

BAY AREA QUALITY MANAGEMENT SYSTEM

CONSUMER SURVEY & FAMILY GUARDIAN SURVEY RESULTS

Consumers Transitioned to the Community

FINAL REPORT

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EXECUTIVE SUMMARY

Background

The plan to close Agnews Developmental Center (Agnews) was developed over a three-year period, formally submitted to the Legislature in January 2005, and approved as part of the Budget Act for Fiscal Year 2005 – 2006. Enabling legislation to support the implementation of the critical elements of the plan has been enacted. This legislation supported the development of permanent housing through the Bay Area Housing Plan, established a pilot of community care licensed homes to serve adults with special health care needs in the Bay Area (San Andreas Regional Center, Regional Center of the East Bay, and Golden Gate Regional Center), and authorized Agnews' employees to work in the community to support the transition of Agnews' residents into community homes. The foundation of the Agnews Closure Plan is the development of sufficient community capacity to support the transition of Agnews' consumers into communities in proximity to their families. New service and support options are being created that provide meaningful choices for each person and that are designed to provide a stable home and service system upon which people can depend. The Agnews closure date was extended from June 30, 2007, to June 30, 2008, to assure that all necessary resources would be in place.

In addition to the implementation of the legislation that supports the Agnews Closure Plan, specific initiatives were developed to ensure the provision of medical and dental services to transitioning individuals. These initiatives include the development and implementation of a Health Transition Plan that includes a comprehensive nursing and risk assessment, the establishment of the Agnews outpatient services clinic in May of 2006, the development of service delivery strategies to expand access to medical services through partnerships between local health plans and the regional centers, and the use of dental coordinators to conduct screenings and assessments and to identify and promote the development of community dental resources.

Another critical component of the Agnews Closure Plan is the Bay Area Quality Management System (QMS). The QMS is based on the values set forth in the Agnews Closure Plan and described in the Department of Developmental Services Strategic Plan. The QMS includes a provider performance expectation and quality improvement tool called Quality Services Review (QSR) that includes 37 provider expectations and 84 measurements of those expectations. A key component of the QSR is its focus on quality outcomes for individuals which are measured using monitoring tools. These tools are implemented by professional staff at regional centers, including registered nurses, psychologists, QMS specialists, and service coordinators as well as by family members, friends and other visitors to the individual's homes (family, friends, and other visitors may complete "snapshot reviews").

The National Core Indicators (NCI) Consumer and Family Satisfaction surveys were selected to be piloted as annual measures of individual outcomes and family

satisfaction. The following report, *Consumer Survey and Family Guardian Survey Results*, includes the results of face-to-face surveys of individuals who transitioned from Agnews in the 2003-04 and 2004-05 fiscal years, as well as phone interviews with their family members.

The QMS includes ongoing mechanisms to measure individual outcomes and satisfaction in addition to the information obtained in the annual NCI Surveys. A Review Commission was established to serve in an advisory capacity to review Bay Area QMS data and reports. The members include two consumers, seven parents, an advocate from Protection and Advocacy, Inc., and one provider. Recommendations for system improvements and capacity building will be made to the DDS and the Bay Area regional centers by the Review Commission. More information on the Agnews Closure Plan is available at www.dds.ca.gov/AgnewsClosure.

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 is 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 has 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.

This report is one of a series of analyses prepared by the Human Services Research Institute (HSRI) to summarize the results of the grant activities related to the first goal stated above. Each report addresses a different target group. The results presented herein represent information gathered from consumers transitioning to the community, their families and advocates, and their residential support staff.

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 24 state developmental disabilities service systems and by one regional center in California. The tools have been tested for validity and reliability, and they also have the advantage of producing cross-state averages 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.

Two surveys, the Consumer Survey (conducted in person) and the Family Guardian Survey (conducted via phone) were administered by a private contractor, XenologiX. The contractor was provided with the standard training and administration protocols specified by NCI. The surveys were administered twice over a two year period. Due to small numbers of surveys completed in the first year (2004-2005), this report focuses solely on year two data (collected in 2005-2006).

