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THE MCNEMAR TEST FOR THE SIGNIFICANCE OF CHANGES

Function

The McNemar test for the significance of changes is particularly applicable to those "before and after" designs in which each person is used as his own control and in which measurement is in the strength of either a nominal or ordinal scale. Thus it might be used to test the effectiveness of a particular treatment (meeting, newspaper editorial, mailed pamphlet, personal visit, etc.) on voters' preferences among various candidates. Or it might be used to test say the effects of farm-to-city moves on people's political affiliations. Notice that these are studies in which people could serve as their own controls and in which nominal measurement would be used to assess the "before to after" change.

Rationale and Method

To test the significance of any observed change by this method, one sets up a fourfold table of frequencies to represent the first and second sets of responses from the same individuals. The general features of such a table are illustrated in Table 5.1, in which + and - are used to signify

TABLE 5.1. FOURFOLD TABLE FOR USE IN TESTING SIGNIFICANCE OF CHANGES

		After	
		-	+
Before	+	A	B
	-	C	D

different responses. Notice that those cases which show changes between the first and second response appear in cells A and D. An individual is tallied in cell A if he changed from + to -. He is tallied in cell D if he changed from - to +. If no change is observed, he is tallied in either cell B (+ responses both before and after) or cell C (- responses both before and after).

Since $A + D$ represents the total number of persons who changed, the expectation under the null hypothesis would be that $\frac{1}{2}(A + D)$ cases changed in one direction and $\frac{1}{2}(A + D)$ cases changed in the other. In other words, $\frac{1}{2}(A + D)$ is the expected frequency under H_0 in both cell A and cell D.

It will be remembered from Chap. 4 that

$$\chi^2 = \sum_{i=1}^k \frac{(O_i - E_i)^2}{E_i} \quad (4.5)$$

where O_i = observed number of cases in i th category

E_i = expected number of cases under H_0 in i th category

In the McNemar test for the significance of changes, we are interested only in cells A and D . Therefore, if A = the observed number of cases in cell A , D = the observed number of cases in cell D , and $\frac{1}{2}(A + D)$ = the expected number of cases in both cell A and cell D , then

$$\chi^2 = \sum_{A,D} \frac{(O - E)^2}{E}$$

$$= \frac{\left(A - \frac{A+D}{2}\right)^2}{\frac{A+D}{2}} + \frac{\left(D - \frac{A+D}{2}\right)^2}{\frac{A+D}{2}}$$

Expanding and collecting terms, we have

$$\chi^2 = \frac{(A - D)^2}{A + D} \quad \text{with } df = 1 \quad (5.1)$$

That is, the sampling distribution under H_0 of χ^2 as yielded by formula (5.1) is distributed approximately as chi square¹ with $df = 1$.

Correction for continuity. The approximation by the chi-square distribution of the sampling distribution of formula (5.1) becomes an excellent one if a correction for continuity is performed. The correction is necessary because a continuous distribution (chi square) is used to approximate a discrete distribution. When all expected frequencies are small, that approximation may be a poor one. The correction for continuity (Yates, 1934) is an attempt to remove this source of error.

With the correction for continuity included

$$\chi^2 = \frac{(|A - D| - 1)^2}{A + D} \quad \text{with } df = 1 \quad (5.2)$$

This expression directs one to subtract 1 from the absolute value of the difference between A and D (that is, from that difference irrespective of sign) before squaring. The significance of any observed value of χ^2 , as computed from formula (5.2), is determined by reference to Table C of the Appendix which gives various critical values of chi square for df 's from 1 to 30. That is, if the observed value of χ^2 is equal to or greater than that shown in Table C for a particular significance level at $df = 1$, the implication is that a "significant" effect was demonstrated in the "before" and "after" responses.

The example which follows illustrates the application of this test.

¹ See footnote on page 43.

Example

Suppose a child psychologist is interested in children's initiation of social contacts. He has observed that children who are new in a nursery school usually initiate interpersonal contacts with adults rather than with other children. He predicts that with increasing familiarity and experience, children will increasingly initiate social contacts with other children rather than with adults. To test this hypothesis, he observes 25 new children on each child's first day at nursery school, and he categorizes their first initiation of social contact according to whether it was directed to an adult or to another child. He then observes each of the 25 children after each has attended nursery school for a month, making the same categorization. Thus his data are cast in the form shown in Table 5.2. His test of the hypothesis follows; this discussion reports artificial data.

TABLE 5.2. FORM OF FOURFOLD TABLE TO SHOW CHANGES IN CHILDREN'S OBJECTS OF INITIATION

		Object of initiation on thirtieth day	
		Child	Adult
Object of initiation on first day	Adult	A	B
	Child	C	D

i. *Null Hypothesis.* H_0 : for those children who change, the probability that any child will change his object of initiation from adult to child (that is, P_A) is equal to the probability that he will change his object of initiation from child to adult (that is, P_D) is equal to one-half. That is, $P_A = P_D = \frac{1}{2}$. * $H_1: P_A > P_D$.

ii. *Statistical Test.* The McNemar test for the significance of changes is chosen because the study uses two related samples, is of the before-and-after type, and uses nominal (classificatory) measurement.

iii. *Significance Level.* Let $\alpha = .05$. $N = 25$, the number of children observed on the first and thirtieth day at school of each.

iv. *Sampling Distribution.* Table C gives critical values of chi-square for various levels of significance. The sampling distribution of χ^2 as computed by formula (5.2) is very closely approximated by the chi-square distribution with $df = 1$.

v. *Rejection Region.* Since H_1 specifies the direction of the pre-

* This statement of H_0 suggests a straightforward application of the binomial test (pages 36 to 42). The relation of the McNemar test to the binomial test is shown in the discussion of small expected frequencies (below).

dicted difference, the region of rejection is one-tailed. The region of rejection consists of all values of χ^2 (computed from data in which $A > D$) which are so large that they have a one-tailed probability associated with their occurrence under H_0 of .05 or less.

vi. *Decision.* The artificial data of this study are shown in Table 5.3. It shows that $A = 14$ = the number of children whose

TABLE 5.3. CHILDREN'S OBJECTS OF INITIATION ON FIRST AND THIRTIETH DAYS IN NURSERY SCHOOL
(Artificial data)

		Object of initiation on thirtieth day	
		Child	Adult
Object of initiation on first day	Adult	14	4
	Child	3	4

objects changed from adult to child, and $D = 4$ = the number of children whose objects changed from child to adult. $B = 4$ and $C = 3$ represent those children whose objects were in the same category on both occasions. We are interested in the children who showed change: those represented in cells A and D .

For these data,

$$\begin{aligned}\chi^2 &= \frac{(|A - D| - 1)^2}{A + D} \\ &= \frac{(|14 - 4| - 1)^2}{14 + 4} \\ &= \frac{9^2}{18} \\ &= 4.5\end{aligned}\quad (5.2)$$

Reference to Table C reveals that when $\chi^2 \geq 4.5$ and $df = 1$, the probability of occurrence under H_0 is $p < \frac{1}{2}(.05)$ which is $p < .025$. (The probability value given in Table C is halved because a one-tailed test is called for and the table gives two-tailed values.)

Inasmuch as the probability under H_0 associated with the occurrence we observed is $p < .025$ and is less than $\alpha = .05$, the observed value of χ^2 is in the region of rejection and thus our decision is to reject H_0 in favor of H_1 . With these artificial data we conclude that children show a significant tendency to change their objects of initiation from adults to children after 30 days of nursery school experience.

Small expected frequencies. If the expected frequency, that is, $\frac{1}{2}(A + D)$, is very small (less than 5), the binomial test (Chap. 4) should be

used rather than the McNemar test. For the binomial test, $N = A + D$, and x = the smaller of the two observed frequencies, either A or D .

Notice that we could have tested the data in Table 5.3 with the binomial test. The null hypothesis would be that the sample of $N = A + D$ cases came from a binomial population where $P = Q = \frac{1}{2}$. For the above data, $N = 18$ and $x = 4$, the smaller of the two frequencies observed. Table D of the Appendix shows the probability under H_0 associated with such a small value is $p = .015$ which is essentially the same p yielded by the McNemar test. The difference between the two p 's is due mainly to the fact that the chi-square table does not include all values between $p = .05$ and $p = .01$.

Summary of procedure. These are the steps in the computation of the McNemar test:

1. Cast the observed frequencies in a fourfold table of the form illustrated in Table 5.1.
2. Determine the expected frequencies in cells A and D .

$$E = \frac{1}{2}(A + D)$$

If the expected frequencies are less than 5, use the binomial test rather than the McNemar test.

3. If the expected frequencies are 5 or larger, compute the value of χ^2 using formula (5.2).

4. Determine the probability under H_0 associated with a value as large as the observed value of χ^2 by referring to Table C. If a one-tailed test is called for, halve the probability shown in that table. If the p shown by Table C for the observed value of χ^2 with $df = 1$ is equal to or less than α , reject H_0 in favor of H_1 .

Power-Efficiency

When the McNemar test is used with nominal measures, the concept of power-efficiency is meaningless inasmuch as there is no alternative with which to compare the test. However, when the measurement and other aspects of the data are such that it is possible to apply the parametric t test, the McNemar test, like the binomial test, has power-efficiency of about 95 per cent for $A + D = 6$, and the power-efficiency declines as the size of $A + D$ increases to an eventual (asymptotic) efficiency of about 63 per cent.

References

Discussions of this test are presented by Bowker (1948) and McNemar (1947; 1955, pp. 228-231).

