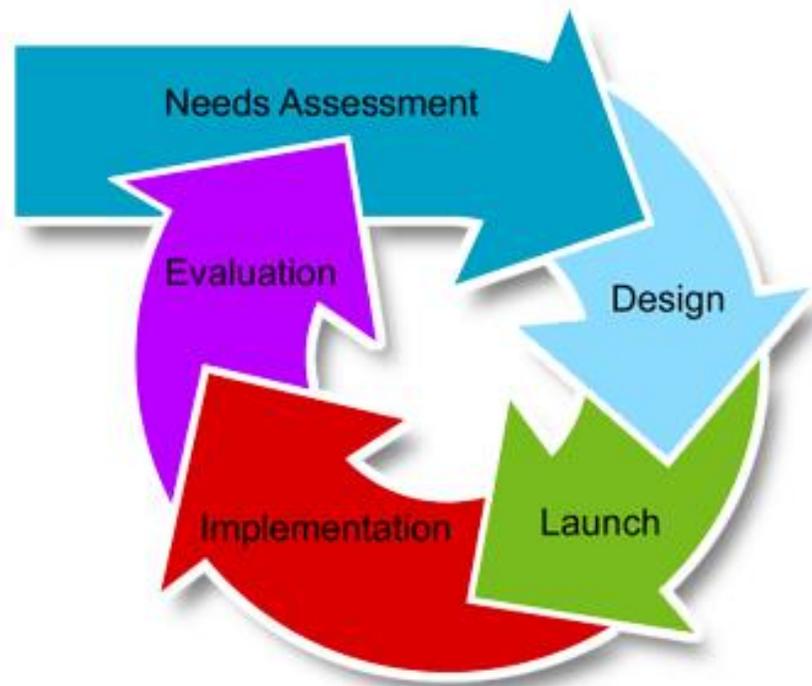


2014-5 RISILC Disability Needs Assessment Survey Results Summary



RI Statewide Independent Living Council

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Background

The Rhode Island Statewide Independent Living Council (RISILC) is a non-profit organization dedicated to promoting Independent Living for consumers with disabilities throughout the state. The Council is federally-mandated under the Americans with Disabilities Rehabilitation Act (ADA) and the majority of its members are required to be persons with disabilities. The Council in collaboration with the Centers for Independent Living are responsible for developing a three year plan which directly addresses the needs that are important to the advancement of Independent Living for consumers with disabilities. The State Plan is responsible for bringing in over one million federal dollars into Rhode Island.

The RISILC's Needs Assessment Committee is consumer controlled. Their task is to gather the needs of consumers in Rhode Island relative to Independent Living. The Independent Living philosophy is about empowering consumers with disabilities to manage and control their own lives. Independent Living is the belief that consumers have the right to make their own choices, and the right and opportunity to live in and be able to access the community like everyone else. This is made possible through community-based services, such as home modifications, assistive technology, information and referral, personal care assistance, peer mentoring, daily living skills training, and advocacy.

Methodology

RISILC's Needs Assessment Committee redesigned the 2012 survey into a shortened user-friendly survey which could be completed in an average of 5 minutes or less. The process began in October 2013.

All survey questions were scrutinized to insure cross disability representation, consumer understanding, and questions which would provide the desired answers. Requirements to partake in the survey were 1} 18 years of age or older, 2} reside in Rhode Island, 3} have a disability, and 4} be cognitively able to provide your own answers. The final survey contained 10 survey questions and 10 demographic questions.

The key objective of the 2014-5 survey was to gather the unmet needs of consumers with disabilities in Rhode Island relative to Independent Living. The second objective was to determine if outreach services were needed for any areas or populations that were un-served or under-served such as the Hispanic, Native American, and Veterans. Also by considering barriers and determining what services were important to Rhode Islanders, advocacy efforts could be prioritized.

The survey and materials were translated into Spanish and large print then uploaded onto the RISILC website in a format compatible with JAWS reading software. Additionally, American Sign Language (ASL) video clips were filmed and were also available on the website.

Although the preferred mode of the survey was web-based, hard copies were available in regular or large print in English and Spanish. Phone surveys were also listed as an alternative mode of responding to the survey.

