

Department for Aging and Rehabilitative Services



Centers for Independent Living Survey

Insight into the CIL Experience

November 2014

Centers for Independent Living (CILs) Survey: Insight into the CIL Experience

Centers for Independent Living (CILs) are private nonprofit organizations controlled and administered by people with disabilities.

- CILs provide services and advocacy to promote the leadership, independence, and productivity of people with disabilities.
- CILs work with individuals as well as local communities, to remove barriers to independence and ensure equality of persons with disabilities.

The Department for Aging and Rehabilitative Services (DARS) has oversight and fiscal responsibility for state funding provided to the 16 Virginia CILs and 4 satellite CILs. This oversight is provided through the DARS Independent Living (IL) Office.

During Federal Fiscal Year 2014 (October to April), a DARS web survey was available to Virginia CIL consumers with short or long term goals. The survey was designed to learn about the Virginia CIL experience as perceived by consumers. Insights gained from survey responses show CILs have addressed issues impacting consumers' lives and contributed to changes in their lives and communities.

Consumers Connected with CILs for Numerous Reasons

Insights gained from the survey were based on 597 consumers who indicated they were receiving or had received CIL services. The most frequently mentioned reasons for these consumers visiting a CIL were related to:

- housing or home modifications,
- personal care or assistance in their home, and
- Medicaid waivers or facilitation.

Eighty-four Percent Reported What Changed Most in Their Lives

When consumers were asked what had changed most in their lives as a result of working with the CIL, top mentioned changes were related to:

- feelings or attitudes about themselves,
- their independence, and
- their ability to be more social or involved in recreation.

Fifty-nine Percent Decided on Services on their Own or With Staff Assistance

An important aspect of CIL service is consumer control in decision making and service delivery. Consumers shared who decided on services they received.

- Fifty-nine percent decided on their own or with assistance of CIL staff.
- Thirty-four percent decided with family/friends or with assistance of CIL staff and family/friends.
- The remaining consumers indicated CIL staff or other combinations of assistance.

Forty-nine Percent Reported What Changed Most in Their Communities

In the recent survey, consumers reported what had changed most in their communities as a result of having a CIL in the area. While consumers reported mostly things that impacted them or their families, other top mentioned changes were related to:

- accessibility,
- CIL as an asset in the community, and
- community awareness.

A Closer Look into the CIL Experience

Further insight into the CIL experience was obtained through consumers sharing how they learned about the CIL, the skills they learned, and the assistance received from CILs and CIL staff. Friends, family, and DARS were the top three ways consumers learned about the CIL. Once connected with the CIL, consumers developed skills related mostly to advocacy, independence or independent living, and transportation.

Assistance Received from CILs

Consumers selected ways they were assisted by CILs from a pre-identified list of areas of assistance. Top mentioned responses showed CILs assisted consumers in:

- becoming more independent in at least one area of life,
- improving ability to advocate or speak up, and
- learning new skills and making better decisions.

Some consumers provided additional or more specific ways they were assisted by CILs. The most frequently mentioned areas were related to:

- housing or home modifications
- personal care or assistance in their home, and
- Medicaid waivers or facilitation.

Assistance Received from CIL Staff

Consumers also reported ways they were assisted by CIL staff from a pre-identified list. Based on top mentioned responses, staff assisted consumers in providing:

- necessary information or tools to make decisions,
- steps that could be taken, and
- encouragement to take the lead.

Additional or more specific means of staff assistance were provided by some consumers. The most frequently mentioned areas were related to staff:

- providing lists, information, or resources;
- assisting with housing or home modifications; and
- assisting with personal care or assistance in their home.

Twenty-five percent of consumers provided additional comments at the end of the survey. Their comments continued to describe primarily CIL appreciation and assistance.

I went to the CIL: Independent living skills training and sign language. I learned: Reading, sign language. What has changed most in my life: Read my own mail, tell time, shop for myself, pay my own bills, take care of my own home, call 911, how to be around other people and got driver's license. What has changed most in my community: People coming together and helping each other. Other comment: The Center has taught me to read and that has changed my life. I can even go into a restaurant and read the menu and order for myself. I understand directions better, too.

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About the Survey of CIL Experience

The recent DARS survey was designed to gain insights into the Virginia CIL experience as perceived by consumers; it was not designed to make generalizations about the Virginia CIL population. The DARS web survey was available from October 16, 2013 to April 7, 2014 for all consumers with short or long term goals.

