

APPENDIX A

EVALUATION PANEL OF EXPERTS

APPENDIX A

Independent Living Evaluation Panel of Experts

Elmer C. Bartels,
Commissioner
Massachusetts Rehabilitation Commission
4 Point Place
27-43 Wormwood Street
Boston, MA 02210-1606
(617) 204-3600
(617) 727-1354 (Fax)
elmer.c.bartels@state.ma.us

Tom Driscoll
Massachusetts Assistive Technology Partnership
Children's Hospital
1295 Boylston Street, Suite 310
Boston, MA 02215
(617) 355-7820
(617) 355-7301 (TTY)
(617) 355-6345 (Fax)
driscoll@cape.com

Michael Blatchford
Vice President
Assist! to Independence
P.O. Box 4133
Tuba City, AZ 86045
(928) 283-6261
(928) 283-6672 (Voice/TTY)
(928) 283-6284 (Fax)
assist@cybertrails.com

Lex Frieden
Senior Vice President, TIRR
Director, Independent Living Research Utilization
1333 Moursund
Houston, TX 77030-3405
(713) 797-5283
(713) 797-5790 (TDD)
(713) 799-7095 (Fax)
lfrieden@bcm.tmc.edu

Joe Bravo
Executive Director
Westchester Independent Living Center
200 Hamilton Avenue
White Plains, NY 10601
(914) 682-3926
(914) 682-8518 (Fax)
Jbravo297@aol.com

Devva Kasnitz, Ph.D.
108 Dunaway Court
Fortuna, CA 95540
(707) 443-1973/ 707-725-9218
devva@earthlink.net

Michael Collins,
Executive Director
Statewide Independent Living Council
1600 K Street, Suite 100
Sacramento, CA 95814
(916) 445-0142
(916) 445-5627 (TTY)
(916) 445-5973 (Fax)
mcollins@calsic.org

Mark Obatake
Executive Director
Hawaii Independent Living Center
414 Kuwili Steet, Suite 102
Honolulu, HI 96817
(808) 522-5400 (V/TTY)
(808) 522-5327 (Fax)
mobatake@DiverseAbilities.org

Tom Osborn, APRIL representative
Executive Director
NCILS, Inc.
1120 25 Avenue
Black Eagle, MT 59414
(406) 452-9834
(800) 823-6245 (V/TDD)
(406) 453-3940 (Fax)
osbncils@valcom.net

Ralph Shelman
Peninsula CIL
2021 B Cunningham Drive, Suite 2
Hampton, VA 23666
(757) 827-0275
(757) 827-0275 TTY
(757) 827-0655 FAX
Iepcil@aol.com

Laura Rauscher
Disability Services Director/ADA Coordinator
Office of Disability Services
Smith College
College Hall Room 3
Northampton, Massachusetts 01063
(413) 585-2071
(413) 585-2072 (TTY)
(413) 585-2206 (Fax)
lrausche@eunice.smith.edu

Nancy Ward
Self-Advocacy Coordinator
Oklahoma People First
16 E. 16th, Suite 405
Tulsa, OK 74119-447
(918) 582-8272
(918) 582-3628 (Fax)
nwardopf@hotmail.com

Lee Schulz, NCIL Representative
Executive Director
Independence FIRST
600 West Virginia Street, Suite 300
Milwaukee, WI 53204
(414) 291-7520 (V/TTY)
(414) 291-7525 (Fax)
lee@independencefirst.org

APPENDIX B

TABLES

APPENDIX B

Table B-1. Service received by CIL location

Service	CIL location (% of CILs in Consumer Survey)			
	Overall	Rural	Suburban	Urban
		(15%)	(3%)	(75%)
% consumers receiving service				
Benefits advisement	41	51	36	39
Getting technology or adaptive equipment	26	36	26	24
Information and referral	59	60	63	58
Peer support	37	32	44	37
ADA training	29	23	33	30
Home modification	26	24	29	26
Employment advisement	20	10	26	21
Independent living skills training	20	16	21	20
Housing referral or assistance	26	9	28	29
Personal assistance services or referral	29	25	23	31
Transportation	19	18	17	20
Transition from school to work	9	4	9	10

Table B-2. Consumer satisfaction with services received by income level

Service	Income level (% consumers)					
	Overall	<\$8,000 (39%)	\$8,001- \$10,000 (17%)	\$10,001- \$20,000 (25%)	\$20,001- \$40,000 (14%)	\$40,000+ (6%)
Transition from school to work	74	93	62	62	93	57
Peer support	62	77	65	48	55	47
Benefits advisement	63	73	57	58	32	73
Information and referral	64	69	61	65	65	56
ADA training	71	61	86	84	73	56
Personal assistance services or referral	74	71	77	82	70	73
Home modification	75	81	70	82	62	62
Transportation	87	91	82	83	93	34
Getting technology or adaptive equipment	73	61	80	78	88	61
Independent living skills training	69	77	57	57	95	100
Housing referral or assistance	65	70	61	47	69	79
Employment advisement	59	62	38	62	39	63

Table B-3. Service received by age group

Service	Age Group (% consumers)					
	Overall	<18 (5%)	18-24 (8%)	25-44 (36%)	45-64 (39%)	65+ (13%)
Information and referral	59	46	66	60	62	45
Employment advisement	20	7	51	26	15	1
Independent living skills training	20	8	48	24	16	6
Peer support	37	31	45	39	43	14
Personal assistance services or referral	29	17	39	31	29	26
Transition from school to work	9	23	37	8	4	2
Transportation	19	11	26	21	19	12
Benefits advisement	41	21	41	47	44	23
Housing referral or assistance	26	.	23	34	26	16
ADA training	29	15	24	33	36	7
Home modification	26	28	22	23	29	24
Getting technology or adaptive equipment	26	16	33	24	24	39

Table B-4. Type of change in life (% of consumers)

Service	I&R	Peer support	Benefits advisement	Personal assistance	ADA	Home modification	Housing	Employment	IL skills	Transportation	Transition from school to work	Assistive devices
Reported change												
Self-perception	19	42	14	12	28	2	3	13	8	8	9	2
IL skills	2	4	8	7	1	11	3	6	68	2	5	3
General independence	17	4	9	24	4	25	9	5	9	15	21	14
Get around	5	5	1	-	3	4	1	-	1	42	12	5
Community participation	5	4	2	5	6	1	4	3	1	14	-	2
Employment	2	1	3	3	-	-	3	31	-	-	5	-
Income/benefits	10	-	41	2	3	-	-	2	2	5	-	-
Communication	4	6	2	6	-	-	1	5	1	-	2	4
Housing	4	3	2	2	2	6	59	3	5	2	4	-
Socialization	3	12	3	1	-	1	1	-	-	5	-	-
Insurance information	1	-	-	-	-	-	-	-	-	-	-	-
Legal	3	1	3	-	33	-	-	8	-	-	-	0
Learn about other services	10	8	10	3	17	2	2	3	-	5	4	8
Education	1	2	-	-	-	-	-	3	-	-	8	1
Home modifications	1	1	-	-	-	34	-	-	-	-	-	-
Computer skills	2	-	-	-	-	-	-	1	-	-	-	8
Personal assistance	3	1	1	27	-	2	-	-	-	-	-	-
Assistive devices	3	1	1	-	-	5	-	-	-	-	-	47

Table B-5. Consumer perception of life quality

Is your life better now than it was before you went to the center? Would you say it is...

Variable	Response (%)				
	Much better	Somewhat better	Same	Somewhat worse	Much worse
Overall	47	29	19	3	2
Gender					
Male	43	32	18	4	3
Female	49	27	21	2	1
Type of Disability					
Physical	48	24	23	3	3
Mental	48	36	13	2	0
Communication	44	36	17	3	1
CIL Size					
Small	49	29	16	3	3
Medium	47	28	22	1	2
Large	43	29	23	4	1
CIL location					
Rural	50	24	20	5	2
Suburban	47	20	25	6	1
Urban	46	31	19	2	2
Age Group					
<18	60	18	10	7	4
18 – 24	52	27	13	8	0
25 – 44	49	28	20	2	1
45 – 64	45	28	21	4	2
65+	36	39	22	0	3
Race					
White	48	31	16	3	2
Non-White	44	23	29	3	1
Hispanic	47	10	35	4	4
Non-Hispanic	46	31	18	3	2
Income					
<8,000	49	24	20	4	3
8,000 – 10,000	45	32	19	4	0
10,001 – 20,000	41	38	19	1	1
20,001 – 40,000	44	34	15	2	4
40,001+	49	28	16	6	0

Table B-6. Summary table

Service	% Receiving service	% Very satisfied	% Gain knowledge or skill	% Change in life
Information and referral	59	64	83	71
Benefits advisement	41	63	80	68
Peer support	37	62	86	76
ADA training	29	71	87	61
Personal assistance	29	74	68	77
Technology/adaptive equipment	26	73	79	74
Home modification	26	75	73	71
Housing referral	26	65	77	69
Employment advisement	20	59	65	55
Independent living skills training	20	69	96	82
Transportation	19	87	72	74
Transition from school to work	9	74	94	71

Table B-7. Summary table

Service	% CILs offering service	% Consumers receiving service	% Consumers very satisfied	% Consumers reporting gain knowledge or skill	% Consumers reporting change in life
Information and referral	100	59	64	83	71
Benefits advisement	89	41	63	80	68
Peer support	92	37	62	86	76
ADA training	93	29	71	87	61
Personal assistance	91	29	74	68	77
Technology/adaptive equipment	93	26	73	79	74
Home modification	86	26	75	73	71
Housing referral	98	26	65	77	69
Employment advisement	80	20	59	65	55
Independent living skills training	99	20	69	96	82
Transportation	33	19	87	72	74
Transition from school to work	76	9	74	94	71

APPENDIX C
CONSUMER SURVEY

APPENDIX C

10OMB Approval Number: 1820-0640
Expiration Date: 03/31/2004

Evaluation of the Centers for Independent Living Program

Spring 2001

ID number: _____
Subject's name: _____
Subject's date of birth: ____/____/____
Center name: _____

Date: _____

Interviewer: _____

Final result code: _____

INTRODUCTION

Hello. May I speak with [Respondent]?

RESPONDENT IS AVAILABLE 1
RESPONDENT IS NOT AVAILABLE 2 } (GO TO I1)

INTRO Hello, my name is [INTERVIEWER NAME]. We are conducting a study for the U.S. Department of Education's Rehabilitation Services Administration [about] about Independent Living programs. We are trying to find out what centers do, how they help people with disabilities, and how happy center consumers are with the services they have received.

This survey will take about 30 minutes to complete. Your participation is voluntary and very important to the success of this study. Your answers to the questions will be kept confidential and will be used only for the purpose of this study.

[GO TO VERIFICATION -V1- PAGE 2]

I1. Is this the correct telephone number to contact [Respondent]?

YES 1
NO 2 } (GO TO I3)

I2. Can you provide me a better time to contact [Respondent]? **RECORD THE RESPONSE & NOTE ON CALL RECORD.**

Thank you I will call back later.

I3. Can you provide me with the correct telephone number for [Respondent]?

YES 1
NO 2 } Thank you for your time.
(CODE PROBLEM)

I4. What is the telephone number for [Respondent]? **RECORD RESPONSE**

(| | | |) | | | | - | | | | | |
(area code) (telephone number)

Thank you for the information.

VERIFICATION

S/P SUBJECT ON THE PHONE 1 } (GO TO V1)
 ASSISTANT ON THE PHONE 2 } (GO TO AST)
 PROXY ON THE PHONE 3 } (GO TO PRX)

AST [If Assistant: We would like the consumer to answer the questions as independently as possible. We want to be sure that, wherever possible, we are getting (CONSUMER'S NAME) actual opinions and responses.]

PRX [(If Proxy For the remainder of the survey when I refer to "you" I would like you to answer as though you were [CONSUMER'S NAME]. All of the following question[s] pertain to him/her Please provide your best estimate as to his/her own response or opinion.)]

V1. Your name is [SUBJECT], is that correct?

 YES – EXACT MATCH 1 } (GO TO V2)
 YES – MATCH WITH EXPLANATION..... 2
 NO..... 3 } (RETURN TO RESP. NOT AVAILABLE)

V1EXPLAIN _____

V2. We have your date of birth as [MM/DD/YYYY], is that correct?

 YES..... 1 } (GO TO V3)
 NO..... 2

V2UPDATE What is your correct date of birth?

 _____/_____/_____
 MM DD YYYY

V3. Are you currently or have you ever accepted any services from a Center for Independent Living?

[IF NEEDED: We show you may have received services from [CENTER NAME].]

 YES..... 1
 NO..... 2 } Thank you, we will check with the center and may be calling you again in the next few days.
 (CODE PROBLEM)

V4. Did the center contact you and ask you if you wanted to participate in this survey?

YES..... 1
NO..... 2

V5. [IF NECESSARY ASK: Are you ...]