Dependent

LEVEL OF MEASURE- MENT	NONPARAMETRIC STATISTICAL TEST*					NONPARAMETRIC OF CORRELATION (Chap. 9)
	One-sample case (Chap. 4)	Two-sample case		k-sample case		
		Related samples (Chap. 5)	Independent samples (Chap. 6)	Related samples (Chap. 7)	Independent samples (Chap. 8)	
Nominal	Binomial test, pp. 36-42 χ^2 one-sample test, pp. 42-47	McNemar test for the significance of changes, pp. 63- 67	Fisher exact proba- bility test, pp. 96- 104 χ^2 test for two inde- pendent samples, pp. 104-111	Cochran Q test, pp. 161-166	χ^2 test for k independent samples, pp. 175-179	Contingency coefficient 196-202
Ordinal	Kolmogorov-Smirnov one-sample test, pp. 47-52 One-sample runs test, pp. 52-58	Sign test, pp. 68-75 Wilcoxon matched- pairs signed-ranks test,† pp. 75-83	Median test, pp. 111-116 Mann-Whitney U test, pp. 116-127 Kolmogorov-Smirnov two-sample test, pp. 127-136 Wald-Wolfowitz runs test, pp. 136-145 Moses test of extreme reactions, pp. 145-152	Friedman two-way analysis of variance, pp. 166-172	Extension of the median test, pp. 179-184 Kruskal-Wallis one-way analysis of variance, pp. 184-193	Spearman rank correlation coefficient: r_s , pp. 196-202 Kendall rank correlation coefficient: τ , pp. 203-204 Kendall partial rank coefficient: $\tau_{xy.z}$, pp. 205-206 Kendall coefficient of concordance: W, pp. 207-208
Interval		Walsh test, pp. 83-87 Randomization test for matched pairs, pp. 88-92	Randomization test for two independent samples, pp. 152- 156			

* Each column lists, cumulatively downward, the tests applicable to the given level of measurement. For example, in the case of k related samples, when ordinal measurement has been achieved both the Friedman two-way analysis of variance and the Cochran Q test are applicable.

† The Wilcoxon test requires ordinal measurement not only within pairs, as is required for the sign test, but also of the differences between pairs. See the discussion on pp. 75-76.

personal experience. This is largely what happens in various "faith" cures and, to some extent, forms the basis for many evaluations of psychotherapeutic programs. While this design can reassure the program administrator that his activities are being well received by his clients, it really provides little evidence as to its actual effectiveness.

It is possible to bolster the plausibility of evidence secured by means of this "after only" design by certain checks upon the validity of the individual's testimony. An attempt can be made retrospectively to reproduce the individual's situation before exposure. While obviously subject to a memory and halo bias, at least some data may be secured to serve as a substitute "before" measure. By subdividing the subjects according to differential amount and types of exposure to the program one may be able to show that increased exposure produced a greater effect. While helpful in some cases, this type of measurement is subject to a self-selective sampling bias in that those individuals most susceptible to an effect or most favorable to the program are likely to expose themselves to a greater degree.

2. The One-Group, Pre-test, Post-test Design

$$O_1 X O_2$$

In this evaluative design, the researcher introduces a base measure before the program is put into effect, to be followed by an "after" measure at the conclusion of the program. While this design does permit one to measure change objectively, it does not allow one to attribute this change to the program being evaluated. Five main sources of "error" are still possible: (1) other extraneous events may occur simultaneously as the experimental stimulus which influence the effect being measured; (2) the effect may be due to "unstimulated" change as a result of time alone, that is, some people improve with or without exposure to the program; (3) the "before" measure itself may constitute a stimulus to change regardless of the program itself; (4) the "after" measure may reflect time changes in measurement due to fatigue or instrument unreliability; and (5) unreliability may produce statistical regression with shifting values toward the mean.

3. The Static Group Comparison

$$\begin{array}{c} X O_1 \\ O_2 \end{array}$$

Two groups are compared in this approach, one having been exposed to the program and the other not. If the exposed group shows a significantly

The Evaluative Research Design

higher incidence of the desired condition or behavior, it is assumed attributable to the program. This is really the basic logic of much demiological research. Two groups with varying frequency of a condition are compared and differences between the two are viewed as possible causes of the disease. However, this design affords no way of knowing that the two groups were equivalent *before* the program, though selective matching and retrospective measures of the two groups according to pre-program characteristics may help.

4. Pre-test, Post-test, Control Group Design

$$\begin{array}{cc} O_1 & X & O_2 \\ O_3 & & O_4 \end{array}$$

We finally come to the classic experimental design as presented previously in the flow chart of evaluative research. We begin by setting up two equivalent groups which are as alike as possible before the program is put into effect. Such equivalence is best obtained by random assignment to experimental and control groups. Where this is not administratively feasible, one may have to resort to selective matching. Then, a "before" measure is made to determine the base line from which change is to be evaluated, and for providing a check on the equivalence of the two groups. One of the groups (the experimental group) is exposed to the program being evaluated while the other (the control group) is not. At the conclusion of the program (or at appropriate time intervals) an "after" measure is made which may be compared with the "before" measure for both experimental and control groups to indicate the change produced by the experimental program.

This design is so crucial we repeat it in another form;⁵

	Before	After	
Experimental	X_1	X_2	$d = X_2 - X_1$
Control	X^1_1	X^1_2	$d^1 = X^1_2 - X^1_1$

The test of program effectiveness is indicated by the significance of the difference between d and d^1 .

The logic of this design is foolproof. Ideally, there is no element of fallibility. Whatever differences are observed between the experimen-

X/1
NO

X/4
X/30

———
occup
h.
mob.

~~NO~~ ~~phys.~~ ~~repeated~~ ~~phys.~~
Assump. ? Goal of
SPD indiv. who
part. in NO. ~~are~~ ^{more} likely
to make observable
changes in ^{core} important
aspects of their lifestyles
relating to personal ~~work~~
following their part.
in the program.

age
tSO
tSNO
urb/rural
phys. abil.
(income)

of part, in NO, then

NO

at perfect change.

Field invs.
July
Sept. or Oct.

use inst. cycle criteria

organizing circumstances
subject

Then look at interesting work.

1 of SCI, then better than
other groups
(planned for SCI).

2 of > 25 , then better
than < 25 .
(young people, more open
to new ideas)

3 of dis. > 4 y, better than
 < 4 y.
(inst. releasing leader)

insec. on control - dis. testing effects
of TS NO. (rel. V)

4 of 2 & 3, better than others

balance
rel. V also V to see if other
var. are constant

5 If more phys., then
better than rest

6 If ~~from~~ ^{live in} urban area,
then better than rural
— (more services)

Those ~~parts~~ ^{indians} who are from urban
settings ~~then~~ they are more
likely than those from
rural settings to become
indep. after partic. in
the N.O. program.

— Justif. for hypot. Defin^{var}
Relevance or import. of hypot.

— (AV)
Def. indep. (first for real,
then for purpose of study)

... observ. indic of approach
to ultimate freedom. tests by
indic are: 1. 4. 0. 1. 2. 3. 4. 5. 6. 7. 8. 9. 10. 11. 12. 13. 14. 15. 16. 17. 18. 19. 20. 21. 22. 23. 24. 25. 26. 27. 28. 29. 30. 31. 32. 33. 34. 35. 36. 37. 38. 39. 40. 41. 42. 43. 44. 45. 46. 47. 48. 49. 50. 51. 52. 53. 54. 55. 56. 57. 58. 59. 60. 61. 62. 63. 64. 65. 66. 67. 68. 69. 70. 71. 72. 73. 74. 75. 76. 77. 78. 79. 80. 81. 82. 83. 84. 85. 86. 87. 88. 89. 90. 91. 92. 93. 94. 95. 96. 97. 98. 99. 100. 101. 102. 103. 104. 105. 106. 107. 108. 109. 110. 111. 112. 113. 114. 115. 116. 117. 118. 119. 120. 121. 122. 123. 124. 125. 126. 127. 128. 129. 130. 131. 132. 133. 134. 135. 136. 137. 138. 139. 140. 141. 142. 143. 144. 145. 146. 147. 148. 149. 150. 151. 152. 153. 154. 155. 156. 157. 158. 159. 160. 161. 162. 163. 164. 165. 166. 167. 168. 169. 170. 171. 172. 173. 174. 175. 176. 177. 178. 179. 180. 181. 182. 183. 184. 185. 186. 187. 188. 189. 190. 191. 192. 193. 194. 195. 196. 197. 198. 199. 200. 201. 202. 203. 204. 205. 206. 207. 208. 209. 210. 211. 212. 213. 214. 215. 216. 217. 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2177. 2178. 2179. 2180. 2181. 2182. 2183. 2184. 2185. 2186. 218

correlate DV scores, SP. (Don't combine for χ^2)

Design is basically a 2 groups design with treatment & control.

urban number of indic. of indep. rural

3
2
1
1
3

9
4
1
1
9

1
1
1
1
1

5
5

$\bar{X} = 2$
 $SSX = 24$
 $(\sum X^2) = 100$

$\bar{X} = 1$
 $SSX = 5$
 $(\sum X^2) = 25$

$$SS = \frac{100}{24} - \frac{5}{5} = 4$$

$$SS = 5 - \frac{25}{5} = 0$$

2-tailed

$$t = \frac{\bar{X}_1 - \bar{X}_2}{\sqrt{\left(\frac{SS_1 + SS_2}{(n_1 - 1) + (n_2 - 1)} \right) \left(\frac{1}{n_1} + \frac{1}{n_2} \right)}}$$