Each CIL was asked to promote the survey to their consumers and follow, to the extent feasible, the survey guidelines. Paper survey completions were mailed to DARS and entered by a DARS Program Support Technician. Self-reported zip codes showed respondents were receiving services or had received services from the Virginia CILs.

Respondents in the Survey

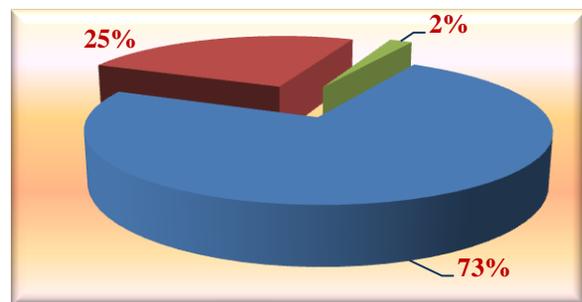
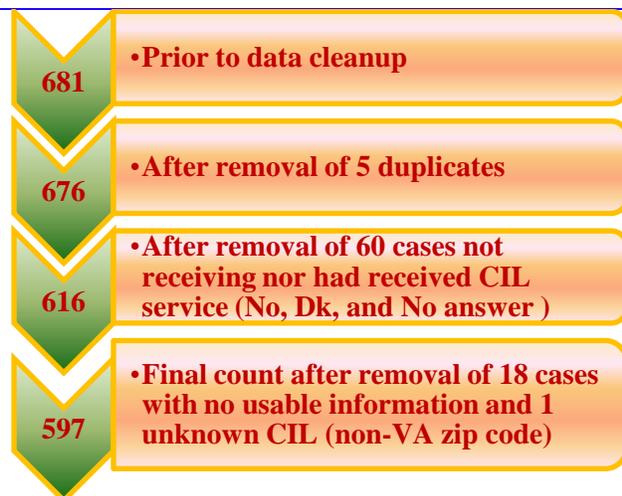
The analysis was based on 597 survey respondents and these respondents self-reported whether they were consumers or had

completed the survey on behalf of a consumer. Responses to survey questions appeared to be candid and represented a consumer experience. Examination of open-ended comments and consumers' ages suggests:

- Some individuals who indicated they completed the survey on behalf of a consumer (such as CIL staff, agency staff, friend, or co-worker) probably assisted the consumer by explaining questions or writing responses.
- Parents of younger children and some family members completing the survey on behalf of elders provided comments that suggest they were consumers seeking CIL assistance for their loved one.

While a small percentage of respondents did not disclose who completed the survey, their comments reflected a consumer experience. Graphs depicting final respondents and their demographics are provided below.

