basic team recommended is an occupational or physical therapist and rehabilitation engineer, with the client/family considered as part of the team. An expanded team consisting of physician, medical social worker, speech pathologist, psychologist or other professional worker, is indicated if:

    a. medical assessment is needed.

    b. there is lack of consensus among referral sources.

    c. requirements are for multiple pieces of equipment.

    d. mental ability status is unclear.

    e. there are discrepancies in background/medical information.

    f. the core team decides for any other reason that consultation is needed.

3. Goals should be established for performance assessment of the assistive device: management goals or motor function goals, or both. Management goals are directed toward:

a. care, comfort, maintenance of health and prevention of ill health of the client, and

b. protection, support and optimal function of the caretaker related to activities with the client.

Motor function goals are directed toward:

a. maintenance or improvement of current motor activities, or

b. fostering new motor activities.

Goals should be identified, stated in the evaluation, and used in justification for funding requests.

4. Consumer participation is an integral and essential requirement for successful provision of assistive devices. Active participation needs to be encouraged during the evaluation process. Technical staff should be trained in interaction skills, and/or have a resource person (e.g. a social worker) who can assist in these areas. Psychosocial needs are an important aspect of success or failure in assistive devices.

5. It should be possible to document in the evaluation the goals, assistive devices recommended, estimated durability, and estimated costs. These should be stated in a form such that they are retrievable for evaluation of:

a. success in matching device to person-environment

b. process success--from evaluation to funding authorization to provision to payment

c. cost/benefit analysis: attainment of goals in relation to costs of assistive devices

6. Follow-up should be incorporated into the process of evaluation and provision of a device. Time costs for fabrication should include time for follow-up at regular intervals.

AREAS FOR FURTHER STUDY

Assessment

An assessment form has been developed, based on our experience with this study. This instrument will be validated in field tests involving clients and rehabilitation engineers within our institution. A proposal for an extensive prospective study using the assessment form and including follow-up should be undertaken (depending upon the validation of the proposed assessment form).

Psychosocial Factors

Further study is needed in psychosocial aspects of assistive device provision. It may be possible to identify predictive psychosocial indicators, and derive information regarding changes in the client's lifestyle. This information may assist in a better choice by the client or a better adjustment to the life style changes.

Some of the questions which require consideration are: What happens to persons when they have no alternative but reliance on a device? How does the device become incorporated into self-image? What happens psychologically when the device malfunctions, breaks down, or needs to be replaced? What is "acceptance"? Does acceptance of the device mean acceptance of the disability, or is there a magical feeling that the device will somehow "cure" the disability? Do disabled clients think of their devices as "tools", in the same way that able-bodied people think of hammers or pliers? Can wheelchairs

be considered as convenient means of transportation by the disabled client, just as bicycles and automobiles are so considered by the non-disabled?

If a piece of hardware needs to become integrated into a person's self-image, more must be learned about device acceptance, and how to facilitate it.

Lifetime and Comparative Cost Factors

Proper perspective relating to costs of technical aids becomes critical as device sophistication and costs rise, and accountability measures are demanded. Data must be collected to answer questions such as:

What are the lifetime costs of devices? Answers would need to include initial cost, repair and maintenance costs.

What are the effects of equipment "downtime" on a disabled person's life? Answers would need to include monetary, psychosocial and caretaker time factors.

How does the provision of devices (cost/benefit) compare with the provision of ancillary services (cost/benefit)? What are the cost savings in ancillary services by providing assistive devices?

What percentage of family budgets goes to extraordinary costs associated with the disability, not including medical and assistive device costs? Time factors such as lost worktime, unpaid attendant care given by family, changes in housing and transport vehicles should be included.

Guidelines: is it possible to formulate guidelines related to the time an assistive device is expected to provide useful service, and to recognize realistic replacement intervals and costs?

Development of a Network of Rehabilitation Engineering Service and Research Centers

More comprehensive and reliable data on the numbers of disabled persons and their needs for engineered devices would provide a useful baseline for consideration of regional networks. In children's prosthetics, the gradual development of centers in California (encouraged by Crippled Children Services) has helped parents in all areas of the state to find a resource within reasonable distance of their homes. Also in California there is a Regional Center of Developmental Disabilities network including 21 Centers serving all areas of the state. In the interim while a network of Rehabilitation Engineering Services is being discussed and organized, the use of a mobil unit may help to alleviate problems of distance and transport. Such a mobil unit is currently being arranged by the State Department of Rehabilitationand the Rehabilitation Engineering Center, Children's Hospital at Stanford.

ASSESSING PSYCHOSOCIAL FACTORS IN THE USE OF ASSISTIVE DEVICES
(Results of an Opinion Questionnaire Administered by
John Preston, Jr., M.S.W.)

Data on a study population consisting of 196 disabled individuals who were assessed for mobility/assistive devices at the REC between May, 1975 and May, 1978, was the basis of the study results reported in the main body of this paper. Direct contact was made with 138 disabled people or their families; and of these 49 were visited in their communities by the study team, of which the author (J.P.) was a member.

Optimum benefit of a device was assessed in this study, using criteria of: effectiveness (utility and goal attainment) and client satisfaction. The team as a whole measured client satisfaction, among the other criteria, by

observation and interpretation of client/family responses during a structured interview. This was scored as part of the team assessment (Table 8.) The author participated in this assessment.

In addition, an opinion questionnaire was administered by the author separately, following the team interview. This was scored separately, without prior knowledge of the team observation score, by assigning numbers to the clients and tabulating questionnaire results without cross-reference to names. When the tabulations were complete, these were cross-checked with the outcome scores of the team evaluation.

Rationale for Questionnaire Section of Study

Providers of services are not always aware of the extent to which psychosocial needs of disabled persons and their families may impinge on successful use of an assistive device. In recommending assistive devices, I believe these psychosocial needs must be considered for optimum benefit to occur. A measure of psychosocial benefit may be evident in lifestyle changes for the person using the device and his/her family.

