

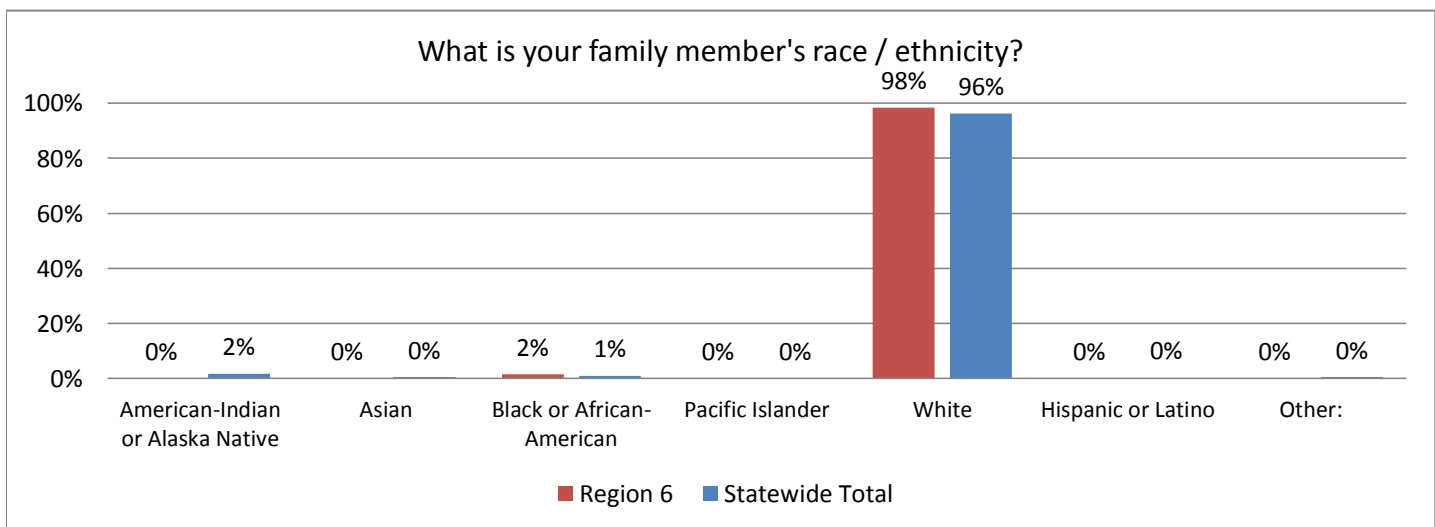
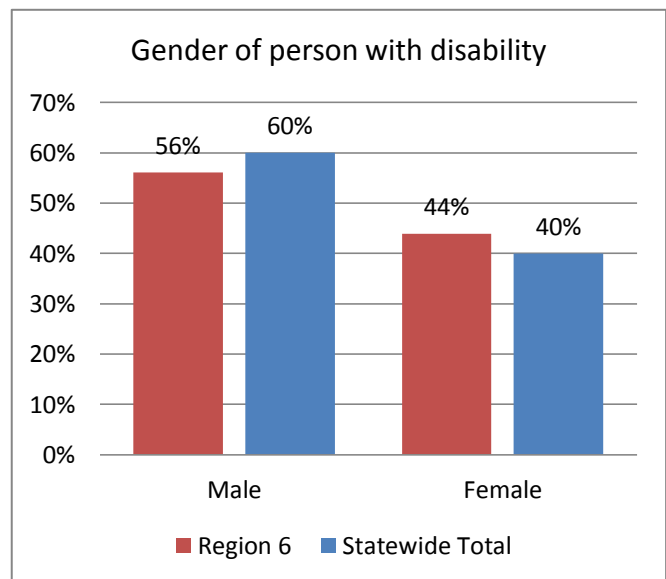
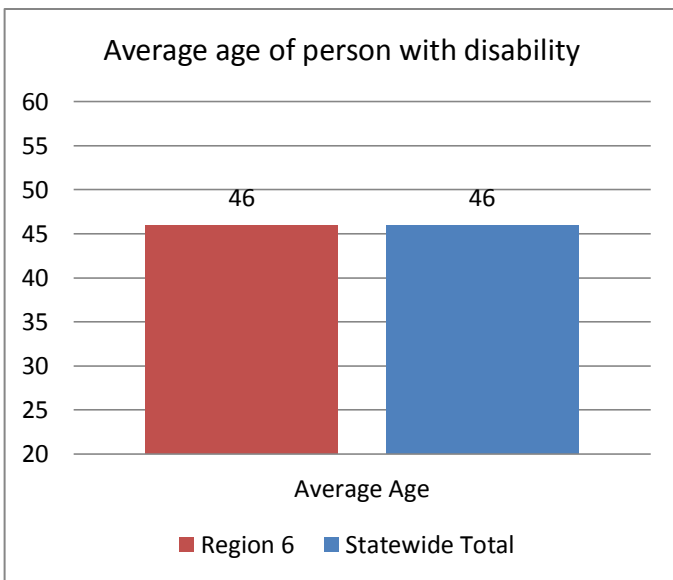
2018 Family Guardian NCI Survey Results
 Region 6 Summary and Statewide Comparison

2018 Family Guardian NCI Survey Results

	Region 6	Statewide
Total Surveys Sent	392	1810
Total Returned	113	535
Return Rate	29%	30%
Number of returned surveys sent to wrong respondent type	47	78
Net Valid Adult Family Responses	66	457
Average Time to Complete (minutes)	27	25

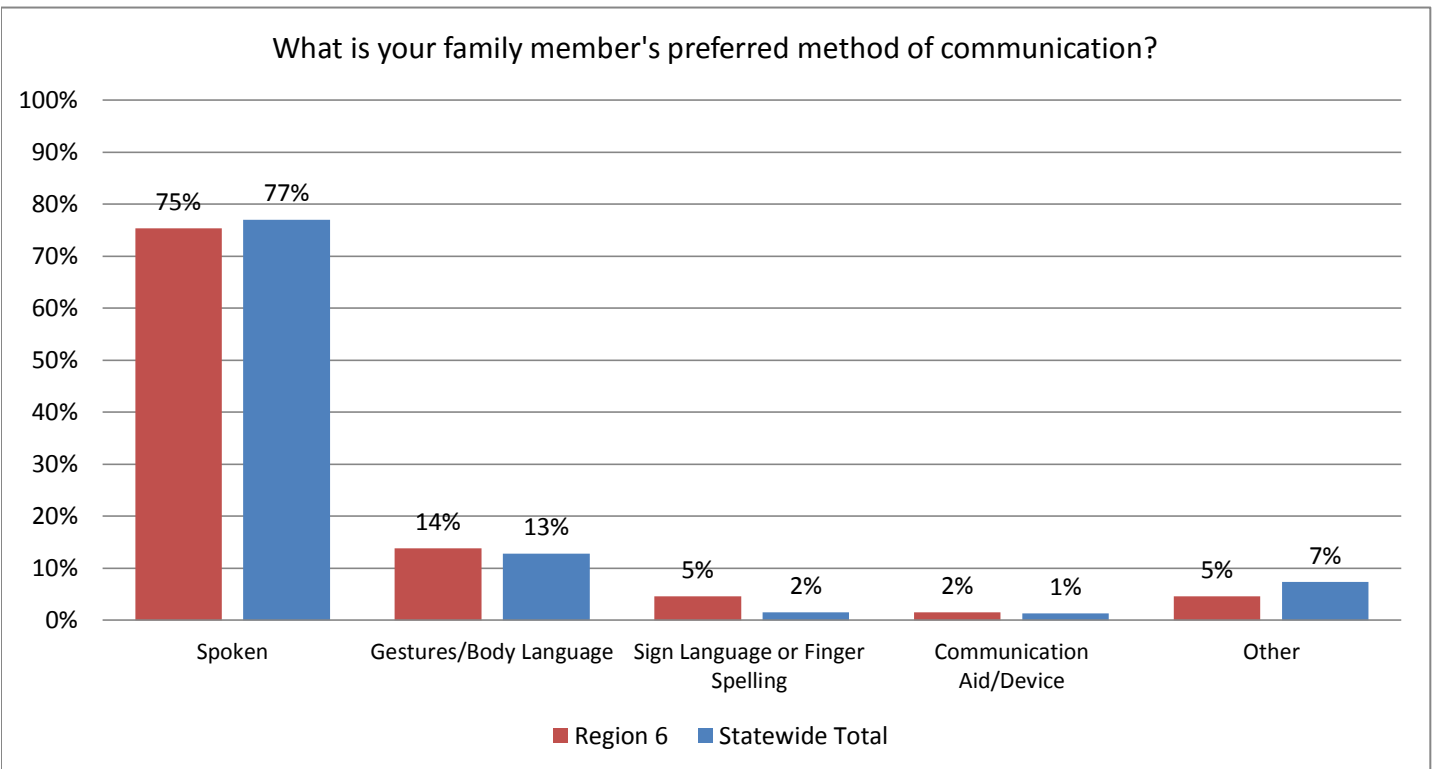
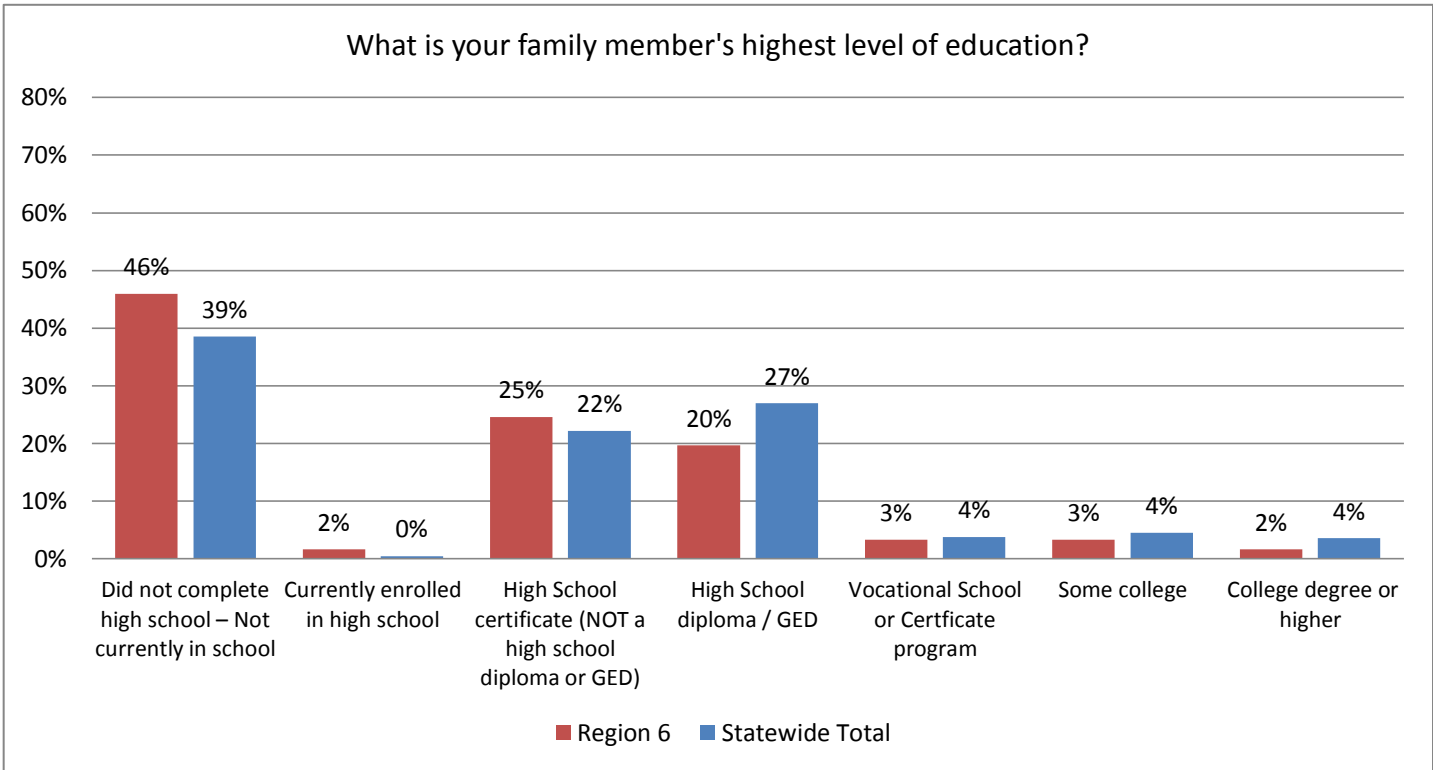
(Family Guardian went to someone who should have gotten Adult Family)

Family Member Demographics:



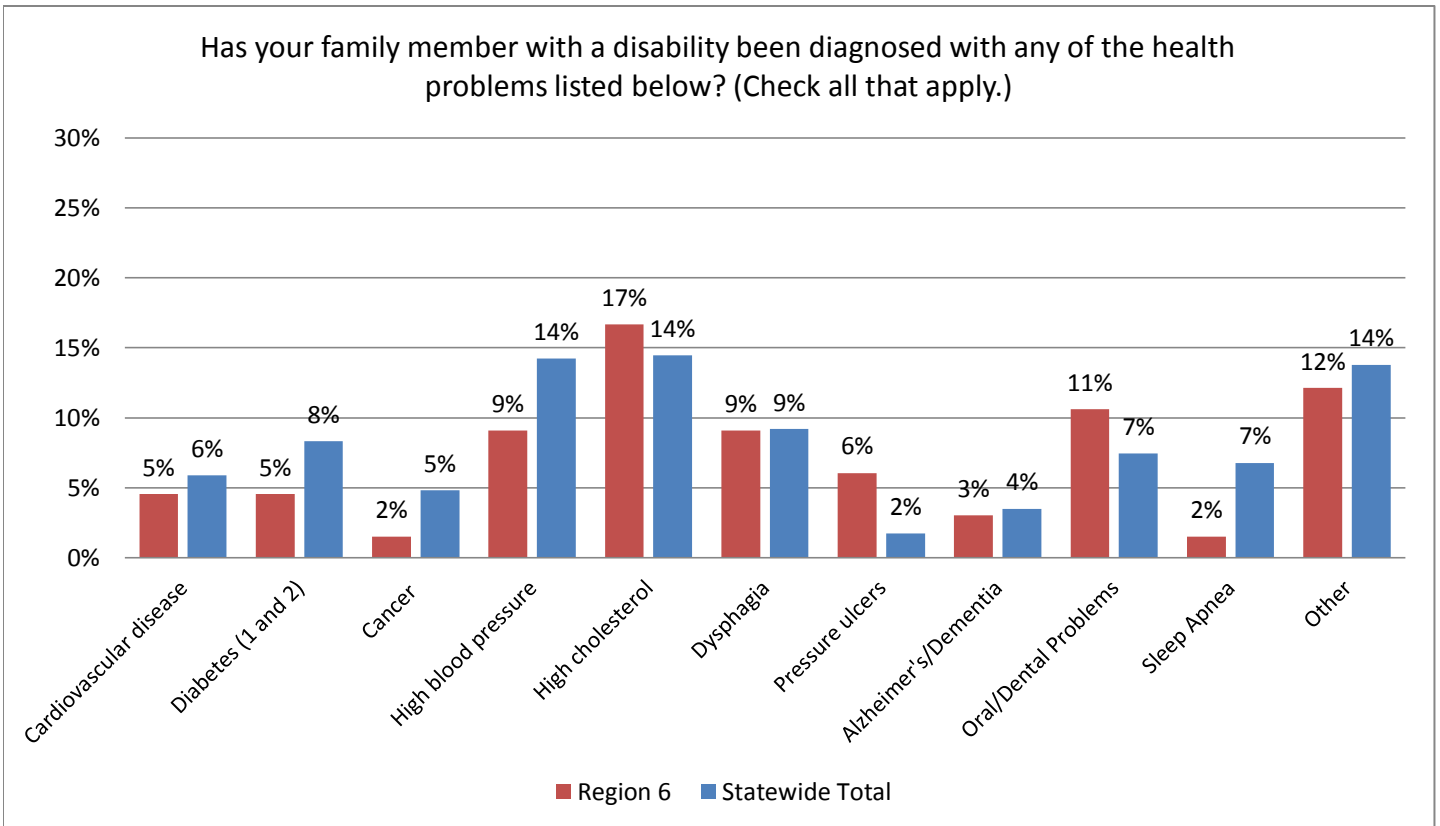
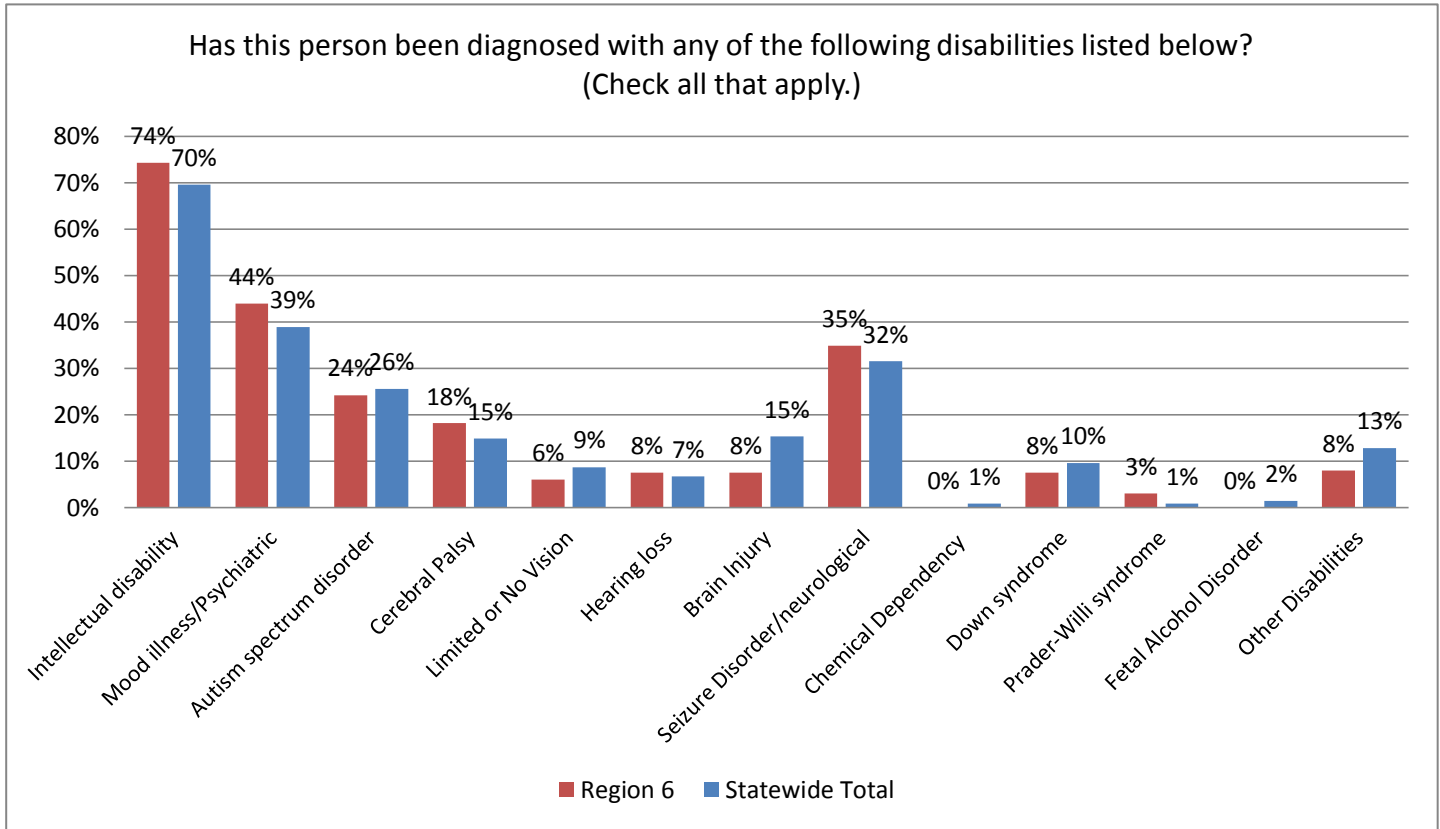
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Family Member Demographics:



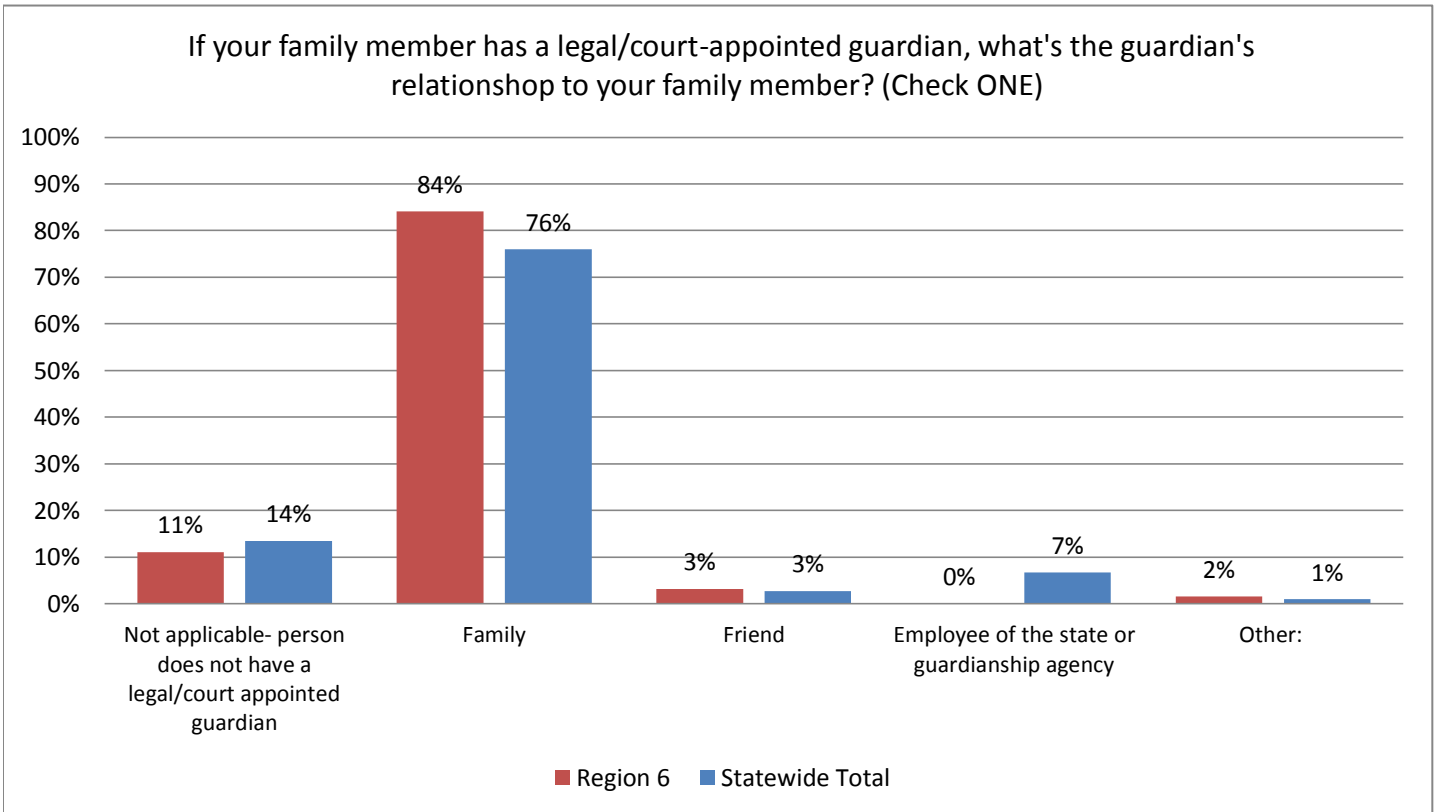
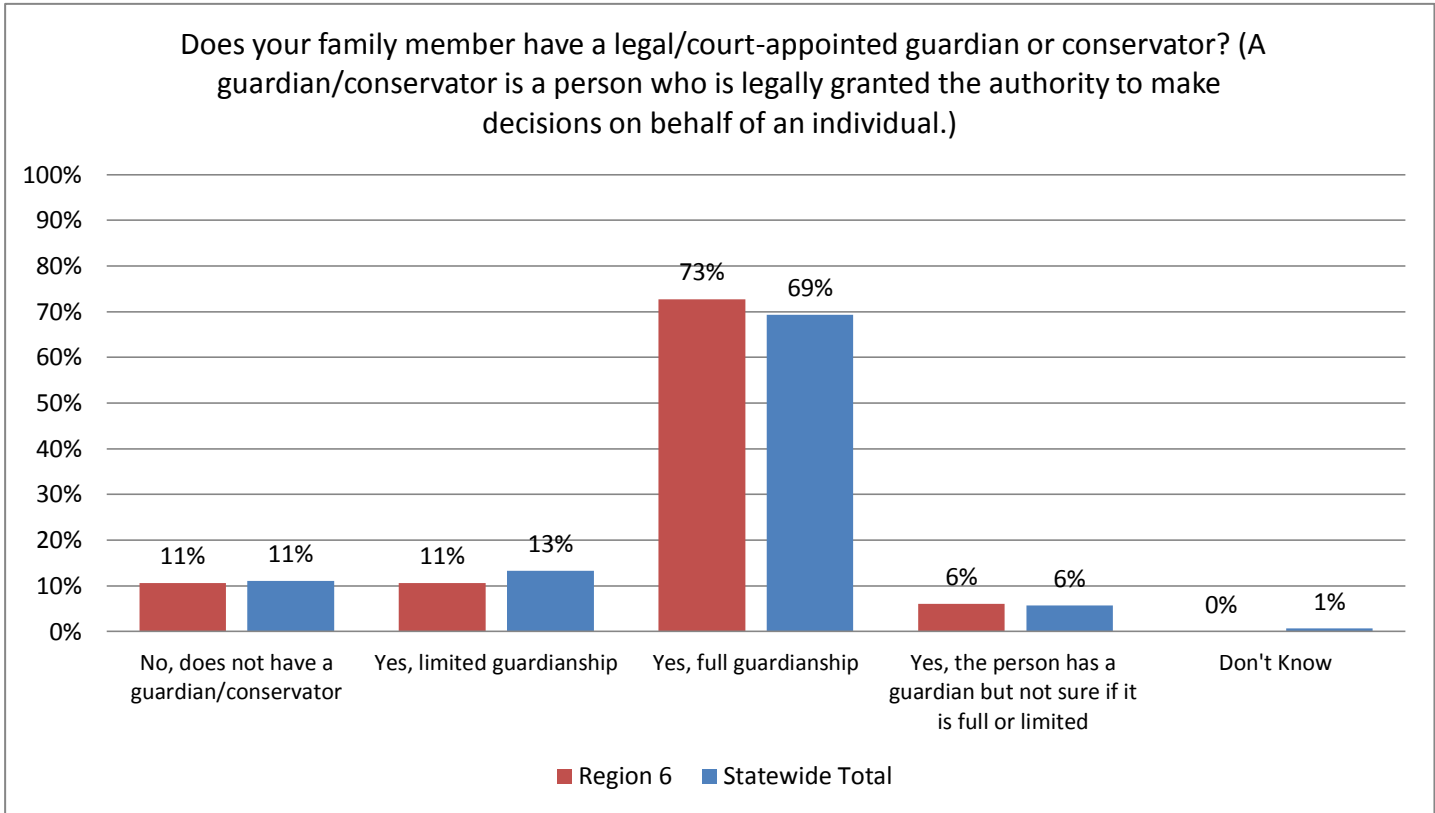
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Family Member Demographics - Diagnosis:

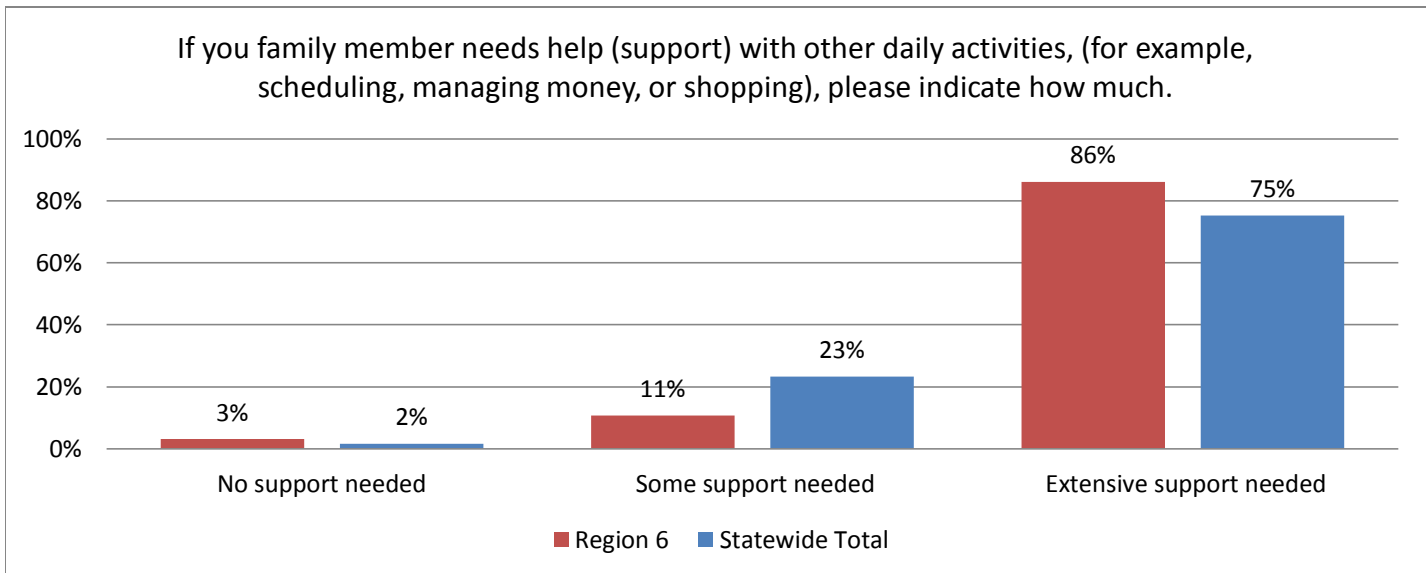
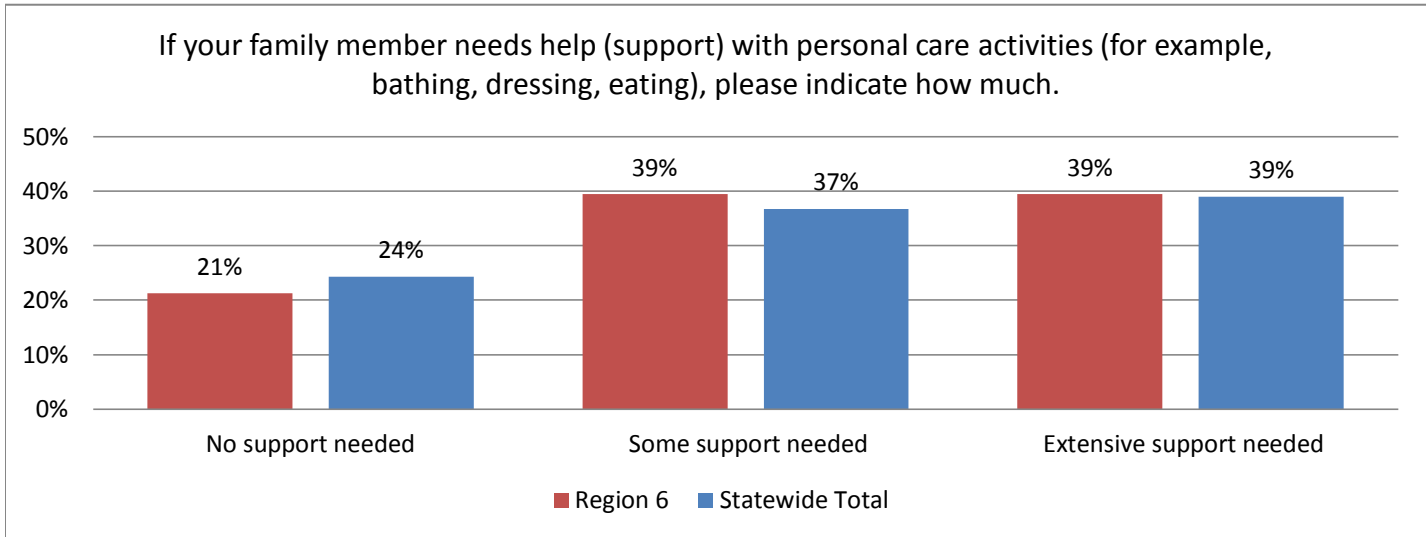
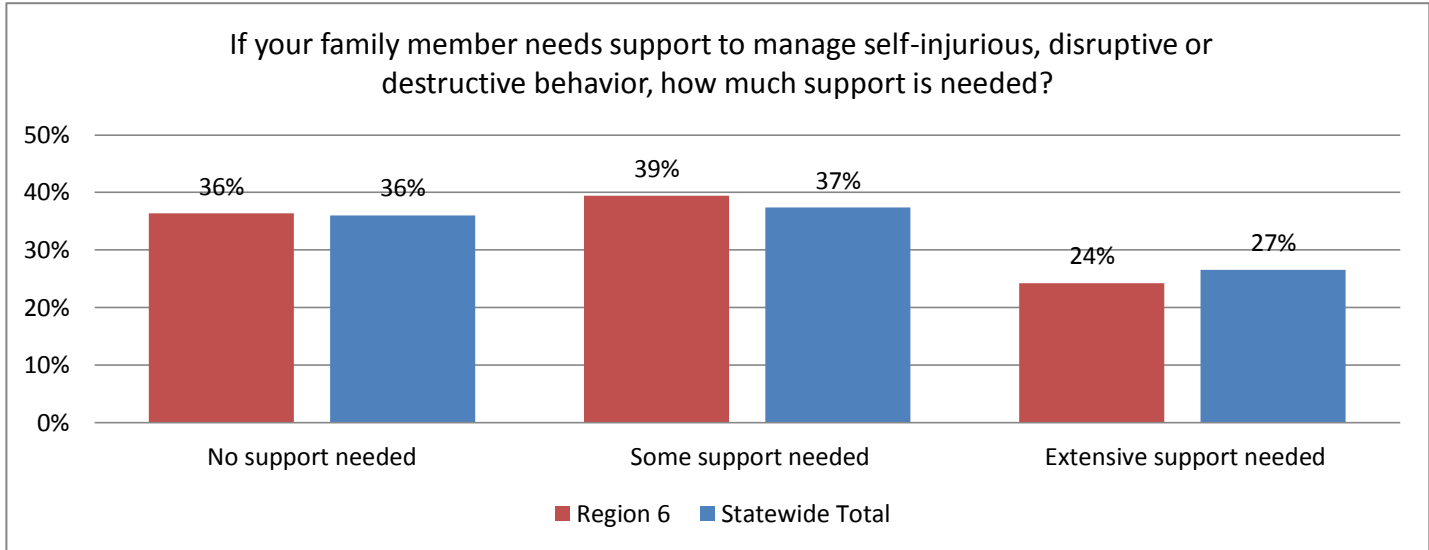