Path to 597 Respondents for Analysis and Self-reported Description of Respondent

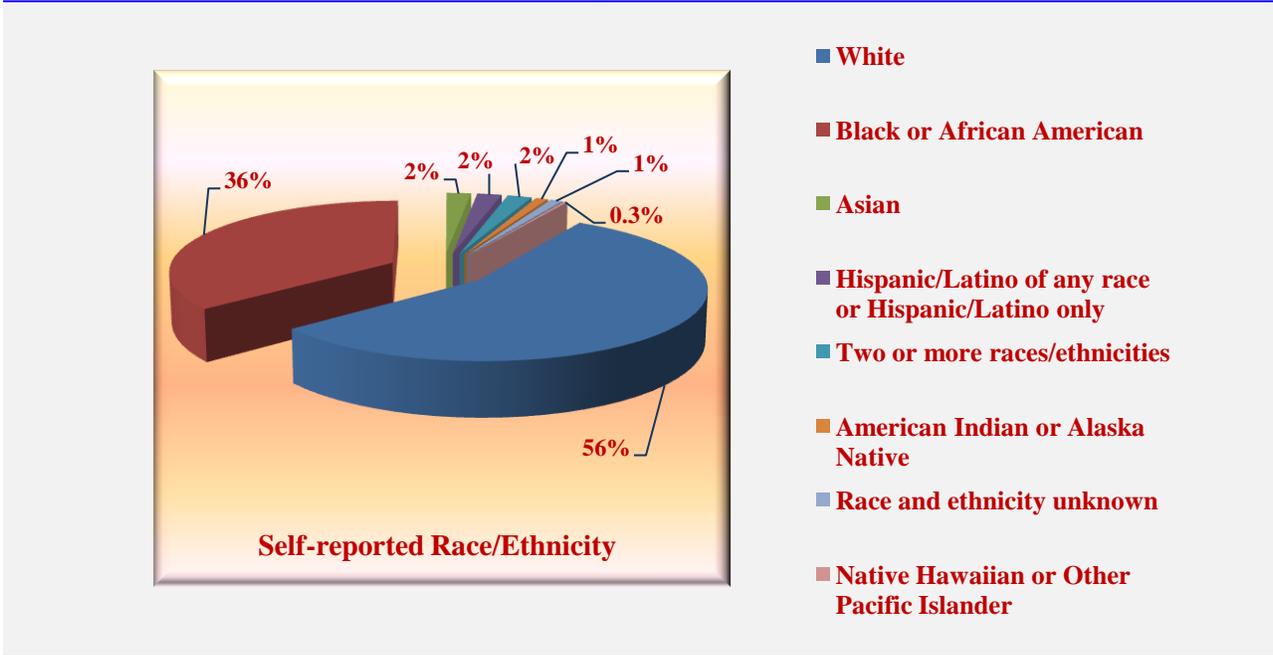
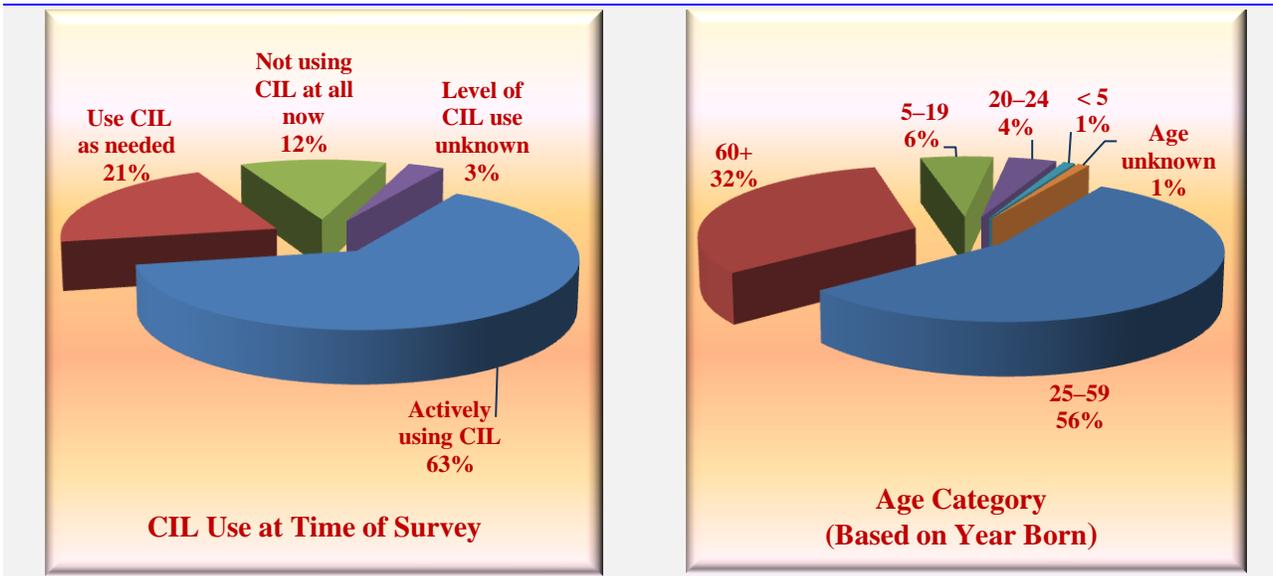


- Consumer
- Completed on behalf of consumer
- Did not indicate who completed the survey

Close to 75 percent of respondents who indicated they completed the survey on behalf of a consumer were family/relatives [parents/guardians (47 percent), children/grandchildren (16 percent), in-laws/step/cousin/niece (11 percent), and spouse (2 percent)].

Centers for Independent Living (CILs) Survey: Insight into the CIL Experience

CIL Use, Age, and Race for 597 Respondents



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Survey Analysis Notes

Since one-on-one interviews and focus groups are costly, the survey was developed with a focus on drawing out qualitative information to help tell a story about the work of Virginia CILs. Thus, survey questions were developed with a focus on questions most relevant to information the survey team was seeking (*consumer direction, service, and CIL outcomes*). Demographic questions were added to provide insight about the type of individual responding to the survey.

