



Quality Improvement  
Services

An Office of the  
Department of Health and Human Services

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# FAMILY GUARDIAN SURVEY 2008 DATA SUMMARY REPORT JULY 2009

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#### An overview of the Family Guardian Survey and methodology

The Family Guardian Survey is a National Core Indicators Project (NCI) tool that is mailed to private guardians of an adult (over 18 years old) receiving services from Developmental Services and living outside the guardian's home. The survey has been developed to assess family satisfaction, exploring specific aspects of service system's capabilities and effectiveness.....3

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#### Discussion and data points to highlight and notes around the possible implications of survey results on quality indicators and service delivery

The Maine DHHS-Developmental Services system continuously monitors service delivery at multiple levels to assure individual needs are met and rights and respected. Analysis and interpretation of survey results are used to assess quality indicators and benchmark performance, while directing decision making and policy planning.....17

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## Family Guardian Survey: 2007-2008 Data Summary Report

**Family and consumer feedback is an essential piece in assessing quality of service delivery.** Survey results are used to inform DHHS: Office of Adult with Cognitive and Physical Disability Services (Developmental Services) and other interested stakeholders on service system performance and outcomes for use in service planning, policy development, and decision making. This report summarizes Maine statewide information and national data from 2007-2008 Family Guardian Survey responses. Data and learnings provide direction to Developmental Services (DS) around the following four indicators outlined in office's quality assurance/quality improvement plan:

- Health and Safety: People are healthy and safe
- Unmet Needs: Peoples needs are met
- Inclusion: People are included in their communities
- Management: Systems are effective and efficient

**The Family Guardian Survey is a National Core Indicators Project (NCI) tool** that is mailed to private guardians of an adult (over 18 years old) receiving services from Developmental Services and living outside the guardian's home. The survey has been developed to assess family satisfaction, exploring specific aspects of service system's capabilities and effectiveness. With a standardized questionnaire format, families may express their overall level of satisfaction and share experiences with services and supports. Results provide an opportunity to monitor and track changes over time, compare results statewide and nationally, and establish focus areas for quality improvement based on input from families.

Beginning in 1996, The National Association of State Directors of Developmental Disabilities Services (NASDDDS) Board of Directors has been assisting in supporting state developmental disabilities authorities in developing and implementing performance/ outcome indicators and related data collection strategies that will enable them to measure service delivery system performance. NASDDDS continues to facilitate states collaboration of data collection and reporting.

The Family Guardian Survey was developed through the Core Indicators Project and first utilized in 2000. The survey was field-tested with seven states, demonstrated an ease in administration and yielded a good response rate. While maintaining survey methodology and data integrity, self reported information provides an overall picture of family experiences and satisfaction with Maine's service system.

**The survey focuses on the system's ability to assist individuals, families and guardians** who receive developmental disability services, support family participation in decision-making, increase community involvement and promote relationships. Along with demographic information, the survey includes questions related to:

- Informational exchange between individuals and services systems and planning for services and supports
- Opportunity for choices and input;
- Access and delivery of services;
- Connections with the community and
- Satisfaction with and outcomes of services received.

In 2005, revisions were made to the Guardian Survey to include questions regarding personal planning processes, mental health services, medical and dental services, and also guardian consent. Additional question were included to accommodate expectations outlined in the Community Consent Decree and CMS waiver compliance and provide additional information on system performance.

**Sampling and Methodology:** Annual mailings are administered using addresses generated through the Enterprise Information System (EIS). The survey targets private guardians of individuals who do not live in the guardians' homes and who receive case management and at least one additional service from Developmental Services. DHHS-Quality Improvement Services (QIS) has the responsibility of the preparation and analysis of data. All data was reviewed for completeness and compliance with standard NCI format.

### Total Number of Surveys Included in Analysis

Maine 2007 506

Maine 2008 473

NCI 2007-08 4,828

Data can be presented and interpreted in many different ways. In reviewing these survey findings, the points should be considered:

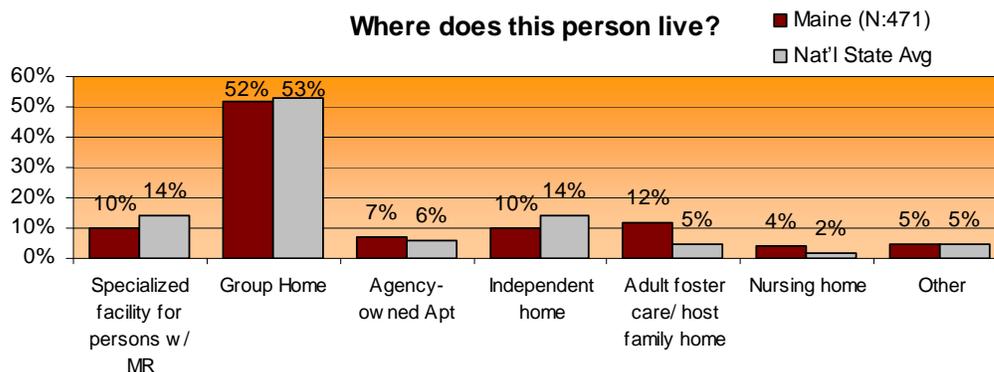
- Survey mailing to 1266 addresses of guardians from September 2008 to November 2008; yielded a return rate of 37%
- When noted, Maine Family Guardian 2007 survey data and information reported in NCI Family Guardian Report 2009 ([www.hsri.org/nci](http://www.hsri.org/nci)) has been included for the purpose of general comparisons.
- Response option 'Not Applicable' is considered missing data and excluded from Maine's analyses. The response 'Don't know' is included unless otherwise noted.
  - 2007-2008 NCI data presented in this report exclude all 'Don't Know' responses.
- Symbols ↑↓ signify a difference of +/- 5% between Maine 2007 and Maine 2008 data.