$d_f = N - 2$ (big $N = \text{all } n$)
rep. 107
set $P @ .05$

> use nonpar sign. of χ^2

2 Obj. of Study:

1. ~~Obj.~~ whether or not ^{some of} usual
rel⁴ var. hold true for ILP's

2. Det what indic (DV)
may be suitable for use as Dr
evol. Outcome of ILR

N.D. Descrip. exp in Section
labeled: Field Setting

under method

1. ~~1~~ ~~2~~ ~~3~~ ~~4~~ ~~5~~ ~~6~~ ~~7~~ ~~8~~ ~~9~~ ~~10~~ ~~11~~ ~~12~~ ~~13~~ ~~14~~ ~~15~~ ~~16~~ ~~17~~ ~~18~~ ~~19~~ ~~20~~ ~~21~~ ~~22~~ ~~23~~ ~~24~~ ~~25~~ ~~26~~ ~~27~~ ~~28~~ ~~29~~ ~~30~~ ~~31~~ ~~32~~ ~~33~~ ~~34~~ ~~35~~ ~~36~~ ~~37~~ ~~38~~ ~~39~~ ~~40~~ ~~41~~ ~~42~~ ~~43~~ ~~44~~ ~~45~~ ~~46~~ ~~47~~ ~~48~~ ~~49~~ ~~50~~ ~~51~~ ~~52~~ ~~53~~ ~~54~~ ~~55~~ ~~56~~ ~~57~~ ~~58~~ ~~59~~ ~~60~~ ~~61~~ ~~62~~ ~~63~~ ~~64~~ ~~65~~ ~~66~~ ~~67~~ ~~68~~ ~~69~~ ~~70~~ ~~71~~ ~~72~~ ~~73~~ ~~74~~ ~~75~~ ~~76~~ ~~77~~ ~~78~~ ~~79~~ ~~80~~ ~~81~~ ~~82~~ ~~83~~ ~~84~~ ~~85~~ ~~86~~ ~~87~~ ~~88~~ ~~89~~ ~~90~~ ~~91~~ ~~92~~ ~~93~~ ~~94~~ ~~95~~ ~~96~~ ~~97~~ ~~98~~ ~~99~~ ~~100~~ ~~101~~ ~~102~~ ~~103~~ ~~104~~ ~~105~~ ~~106~~ ~~107~~ ~~108~~ ~~109~~ ~~110~~ ~~111~~ ~~112~~ ~~113~~ ~~114~~ ~~115~~ ~~116~~ ~~117~~ ~~118~~ ~~119~~ ~~120~~ ~~121~~ ~~122~~ ~~123~~ ~~124~~ ~~125~~ ~~126~~ ~~127~~ ~~128~~ ~~129~~ ~~130~~ ~~131~~ ~~132~~ ~~133~~ ~~134~~ ~~135~~ ~~136~~ ~~137~~ ~~138~~ 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✓				52
✓				43
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// make this test
 if no dif., disregard
 effect.

if yes dif., ✓ for
 balancing.
 if not balanced,
 throw out.

Procedure

All ~~Each~~ participants in the New Options program completed three questionnaires before they participated or within the first few days of their participation in the six week independent living skills training program. Additionally, each participant will be called and interviewed over the telephone some time several months after ~~their~~ ^{his or her} participation in the program. The duration between participation in the program and the followup interview will vary from four to thirty months.

Issue

Intro for I.L. in History
Review part of debate
+ No. descrip. therein

The purpose of the
proposed study is to
evaluate the effects ~~of~~
~~parts~~ of the N.O. program
related to its goal of
facilitating indep. living.
The hypothesis to be
tested in this study
is ...

Method

The proposed research will
employ a longitudinal
multimeasure design to
evaluate the effects of
the program (independent

Key Words:

List two or three key words that best describe the subject matter of this paper.

independent living research

If my paper is accepted, I am willing to present at:

Academy	Congress	Either	
☐	☐	☐	Poster or Paper Session
☐	☒	☐	Paper Session only
☐	☐	☐	Poster or Paper Session

TITLE OF PAPER: Transition to Independence: A Report on Outcome Research Done at the New Options Transitional Living Program.

AUTHOR(S): Give full name, academic degree and institutional affiliation, as you wish it to be listed in the printed program. List PRIMARY AUTHOR first.

Lex Frieden, M.A. New Options Research Director, TIRR, Houston, Texas

Jean A. Cole, Ph.D. New Options Project Director, TIRR, Houston, Texas

Mary Ann Board, MSW New Options Social Worker, TIRR, Houston, Texas

ABSTRACT

Submit in duplicate, typewritten and not more than 200 words. Be concise and informative, giving statement of study's specific objective (could be stated in the title), brief method, specific results obtained, and a statement of conclusion based on the results. Use complete, connected sentences; define unfamiliar terms, abbreviations, and symbols the first time used. THIS ABSTRACT WILL BE PUBLISHED IN THE OFFICIAL CONVENTION PROGRAM.

METHODS: *holistic* A follow-up study *will be* was done to determine the possible behavioral and social psychological effects of the New Options program at The Institute for Rehabilitation and Research, in Houston, Texas. Detailed telephone interviews *will be* were conducted with most of the ninety severely physically disabled individuals who participated in the six-week program between 1976 and 1979. Data from these interviews *will be* which occurred from three to thirty months after each individual participated in the program *will be* were compared to similar data obtained before the individual entered the program.

RESULTS: Results of this study indicate that a variety of changes may have been initiated by participation in the New Options program. These changes include moving into non-institutional independent living arrangements, becoming more mobile in the community, acquiring new friends, and engaging in productive vocational activities. The results are analyzed in terms of important demographic and subject variables, and compared with information obtained from similar programs by the Comprehensive Needs Study.

CONCLUSIONS: New Options appears to be a comparatively effective independent living skills training program with wide ranging effects on various individual participants. This study indicates that transitional programs like New Options may be a missing link between medical rehabilitation and successful reintegration into the community for severely disabled individuals.

DATE: April 25, 1979 PRIMARY AUTHOR

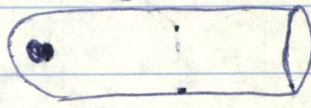
Lex Frieden, M.A.
TIRR, 1333 Moursund
Houston, Texas 770
713-782-1440 ext

variable) on four
basic functional
aspects of people's
lives (dependent variables).

~~Life~~ The four ^{key} aspects of
~~life~~ which shall be
examined in this
study ~~are~~ of severely
physically disabled people are.

Physical independence -
ability to perform activities
of daily living / or ability
~~demand~~ ^{and direct} to access ~~needed~~
attendant care as needed.

Mobility - access to
and ability to use personal transportation
or Demand responsive
public transportation system.
~~or private~~

a) physical ability
in AML or access to
participant directed attendant care
b) mobility or access
to demand responsive
transportation. 

c) living arrangement
in a non-institutionally
typed setting away from
parents and d)

principal occupation

In order to test the
hypothesis

5) vocational emphasis (primary-incidental) In some cases, programs may be seen as adjunct to or prerequisite to vocational involvement and training. On the other hand, they may be seen as independent from though not necessarily exclusive of vocational involvement.

6) goal orientation (transitional-static) Some programs are very goal oriented and transitional in nature. Their objective is to help people move from a level of dependence to one of independence.

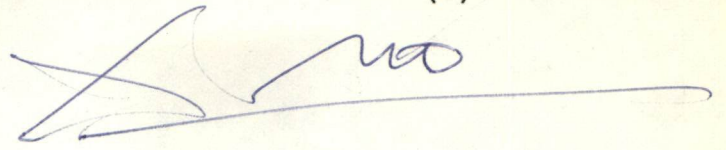
Other programs are designed to provide ongoing support for persons who may already have reached a level of relative independence.

By assessing programs on the basis of these aspects, it is possible to describe quite clearly what may at first appear to be subtle differences between programs. For example, the following illustration shows how one might project the three programs described earlier.

Insert Graph

By this analysis, it becomes apparent that while all three of these programs are similar in some respects, they also vary dramatically in some ways. They are much alike in terms of helping style, service delivery style, or methods, and vocational emphasis. In contrast, they function in different settings, their goal orientations diverge and their clientele or service constituencies differ. This is all in spite of the fact that they provide most of the same services.

Although the key variables may be identified, it is virtually impossible to say what makes an independent living program successful or not. There



Six major dimensions along which independent living programs are likely to differ have been outlined by Pflueger (1977). Each of these may be viewed as a continuum along which every independent living program will fall.

Basically, the variables are:

- 1) service setting (residential-non/residential) The setting in which services are provided will vary from strictly residential to totally non-residential. Services may be organized around specific housing projects or they may be provided in a non-residential service center.
- 2) service delivery method (direct-indirect) Services may either be delivered directly by an independent living program, or indirectly by referral to other service providers. The latter method is used mostly by programs which aim to coordinate existing services in the community. Many programs use a combination of service delivery methods.
- 3) range of disability type served (single disability type-many disability types) Programs often vary as a result of the personal characteristics of the individuals they are trying to serve. Some programs focus on serving persons with specific disability types while others are less specialized and serve people with a broader range of disabilities.
- 4) helping style (paternal-peer) The image and feel of programs will vary from being paternalistic and authoritarian to being earthy and egalitarian. Programs which employ many disabled people and many non-professional or para-professional staff persons will obviously be more oriented towards self-help than those programs which employ mainly non-disabled professional people who adhere to staunch academic backgrounds.

Programs for
INDEPENDENT LIVING PROGRAMS IN HOUSTON

by Lex Frieden *

Background

live more indep.

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 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

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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

is a vol. org. of dis & non dis people which sponsors as
~~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.

