

2013 Adult Family Survey Demographics

Mail Survey of Family Members of Adults with MR/DD Who Live in their Home

Mailed 1200 Surveys in August 2013 and 500 Surveys in November 2013

Yielding 433 Useable Responses

Average age of family member	36.1
Percent who are the primary caregiver	94.5%
Percent who are guardian/conservator	59.1%
Family member lives at home	97.0%
More than one family member with disability	13.6%

Gender	
Male	60.8%
Female	39.2%

Respondent's Age	
Under 35	8.0%
35-54	26.8%
55-74	51.6%
75+	13.6%

Race & Ethnicity	
African American	17.9%
White	59.2%
American Indian/Alaska Native	1.9%
Asian	1.0%
Native Hawaiian/Pacific Islander	0.2%
Multiracial	3.6%
Other	1.0%
Hispanic	17.9%

Out of Pocket Money Spent	
Nothing	24.7%
\$1- \$100	12.6%
\$101- \$1,000	36.6%
\$1,001- \$10,000	23.5%
Over \$10,000	2.6%

Relationship to Family Member	
Parent	85.6%
Sibling	5.6%
Spouse	0.2%
Other	8.6%

Primary Means of Expression	
Spoken	69.5%
Gestures/Body Language	21.8%
Sign Language/Finger Spelling	2.4%
Communication Aid/ Device	2.2%
Other	4.1%

Services Received	
Financial Support	12.5%
In-Home Support	50.9%
Out-of-Home Respite	27.1%
Day/Employment	45.7%
Transportation	52.1%
Other	25.8%
Social Security Benefits	92.0%

Respondent's Health	
Excellent	8.5%
Good	49.9%
Fair	30.3%
Poor	11.3%

Household Income	
Below \$15,000	37.6%
\$15,001-\$25,000	20.2%
\$25,001-\$50,000	24.5%
\$50,001-\$75,000	7.4%
Over \$75,000	10.3%

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Other Disabilities

Mental Illness	39.7%
Autism	36.2%
Cerebral Palsy	37.6%
Brain Injury	28.7%
Seizure Disorder	49.1%
Chemical Dependency	7.8%
Limited or No Vision	16.3%
Hearing Loss	12.0%
Alzheimer's Disease	1.7%
Down Syndrome	28.2%
Prader-Willi Syndrome	5.2%
Other Disability	43.0%

Adults living in home- not Family member

One	33.2%
Two	47.3%
Three	14.4%
Four or More	5.2%

Requiring Medical Care:

Less frequently than once/month	72.3%
At least once/month, but not once/week	21.7%
At least once/week, or more frequently	6.0%

Support to manage behaviors:

No Support Needed	54.1%
Some Support Needed	32.7%
Extensive Support Needed	13.3%

Level of help with daily activities

None	21.3%
Little	20.3%
Moderate	23.4%
Complete	34.9%

Primary Language

English	86.3%
Spanish	9.4%
Other	4.3%

What does family member do during day

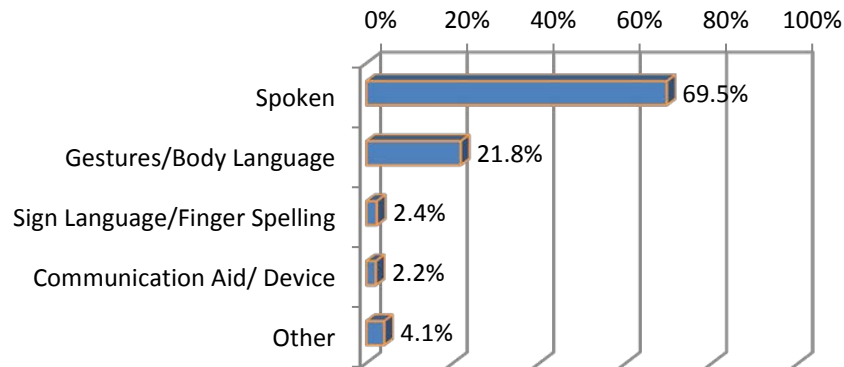
Out of Home Day Program-unpaid	31.3%
Out of Home Day Program-paid	12.0%
Vocational Training	4.3%
Community Employment-unpaid	4.1%
Community Employment-paid	5.1%
In-home Day Supports	18.3%
At home-by choice	12.0%
At home-no services	5.8%
At home-other	7.7%
Other	14.5%

Highest Education Level:

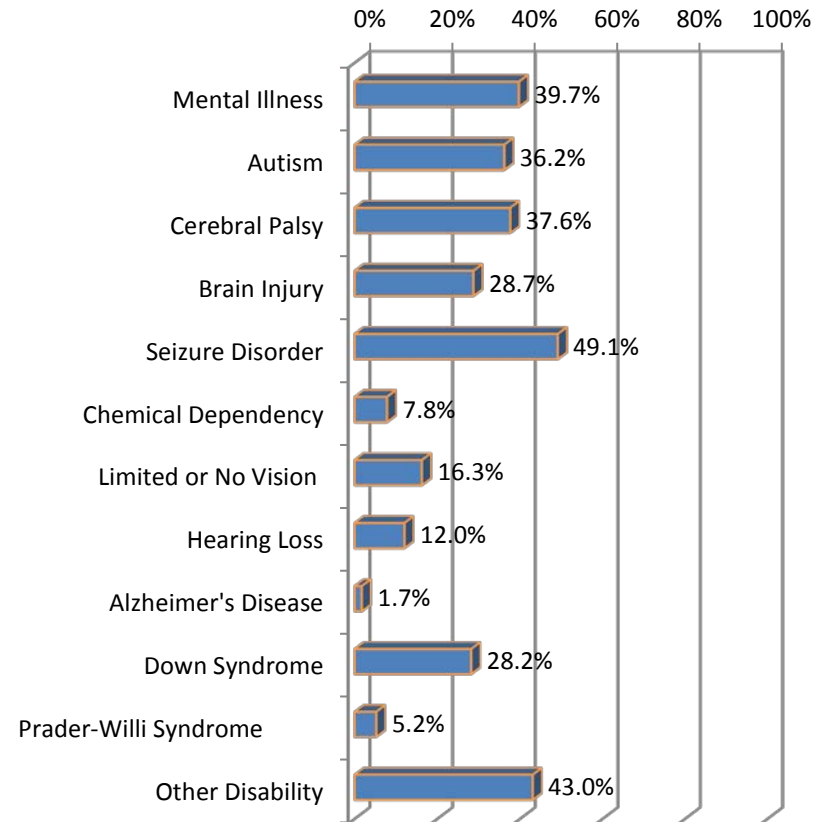
	Family Member	Respondent
Less than High School Diploma/GED	49.2%	13.3%
High School Diploma/ GED	45.8%	32.5%
Vocational School	2.9%	6.7%
Some College	1.0%	23.2%
College Degree	1.0%	24.4%

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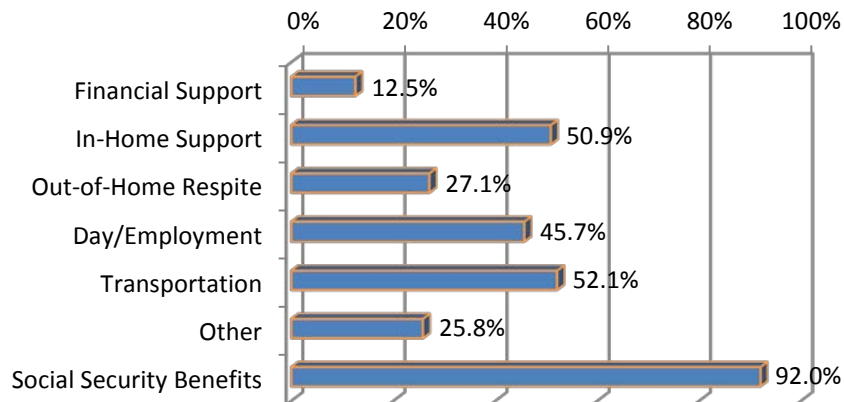
Primary Means of Expression