Lifestyle as a concept encompasses participation in daily activities, social interaction within the environment, perception of life tasks, aspirations and values, and one's self-concept of success or failure in these areas. For disabled and non-disabled people, a lifestyle of homeostatic balance is maintained unless stress is overwhelming. Studies have shown that individuals in several different countries tend to rate 40-50 life stressful events equivalently as to degree of stress (Hurst et al.). It is the author's opinion that analogies exist between these stressful life events and the introduction of an assistive device into the disabled person's lifestyle.

Part of the adjustment process to a disability lies in learning to live in satisfying equilibrium with one's surroundings. In this context, provision of an assistive device constitutes a change in the support environment, and should result in a change in lifestyle, with the additional stress requiring further adjustment toward equilibrium.

The purpose of this inquiry was to determine whether an opinion questionnaire could identify such changes in lifestyle - after receiving an assistive device.

Survey Methodology

A questionnaire was constructed using certain life events that have been identified (empirically) as stressful in and of themselves.

This questionnaire solicited the individual's opinions as to whether they had perceived certain life style changes since receiving the device. All questions were scored on a 7 point Likert-type scale in which the range was from 1 ("Agree very strongly") to 7 ("Disagree very strongly"). (Questionnaire attached.)

Results

When asked to respond as to whether the family enjoyed more social life or interacted more as a family unit since receiving the device 81% said having the device made a difference. Nine percent had no opinion and 10% disagreed.

In response to whether the device allowed for more independence, 71% agreed. Sixty-seven percent of the respondents said the device had allowed them to increase their social activities as well as more contact with peers and 56% said they had increased their activities in school.

In a previous report, (Preston, 1979) it was concluded that some individuals are willing to accept the unattractive appearance of a device if it provides dependable and functional service. However, 54% of the respondents in this study did say that they liked the appearance of the device.

Fifty-six percent agreed that their sitting habits had changed, with the majority noting increased sitting time due to positioning or improved seating systems. 54% of the respondents interviewed indicated that their daily living habits were more ordered. It was noted that prior to obtaining the device, some families' daily routines were arranged or scheduled according to the amount of involvement with the disabled person. The disabled person arranged his/her daily schedule according to times when family members were available to assist.

In response to whether more time was required of other family members for physical support, 40% agreed, 11% had no opinion and 49% indicated no further support was needed. Respondents listed portability, assistance in transfer, mechanical problems, and transportation as reasons for needing more assistance. In addition, some respondents related that since receiving the device, they were able to engage in more activities, thus involving other family members in more outside activities. This response was therefore not a negative response to receipt of the device, only an indication of change.

Forty-three percent of the respondents said that some form of modification to the environment was needed since receiving the device. The most notable were ramps, bathroom modification and fixtures, wider doorways, elevators and stair glides.

Approximately 31% felt an increased need for outside help due primarily to the fact that they were in independent living situations or were

seeking attendant care for independent living. This again is a change usually considered to be positive.

In reference to whether there had been a change in occupational roles, 18% agreed, 6% had no opinion, and 76% said there was no change.

Although the majority of respondents listed the mother's primary occupation as homemaker, several mothers indicated feeling more secure in leaving the disabled person alone or with someone else, and had secured part time jobs or were engaging in other activities.

The most frequent response given for not utilizing the device to a greater extent was the amount of upkeep needed. Thirty-two percent of respondents said that frequent trips to medical facilities were required for maintenance of the device.

When asked to respond to eating, sleeping, or toileting habits most of the respondents 90%, 89%, and 89% respectively disagreed as to any significant change occurring. Most of the respondents did not expect their device to effect change in any of these areas.

The overall response to the survey was that 79% perceived significant life style changes after receiving the device and 21% indicated no or little change.

The most important finding in this study is the correlation between those devices that were rated 0-1 in the follow-up study and how those individuals responded to Life Style changes perceived to be brought about by the device. It was found that those individuals who received 0 or 1 as a device score (21%) also indicated that they did not experience any significant lifestyle changes after receiving the device (21%). The 79% of the population who did experience a significant lifestyle change, were identical to the 79% of the population whose devices were scored as 2 or 3 ("met most or all needs").

Question-area	Agree (%)	Disagree (%)	Neither Agree Nor Disagree (%)
Family enjoys more social life	81	10	9
More independence	71	21	8
Increase in social activities	67	26	7
More contact with peers	67	23	10
Allows more normal function	62	22	16
Increased activities in school	56	27	17
Sitting habits changed	56	28	16
Likes device's looks (self-concept with device)	54	27	19
Family living habits more ordered	54	30	16
Restructuring of physical surroundings required	43	48	9
More time required of others for physical support	40	49	11
Frequent trips to medical facilities required	32	47	21
Increased help for outside help in management	31	53	16
Changes in occupational role	18	76	6
Changes in health of others in family	17	67	16
Sleeping habits changed	8	89	3
Toileting habits changed	8	89	3
Eating habits changed	6	90	4

Discussion

Rehabilitation Engineering settings are sensitive to the physical needs of the severely disabled. Although we have witnessed significant technological advances there is a tendency to be less sensitive to the emotional and social components related to the uses of an assistive device. Katz suggests that many of the new technologies do little to improve the life adjustment of the disabled, but simply extend lives.

Much of our understanding regarding the rehabilitation of the disabled has been seen as a medical problem. However, more emphasis is now being placed on the role of an individual's life style in relation to disease and the rehabilitation process. Thus, the emphasis on intervention is not aimed at the emotional response to the disability per se, but on the adaptive response to the stress involved in the adjustment process. For the purpose of this study, the stress was involved with the introduction of an assistive device into the person's life style. Thus stress is defined more in terms of the occurence of certain stimulus related to using the device rather than in terms of one's emotional response to the disability.