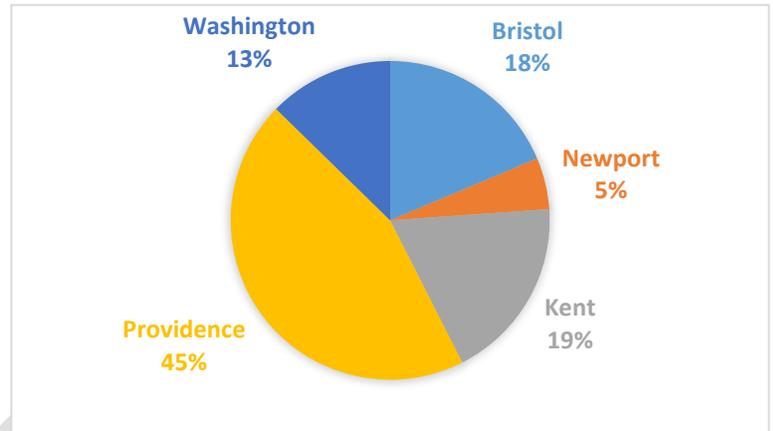
Survey participants were given the option to request information about the RISILC, OSCIL Independent Living Centers, and/or to enter into a gift card drawing. Because this required responders to provide their name and contact information, maintaining confidentiality was an essential part of the planning process. All answers were received and recorded separately; therefore, individual names were not connected to survey answers.

The survey information as well as hard copies of the survey were distributed from April 2014 to August 2015 via contact with disability organizations, presentations, conferences, Governor's Commission on Disabilities Public Forums, and public events.

Results

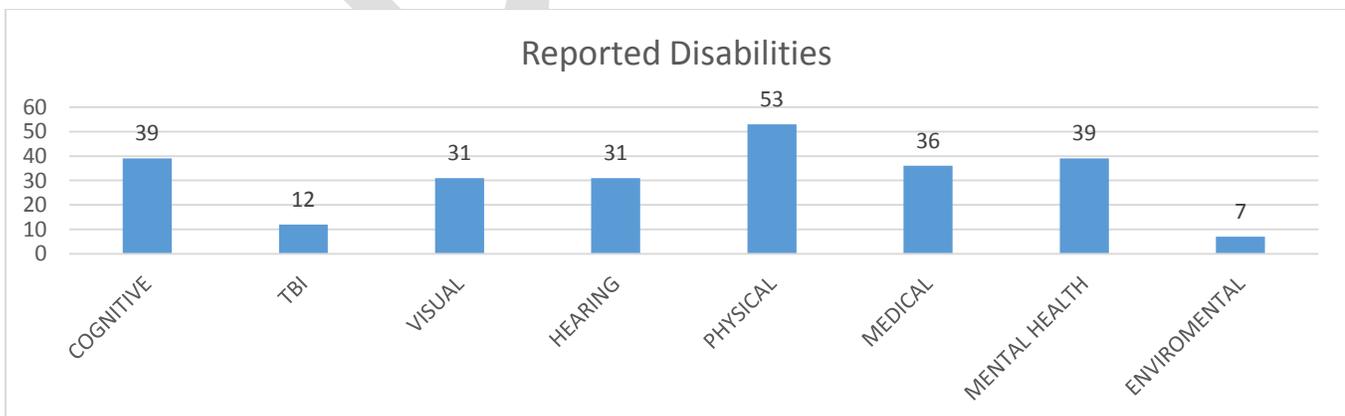
QUESTION 1: What is your zip code (or city or town) of residence?

All counties in Rhode Island were represented; the largest amount of participants were from Providence County with sixty (45%); the smallest from Newport County with seven (5%). Bristol County and Kent County each had twenty five (19%) participants; Washington County had seventeen (12%).

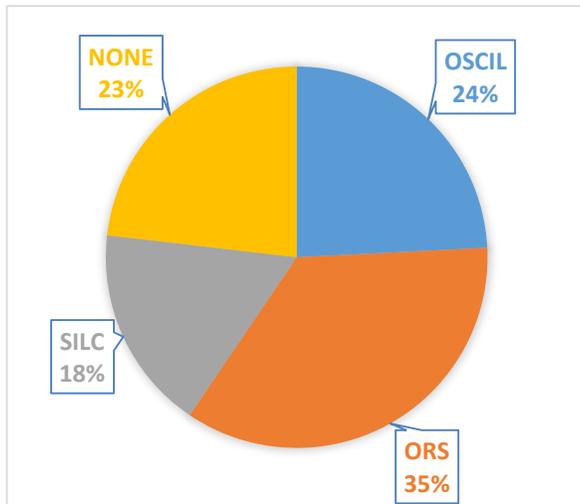


Question 2: What is your disability or condition? Check all that apply.

Survey participants were able to check multiple answers to describe their disabilities. Six consumers (4%) checked preferred not to answer or left the answer blank. Forty-eight consumers (38%) reported having more than one disability. The highest occurrence of disability reported was physical with fifty-three (41%) followed by cognitive and mental health each with thirty-nine (31%). Thirty six consumers (28%) reported having chronic medical issues; thirty-one (24%) visual disabilities as well as thirty-one (24%) reported being Deaf and/or Hard of Hearing. Twelve consumers (9%) reported having a traumatic brain injury and seven consumers (5%) an environment/chemical sensitivity.