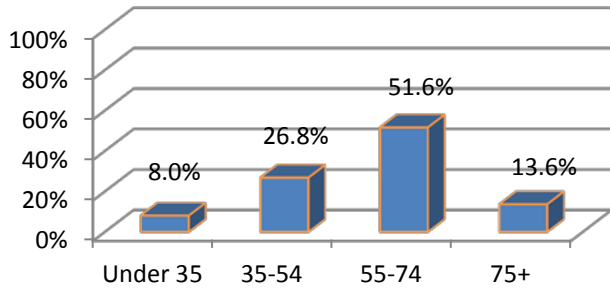
Other Disabilities



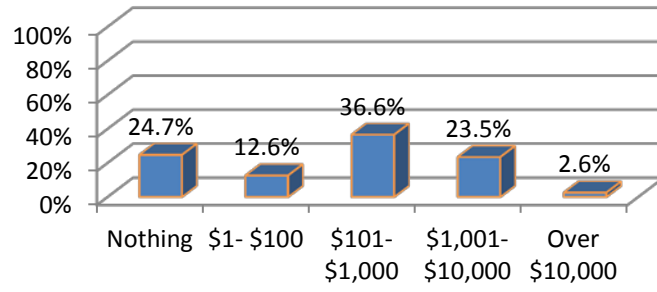
Services Received



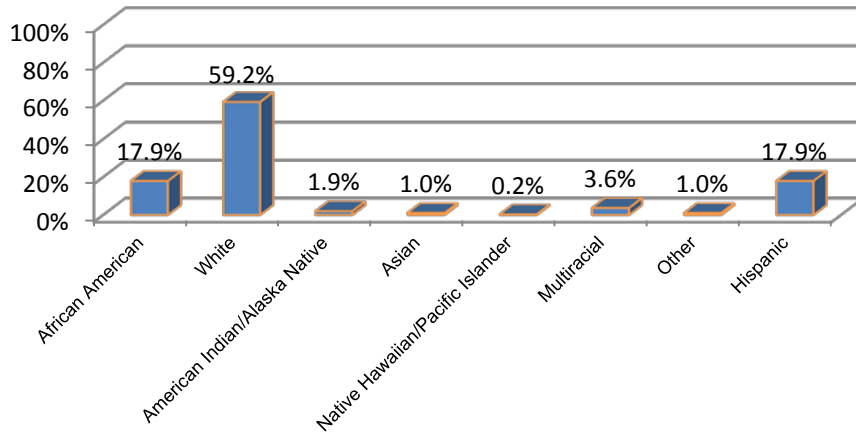
Respondent's Age



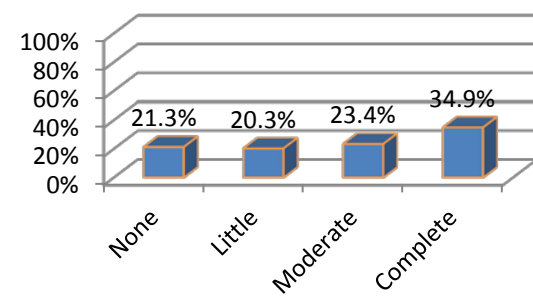
Out of Pocket Money Spent



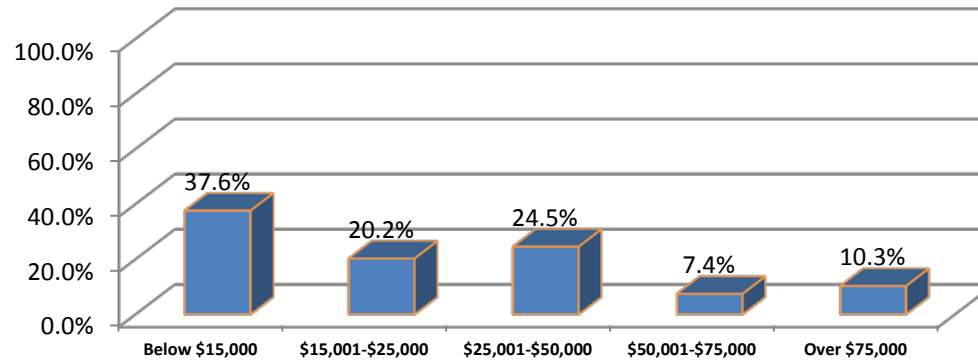