CH 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~~ *have* 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

Field Settings
~~The original Cooperative Living project~~ actually evolved into an independent living skills training program called New

The field setting for this study is

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,

inset
CBFL
org

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~~

and other services

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

Institutions And The Person

Becker, Geer, Reisman, Weiss 1968

The Housing Environment And Family Life

Wilner, Warkley, Pinkerton, Jayback
1962

Thesis

- 256 11 24

~~Proposed~~

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~~RI Report~~

- 2345

get Choosing a LR published

~~look up last years papers & pres.~~

~~call Samuel, Adler
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" Samuel / Obj. Dir.
+ Stuart / Dental
see Wilner / app. @
Reiss~~

Comment

Some comments
about the ^{research} design ~~of~~ and
the instruments
used in this study
are appropriate here.
Independent living is a
new field of practice
and study in rehab-
ilitation. As such,
there are no clear
recipes for ~~study~~
research designs or
measurement methods.
In fact, there are
only a few ideas
about what should
be measured and,
prior to this study,
hardly any idea ^{at all} about

how to measure
independent living
status or gain change.

New Options ^{served} not only
~~serves~~ as a service
demonstration project,
but also as a research
demonstration project.
As such, several
design related suggestions
are in order.



THE URBAN INSTITUTE

TIMOTHY C. MUZZIO

Lex,

Here is a rough draft of the paper on evaluation. I hope you find it useful in providing ideas on the topic. In the final paper, I will include a few pages at the beginning talking about the purpose and use of the paper. The last chapter will be totally re-written (under time pressures, I essentially scribbled down notes).

The other ~~ch~~ sections will be reviewed.

If you have any questions before your meetings I should tell you that I may be working at home on Tuesday + Wed. (Feb 19-20). Feel free to call (703) 494-5551. If I'm not there, I'll be at my office.

Tim

DRAFT

The Need for Evaluation in ILR

Recent rehabilitation legislation authorizes a program of Independent Living Rehabilitation. The purpose of the program is to help the handicapped person to "... improve significantly, either his ability to engage in employment or his ability to function independently in his family or community."¹ The legislation was a long sought after first step in providing ~~rehabilitation~~ services to ~~the most needy of~~ the handicapped population, ^{most in need of such services} and the future direction of the program will be highly dependent upon the critical first few years of effort.

The task of meeting the needs of severely disabled persons will be challenging. We have little experience in the provision of ILR services and the population of severely disabled people ^{has} ~~have~~ diverse, multiple and changing needs. This was demonstrated in the evaluation of five ILR projects funded by RSA.² In that study the average number of unmet service needs ^(e.g. surgery, psychological therapy, home modifications, etc.) for the clients served was 4.81 at intake, and the average number of unmet equipment needs ^(e.g. wheelchairs, helpers for limbs, ramps, etc.) was 1.55. The ranges in number of unmet needs were 0-16 and 0-10 for service and equipment respectively. Furthermore, the types of need were diverse. Of the 36 types of needs listed on the reporting forms, almost all were identified by some as a need, and few needs stood out as being more needed than others. Further complicating the situation was the finding that the needs of clients drastically changed

¹Public Law 95-602, Title VII, Section 702, Rehabilitation, Comprehensive Services, and Developmental Disabilities Amendments of 1978, November 6, 1979.

²The Urban Institute, Planning for Independent Living: Lessons from the Section 130 demonstrations, Washington, D.C., 1979.

while the clients proceeded through their rehabilitation program. As critical or basic needs were met, the client gained increased ability which, in turn, created another set of needs. We have had little experience in dealing with programs serving a population with such a diverse and changing set of needs. Effectively meeting needs with the limited funds available will require imagination and experimentation.

~~Another reason that meeting the needs of the ILR population will be challenging is that ILR dollars are few.~~ ^{challenge arises from the paucity of the funds appropriated} In the first year of the program 2 million dollars were ^{made} available for 10 projects to implement the ILR legislation. ^{this, the} In ~~the~~ second year, 15 million ^{are} ~~were~~ available. Effectively meeting the needs of the ILR population with such a limited budget will require efficient use of the money available.

One of the best ways of learning to make best use of the ILR dollar is to collect regular information on programs--their approach, ^{the} services provided and their costs, who their clients ^{are} ~~were~~, and how the clients benefitted ~~from their~~ participation in the program. If this information were collected, ^{the ILR and} other programs could see the results of various approaches, identify areas of strength and weakness in their efforts and see how use of funding sources can be best used in providing services (thereby maximizing the use of the ILR dollar). Using such information, programs can improve the effectiveness and efficiency of their efforts.

A system for program evaluation would be instrumental in providing such needed information. There are also many other reasons why a system of evaluation is critically needed in these, the early years of ILR.

First of all, any program, especially a new one, must justify its existence. Congress authorized the program of ILR. It will closely ^{monitor} ~~eye~~ the program to see if it is fulfilling its intended purpose. To

demonstrate that the program is (or is not) fulfilling its purpose, data are needed, and an evaluation system is needed to provide the data.

Secondly, the program must justify its level of expenditures. ILR dollars are few. Congress and the administration will be hesitant to increase expenditures if they cannot see what is being done with the money ~~they receive~~ *made available for the program*.

Thirdly, the issue of limited funding means ILR must make maximum use of other funding sources. This can be enhanced through analysis of what funding sources were used for what purpose. Such information can be collected through an evaluation system.

Fourthly, we must insure that the target population is being served. The ILR program was set up to serve ~~clients~~ *People* who are severely disabled and who cannot be served under other programs. If other populations are served, there will be fewer dollars to serve the ~~needy~~ *most in need and for whom* population ~~the program was set up for~~ *established*.

Fifthly, the Rehabilitation Service Administration (which administers the ILR program) has reporting requirements *to the president and to the Congress* under the ILR legislation. Data must be collected and analyzed for those reports. The creation of an evaluation system seems essential.

⁵ There are reasons are all important, but ultimately, the most important is *need to determine the best ways of meeting the* the needs of the ILR client population. To repeat a previous statement, ILR is in its infancy and we need to experiment with ways of conducting ILR programs. Evaluation is critical if experimentation with various methods is to be successful.

As set up in the present ILR regulations³, such ILR programs funded under

³ Office of Human Development Services, "Vocational Rehabilitation and Independent Living Rehabilitation Programs; Proposed Rulemaking." Federal Register, November 29, 1979.

establish and apply its own evaluation procedures
Title VII must ~~evaluate its own program~~ until a common system is devised. ~~RSA~~
a common evaluation system is urgently needed
~~should work on~~ development of ~~such a system in short order~~ because self-evaluation has many inherent problems.

Data from different systems of evaluation are often incompatible. For example, it is likely that programs will use different measures of client improvement. Different measures of improvement do not allow for comparisons, nor do they tell how well either program is doing. They also do not allow for the compilation of data needed to justify the program and its expenditures to Congress, nor do they provide data in the form needed for reporting requirements. A common evaluation system, if properly developed, could provide for some common measure of success.

Also, as program dollars are few, most programs would rightly prefer to spend their resources on working with clients rather than developing an evaluation system. The result might be poor evaluation systems.

Perhaps the major problem with the development of separate evaluation systems is the difficulty of the task. As we will see in other sections of this paper, the development of certain criteria, especially measures of client improvement, presents many problems. A poorly developed set of evaluation criteria may do more harm than good. It is of the highest importance that evaluation of ILR efforts be based on valid, well developed measures.

While we have made the case for a common evaluation system, we must now face the reality of the situation. A common evaluation system may not be developed for some time. A good, common system, applicable to a variety of ILR programs takes time to develop, and funds must be found to construct the system. Until such a system is developed, it is important that ILR programs do their best to develop their own means of evaluation, and that those means be the best possible. It is ~~my~~ hope that the information in this paper will help

in the development of such systems.

Growing Principles for development of evaluation systems

In this section, ~~I will present~~ *are presented* a few "guiding principles" for the design of an evaluation system for an ILR program. Many of these principles are straight forward and very basic. Often, however, these principles are overlooked by those designing systems, and, as a result, their systems are unresponsive to the needs of the programs. Keeping these principles in mind will help designers to construct a system which meets program needs, and does so in an economical fashion.

The first principle is very basic--an evaluation system must be linked to program needs. This principle, however, is often forgotten once designers begin to structure systems. What are we trying to do with an evaluating system? Generally, we are looking at the effectiveness and efficiency of the program and trying to identify strengths and weaknesses in the program. There may be other interesting issues, a few of which a program may wish to explore. However, systems are sometimes designed to try to answer too many questions. The result is usually ~~such~~ *often* a long set of forms that no one cares to fill out, ~~and~~ *often* no one knows what to do with all of the data collected, and the primary purposes of assessing effectiveness, efficiency and program strengths and weaknesses are lost. We can look at other interesting issues by doing special studies, or by experimenting with supplemental forms at a later date. It is of primary importance to see if our programs are doing what they are supposed to do (improve independence of ~~the~~ *people who are* severely disabled), in an efficient (i.e., dollar wise) fashion. Furthermore it is important to determine why we are doing so well (program strengths) or so poorly (program weaknesses) *with the* ~~in~~ various approaches we use.

Reference has already been made to a second guiding principle--economy of the system. Counselors and other rehabilitation professionals have enough

paperwork to keep them busy. We cannot expect enthusiasm for another 20 page form. What we need is a brief, simple yet thorough evaluation form. This is especially important now. ILR programs have alot to do with very little money. We ~~should~~ ^{Cannot} not waste valuable professional time filling out ~~forms~~ ^{Unnecessary or items in forms.}. In construction of evaluation forms then, we must continually ask ourselves if each item is necessary, is there a simpler way to get needed information, and conversely, are we capturing all the information we need?

Another very practical issue concerning economy of the system is the expected life of the system. RSA will, in all likelihood, develop a common evaluation system for all ILR ~~projects~~. A simple system, collecting only basic information can fulfill our short term evaluation needs. Why invest in an elaborate system when it may only be in use for a couple of years. A simple, yet valid system, which collects very basic data is practical, will ^{provide} ~~give us~~ plenty of information to work with while we learn more about ILR, and will maintain the emphasis on providing services rather than filling out forms.