Question 3: Are you familiar with any of the following organizations?

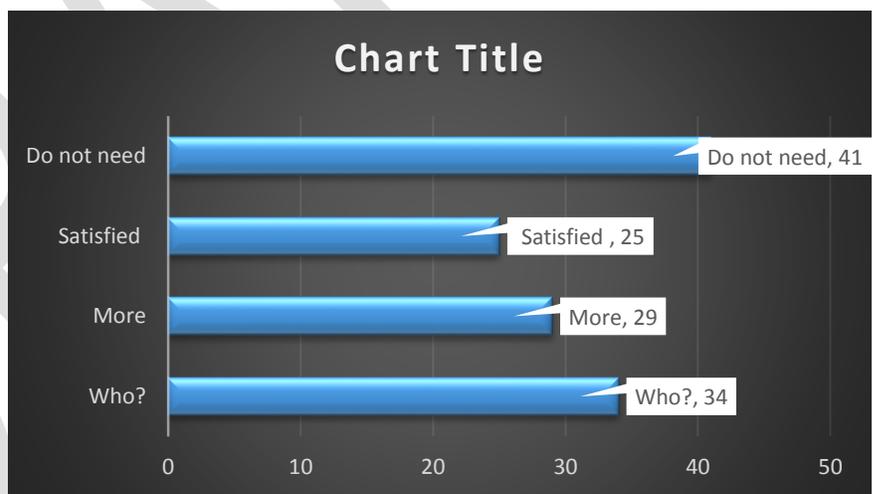


Survey participants were able to check all that applied. Sixty-seven participants (50%) reported that they were aware of the Office of Rehabilitation Services (ORS); forty-six (34%) were aware of the Ocean State Center for Independent Living (OSCIL); thirty-three (25%) were aware of the RI Statewide Independent Living Council (RISILC). Forty-four participants (33%) reported having no knowledge of the ORS, OSCIL, or RISILC.

Question 4: Which statement best described your current situation?

The choices were:

- **I do not know who to contact to get the IL services that I need.**
- **I need more IL services than I currently receive.**
- **I am satisfied with the IL services that I receive/received.**
- **I don't need IL services at this time.**



One hundred and twenty three consumers answered this question. Nine consumers chose more than one answer and, in all cases, also checked that they did not know where to get services.

Forty-one respondents (33%) reported that they do not need or use IL services at this time and twenty-five (20%) were satisfied with their current services. Twenty-nine participants (24%) reported that they needed more services than they current receive and thirty four (28%) did not know who to contact to access IL services.

Question 5: Which agencies currently provide you with IL services? Check all that apply. OSCIL, ORS, Mental Health Agency, Veteran’s Administration (VA), Other (Blank Line provided).

Sixty-four participants answered this question and reported receiving some type of IL services with nearly half listing more than one agency. Of the listed choices ten respondents (15%) were currently receiving services from OSCIL, twenty-three (36%) from ORS, seven from (11%) Mental Health Agency, and eleven (17%) from the Veteran’s Administration. Other agencies listed included day programs, Ride, family members, and medical services. See appendix Exhibit A for complete list.



Question 6: What IL services do you currently receive? (Blank lines provided.)

