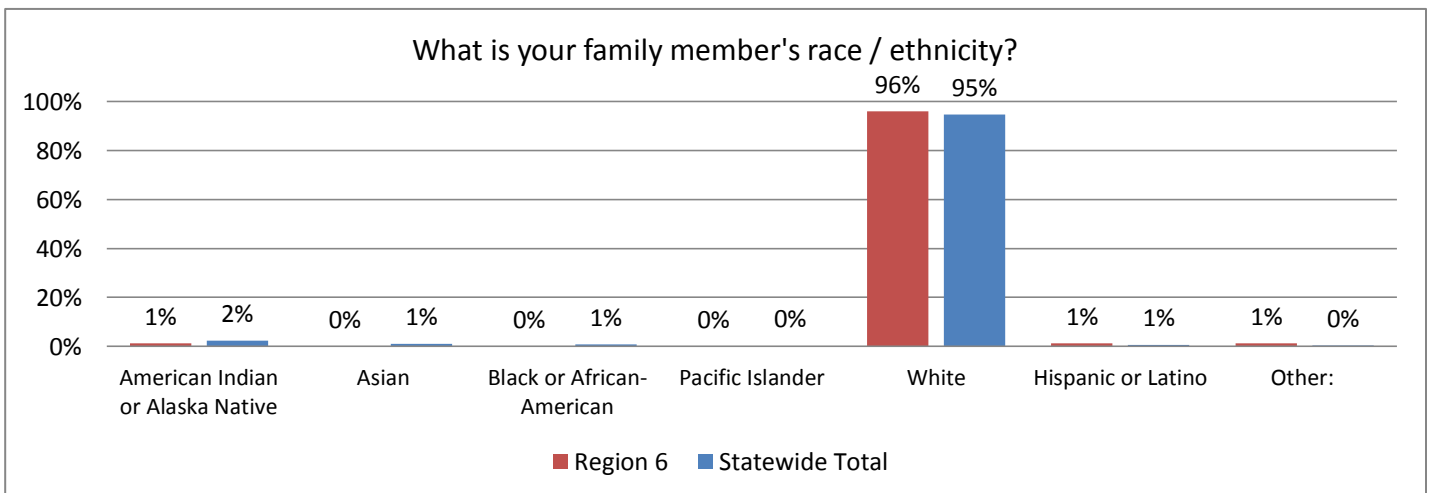
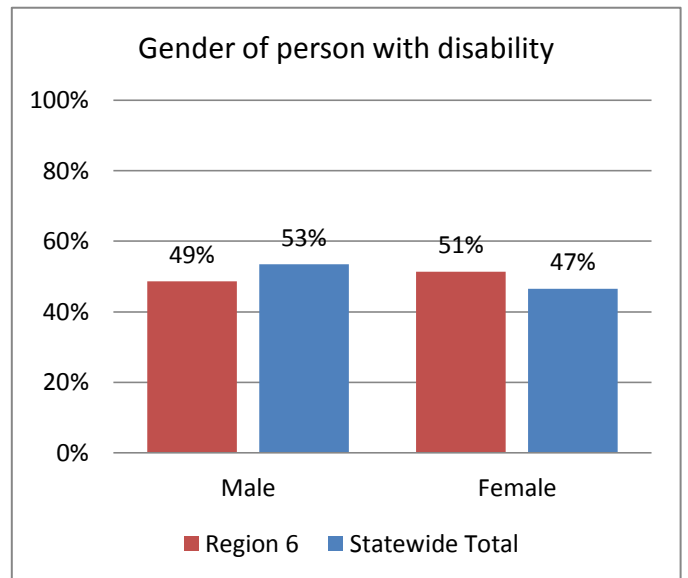
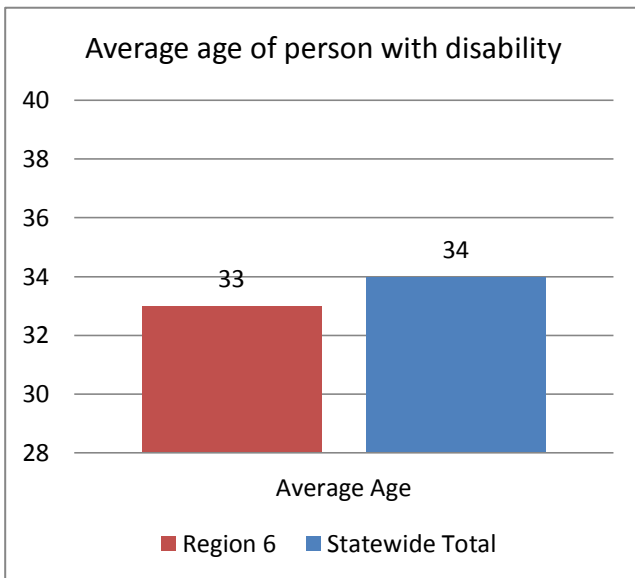


2018 Adult Family NCI Survey Results
Region 6 Summary and Statewide Comparison

2018 Adult Family NCI Survey Results

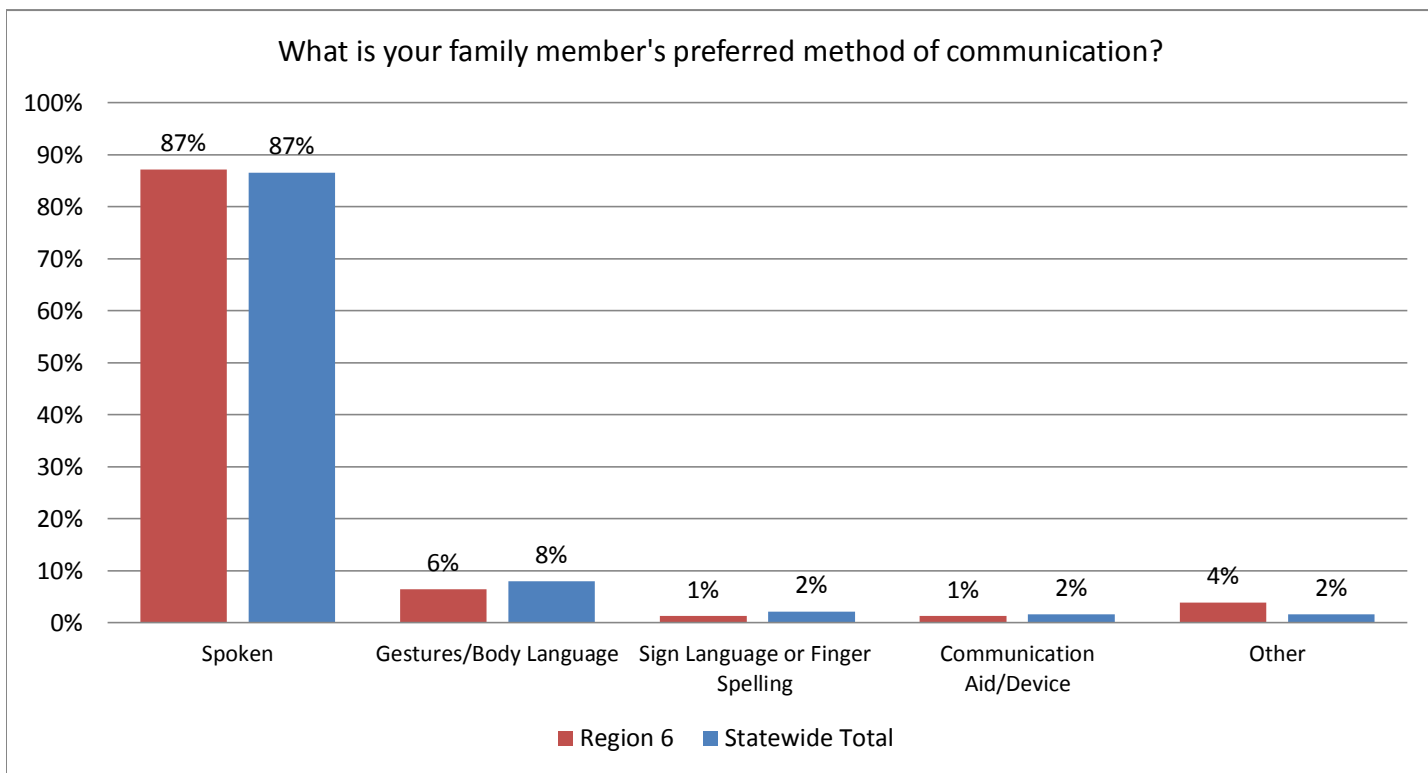
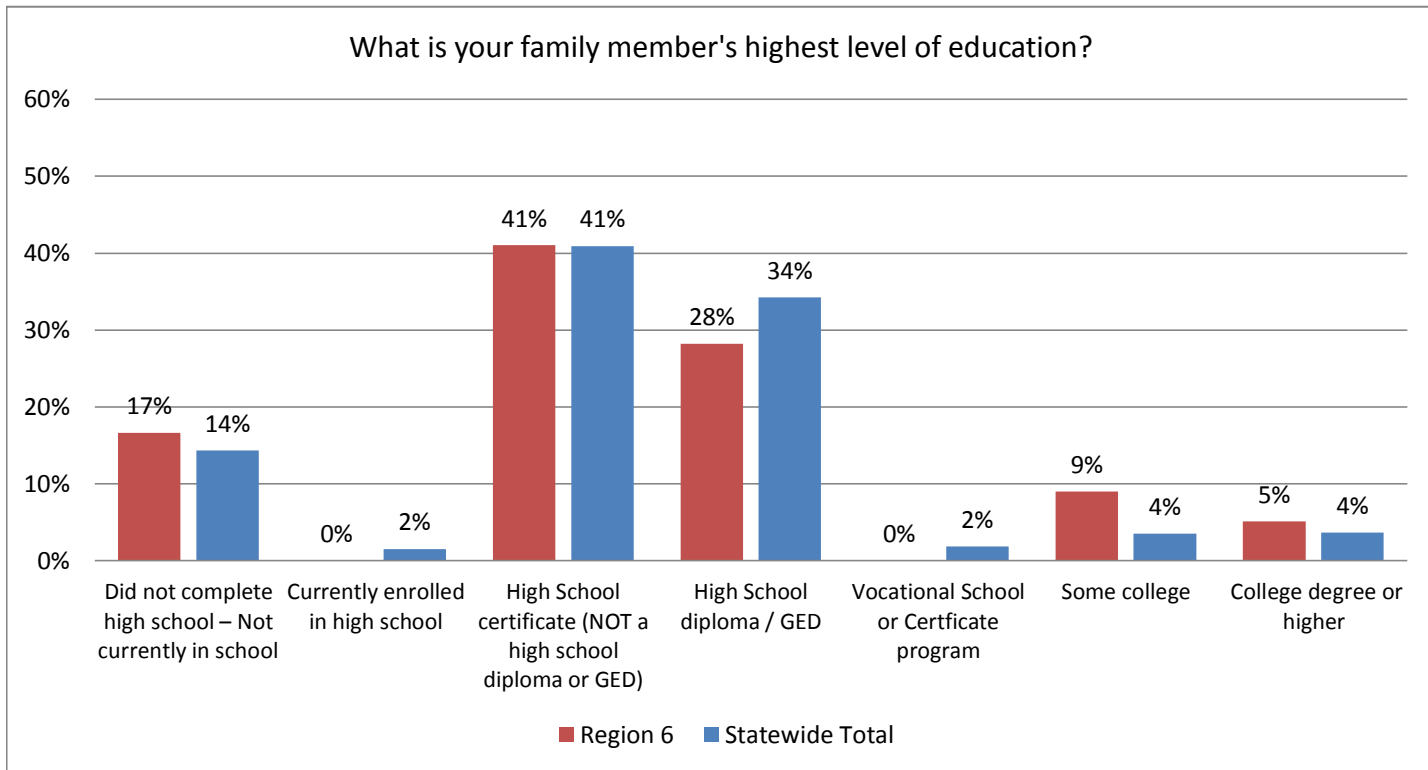
	Region 6	Statewide	
Total Surveys Sent	217	1977	
Total Returned	92	682	
Return Rate	42%	34%	
Number of returned surveys sent to wrong respondent type	14	68	(Adult Family went to someone who should have gotten Family Guardian)
Net Valid Adult Family Responses	78	614	
Average Time to Complete (minutes)	23	23	

Family Member Demographics:



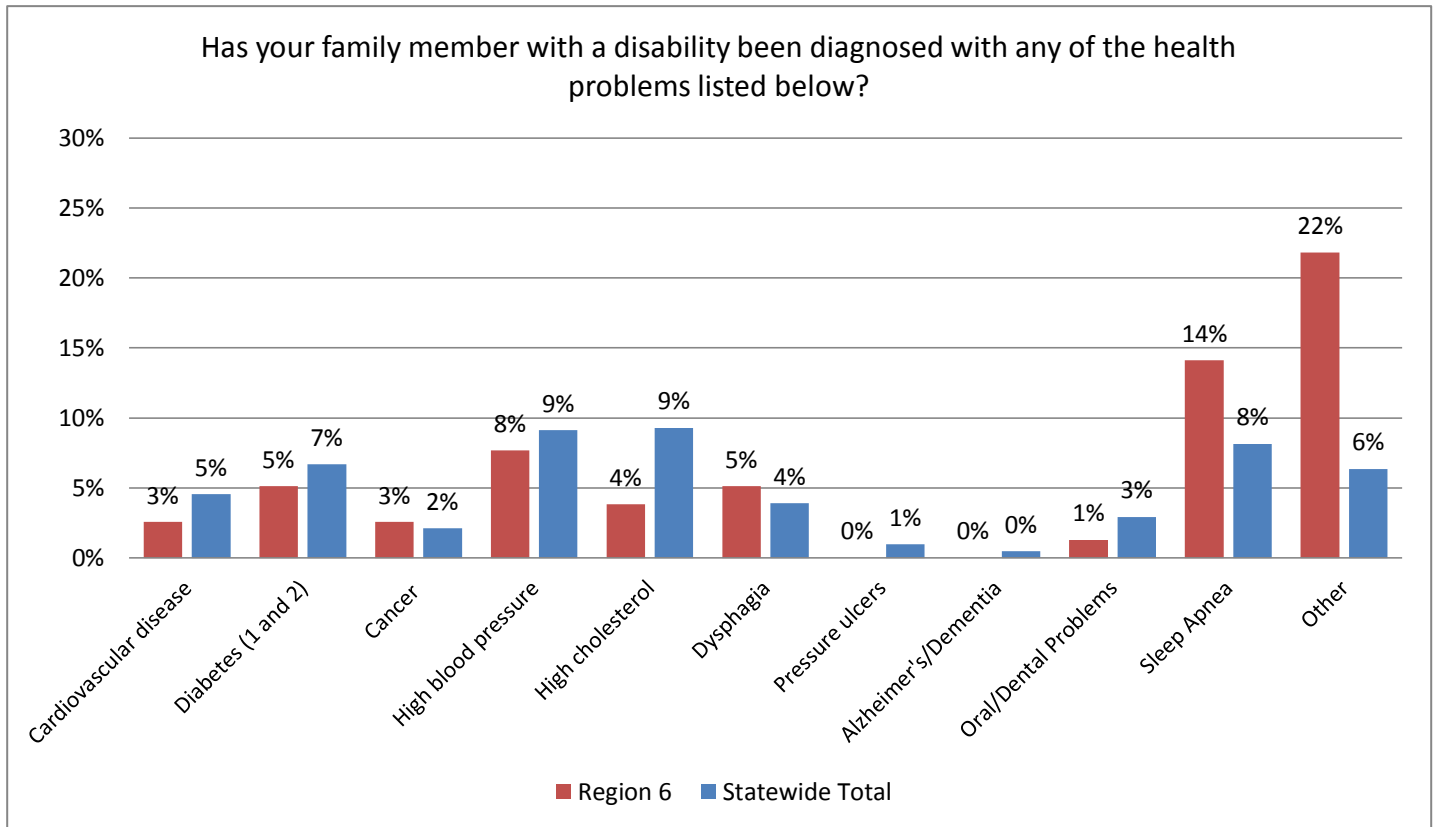
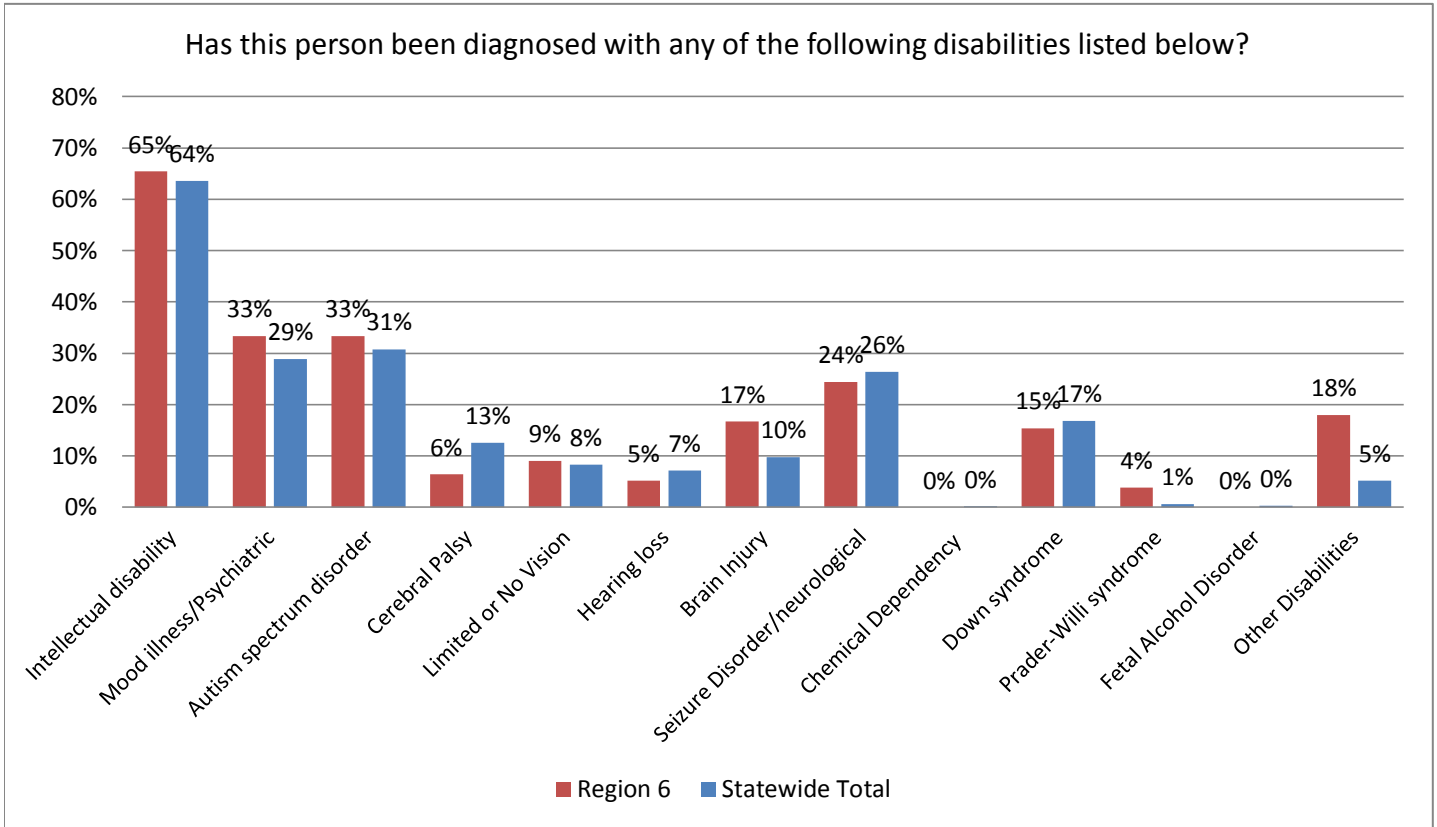
2018 Adult Family NCI Survey Results
 Region 6 Summary and Statewide Comparison

Family Member Demographics:



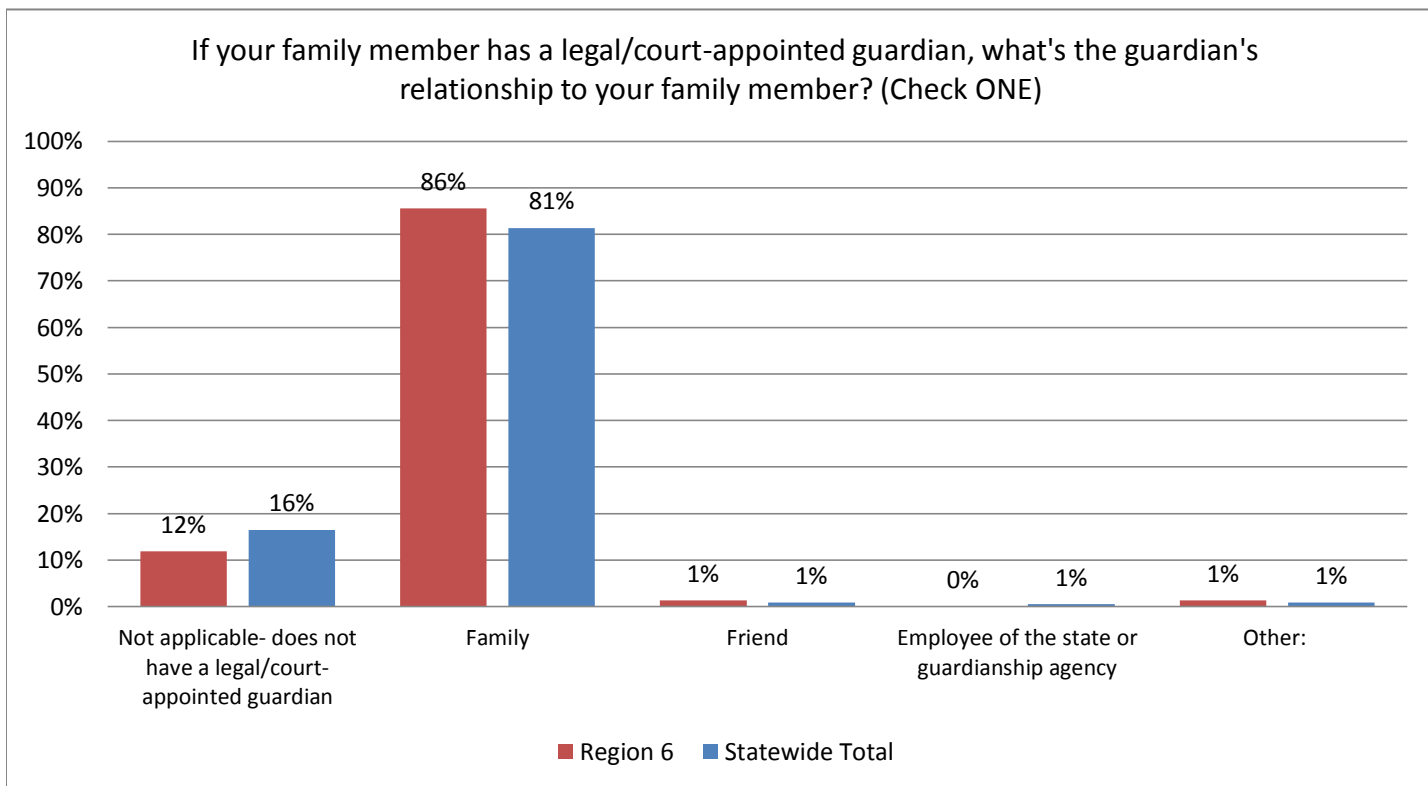
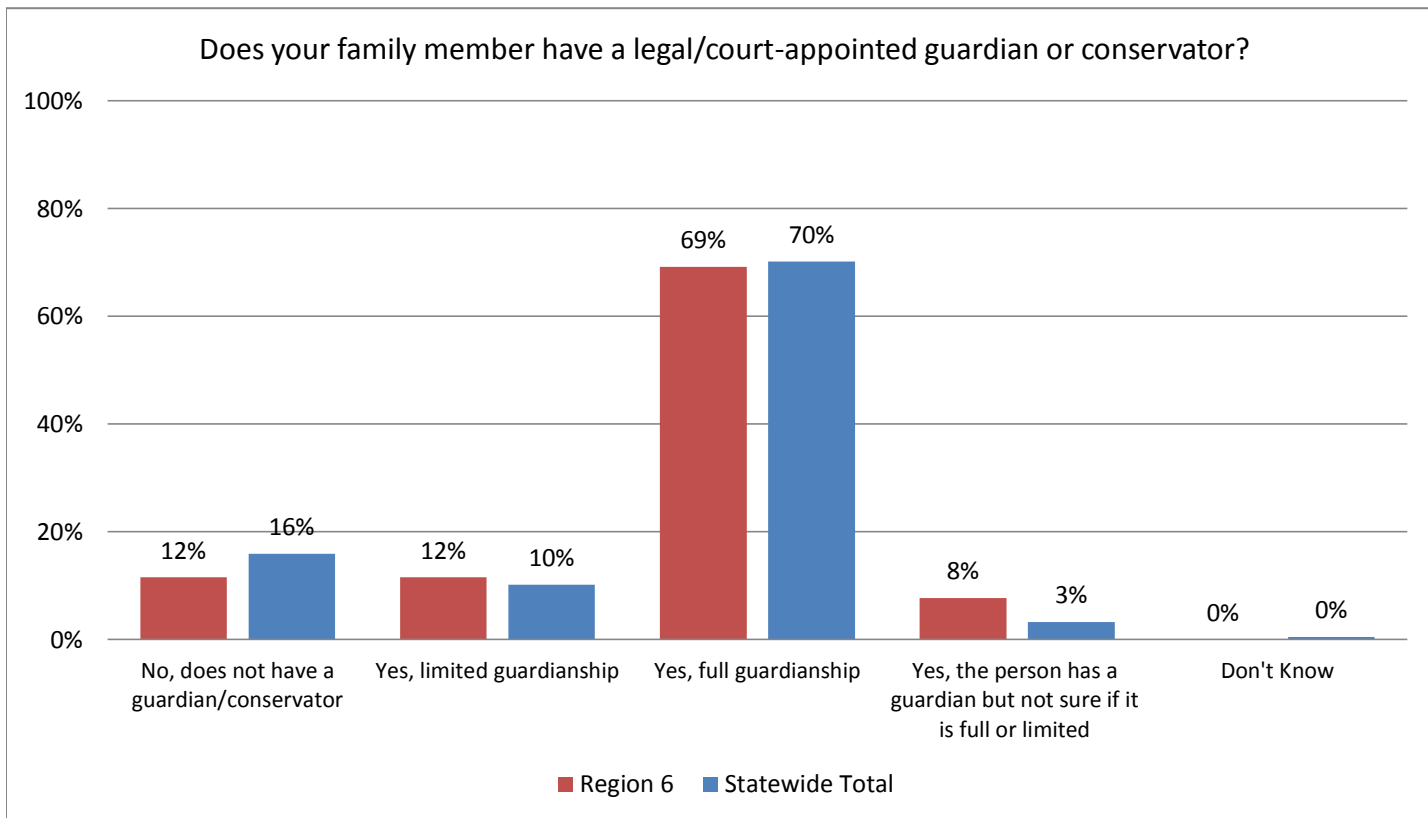
2018 Adult Family NCI Survey Results
Region 6 Summary and Statewide Comparison

Family Member Demographics - Diagnosis:

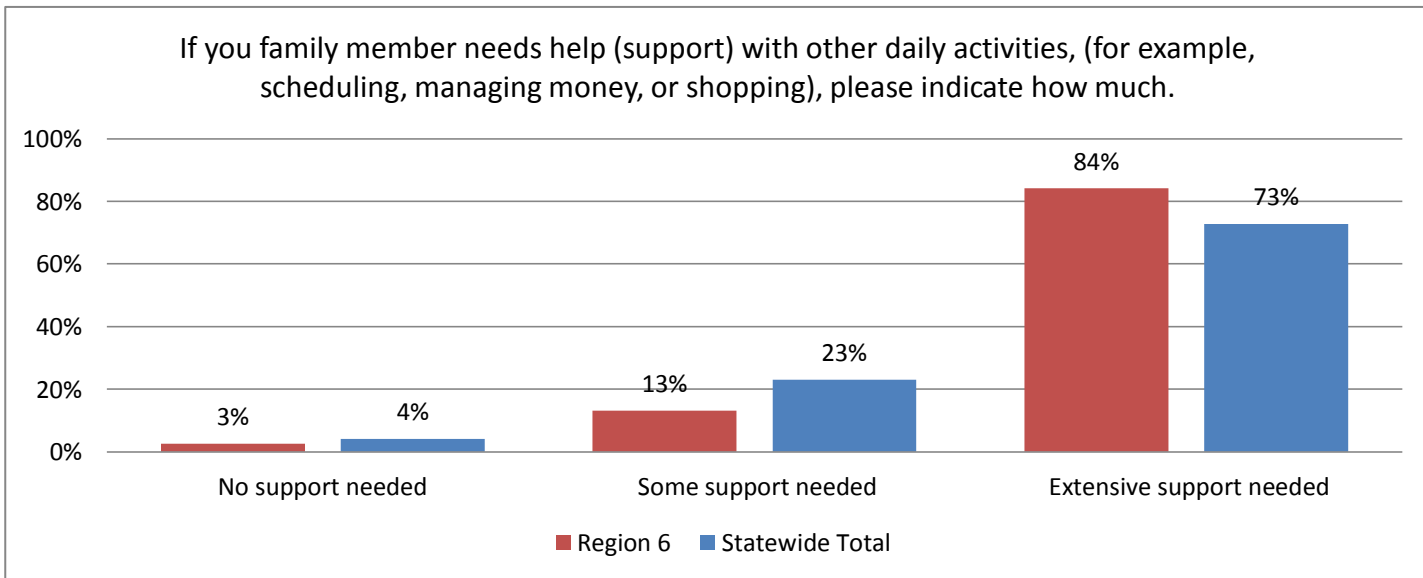
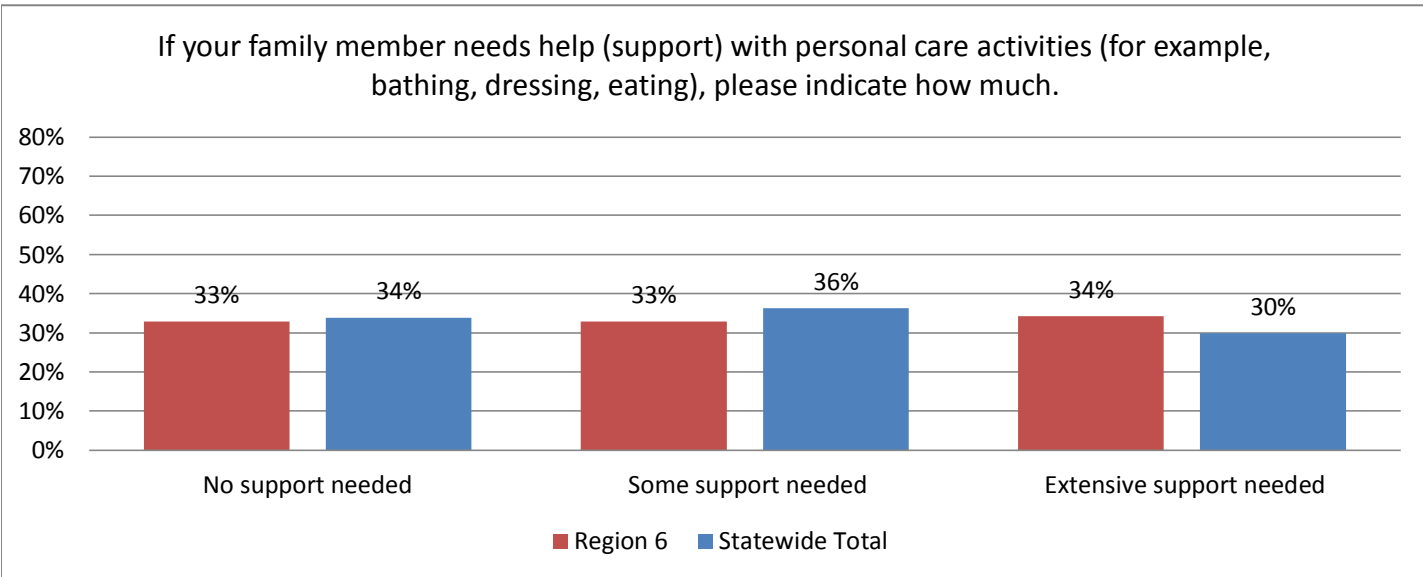
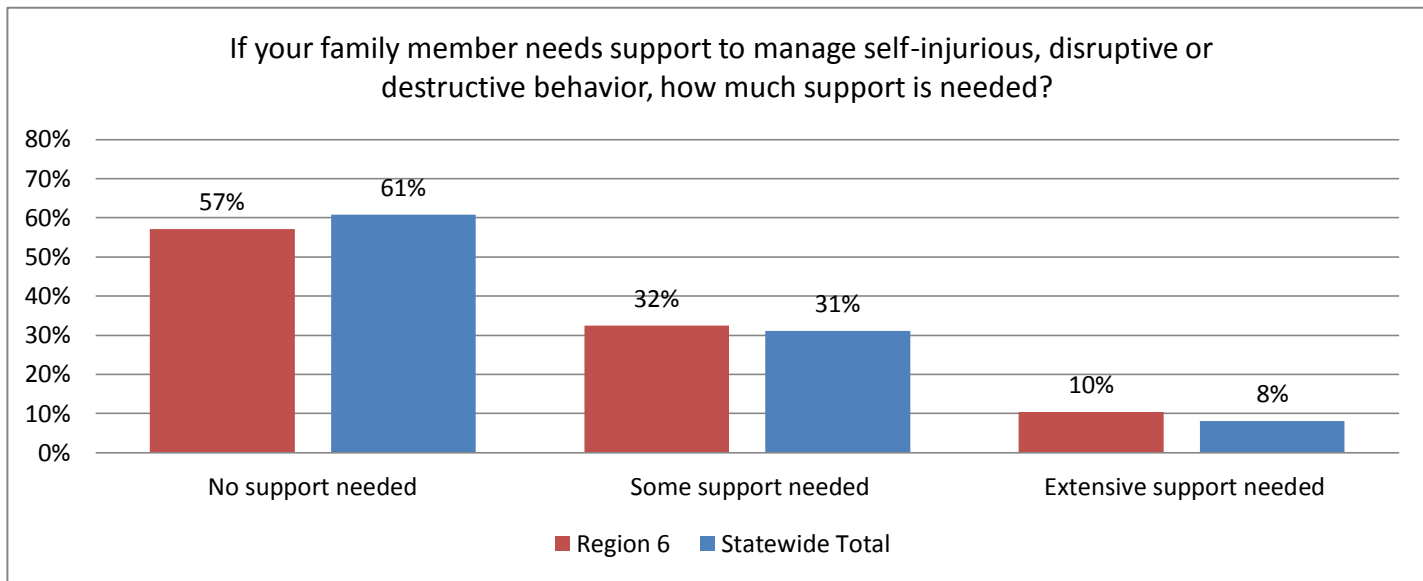


