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Record Group/Collection: Donated Historical Materials
Collection/Office of Origin: Frieden, Lex, Collection
Series: Disability Rights Organizations
Subseries:

OA/ID Number: 52064
Folder ID Number: 52064-004

Folder Title:
[TIRR] Miscellaneous Notes - New Options [1978]

Stack:

Row:

Section:

Shelf:

Position:

Intro.

AK art.

~~make a report of
the situation~~

add legis. & conclude w
need for res. & obj.

Most recently, on
Nov. 6, 1978, Pres-
Carter signed legis.
which authorizes, for
the first time, ~~the~~
federal ~~program~~ ^{support of} for
71 ~~programs~~ ^{programs} (PL 95-602,
Title V is). Among
~~other things~~

the new law provides
no support of ~~programs~~
~~called~~ Centers for
[maybe you are in]
[B & L papers]

Despite sig. prog. in
the movement to support
L by dev. individual
programs very little has
been done to expand

the effect of these
prog. on indiv. parts
or clients. Those studies
which have been

provide very little
some ~~are very~~ useful info.
~~limited~~ - CL, BCK?,
~~AK~~

camp needs.
[get Behav Brief & Count]

The purpose of the
proposed study is to
augment the available
res. on the effects of
IC psys. by evaluating
the outcome of training
certain aspects of the
life styles of SAD indiv.
both before and after

Gen part is a
trans. living object
designed to find the
~~the~~ increased soc. psych.
and beh indep.

Method
Design:

IV des. NR

DV
~~measures~~ instr.
subs.
potential

Results:

Results: etc.

Will be comp'd with
similar data from the
planning inter ~~at~~ ~~the~~
to QV, whether

What if any changes occur
in the ~~particulars~~ ~~the~~ psychosoc.
aspects
of past, ~~just~~ ~~as~~ during
~~between the time~~ ~~of~~

The results of these
comps. will be analyzed
and discussed in QV.

of important demographic
and subject results such as
time since birth in the
family, time since onset
of dis., age, IQ, socio
econ. status, etc.

In addition, the results
will be comp. to those
~~reported~~ by other studies
to see how far
of IL range.

~~Meas. IQ will be meas.~~

~~The results will also be
analyzed according to the~~

#1 Those aspects which will be examined include living arrangements, mobility, occupations, ^{arts, physical abilities} ~~friendships~~, and so forth.

Method: (for ACRM 77)

Design: A longitudinal, within S design will be employed in this descriptive outcome study.

evaluation. ~~Although~~ ^{the study will be} naturalistic and non experimental

to the extent that no control groups will

be used and certain
conjectures will be based on presumptive
information.
Subjects: Efforts will be

made to include each
of the ninety persons
who participated in
the WD program over
a three year period

between 1976 + 1979

in the study sample.

~~Subject
to
res
rep~~

About ~~70%~~ of these people
were ~~male~~ quadriplegic
as a result of traumatic
SCI. The rest were
disabled by CP, polio,
brain damage, MD and ~~others~~
to fish in

All but two used wheelchairs as their primary means of mobility. They ranged in age from 17 to 63 and came from a variety of socioeconomic and backgrounds. All of the participants ~~had~~ had been living in institutions or with their parents before they came to the program. Only a few had been engaged in productive occupations.

IV: ~~The~~ program
(ind. var.) ~~to be~~
evaluated
~~used~~ In this ~~evaluative~~
field study is the New
Options Transitional
Project ^{Hayden} ~~at~~ ~~TPR~~ in
~~Houston~~ [p. 5]
... agendas. [p. 6]

DV: ~~The~~ ^{preme} qualitative
trait (dep. var.) ~~which~~
to ~~will~~ be ~~examined~~ ~~observed~~ in this
study is personal
independence. ~~The~~

Several of these
✓ indices, which will
be measured and
compared are time usage,
mobility arrangements,
occupations, ^{and physical ability} ~~freedom of~~ ^{of} ~~the~~ ₁₆
~~and so forth~~

Instruments: The Data
gathering instruments to be
used in this study
include ✓ interviews and
questionnaires ^{nonreactive} which
are designed to acquire
information about behavior
and psychosocial aspects

of the subjects' lifestyles. These questionnaires which ~~are~~

(attachments A, ~~B and C~~)

are ^{routinely} completed by the subjects ~~under~~ with supervision by the researcher, immediately prior to or during

the subjects' first few in-clinic sessions of program.