At the end of the survey period, data were examined for key questions related to receipt of CIL services, the individual completing the survey, level of CIL use, and level of consumer decision making. Final data cleanup was then performed and resulted in 597 respondents included in the analysis.

Percentages for demographics and consumer choice in decision making were based on number of consumers using IBM SPSS (Statistical Package for the Social Sciences) Frequency Analysis. The SPSS Multiple Response Analysis was used for the various open-ended questions as well as questions where consumers could select all that apply. Percentages for these questions were based on number of responses since the primary focus was to capture all responses provided by consumers.

- Coding of open-ended responses was conducted in Microsoft Excel and merged with other survey data in SPSS.
- Attempts were made to keep coding of open-ended responses close to actual consumer responses rather than fit them into pre-determined categories. This allowed for a wider view of consumer responses.
- Codes for open-ended responses were created by a DARS research analyst and reviewed by an IL staff member on the CIL survey team.
- Actual open-ended comments were also joined together to provide individual respondent stories for sharing CIL accomplishments. Several samples are provided in this Appendix.

Sample of Stories Developed from Open-Ended Comments

<p><i>I went to the CIL:</i> Housing - getting out of nursing home. <i>I learned:</i> Living on my own. <i>What has changed most in my life:</i> I am not in a nursing home. <i>Other comment:</i> I would still be in a nursing home without help.</p> <p><i>I went to the CIL:</i> I needed to locate personal attendant services for my granddaughter. <i>I learned:</i> There are not only agency personal attendants but also consumer-directed services. <i>What has changed most in my life:</i> My granddaughter is getting services necessary for a more independent life style. <i>What has changed most in my community:</i> Many disabled children and people are gaining more independence on managing their own lives. <i>Other comment:</i> The CILs are great advocates for disabled people and for the community at large.</p>	<p><i>I went to the CIL:</i> To learn more about my disability rights. <i>I learned:</i> My own self importance as an individual with a disability. <i>What has changed most in my life:</i> My independence, and my fear of what would happen to me as a person with a disability if I didn't have services in place. <i>What has changed most in my community:</i> We got a lot more ramps. I am able to go to stores by myself because of this. <i>Other comment:</i> All of the CILs are needed for every person with a disability and for parents of those with disabilities. I hope CILs will be around for a long time.</p>
<p><i>I went to the CIL:</i> I needed housing, employment and disability supports. <i>I learned:</i> Interpersonal skills, learned how to ask for help, and learned how to set realistic goals. <i>What has changed most in my life:</i> Housing has improved and no longer being homeless. Having someone who understands my disability and situation, I can sound off to them without being judged. <i>What has changed most in my community:</i> The CIL has worked to educate individuals in the community about affordable and accessible housing, educate about resources for people with disabilities and has tried to mesh the able bodied and disabled community together to increase understanding. <i>Other comment:</i> The advocates really care. They will call you on their days off and try to resolve issues for you. Even if they can't help you with the resolution of a problem, they are there to listen. They understand, they've been through it. They are not in the position just to earn a check.</p>	<p><i>I went to the CIL:</i> Assistance with transportation issues and advocating for myself. <i>I learned:</i> Advocacy, word choice, navigating tons of resources, learning from people that have similar disabilities and sharing experiences. <i>What has changed most in my life:</i> Confidence, greater access, knowledge of my rights, laws and other things important to being successful. <i>What has changed most in my community:</i> Improved services/programs for ALL people with disabilities. <i>Other comment:</i> There is currently no other agency like the Centers of Independent where services and programs are run and governed by actual persons with disabilities. It is vital for one's success to see persons in the exact place you desire to be in when you arrive for your initial intake - that is, gainfully employed, masterful over their disability, comfortable in their abilities, knowledgeable about resources available and experienced to share pros and cons of anything you can think to ask about.</p>

What was your main reason for going to the CIL?

Ninety-seven percent (n=579) of consumers provided reasons for going to the CIL. Percentages are based on number of responses (n=721) since some consumers provided multiple reasons.