Ease of use is another guiding principle. Users of forms are often frustrated by vague questions and complicated instructions, they are intimidated by long, awkward forms, and they have little time for such nonsense. For example, the concept of branching is often used in evaluation systems, and can be an effective means for increasing the economy of the system. In branching, the first in a series of questions tells the user whether to proceed to the next question or to skip to another section, depending upon his answer. If designed properly and used occasionally, a user has few problems. If ^{branching} ~~patterns~~ are poorly designed and used too often, the most experienced "form filler" can lose track of where he should be, skips sections which he should fill out, and becomes frustrated. Clarity and simplicity should be built into the forms.

Furthermore, the physical layout of the form can present problems. Some forms require frequent thumbing through pages to fill them out. Some start in the upper right hand corner, go down through the middle of the page, then to the upper left hand corner, and then to the lower portion. Some use print so fine that they can hardly be read. Others waste so much space that the number of pages alone is intimidating. As easy to follow series of items, properly spaced, and easy to identify response blocks can go a long way in reducing the time needed to complete the form and saves wear on the nerves of the user.

One final "guiding principle" relates to use of the data. Often when data items are constructed, the developed^r forgets that the data must be analyzed. When the data come in, the ~~evaluator~~^{evaluator} must try to analyze data that are not in the correct form^{for analysis} and some of the relationships between variables are forgotten. It is important to design a priori plans for analysis at the time the data forms are developed. It insures that data will be captured in their proper form. It also speeds up the time between collection of data and feedback to program personnel. It takes little time to construct the specific plans for analysis when the system is originally designed. But if left for a latter date, no one can recall why certain items were included ~~and~~^{or} how to analyze others. Under pressure to complete a report, a skimpy, often useless document is prepared, and the evaluator, tired of looking at the data, puts off the development of an analysis strategy for another year (until the next report is due).

When developing an evaluation system, one should develop a step by step process for data analyses--what tabulations will be made, which items will be compared and contrasted, what statistical methods (if any) will be used, what the results of comparisons mean, and exactly how the data will be presented after analysis. Under these conditions, the evaluator simply follows these

a priori steps and ends up with a meaningful report in a short period of time. Counselors, administrators and others can immediately see how this program fared, and begin to strengthen weak areas, and continue in strong areas. Other programs can look at the same information and see how certain aspects can be incorporated into their program to strengthen weak areas. In addition, reporting requirements to state and federal agencies can be delivered on time, and in good form.

^{we} I have by no means covered all things which should be kept in mind in the development of evaluation systems. ^{On the contrary, we have discussed only} ~~I have included~~ simple factors which ~~I~~ ^{are often overlooked} ~~have seen many forget about~~, yet are so basic and important, that without them the evaluation process becomes a meaningless exercise.

Armed, then, with the knowledge of why we are evaluating ILR programs, and certain pitfalls we should avoid, we can begin to discuss specific types of data needed for an effective, efficient ILR evaluation system.

Components of the System

In this and the next section, we will consider components of evaluation systems for ILR programs. It is not ^{my} ~~our~~ intention to lay out specific items, nor to discuss all types of items a particular program may need or wish to collect. In addition, some ILR projects have areas of special emphasis and will, of course, have to develop items for those areas. Rather, we will consider basic areas needed for a simple, yet effective ILR evaluation system. Discussion ^{of} ~~client~~ improvement indicators is reserved for the next section as these are the most difficult, yet, in many ways, the most important to collect.

The first ^{are} ~~topic~~ that ~~should be completed by~~ ^{staff should tackle, even} ILR programs ^{the development of} prior to the development of the system, ^{is} a complete program description. One must first know what information he or she is trying to capture, and how it might best be captured by the evaluation system. What is the specific purpose of the program, and what are its goals. What methods of treatment will be employed? What is the organization of the agency? Does the program have special areas of emphasis such as transportation or housing? What is the target population? Is the program involved in coordination or advocacy efforts. If so, what are they? How does the program involve consumers? Developing the system after the program is fully described helps to tailor the system to the program. When ⁿ the yearly evaluation report is compiled, a review of the program description ^{will} ~~might~~ help to put the results into perspective--especially to outsiders. It also informs other programs about techniques used so that they might identify ways they can improve areas of weakness in their program.

The description should be brief, yet specific and clear. Few will read long detailed descriptions. If staff of another program see an area of

potential interest to them, they can inquire for more information. Length is not important, but specificity is.

With a good program description in hand, the rest of the evaluation system can be tailored to it.

Collecting information on
~~The next area--~~demographic characteristics, serves two important functions. It can help determine if the target group is being served, and it is essential for most governmental reporting requirements. Many areas have need studies which usually describe the disabled population in their geographic areas. If those studies do not yet exist, they will soon, as such studies are required in the new rehabilitation legislation. If such studies exist, it would be wise to simply use the key items used in the *needs* study for the evaluation system. Comparing basic characteristics tells, generally, if the target population of a given local is being served.

Another important reason for collecting such information is for use in combining these factors with other ~~factors~~. For example, average client income will be deflated if persons under the age of 18 (who often are not in the labor force, or do not directly receive certain government subsidies), and over 65 (who also are less likely to be in the labor force) are included.

Demographic characteristics are straightforward so little time will need to be devoted to describing them. Age, sex, race, marital status, education ~~and income~~ *and the like* leave little to the imagination when developing an evaluation system. Disability type (primary and secondary) can be more challenging. If the program staff is familiar with the RSA Disability Codes, found in the "R-300" (there are about 170 of them), it might make sense to use them. If not, major diagnostic categories can be formed by collapsing the RSA codes. This allows for a simplified system, yet keeps it analytically comparable to RSA codes. (Many might argue that disability type is unimportant--rather ~~functional indicators are what is needed. I disagree and feel both are im-~~
~~portant~~

functional indicators are what is needed. I disagree and feel both are important. "Communication limitation," for example, tells me little unless I know whether the limitation is due to deafness, stroke, a traumatic injury, etc.).

The next area, severity indicators, is a difficult area on which to capture information. When discussing them, I will make an arbitrary distinction between severity indicators and improvement indicators. In practice, the two areas overlap a great deal. I discuss them separately because on one hand, programs must show that they are serving the target population (the severely disabled). On the other hand, programs must demonstrate client progress. I refer to the former as severity indicators, and to the latter as improvement indicators.

The ILR program is intended to serve clients without an immediate vocational goal, or those who need services to continue in employment, or those who need extensive services to function more independently because the severity of the disability is so great. It is difficult to operationalize such factors. The Urban Institute⁶ used relatively simple criteria and found them to be quite useful. The indicators they found most useful with their population were Barthel Scale, presence of Blindness with some ~~other severe handicap~~ ^{disability}, other severe limitation (functional indicators, some of which are discussed in the client improvement indicators section of this paper), and a substantial disability combined with a poor employment history, severe communication disorder, old age or poor education.

While these indicators were useful, it must be remembered that the popu-

⁶Muzzio, T., LaRocca, J., et al, Planning for Independent Living Rehabilitation Lessons from the Section 130 Demonstrations. Urban Institute, Final Report, 1979.

lation studied consisted of mostly physically disabled persons, or persons who were blind/multiply handicapped. For programmatic purposes, other indicators seem necessary. For example, we need indicators of mental and emotional severity, and information on the progressive nature of certain ~~conditions~~ ^{Conditions} (The Urban Institute Study Population included persons with progressive diseases, but captured severity information through other means). We also should allow for some discretion by the rehabilitation professional since we do not know how to capture all the information we need for a rating of severity.

A severity indicators section, then, might include such information as

Physical Index⁷ (such as the Barthel Index⁷, which was found to be a relatively good severity indicator when used with a physically disabled population)

Blind/Multiply Handicapped (although trying to stay away from diagnostic labels, they will continue to be necessary until we improve methods of measuring severity)

IQ or other measure of mental limitations

Severe Emotional Limitations (so little is known in this area, that it is difficult to identify a good, relatively brief indicator of emotional limitation)

Existence of progressive disease which usually results in severe disability

Substantial disability combined with one or more of the following
poor employment history
severe communication disorder
old age
poor education

Other Severity Indicator (Used for counselor discretion. Specification of reason may help in refining the system).

These areas are not intended to be specific items. Rather, they are intended to identify areas which should be looked at when designing severity indicators. In addition, there may be other areas which should be included. Experience with ILR clients may provide valuable insight into improved indicators.

⁷ Mahoney, op. cit.

It might also be mentioned here that a number of these severity indicators will probably be picked up elsewhere in the evaluation system. Using the areas above as examples, blind/multiply handicapped, existence of a progressive disease..., substantial disability, old age, and poor education will definitely be picked up elsewhere in the system. Barthel, ~~Emotional~~ ^{Limitation} poor employment history, IQ and severe communication disorders may be picked up elsewhere. ^{depending upon how the system is designed.} It may not be necessary, then, to create a separate section on severity. The "other" category may be picked up by inclusion of an item which ~~asks for~~ ^{which asks for the primary reason for determinants as severely disabled.} If the aforementioned factors find no evidence of severity, the latter item can be viewed.

So far, we know a little about who the clients are, and that they are severely disabled. We now need to know how they were served.