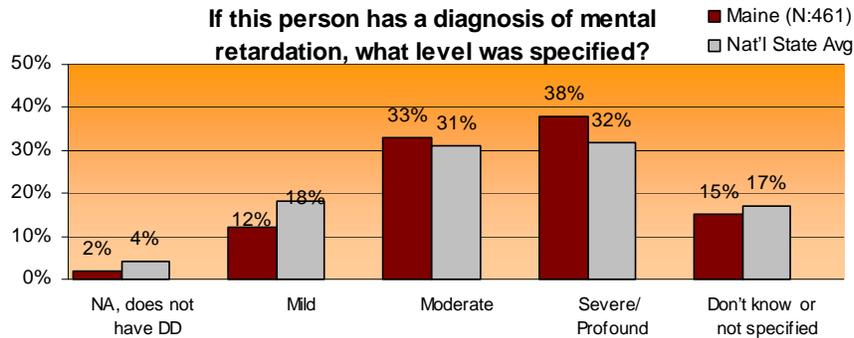
## 2008 Survey Result Summary

### Characteristics: Service Recipient

Survey respondents asked to answer questions about their family member with a developmental disability

- In Maine, over half (52%) of the family members with a developmental disability lived in group homes; this is comparable to the overall national average (53%)
- On average, across the states and in Maine, just over one-third of all family members had a diagnosis of severe or profound level of developmental disability. Similarly, percentages of family members with moderate levels were near one third. Less than 20% of family members were reported to have a level of mild developmental disability.
- Maine is consistent with overall national averages around gender and age.
  - A higher percent of males (55%) than female family members has been reported statewide and nationally.
  - The average age of Maine's family members with a disability is 46 years old, ranging between 18-89 years old, comparable to the national average of 45 years old and range of 18-94.
- Prevalence of other disabilities reported in Maine compare to national averages. Twenty percent (20%) or more of family members are reported to also have one of the following disabilities: seizure disorder/neurological problems, physical disabilities, communication disorders, mental illness and vision/hearing impairments.



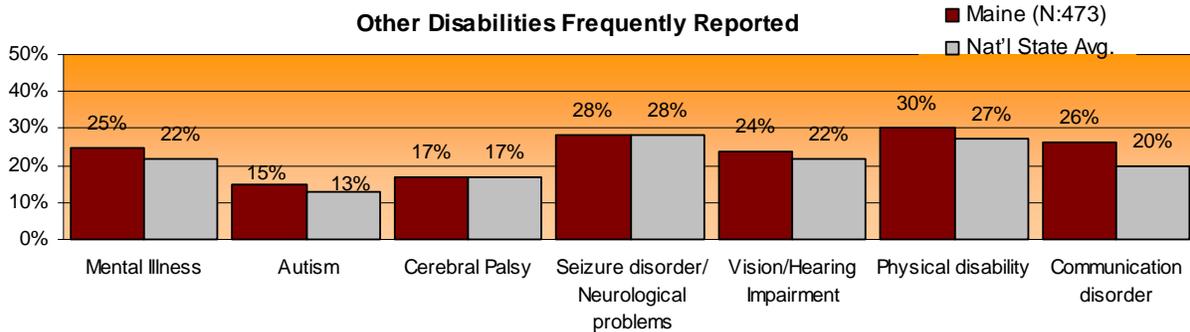


**How old is your family member?**

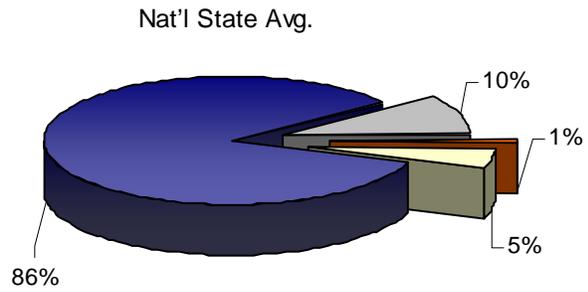
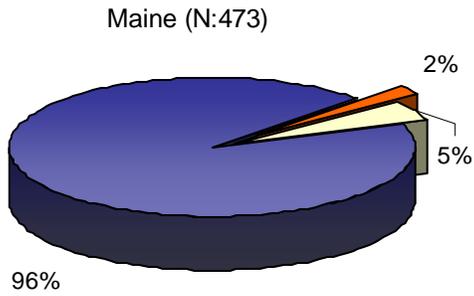
Maine (N:473)	Age range: 19-89	Average: 46
Nat'l State Avg	Age range: 18-94	Average: 45

**What is the gender of this person?**

Maine (N:473)	Male: 56%; Female: 44%
Nat'l State Avg	Male: 55%; Female: 45%



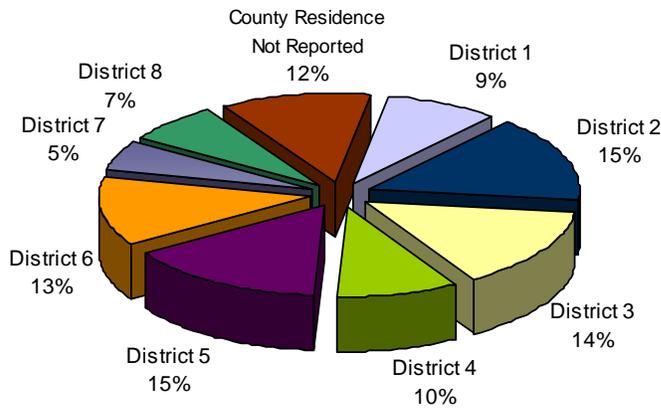
**What is the race of this person?**



*\*Respondents may select multiple race categories. Total percentage may exceed 100%.*

- White
- Black/African American
- American Indian/ Alaskan Native
- All others combined

**County Residence of Family Member Receiving Services (n:473)**



% Surveys Received	D.S. District # and Counties
9%	District 1 - York District (York County)
15%	District 2 - Cumberland District (Cumberland County)
14%	District 3 - Western Maine District (Androscoggin, Oxford and Franklin Counties)
10%	District 4 - Mid Coast District (Lincoln, Knox, Waldo and Sagadahoc Counties)
15%	District 5 - Central Maine District (Somerset and Kennebec Counties)
13%	District 6 - Penquis District (Piscataquis and Penobscot Counties)
5%	District 7 - Downeast District (Washington and Hancock Counties)
7%	District 8 - Aroostook District (Aroostook County)
2%	Resident County Not Reported

**Characteristics: Survey Respondent**

Survey respondents were asked to answer questions about themselves

- 60% of Maine’s survey respondents were between the ages of 55-74, just higher than the 57% of respondents nationally who fell within this age range.
- Just over 60% of respondents in Maine and 57% across the states, reported as the parents of adult children with disabilities.
- More than half (59%) of both Maine and national survey respondents report visiting family members at least 12 times a year.
- Nearly 99% of Maine respondents reported being the family member’s guardian, similar to Wyoming but higher percent than the 72% of respondents reporting nation wide.

