

## 2013 Family Guardian Survey Demographics

### Mail Survey of Family Members of Adults with MR/DD Who Live Away from Home

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

Yielding 406 Useable Responses

<b>Average age of family member</b>	42.5
<b>Percent who are guardian/conservator</b>	74.9%
<b>Family member lives at home</b>	5.9%

<b>Gender</b>	
Male	53.5%
Female	46.5%

<b>Respondent's Age</b>	
Under 35	1.9%
35-54	18.7%
55-74	59.8%
75+	19.6%

<b>Race &amp; Ethnicity</b>	
African American	12.8%
White	77.0%
American Indian/Alaska Native	1.1%
Asian	1.3%
Native Hawaiian/Pacific Islander	0.5%
Multiracial	0.8%
Other	0.3%
Hispanic	7.2%

<b>Out of Pocket Money Spent</b>	
Nothing	41.1%
\$1- \$100	10.5%
\$101- \$1,000	28.3%
\$1,001- \$10,000	16.9%
Over \$10,000	3.2%

<b>Relationship to Family Member</b>	
Parent	59.9%
Sibling	17.1%
Spouse	0.0%
Public Guardian	4.5%
Private Guardian	9.1%
Other	9.4%

<b>Primary Means of Expression</b>	
Spoken	72.7%
Gestures/Body Language	21.1%
Sign Language/Finger Spelling	1.6%
Communication Aid/ Device	0.5%
Other	4.1%

<b>Services Received</b>	
Residential Supports	96.1%
Day/Employment	70.2%
Transportation	90.6%
Other	67.7%
Social Security Benefits	94.0%

<b>How Often Do You See Individual</b>	
Less than once a year	3.8%
1-3 times a year	8.4%
4-6 times a year	11.9%
7-12 times a year	13.5%
More than 12 times a year	62.5%

## 2013 Family Guardian Survey Demographics

### Other Disabilities

Mental Illness	58.7%
Autism	41.3%
Cerebral Palsy	29.6%
Brain Injury	27.9%
Seizure Disorder	47.6%
Chemical Dependency	7.5%
Limited or No Vision	17.4%
Hearing Loss	9.3%
Alzheimer's Disease	6.5%
Down Syndrome	22.0%
Prader-Willi Syndrome	2.2%
Other Disability	41.1%

### Where family member lives

Specialized ID facility	9.8%
Group Home	64.5%
Agency-owned apartment	2.2%
Independent home/apartment	17.1%
Adult foster care/host family home	1.6%
Nursing home	1.4%
Other	3.5%

### Requiring Medical Care:

Less frequently than once/month	59.0%
At least once/month, but not once/week	29.2%
At least once/week, or more frequently	11.8%

### Support to manage behaviors:

No Support Needed	33.7%
Some Support Needed	35.3%
Extensive Support Needed	31.0%

### Household Income

Below \$15,000	18.8%
\$15,001-\$25,000	20.6%
\$25,001-\$50,000	29.1%
\$50,001-\$75,000	14.2%
Over \$75,000	17.4%

### Level of help with daily activities

None	17.8%
Little	20.2%
Moderate	33.3%
Complete	28.7%

### Primary Language

English	92.8%
Spanish	3.2%
Other	4.0%

### What does family member do during day

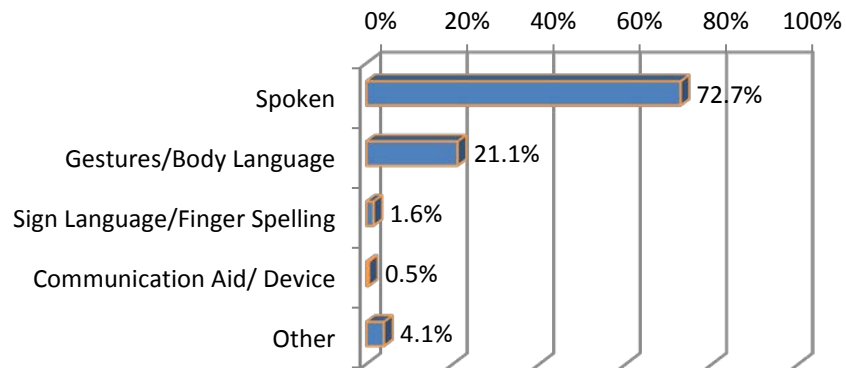
Out of Home Day Program-unpaid	38.7%
Out of Home Day Program-paid	12.4%
Vocational Training	10.2%
Community Employment-unpaid	3.4%
Community Employment-paid	5.4%
In-home Day Supports	13.6%
At home-by choice	4.0%
At home-no services	2.8%
At home-other	3.4%
Other	22.3%

### Highest Education Level:

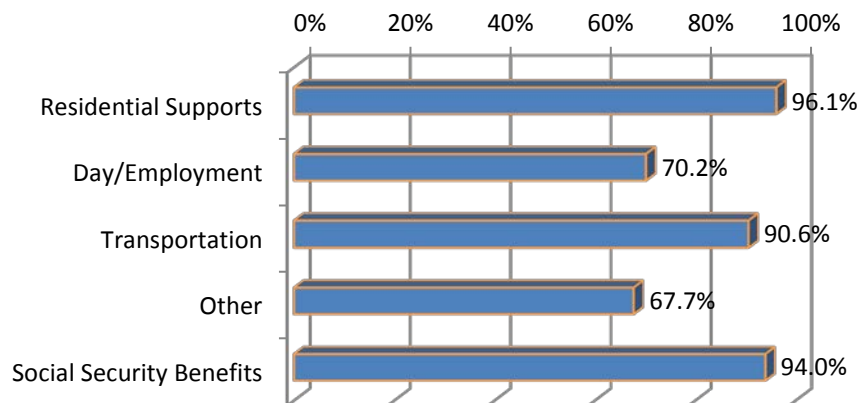
	Family Member	Respondent
Less than High School Diploma/GED	68.9%	6.7%
High School Diploma/ GED	28.0%	23.2%
Vocational School	2.0%	4.3%
Some College	0.6%	21.8%
College Degree	0.6%	43.9%