Reactions to disability by some individuals and family members may be highly subjective and unrelated to the realities of an assistive device and the ramifications of physical limitations. Bracht suggests that the way individuals are affected is dependent upon:

(1) The importance or salience of the relationships that become disordered under conditions of social disorganization.

(2) The position of the individual experiencing such disordered relationships in the status hierarchy.

(3) The degree to which the population under study has been prepared by previous experience for this particular situation.

(4) The nature and strength of the available group supports.

Caring for a disabled family member at home can create stress that may exacerbate existing dysfunction in the family. The unusual problems encountered by having the person in the home may only add to a long list of accumulated deprivations. Sometimes, an assistive device is resisted by parents who feel it represents visible evidence of functional disability and are unable to recognize the positive life style changes associated with the device.

Example:

> In my social work case load, there was a family who had led a very active life until their 9 year old son was diagnosed as having a neuromuscular disorder. During a clinic visit the mother related that the family no longer engaged in recreational activities due to their son's weakness, easy fatiguability and inability to participate in activities such as walking to the beach, campsite, etc.
>
> Although the prognosis for her son's illness was a slow progression with eventual non-ambulatory status, she had been encouraged to have him remain walking as long as possible. She also confirmed that she had not given up hope and felt that a wheelchair represented the final stages of disability for her son.
>
> After much discussion, it was suggested that the family utilize a manual wheelchair only to transport their son to and from certain activities thus reserving his energy for play activities. Although therapeutic intervention was initiated to help deal with her emotional response to her son's illness, the primary emphasis on prescribing the chair was aimed at the family response to giving up recreational activities.

It is important to note that life style changes can be a result of using the device or can have causal effect in changed requirements for assistive device/s. Using one device can cause increased demands for other devices or support systems. If the client and/or family have not been prepared for the implications of acquiring greater mobility or other function, the new skills may be regarded in a negative way and as an additional problem to the family.

Example:

A severely disabled young man was provided with an electric wheelchair. He wished to operate it outdoors, in his neighborhood, and eventually wished to attend junior college. These desires, nor possible to achieve, required construction of a ramp which had not been necessary previously, and arrangements for transportation of the young man and the chair to the college. When all these activities were carried out, a new lifestyle could be enjoyed by the client, but during the interval of change, a great deal more effort was required of his family.

It is important to consider the emotional reactions of the person or family regarding the device.

Example: (From my social case work in the child prosthetic clinic)

The physician and the prothesist had recommended a terminal device (hook) to the mother of a 2 year old daughter who had had an amputation. Later during the interview, the mother admitted that for 2 years she had shielded her daughter's arm from the public by keeping it covered. She had just begun to deal with people's responses to her daughter's amputated arm. She then confided that she did not feel that she was emotionally ready to deal with the terminal device nor other's reactions to the child wearing the device.

This reaffirms that "it is not always what happens to you that induces stress but your response to it." Thus part of the assessment process is the inquiry into those aspects in a person's lifestyle which need to be considered in an attempt to provide anticipatory guidance and ameliorate stress related to the provision of the device.

The social worker may be a very useful member of a team which assesses disabled individuals for assistive devices. However, when the social worker functions as a member of such a team, he/she has a professional obligation to become knowledgeable in the appropriate use of devices and their effects in changing lifestyle.

Pincus and Minahan define social work as being "concerned with the interaction between people and their social environment which affect the

ability of people to accomplish their life task, alleviate stress and realize their aspirations and values."

Dona Lansing Bracht, in a paper entitled "Assessing the Psychosocial Effects of Illness," states that:

> "A major aspect of social work in health care is helping people to redesign their life styles as a means to manage current problems dealing with the stresses and strains of everyday life and to avoid future crises."

The results of the present inquiry indicate that life style changes do occur when devices are useful and appropriate to the client's needs. In other words, a psychosocial change has taken place, with the adjustment process which is always required with change. It appears that assessment of psychosocial factors during the initial evaluation of a disabled client may facilitate acceptance and incorporation of an assistive device into an altered lifestyle. Clinical social workers experienced in work with disabled clients in redesigning lifestyles can provide valuable assistance to rehabilitation engineers.

Summary

An opinion questionnaire administered to 49 disabled individuals and/or their families indicated that 21% perceived no change in lifestyle. These same 21% had devices scoring 0 to 1, denoting minimal or no effectiveness in achieving their objectives. For those 79% who perceived significant change in lifestyle, the device score was 2 or 3, indicating moderate to optimal effectiveness.

It appears that assessment of psychosocial factors in prescribing devices may be possible and valuable. Further study will be needed to determine how prospective psychosocial assessment can be integrated into the rehabilitation engineering evaluation process.

SOCIAL SERVICE EVALUATION
OF POSSIBLE LIFE STYLE CHANGES
SINCE OBTAINING ASSISTIVE DEVICE(S)

I AM INTERESTED IN LEARNING FROM YOU WHETHER CERTAIN LIFE STYLE CHANGES HAVE OCCURRED SINCE OBTAINING THE DEVICE.

PLEASE RESPOND TO THE FOLLOWING STATEMENTS BY INDICATING THE NUMBER WHICH CORRESPONDS TO THE FOLLOWING DESCRIPTIVE ADJECTIVES, WHICH MOST REPRESENT YOUR FEELINGS.