<b>What is your age?</b>				
	<b>Under 35</b>	<b>35-54</b>	<b>55-74</b>	<b>75 or older</b>
Maine (n:467)	1.3%	19.3%	61.0%	18.4%
Nat'l State Avg.	1.5%	20.5%	56.8%	21.2%

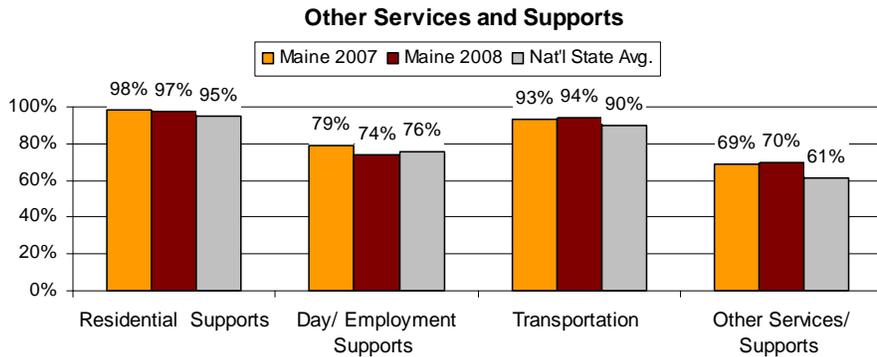
<b>How are you related to this person?</b>				
	<b>Parent</b>	<b>Sibling</b>	<b>Spouse</b>	<b>Other</b>
Maine (n:470)	60.2%	28.3%	0.0%	11.5%
Nat'l State Avg.	61.8%	24.2%	0.1%	13.9%

<b>Typically, how often do you see this person each year?</b>					
	<b>Less than once</b>	<b>1 to 3</b>	<b>4 to 6</b>	<b>7 to 12</b>	<b>More than 12 times</b>
Maine (n:470)	3.0%	7.5%	14.7%	16.0%	58.8%
Nat'l State Avg.	3.8%	10.8%	12.1%	14.4%	58.9%

**Questions about the services and supports family members received:**

- Overall, residential, day/employment, and transportation were all services highly utilized. Reported service use is consistent with previous year's survey data and overall national averages.

<b>Services and Supports 2008 (N:473)</b>	<b># Respondents Reporting Service</b>	<b>% of Total Respondents</b>
<b>Residential Supports</b> - your family member with developmental disability receives care and support in a residence outside of your home	460	97.5%
<b>Day/Employment Supports</b> - your family member with a developmental disability goes to day program, workshop, or receives vocational supports such as job training or hob coaching at a hob in the community.	349	73.8%
<b>Transportation</b> - someone arranges for transportation for your family member with a developmental disability to go to a day program, work, medical appointments, etc.	446	94.3%
<b>Other Services/Supports</b> - your family member with a disability receives mental health care or other kinds of therapies (such as physical therapy, occupational therapy, speech, or recreational therapy).	330	69.7%



<b>2008 Survey Domain</b>	<b>Avg. % Always/ Usually</b>	<b>Avg. % Sometimes</b>	<b>Avg. % Seldom/ Never</b>	<b>Avg. % Don't Know</b>
<b>Information and Planning (Q1-8)</b> Families/family members with disabilities have the information and support necessary to plan for their services and supports	85.9%	11.3%	1.7%	1.2%
<b>Access and Delivery of Supports (Q9-17)</b> Families/family members with disabilities get the services and supports they need	75.2%	16.6%	5.9%	2.3%
<b>Choice and Control (Q18-24)</b> Families/family members with disabilities determine the services and supports they receive, and the individuals or agencies who provide them	37.5%	17.4%	32.7%	12.4%
<b>Community Connections (Q34-38)</b> Families/family members use integrated community services and participate in everyday community activities	71.3%	20.4%	4.6%	3.7%
<b>Satisfaction (Q50-52);</b> Families/family members with disabilities receive adequate and satisfactory supports	75.2%	11.1%	3.9%	9.8%
<b>Outcomes (Q53, 54)</b> Families/family members are positively impacted by services and supports	87.7%	10.8%	0.8%	0.7%
<b>Medical and Dental (Q31-33); Informed Consent (Q25-30)</b> Families are informed and consulted about medical and dental services/treatment including routine and emergent care	84.9%	9.2%	4.6%	1.3%
<b>Mental Health Services including Crisis</b> Families/Family Members receive services and supports for mental health care (Q42,45-49)	54%	14.9%	4.1%	26.9%

\*The domain average displayed in the table above is calculated using the total number of responses to each question and excludes response option of 'Not Applicable'.

**Survey Domain- Information and Planning-**

Families were asked to respond to questions regarding development, assistance, support and accessibility to planning.

**Quality Indicator: Management- Maine systems are effective and efficient-**

Families/family members with disabilities have the information and support necessary to plan for their services and supports

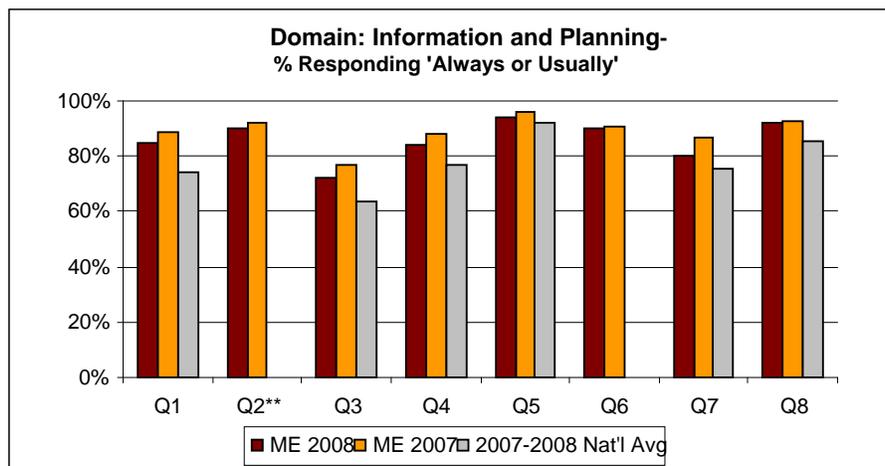
- Maine ranks consistently above or comparable to responses reported nationally around information and planning.
- Near 90% of guardians report that they are always or usually satisfied with staff efforts to involve them in the planning process.
  - Seventy-two (72%) percent of guardians report always or usually helping to develop the plan, 20% participate in the development some of the time and less than 5% indicated helping seldom or never.
- The majority of guardians (92%) report that they are always or usually able to contact staff who assist with planning.