## 2013 Family Guardian Survey Demographics

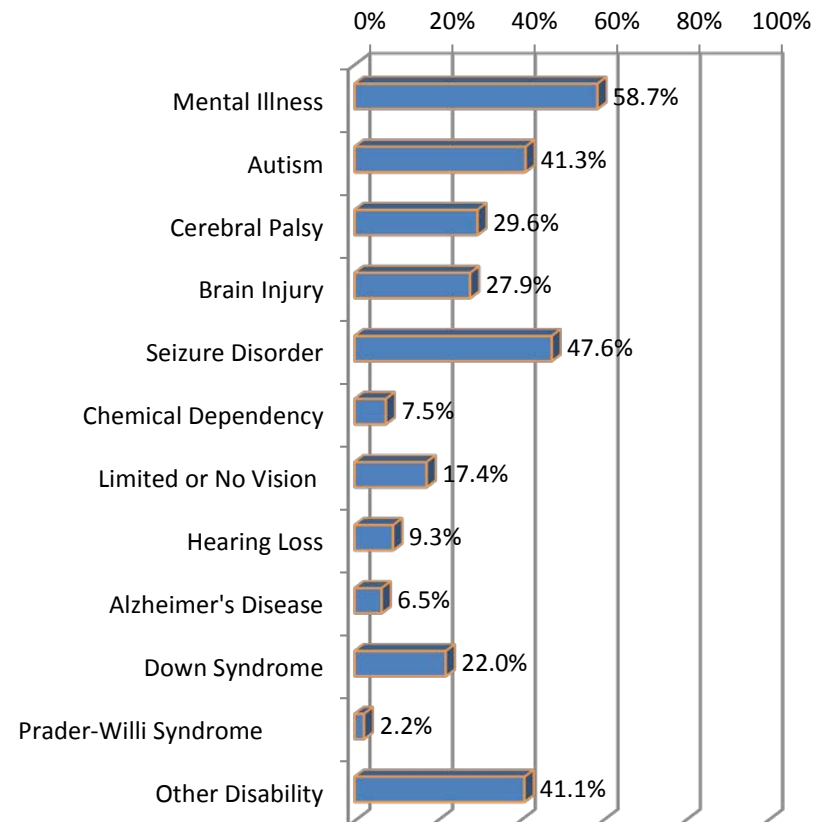
### Primary Means of Expression



### Services Received

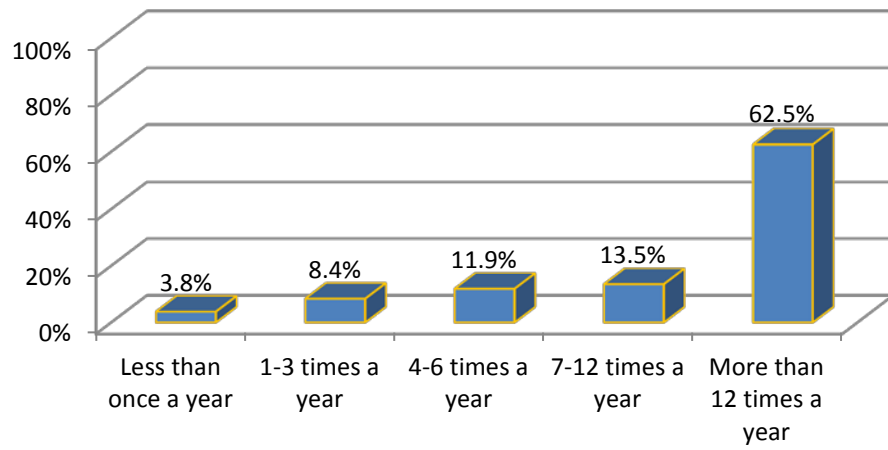


### Other Disabilities

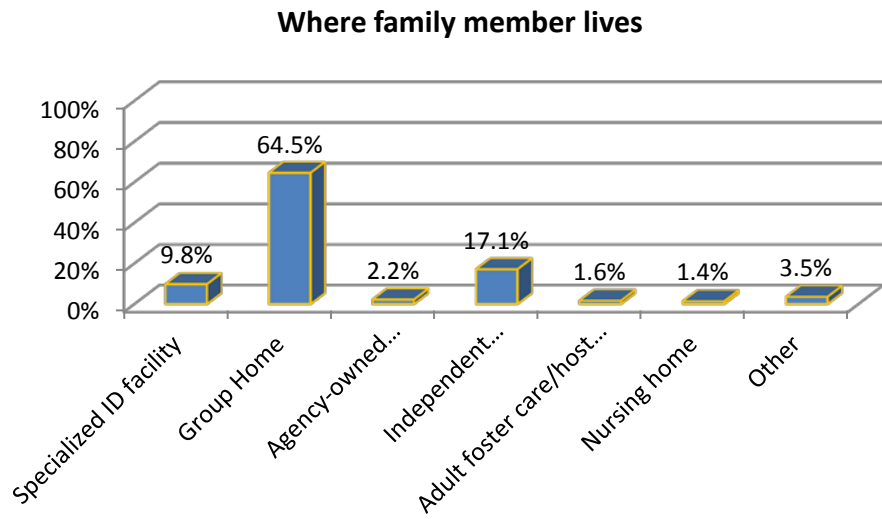


## 2013 Family Guardian Survey Demographics

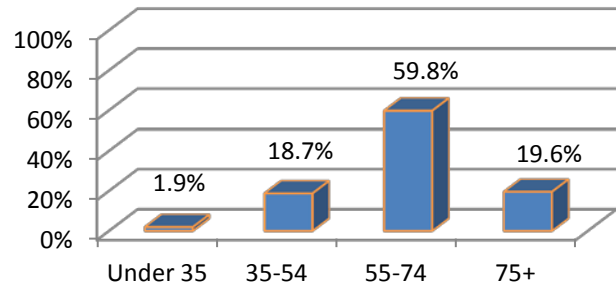
How Often Do You See Individual



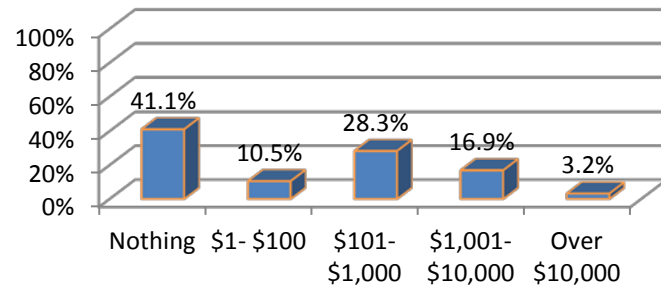
## 2013 Family Guardian Survey Demographics