Sample

Among the Agnews Movers group there were a total 98 individuals. Of this group 83 consents for the Consumer Survey were obtained and 76 individuals were ultimately interviewed. Family members/guardians of these individuals were also invited to participate in a phone survey. Of the 76 individuals for whom a family/guardian contact was identified, 29 gave consent to participate in a phone interview, and 17 Family Guardian Surveys were ultimately completed across the three Regional Centers in year two. Family Guardian Survey results should be viewed with caution since the sample size is still quite small. The majority of the surveys were completed by parents (71%) or siblings (24%) of the consumer. For the Consumer Survey, only 6 individuals were able to respond to Section I, which contains the more subjective questions. This number varies from the approximately 60% response rate for NCI generally given that approximately 75% of this cohort of individuals fell into the severe/profound level of intellectual disability. Since Section I items can only be answered by consumers, they are not reported here due to the small number of respondents. However, for Section II, which contains the more factual questions, responses were provided for 76 consumers. The majority of these responses (97%) were provided by residential support staff on behalf of the consumer.

Positive Findings and Trends

The analysis of the Consumer Survey and Family Guardian Survey data revealed several key findings regarding satisfaction and positive outcomes for the sample of individuals who transitioned to the community from the Agnews Developmental Center.

Positive findings include:

- ◆ The majority of family respondents (80%) report that they have enough information to help plan services for their family member, and 80% reported that the service plan includes things that are important to them. Most families also reported that the case managers were respectful, effective, and can be contacted when necessary.
- ◆ 100% of Family Guardian Survey respondents and 96% of Consumer Survey respondents indicated that consumers were receiving the supports they need.
- ◆ Family respondents expressed extremely high levels of satisfaction with the transition process, in particular giving high praise to the case managers who

have worked with them to ensure a smooth transition. All family respondents reported that they were satisfied overall with the services and supports the consumer receives, that these supports have made a positive difference in the life of their family, and that they feel the consumer is happy.

- ◆ In the open-ended comments section of the survey, several families remarked that although they had been hesitant or fearful about making the transition, they were extremely pleased with how well the consumer was doing and encouraged other families to do the same. Many also complimented the community residential staff and the care that is being provided in the community homes.
- ◆ All individuals in the consumer survey sample reportedly received a physical exam within the previous year. For women, 64% received a GYN exam in the last year.¹ Just over half of the sample (54%) reported having a dentist visit within the last six months.²
- ◆ 100% families surveyed felt that residential and day settings are healthy and safe environments.
- ◆ The majority of consumers in the survey sample reportedly participated in a variety of community activities, and most families reported that consumers have access to typical activities and supports in the community.
- ◆ In some areas of choice and decision-making, approximately half of the consumer survey respondents were involved in making important decisions. For example, 56% had some input in where they live, and 45% had some input in where they go during the day. Before making these choices, 45% looked at more than one option for both residential and day settings.

Possible Target Areas for Quality Improvement

- ◆ One family expressed concern about the need for improved communication with residential staff and that staff are “not always well trained.” It is not clear what the specific concern is, e.g. frequency of communication, language skills, basic knowledge, or some other issue. Perhaps a related finding is that 27% of family respondents indicated that support workers who can communicate with their family member in their chosen mode of communication (e.g., language and or mode) are only “sometimes” available. This is an area that may warrant further exploration.
- ◆ A request was made for general financial information such as how to set up trusts. This is an area where resources exist and DDS or the Regional Centers could likely provide additional information to families.

¹ In order to screen out people who might have had a physical or GYN exam at Agnews prior to their transition, the analysis selected only those individuals who had been living in the community for at least one year (N=65). Everyone in the sample had been living in the community for at least six months.