Response Category	Responses	
	N	Percent
housing/home modifications	118	16
personal care/assistance in their home	92	13
Medicaid waivers/facilitation	56	8
assistance with services	42	6
skills	39	5
assistive technology	38	5
vocational	38	5
knowledge of services	36	5
social/recreation	36	5
mobility/transportation	31	4
improve independence	21	3
counseling/mentoring/support	18	2
physical issues	18	2
advocacy	15	2
move out of NH	14	2
other	13	2
money management	12	2
SSA/payee	11	2
live/stay in home/community	10	1
recommended/referred by others	10	1
education/training	9	1
medications	8	1
knowledge of disability	6	1
technology/use of technology	6	1
communication	5	1
youth	5	1
volunteer	3	0.4
accessibility	2	0.3
events and activities	2	0.3
feeling/attitude about self	2	0.3
Money Follows the Person (MFP)	2	0.3
health/life	1	0.1
improve community accessibility	1	0.1
improve quality of living	1	0.1

What has changed most in your life as a result of working with the CIL?

Eighty-four percent (n=500) of consumers reported what had changed most in their lives. Percentages are based on number of responses (n=631) since some consumers provided multiple changes in their lives.

Response Category	Responses	
	N	Percent
feeling/attitude about self	88	14
independence	77	12
social/recreation	62	10
personal care/assistance in their home	44	7
remain in home/community	41	6
mobility/transportation	38	6
housing/home modifications	33	5
advocacy	24	4
vocational knowledge/outcome	21	3
quality of life/health	17	3
awareness/understanding of services	16	3
communication	16	3
access to services	14	2
increased functions	14	2
living alone	14	2
assistive technology	13	2
have support	10	2
nursing home – not in one/relocation from	10	2
disability understanding/adjusting	9	1
money management	8	1
other	8	1
understanding of/improved independent living	8	1
physical restoration	6	1
improved assistance for caregiver	5	1
living arrangement	5	1
accessibility	4	1
counseling/mentoring/support	4	1
education/training	4	1
medical/medication	4	1

Response Category	Responses	
	N	Percent
skills	4	1
CIL worker/volunteer	3	0.5
partners in policymaking	2	0.3
tell others about CIL	2	0.3
assistance	1	0.2
direction	1	0.2
technology	1	0.2

In working with the CIL, who has decided on the services to assist you?

Ninety-six percent (n=576) of consumers reported who decided on services they received. Percentages are based on the number of consumers (n=576).

Category	Consumers	
	N	Percent
I have	159	28
CIL staff	26	5
I have with assistance of CIL staff	180	31
I have with the assistance of family or friends	73	13
I have with assistance of CIL staff and family or friends	120	21
Other combinations of assistance*	18	3

*Other combinations represents consumers who created their own combination of who decided on services (As an example, one consumer indicated he/she did and CIL staff while another consumer indicated CIL staff and I have with CIL staff). The self-created combinations suggest that “who decided” depended on the decision being made.

What has changed most in your community as a result of having the CIL in your area?

Forty-nine percent (n=290) provided answers to this question. Percentages are based on the number of responses (n=316) since some consumers provided multiple changes.

Response Category	Responses	
	N	Percent
personal/family impact	57	18
accessibility	34	11
CIL asset in community	34	11
community awareness regarding individuals with disabilities	30	9
more people being helped/seeking help	25	8
access to services/resources	20	6
consumer now advocate/CIL advocate	18	6
more independence/interaction	18	6
attitudes towards people with disabilities	13	4
advocacy	12	4
more awareness of assistance/services	8	3
choice regarding living in home/community	6	2
other	6	2
transportation	6	2
housing for people with disabilities	5	2
more informed about CIL	3	1
better supported	2	1
city official support	2	1
higher quality of life	2	1
less people in nursing homes	2	1
public ADA compliance	2	1
sense of community	2	1
connection with others	1	0.3
freedom	1	0.3
improved functions	1	0.3
lives	1	0.3
more individuals aware of rights	1	0.3
more living alone	1	0.3
new laws related to disability	1	0.3
safer	1	0.3
saving the taxpayer	1	0.3

If you would like to share more about how the CIL has helped you or your family, please provide your comments.

Twenty-five percent (n=149) of consumers provided answers to the question. Percentages are based on the number of responses (n=169) since some consumers mentioned several things.

Response Category	Responses	
	N	Percent
CIL appreciation	62	37
CIL accomplishment	39	23
staff appreciation	24	14
general satisfaction	15	9
consumer needs help	9	5
CILs need support/funding	4	2
other	3	2
staff accomplishment	3	2
would refer CIL	3	2
possible un-served area	2	1
advocacy	1	1
consumer accomplishment	1	1
like to see more detail on some CIL skills training	1	1
social/recreation	1	1
thanks to person who referred consumer to CIL	1	1

If you have received services or currently receiving services from a Center for Independent Living (CIL), how did you learn about the CIL?