Race and Ethnicity



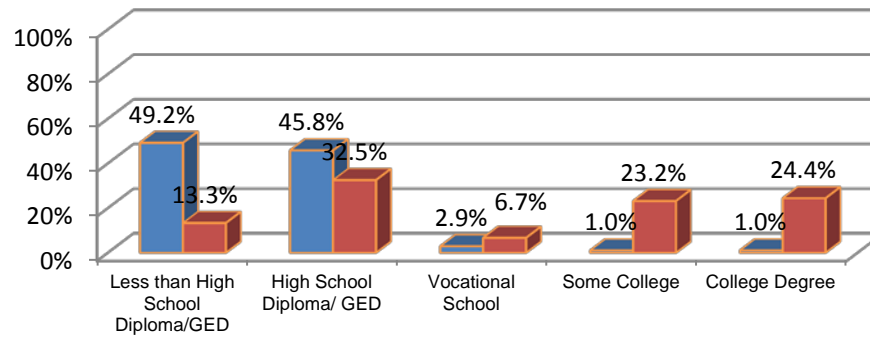
Level of Help with Daily Activities



Household Income



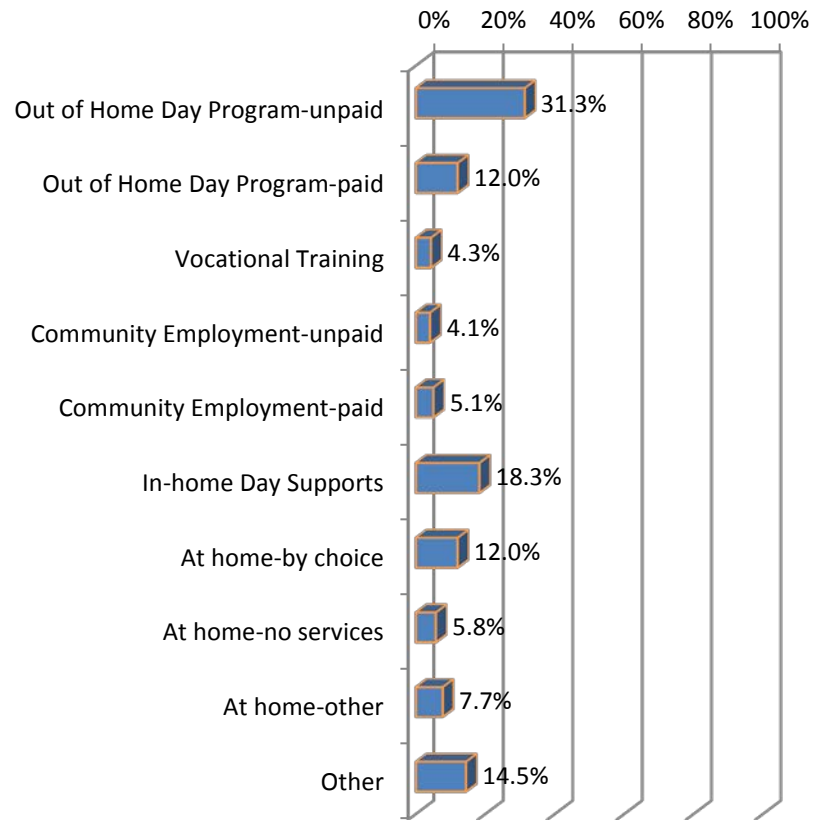
Highest Education Level



Axis Title

■ Family Member ■ Respondent

What Does Family Member Do During Day?