² The generally recommended frequency of dental examinations is 6 months (<http://www.dental-health-index.com/dentalexam.html>)

- ◆ Out of the 15 Family/Guardian Survey respondents, 40% reported that they did not help develop the person's service plan.
- ◆ Of family respondents, 59% reported that they did not know the process for filing a complaint or grievance regarding services and supports. This is another area where more education and information could be provided to families.
- ◆ Basic health care beyond an annual physical should be watched for trends. Of the 28 women in the Consumer Survey sample, only 18 (64%) reported having a GYN exam within the past year. Another 6 (25%) of women had an exam over one year ago, 1 had never had one, and the information was not available for 3 consumers. While this outcome is somewhat consistent with national trends³, it is important to ensure that access to preventative care does not decline for women living in the community. The same caution is true for dental care. Across the country, the availability of dental services for people with disabilities in the community has been constrained by inadequate rates, the need in some instances for anesthesia, lack of staff to support the individual, and lack of training among dentists regarding the needs of people with developmental disabilities.
- ◆ Lack of opportunities for physical activity was one concern that was expressed on the family survey⁴. This issue is also evident in the Consumer Survey results, where being overweight was a concern for 13% of consumers in the sample.
- ◆ With respect to physical activity, 17% were described as being physically inactive. It is not known what proportion of these individuals was constrained from activity because of physical limitations.
- ◆ While access to activities in the community is high, participation is typically with staff and other residents, and about half of the sample reported that the events are specifically for people with disabilities. Thus, there is clearly some room for expanding outcomes around more inclusive community participation.
- ◆ Most consumer survey respondents (87%) indicated that someone other than the consumer chose the person's housemates. Of the 18 consumers who share a room, 10 (56%) had their roommate selected for them as well. Affording greater choice, particularly of a roommate, could be a target area for improvement.
- ◆ Consumers in the survey sample typically did not choose home staff, work staff, or their case managers. In many cases the respondent indicated that the person could request a change if desired. Since the respondents were primarily residential support staff, it is not clear whether individuals or families know that they could request a change. This is an area that could be

³ In 2005-2006, of women in the NCI cross-state sample who receive Medicaid Waiver services, 72% reported having a GYN exam in the last year.

⁴ Low levels of physical activity may be due to physical limitations

developed further in order to promote increased individual choice and control.

- ◆ Most families (82%) reported that the agency providing residential services involves them in important decisions, however only 29% reported having the same involvement with day service providers.
- ◆ The rights questions added to the survey (“Has anyone ever spoken to you about your rights...” and “If you haven’t voted in the past 5 years, would you like to vote”) may not be reliable since they were answered by a staff person. These items should either be reworded or moved to Section I.
- ◆ Only 58% of consumers can have unsupervised visits with guests in the home.
- ◆ Very few consumers (12%) had participated in a self-advocacy group.

I. INTRODUCTION

The plan to close Agnews Developmental Center (Agnews) was developed over a three-year period, formally submitted to the Legislature in January 2005, and approved as part of the Budget Act for Fiscal Year 2005 – 2006. Enabling legislation to support the implementation of the critical elements of the plan has been enacted. This legislation supported the development of permanent housing through the Bay Area Housing Plan, established a pilot of community care licensed homes to serve adults with special health care needs in the Bay Area (San Andreas Regional Center, Regional Center of the East Bay, and Golden Gate Regional Center), and authorized Agnews' employees to work in the community to support the transition of Agnews' residents into community homes. The foundation of the Agnews Closure Plan is the development of sufficient community capacity to support the transition of Agnews' consumers into communities in proximity to their families. New service and support options are being created that provide meaningful choices for each person and that are designed to provide a stable home and service system upon which people can depend. The Agnews closure date was extended from June 30, 2007, to June 30, 2008, to assure that all necessary resources would be in place.

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The QSR is currently being implemented with service providers. In each regional center, QMS Specialists are working with existing Unified Plan providers (service providers funded through the Bay Area Unified Community Placement Plan) on meeting the provider quality expectations. An implementation schedule has been developed to

match the creation of new housing through the Bay Area Housing Plan and the development of residential services.

A central information and integration system using Microsoft Access software has been developed. The system has been installed at each of the Unified Plan regional centers. Extensive training has been completed for the users of the new system. The Quality Management Information System manages QMS data storage and display. These reports are reviewed by regional center QMS Specialists and used in working with providers to continuously improve their services and ensure services meet the entire array of provider quality expectations. The system also includes a response tracking process for areas needing attention during the quality improvement efforts.