2018 Adult Family NCI Survey Results
 Region 6 Summary and Statewide Comparison

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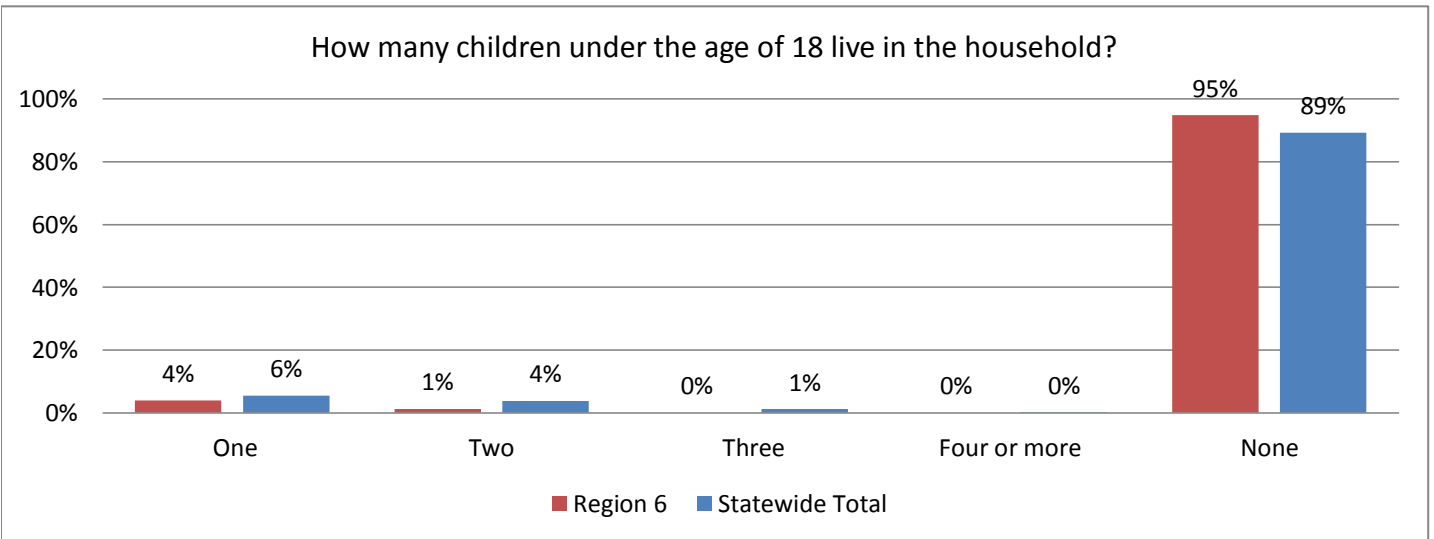
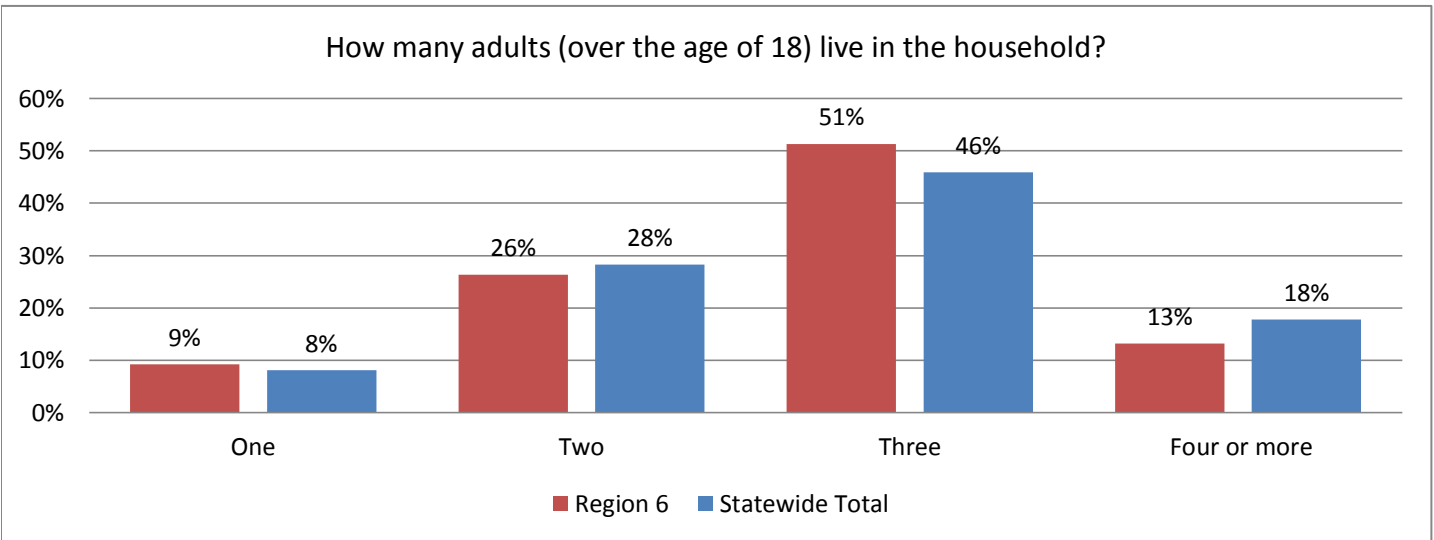
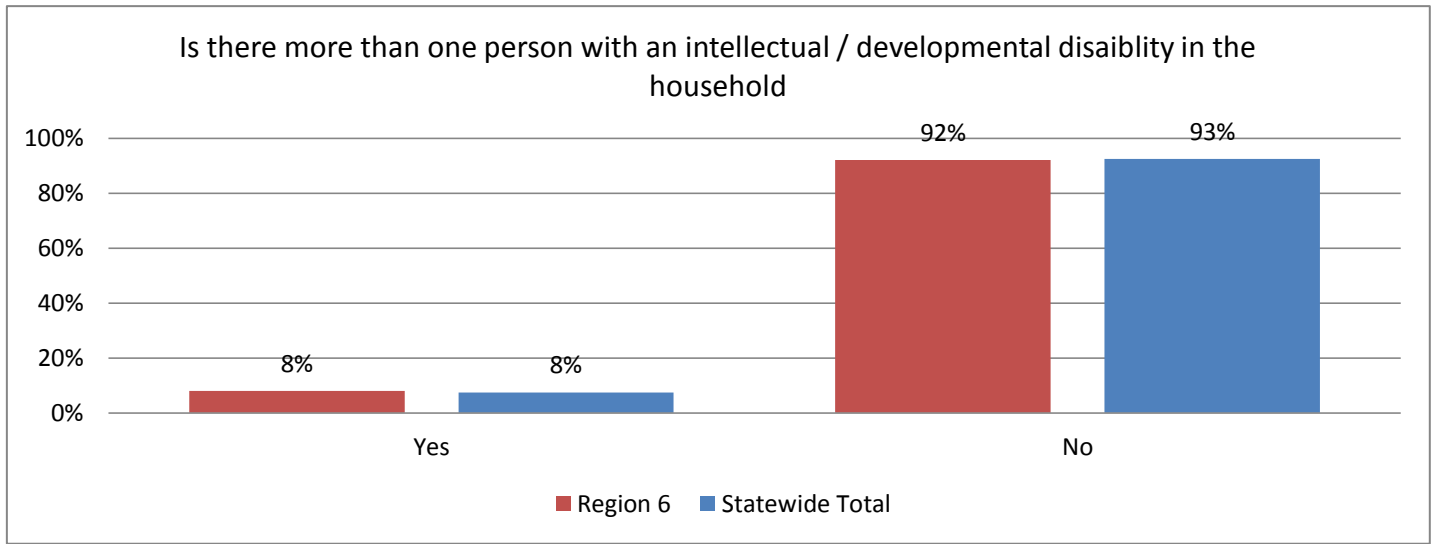


Family Member Demographics - Supports Needed



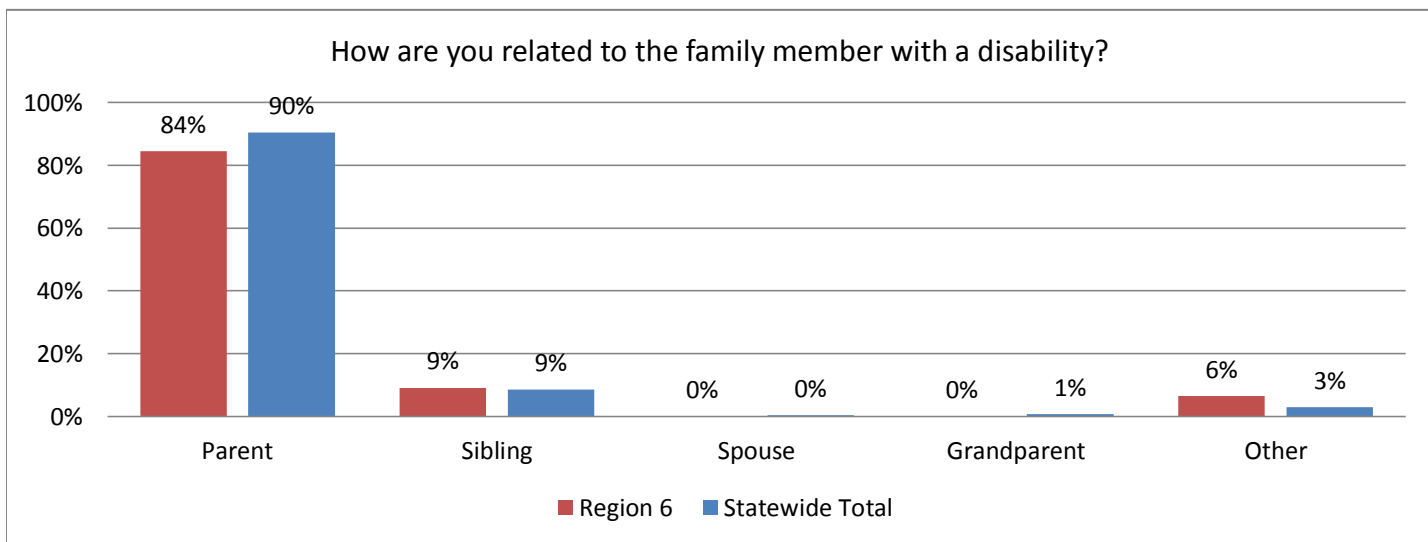
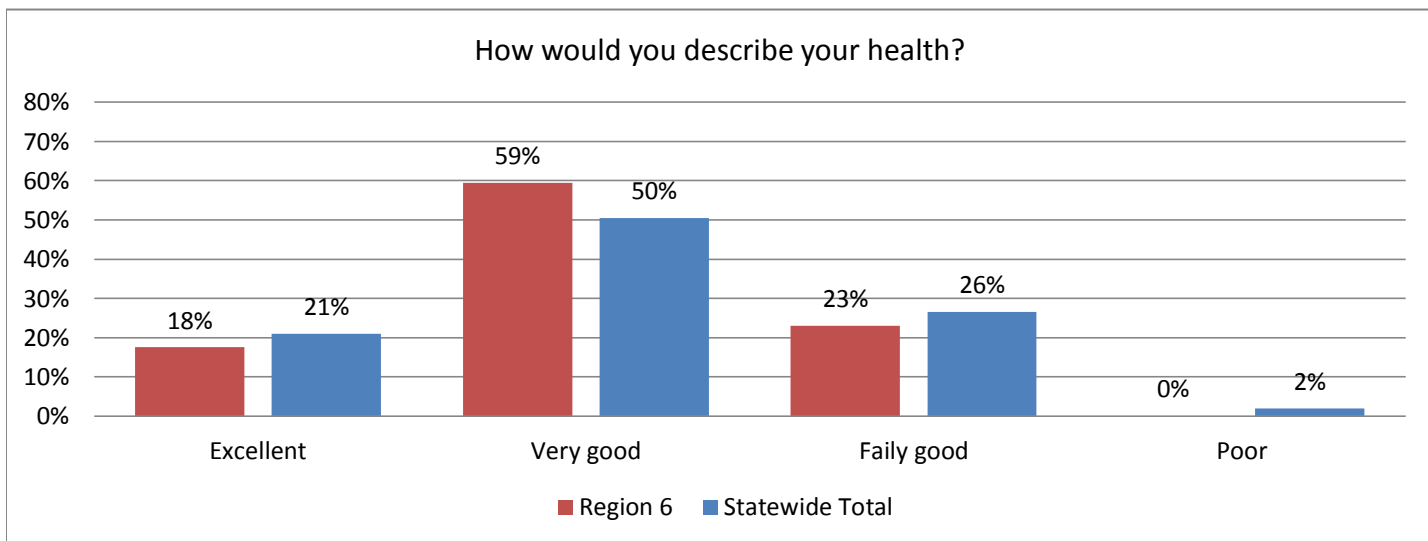
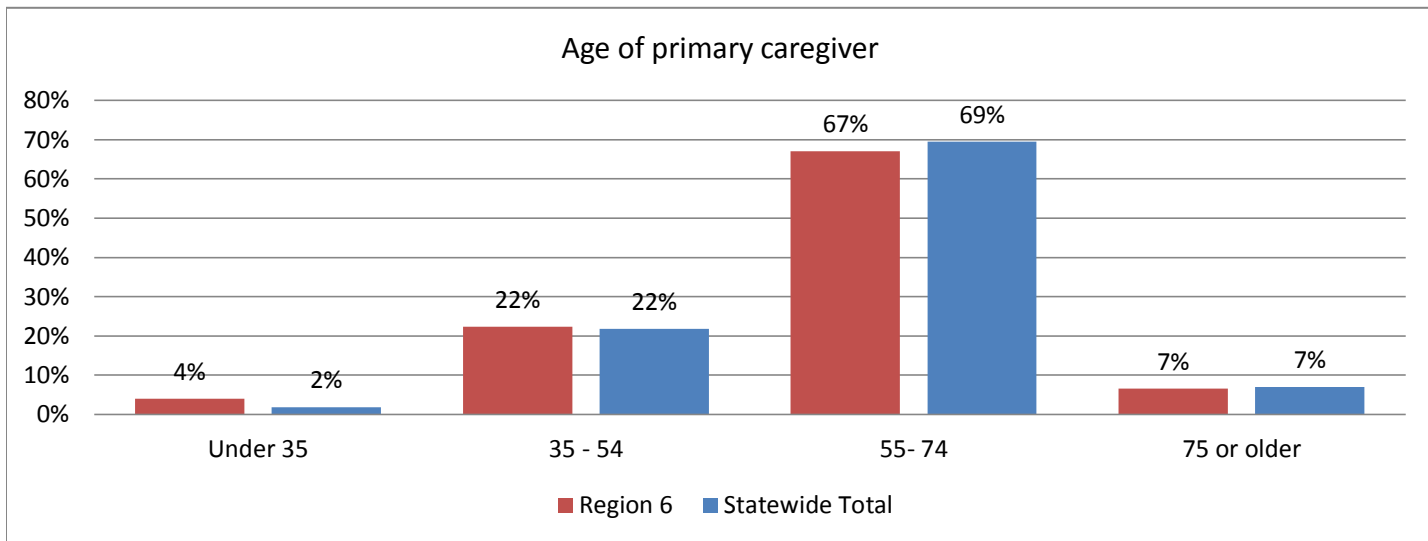
2018 Adult Family NCI Survey Results
 Region 6 Summary and Statewide Comparison

Caregiver / Household Demographics



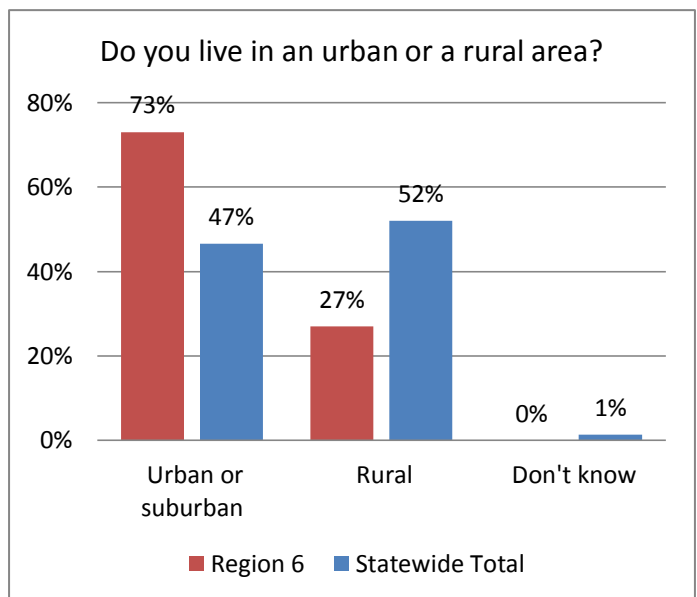
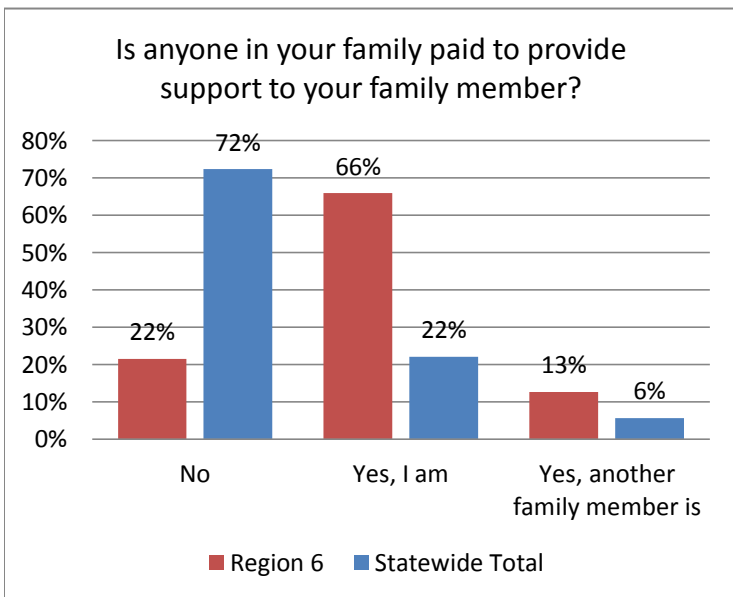
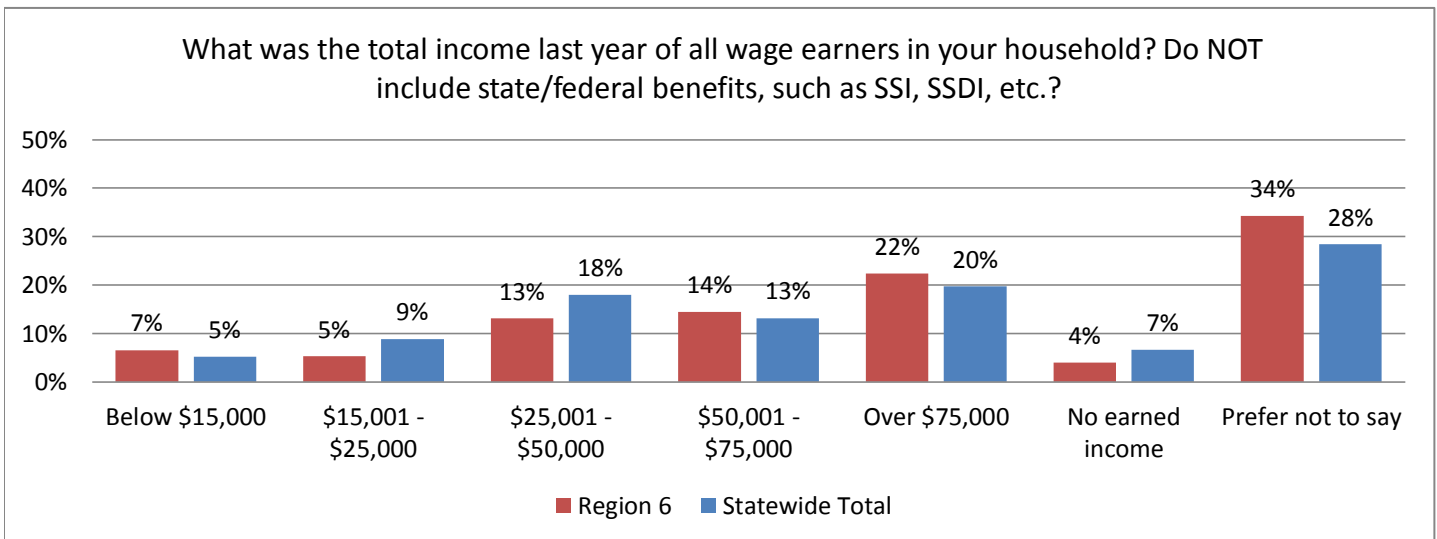
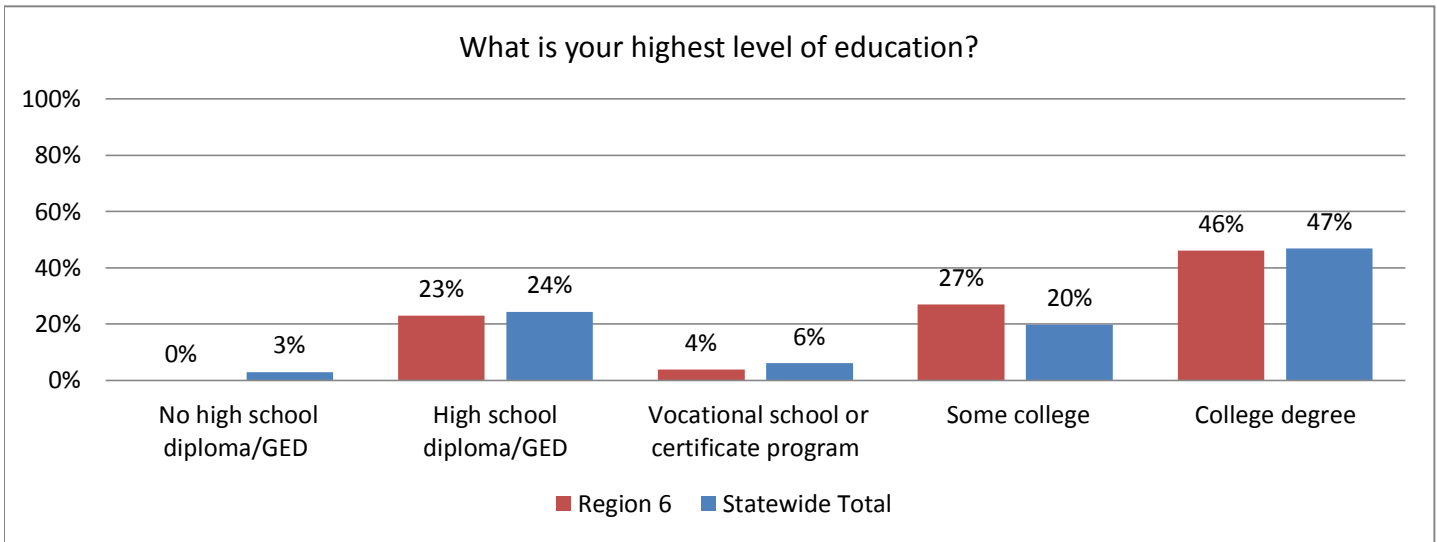
2018 Adult Family NCI Survey Results
 Region 6 Summary and Statewide Comparison

Caregiver / Household Demographics



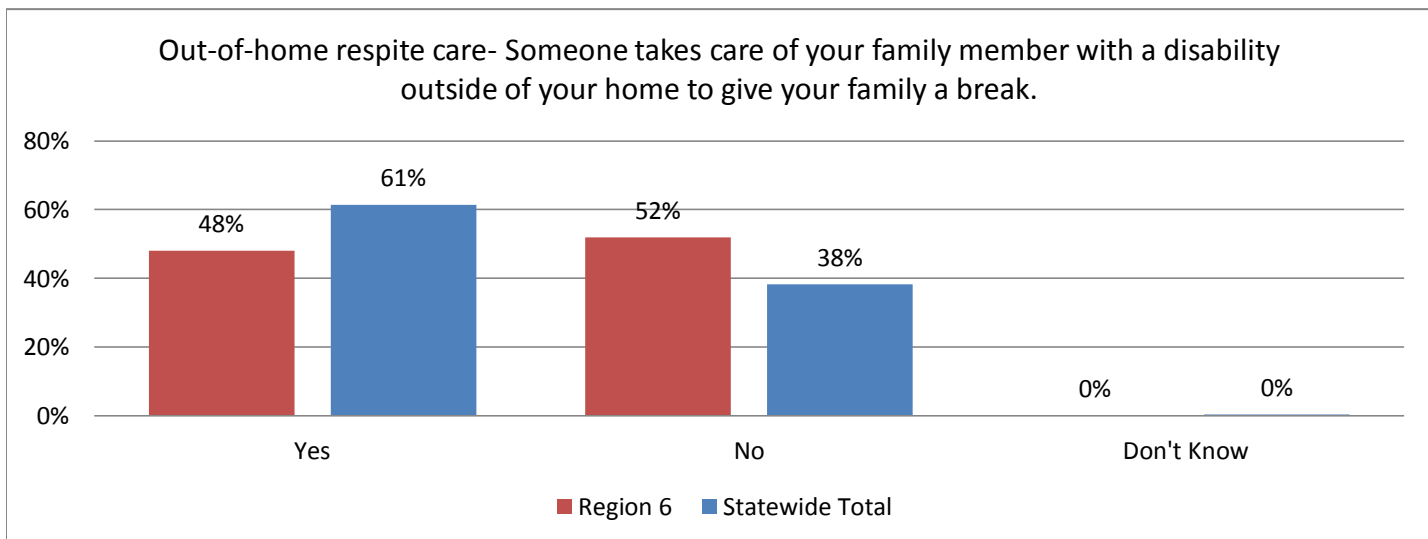
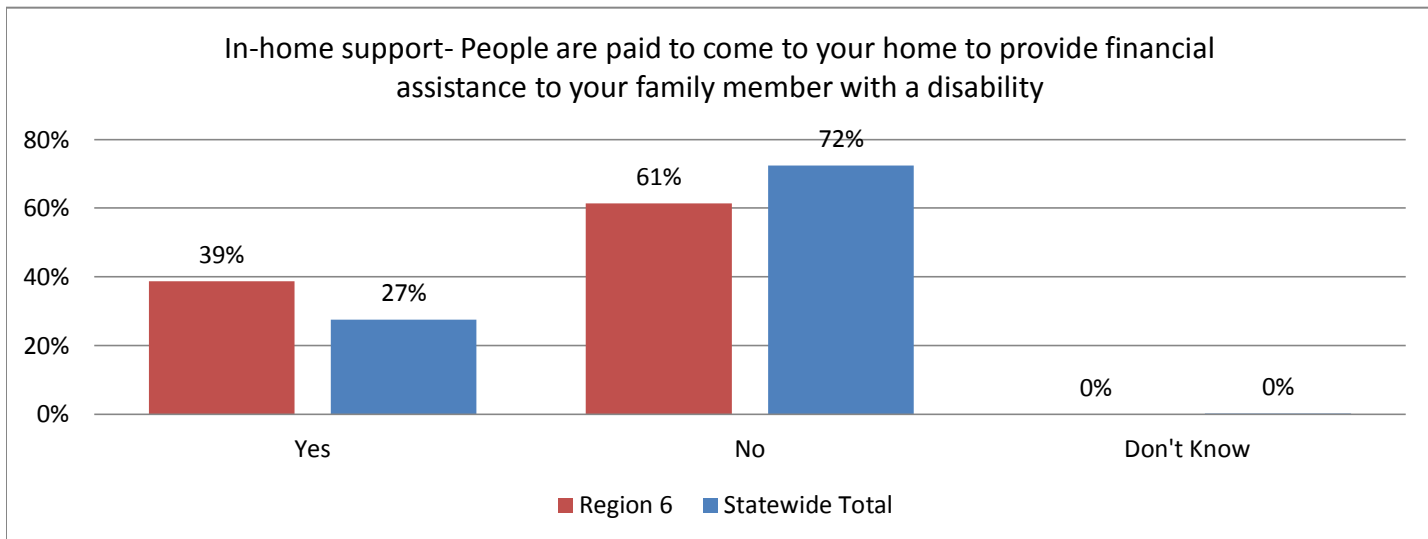
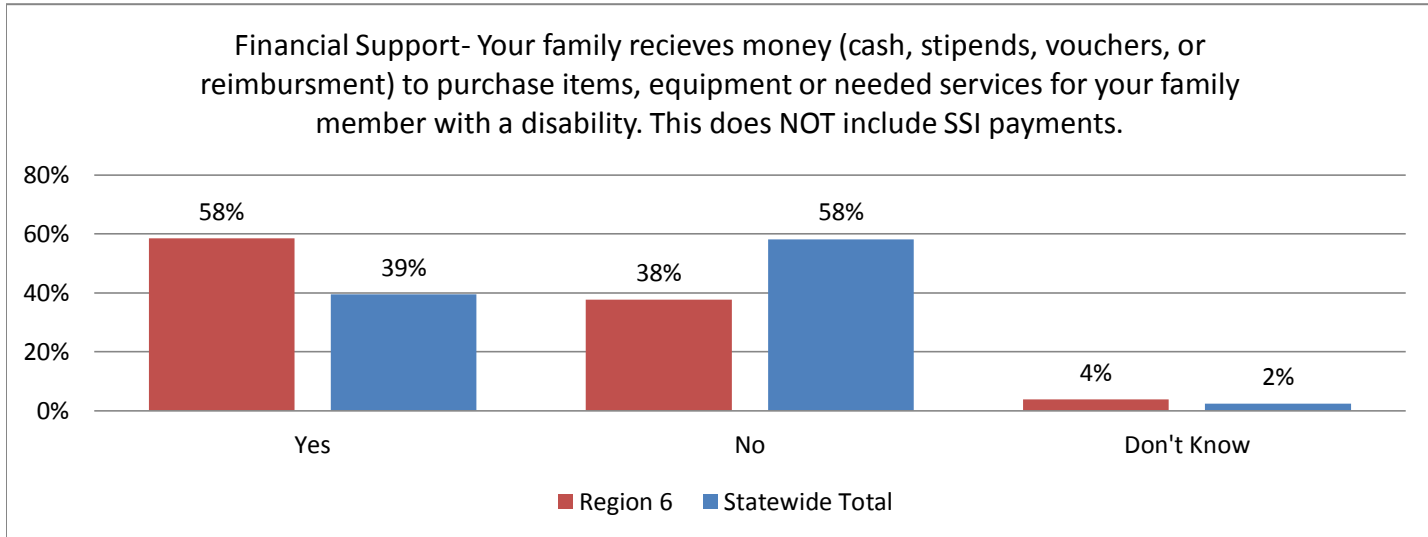
2018 Adult Family NCI Survey Results
 Region 6 Summary and Statewide Comparison

