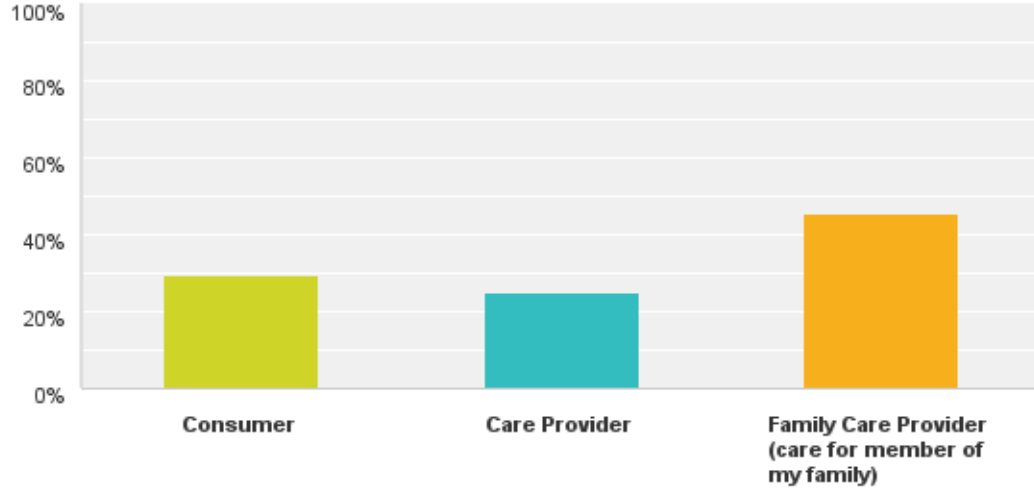


Consumer/Provider Survey Results March 2017

Q1 I am a _____!

Answered: 129 Skipped: 0



Answer Choices

Consumer
Care Provider
Family Care Provider (care for member of family)

Responses

38 29.46%
32 24.81%
59 45.74%

Total Responses

129

Q2 How many hours do you have allotted per month (for providers, how many worked)?

- Answered: 128
- Skipped: 1

Answer Choices

Consumer Monthly Total
Care Provider worked per month
Family Care Provider Monthly Hours Allotted

Responses

85 66.41%
66 51.56%
84 65.63%

Consumer Monthly Total Responses:

1. 282	2. 24.6	3. 283
4. 283	5. 232	6. 75
7. 165	8. 351	9. 283
10. 283	11. 212.06	12. 50
13. 373	14. 254	15. 180
16. 148	17. 173.6	18. 75
19. 350	20. 250	21. 262

22. 160	23. 203	24. 237
25. 283	26. 283	27. 74.55
28. 0	29. 283	30. 283
31. 258	32. 42.41	33. 283
34. 105.26	35. 283	36. 56.45
37. 446	38. 194	39. 283
40. 212.34	41. 283	42. 234.59
43. 279	44. 178	45. 208
46. 283	47. 60	48. 283
49. 41.9	50. 232	51. 250.17
52. 424 IHSS 283 & IH0 141	53. 273	54. 156.27
55. 530	56. 40	57. 283
58. 197	59. 125.01	60. 104
61. 281	62. 64	63. 283
64. 200	65. 14	66. 20-30
67. 283	68. 243	69. 283
70. 283	71. 283	72. 173.06
73. 283	74. 283	75. 755
76. 252	77. 283	78. 140
79. 283	80. 283	81. 110.54
82. 283+	83. 1000	84. 211
85. 283		

Care Provider Hours Worked Per Month Responses:

1. 132	2. 40	3. 104
4. 20.5	5. 84	6. 35
7. 165	8. 270	9. 283
10. 283	11. 212.06	12. 40
13. 310	14. 254	15. 148
16. 200	17. 350	18. 250
19. 24/7	20. 96	21. 160
22. 160	23. 283	24. 283
25. 74.55	26. 283	27. 200
28. 42.41	29. 80.26	30. 360
31. 194	32. 212.34	33. 283
34. 279	35. 19.40	36. 90
37. 60	38. 60	39. 232
40. 360 Because of cap lost 64 hours		41. 0
42. 156.27	43. 70	44. 40
45. 40	46. 283	47. 125.01
48. 552	49. 15	50. 283
51. 145	52. 80-100	53. 283
54. 283	55. 80	56. 173
57. 283	58. 283	59. 40
60. 124	61. 14	62. usually much less
63. 283	64. 283	65. 211
66. 283		

Family Care Provider monthly hours allotted responses:

1. 70	2. 232	3. 80
4. 283	5. 185	6. 283
7. 251	8. 283	9. 283
10. 212.06	11. 270	12. None
13. 373	14. 254	15. 180
16. Max allowed for two kids		17. 173.6
18. 256	19. 283	20. 90
21. 283	22. 276	23. 250
24. 262	25. 74.4	26. 206
27. 211	28. 0	29. 237
30. 283	31. 283	32. 0
33. 180.15	34. 360	35. 0
36. 212.34	37. 199.5	38. 243
39. 84	40. 234.59	41. 283
42. 360	43. 283	44. Family
45. 256	46. 41.9	47. 232
48. 250.17	49. 98	50. 234
51. 273	52. 283	53. 206
54. 156.27	55. 253	56. 360
57. 280	58. 283	59. 253.58
60. 283	61. 200+	62. 281
63. Family	64. 283	65. 207.16
66. 248	67. 283	68. 215
69. 283	70. 173.06	71. 0
72. 283	73. 283	74. 360
75. 238	76. 0	77. 283
78. 110.54	79. 180	80. 360
81. 211	82. 360	82. 283
84. 143		

Q3 What county are you in?

- Answered: 128
- Skipped: 1

Answer Choices

The County I am in is
 Do you live in an urban, rural, or suburban area?

Responses

128 100.00%
 107 83.59%

The County I am in is _____

Alameda – 5	Butte – 6	Contra Costa – 3
Del Norte – 1	El Dorado – 2	Fresno – 4
Humboldt – 3	Kern – 1	Los Angeles – 21
Marin – 1	Mendocino – 1	Merced – 1
Orange – 11	Placer – 13	Riverside – 15
Sacramento – 7	San Bernardino – 7	San Diego – 10
San Joaquin – 1	Santa Clara – 1	Shasta – 1
Solano – 2	Sonoma – 1	Tuolumne – 2
Ventura – 2	Yolo – 1	United States – 4

Do you live in an urban, rural, or suburban area?

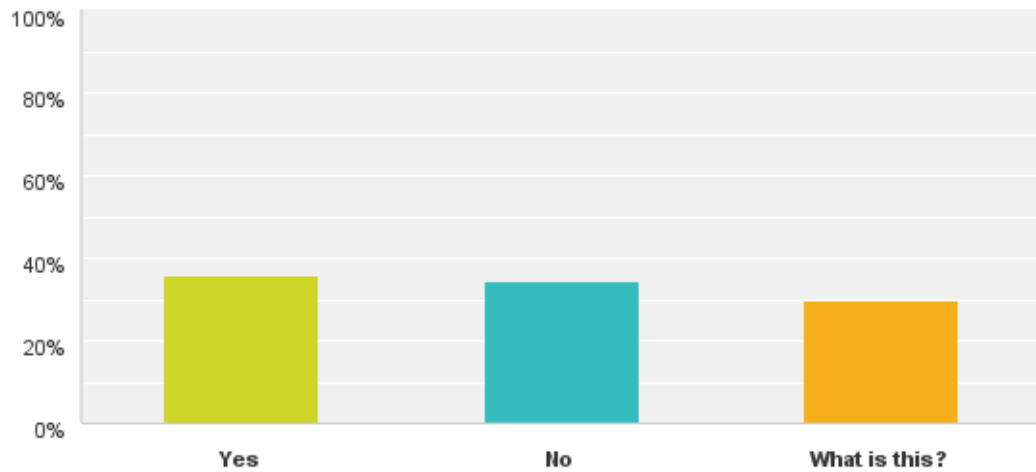
Urban – 23
Yes – 3

Rural – 19
No – 8

Suburban – 48
Not Sure – 2

Q4 Do you know your County's In-Home Supportive Services Advisory Committee is required to have a majority of consumers serving on it?

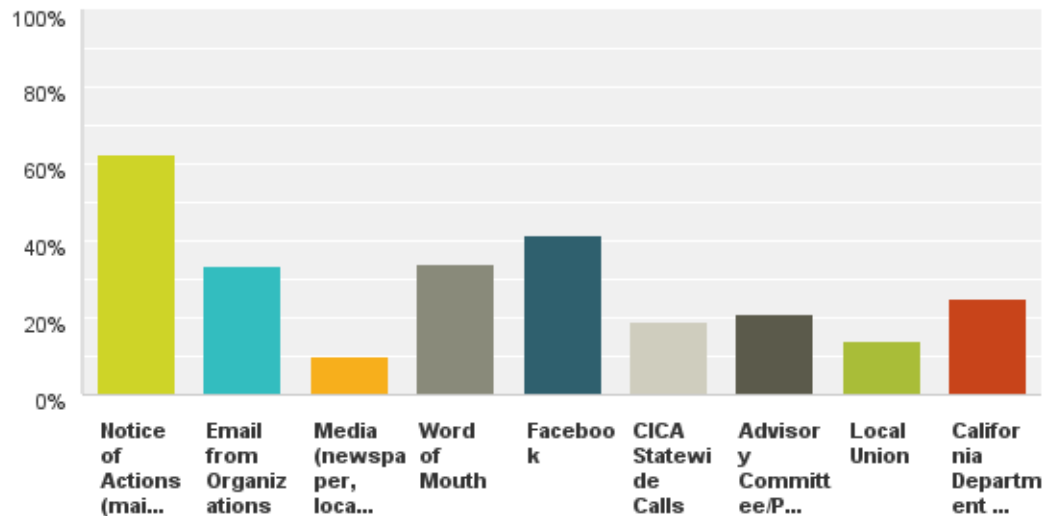
Answered: 128 Skipped: 1



Answer Choices	Responses	Percentage
Yes	46	35.94%
No	44	34.38%
What is this?	38	29.69%
Total Responses	128	

Q5 How do you get information about the In-Home Supportive Services program?