**Information and Planning**

%	Survey Question
85.0↓	1*. Do you get enough information to help you participate in planning services for your family member?
89.7	2.** Are you satisfied with the effort staff makes to include you in the planning process (i.e. notification/invitation of the planning meeting, accommodating schedules, providing a copy of the plan etc.)
72.2↓	3*. If your family has a service plan, did you help develop the plan?
84.2	4. If your family member has a service plan, does the plan include things that are important to you?
93.7	5. Are the staff who assist you with planning generally respectful and courteous?
90.5	6. Are staff who assist you with planning respectful of your choices and opinions?
79.1↓	7*. Are the staff who assist you with planning generally effective?
92.0	8. Can you contact the staff who assist you with planning whenever you want to?

\*Symbols ↑↓ signify a difference of +/- 5% between Maine 2007 and Maine 2008 data

\*\* Question is specific to Maine guardian survey



**Survey Domain- Access and Support Delivery-**

Questions relate to supports used by family members, including availability of services, staff providing these services and conditions in which these are provided.

**Quality Indicator: Unmet Needs- Peoples needs are met-**

Families/family members with disabilities get the services and supports they need

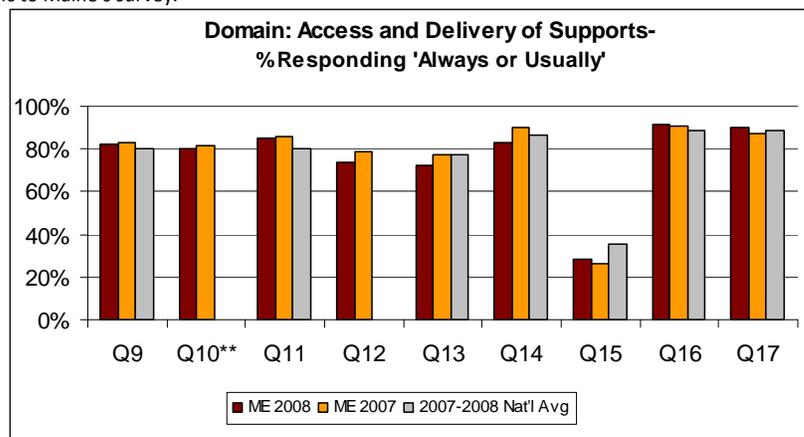
- The survey results demonstrate consistency in overall guardian satisfaction with access and delivery of services.
- Eighty percent (80%) of guardian respondents indicated they are usually satisfied with how often they and family members are connecting with case managers.
- Over two-thirds (66%) of guardian respondents, just higher than the over national average of 64%, indicated that frequent changes to support staff were a problem at least some of the time.
- In 2008, fewer guardians indicated that they usually have access to the special equipment or accommodations for family members, showing a decrease from 90% in 2007 to 83% in 2008.

**Access and Delivery of Supports**

% Always/ Usually	Survey Question
82.3	9. When you ask DHHS service coordinator for assistance, does he/she help you get what you need?
80.4	10. Are you satisfied with how often you and your family member connect with your case manager?*
84.8	11. Does your family member get the services and supports he/she needs?
73.7	12. Are you satisfied with the information you receive from your case manager about other services and supports available to you and your family members (i.e. vocational, day or residential supports, community activities etc.)?
72.6	13. If your family member does not speak English or uses a different way to communicate (ex. sign language), are there enough support workers available who can communicate with him/her?
83.2↓	14. Does you family member have access to the special equipment or accommodations that he/she needs (ex. wheelchairs, ramps, communication boards)?
21.7	15. Are frequent changes in support staff a problem for your family member?
91.8	16. Do you feel that your family member's residential setting is a healthy and safe environment?
90.5	17. Do you feel that your family member's day/employment setting is a healthy and safe environment?

\*Symbols ↑↓ signify a difference of +/- 5% between Maine 2007 and Maine 2008 data

\*\* Survey question is specific to Maine's survey.



**Survey Domain: Choice and Control:**

Families were asked about their roles in important decisions and the management of staff

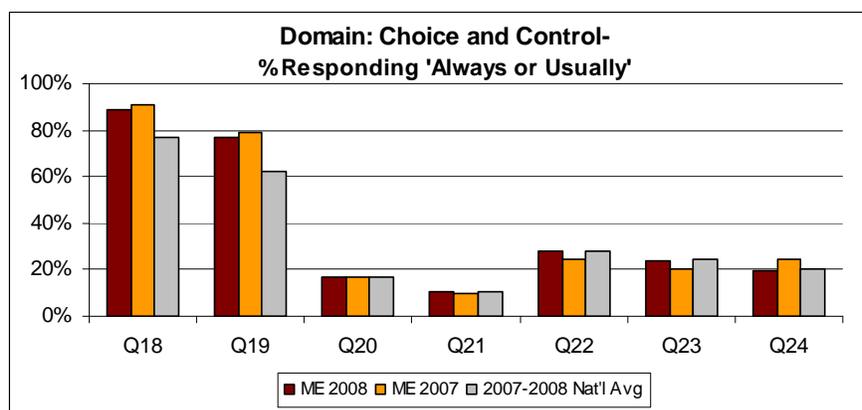
**Quality Indicator: Management- Maine systems are effective and efficient-**

Families/family members with disabilities determine the services and supports they receive, and the individuals or agencies who provide them

- Overall, percentages of positive responses are higher or comparable to national state averages and show little change from Maine 2007 survey responses.
- Eighty-nine (89%) of Maine respondents indicate agencies providing residential services involve them in important decisions, over 10% higher than national average of 77%.
- Among those receiving day/employment services, 77% of guardians indicate the agency providing the day service involves them in important decisions, 15% higher than the overall national average of 62%.
- Twenty-Eight percent (28%) of Maine respondents indicate wanting control or input over the hiring and management of support workers, nearly three times the national average (11%).