Ninety-eight (n=583) percent of consumers provided answers to the question. Percentages are based on number of responses (n=599) since some consumers provided multiple sources.

Response Category	Responses	
	N	Percent
friend	143	24
family	126	21
DARS	76	13
did not indicate name of other source	68	11
social services	44	7
agency/program	40	7
brochure/news/phone/internet	18	3
doctor/hospital/medical	18	3
social worker/counselor/case manager	16	3
school	15	3
CIL or CIL staff	8	1
current/former CIL client/CIL board member or worker	8	1
other individuals	8	1
church/county/shelter	5	1
on my own	4	1
event	2	0.3

What new skill(s) have you learned as a result of working with the CIL?

Sixty-eight percent (n=405) of consumers provided skills learned as a result of working with the CIL. Percentages are based on total responses (n=558) since some consumers mentioned multiple skills.

Response Category	Responses	
	N	%
advocacy	116	21
being independent/independent living	83	15
transportation	49	9
social/recreation	39	7
personal care/assistance in their home	34	6
access contacts/resources/services	33	6
feeling/attitude about self	27	5
money management	26	5
vocational	21	4
communication	20	4
technology – computer	18	3
gaining/use of assistive technology	14	3
applying/information on housing/modifications	12	2
decision making/choice	12	2
general learning	9	2
mobility in and around home	9	2
disability training	8	1
other assistance	4	1
art/craft	2	0.4
health	2	0.4
leadership	2	0.4
peer counseling	2	0.4
timesheets/scheduling	2	0.4
understanding CIL program	2	0.4
CIL volunteer/board	1	0.2
economic	1	0.2
education	1	0.2
housing	1	0.2
issues	1	0.2
other	1	0.2

Response Category	Responses	
	N	%
physical restoration	1	0.2
power of attorney	1	0.2
reservations	1	0.2
resourceful	1	0.2
supervisory	1	0.2
word choice	1	0.2

How has the CIL assisted you?

Eighty-seven (n=521) percent of consumers provided answers to the question. Percentages are based on number of responses (n=1436) since consumers could select all that applied to them.

Response Category	Responses	
	N	Percent
becoming more independent in at least one area of my life	369	26
improving my ability to advocate or speak up for myself to get services I need	289	20
learning new skills and making better decisions	248	17
gaining access to transportation that was not available to me	179	12
gaining access to assistive technology that was not available to me	166	12
changing things in my community to assist people with disabilities	139	10
moving from a nursing home to a place in the community	46	3

Additional or specific CIL assistance shared by consumers

Twenty-percent (n=118) of the consumers provided additional or other specific assistance received from the CILs. Percentages are based on number of responses (n=129) since some provided more than one type of assistance.

Response Category	Responses	
	N	Percent
housing/home modifications	24	19
personal care/assistance in their home	23	18
Medicaid waivers/facilitation	15	12
remain in home	8	6
vocational knowledge/outcomes	7	5
assistance with services	6	5
mobility/transportation	6	5
other	5	4
social/recreation	5	4
advocacy	4	3
feeling/attitude about self	4	3
medical/medication	3	2
prevent nursing home/institution	3	2
communication	2	2
lists/information/resources	2	2
live alone	2	2
money management	2	2
SSA	2	2
counseling/mentoring/support	1	1
knowledge of disability	1	1
physical restoration	1	1
skills	1	1
working towards goals	1	1
youth	1	1

How has CIL staff assisted you with what you want to do?

Eighty-nine percent (n=532) reported how CIL staff had assisted them. Percentages are based on total number of responses (n=1244) since consumers could select all that applied to them.

Response Category	Responses	
	N	%
provided me with necessary information/tools to make right decisions	412	33
provided me with steps that could be taken to get me where I want to go	328	26
encouraged me to take the lead in developing my goals or plans	298	24
assisted me in deciding on what I want to do or where I want to go in life	206	17

Additional or specific staff assistance shared by consumers

Eleven percent (n=64) of consumers provided additional or other specific assistance received from staff. Percentages are based on number of responses (n=66) since some provided more than one type of assistance.