Male 1
Female..... 2

The first set of questions asks about the timeframe during which you received services.

1a. When did you first contact the center for services?

____/____/_____
MM DD YYYY

b. Are you still receiving services from the center?

YES..... 1 } GO TO Q.2
NO..... 2
REFUSED..... -7 ↑ (GO TO 2)
DON'T KNOW -8 →

c. How long has it been since you received services from the center? Would you say...

Less than three months,..... 1
Three to six months, 2
Seven months to one year, or 3
More than one year? 4
REFUSED..... -7
DON'T KNOW -8

d. Why are you no longer receiving services from the center? Would you say it's because...

You already met your goal,..... 1
There was nothing more the center could
do for you, 2
You were dissatisfied with services, or 3
Some other reason? 91
(SPECIFY) _____
REFUSED..... -7
DON'T KNOW -8

e. Are you still involved with the center as a volunteer or on some advocacy issue?

YES..... 1
NO..... 2 ↑
REFUSED..... -7 ° GO TO Q.1g
DON'T KNOW -8 →

f. Is that involvement as a volunteer, activist, or in some other way?

VOLUNTEER..... 1
ACTIVIST..... 2
IN SOME OTHER WAY 3
(SPECIFY) _____
REFUSED..... -7
DON'T KNOW -8

g. Would you go back to the center if you needed additional services or if you decided to work on an advocacy issue?

- YES..... 1
- NO..... 2
- REFUSED..... -7
- DON'T KNOW -8

2. Have you ever received services from an IL [Independent Living] center other than the one that asked you to participate in this survey?

- YES..... 1
- NO..... 2
- REFUSED..... -7
- DON'T KNOW -8

This next set of questions asks about getting to and using center services and programs.

3a. Have you ever visited the center for independent living?

- YES..... 1
- NO..... 2 } GO TO Q.4h
- REFUSED..... -7 ↑ (GO TO 4h)
- DON'T KNOW -8 →

b. Did you visit the main center office or a satellite or branch office?

- MAIN 1
- SATELLITE 2
- REFUSED..... -7
- DON'T KNOW -8

c. How [do/did] you usually get to the center?

- I DRIVE..... 1
- I GET A RIDE FROM SOMEONE 2
- I TAKE REGULAR ROUTE TRANSIT 3
- I TAKE A DOOR-TO-DOOR
TRANSPORTATION SERVICE 4
- I WALK 5
- I TAKE TRANSPORTATION PROVIDED
BY THE CENTER..... 6
- OTHER? 91
- (SPECIFY) _____
- REFUSED..... -7
- DON'T KNOW -8

4. How would you rate the following statements about the center you [use/used]? Please tell me whether you strongly disagree, somewhat disagree, neither disagree nor agree, somewhat agree, or strongly agree with each statement.

	STRONGLY DISAGREE	SOMEWHAT DISAGREE	NEITHER DISAGREE NOR AGREE	SOMEWHAT AGREE	STRONGLY AGREE	RF	DK	NA
a. I was easily able to enter or leave the building and could easily use any telephone security system that might exist.	1	2	3	4	5	-7	-8	-9
b. I could physically move around individual offices easily once inside the center.	1	2	3	4	5	-7	-8	-9
c. Accessible parking was located close to the entrance I used.	1	2	3	4	5	-7	-8	-9
d. The center was accessible using regular route or door-to-door transportation.	1	2	3	4	5	-7	-8	-9
e. Center services and programs were scheduled at convenient times, so I did not have to miss work or school .	1	2	3	4	5	-7	-8	-9
f. I was usually able to see the center staff person within 15 minutes of my scheduled appointment.	1	2	3	4	5	-7	-8	-9
g. The center offered me the opportunity to register to vote.	1	2	3	4	5	-7	-8	-9
h. I could contact the center easily by telephone on my first attempt.	1	2	3	4	5	-7	-8	-9
i. The telephone voice mail system (if any) was easy to use.	1	2	3	4	5	-7	-8	-9
j. If I needed to leave a message for someone, I was called back by the next day the center was open.	1	2	3	4	5	-7	-8	-9
k. I did not have to visit the center, because they helped with the problem over the phone.	1	2	3	4	5	-7	-8	-9
l. I was able to get center services as soon as I needed them.	1	2	3	4	5	-7	-8	-9
m. I could read and understand all written material the Center gave to me.	1	2	3	4	5	-7	-8	-9
n. I got an appointment with someone at the center within the period of time I wanted.	1	2	3	4	5	-7	-8	-9
o. The amount of paperwork I had to complete to get services from the center was appropriate.	1	2	3	4	5	-7	-8	-9

Now, I will ask you some questions about written and oral communications with the center:

5a. Do you need printed materials in alternative format such as Braille, large print or cassette tape?

- YES..... 1
- NO..... 2 ↑
- REFUSED..... -7 ° GO TO Q.6a
- DON'T KNOW -8 →

b. [Do/Did] you receive written materials in the format you need from the center?

- YES..... 1
- NO..... 2
- REFUSED..... -7
- DON'T KNOW -8

6a. Do you need a sign language interpreter or CART reporter to communicate?

- ALWAYS..... 1
- SOMETIMES..... 2
- NEVER 3 ↑
- REFUSED..... -7 ° GO TO BOX 1
- DON'T KNOW -8 →

b. Was there a sign language interpreter or CART reporter available at your center appointments or other center activities you attended? Would you say . . .

- Always 1
- Sometimes, or 2
- Never? 3
- REFUSED..... -7
- DON'T KNOW -8

BOX 1

INTERVIEWER NOTE: IF Q3a = 2, -7, -8, CHECK THIS BOX • AND GO TO Q.9.

7a. How often did you have face-to-face contact with someone from the Center during the last year? Would you say...

- Once per week or more, 1
- Two to three times per month, 2
- Once per month, 3
- Once every three months, 4
- Once or twice per year, or 5
- Not at all? 6 ↑
- REFUSED..... -7 ° GO TO Q.9
- DON'T KNOW -8 →

b. Did you need an appointment to receive center services or were you able to just “walk in?”

NEEDED AN APPOINTMENT 1
WALK-IN..... 2
DEPENDED UPON SERVICE 3
REFUSED..... -7
DON'T KNOW -8

8a. Did you request a phone call to remind you about your appointments with the center?

YES..... 1
NO..... 2 ↑
REFUSED..... -7 ° GO TO Q.9
DON'T KNOW -8 →

b. Did the center call you?

YES..... 1
NO..... 2
REFUSED..... -7
DON'T KNOW -8

9. Did the center tell you how to file a complaint with the Client Assistance Program if you were unhappy with any of the center’s services?

YES..... 1
NO..... 2
REFUSED..... -7
DON'T KNOW -8

Now, please think back to when you first contacted the center.

10. In which of the following areas of life did you have a problem you wanted to solve or a goal you wanted to achieve?

	YES	NO	RF	DK	NA
a. Community integration - amount of time you spend participating in your community.....	1	2	-7	-8	-9
b. Self-esteem	1	2	-7	-8	-9
c. Employment	1	2	-7	-8	-9
d. Education level	1	2	-7	-8	-9
e. Knowledge of disability rights laws	1	2	-7	-8	-9
f. Housing.....	1	2	-7	-8	-9
g. Personal assistance services	1	2	-7	-8	-9
h. Ability to get around in your community	1	2	-7	-8	-9
i. Knowledge of disability services	1	2	-7	-8	-9
j. Entertainment or recreational activities	1	2	-7	-8	-9
k. Income.....	1	2	-7	-8	-9
l. Increased level or number of benefits	1	2	-7	-8	-9
m. Some other area? (SPECIFY) _____	1	2	-7	-8	-9

11. Did the center give you information about different options that would help you reach your IL goal?

YES.....	1
NO.....	2
REFUSED.....	-7
DON'T KNOW	-8

12. Who decided on the services that you would get in order to reach your goal?

I DID	1
THE IL STAFF PERSON.....	2
I DECIDED ALONG WITH AN IL STAFF PERSON.....	3
A FRIEND OR FAMILY MEMBER.....	4
OTHER?	91
(SPECIFY) _____	
REFUSED.....	-7
DON'T KNOW	-8

13a. Did you achieve your goal or solve the problem? Would you say . . .

Yes,.....	1	↑	GO TO Q.14INTRO
Partially, or	2	→	
No	3	}	GO TO Q.13b
REFUSED.....	-7	↑	GO TO Q.14INTRO
DON'T KNOW	-8	→	

b. Why have you not achieved your goal or solved the problem?

STILL WORKING ON IT.....	1
CHANGED MY MIND.....	2
OTHER?	91
(SPECIFY) _____	
REFUSED.....	-7
DON'T KNOW	-8

14INTRO. I'm going to read you a list of services that centers provide. Please tell me whether or not you received each service.

INTERVIEWER: FOR EACH SERVICE RECEIVED, ASK THE FOLLOW-UP QUESTIONS BEFORE PROCEEDING TO NEXT SERVICE.

Please tell me whether you were very dissatisfied, somewhat dissatisfied, neither dissatisfied nor satisfied, somewhat satisfied, or very satisfied with the service you received.

Do you think that you gained knowledge or a skill as a result of this service?

Did you make any changes in your life as a result of this service?.

IF CHANGES WERE MADE, ASK: What change did you make?

SERVICE	COL. A RECEIVED?		IF YES IN COL. A: NEITHER DISSATISFIED NOR SATISFIED					COL. C GAINED KNOWLEDGE OR SKILL?		COL. D CHANGED IN LIFE?		IF YES IN COL. D.:
	YES	NO	VERY DISSATISFIED	SOMEWHAT DISSATISFIED	SOMEWHAT SATISFIED	VERY SATISFIED	YES	NO	YES	NO	WHAT CHANGE?	
14. Information and referral, where a staff person gives you the name and phone number of another agency, or tells you where you can get a particular service	1	2	1	2	3	4	5	1	2	1	2	
15. Peer support, where you meet with one person or a group of people who have disabilities to talk about and solve problems .	1	2	1	2	3	4	5	1	2	1	2	
16. Benefits advisement, where someone tells you about SSI, SSDI, Medicaid, food stamps, or other benefits	1	2	1	2	3	4	5	1	2	1	2	
17. Independent living skills training, where you learn how to manage a budget, shop for food, or do other things necessary to live independently	1	2	1	2	3	4	5	1	2	1	2	

Continued:

SERVICE	COL. A RECEIVED?		IF YES IN COL. A: NEITHER DISSATISFIED NOR SATISFIED					COL. C GAINED KNOWLEDGE OR SKILL?		COL. D CHANGED IN LIFE?		IF YES IN COL. D.:
	YES	NO	VERY DISSATISFIED	SOMEWHAT DISSATISFIED	SOMEWHAT SATISFIED	VERY SATISFIED	YES	NO	YES	NO	WHAT CHANGE?	
18. Housing referral or assistance, where someone helps you look for a place to live	1	2	1	2	3	4	5	1	2	1	2	
19. Personal assistance services or referral, where someone helps you learn how to use a personal assistant or refers you to someone who can be a personal assistant	1	2	1	2	3	4	5	1	2	1	2	
20. Help with modifications at home, where someone helps to make your home more accessible to you	1	2	1	2	3	4	5	1	2	1	2	
21. Employment advisement, training, or referral, where someone helps you look for a job or with problems you are having on the job	1	2	1	2	3	4	5	1	2	1	2	
22. Transition from school to work or independent living, where someone helps you plan for work or living independently when you leave school	1	2	1	2	3	4	5	1	2	1	2	
23. Getting technology or adaptive equipment, like wheelchairs, adapted computers, or hearing aids.....	1	2	1	2	3	4	5	1	2	1	2	

Continued:

SERVICE	COL. A RECEIVED?		IF YES IN COL. A: NEITHER DISSATISFIED NOR SATISFIED					COL. C GAINED KNOWLEDGE OR SKILL?		COL. D CHANGED IN LIFE?		IF YES IN COL. D: WHAT CHANGE?
	YES	NO	VERY DISSATISFIED	SOMEWHAT DISSATISFIED		SOMEWHAT SATISFIED	VERY SATISFIED	YES	NO	YES	NO	
24. Transportation, where the center picks you up and takes you to an appointment or an activity that is not sponsored by the center, arranges transportation for you, or helps you pay for transportation	1	2	1	2	3	4	5	1	2	1	2	
25. ADA training, where the center teaches you about your rights under the Americans with Disabilities Act.....	1	2	1	2	3	4	5	1	2	1	2	
26. Any other services? (SPECIFY) _____	1	2	1	2	3	4	5	1	2	1	2	

27a. Have you ever had difficulty receiving services from or gaining access to an agency other than the center because of your disability?

- YES..... 1
- NO..... 2 ↑
- REFUSED..... -7 ° GO TO Q.28
- DON'T KNOW -8 →

b. Did the problem get solved? Would you say . . .