~~One of the questionnaires~~

(all ~~B and C~~) ~~are~~

~~completed~~ & telephone interview

(after 1) will be
conducted by the
researcher with the
participants at least
four months and at
most thirty months
following their parti-
cipation in New Options.

Procedure: Each parti-
cipant in the New
Options program
completed three questionnaires
~~relating~~ before they
participated or within

the first few days of
their participation in
the program. Additionally,
6 week of skills training
each participant will
be called and interviewed
over the telephone some
time several months
after their participation
in the program. The
duration between
~~participation leaving~~
participation in the
program and the
followup interview

will vary from four
to thirty months. $\frac{1}{2}$

Within S
Quasi - Exp
Non Exp.
Longitudinal

Evaluative
Descriptive

Survey method
Naturalistic
Static Descriptors
checklist
interview (structured)

nonreactive } methods
unobtrusive

indices of Criterion meas (Presumed trait)
depend on multimeasures

Field investig.
ex post facto
field test of theory

①
Name, sex, soc, Dis. type.
NO. cycle #, Previous slab.

De NO Discharge Following Bone

Date of: -
exam
time since NO. -

time since
out of dys. -

Age - - -

place of
resid.

type of car
urban/rural

carriers in home

lives with

provides care

needs hrs. of care

transpo. type
availability of transpo.

voc. status

educ. status

3

who manages money

who makes major decisions

who else makes decisions

social/recreational activities

social partners

frequency away from h.c.

frequency of contact w friends

Active participation / making decisions
Operational Def
of indep.

- * 1 access to board
at least care or phys.
indep. - able to perform
all ADL
- * 2 transpo. (mobility)
access to demand responsive
system
- * 3 income — not nec.
- * 4 attitude (guided by other beh.)
(goal, self concept)
indep. indep.
- * (6) not dual. indep. indep.
~~occup. ~~not~~~~
- ~~not barrier free housing~~
~~not housing because w~~
~~it is not necessary.~~
- * (5) non-institutionalized
h.a. may be incl.
apart from parents
income may var. w
1, 2, and h.a.
although not nec. }
- each are nec. but
not sufficient conditions

A (Lo) voc. or avoc.
activity may be incl.

N = 50

Pre / Post

baseline - 2 yrs. since
partic. in N.O.

Obj. - to evaluate
the effects of N.O.
rel. to its goal of
facil or < 12.

must estab. criteria for
all 4 determinants

look @ ^{subject or} interviewing var:

sex

age

race

time & onset

time & NO.