Caregiver / Household Demographics



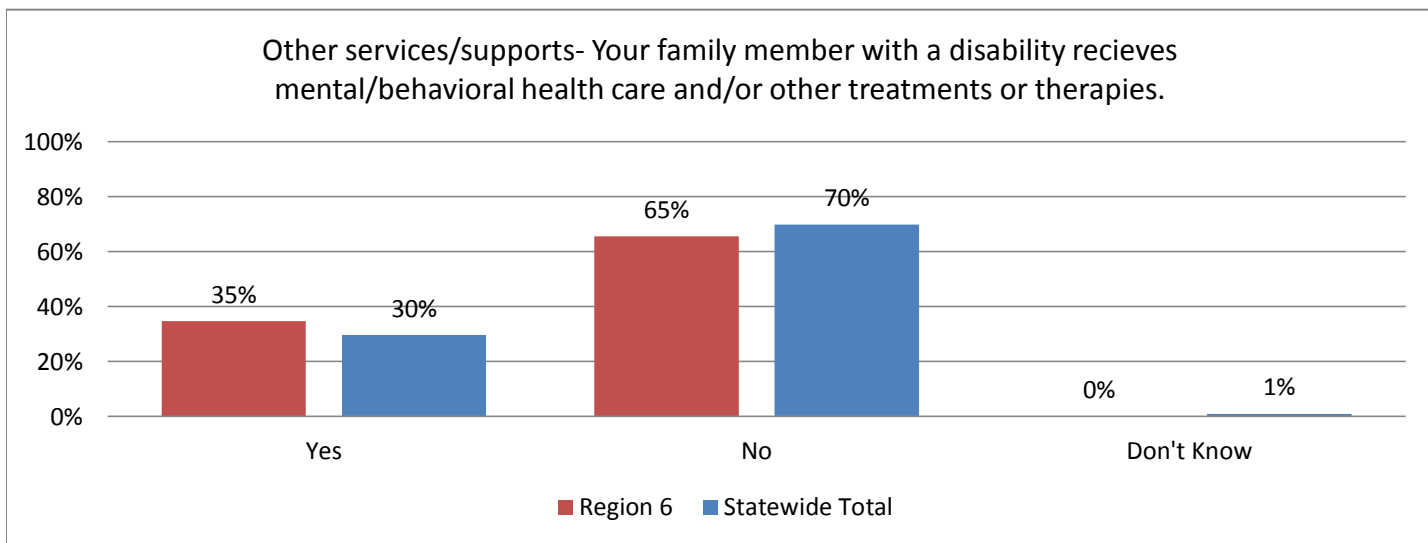
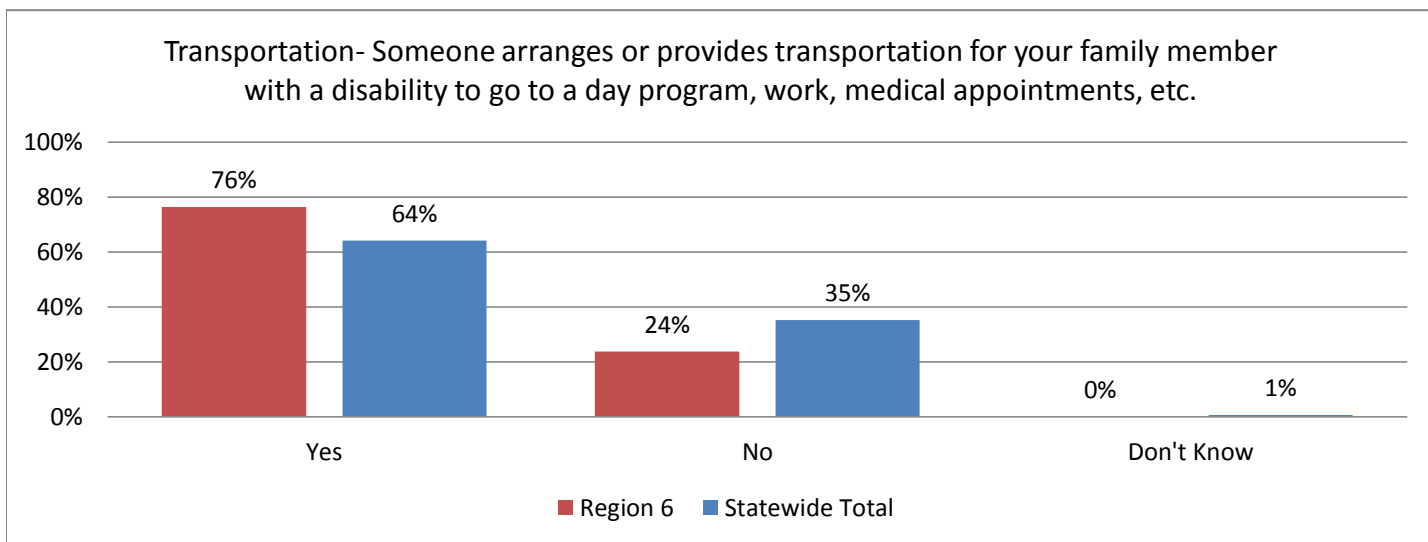
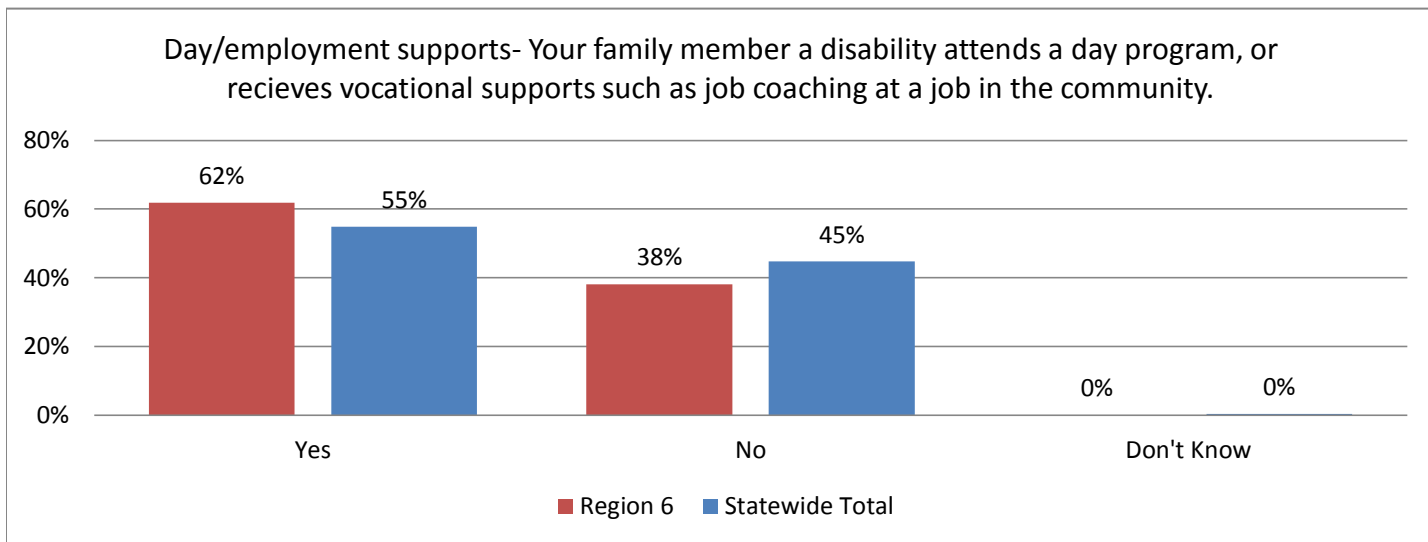
2018 Adult Family NCI Survey Results
Region 6 Summary and Statewide Comparison

Current Supports:



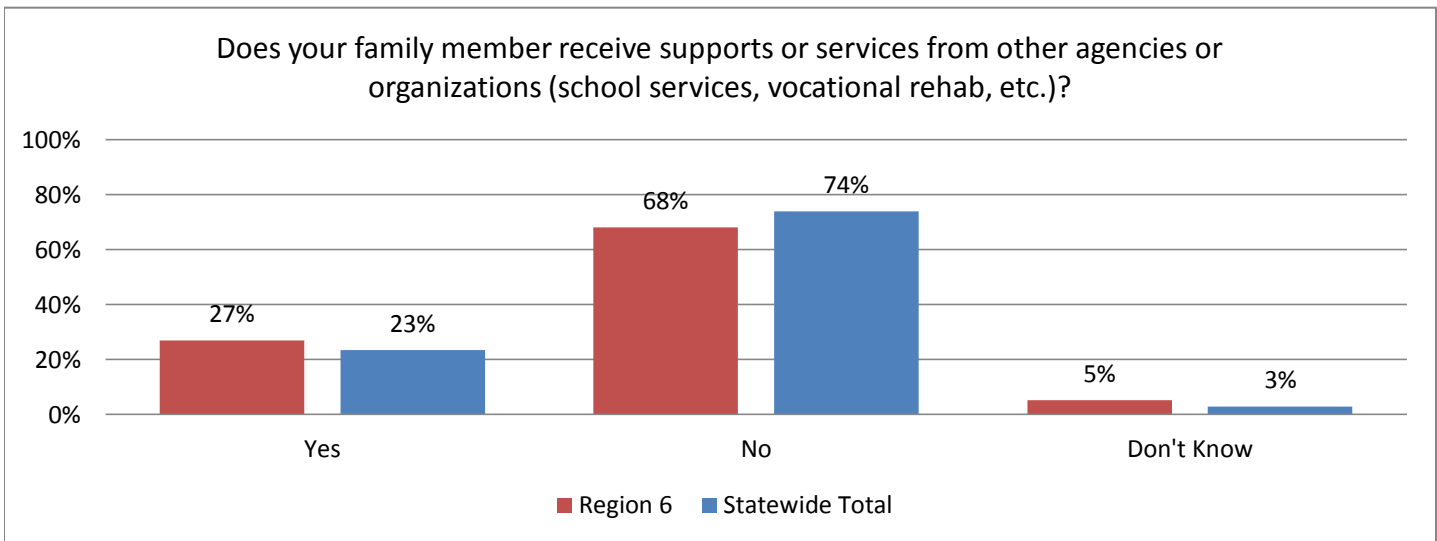
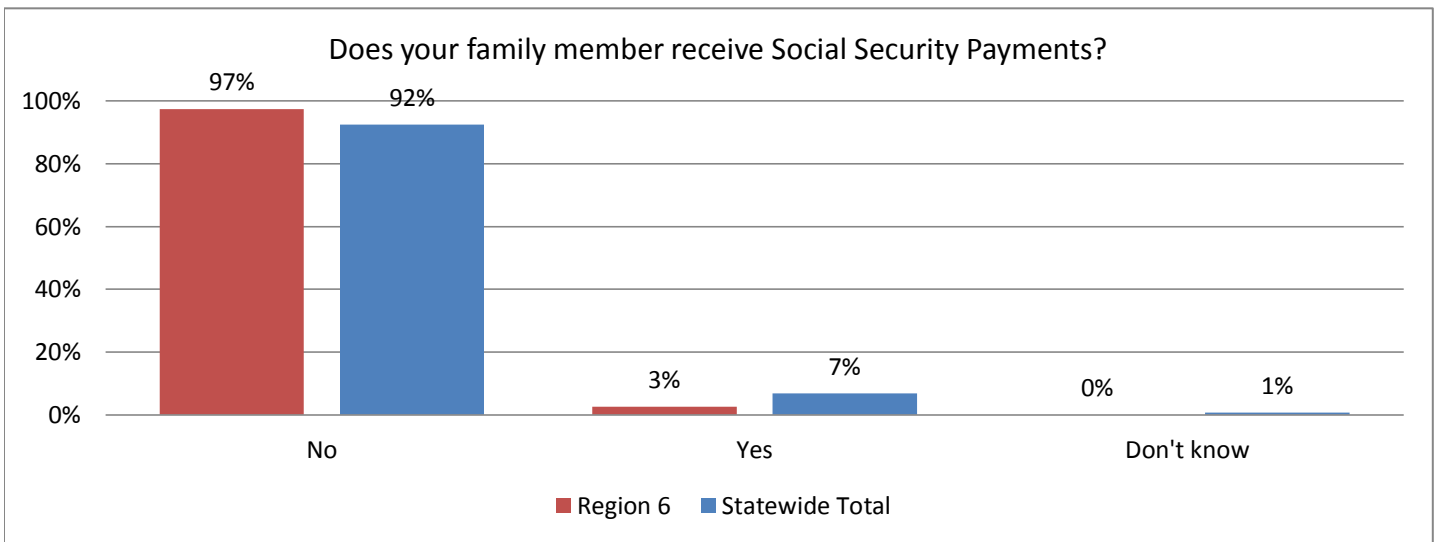
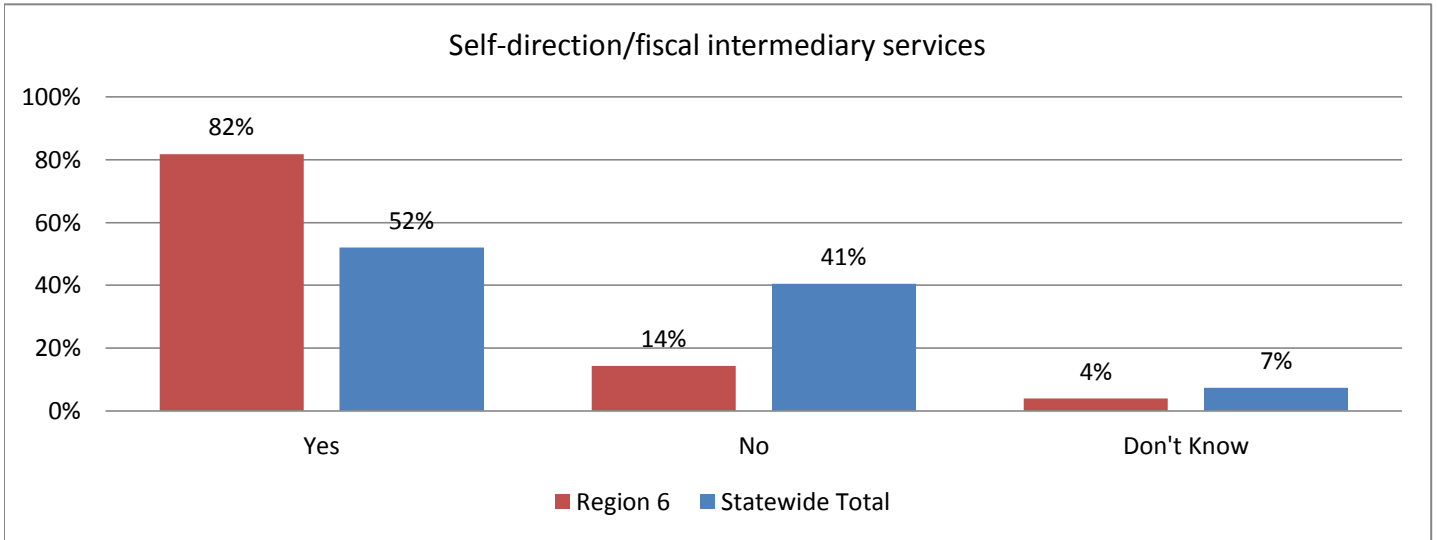
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 Region 6 Summary and Statewide Comparison

Current Supports:



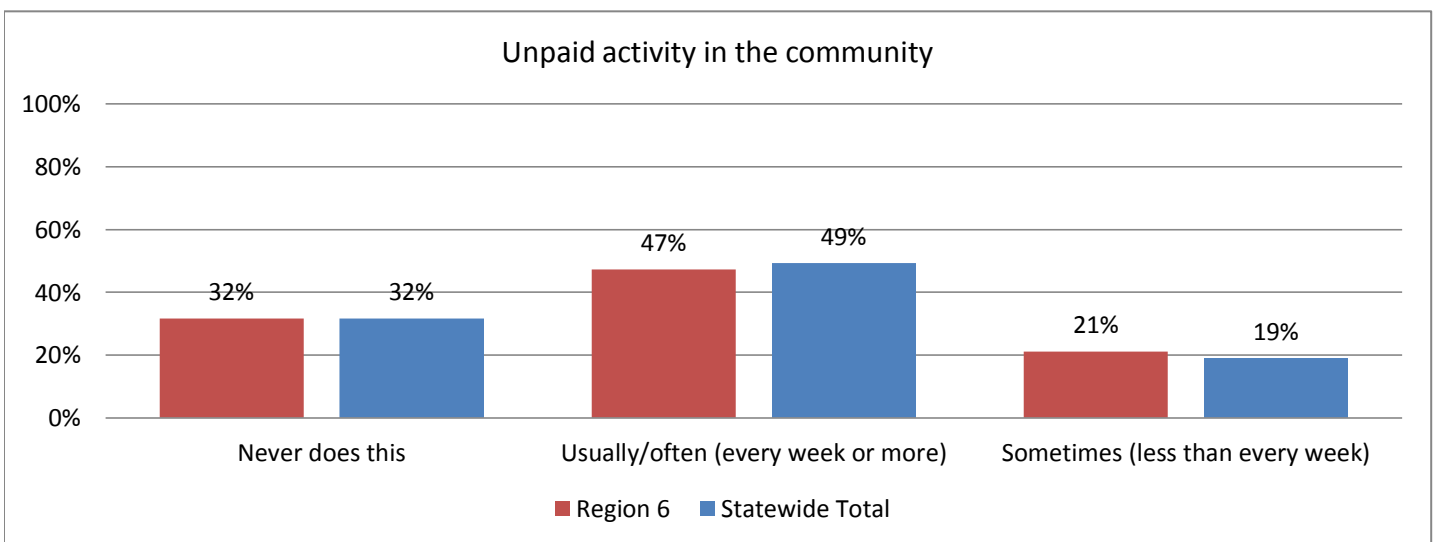
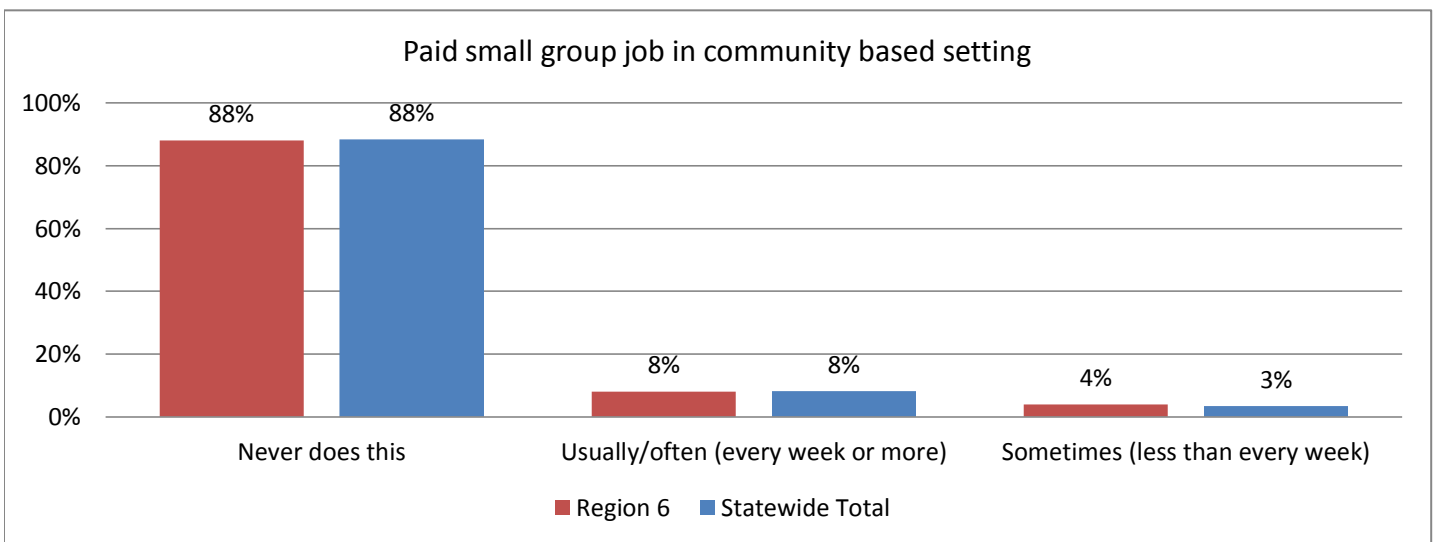
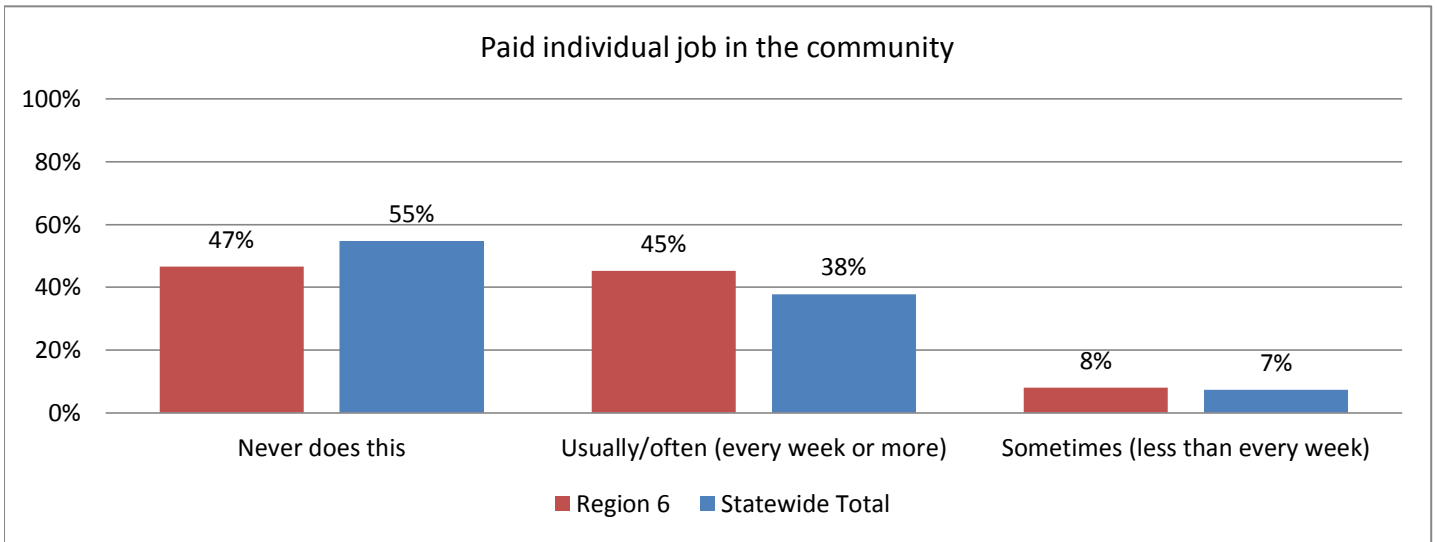
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Region 6 Summary and Statewide Comparison

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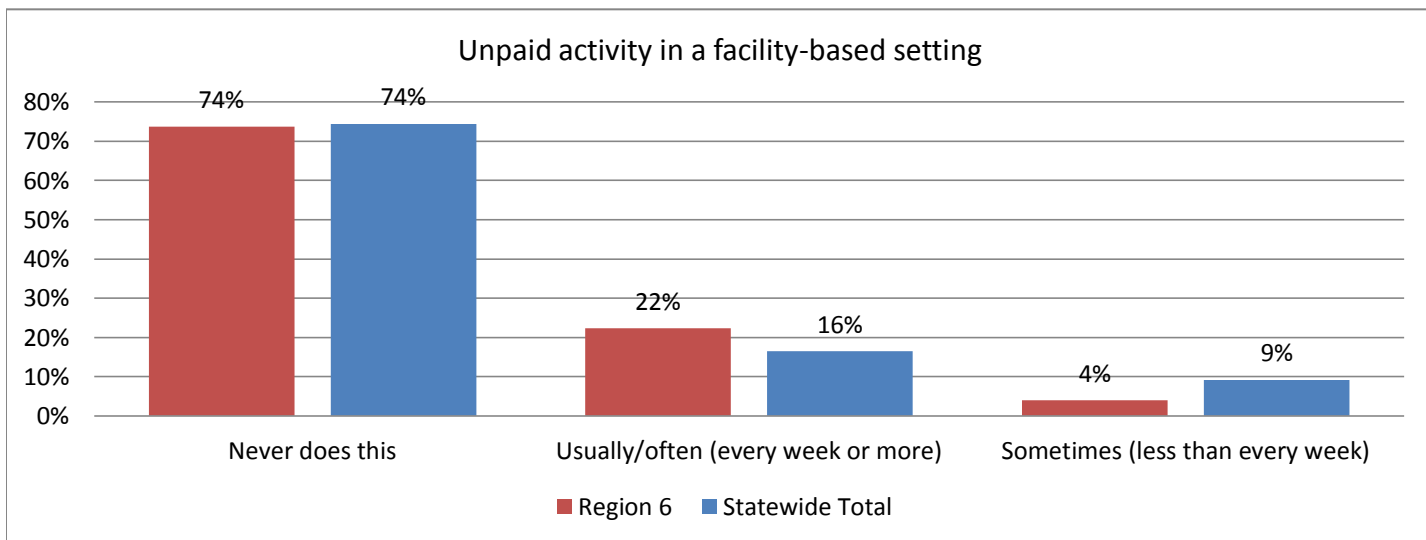
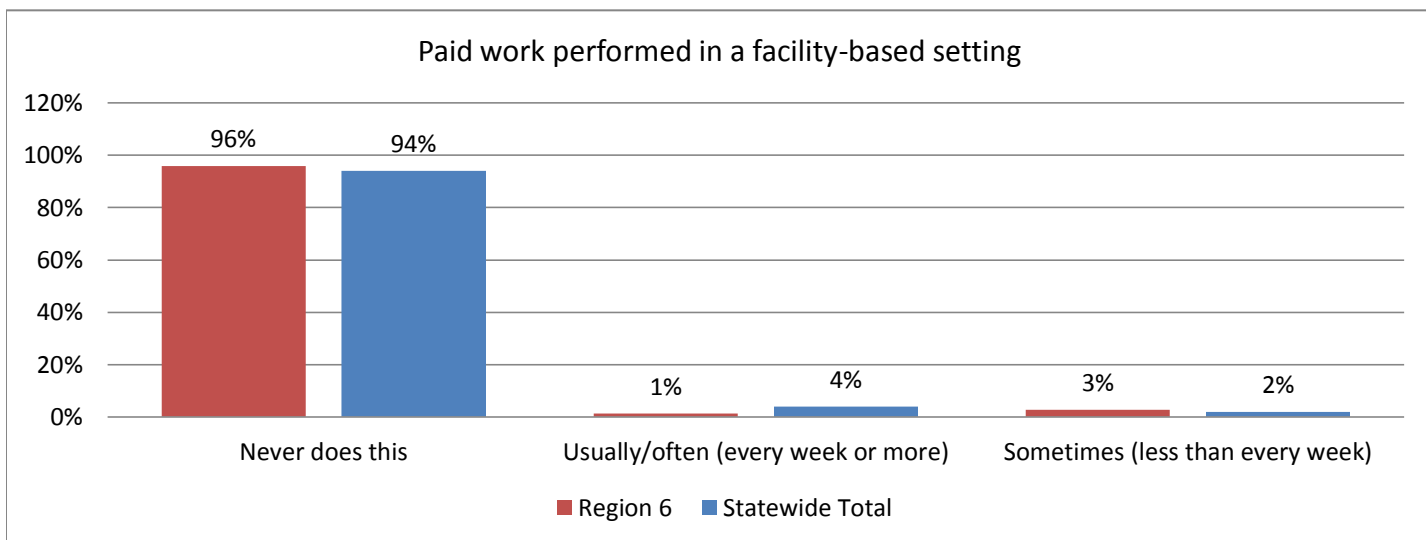
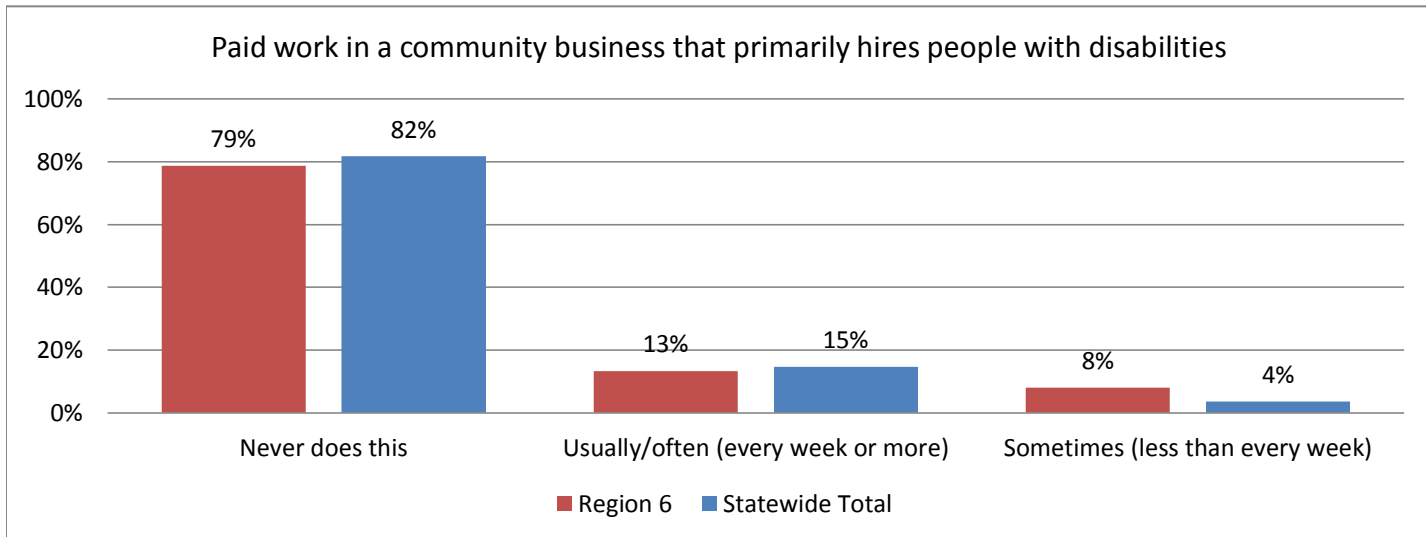
2018 Adult Family NCI Survey Results
 Region 6 Summary and Statewide Comparison

Daily Activities:



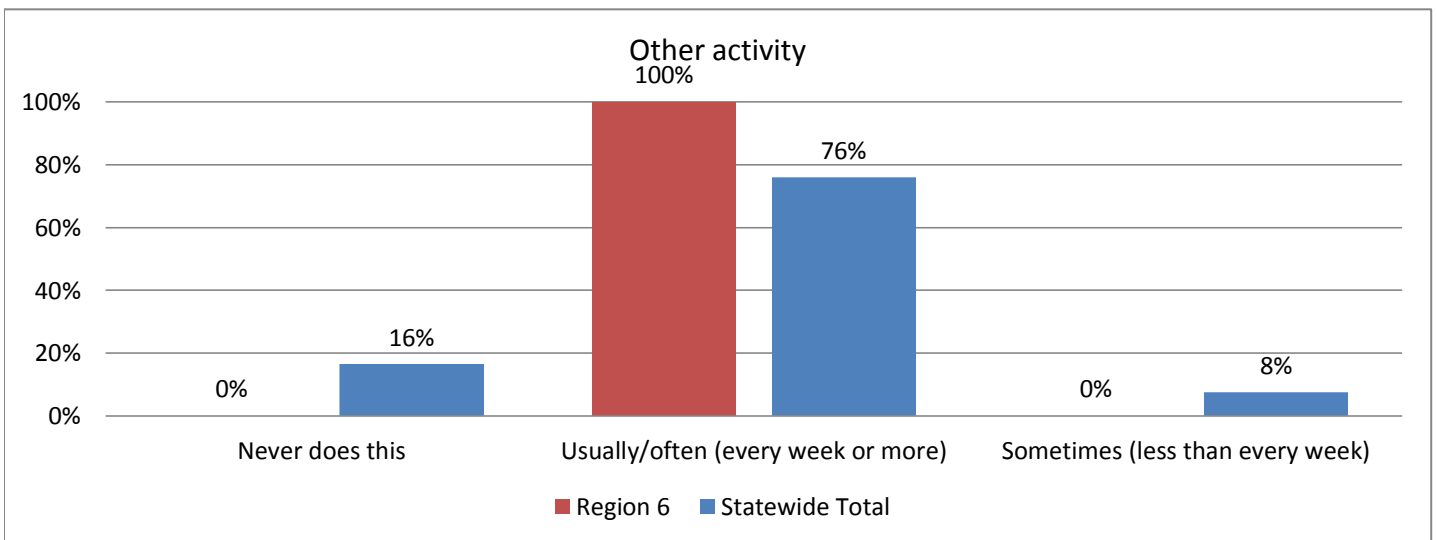
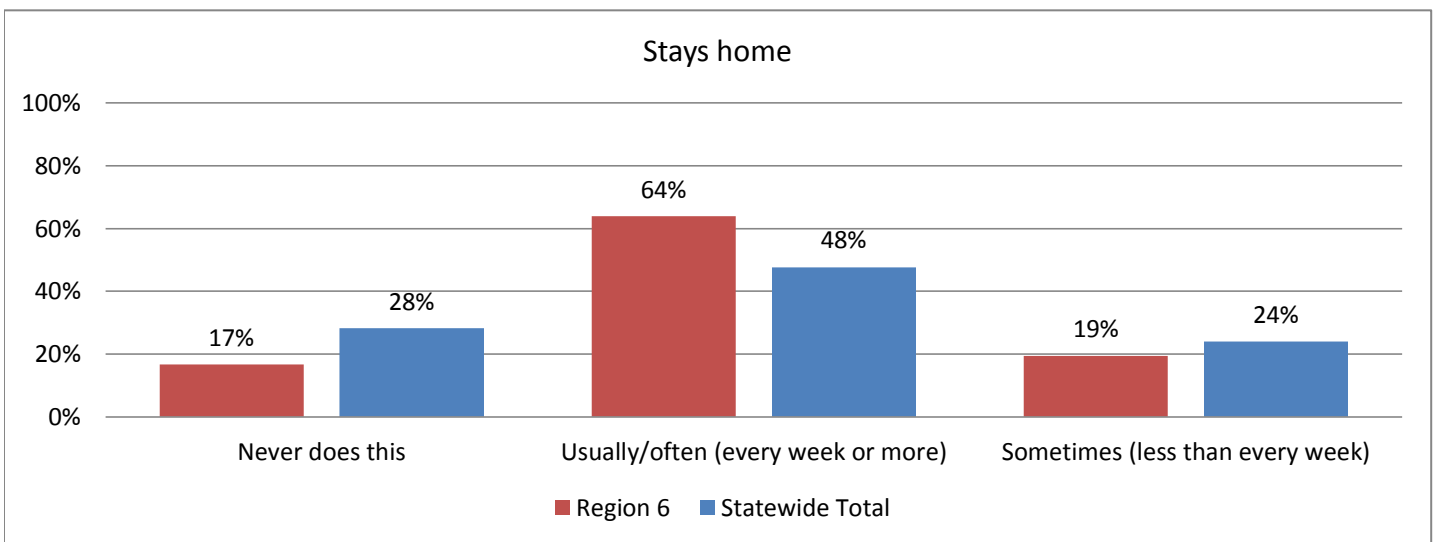
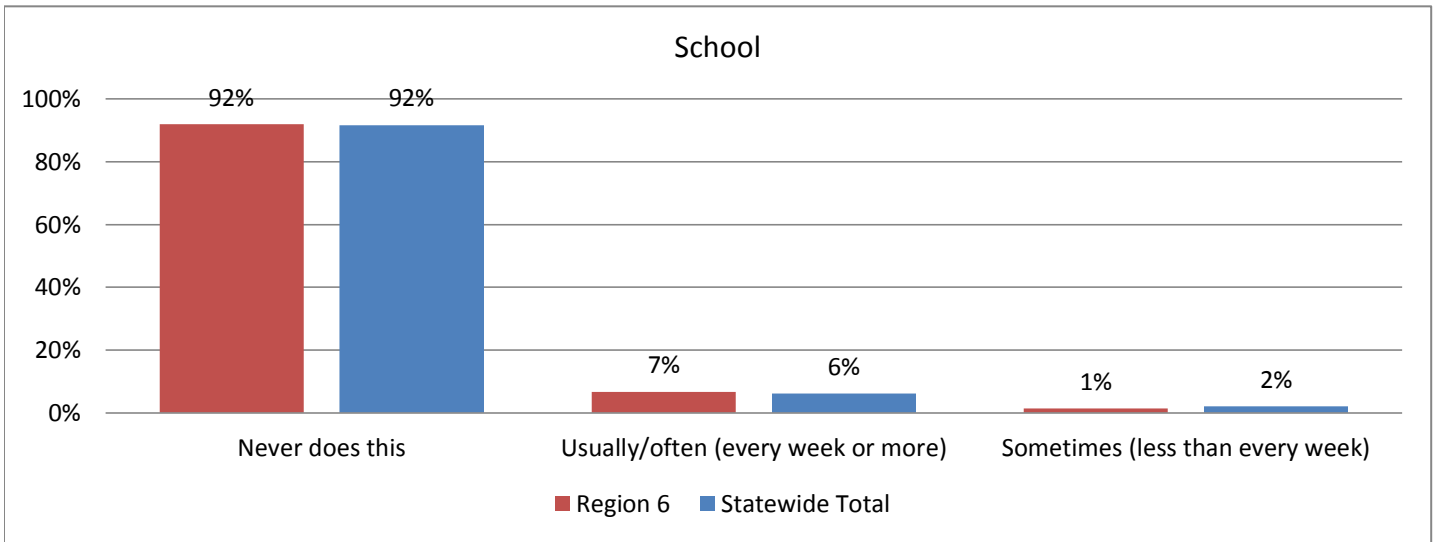
2018 Adult Family NCI Survey Results
 Region 6 Summary and Statewide Comparison

Daily Activities:



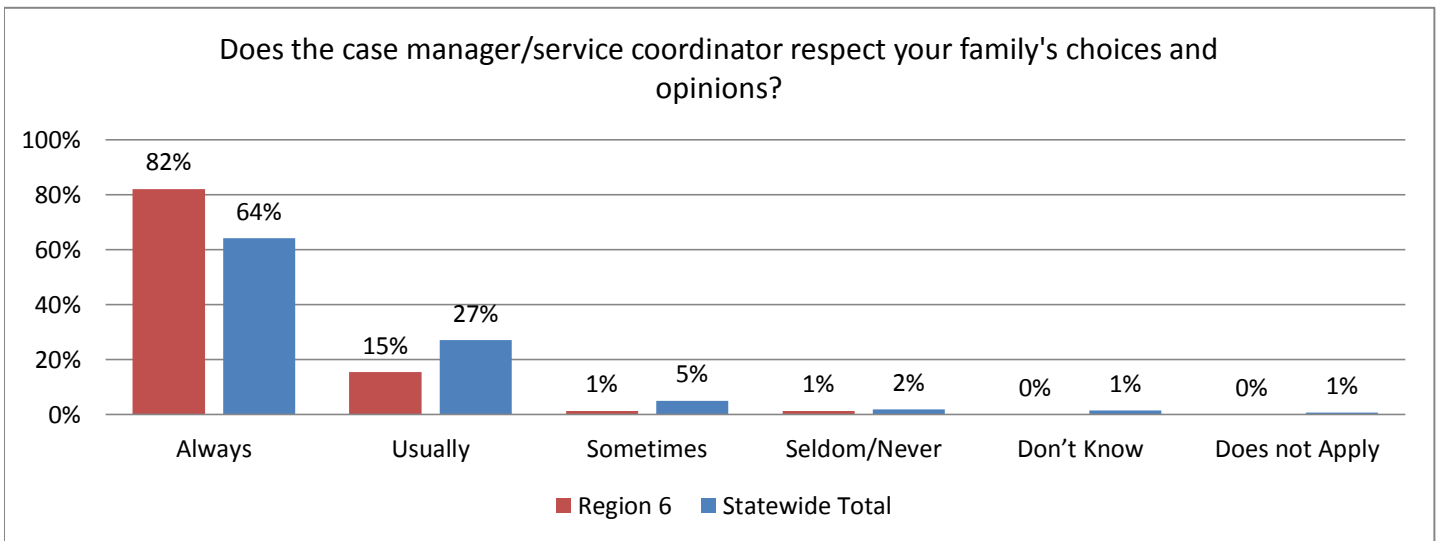
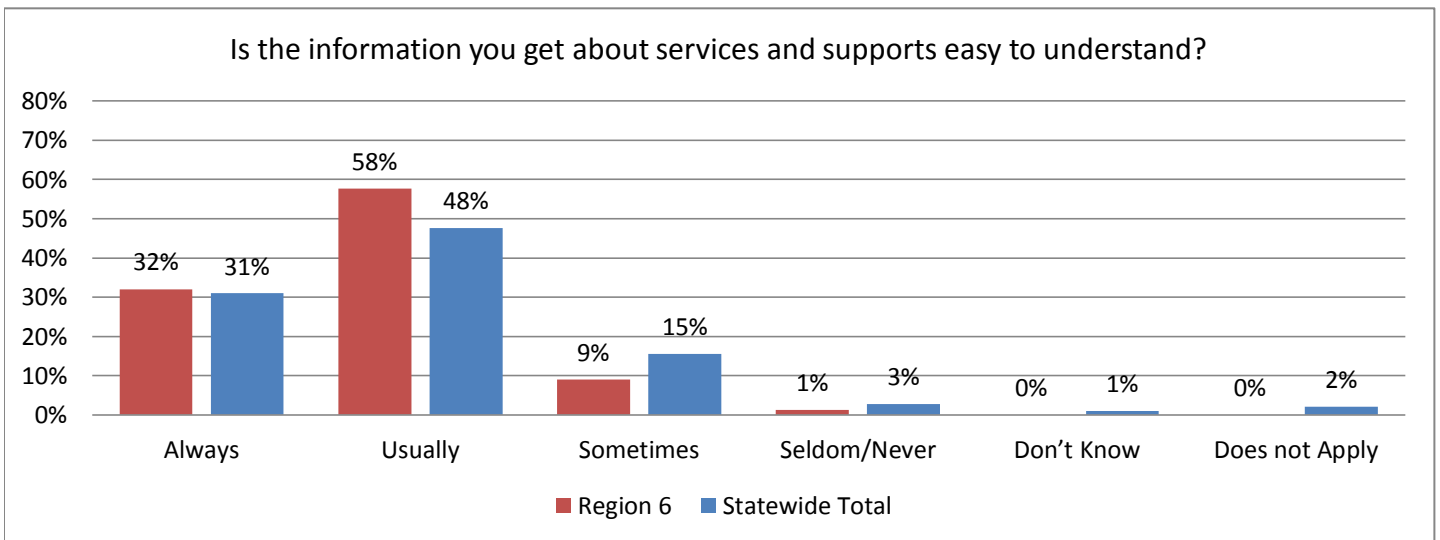
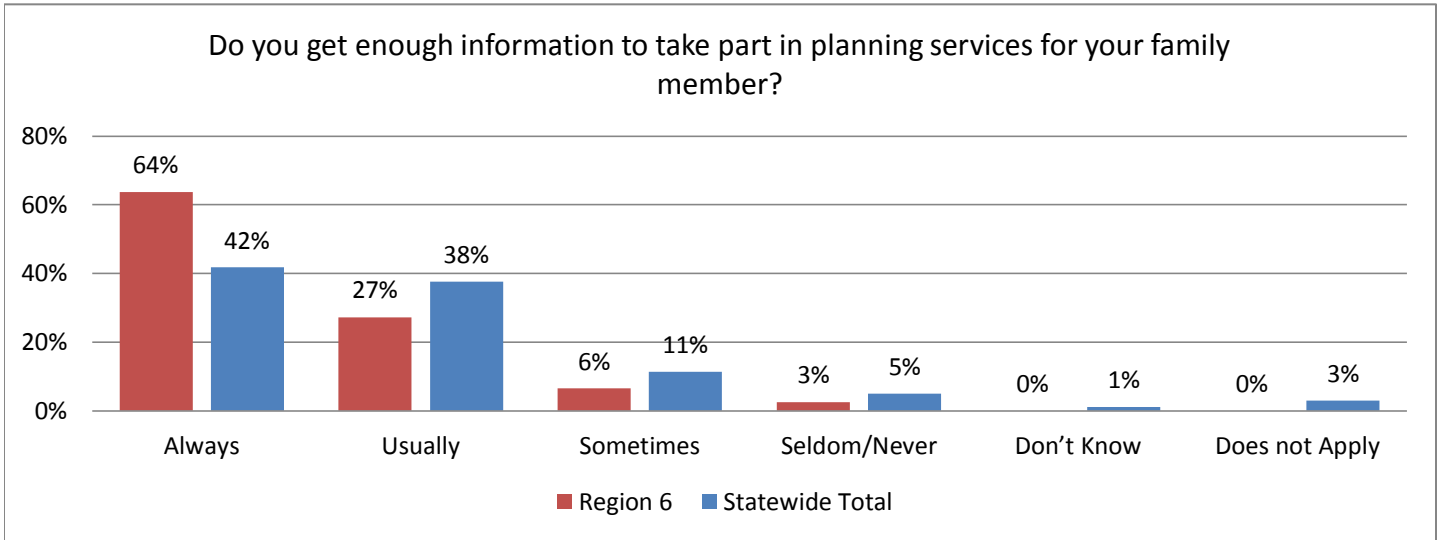
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 Region 6 Summary and Statewide Comparison

Daily Activities:



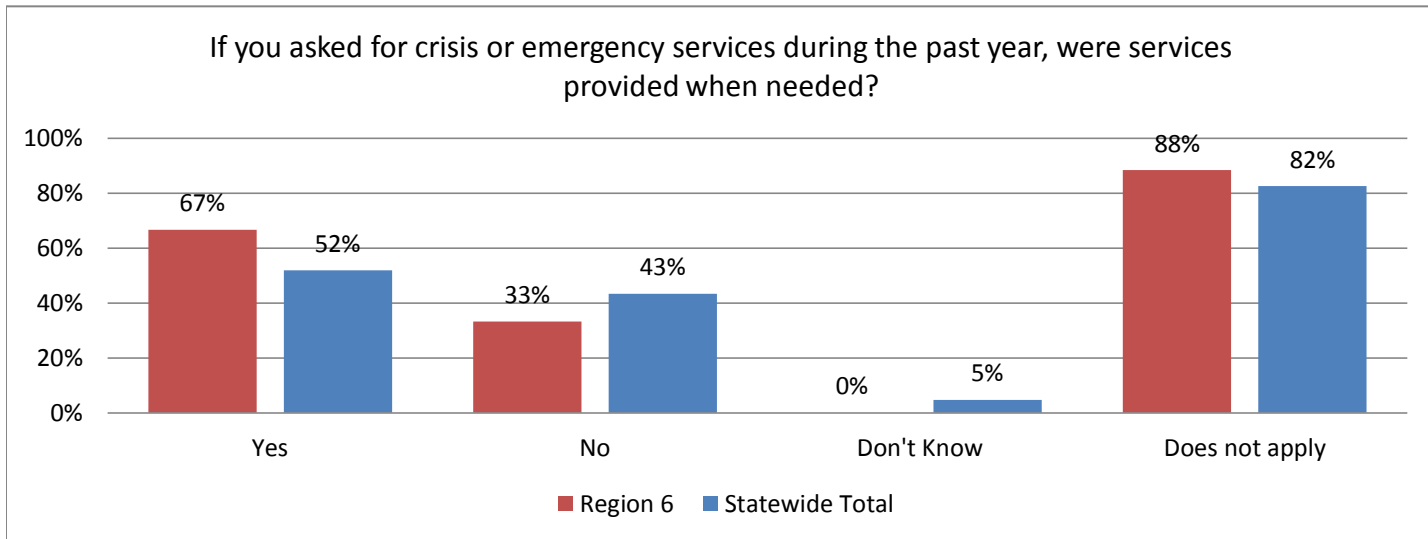
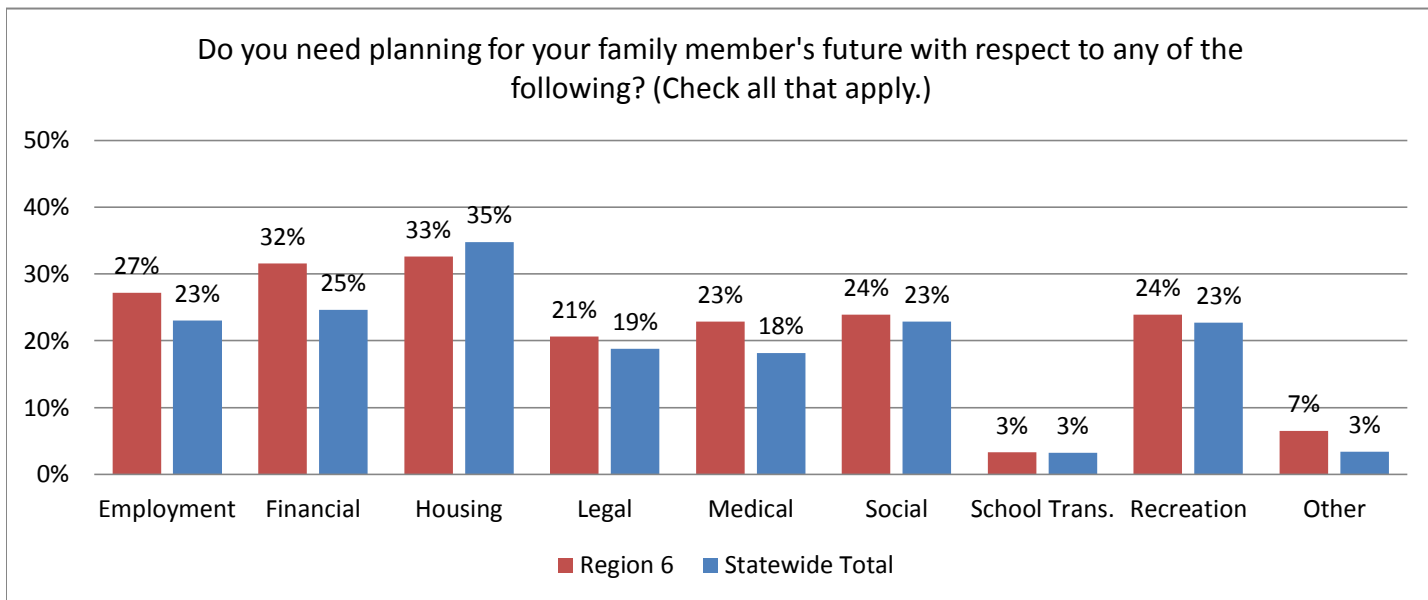
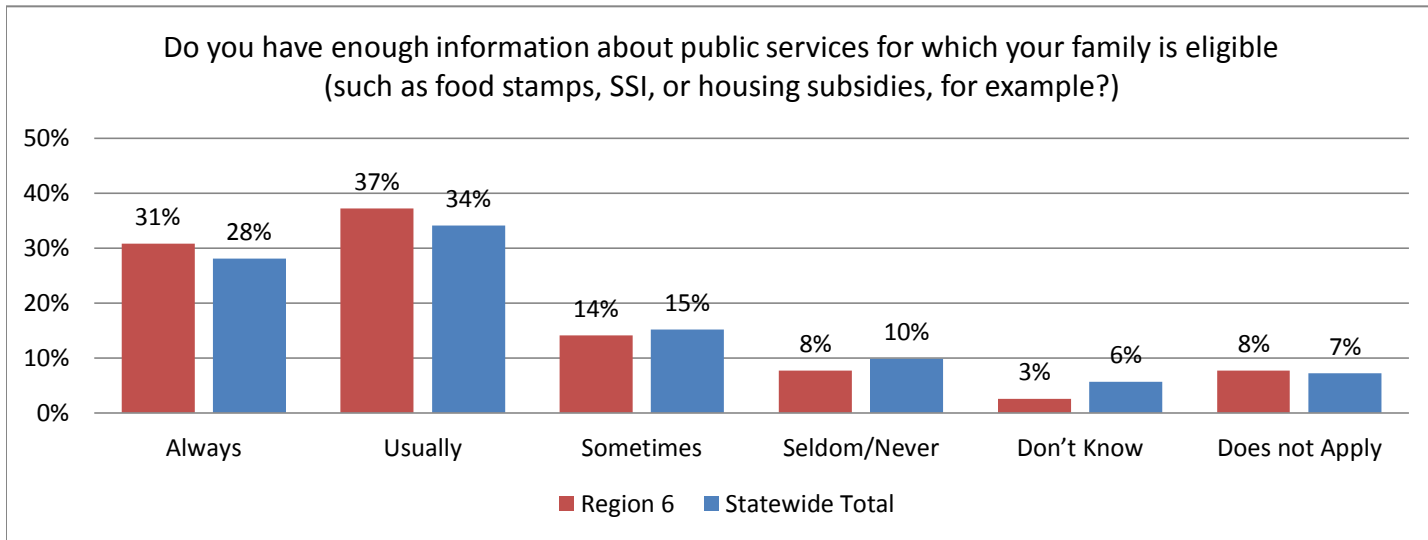
2018 Adult Family NCI Survey Results
 Region 6 Summary and Statewide Comparison

Satisfaction:



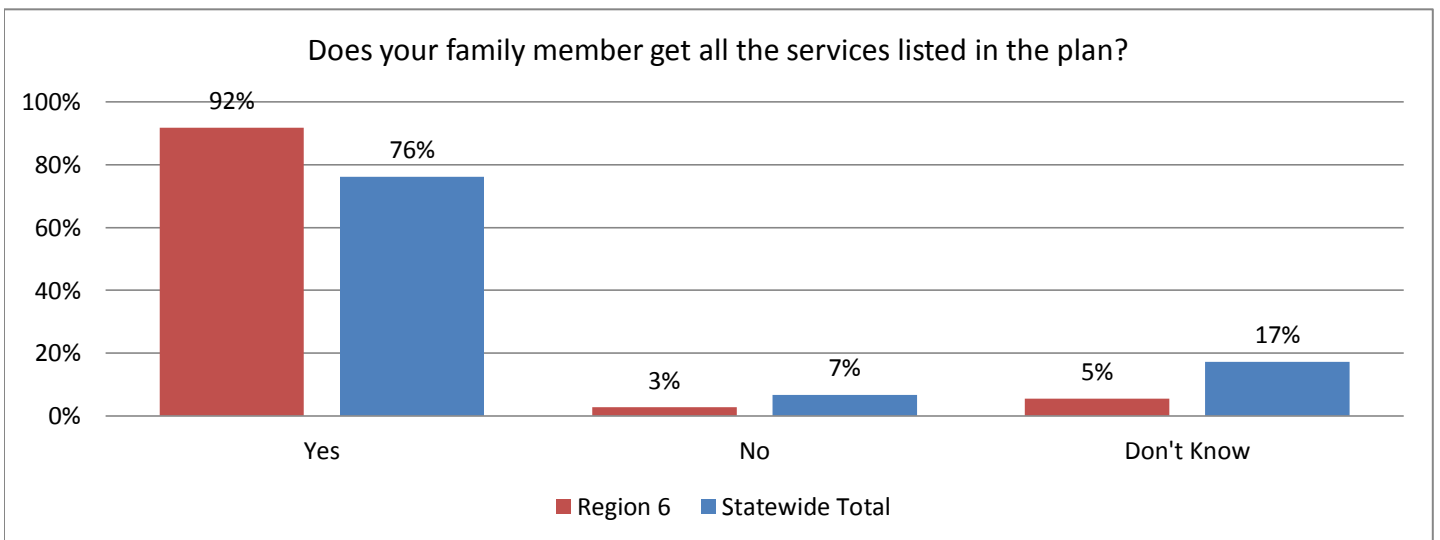
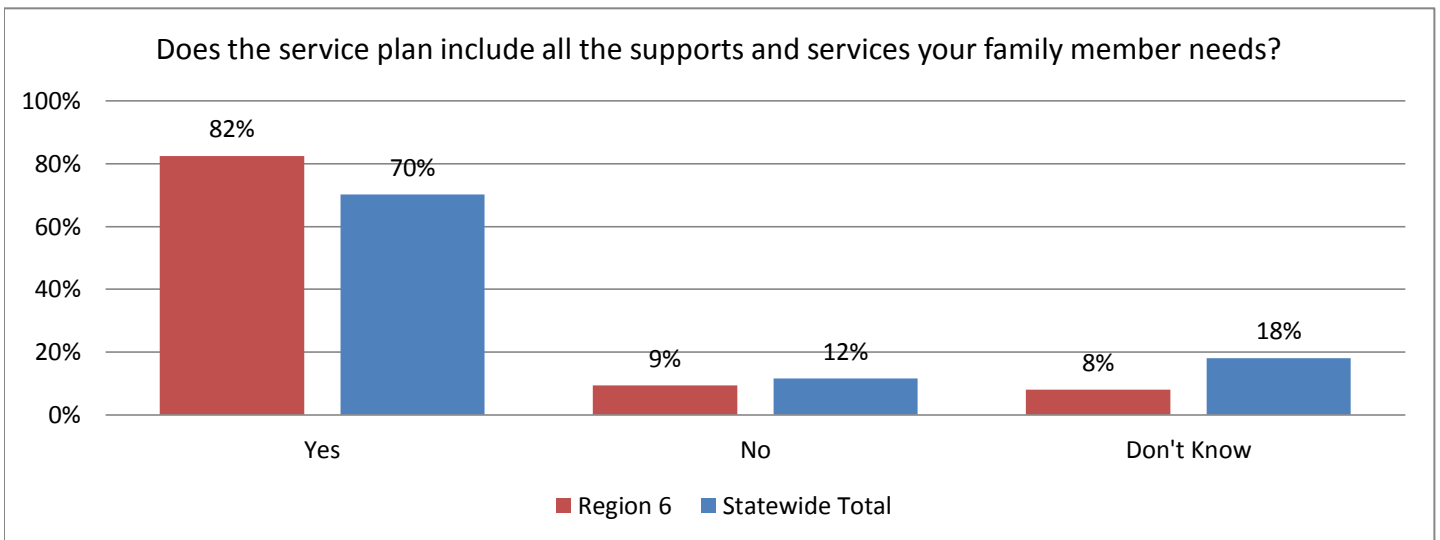
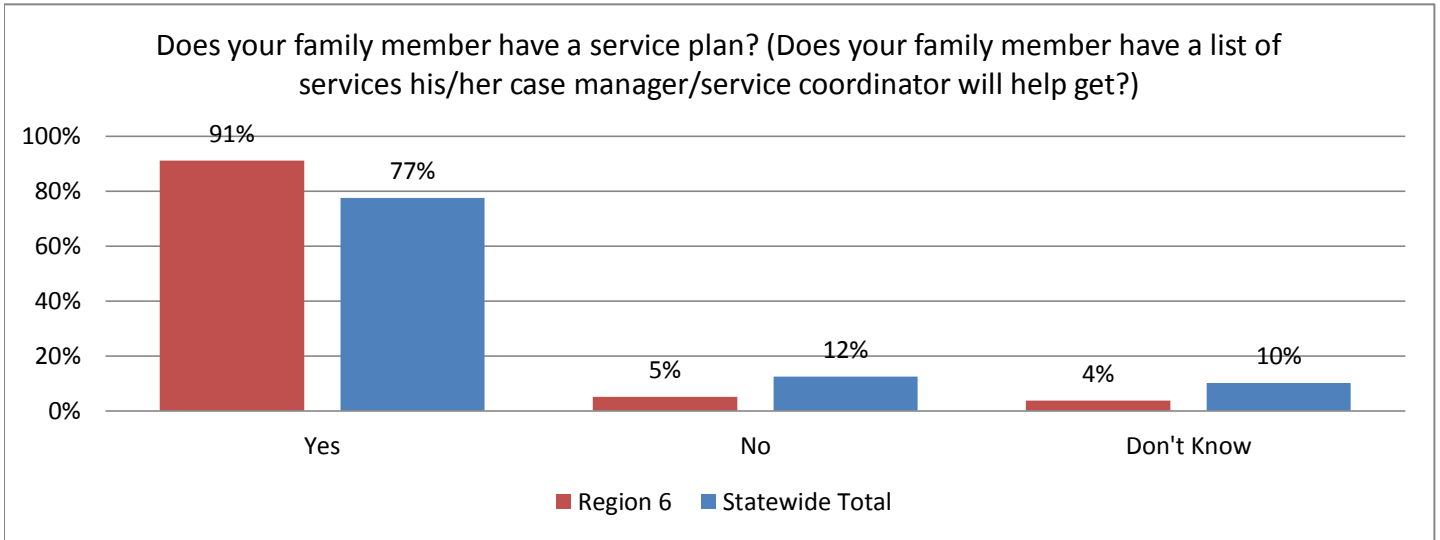
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Region 6 Summary and Statewide Comparison

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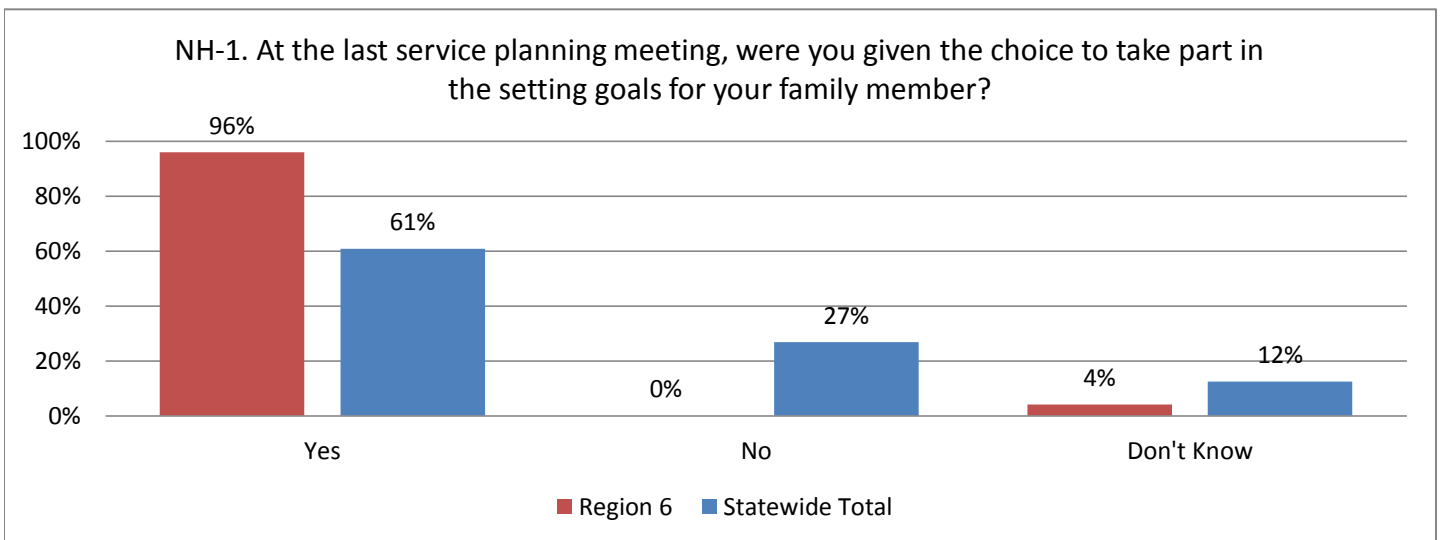
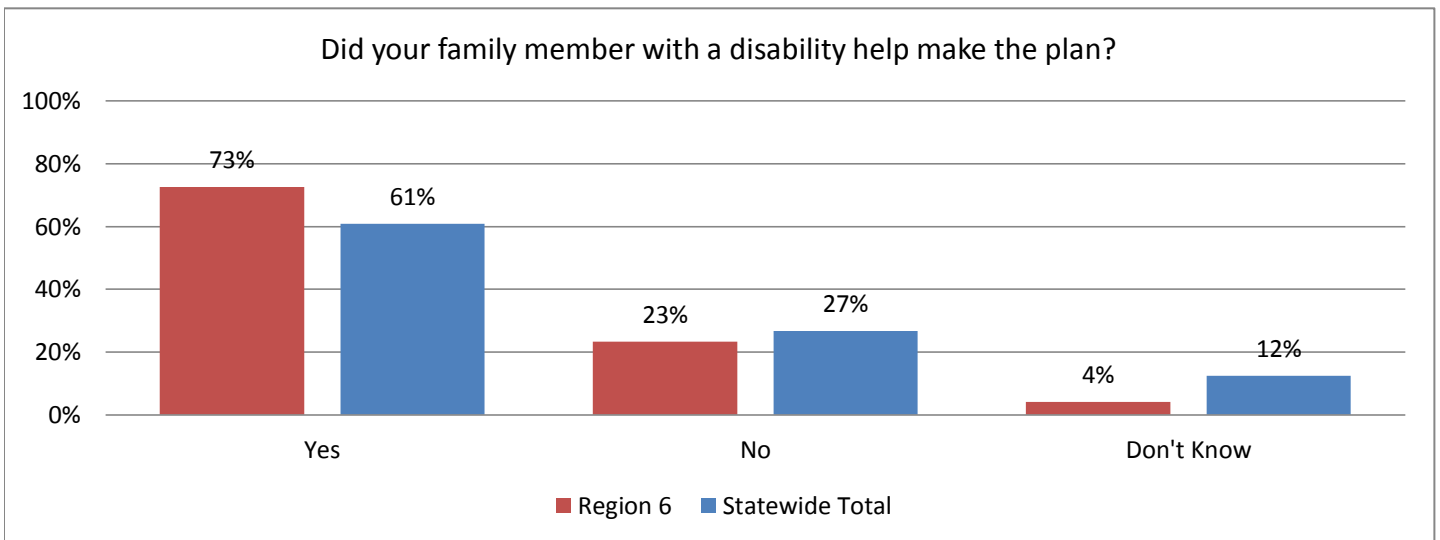
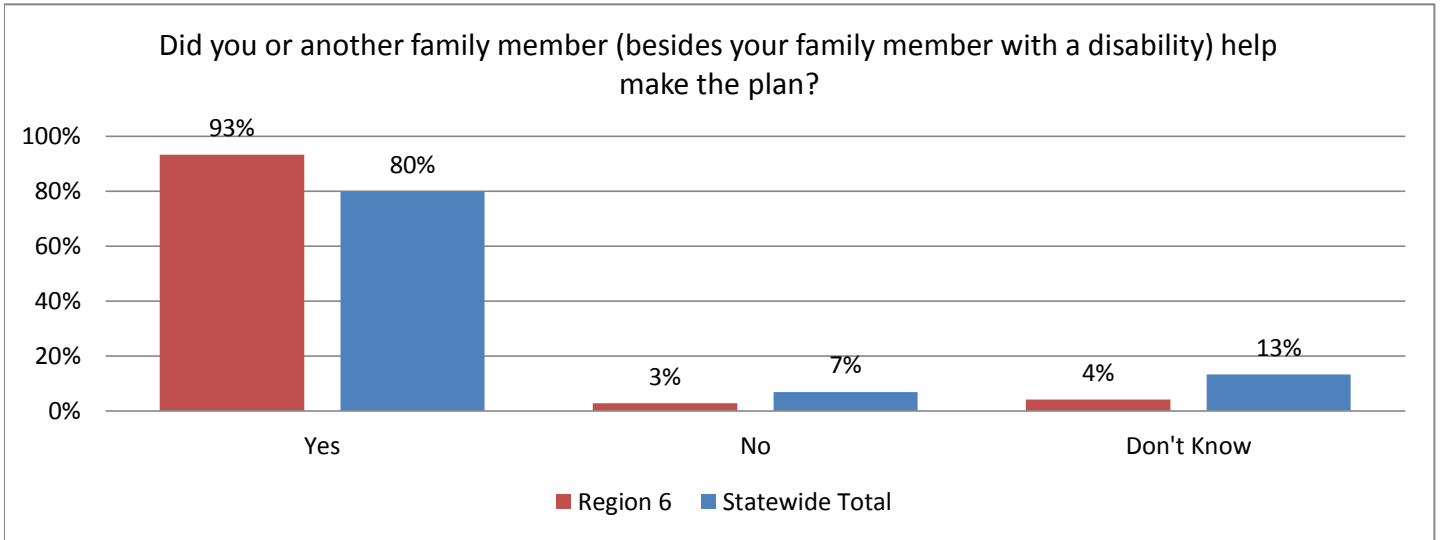
2018 Adult Family NCI Survey Results
 Region 6 Summary and Statewide Comparison

Satisfaction - Service Plan:



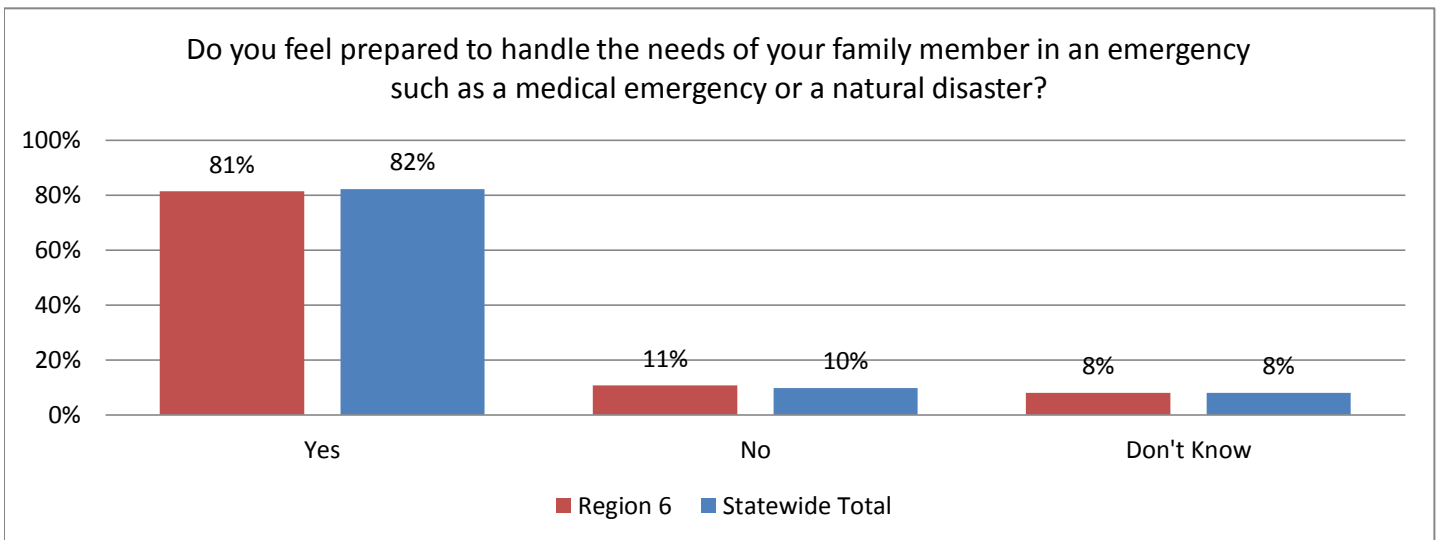
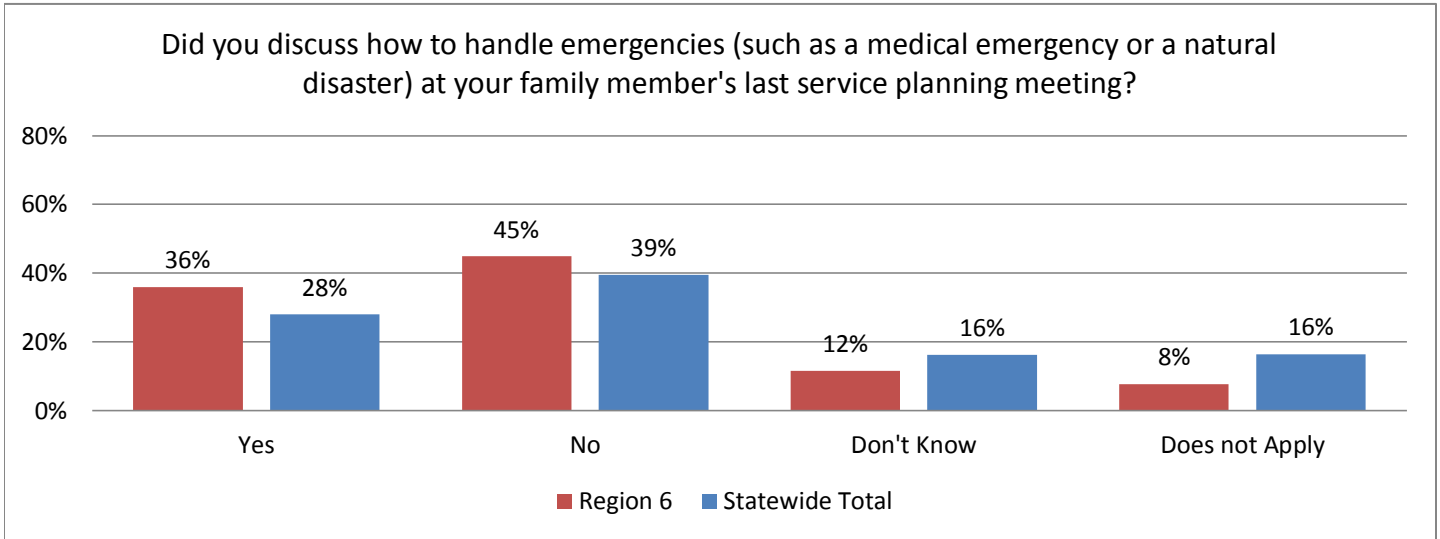
2018 Adult Family NCI Survey Results
Region 6 Summary and Statewide Comparison