Answered: 120 Skipped: 9



Answer Choices

Notice of Actions (mailed by state)
 Email from organizations
 Media (newspapers, local news, radio, etc.)
 Word of Mouth
 Facebook
 CICA Statewide Calls
 Advisory Committee/Public Authority Newsletter
 Local union
 California Department of Social Services (CDSS) Website

Responses

75 62.50%
 40 33.33%
 12 10.00%
 41 34.17%
 50 41.67%
 23 19.17%
 25 20.83%
 17 14.17%
 30 25.00%

Total Responses

120

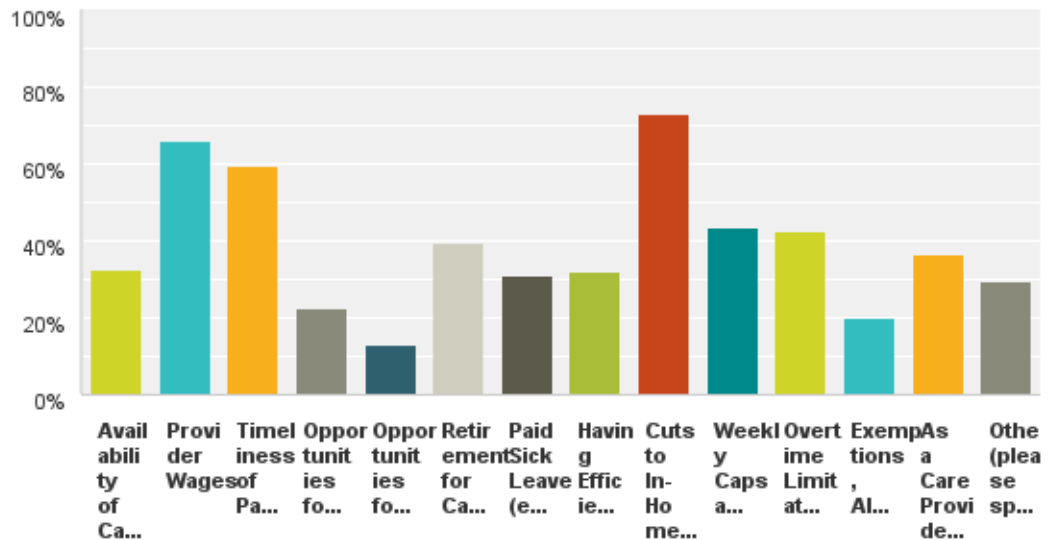
31 Comments:

1. Me on the IHSS advisory committee and get it from interpreters
2. Network of friends also in IHSS
3. I get 98% info from fb groups
4. Social Media groups are very informative and helpful. I have many contacts in my county and Sacramento
5. My IHSS Case Worker.
6. Social worker at Kaiser Permanente during a hospitalization
7. I, the disabled, must try to research what's going on. I never receive information from anyone regarding changes except to increase/decrease my hours
8. Regional center
9. IHSS coalition, CDCAN.
10. JUSTICE IN AGING CICA CARA LOCAL LEGISLATORS
11. When I applied for my daughter for SSI when she turned 18 :(

12. Disability Rights Advocate, Former IHSS Public Authority Advisory Committee Member, Formed CICA
13. From Disability Rights CA when we went to them for help with Kern Regional Center
14. Social Security office worker told me about it also.
15. I would like more information. When I have tried to call to get info most people who answer the phone don't know much. I wanted to find the provider registry to get help and no one knew what it was or that it existed!!
16. Thru new friends at the college who are caregivers
17. I don't
18. Public Authority website
19. PASC sends me information.
20. When the recipient don't sign your time sheet you the Provider has work don't get paid and IHSS and other state agency close the door are hang up ending I can't help you. Who do the Provider go to?
21. California IHSS Consumer Alliance
22. Local IHSS PA & Advisory Committee CAPA; Karen Keesler DRC; Deborah Doctor Facebook Groups / email: IHSS Coalition IHSS Consumer's Union CICA UDW Care Providers Union Websites (DRC; CDSS; CICA; UDW)
23. I'm a member of the PASC Board of Directors
24. CDCAN....Thanks, to Marty Omoto. ?? CICA....Thanks, not Charlie Bean..??
25. I was a former member of the RC IHSS AC, I still attend the quarterly meeting of the AC to keep up with current information and be updated on RC PA/IHSS activities.
26. By battling to keep eligibility
27. CDCAN, Networking with Advocates and Disability Rights Attorney's.
28. I'm a board member of the IHSS Advisory Board for Humboldt county
29. Friends I have made online DDS
30. CICA and IHSS FB Group
31. Westside Regional Center caseworker

Q6 What are your concerns about the In-Home Supportive Services program?

Answered: 129 Skipped: 0



Answer Choices

Responses

Availability of Care Providers	42	32.56%
Provider Wages	85	65.89%
Timeliness of Payroll/Compensation to Providers	77	59.69%
Opportunities for Provider Training	29	22.48%
Opportunities for Consumer Training	17	13.18%
Retirement for Care Providers	51	39.53%
Paid Sick Leave (effective July 2018)	40	31.01%
Having Efficient Back-up Providers to Cover Needed for those on sick leave	41	31.78%
Cuts to In-Home Supportive Services (future hours reductions)	94	72.87%
Weekly Caps a Provider can Work	56	43.41%
Overtime Limitations	55	42.64%
Exemptions, Allowances for As a Care Provider for a Family Member, who would Care for my Family Member if I become Ill?	26	20.16%
Other (please specify)	38	29.46%

Other Responses:

1. None everything and everyone one has been very good to work and deal with
2. This is a very good program for the elderly. Making SURE there is NO FRAUD
3. English is a very weak second language spoken in the Orange County, Calif. IHSS office. Very difficult to communicate with.
4. Mail-in time sheets vs electronic, lack of communication with case worker
5. Parents who have severely ill children shouldn't fear loss of pay and becoming homeless because child is hospitalized for a week or two... there

has to be a way for those parents to be paid as they do just as much if not more work caring for their child in a hospital. We all know hospitals don't offer 24/7 protective supervision.

6. Payroll needs to be more accurate and paid more timely
7. Much of the time as a recipient , I'm left out of discussion , decisions - this doesn't seem like consumer driven inclusion at all, it feels like medical model existence
8. How often IHSS lies to us
9. My hours are reduced because I'm the spouse caring for my husband.
10. Stupid "Violation" Rules
11. Transparency of UDW AFSCME Local 3930 and continued harassment providers to join their union
12. No Emergency Back-Up Services
13. Care Providers who emotionally abuse Consumers & IHSS's unwillingness to help-saying it is my word against hers
14. AB1930
15. Demeaning and paternalistic attitude of CDSS and legislature
16. Terribly negligent lack of sufficient backup services for people who are significantly disabled like Maxim with 24/7 capacity
17. Who will take care of me if my mom is sick?
18. To Whom It May Concern: The IHSS system is severely broken for end-users with severe disabilities who do not have family member or spouse IHSS providers to help them. The major problems that IHSS recipients are facing are: 1) No reliable and accessible urgent care back-up system of IHSS providers for emergency situations exists and those counties that offer such services bury the number to call within their phone tree system to defeat use of such urgent care system and limit the monthly use amount so an IHSS recipient cannot make it from a Friday to a Monday with help; 2) IHSS Public Authority Caregiver Registry lists are useless for finding competent providers to meet the needs of persons with severe disabilities (IHSS recipients) especially wheelchair users who need more daily help with tasks and a multitude of activities of daily living (ADLs); 3) Sick Leave Policies do not account for additional IHSS hours allotment or provider replacement for those claiming sick pay and leaving IHSS Recipients stranded with no help; 4) IHSS Pay Rates Across Counties for IHSS Providers Assisting those IHSS Recipients Defined as Severely Disabled is too low for such individuals with severe disabilities to locate required multiple providers to meet daily, weekly, and monthly needs for help with tasks authorized by laws to be provided; 5) IHSS Providers paid a meager sum are able to be paid more by private pay clients competing against IHSS Recipients for needed care; 6) IHSS Providers cherry pick easier IHSS recipients needing less help leaving those with the highest level of disabilities to struggle to find IHSS providers/caregivers needed to remain independent in the community and the provider turn-over rate is high for recipients with severe disabilities; 7) IHSS Recipients are NOT Patients as so many IHSS Providers who call recipients for jobs refer to their clients (we are not the patients of our IHSS providers/caregivers); 8) IHSS & Medi-Cal Share-of-Cost Buy-out remains a major inhibitor for qualified IHSS recipients receiving the care and IHSS services they need causing institutionalization of IHSS recipients; 9) SSI