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Family Member Demographics - Guardianship:

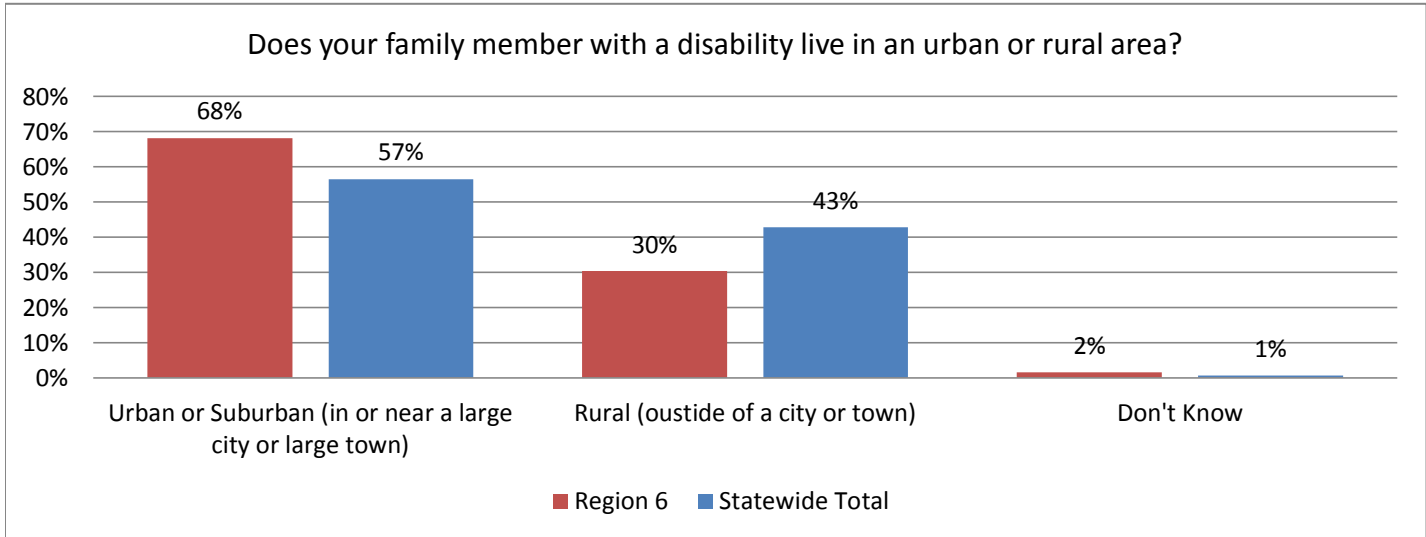
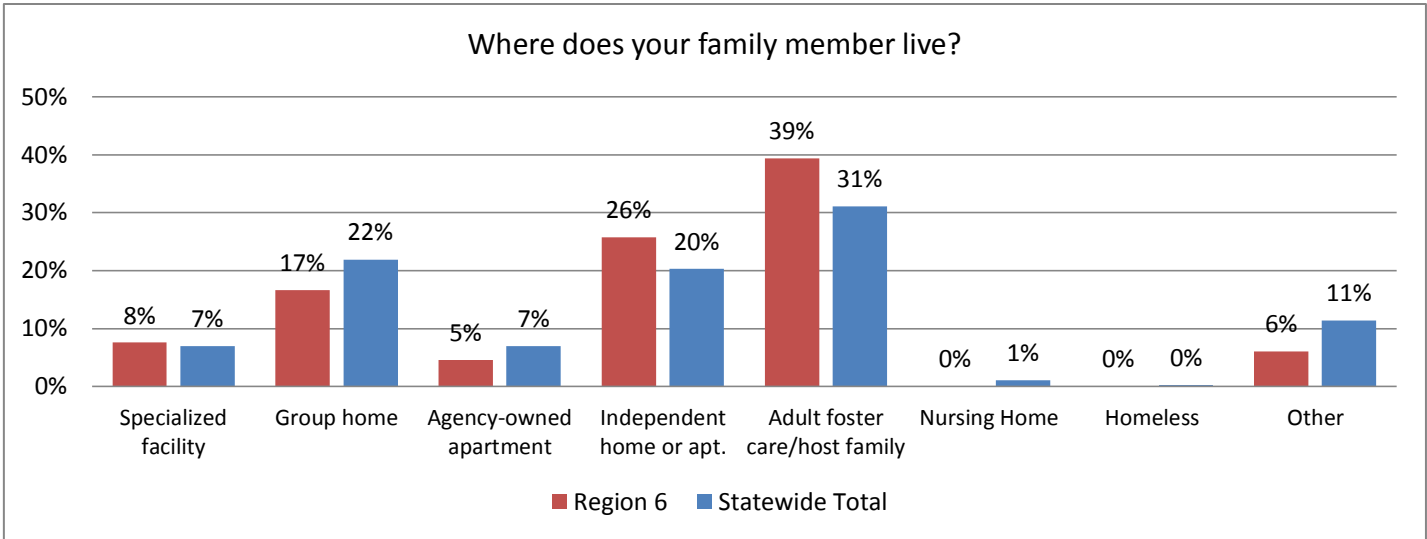


Family Member Demographics - Supports Needed



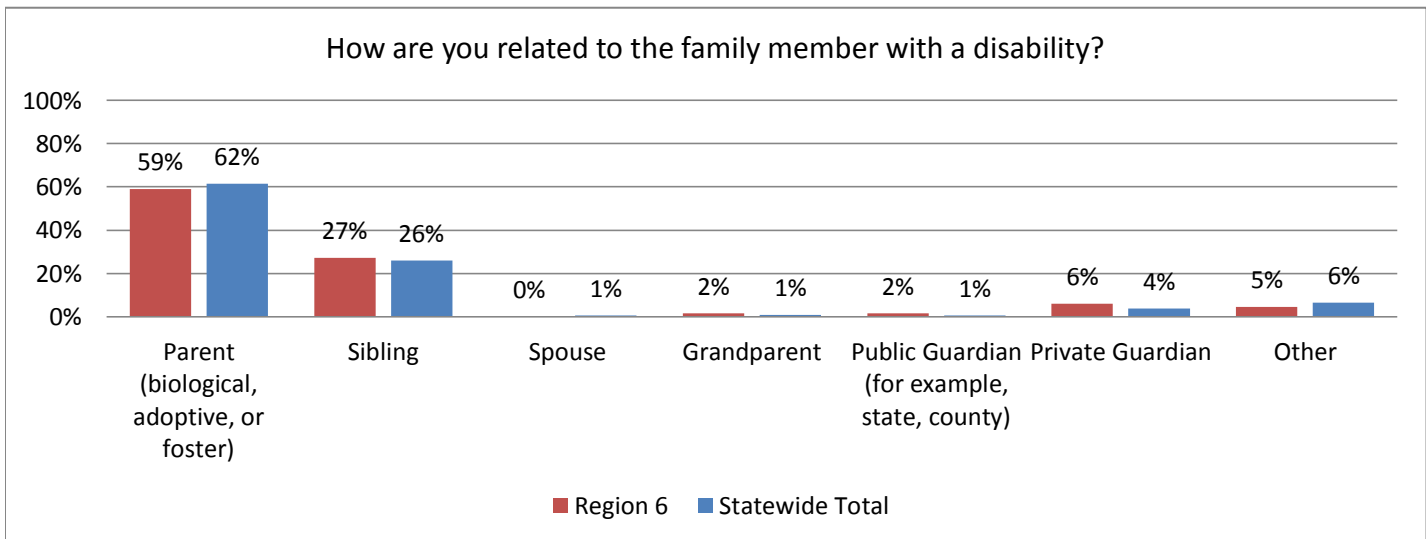
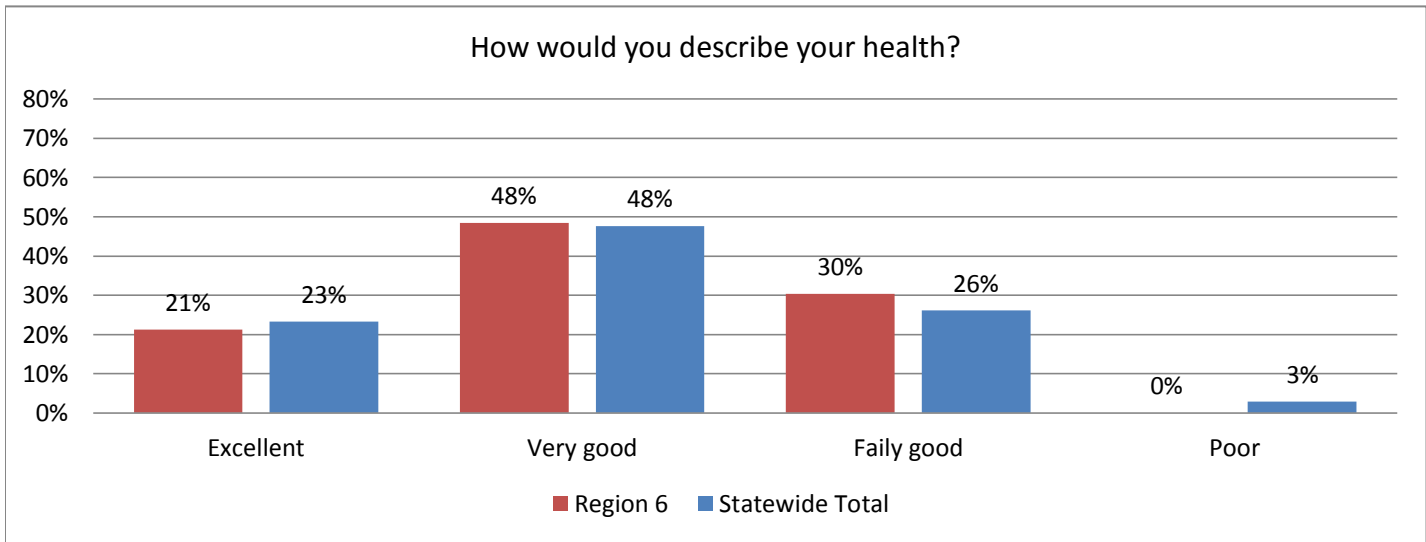
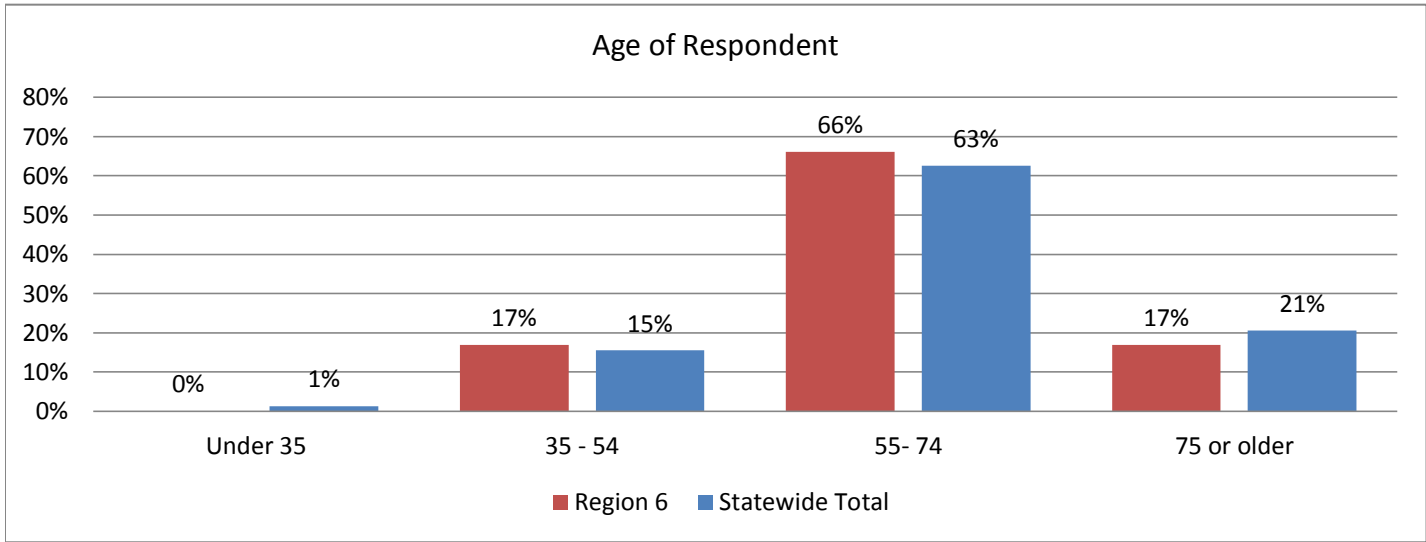
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Family Member Demographics - Living Arrangement and Daily Activities



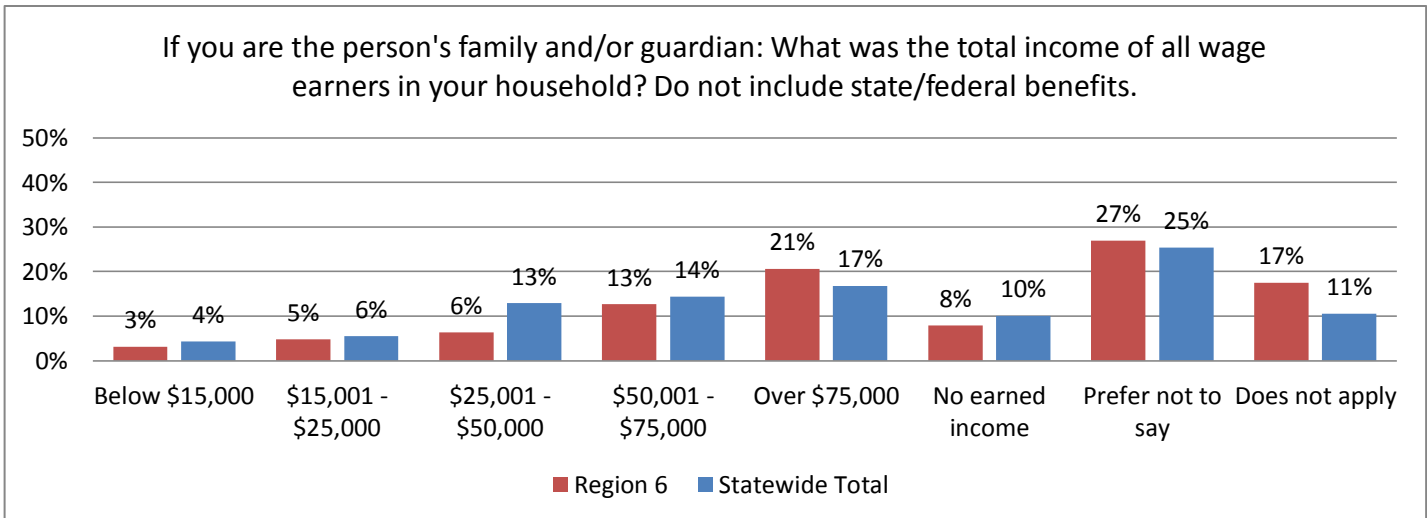
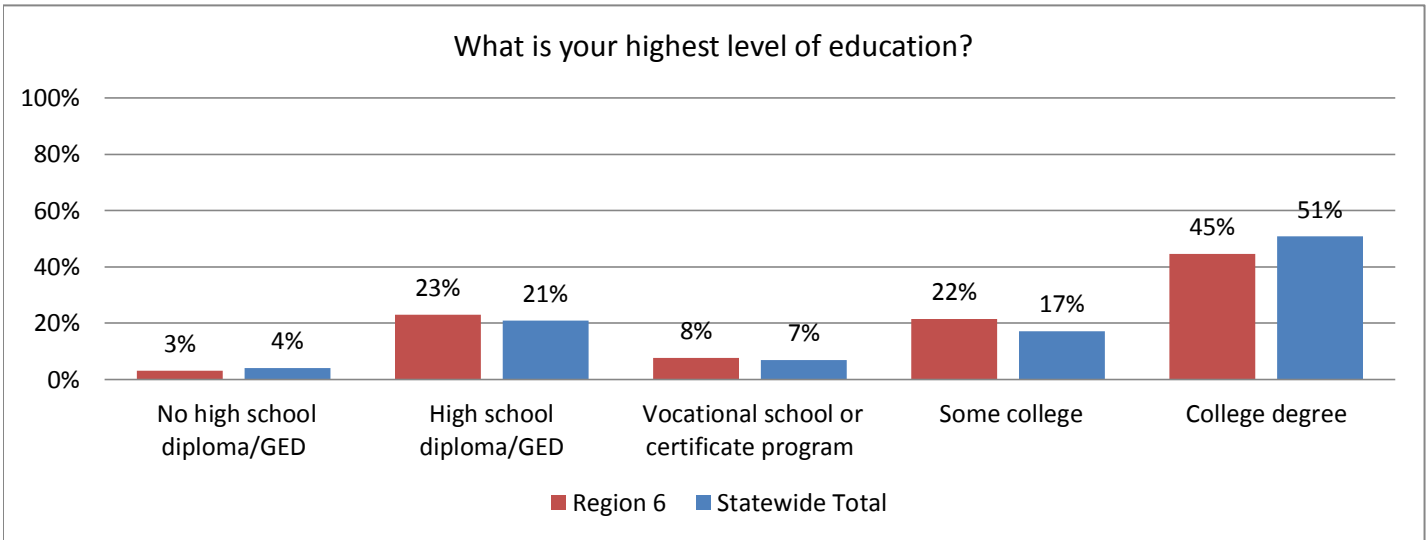
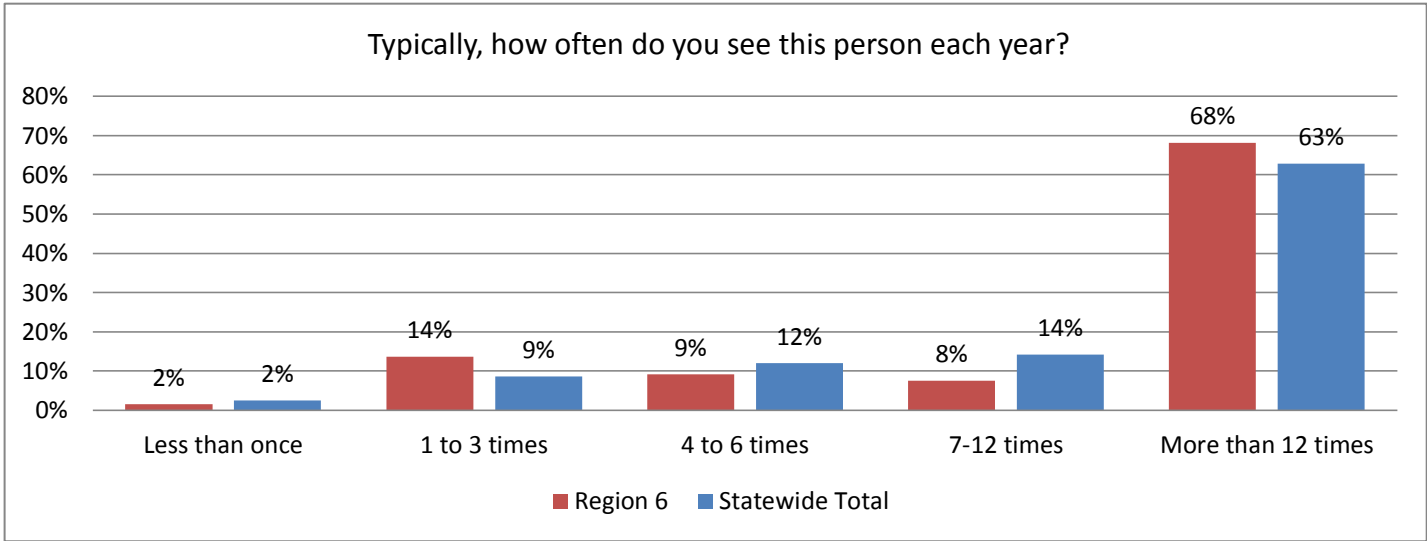
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Respondent Demographics



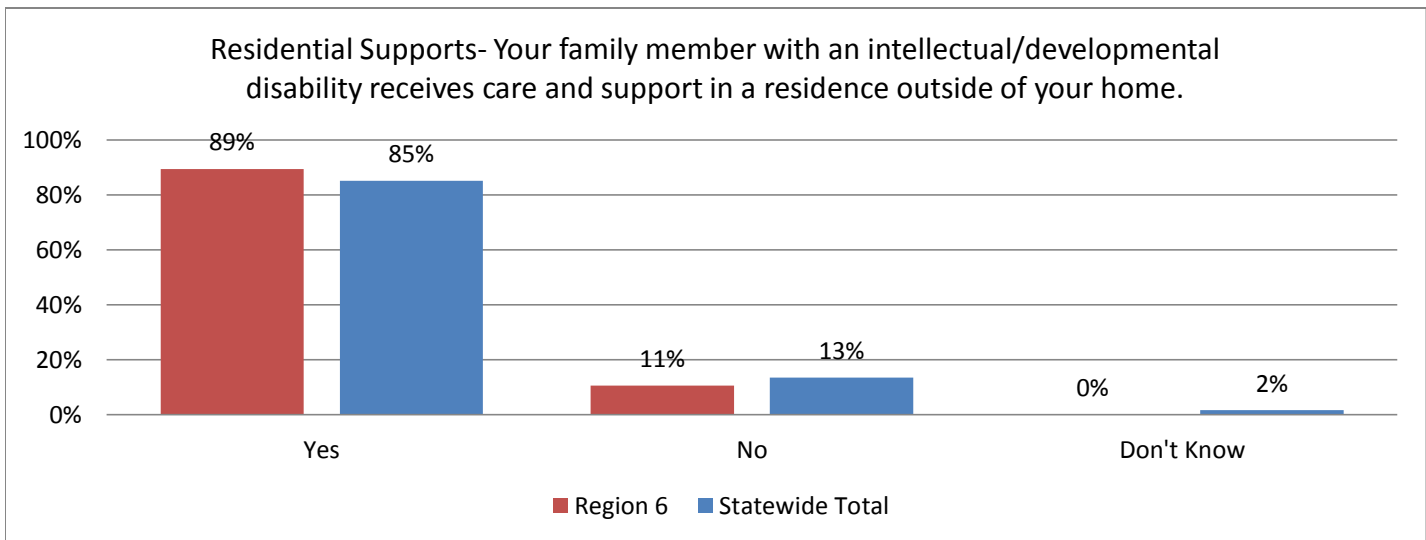
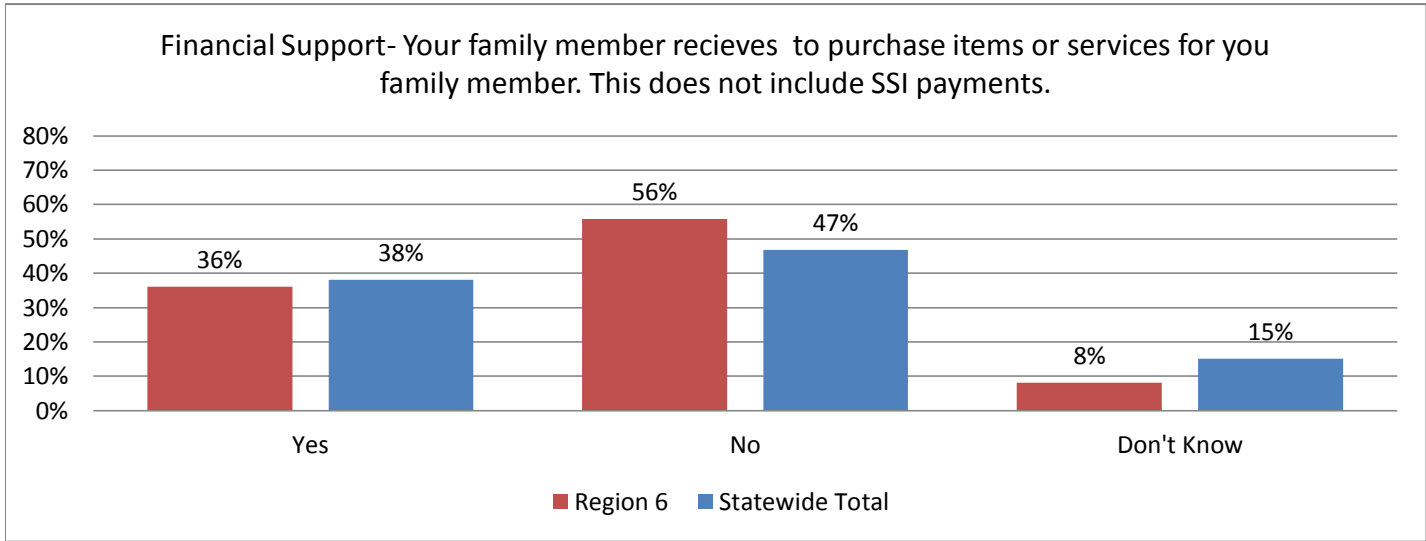
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Respondent Demographics



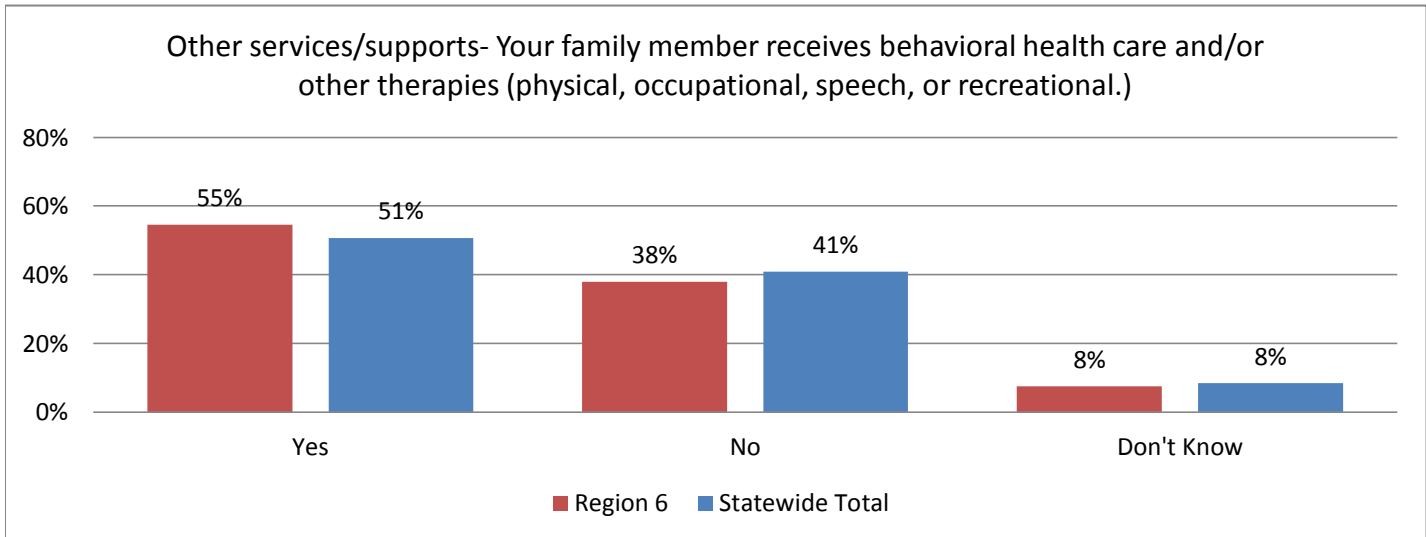
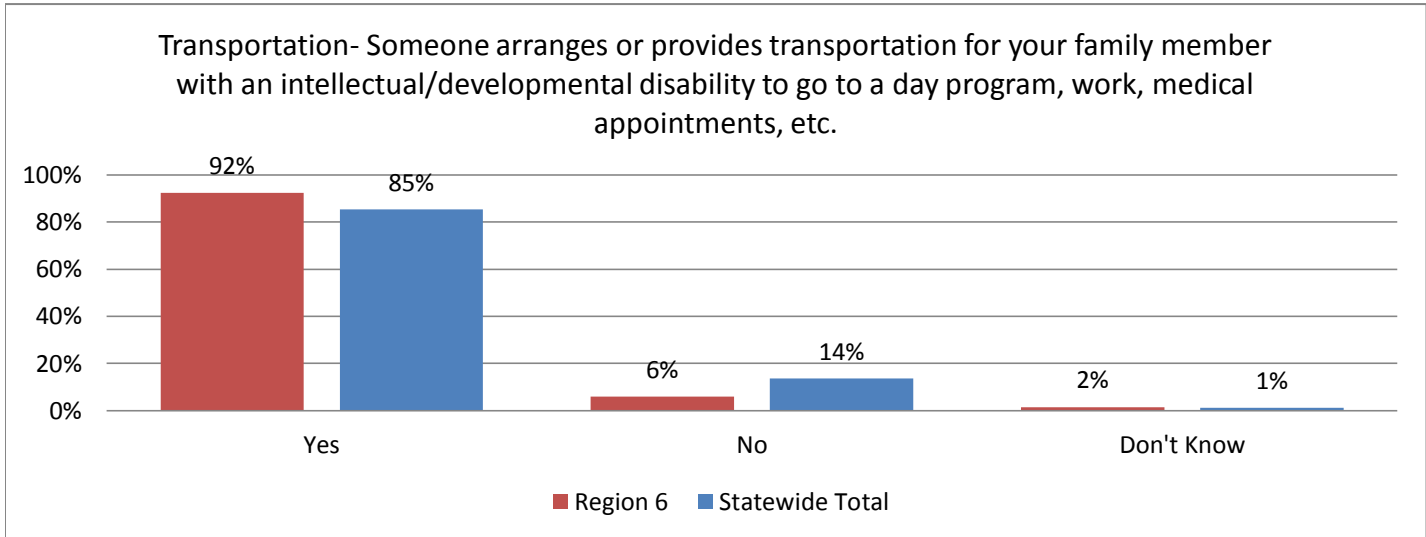
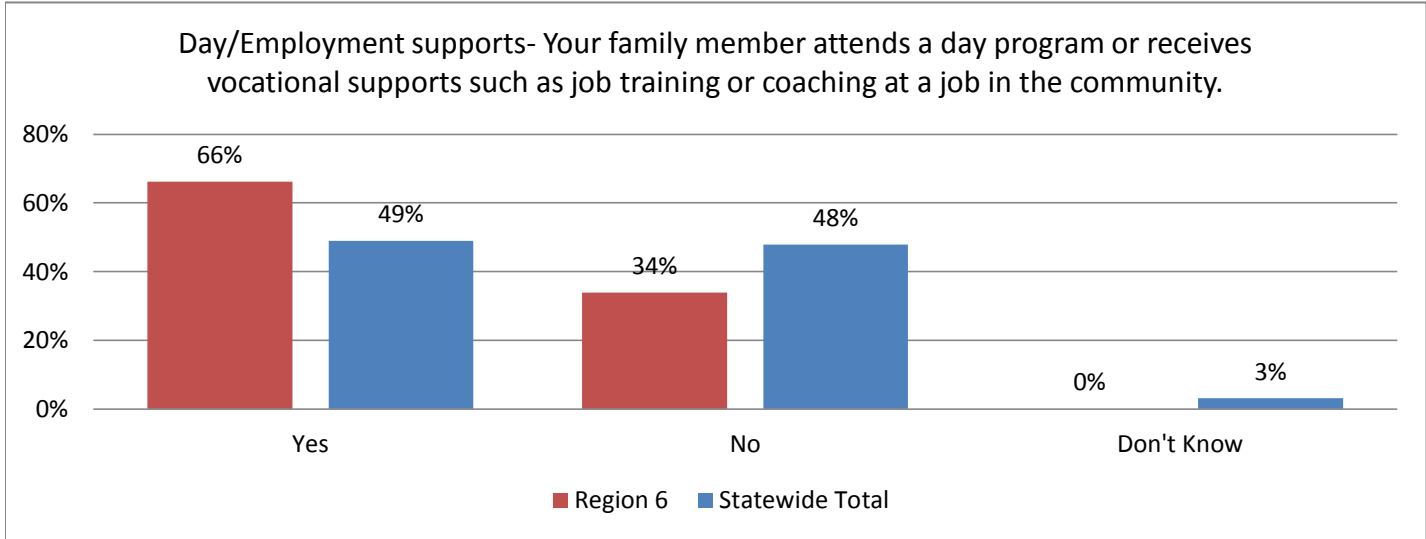
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Current Supports:



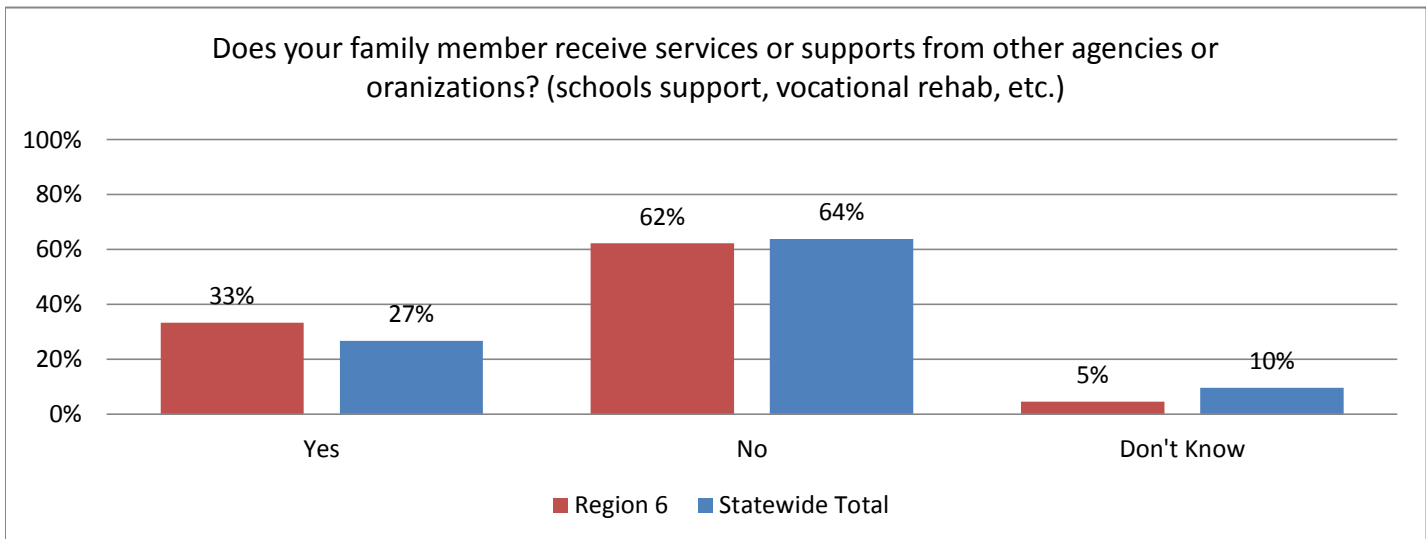
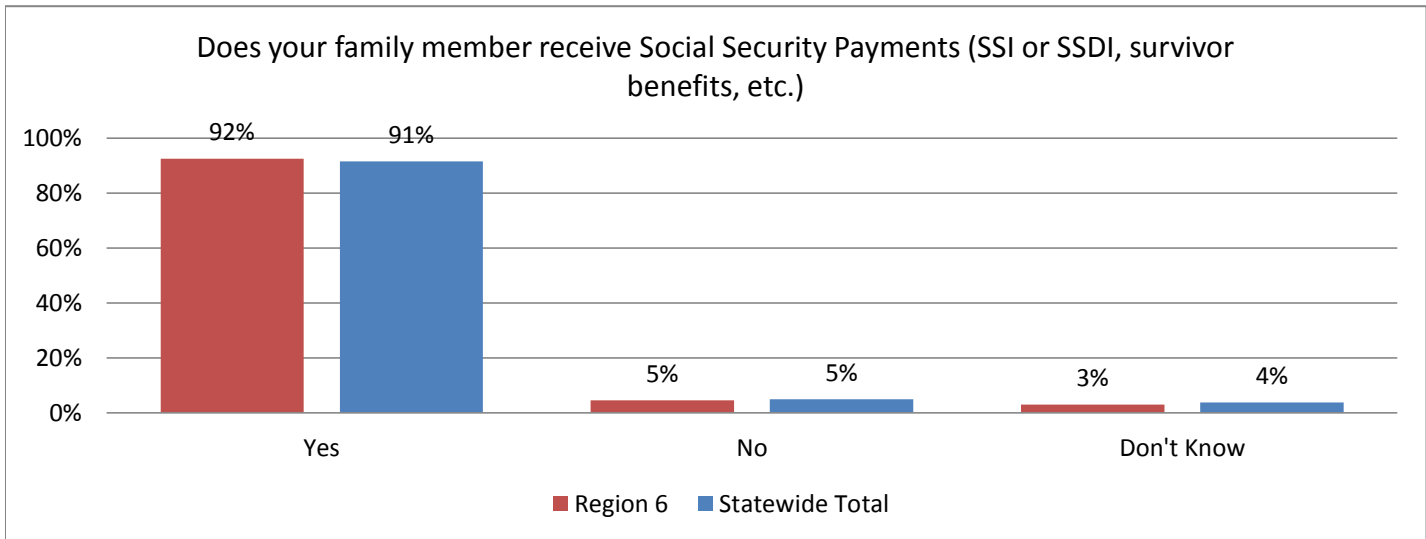
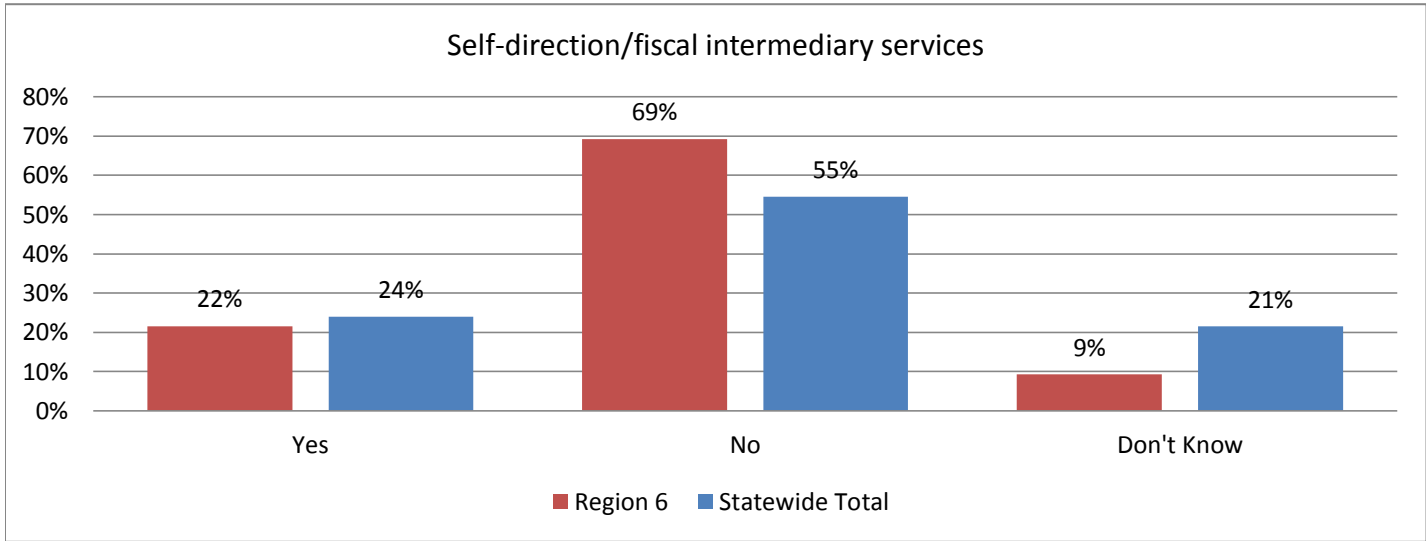
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Current Supports:



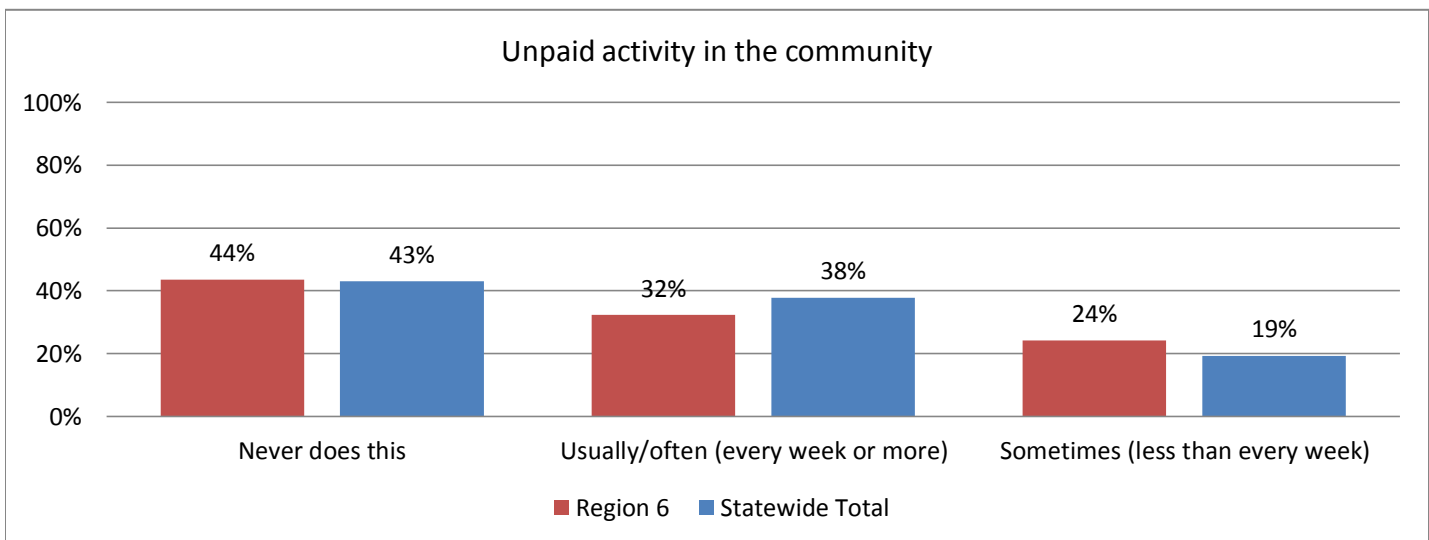
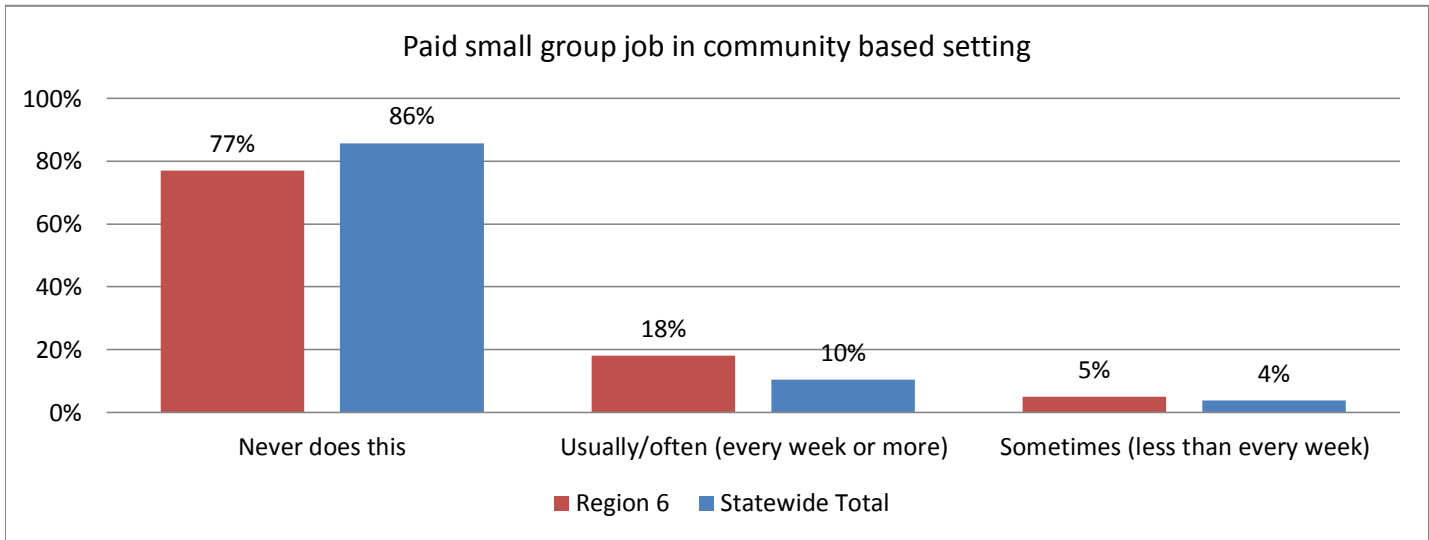
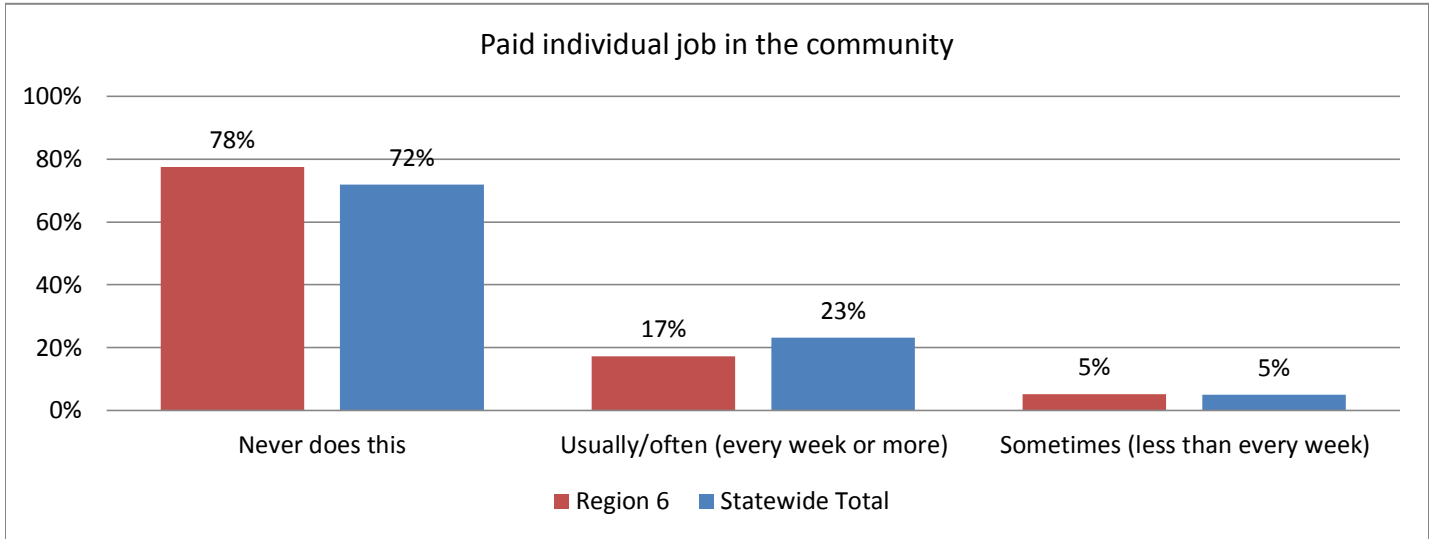
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Current Supports:



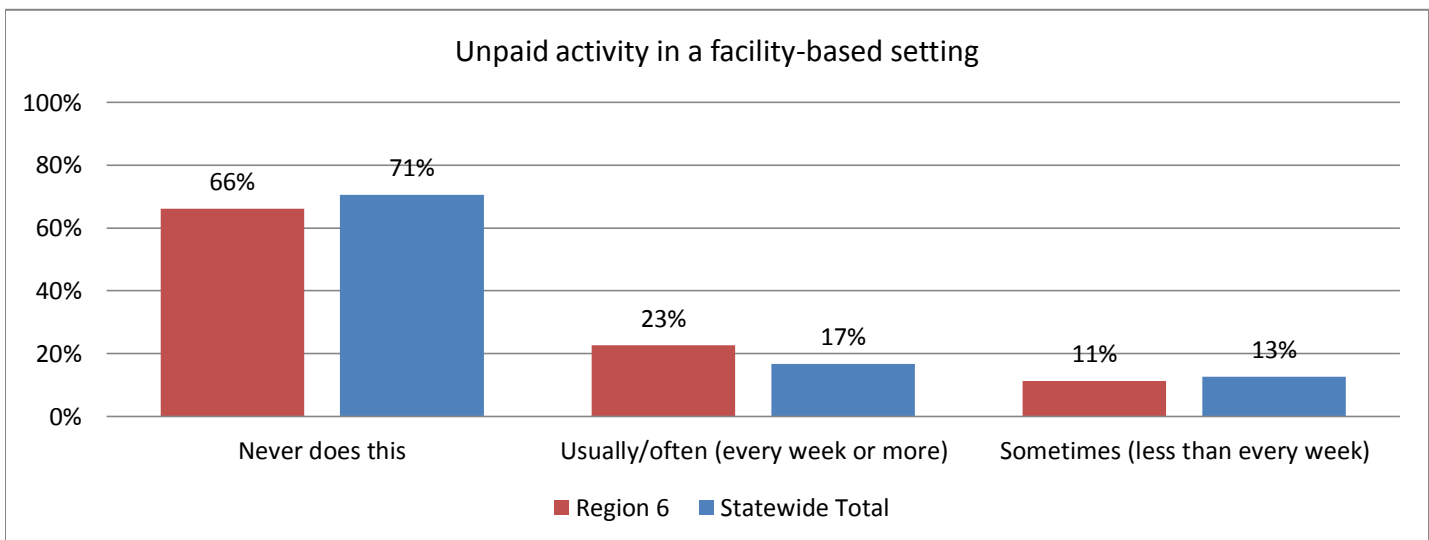
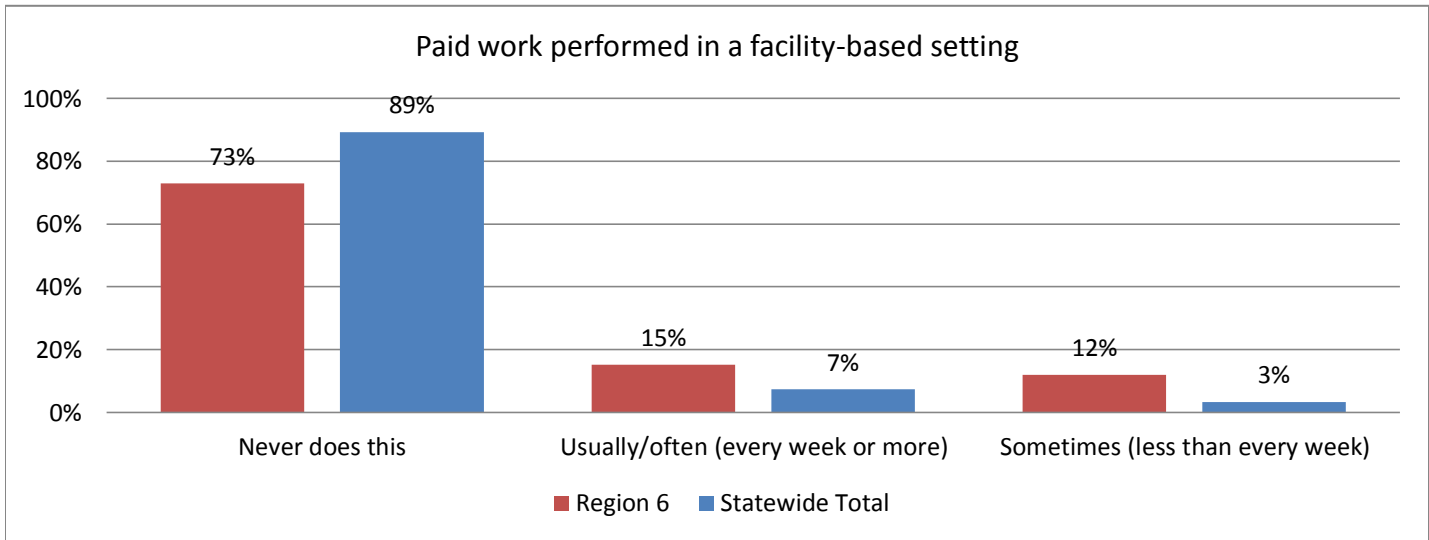
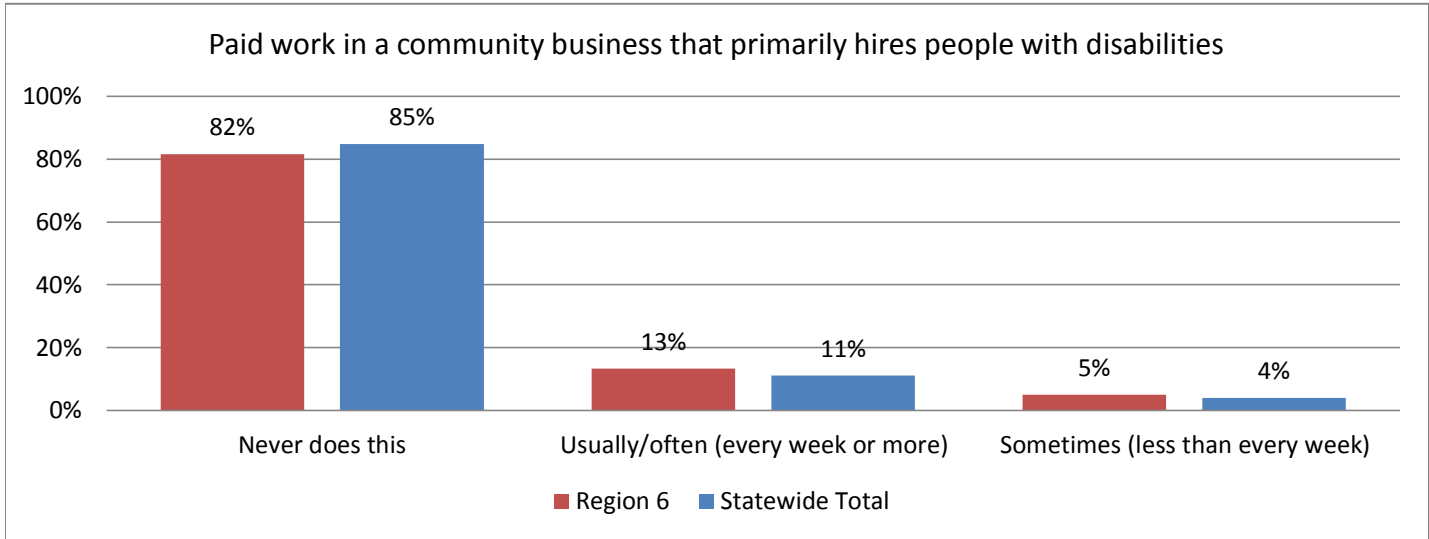
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Daily Activities:



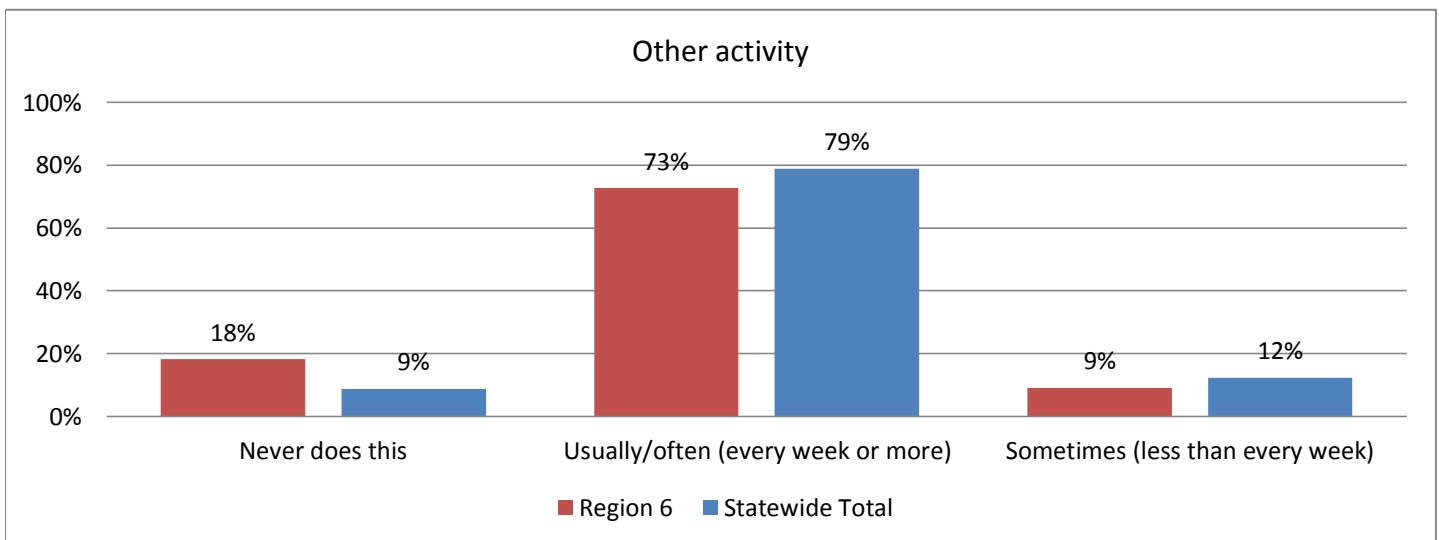
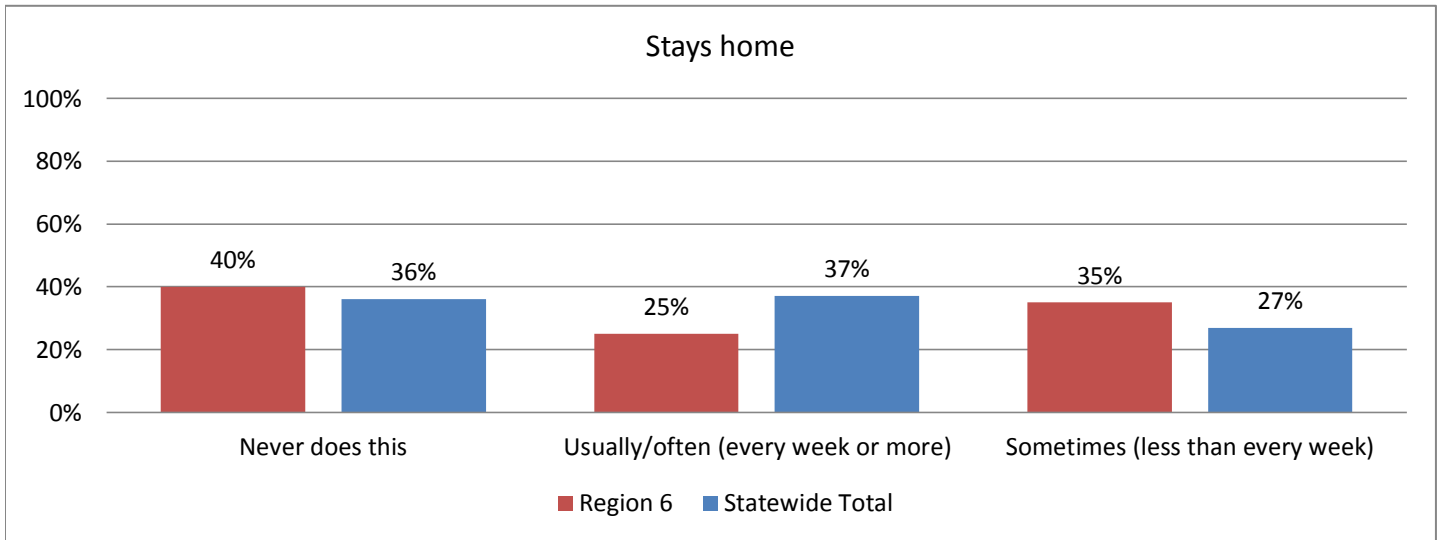
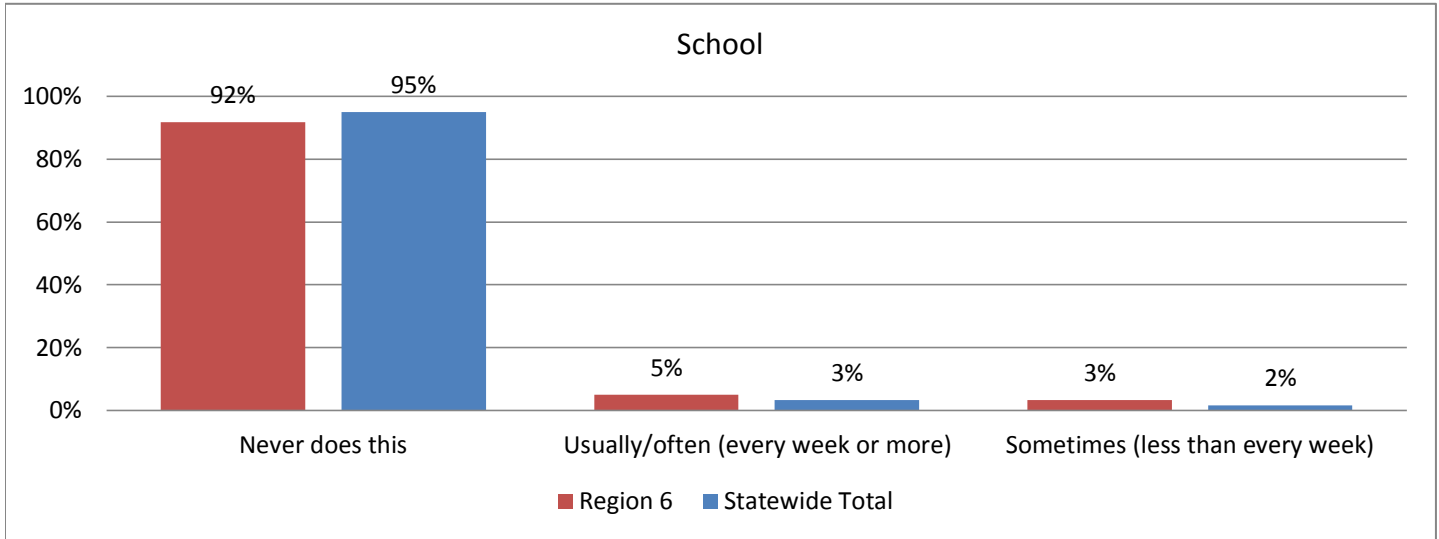
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Daily Activities:



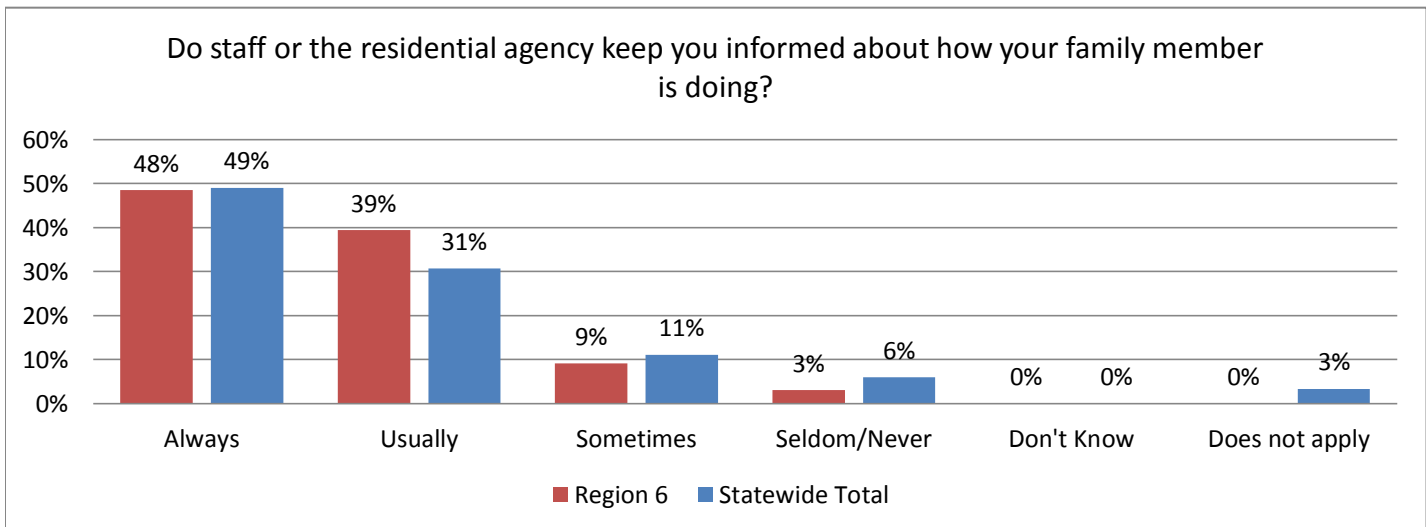
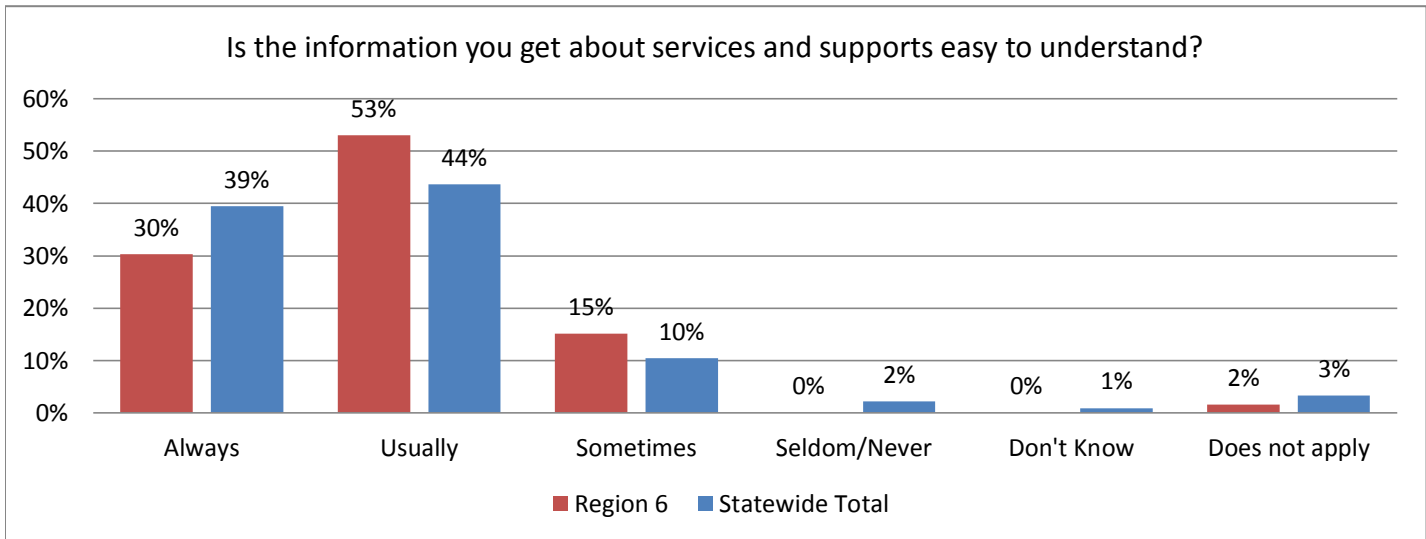
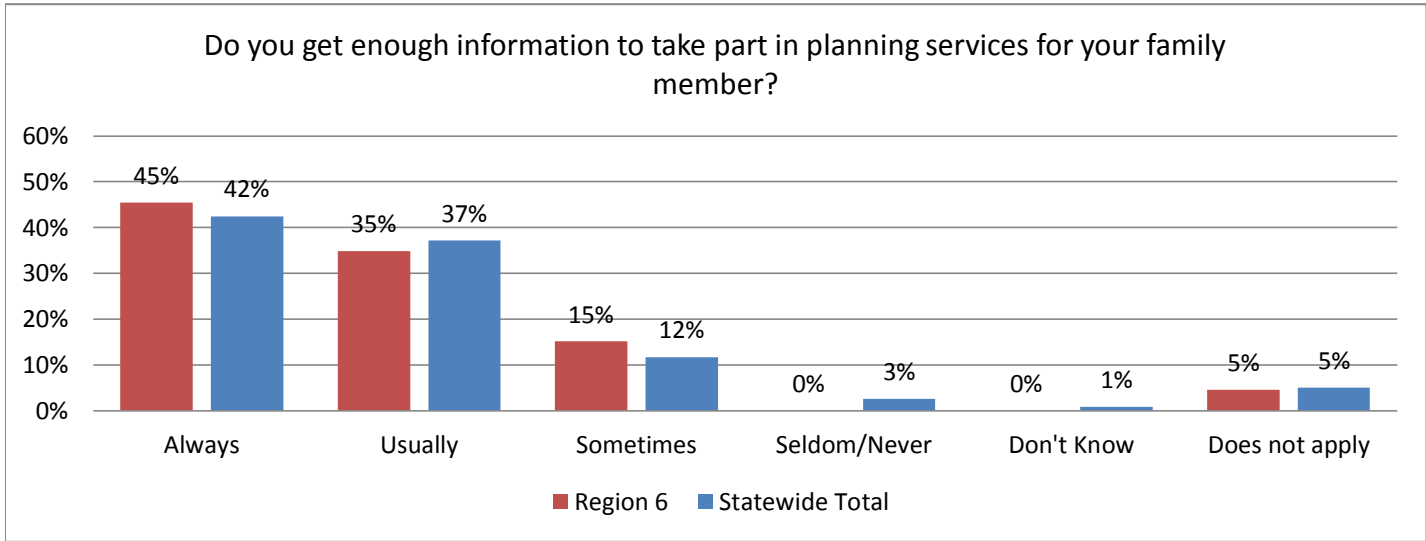
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Daily Activities:



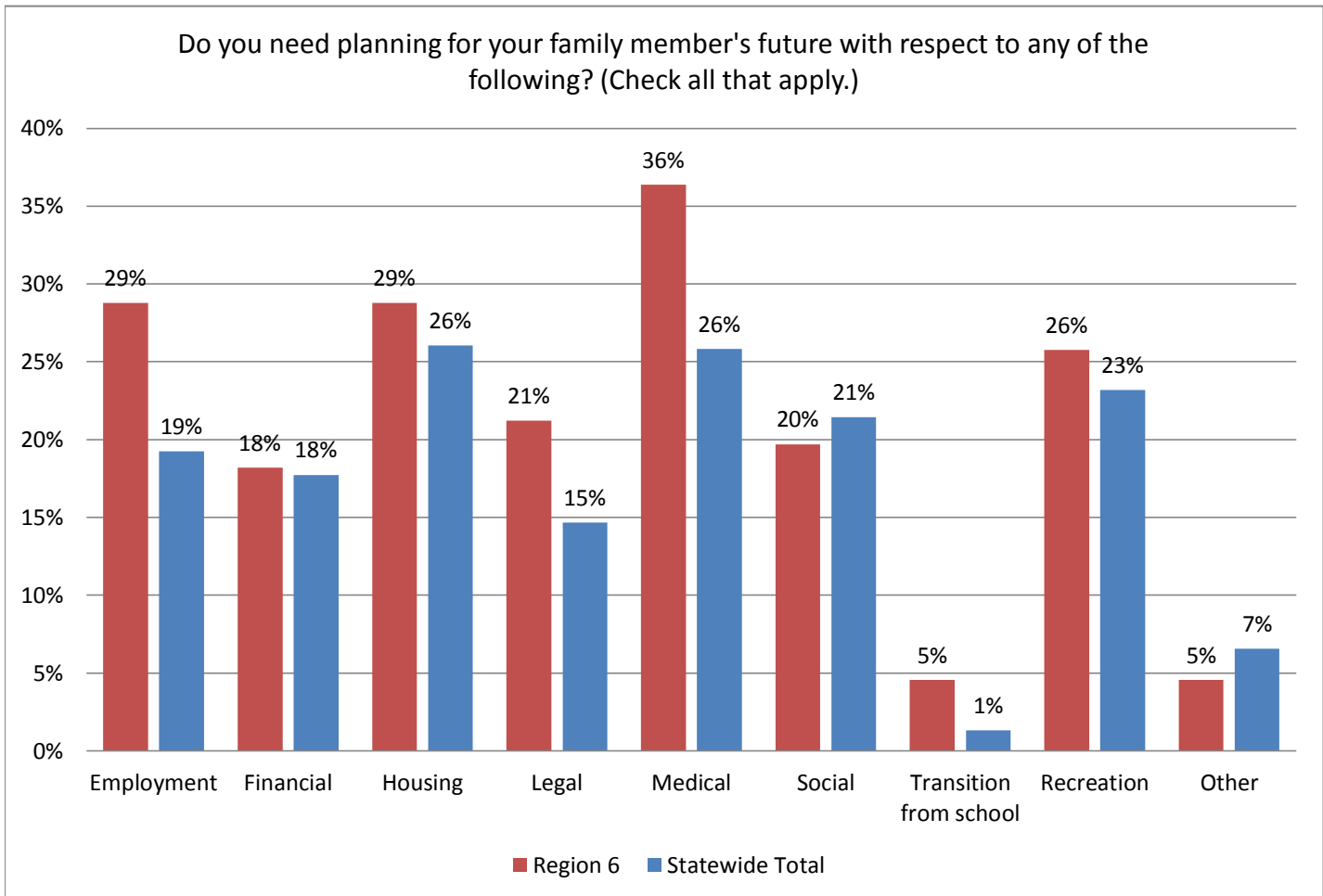
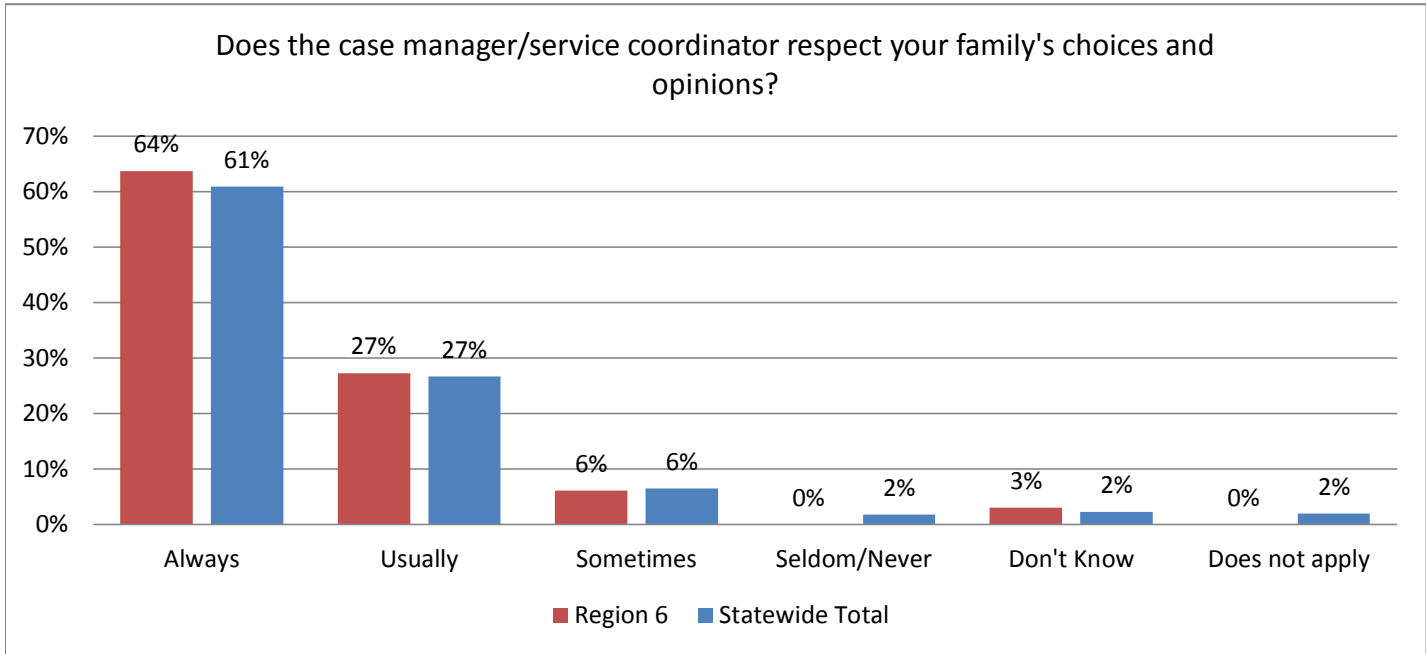
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Satisfaction:



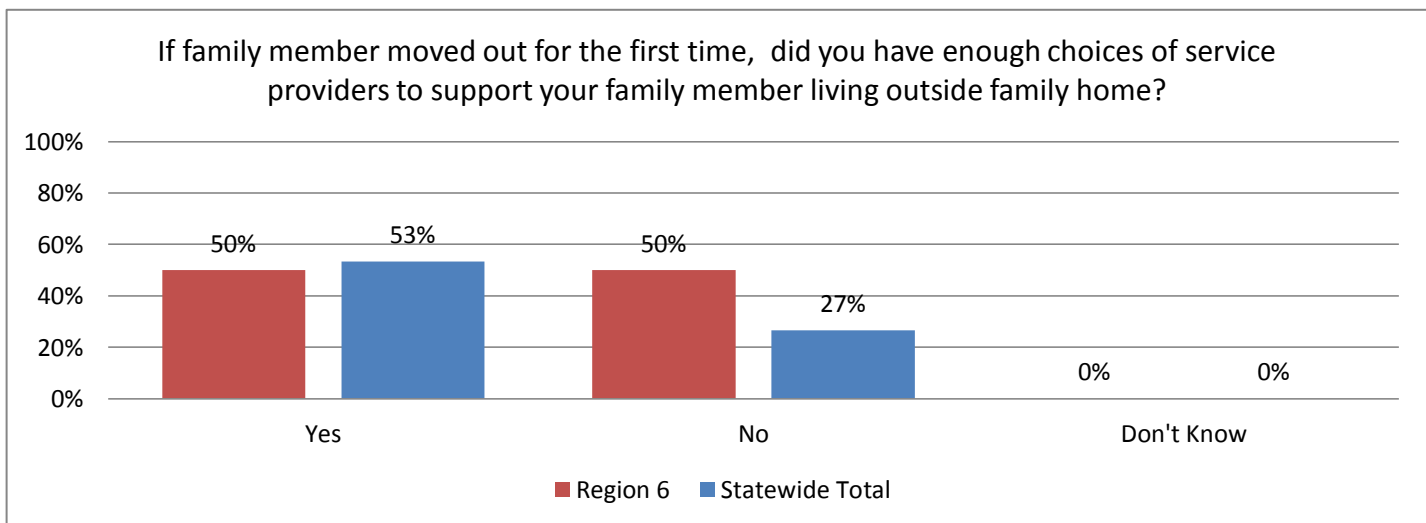
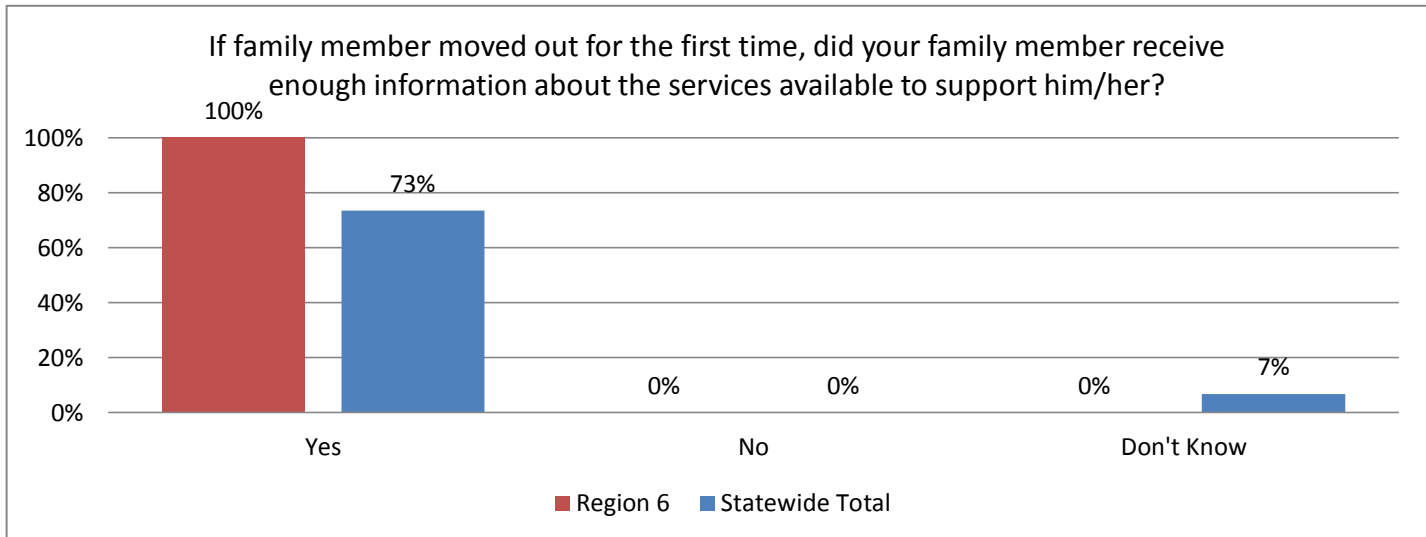
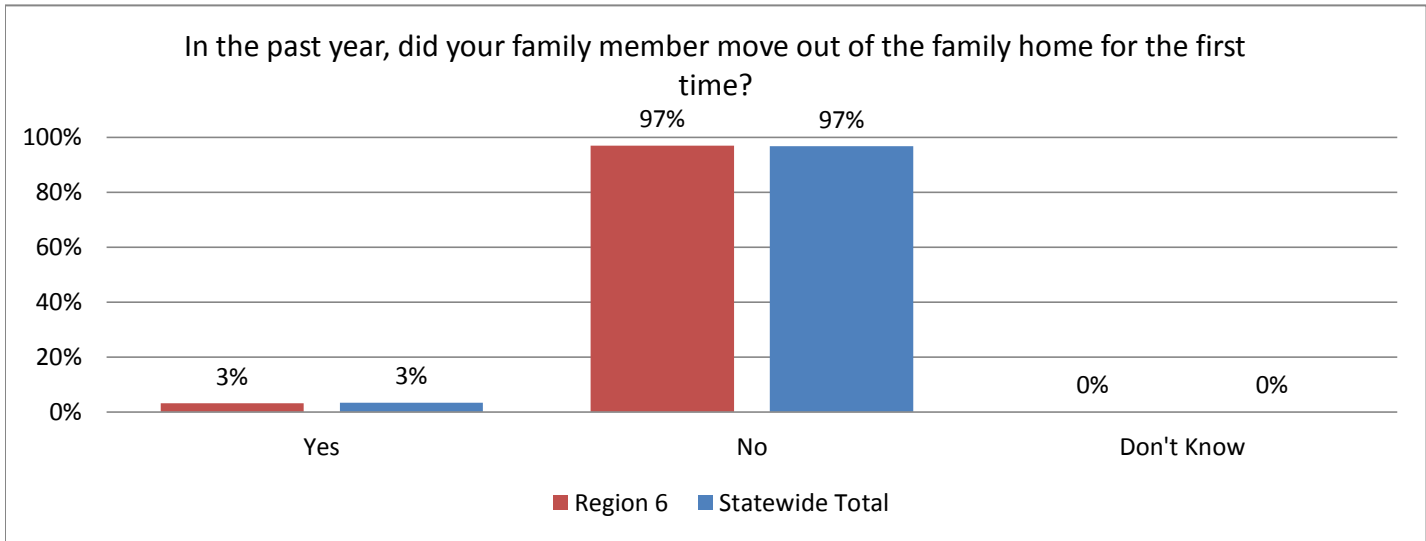
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Satisfaction:



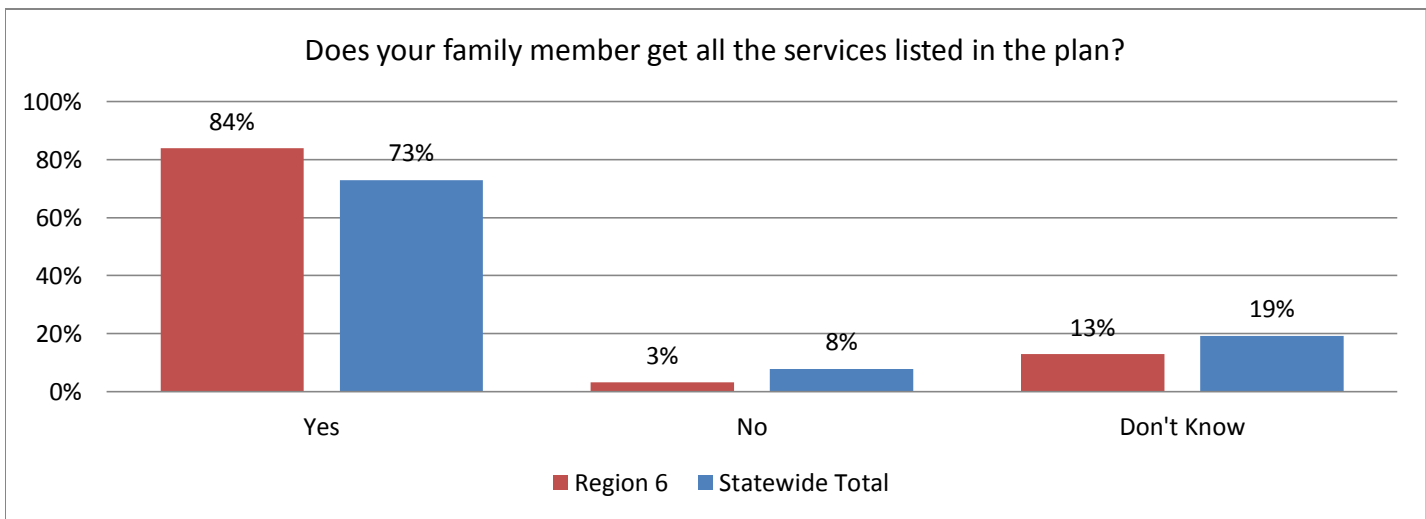
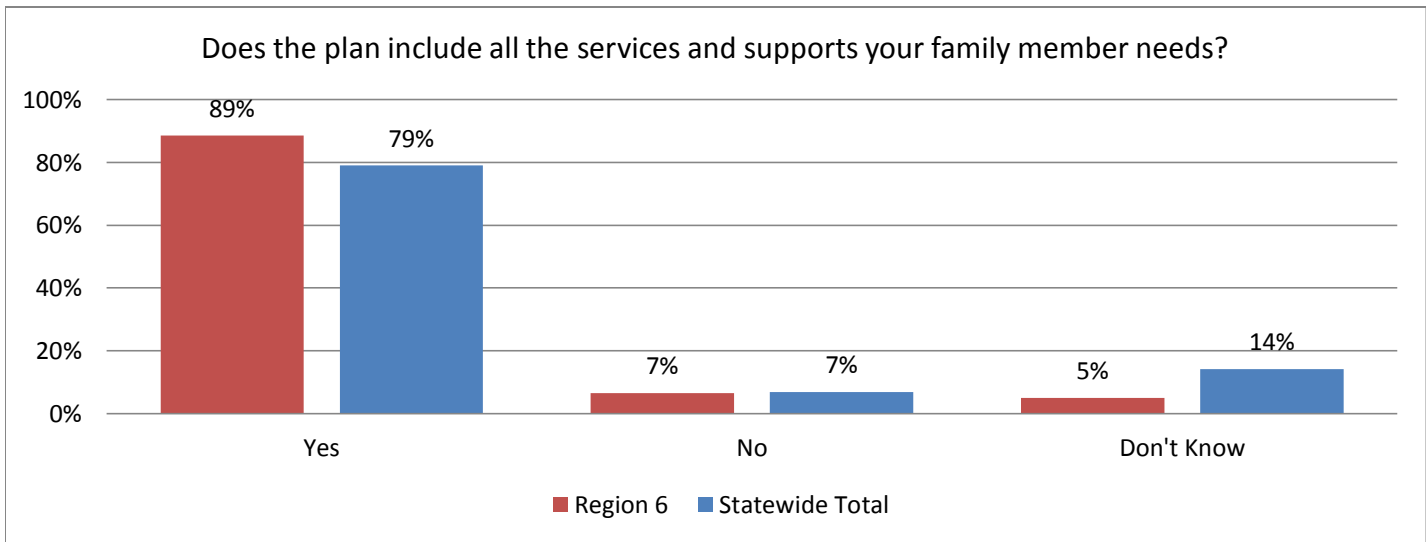
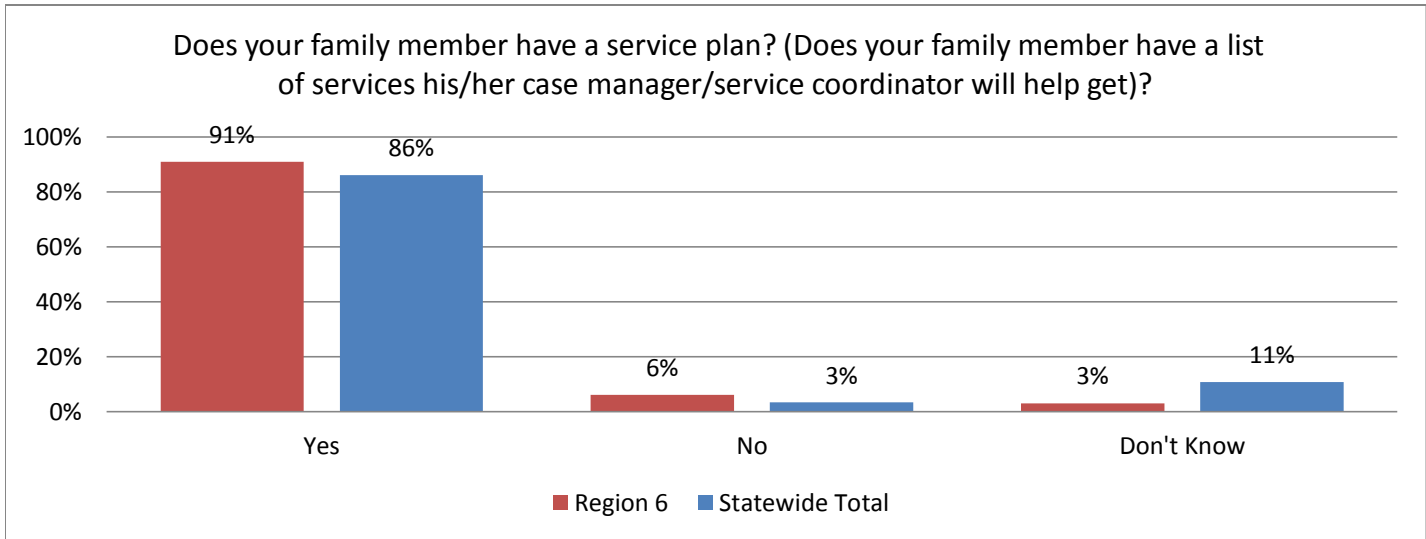
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Satisfaction - Transition out of Family Home:



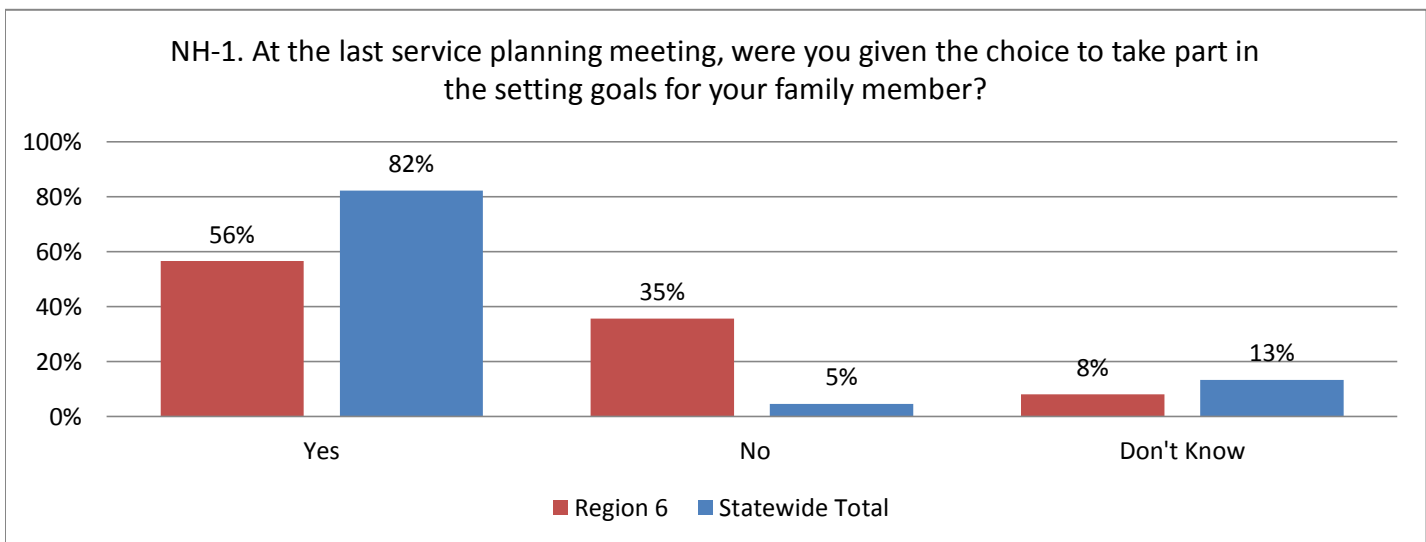
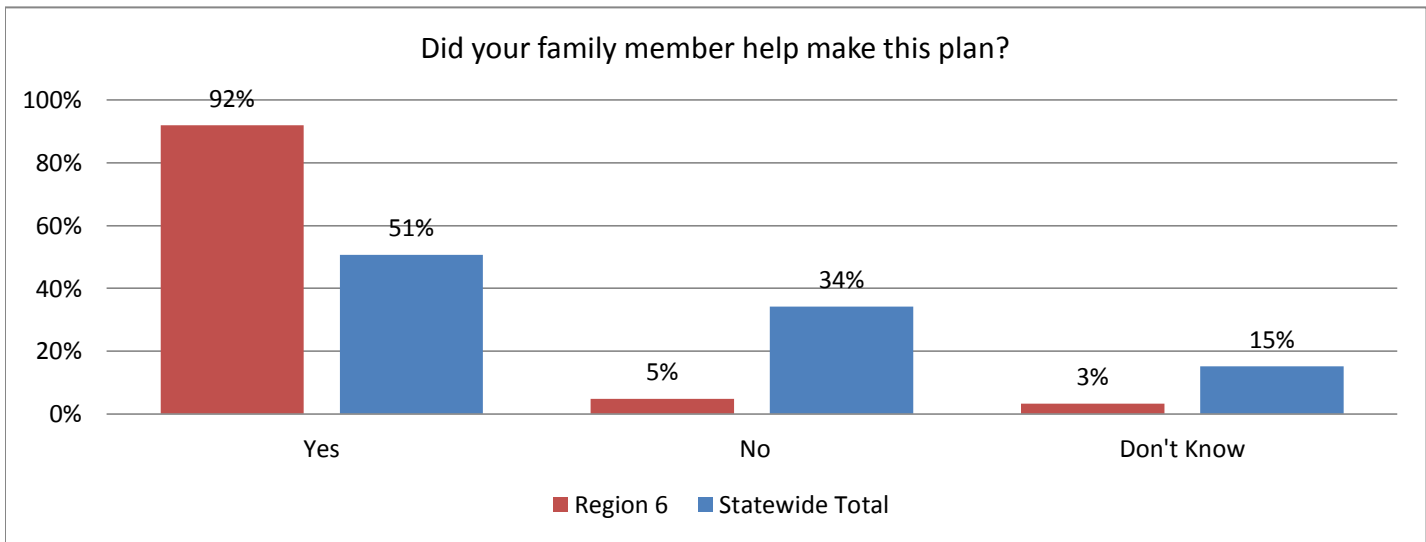
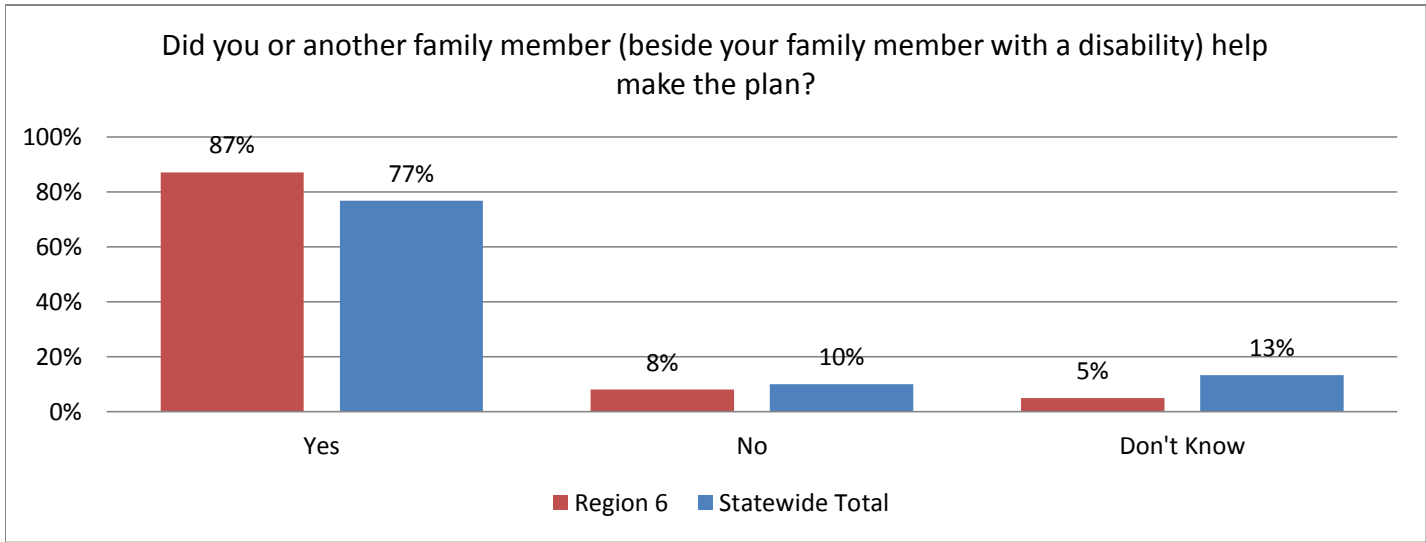
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Satisfaction - Service Plan:



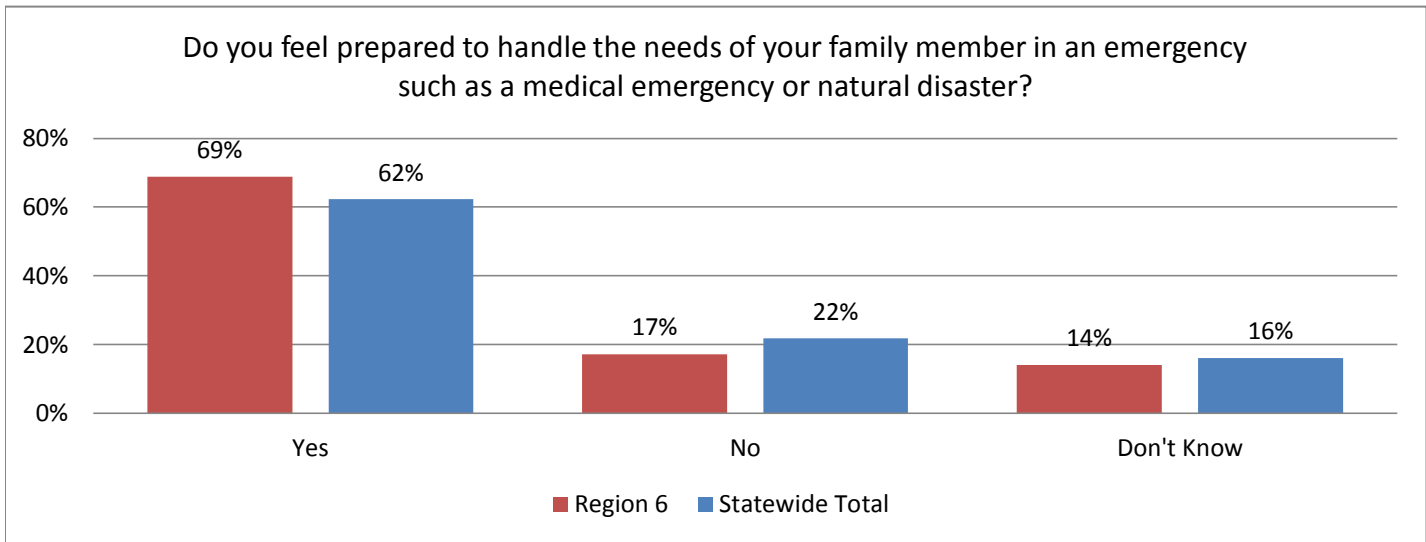
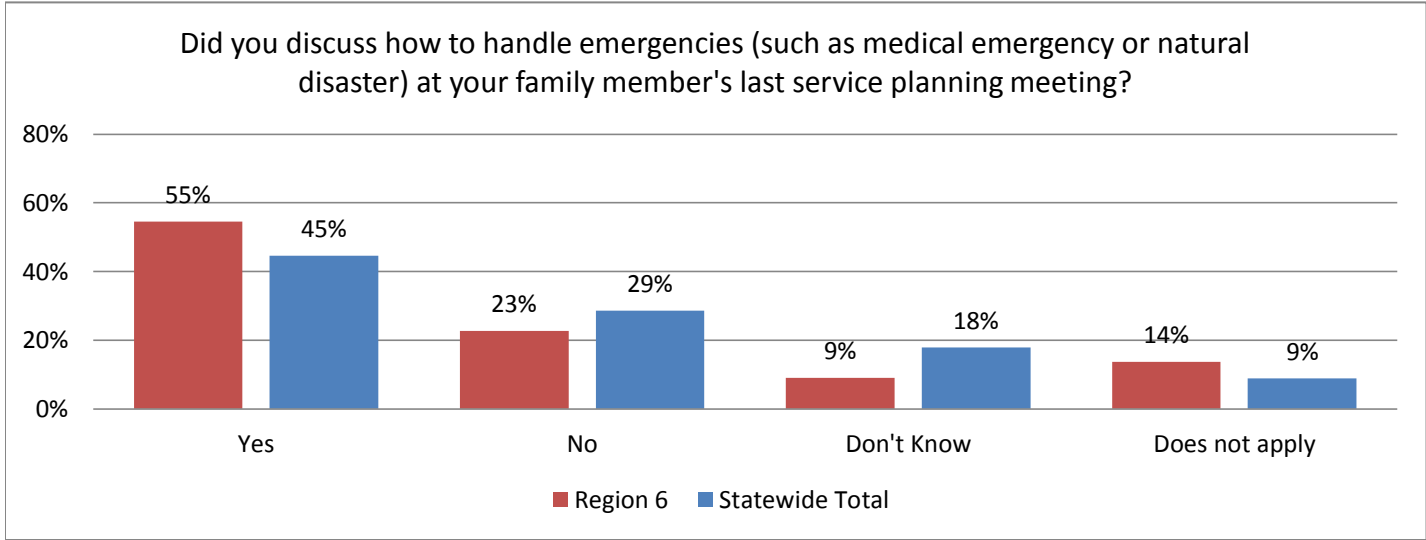
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Satisfaction - Service Plan:



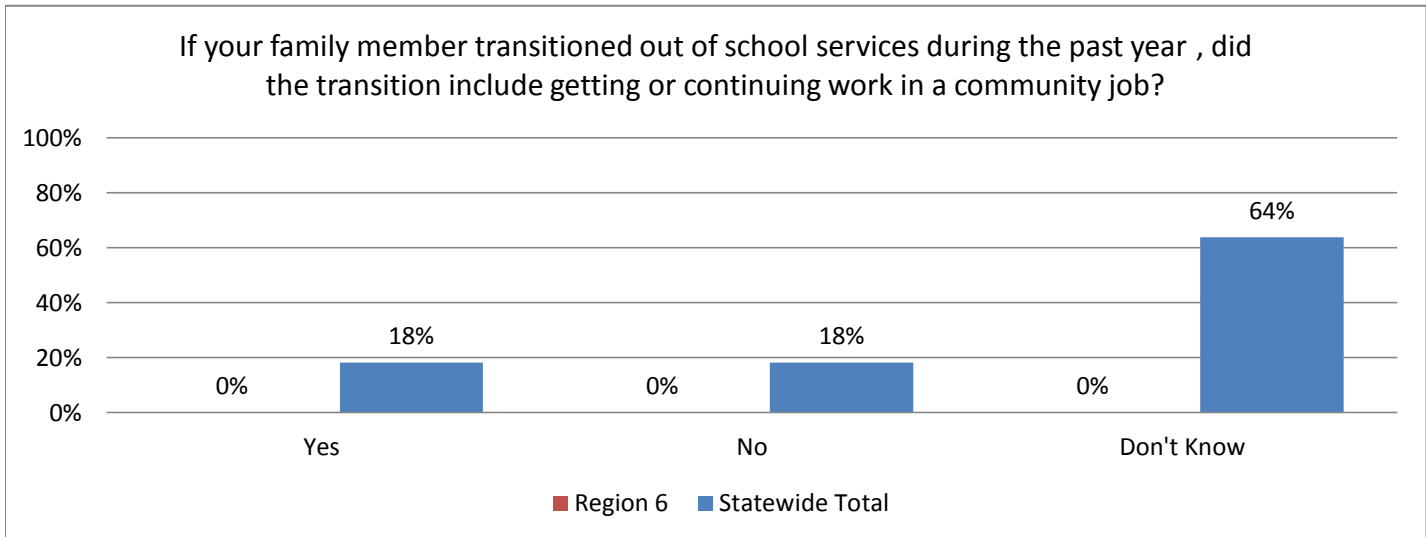
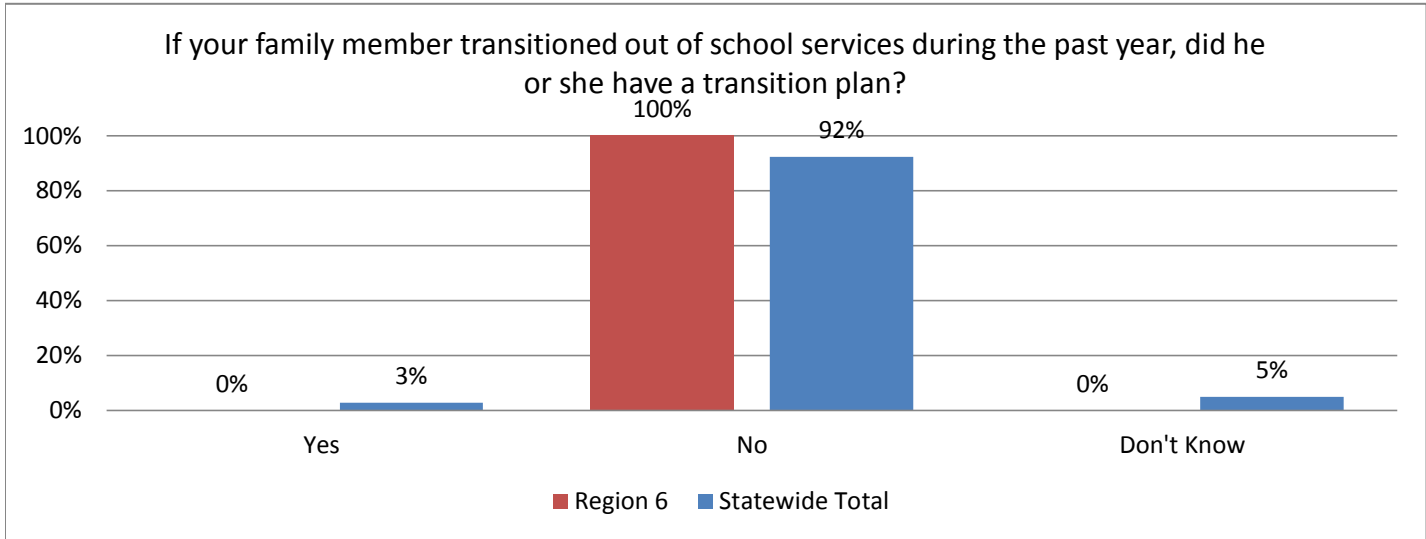
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Satisfaction - Emergencies:



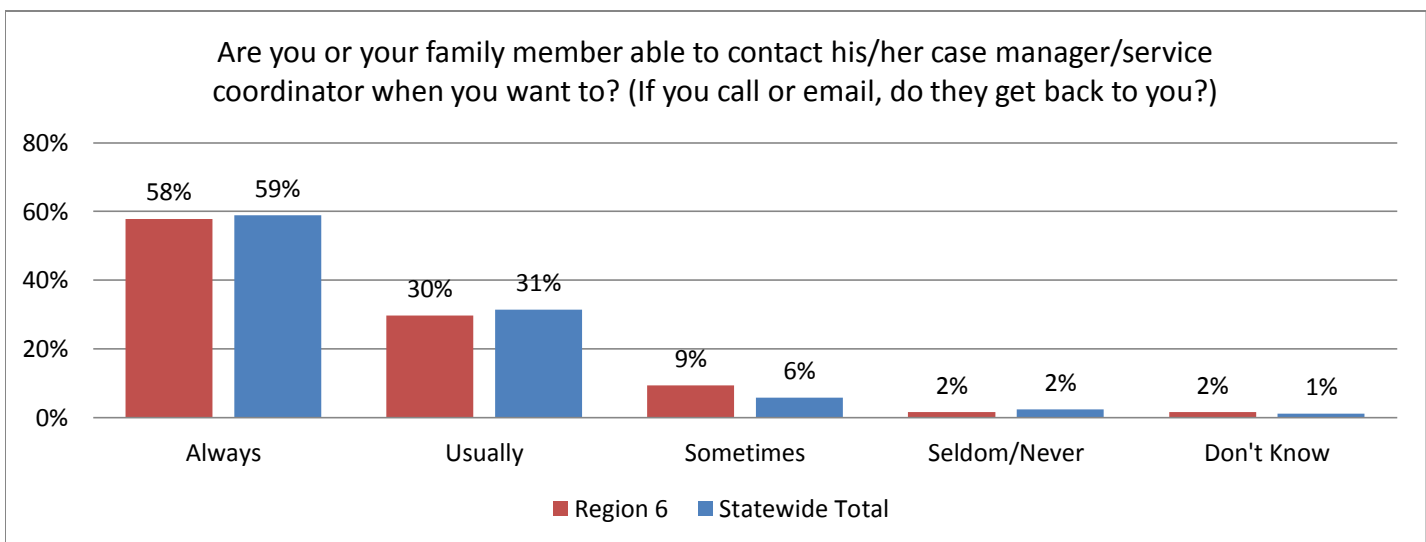
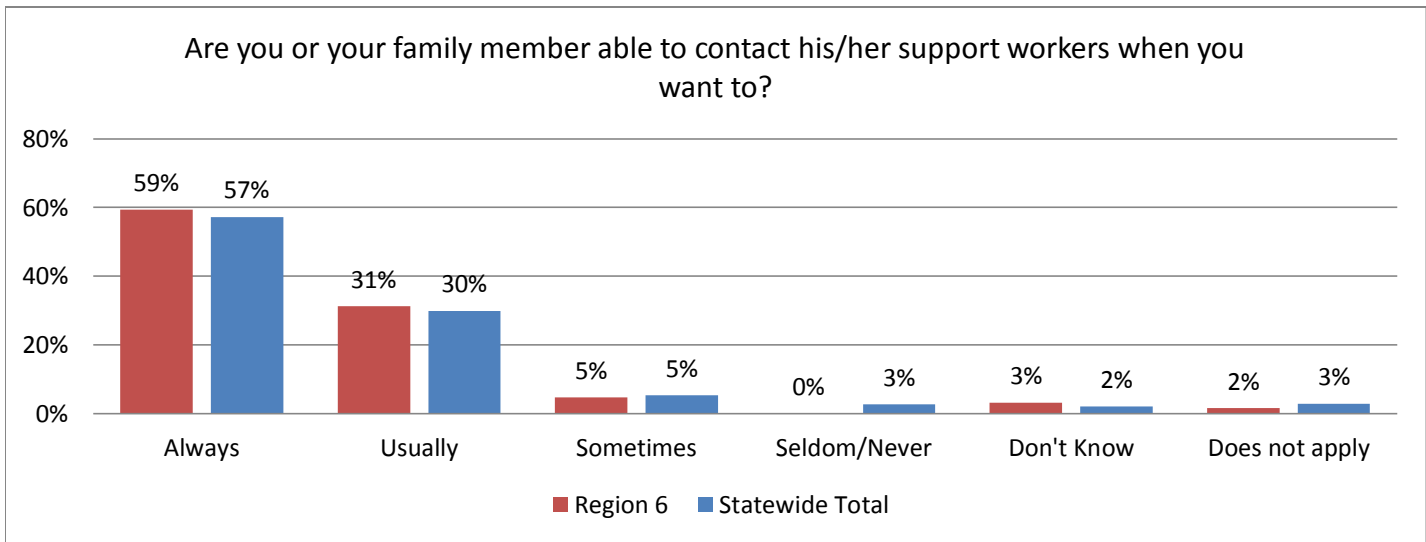
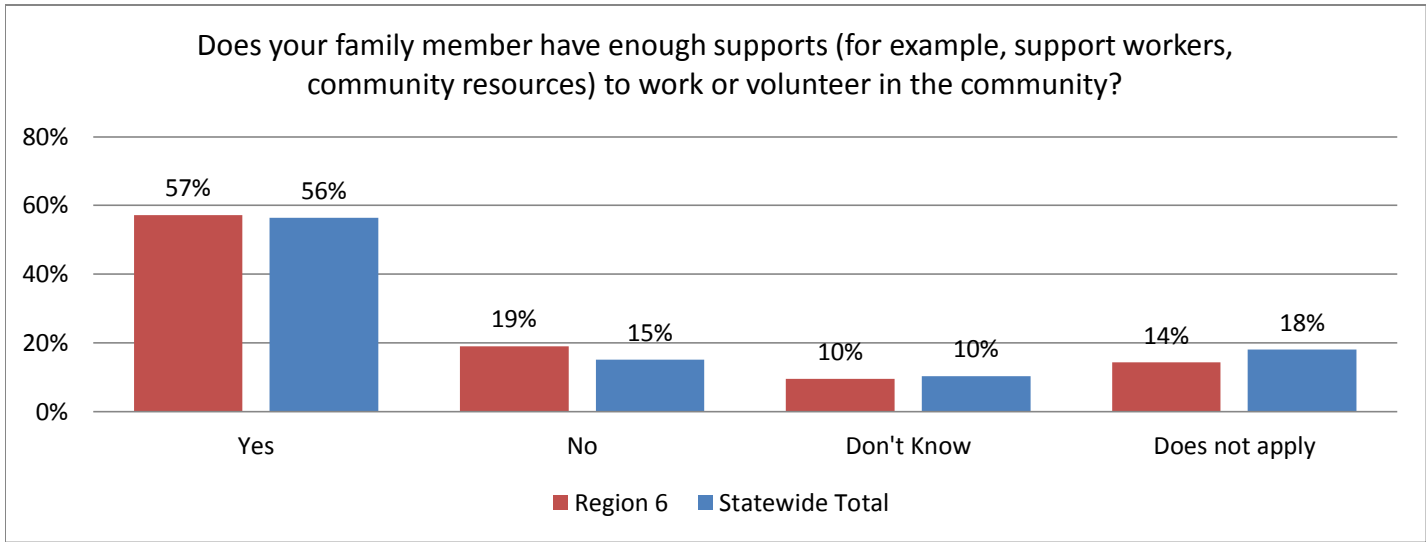
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Satisfaction - School Transition:



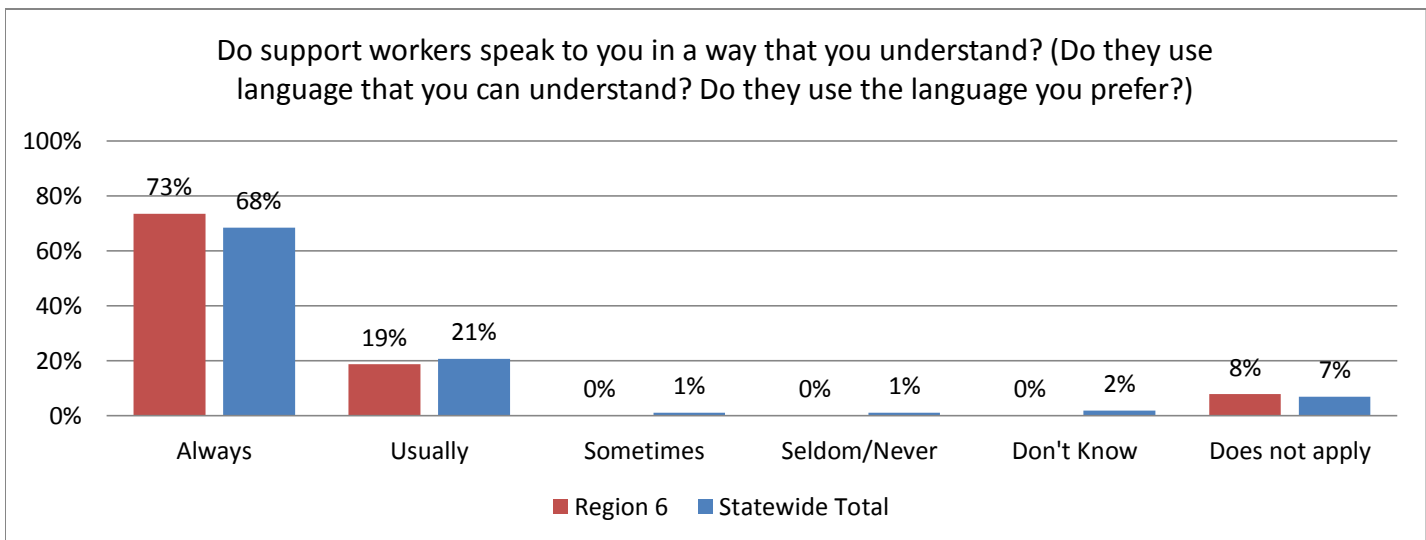
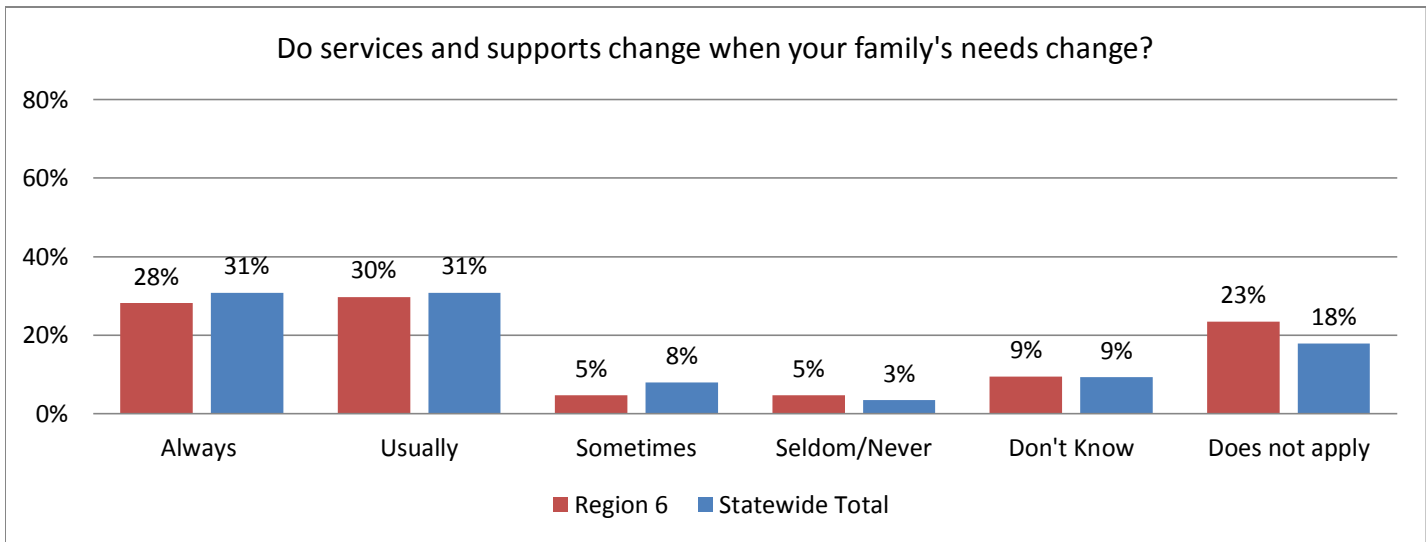
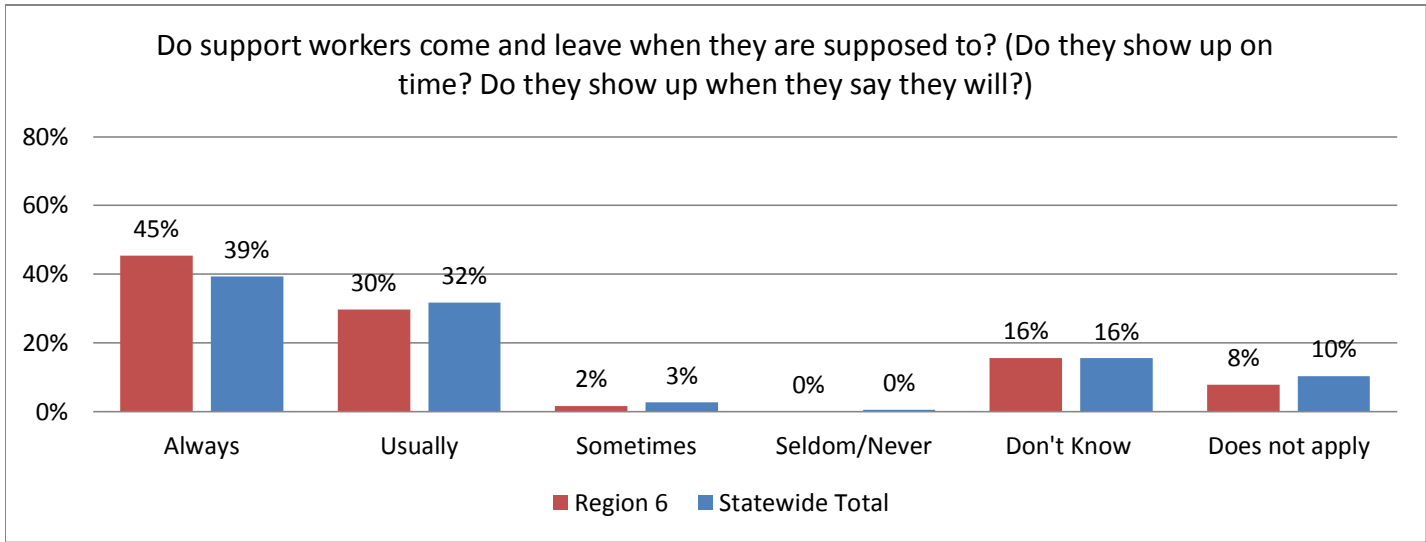
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Satisfaction:



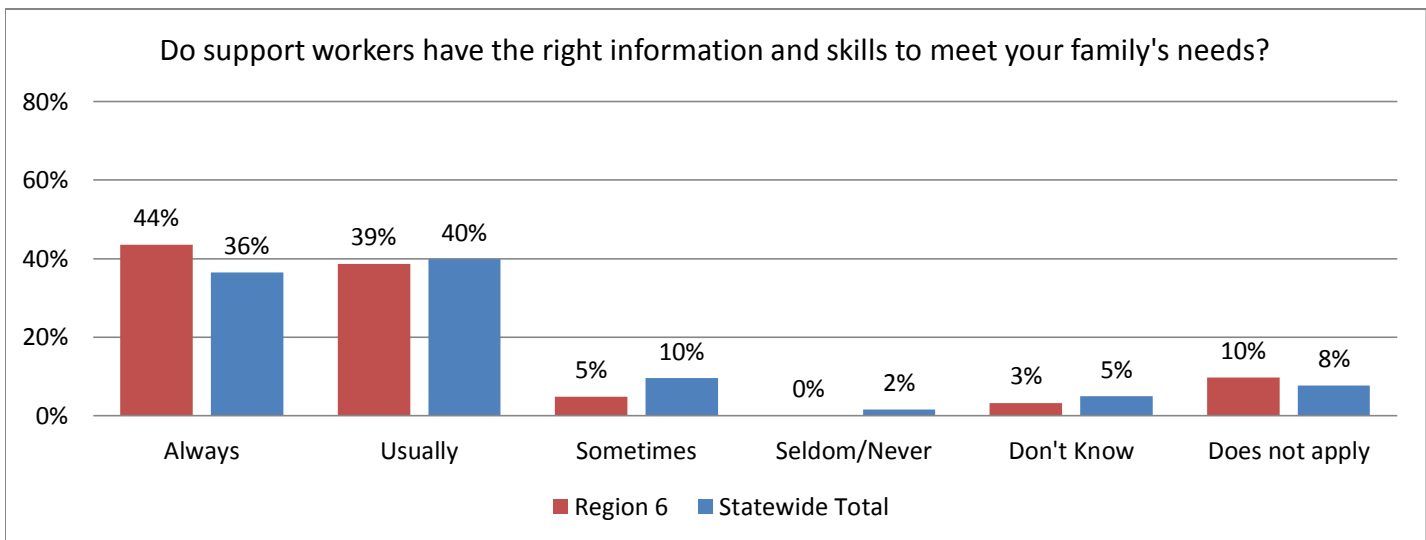
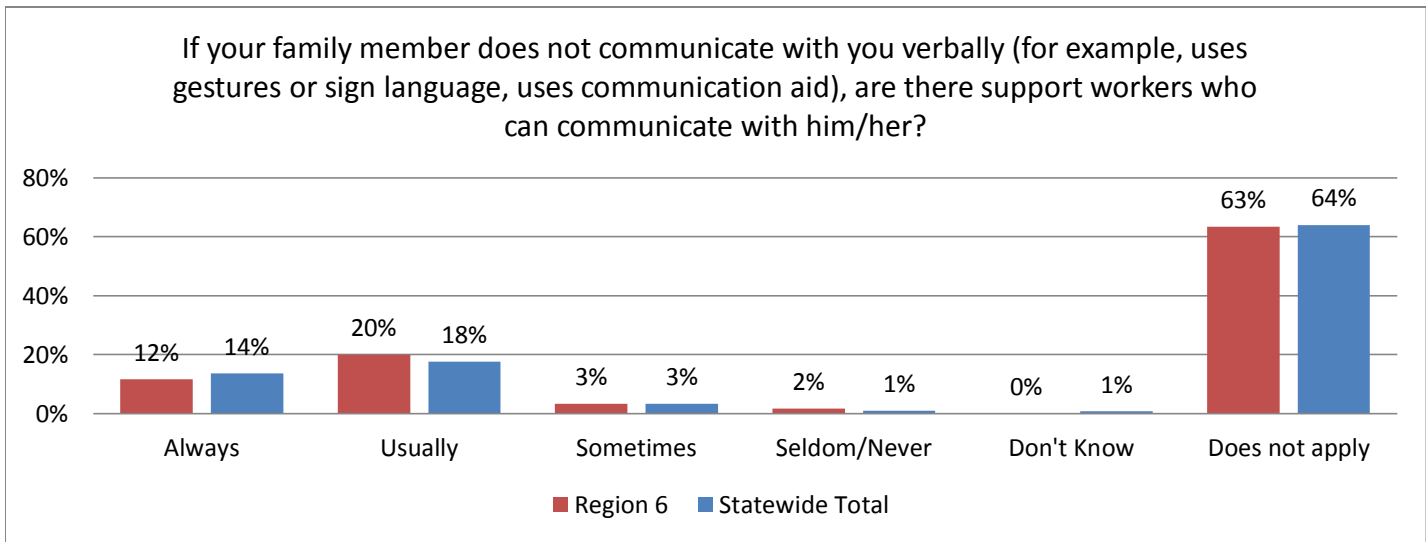
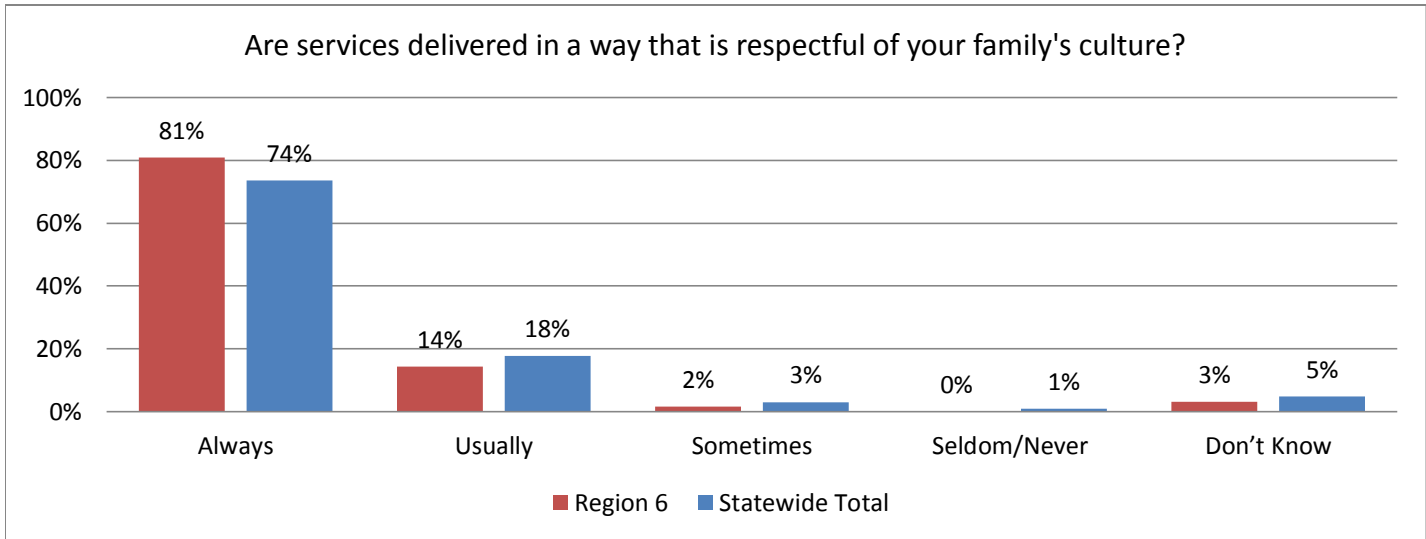
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Satisfaction - Service Delivery:



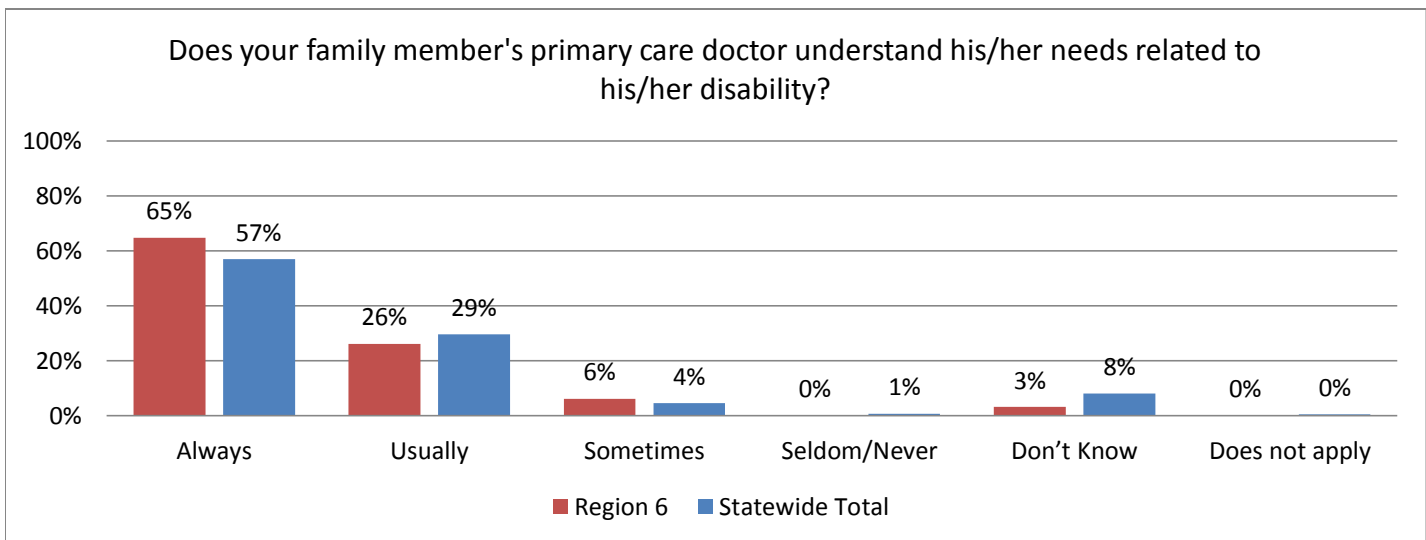
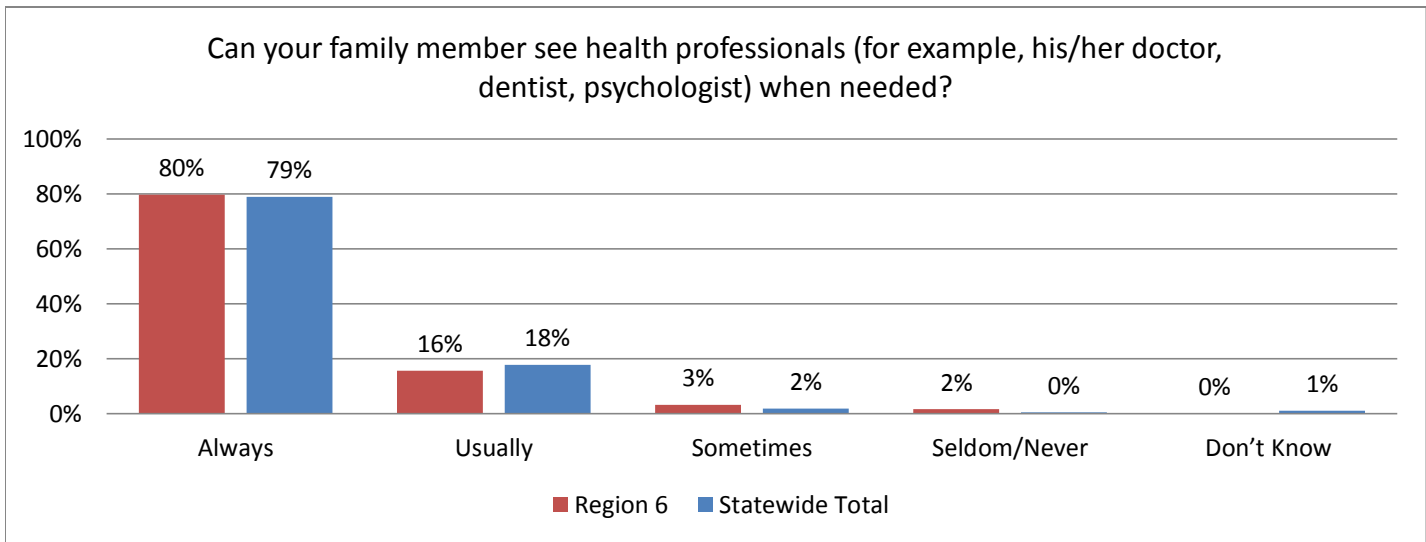
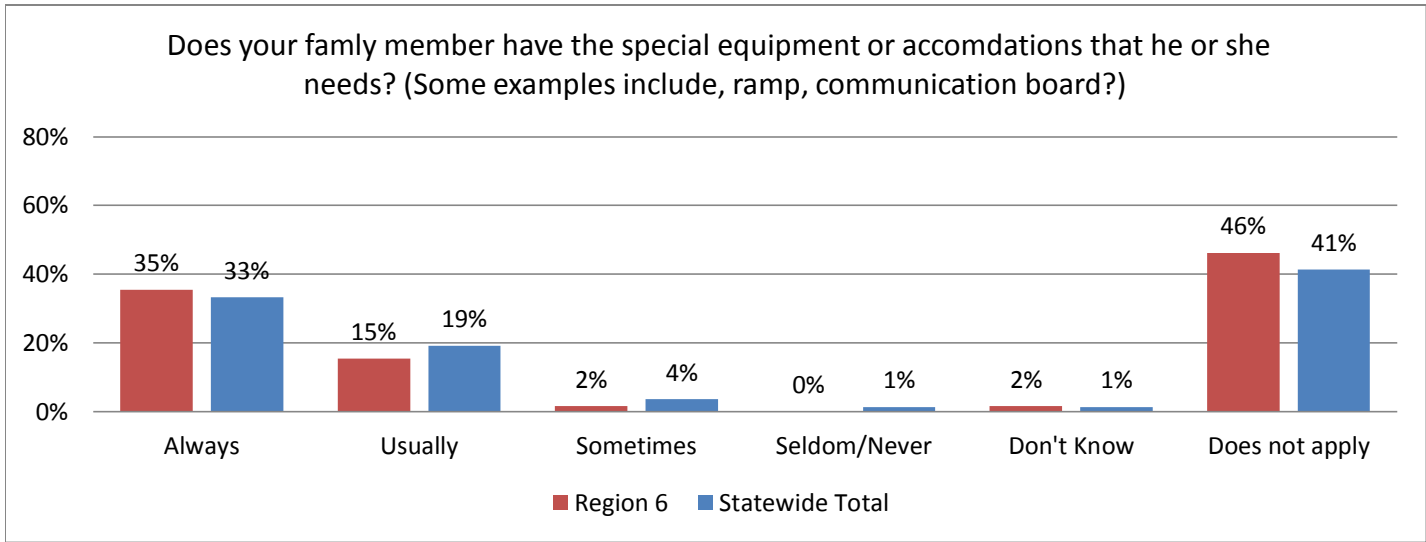
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Satisfaction - Service Delivery:



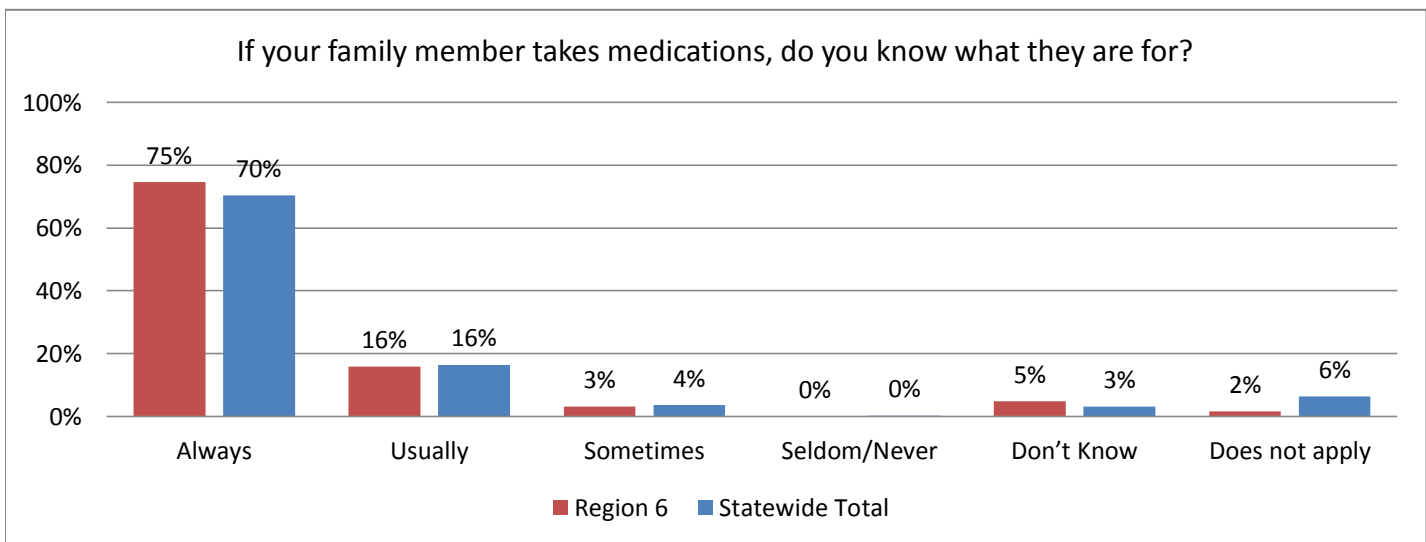
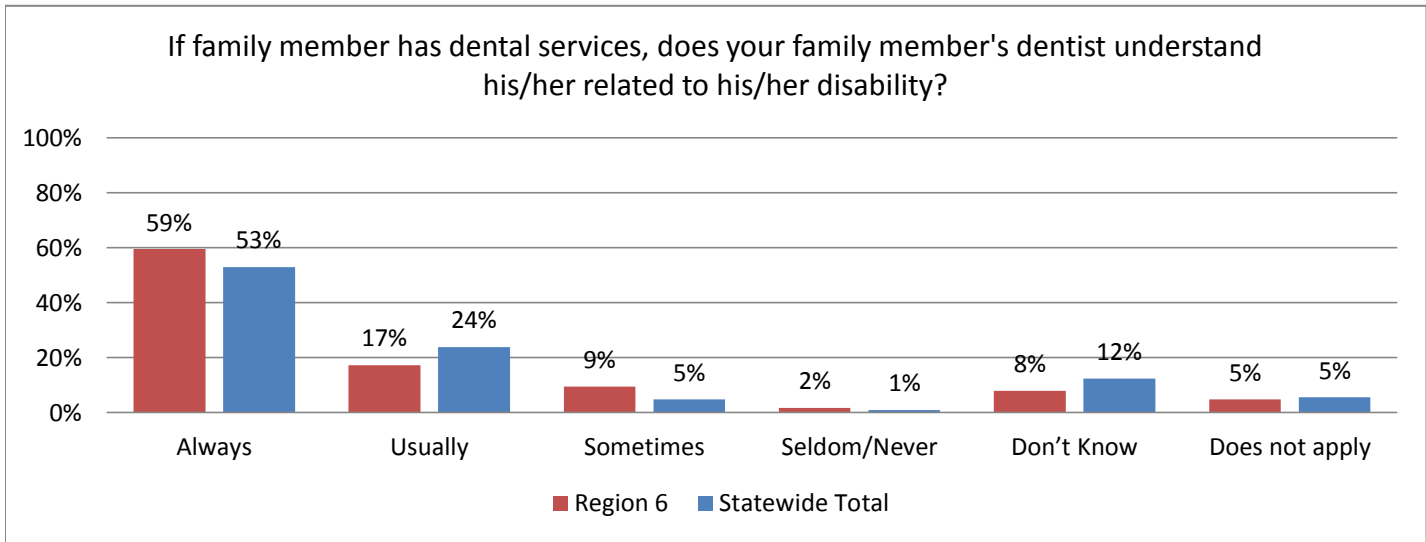
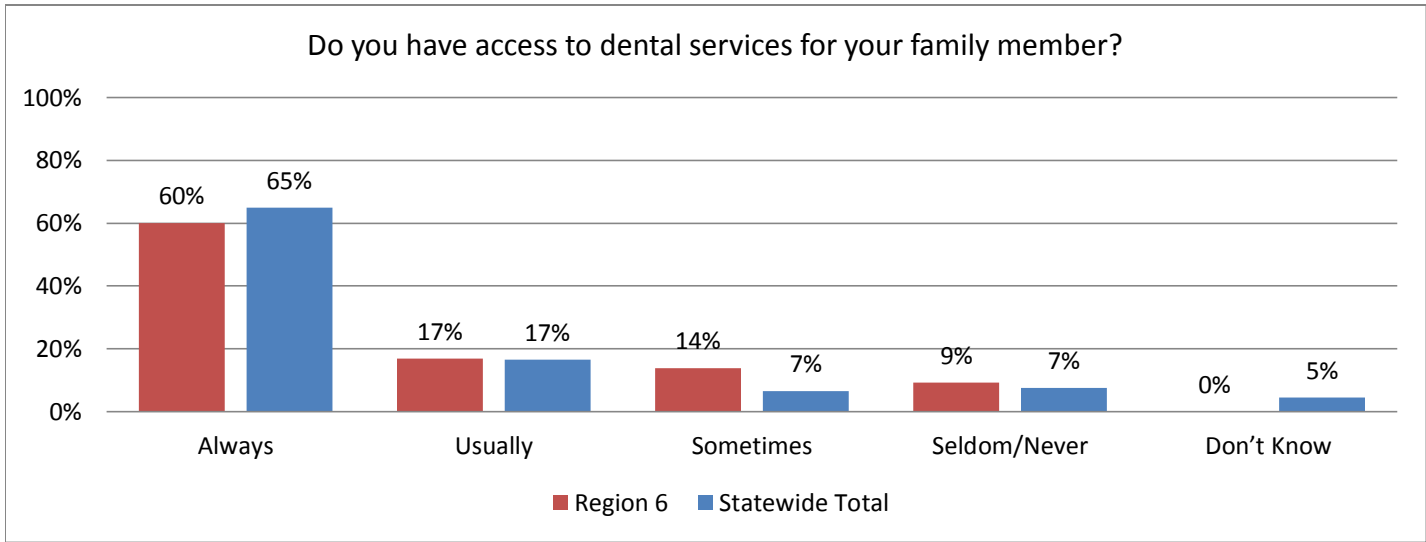
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Satisfaction - Supports:



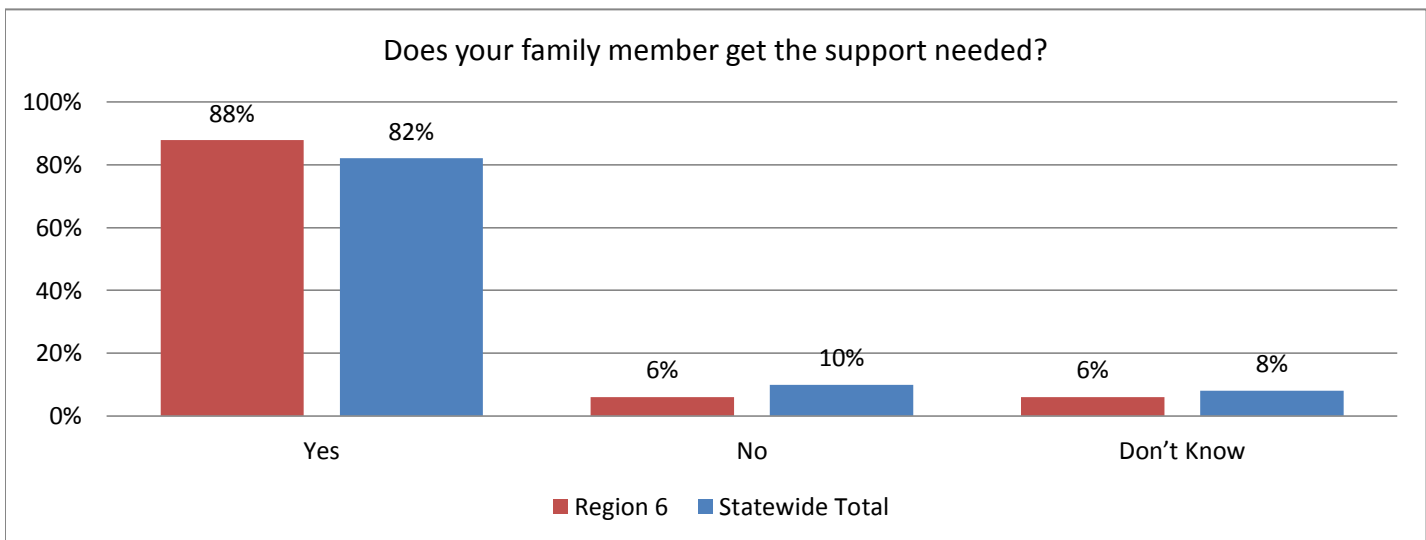
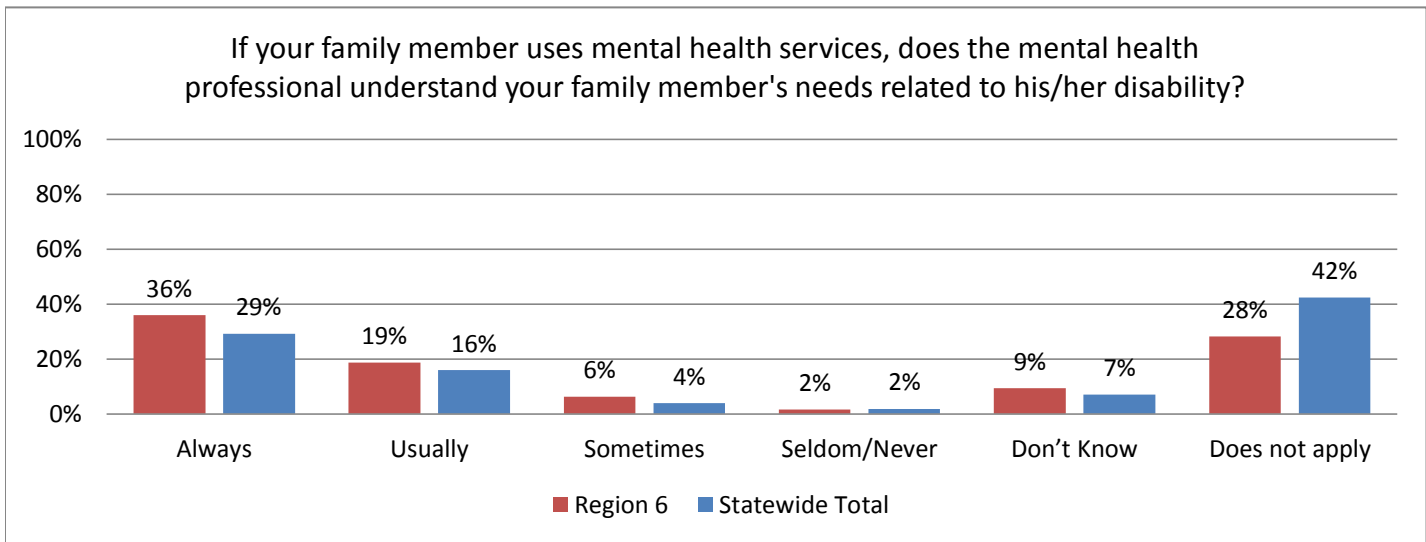
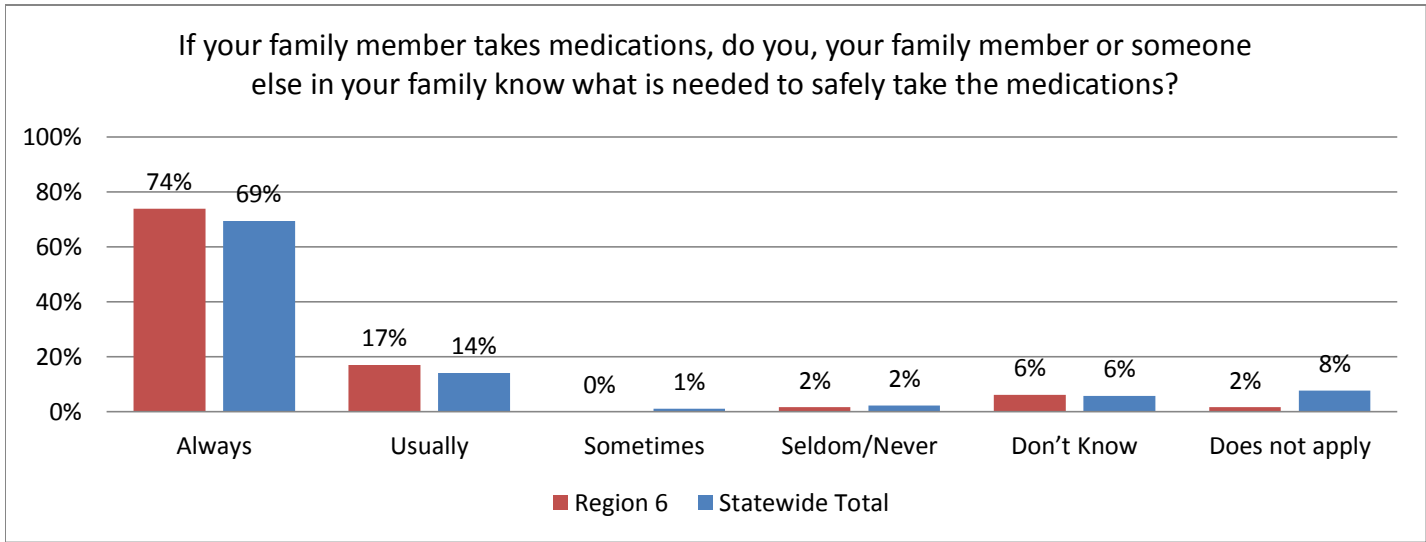
2018 Family Guardian NCI Survey Results
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Satisfaction - Supports:



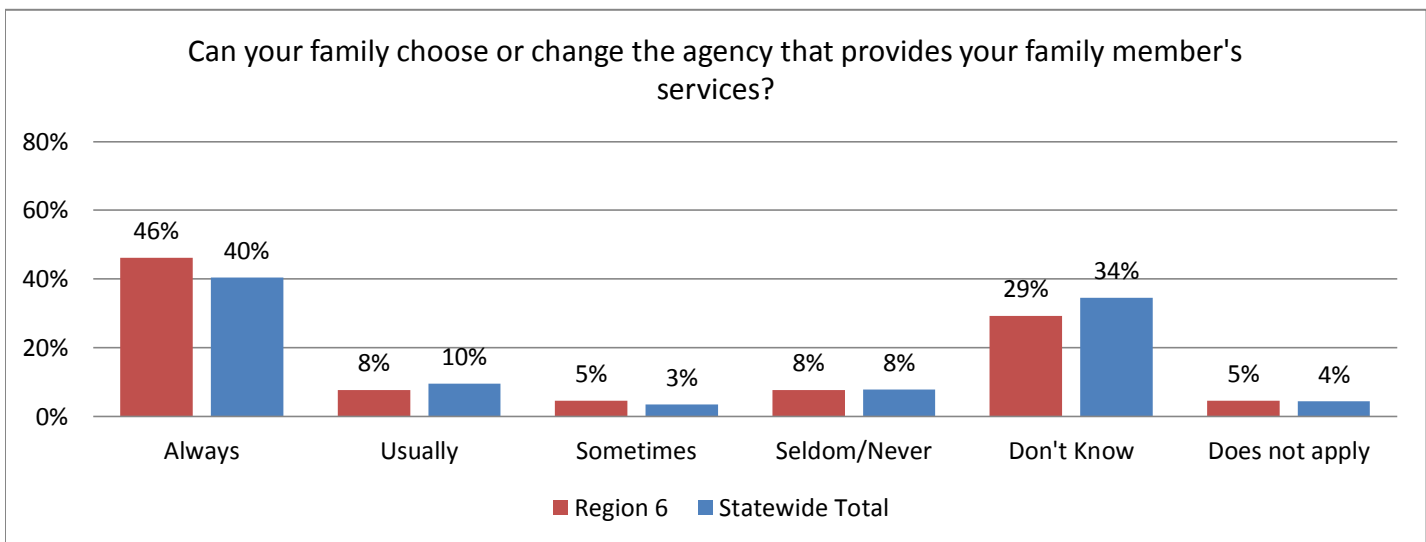
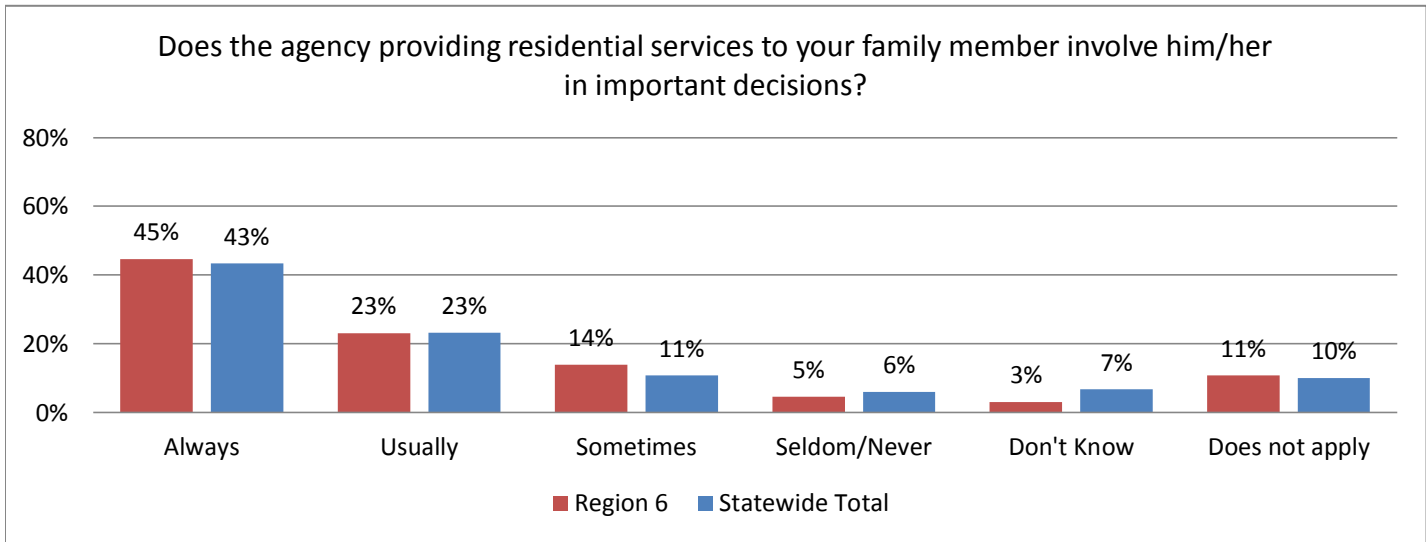
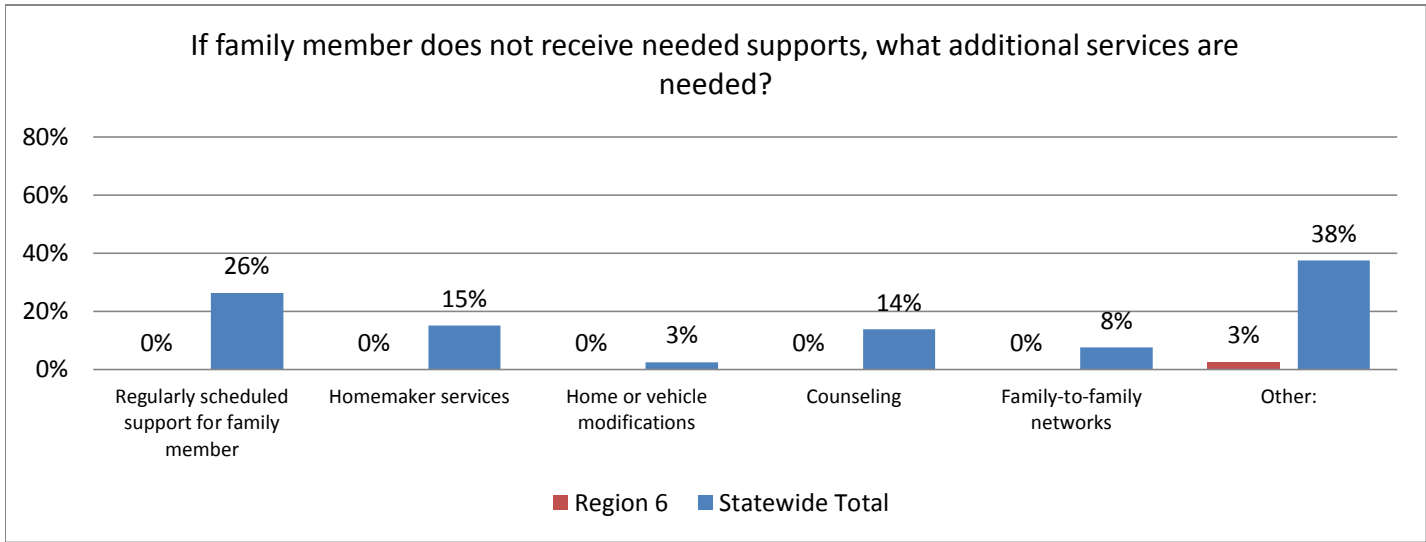
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Satisfaction - Supports:



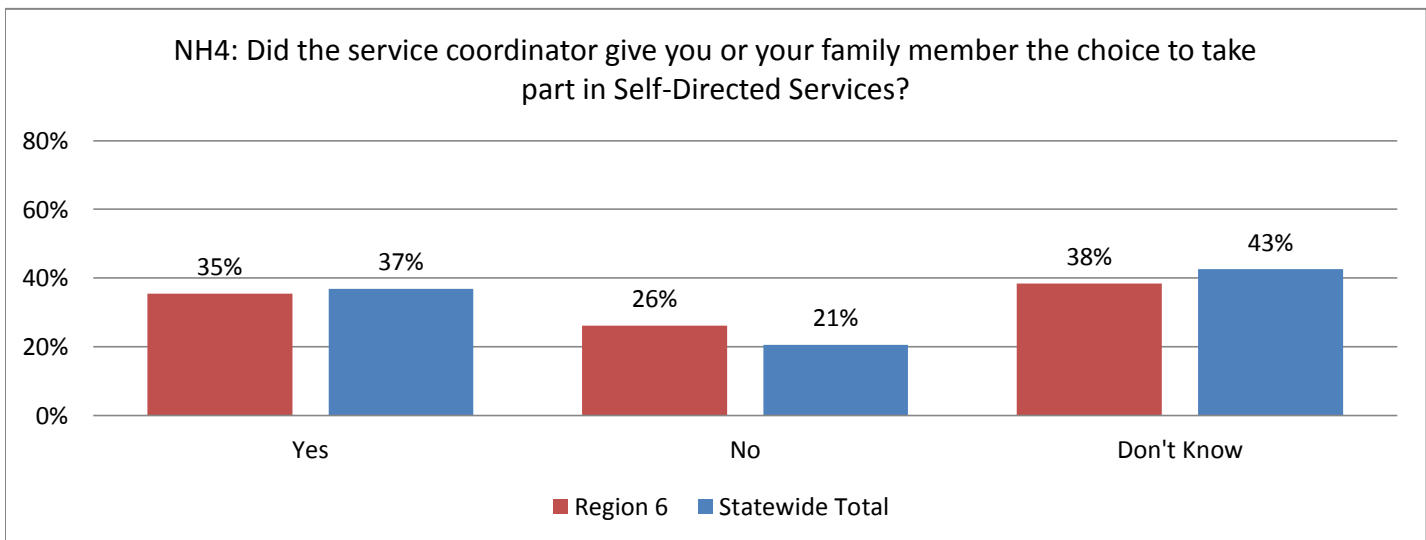
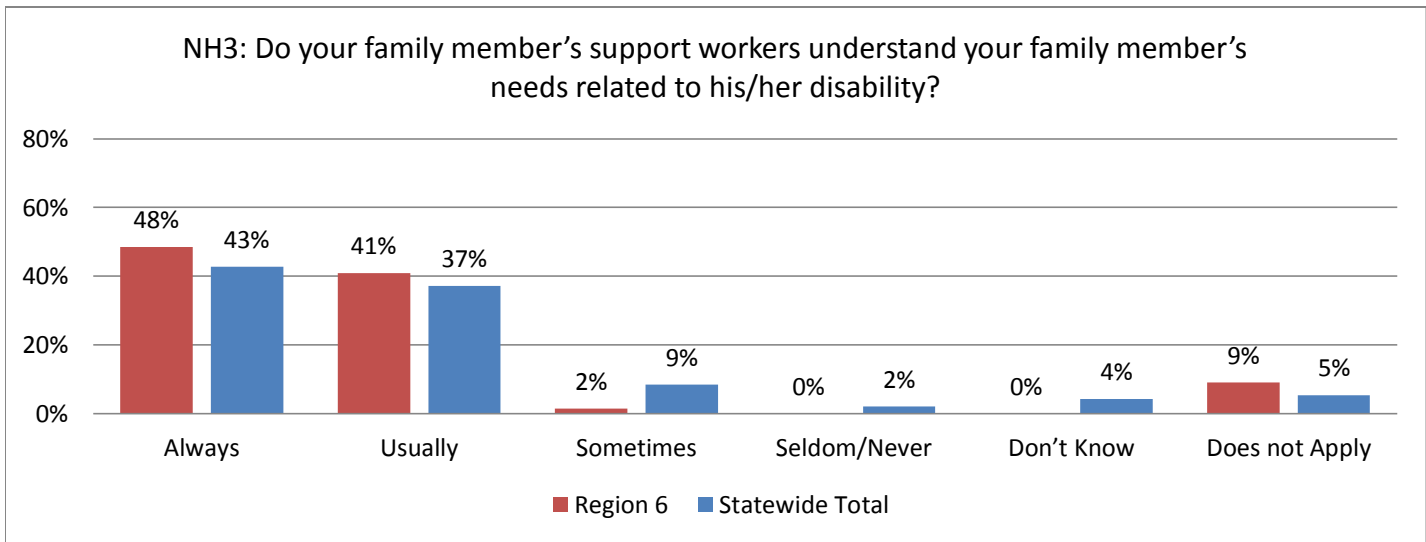
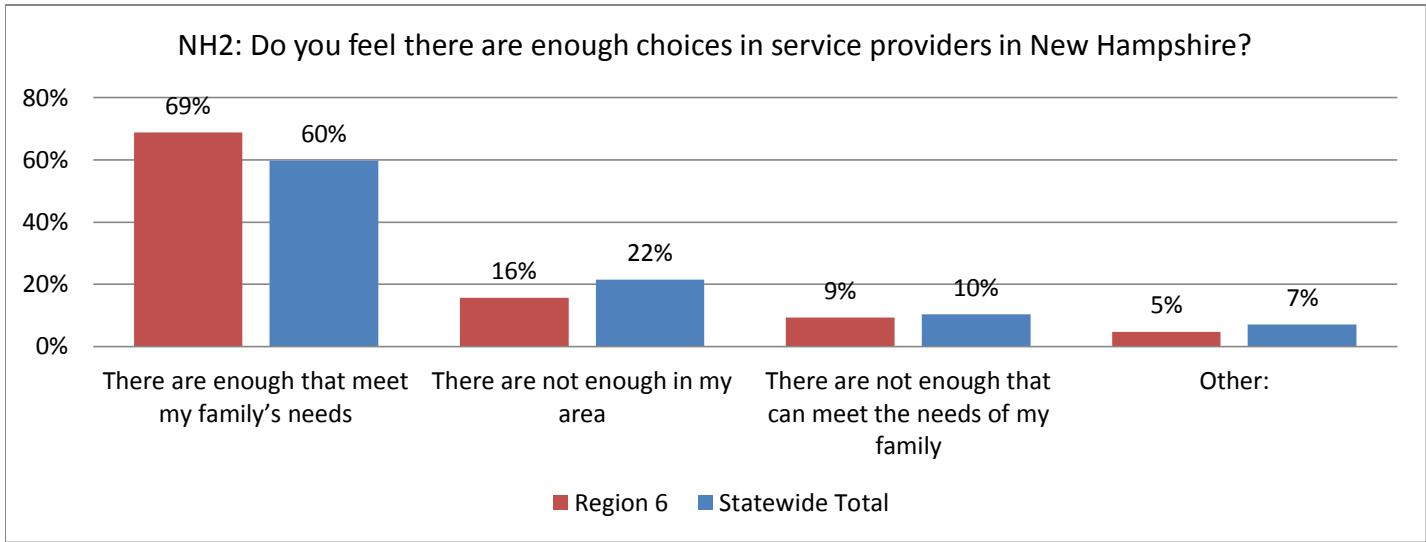
2018 Family Guardian NCI Survey Results
Region 6 Summary and Statewide Comparison