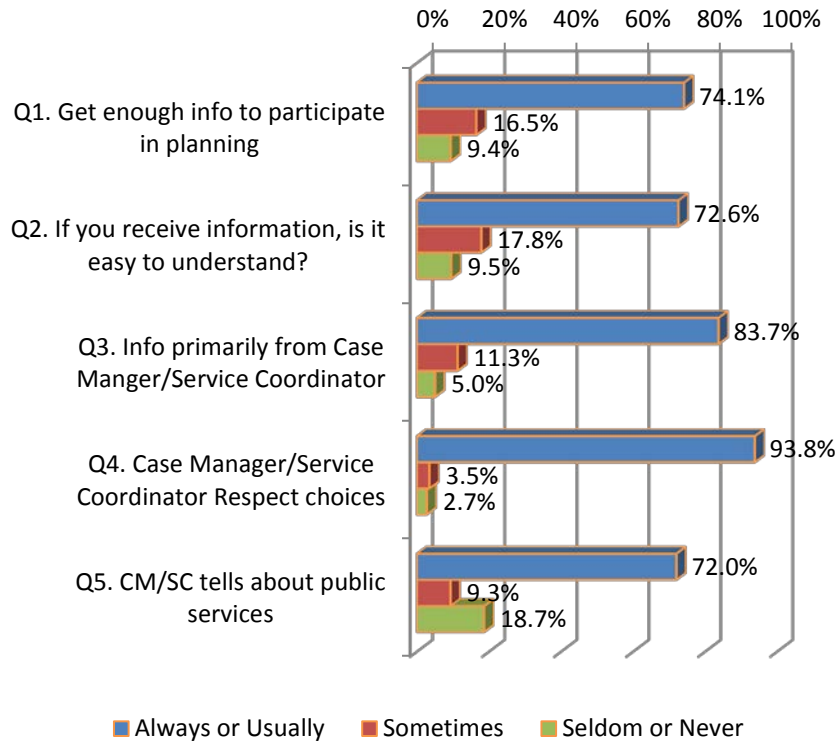


Info & Plan

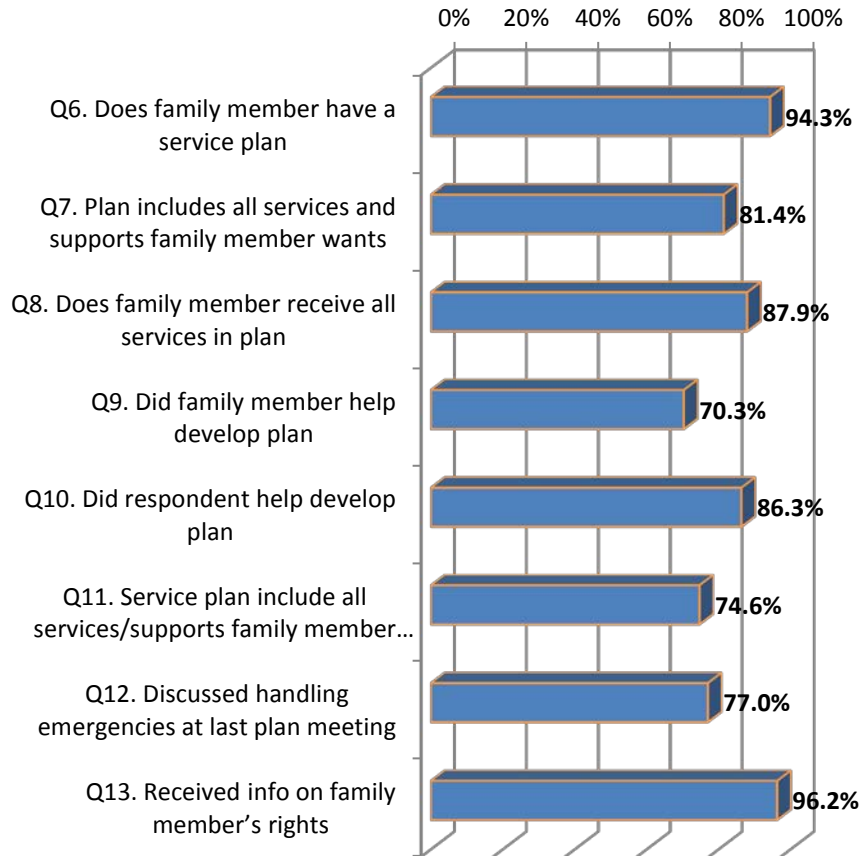
Adult Family 2013 Results

Q1. Get enough info to participate in planning	
Always or Usually	74.1%
Sometimes	16.5%
Seldom or Never	9.4%
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Q2. If you receive information, is it easy to understand?	
Always or Usually	72.6%
Sometimes	17.8%
Seldom or Never	9.5%
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Q3. Info primarily from Case Manger/Service Coordinator	
Always or Usually	83.7%
Sometimes	11.3%
Seldom or Never	5.0%
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Q4. Case Manager/Service Coordinator Respect choices	
Always or Usually	93.8%
Sometimes	3.5%
Seldom or Never	2.7%
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Q5. CM/SC tells about public services	
Always or Usually	72.0%
Sometimes	9.3%
Seldom or Never	18.7%
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Q6. Does family member have a service plan	
Yes	94.3%
<hr/>	
Q7. Plan includes all services and supports family member wants	
Yes	81.4%
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Q8. Does family member receive all services in plan	
Yes	87.9%
<hr/>	
Q9. Did family member help develop plan	
Yes	70.3%
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Q10. Did respondent help develop plan	
Yes	86.3%
<hr/>	
Q11. Service plan include all services/supports family member needs	
Yes	74.6%
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Q12. Discussed handling emergencies at last plan meeting	
Yes	77.0%
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Q13. Received info on family member's rights	
Yes	96.2%