(7) AGREE VERY STRONGLY

(6) AGREE STRONGLY

(5) AGREE

(4) NEITHER AGREE NOR DISAGREE

(3) DISAGREE

(2) DISAGREE STRONGLY

(1) DISAGREE VERY STRONGLY

EXAMPLE: CHANGED COLOR OF HAIR. _____1_____

PSYCHOSOCIAL FACTORS

1) FAMILY ENJOYS MORE SOCIAL LIFE _____

2) MORE TIME IS REQUIRED OF OTHER FAMILY MEMBERS FOR PHYSICAL SUPPORT _____

3) FAMILY DAILY LIVING HABITS ARE MORE ORDERED _____

4) INCREASED NEED FOR OUTSIDE HELP IN MANAGEMENT OF INDIVIDUAL _____

_____

5) CHANGE(S) IN OCCUPATIONAL ROLE BROUGHT ON BY DEVICE, PLEASE SPECIFY

_____

6) CHANGE(S) IN HEALTH OF OTHER FAMILY MEMBERS, PLEASE SPECIFY _____

_____

7) FREQUENT TRIPS TO MEDICAL FACILITIES ARE REQUIRED FOR MAINTENANCE OF DEVICE _____

8) RESTRUCTURING OF PHYSICAL SURROUNDINGS _____

9) THE DEVICE HAS ALLOWED INDIVIDUAL TO INCREASE SOCIAL ACTIVITIES

_____

10) MORE CONTACT WITH PEERS _____

11) THE DEVICE ALLOWS FOR MORE INDEPENDENCE _____

12) I LIKE THE WAY DEVICE LOOKS _____

13) DEVICE ALLOWS INDIVIDUAL TO FUNCTION NORMALLY _____

14) INCREASED ACTIVITIES IN SCHOOL _____

15) SLEEPING HABITS HAVE CHANGED? PLEASE SPECIFY _____

16) EATING HABITS HAVE CHANGED? PLEASE SPECIFY _____

_____

17) TOILETING HABITS HAVE CHANGED? PLEASE SPECIFY _____

_____

18) SITTING HABITS HAVE CHANGED? PLEASE SPECIFY _____

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APPENDICES

The following attachments provide additional descriptive and illustrative detail relating to this study.

A-1 Definitions

A-2 Table of Population Comparison

A-3 Equipment Pictures

A-4 Follow-Up Study Team

A-5 Proposed Assessment Form

A-1

DEFINITIONS

Definitions of Terms Used in Study Tally Sheets

Age:

All ages are calculated to January 1, 1980.

Diagnosis:

Primary disability; diagnostic categories were considered secondary to functional levels (see total body involvement).

Progressive:

Yes - deterioration due to disability, e.g., Muscular Dystrophy.

No - disability is relatively stable, e.g., Cerebral Palsy.

Total Body Involvement:

Non ambulatory-severe: poor head control, poor trunk control, often severe spinal curvature, virtually no use of hands.

Non ambulatory-moderate: fair head control, poor trunk control, moderate use of hands.

Non ambulatory-minimal: good head control, fair trunk control, somewhat unstable in sitting position.

Other: has some ambulation.

Scoliosis: Yes - either fixed or flexible spinal curvature present.

Contractures: Yes - loss of full passive range of motion in any joint.

Seizures: Yes - controlled--any type of seizure history under control through medication.

Yes - uncontrolled--any type of seizure not under control by medication.

Visual deficit: Yes - deficit sufficient to require consideration in the Rx of device.

Hearing deficit: Yes - deficit sufficient to require consideration in the Rx of device.

Speech deficit: Yes - lack of usable verbal communicative ability.

Estimated Mental Ability:

Near normal or above: able to participate in regular school activities.

Mildly retarded: generally considered EMR or TMR.

Severely retarded: generally considered profoundly retarded.

Type of Living Situation:

Home: lives independently or with family.

Foster home: lives out of home with foster family.

Institution: lives out of home in a residential school or institution.

Accessibility:

Low - steps, impossible to independently enter/exit.

Medium - enter/exit possible independently, and major parts of house accessible.

High - completely accessible and usable, including bathroom, bedroom and eating area.

Family Type:

Active - knowledgeably and precisely describe their wants and needs.

Intermediate - between active and passive.

Passive - delegates all decisions to professionals.

Funding Source:

Public - controlled by public sector legislation.

Mixed - combination of public and private funding.

Private - not controlled by public sector legislation.

Goals:

Management - those directed toward (1) care, comfort, maintenance of health and prevention of ill health of the client, and (2) protection, support and optimal function of the caretaker related to the activities with the client.

Motor ability - those directed at improving and/or maintaining current motor function or fostering new motor activities.

Interface:

The boundary between two systems; a device which facilitates the transfer of information of control across such a boundary; anything put between two systems which enables them to work together.

Control (or control device):

A method or mechanism by which a person operates a device.

System Compatibility (estimate):

High - all devices and/or adaptations used work together smoothly as a system.

Medium - all devices and/or adaptations used work together but with minor problems.

Low - all devices and/or adaptations used present major problems to working together as a system.

Explanatory Notes on Demographic Data Base

Payment date - reflects date of last payment or the date payment was written off by CH@S billing department.

Ages and dates are calculated to January, 1980.

Demographic data - reflects information obtained through chart review, supplemented by first-hand data when available.