**Choice and Control**

% Always/ Usually	Survey Question
88.7	18. Does the agency providing residential services to your family member involve you in important decisions?
76.9	19. If your family member gets day or employment services, does the agency providing these services involve you in important decisions?
16.8	20. Do you or your family member choose the support workers who work with your family member?
10.2	21. Do you or your family member have control and/or input over the hiring and management of your family member's support workers?
28.0	22. Do you or your family member want to have control and/or input over the hiring and management of your family member's support workers?
23.9	23. Do you or your family member know how much money is spent by the agency on behalf of your family member with a developmental disability?
19.6	24. Do you or your family member get to decide how this money is spent?



**Survey Domain: Community Connections:**

Questions focused on family members' natural supports and community participation.

**Quality Indicator: Inclusion- People are included in their communities-**

Families/family members use integrated community services and participate in everyday community activities

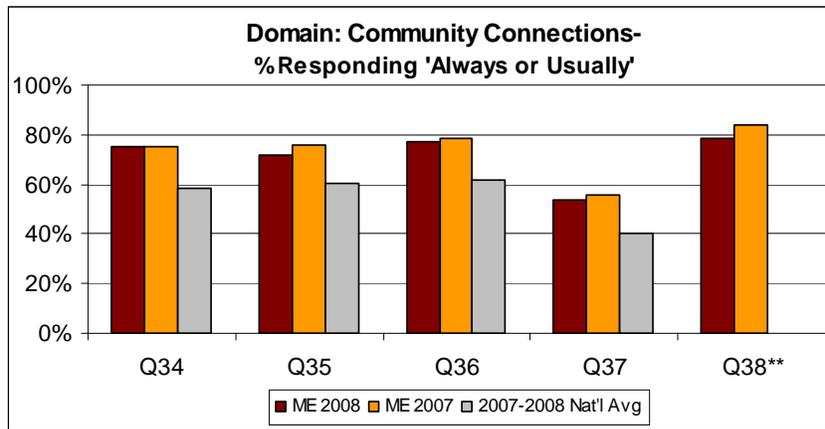
- With close to three quarters (75%) of guardians, Maine ranks above the overall national average (58%) of respondents indicating staff help them connect with supports if family members want to use typical supports in the community.
- Maine shows stability in guardians reporting family members participate in community activities with 55% of respondents in 2007 and 54% in 2008.
- In 2008, over 78% of family guardians reported that they were satisfied with staff's effort to provide opportunity for community participation, a decrease from 84% of families in 2007.
- Close to 78% of 2007 and 2008 guardian respondents reported family members usually have access to community activities.

**Community Connections**

% Always/ Usually	Survey Question
74.9	34. If your family member wants to use typical supports in your community (ex. through recreation departments or churches) do either the staff who help plan or who provide support help connect him/her to these supports?
72.0	35. If your family member would like to use family, friends or neighbors to provide some of the supports he/she needs, do either the staff who help or plan or who provide support help him/her do this?
77.5	36. Do you feel that your family member has access to community activities?
54.0	37. Does your family member participate in community activities?
78.2↓	38.** Are you satisfied with effort made by staff to provide opportunity for community participation?

\*Symbols ↑↓ signify a difference of +/- 5% between Maine 2007 and Maine 2008 data

\*\*Questions are specific to Maine's survey



**Survey Domain- Medical and Dental-**

Questions sought families input regarding access to and receipt of health and dental services.

**Quality Indicator: Health- People are healthy and Safe-**

Individuals receive timely and appropriate medical and dental services and families are informed and consulted about medical and dental services/treatment including routine and emergent care to support

- Most guardians (91% in 2007 and 87% in 2008) were always/usually satisfied with the amount of information from residential agencies provide them to make informed decisions about a family members' medical and dental care.

**Medical and Dental**

%  
Always/  
Usually

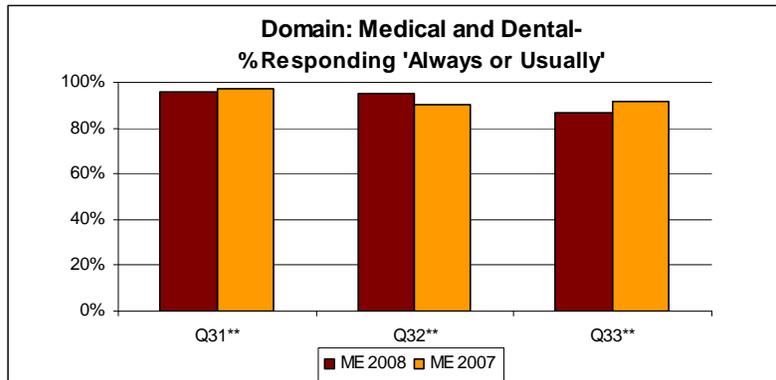
Survey Question

95.5      31.\*\* Does your family member have a routine physical at least every twelve months?

85.3      32.\*\* Does your family member have a routine dental treatment at least every six to twelve months?

86.8↓      33.\*\* Are you satisfied that the residential agency provides you with enough information to make informed decisions about your family member's medical and dental care?

\*\*Questions are specific to Maine's survey.



**Survey Domain: Informed Consent-**

Questions focused on practice of communicating with guardians around a family member's medical and dental care and treatments.