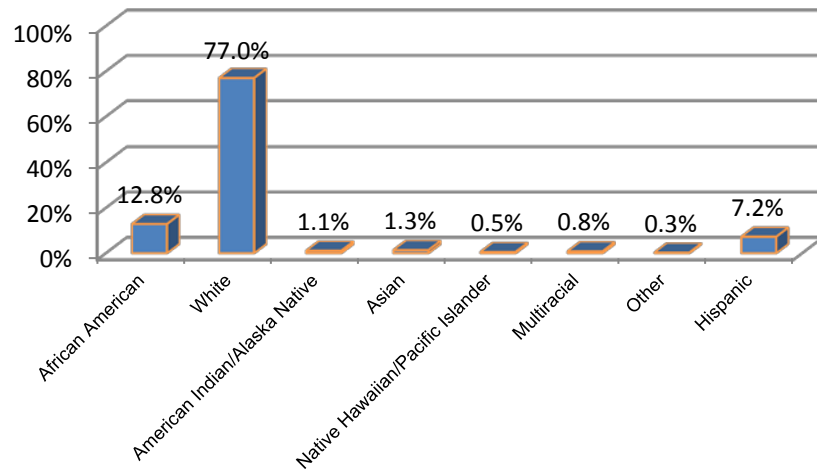
**Respondent's Age**



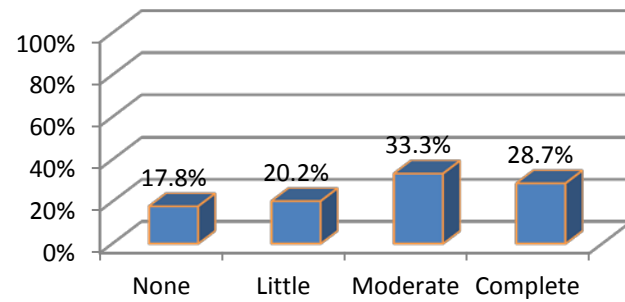
**Out of Pocket Money Spent**



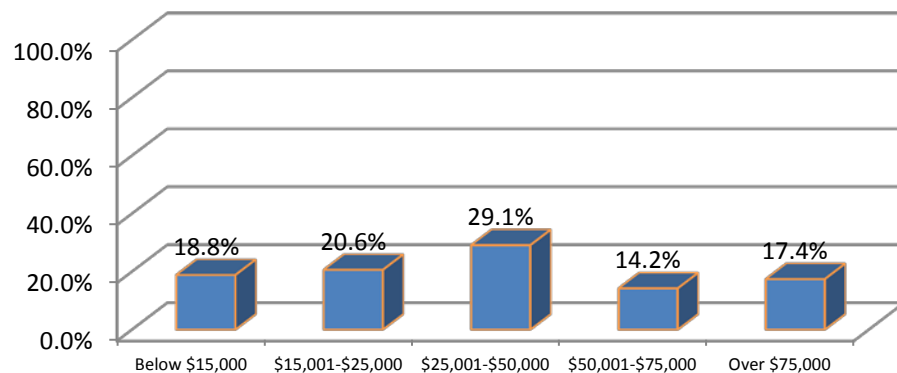
**Race and Ethnicity**



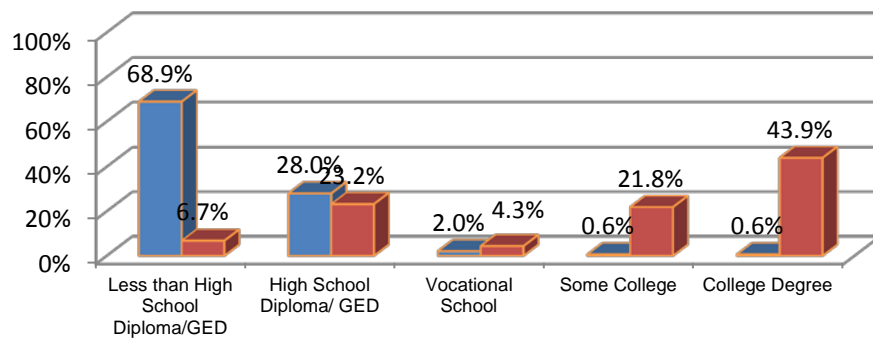