urban/rural background

income

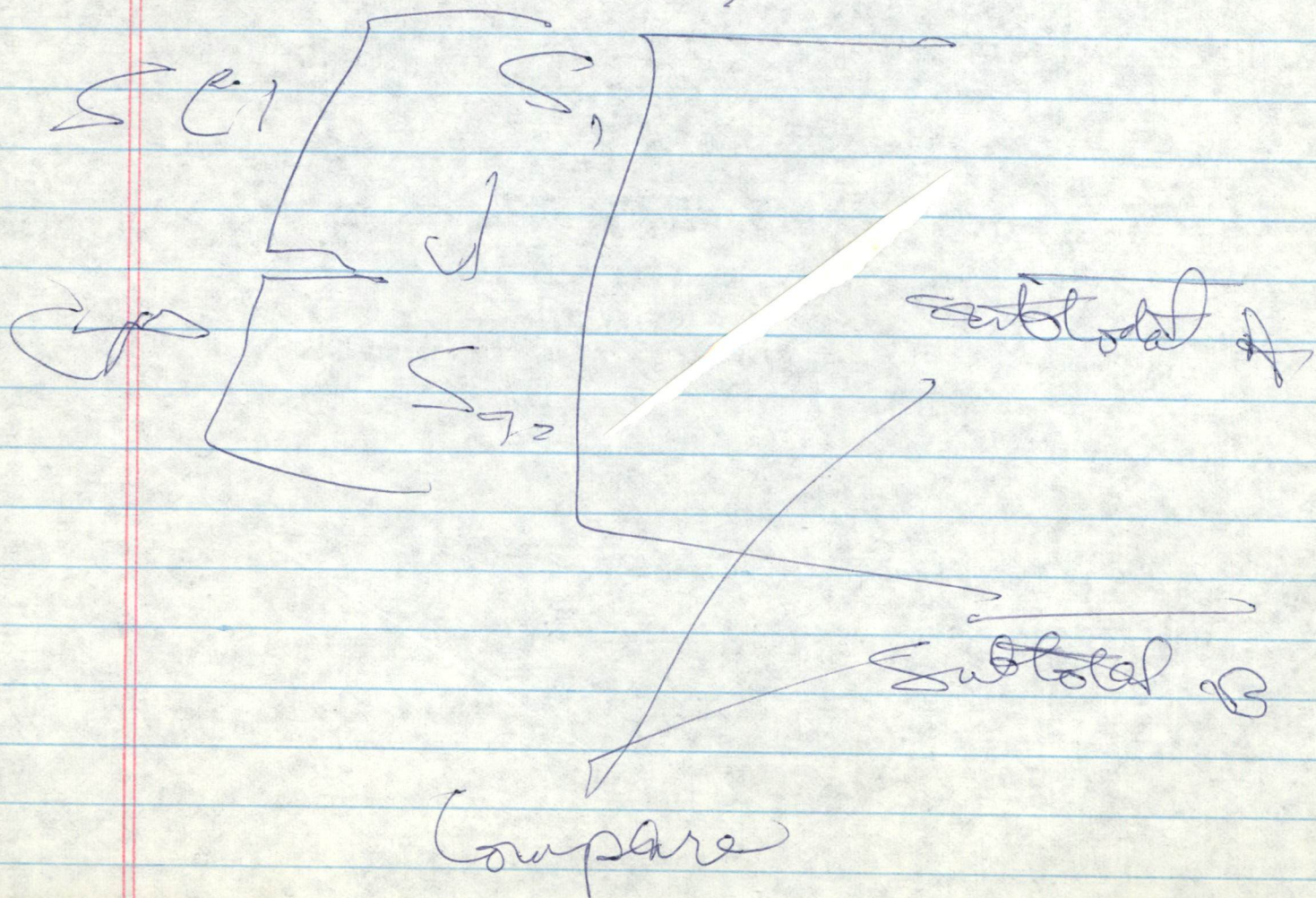
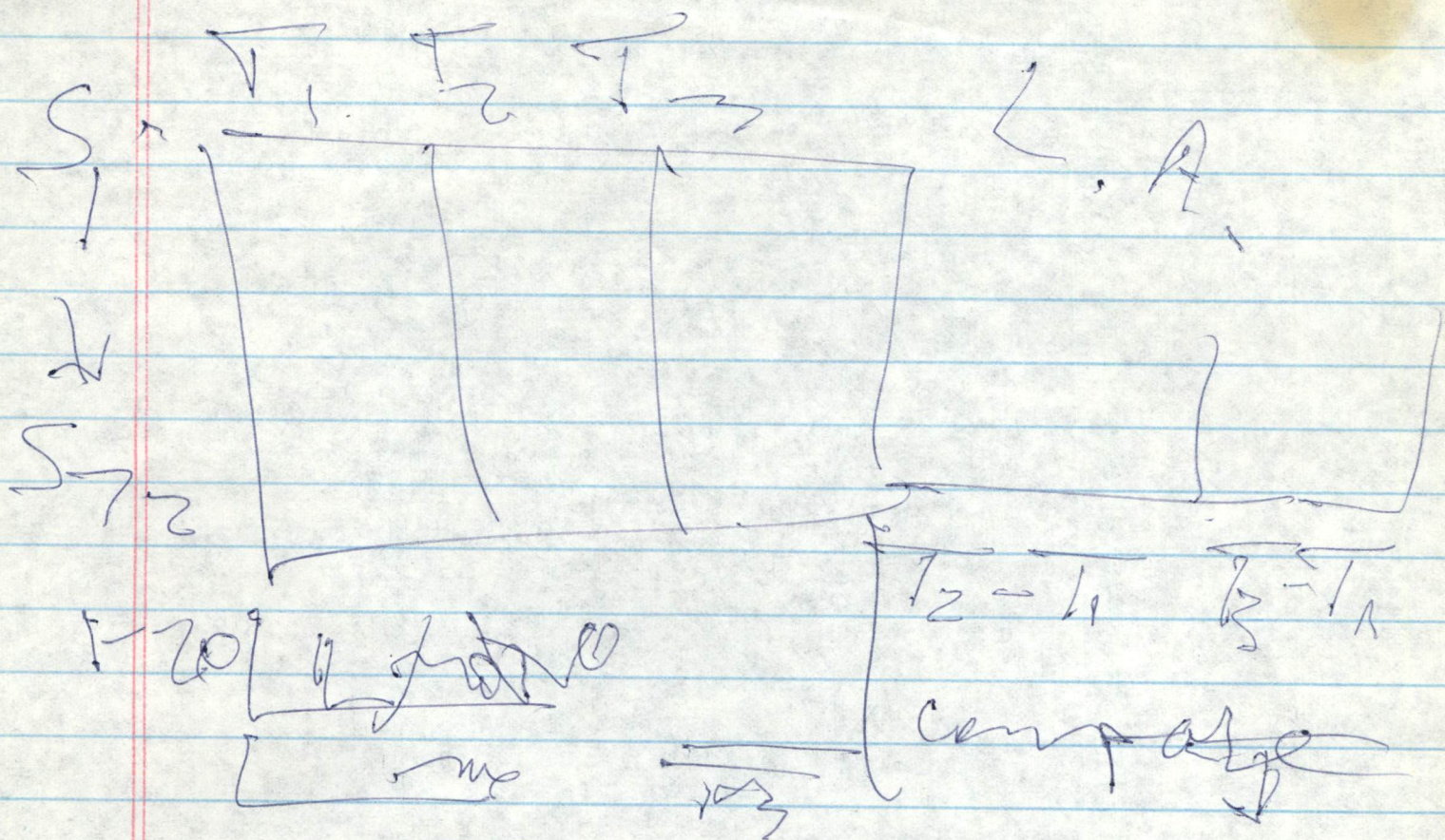
extent of rehab