Services provided can easily be combined with other important, needed information--cost and sources of funds. ^{used to pay for services} Such information is relatively easy to collect and can be done so at many levels of detail. For example, the Section 130 Independent Living Demonstration reported client cost on a form with 33 cost categories. Following each category, there were 5 columns asking for description of services, expenditures, percent paid for by project funds, percent by other funding sources, and ^(if other funding source was used) identification (by code) of the primary other funding source. Project personnel found the information provided overwhelming. For most analyses, they needed only major category of service (counseling; Diagnostic and Evaluation; physical and Mental Restoration; Training; Placement; Maintenance; Services to Family Members; Transportation; Aid and Attendant Services; and other), ^(project and other) expenditures, and identification of the primary other funding sources. The information provided by these areas gave a good picture of average client cost, types of services most and least needed, ^{and} how such information compared with similar data for other populations, ~~and~~

~~with similar data for other populations, and~~ ^{The data also} could have great importance for finding how other funding sources could be most effectively used.

With one rather small group of items, ^{a new evaluation system could determine services provided,} ~~the service, cost and information~~ on the use of other funding sources, ~~could be ascertained.~~ ^{format could be} The ~~form~~ is clear and easy to use, and provides an excellent example of the principles laid out earlier in this paper--it provides useful information, collects information economically, is easy for the user ^r to fill in, and can be easily analyzed.

So far, we have information on the client for use in determining if we are generally serving the intended ~~regional~~ target population, for use in analysis of other variables (e.g., average income), and for providing a general picture of the client population. We have information on the severity of disability. While we cannot rate the ^{precise degree of} severity, we can get a picture of the cause of their severity of disability and demonstrate whether we are or are not serving the target group specified in the legislation. We are doing this with few added items as most information is picked up by other areas of the firm, thus facilitating economy of the system. We also have captured highly useful information on services provided, cost and how other funding sources were used (thus stretching use of ILR dollars), in an economical, simple, and easy to analyze fashion.

We now need to show that the clients have somehow improved as a result of providing services. These client improvement indicators are perhaps the most difficult to capture, yet in many ways are the most important, as they show program effectiveness. Because of their importance and the difficulty involved in capturing such information, a separate section on them follows.

Client Improvement Indicators

The vocational rehabilitation system has a relatively simple measure of program success--employment. ILR has no such simple measure. "Success" in ILR refers to increased independence in the family or community. What is increased independence? How does one measure it? Are indicators available, or must new ones be developed? All of these questions are crucial ones for the evaluation of ILR. If we are unable to demonstrate increased independence, we cannot demonstrate that the objectives of ILR are being met.

There are two basic approaches for obtaining client improvement information. The first is to use already existing scales and measures. The other is to create indicators. Even if the former approach is used, the latter will have to supplement it, because there are some types of information needed that are present in few, if any, existing scales. I will highlight two examples.

The progressive nature of certain conditions makes measurement of improvement difficult. For example, a client with multiple sclerosis may deteriorate rapidly in functional ability without provision of services. His rate of deterioration in some areas may slow down or stop when services are provided, but functional indicators would still show that the client is not improving in absolute terms as a result of participation in the program. In actuality, he is improving in the sense that worsening of condition is slowed, and provision of services may make life a little better. The ILR regulations would agree that this would be considered improvement. We need, then to somehow capture information on the progressive nature of certain conditions and demonstrate that services are somehow helping the client.

The second example concerns client assessment of services. Most measures look at what the client does. Few look at ~~how satisfied the client~~ ^{satisfaction} with services.

One will always find some people never satisfied, regardless of what is done while other will be satisfied even if nothing is done. But a good general indicator of program success is client satisfaction. If a disproportionate number of clients are dissatisfied, and the major reasons are uncovered, program staff can work to improve the program areas creating the dissatisfaction. It is easy to obtain this information. While lacking in objectivity, it can be very helpful in identification of weak program areas.

So, how are we to obtain indicators of client improvement? One of the major means identified is to use existing measures, supplemented with other items. In this approach, one must be careful to make certain that ^{the selected instrument} ~~it~~ captures the needed information. Is it usable with persons with sensory, mental, emotional and physical disabilities? Is it sensitive to client improvement or does it measure only unchanging qualities (e.g., does it measure communication ability as opposed to such things as degree of hearing loss?). Can the results be interpreted? Is the instrument brief and easy to use?

The reader may find a report by Muzzio and Burris⁸ helpful in better ~~understandin~~ understanding these and other issues. In that study, the authors address the areas of users of such instruments and their needs, unique client populations, ~~criteri~~ criteria for and components of instruments, and utilization issues. In addition, the study has an extensive bibliography and describes a number of functional limitation instruments.

Because of the existence of the report, I will only briefly describe some of the available instruments, and then move into the creation of other indicators.

⁸Muzzio, T. and Burris, C. Functional Limitations: A State of the Art Review, Indices Inc., Arlington, VA 1979

The Barthel Index⁹ has been in use for some time, and many studies, including the evaluation of the Section 130 ILR demonstrations, have found it useful as a measure of severity and improvement of physically disabled people. It is brief and easy to use. Its major drawback is that it can be used ^{only} with a physically disabled population (i.e., use of this index would require use of additional indicators for other populations).

The Functional Assessment Inventory¹⁰ covers sensory, motor, psychological and intellectual, social and biographical factors. It is brief and easy to use. Preliminary field testing has shown it to be helpful in the construction of rehabilitation plans, and assessing client improvement.

The Rehabilitation Indicators Project¹¹ is being developed to identify observable, measurable and potentially modifiable aspects of the client and his environment. The project is currently field testing the instrument. While not immediately available for use, it holds great promise both as a means to identify areas of service need and to assess client progress.

Many other instruments are available, and I would encourage the interested reader to obtain a copy of the Muzzio and Burris report. Let me re-state that before any instrument is used, it should be carefully examined to ensure it meets the needs of the program.

Turning from instruments to other means to assess client improvement, I will discuss a few simple types of measures which are both important and useful. I do not intend to cover all areas, but rather I hope to stimulate thinking on ways in which useful measures can be constructed.

⁹ Mahoney, op.cit.

¹⁰ developed by Dr. S. Nancy Crewe and Gary Athelstan, Rehabilitative Research and Training Center, University of Minnesota

¹¹ M. Brown, Institute of Rehabilitation Medicine at the New York University Medical Center

One of the most useful measures found in the section 130 ILR demonstration was frequency of social interaction. The specific item asked simply how often in the past 30 days, the client engaged in activities such as visiting or being visited by friends, attended meetings, and public entertainment, went shopping, and so forth. The study found increases in frequency of social interaction. This measure is simple, yet directly measures participation in society, which is what ILR is all about.

Another measure, which is slightly more difficult to analyze, is reduction in unmet service and equipment needs, such as hospitalization, surgery, various types of therapy and counseling, wheelchairs, typewriters, helpers for limbs, specially equipped autos and the like. Generally, if the client experiences reduced need, we can argue that the client has benefited by being in the program. Unfortunately, the measure is not all that simple. The results of the Section 130 ILR Projects demonstrate that gross number of unmet needs often increase as the client proceeds through his rehabilitation program. As basic, critical needs, such as need for surgery, wheelchairs, and physical therapy decrease, other, ^{ive} supported ~~ed~~ needs, such as specially equipped ~~autos~~, special phone equipment and education increase. In other words, as the client has his basic needs fulfilled, his ability increases, which creates the need for other types of less basic equipment and services. By distinguishing between basic and supportive services (which is possible, but not simple to do), improvement can be measured through use of number of unmet needs as an indicator. Other types of indicators can also be helpful.

It would be easy to fill up pages with numerous additional examples. However, the main idea of creating simple yet useful measures has been presented. With a little work and imagination, other measures can be constructed. Information on ability to move about in one's home, to use various types of

transportation, communication ability, and ability to undertake, or need for assistance in, financial and homemaking activities, and other areas are potential indicators and can demonstrate whether or not a client has benefitted from participation in the program. When combined with items on client assessment of services, presence of a progressive disease, a program can develop simple, yet effective measures of success.

These types of items can lend themselves to a very brief form or an extensive one. Regardless of detail however, they should all be helpful in evaluation efforts, if properly used. The factors of simplicity, clarity and other guiding principles mentioned in a previous section of this paper will help in developing a useful system. There is one other factor, however, which must be remembered when using client assessment indicators.

The types of items discussed here cannot be developed to yield "scores." Areas such as housing needs and frequency of social interaction cannot be weighted for relative importance without intensive research. Categories within a given area cannot be rated on an equal internal scale. Developing overall "independence scores" will lead to inappropriate comparisons and would be especially meaningless when trying to compare two individuals or populations with different disabilities.

It is suggested then, that each individual area be seen as a separate one. For example, in the area of social intervention, results could show that X people increased in frequency of social ^{ac}intervention, or that the average number of social interactions increased from Y to Z, which shows general improvement. The worst possible thing to do would be to state "that clients ~~doubled i~~ doubled in their frequency of social interaction, but there was only a 10% increase in mobility--why are we doing so poorly in the mobility area?" In actuality, the mobility program may be a very strong feature of the program, only the item is not structured to show the degree of increase.

An appropriate use of the data would be to look at areas in which no average improvement occurred, or only slight improvement occurred. At that point a review of how the items providing the data were structured would help to determine whether it is a problem area for the program or not. One should also look at such things as client characteristics to see if the lack of improvement was due to other factors. If the population contained a high number of people under 18, one might not expect a high increase in the number of people living alone or with friends as opposed to living with parents (a possible item which could be used to look at living status). In other words, one must use caution in interpreting the results of client improvement indicators. They can give a general picture of what is happening in the program. As discussed here, they cannot specify the exact degree to which clients improved.

Client improvement indicators then, can be developed. They can be simple and easy to use, and they can provide valuable information on program strengths and weaknesses. They can also help the rehabilitation professional determine client problem areas which need attention. They might not tell why there is a problem in an area nor how to help the client, but they will identify areas to further explore with the client.