- The problem was solved,..... 1
- The problem was partially solved, or 2 ↑
- The problem was not solved? 3 ° GO TO Q.28
- REFUSED..... -7 .
- DON'T KNOW -8 →

c. Did the center help you solve the problem?

- YES..... 1
- NO..... 2 ↑
- REFUSED..... -7 ° GO TO Q.28
- DON'T KNOW -8 →

d. Which statement most closely matches what happened? Would you say . . .

- The center staff solved it for me, 1
- Center staff told me how to solve it myself, ... 2
- The staff worked with me to solve the problem, or 3
- Staff put me in touch with other people with disabilities and we solved it together? 4
- REFUSED..... -7
- DON'T KNOW -8

e. The next time this or a similar situation comes up, how would you handle it? Will you . . .

- Contact the center and let them solve the problem,..... 1
- Solve the problem yourself, 2
- Work with center staff to solve the problem, or 3
- Get in touch with other people with disabilities to solve the problem together? 4
- REFUSED..... -7
- DON'T KNOW -8

The next questions focus on your experiences working with center staff. First, we want to know how the center staff treated you as an individual.

28. How well did the IL staff person you worked with the most understand your disability? Would you say...

- Very well, 1
- Somewhat, 2
- Poorly, or 3
- Not at all? 4
- REFUSED..... -7
- DON'T KNOW -8

29. How sensitive to your cultural or ethnic customs was the IL staff you worked with the most? Would you say . . .

- Very sensitive, 1
- Somewhat sensitive, 2
- Somewhat insensitive, 3
- Very insensitive, or 4
- My culture was not relevant? 5
- REFUSED..... -7
- DON'T KNOW -8

30. Did the IL staff you saw most often communicate with you in your preferred language?

- YES..... 1
- NO..... 2
- REFUSED..... -7
- DON'T KNOW -8

31. Did the IL staff person you saw most often listen to your individual ideas and suggestions? Would you say . . .

- Always, 1
- Sometimes, 2
- Rarely, or 3
- Never? 4
- REFUSED..... -7
- DON'T KNOW -8

32a. Would you have liked the IL staff to have done something differently?

YES..... 1
NO..... 2 } GO TO Q.33
REFUSED..... -7
DON'T KNOW -8

b. What would it be?

33. Did the center tell you about the Independent Living movement, or about it's philosophy on IL?

YES..... 1
NO..... 2
REFUSED..... -7
DON'T KNOW -8

34. Did the center staff tell you about groups of people with disabilities with whom you could share problems, sometimes known as peer support groups?

YES..... 1
NO..... 2
REFUSED..... -7
DON'T KNOW -8

35. Did the center staff encourage you to advocate for yourself?

YES..... 1
NO..... 2
REFUSED..... -7
DON'T KNOW -8

36. Did the center provide you with training or information about federal, state, or local advocacy issues, while you were involved in the center?

YES..... 1
NO..... 2
REFUSED..... -7
DON'T KNOW -8

37. Did you get involved in advocacy issues to change systems or programs for people with disabilities?
- YES..... 1
 NO..... 2
 REFUSED..... -7
 DON'T KNOW -8
38. Overall, did the center staff help you to develop a positive view of yourself? Would you say . . .
- Yes,..... 1
 No, or..... 2
 I already had a positive view of myself?..... 3
 REFUSED..... -7
 DON'T KNOW -8
39. Overall, how satisfied were you with the IL staff efforts to help you work toward your goal? Would you say . . .
- Very satisfied, 1
 Somewhat satisfied, 2
 Neither satisfied nor dissatisfied, 3
 Somewhat dissatisfied, or 4
 Very dissatisfied? 5
 REFUSED..... -7
 DON'T KNOW -8
40. If you thought the center should be doing something differently, would you do any of the following? How about.... . .
- | | YES | NO | RF | DK |
|---|-----|----|----|----|
| Talk to a center staff person? | 1 | 2 | -7 | -8 |
| Talk to the executive director? | 1 | 2 | -7 | -8 |
| Talk to a board member? | 1 | 2 | -7 | -8 |
| Talk to a friend?..... | 1 | 2 | -7 | -8 |
| Talk to an advocacy organization? | 1 | 2 | -7 | -8 |
| Something else? | 1 | 2 | -7 | -8 |
| (SPECIFY) _____ | | | | |
41. Overall, how satisfied were you with your experience at the center? Would you say . . .
- Very satisfied, 1
 Somewhat satisfied, 2
 Neither satisfied nor dissatisfied, 3
 Somewhat dissatisfied, or 4
 Very dissatisfied? 5
 REFUSED..... -7
 DON'T KNOW -8

42. Overall, how helpful would you say the center has been in achieving your independent living goals? Would you say . . .

- Very helpful, 1
- Somewhat helpful, 2
- Neither helpful nor unhelpful, 3
- Somewhat unhelpful, or 4
- Not at all helpful? 5
- REFUSED..... -7
- DON'T KNOW -8

43. Is your life better now than it was before you went to the center? Would you say it is . . .

- Much better, 1
- Somewhat better, 2
- The same, 3
- Somewhat worse, or 4
- Much worse? 5
- REFUSED..... -7
- DON'T KNOW -8

44. Now, I will read you a list of areas of life. Please tell me whether each life area has not improved at all, has improved somewhat, or has improved a great deal as a result of your contact with the center.

	RATE			RF	DK	NA
	NOT IMPROVED AT ALL	IMPROVED SOMEWHAT	HAS IMPROVED A GREAT DEAL			
a. Community integration - amount of time you spend participating in your community.....	1	2	3	-7	-8	-9
b. Self-esteem.....	1	2	3	-7	-8	-9
c. Employment.....	1	2	3	-7	-8	-9
d. Education level.....	1	2	3	-7	-8	-9
e. Knowledge of disability rights laws.....	1	2	3	-7	-8	-9
f. Housing.....	1	2	3	-7	-8	-9
g. Personal assistance services.....	1	2	3	-7	-8	-9
h. Ability to get around in your community.....	1	2	3	-7	-8	-9
i. Knowledge of disability services.....	1	2	3	-7	-8	-9
j. Entertainment or recreational activities.....	1	2	3	-7	-8	-9
k. Income.....	1	2	3	-7	-8	-9
l. Increased level or number of benefits.....	1	2	3	-7	-8	-9
m. Some other area? (SPECIFY)_____	1	2	3	-7	-8	-9

45a. Would you refer a friend to the IL center if they needed similar services or had a similar problem?

YES..... 1
NO..... 2 ↑
REFUSED..... -7 ° GO TO Q.46
DON'T KNOW -8 →

b. Have you ever done so?

YES..... 1
NO..... 2
REFUSED..... -7
DON'T KNOW -8

46. Do you do any volunteer work for the center, for example, serving on the board, an advisory committee, working in the center's advocacy organization or answering the telephone?

YES..... 1
NO..... 2
REFUSED..... -7
DON'T KNOW -8

47 INTRO. Now, I am going to ask you some questions about other services that you may have received, services you may need, and how you feel about certain aspects of your life. These questions are not related to centers for independent living. I am asking these questions so that we know what other services center consumers need, and so that we can compare people who get center services with those who do not receive services from a center. All of your answers will be kept strictly confidential and we will not attach your name to any answers you give. [If you feel uncomfortable answering these questions, we can skip the ones you don't want to answer or we can stop at any time.]

47a. (NHIS-D) Vocational rehabilitation provides equipment and services to people to improve their ability to work. Have you ever received any equipment or services through a vocational rehabilitation agency?

YES..... 1
NO..... 2 ↑
REFUSED..... -7 ° GO TO Q.48a
DON'T KNOW -8 →

b. How satisfied were you with the services you received? Would you say . . .

Very satisfied, 1
Somewhat satisfied, 2
Neither satisfied nor dissatisfied, 3
Somewhat dissatisfied, or 4
Very dissatisfied? 5
REFUSED..... -7
DON'T KNOW -8

48. (NHIS-D) Do you have any difficulty doing the following? How about....

	YES	NO	RF	DK
a. Entering or leaving your home?	1	2	-7	-8
b. Opening or closing any of the doors in your home?	1	2	-7	-8
c. Reaching or opening cabinets in your home?	1	2	-7	-8
d. Using the bathroom in your home?	1	2	-7	-8

49. (NHIS-D) Some residences have special features to assist persons who have disabilities. Whether you use them or not, please tell us if your residence has any of these features and whether you need any of them. How about...

FEATURE	HAS FEATURE?				NEED FEATURE?			
	YES	NO	REF	DK	YES	NO	REF	DK
a. Widened doorways or hallways?	1	2	-7	-8	1	2	-7	-8
b. Ramps or street level entrances?	1	2	-7	-8	1	2	-7	-8
c. Railings?	1	2	-7	-8	1	2	-7	-8
d. Automatic or easy-to-open doors?	1	2	-7	-8	1	2	-7	-8
e. Accessible parking or drop-off site?	1	2	-7	-8	1	2	-7	-8
f. Bathroom modifications?	1	2	-7	-8	1	2	-7	-8
g. Kitchen modifications?	1	2	-7	-8	1	2	-7	-8
h. Elevator, chair lift, or stair glide?	1	2	-7	-8	1	2	-7	-8
i. Alerting devices?	1	2	-7	-8	1	2	-7	-8
j. Any other special features? (SPECIFY)_____	1	2	-7	-8	1	2	-7	-8

50a. (NHIS-D) Some communities have special bus, cab or van services for people who have difficulty using the regular public transportation service. When using this special service, people can call ahead and ask to be picked up. Is such a service available in your area?

YES.....	1
NO.....	2
REFUSED.....	-7
DON'T KNOW	-8

b. Have you used this special service in the past 12 months?

YES.....	1	} GO TO Q.51a
NO.....	2	
REFUSED.....	-7	
DON'T KNOW	-8	

c. Why haven't you used this service in the past 12 months?

	YES	NO	RF	DK
1. You don't know how to use the service?	1	2	-7	-8
2. You need help from another person?	1	2	-7	-8
3. You can't use the service alone?	1	2	-7	-8
4. You can't use a telephone?	1	2	-7	-8
5. You don't have a telephone?	1	2	-7	-8
6. You can't read?	1	2	-7	-8
7. Because of illness?	1	2	-7	-8
8. You can't get reservation for service?	1	2	-7	-8
9. Hours of service are inadequate?	1	2	-7	-8
10. Pickup is unreliable or inconvenient?	1	2	-7	-8
11. Because of the cost?	1	2	-7	-8
12. You were denied use of the service?	1	2	-7	-8
13. The service is not needed or wanted?	1	2	-7	-8
14. Some other reason?	1	2	-7	-8
(SPECIFY) _____				

51a. (NHIS-D) During the past 12 months, have you used local public transportation, such as a regular bus line, rapid transit, subway, or street car?

YES	1	
NO	2	↑
NO PUBLIC SYSTEM AVAILABLE	3	° GO TO Q.52
REFUSED	-7	.
DON'T KNOW	-8	→

b. Does an impairment or health problem limit your use of the public transportation service?

YES	1
NO	2
REFUSED	-7
DON'T KNOW	-8

c. During the past 12 months, how often did you use the local public transportation service? Would you say . . .

Everyday or almost everyday,	1
Occasionally, or	2
Seldom?	3
REFUSED	-7
DON'T KNOW	-8

56. How confident are you in your ability to deal with daily living? Would you say you feel . . .

- Very confident, 1
- Somewhat confident, or..... 2
- Not confident? 3
- REFUSED..... -7
- DON'T KNOW -8

57. How much do you worry about not knowing who to turn to for help? Would you say you worry . . .

- A lot,..... 1
- Some, or 2
- Not at all? 3
- REFUSED..... -7
- DON'T KNOW -8

Now, in our final section, we just need to know a little bit more about you.

58a. Please tell me which of the following disabilities you have.

	YES	NO	RF	DK
1. Visual impairment?	1	2	-7	-8
2. Hearing impairment?.....	1	2	-7	-8
3. Orthopedic, including amputations?	1	2	-7	-8
4. Non-orthopedic, physical?	1	2	-7	-8
5. Mental illness/Psychiatric disability?.....	1	2	-7	-8
6. Mental retardation?	1	2	-7	-8
7. Substance abuse?.....	1	2	-7	-8
8. Learning disability?	1	2	-7	-8
9. Traumatic brain injury?.....	1	2	-7	-8
10. Environmental illness?	1	2	-7	-8
11. Something else?	1	2	-7	-8
(SPECIFY) _____				

b. Please tell me which category most closely describes your primary disability. Would you say your primary disability is related to:

- a physical impairment 1
- a visual impairment 2
- a hearing impairment 3
- a cognitive impairment 4
- a mental health or substance abuse problem 5
- a speech impairment, or 6
- something else? 7
- (SPECIFY) _____
- REFUSED..... -7
- DON'T KNOW -8

59. Now, I'd like to ask you some questions about your disability and the type of assistance you need. Please tell me whether you can do each of the following activities by yourself, if you can do them with assistance from technology or another person, or whether you can not do them at all.