**Quality Indicator: Health- People are healthy and safe-**

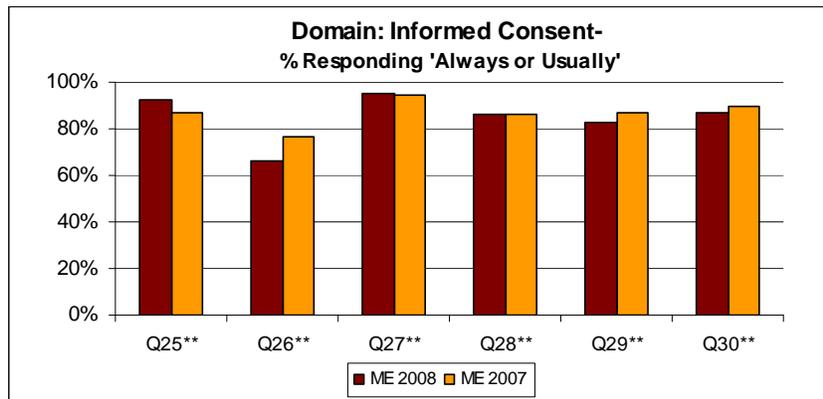
Families are informed and consulted about medical and dental services/treatment including routine and emergent care

- Ninety-two percent (92%) of 2008 guardian respondents indicated residential agencies gain their consent for all routine medical and dental treatments for family members, a slight increase from 87% in 2007.
- Over 85% of 2007 and 2008 Maine guardians indicate reviewing, at least annually, an agreement with the residential agency to provide emergency medical and/or dental care to family members.
- In 2008, 66% of guardians indicated the residential agency consults with them before all medical and dental treatment, showing a decrease of near 10% from 77% in 2007.
  - The remaining, about one third (34%) in 2008 and 23% in 2007 indicated only sometime or seldom/never being consulted by the residential agency before a family member's medical or dental appointments.
- The majority of respondent felt satisfied always or usually with the efforts staff make to keep them informed about their family member's health care, with 89% in 2007, and 87% in 2008 reporting positively.

**Guardian Informed Consent**

% Always/ Usually	Survey Question
92.2	25. Does the residential agency gain consent from you at least annually for all routine medical and dental treatments for your family member?
66.0↓↓	26. Does the residential agency consult with you before all medical and dental appointments?
94.9	27. Does the residential agency have an agreement with you to provide medical and dental treatment in the event of an emergency?
86.4	28. If you have an agreement with the residential agency, do you review this agreement at least once a year?
83.1	29. If your family member receives medication, does the residential agency gain consent from you for the use of medication?
86.9	30. Are you satisfied with the efforts staff make to keep you informed about your family member's health care (e.g. medical, dental, and medication needs and services)?

\*\* Domain and questions are specific to Maine's survey



**Survey Domain- Satisfaction and Outcomes-**

*Families responded to questions considering satisfaction and effectiveness of services.*

**Quality Indicator: Unmet Needs- Peoples needs are met-**

*Families/family members with disabilities get the services and supports they need*

**Quality Indicator: Management- Maine systems are effective and efficient-**

*Families/family members with disabilities determine the services and supports they receive, and the individuals or agencies who provide them*

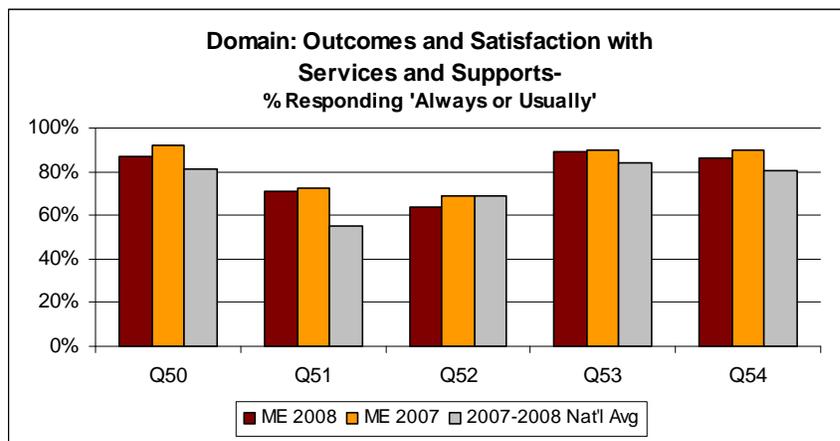
- On average most respondents were satisfied with the services and supports their family member received, with the Maine percentage (87%) slightly higher than the national average (81%), but below the 92% reported the previous year.
- Respondents indicating they were satisfied with the way complaints/grievances are handled and resolved decreased from 69% in 2007 to 64% in 2008. Overall national average (68%) fell in between.
- Over 70% of respondents in 2007 and 2008 indicate they are familiar with the process for filing a complaint or grievance regarding services or staff; Maine percentages are substantially higher than the overall national average (56%).
- The majority (above 98%) of 2007 and 2008 respondents indicate their family members are happy at least sometimes if not always.

**Satisfaction**

% Always/Usually	Survey Question
86.6↓	50. Overall, are you satisfied with the services and supports your family member currently receives?
71.1	51. Are you familiar with the process for filing a complaint or grievance regarding services you receive or staff who provide them?
64.1↓	52. Are you satisfied with the way complaints/grievances are handled and resolved?

**Outcomes**

% Always/Usually	Survey Question
89.2	53. Do you feel that services and supports have made a positive difference in the life of your family?
86.3	54. Overall, do you feel that your family member is happy?



**Survey Domain- Mental Health and Crisis Services-**

*Questions focus on mental health services including crisis and ask families to respond on behalf of family members with a mental health diagnosis and behavior management plans.*

**Quality Indicator: Health- People are healthy and safe-**

*Families are informed and consulted about medical and dental services/treatment including routine and emergent care*

**Quality Indicator: Unmet Needs-Peoples needs are met-**

*Families/Family Members receive services and supports for mental health care*

*\* Domain and questions are specific to Maine's survey.*

- Over one-half (55%) of families indicated their family member has a mental health diagnosis. Of the remaining, 32% indicated their family member did not have a mental health diagnosis, while 13% did not know.
- Among those responding on behalf of family member who receives mental health services, families report medication management and psychiatric care as the services most often received by family members.
- Less than half of respondents (48%) reported their family member has a behavior management plan, 28% indicated their family member did not have a behavior management plan, and the remaining 25% indicated they were unsure if their family member had a behavior management plan.
- Over 50% of those families reporting to have contact with crisis services within the last year indicated the crisis team member was easy to access, responsive, respectful and worked well with staff and family, and felt the crisis team members was helpful.

