

# **BAY AREA QUALITY MANAGEMENT SYSTEM**

## **NCI Consumer & Family Survey Results Executive Summary**

**Medicaid Waiver Sample  
Year One Data**

### **FINAL REPORT**

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## EXECUTIVE SUMMARY

This summary compiles major findings from three data sources, the Consumer Survey, Adult Family Survey, and Family Guardian Survey, which were all administered in 2005 to randomly-selected Medicaid Waiver recipients across the three Bay Area Regional Centers. Separate detailed reports were produced for each set of survey results. This Executive Summary integrates results from all three data sources and describes key findings by topic area, identifying where the different sources yielded similar results and where there were discrepancies. Key positive findings and opportunities for improvement are also indicated. The purpose of this summary is to provide a brief overview of results contained in the full reports. Readers are strongly encouraged to review the individual reports, which provide a complete picture of Year One findings.

### **Background**

The California Department of Developmental Services (DDS) was awarded a *Real Choice Systems Change* grant from the Centers for Medicare and Medicaid Services (CMS) in 2003 to strengthen its current quality assurance and improvement system. One of the primary objectives of the grant was to develop a process for measuring participant satisfaction and outcomes. To achieve this goal, the Department implemented a pilot project in the San Francisco Bay Area across three sites: Golden Gate Regional Center (GGRC), Regional Center of the East Bay (RCEB), and San Andreas Regional Center (SARC).

The three-year pilot project had two overarching goals: (1) to provide data for the *Bay Area Quality Management System (QMS)*, which is involved with the transition of people from the Agnews Developmental Center to community-based settings, and (2) to pilot an assessment tool that may potentially be used across California's 21 regional centers.

A series of analyses were prepared by the Human Services Research Institute (HSRI) to summarize the results of the grant activities related to the first goal stated above. The first Bay Area Quality Management Report, *Consumer and Family Survey Results for Consumers Transitioned to the Community*, is available on the DDS website at: [http://www.dds.cahw.net.gov/agnewsclosure/docs/BayAreaQMS\\_SurveyResults.pdf](http://www.dds.cahw.net.gov/agnewsclosure/docs/BayAreaQMS_SurveyResults.pdf)

This Executive Summary pulls together findings from the three other reports that have been produced, including:

- *Consumer Survey Results - Medicaid Waiver Sample Year One Data (2005)* – this information was gathered through in-person interviews with Medicaid Waiver recipients and, in some cases, others who know them well enough to respond on their behalf.
- *Adult Family Survey Results - Medicaid Waiver Sample Year One Data (2005)* – this survey was conducted by mail with families of adult Medicaid Waiver recipients who live at home with their families.

- *Family Guardian Survey Results - Medicaid Waiver Sample Year One Data (2005)* – this survey was conducted by mail with families/guardians of adult Medicaid Waiver recipients who live outside of the family home.

### **Methods**

The pilot project steering committee selected the National Core Indicators (NCI) instruments to be used as the data collection tools for this activity. These surveys are used across the country by 27 state developmental disabilities service systems and by one other regional center in California. The tools have been tested for validity and reliability, and they also have the advantage of producing national benchmarks for comparison purposes. The surveys are specifically designed to measure performance and outcome indicators. The committee selected these tools for their benchmarking potential and for their correspondence with the quality measure domains of interest to the California DDS.

All three surveys were administered by a private contractor, XenologiX. The contractor was provided with the standard training and administration protocols specified by NCI. The first year of data collection took place in 2005.

### **Sample**

The Bay Area Pilot Project focused on consumers over 18 years of age who receive Medicaid Waiver services, as well as consumers from Agnews Developmental Center who have transitioned to community-based services. This report includes only those consumers who were in the Medicaid Waiver sample. XenologiX designed a sampling plan to ensure statistically significant data, or a 95% certainty that the data represents the population served by SARC, RCEB, and GGRC. Due to conflicting timeline and workload constraints at the regional centers, the 95% confidence interval was reduced to 90% mid-study, with a 5% margin of error.