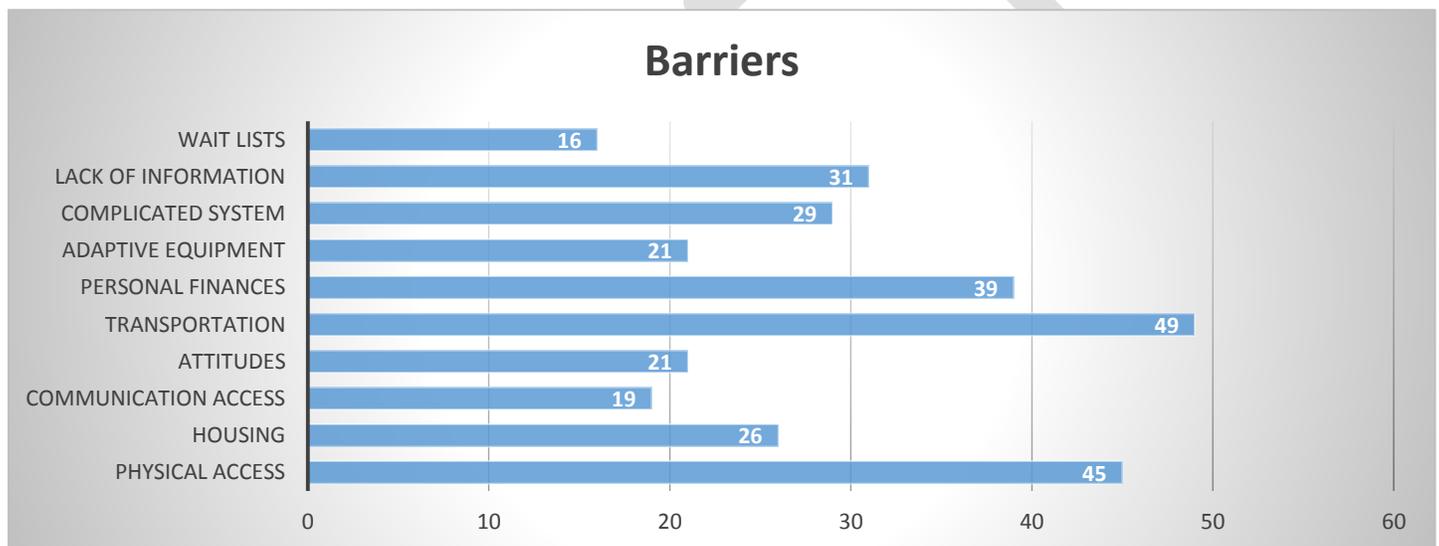
Answer: Fifty five respondents listed services that they currently received including Ride, CPA, vocational training, living skills, community supports, and day programs. See Appendix Exhibit B for complete list.

Question 7: List three IL services that you do not currently receive that would help you live more independently? (Blank lines provided.)

Forty-four participants listed IL services that they do not currently receive including some IL services that are offered by a Center for Independent Living and vocational services through ORS. Additional services needed included improved transportation, housing, and home aids beyond the role of the CPA. See appendix Exhibit C for list of services.

Question 8: What are your major barriers/obstacles that hinder your ability to live independently in the community and access public events? Choices given: Physical mobility access, communication access (ASL, CART, captions, braille), funding for adaptive equipment, reliable transportation, lack of information, accessible/affordable housing, attitudes/discrimination, personal financial resources, complicated system, waiting lists.

One hundred and eight participants listed at least one barrier; most responding with multiple answers. The top barriers were transportation (45%); physical access (42%); finance (36%); lack of information (29%); complicated system (27%); housing (24%). Also listed were discrimination (19%); adaptive equipment funding (19%); communication access (18%); wait list (16%).

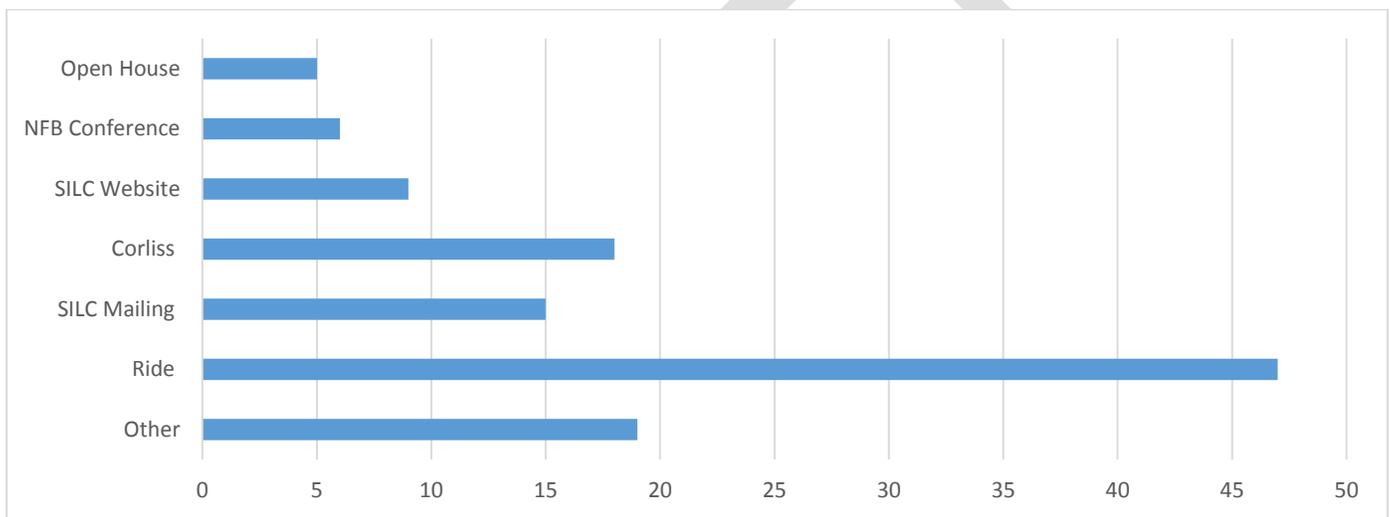


Question 9: Please list additional barriers or clarify information checked in #8. (Blank lines provided.)