Response Category	Responses	
	N	%
lists/information/resources	11	17
housing/home modifications	7	11
personal care/assistance in their home	7	11
assess/explain/decision	5	8
feeling/attitude about self	5	8
remain in home	5	8
Medicaid waivers/facilitation	4	6
family	3	5
transportation	3	5
ADA/advocacy	2	3
assistive technology	2	3
counseling/mentoring/support	2	3
education/training	2	3
medical/medication	2	3
other	2	3
physical restoration	1	2
quality of life	1	2
social	1	2
vocational	1	2

Demographic Information

Self-Reported Description of Respondents

Category	N	%
Consumer	433	73
Completed on behalf of consumer	150	25
Did not indicate who completed the survey	14	2

Self-reported Description of CIL use at time of the survey

Category	N	%
Actively using	378	63
Use as needed	126	21
Not using at all now*	73	12
Level of use unavailable	20	3

*Eighty-six percent of consumers not using the CIL at the time of the survey reported they would return if they needed additional services.

Age based on self-reported year born

Category	N	%
Ages 25–59	336	56
Age 60 and Older	191	32
Ages 5–19	34	6
Ages 20–24	25	4
Age unavailable	8	1
Under 5 years old	3	1

Self-Reported Race/Ethnicity

Category	N	%
White	336	56
Black or African American	213	36
Two or more races-ethnicities	14	2
Hispanic/Latino of any race or Hispanic/Latino only	12	2
Asian	11	2
Race and ethnicity unknown	6	1
American Indian or Alaska Native	3	1
Native Hawaiian or Other Pacific Islander	2	0.3

Survey Questions

Before we begin the survey, we would like to learn a little about you. [If you are completing the survey on behalf of a person with a disability, please answer all questions based on that individual.]

1. What is your current zip code? _____

2. In what year were you born? (For example, 1970) _____

3. Please select ONE (1) answer that best describes your race/ethnicity.

_____ American Indian or Alaska Native

_____ Asian

_____ Black or African American

_____ Native Hawaiian or Other Pacific Islander

_____ White

_____ Hispanic/Latino of any race or Hispanic/Latino only

_____ Two or more races/ethnicities

_____ Race and ethnicity unknown

If other, please specify _____

4. Have you received or are you currently receiving services from a Center for Independent Living (CIL) in Virginia?

_____ Yes

_____ No

_____ I don't know

IF YOU HAVE RECEIVED OR ARE CURRENTLY RECEIVING CIL SERVICES, PLEASE CONTINUE WITH THE SURVEY.

5. If you have received services or are currently receiving services from a Center for Independent Living (CIL), how did you learn about the CIL?

_____ Family

_____ Friend

_____ Department for Aging and Rehabilitative Services (DARS) [formerly Department of Rehabilitative Services (DRS)]

_____ Other service providers

Other (please specify) _____

6. What was your main reason for going to the CIL? _____

7. How has the CIL assisted you? The CIL has assisted me in ... (Select all that apply)

- Moving from a nursing home to a place in the community
- Gaining access to transportation that was not available to me
- Gaining access to assistive technology that was not available to me
- Changing things in my community to assist people with disabilities
- Improving my ability to advocate or speak up for myself to get services I need
- Learning new skills and making better decisions
- Becoming more independent in at least one area of my life
- Other (please specify) _____

8. What new skill(s) have you learned as a result of working with the CIL?

9. What has changed most in YOUR LIFE as a result of working with the CIL?

10. What has changed most in YOUR COMMUNITY as a result of having the CIL in your area?

11. In working with the CIL, who has decided on the services to assist you? (Select only one)

- I have
- CIL staff
- I have with the assistance of CIL staff
- I have with the assistance of family or friends
- I have with the assistance of CIL staff and family/friends
- Other (please specify) _____

12. How has CIL staff assisted you with what you want to do? The CIL staff has ... (Select all that apply)

Assisted me in deciding on what I want to do or where I want to go in life

Provided me with steps that could be taken to get me where I want to go

Encouraged me to take the lead in developing my goals or plans

Provided me with necessary information/tools to make right decisions

Other (please specify) _____

13. Please select the answer that best describes how you are using the CIL now?

I am actively using the CIL to help me

I use the CIL as needed

I am not using the CIL at all now

Other (please specify) _____

14. If you are not currently using the CIL, would you return to the CIL if you needed additional services?

Yes

No

I don't know

15. Please select the answer that best describes who completed this survey.

I am receiving or have received CIL services and I completed this survey on my own or with help from someone.

I am completing this survey on behalf of someone who is receiving or has received services CIL services.

My relationship to the individual is _____.

We thank you so much for taking the time to complete this survey. If you would like to share more about how the CIL has helped you or your family, please provide your comments.