At the time of the survey, there were 7,901 consumers over age 18 on the Medicaid Waiver. A total of 713 Consumer Surveys were completed across the three Regional Centers in year one. The breakdown by region was 221 from GGRC, 249 from RCEB, and 243 from SARC. To take into account differential sample size by region, a weight was applied during the analysis.

Adult Family Surveys were mailed to a sample of 773 families across the three regional centers. A total of 190 useable Adult Family Survey responses were obtained.

In addition to the Medicaid Waiver recipients, there were 64 consumers who had transitioned from Agnews at the time of the survey. Families and/or guardians of these individuals were also included in the Family Guardian Survey, which was administered by mail to a sample of 1,223 families across the three regional centers. A total of 192 useable Family Guardian Survey responses were obtained.

**Consolidated Findings by Outcome Area**

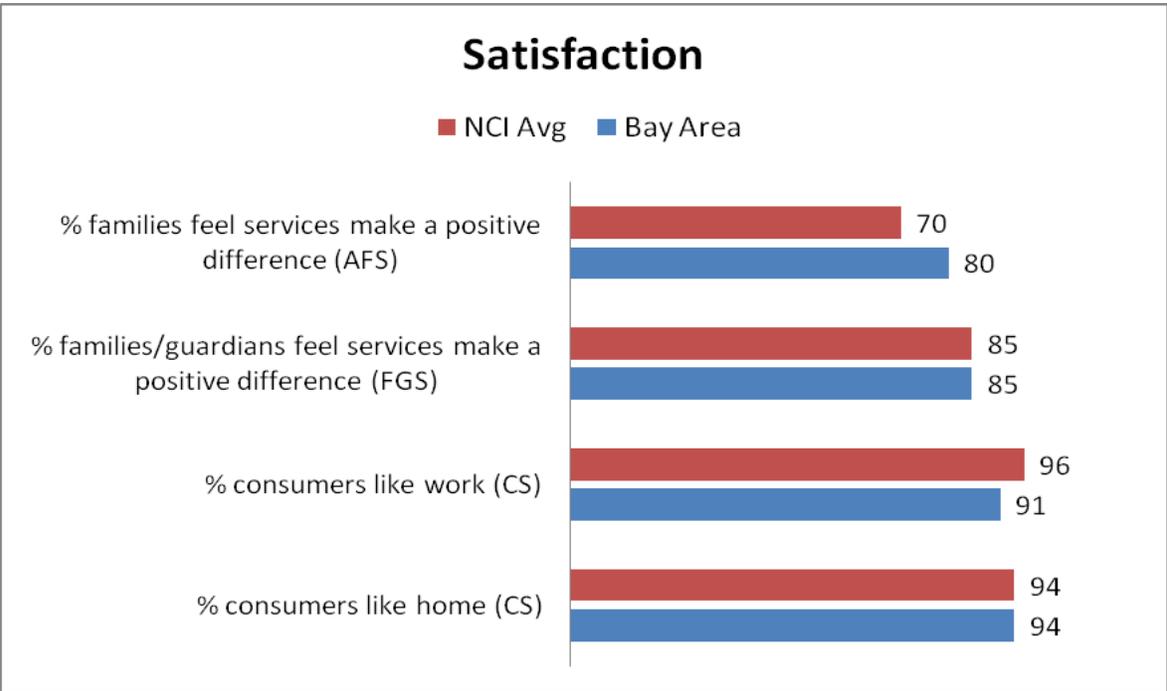
Key findings are summarized by outcome area below. Overall, the findings across the Bay Area Regional Centers were similar to national averages (across participating NCI states), with some exceptions, as noted below. The summary below draws from all three data sources and notes areas of agreement and disagreement. Each finding includes a reference to the particular data source, noted in parentheses using the following key:

- CS = Consumer Survey
- FGS = Family Guardian Survey
- AFS = Adult Family Survey