A-2

TABLE OF POPULATION COMPARISON

POPULATION COMPARISON

		Contact		Visit		No Response		Contact + Visited Groups		Total	
		C=89 (45%)		V=49 (25%)		NR=58 (30%)		C+V=138 (70%)		TOTAL=196 (100%)	
		#	%	#	%	#	%	#	%	#	%
SEX	Male	55	62	29	59	27	47	84	61	111	57
	Female	34	38	20	41	31	53	54	39	85	43
AGE	0-2	2	2	7	2	0	0	3	12	3	2
	3-5	13	15	4	8	6	10	17	12	23	12
	6-8	13	15	7	14	7	12	20	13	27	14
	9-12	15	17	11	22	12	21	26	19	38	19
	13-18	19	21	8	16	17	29	27	20	44	22
	19-22	2	10	8	16	7	12	17	12	24	12
	23-35	12	14	7	14	5	9	19	14	24	12
	Over 35	6	7	3	6	4	7	9	7	13	7
DIAGNOSIS	CP	53	60	27	55	34	59	80	58	114	58
	SCI	2	2	2	4	3	5	4	3	7	3
	SB	6	7	3	6	4	7	9	7	13	7
	OI	3	3	2	4	1	2	5	4	6	3
	NM	13	15	7	14	3	12	20	15	27	14
	OTHER	12	13	8	17	9	16	20	14	29	15
BODY INVOLVEMENT	Min	7	7	3	6	11	19	10	7	21	11
	Mod	14	16	9	18	10	17	23	17	33	17
	Severe	59	66	33	67	26	45	92	67	118	60
	Other	17	8	4	8	8	14	11	8	19	10
	Unknown	2	2	0		3	5	2	1	5	2
SPEECH DEFICIT	Yes	50	56	25	51	27	47	75	54	102	52
	No	25	28	24	49	21	36	49	36	70	36
	Unknown	14	16			10	17	14	10	24	12
MENTAL ABILITY	Normal	46	31	27	55	30	52	73	53	103	52
	Mild	13	15	6	12	12	21	19	14	31	16
	Severe	24	26	12	24	13	22	36	26	49	25
	Unknown	6	7	4	8	3	3	10	7	13	7
LIVING SITUATION	Home	70	79	36	73	45	78	106	77	151	77
	Foster	8	9	4	8	6	10	12	9	18	9
	Institution	11	12	9	18	6	10	20	15	26	13
	Unknown					1	2			1	1

POPULATION COMPARISON (continued)

		Contact		Visit		No Response		Contact + Visited Groups		Total	
		C=89 (45%)		V=49 (25%)		NR=58 (30%)		C+V=138 (70%)		TOTAL=196 (100%)	
		#	%	#	%	#	%	#	%	#	%
DISTANCE = Miles											
	Under 5	2	2	4	8	1	2	6	4	7	3
	5-14	7	8	6	12	6	10	13	9	19	10
	15-29	22	25	14	29	17	29	36	26	53	27
	30-49	11	12	5	10	4	7	16	12	20	10
	59-80	15	17	11	22	3	5	26	19	29	15
	Over 80	32	36	9	18	27	47	41	30	68	35
FUNDING	Private	28	31	15	30	18	31	43	31	61	31
	Mixed	14	20	10	20	12	20	28	20	40	20
	Public	43	48	22	45	28	48	65	47	93	47
	Other			2	4	2	1	2	1	4	2
GOAL	Management	40	45	19	39	20	35	59	43	79	40
	Motor	38	43	19	39	31	53	57	41	88	45
	Both	11	12	11	22	7	12	22	16	29	15

*Note on population comparison:

When the ten variables used for comparison of the group from which we had direct information and the group on which we had only demographic information were examined (see TABLE 3), the groups were found to be essentially the same, with only the following exceptions. There were fewer people in the "no response" group with severe total body involvement, and this same group had fewer "management only" goals. This finding is in keeping with other studies which show that the less severely disabled individual tend to be lost to followup. Because of the positive correlation between severe body involvement and management-only goals, it was expected that a lower percentage of management goals would also be found in this group, as in fact was the case.

Degree of Total Body Involvement

	Directo Info. Group (n=138)		Demographic Info. Only Group (n=58)	
severe	92	67%	26	45%
moderate	23	17%	10	17%
minimum	10	7%	11	19%
other	11	8%	8	14%
unknown	2	1%	3	5%

Less easily explained was the difference in numbers of men and women in the two groups.

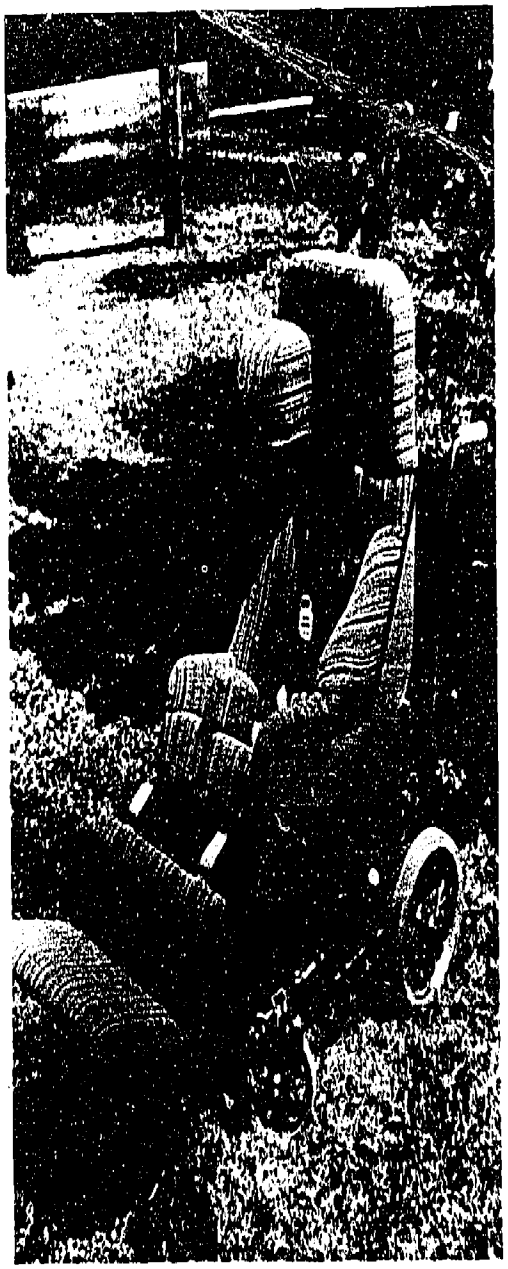
	Direct Info. Group (n=138)		Demographic Info. Only Group (n=58)	
Male	84	61%	27	47%
Female	54	39%	31	53%

This may also be explained by the same phenomenon as noted above--as there are statistically more disabled men than women, and more severely disabled men than women, and we may have lost more women in the study because they tended to be the less disabled.