Once we have constructed some client improvement indicators, we can combine it with the other items to complete an evaluation form. The evaluation system, however, is not yet completed. We must still design a mechanism for collecting, analyzing, summarizing and disseminating the results. Constructing this part of the system takes some time, but is not as difficult as many believe. The investment pays off well in the long run, however, as we will see in the next section.

Pulling the System Together

All too often, the time between collection of data and ~~subseq~~ completion of a report is too long. ~~Once the raw data is collected,~~ ~~no~~ Between not knowing who should do what with the data and the ~~two~~ months needed to write the report, ~~the result~~ the result is usually an outdated document with useless data. Developing a plan for using the data can often prevent these problems.

The primary factors involved in this planning process are 1) development of a priori analytic techniques 2) development of ~~means~~ to operational means to analyze the data 3) development of a reporting format and 4) dissemination plans.

The first factor has already been addressed. ~~Well~~ Well intentioned evaluators sometimes create variables on which data are collected. At the time, the evaluator knows why the variables are there -- he has a specific question in mind. When the time comes for analysis of the data, the evaluator has moved on to other projects, or has done so many other things that he forgets why an item was included. ~~It is also possible~~ It can also be the case that the data obtained from the variable cannot be used because it is not analytically comparable to other data. These problems can often be solved through the development of a-priori plans for analysis (such plans also have more validity than a post-hoc analysis). Knowing ^{precisely} how the data will be used helps to

ensure that data are captured in their proper form, that
reporting form, and that the results of the analysis will
be meaningful. Regardless of whether sample tables
are to be used, or multiple regression, a prior plan
is the first, and perhaps most important factor for
pulling the system together.

~~closely related to development of a prior plan~~
closely related to development of a prior plan,
is development of operational means to implement these

plans. In its simplest form, this might be the designation
of a staff person to manually go through the form and tally
the results. This would quite well suit programs requiring
a small number of clients, and which called for minimal
information. Larger programs require other techniques. For
example, if a large program wishes to use statistical tests of
significance, a computer program is essential. In the largest
of imaginable systems, one needs to make timely requirements
develop computer programs to handle the data, develop

well ahead of time

appropriate edit programs, and know well ahead of time ~~how to interpret~~
the results of the analysis.

~~There are three effects with~~

Small highlight here effect which have developed
excellent methods in this respect. The Tift Long Range
Evaluation Summary collect client evaluation information at

various stages of rehabilitation ^{and} feeds the information into a computer. The information is analyzed and fed back to rehabilitation and medical personnel in summary form, including certain primary ^{ability} indicators. Although ~~promoted~~ designed for use in the medical center, the approach serves as a good ^{process} model. Data are analyzed quickly, and output is in ~~usable~~ a form readily usable by rehabilitation personnel. Summary statistics across client populations can also be easily generated.

A system called the Hospital Utilization Project¹¹ collects client data from many types of hospitals and rehabilitation facilities across the country. Included is information on functional limitations. Data The system is set up to collect admission, discharge and followup data. Summary statistics are sent to member facilities which compare their facilities to others. ~~I mention this~~ Although this is not a system for use by an individual ~~project~~ program, I think it is important to show that a banding together of programs can help in creating a useful, responsive system. It releases program staff from the burden of data analysis and report writing. While this might be a model ~~program~~ for a national program, there is no reason why a number of programs funded under title IV could not create a similar program on a smaller scale.

¹¹ Hospital Utilization Project of Western Pennsylvania, Pittsburgh, Pa.

These programs (The Long Range Evaluation Summary and the Hospital Utilization Program) also demonstrate ~~two other~~ the remaining factors involved in tying together ~~the~~ an evaluation system -- format for reports and dissemination.

While both systems are designed for use by administrators ^{rehabilitation} ~~not~~ or professionals, ^{they both include} the idea of having a predesigned format for the results of the analysis. ICR programs may ~~take~~ take a slightly different approach, but the idea is the same -- having plans for the format of the report. If a format is designed which contains the tables to be used, what will be contained in each section of the report, and ~~and~~ the type of text to be used for the tables, the process of ~~placing it~~ completing a report is relatively simple, and takes little time. Once data are received from the computer printouts or the tallies done by a staff member, they can be inserted into the predesigned tables. Knowing generally what will be contained in the text helps the writer to complete the report in a timely fashion. Undoubtedly there will be problems -- data which doesn't seem to make sense, an erroneous figure and the like. But overall, the process of ~~the~~ completing a report ~~would~~ will be greatly facilitated.

Finally, predesigned dissemination plans help to ensure that the data will be used. A mailing list for program, ~~and~~ state and federal officials, to other ICR projects, to others ~~which~~ the program feels should have the report is simple to construct. It saves a lot of time in getting

the report to people who need them

Most of what I have written in this paper is simple, common sense information. However, ~~also~~ there are all areas which are often overlooked in the design of evaluation systems. There is no reason why evaluation should be difficult. The information I have presented stresses simplicity. ~~alth~~ While not a step by step process for designing a system, it should give ~~p~~ ideas on how to develop useful evaluation systems for I.R.

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NEW OPTIONS: FACILITATING THE MOVEMENT TOWARDS INDEPENDENCE
BY SEVERELY PHYSICALLY DISABLED PERSONS¹

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Recent developments in rehabilitation have placed an increased emphasis on creating opportunities for special housing, education, and employment for severely physically handicapped persons. The Rehabilitation Act of 1973 recognizes the special and unique needs of the severely disabled. The provision of opportunities offered by the Act has permitted some individuals who were formerly isolated in institutions such as nursing homes or in dependent home situations to begin lives of independence and productivity. These efforts, though important, have been slow to evolve, they lack comprehensiveness, and too few persons have been offered maximum options and opportunities.

There are countless individuals who find it overwhelmingly difficult to assume the responsibilities that these new opportunities afford. Many of these persons have the basic untapped capabilities necessary to become independent and develop a lifestyle of personal satisfaction and productivity. However, due to a fragmented approach of limited scope, and the absence of a model of transition, many severely

¹Presented at the annual meeting of the American Psychological Association, San Francisco, California, August 30, 1977.

physically handicapped persons cannot bridge the gap between a protected institutional existence or an isolated and confining home situation to the management and assumption of an independent life-style.

Even with maximum personal capabilities, the process of moving from a dependent to an independent living arrangement or situation is difficult and includes many obstacles. The exceptional person is usually successful in negotiating a new life style, but the more typical person easily becomes isolated and confined to a closed environment by his disability. The potential for productivity and personal happiness, if such persons were given opportunities, remains mostly unexploited. Our system of rehabilitation services should be able to offer persons an environment where they can extend their basic abilities, build upon new learning experiences, and establish reasonable goals that are supported by carefully segmented planning and individual learning. When an individual possesses potentials for self-direction and vocational productivity, appropriate assistance is crucial in order to avoid stifling his/her capabilities and motivation.

Experience has shown that persons with severe disability who want to live independently are usually required to assume the responsibilities for medical, social, and economic necessities simultaneously. The complexity of these demands can frequently lead to deterioration of their physical well-being. The severely physically handicapped individual is prone to a variety of medical problems -- skin

breakdown, urological complications, muscle atrophy, and the physiological results of inactivity. Furthermore, when the severely physically handicapped person is reintegrated into the family, many pressures outside of those required to meet the prescribed medical treatment can become paramount concerns to the family. Therefore, even though medical needs should be given a higher priority by the family they often become secondary. Consequently, medical complications develop and re-admission to a hospital is imperative. This sets up a vicious cycle.

It has also been documented that in many family situations, the integration of the severely physically handicapped individual into the home must be a carefully planned process with maximum emphasis upon education and communication. A transitional experience is needed for many persons and their families to establish the necessary physical care, mobility, and emotional supports. A program of preparation that extends beyond the formal institution is the goal of a transitional experience. This experience should have a significant impact on the problems of medical recidivism.

Present national programming offers few prototypes that prepare the severely physically handicapped individual to move from a dependent setting into an independent setting. Structured programs which place an emphasis on offering maximum opportunities at cost-effective levels are essentially non-existent. Emphasis is not placed on allowing the severely physically handicapped person to assume the

multiple stresses of independent living and employment in a gradual manner.

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In June, 1976, Texas Institute for Rehabilitation and Research began a model transitional living program called New Options which is ^{was} designed to foster the integration of severely physically handicapped individuals into their communities. Goals of integration ~~may included~~ the establishment of independent living, involvement in educational and vocational opportunities, active social participation in the mainstream of society, the enhancement of personal skills important in daily problem solving, and the stabilization of goals and objectives required to maintain a satisfying quality of life. The planning and initial months of operation of New Options were supported in part by RT-4 funds ~~which continue to support a portion of the research to evaluate program effectiveness.~~ In October of 1976 an R&D grant (13-P-57889/6-01) was funded by RSA. ~~This has substantially increased the project's capability to conduct service demonstrations and evaluation research.~~

As many of you know,
New Options presents certain information, skill training, and experiences in an effort to facilitate the behavioral adaptation and personal adjustment of individuals to severe physical disabilities.

the program was
~~New Options~~ is a six week live-in ^{experience for the severely} program composed of three primary elements, (1) a residential support system, (2) individual counseling and consultation, and (3) training, practice, and information modules.

The residential support system includes ⁸ attendant service, food service, and transportation service. Participants in ~~the New Options program~~ live ⁱⁿ the TIRR Maximum Independence Center, a barrier-free dormitory style facility where non-professional attendant care ^{not} is provided 24 hours a day on a shared basis. Meals ^{are} prepared by a kitchen staff in the facility, and the project ~~owns and operates~~ ^a van type vehicle suitable for transporting seven persons in wheelchairs at one time. The residential support system at New Options ^{not} is patterned after the system developed in the Cooperative Living Residential Project sponsored by TIRR and the Rehabilitation Services Administration from 1972 through 1975.