**Outcome Area: Satisfaction with Services and Supports**

*Positive Findings and Trends*

- Similar to the national averages, consumer satisfaction with home and work is typically high, at over 80%. Additionally, most people reported that they do not want to move from their current residence, and that they get along with their housemates. (CS)
- Approximately 80% of families/guardians report that they are satisfied with services and supports received by their family member. 85% feel that services have made a positive difference in their lives, and 83% report that their family member is happy (other NCI states: 84%, 85%, and 83%). (FGS)
- 80% of Adult Family Survey respondents state that services and supports have made a positive difference in the life of their family member (other NCI states: 70%). (AFS)



### *Possible Target Areas for Quality Improvement*

- Consumer satisfaction with day activities was generally good; however, 30% did report that they would prefer another day activity. (CS)

## **Outcome Area: Access and Delivery of Services and Supports**

### *Positive Findings and Trends*

- A greater percentage of Bay Area families (67%) are having their needs met by services and supports than in the other NCI states (58%). (AFS)

### *Possible Target Areas for Quality Improvement*

- Most consumer respondents reported that they had access to transportation, yet 27% said it was unreliable or unavailable. (CS)
- 20% of families/guardians report lack of access to special adaptive equipment at least some of the time, compared to the NCI state average of 13%.
- 42% of families/guardians report that they do not know the process for filing a complaint or grievance, compared with the National Benchmark of 36%. (FGS)
- Only a little over half (53%) of family respondents receive help when asking for services or supports in an emergency or crisis. These findings are similar to the other NCI states. (AFS)

## **Outcome Area: Relationships**

### *Positive Findings and Trends*

- Consumers typically report having friends and being able to maintain close personal relationships. (CS)
- Almost half the consumer sample (42%) reported having frequent chances to meet new people. (CS)

### *Possible Target Areas for Quality Improvement*

- Loneliness, which is a major concern nationally, also appears to be an issue in the Bay Area, with 40% of consumer respondents reporting that they sometimes or often feel lonely. (CS)