**Level of Help with Daily Activities**



### Household Income



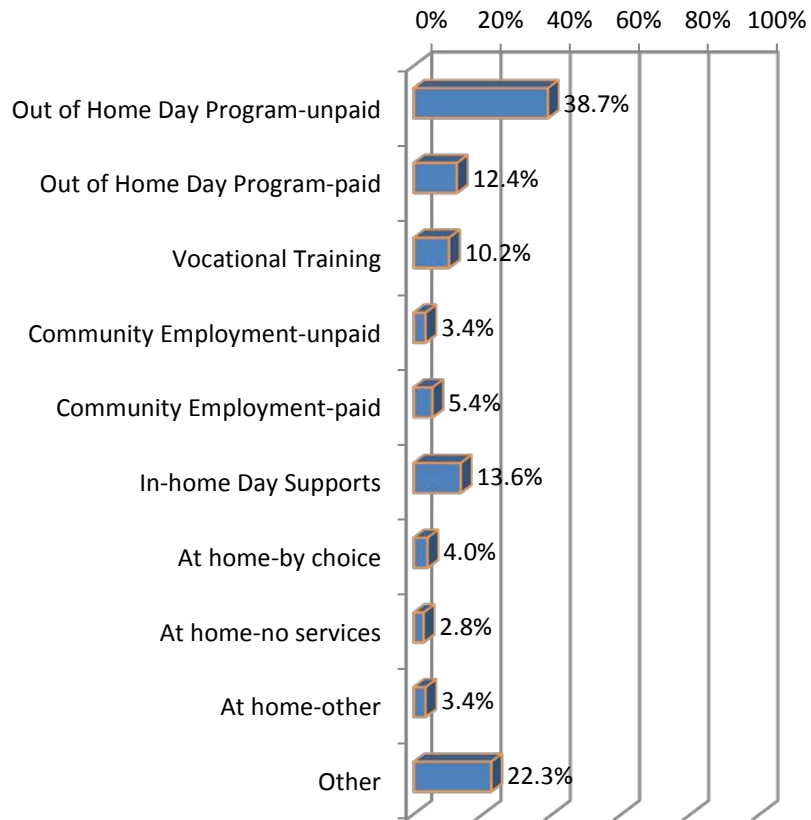
### Highest Education Level



Axis Title

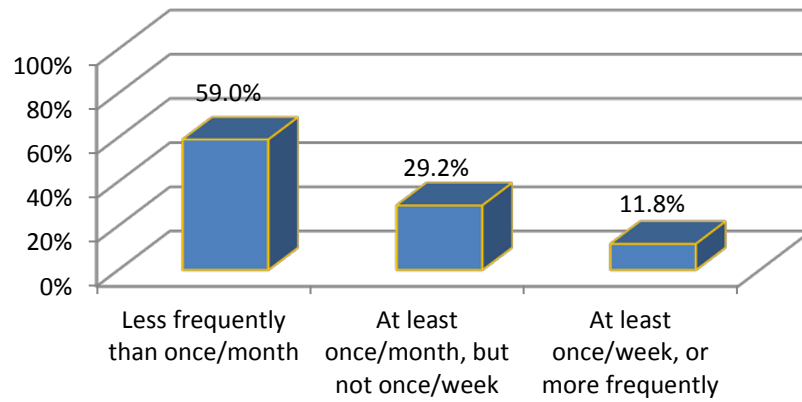
■ Family Member ■ Respondent

### What Does Family Member Do During Day?

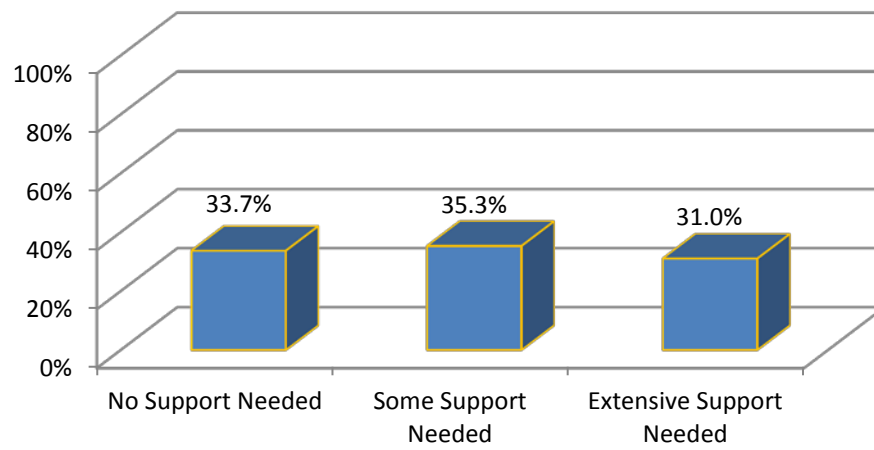