A-3

EQUIPMENT PICTURES

ORTHOPEDIC SEAT INSERTS

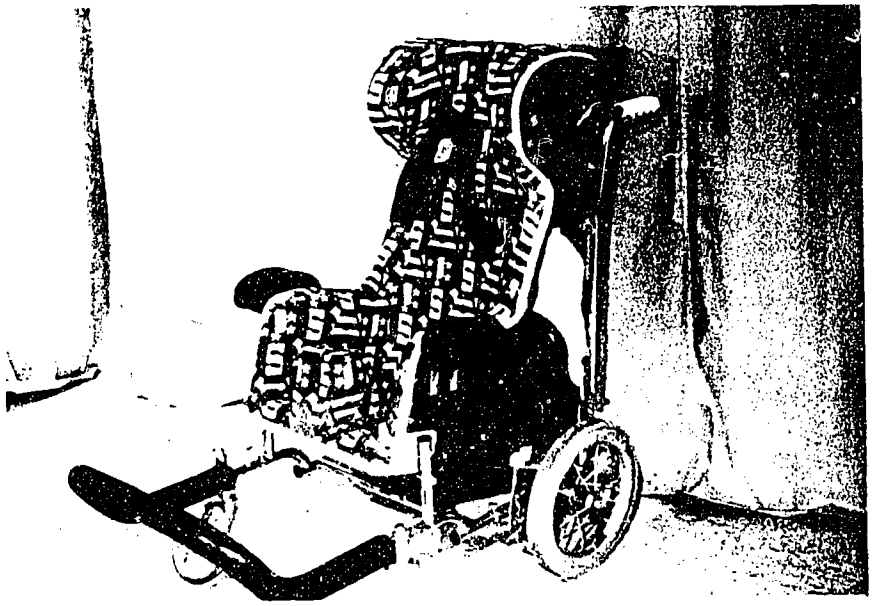


A seat insert is a specially constructed custonm seat for a person that cannot be accommodated by a regular chair. Seat inserts and trunk supports are constructed either out of molded plastic and appropriately padded or more commonly from from a standardized plywood seat that is then filled with foam plastic carved out to fit the patient's trunk and head, if necessary, to provide optimum support, and in the case of cerebral palsy, optimum relaxation as well. Each child is analyzed to see which position in space creates the most relaxation and what support is needed. For small children such wheelchair inserts are made to double as car seats so that the child is easily transported by the mother or by the treatment facility.

CASTER CART

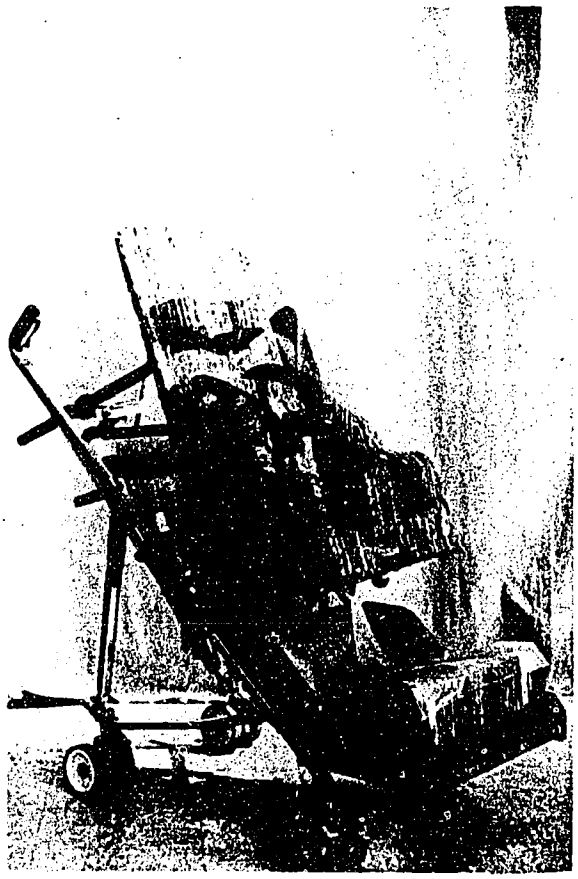
The caster cart is really a miniature on-the-floor wheelchair with trunk support that can be adapted for the needs and posture of the child. It can double as a stroller and as a car seat. It is prescribed at the developmental age when the child needs to explore his environment but has no ability to walk. It has been particularly useful in spina bifida and osteogenesis imperfecta cases.

Uses: Motivation to move from one place to another. Protection of desensitized skin. Increasing sitting balance. Good play and fun position. Developing some independence. Upper limb and trunk strengthening. Conjunction with or prior to a bracing device. Exploration at floor level with his peers at the crawling stage. Protection at floor level against others in wheelchairs, tricycles, etc. Freedom of hands for bilateral functional activities and exploration rather than being used for trunk balance.



Above: Orthopedic seat insert made for Mooney Base to be used as foot-propelled push chair.

Left: Shoulder and chest restraints for body control.



Left: Orthopedic seat insert made for collapsible MacLaren Buggy Major. System has three positions-for function, feeding and relaxation.

Below: Orthopedic seat insert for young child, made by modifying a Peterson car seat and adding clear lap tray.