## **Outcome Area: Community Inclusion**

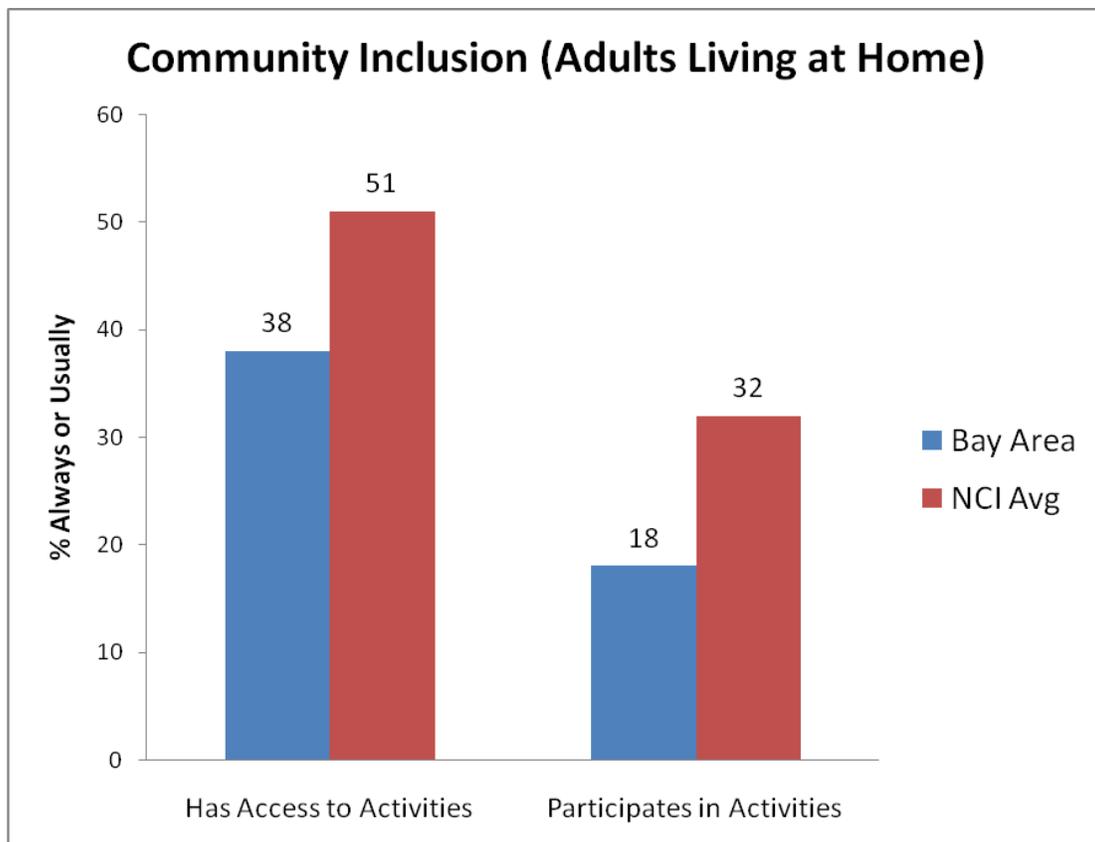
### *Positive Findings and Trends*

- Nearly all consumers interviewed took part in some activity in the community. (CS)

- Similar to the NCI state average (59%), just over half (58%) of Bay Area families/guardians report that their family members who live outside the family home have access to typical supports and activities in the community. (FGS)

*Possible Target Areas for Quality Improvement*

- The proportion of consumers who engage in physical exercise in integrated community settings is low (35%), and 20% of people report that they do not get any exercise. (CS)
- Most consumers (58%) report that they are accompanied by staff and/or housemates when they go into the community, and about 30% usually attend segregated activities. (CS)
- Community *participation* is rated somewhat lower than the NCI states, with 22% of families/guardians stating that their family members “seldom or never” participate in community activities, compared with 16% in the other states. (FGS)
- Community inclusion appears to be a greater challenge for adults living at home with family. Only 38% of respondents state that their family member has access to community activities (other NCI states: 51%), and 18% report that their family member participates in community activities (other NCI states: 32%). (AFS)