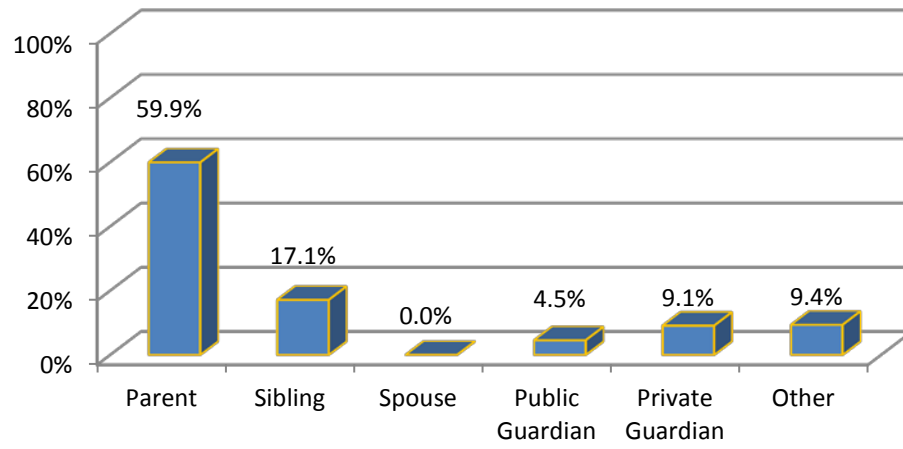
### Requires Medical Care



### Support to Manage Behaviors



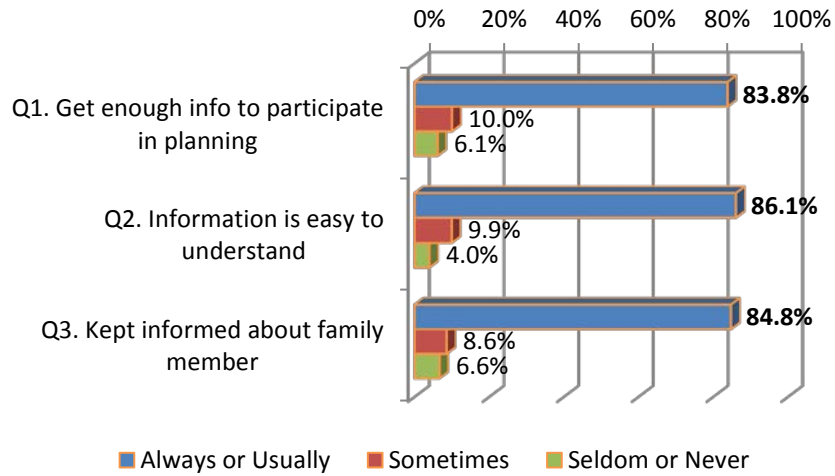
### Relationship to Family Member



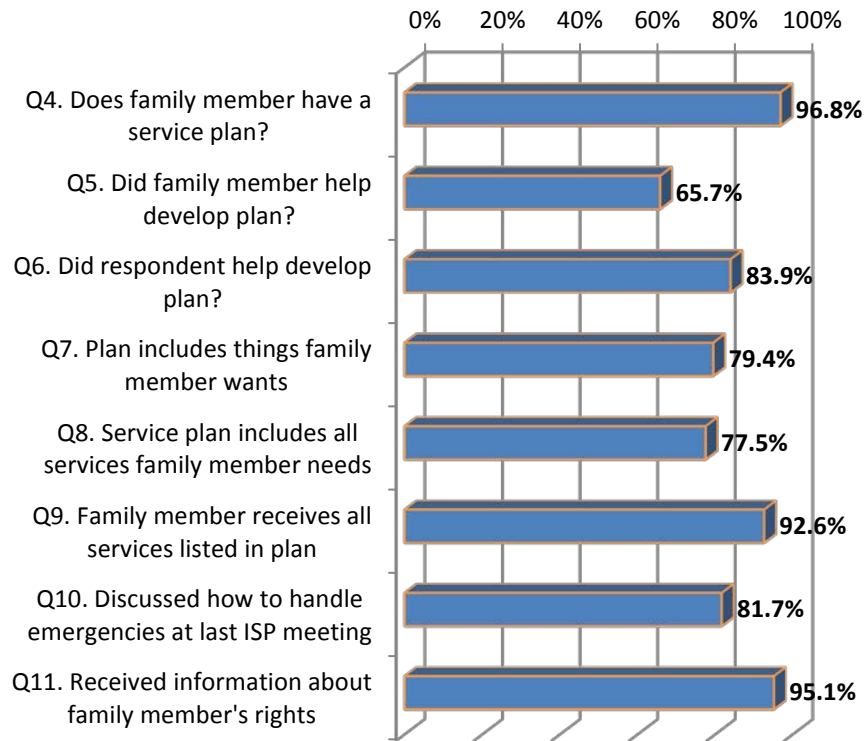
## Info & Plan      Family Guardian 2013 Results