meager raise insufficient to bring IHSS recipients and those with disabilities ability to afford basic costs of shelter, food, or clothing or afford any IHSS Advance Pay Overpayment demands by CDSS or the county who negate any IHSS systematic problems with the entire IHSS recipient & provider timesheet availability or process; 10) CDSS IHSS Overpayment Policy violates the civil rights of persons with severe disabilities and fails to consider IHSS system errors including sending IHSS Advance Pay timesheets directly to IHSS recipients (the employer as an option) for their IHSS providers and tries to collect money from poor recipients for receipt of IHSS Advance Payment with no regard to problems of recipients/providers receiving IHSS Advance Pay timesheets in a timely manner each month or having to repeatedly request and await receipt of such replacement IHSS timesheets in any kind of a timely manner; 11) IHSS system of criminal background information (CBI) checks turnaround time takes too long, Social Security number verification, mandatory IHSS Orientation attendance and overwhelming paperwork for IHSS providers (and recipients adding new providers) is too slow to have new found providers interested in working in the field for a recipient and in being added to work as an IHSS provider in order for the newly hired provider by a severely disabled IHSS recipient to receive timesheets before they leave a job (which can subject an IHSS recipient to a state CDSS imposed IHSS Overpayment); 12) IHSS provider recruitment efforts lack identification of providers interested in working for those individuals with severe disabilities; 13) IHSS recipients and IHSS providers must be a match of skills and personalities for the working relationship to be viable, symbiotic, and a good match; 14) IHSS Registry computer software systems and applications do a bad job of matching applicants living in a city to the tasks needed to be done by the IHSS recipient living in their own home (including provider allergies to pets, ability to assist with catheter care and bowel program needs, ability to do water therapy and other therapy needs of a recipient, ability to cook (real food) other than making microwave dinners or a sandwich, ability to do personal care, lifting, or move an electric wheelchair, etc.); 15) IHSS recipients receive too few names of IHSS Providers from IHSS Registry systems and Registries do not actively recruit potential new IHSS providers from diverse communities to maintain caregivers lists who are available to work for IHSS recipients (I can get a list and make calls to no avail); 16) Some IHSS Providers allege IHSS recipients (employers) who have hired them refuse to sign their IHSS timesheets so they do not get paid for the work they did and it hurts other recipients searching for new replacement IHSS providers who are deterred from working for IHSS recipients from a prior bad experience (maybe a result of the persons' disability, dispute over hours claimed to have been worked, or unknown factors); 17) IHSS providers not receiving monthly IHSS timesheets (or requested replacement timesheets) have been subjected to waiting months to receive timesheets to be paid (an alleged pattern and practice of delaying IHSS provider payments by the state and counties to pocket and collect General Fund bank interest from unpaid and delayed IHSS provider payments by keeping state/county money in the bank longer); 18) Too restrictive IHSS & IHO Waiver Overtime caps that restrict the lives of persons with disabilities to travel, take employment or student internship opportunities, or have one or more providers work more

weekly hours when another provider is sick, on vacation, or quits their job for an IHSS recipient with a severe disability with multiple providers who does not qualify for DD and Regional Center services under the Lantern Act; 19) Promotion of union-backed IHSS program provider enhancement ideas without balance for the interests of IHSS recipient's needs, lives, and ability to remain independent in our own homes and live our lives as we desire; 20) An IHSS Public Authority statewide system that is not functioning to meet the 24/7 needs of IHSS recipients with severe disabilities to sustain independent living in the community with home and community-based services, including, but not limited to, outside of regular IHSS Public Authority business hours) whereby IHSS recipients have too few providers in their communities available to choose from to work for them that can be a match to the recipients' needs, too few with needed skills or ability to do this type of work because some applicants see it as an easy job for a senior where it amounts to companionship rather than real work, inadequate pay scale for those willing to work for those with severe disabilities, lack of outreach to potential providers and lack of interest in the field by youth based on a lack of respect for providers willing to do this work defined society as "women's work," "a duty of family to provide care," and failed policies that disrespect workers/providers by denial of timesheets and receipt of timely pay; 21) Counties and IHSS social workers that fail to document the unmet needs to IHSS recipients with severe disabilities and lack of knowledge about IHO Waivers to insure the additional attendant care extra help needs of IHSS recipients; 22) County IHSS departments that fail to inform IHSS recipients and their families how the IHSS system works so they are informed about how to hire IHSS providers when they are new to the IHSS program and system, including those who are IHSS eligible who may come from diverse and minority communities; 23) Failure to send IHSS timesheets in a timely fashion to IHSS recipients deemed capable of managing them for IHSS providers since the IHSS recipient is deemed the employer except for purposes of collective bargaining etc.; 24) Able-bodied mouth-pieces deemed working IHSS advocates who do not live with the help of IHSS services who do not know what they are talking about as they espouse how great the IHSS system is working for persons eligible for such services since the IHSS Public Authorities came into being and since the paternal criminal background checks and quality assurance system was imposed for the IHSS program; 25) Numerous problems with the new 117 page All County Letter (ACL) 16-89 dated October 13, 2016 including, but not limited to, procedures for IHSS Advance Pay and timesheets being issued to IHSS providers and not directly to IHSS Advance Pay recipients and proposed policies governing unreconciled advance pay (UAP) cause and effect imposing overpayments on IHSS Advance Pay recipients by a broken IHSS system that has become overly bureaucratic, burdensome and oppressive for IHSS recipients and IHSS providers (see <http://www.cdss.ca.gov/lettersnotices/entres/getinfo/acl/2016/16-89.pdf> and IHSS Letters and Notices (2010-Current) and IHSS Letters and Notices (2010-Current) 26) IHSS Provider earnings statements for IHSS Advance Pay and IHO WPCS (IHSS) providers that are confusing rather than the prior IHSS Advance Pay and IHO Waiver Personal Care Services (WPCS) earning

statements that recipients and providers could tell which was income from IHSS versus income from IHO WPCS or IHO Waiver services under the new two-pay period IHSS Advance Pay timesheet system put in place October 2016; and 27) CDSS and IHSS Quality Assurance system is out of control making ad-lib policies, procedures, and a multitude of forms that are detrimental for IHSS recipients and IHSS providers by creating a penalty system with IHSS provider overtime caps negatively impacting the daily lives of IHSS recipients to continue to reside in our own homes with home and community-based services (HCBS) and In-Home Supportive Services (IHSS). There are so many problems with IHSS that the system begs a lawsuit to protect IHSS recipients from policies that deny the right of the U.S. Supreme Court Olmstead decision to IHSS recipients to receipt of services in the community to remain living independently. Respectfully, Connie Arnold
 Disability Rights Advocate & IHSS Policy Expert

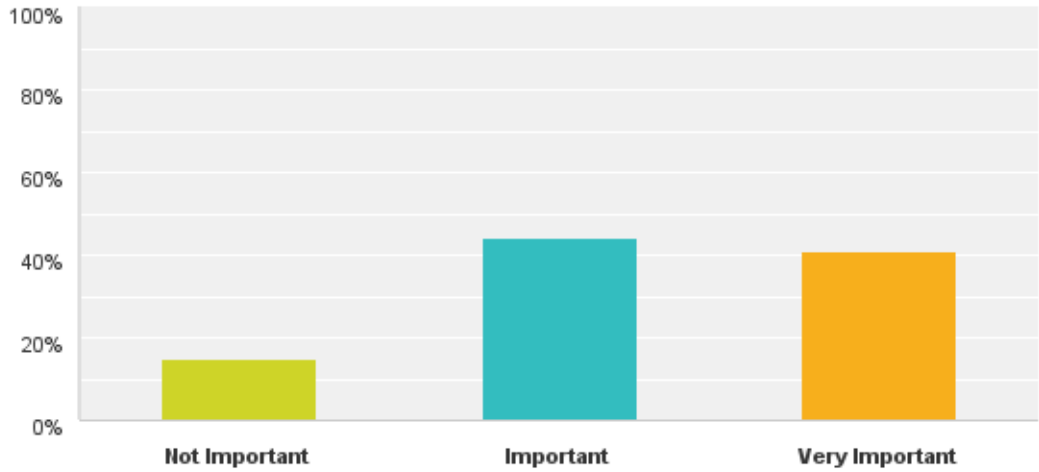
19. Health coverage
20. Parent/Spouse Providers not eligible for Medicare, SS & unemployment insurance. Also, violations & Providers being terminated.
21. Social Workers having too much authority and not sharing the rules equally
22. As a family member I have 530 hours for my 2 sons but we can only use 360. It is not fair. Having 2 disabled kids is enormously hard, yet my hours were REDUCED! The max hours may work out for one child, but many of us have more than one child with disabilities. My younger son is 24/7 constant care, but because of random, arbitrary rules, I only get to use 360 out of my 530 hours per month.
23. Unemployment eligibility
24. The way it conflicts with social security
25. The enrollment processing time for new clients
26. Social security benefits for family caregivers and unemployment benefits for family caregivers
27. Extremely concerned about the amount of abuse to which I have been subjected by multiple providers during the past year.
28. Spouse/Parent/Parent of Adult child unable to pay into SS, Medicare, or unemployment. No retirement plan
29. An IHO provider
30. 1) (most important) IHSS Program being cut 2) Back-up (respite) for providers 3) Consumer training
31. I do a 24/7 but don't get paid for it because I'm a family member
32. Older providers who care for their adult children will not be allowed IHSS for themselves.....never mind not being able to receive social security benefits. This probably includes Medical, also.....I'm healthy and hope to stay that way, but what about others?? A retirement fund is Not sufficient.....we won't even be eligible for nursing facilities. Something to think about.....If we get sick, and cannot work for IHSS, we lose our insurance...then what??
33. Change the payroll system to a bi-weekly pay period. This will eliminate confusion on overtime reporting
34. Training of social workers and providers, Medi-Cal bullshit
35. How long it takes for a Provider to receive information on Orientation, Fingerprinting, Back-ground Check and when completed again, how long it

- takes for a Provider to be receive timesheets. The wait can be 4 months or longer. No one can keep a Provider for 4 months who isn't being compensated.
36. Un-necessary changes such as the most recent Advance Pay double timesheets and redundant, now 2x a month reconcile of wages reported.
 37. I hate how IHSS makes you fight for everything. They lie to providers and lie even during the hearings. They never offer help and this new cap for family hours never gave us any increase at all in income. Even with the wage increase. My payments are not increased. I think the union is horrible and deceiving to consumers and providers. There is not one person you can trust. I'm worse off with these new rules. It's disgusting.
 38. The amount of Rules, Regulations, Violations, Limitations are becoming overwhelming. I am a parent provider, IHSS program's first goal should be to make it easier for my adult children to continue to rec awesome care, live in their home, choose who is their provider and support the parent provider in any way to achieve this, but IHSS program has over time come to treat the parent providers and consumers of IHSS as criminals. To compound the hard job that parent providers do, along with long hours, endless paperwork, threats of termination for simple mistakes and difficult for providers to receive pay, on top of every changing rules. My concern as a parent provider is to ensure my adult children continue to live in their own homes, remain safe, loved and get to choose who their provider is. I think the IHSS program is no longer concerned with Consumers/Recipients but with rules and regulations at the cost of the very people this program was created for.