ITEM	WITHOUT ASSISTANCE	WITH ASSISTANCE FROM TECHNOLOGY/ EQUIPMENT OR FROM ANOTHER PERSON	CAN NOT DO ACTIVITY	RF	DK
Walking for a quarter of a mile - about three city blocks?	1	2	4	-7	-8
Walking up a flight of stairs without resting?	1	2	4	-7	-8
Doing heavy housework (such as scrubbing floors, or washing windows)?	1	2	4	-7	-8
Getting around outside the house?	1	2	4	-7	-8
Reading and understanding the newspaper?	1	2	4	-7	-8
Writing?	1	2	4	-7	-8
Using the telephone?	1	2	4	-7	-8
Managing your money (such as keeping track of expenses or paying bills)?	1	2	4	-7	-8
Shopping for personal items (such as toilet items or medicines)?	1	2	4	-7	-8
Driving?	1	2	4	-7	-8
Using public transportation?	1	2	4	-7	-8
Using the toilet, including getting to the toilet?	1	2	4	-7	-8
Dressing?	1	2	4	-7	-8
Bathing or showering?	1	2	4	-7	-8
Getting into and out of bed?	1	2	4	-7	-8
Eating?	1	2	4	-7	-8

60. Would you say your health in general is excellent, very good, good, fair, or poor?

- EXCELLENT 1
- VERY GOOD 2
- GOOD 3
- FAIR 4
- POOR 5
- REFUSED..... -7
- DON'T KNOW -8

61. In the past 12 months, how often did you feel sad or depressed? Would you say you were sad or depressed . . .

- All of the time, 1
- Some of the time, 2
- A little of the time, or 3
- None of the time? 4
- REFUSED..... -7
- DON'T KNOW -8

62. Compared to your own level of physical activity 1 year ago, would you say you are now more active, less active, or about the same as you were then?

- MORE ACTIVE 1
- LESS ACTIVE 2
- ABOUT THE SAME 3
- REFUSED..... -7
- DON'T KNOW -8

63. What is the highest level of education you've completed?

- LESS THAN HIGH SCHOOL COMPLETED. 1
- HIGH SCHOOL GRADUATE OR GED..... 2
- SOME COLLEGE (NO DEGREE)..... 3
- ASSOCIATE DEGREE (AA)..... 4
- COLLEGE GRADUATE (BA, BS)..... 5
- GRADUATE STUDY 6
- GRADUATE DEGREE (MA, MS, MBA, PHD) 7
- VOCATIONAL OR TRADE SCHOOL..... 8
- OTHER..... 9
- (SPECIFY)_____
- REFUSED..... -7
- DON'T KNOW -8

64. Are you of Spanish, Hispanic, or Latino origin?

- YES 1
- NO..... 2
- REFUSED..... -7
- DON'T KNOW -8

65. Would you classify your race as . . .

- White, 1
- Black or African American, 2
- Asian, 3
- Native Hawaiian or Pacific Islander, or 4
- Native American or Alaskan Native? 5
- OTHER? 91
- (SPECIFY) _____
- REFUSED..... -7
- DON'T KNOW -8

66a. Are you currently employed?

- YES 1
- NO..... 2 ↑
- REFUSED..... -7 ° GO TO Q.67
- DON'T KNOW -8 →

b. Are you currently employed full time, that is 35 hours a week or more, or part time?

- FULL TIME 1
- PART TIME 2
- REFUSED..... -7
- DON'T KNOW -8

67. What is your current marital status?

- MARRIED..... 1
- NEVER MARRIED..... 2
- WIDOWED..... 3
- SEPARATED OR DIVORCED..... 4
- REFUSED..... -7
- DON'T KNOW -8

68. How many people, including yourself, live in your household?

- NUMBER | | |
- REFUSED..... -7
- DON'T KNOW -8

69. Information about income is a common way of measuring available financial resources. Considering income from all sources, including salary, wages, Social Security, welfare, and any other income, what was your total household income before taxes for 2000? Would you say . . .

Less than \$8,000	1
\$8,001 - \$10,000	2
\$10,001 - \$20,000	3
\$20,001 - \$40,000	4
\$40,001 - \$60,000	5
\$60,001 - \$80,000	6
Over \$80,000	7
REFUSED	-7
DON'T KNOW	-8

That's all the questions I have for you. Thank you very much for taking the time to speak with me. Your opinions are very important in helping us improve or expand independent living services and independent living centers.

CONTINUE TO NEXT PAGE.

"Please give me the name you would like on your \$10 check, and the address you would like us to send the check to."

_____	_____	_____
Title (Mr, Mrs, Ms, etc)	First Name	Last Name
_____	_____	_____
Street Number	Street Name	Apt. Number
_____	_____	_____
City	State	Zip Code
_____	_____	_____
Area Code	Telephone Number	

IF INTERPRETER/TRANSLATOR USED:

"Please give me the name you would like on your \$50 check, and the address you would like us to send the check to."

_____	_____	_____
Title (Mr, Mrs, Ms, etc)	First Name	Last Name
_____	_____	_____
Street Number	Street Name	Apt. Number
_____	_____	_____
City	State	Zip Code
_____	_____	_____
Area Code	Telephone Number	

APPENDIX D

EXECUTIVE DIRECTOR SURVEY

APPENDIX D

<p style="text-align: center;">EVALUATION OF THE CENTERS FOR INDEPENDENT LIVING PROGRAM SURVEY FOR IL DIRECTORS</p>
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(For an electronic copy of this survey, please contact Marcie Goldstein at marcieg@cessi.net)

Introduction

The Rehabilitation Services Administration (RSA), Department of Education is conducting a national evaluation of Centers for Independent Living. The purpose of this evaluation is to gain an overall picture of IL program activities, consumer and community outcomes, and consumer satisfaction. We are assessing the independent living program as a whole rather than comparing any particular center to another. We are speaking with center consumers and surveying executive directors for this study.

Your answers will be treated with the strictest confidence. No one outside the organization conducting the study will see your answers.

We estimate that this survey should take 45-60 minutes to complete. The survey consists of eight short sections:

- Independent Living Philosophy
- Services and Community Change/Impact
- Diversity
- Board of Directors
- Staff Training
- Relationships with Other Agencies/Organizations
- Evaluation and Monitoring
- Resources and Funding

Some questions will ask you to check the appropriate box, while others require a short answer. Please keep your answers short and please **print legibly**. If you would prefer to complete this survey by telephone or by e-mail, please call Marcie Goldstein at (703) 448-6155 or e-mail her at marcieg@cessi.net.

[ID _____]

I. INDEPENDENT LIVING PHILOSOPHY

1. What does your center believe are the basic components of the independent living movement's philosophy?

II. SERVICES AND COMMUNITY CHANGE/IMPACT

2. Below is a list of methods used to assess community needs for center services and advocacy. How useful have these methods been in assessing community needs at your center? (Please circle one number for each method.)

Method	RATE				
	1 = Not at all Useful	2	3	4	5 = Very Useful
a. Analysis of census or other existing data	1	2	3	4	5
b. Consumer needs survey.....	1	2	3	4	5
c. Board/staff planning process	1	2	3	4	5
d. Community forum	1	2	3	4	5
e. Expectations/availability of funding sources.....	1	2	3	4	5
f. Contacts with community agencies	1	2	3	4	5
g. Contacts with disability/consumer groups	1	2	3	4	5
h. Other (please specify) _____	1	2	3	4	5

3. Please indicate whether or not your center provides each of the following services.

Service	<u>YES</u>	<u>NO</u>
a. Peer counseling	1	2
b. Information & referral	1	2
c. Group support	1	2
d. Benefits advisement	1	2
e. Legal advisement.....	1	2
f. IL skills training.....	1	2
g. Housing referral or assistance.....	1	2
h. Personal assistance services or referral.....	1	2
i. Assistance with modifications at home	1	2
j. Employment training or referral.....	1	2
k. Transition from school to work or independent living	1	2
l. Education/Literacy/GED	1	2
m. Assistance acquiring technology or adaptive equipment....	1	2
n. Technical assistance on access.....	1	2
o. Individual advocacy.....	1	2
p. ADA training	1	2
q. Advocacy training	1	2
r. Interpreter services	1	2
s. Transportation (other than to and from the center)	1	2
t. Services for specific disability groups	1	2
(please specify group) _____		
u. Systems advocacy.....	1	2
v. Other (please specify) _____	1	2
w. Other (please specify) _____	1	2
x. Other (please specify) _____	1	2

4. Please complete the following table about disability issues. For each issue, please indicate:

- Whether or not your center worked on it in Fiscal Year 2000;

- IF YOUR CENTER WORKED ON AN ISSUE:

- whether it was at the federal, state, or local level, how much time your center spent on it; activities to achieve change, and groups who were involved in that change.

Issue	Col. A Worked on in last year? (Circle one)	Col. B. If Col. A is YES, Level? (Circle yes or no for each)		Col. C Amount of time spent? Rate 1 = Little to 5 = A lot (Circle one)					If YES in Col. A: Col. D Activity to achieve change (✓ all that apply)	Col. E Groups involved in advocacy (✓ all that apply)
		Yes	No	1	2	3	4	5		
Deinstitutionalization	Yes..... 1 No 2	Federal 1 2 State..... 1 2 Local 1 2		1	2	3	4	5	Worked with agency or organizational representatives ... <input type="checkbox"/> Worked with decision makers, such as agency administrators or elected officials..... <input type="checkbox"/> Worked with the media..... <input type="checkbox"/> Took legal action <input type="checkbox"/> Participated in committees or working groups <input type="checkbox"/> Conducted demonstrations <input type="checkbox"/> Conducted in-service training, accessibility surveys, or provided technical assistance..... <input type="checkbox"/> Trained grassroots organizations or organizers <input type="checkbox"/> Other (please describe) <input type="checkbox"/>	Consumers <input type="checkbox"/> Board <input type="checkbox"/> Staff..... <input type="checkbox"/> Other disability organizations or agencies <input type="checkbox"/> Non-disability organizations or agencies <input type="checkbox"/> Other (please specify)..... <input type="checkbox"/>

4. (continued)

Issue	Col. A Worked on in last year? (Circle one)	Col. B. If Col. A is YES, Level? (Circle yes or no for each)		Col. C Amount of time spent? Rate 1 = Little to 5 = A lot (Circle one)					If YES in Col. A:	Col. E
		Yes	No	1	2	3	4	5	Col. D Activity to achieve change (✓ all that apply)	Groups involved in advocacy (✓ all that apply)
Integrated community housing	Yes..... 1 No 2	Federal 1 State..... 1 Local 1	2 2 2	1	2	3	4	5	Worked with agency or organizational representatives ... <input type="checkbox"/> Worked with decision makers, such as agency administrators or elected officials..... <input type="checkbox"/> Worked with the media <input type="checkbox"/> Took legal action <input type="checkbox"/> Participated in committees or working groups <input type="checkbox"/> Conducted demonstrations..... <input type="checkbox"/> Conducted in-service training, accessibility surveys, or provided technical assistance..... <input type="checkbox"/> Trained grassroots organizations or organizers <input type="checkbox"/> Other (please describe)	Consumers <input type="checkbox"/> Board <input type="checkbox"/> Staff..... <input type="checkbox"/> Other disability organizations or agencies <input type="checkbox"/> Non-disability organizations or agencies <input type="checkbox"/> Other (please specify)..... <input type="checkbox"/>
Transportation	Yes..... 1 No 2	Federal 1 State..... 1 Local 1	2 2 2	1	2	3	4	5	Worked with agency or organizational representatives ... <input type="checkbox"/> Worked with decision makers, such as agency administrators or elected officials..... <input type="checkbox"/> Worked with the media <input type="checkbox"/> Took legal action <input type="checkbox"/> Participated in committees or working groups <input type="checkbox"/> Conducted demonstrations..... <input type="checkbox"/> Conducted in-service training, accessibility surveys, or provided technical assistance..... <input type="checkbox"/> Trained grassroots organizations or organizers <input type="checkbox"/> Other (please describe)	Consumers <input type="checkbox"/> Board <input type="checkbox"/> Staff..... <input type="checkbox"/> Other disability organizations or agencies <input type="checkbox"/> Non-disability organizations or agencies <input type="checkbox"/> Other (please specify)..... <input type="checkbox"/>

4. (continued)