A-4

FOLLOW-UP STUDY TEAM

FOLLOW-UP STUDY TEAM

Medical	Jean G. Kohn, M.D., M.P.H.
Functional	Sandi Enders, O.T.R.
Psychosocial	John Preston, Jr., M.S.W.
Rehabilitation Engineering	Wallace M. Motloch, C.O.
Technical	Brian J. Allison

Jean G. Kohn (M.D. University of Chicago, 1950, M.P.H. University of California School of Public Health, Berkeley, 1973) is currently Lecturer and Field Program Supervisor in Maternal and Child Health, University of California, Berkeley School of Public Health, and Medical Coordinator of the Child Prosthetic Clinic, Children's Hospital at Stanford. Also pediatric consultant to California Children's Services (formerly Crippled Children's Services) she is co-author with Dr. Peter Cohen of a 15-year follow-up study of 319 patients with cerebral palsy (Western Journal of Medicine, 130: 6-11, Jan. 1979). A Fellow of the American Academy of Pediatrics and the American Academy for Cerebral Palsy and Developmental Medicine, for the past twenty years Dr. Kohn has spent her professional time in the field of handicapping conditions in children.

Sandi Enders (B.S. in Occupational Therapy from San Jose State University, 1973) directed a federally-funded Equipment Evaluation Project at the Center for Independent Living, Berkeley, California, headed a program in Independent Living Skills Counseling, and a technical assistance unit for Independent Living Program development. Currently she is coordinating education, training and information dissemination activities under a federal research grant at the REC, Children's Hospital at Stanford.

John Preston, Jr. (B.S. in Business Administration and M.S.W. in Welfare Admnistration, University of Illinois, 1975). The degrees were obtained under the Handicapped Students Program, Mr. Preston having sustained an injury at 16 years of age which rendered him paraplegic (T6 level). Currently he is Clinical Counselor to children and families in the Neuromuscular Clinic, Children's Hospital at Stanford, and Research Associate at the REC, Children's Hospital at Stanford.

Wallace M. Motloch (C.O. School of Orthotics, Ontario Crippled Children Center, 1964, B.S. in Business Administration, University of San Francisco, 1975). Has developed a number of originally designed assistive devices, with major focus on seating and mobility devices (Parapodium, Mobilpodium). In 16 years of clinical practice, Mr. Motloch has designed and supervised construction of a wide variety of devices for severely and multiply handicapped persons. Currently, he is Director of Patient Services at the REC, Children's Hospital at Stanford.

Brian Allison was trained as a paramedic, with experience in electronics and telemetry, working in an emergency room setting. For the past three years he has been a seating and mobility specialist working under Mr. Motloch at the REC, Children's Hospital at Stanford.

A-5

PROPOSED ASSESSMENT FORM

ASSESSMENT FORM

Explanation:

This proposed assessment form is designed to be filled out by the core team: client/family, rehabilitation engineer and therapist, OR it can be used as a guideline for a narrative dictation to be filed in the record or sent to a referring source.

A letter is to be sent to the client/family at the time an appointment is made for evaluation. (Letter attached.) The purpose of the letter is to help those coming to the REC be better prepared for the evaluation process. Even if the forms attached to the letter are not filled out, the client/family will be encouraged to think about aspects of the device that may be important to consider in their home environment and for what they want it to do for them.

SEATING AND MOBILITY

Examiner:
Date:

CLIENT PROFILE

Name_____ SUH#___ ___ ___ Sex: M F D.O.B.___ ___ ___

Diagnosis:_____ Age:_____

Body involvement: AMB NON.AMB. - MIN. MOD. SEV.

Reason for Visit:

People Present:

Goals: Motor Management

Living Situation: IND. FAMILY FOSTER/GROUP HOME INST.

Distance from REC:_____miles _____ hr.

Current Therapy Program: NO YES--Therapist:_____

Current Education Program: School: _____

REG. O.H. DEV. CTR. NONE

Referral Source: Funding Source:

Other Agencies Involved:

DEVICE PROFILE

Assessment of current device. Identify device:_____

Length of use:_____mo. Include: current problems, advantages, disadvantages, etc.

Repair or modification feasible: YES NO Why?_____

Sitting tolerance in present device: Max. Hr._____ Tot. Hr./Day_____

Describe positioning: Photograph: YES NO

Static:

Dynamic:

Functional: (include restrictions to line of gaze, etc.)

Other considerations:

CHRONIC PROBLEMS which may interfere with function: (check and describe)

Sensory:
- Hearing impairment
- Visual impairment
- Sensation deficit/tissue trauma
- Pain

Control:
- Incoordination/balance problem
- Tone: spasticity/athetosis/ataxia
- Reflexes: extensor thrust, ATNR, etc.
- Head control
- Upper extremity control
- Trunk control
- Lower extremity control

Central:
- Difficulty interpreting information
- Seizures: controlled/uncontrolled
- Speech impairment: (unable to signal, etc.)
- Eating/drinking difficulty

Physical:
- Extremes of size or weight/growth rate
- Spinal deformity: fixed/flexible
- Contracture/limited ROM
- Dislocation
- Unusual fatigue

Other:
- Medication
- Restrictions due to organic disease (as osteogenesis imperfecta-protectic heart disease--exertion)

ENVIRONMENTAL FACTORS

Home Access: HIGH MED. LOW (include narrow doorways, steps, second floor, low tables, tight bathrooms, etc.)

Where used: INDOORS OUTDOORS BOTH

How used: HEAVY MOD. LIGHT

Frequency of use: _____ Hr./Day _____ Days/Wk.

Compatibility: What other devices will it need to fit or work with?

Transportation modes: CAR VAN SCHOOL BUS/VAN BUS BART AIRPLANE
Other: (Transported whole or in sections, with or without client)

Possible hazards to others (e.g., needs protection to switches, etc.)

Technical/repair services available locally?

<u>Additional Information Needed</u> (psychosocial factors identified in eval.)