Answer Choices

Q7 How important is it to you for your county or the State to create a Provider Back-up System to fill-in when your provider is sick?

Answered: 127 Skipped: 2



Answer Choices

Not Important

Important

Very Important

Total Responses

Responses

19 14.96%

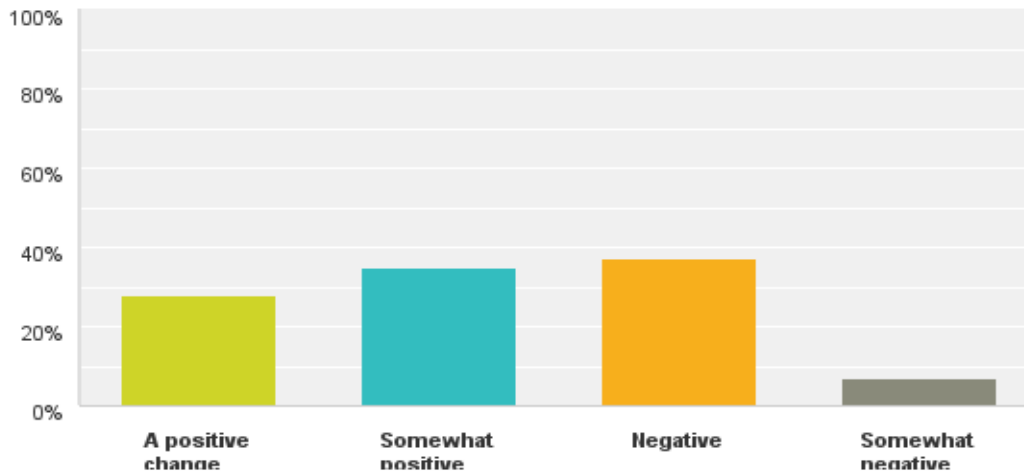
56 44.09%

52 40.94%

127

Q8 If you are an In-Home Supportive Services Consumer in one of the Counties involved in the Coordinated Care Initiative (CCI) do you feel it is?

Answered: 43 Skipped: 86



Answer Choices

- A positive change
- Somewhat positive
- Negative
- Somewhat negative

Responses

12	27.91%
15	34.88%
16	37.21%
3	6.98%

Total responses

43

38 comments:

1. NA
2. Do not understand
3. Would choose FFS Medi Cal and Medicare. Do not feel plans have adequate networks for Specialists
4. Can be convoluted and difficult.
5. I'm too new to answer this as have no comparison
6. NA
7. The quality of the plan facilities are low to put it mildly. Also these plans aren't equipped to care for the needs of people with disabilities.
8. Not certain
9. I don't know what this is.
10. Being forced into a low performing HMO (LA Care) in order to retain IHSS has had a drastically negative effect on my ability to receive appropriate services. Not only is this true for my personal care, but my DME needs as well.
11. I was not affected by the change
12. Read and heard consumer bad experiences.
13. Because I don't know what CCI is really. My illnesses make it difficult/impossible for me to understand everything. I am alone. I mistakenly thought the Social

Worker was the Consumers first line of support, defense & advocate. As a Consumer I don't have a Union or anyone to make sure that I'm being treated with compassion, appropriate care, that my hours are used for my care not the Provider's interests, that my Provider doesn't steal or damage my possessions. I could list more experiences with untrained, uncaring and passive-aggressive Providers. But the interest and advocacy seems to be about Providers only and not Consumers who have no family, no friends, no Union, no IHSS representative to care about the wellbeing of the vulnerable and helpless disabled Consumers who are at the mercy of healthy people who can deny & blame the Consumer.

14. Do not know what that is.
15. I don't have any ideas of what it's this
16. It is an added, and costly, bureaucratic intrusion.
17. Insufficient availability of specialists a negligent refusal to make appropriate referrals to specialists when necessary
18. Don't know about it
19. I don't know what is that
20. Dual Eligible consumers are suffering under the CCI. Everyone is in the counties that have it.
21. IDK what this means
22. Too much confusion & hard for people to understand. It does not seem to benefit Consumers & Providers in any way. The old straight Medi-Cal FFS is much better.
23. Not sure
24. This is positive because agencies and healthcare providers are collaborating care for more efficiency.
25. I don't know what the Coordinated Care Initiative is.
26. I am uninformed as to what this is.
27. What is this?
28. I am not in one of the counties involved in the CCI as of yet.
29. ?
30. No opinion
31. In Riverside County, I have more doctors available through a Plan than I had with straight Medi-Cal. I also have additional services like medical transportation that were not available before. Finally, I consider "Care Teams" to be an advantage for my case management.
32. No clue
33. All health plans in the CCI are low quality rinky-dink facilities that the more affluent neighborhoods wouldn't consider having in their communities!
34. I don't get Medicare, so I don't have first-hand experience with CCI.
35. My daughter who is the consumer is exempted from joining the program as she has other health insurance coverage through the VA. As such, I have no experience in dealing with the system. But I feel it is a good program for those who are qualified to access the program.
36. Totally against this. For nearly all people with Medi-Cal: The state will require mandatory enrollment into a Medi-Cal health plan. This means that nearly all people with Medi-Cal in the seven CCI counties MUST get all their Medi-Cal benefits, including long-term services and supports, through a Medi-Cal health plan. Most people with only Medi-Cal already are enrolled in a Medi-Cal health

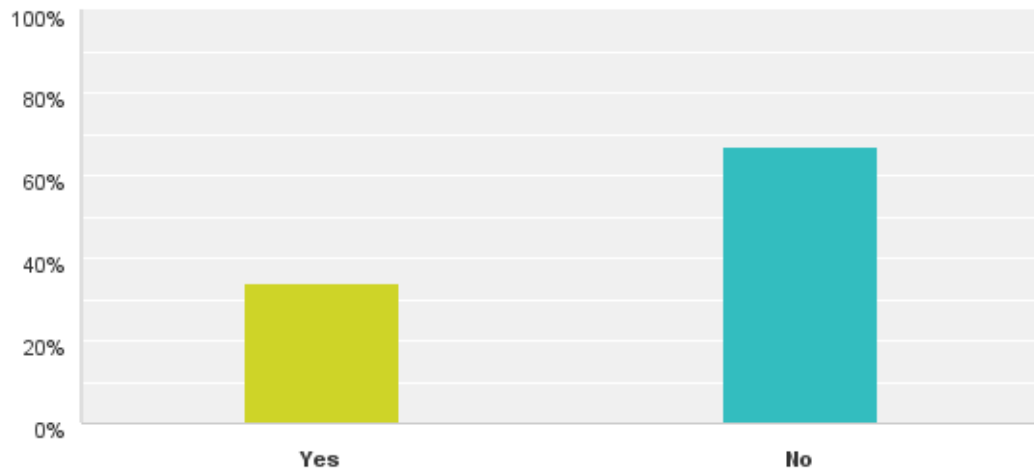
plan; now they will also get their long-term supports and services through their health plan. These plans do not have a system in place to care for the disabled who have a chronic medical condition. It is an experiment and the disabled and seniors are the guinea pigs.

37. Don't know about that program

38. I feel like it is another way to Nickle and dime an already working system and put the disabled in managed care, which will deny, refuse access to specialist and needed services. FFS medical was working just fine. This is about \$\$\$ not about care. They are saving pennies off the backs of the disabled.

Q9 As an IHSS Consumer do you feel adequately included (represented) in decisions about the In-Home Supportive Services program?

Answered: 94 Skipped: 35



Answer Choices

Yes

No

Responses

32 34.04%

63 67.02%

Total Responses

94

30 Comments:

1. For caregiver to learn about deaf culture people to help them on their daily life
2. The State should do surveys mailed out to each person be it a Recipient or a Provider and see if their streamline ideas actually make things easier for the Consumer. Currently they implement difficult changes and add stress to the disabled person's life. They do not live in the disabled world. IHSS should include folks that are disabled in all decisions pertaining to IHSS. This is inclusion.
3. Being allowed to give more input.