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The QMS includes ongoing mechanisms to measure individual outcomes and satisfaction in addition to the information obtained in the annual NCI Surveys. A Review Commission was established to serve in an advisory capacity to review Bay Area QMS data and reports. The members include two consumers, seven parents, an advocate from Protection and Advocacy, Inc., and one provider. Recommendations for system improvements and capacity building will be made to the DDS and the Bay Area regional centers by the Review Commission. More information on the Agnews Closure Plan is available at www.dds.ca.gov/AgnewsClosure.

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 is 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).

Overall Purpose of the Study

The three-year pilot project has 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.

The specific goals of the pilot project are to:

- ◆ Support value based outcomes
- ◆ Keep people safe and ensure their well-being
- ◆ Ensure consumer and family satisfaction

- ◆ Identify and close gaps in the community system
- ◆ Develop a system with potential for statewide use
- ◆ Meet the expectations of the Centers for Medicare and Medicaid Services

In 2004, the project Steering Committee selected the National Core Indicators (NCI) as the best assessment tool to gauge participant satisfaction and designated a private company, XenologiX, to carry out evaluation activities. Both the NCI Consumer Survey and Family Guardian Survey were administered to consumers who transitioned to the community.

Focus of this Report

This report is one of a series of analyses prepared by the Human Services Research Institute (HSRI) to summarize the results of the grant activities for the Bay Area QMS. Each report addresses a different target group. The results presented herein represent information gathered from consumers transitioning to the community, their families and advocates, and their residential support staff.

Data collected from the two primary data sources are presented in this report by outcome area so that the Bay Area QMS can evaluate how well the measures inform the stated Outcome Performance Indicators, many of which correspond to the National Core Indicators domains. The data included here are from the second year of data collection (2005-2006). The first year baseline data are not included due to the small sample size. Both quantitative and qualitative data are presented in an effort to capture the nuances of the experiences of consumers and families who have been involved in the transition process. The data are organized by the following domains:

- ◆ Information & Planning
- ◆ Access and Delivery of Supports
- ◆ Satisfaction
- ◆ Health
- ◆ Community Activities
- ◆ Choice & Decision-Making
- ◆ Respect & Rights

II. METHODS

This section describes the survey tools, research methodology, and administrative procedures used to collect the data and to ensure the validity of the information gathered.

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 24 state developmental disabilities service systems and by one regional center in California. The tools have been tested for validity and reliability, and they also have the advantage of producing cross-state averages 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.

Two surveys, the Consumer Survey (conducted in person) and the Family Guardian Survey (conducted via phone) were administered by a private contractor, XenologiX. The contractor was provided with the standard training and administration protocols specified by NCI. The surveys were administered twice over a two year period. Due to small numbers of surveys completed in the first year (2004-2005), this report focuses solely on year two data (collected in 2005-2006).

Description of the NCI Consumer Survey

The NCI Consumer Survey was initially developed by a technical advisory subcommittee with the purpose of collecting information directly from individuals with developmental disabilities and their families or advocates. The survey is designed to measure specific performance indicators. Many questions were drawn from survey instruments already in use in the field; other questions were developed specifically for NCI. NCI staff have tested and refined the instrument each year based on feedback from interviewers.

The Consumer Survey is composed of a pre-survey form and three main sections.

- ◆ The Pre-Survey Form provides interviewers with information necessary to schedule face-to-face interviews, including contact information for consumers, and the names of guardians, advocates, or other individuals who might be asked to provide responses. The form also was used by interviewers to identify, prior to the interview, special communication needs that individuals might have, define terms the individual would be most familiar with, and document that verbal consent was obtained.
- ◆ The Background Information Section requests demographic information and some items related to health status.
- ◆ Section I of the survey consists of questions that seek to obtain the individual consumer's perspective and opinions about his or her services and supports. This section may only be completed through a direct interview with the individual; proxy responses are not acceptable.
- ◆ Section II questions are less subjective and are also answered by the individual if possible. If the person is unable to respond, a proxy is asked to answer.
- ◆ The last page of the survey is the Surveyor Feedback Sheet. Surveyors are asked to record the length of the interview with the individual and describe any problematic questions.

Supplemental questions

The survey tool used by DDS contained additional questions as requested by the project Steering Committee. Six supplemental questions were added to Section I of the survey and seven to Section II. Supplemental questions in Section I further explore the issues of work and daytime activities, home, and satisfaction with services/supports.