<b>Q1. Get enough info to participate in planning</b>	
Always or Usually	83.8%
Sometimes	10.0%
Seldom or Never	6.1%
<b>Q2. Information is easy to understand</b>	
Always or Usually	86.1%
Sometimes	9.9%
Seldom or Never	4.0%
<b>Q3. Kept informed about family member</b>	
Always or Usually	84.8%
Sometimes	8.6%
Seldom or Never	6.6%
<b>Q4. Does family member have a service plan?</b>	
Yes	96.8%
<b>Q5. Did family member help develop plan?</b>	
Yes	65.7%
<b>Q6. Did respondent help develop plan?</b>	
Yes	83.9%
<b>Q7. Plan includes things family member wants</b>	
Yes	79.4%
<b>Q8. Service plan includes all services family member needs</b>	
Yes	77.5%
<b>Q9. Family member receives all services listed in plan</b>	
Yes	92.6%
<b>Q10. Discussed how to handle emergencies at last ISP meeting</b>	
Yes	81.7%
<b>Q11. Received information about family member's rights</b>	
Yes	95.1%

**NCI Information and Planning Questions 1 - 3**



**NCI Information and Planning Questions 4 - 11  
Percent Yes**

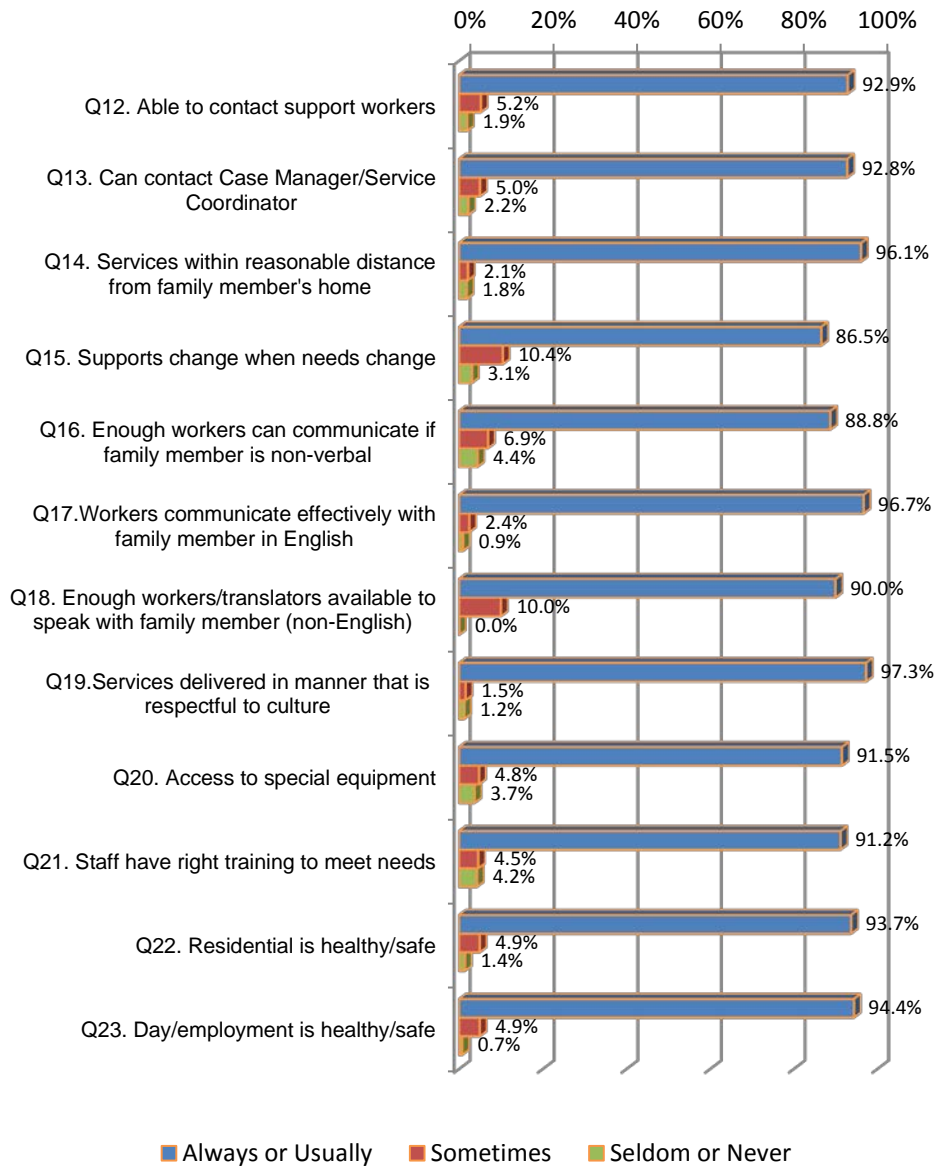


## Acces & Del

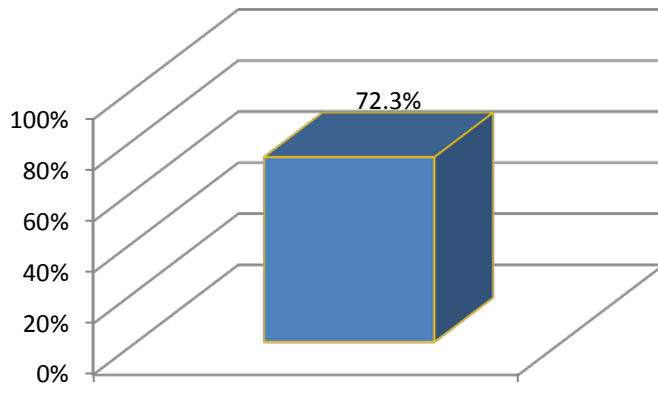
## Family Guardian 2013 Results

<b>Q12. Able to contact support workers</b>	
Always or Usually	92.9%
Sometimes	5.2%
Seldom or Never	1.9%
<b>Q13. Can contact Case Manager/Service Coordinator</b>	
Always or Usually	92.8%
Sometimes	5.0%
Seldom or Never	2.2%
<b>Q14. Services within reasonable distance from family member's home</b>	
Always or Usually	96.1%
Sometimes	2.1%
Seldom or Never	1.8%
<b>Q15. Supports change when needs change</b>	
Always or Usually	86.5%
Sometimes	10.4%
Seldom or Never	3.1%
<b>Q16. Enough workers can communicate if family member is non-verbal</b>	
Always or Usually	88.8%
Sometimes	6.9%
Seldom or Never	4.4%
<b>Q17. Workers communicate effectively with family member in English</b>	
Always or Usually	96.7%
Sometimes	2.4%
Seldom or Never	0.9%
<b>Q18. Enough workers/translators available to speak with family member (non-English)</b>	
Always or Usually	90.0%
Sometimes	10.0%
Seldom or Never	0.0%
<b>Q19. Services delivered in manner that is respectful to culture</b>	
Always or Usually	97.3%
Sometimes	1.5%
Seldom or Never	1.2%
<b>Q20. Access to special equipment</b>	
Always or Usually	91.5%
Sometimes	4.8%
Seldom or Never	3.7%
<b>Q21. Staff have right training to meet needs</b>	
Always or Usually	91.2%
Sometimes	4.5%
Seldom or Never	4.2%
<b>Q22. Residential is healthy/safe</b>	
Always or Usually	93.7%
Sometimes	4.9%
Seldom or Never	1.4%
<b>Q23. Day/employment is healthy/safe</b>	
Always or Usually	94.4%
Sometimes	4.9%
Seldom or Never	0.7%
<b>Q24. Happy with transition process from school to state services</b>	
Yes	72.3%