from N.O. Desrip, 5.6

A The purpose of the proposed study is to evaluate the effectiveness of the N.O. program by comparing ^{certain} ~~aspects~~ ~~of~~ the ~~lifestyles~~ ~~of~~ the ~~present~~ ~~lifestyles~~ of former N.O. participants to those ^{aspects} of their lifestyles before they participated in the program. ^{of the subjects' lifestyle} Those aspects which will be of particular importance in this study are: living arrangement (dwelling type and household constellation), transport, personal care arrangement, occupation, social activity, and extent of self determination.

we know:
dis. type / sex
func. difficulty
(Barthel)
living envts
+ obstacles in
occupation
econ. status
self esteem
trans. mode
+ obstacles in
obstacles in care
time and cost

[find out who is attended?]



Compare :

sep
age

time since ~~start~~

dis. type

(rotate other var)

or by transitional programs 12/1/78
Designed to teach adaptive life
~~skills~~
INDEPENDENT LIVING PROGRAMS IN HOUSTON
by Lex Frieden *
behavior and condition
independent thinking

Background

Independent living means participating actively in day to day life and making decisions that lead to self determination. For disabled people, this implies living in the community away from custodial institutions and being responsible for one's own affairs.

This style of independent living may be facilitated by community based programs which provide ^{ongoing} services like attendant care, transportation, peer counseling, equipment maintenance, and information about other services. In Houston, a variety of independent living programs have evolved to assist severely physically disabled persons. This first of these programs was the Cooperative Living Residential Project which operated from 1972 through 1975.

Cooperative Living:

Organized by a group of severely physically disabled people who were former patients of the Institute for Rehabilitation and Research, Cooperative Living demonstrated the benefits of sharing services required to support independent living. Housed in a barrier-free dormitory - style building near downtown Houston, the Cooperative Living residents hired and managed their own attendants, arranged for their own transportation on a shared basis, and generally practiced the skills required in order to live independently. Most of the 40 people who lived in the project

*Mr. Frieden is New Options Research Director, The Institute for Rehabilitation and Research (TIIR), Houston, Texas

in its 3 years of operation as a research and demonstration project began working or going to school while they lived there. The average number of residents in the program at any given time was 12.

Most people graduated from the Cooperative Living program in about 15 months and moved to more independent living arrangements in the community. Many of these people chose to continue sharing support services and formed their own corporations to provide independent living services. These organizations like Independent Lifestyles, Free Lives, and CLASP (Cluster Living and Shared Providers) exist in Houston today as independent entities.