Satisfaction - Service Plan:



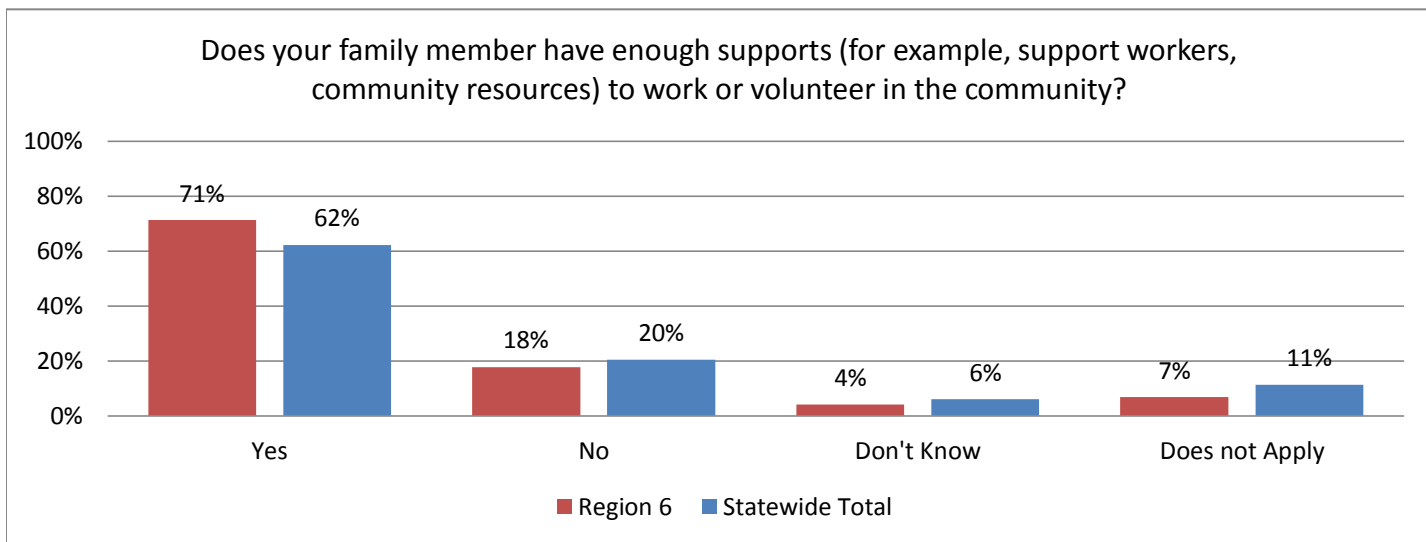
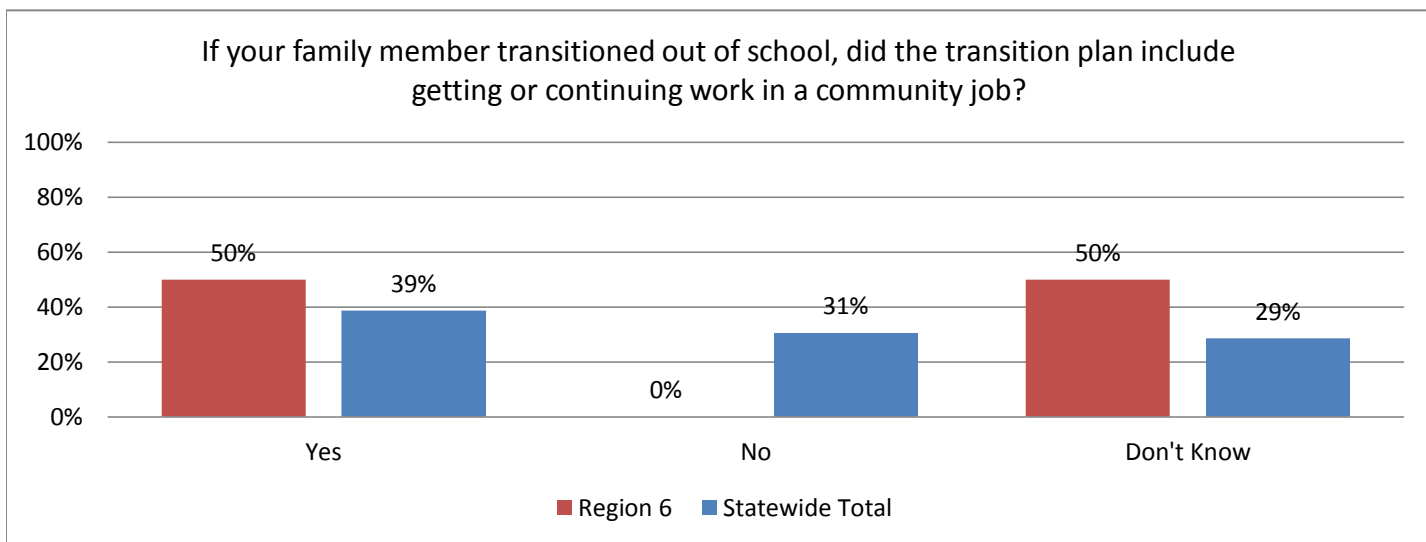
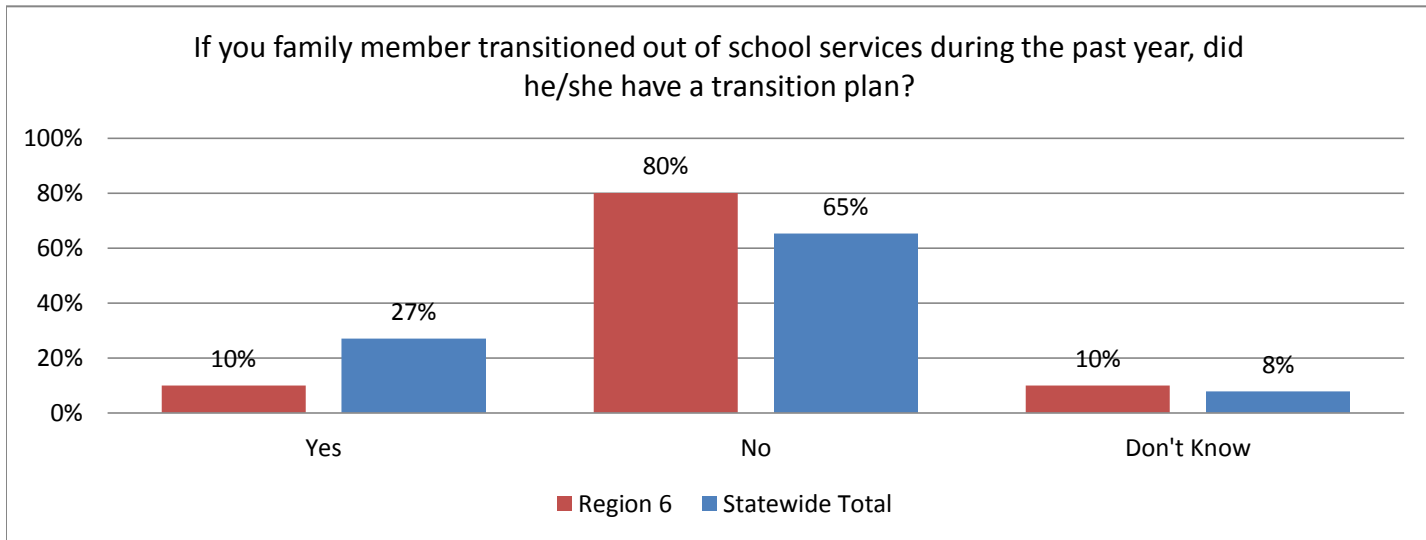
2018 Adult Family NCI Survey Results
Region 6 Summary and Statewide Comparison

Satisfaction - Service Plan:



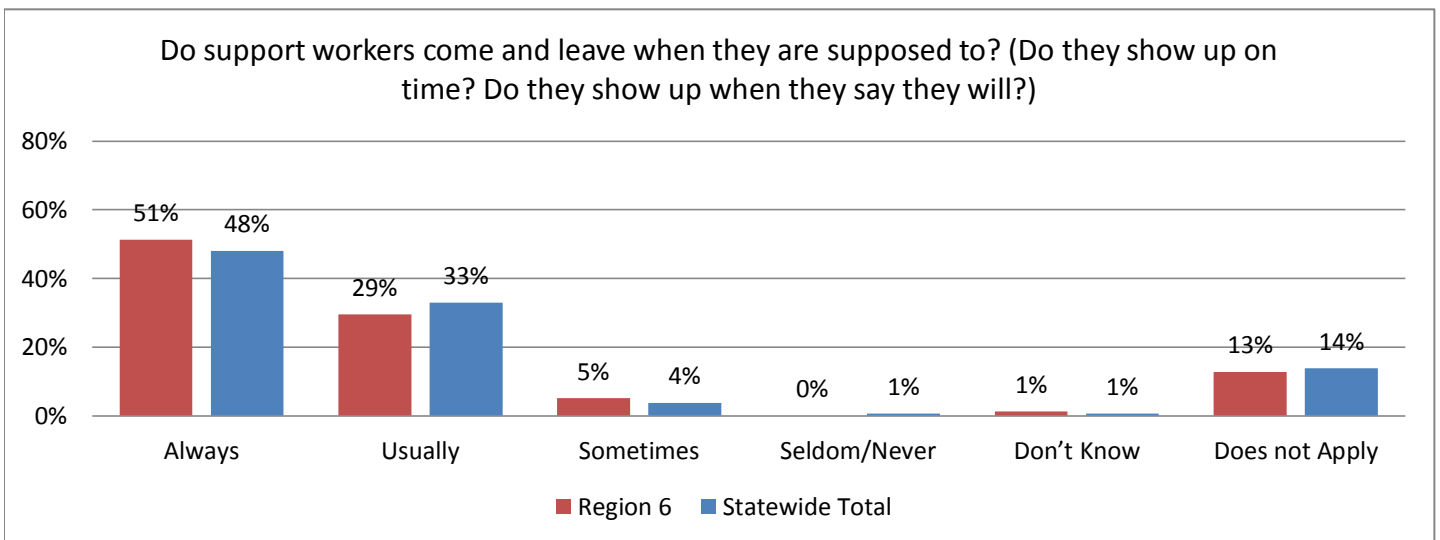
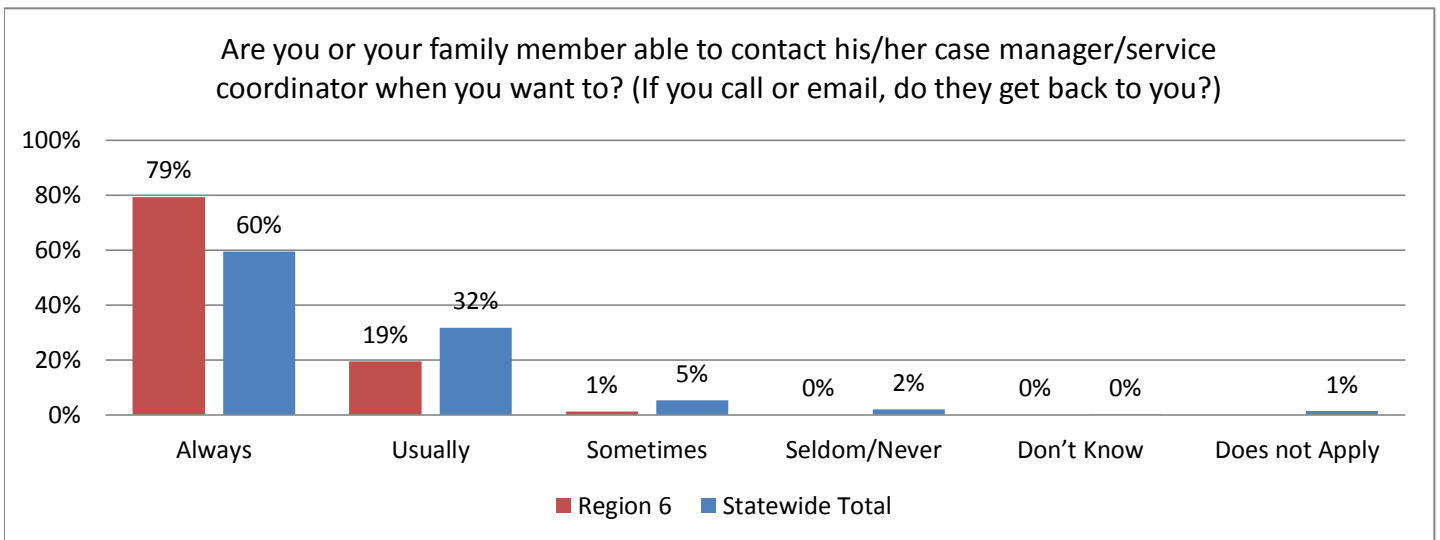
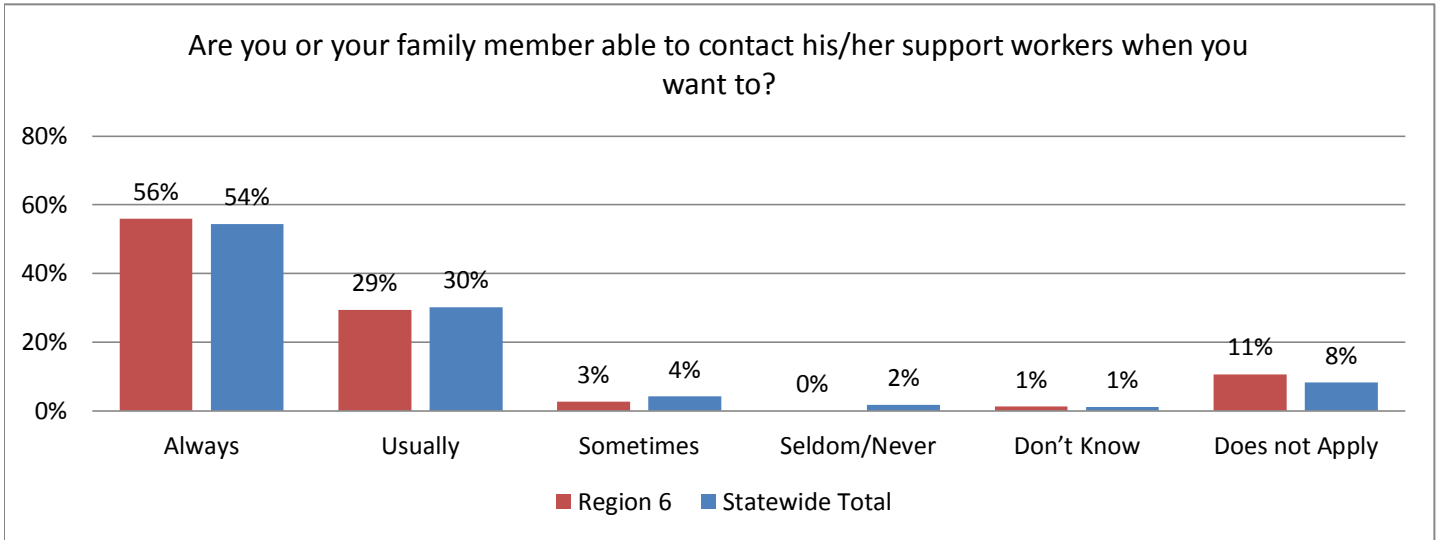
2018 Adult Family NCI Survey Results
 Region 6 Summary and Statewide Comparison

Satisfaction:



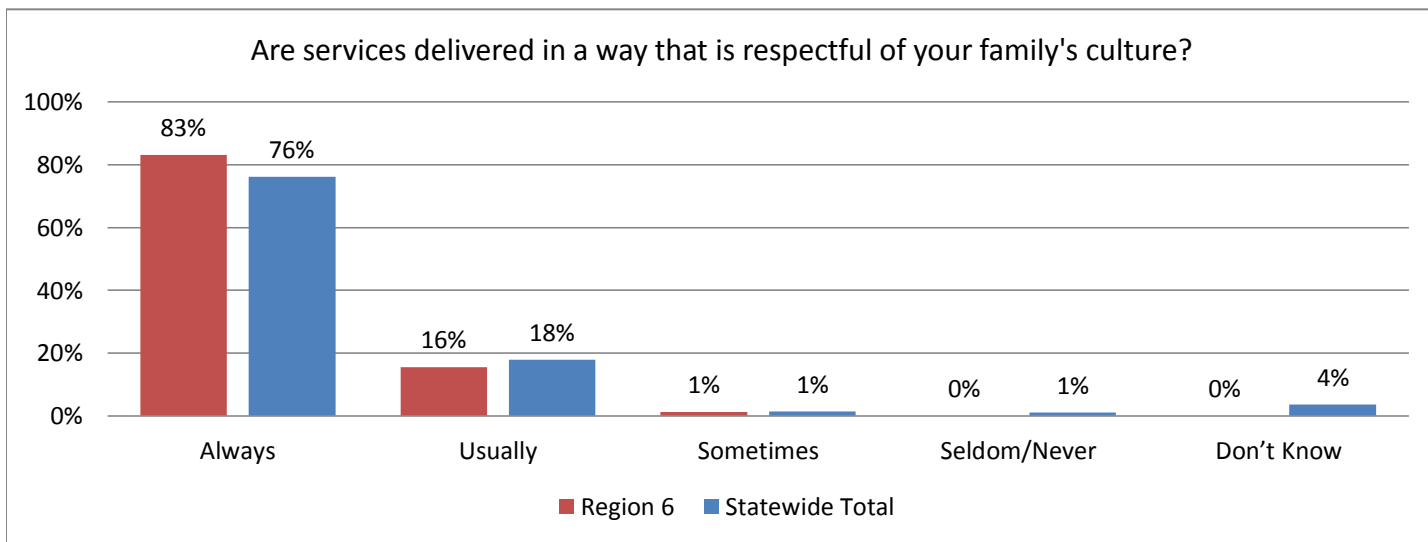
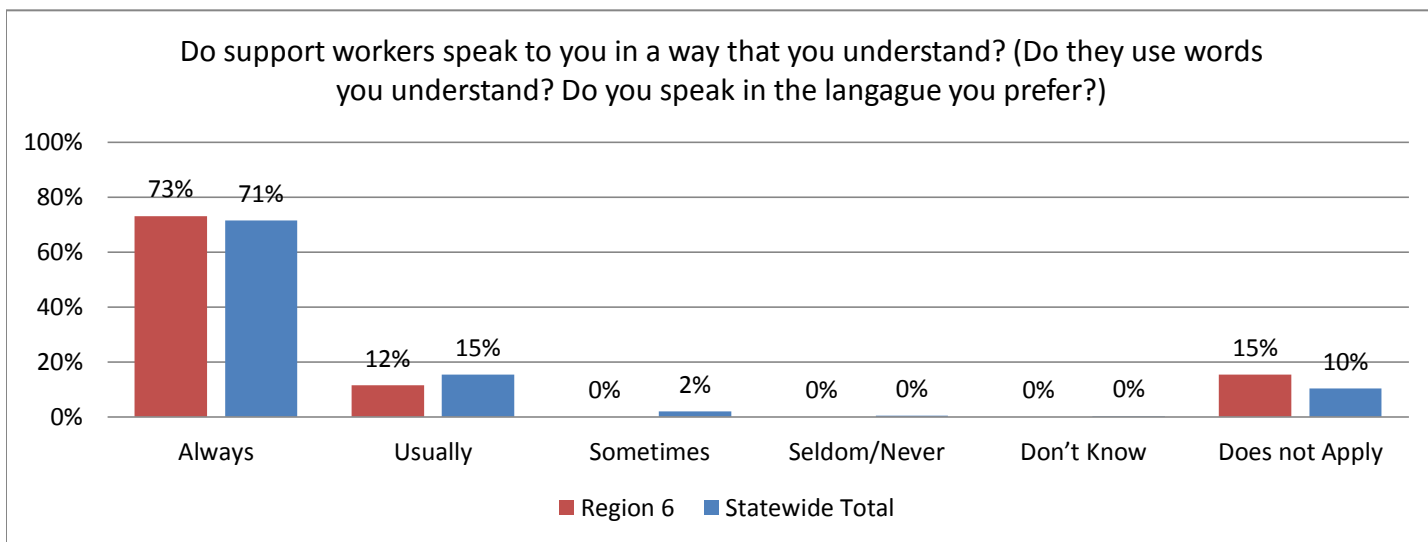
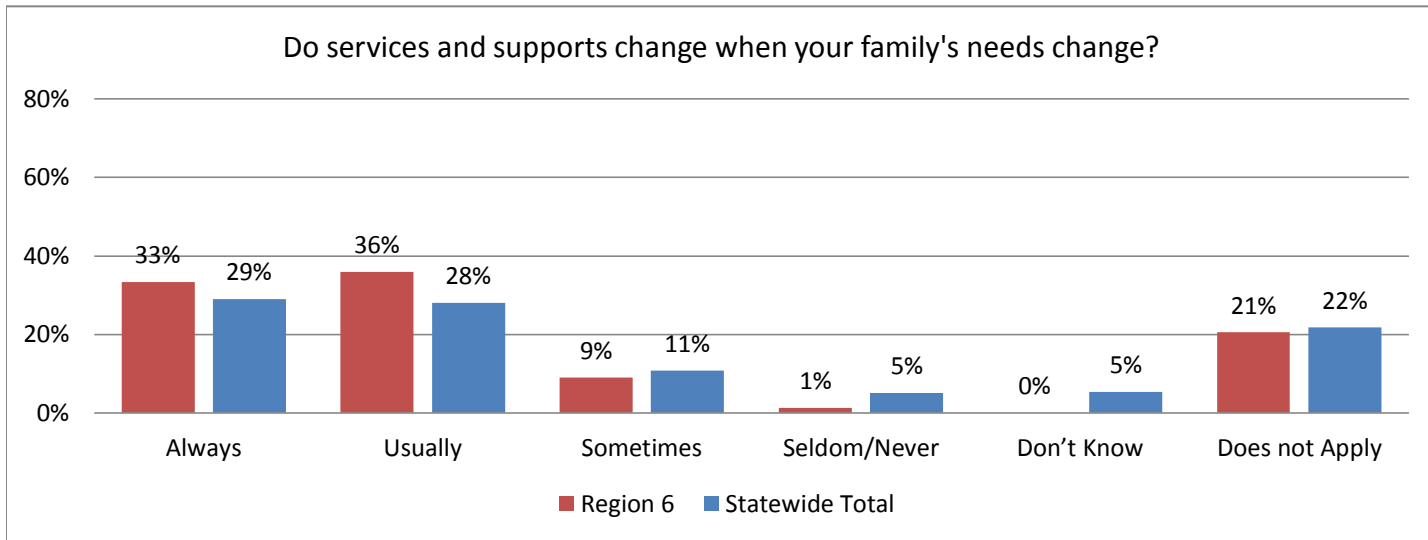
2018 Adult Family NCI Survey Results
Region 6 Summary and Statewide Comparison

Satisfaction - Supports:



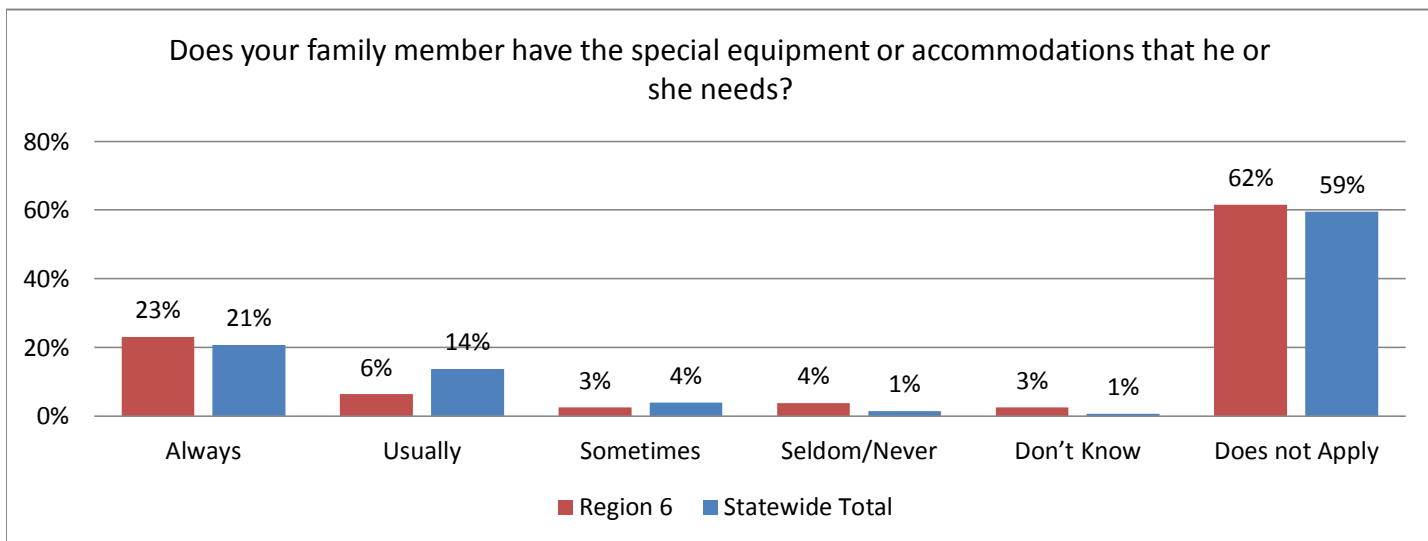
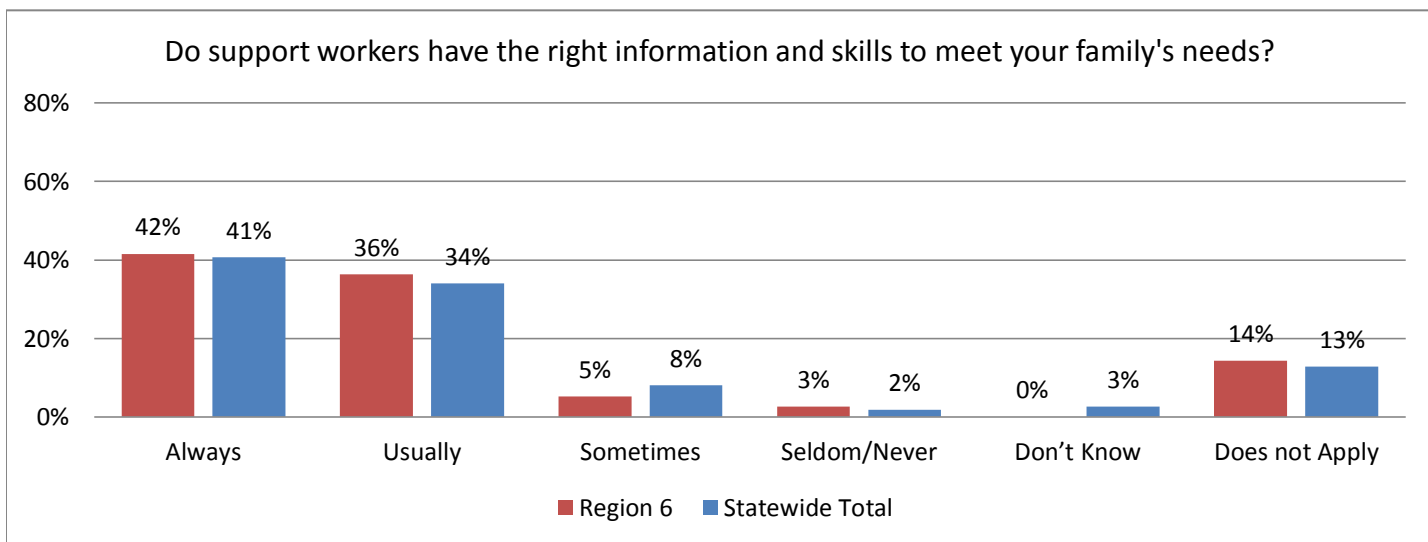
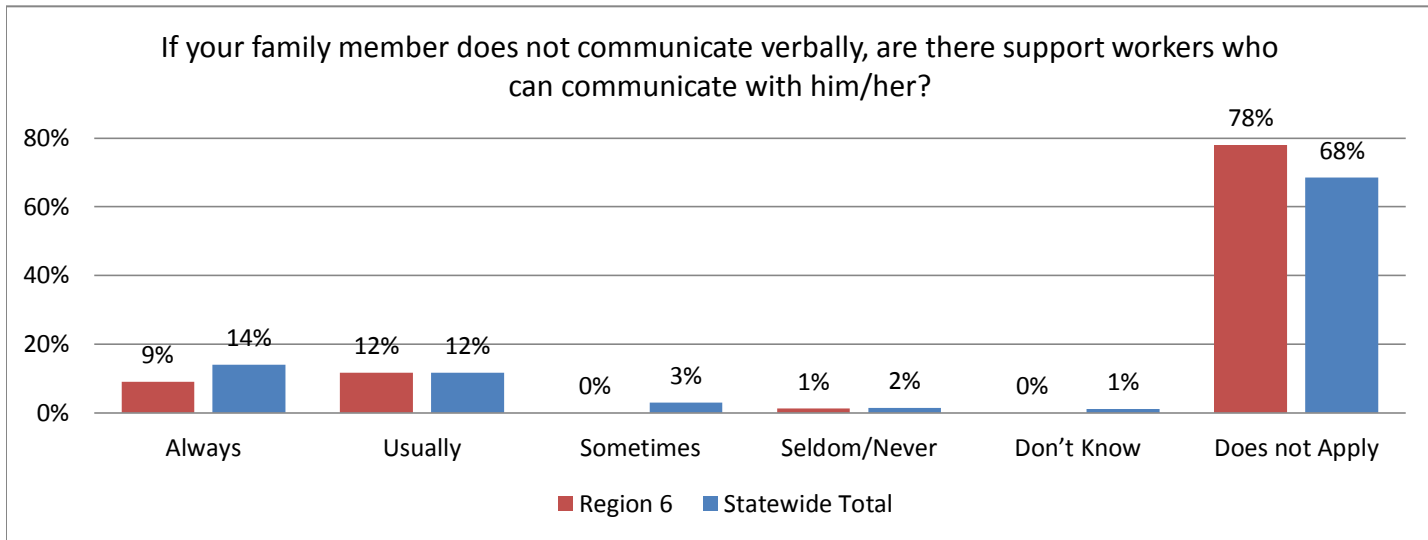
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 Region 6 Summary and Statewide Comparison