Satisfaction - Supports & Choice:



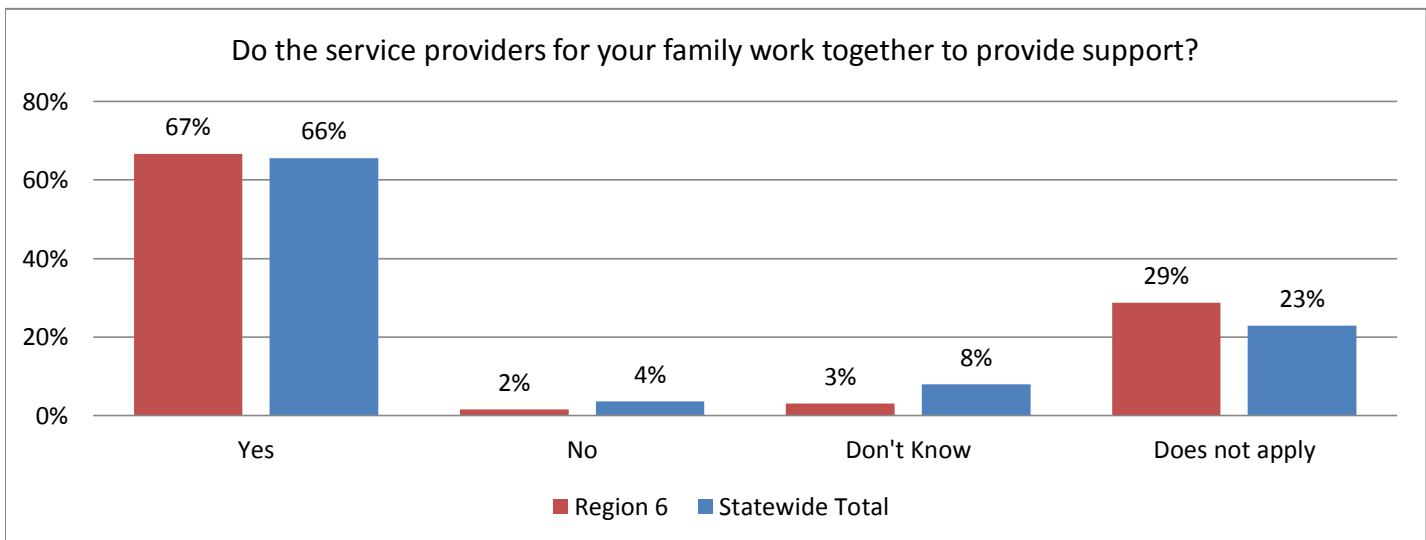
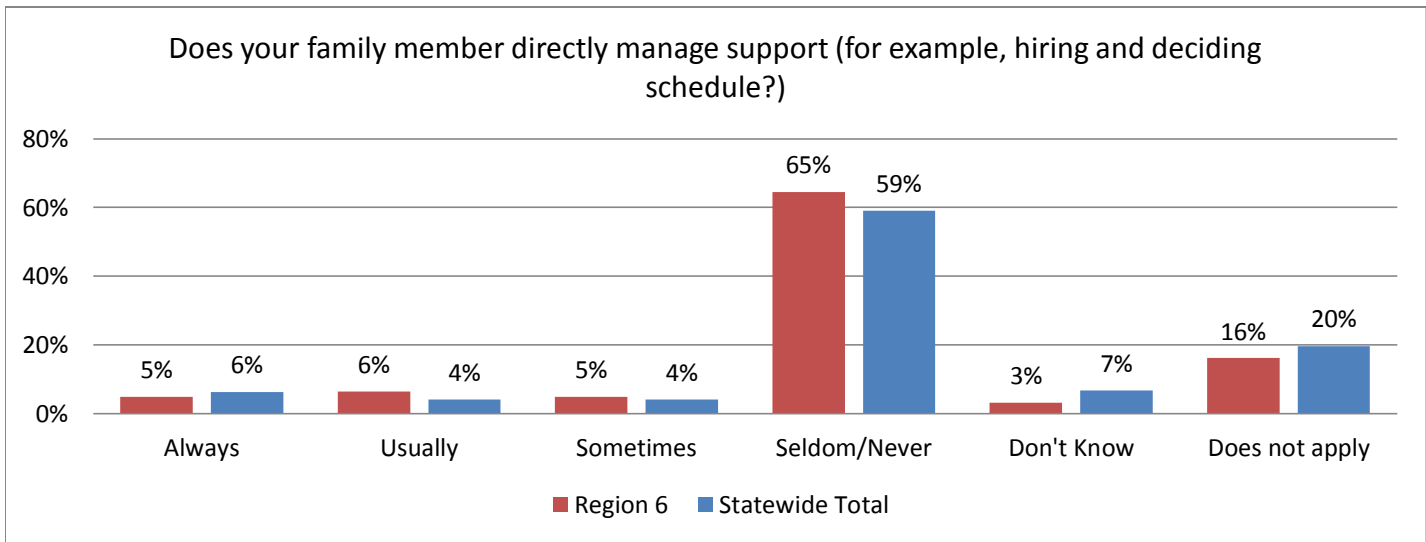
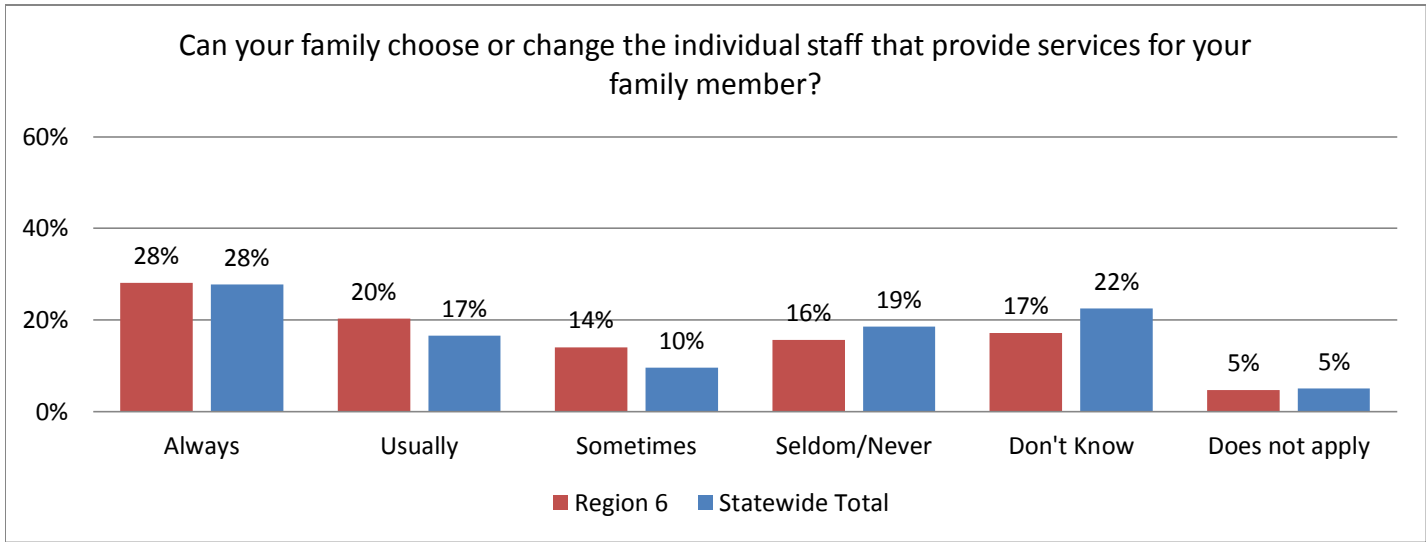
2018 Family Guardian NCI Survey Results
Region 6 Summary and Statewide Comparison

Satisfaction - Choice



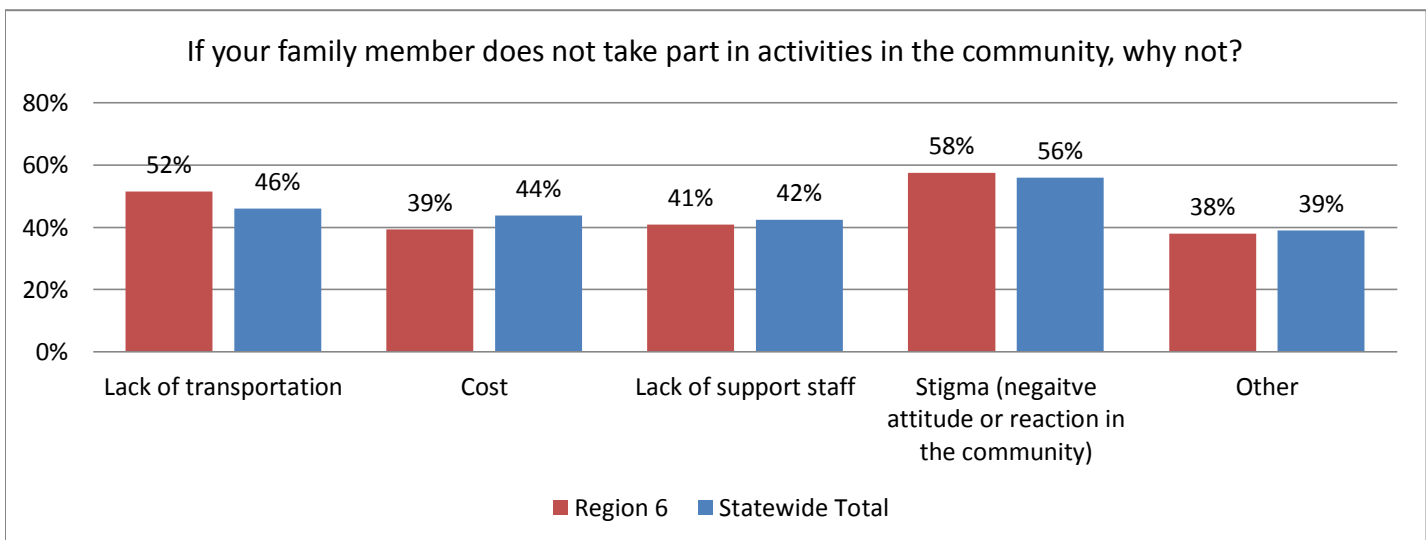
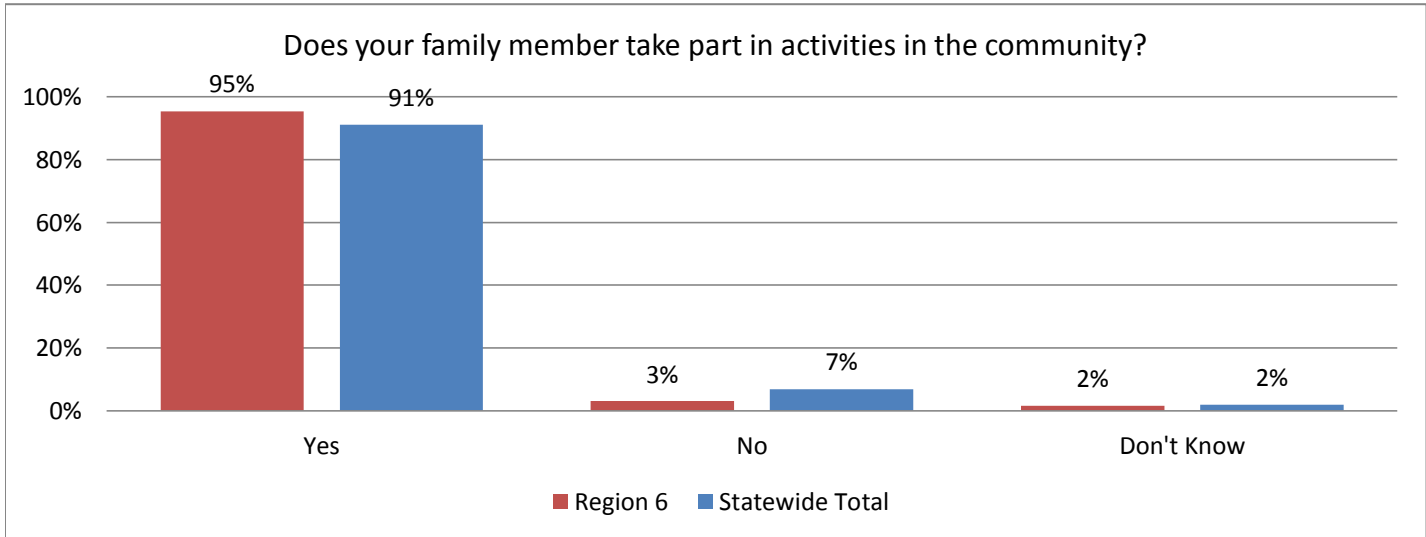
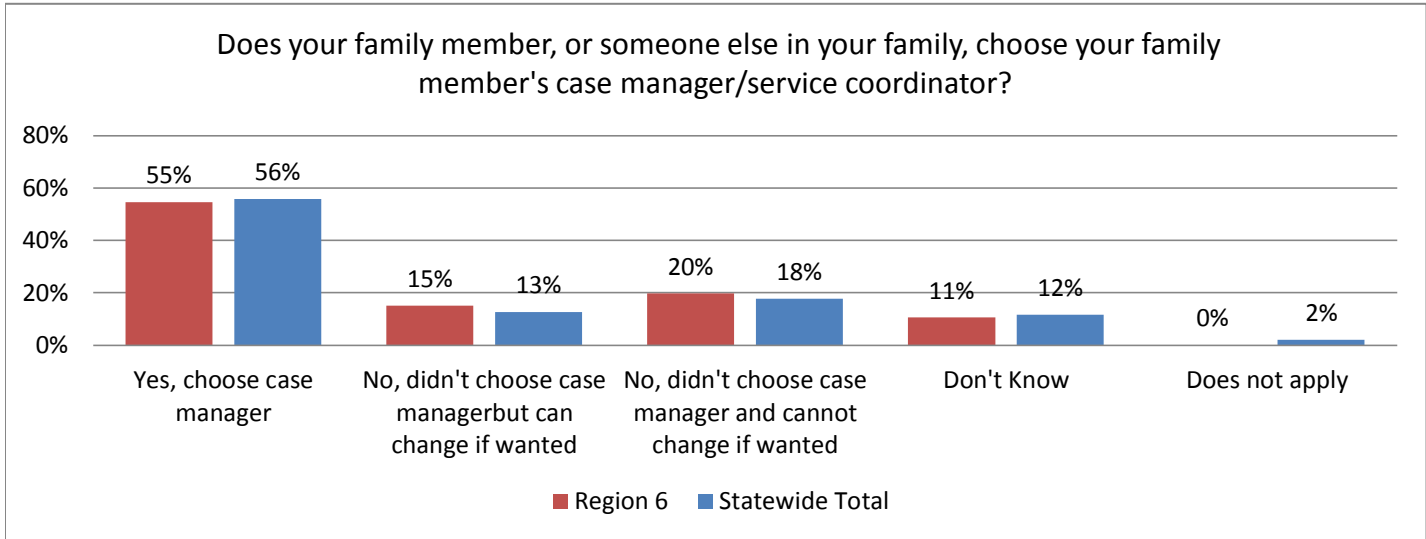
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Satisfaction - Choice



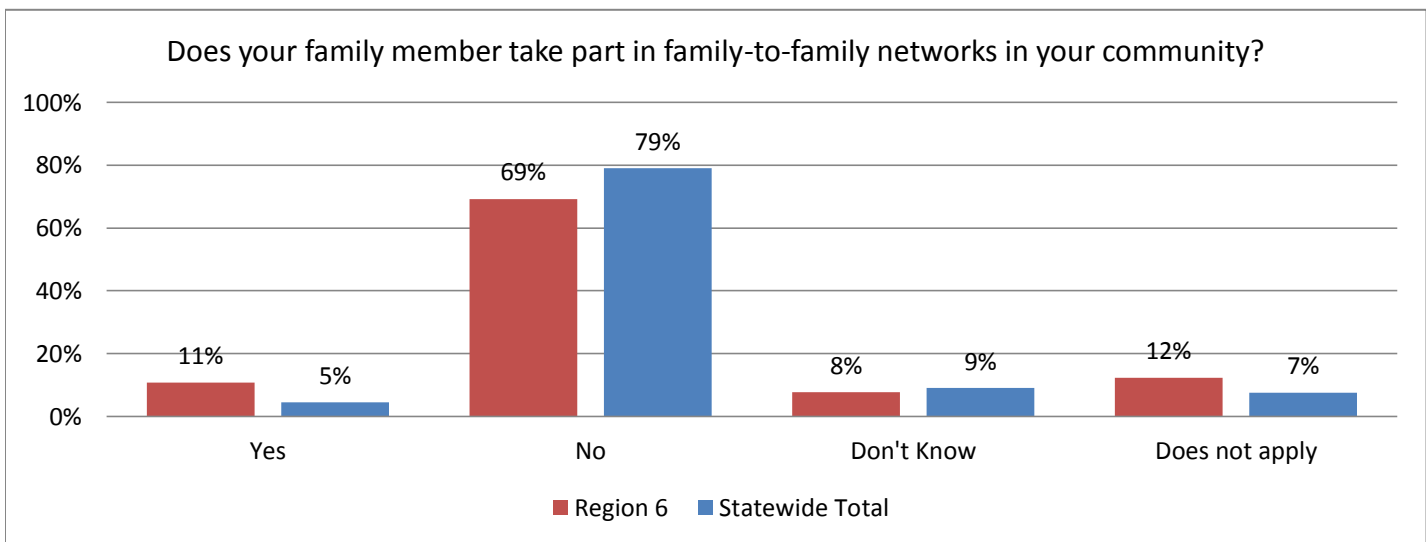
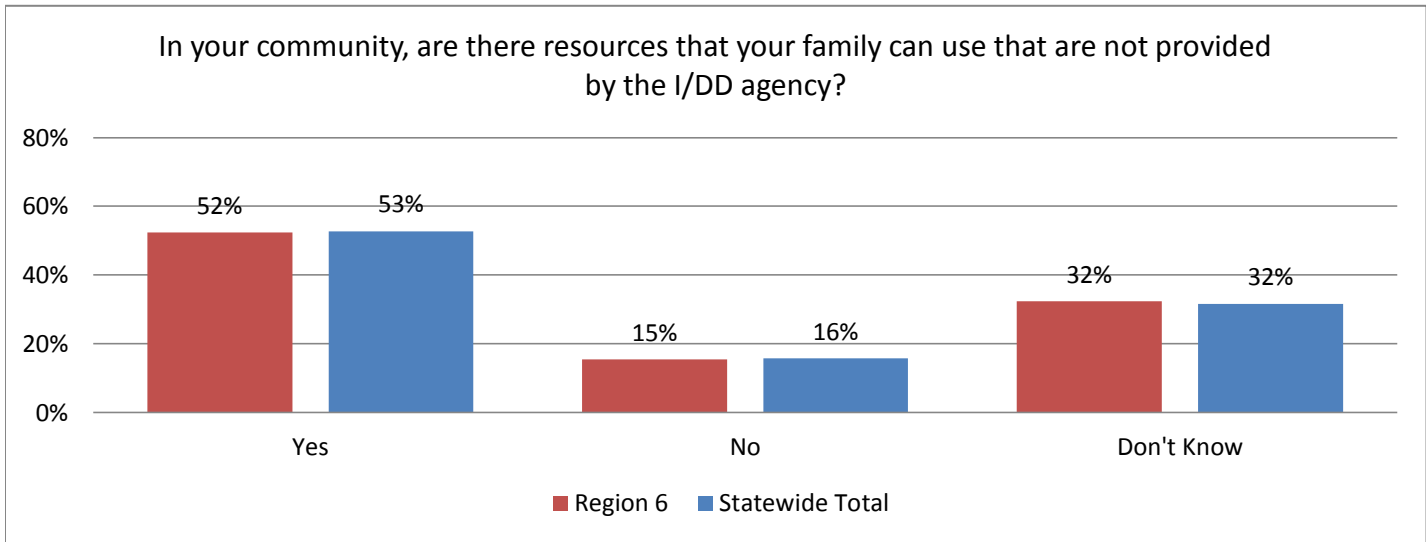
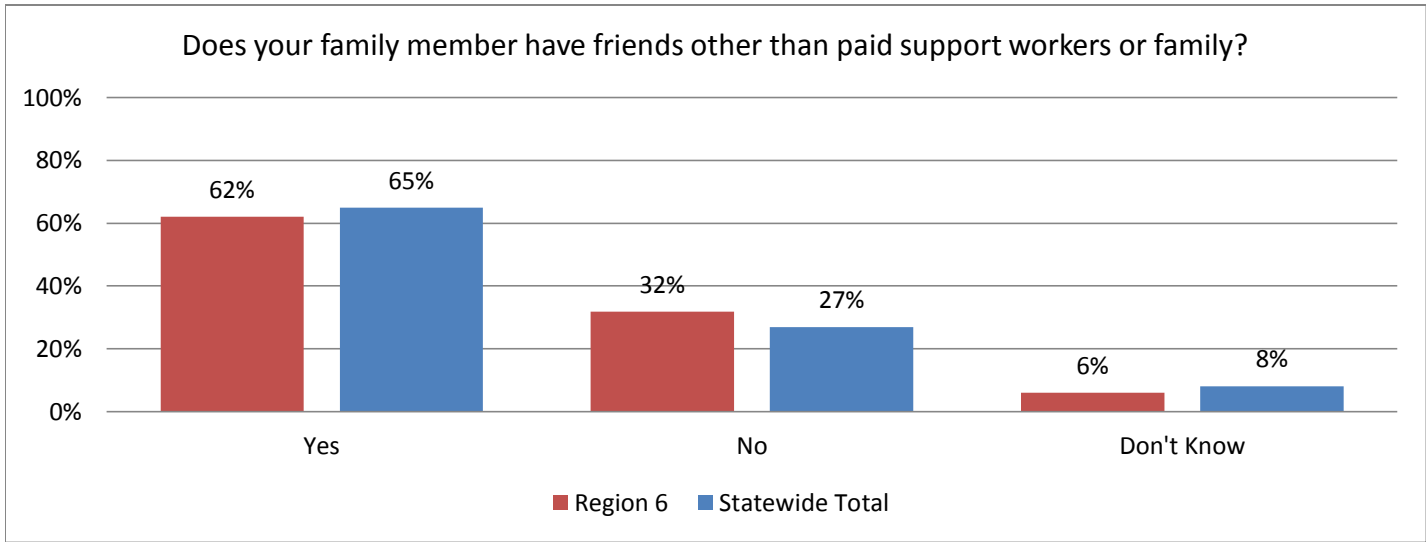
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Satisfaction - Choice



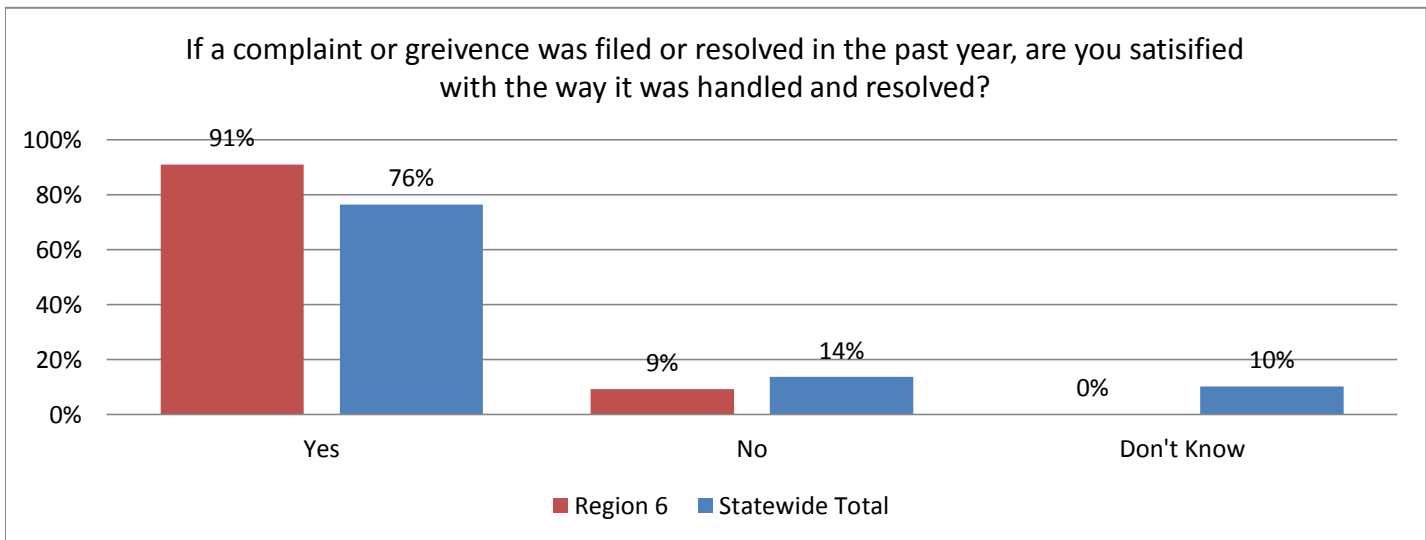
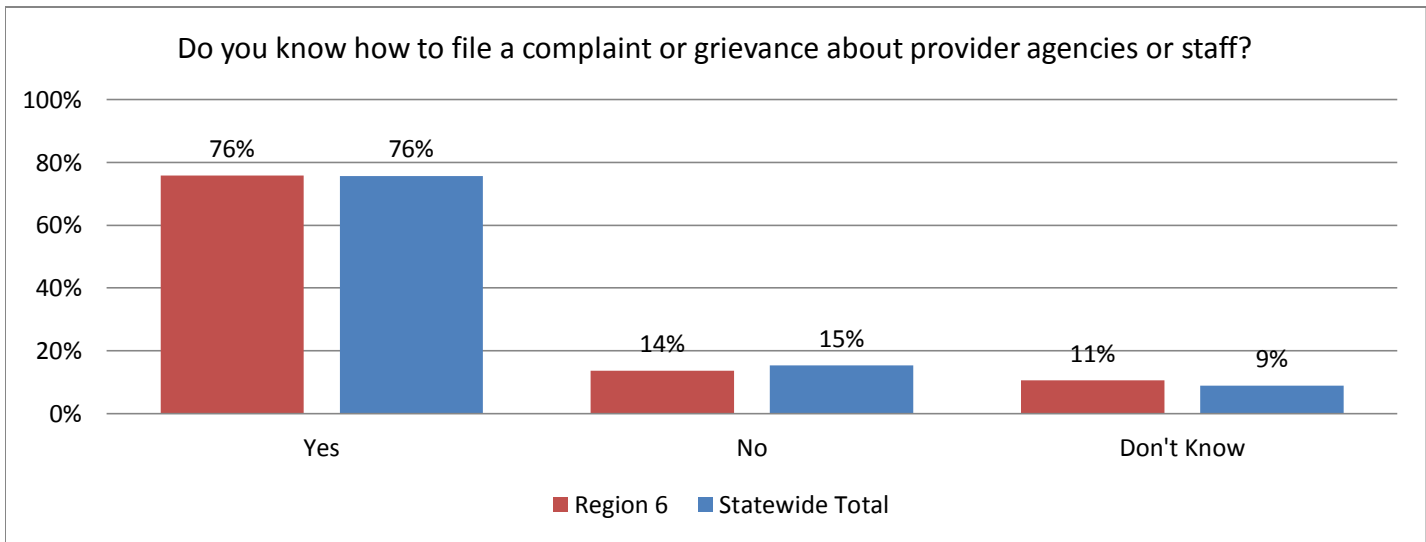
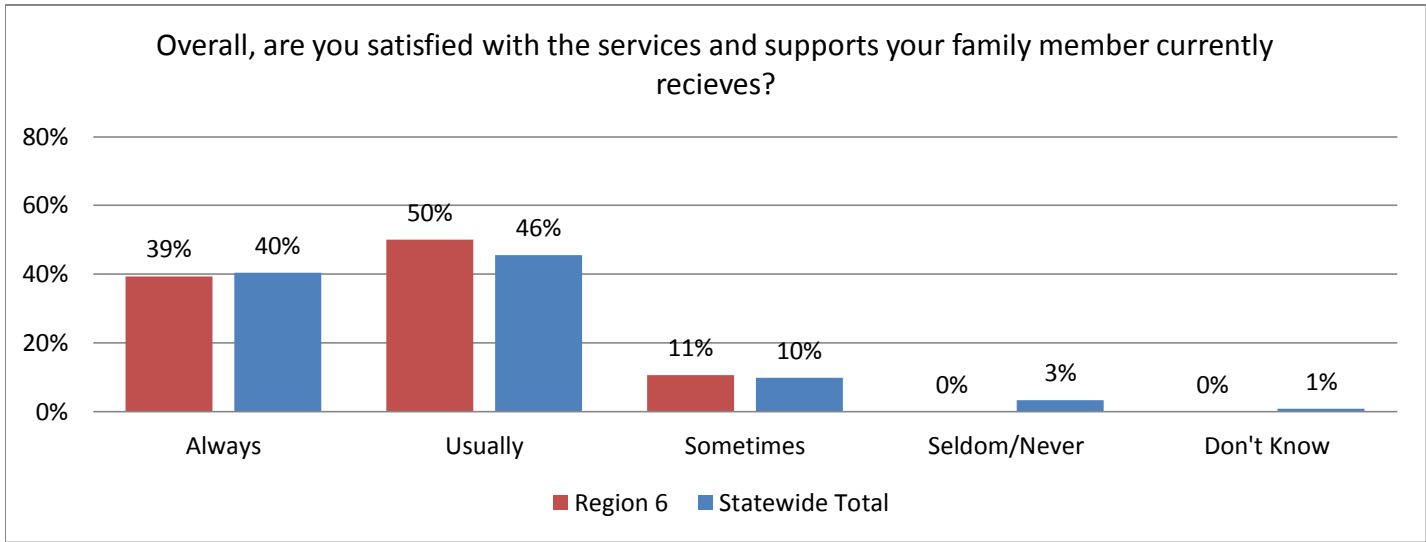
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Satisfaction - Choice