Issue	Col. A Worked on in last year? (Circle one)	Col. B. If Col. A is YES, Level? (Circle yes or no for each)		Col. C Amount of time spent? Rate 1 = Little to 5 = A lot (Circle one)					If YES in Col. A:	Col. E
		Yes	No	1	2	3	4	5	Col. D Activity to achieve change (✓ all that apply)	Groups involved in advocacy (✓ all that apply)
Personal assistance services	Yes..... 1 No 2	Federal 1 State..... 1 Local 1	2 2 2	1	2	3	4	5	Worked with agency or organizational representatives ... <input type="checkbox"/> Worked with decision makers, such as agency administrators or elected officials..... <input type="checkbox"/> Worked with the media <input type="checkbox"/> Took legal action <input type="checkbox"/> Participated in committees or working groups <input type="checkbox"/> Conducted demonstrations..... <input type="checkbox"/> Conducted in-service training, accessibility surveys, or provided technical assistance..... <input type="checkbox"/> Trained grassroots organizations or organizers <input type="checkbox"/> Other (please describe)	Consumers <input type="checkbox"/> Board <input type="checkbox"/> Staff..... <input type="checkbox"/> Other disability organizations or agencies <input type="checkbox"/> Non-disability organizations or agencies <input type="checkbox"/> Other (please specify)..... <input type="checkbox"/>
Federal, state, or local civil rights laws, including physical and program access	Yes..... 1 No 2	Federal 1 State..... 1 Local 1	2 2 2	1	2	3	4	5	Worked with agency or organizational representatives ... <input type="checkbox"/> Worked with decision makers, such as agency administrators or elected officials..... <input type="checkbox"/> Worked with the media <input type="checkbox"/> Took legal action <input type="checkbox"/> Participated in committees or working groups <input type="checkbox"/> Conducted demonstrations..... <input type="checkbox"/> Conducted in-service training, accessibility surveys, or provided technical assistance..... <input type="checkbox"/> Trained grassroots organizations or organizers <input type="checkbox"/> Other (please describe)	Consumers <input type="checkbox"/> Board <input type="checkbox"/> Staff..... <input type="checkbox"/> Other disability organizations or agencies <input type="checkbox"/> Non-disability organizations or agencies <input type="checkbox"/> Other (please specify)..... <input type="checkbox"/>

4. (continued)

Issue	Col. A Worked on in last year? (Circle one)	Col. B. If Col. A is YES, Level? (Circle yes or no for each)		Col. C Amount of time spent? Rate 1 = Little to 5 = A lot (Circle one)					If YES in Col. A:	Col. E
		Yes	No	1	2	3	4	5	Col. D Activity to achieve change (✓ all that apply)	Groups involved in advocacy (✓ all that apply)
Health care	Yes..... 1 No 2	Federal 1 State..... 1 Local 1	2 2 2	1	2	3	4	5	Worked with agency or organizational representatives ... <input type="checkbox"/> Worked with decision makers, such as agency administrators or elected officials..... <input type="checkbox"/> Worked with the media <input type="checkbox"/> Took legal action <input type="checkbox"/> Participated in committees or working groups <input type="checkbox"/> Conducted demonstrations..... <input type="checkbox"/> Conducted in-service training, accessibility surveys, or provided technical assistance..... <input type="checkbox"/> Trained grassroots organizations or organizers <input type="checkbox"/> Other (please describe)	Consumers <input type="checkbox"/> Board <input type="checkbox"/> Staff..... <input type="checkbox"/> Other disability organizations or agencies <input type="checkbox"/> Non-disability organizations or agencies <input type="checkbox"/> Other (please specify)..... <input type="checkbox"/>
Education	Yes..... 1 No 2	Federal 1 State..... 1 Local 1	2 2 2	1	2	3	4	5	Worked with agency or organizational representatives ... <input type="checkbox"/> Worked with decision makers, such as agency administrators or elected officials..... <input type="checkbox"/> Worked with the media <input type="checkbox"/> Took legal action <input type="checkbox"/> Participated in committees or working groups <input type="checkbox"/> Conducted demonstrations..... <input type="checkbox"/> Conducted in-service training, accessibility surveys, or provided technical assistance..... <input type="checkbox"/> Trained grassroots organizations or organizers <input type="checkbox"/> Other (please describe)	Consumers <input type="checkbox"/> Board <input type="checkbox"/> Staff..... <input type="checkbox"/> Other disability organizations or agencies <input type="checkbox"/> Non-disability organizations or agencies <input type="checkbox"/> Other (please specify)..... <input type="checkbox"/>

4. (continued)

Issue	Col. A Worked on in last year? (Circle one)	Col. B. If Col A is YES, Level? (Circle yes or no for each)		Col. C Amount of time spent? Rate 1 = Little to 5 = A lot (Circle one)					If YES in Col. A:	Col. E
		Yes	No	1	2	3	4	5	Col. D Activity to achieve change (✓ all that apply)	Groups involved in advocacy (✓ all that apply)
Employment	Yes..... 1 No 2	Federal 1 State..... 1 Local 1	2 2 2	1	2	3	4	5	Worked with agency or organizational representatives ... <input type="checkbox"/> Worked with decision makers, such as agency administrators or elected officials..... <input type="checkbox"/> Worked with the media <input type="checkbox"/> Took legal action <input type="checkbox"/> Participated in committees or working groups <input type="checkbox"/> Conducted demonstrations..... <input type="checkbox"/> Conducted in-service training, accessibility surveys, or provided technical assistance..... <input type="checkbox"/> Trained grassroots organizations or organizers <input type="checkbox"/> Other (please describe)	Consumers <input type="checkbox"/> Board <input type="checkbox"/> Staff..... <input type="checkbox"/> Other disability organizations or agencies <input type="checkbox"/> Non-disability organizations or agencies <input type="checkbox"/> Other (please specify)..... <input type="checkbox"/>
Youth transition	Yes..... 1 No 2	Federal 1 State..... 1 Local 1	2 2 2	1	2	3	4	5	Worked with agency or organizational representatives ... <input type="checkbox"/> Worked with decision makers, such as agency administrators or elected officials..... <input type="checkbox"/> Worked with the media <input type="checkbox"/> Took legal action <input type="checkbox"/> Participated in committees or working groups <input type="checkbox"/> Conducted demonstrations..... <input type="checkbox"/> Conducted in-service training, accessibility surveys, or provided technical assistance..... <input type="checkbox"/> Trained grassroots organizations or organizers <input type="checkbox"/> Other (please describe)	Consumers <input type="checkbox"/> Board <input type="checkbox"/> Staff..... <input type="checkbox"/> Other disability organizations or agencies <input type="checkbox"/> Non-disability organizations or agencies <input type="checkbox"/> Other (please specify)..... <input type="checkbox"/>

4. (continued)

Issue	Col. A Worked on in last year? (Circle one)	Col. B. If Col A is YES, Level? (Circle yes or no for each)		Col. C Amount of time spent? Rate 1 = Little to 5 = A lot (Circle one)					If YES in Col. A:	Col. E
		Yes	No	1	2	3	4	5	Col. D Activity to achieve change (✓ all that apply)	Groups involved in advocacy (✓ all that apply)
Other (please specify) _____ _____	Yes..... 1 No 2	Federal 1 2 State..... 1 2 Local 1 2							Worked with agency or organizational representatives ... <input type="checkbox"/> Worked with decision makers, such as agency administrators or elected officials..... <input type="checkbox"/> Worked with the media <input type="checkbox"/> Took legal action <input type="checkbox"/> Participated in committees or working groups <input type="checkbox"/> Conducted demonstrations..... <input type="checkbox"/> Conducted in-service training, accessibility surveys, or provided technical assistance..... <input type="checkbox"/> Trained grassroots organizations or organizers <input type="checkbox"/> Other (please describe)	Consumers <input type="checkbox"/> Board <input type="checkbox"/> Staff..... <input type="checkbox"/> Other disability organizations or agencies <input type="checkbox"/> Non-disability organizations or agencies <input type="checkbox"/> Other (please specify)..... <input type="checkbox"/>

5. What are the most significant issues for community advocacy/systems change for your center during the next five years? Please rate the issues, from one to five, based upon their importance to your center. "1" is not at all important and "5" is very important.

Issue	RATE				
	1 = Not at all Important	2	3	4	5 = Very Important
a. Deinstitutionalization.....	1	2	3	4	5
b. Integrated community housing	1	2	3	4	5
c. Transportation	1	2	3	4	5
d. Personal Assistance Services	1	2	3	4	5
e. Civil rights, including physical and program access	1	2	3	4	5
f. Health care	1	2	3	4	5
g. Education	1	2	3	4	5
h. Employment.....	1	2	3	4	5
i. Other (please specify)_____	1	2	3	4	5

6. What are the primary barriers to YOUR CENTER in achieving systems change? Please rate the barriers, from one to five, based upon their importance. "1" is not at all important and "5" is very important.

Barrier	RATE				
	1 = Not at all Important	2	3	4	5 = Very Important
a. Not enough center resources to hire staff	1	2	3	4	5
b. Lack of knowledgeable staff	1	2	3	4	5
c. Not enough time to devote to the issue	1	2	3	4	5
d. Lack of involvement from consumers.....	1	2	3	4	5
e. Board concerns	1	2	3	4	5
f. Concern about center reputation	1	2	3	4	5
g. Concern about funding	1	2	3	4	5
h. Resistance of the agency or entity you are trying to change	1	2	3	4	5
i. Lack of agency funding to implement the service or program.....	1	2	3	4	5
j. Other (please specify)_____	1	2	3	4	5

7. What are the primary facilitators to YOUR CENTER in achieving systems change? Please rate the facilitators, from one to five, based upon their importance. "1" is not at all important and "5" is very important.

Facilitator	RATE				
	1 = Not at all Important	2	3	4	5 = Very Important
a. Sufficient resources to hire staff	1	2	3	4	5
b. Staff knowledge and expertise	1	2	3	4	5
c. Concentrating efforts on a few important issues .	1	2	3	4	5
d. Strong consumer involvement.....	1	2	3	4	5
e. Strong board involvement	1	2	3	4	5
f. Good coalition with other agencies and consumer groups	1	2	3	4	5
g. Allies inside the agency or entity you are trying to change	1	2	3	4	5
h. Political contacts; e.g., Governor, legislators, or city council members	1	2	3	4	5
i. Public support.....	1	2	3	4	5
j. Media coverage	1	2	3	4	5
k. Other (please specify) _____	1	2	3	4	5

III. DIVERSITY

8. The next few questions relate to ethnic and disability constituencies served by your center.

Constituency	Col. A Present in Service Area?		Col. B If Col. A "Yes," please rate your degree of success of each of the following strategies, from 1 (low) to 5 (high). If you have not used a strategy, please leave it blank.						Col. C Adequately Serving?		If Col. C "No," What is the primary barrier to serving group?
			Provided written information in languages other than English?	Employed staff from the constituency you are trying to reach?	Accessed resources to assist people who do not speak English?	Worked with social service agencies that serve a variety of ethnic groups?	Satellite or branch offices in areas that serve a variety of ethnic groups?	Worked with community organizations to develop a common advocacy agenda?			
	Yes	No	Yes	No	Yes	No	Yes	No			
White	1	2							1	2	
Black/African American	1	2							1	2	
Asian/Pacific Islander	1	2							1	2	
Alaskan Native/ Native American	1	2							1	2	
Hispanic/Latino	1	2							1	2	
Other (Please Specify)	1	2							1	2	

9. Disabilities that are sometimes not served or under served by centers are listed below. Please indicate, by circling the appropriate response, whether or not you feel you are adequately serving each of the listed constituencies. Then, for those constituencies that you indicated were not adequately served, rate your success from **1 (low) to 5 (high)** with reaching the constituency by using that activity.

Constituency	Col. A Adequately Serving?		Col. B If Col. A "No," please rate your degree of success of each of the following strategies, from <u>1 (low) to 5 (high)</u> . If you have not used a strategy, please leave it blank.					
	Yes	No	Provide written information in alternative formats (Braille, Tape, simple language, etc)	Employ staff from the constituency you are trying to reach	Access specialized resources, such as sign language interpreters or Braille teachers, to meet specific needs	Work with disability specific agencies that serve a particular constituency	Work with disability organizations to develop a common advocacy agenda	Other (specify)
Deaf/Hearing Impaired	1	2						
Blind/Visually Impaired	1	2						
Psychiatric Disability	1	2						
Cognitive Disability	1	2						
Multiple Chemical Sensitivity (MCS) or environmental illness	1	2						
Other (please specify) _____	1	2						

10. Please indicate whether or not your center provides the following alternative communication methods.

Method	<u>YES</u>	<u>NO</u>
a. Large print.....	1	2
b. Braille.....	1	2
c. Cassette tape	1	2
d. Computer disk.....	1	2
e. Sign language interpreter.....	1	2
f. Simplified English	1	2
g. CART Reporting.....	1	2

11. To what extent is your center able to meet all requests for alternative communication? (Please circle the appropriate number.)

1 2 3 4 5
Not **Fully**
Able **Able**

12. Is your center accessible by public transportation or paratransit services?

Yes 1
 No 2
 There are no public
 transportation services in our
 community..... 3

13. Would you say that your center's service area is ...

Urban 1
 Suburban..... 2
 Rural..... 3
 Mixed 4

IV. BOARD OF DIRECTORS

14. Board members can be recruited in many ways. Some possible sources of good board members are listed below. Please indicate how successful your center has found each recruitment source to be by circling the appropriate number for each source.