**Mental Health and Crisis Services**

**Survey Question**

**Q39. Does your family member have a mental health diagnosis? (N=374)**

- Just over one-half (55%) of guardians reported their family member had a mental health diagnosis.
- Thirty-two percent (32%) of guardians reported their family member was not diagnosed with a mental illness, and 13% responded "Don't Know".

**Q40. If your family member receives mental health services, what type of professional mental health services does your family member receive? (N:473)**

- Of those 473 guardians surveyed, 45% reported family members are receiving medication management
- Fifteen percent (15%) of guardians indicated their family member receives counseling, 28% reported family members receive psychiatric services and 16% reported psychological services.
- Twenty-one percent (21%) indicated they did not know the type of mental health services they family member receives.

**Q41. Does your family member have a behavior management plan? (N:404)**

- Of the total 404 guardians responding, 48% report their family member has a behavior management plan,
- Twenty-eight percent (28%) indicated family members do not have a behavior management plan,
- And 25% of guardian respondents did not know if their family members had a behavior management plan.

**Q42. If your family member is prescribed a medication for behavior reasons, are you satisfied that you receive enough information about the positive/negative effects of the medication to assist your family member in making informed medical decisions? (N:192)**

- Seventy-five percent (75%) of guardians report being satisfied with the amount of information they receive, while 20% are only sometime or seldom satisfied with the amount of information received to help in decisions around medication. The remaining 5% responded 'Don't know'.

**Q43. If your family member is prescribed a medication for behavioral reasons, who provides information to you and your family member about the positive and negative effects of medication? (N:243)**

- Nearly 40% of guardians report the prescribing doctor provides information about positive and negative effects of medication.
- Thirteen percent (13%) receive this information from the pharmacy, while 20% of guardians report case managers share information to them and their family members, 40% indicate they get information from the provider/agency.

**Q44. If your family connected with DHHS Crisis Services within the past year, when was the most recent contact?**

- The majority (59% of 49 respondents) report their family connected with Crisis Services over 3 months ago, while the remaining 41% indicated more recent contact (within the last 3 months).
- One hundred fifty five (155) guardians indicated no contact with Crisis Services within the past year.

**Mental Health and Crisis Services**

Survey Question	Responses				
	N	% Always/Usually	% Sometimes	% Seldom/ Never	% Don't Know
45. If your family member has had contact with DHHS Crisis Services within the past year, was the Crisis Team Member easy to access?	53	52.8	22.6	5.7	18.9
46. If your family member has had contact with Crisis Services within the past year, was the time it took for services to respond reasonable?	54	53.7	20.4	5.6	20.4
47. If your family member has had contact with Crisis Services within the past year, was the Crisis Team Member respectful?	53	66.0	7.5	1.9	24.5
48. If your family member has had contact with Crisis Services within the past year, did the Crisis Team Member work well with staff and family?	52	53.8	17.3	5.8	23.1
49. If your family member has had contact with Crisis Services within the past year, do you feel the Crisis Team Member was helpful?	53	54.7	22.6	5.7	17.0

**Learnings:**

The Maine DHHS-Developmental Services system continuously monitors service delivery at multiple levels to assure individual needs are met and rights are respected. Consumer and family input gathered through surveying is an example of one of the office’s quality assurance processes. This summary report explores experiences shared by guardians with family members receiving Developmental Services. Guardians’ feedback to questions relating to planning, service delivery, autonomy, inclusion, and health and safety provides an opportunity to review areas outlined in Developmental Services quality framework and its four quality indicators. Analysis and interpretation of survey results are used to assess quality indicators and benchmark performance, while providing direction to decision-making and policy planning.

**Discussion and Data Points**

The information collected and reported from year to year allows for statewide and national comparisons and the identification of areas to monitor for quality improvement.

- Overall, Maine results compare favorable to national averages.
- In general, survey data indicates Maine’s service system is successful in major focus areas including efforts to communicate with and involve guardians in an effective planning process, provide access to services to meet individual needs and interests and assure health and safety.
- Maine’s survey data from 2007 to 2008 shows a decrease in the percentages of positive responses to questions about guardians receiving enough information and participating in the development of a family member’s plan.
- Data also indicates a decline in satisfaction reported around the effectiveness of staff who help to plan and access services, provide opportunity for community connectedness and inform around medical services.

**Health and Safety: People are safe and healthy**

- Among those receiving residential services in Maine, nearly all (92%) guardians felt their family member’s residential setting was always a safe and healthy environment. The remaining 8% of respondents felt the residence was only sometimes or seldom safe.
- Over 95% of guardian respondents indicated that their family members receive a routine physical at least annually. More than 85% of guardians indicate family members receive routine dental services at least every 6 to 12 months.

**Unmet Needs: People needs are met**

- 85% of guardian respondents indicate family members receive the services and supports they need.
- Survey respondents report specialized equipment and/or accommodations are accessible 83% most of the time, while close to 13% indicate this is available only sometimes or seldom.

**Inclusion: People are included in their communities**

- Nearly 80% of respondents indicated usually being satisfied with the effort staff makes to provide opportunity for family members to participate in community activities, 17% report that they were sometimes satisfied with these efforts.

**Management: Systems are effective and efficient**

- Near 90% of guardian respondents report services and supports have made a positive difference in the life of their family.

## APPENDIX

## Information and Planning

% Always/ Usually	% Sometimes	% Seldom/ Never	% Don't Know	# Total Survey Respondents	Survey Question
85.0↓	12.7	2.1	0.2	466	1*. Do you get enough information to help you participate in planning services for your family member?
89.7	8.8	1.5	0.0	467	2. Are you satisfied with the effort staff makes to include you in the planning process (i.e. notification/invitation of the planning meeting, accommodating schedules, providing a copy of the plan etc.)
72.2↓	20.7	4.2	2.9	454	3*. If your family has a service plan, did you help develop the plan?
84.2	12.8	0.9	2.2	461	4. If your family member has a service plan, does the plan include things that are important to you?
93.7	5.2	0.4	0.7	461	5. Are the staff who assist you with planning generally respectful and courteous?
90.5	7.4	1.3	0.9	462	6. Are staff who assist you with planning respectful of your choices and opinions?
79.1↓	16.1	2.2	2.4	458	7*. Are the staff who assist you with planning generally effective?
92.0	6.7	1.1	0.2	461	8. Can you contact the staff who assist you with planning whenever you want to?