4. As an IHSS Advocate of all 58 counties I have affiliations and contact with those who run this program, use conference calls and webinars to make sure our voices are heard~
5. We are urged to contact our legislators - but it doesn't make a difference I can see. We are left out of union discussions about provider issues as the consumers - quite frankly it feels disenfranchised fits. Folks assume we have access to smart phone interface for example - I have an "Obama" phone under state low income that doesn't get signal here in this rural area, poor public transportation, semi-house bound, no TV or cable - how is it we are included in much of anything that directs or governs our lives so fully in daily reality? How am I asked or invited to really participate in governance?
6. IHSS makes us fight for everything. The union is a scam. The cap on two kids made it so I got no increase financially with the raise. It is the 16th and I still haven't got my checks and accounting hasn't returned my call. So much lying.
7. To have a seat at the table with DPSS. I currently serve on the PASC BOD. I have spoken to DPSS about their need to form a consumer advisory committee. No response yet!
8. Need to meet with state representatives to explain needs.
9. More competent help and happier help
10. Take IHSS out of the pocket of the SEIU! The 51% of stakeholders are yes men for the union. Actively seek out diverse people with disabilities, rather than keeping the same few voices in the room.
11. Need to hear more from severely disabled who have knowledge about rules and regulations of IHSS system.
12. An IHSS CONSUMER REPRESENTATIVE to perform random home visits, to ensure the Consumer is being appropriately cared for with dignity and respect. For someone to care about the Consumer and pay attention to what happens after the Provider is hired so that the turnover of Providers doesn't cause IHSS to threaten to stop the Consumer's assistance or to have the Consumer placed in facility.
13. Not familiar with how representation is handled, other than the union which I think has a bigger agenda
14. We need to be heard and part of the process before any changes are made, i.e. cuts, caps, etc.
15. Take away caps and pay people a decent pay rate. Too many regulations now.
16. If the legislature would just listen!
17. No, everything is decided by people who don't understand what it's like to live on the program either consumers or providers.
18. Lack of communication
19. Video Consumer & rand & file Providers' testimonies at legislative hearings.
20. I don't know
21. The inclusion could be improved by empowering our providers to be able to speak on our behalf at your forms and meeting, for those that are homebound.
22. Have meetings afternoon so adult consumers can participate!
23. I would like to join the IHSS Consumer Council. I've tried expressing my concerns to my social worker and to several people at PASC, but am ignored.
24. More and regular surveys such as this one.

25. ?
26. IHSS Consumers should be involved in all aspects of policy for IHSS - not only as Advisors. I feel like we are sometimes consulted but then our suggestions are ignored; other times consumers/recipients are not even included at the table (such as with statewide bargaining).
27. If DPSS had a consumer advisory committee this would go a long way towards improving consumer input.
28. Get Medi-Cal out of the eligibility picture and control
29. When a Draft is sent out asking for our input they should give us time to be included prior to their decision making.
30. Have people who are actually recipients of IHSS in on making decisions about the program. Put the needs of the disabled first, by writing policies and rules that make it easier for them to use the program, not harder. Allow the disabled to be part of the IHSS program and allow a panel of them to audit the process and recommend changes. One extra: Have Social workers, Supervisors and people who are on the ground level with processing and dealing with IHSS annual cases, be required to have a training led by disabled people, on topics that are about disabled. So county personnel can go into these annual reviews and appointments with an open view.

Q10 As a parent provider what are your concerns (list up to three)?

Answered: 65

Skipped: 64

1. Communication with IHSS representatives. Timely response from IHSS representatives. Difficult to understand responses from IHSS representative, poor enunciation of English.
2. How the job is done to care for children and to guide them to learn their disabilities is important 2 ask for help as needed 3 to know where to go for help when you not able to call 911
3. Hours cut, wage rates, benefits when I retire. Due to inability to find employment to care for disabled family member
4. All
5. Lack of case worker availability back up care provider availability Medicaid changes.
6. 1. EVV and how it will affect our families ability to live a normal life without restrictions as to where we go, what time we get home, and being treated like we are on lock down in our homes instead of having a consumer directed program and allowing the disabled to enjoy life in their community. 2. Advanced Pay changes to timesheets now every 2 weeks instead of once a month. It does not make the Overtime checks appear timelier. It delays them. Also, there is no mention of Advanced Pay on the Notice of Action and the asterisks have been removed. Therefore no one knows to ask for Advanced Pay. 3. No mention of Aid Paid Pending (which means the person appealing has to appeal within 10 days and request Aid Paid Pending on the back of the Notice of Action. How would one know they can request Aid Paid Pending?
7. Retirement (SS) Wages CVV

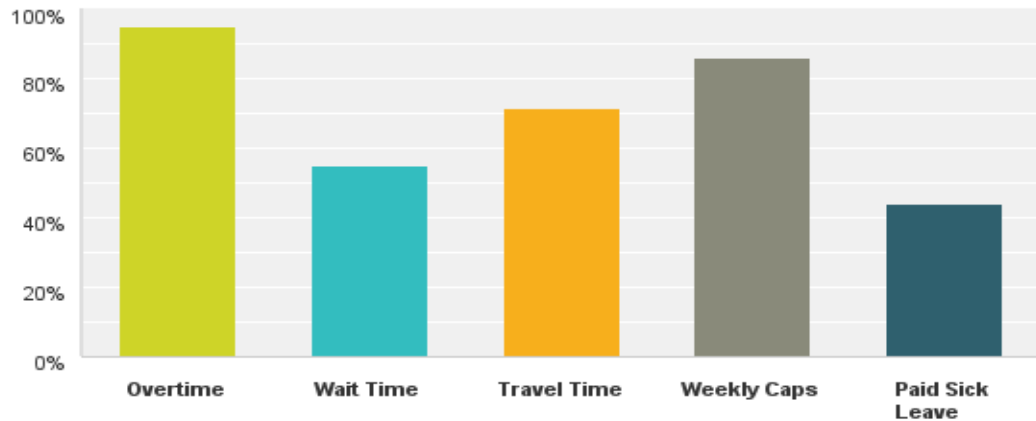
8. Fear cuts to services which could result in leaving the hard decision of me having to possibly leave my daughter who needs 24/7 protective supervision So I could work or us losing our home...(I am a single parent no living family members to help) Second would be the way doctors paperwork is handled paperwork from 3 doctors should have been enough when applied it was waste to be forced to appeal and see a ALJ when even HE said it was a waste of his time since I had turned so much documentation in..
9. Travel time needs to include round trip drop off + round trip pick up. Electronic timesheets!
10. Being paid on time
11. Always having care for my child, receiving enough hours
12. NA
13. That we (who have multiple kids) received no increase with the raise. That IHSS tries to cut my hours every year and I have to fight for them back. Last year it happened 4 times and they lied under oath. They don't make our lives easier. They don't help. They don't care
14. N/A
15. Hours cut Retirement for care providers Overtime
16. Budget/ hours cut Lack of Medi-Cal Medical providers locally
17. N/A
18. Cuts to my hours and wages Not being able to have SS taken out of paycheck
19. What happens if I get sick and cannot work Constantly being afraid to get hours cut Late time sheets and pay
20. Worried that IHSS will get cut because of budget cuts
21. Not given enough hours for care low wages reductions in hours
22. Future care mental health
23. My son Being able to be there for him Safety
24. Retirement. Who takes care of my son if I'm sick? Benefits
25. Hours My daughters health Timely payroll
26. Not giving Protective Services hours to take care of him and keep him safe
27. NA
28. Social security Unemployment Timely Pay
29. Doing more hours than what I'm paid for. Pay increase
30. Retirement, pay on time, wages
31. Moving from one county to another and continuity of pay.
32. This comment is for question 11. I know about these changes but my social worker doesn't. She said my provider does not get paid wait time and has not given me wait time for all my doctor visits nor travel time. She claims they only get paid to wheel you in and wheel me out of doctor
33. Overtime limits (I now make less money). Hours that my children "share" for PS when an outside worker will not watch all three kids. I have no back-up if I'm sick.
34. N/A
35. Cuts, no retirement, no sick days.
36. Pay, health coverage for providers, hours
37. Social Worker changing hours. Won case thru judge
38. My sons hours being cut and having no one to fight for him when I am not around anymore. He's likely to become homeless or not cared for properly

39. Cuts and uncertainty of program because of new president. Providing for family as single parent. no retirement benefits
40. No communication between social worker and provider
41. Timecard processing - it needs to be online. Who will take over when I'm ill or dead? Program overhauls that reduce hours or pay.
42. 1. We are penalized for being parents with more than 1 child with special needs. 530 hours becomes 360 because of overtime limits- NOT FAIR!!! 2. Timecards are always getting lost, then I'm told I am taking too long getting the filled out timecard in to the office. I usually have to call and have someone figure out what happened. I am usually scolded for taking too long to get the time card in!
43. Having more than one child as a consumer. Once our child turns 18 it affects their Social Security.
44. If my child outlives me what will happen to him Wages our county has not had a raise Social security and unemployment benefits for family caregivers
45. N/A
46. Who will care for my child, if something happens to us? Qualified providers. Updates on rules and regulations for Providers.
47. -Who will care for him? What will happen to my son when I'm gone or if I became incapacitated when I'm older and cannot care for him? -The amount of time he is allotted is a fraction of the amount of time I provide care for him. What is going to happen to him when I'm gone? -The time sheet/payroll system is very poor and slow. It causes problems for me to pay bills, expenses for us.
48. NO Social Security NO Medicare NO unemployment.
49. Competent back up if I am unable to do care
50. I am not a parent provider
51. The mix up in all the paper work. Calling one person and them giving us all the wrong info
52. 1. Hourly wages must keep up with the actual living wage for each county 2. Risk of hours/wage reductions when the state runs short of funds
53. N/A
54. Sick pay, Workman's comp, getting person's to take over my hrs. in an emergency.
55. Wanting my child to continue to have someone to look after him when I'm gone.
56. N/A
57. SS for myself when age of retirement Cutbacks on hours & decreasing income Some local, state, gov't programs still include and count exempt income. Seems as if programs are benefiting certain counties.
58. Back-up providers....even if we pay for them ourselves. We need to know that there are adequate caregivers that meet our children's needs. Social security and retirement..... A fair and honest Union.....who will actually have our backs. ??
59. 1. A good back up system for emergency provider. 2. Ability to connect with other parent providers. 3. A program where parents will be educated on how to provide care to their children when parents die
60. EVV is the biggest concern I have

- 61. The cap is completely a joke. It made it so families with two or more consumers received no raise in income. Even went down in income IHSS lies to our faces and in hearings as well. There is no SSI when we reach 65. We have nothing.
- 62. No suitable providers for weekly respite hours no back up providers if I'm sick or otherwise unavailable
- 63. 1)Violations: rec violations for making simple mistakes 2)Caps: This is egregious, when you consider parent providers, never really clock out, stop working, or stop caring for their disabled children, adult or minors. But the county believes it is worth limiting the compensation of parent providers and all providers. Which basically breaks down to, they know, most of us work 24/7, but they are only allowing us to provide up to the cap. 3) Violating the rights of our Children/loved one: minors or adults by forcing caps on providers. Thus forcing our children or loved ones to take on second, third or even 4th providers... which to be honest, who the hell wants strangers touching them.
- 64. Timely paychecks Needed implementation of online time sheet processing Comparable market hourly wage for care providers
- 65. Retirement for parent providers, a better system for timely paychecks, and increased compensation for the hard work we do

Q11 Do you know about the below changes (check those that apply)?