Forty-six participants also listed additional barriers or provided clarification. Many included problems with transportation services, physical accessibility, and personal barriers unique to their own situation. See appendix Exhibit D for complete list.

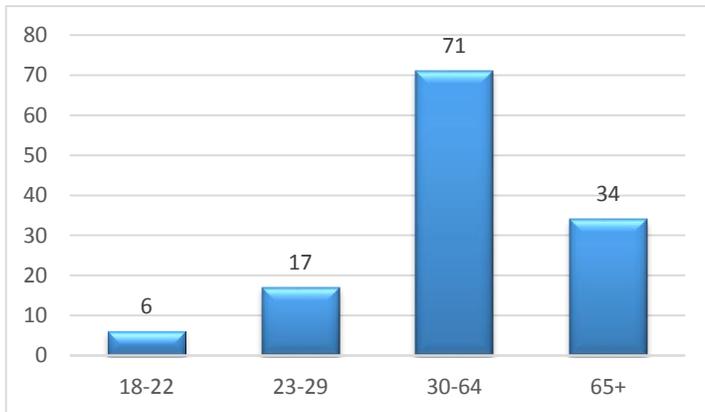
Question 10: Where did you hear about the survey? Choices: Email, Mail; Website, Name of website (Blank line provided); Conference/Presentation/event, Name of event (Blank line provided); Other (Blank lines provided).

One hundred and nineteen consumer answered this question. Eighty (67%) respondents identified hearing about the survey from the Ride Program (40%), Corliss (15%), and mailing to consumers who had taken the 2012 survey (13%). All eighty respondents had received a hard copy of the survey either in person or through the mail. Thirty nine identified other sources such as website, Facebook, email, and other events. See Exhibit E for complete list.



Demographics

Question 1: Please indicate your age category. Choices 18-22, 23-29, 30-64, 65 and older.



One hundred and twenty eight consumers answered this question. More than half of the respondents (55%) fell into the 30-64 age category; followed by 65+ (27%). Only twenty-three respondents were under age 30 and only six between the ages of 18-22.

Question 2: Do you identify yourself as one of the following? Choices: American Indian/Tribal; Hispanic or Latino; Neither.

Nine participants identified themselves as American Indian/Tribal and five as Hispanic/Latino.

Question 3: Are you a veteran? Choices: Yes; No.

Question 3A. If yes, do you receive service-connected services from the Veteran's Administration (VA)?

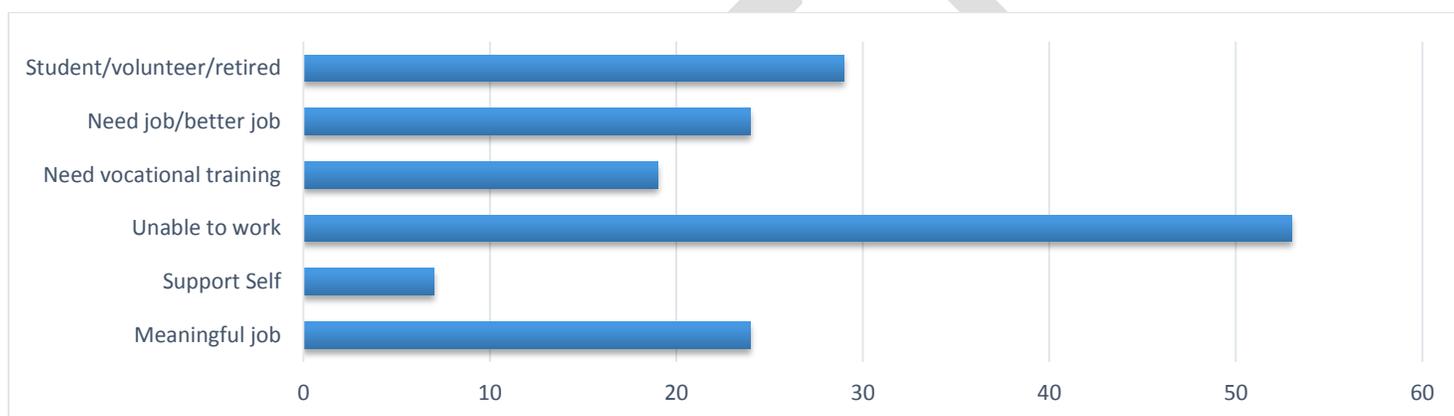
Question 3B. Do you need additional services not provided by the Veteran's Administration (VA)? Choices: Yes; No.