Source	Usefulness in Recruiting Board Members				
	Poor	Fair	Good	Very Good	Excellent
Disability Organization	1	2	3	4	5
Former Staff	1	2	3	4	5
Recommendations of Board	1	2	3	4	5
Recommendations of Staff	1	2	3	4	5
Human Service Agencies	1	2	3	4	5
Elected Officials	1	2	3	4	5
Consumers	1	2	3	4	5
Relatives of Consumers	1	2	3	4	5
Representatives of Center funding Sources	1	2	3	4	5
Private Business	1	2	3	4	5
Other (please specify) _____	1	2	3	4	5
Other _____	1	2	3	4	5

15. Which statement best describes the type of training your center conducts for board members?

- We do not conduct formal board training. Board members learn through participation on the board 1
- We conduct board training using center board and staff members 2
- We bring in an expert on board development or on independent living to conduct board training 3
- Other (please specify) _____ 4

16. How effective would you say this board training has been in assisting your board to fulfill the center's mission?

- Very effective 1
- Somewhat effective 2
- Neutral..... 3
- Somewhat ineffective 4
- Very ineffective 5

17. How would you characterize the relationship between YOUR CENTER'S board and staff members?

- Very positive/supportive 1
- Somewhat positive/supportive 2
- Neutral..... 3 } **GO TO Q.20**
- Somewhat adversarial..... 4 } **(GO TO Q.19)**
- Very adversarial 5 }

18. What factors do you think contribute most to a positive working relationship between YOUR CENTER'S board and staff?

19. What factors do you think contribute most to an adversarial relationship between a center's board and staff members?

V. STAFF TRAINING

20. With your experience in running a center and in understanding the experiences of other center directors, what would you identify as the three issues that make the difference between success and failure for CILs?

1. _____

2. _____

3. _____

21. Describe the three most pressing training needs of YOUR CIL.

1. _____

2. _____

3. _____

22. Describe the three most pressing technical assistance needs of YOUR CIL.

1. _____

2. _____

3. _____

23. Please tell us the three IL-related topics which you would most like to read about in newsletters, guides, and journals.

- 1. _____
- 2. _____
- 3. _____

VI. RELATIONSHIPS WITH OTHER AGENCIES

24a. To what extent is the Designated State Unit (DSU) supportive of your CIL? The DSU is the agency that provides vocational rehabilitation services under Title I of the Rehabilitation Act, generally referred to as the State Rehabilitation Agency or the Department of Rehabilitation Services? (Circle one)

- Very supportive 1 } (GO TO Q.24b)
- Somewhat supportive 2 } (GO TO Q.24b)
- Neutral 3 ⇐ (GO TO Q.24d)
- Somewhat adversarial 4 } (GO TO Q.24c)
- Very adversarial 5 } (GO TO Q.24c)
- No relationship 6 } (GO TO Q.24d)
- Other (please specify) 7 } (GO TO Q.24d)

24b. What factors do you think have contributed most to the supportive nature of the relationship between your center and the DSU?

(GO TO Q.24d)

24c. What factors do you think have contributed to the adversarial nature of the relationship between your center and the DSU?

24d. What actions, if any, could RSA take to foster a positive relationship between your center and the DSU?

The next few questions focus on the State Independent Living Council (SILC).

25. Which statement(s) describes your representation on the SILC?

Statement	<u>YES</u>	<u>NO</u>
a. I serve on the SILC.....	1	2
b. A member of the center’s staff serves on the SILC	1	2
c. A member of the center’s board of directors serves on the SILC.....	1	2
d. A consumer affiliated with the center serves on the SILC ..	1	2
e. I elect someone who represents centers for independent living to serve on the SILC	1	2
f. I have no representation on the SILC	1	2
g. Other (please specify) _____	1	2

26. Please rate the SILC in your state on the following SILC purposes by circling the appropriate number for each statement.

Purpose	SILC Rating					
	Poor	Fair	Good	Very Good	Excellent	Don’t Know
Outreach to unserved and underserved populations	1	2	3	4	5	8
Assessment of community needs	1	2	3	4	5	8
Obtaining consumer input on the state IL plan	1	2	3	4	5	8
Development of the state IL plan	1	2	3	4	5	8
Oversight and monitoring of the state IL plan	1	2	3	4	5	8
Evaluation of the state plan	1	2	3	4	5	8
Evaluation of consumer satisfaction	1	2	3	4	5	8
Development of a network of centers for independent living across the state	1	2	3	4	5	8
Establishing a consumer network to advocate for additional funding, services, or legislation	1	2	3	4	5	8

27. To what extent would you say the SILC composition meets each of the following criteria? Please circle the appropriate number for each criteria.

Criteria	SILC Composition			
	Not at All	To Some Extent	To a Great Extent	Don't Know
Provides statewide representation	1	2	3	8
Represents a broad range of individuals with disabilities from diverse backgrounds	1	2	3	8
Individuals are knowledgeable about centers for independent living and independent living services	1	2	3	8
A majority of members are individuals with disabilities who do not work for any state agency or center for independent living	1	2	3	8

28a. To what extent is the SILC supportive of your center?

- Very supportive 1 } (GO TO Q.28b)
- Somewhat supportive 2 } (GO TO Q.28b)
- Neutral 3 ⇐ (GO TO Q.28d)
- Somewhat adversarial 4 } (GO TO Q.28c)
- Very adversarial 5 } (GO TO Q.28c)
- No relationship 6 } (GO TO Q.28d)
- Other (please specify) 7 } (GO TO Q.28d)

28b. What factors do you think have contributed most to the supportive nature of the relationship between your center and the SILC?

(GO TO Q.28d)

28c. What factors do you think have contributed to the adversarial nature of the relationship between your center and the SILC?

28d. What actions, if any, could RSA take to foster a positive relationship between your center and the SILC?

29a. Some states have a state rehabilitation agency serving people who are blind or visually impaired that is separate from the rehabilitation agency that serves people with other disabilities. Do you have a separate agency for the blind in your state?

Yes 1
No 2 ← **(GO TO Q.30)**

29b. To what extent is the agency for the blind supportive of your CIL?

- Very supportive 1
 - Somewhat supportive 2
 - Neutral 3 ← (GO TO Q.29e)
 - Somewhat adversarial..... 4 } (GO TO Q.29d)
 - Very adversarial 5 }
 - No relationship 6 } (GO TO Q.29e)
 - Other (please specify) 7 }
-

29c. What factors do you think have contributed most to the supportive nature of the relationship between your center and the state agency for the blind?

(GO TO Q.30)

29d. What factors do you think have contributed to the adversarial nature of the relationship between your center and the state agency for the blind?

29e. What actions, if any, could RSA take to foster a positive relationship between your center and the state agency for the blind?

VII. EVALUATION AND MONITORING

The next few questions address the evaluation report required under Section 704 of the Rehabilitation Act and the periodic site reviews conducted by RSA or the DSU.

30. Approximately how many days would you say it takes to prepare for and complete the 704 Report?

Number of days

31. How helpful to you and your staff is the information gathered for the 704 Report in assessing the quality of the services and advocacy your center provides?

- Very helpful..... 1
- Somewhat helpful 2
- Neutral..... 3
- Somewhat unhelpful..... 4
- Not helpful..... 5

32. What suggestions would you make to improve the 704 Report?

33. RSA conducts periodic site reviews of each center. Has your center had a site visit by RSA in the last three years?

- Yes 1
- No 2 ⇐ **(GO TO Q.34)**

33a. About how many days would you say it took to prepare for and complete the RSA site review?

Number of days

33b. How helpful is the RSA site review process in assessing the quality of the services and advocacy your center provides?

- Very helpful..... 1
- Somewhat help ful 2
- Neutral..... 3
- Somewhat unhelpful..... 4
- Not helpful..... 5

33c. What suggestions would you make to improve the RSA site review?

34. DSUs also conduct periodic site reviews or other ongoing monitoring activities. Has your center had a review by your DSU in the last three years?

- Yes 1
- No 2 ⇐ **(GO TO Q.35)**

34b. About how many days would you say it took to prepare for and complete the DSU review?

Number of days

34c. How helpful is the DSU review process in assessing the quality of the services and advocacy your center provides?

- Very helpful..... 1
- Somewhat helpful 2
- Neutral..... 3
- Somewhat unhelpful..... 4
- Not helpful..... 5

34d. What suggestions would you make to improve the DSU review?

VIII. RESOURCES AND FUNDING

35. Please indicate whether or not you received the following sources of funding in Federal Fiscal Year 2000.

- Indicate in Col. B whether or not there have been any problems or difficulties (e.g., record keeping burden, eligibility rules, inconsistencies with IL philosophy, etc.) that have arisen as a result of acquiring any of these resources; and
- Briefly describe the problem in Col. C.

Source	If YES in Col. A				Col. C (If YES in Col. B) What were they?
	Col. A Received?		Col. B Problems or Difficulties?		
	YES	NO	YES	NO	
Federal Funds					
Title VII, Part B, Chapter1	1	2	1	2	
Title VII, Part C, Chapter 1	1	2	1	2	
Title VII, Chapter II	1	2	1	2	
Other federal funds	1	2	1	2	
Other Government Funds					
State government funds	1	2	1	2	
Local government funds	1	2	1	2	
	1	2	1	2	
Private Funds					
Foundations, corporation, or trust grants	1	2	1	2	
Donations from individuals	1	2	1	2	
Memberships	1	2	1	2	
Investment income	1	2	1	2	
Fee for Service (program income)	1	2	1	2	
Other income/resources (in-kind etc)	1	2	1	2	

36a. Are there any funds that your center no longer receive with which you had problems or difficulties?

Yes 1
No 2 ← (GO TO Q.37)

b. Please indicate which type of funds your center received and briefly describe the difficulties with these funds.

Type of Fund	Difficulty

37. In general, what factors have facilitated the acquisition of other resources?

38. What factors have impeded the acquisition of other resources?

39. Approximately what percentage of your budget is allocated to the following areas:

<u>Budget Area</u>	<u>% of Budget Allocated</u>
Services	_____
Systems change advocacy	_____
Administration	_____

40. Approximately what percentage of your funding is discretionary—that is, not linked to a particular service and is available to be used for advocacy?

_____ %
% of Funding that is Discretionary

Finally, we need a few demographics and contact information in case we need to contact you to clarify a response.

41. What is your name and job title?

Name: _____

Job Title: _____

42. How long have you served in this position?

Number of Years

43. How long have you been affiliated with a center for independent living, either as a staff person, board member, or consumer?

Number of Years

44a. Did anyone else assist you in completing this survey?

Yes 1
No 2 ← **(GO TO END)**

b. What is their position at the center?

Job Title: _____

45. How long has your center been in existence as a non-profit agency with a board of directors comprised of a majority of people with disabilities?

Number of Years

Thank you very much for taking the time to complete this survey. Please return it in the enclosed self-addressed postage-paid envelope by

DUE DATE

or mail to:

**CESSI
Attn: Marcie Goldstein
6858 Old Dominion Drive
Suite 250
McLean, VA 22101**

APPENDIX E

EXAMPLES OF COMMUNITY OUTCOMES FROM THE 704 REPORTS

APPENDIX E

EXAMPLES OF COMMUNITY OUTCOMES

FROM THE FY 2001 704 REPORTS

PERSONAL ASSISTANCE/DEINSTITUTIONALIZATION

Legislation

Passage of HB1197, which requires the state to apply for a Medicaid waiver for publicly funded assisted living, adult foster care and expanded day care.

Policy

1. As a result of the center's advocacy, Utah's Director of Medicaid initiated changes needed to allow individuals who are currently living in nursing homes but could move into the community with personal assistance to access services from the Physical Disabilities Medicaid Waiver without being placed on the waiting list to compete with people in the community also trying to access funding. This is a major system change having a two fold benefit for both nursing home residents and people in the community waiting for personal assistance.
2. Efforts to develop a plan in our state, which would implement the Supreme Court decision of the Olmstead Case, began in earnest in February. It began with Ralph Rouse and others from the Regional Office of Civil Rights coming to Arkansas and educating both DHS and advocates on the Supreme Court's decision and its implications. At this first meeting it was determined to establish an Olmstead Coalition. This Coalition included advocates, service providers and consumers. SAILS had staff representation on the Coalition from the beginning. The Coalition, which met weekly, was successful in holding forums around the state to educate people and gather input for the development of a state plan. They also got the Governor to sign an Executive Order for a state plan to be developed and appoint an Olmstead Work Group. This group met weekly also. Our representative attended both weekly meetings. These meetings lasted from February through October, ending with a draft plan to submit to the state.

Service Improvement

1. As proposed, CRS focused its efforts on a systematic advocacy issue that affects people with disabilities In Home Support Services (IHSS). The ELA and CLA Advocate were part of a major effort of a change that occurred this past year with IHSS. Salaries for IHSS workers have increased twice, from minimum (\$5.75 per hour) to \$6.25 and

finally to \$6.75. This increase has had a positive impact with the recruitment and retention of qualified IHSS workers that provide services to persons with disabilities. The ELA Advocate was involved in this process through collaboration in monthly IHSS coalition meetings. Last year the Advocate along with 15-20 consumers participated in a rally concerning IHSS worker's wages. Additionally, the ELA Advocate participated in a press conference regarding IHSS issues and was the "Spanish Speaking Voice" for consumers.