The supplemental questions added to Section II of the original survey further explore the issues of community participation, choices and rights.

Consumer Survey Administrative Procedures

During the early phases of this project a senior HSRI staff person conducted a “train-the-trainer” module over the phone to illustrate the use of the survey and provide guidance on how to conduct successful interviews. Topics covered by the training include:

- ◆ Background and basics about the National Core Indicators
- ◆ Role of consumer surveys in quality management
- ◆ Overview of survey tool

At this time the different components of the survey were illustrated and critical parts of the interviewing process reviewed and explained thoroughly.

For the Consumer Survey, the three regional centers contacted potential participants either via telephone, mail or in-person to introduce the project and gain the consumer’s consent to participate. If the consumer agreed to participate, the regional centers provided selected Pre-Survey and Background Information via the Internet. Once this data was provided, additional data to complete these sections was provided from the regional center databases. Pre-Survey information was then provided to XenologiX for independent, trained interviewers to schedule in-person interviews with consumers at a time and location of their choice.⁵

Description of the Family Guardian Survey

The Family Guardian Survey asks families to express their overall level of satisfaction with services and supports their family member receives, as well as probes specific aspects of the service system’s effectiveness. Along with demographic information, the survey includes questions related to: the planning for services and supports; access to and delivery of services and supports; choice in and control over supports; connections with the community; and satisfaction and outcomes. Combined, this information provides an overall picture of family satisfaction.

- ◆ Demographics – The survey instrument begins with a series of questions tied to characteristics of the family member with disabilities (e.g., individual’s gender, age, race, type and level of disability), followed by questions pertaining to the respondent (e.g., respondent’s age, relationship to individual, guardianship and frequency of visits with family member).
- ◆ Services Received – This section of the survey asks respondents to identify the services and supports their family member receives.

⁵ Description of administrative procedures is taken from an earlier XenologiX report.

- ◆ Service Planning, Delivery & Outcomes – The survey contains several groupings of questions that probe specific areas of quality service provision (information and planning, access to and delivery of services, choice and control, community connections, satisfaction and outcomes). Each question is constructed so that the respondent can select from three possible responses ("always or usually", "sometimes", and "seldom or never"). Respondents also have the option to indicate that they don't know the answer to a question, or that the question is not applicable.
- ◆ Additional Comments – Finally, the survey provides an opportunity for respondents to make additional open-ended comments concerning their family member's participation in and experiences with the service system.

Sample

Among the Agnews Movers group there were a total 98 individuals. Of this group 83 consents for the consumer survey were obtained and 76 individuals were ultimately interviewed. Family members/guardians of these individuals were also invited to participate in a phone survey. Of the 76 individuals for whom a family/guardian contact was identified, 29 gave consent to participate in a phone interview, and 17 Family Guardian Surveys were ultimately completed across the three Regional Centers in year two. Family Guardian Survey results should be viewed with caution since the sample size is still quite small. The majority of the surveys were completed by parents (71%) or siblings (24%) of the consumer. For the Consumer Survey, only 6 individuals were able to respond to Section I, which contains the more subjective questions. This number varies from the approximately 60% response rate for NCI generally given that approximately 75% of this cohort of individuals fell into the severe/profound level of intellectual disability. Since Section I items can only be answered by consumers, they are not reported here due to the small number of respondents. However, for Section II, which contains the more factual questions, responses were provided for 76 consumers. The majority of these responses (97%) were provided by residential support staff on behalf of the consumer.

Limitations

As with any data collection effort, there are some caveats that need to be considered when interpreting results. Specifically, it is important to note that since the vast majority of consumers were not able to respond to the Consumer Survey, responses were generally provided by residential staff who knew the consumer well. While this is certainly not preferable, it is generally accepted practice in the field of developmental disabilities for proxy respondents to provide answers to questions that are objective in nature when the individual is not able to respond⁶. However, when looking at the results, one should keep in mind that the perspective of a staff person may differ from that of the consumer. Another caution to bear in mind is that the sample for the Family Guardian Survey is quite small, with only 17 respondents (out of a possible 76), thus making it difficult to generalize findings to all families and guardians.