## Access and Delivery of Supports

% Always/ Usually	% Sometimes	% Seldom/ Never	% Don't Know	# Total Surveys	Survey Question
82.3	12.9	2.7	2.0	441	9. When you ask DHHS service coordinator for assistance, does he/she help you get what you need?
80.4	12.2	5.0	2.4	459	10. Are you satisfied with how often you and your family member connect with your case manager?
84.8	13.5	1.5	0.2	459	11. Does your family member get the services and supports he/she needs?
73.7	20.0	5.0	1.4	441	12. Are you satisfied with the information you receive from your case manager about other services and supports available to you and your family members (i.e. vocational, day or residential supports, community activities etc.)?
72.6	18.8	2.7	5.9	186	13. If your family member does not speak English or uses a different way to communicate (ex. sign language), are there enough support workers available who can communicate with him/her?
83.2↓	12.5	1.3	3.0	297	14. Does your family member have access to the special equipment or accommodations that he/she needs (ex. wheelchairs, ramps, communication boards)?
21.7	43.8	28.7	5.9	443	15. Are frequent changes in support staff a problem for your family member?*
91.8	6.8	1.1	0.2	453	16. Do you feel that your family member's residential setting is a healthy and safe environment?
90.5	7.1	0.3	2.2	325	17. Do you feel that your family member's day/employment setting is a healthy and safe environment?

**Choice and Control**

<b>% Always/ Usually</b>	<b>% Sometimes</b>	<b>% Seldom/ Never</b>	<b>% Don't Know</b>	<b># Total Surveys</b>	<b>Survey Question</b>
88.7	9.8	1.6	0.0	451	18. Does the agency providing residential services to your family member involve you in important decisions?
76.9	16.5	5.3	1.3	303	19. If your family member gets day or employment services, does the agency providing these services involve you in important decisions?
16.8	18.6	60.1	4.5	381	20. Do you or your family member choose the support workers who work with your family member?
10.2	11.2	70.1	8.6	384	21. Do you or your family member have control and/or input over the hiring and management of your family member's support workers?
28.0	31.9	31.0	9.1	361	22. Do you or your family member want to have control and/or input over the hiring and management of your family member's support workers?
23.9	12.2	19.63	44.6	435	23. Do you or your family member know how much money is spent by the agency on behalf of your family member with a developmental disability?
19.6	24.0	42.8	13.6	404	24. Do you or your family member get to decide how this money is spent?

**Community Connections**

<b>% Always/ Usually</b>	<b>% Sometimes</b>	<b>% Seldom/ Never</b>	<b>% Don't Know</b>	<b># Total Surveys</b>	<b>Survey Question</b>
74.9	16.7	3.9	4.4	406	34. If your family member wants to use typical supports in your community (ex. through recreation departments or churches) do either the staff who help plan or who provide support help connect him/her to these supports?
72.0	15.2	5.8	7.5	361	35. If your family member would like to use family, friends or neighbors to provide some of the supports he/she needs, do either the staff who help or plan or who provide support help him/her do this?
77.5	19.2	2.2	0.9	452	36. Do you feel that your family member has access to community activities?
54.0	32.6	9.4	4.0	448	37. Does your family member participate in community activities?
78.2↓	16.9	2.2	2.7	450	38. Are you satisfied with effort made by staff to provide opportunity for community participation?

## DHHS-OACPDS Family Guardian Survey 2008 Data Summary Report

### Medical and Dental

% Always/ Usually	% Sometimes	% Seldom/ Never	% Don't Know	# Total Surveys	Survey Question
95.5	1.5	0.2	2.8	465	31. Does your family member have a routine physical at least every twelve months?
85.3	7.8	2.3	4.6	435	32. Does your family member have a routine dental treatment at least every six to twelve months?
86.8↓	11.2	2.0	0.0	454	33. Are you satisfied that the residential agency provides you with enough information to make informed decisions about your family member's medical and dental care?

### Guardian Informed Consent

% Always/ Usually	% Sometimes	% Seldom/ Never	% Don't Know	# Total Surveys	Survey Question
92.2	5.2	1.8	0.9	446	25. Does the residential agency gain consent from you at least annually for all routine medical and dental treatments for your family member?
66.0↓↓	24.5	9.1	0.5	441	26. Does the residential agency consult with you before all medical and dental appointments?
94.9	1.1	1.4	2.5	436	27. Does the residential agency have an agreement with you to provide medical and dental treatment in the event of an emergency?
86.4	5.2	6.1	2.4	425	28. If you have an agreement with the residential agency, do you review this agreement at least once a year?
83.1	8.8	6.9	1.2	433	29. If your family member receives medication, does the residential agency gain consent from you for the use of medication?
86.9	10.5	2.4	0.2	459	30. Are you satisfied with the efforts staff make to keep you informed about your family member's health care (e.g. medical, dental, and medication needs and services)?

### Satisfaction

% Always/ Usually	% Sometimes	% Seldom/ Never	% Don't Know	# Total Surveys	Survey Question
86.6↓	12.1	1.1	0.2	461	50. Overall, are you satisfied with the services and supports your family member currently receives?
71.1	6.5	6.5	15.3	431	51. Are you familiar with the process for filing a complaint or grievance regarding services you receive or staff who provide them?
64.1↓	15.6	4.4	15.9	340	52. Are you satisfied with the way complaints/grievances are handled and resolved?

**Outcomes**

<b>% Always/ Usually</b>	<b>% Sometimes</b>	<b>% Seldom/ Never</b>	<b>% Don't Know</b>	<b># Total Surveys</b>	<b>Survey Question</b>
89.2	8.8	1.1	0.9	454	53. Do you feel that services and supports have made a positive difference in the life of your family?
86.3	12.9	0.4	0.4	459	54. Overall, do you feel that your family member is happy?



John E. Baldacci, Governor

Brenda M. Harvey, Commissioner

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