Answered: 116 Skipped: 13



Answer Choices

- Overtime
- Wait Time
- Travel Time
- Weekly Caps
- Paid Sick Leave

Responses

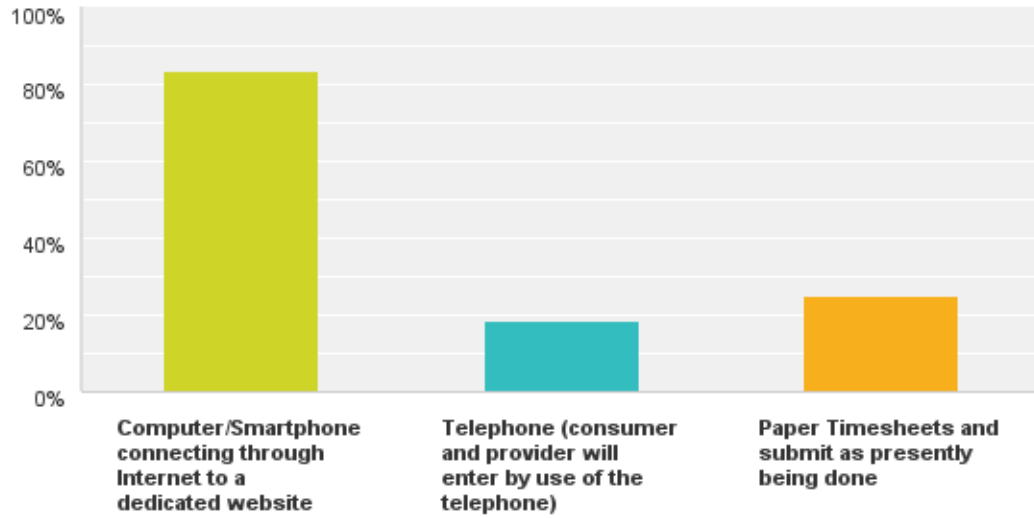
110	94.83%
64	55.17%
83	71.55%
100	86.21%
51	43.97%

Total Responses

116

Q12 The State is presently working on an Electronic Timesheet Submission program. Providers will be allowed to opt-in or out on how they would like to manage their timesheets. Below are the proposed options, choose which one(s) you would like to use:

Answered: 128 Skipped: 1



Answer Choices

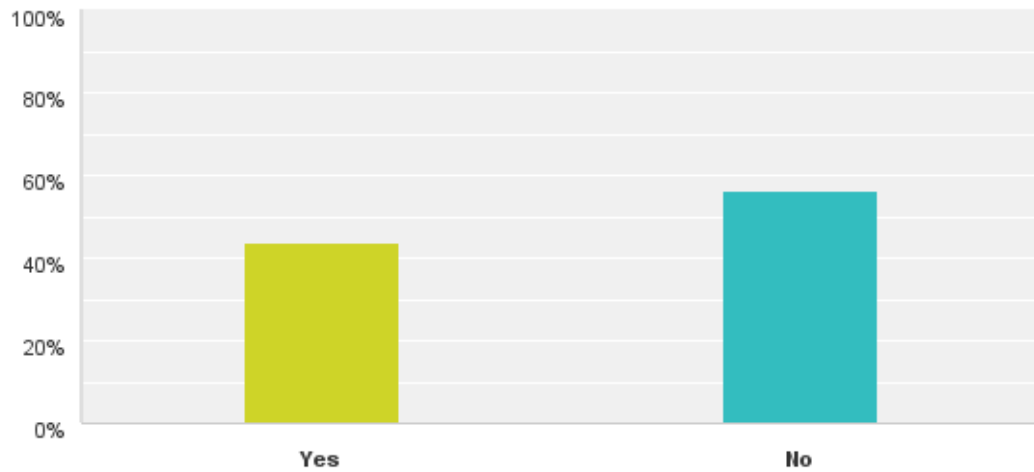
Computer/Smartphone connecting through Internet to a dedicated website
 Telephone (consumer and provider will enter by use of the telephone)
 Paper Timesheets and submit as presently being done
 Total Responses

Responses

107 83.59%
 24 18.75%
 32 25.00%
 128

Q13 Are you familiar with CICA's monthly statewide phone calls?

Answered: 126 Skipped: 3



Answer Choices

Yes

No

71

Responses

55

43.65%

55.35%

Total Responses

126

49 Comments:

1. Hours worked per month for family members
2. 1. Electronic Visit Verification (EVV)
3. Continuity of program(s) implementation.
4. Would like to learn more
5. Phone access be available to all so they can participate!
6. I feel like no matter what I want to talk about there is no point. Nothing will change
7. What to do about the lack of back up providers
8. Budget stability
9. California
10. CA
11. CA
12. Spouse's hours not being lowered. I work 24 hours a day caring for my husband and only paid for 237 month. I don't get paid for waiting with him at the doctor either.
13. Healthcare for providers
14. California
15. More hours and better training
16. How IHSS shares provider personal information with the union and harassment by the union to recruit providers
17. Do not know
18. California

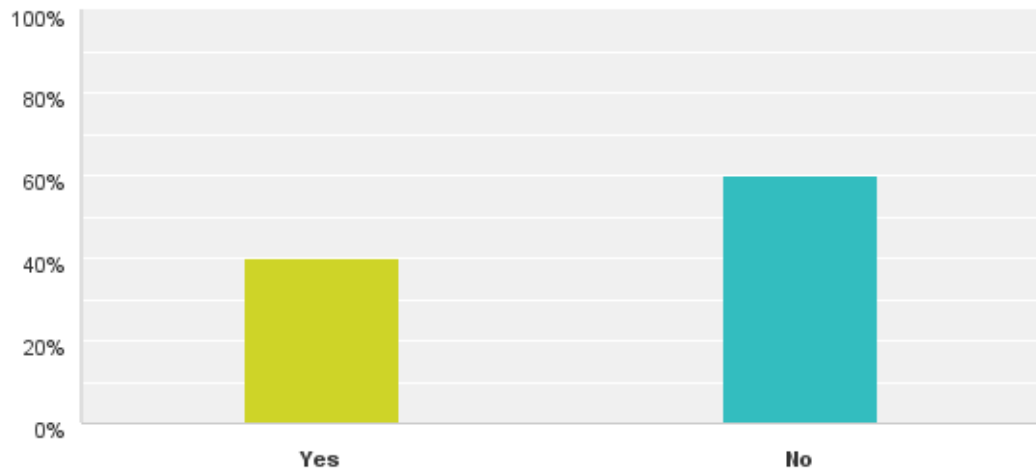
19. The statewide calls are convened by consultants who need to learn from those on the calls rather than the other way around. Consultants need to learn from consumers and providers
20. Lack of truly available workers on provider registry. Over 90% do not answer phone or call back. Most of the few that do answer want to work. Took me well over a year to find someone. Way not acceptable. Also there is no emergency help. You can't depend on an agency that has never sent me help even when requested several times.
21. Cuts and retirement programs for providers.
22. CA
23. As above
24. AB 1930, Provider Back up for sick leave.
25. California
26. California
27. As the cost of living increases, what is the factors that go into the lowering of hours?
28. Family provider benefits social security and unemployment
29. There should be an updated database with more providers and a well-functioning backup program
30. Information on Electronic Timesheet Submission. Information on wage increases
31. California
32. California
33. Being given incorrect info by staff, no feeling of urgency. When we are not properly paid or staff is indifferent it is a huge issue
34. Unpaid wages, caps on client
35. I would like to hear from representatives from counties that have successful Provider Back-up Systems and how those programs were implemented and any problems they overcame
36. CA
37. Electronic timesheet submission
38. California
39. Provider respite (back-up) Plan Updates; Legislative planning & updates
40. California
41. 1. Filling the provider sick leave gap for consumers. 2. Weekly hour capping
42. 1. Decreasing the time for new providers to be enrolled and get timesheets. 2. Lessen red tape.
43. I would love to participate in the calls, unfortunately they are at the busiest time of my day. I try to stay updated on valuable information. Unions and county social workers.....both entities need to treat parent providers with fairness and dignity. ??
44. Prepare parents to set up arrangements for the future care of their love ones after parents' death.
45. Education of social workers and m-cal's influence over IHSS
46. California
47. The cap is ridiculous. It made it so the wage increase accomplished absolutely nothing for us. Struggling financially. In addition the rules for violations are horrible. They are setting people up for failure. Looking for ways

to weed people out. I know parents who have had a stroke/mental breakdowns/scared due to these

- 48. California
- 49. Violations and Pay

Q14 Do you have knowledge of the In-Home Supportive Service Stakeholder Advisory Committee?