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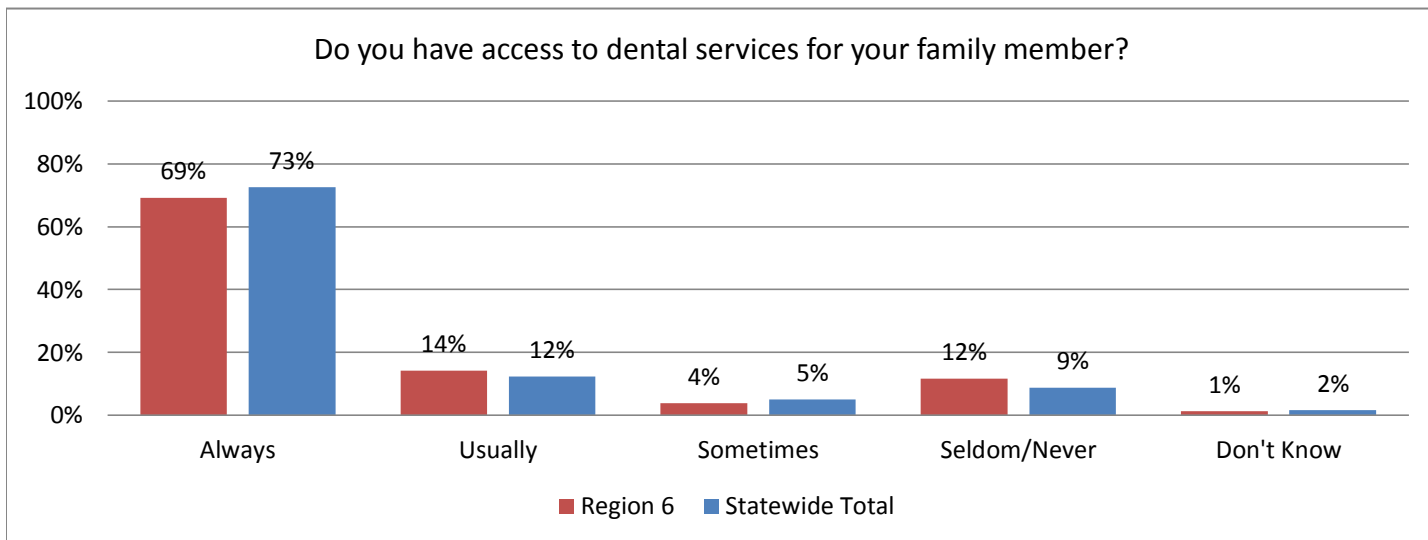
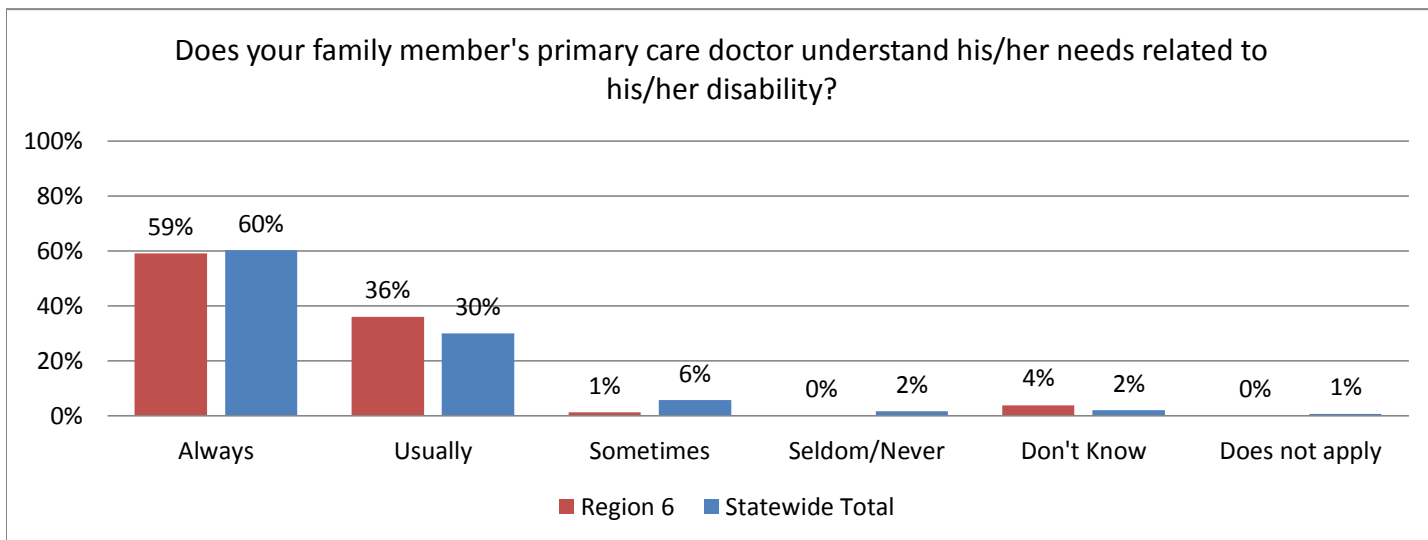
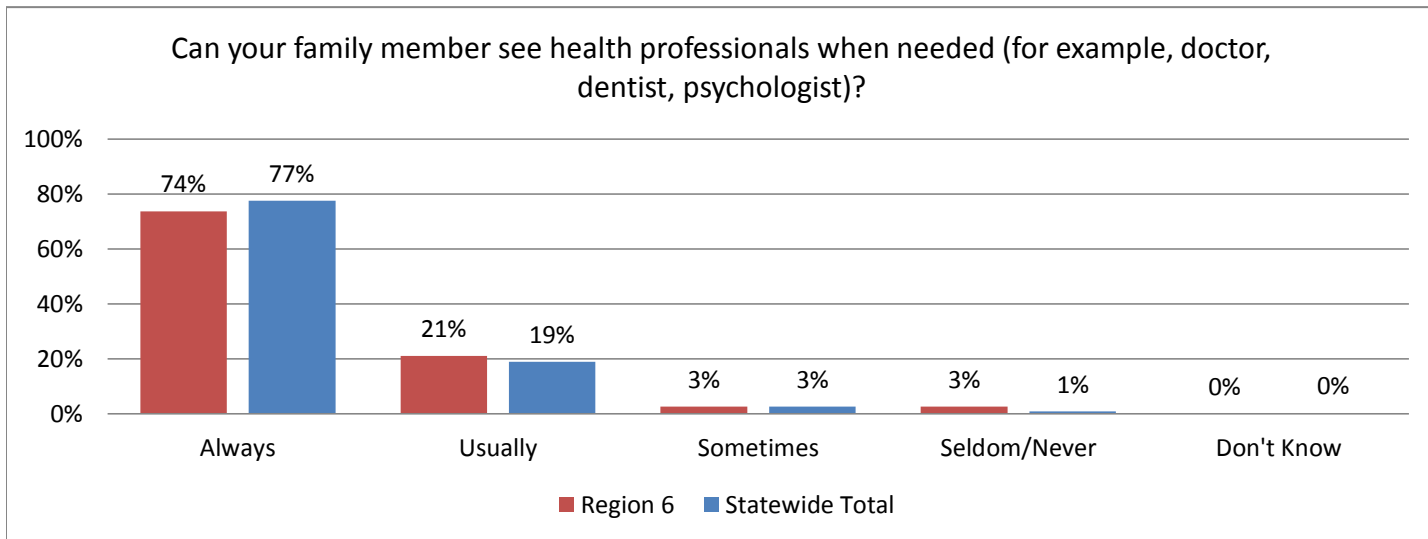
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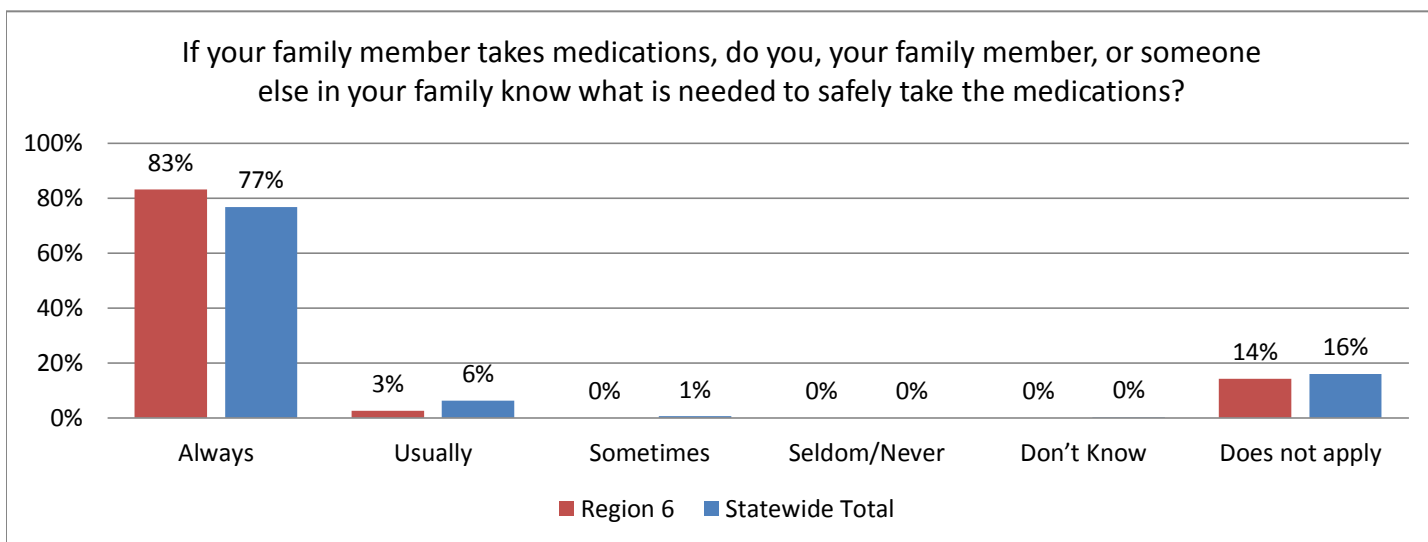
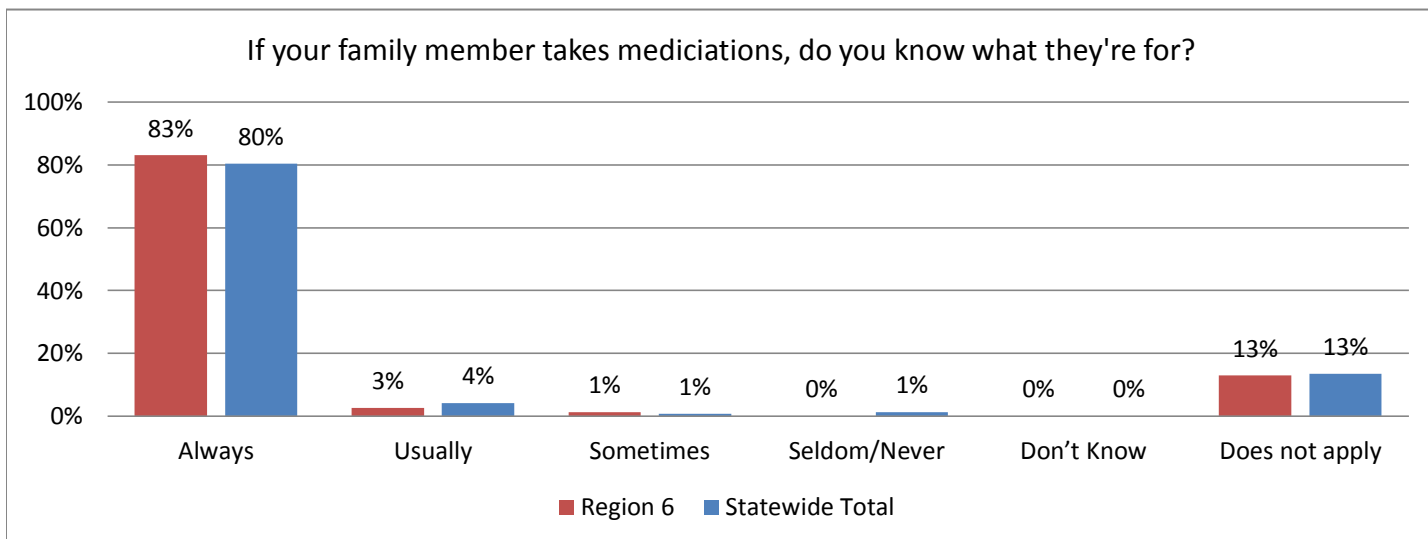
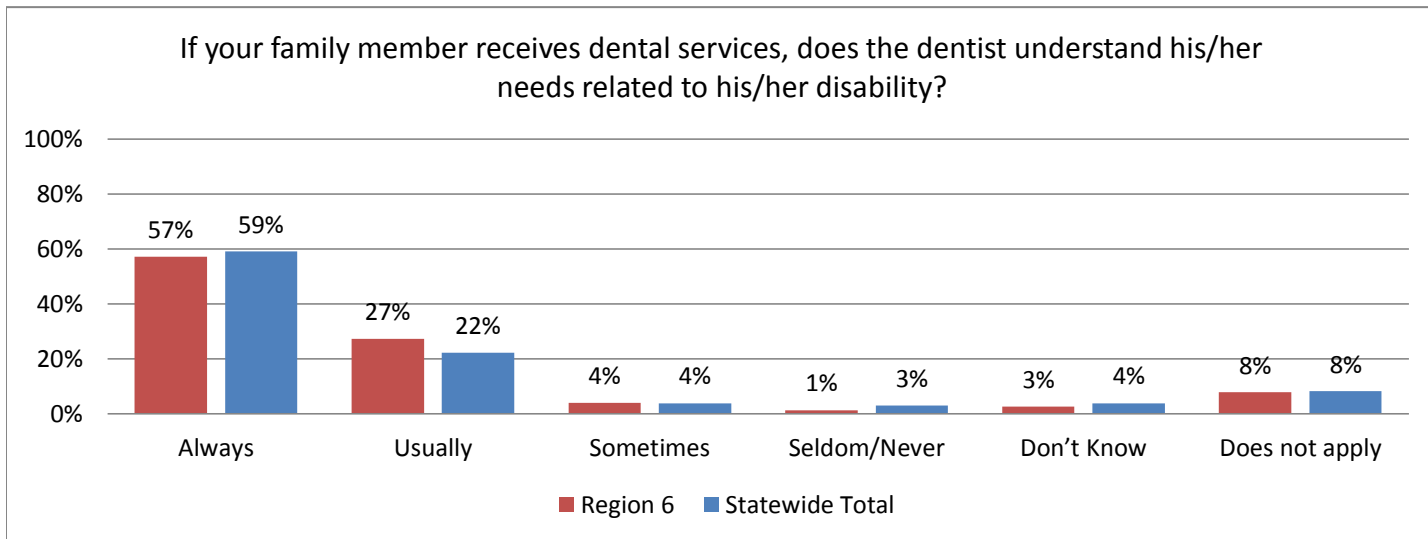
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Region 6 Summary and Statewide Comparison

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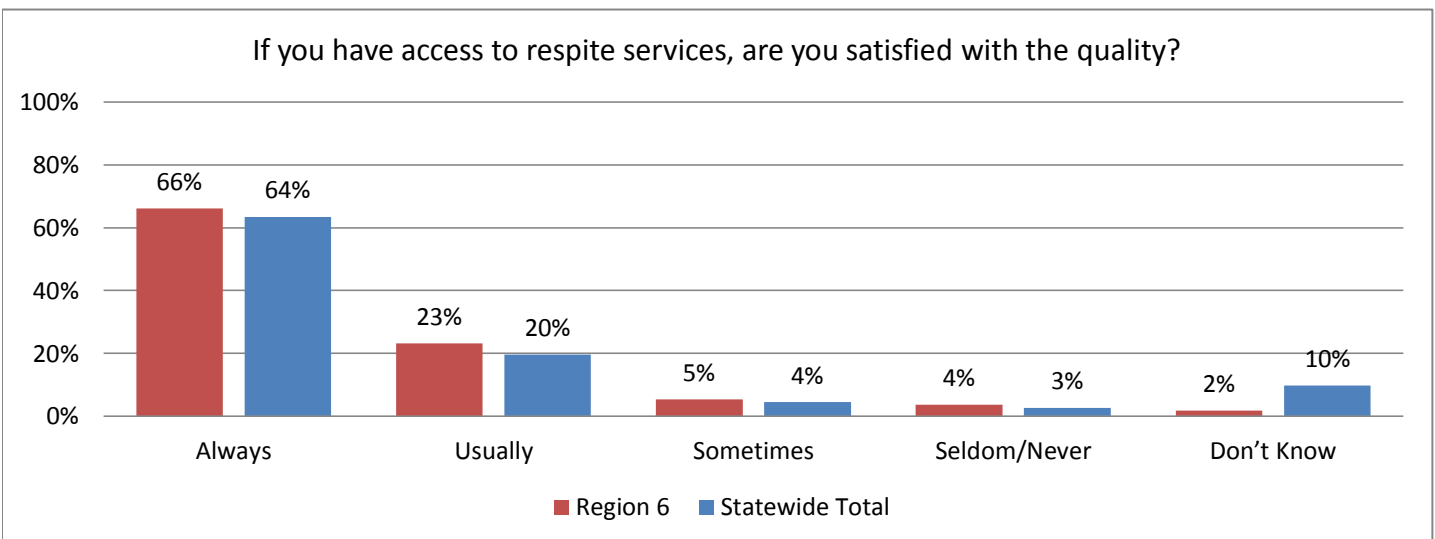
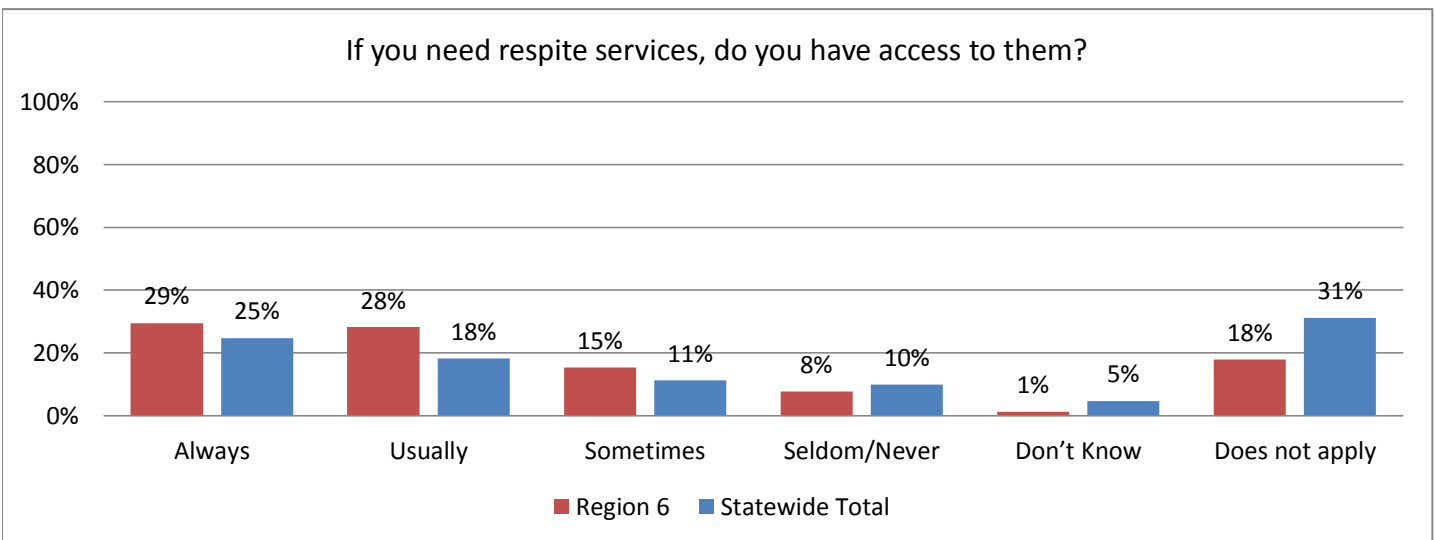
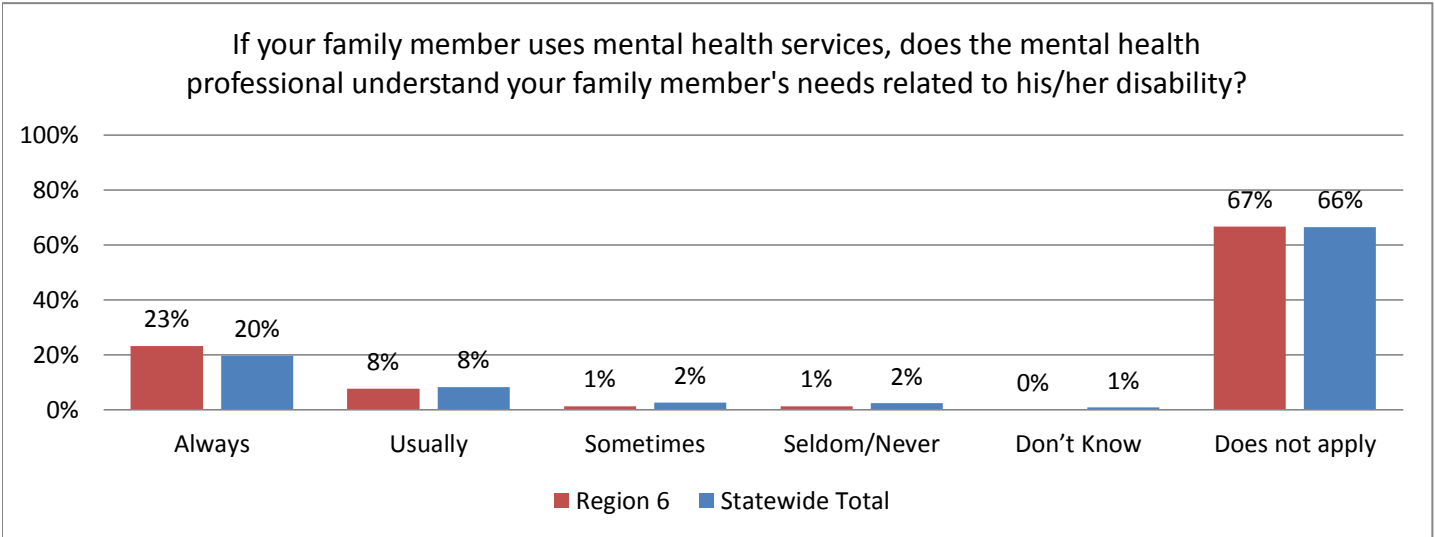
2018 Adult Family NCI Survey Results
Region 6 Summary and Statewide Comparison

Satisfaction - Supports:



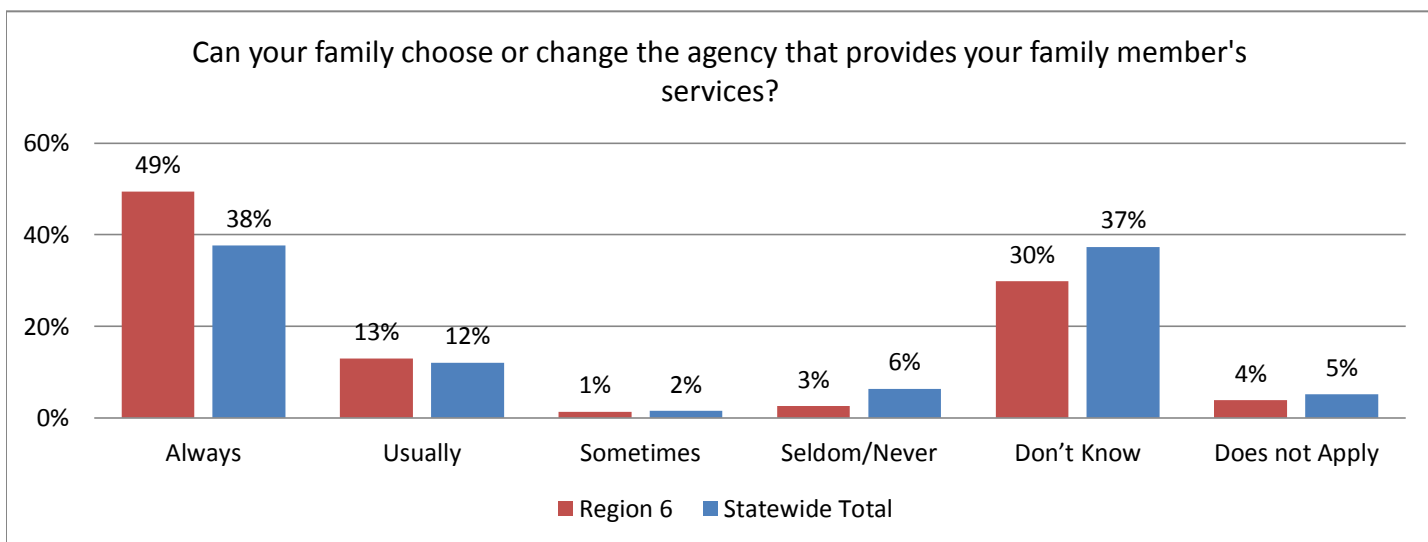
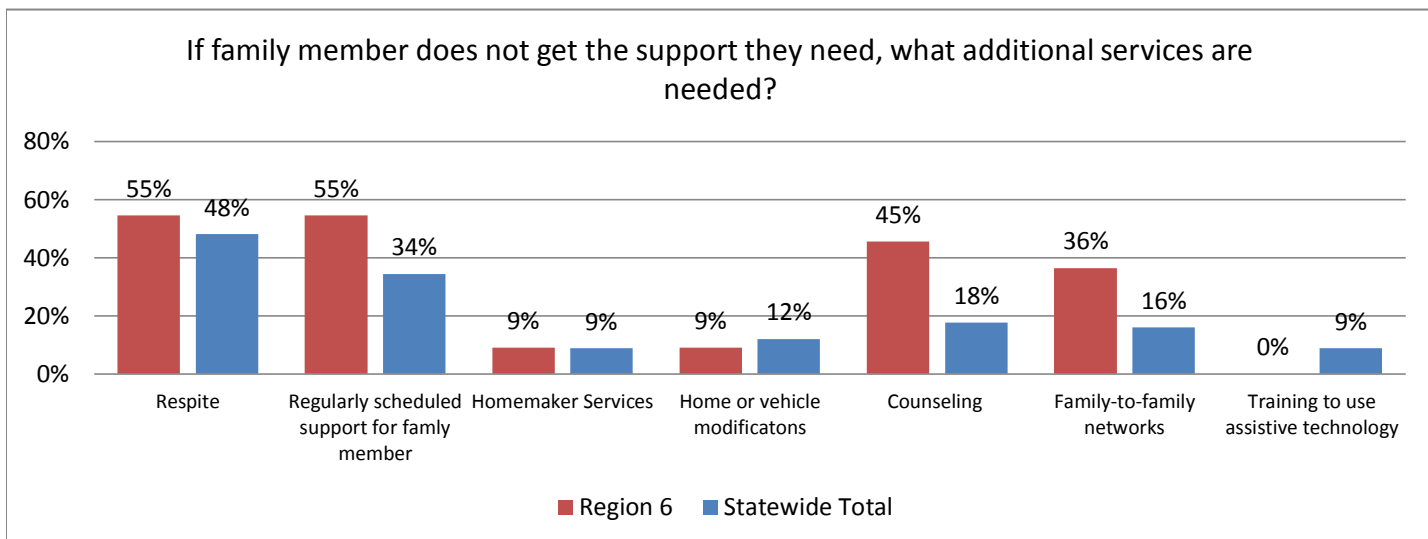
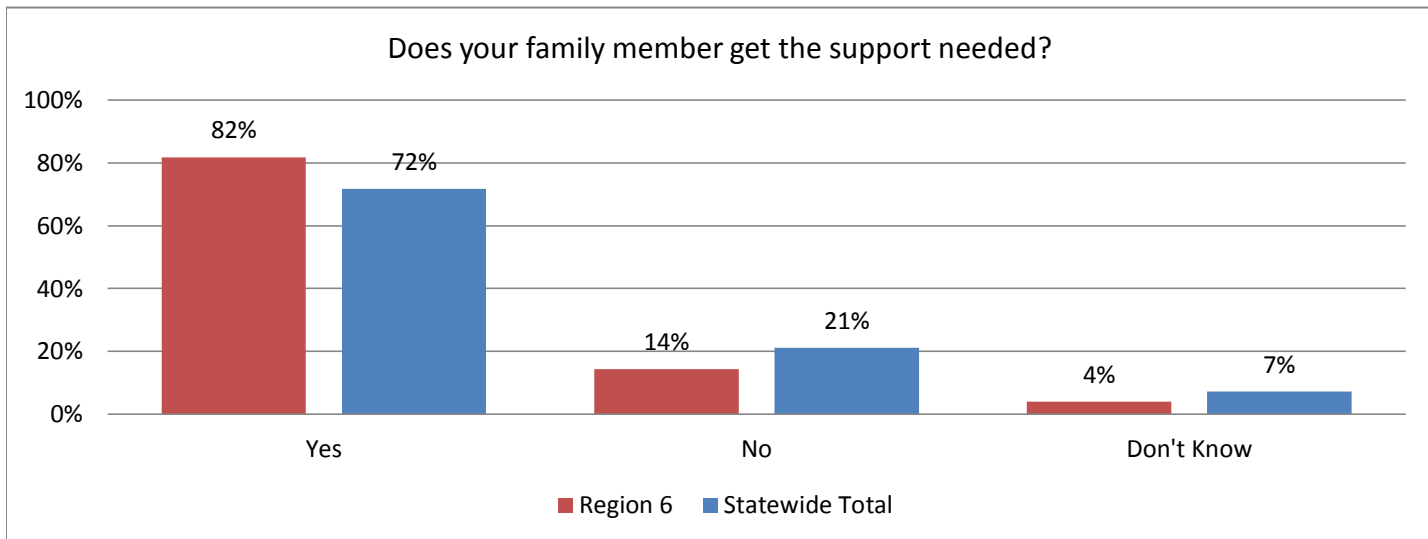
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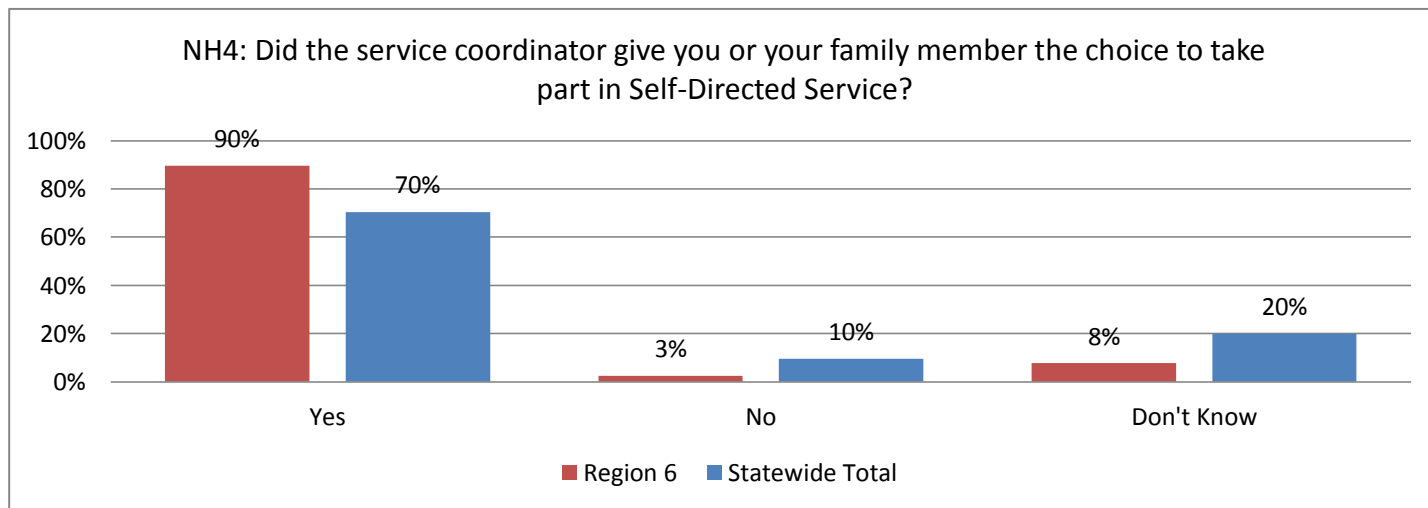
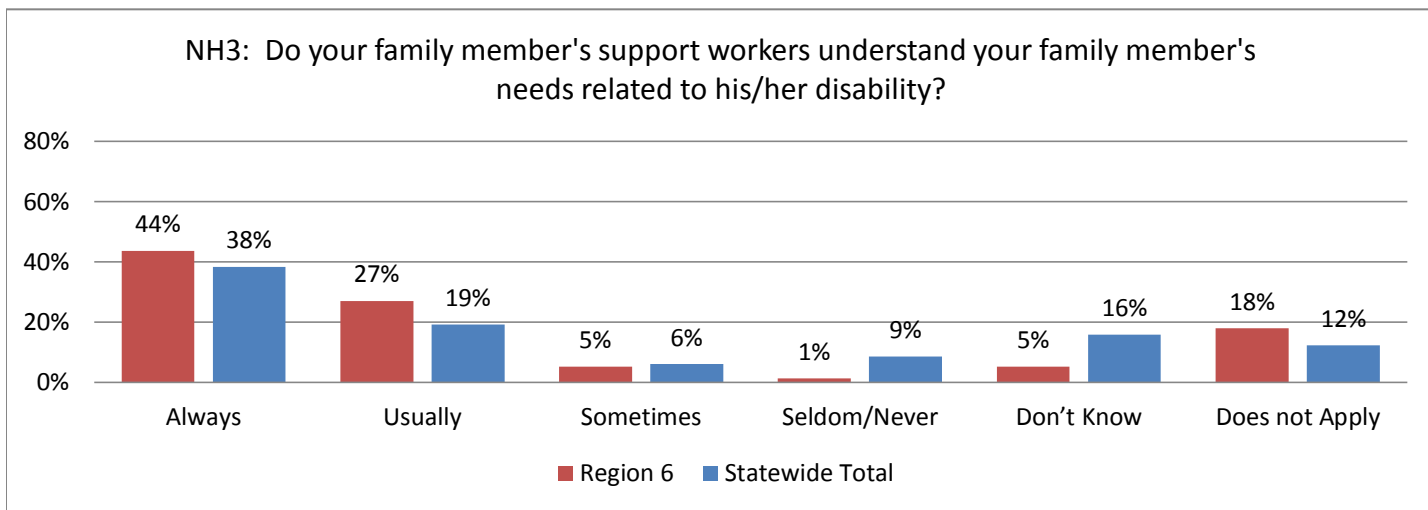
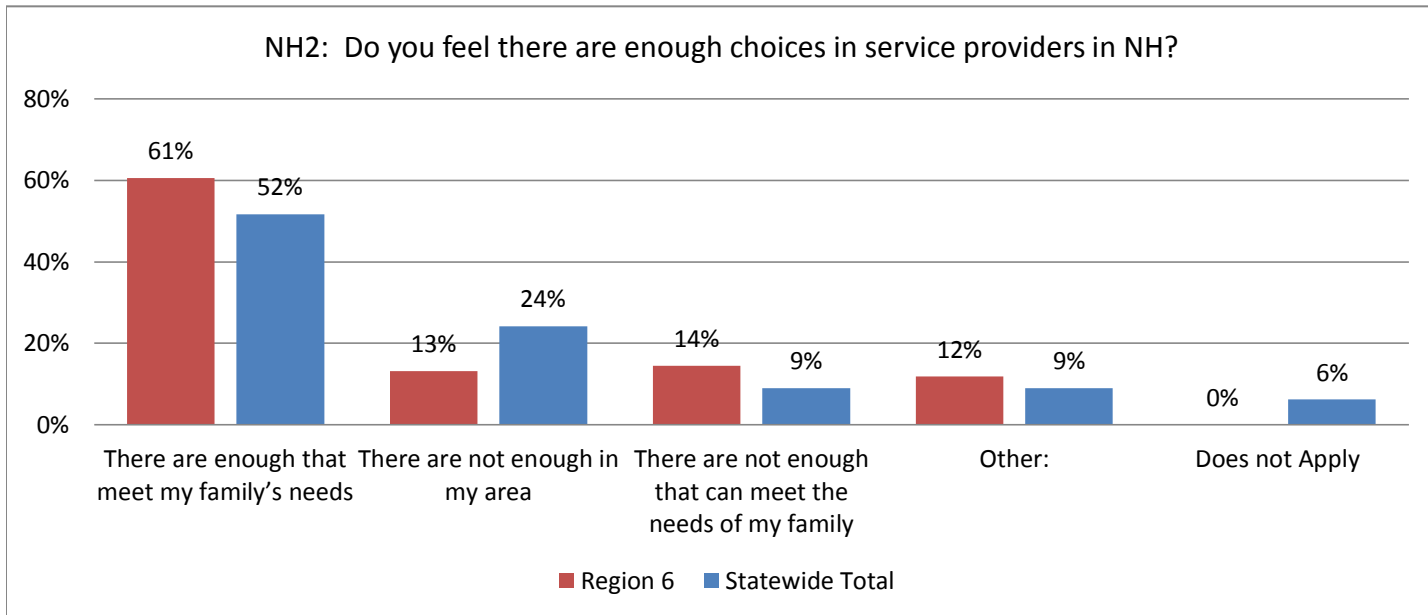
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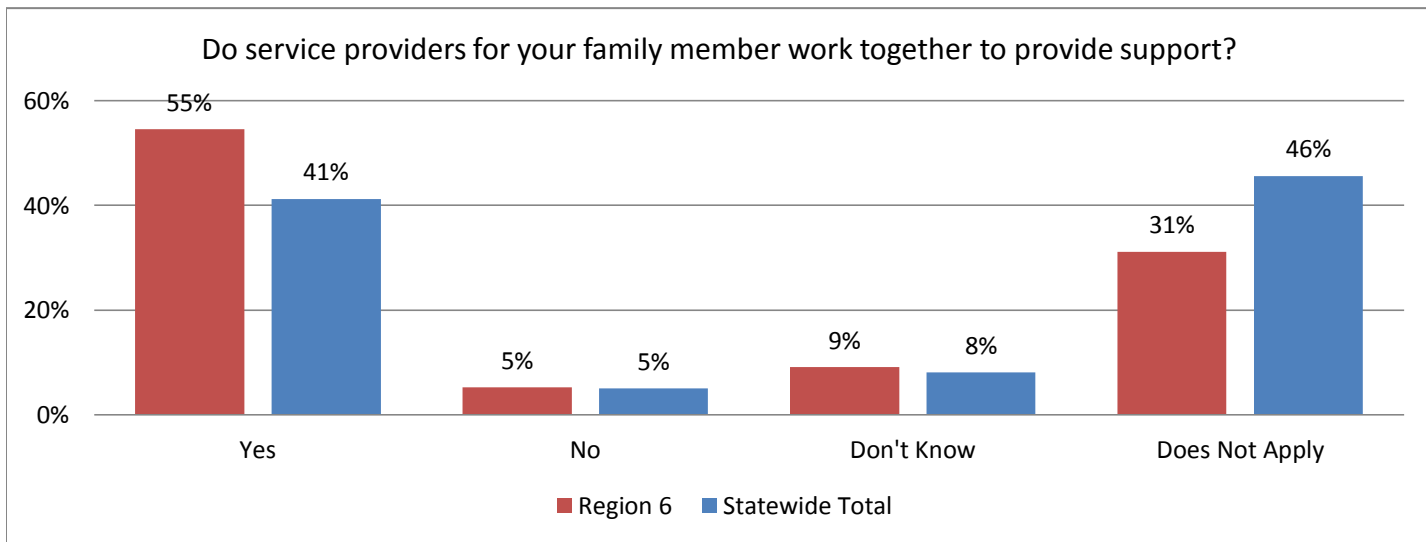
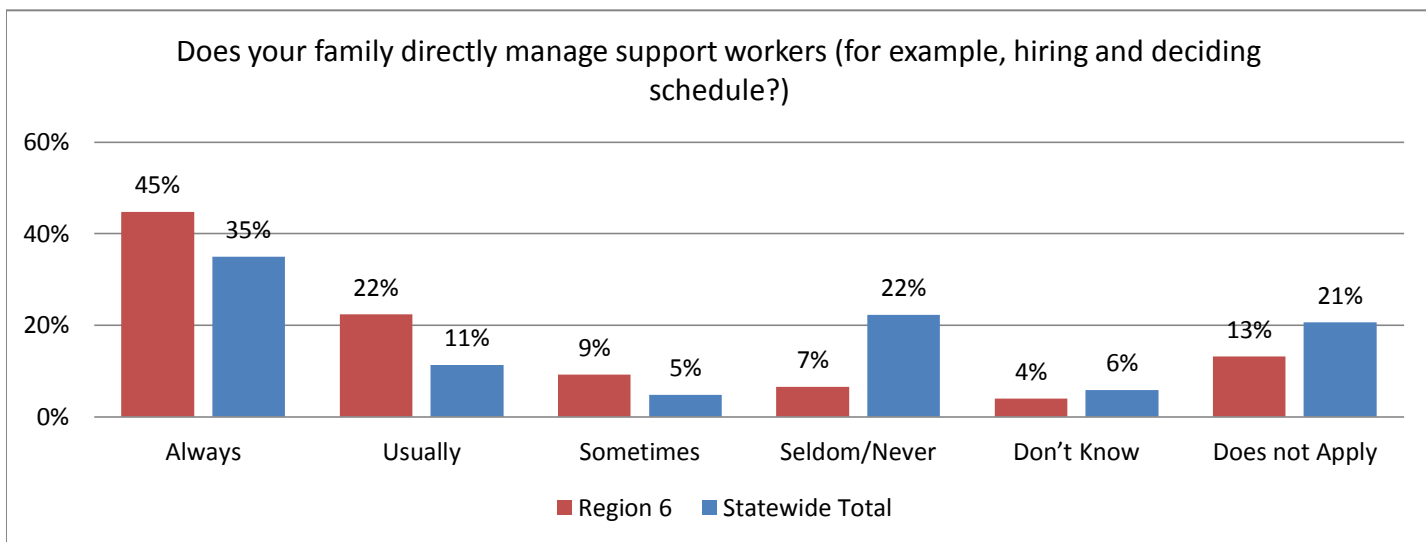
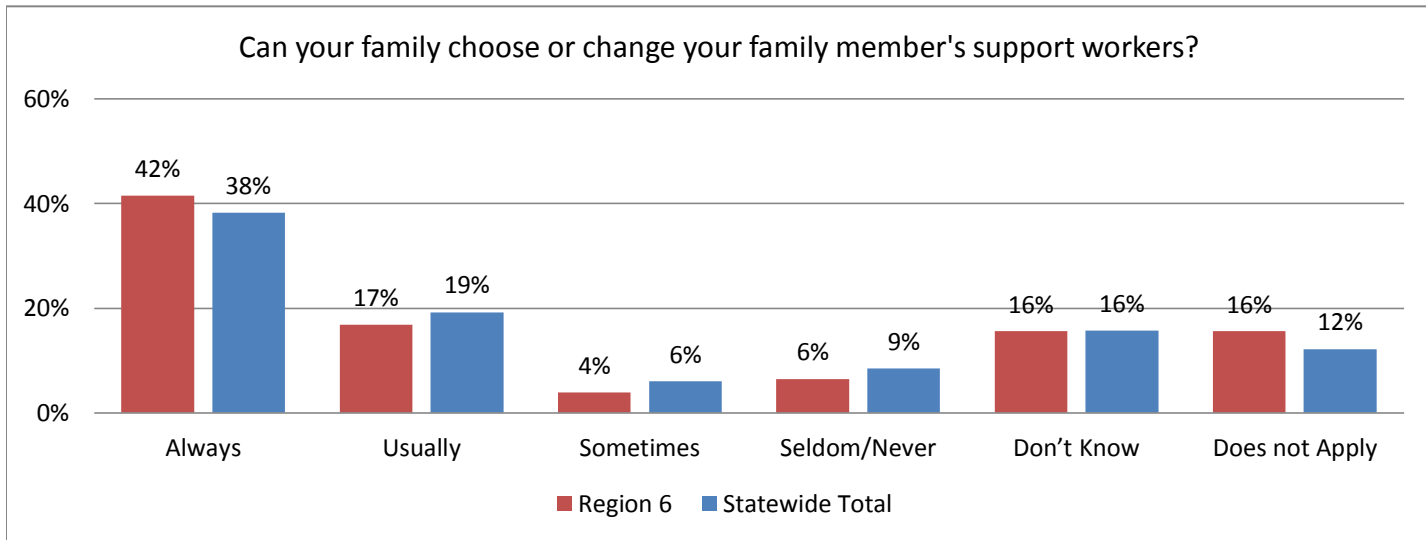
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 Region 6 Summary and Statewide Comparison