⁶ Sheppard-Jones, K., Prout, H.T., & Kleinert, H. (2005). Quality of Life Dimensions for Adults with Developmental Disabilities: A Comparative Study. *Mental Retardation*, 43(4), 281-291.

Given these limitations, the outcome data from this pilot study should be considered valid and can certainly provide general direction to the Bay Area QMS.

Data Analysis

All persons selected in the survey sample are given an opportunity to respond to questions in a face-to-face interview. There is no pre-screening procedure. Exclusion of responses is done at the time of data analysis, based on specific criteria described below.

Section I is administered only to the person receiving services. A person's responses are excluded if any of the following criteria are met:

- ◆ The consumer responded to less than half of the questions in Section I.
- ◆ The interviewer recorded that the person did not understand the questions being asked.
- ◆ The interviewer recorded that the person gave inconsistent responses.

After excluding incomplete and inconsistent responses, we found that only 6 individuals provided valid responses to Section I. Due to this low number of responses, **Section I items are not included in this analysis.**

Section II allows multiple respondents. Other informants (e.g., family, friend, support worker) are permitted to answer these questions. In the final analysis, if a respondent is excluded from Section I, his or her responses are also excluded from Section II. Otherwise, all responses to questions in Section II are included in the analysis, regardless of how many questions were answered.

III. RESULTS

Demographic Profile of Survey Respondents

In the second year of data collection (2005-2006), XenologiX completed 76 *NCI Consumer Surveys* of people who had transitioned from Agnews to the community. Additionally, the *NCI Family Guardian Survey* was filled out by 17 families of this same group of individuals. This section presents descriptive characteristics of the respondents to each of the surveys.

Consumer Survey: Consumer Characteristics		
	N	%
Gender:		
Male	46	60.5
Female	30	39.5
Total	76	
Race:		
Asian	3	3.9
Black or African American	6	7.9
White	51	67.1
Other race not listed	16	21.1
Don't know	0	0.0
Total	76	
Ethnicity:		
Non-Hispanic	63	82.9
Hispanic	13	17.1
Don't know	0	0.0
Total	76	
Level of cognitive disability:		
No MR label	1	1.3
Mild	7	9.3
Moderate	8	10.7
Severe	18	24.0
Profound	40	53.3
Unspecified/unknown	1	1.3
Total	75	
Other Diagnoses (duplicated counts):		
Mental Illness/Psychiatric Diagnosis	28	36.8
Autism	16	21.1
Cerebral Palsy	20	26.3
Seizure Disorder/Neurological Problem	33	44.0
Vision Problems	0	0.0
Physical Disability	23	30.7
Type of Residence:		
Specialized facility (includes private ICFs/MR)	26	34.2
Group home	48	63.2
Other	2	2.6
Total	76	

Family Guardian Survey: Consumer Characteristics		
Number of surveys	17	
	N	%
Gender:		
Male	11	64.7
Female	6	35.3
Total	17	
Age:		
Mean (Range)	47.4 (24-68)	
Type of Residence		
Specialized MR Facility	3	17.6
Group Home	12	70.6
Agency-Owned Apartment	0	0.0
Own Home/Apartment	0	0.0
Adult Foster Care/Host Family Home	1	5.9
Nursing Home	0	0.0
Other	1	5.9
Total	17	
Level of MR:		
No MR label	0	0.0
Mild	1	5.9
Moderate	7	41.2
Severe	2	11.8
Profound	6	35.3
Don't know	1	5.9
Total	17	
Race/Ethnicity (duplicated counts):		
White	13	76.5
Black/African-American	1	5.9
Asian	0	0.0
American Indian/Alaska Native	0	0.0
Hawaiian/Pacific Islander	0	0.0
Hispanic	2	11.8
Mixed races	1	5.9
Other/Unknown	0	0.0
Other disabilities (duplicated counts):		
Mental illness	6	35.3
Autism	4	25.0
Cerebral palsy	3	18.8
Brain injury	3	17.6
Seizure disorder/ neurological problem	6	35.3
Chemical dependency	0	0.0
Vision or hearing impairments	5	29.4
Physical disability	5	29.4
Communication disorder	10	58.8
Alzheimer's disease	0	0.0
Down Syndrome	2	11.8
Other disability	2	11.8