Independent Lifestyles

Independent Lifestyles, Inc. provides supportive services for 23 severely physically disabled individuals who live at Banyan Townhomes, a group of condominiums developed and financed by the residents themselves. Attendant care is available on a 24-hour basis. Each resident pays for his or her own attendant care according to the number of hours of service which he or she subscribes to each month. The average monthly charge for attendant care ranges from \$175 to \$230. Independent Lifestyles has an office where attendants activities are coordinated through the use of an activity board. The activity board has the residents listed with their apartment number and a code by which the attendants know what is needed each day for each resident, such as dressing, preparing a meal, turning and transferring, personal hygiene, and so on. Each

resident is responsible for making sure that each service he or she requires is recorded on the activity board.

Transportation to and from necessary activities is provided by the project from 7:00 a.m. to 6:00 p.m., Monday through Friday, in a specially equipped van. Transportation charges for residents average \$85 per month. Independent Lifestyles is recognized by the Texas Rehabilitation Commission as an approved vendor of services. The project is directed by a Board elected from the residents themselves. Financial support for the program comes from charges to residents which are below the actual cost of providing the service, and from contributions.

FREE LIVES

Free Lives is a cluster of 11 severely disabled persons who live in the same wing of the 292-unit Independence Hall, an FHA 236 project for the handicapped and elderly. Each resident has his or her own barrier free apartment and subscribes to a cooperative attendant service. Routine physical care activities are scheduled by the residents, and the 12 person staff is managed by a chief attendant. Cafeteria service is available in the complex, although some residents prefer to use their own kitchens for preparing meals.

Transportation is provided on a prescheduled basis by the apartment sponsors, Houston Goodwill. Service charges are based on mileage. The City of Houston also operates an accessible dial-a-ride service which serves Independence Hall. Apartment rent ranges from \$97.50 to \$172 per month, depending on the resident's ability to pay. Attendant services are \$260 per month. Some resident's services are subsidized by the Texas

Rehabilitation Commission and Goodwill. Free Lives has an elected grievance council and a resident administrator who interact with the attendant manager and the project management.

CLASP

CLASP is an independent living service program sponsored by the Texas State Department of Human Resources. The project is presently located at Willow Woods Apartments in Southwest Houston. In contrast to Banyan Townhomes and Independence Hall, Willow Woods is an ordinary apartment complex where most tenants are able bodied. Twenty units in the complex have been adapted to be relatively barrier-free.

CLASP coordinates attendant care and transportation for 29 severely disabled individuals who live at Willow Woods. Residents pay \$220 per month for attendant care. Some residents receive Medicaid benefits which help pay their attendant care expenses. Although some residents are eligible for Section 8 rent subsidy from the Houston Housing Authority, the apartment owners are planning to discontinue Section 8 agreements. Monthly rent at Willow Woods is \$325 for a two bedroom apartment. Transportation is available via Houston's Pick Me Up service for disabled people on an advance reservation basis at \$1.00 per trip, or on a limited no cost basis from Creative Handicaps, a voluntary organization.

New Options

One such program is
~~The original Cooperative Living project actually evolved into an independent living skills training program called New~~

transitional

Options. New Options is a 6 week live-in program supported by Rehabilitation and Training Center 4 at TIRR, and the Texas Rehabilitation Commission. The program presents certain information, skill training, and experiences in an effort to facilitate the behavioral adaptation and personal adjustment of individuals to severe physical disabilities. It is composed of 3 primary elements, (1) a residential support system, (2) individual counseling and consultation, and (3) training, practice, and information modules. The residential support system includes attendant service, food service, and transportation service. Individual counseling and consultation at New Options is provided primarily by a full time professional staff. Counseling is directed toward solving specific individual problems, identifying needs, and developing future plans.

The key element of New Options is the training module. Presently there are 11 such modules in the program focusing on such subjects as financial management, consumer affairs, living arrangements, functional skills, mobility, sexuality, home-making skills, vocational-educational opportunities, medical needs, and social skills. Active disabled persons who serve as role models are employed by the project to lead the modules. Each module generally meets one time per week for a period of two to four hours. A number of educational techniques, mostly of an experiential nature, are used in the modules to transmit information. Fieldtrips are used extensively to provide opportunities for participants to observe various situations first hand. Considerable free time is programmed into the schedule so

balancing?