**NCI Access and Delivery of Supports Questions 12 - 23**



**NCI Access and Delivery of Supports Question 24**

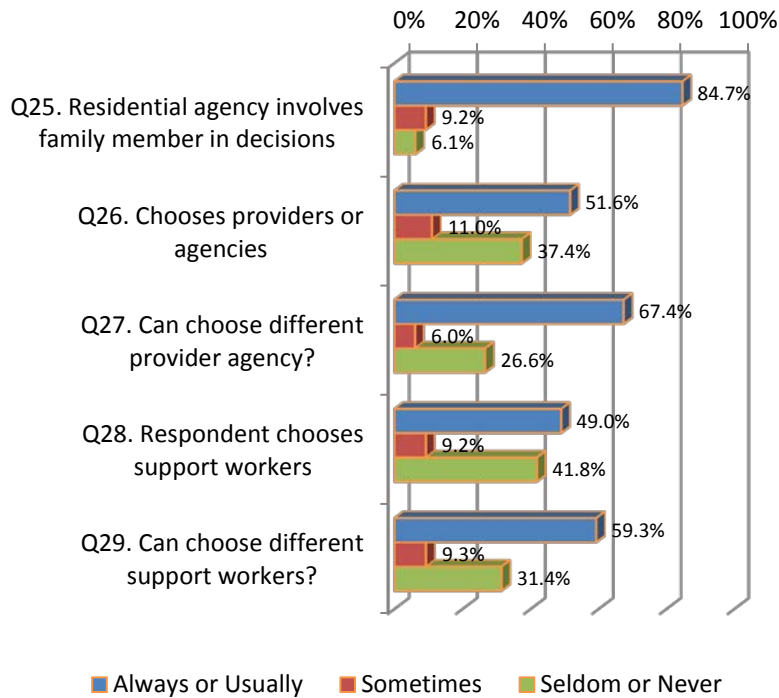


Q24. Happy with transition process from school to state services

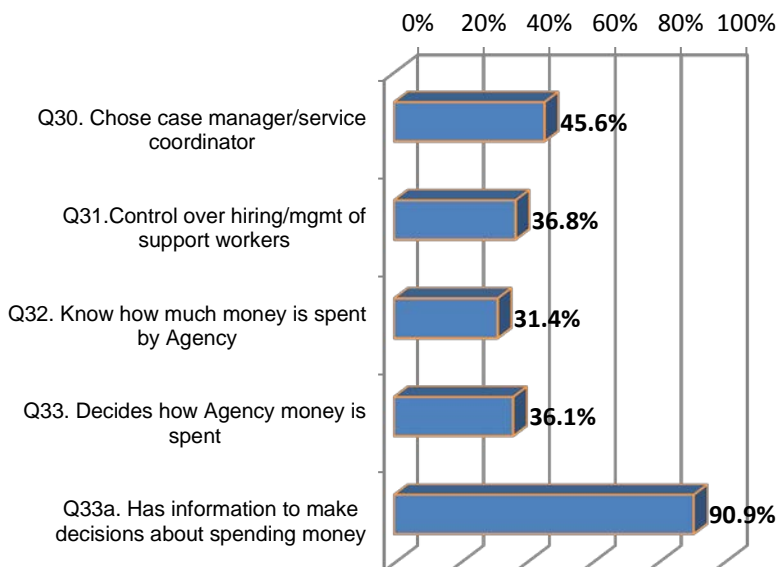




### NCI Choice and Control Questions 25-29



### NCI Choice and Control Questions 30-33 Percent Yes



## Community

## Family Guardian 2013 Results

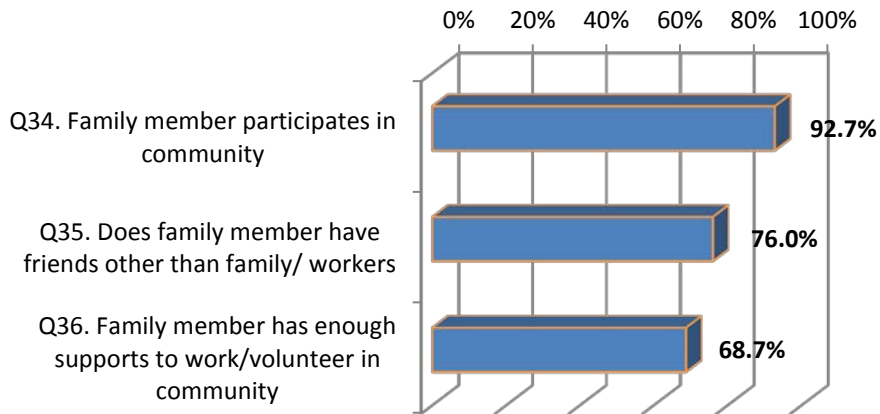
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<b>Q34. Family member participates in community</b>	
Yes	92.7%
<b>Q35. Does family member have friends other than family/ workers</b>	
Yes	76.0%
<b>Q36. Family member has enough supports to work/volunteer in community</b>	
Yes	68.7%
<b>Q34a. If No to Q34, why?</b>	
Lack of transporation	23.5%
Cost	11.8%
Lack of support staff	29.4%
Negative attitudes from community members	0.0%
Other	41.2%

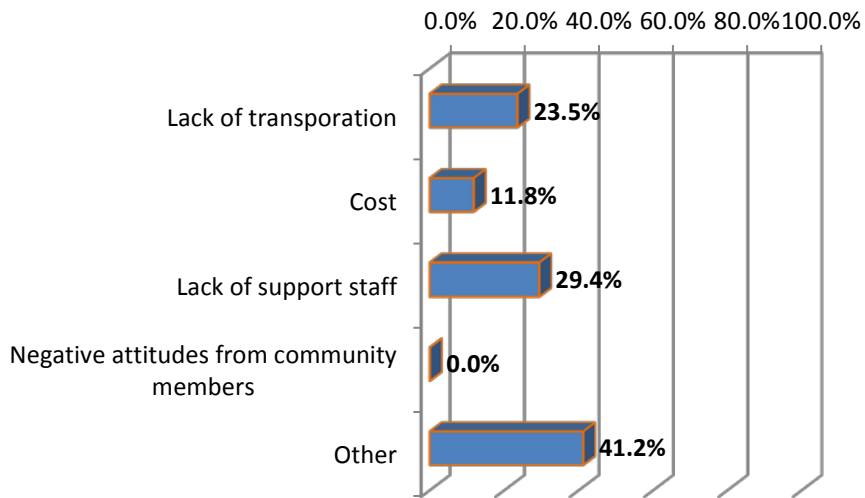
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Percent of No Answers to Q34

**NCI Community Questions 34-36  
Percent Yes**