NCI Information and Planning Questions 1 - 5



NCI Information and Planning Questions 6 - 13
Percent Yes

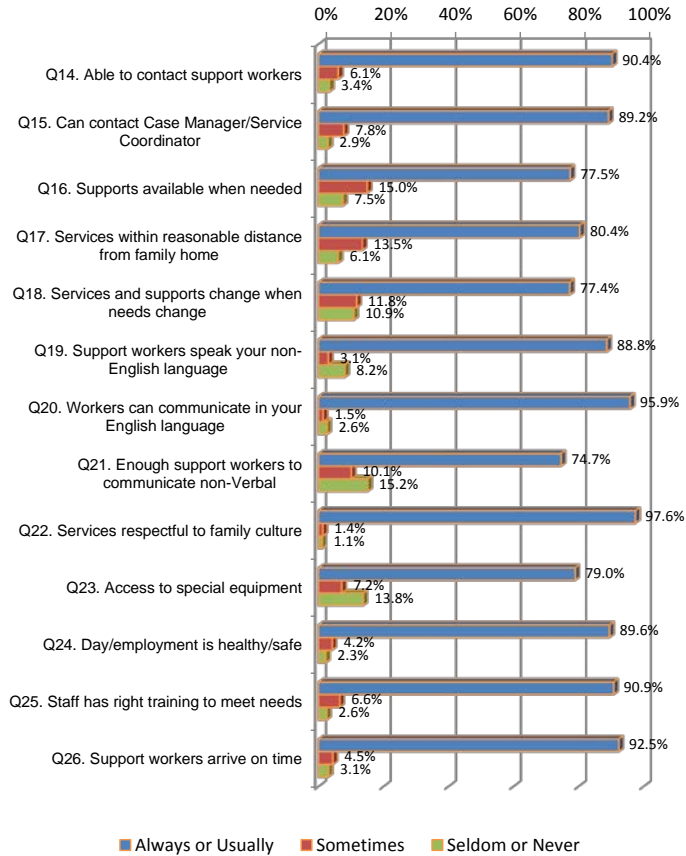


Acces & Del

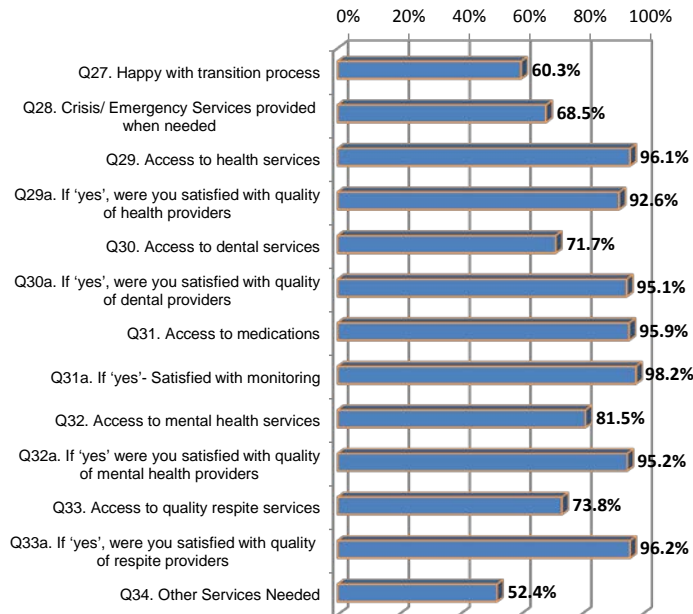
Adult Family 2013 Results

Q14. Able to contact support workers	
Always or Usually	90.4%
Sometimes	6.1%
Seldom or Never	3.4%
Q15. Can contact Case Manager/Service Coordinator	
Always or Usually	89.2%
Sometimes	7.8%
Seldom or Never	2.9%
Q16. Supports available when needed	
Always or Usually	77.5%
Sometimes	15.0%
Seldom or Never	7.5%
Q17. Services within reasonable distance from family home	
Always or Usually	80.4%
Sometimes	13.5%
Seldom or Never	6.1%
Q18. Services and supports change when needs change	
Always or Usually	77.4%
Sometimes	11.8%
Seldom or Never	10.9%
Q19. Support workers speak your non-English language	
Always or Usually	88.8%
Sometimes	3.1%
Seldom or Never	8.2%
Q20. Workers can communicate in your English language	
Always or Usually	95.9%
Sometimes	1.5%
Seldom or Never	2.6%
Q21. Enough support workers to communicate non-Verbal	
Always or Usually	74.7%
Sometimes	10.1%
Seldom or Never	15.2%
Q22. Services respectful to family culture	
Always or Usually	97.6%
Sometimes	1.4%
Seldom or Never	1.1%
Q23. Access to special equipment	
Always or Usually	79.0%
Sometimes	7.2%
Seldom or Never	13.8%
Q24. Day/employment is healthy/safe	
Always or Usually	89.6%
Sometimes	4.2%
Seldom or Never	2.3%
Q25. Staff has right training to meet needs	
Always or Usually	90.9%
Sometimes	6.6%
Seldom or Never	2.6%
Q26. Support workers arrive on time	
Always or Usually	92.5%
Sometimes	4.5%
Seldom or Never	3.1%
Q27. Happy with transition process	
Yes	60.3%
Q28. Crisis/ Emergency Services provided when needed	
Yes	68.5%
Q29. Access to health services	
Yes	96.1%
Q29a. If 'yes', were you satisfied with quality of health providers	
Yes	92.6%
Q30. Access to dental services	
Yes	71.7%
Q30a. If 'yes', were you satisfied with quality of dental providers	
Yes	95.1%
Q31. Access to medications	
Yes	95.9%
Q31a. If 'yes'- Satisfied with monitoring	
Yes	98.2%
Q32. Access to mental health services	
Yes	81.5%
Q32a. If 'yes' were you satisfied with quality of mental health providers	
Yes	95.2%
Q33. Access to quality respite services	
Yes	73.8%
Q33a. If 'yes', were you satisfied with quality of respite providers	
Yes	96.2%
Q34. Other Services Needed	
Yes	52.4%