Design

longit. (multi ^{var.} meas)

subj. approx. 50 per cent

IV program DV aspects

improvement

NO. fac. IL by DP

P.A		
	post	dy
5	+	+
1	-	0
2	+	+
7		+

sign test

trans.



method - use for data
at telephone followup

interview time
since V.D.
ref. usual

that participants may explore the community on their own, practice activities individually, or complete personal agendas.

Eighty people have participated in the New Options program thus far. Most of these individuals were living in nursing homes or with their parents before they entered the program. Only a few of them had tried to work or go to school. Now, almost half of the former participants are living more independently than they were before, and more than half of them are working or going to school.

New Initiatives

In spite of these progressive programs, the greatest barriers to independent living by severely disabled persons in the Houston area are the lack of comprehensive community-based service programs, and the absence of sufficient numbers of barrier-free living units. The Coalition for Barrier Free Living (CBFL), a local disabled rights advocacy organization, is presently attempting to alleviate these problems by encouraging and assisting the development of new programs in the areas of transportation, attendant care, job placement, housing, barrier removal, and information sharing.

CBFL recently proposed and was granted authority by the City of Houston Community Development Division to build a Center for the Handicapped. The project was awarded a 3 million dollar grant from the U.S. Department of Housing and Urban Development. Plans call for this Center to be managed by a Board composed primarily of disabled individuals appointed by the CBFL. The facility will house a completely accessible gymnasium and swimming pool, a specially adapted auditorium,

of the proposed study
The purpose is to
look at the effects
~~study~~ of a trans. prog.

to be more specific,
the major objective ~~focus~~ of this
study will be
those aspects

The particular program
to be evaluated in this
study is an 16 skills
training program called N.O.

equipment repair areas, meeting rooms, classrooms, and office space. Services offered through the Center will include attendant referral and training, financial and legal advocacy, peer counseling, housing locating and modification, transportation information and referral, public education programs, and others. All of these services should enhance the feasibility of independent living by severely disabled individuals in Houston.

Conclusions

Several interesting conclusions may be drawn from the Houston experience. First, there is no doubt that well conceived and well managed service programs can provide the support required for most severely disabled persons to live independently. Also, it appears as if a broad range of independent living services must be provided in order for a program to be really effective and to meet the needs of persons with varying degrees of severe disability. In addition, programs must be flexible enough to evolve over time as the environment and the needs of the disabled community change. Furthermore, programs should be planned and managed with substantial involvement of disabled individuals throughout the process in order to maintain self-determination. Finally, programs need to be community-based and comparatively non-institutional to avoid paternalism and encourage integration.

Today, as a result of independent living programs, many severely disabled people are living independent and productive lives. However, the need for more programs providing attendant care, transportation, and housing in a coordinated fashion is

~~for~~ disabled people
who have ~~participated~~
in and used these teen

Programs, and there are
reports by casual observers
which support ^{those} claims.

Of However, ~~with~~ there
~~exception of~~ are only a
~~few~~ ^{well} few documented,

systematic studies of
program effectiveness to
date. Of those ^{studies} which
are ~~available~~ ^{known}, there
are none which examine
a transitional type program.

critical. Without these additional programs and the funding needed to support them, independent living will remain only a dream for thousands of people confined to nursing homes or living with their parents because there are no suitable alternatives.

There are only about 35
of these programs in
the U.S. today, and
most of them are less
than four years old.

~~Programs~~
Federal support for 12
programs was authorized ~~only~~ just last
year, and thus far ~~only~~
~~only~~ a few projects have been
demonstration
funded. In fact,

and some privately
organized programs

Little is known about the
effectiveness of these programs.
Certainly there are reports of
enhanced independence.