2. The Center coordinated efforts throughout the state for increased funding for the Kentucky Personal Care Attendant Program. Advocates worked statewide to call, visit, and write letters to the legislators explaining the importance of the program. The effort was successful, and the program was granted expansion funds to enroll approximately 100 new consumers. This is just a drop in the bucket for the lengthy waiting list, but it is a start from the General Assembly with a promise of more funds to come, and a promise from the consumers of increased advocacy in the future.

Service Maintenance

One other major gain around PCAs that CORD led on behalf of the coalition was getting language--for the fifth straight year--put in the state budget that prevents the Division of Medical Assistance from changing the regulations of the PCA program without the input of disability advocates (representatives of the SILC, Governor's Advisory Commission on Disability, and the state Office on Disability). This language has been the pivot point for progressive change and vital program protection since the mid 1990s.

HEALTH CARE

Communication Access

The Walker County staff advocated for qualified interpreters for individuals with hearing impairments with the Walker Baptist Medical Center.

Legislation

ABIL worked with a Health Care Reform Coalition during the 2000 legislative session to pass a HMO Reform bill that included 1) that HMO's had to reimburse providers within a time frame, 2) that consumers had the right to sue HMO's for negligence, 3) that HMO's had to offer chiropractic care. Consumers got involved by attending a Legislative Lobby Day with a press conference and visited every member of the legislature demanding that they pass "real" health care reform.

Policy

Adequate health care and personal assistance continue to be top priorities to HCIL consumers. The Houston Center for Independent Living has actively participated in efforts to improve health care. During the year, we held educational meetings on the Star Plus managed care pilot for consumers. More importantly, we have collaborated in the development of a new regional model to increase access to long term care as mandated by Texas Senate Bill 374. HCIL participated in open meeting discussions with the Texas Department of Human Services, the Area Agency on Aging, the Texas Department of Health, a representative from the Houston Mayor's Office on Disability, and service providers to seniors and people with disabilities. HCIL made recommendations, which have been incorporated, into the final proposal, reflecting the necessity for greater consumer control.

Service Improvement

1. Community Based Services for people with psychiatric disabilities: As a member of a large coalition, called Keeping the Promise, the Center played a role in the defeat of proposed state legislation that would made it easier to commit people to involuntary outpatient programs and involuntary in-patient medication programs. We worked to successfully secure new appropriations for two community based services for people with psychiatric disabilities.
2. TTH staff supported a grass roots effort by local tribal community members to advocate for needed health care. Indian Health Service (the primary health care provider) re- interpreted federal regulation which resulted in 3 tribal communities being excluded from contract health services (specialty health care services such as ENT, orthopedics, Neurologists etc). Many of these services are essential for persons with disabilities. The group was able to address the tribal council demanding their needs be addressed. This was successful in that a special council meeting was convened in their local community center to begin to develop a plan to address the issue.

HOUSING

Monitoring

DAC staff and volunteers helped perform and coordinate Fair Housing Testing in cooperation with the Intermountain Fair Housing Council. As a result of these and other enforcement activities, the state of Idaho has been able to create a fund to assist people with disabilities to make their homes accessible. The program is coordinated through the Idaho Housing and Finance Association with CILs assisting consumers with the application process.

Physical Access

The Legal Department received final settlement on two suits that it had filed concerning accessibility issues. One against Washburn Apartments for failing to comply with Fair Housing building requirements

Policy

1. As we were working with several coordinated religious groups in the San Fernando Valley, we were informed that they were supporting Habitat for Humanity. We discussed the fact that their housing was not being opened to persons with disabilities. This was for two reasons: 1) the housing was not designed for accessibility; 2) the policies, procedures, and eligibility would have excluded persons with disabilities. The religious groups called on Habitat for Humanity and changes were adopted. A client of ILCSC was made eligible, and their house has just been completed.
2. Liberty Resources and Disabled In Action, as plaintiffs, won a court decision in their suit against the Philadelphia Housing Authority (PHA). PHA cannot develop new or renovate existing housing sites unless at least five percent (5%) of the units are accessible to Persons with Disabilities.

Service Improvement

SMILE requested recommendation from the Yuma Citizens' Advisory Committee to the City Council for a home modification program for the city's disabled population. The outcome of this request was that a Community Development Block Grant was awarded to the CIL to finance this program.

Through our advocacy, two single family accessible rental homes are planned using Community Development Block Grant funds, and two CIL consumers currently living in nursing homes will be offered this housing option. Partnerships with local realtors and banks have given us entry to affordable, accessible apartments and single-family homes, as well as homeownership.

EDUCATION

Communication Access

DAC advocacy efforts promoted the implementation of Richland School District One in implementing policy and procedure for obtaining qualified interpreting services for Deaf parents with hearing children in school. This will enhance the Deaf parent's ability to stay involved in their child's education and events at the school.

Service Improvement

Parent Advocate responded to several complaints from Families in the Lyme School District by organizing a meeting. At this meeting, the five Families in attendance shared their frustrations and identified several common issues. Parent Advocate provided these Families with background on the IDEA and on their rights. The parents expressed an interest in inviting members of the School Board to a subsequent meeting. At this meeting, attended by the School Board President and another member of the Board, nine Parents each described their issues while Board members listened and took notes. Some of the issues identified were not implementing IEP's, holding CSE meetings without the Parent, failing to make referrals for evaluations for Children with significant educational delays, lack of staff training, transportation problems, and failing to provide Families with their "Parents Guide to Special Education". The two board members in attendance brought the information back to the rest of the School Board.

Since the initial meeting of these Parents the following has resulted:

- Parents have formed a Parent-to-Parent Network in the Lyme area and are now meeting on a regular basis.

- The CSE Chairperson resigned at Lyme Central School

- Several Children have received evaluations that revealed various disabilities, qualifying them for Special Education and

- A favorable relationship and communication between parents and the school board has developed.

Service Maintenance

CORD yet again rallied its troops to fight changes in the Massachusetts special education law, Chapter 766. The group sent a bus load and then some to a State House hearing in late spring, meeting with six of seven members of the Cape's legislative delegation. Mailings were also sent to hundreds, urging them to join in this education campaign. Changes weakening the law were passed in early summer--including the phase out of maximum feasible benefit--but CORD, as part of an effort coordinated by the Mass. Advocacy Center, among others, was able to help lessen the impact, as independent evaluations were saved for low and moderate-income children and eligibility standards were not gutted, as had been proposed.

Physical Access

The Center placed two ramps at Malabar School that will allow students who have disabilities to access a project garden. Until the ramps were placed, these students could not accomplish the hands on study required in their science studies. With a cooperative agreement with the school administration, these students now can enjoy the same outside activities as their classmates.

Policy

The center successfully advocated with the Carbon School District for integrated transportation to and from elementary school on behalf of a child with muscular dystrophy. The School District wanted the child to ride on a bus with individuals with mental retardation who attend a different school instead of with her peers and classmates.

CIVIL RIGHTS

Communication Access

The Walker County staff advocated successfully with the deaf community for a public TDD at the Jasper mall.

Monitoring

In spite of the Americans with Disabilities Act having been law for better than 10 years, city/county planners, inspectors, and developers still do not accord close enough attention to the ADAAG. Sources continue to find itself having to point out deficiencies in a number of retail establishments after they were given certificates of occupancy that allows them to be open for business. This has been discouraging because these were not projects that were just getting a facelift (still subject to the ADA) but were new construction. To assure that these unfortunate slipups are non-recurring, we insist that city building inspection officials accompany us to all sites that we challenge do not meet the ADA. We do this, so that inspectors can get a first hand understanding of how important it is to pay close attention to all the provisions of the accessibility guidelines and that no accommodation, regardless of how small, should be overlooked. We are encouraged that we may be having an impact in that we have seen a dramatic increase in requests for technical assistance in ADA matters from city/ county building inspectors as well as from architects and developers.

Policy

ECCIL provided information and technical assistance to a number of small businesses and agencies throughout the fiscal year. In addition, a great deal of follow-up effort went toward resolution of previously-identified barriers to full participation by persons with disabilities presented by Whiteco, a multi-billion dollar international corporation which owns many local hotels, restaurants and recreation centers. Due to its high visibility and position of influence on other area businesses, as well as its steadfast refusal to bring its facilities and policies into compliance with the ADA, Whiteco was selected as an ideal "target" by which to educate and obtain cooperation from others who also continued to delay compliance with ADA standards. In response to ECCIL's demands, Whiteco had contracted with the area DBTAC to conduct a site survey. Although Whiteco later reported having addressed the majority of the findings from that survey, local consumers reported otherwise. ECCIL facilitated a meeting between those consumers and Whiteco

representative, who then agreed to bring the DBTAC out to conduct a second site survey. The results of that survey support consumer concerns. At the time this report was prepared, additional meetings were set for early in the next fiscal year to discuss not only physical accessibility, but also policies and procedures.

Physical Access

The center proposed repairs/replacements for curb cuts and sidewalks totaling \$200,000. The work was completed

Service Improvement

CCCIL was a member of the Salinas ADA Ad-Hoc Committee that assisted in establishing the ADA Transition Plan for the City of Salinas. CCCIL's successful efforts included: modifications to be made to Steinbeck Public Library which became compliant with the ADA in July, 2000; the establishment of accessible emergency call boxes on highway 101; new curb cuts in the cities of Pacific Grove, Seaside and Salinas; Paratransit services to South Monterey county, the most rural part of our community and; the establishment of a transportation task force which is focusing on developing methods if improving current Paratransit services, to name a few.

Service Maintenance

Our center succeeded in advocacy efforts to upgrade Hall County Park. There is now a new accessible unisex restroom, a new accessible drinking fountain, two new accessible parking lots, new accessible routes, and new signage all over the park directing the public to the accessible features. Plans have also been made for two additional new accessible restrooms.

EMPLOYMENT

Communication Access

Advocacy was done at the US Censor Bureau, WITH Mr. Chuck Reilly to provide a temporary TTY phone line for consumers to call for job placement.

Legislation

ABIL mobilized consumers locally and nationally to advocate for the successful passage of the Ticket to Work and Work Incentives Improvement Act of 1999 which will remove many of the current barriers to employment for people with disabilities. ABIL's Executive Director at that time, Susan Webb, traveled to Washington D.C. to testify before Congress on the need for TWWIIA and educated people across our state on its contents.

Physical Access

Lobbied for move of not fully accessible Middleton career center and in FY'01 this career center will be moved to a fully accessible site in Salem.

Policy

RCIL has been involved in system change initiatives in the employment area. As a member of the Workforce Investment Board, RCIL has been very involved in the establishment of the One Stop Service Centers, four of which will be located in the three county area. RCIL has made specific recommendations to make all sites totally accessible. This includes recommendations for technology. RCIL drafted a diversity statement for the selection of staff and general access issues. This was incorporated into the overall policy of the One Stop overseen by the Workforce Investment Board and is now being replicated by other Workforce Investment Boards in the state. RCIL's involvement resulted in training, activities, services and products, designed to comply with the mandates of the ADA, Section 504 of the Rehabilitation Act, the Workforce Investment Act (WIA), and the NYS Department of Labor.

Service Improvement

At the request of a consumer, Staff contacted the Blood Services Division of the American Red Cross regarding difficulties that persons with disabilities had after being placed there by a state vocational rehabilitation agency. Consumers reported being threatened by staff about bringing a service animal into the workplace, and difficulties in providing reasonable accommodation with regard to scheduling and other policies. Staff spoke to the head of the local blood services division, and discussed the issue. It was agreed that training and technical support were needed, as the persons placed, and others projected to be placed, constituted a valuable asset to the Red Cross work force.

TRANSPORTATION

Legislation

We worked toward successful passage of HB 4995. In our efforts to support this bill, we provided oral testimony to the House Transportation Committee and written testimony to the Senate Transportation Committee. The bill is now law and makes it illegal to park in the access aisles adjacent to accessible parking spaces or in front of curb cuts.

Physical Access

ECNV also assisted the process for WMATA's proposed changes to the Pentagon Metro station that resulted in making the renovation construction plan be more accessible.

Policy

The CIL serves on a committee worked on the Taxi Cab ordinance (for the first time in Charlotte history) that will include a section on private vehicles that transport individuals who use wheelchairs.

Service Improvement

The Columbia Transit Service announced plans for purchasing new lift equipped buses and installing 30 benches and five (5) shelters along Columbia bus routes. The City of Columbia also began making improvements to downtown sidewalks as recommended by the Disabilities Commission. Board Members Lee Henson, Christy Welliver, Kathleen Weinschenck and staff member Jerry Morris serve on the commission.