Question 3C. If yes, are you aware that you can also access IL services provided by the Ocean State Center for Independent Living (OSCIL)? Choices: Yes; No.

Thirteen participants (10%) identified themselves as Veteran's. Of those, six reported that they received services from the VA; four of which reporting that they needing more services not provided by the VA. Six respondents reported that they were aware that they could access additional services provided by OSCIL.

Question 4: What is your current employment status? Check all that apply. Choices were: I am employed in a meaningful full or part time job; I am unable to work due to my disability; I make sufficient salary to support myself; I need (or am receiving) vocational training; I am seeking employment or a better job; I am a student, volunteer, or retired.

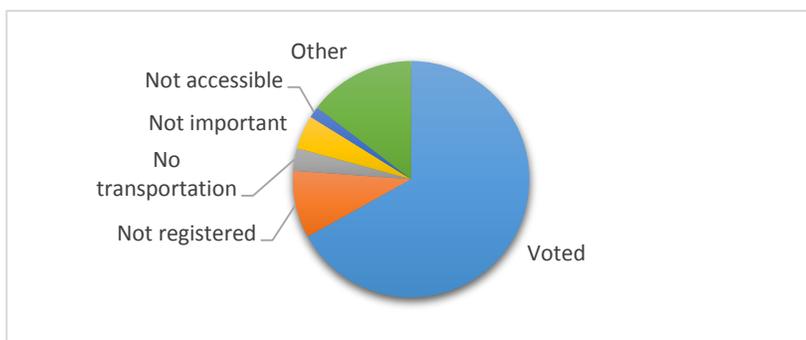
One hundred and twenty participants answered this question. Multiple answers were given. Fifty-three consumers (44%) reported that they were unable to work due to their disability and only seven (<6%) reported being self-sufficient. Twenty four participants (20%) were employed in a meaningful job; twenty-four (20%) stated they were seeking employment; nineteen (16%) needed vocational training. Twenty-nine consumers (24%) reported that they were a student, volunteer, or retired.



Question 5: Did you vote in the last election? Choices: Yes; No; If no, why? Check all that apply. Choices: Lack of transportation, my vote is not important; Polls not accessible; Other (Black line provided).

One hundred and eighteen consumers answered this question. Eighty-seven participants (74%) reported that they voted in the last election and twelve (10%) were not registered.

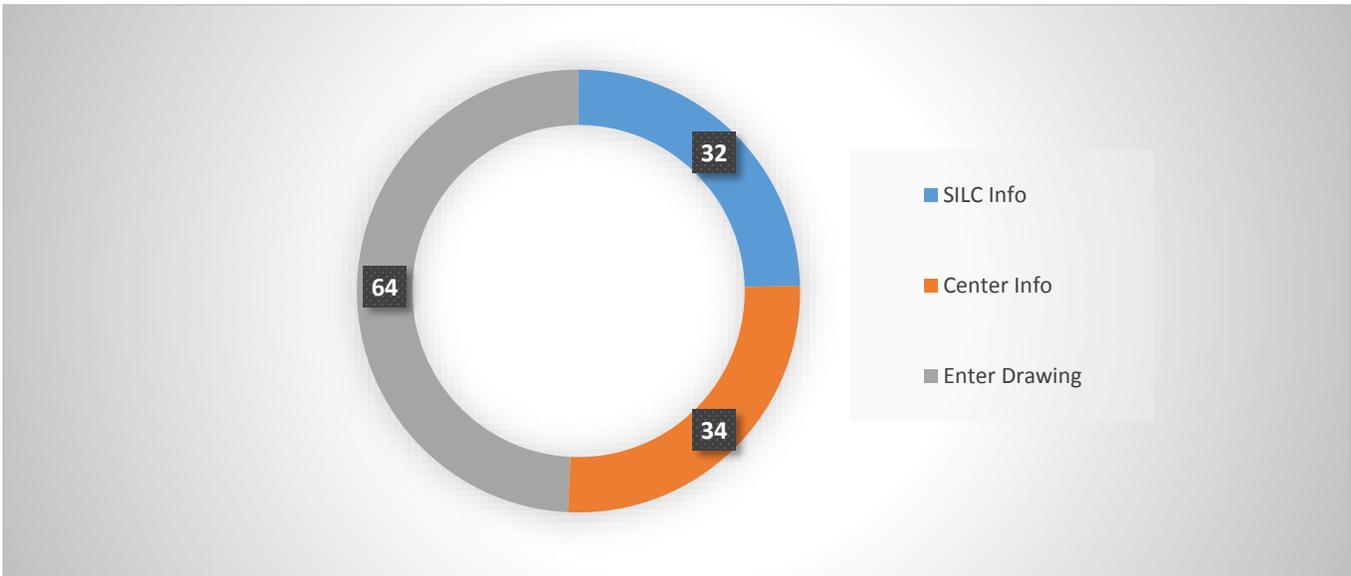
Four consumers reported not voting due to lack of transportation, six felt that their vote was not important; two stated the polls were not accessible. Nineteen consumers checked 'Other' with sixteen listing reasons. Many of the reasons listed were lack of