Answered: 128 Skipped: 1



Answer Choices

Yes
No

Responses

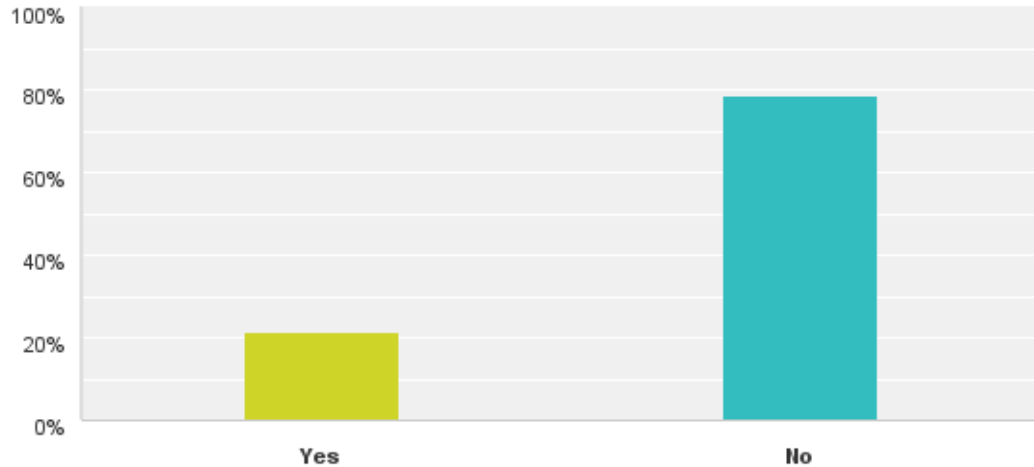
51 39.84%
77 60.16%

Total Responses

128

Q15 Have you participated and/or provided input to the In-Home Supportive Services Stakeholder Advisory Committee?

Answered: 127 Skipped: 2



Answer Choices

Yes

No

Responses

27 21.26%

100 78.74%

Total Responses

127

Q 16 What In-Home Supportive Services program area do you believe the Statewide Advisory Committee should focus on (list up to three)?

Answered: 79

Skipped: 50

First Choice Responses (79):

1. Needed care for seniors
2. Training of providers
3. Improvement of the English language for IHSS employees.
4. Consumers' hours to 24 hours a day.
5. Timesheets
6. EVV
7. No cuts to programs
8. Timesheet improvements
9. Direct access to website to follow up on check status
10. Payroll
11. Least restrictive environment support
12. Get rid of caps
13. Emergency Back Up Providers

14. No cuts
15. Disabled children
16. Hours
17. Providers working hours
18. Raise wages
19. Payroll
20. Skilled emergency care provider backup list
21. Retirement
22. Streamline hiring and paying providers
23. Better screening for IHSS providers
24. Making provider enrollment easier and faster
25. Wages
26. Ensuring providers are paid decent living wages.
27. Alameda
28. Overtime cap
29. Back-up services
30. Provider training
31. Electronic Timesheets
32. AB 1930
33. Listen
34. Timely pay
35. Pay
36. Timeliness of pay
37. Emergency backup services for severely disabled by Maxim 24/7 that handle
lo waivers
38. The lack of providers
39. Electronic Payroll
40. Parent provider being able to collect unemployment and SSI
41. Paid on time
42. Social Security for family providers
43. I need more. Hours
44. Simplify Provider Enrollment to Past Method, Allow Downloadable IHSS
Provider Timesheets, & Populate Provider Timesheets for Those with Set
Provider, Keep Fluctuating Hours for Those with Providers Working Different
Hours Hrs.
45. Updated time card system
46. Cut backs on care when state is in crisis
47. AB 1930
48. All IHSS programs should be focused on
49. Emergency support
50. Competitive wages
51. Time card issues
52. Overtime penalties for parents with more than one special needs child. We
have had our hours drastically cut for no good reason. Why should I only get
360 hours when it was felt I needed 530?
53. Spousal caregiver eligibility for unemployment
54. Better parameters to determine need for hours
55. Wages and benefits
56. Provider abuse and theft - there is no accountability for this common problem

57. Timely payment from timesheets
58. I need more. Hours
59. Social workers tell me they don't know what's going on request pay. They tell me to call payroll. Shouldn't call them they certainly have secret numbers to get a fast answer, when I call I only get a machine and No one ever calls back.
60. Los Angeles
61. Time sheet and provider payment process
62. Electronic Submission of Timesheets
63. Payroll system
64. Provider respite (back-up)
65. Back up attendant registry
66. Decreasing the time for new providers to be enrolled and get timesheets
67. Wages
68. Helping to make sure that the transition to electronic time sheets goes smooth
69. Push on the bi-weekly pay period.
70. Electronic Time sheets
71. Training
72. EVV
73. Humboldt
74. Hours cap for more than one consumer
75. Timeliness of pay/ease of timecard submission
76. Payroll/time sheet processing
77. Violations
78. Time sheets processing
79. NA

Second Choice (67):

1. Checking of references
2. Continue to support the wages for IHSS providers.
3. Backup on caregiver then caregiver sick
4. Hours per month
5. Coverage for parents with kids who end up in hospital short term
6. Get English speaking IHSS Employees
7. Up to date IHSS changes, budget cut effecting IHSS
8. More continuity in IHSS; within county offices & SW
9. Emergency backup provider services (provider ill /can't work =replacement)
10. More hours
11. Streamlining the Payroll Process
12. Retirement for care providers
13. Disabled elderly
14. Overtime
15. Health benefits
16. More hours
17. Increase hours
18. More understanding of recipients needs for more caregiver hours
19. Family insurance
20. Improve benefits for providers
21. Better pay for them

22. Developing a real emergency backup system
23. Tie Sheet Process
24. Developing a better registry of available providers
25. Wages
26. Timesheets Not Downloadable & Processing Nightmare
27. Assuring Consumers are up to date on all aspects
28. Back-up providers
29. No caps
30. Listen
31. Caregiver retirement
32. Hours
33. Moving to another county
34. Paying enrolling providers within the first month/reliable pay days
35. The ridiculous registry list of non-viable workers
36. BACK UP PROGRAM
37. Retirement for family providers
38. Keeping providers happy
39. Back-Up Contract with Agency Like Maxim Available 24/7
40. Increase pay for those with training
41. Health coverage for providers
42. Electronic timesheets
43. Program safe from constant cuts
44. Social workers ineptness
45. More caregiver support groups
46. How do we match providers to consumers?
47. Overtime exceptions
48. Providers should be paid in a timely manner
49. Wage Increases
50. Keeping providers happy
51. Inland empire
52. Provider back-up systems for when a recipient's provider is sick
53. An interactive web portal for IHSS providers to validate consumer/provider's profile and current activity
54. Payroll system
55. Payroll & timesheet issues
56. Regular paydays for providers
57. Cut some of the red tape and simplify the process
58. Hours/guidelines
59. Monitoring the public authorities to make sure that there are back-up providers in the registries
60. Explain IHSS program in layman's term, i.e. simple language
61. Pay Raise
62. Efficient processing
63. Asterisks are not on the NOA anymore. No explanation of the category "Services Refused or Gets From Others"
64. Trinity
65. Regulate IHSS case advisors and managers because they are never held accountable for their lying
66. Better training for social workers so they actually know and follow the law

67. Caps

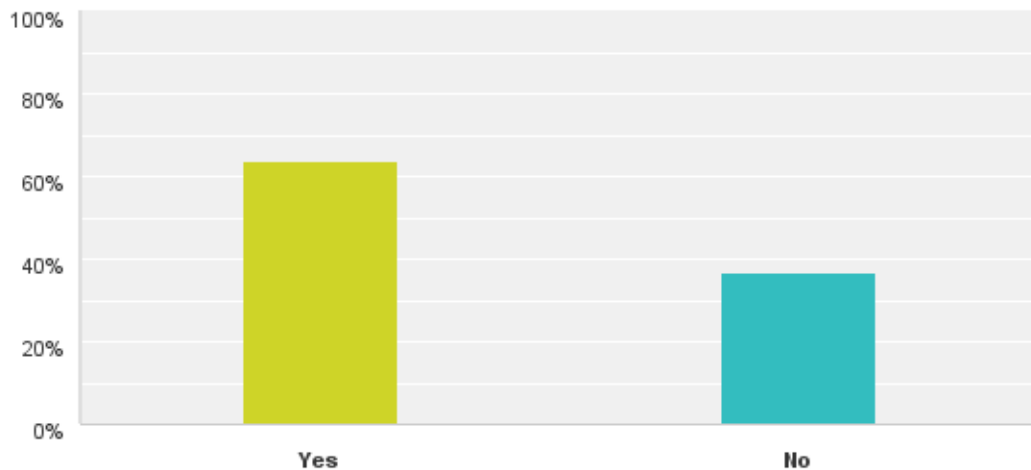
Third Choice (58):