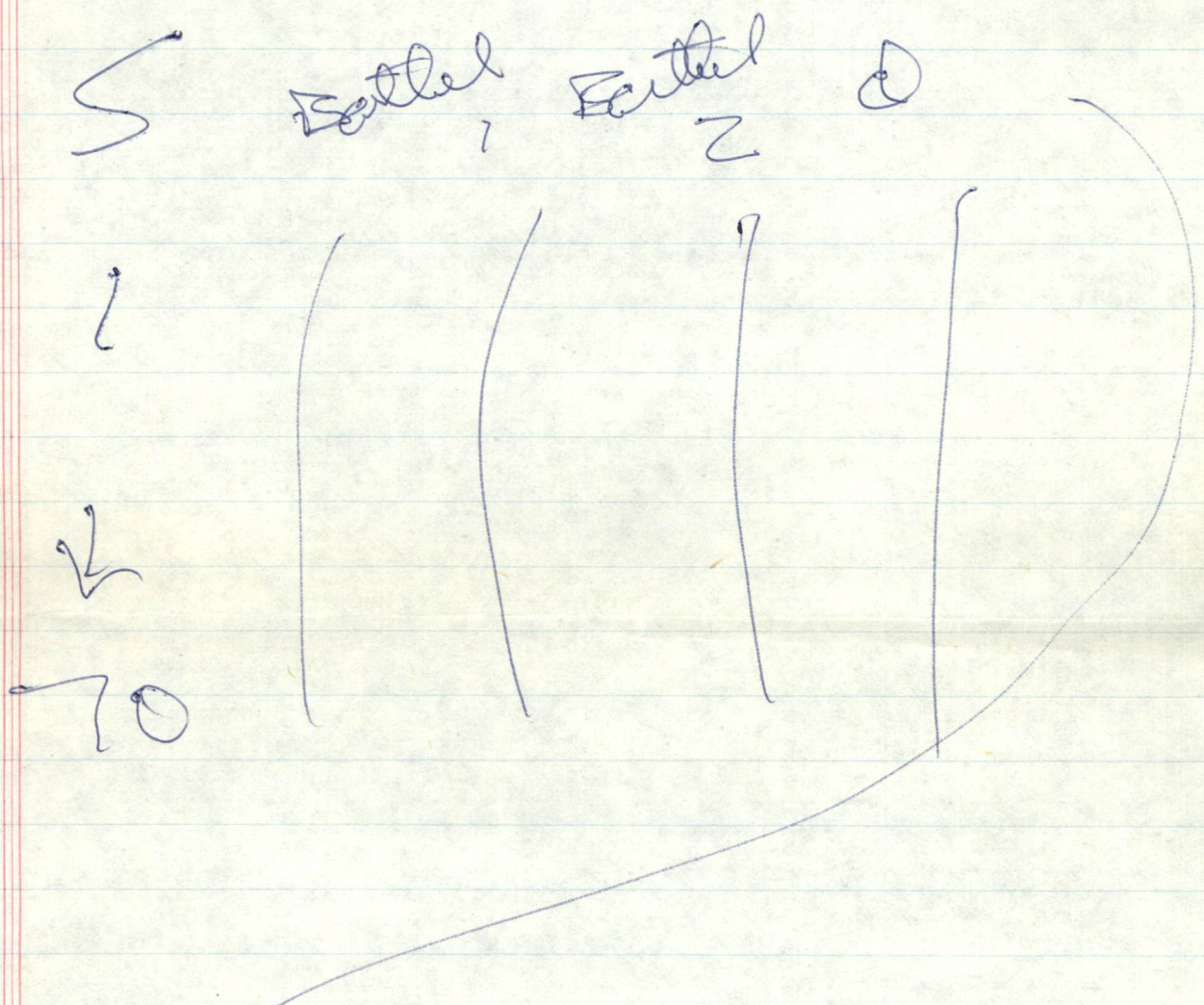
<

set cog too up ^{cast} in ~~set~~

↑

↓

70



~~trans~~ I know deep
 inside
 or
 now

yes ^{school} _{work}
 no

~~600~~
~~30,000~~
~~75,000~~

Purpose 1) To document

~~comparative~~ ~~indicators~~ of
appreciable
changes in lifestyles

~~cross indicators~~ of
former
of N.O. parts. ~~immediately~~ following

their part in the
N.O. program

→ which may ^{have} occurred as
a result of

NH
and 2) to determine
what, if any the
(demographic)
~~individual~~ character-
istics may indicate
a prediction to
~~have~~ change lifestyles
after participating in
the N.O. program.

Variables?

1/ - program

(1) Intervening V - sex, age, income, race, urban/rural, comp rehab, time since onset

(3) DV - phys. cap. (Barthel)
occupation/school, work
living cost. / housing
~~transportation~~

[observable, tangible, gross]
mobility (transpo.)

S: ~50 10. parts.

Design: Pre test -

Post test (4 - 12 mo
followup)

N 4 - 12 mo. post discharge
combination of mail
responses, ~~and~~ telephone
survey, and personal interview.