understanding, or cognitively based including dementia, stroke, cannot read, and guardianship. See appendix Exhibit F for complete list.

Consumers were given the opportunity to request for information about the RISILC, IL services, and/or enter into a gift card drawing:

Eighty survey takers (60%) provided their name and contact information. Of those, thirty-two consumers (40%) requested information about the RISILC; thirty-four (43%) requested information about IL services; sixty-four (80%) requested to be entered into the drawing.



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Appendix

Exhibit A: List of agencies providing IL services

Family (2)
Ride (8)
Medicaid/SSI/NHP (3)
Corliss (4)
Housing assistance
DD agency (4)
Looking Upwards
Grodin Center
Spurwink
Insight
VNA
UCP
Community Works
Arc Blackstone Valley
Private
Dialysis Center
S Kingstown Adult Day

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Exhibit B: List of IL services received

Ride/Logisticare/ transportation services (22)

Vocational (12)

Blind services

None (3)

Medication only

VA hearing and low vision services

Job advocate

Bus pass, Medicaid, food stamps

VA Blind rehab (3)

Counseling (2)

Information and referral

Housing assistance

Living Skills (4)

PCA (6)

OT (2)

CAN (2)

PT (1)

RN (1)

Social Worker (1)

Counseling (3)

Community/job supports (5)

Home mods (3)

Living skills (4)

Pay privately for aide

Medication only

Day program (11)

OSCIL phone support

Food stamps/Medicaid/Bus pass (4)

Comments:

ORS does not have good contractor for my employment needs, they always fall apart for some reasons/resume development, job referrals, development etc.

Many of my supports come through my family

Living at home (where the most IL people should do)

Exhibit C: Needed IL Services

Transportation/Better transportation (9)

PCA (6)

Homemaker/Helper (7)

Home Modifications (6)

Housing Assistance (11)

Information and Referral (3)

Advocacy (3)

Living Skills (6)

Peer Counseling (4)

Vocational Services (4)

Nursing Home Transition (1)

Adaptive Technology/Tech services (6)

Assistance with Benefits (2)

Finances (3)

Occupational Therapy

Treatment

Service Dog

Respite

Day Program

Mobility Training

Comments:

I & R referral for employment, resume referral, interviewing techniques, classes to go on interviews, education technology assistance

Advocacy for internet visual accessibility

VA refuses to grant electric wheelchair

Less toxic/green affordable housing services, less tox/green accessible work environments, less tox/green social/public places

A place to live

My own place to live

Live far from nearest RIPTA bus stop

Bath tub and stairs are obstacles

Finances/housing - my situation is such that I cannot request nor expect repairs

Don't know state Medicare nurse has been helping

Grocery shopping help/help getting in and out of shower/light house cleaning help

In-home organizational support; strategies for OCD condition/case management (Medicare does not cover this)

Support for filling out paperwork for SSI/SSDI and employment incentives
Help updating my resume
Help coordinating medical appointments and lab tests and insurance issues
Housecleaning
Someone to shovel snow, take me grocery shopping
Person to assist with food shopping
A way to voice a concern that will be acted/investigated beyond the agency and state,
needs to be independent review
LIKE BE INDEPENDENT
Bankcard

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EXHIBIT D: Additional Barriers / Clarification

Not receiving consistent information on website versus in person

Reliable transportation

Don't have money to paint and repair house (lead paint), can't move to senior housing because own home. If I sell then I have nowhere to live because of senior housing wait list, obligated to keep up house because of reverse mortgage but roof man didn't finish roof, new gutter man (with last money I had) left job undone making tons of promises but never returning. Called Channel 12 but they didn't help and have no one to fight for me. I've been told that the wood on my house is deteriorating from lack of paint but I can't keep up with medical bills

RIPTA/RIde services limited

When going to a doctor's office and they want whoever is with me to fill out paperwork instead of doing it with me in a private room