1. Interviewing
2. IHSS and provider communication arenas
3. Sick leave for caregivers
4. Wages
5. Better communication
6. Reduce errors
7. Trainings including difficult clients
8. Provider Back Up Plans
9. Delay's in social worker response/delays in providers pay received
10. No threats from IHSS telling us we have to use one of their providers if we can't
11. N/A
12. Overtime
13. Retirement plan for providers
14. Improve time sheets
15. Easier way to report abusive behavior from a third party
16. Sick leave
17. Improve benefits for consumers
18. More hours for me and them
19. Ensuring hours are not capped
20. Backup provider registry
21. Cuts to program
22. Eliminate Provider Overtime Caps
23. Consumer Representation, Protection & Advocacy
24. Determining hours is out dated
25. Listen
26. Increase caregiver hourly pay
27. Sick Leave
28. Creating stability by assuring no cuts
29. Increasing hourly wage and low-wage Counties and higher pay grade for those who deal with severely disabled.
30. Viable emergency help
31. SOCIAL SECURITY FOR FAMILY PROVIDERS
32. Unemployment for family providers
33. Overtime
34. IHSS Provider Pay Rate/Higher Grade for Severely Disabled & Complex Medical Conditions with Step Increase in Pay for Continuing to Work in field and for Severely Disabled Recipient/Participant on an annual yrly basis
35. Increase funding
36. Electronic time sheets.
37. Lack of Exemption info
38. Training
39. The length of time to secure a provider or recruitment.
40. Family provider social security benefits and unemployment
41. Every IHSS consumer should have a voice which is heard and acted upon
42. Hourly/monthly hours increase

- 43. Overtime
- 44. San Diego
- 45. Recipient education to prevent fraud (both in hours worked and tasks completed)
- 46. Payroll system
- 47. Better communication to consumers & providers on all levels
- 48. One Stop Solution Enrollment for Providers
- 49. Providing more incentive to prospective providers
- 50. Finding a way to stop unions from harassing providers at their private residences
- 51. Review guidelines on allocating hours to different task - like grocery shopping, food preparation, etc.
- 52. Another Pay Raise
- 53. Accurate assessments
- 54. Right to receive Aid Paid Pending on the back of the NOA. No longer there.
- 55. Del Norte
- 56. Have IHSS actually HELP families not bully them
- 57. Better pay for providers
- 58. Electronic Timesheets Without EVV

Q17 Would you like to be added to the IHSS Stakeholder Advisory Committee's email lists?

Answered: 119 Skipped: 10



Answer Choices

Yes
No

Responses

76 63.87%
44 36.97%

Total Responses

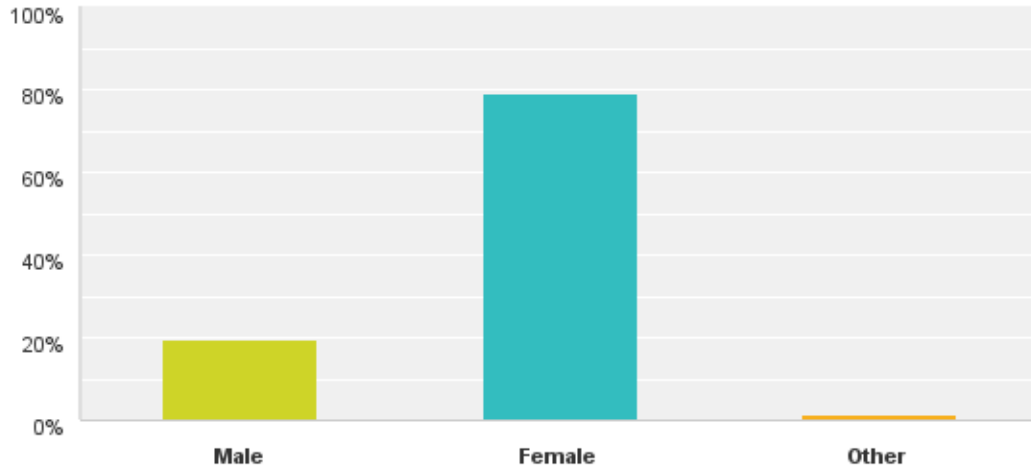
119

Comments (2):

1. What is a Stakeholder? I'm not able to comprehend and represent myself at all times in so many issues. Can't the Consumer be informed of what pertains directly to the Consumer? And then I won't be overwhelmed with everything else on top of my disability to the point that my life is made worse rather than better by having help from IHSS.
2. In the meeting I heard I felt the agenda was not set by consumers or providers. Nancy Becker Kennedy

Q18 What is your gender?

Answered: 129 Skipped: 0



Answer Choices

Male

Females

Other

Total Responses

Responses

25 19.38%

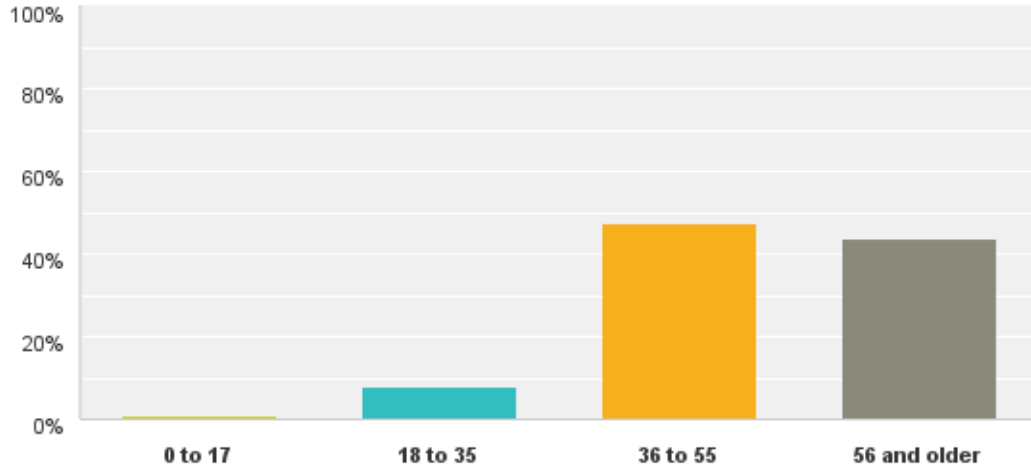
102 79.07%

2 1.55%

129

Q19 What is your age?

Answered: 128 Skipped: 1



Answer Choices

0 to 17
18 to 35
36 to 55
56 and older

Responses

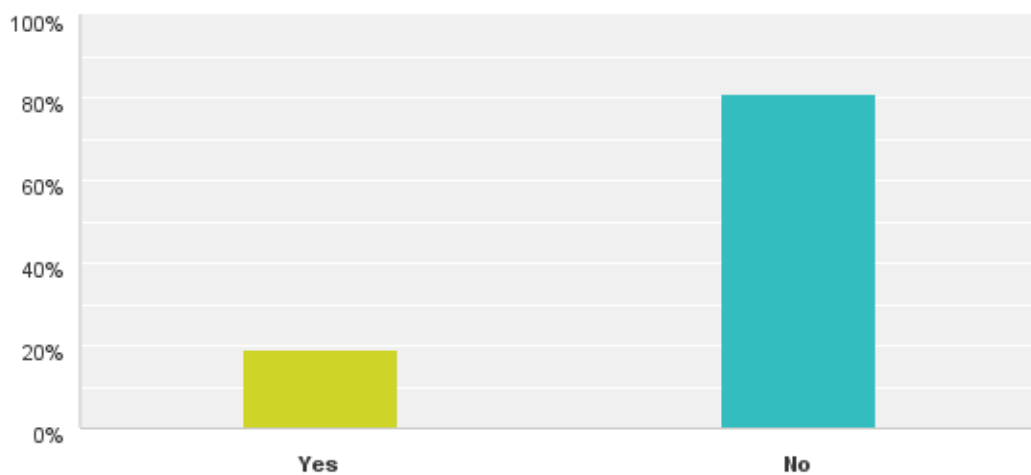
1 0.78%
10 7.81%
61 47.66%
56 43.75%

Total Responses

128

Q20 Do you speak a language other than English in your home?

Answered: 126 Skipped: 3



Answer Choices

Yes
No

Responses

24 19.05%
102 80.95%

Total Responses

126

19 Comments:

Sign Language – 2
Russian – 1
Italian – 2

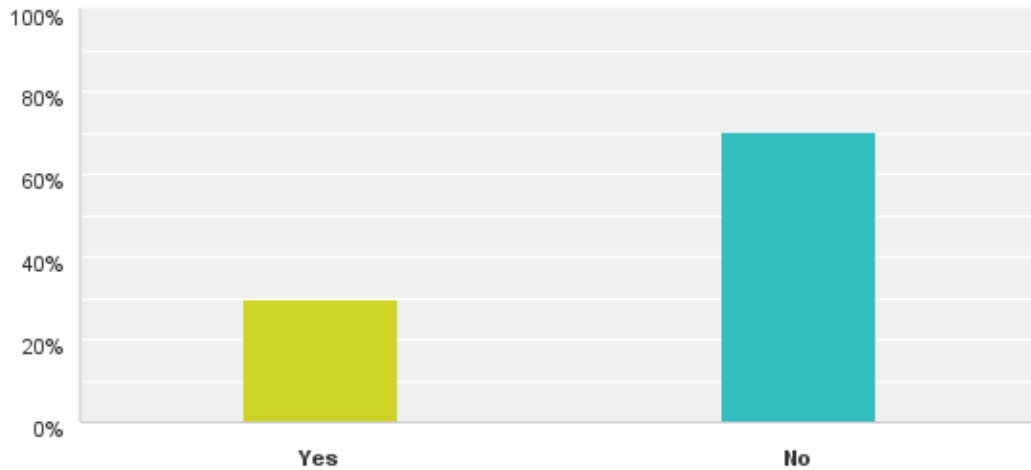
Armenian – 1
English – 5
French – 1

Spanish – 6
ASL – 2
German – 1

A couple spoke multi languages

Q21 Are you on CICA's mailing list?

Answered: 125 Skipped: 4



Answer Choices

Yes
No

Responses

37 29.60%
88 70.40%

Total Responses

125