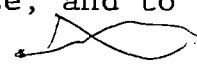
Individual counseling and consultation at New Options ^{was} is provided primarily by a full time professional staff which includes ⁸ the Project Director, Research Director, Personal Independence Counselor, and Functional Skills Adviser. Other individual counseling ^{has} is done by consulting physicians, vocational counselors, occupational therapists, and active handicapped persons from the community. Counseling ^{not} is directed toward solving specific individual problems as well as validating experiences and identifying needs.

The key element of New Options is the training module . ^{was} Presently, there are eleven such modules in the program focusing on such subjects as financial management, consumer affairs, living arrangements, functional skills, mobility, sexuality, home-making skills, voca-

tional-educational opportunities, medical needs, and social skills. The basic responsibility for planning and arranging each module is divided among the professional staff people in the project. Additionally, active disabled persons who can serve as role models are employed as associates to assist with each module. In some cases, these associates assume almost total responsibility for the operation of their respective module. Each subject 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 each module to transmit information. Field trips are used extensively to provide opportunities for participants to observe various living arrangements, vocational and educational programs, recreational facilities, and so forth. Visits are made to agency offices, job sites, university campuses, apartment complexes, and private residences. Meetings are arranged with public officials, agency representatives, building managers, program administrators, and active handicapped persons throughout the community.

Considerable free time is programmed into the schedule so that participants may explore the community on their own, practice activities individually, complete personal agendas, or do whatever they want. Participants frequently use free time to run personal errands, to socialize, and to engage in recreational activities.



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As of July 25, 1977, *was* *during 3 yr. period.* ~~forty-nine~~ individuals had been admitted to the New Options transitional project. ~~Forty-three~~ of these individuals ~~were male and six were female.~~ *was* *during 3 yr. period.* ~~Thirty-eight~~ New Options participants ~~were single and eleven were married, divorced, or separated.~~ ~~Forty-one~~ of the ~~forty-nine~~ individuals were spinal cord injured and the others were severely disabled as a result of cerebral palsy, muscular dystrophy, polio, brain damage, and ataxia. Most of the individuals in the program were from 20-25 years old. The exact age range was from 17-53 years.

Staff members and the project Department of Vocational Rehabilitation courtesy counselor largely agree on the following characteristics as important traits in persons who seem to have benefitted from the project: readiness to face life as a severely disabled individual; desire to make changes in lifestyle; willingness to set and work on some goals; willingness to risk experimenting with new ways of doing things and new kinds of behaviors; average intellectual capacity (comprehension of verbal input, no major memory deficits, reasonable attention span); ability to read; ability to speak well enough to be generally understood; ability to hear; no severe emotional pathology; and physical endurance for program (sitting tolerance, bowel control that is predictable, suitable urinary management).

One variable which may prove to be critical in determining who can benefit most from the New Options program is time since onset of disability. Thirty-three percent of the participants in the program had been disabled less than two years when they entered New Options. The most recent time since onset of disability was eight months. Another thirty-three percent of the program participants had been disabled two to five years before they came to New Options. Finally, thirty-three percent had been disabled more than five years before they participated in the program. The longest period from onset of disability to admission in New Options was twenty-four years.

Another critical variable which may later be tied to potential to benefit from this program is the individuals pre-admission living arrangement. Approximately half of the participants came from rural communities, and the other half were from metropolitan areas. Perhaps more importantly, eighty-two percent of the New Options participants were living with their family before they came to the program and the remainder came from institutionalized settings such as junior colleges, hospitals, and nursing homes. With respect to transportation, all but two of the forty-nine participants were dependent on someone else to drive them. Seventy-five percent of these individuals depended directly on family members or close friends.

With the exception of one individual, each of the participants in the program used either an electric or manual wheelchair for

mobility. All of the participants had special bowel care needs, and eighty-six percent depended on an assistive urinary device of some sort. Two-thirds of the individuals in the program needed help transferring from their bed to their wheelchair or from their wheelchair to their bed. Most of them needed physical assistance dressing and bathing. Some needed assistance feeding and writing. Most of their physical assistance before they came to New Options was provided by family members or by individuals in the institution where they lived. Only five of the participants were physically independent from a functional viewpoint.

Another key variable to which much attention has been directed is that of income or economic level. More than two-thirds of the individuals in the program had an income below \$200 per month before they came to New Options. Only two of the thirty-five had incomes of more than \$500 per month and one of these two supports a family of thirteen.

Fifty percent of the participants had some kind of comprehensive medical rehabilitation before they came to the program. Thirty percent had limited medical or vocational rehabilitation, and twenty percent had no previous rehabilitation. About fifty per cent of the New Options participants had been in school before they were disabled. The remaining fifty percent had been working. Most of these individuals had been doing mechanical labor such as construction work, mechanics work, and agricultural work.

Since the onset of their disability and before participating in New Options, about half of the individuals had tried to attend school. The other half had tried a variety of activities including reading, painting, mechanical work, stamp collecting, traveling, fishing, and "just getting by".

Since previous research suggests that gross behavioral activity levels in naturalistic settings may be better indicators of personal independence and behavioral adjustment than standardized muscle and function tests, several unobstrusive monitoring techniques including the Rest Time Monitor and Wheelchair Odometer are being used to continuously measure gross activity levels of New Options participants.

The average daily out of bed time for New Options participants was 11.2 hours per day. This compares to a daily best week average of 8.5 hours per day for paraplegics and quadriplegics who were in comprehensive rehabilitation programs at TIRR. Individual's mileage per week for the entire forty-three subject sample ranged from 1.1 to 35.8 miles. The average weekly mileage per individual across the entire sample was 7.3 miles, or approximately one mile per day average per individual.

In an effort to document the individual effects of the program on New Options participants, follow-up is routinely done three to

four months after each participant leaves the model transitional program. Several significant changes in living arrangements may be noted for those individuals on whom follow up data are complete. About half of the former participants are now living comparably more independently than they were before their participation in New Options. Additionally, nearly three fourths of the former participants are now in school, or have part time or full time jobs.

Observations made during the transition from protected settings such as nursing homes and parents homes to less well protected or more independent settings such as apartment units and college dormitories may lead to valuable insights regarding the psychological adjustment and adaptation of individual's to severe physical disabilities. ~~For example:~~ The number and variety of references to changing self images or self concepts by former transitional project participants is striking.

The following statements illustrate the sort of comments made by participants who experienced this change while in the program:

"It is really hard to believe what can and is being done from wheelchairs. There are some very intelligent people in wheelchairs."; "Being in a wheelchair puts you in a minority but it doesn't stop you from living a normal life."; "Most people just don't realize that people in wheelchairs are normal too, they just have some kind of handicap. Everyone has a handicap of some sort, whether it be

large or small. Some people in wheelchairs are better off than some able bodied people."; "It is very hard for some people to adjust to being in a wheelchair. It is easier for some than for others, but it can be done."; "New Options opened my eyes and my mind to what a fulfilling life I could have in spite of my handicap."; "I cannot tell you how much self confidence I acquired in those few weeks - I got over being ashamed that I was in a wheelchair."

Could it be that these references are merely abstract descriptions of persons who realize they have more control over their environment than they once thought? Or, could it be that these references are merely reports of yet unfulfilled expectations? Perhaps these are references to newly acquired or internalized goals. Maybe these persons are practicing newly acquired skills or behaviors which affect their self image.

Judging from the program design, each one of the afore mentioned hypotheses may have some degree of validity. Certainly the program teaches information and skills which may change persons impressions about the relative influence they have over their own destiny. In some cases, information or skills acquired in the project may actually increase individual's capacities to control their environment and thus influence their own destinies. Goal setting and problem solving are important conceptual and operational bases of the program, and it is likely that repeated practice in these areas improves one's ability to function with more

self control in this complex social and physical environment. Finally, there is no doubt that the project staff, persons who refer individuals to the program, and participants as well, expect the program to have a positive effect.

Self reports by former participants are substantiated and validated by follow-up information and feedback received from counselors who sponsored individuals in the program. Most counselors agreed with their clients by saying that they seemed to be more self-sufficient, more self-confident, or more independent after they participated in New Options. Several counselors reported that they noticed a better outlook, a better attitude, or more motivation on the part of their client following participation in the program. Other counselors claimed that their clients were more goal oriented than they were before. Most comments from counselors who sponsored clients in the program were typified by the statement that "my client realized that he is ultimately responsible for meeting his own needs".

These reports raise questions about the degree of correlation between improved motivation and enhanced self image. Are reports of improved motivation based on observations of verbal assertiveness or behavioral achievement? Is motivation the manifest realization of critical consequences and behavioral contingencies? How does motivation relate to goal setting, or problem solving, or independence? Perhaps further research will lead to the answers for many of these questions.

The preceeding observations and descriptions characterize an apparently successful program designed to facilitate independence by severely physically disabled persons. However, the harsh reality is that neither New Options nor any other program like it can be extremely effective until society expands its definition of roles for independent handicapped persons, reverses discrepant contingencies, eliminates disincentives, and generally removes programmed barriers to self control and independence of severely disabled individuals.

Hopefully, the results of this project may justify a shift of emphasis by public welfare and vocational rehabilitation agencies from treatment, training, and vocational placement to treatment, training, and socio-environmental placement. Specifically, this means that traditionally conservative state departments of public welfare may realize that independent living is ultimately a viable and cost effective alternative to institutionalization for severely disabled individuals. New Options may serve to emphasize the need to treat chronically disabled individuals as a part of the total environment rather than as patients with problems that require narrowly focused attention.