Service Maintenance

BILC advocated for improved transportation services for people with disabilities, including compliance with ADA requirements. The center staff and consumers participated in public meetings regarding transportation issues, including the transit system advisory committee. The Center organized a May, 2000 March to City Hall in support of City funding for public transportation. Despite cuts in funding for fixed route transit, the City Council maintained funding for evening and weekend paratransit services.

OTHER ACTIVITIES

Communication Access

For the past 5 years, SAIL has attempted to have the Alaska equivalent of C-span, Gavel to Gavel, close-captioned for the deaf/hard of hearing community. The effort is finally bearing fruit, and the local PBS television station is seeking financial sponsors to accomplish this. This would affect a statewide audience.

Legislation

OIL assisted in the drive to establish an Oklahoma State Independent Living Act. OIL served as an education tool to bring about awareness and understanding of the Act. The Act mirrored federal law and regulations. The IL Act was adopted into Oklahoma law.

Physical Access

ILR continued through this year to house the local ADAPT Chapter as part of the center's commitment to advancing community advocacy locally and nationally. A number of victories in this arena were won due to these efforts this past year. A recent effort by ADAPT occurred this past summer when NIKE introduced a controversial ad that was

devastating for the disabled. ADAPT arranged for a national apology and is currently working on ensuring that NIKE and their advertising agents receive disability awareness training. This is still a work in progress

Policy

The Consumer Advocacy Committee brought A+ Links and the Supervisor of Elections together in order to set up a voter registration system in which the A+ Links drivers were required to inquire if paratransit riders are registered voters. If the riders were not already registered, the driver provides the necessary voter registration forms to enable the rider to register to vote.

Service Maintenance

In October, 1999 the center lead a coalition that sponsored a candidates forum for the Mayor's race (of Birmingham). All major candidates participated, including the winner. Over 100 people attended. Candidates were asked their position on various disability issues and responded to questions posed by the audience. BILC staff and board met with the new mayor to advocate for the re-vitalization of the Mayor's advisory committee on disability issues, hiring a liaison to the disability community, and other issues. Names were submitted to the Mayor to fill the liaison position.

Service Improvement

1. The ILRC was instrumental in the establishment of a Disability Awareness Task force made up of representatives from the entire City Training Divisions for the purpose of training not only the Sheriff's department, but the Jail staff, fire and rescue etc.
2. During the 1999-2000 Program Year, the Independent Living Resource joined the California Foundation of Independent Living Centers to advocate for a budgetary augmentation through the state to establish assistive technology components within centers. This effort was successful and each center received \$75,000 for this purpose. In this context, the term "assistive technology" (AT), is broad in scope and encompasses any equipment, devices, assistance, or structural modifications that enhance the independence of people with disabilities.

APPENDIX F

INSTRUCTIONS FOR CENTERS ON SELECTING CONSUMERS

Appendix F

Dear _____:

The Rehabilitation Services Administration (RSA), in the Office of Special Education and Rehabilitation Services (OSERS), U.S. Department of Education, has funded a comprehensive two-year evaluation of Parts B and C of the Centers for Independent Living (CIL) program. Cherry Engineering Support Services, Inc. is under contract with RSA to conduct the study. This evaluation will include a survey of executive directors of all federally funded CILs and a telephone survey of a nationally representative sample of current and former consumers of CIL services. The surveys will evaluate outcomes of community advocacy and center services, as well as consumer satisfaction. In late January, you received a letter from Judy Heumann, Assistant Secretary of OSERS, telling you about this study and requesting your cooperation.

You will receive the survey of executive directors under separate cover. In addition to filling out the executive director survey, your center has been randomly selected to participate in the consumer survey. Information about the consumer survey and instructions for selecting respondents are enclosed.

As a subcontractor to CESSI, Westat is responsible for conducting all operations related to the administration of the consumer questionnaire. Because we recognize that CIL consumer information is confidential, we are asking for your assistance in recruiting respondents for the survey.

The enclosed Sampling Instructions describe the steps you will need to take to select consumers for the survey. We want you to select consumers who are currently receiving services from your CIL as well as those who have stopped receiving services within the last six months. The Consumer Contact Steps and Information are based on Westat's extensive experience recruiting survey participants. However, since you are familiar with your consumers, please feel free to tailor the scripts to your situation. You will be working with Jean Wilson from Westat to complete this procedure. If you have any questions, you may call her at 1-800-937-8282 EXT. 2836

Westat will only contact consumers who have agreed to participate in the survey. It is important for you to encourage those selected to be in the survey and to let them know that their input is very important. The information they provide will be used to determine consumer satisfaction with the CILs. All of their responses will be completely confidential and will not be linked with your CIL. If you have any questions, please contact me at (703) 845-3436. On behalf of the Rehabilitation Services Administration, Department of Education, CESSI and Westat, I would like to thank you for your assistance in this project. Your help is invaluable for the completion of this study.

Sincerely yours,

Bonnie O'Day
Senior Research Associate
CESSI

Evaluation of Independent Living Centers

About the Study: The U.S. Department of Education's Rehabilitation Services Administration is conducting a study to describe the activities and services of Centers for Independent Living, how Centers help people with disabilities, and how satisfied consumers are with the services they receive. Your Center was selected as part of a representative sample of all Independent Living programs in the United States, and your participation is essential for the success of this study. We are looking forward to working with you and are committed to making this as efficient and effective an effort as possible.

What we are asking you to do?

A staff member from Westat will be contacting you within the next several days to go over your participation in this important study. We will be reviewing the packet of materials; so please have the enclosed information available when we call.

It would also be helpful if you are able to complete the following step prior to our call:

- 1) **You will need to have a numbered list of consumers:** This list should consist of consumers who have received services within the last six months (whether their cases are open or closed). If you have several lists of consumers, e.g., open and closed cases, we just need to know the total number of consumers who have received services within the last six months across all the lists.

Once you have prepared the list of consumers,

- 2) **If you would like to, you may go ahead and call Jean Wilson at Westat.** Her telephone number is 1-800-937-8281 EXT. 2836. Tell Jean how many consumers are on the list.
- 3) **Jean Wilson will put that information into her computer.** The computer will select 15 consumers from your list by giving you line numbers to match with consumers on your list. These line numbers tell us which 15 numbered consumers have been selected for the survey.

The remaining material in this packet covers activities that will occur after selecting the consumer sample from your list(s). We will be going over these steps when we call and can answer any questions you may have.

Evaluation of Independent Living Centers
Consumer Contact Steps and Information

Steps for Contacting Consumers

These instructions identify how we would like you to contact consumers to be part of the survey for the Evaluation of Independent Living Programs.

The following steps are needed to complete the contacting of Center for Independent Living Consumers for the Survey:

- 1) **You will contact the consumers Jean has asked you to contact.** The information you need to know to contact the consumers for the study is given in the **Consumer Contact Steps and Information**. Please complete this process by June 29, 2001. If you are not able to reach the consumers at the telephone number they gave you, please try to reach them through other contact information you may have in their file.
- 2) **If you are unable to reach a consumer by telephone (either theirs or another contact's telephone number), mail them one of the enclosed postcards.** Be sure you fill in the name of the consumer, sign it, and fill in the name of your CIL as well.
- 3) **Do not substitute one consumer for another.** If you are not able to reach a consumer or have them agree to participate in the study, tell us that. We need to know how many of the selected consumers agreed to participate and how many were not contacted or refused to participate for statistical purposes. We do not need the names and telephone numbers of consumers who refuse to participate or who can not be reached.
- 4) **Once you have contacted the consumer and secured permission from them, you will give Jean the information from the attached "Tracking Calls for Scheduled Interviews" form for each consumer who agrees to be part of the study:** name, address, telephone number, best time to contact the consumer, and any accommodations they will need to complete the survey. Please contact Jean no later than July 6, 2001.
- 5) **If they have an interpreter they usually use, or want us to interview a proxy, be sure to get that person's name and telephone number.** We would prefer to interview the consumer, rather than a proxy, if at all possible. Although proxies will not be paid for their participation, interpreters/translators will be paid \$50 for their time. Please advise consumers and/or any interpreters or translators you speak with that \$50 is the only amount we will pay for the translator's/interpreter's participation in the survey.
- 6) **Please call Jean with this information. We also need you to send the completed form to us.** You may send this file to Jean via email (WILSONJ1@westat.com), via fax (301-294-2829 or 301-610-5128) or by mail in the enclosed envelope:

Jean Wilson
1650 Research Blvd
RP 4027
Rockville, MD 20850.

- 7) **Westat will then contact these consumers and conduct the interview.** *Each consumer who completes the survey will receive \$10 as a thank-you gift for participating.*

Consumer Contact Information

Suggestions for Contacting Consumers

- Make a minimum of **four** attempts to reach the consumer (different times in the day and different days of the week). Some people can only be reached on the weekends. Other people may need a postcard mailed to them, and they will contact you. *The attached grid will help you keep track of the calls and when the scheduled interviews will take place.*
- Explain the purpose of the study.
- Emphasize that this is a phone interview, but if an interpreter is needed, we can accommodate the interpreter's schedule.
- If necessary, we can mail the questionnaire, but this is only as a last resort. The questionnaire is designed to be a telephone interview.

Talking Points

- The survey will take only 30 minutes.
- All information gathered will be strictly confidential, and no identifying information will be released.
- The survey is being conducted by Westat, a research firm in Maryland, contracted by the Rehabilitation Services Agency, Department of Education.
- It should be pointed out that they (the consumer) will be assisting RSA and Westat in the gathering of information on consumer satisfaction with services they receive from CILs. However, their responses will NOT be associated with their CIL. It is a survey of consumers from many CILs. We are offering \$10 for their participation.

Who Can Be A Proxy

The proxy should live with the consumer or spend most of their time caring for the consumer on a daily basis. A proxy should be able to answer questions for the consumer as if they were the consumer. Tell the proxy the questions will ask about the consumer's experiences with the Center; the consumer's satisfaction with the services they received from the Center, plus questions about the consumer's life in general. If the proxy does not feel comfortable answering those kinds of questions for the consumer, then another proxy needs to be designated. A proxy can be the consumer's:

Caretaker

Spouse

Adult Child

Sibling

Anyone else who knows the consumer really well and who has been designated by the consumer as a proxy.

A proxy will not be paid for their participation in the survey. Employees of the CIL can not act as proxies for this questionnaire.

Who Can Be Interpreters/Translators

The interpreter can be the consumer's:

Caretaker

Spouse

Child aged 14 or older

Sibling

Anyone else who has been designated by the consumer as an interpreter.

The interpreter can also be a paid professional interpreter/translator.

Anyone who acts as an interpreter/translator will be paid \$50.

Remember: We can administer the questionnaire directly to the consumer in Spanish. Therefore, Spanish speaking consumers should not need an interpreter.

Employees of the CIL can not act as interpreters/translators for this study.

Suggested Script

Good Morning (afternoon), may I please speak with _____(name of consumer)? (If they are not at home, find out when a good time would be to call them back.)

OR

Good Morning (afternoon) _____(consumer's name). My name is _____(your name). I am calling from _____(name of CIL) to ask you to participate in an important study sponsored by the Rehabilitation Services Administration of the U.S. Dept. of Education. With your permission, a representative from Westat, a research firm hired to conduct the study, will be calling you to conduct the interview. The survey will take approximately 30 minutes. Your answers to the questions will be kept confidential and will be used only for the purpose of this study. You will be given \$10 for your efforts. May I give your name, address, and telephone number to Westat so that you can be part of this study?

Evaluation of Independent Living Centers

Consumer Contact Materials

Name of Consumer	Date of Birth	Area Code/ Phone No.	Day of Call	Time Called	Outcome of Phone Call If telephone disconnected or consumer no longer at that telephone number, send postcard.	Address of Consumer House Number, Street, Apt # City, State, Zip Code	Best Days/Times for Interview (DO NOT SCHEDULE A SPECIFIC TIME)	ACCOMMODATIONS if needed (interpreter name and telephone number/ proxy name and telephone number) or Comments
<i>Example: Mary Brown</i>	<i>8/8/55</i>	<i>301-641-1121</i>	<i>Wed.</i>	<i>11:00 AM</i>	<i>Consumer not in</i>	<i>14 Windmill Road Silver Spring, MD 20902</i>	<i>After 6:00PM Mon, Wed, Fri</i>	<i>Caregiver answered; will speak with consumer on return to see if she is willing to do interview</i>
					Date postcard sent:			
					Date postcard sent:			

Name of Center

Dear -----

We were looking at some of our consumer records and were unable to reach you when we tried to call. Please contact us as soon as possible. We would like to update our records with your current information.

We would also like to speak with you about being part of a national evaluation of centers for independent living. If you agree to be part of this evaluation and are selected to be interviewed, you will be paid \$10 and will only need to complete a 30 minute telephone questionnaire. If you need an interpreter/translator, that person will also be reimbursed for their time as well.

Sincerely,