PROPOSED MOBILITY/POSITIONING SYSTEM

GOALS

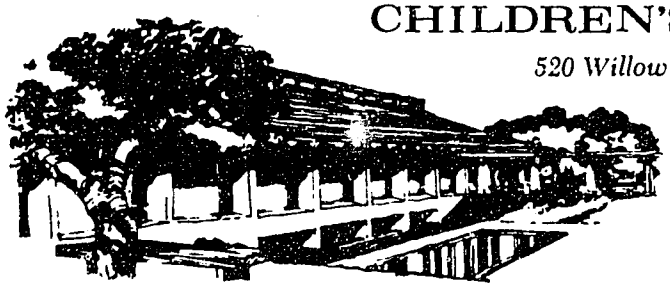
- Motor function
  - Independent mobility
  - Increase motor function
    - Increase range/distance
    - Increase community participation
    - Increase independent living skills
    - Improve upper extremity use
    - Increase sitting time
    - Improve sitting stability
- Management
  - Facilitate care/management
  - Improve/stabilize physical status
  - Prevent deformity
  - Control scoliosis
  - Reduce pain
  - Reduce discomfort
  - Provide physical protection
  - Facilitate care by parent/attendant
- Communication Skills (for detailed assessment form see comm. form)
  - Increase communication skills
- Other
  - Portability
  - As transportation
  - Increase independent living skills
  - Improve psychosocial situation
  - Other

IDENTIFY DEVICE:

CONTROL and LOCATION OF CONTROL:

Describe DEVICE: advantages, disadvantages, life expectancy of device; relate to reason for prescription and goals:

CHILDREN'S HOSPITAL at Stanford
520 Willow Road, Palo Alto, California 94304 / (415) 327-4800



We are pleased that you are coming to the Rehabilitation Engineering Center for a seating and mobility evaluation. To provide you with the best service, we need to understand clearly your current needs and expectations. Please look over the attached questions and complete the enclosed forms and bring them with you on the day of appointment. We would like you to have an opportunity to think about some of the areas mentioned, before your visit. In this way we can help you obtain the type of equipment that is best suited to your living and occupational situation.

THINGS TO THINK ABOUT

1. What do you want the equipment to do? There are usually primary needs, and then other considerations.

2. Where will it have to go? Home, community, school, job, indoors and outdoors or primarily one place?

3. What do you use at the present time for mobility?

4. What problems are you having with your current equipment? Why has a change been suggested?

5. What is the widest and longest the device can be? Do you have narrow doorways, tight corners, etc., where the equipment must be used?

6. What is the tallest the device can be with you in it? Is there a short roof height in any vehicle you must use?

7. What is the heaviest the device can be? Consider who will lift the device, either empty or with you in it.

8. Will any parts need to be removable or adjustable? Will you need footrests that swing away, for bathroom transfers, for instance, or arm rests which need to be removed to fit chair under dining room or study table?

9. How will you transport the device? Does it need to go on a schol bus with "tie-downs"? Will it need to fold up or come apart in some way for transport?

10. What other alternatives have been considered or, what have you already tried which has been unworkable in some way?

NOW, PLEASE FILL IN THE NEXT PAGES:

A. Environment Profile

B. Experience with other special equipment.

C. Functional Level of Independence and Priority of Needs

THANK YOU VERY MUCH. WE WILL LOOK FORWARD TO MEETING WITH YOU.

Note: We are sending you an additional form which can be filled out by a therapist, if there is one currently seeing you or your child. If not, please just bring it with you and it can be filled out on the day of your visit.

ENVIRONMENTAL PROFILE

Describe a typical day: (i.e., time at home, time at school or job, means of transport, general requirements of sitting or activities.

_____

_____

_____

Current Education Program: Mainstream OH Development Center None

Current Therapy Program: NO YES--Goals: _____

Name of therapist and where can be contacted: _____

_____

Other agencies involved: _____

_____

Distance from Rehabilitation Engineering Center: _____ miles _____ Est. time

Living situation: Independent Family Foster Home Institution

Access to living area: High (ramped, level from street, etc.)
Medium (a few stairs, assistance required)
Low (barriers such as flight of stairs, second floor, difficult doors, etc.)

Estimate of how much wear client will put on device:
Heavy Moderate Light

Frequency of Use: _____ hours/day _____ days/week

How long will you expect the device to last? _____
Reason, if known, i.e., growth, expected change in client, etc.

_____

Will you need to fit or work with other devices? If so, which ones?

_____

Transportation modes: Car Van School Bus/Van Bus

Rapid transit (BART) Airplane Other: _____

Are there any occupational/educational hazards to be considered?

_____

Is someone locally available and known to you who can do minor repairs or help with maintenance, or do you feel capable of doing these yourself?

_____

FUNCTIONAL LEVELS OF INDEPENDENCE		INDEPENDENT	INDEPENDENT WITH A TECHNICAL AID	REQUIRES MINIMAL ASSISTANCE	REQUIRES CONSIDERABLE ASSISTANCE	DEPENDENT	PRIORITY OF NEEDS: PLEASE RANK ON A 1-7 SCALE: (1) MOST IMPORTANT TO (7) LEAST IMPORTANT, THOSE SKILLS WHICH ARE MOST IMPORTANT IN YOUR OPINION
MOBILITY	Walking						
	Wheelchair						
	Transfers						
A.D.L.	Feeding						
	Dressing						
	Toileting						
	Communication						

Experience with Other Special Equipment

	Has Ever Used	Still Using	Will Be Acquired
Manual Wheelchair			
Powered Wheelchair			
Caster Cart			
Wheelchair Cushion/Seating Insert			
Braces			
Crutches/Cane			
Tray Communication Device			
Sensory Aid (Glasses, Hearing Aid)			
Toileting Aids			
Bath Aids			
Sleep Aids			
Respiration Aids			
Recreation Aids			
Educational Aids			
Vocational Aids			
Other:			