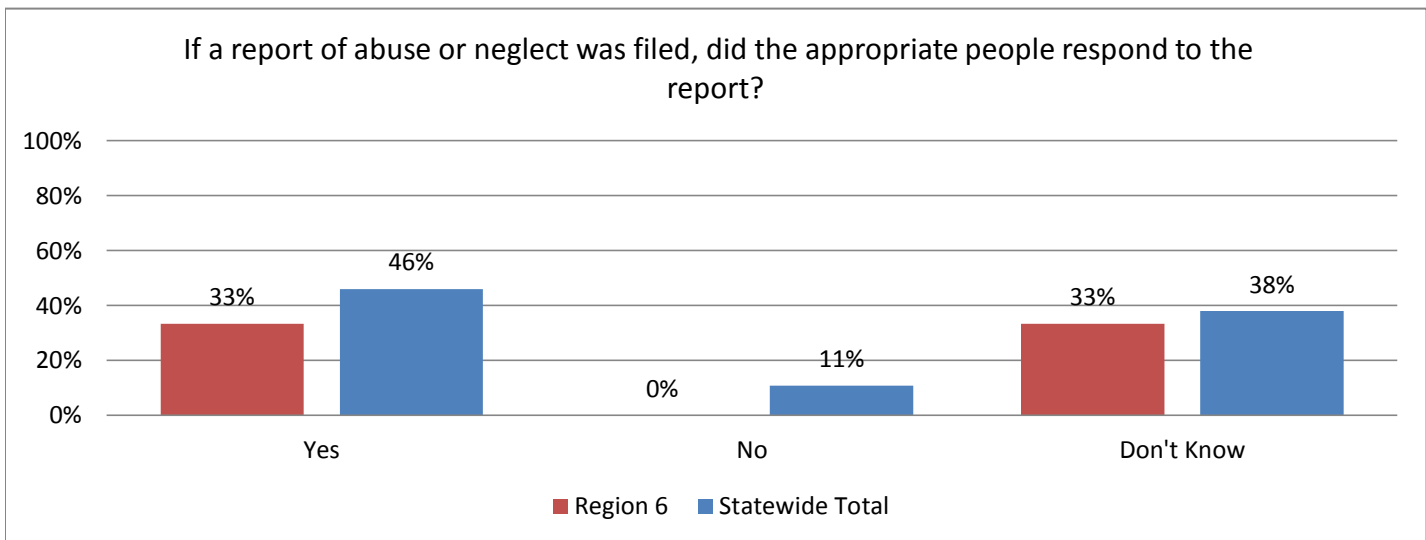
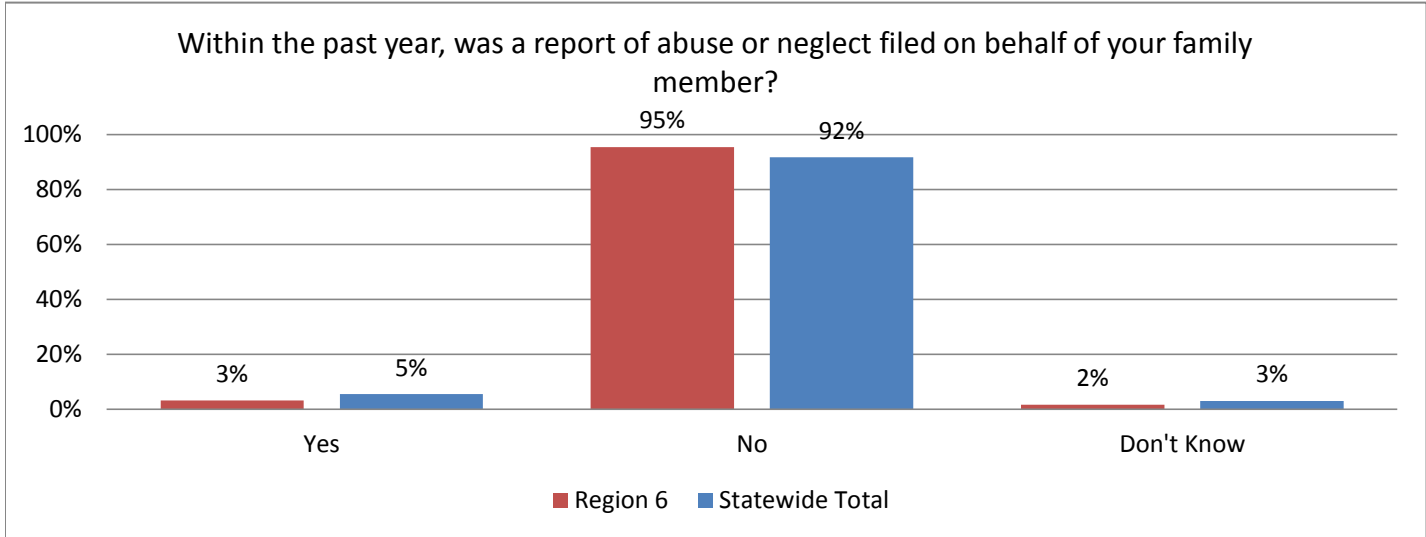
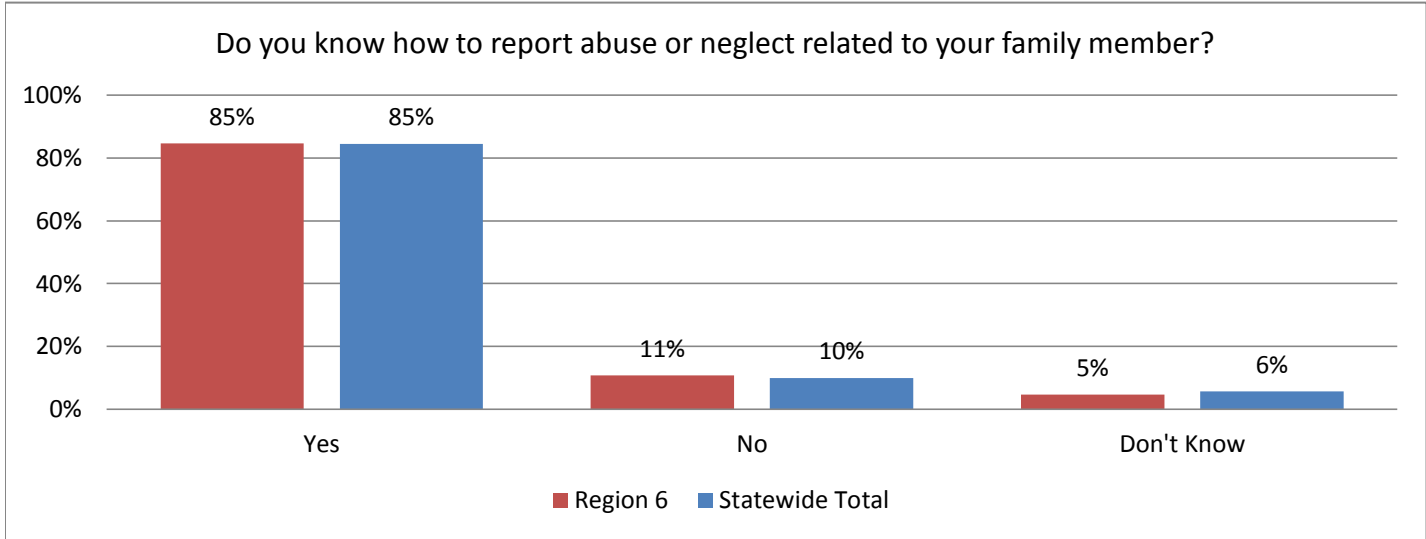
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Satisfaction & Complaint Filing:



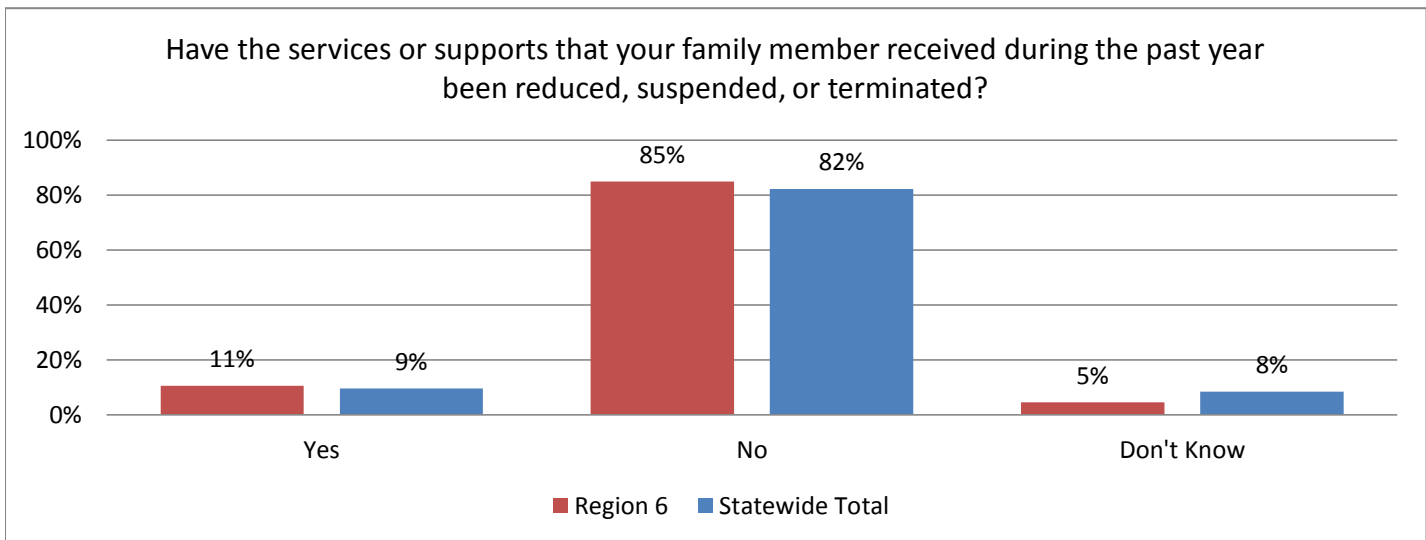
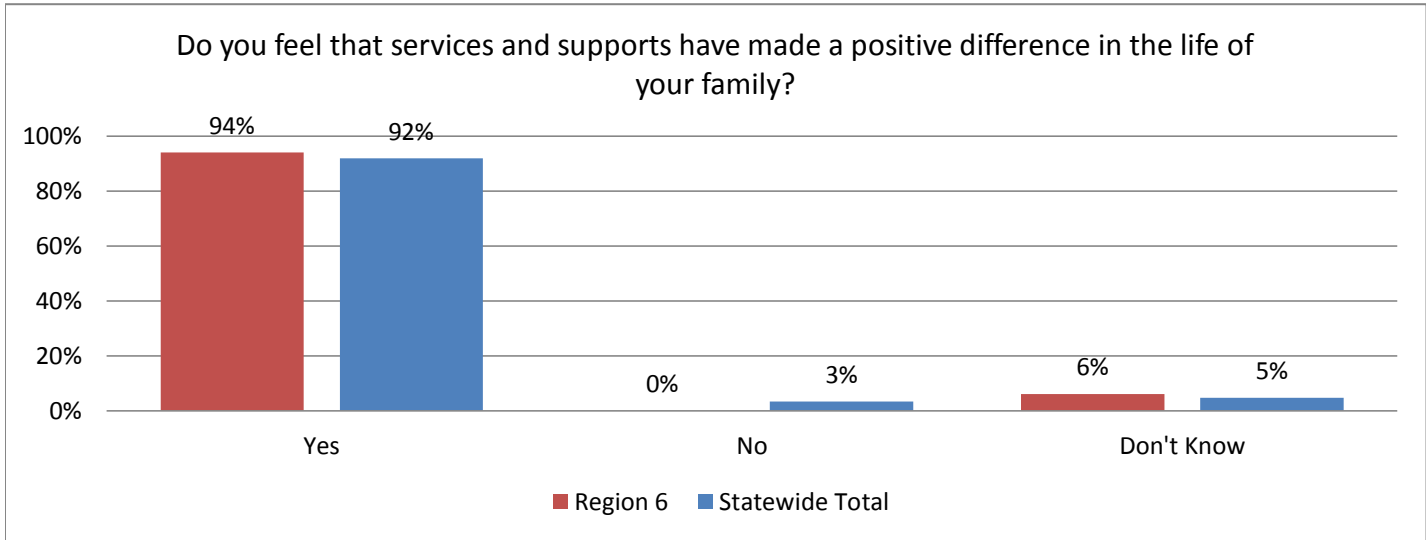
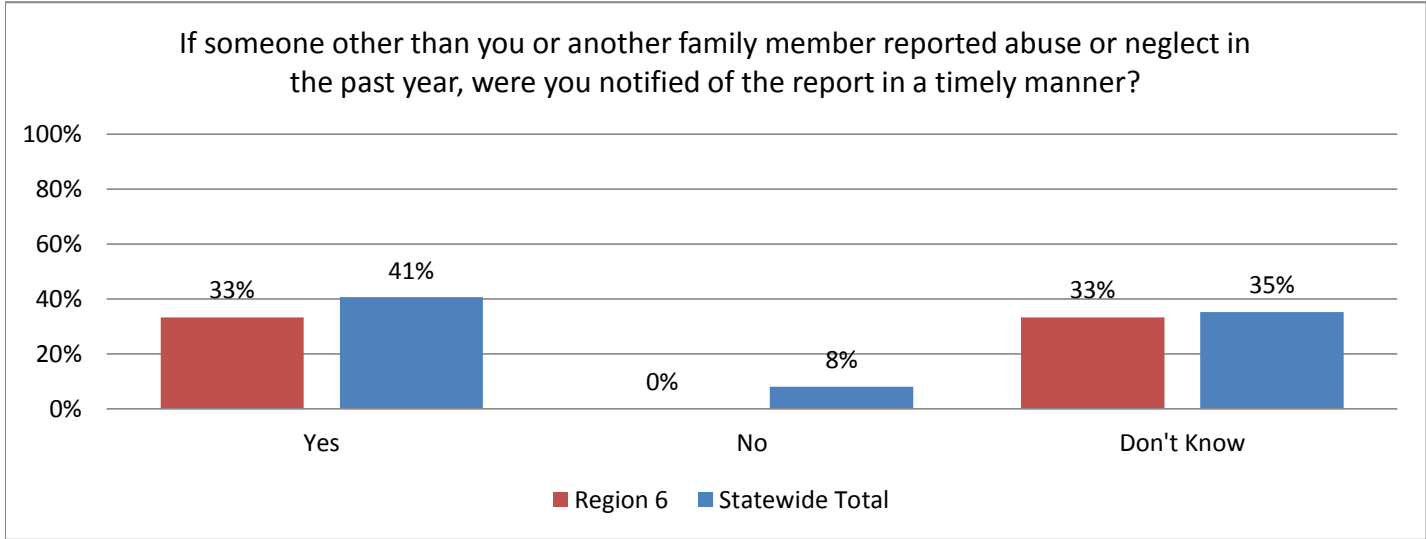
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Satisfaction - Abuse & Neglect Reporting:



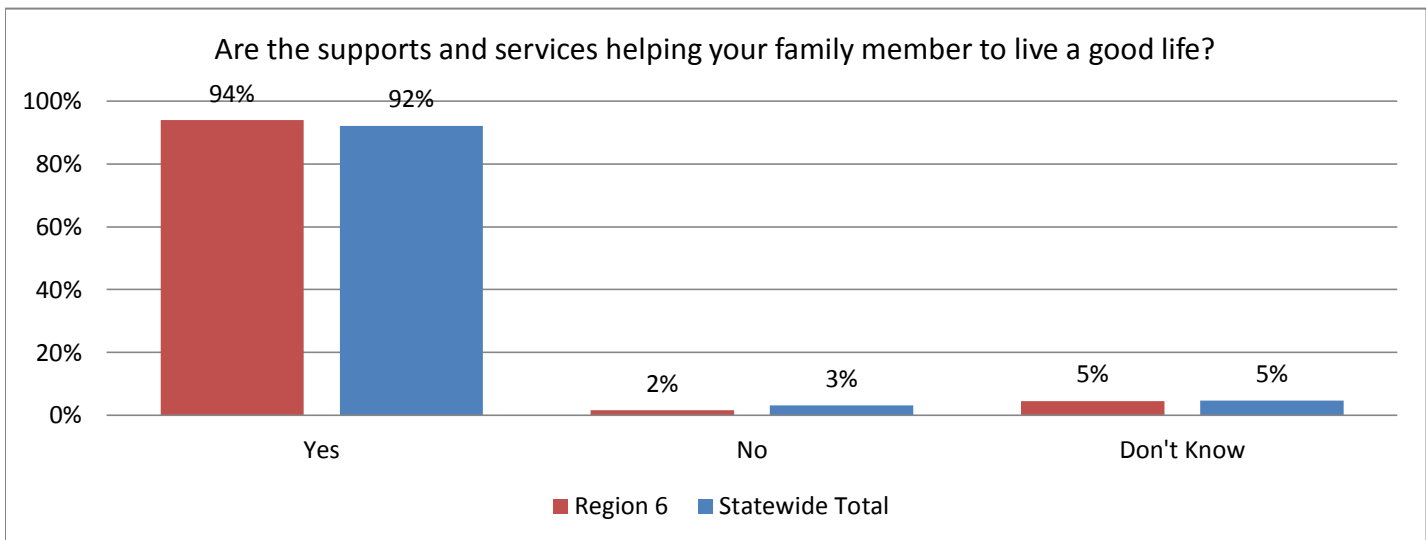
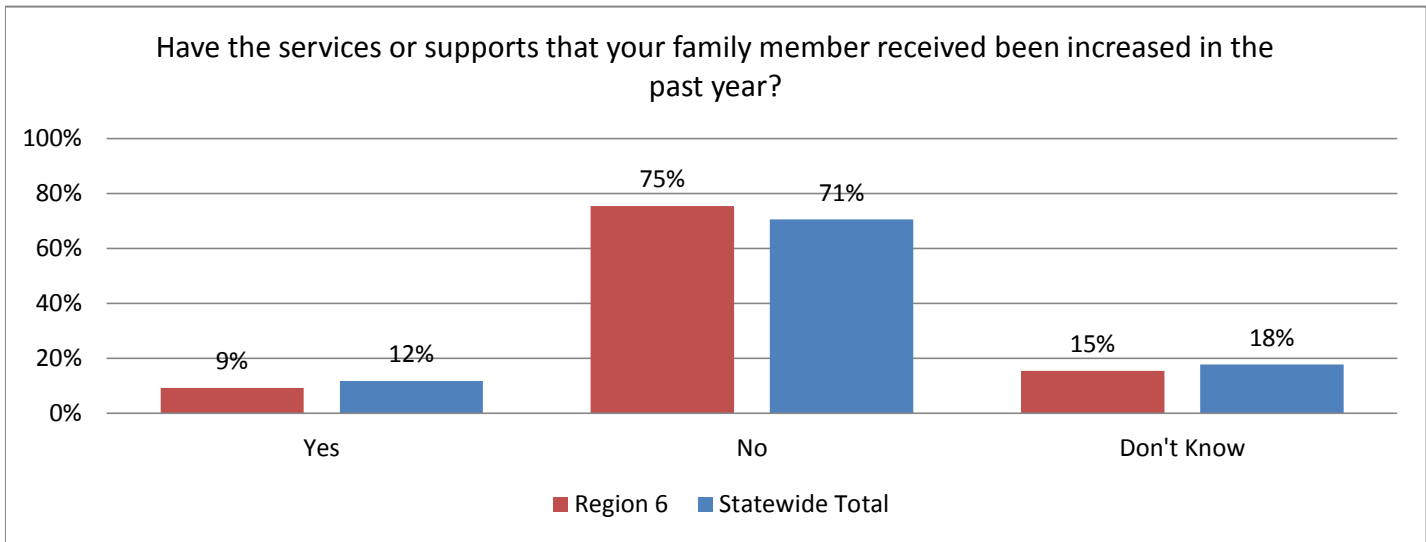
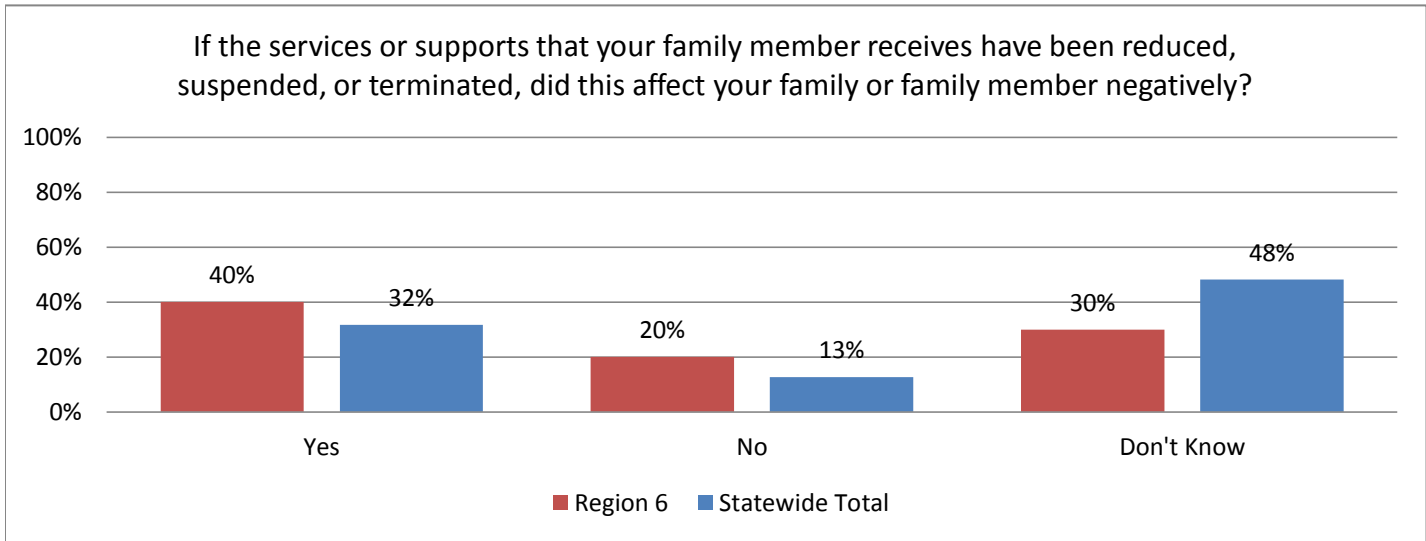
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Satisfaction:



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Satisfaction:



Comments - In-survey "Other"

B: Where Family Member Lives

Enhanced family home with another disabled adult
ISO
Parents
Residential school setting - out of district placement

F13: Other Disability

ADHD, visual motor impairment
Aspergers syndrome
Chromosomal disorder
Frail body
Moderate mental retardation, intermittant explosive disorder, impulse control disorder, adjustment disorder
Mutism, OCD
Non verbal
note: Brain injury due to lack of O2
SID, ADHD

G7: Other Health Condition

Chronic constipation
Hypoglycemic
Kidney
Narrow pallet
Obese, osteoarthritis knees and hip
Obesity
Scoliosis, tight heel cords corneal scratches ongoing
Thyroid disorder

I5: Other Communication

ASL, basic written English
Gestures and sign language
Sign language, she can hear and talk

M9: Other Guardian Relation

Previous foster mom

M9: Other Daytime Activities

Does outings with host family and her guardian
Easter Seals day program
Full time school
Goes out in the community
Goes to ISN office (too much)
Has new program in community working toward voc rehab, has worked in the past
Outings food shopping supervised
Sells Avon
Sheltered workshop/community center activities
Visits home two weeks in spring and 4 weeks in summer
Visits with guardians every other weekend
Weekday shopping, weekend events

S: Other Respondent Relationship

Friend/person has no family
Self
Step father

5: Other Planning Help

Behavior management
Funeral/cremation services
Who is going to take care of her when we are gone

36: Other Services Needed

Consistency with staff
Dentist
Psychiatrist. All other services are well provided. Psychiatrist is VERY difficult to find.

NH2: Other Enough Services

Not sure
Nothing in NH for PWS
There is a great need for more group homes

44: Other Community Involvement Barriers

Behavior, inappropriate aggressive behavior in community
Behaviors
Behaviors, social difficulties at times
Bi Polar (depends on mental status)
Deceased
Depends on client's moods
Difficulty trying something new
Hard time communicating
His own lack of motivation to participate
Likes to isolate
Mobility - has history of falling
Mobility issues, wheelchair van
No interest (except for dining)/non participant
Physical condition
Physical limitations, attends activities with host family
She chooses not to go into the community except for restaurants or shopping
She usually gets to do what she wants to

2018 Family Guardian NCI Survey Results
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Comments - Information & Planning:

All is well

Client had 7 providers in 15 years. We feel client needs consistency of a group home.

Communication with parent/guardian sporadic/inconsistent at best

Contact/information is always maintained with the ISO home and direct staff at the day/job site. Less communication with case worker/manager, agencies, often numerous messages must be left before a call back.

Happy with current placement - information is readily given should there be a need. Included in most planning and/or changes.

I have been informed when family member needs to go to a doctor

Information on resources provided for family member financially would be helpful

Informational meetings re: changes in law, both state and national, should be offered in a variety of locations around the state and open to anyone.

More contact would be helpful. Planning for transition has been poor and could be greatly improved

Pleased with the direction the planning for housing and supports is taking.

She sells Avon and volunteers at a local hospital. Also bowls on a Friday night bowling league which includes special olympics. She also attends dances and church.

The provider reports to me regularly about planning and any changes

The staff does a great job

The team almost always seeks input for planning daily activities however the follow through has not been as good.

There is too little for people with disabilities to do in NH. How can you plan a day for nothing to do?

This area has been adequate

Too many meetings, too much paperwork, too many meetings that not much can be finalized which leads to another meeting. It's difficult to get a team together with schedules & work, etc.

We plan for family member at annual mtg. All has gone well and smoothly

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Access & Delivery:

Again, contact/information is always there with the ISO home and direct day staff. Case worker/manager, agencies often 'forget' to pass on information, dates of meeting, etc.

Constant changing of staff and case management in the last year has been confusing and frustrating as it doesn't provide good service and continuity of care

Dental and therapist for dealing with depression are lacking.

Difficulty of finding and maintaining of staff.

Family member receives 1-1 support for community & work activities; constrained by budget

Family member's support services are very good. No problems.

If staff were paid more for the job they do we would have more access to interested people.

Information is a plus

It seems that my son has a good system of supports

Receives good support in all needs.

Staffing has been a problem. Kate's staff has changed quite a bit over the last year and the agency has been understaffed for some time - many months.

Support staff is good mostly, but often physically worse off than client. Cannot really support.

Team support is #1 all working for the same goal.

The staff cares for her in a very positive way

There are an inadequate supported employment opportunities

This area lacks in staff who can fully communicate with family member

Very good

Very good, however burnout among providers, very hard to get and keep good providers, providers need to have support, more money, and services to support them from burnout.

Choice & Control:

Because the pay rate is so low, it makes it very difficult to find and keep qualified staff. It takes a great deal of time to adequately train staff. With a huge turnover in this field it can be very difficult.

Case managers and direct support staff change too often to have any consistency. Work overload or low pay probably reason. We do get to meet a lot of people!

Case managers frequently change, I did not think we could request a change as it seems based on staffing. We have never felt the need to change. consistency is best for us.

Choice and control is always there with ISO and direct day staff. Not always so with case worker/manager, agency.

Do not always have a say in choice of living situations, current environment is satisfactory.

Far too much time spend in 'daycare' environment

It's all temam work choices discussed and we reach the one that is the best fit for the situation.

Not enough choices in Hillsborough county. Had to reach out to another county. Not enough funds, wait on lists & lists.

Same as above.

She always is included in decisions regarding her care.

There is NO other placement in NH that would be appropriate for family member

Very much so

We have had many changes in case managers but with communication to management, adequate changes have been made.

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Comments - Involvement in Community:

As much involvement with the community as possible.

Client would not enjoy many community activities due to limitations.

Family member always has opportunity to go out and socialize. Depends on his mental state mostly.

Good

Increase social opportunities, organized activities w/peers, dances, socials

It is important for my son to participate in religious activities he has always enjoyed. The provider assures that he does, even though it isn't the same religion they practice.

Member's own lack of motivation to participate is greatest obstacle. Money to do things is second.

Need more support groups for siblings, parents, etc.

Not enough programs. Companies need more training to employ adults w/disabilities. We need more work and more companies willing to step up and hire. Voc rehab programs need more job openings.

Our family member is very busy during the week but very bored on Saturdays choices are quite slim.

Our son volunteers at a haunted house annually. He volunteers at a blood bank at the anime convention.

Overall, we are blessed with caring providers. However, there is a degree of 'warehousing' in regards to weekly program activities.

She participates as best possible for her age and development

Working on that more as we move ahead.

Satisfaction with Services:

All needs are well met

Could not be happier with adult foster care providers - angels!

Definitely satisfied with member of the ISO and direct staff during the day/home services. All her providers in the above keep us included and well informed. We make plans and present decisions as a team.

Family member is doing exceptionally well. Very well cared for!

Generally satisfied and grateful for the help!

Happy with services.

I would say that we are satisfied with what has been done so far, but it's a work in progress.

I'm very satisfied w/the care and treatment by the staff, they do a wonderful job.

More personal work/activities need to be available

My daughter is receiving great services and support from all who care for her.

Need more job development to get a job!

Overall we feel our supports are doing the very best they can with resources provided.

Responsive when asked. Our case manager has attended all IEP meetings and is wonderful!

Thank you one and all!

The service provider is doing a good job in spite of having difficulties finding staff

This is adequate

Very happy he has the services he does.

Very satisfied

Very satisfied with agency and vendors. Not satisfied with employment services. Too much red tape. Too long process.

We have great services.

Would be more satisfied if more consistency with staff and got things I have requested for years and years.

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Additional Comments:

Everyone we have worked with have been great the agencies do a great job providing people with services and improving the well being of and lives of people with disabilities. We thank you all for the great work you do. It makes my work easy and my peace of mind is eased.

Family member is deceased. There is no need to fill out any more surveys.

I always have to ask for reports on my ward. I never get any daily/weekly reports. I am not informed about Dr. appointments. The ward is allowed to sign at doctors.

I don't like feeling like if I do not provide funds medical/dental needs will not be addressed

I think more information about self advocacy groups needs to be shared with service coordinators and families as well as the adult with the disability.

My family member has not had a job and is still waiting 3 months for all paperwork to be pushed through. State Voc Rehab program very slow. We need to get many more GOOD employers on board to be willing to HIRE. We need more natural supports trained at these work sites to support. People with disabilities are GREAT workers if given a chance. Very frustrating. Job support needed badly!! Great jobs needed badly!!

NH has extremely poor access and lack of services. We have had to have a majority of services - hospitalizations, schooling, etc - out of state as NH has NOTHING ADEQUATE. Extremely difficult to get/have access to any mental health agencies (therapy, psych, etc)

Not as satisfied with the area agency, case worker, manager. We are often not included in decisions. For example her case manager was recently changed. Neither us nor her ISO family were ever informed. We found out when we made a phone call to the agency! Her service plan meeting was made without checking the dates we were available. As parents/guardians this was important. We were told the date on the morning of the meeting by another staff member. Needless to say the meeting did not take place. Meeting rescheduled, but we had to keep calling about the date. Not all her support staff such as direct day staff had been informed.

Not at this time

Our family member in the past year moved from a very poor service provider to a very good one. The area agency was very involved and critical to success of this move

There is a need for consistency for caregivers and especially new parents (and old like me). A child with disabilities is very traumatic. In my case total surprise at birth and 44 years later still is. No one or agency has really ever explained how and where to get support, counseling, or explained all there is available. How to get funding, how to manage their monies. Young new parents need a lot of support to get rid of that 'all alone' feeling. Should be part of every plan. Should be implement at the hospital at birth!

We are concerned that over time the state provided financial support will erode in terms of buying power due to inflation. We would like to see a COLA implemented similar to what is done in social security.

We do not have the confidence our family member would be receiving the cre needed if we weren't as involved as we are. Our desire is to be able to step back and not be as involved.

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Survey Comments:

Hope this is of benefit to you.

I have filled out numerous of these in 43 years. Never heard of or seen results, would be interesting. I would really like to see more for parents concerning their mental support. Guy (sp?) Goodwin (sp?) Chichester, 603-486-2675

I hope this info helps you with what you need. Glad to help.

I live on my own so I filled the survey out myself. Next time could you not make it sound like it's just for disabled people living with a family.

I miss the days when dental care was provided. To use personal monies to pay for dental care puts a strain on funds used for more community time, vacation and other needs that arise throughout the year.

Not sure what this was about

The survey will only work if area agencies and vendors and employment services fix the problem. Funding is a huge problem. Burnout problem. If you can get these great young adults out in the community and working and supported without burnout of staff and turnover. They will be successful. **Take care of support staff, help them not burnout or leave for more money. We need more employers to hire, more transportation and driving programs. Sunday bus hours, etc.

There is little in this survey that takes into account mobility challenges

This survey was great to help us understand staff and services provided to us.

Very pleased with Kenelark, he keeps me aware of everything.

Wasn't completely sure who/where these questions were referring to. Most of our services except our case manager is out of state (so answers to questions are for out of state) due to NH lack of services.

We are extremely happy with the ISO family and direct staff at her day program. We are not as happy with the agency staff, case worker, etc. They often neglect to inform us about important information (such as changing case managers) then wonder why we question their decisions. It is counterproductive to leave half of her team out of the loop. It not only wastes time and energy but keeps the team divided. We need to actually work as a team!

Will we get feedback? Will this make any difference in family member's services? If not, I've wasted 20 minutes! i would much prefer this survey not to be anonymous. It's a lost opportunity, names should be optional

Yes, under the comments. There are headings of Access and Delivery of Supports and Satisfaction with Services, but then we are told not to enter any personal information such as names of providers, case managers, agencies, or contact information. Sue has several different supports. How do you know who or what support my answer refers to?