Transportation isn't effective in Westerly to get to Providence or any other areas that would enable me to go to functions or events

Having to live in a house where a neighbor smokes and it comes in through the vents and other areas even though I am on oxygen at night and it bothers my breathing issues, I can't move because most people discriminate against being blind

Not having 'wheels' is frustrating, no adequate substitute (electric wheelchair)

Handrails & Safety modifications

Mortgage refinancing assistance

Although my wife drives me at present, anyone who I know uses RIde or other services complain of lack of availability and long rides and wait times

More education and sensitivity awareness is needed for hidden disabilities, fragrance green/green/less toxic work and public places including bathrooms with air fresheners, there is no affordable HUD green individual housing in RI via left to find it in the private sector and fight with Hud for assistance to pay high prices, 4% 12 million plus are

disabled with multiple chemical sensitivities, MCS. 1% is wheelchair disabled, visual or hearing impaired. Though more disabled with MCS No accessible housing work or public places are offered in RI

Homeless without family support

Financial iPhone and internet fees

Transportation doesn't show up on time, not enough notice to cancel appt with one when they call

VA transport not reliable

Where I currently live, it is becoming too demanding physically to meet my needs/if I move affordable housing and utilities are an issue and groceries are an issue; waiting lists long, I am not 65 yet and I have a little dog.

Access to reliable transportation that is affordable is an issue

Attitudes more so than discrimination, people judge too quickly

Learning how to budget/I don't have much understanding as to many resources to being disabled

NEED more communication accessibility in media, on internet, etc.

Lack of reliable transportation in the state

Stairs at present are an issue in some places /I cannot stand or walk for long periods, a scooter would be beneficial in some circumstances but I can't afford the cost

People sometimes treat me as though I am invisible. I feel excluded from activities and people sometimes assume I am intellectually impaired because of my physical limitations

Sign language interpreters walled themselves from us (ie remain faceless, refer to an agency, etc) - they see us as cash cows not people with dignity and whom they can benefit for their signing development/I think outside the box when it comes to open doors for opportunities if I do recognize my talents within (E.g. sign language) and at first, I had to break the ice when I try to introduce something that will benefit all parties involved, hence, their attitude becomes suspicious (perhaps, they have been in status quo for so long) after a while, they finally got it and find my idea useful - sure if I had an interpreter,

that will shorten the "delay"/ the sign language community (deaf/hearing/interpreters/CDHH/etc.) is so diverse here in RI - that is my experience living here two years

Living situation with family complicated

It is difficult to maneuver on the streets and sidewalks in a wheelchair

Bathroom accessibility/financial resources to stay in my own home

Ride program does not work/ need wheelchair accessible van

I have an old hoarding issue, ORS is loathe to support me with this service/OTRS lawyer said no after rehab counselor said yes

Reliable transportation to and from work, being able to get to doctor's office regardless of location, legally blind so a 'handy man' would be helpful for things like hanging photos, miscellaneous things in home, currently friends assist and perform yardwork

Distance. Everything is located in the Providence Metro area, not where the rest of us are

I have to pay for staff to attend the event with me. I am on a limited budget as are they. Staff schedules often do not accommodate when I want to go out when I have not given 10 day notice. Finding affordable housing that is not tied to an agency.

There are events out of my area that run late (8-11pm), Ride does not run and is unavailable to me so I miss events, arts, and all that is important to me

Using walker in snow and ice

Want to leave my husband at some point but need to be able to live independently with my two teenagers

Physical mobility had surgery on back, hard to get around, I trip on my kitchen floor, I have a tub with no seat

Not every place in community are handicap accessible

Some transportation agencies are not so easy to access

Interested in learning about adaptive equipment for my apartment

I have never heard of any of these groups. Limited income, retire, no work at 61,

EXHIBIT E: Heard about Survey

Ride (47)
SILC Mailing (15)
Corliss (18)
SILC Website (9)
VA Blind Support Group (4)
NFB Conference (6)
TBI Conference (2)
Open House (5)
TBI Facebook (3)
Friend/Relative (4)
Email (2)
MS Positive Prospective Meeting (3)
Day Program (1)

Exhibit F: Reasons for not voting

Too depressed to go anywhere
Stroke
Cannot read
Out of state absentee ballot complicated
Lack of understanding
Guardianship
Wants not "unlegitable"
Don't understand process
Dementia
Application denied for whatever reason
I did not have a picture ID which should be eliminated
Lack of cognitive ability
Cognitive
Do not understand
Automark was not working. Had to use paper ballot with a reader
Forgot to register
Just moved to RI

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