NCI Access and Delivery of Supports Questions 14 - 26



**NCI Access and Delivery of Supports Questions 27- 34
Percent Yes**

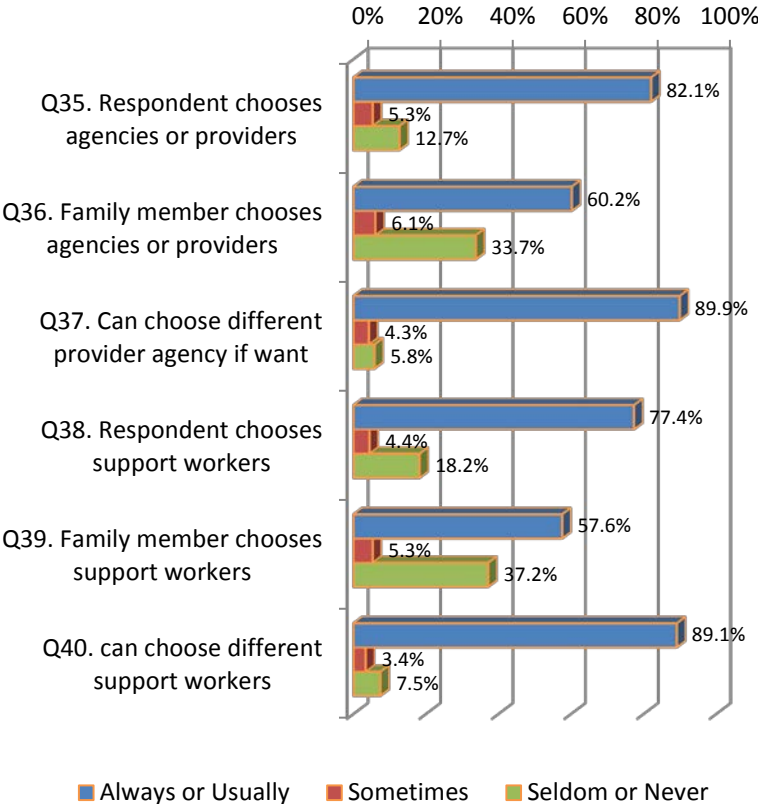


Choice & Control

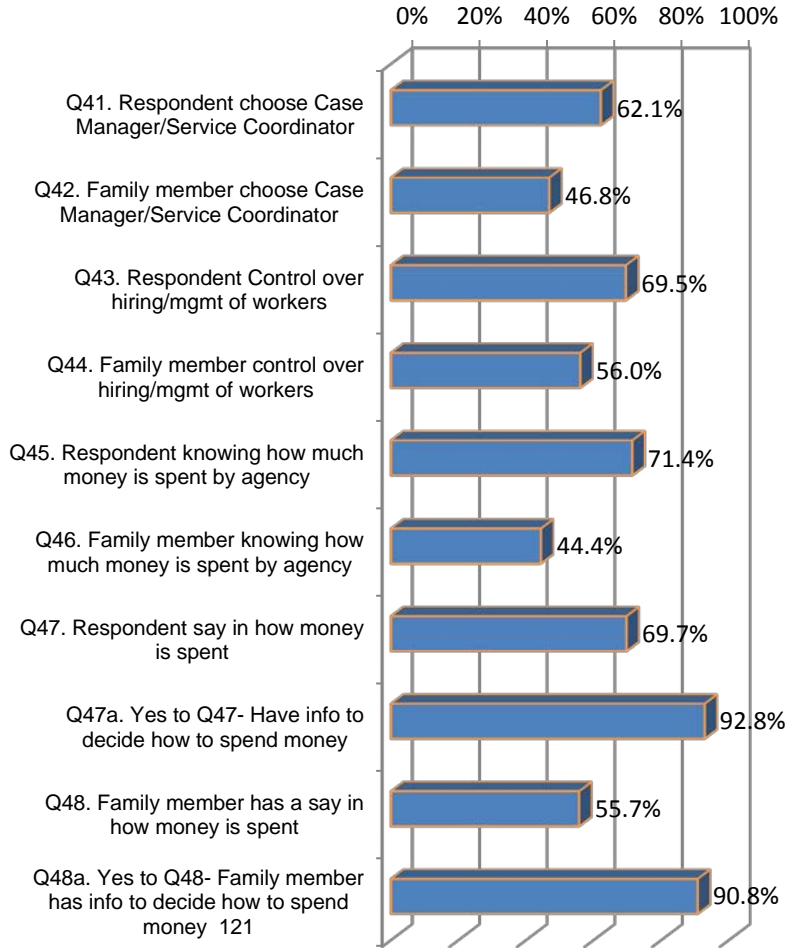
Adult Family 2013 Results

Q35. Respondent chooses agencies or providers	
Always or Usually	82.1%
Sometimes	5.3%
Seldom or Never	12.7%
Q36. Family member chooses agencies or providers	
Always or Usually	60.2%
Sometimes	6.1%
Seldom or Never	33.7%
Q37. Can choose different provider agency if want	
Always or Usually	89.9%
Sometimes	4.3%
Seldom or Never	5.8%
Q38. Respondent chooses support workers	
Always or Usually	77.4%
Sometimes	4.4%
Seldom or Never	18.2%
Q39. Family member chooses support workers	
Always or Usually	57.6%
Sometimes	5.3%
Seldom or Never	37.2%
Q40. can choose different support workers	
Always or Usually	89.1%
Sometimes	3.4%
Seldom or Never/Don't Know	7.5%
Q41. Respondent choose Case Manager/Service Coordinator	
Yes	62.1%
Q42. Family member choose Case Manager/Service Coordinator	
Yes	46.8%
Q43. Respondent Control over hiring/mgmt of workers	
Yes	69.5%
Q44. Family member control over hiring/mgmt of workers	
Yes	56.0%
Q45. Respondent knowing how much money is spent by agency	
Yes	71.4%
Q46. Family member knowing how much money is spent by agency	
Yes	44.4%
Q47. Respondent say in how money is spent	
Yes	69.7%
Q47a. Yes to Q47- Have info to decide how to spend money	
Yes	92.8%
Q48. Family member has a say in how money is spent	
Yes	55.7%
Q48a. Yes to Q48- Family member has info to decide how to spend money 121	
Yes	90.8%