**Q34a. If No to Q34, why?**



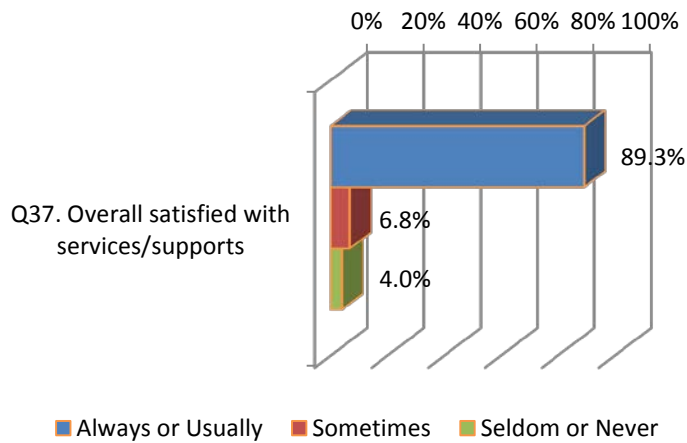
■ Percent of No Answers to Q34

## Satisfaction & Outcomes Family Guardian 2013 Results

<b>Q37. Overall satisfied with services/supports</b>	
Always or Usually	89.3%
Sometimes	6.8%
Seldom or Never	4.0%
<b>Q38. Familiar with filing grievances procedure</b>	
Yes	83.9%
<b>Q39. Satisfied with grievance procedure</b>	
Yes	86.3%
<b>Q40. Know how to report abuse/ neglect</b>	
Yes	92.0%
<b>Q41. In the past year did you report abuse/ neglect</b>	
Yes	53.0%
<b>Q41a. If yes on Q41- were parties responsive to report</b>	
Yes	93.1%
<b>Q42. Supports have made positive difference</b>	
Yes	97.0%
<b>Q43. Services and supports reduced family's expenses for care</b>	
Yes	91.8%
<b>Q44. Services/supports reduced, suspended, or terminated in past year</b>	
Yes	51.6%
<b>Q44a. If yes to Q44, did reduction/suspension/termination affect family member negatively</b>	
Yes	80.0%

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### NCI Satisfaction & Outcomes Question 37



### NCI Satisfaction & Outcomes Questions 38-44 Percent Yes