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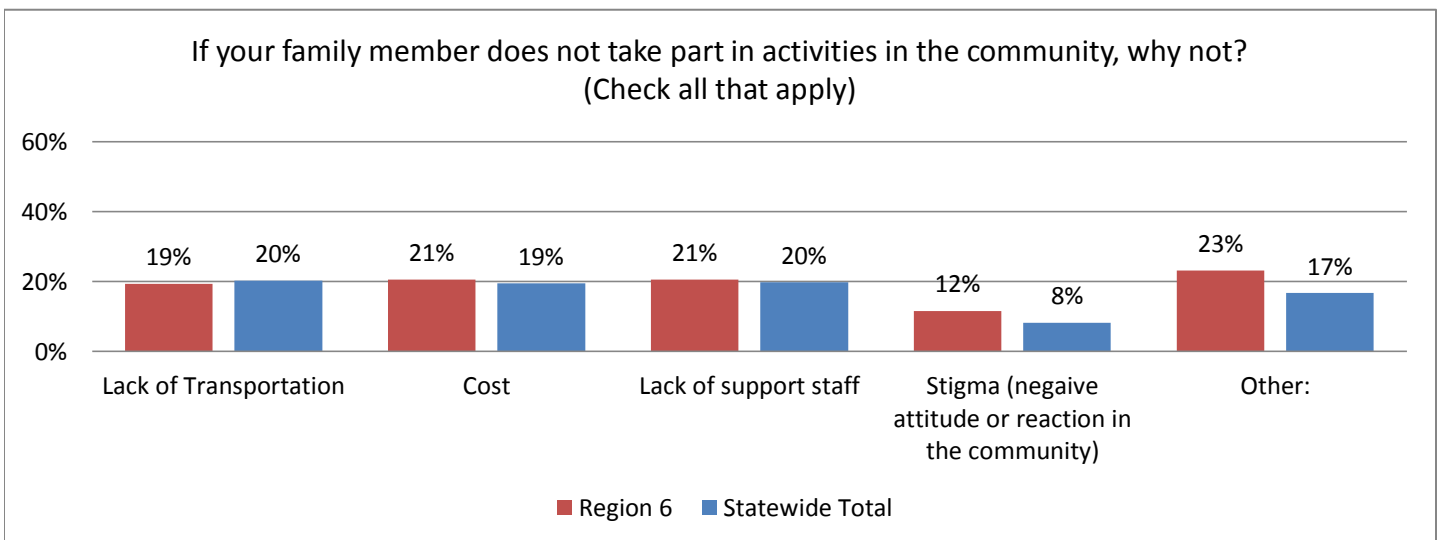
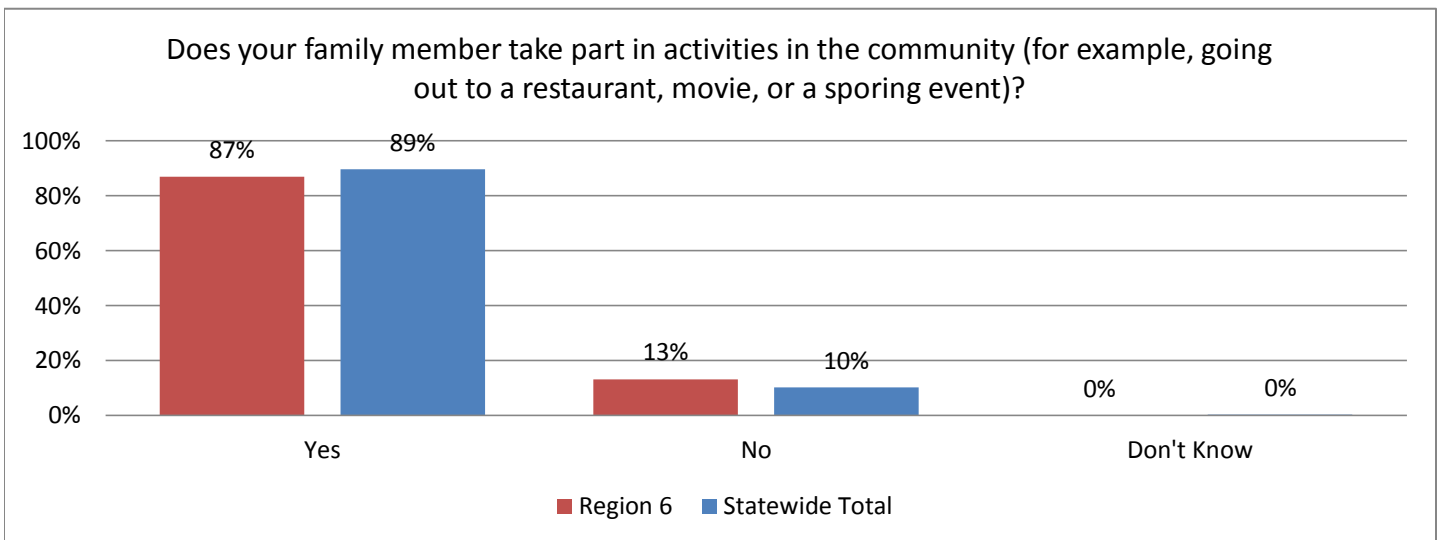
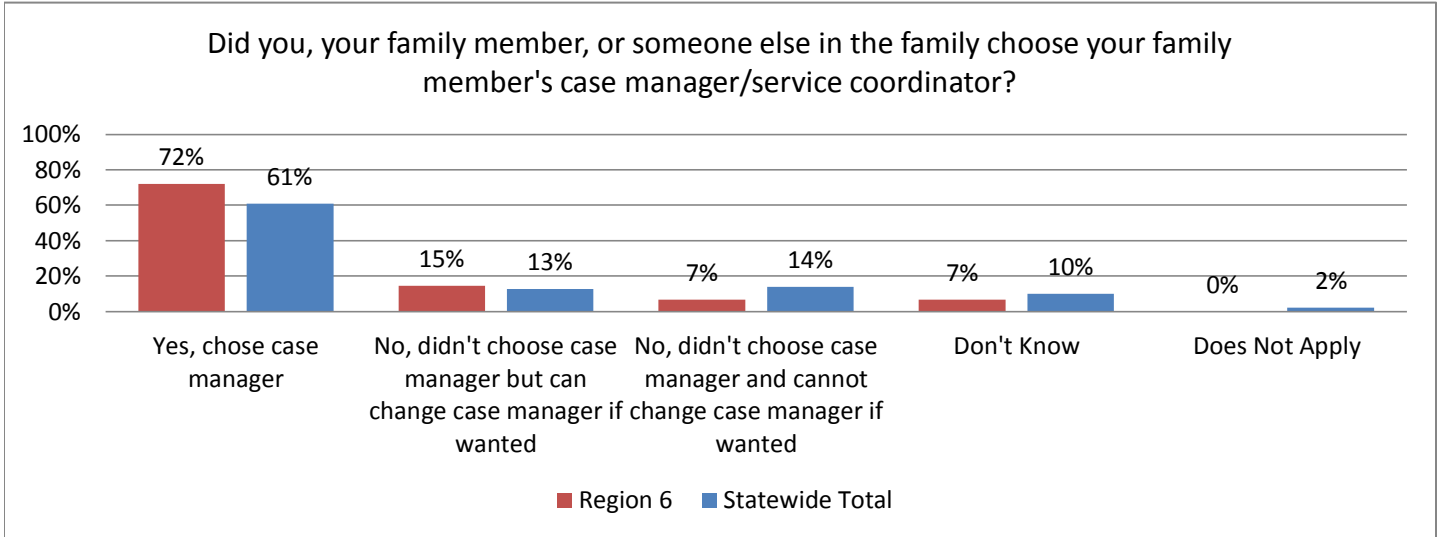
2018 Adult Family NCI Survey Results
Region 6 Summary and Statewide Comparison

Satisfaction:



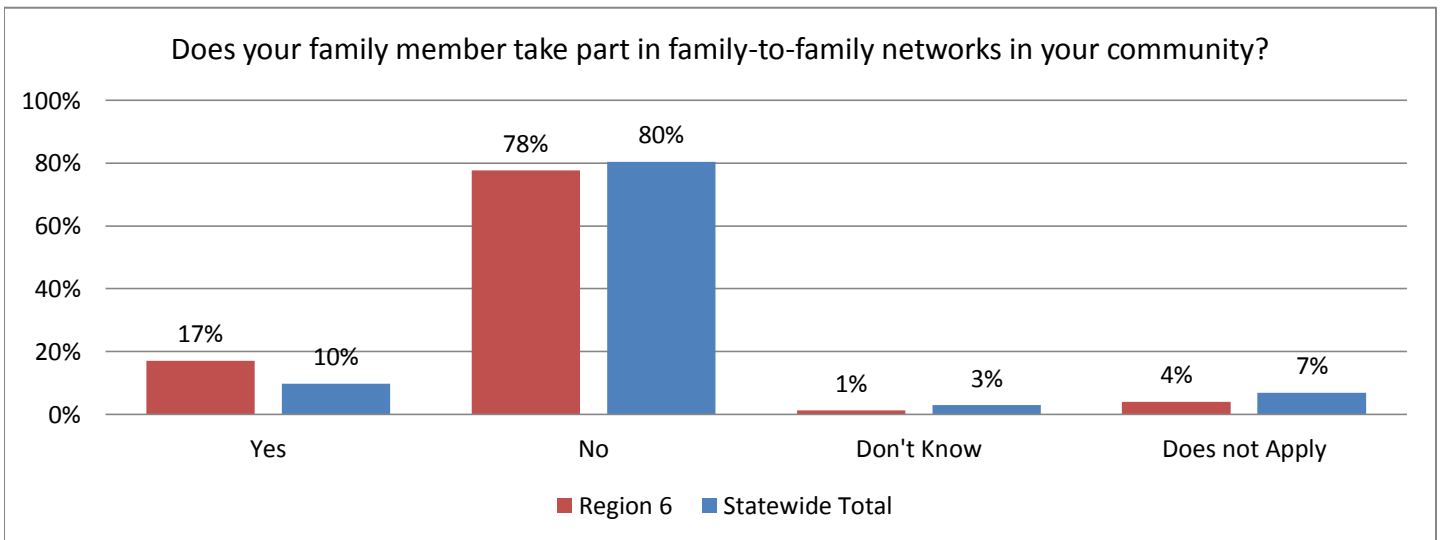
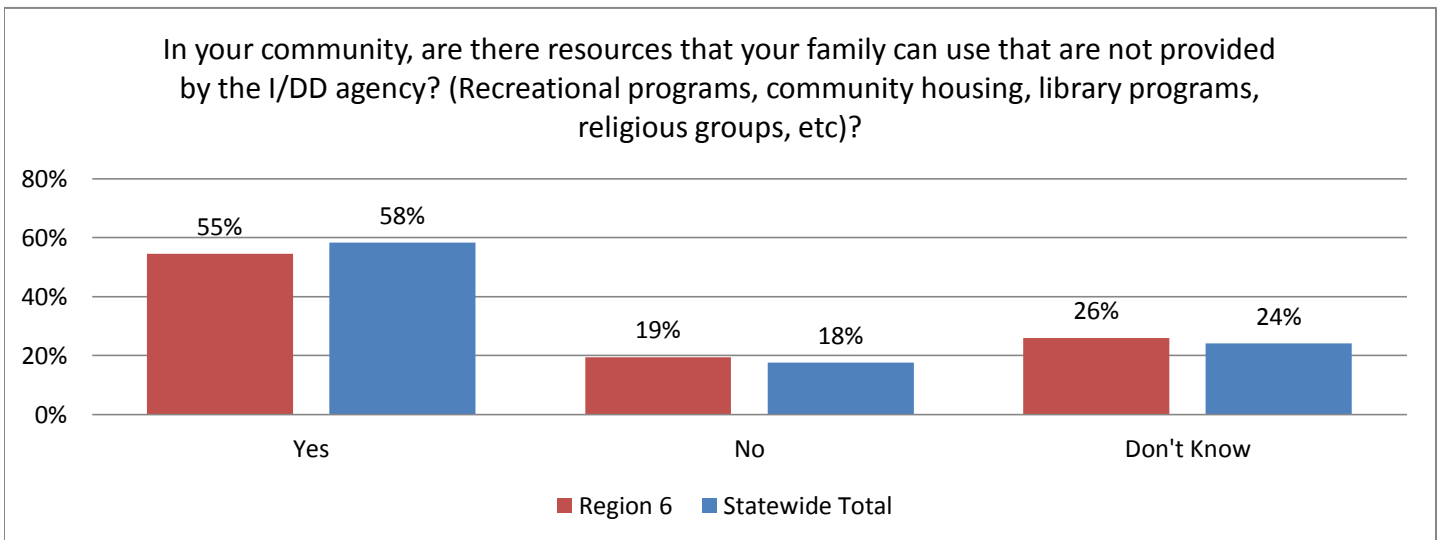
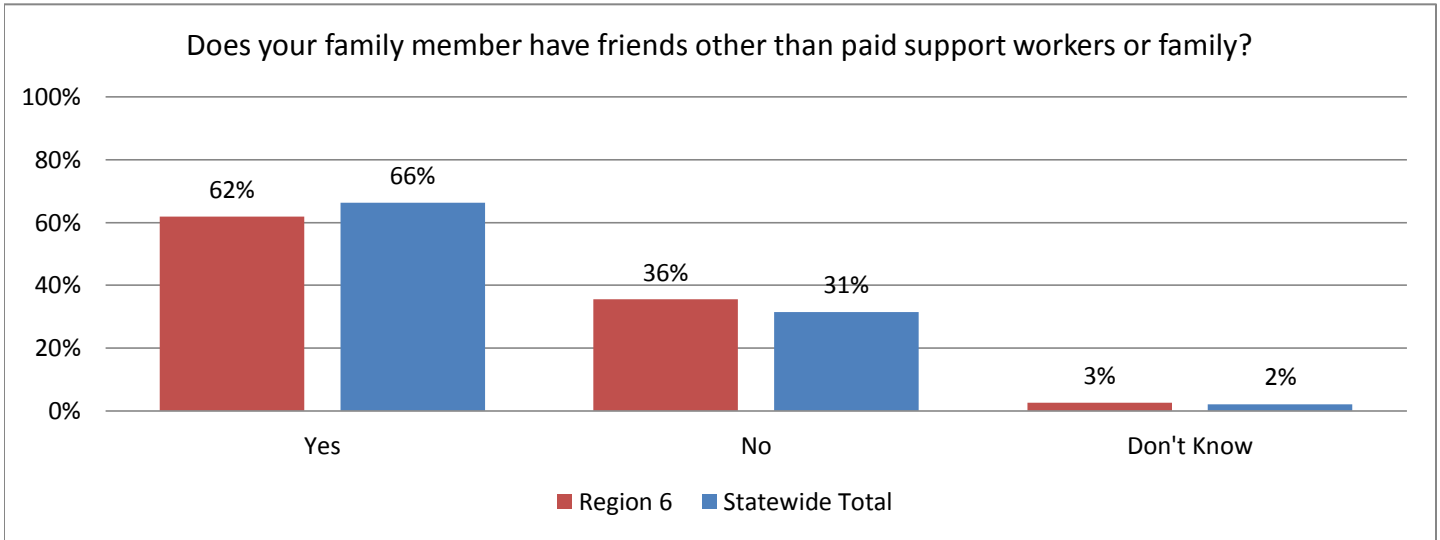
2018 Adult Family NCI Survey Results
Region 6 Summary and Statewide Comparison