NCI Choice and Control Questions 35-40



NCI Choice and Control Questions 41-48
Percent Yes



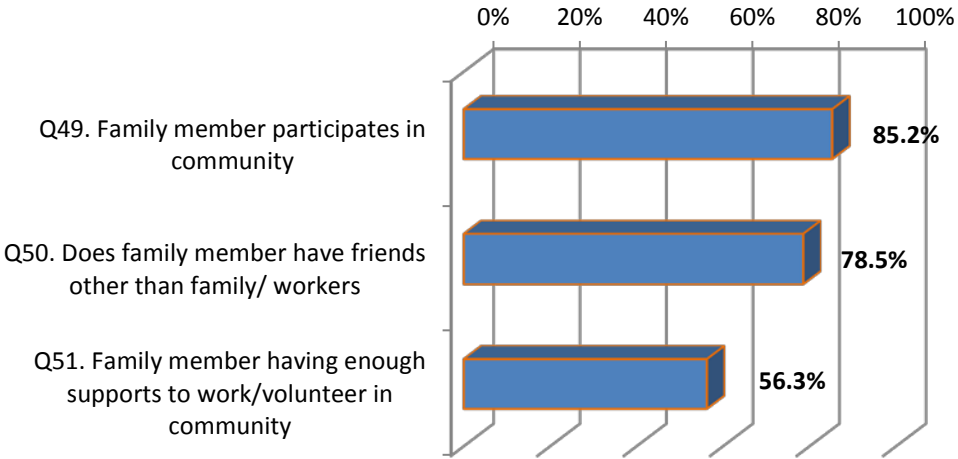
Community

Adult Family 2013 Results

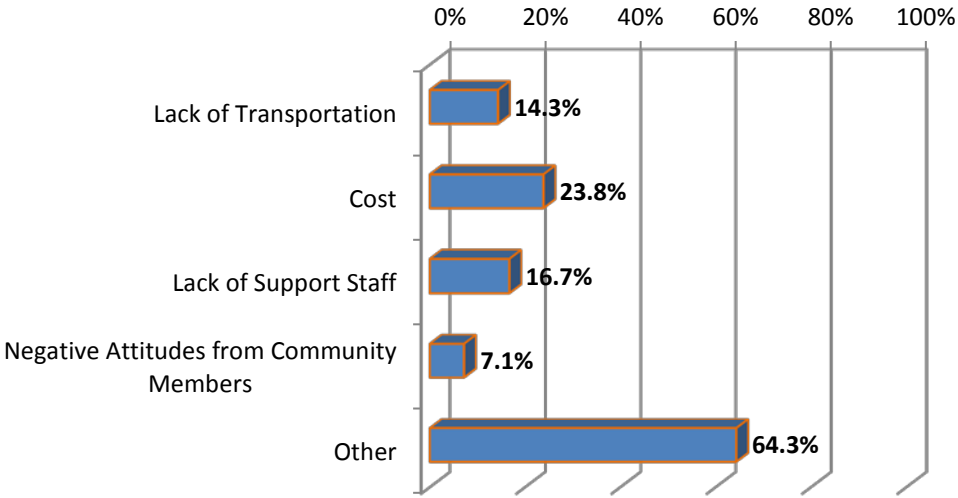
Q49. Family member participates in community	
Yes	85.2%
Q50. Does family member have friends other than family/ workers	
Yes	78.5%
Q51. Family member having enough supports to work/volunteer in community	
Yes	56.3%
Q49a. If No to Q49, why	
Lack of Transportation	14.3%
Cost	23.8%
Lack of Support Staff	16.7%
Negative Attitudes from Community Members	7.1%
Other	64.3%

Percent of 'No' responses to Q49

**NCI Community Connections Questions 49-51
Percent Yes**



Q49a. If No to Q49, why?

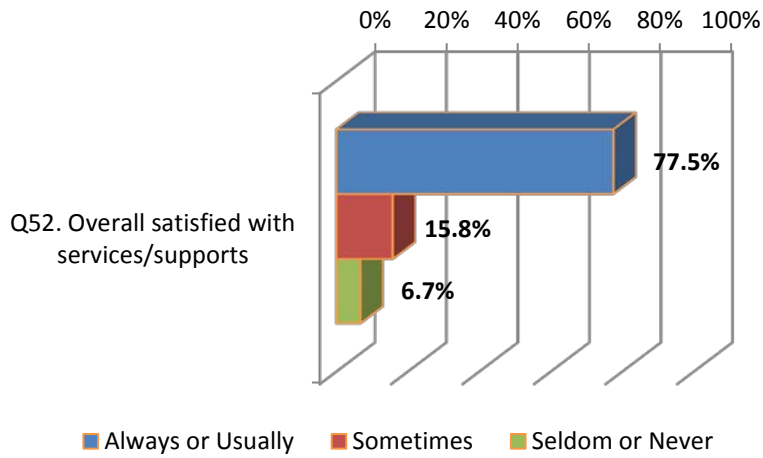


■ Percent of 'No' responses to Q49

Satisfaction & Outcomes Adult Family 2013 Results

Q52. Overall satisfied with services/supports	
Always or Usually	77.5%
Sometimes	15.8%
Seldom or Never	6.7%
Q53. Familiar with filing grievances procedure	
Yes	80.6%
Q54. Satisfied with grievance procedure	
Yes	85.7%
Q55. Know how to report abuse/ neglect	
Yes	93.8%
Q56. In the past year did you report abuse/ neglect	
Yes	93.8%
Q56a. If yes on Q56- were parties responsive to report	
Yes	94.4%
Q57. Supports have made positive difference	
Yes	93.4%
Q58. Supports reduced out of pocket expenses	
Yes	79.0%
Q59. Services reduced/suspended /terminated in past year	
Yes	59.5%
Q59a. If yes to Q59 - reduction/suspension /termination affect family/family member negatively	
Yes	81.3%

NCI Satisfaction & Outcomes Question 52



NCI Satisfaction & Outcomes Questions 53-59 Percent Yes