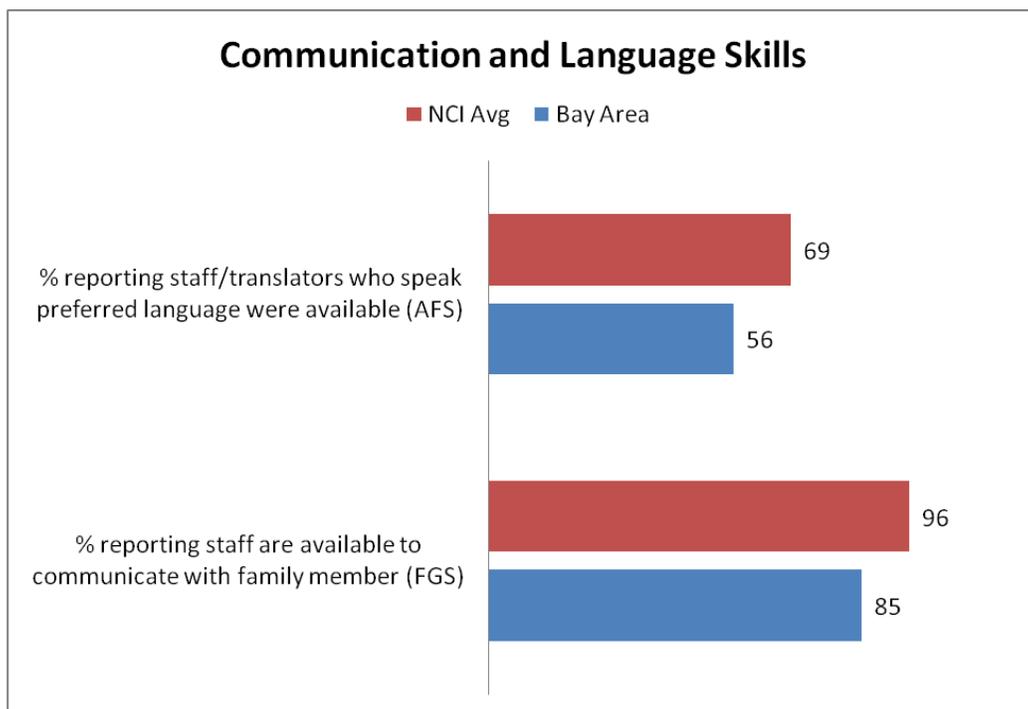
## Outcome Area: Direct Support Workers

### Positive Findings and Trends

- Staff turnover appears to be somewhat less of a concern for families/guardians in the Bay Area than in other NCI states. In the other states, 22% report that frequent staff changes are usually a problem, while in the Bay Area only 13% checked this response. (FGS)
- Similarly, Adult Family Survey respondents in the Bay Area report that staff turnover is less of a problem than it is in other NCI states. Only 14% reported that frequent changes in support staff are a problem for the family; this is compared to 23% in other NCI states. (AFS)
- As with other NCI states, most consumer respondents (over 80%) report that they are treated respectfully by support workers and that their basic rights are respected. (CS)

### Possible Target Areas for Quality Improvement

- Of Bay Area respondents with communication as a concern, 15% of families/guardians report that support workers who are competent to communicate with their family member are “seldom or never” available. In NCI states, this figure was 4%. (FGS)
- Of those family respondents whose first language was not English, only 56% report that there were support workers or translators available to them who spoke in their preferred language. This was compared to 69% in other NCI states. (AFS)



## **Outcome Area: Service Coordination**

### *Positive Findings and Trends*

- Nearly all consumer survey respondents report knowing their service coordinator, and over 80% reported that their service coordinator gets them what they need. (CS)
- Family/guardian survey respondents generally reported having enough involvement in planning and that case management staff are effective, respectful, and able to be contacted. Over 80% reported that case managers provide them with needed assistance, and that their family member receives needed services. These findings are similar to the NCI state averages. (FGS)

### *Possible Target Areas for Quality Improvement*

- A lower percentage of family/guardian respondents (65%) reported usually having enough information to participate in planning as compared to the national average of 76%. (FGS)
- Less than half (46%) of Bay Area families caring for a family member at home report receiving enough information to help participate in the planning of services. This was compared to 52% in the other NCI states. (AFS)

## **Outcome Area: Choice and Control**

### *Positive Findings and Trends*

- Most consumer survey respondents have some input into making daily choices and decisions such as what to do during the day and how to spend their money. (CS)
- The majority of family/guardian respondents report that providers involve them in making important decisions for their family members. (FGS)
- Only 7% of family respondents report that they have seldom or never helped with developing their family member's service plan. (AFS)
- A much greater percentage of Adult Family Survey respondents (46%) report that they know how much money is spent by the MR/DD agency on behalf of their family member as compared to the other NCI states (27%). (AFS)

### *Possible Target Areas for Quality Improvement*

- Choice and control over support workers by families/guardians is reportedly low but in line with the NCI state average. (FGS)
- While 60% of Adult Family Survey respondents want themselves or their family member to have control over hiring/management of the support workers, only 41% actually have it. (AFS)

## **Outcome Area: Health and Safety**

### *Positive Findings and Trends*

- The vast majority (90%) of consumer survey respondents report having had a physical exam in the past year, similar to the NCI average of 92%. (CS)
- 93% of family/guardian respondents feel that the consumer's residential setting is a healthy and safe environment, and 92% express the same about the day/employment setting. The Bay Area results are slightly higher than the NCI state averages (89% and 90%, respectively). (FGS)
- 91% of Bay Area families with adults living at home have access to necessary medications for their family member. This is in line with the national benchmark of 92%. (AFS)