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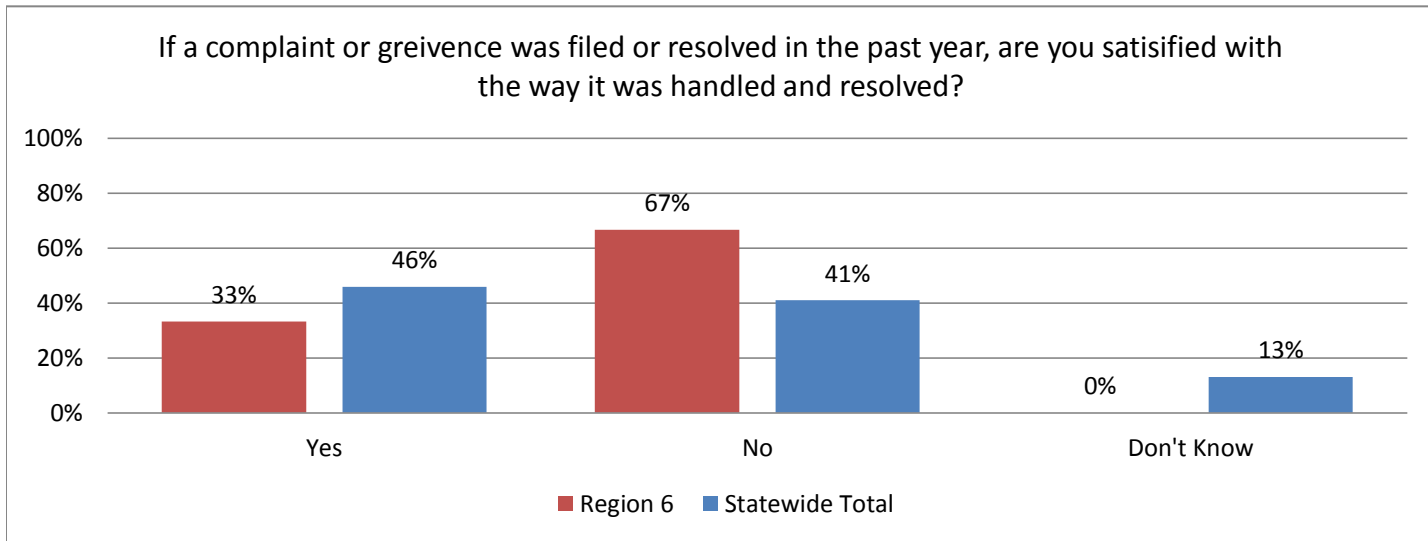
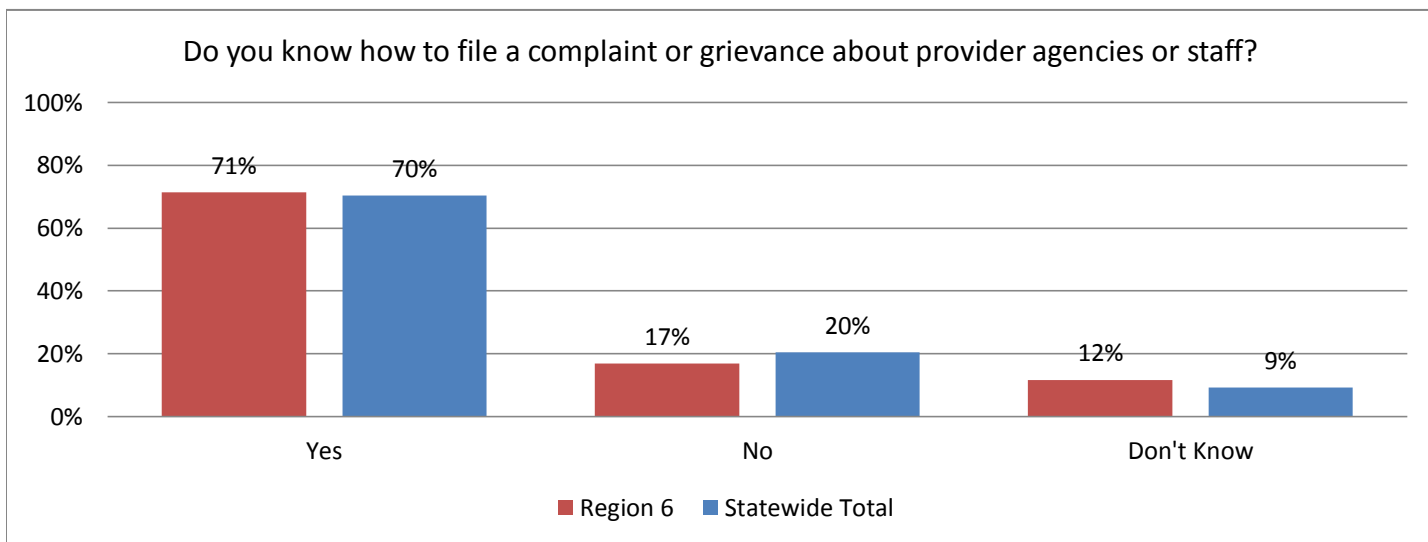
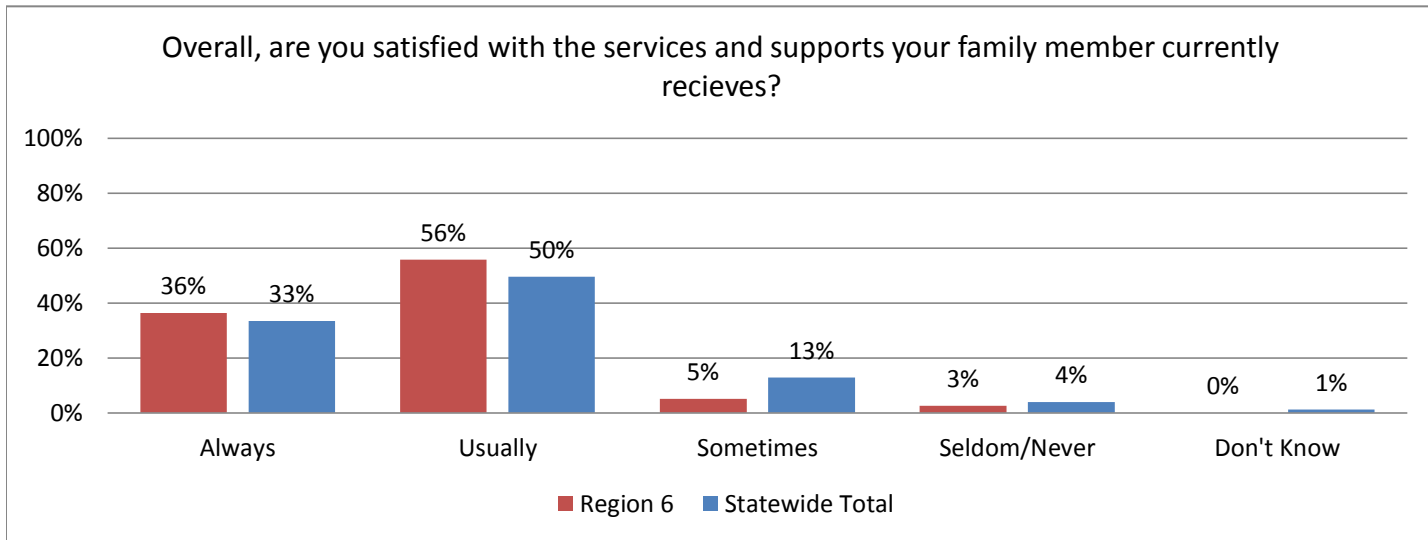
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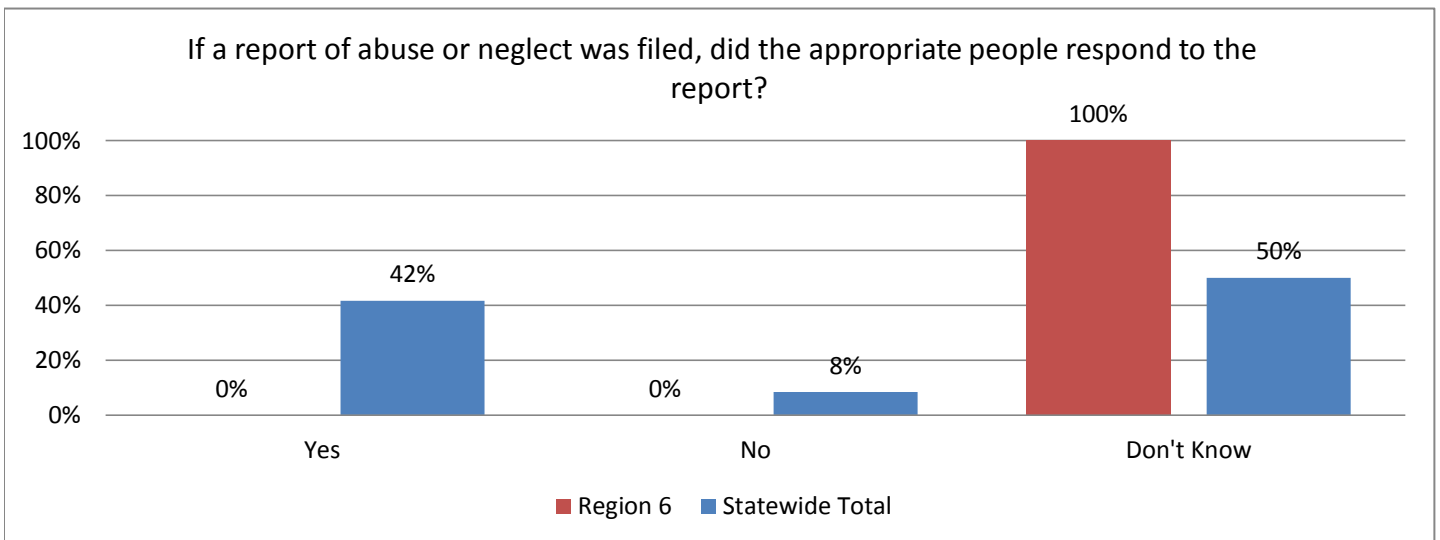
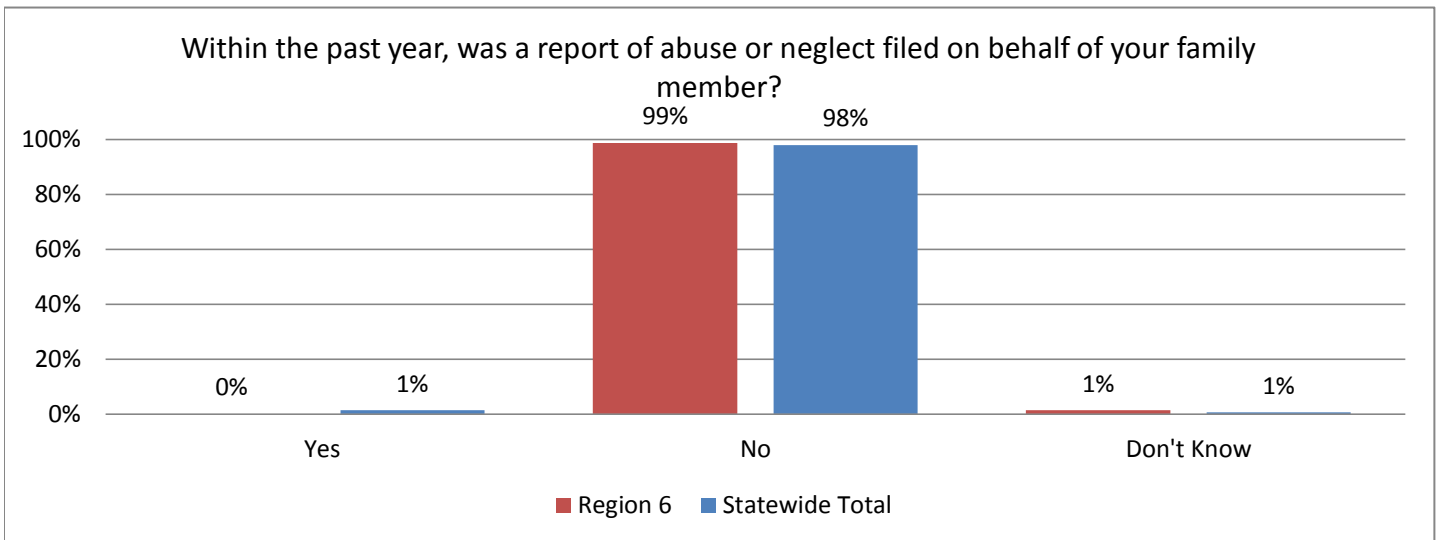
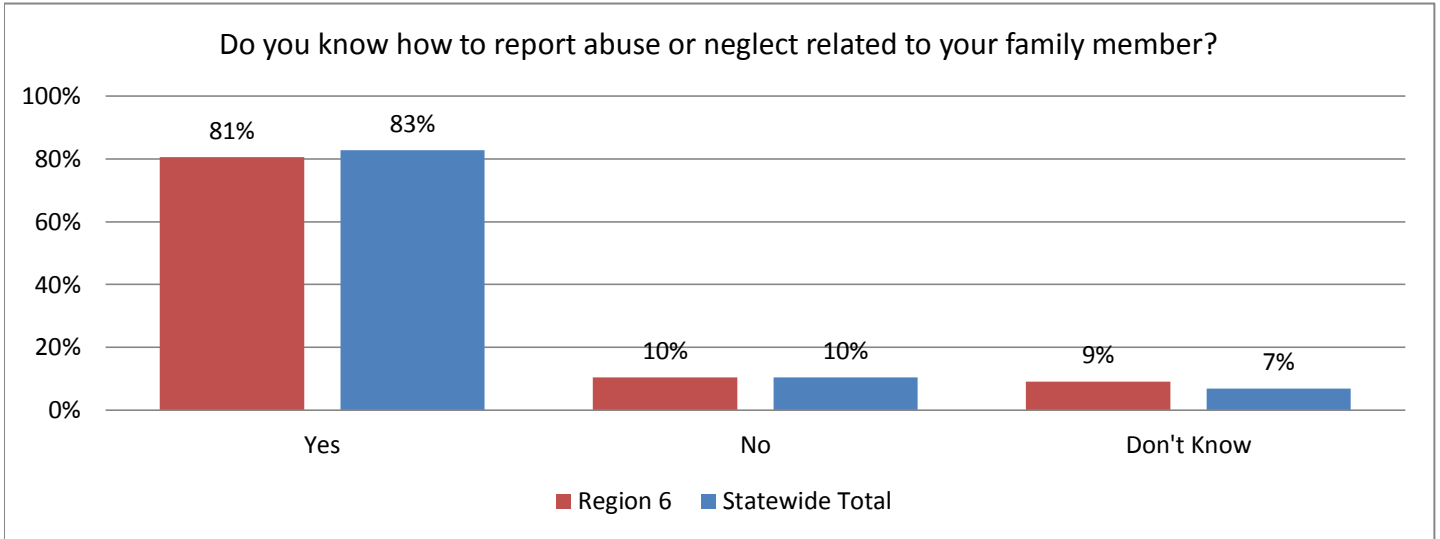
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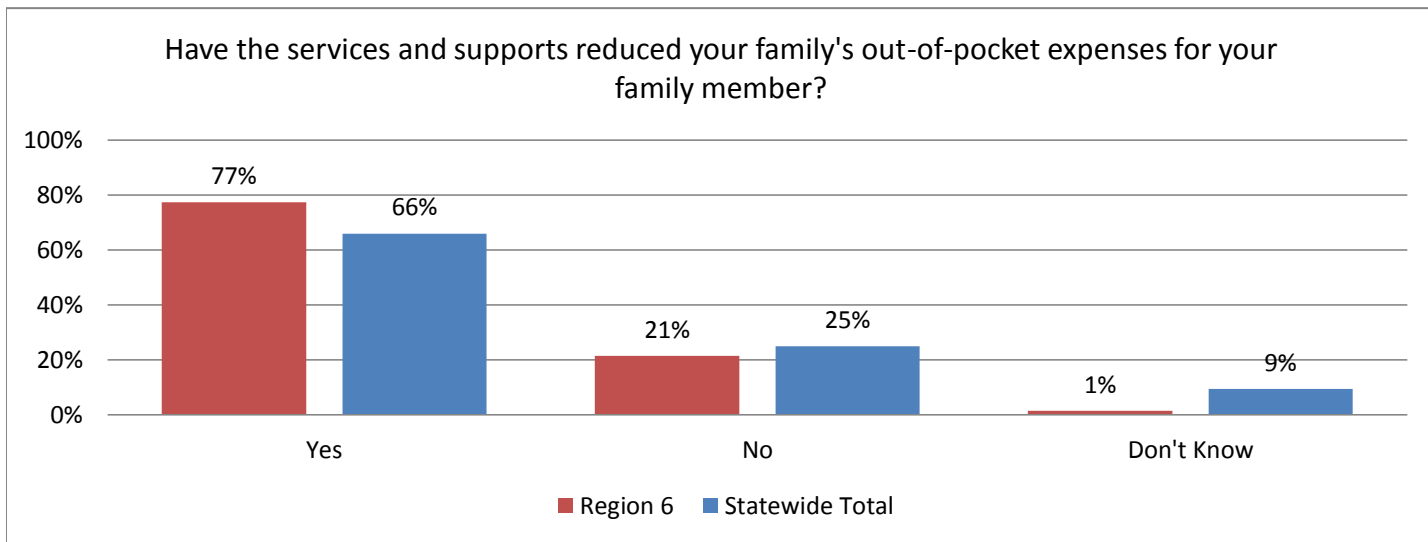
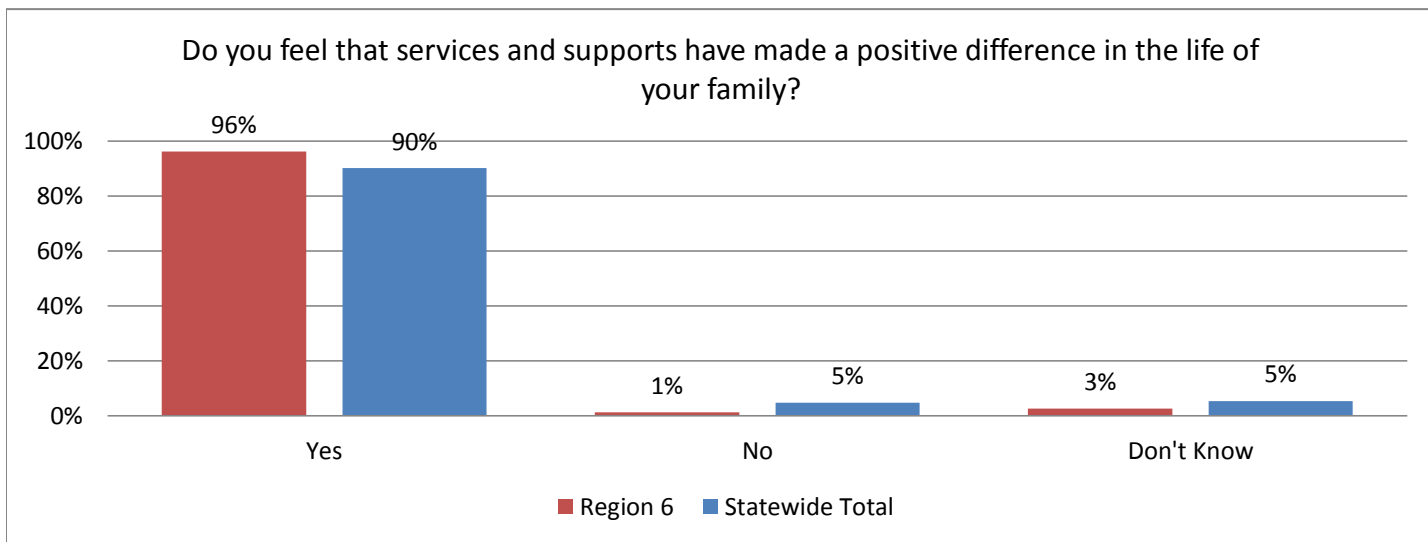
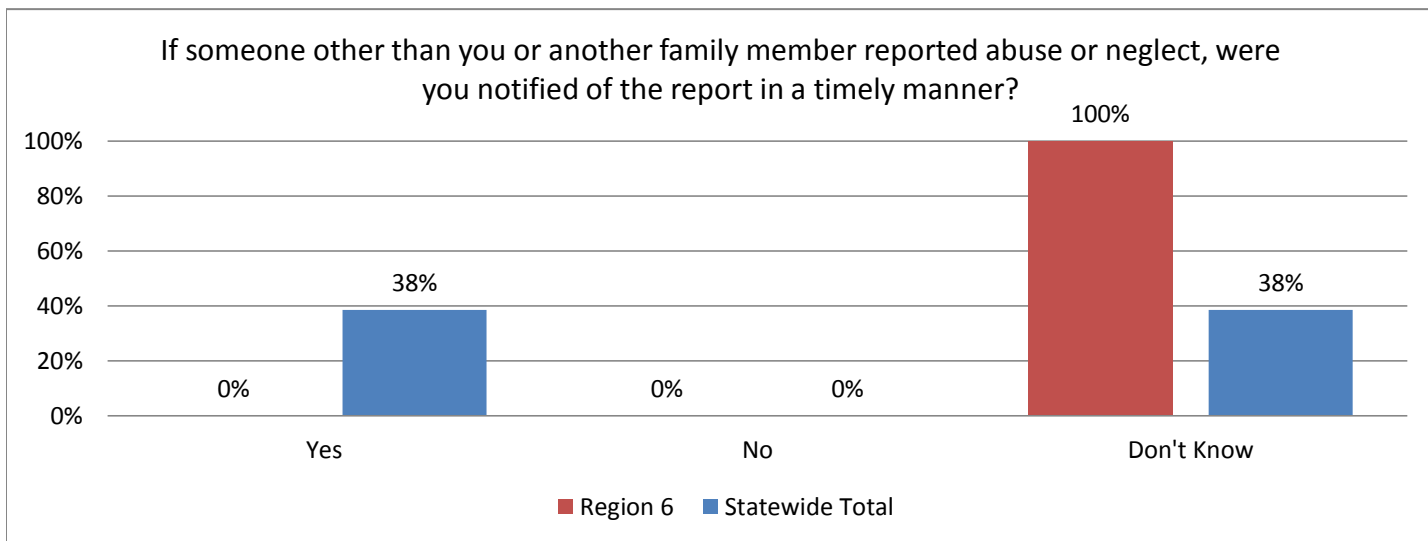
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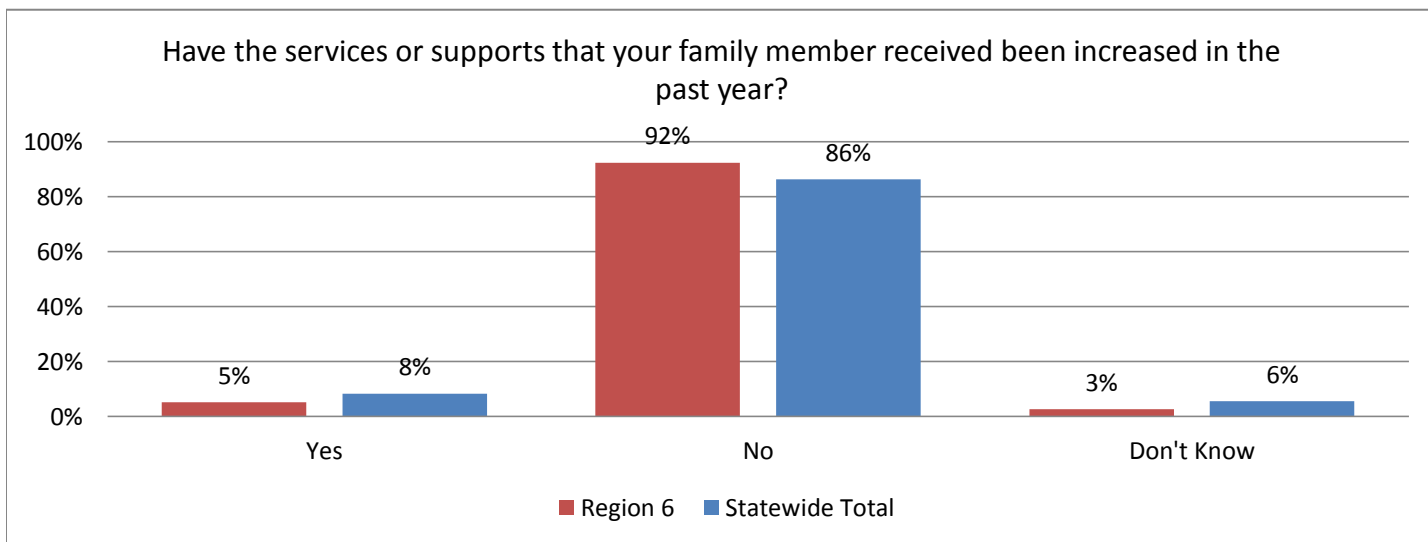
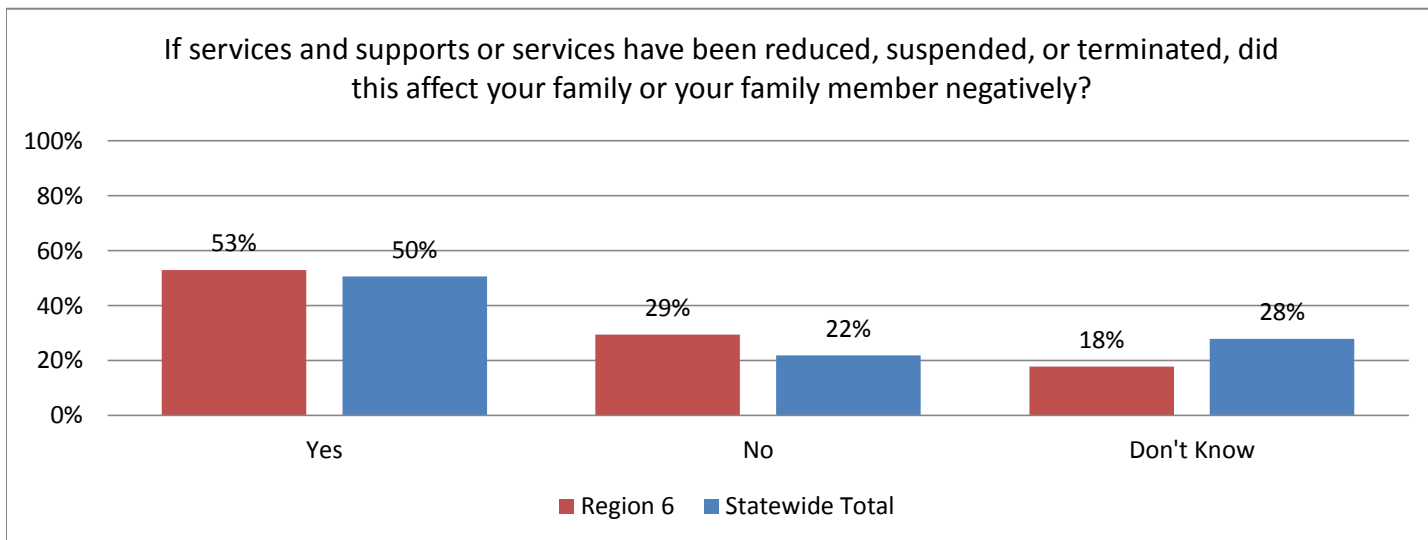
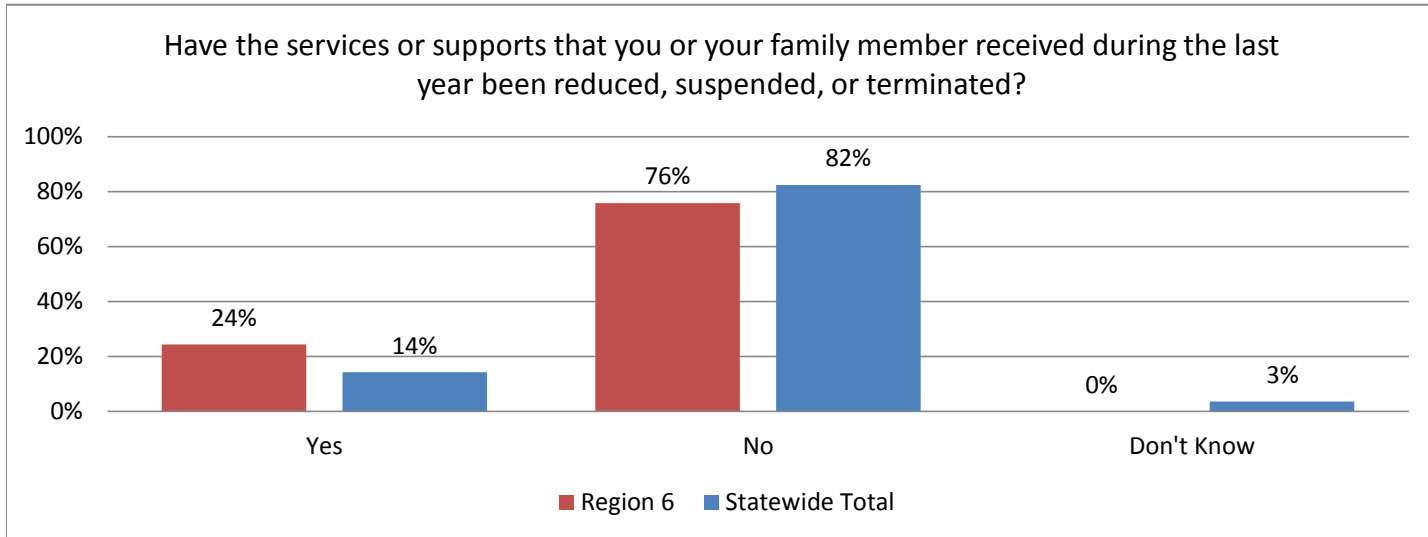
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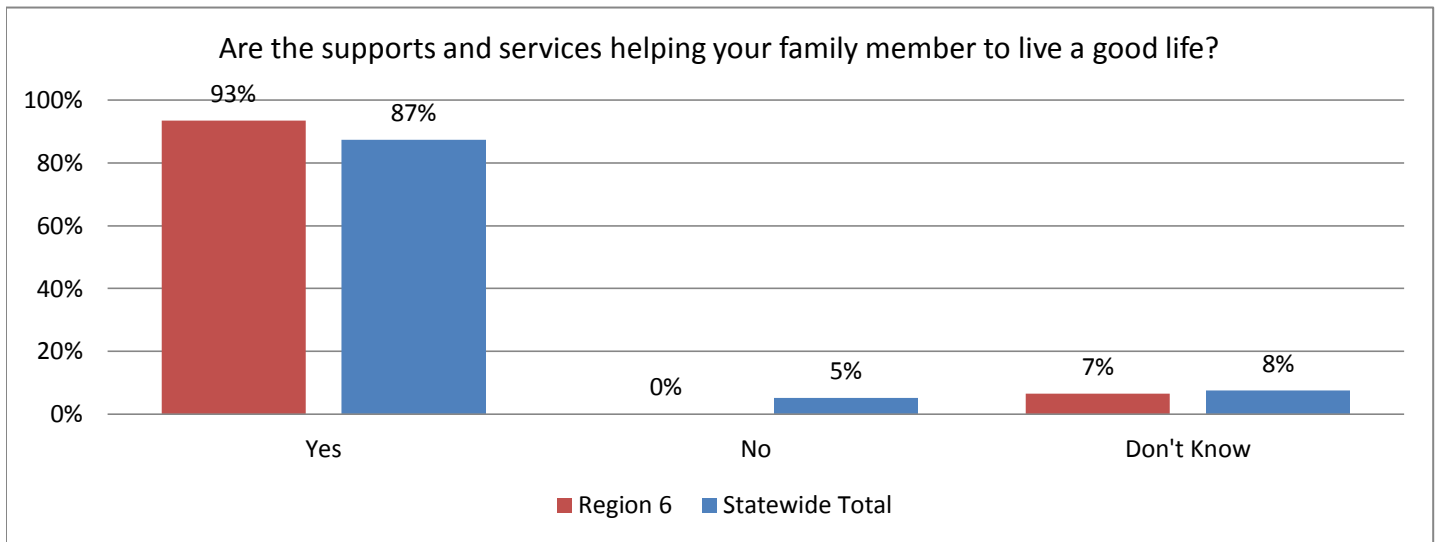
2018 Adult Family NCI Survey Results
 Region 6 Summary and Statewide Comparison

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2018 Adult Family NCI Survey Results
Region 6 Summary and Statewide Comparison

Satisfaction:



COMMENTS:

E: Other Disabilities

ADHD
Microcephaly
Mobility issues/wheel chair bound
Myotonic MD
Nonverbal learning disabilities
OCD ADHD Tourett
Osteopenia
Osteoporosis, liton, GERD, hydradenitus supretive
Polio
Severe language impairment
Speech & lauguage, MR, LD
Speech and language

F: Other Health Condition

Asthma
Congenital heart disease, scoliosis, pharynegal flap dificiency
Fluid around his heart
G Tube fed
GERD
GERD, sleep disorder
Hypothyroid
Hypothyroidism, osteoporosis
Ictheosis vulgaris
Low thyroid
Obesity, Constipation
Obesity, pre cancerous polyups requiring colonoscopy 23 yrs
OCD, severe colon & intenstinal issues, chews on fingers, decalcification of teeth, eye issues
Osteopenia
Overweight

H: Other Race/Ethnicity

Human

H: Other Communication

Combination of one phrase language/gestures
Gestures, Sign language, communication aid device
Limited spoken language - paper pen - google internet

L9: Other Daily Activities

At home between work and activity programs weekly
Day program after work
Goes to program 3 days a week out of home
In community 5-7 days per week
Math and reading tutoring lessons, meditation classes
Regular family activities in and out of home
Spend time at health club
Unpaid (except by family) work in a community business (Cravings)
Volunteers, soup kitchen, gym, part time work
Works 3 days a week at Burlington Coat Factory attends math tutoring 1 hr week
Works 3 days/week, home other days or attending activities socially
Works at family business

R: Other Respondent Relationship

Brother in law
Home provider
I am the person who gets services
Myself

5: Other Future Planning

Depending on if she ever wants to be on her own it would have to be a group home type w/supervision
Long term planning options
Not sure
There are simply no available supports in these areas (social/recreation). Parents of dual diagnosis (DD/MH) ALL struggle with this aspect. AND Direct support professionals are extremely difficult to locate. I have found vendors to simply be unqualified or understaffed or not dependable.
Transportation
What happens when I die?

36: Other Additional Services

Options for an occasional respite would be wonderful but it seems you have to provide the personnel to do that if we had them we wouldn't need it
Vendor supported day program and 1:1 job supports

NH2: Other Enough Provider Choices

Day program vendors are short staffed and inconsistent
Don't know
Quality is an issue
There are choices but some provide little support opportunities
Would not want to be locked into area agency because of where I live

43: Other Community Participation Obstacles

A viable social network of friends
Anxiety level dependent
Cognitively disabled
Concern with behavior/anxiety
Food access
He has no interest in most activities which are social
Lack of desire
Lack of socializing with others
limited opportunities, social, employment
Mobility issues
My daughter chooses not to participate (other than work) with members of the disability community
Overwhelming, little interest/knowledge of such
Profound MR, aggressive & violent behaviors
Safety, ability to participate
Sensory issues, lighting, crowds, volume of noise, confusion & overload
Severe anxieties
Social anxiety, communication difficulties
Timing/scheduling

2018 Adult Family NCI Survey Results
Region 6 Summary and Statewide Comparison

Information & Planning:

Because I am in my eighties, I need more information to plan for my daughter when I am not available to help! housing, care, day to day supervision, etc.

Budgets run very tight. Last year we were overspent and had to provide out of pocket. Increase in our budget would make things less stressful.

Case manager is phenomenally supportive / the SYSTEM fails in supporting the needs D/T structure.

Case managers and providers have all shown a very personal interest in helping the family member mature and learn.

Excellent case management personnel

Finding a job appropriate for the client is difficult/impossible, as job development info isn't shared, or offered.

I am concerned about her future housing options. I wish there were more housing communities in NH for people with disabilities this is my #1 concern.

I am overjoyed with our current case manager. I am also very pleased that we haven't had to change our case manager frequently.

I am pleased with all the services we have been provided

It would be nice to have some consistent caregivers. It would also be nice to find a life coach who would not be overbearing and judgmental.

L1 & L4 works at two jobs on various days part time would be easier if she could find onejob part time to be more consistent

More information on activities and social groups in the area. Calendar of events.

Our case manager/service coordinator is extremely helpful and supportive. They have made using CDS a lot easier

Our new case manager has provided more valuable information this year that we were not aware of, and, has been more accessible and available when we've needed her.

Planning for when parents die!

Sometimes goals are set too challenging for family member. Need to consider more of the intellectual & physical limitations to achieve

There is a lack of honesty and transparency in the distribution of funds - wait list - annual budgets, etc. We were referred to Concord for request for additional funds and Concord reports that local AA has full autonomy (which they deny)

Understanding SSDI and when working results in losing SSDI this doesn't seem to be addressed for those more capable but still on low end of income and not able to be on their own. Balance on that system needs to be instituted so they can work as much as able but still be covered if job and supports or hours are cut due to seasonal fluctuations

Very satisfied

2018 Adult Family NCI Survey Results
Region 6 Summary and Statewide Comparison

Comments - Access & Delivery:

All is good. Everyone involved working together for benefit of family member

At this point in time supports are adequate, but the future is unsure

Attends day program prior to work only because transportation not available when wanted/needed, therefore unable to do outside activities she would like to support workers only provide transportation, workers vary day to day

Brain injury counselling for client and family. Day program for people with brain injuries.

Consumer directed services does not work if there is not a sufficient amount of available care providers to hire and for family to manage. Local AA has not been effective in supporting families in this crisis - in fact - may benefit due to families not spending their funds.

Difficult/needs are somewhat known but difficult to obtain supports that are appropriate

Excellent

My son has tried the community college and they are not accommodating and it would be nice for him to get educated with assistance and not become part of the system.

Often asked if changes are needed or other services appropriate.

Our community directed service organization is a group of caring professionals. Paperwork required is kind of over the top.

Psychiatrist DD/Bipolar director @ Mass General - NOTHING available in NH. Difficult to find DBT therapist in NH, beginning in Mass soon.

Really wish for more support for families start support groups to talk about housing options and friendships, if parents have place to shove ideas and support. It would be helpful.

Short staffed, need to hire more people.

The client would benefit from a classroom setting for areas of interest (history) & not enough DSP's to allow social interaction beyond what is currently offered.

Vendor supports could do better in the areas of staffing, communication, and consistency. They cancel often and last minute due to staffing issues.

Very satisfied

We are very pleased with case manager

We need to pay providers a better wage so that we get professional providers. If we don't it is crap in crap out!

2018 Adult Family NCI Survey Results
Region 6 Summary and Statewide Comparison

Comments - Choice & Control:

Excellent, fosters independence for my family member

Excellent. Family member has a normal, happy lifestyle in and out of home.

Fearful to change service provider

I like having the choices and control to manage my son's care and it gives him the life he has.

I would like my son to have a future. He is bright. No one seems to want to help him because he is outspoken, I won't name the agency on Chestnut St. but they keep pushing him aside.

It has always been a team effort with helpful inputs from all participants

It would be good to have specific information about future opportunities or lack of them

Our case manager is extremely informative when it comes to choices and respects our decisions regarding our daughter

Parents could come up with good ideas and would be able to share what works and what doesn't. There is so much isolation in caring for our kids.

The shortage of job developers, and support personnel, make it difficult to keep the client involved/active.

This opportunity is well supported just finding appropriate supports is elusive

Very satisfied

Wish we had more choices with activities, social networks.

Comments: Involvement in Community:

An opportunity for community involvement would be welcome

Community involvement is difficult as there is no access to transportation and/or support staff. Community involvement is only with family.

Family member has many choices & easy access to participate based on interest & scheduling & adult supervision

He loves being a part of the community

High functioning support/social groups are non-existent very frustrating

I wish my daughter was more open to participating in community activities that involved people with the same disabilities.

Lack of social network, friends

No issues

Very challenging / I know that my child needs support that is therapeutic and in the community, 'real life' learning / almost impossible/workers are NOT paid enough to interact at the level needed.

Volunteer w/support to humane society would be a good possibility, don't think it's available

We are fortunate that our private health club is very open to my son spending many hours there, there is no 'sheltered workshop' or community center for individuals w/autism. our local AA has no interest in promoting this need.

Would like to hear more about how to be involved in the community.

2018 Adult Family NCI Survey Results
Region 6 Summary and Statewide Comparison

Comments - Satisfaction with Services:

Budget cut last year because % of money not used by 1/1/17 - majority of services used during November-June caused problems the next year

Case manager is tremendously helpful a great resource who is kind and knowledgeable

Changing case manager too often

Extremely satisfied w/services

I am pleased with the services we have

I am so satisfied with our agency in general and our case manager in particular. Our family has been extremely blessed!

I am very satisfied with the services I get from Gateways

It is difficult to have the consistency of appropriate service providers which present challenges: lack of continuity / dependability does not allow for meaningful plan to be put in place

It would be nice to know where our 10% goes at Gateways!

Need to hire more support staff at agencies.

Our local AA does not foster family to family contact. Instead we all 'reinvent the wheel' and fight each other for limited resources.

Overall were happy with services provided. Budget increase would help.

Satisfied

Services received are vital to support family member and family all together. Services provide family member with a very active life in community, including serving others

Very happy with services and the results

Very satisfied

Very satisfied.

We are so thankful for the services Gateways has provided to our family. the case manager celebrates our daughter's accomplishments and doesn't make her feel badly when goals haven't been reached.

We have always been satisfied with the services we've received.

2018 Adult Family NCI Survey Results
Region 6 Summary and Statewide Comparison

Comments - General Comments:

As we are involved w/many activity groups around the state, we are very aware of the different attitudes and services among service providers. It is so sad when we see so many folk have compromised health because they are not able to take care of their teeth. Your teeth are a window to your health. It is necessary to care for dental needs. We are fortunate as we currently have dental insurance. There was a time we didn't. My daughter was in great pain. The insurance did not want to cover any anasthetic at that time. We had to delay for 3 years until we had appropriate coverage. No way would she sit in a chair & year your cut, crunch, an drip out her teeth. So sad & wrong. We resolved our problem, others can't

I am presently extremely fortunate to have an incredible case manager, knowledgeable and compassionate. Our greatest challenge is locating direct support professionals with experience with both DD and mental health challenges. We need two vendor agencies the first simply did not have the staffing and the second was poorly managed & was a 'child care' service, oblivious to meeting the client's goals. Many parents of 20 somethings w/DD struggle with social activities & social groups for their family member. the most valuable resource for families is the NH Family Support conference, which has proven to be an invaluable networking opportunity, in addition to bringing many support services under one roof.

Not sure if question should be directed to you (?) Would like to know if family member is eligible for any cash assistance, food stamps, heat assistance, dental coverage. The only financial assistance family member is able to assist with is SS income which only equals about 1/4 of what should be. Respondent pays 3/4 in addition to personal needs, dental, auto ins (for vehicles family member is passenger in) AAA, clothing food entertainment. Thank you!

One of the greatest challenges is a person is 'on the DD side or the Behavioral Health side' It is impossible to get personal individualized appropriate services. For MANY folks, they need both kinds of support. So much of what we are doing is out of pocket, even tho my adult child has individualized self directed plan. There are financial limits to employing people who might be able to interact in a meaningful therapeutic way in the community. Much of my child'd monies go back to the agency for others Not for Lack Of Need but for lack of being able to hire appropriate service providers. Our CM is fantastic but it is the regulations and constraints that get in the way. It is time we truly acknowledge that people are people not their primary label. Many times due to the 'DD Label' the supports that would be most needed & avert crises are blocked. I believe that a log of workers could/would do more if they were respected & that was reflected in the compensation afforded them. Our agencies: DD, BH, VR are silo'ed. Until they all can work together instead of competing (who does what service/gets paid) many of our citizens with disabilities will not get the support they need or deserve.

Sometimes activities get canceled because there is not enough staff. Agencies need to hire more staff!

Survey asked about a reduction in budget, but did not address an increase in budget. An increase would allow more services for my son which would benefit both him and his family.

The individual budget through our PDMS program is frustration & difficult to read & understand due to template changes. We require support each month to monitor our budget and have been told we are not the only ones.

The only issue is due to my company relocating I am moving to Florida. I tried to understand what services Joe would be if I took him with me. I did not get a lot of cooperation. I was given web links and phone number and spent several days trying to find someone to help me and was unable. Due to this I had to make arrangements with other family members to look after Joe at my property in NH while I am in Florida. My preference is to bring Joe with me to Florida and sell my house in NH but until I can sort this out I am reluctant to make the change.

There needs to be a transitional program for older adults in the system who have been cared for by their families. These people did not have a transitional program when they completed high school. families need more help and knowledge about what will happen in the coming years.

2018 Adult Family NCI Survey Results
Region 6 Summary and Statewide Comparison

Comments - General Comments (continued):

Transportation has been and continues to be our major issue

Vendor model does not work. Too many layers of admin using up \$\$\$\$\$. Self directed models work only when families have people to hire and train. Our family went 5 months without a provider for our son. While our agency tried to assist - no one came forward to hire. My husband and I both came close to losing our jobs when we found a provider through a former employee. We felt 'indifference' from our case manager 'as many families are experiencing this' still - our AA is managing to expand and hire admin staff.

Without the services we have acquired my son's life would be less than a normal life. Because of the services he is a happy and productive person.

You need a lot of improvement.

G is not a question anyone should have to answer. Not all questions were appropriate or answerable. Wording was the issue

I couldn't have done this in 15 min even if I were a speed reader!!

Long redundant questions, won't make any difference, missing ideas suggestion that could actually be done

Many adults get plenty of services, but lack social interaction with other peers.

Some questions need space for additional information to answer accurately

Support workers for my family member = DSPs who work at the vendor day program only during program hours with staff scheduled by management/program coordinators & never in the house

Thanks

The only concern I have is that the name on the address label was the respondents, in care of, the family member. I believe it should have been the family member, in care of the respondent (??)

Unclear if support workers/staff refers to workers at day program or to workers hired thru Area Agency (Gateways). Do not have workers/care providers thru Gateways Area Agency, only thru day program.

Was very difficult to answer questions regarding DSP's as we have had 8+ over the past year. Some were incredible, some undependable.

We truly appreciate all of the services and help we receive. It has all been a huge blessing to our family. Keep up the great work! :)

Wish Gateways could be more transparent, open to families & encourage partnerships with industry, educational institutes, and community leaders. BAE (lots of \$\$); Rivier University; SNHU; NCCC (for internships & job growth); Community Center for day programs; Better communication with families; Encourage families to share best practices; More transparency w/wait list

Yes say its about family member w/disability but ask of income of whole family or person w/disability, not clear.