Family Guardian Survey: Characteristics of Respondents		
Number of surveys	17	
	N	%
Age of Respondent:		
Under 35	0	0.0
35 – 54	3	17.6
55 – 74	6	35.3
75 and Over	8	47.1
Total	17	
Relationship to Family Member:		
Parent	12	70.6
Sibling	4	23.5
Spouse	0	0.0
Other	1	5.9
Total	17	
If other relationship, please specify:		
Grandparent	0	0.0
Step-parent	0	0.0
Self	0	0.0
Uncle	0	0.0
Sister-in-law	1	100.0
Total	1	
Respondent is guardian or conservator:		
Yes	11	64.7
No	6	35.3
Total	17	
Frequency of Visits with Family Member:		
Less than once/year	0	0.0
1-3 times/year	5	29.4
4-6 times/year	2	11.8
7-12 times/year	3	17.6
More than 12 times/year	7	41.2
Total	17	

Family Guardian Survey: Services & Supports Received		
Number of surveys	17	
	N	%
Residential Supports		
Yes	17	100.0
No	0	0.0
Total	17	
Day/Employment Supports		
Yes	15	93.8
No	1	6.3
Total	16	
Transportation		
Yes	16	94.1
No	1	5.9
Total	17	
Other Services/Supports		
Yes	5	35.7
No	9	64.3
Total	14	

Consumer and Family Guardian Survey Results

This section presents the results for both surveys conducted in 2005-2006 with consumers transitioned to the community and their families. The following tables display the breakdown of each response choice for each question on the surveys. The items are grouped by topic area and the sources are listed at the top of the table. Unless otherwise specified, “don’t know” and “not applicable” responses are excluded from the totals.

Due to the low response rate to Section I (only 6 consumers were able to respond independently), these questions are omitted from the analysis. Only Section II questions are displayed. Most Section II responses were provided by proxies. Home staff provided answers in 97% of cases (74 out of 76). Advocates were the sole respondent in the other two cases (3%). Consumers were present and may have contributed to responses in 7 of the 76 interviews (9%).

For the purposes of this project, 13 questions (6 in Section I plus 7 in Section II) were added to the NCI Consumer Survey in order to obtain additional information on community inclusion, choice, and rights. The relevant questions from Section II are included below and referred to as “Questions Added by Bay Area Project.”

The Family Guardian Survey includes a write-in section at the end where respondents can include comments. All comments are included in this report, organized by relevant topic area at the end of each table. While they are not necessarily representative of all opinions, the remarks do provide an additional qualitative description of families’ experiences with the transition process and suggestions for improvement.

INFORMATION AND PLANNING

Source: Family Guardian Survey		
Q1. Do you get enough information to help you participate in planning services for your family member?		
Number of surveys		15
	% always or usually	80.0
	% sometimes	13.3
	% seldom or never	6.7
Q2. If your family member has a service plan, did you help develop the plan?		
Number of surveys		15
	% always or usually	53.3
	% sometimes	6.7
	% seldom or never	40.0
Q3. If your family member has a service plan, does the plan include things that are important to you?		
Number of surveys		15
	% always or usually	80.0
	% sometimes	20.0
	% seldom or never	0.0
Q4. Are the staff who assist you with planning generally respectful and courteous?		
Number of surveys		15
	% always or usually	100.0
	% sometimes	0.0
	% seldom or never	0.0
Q5. Are the staff who assist you with planning generally effective?		
Number of surveys		15
	% always or usually	93.3
	% sometimes	6.7
	% seldom or never	0.0
Q6. Can you contact the staff who assist you with planning whenever you want to?		
Number of surveys		15
	% always or usually	86.7
	% sometimes	6.7
	% seldom or never	6.7
Related Comments:		
<ul style="list-style-type: none"> ♦ Would like the family he is living with to check in once a month with me to update. ♦ They are doing real great with him. I receive a full report before each meeting. I'm happy with it. ♦ Communication is difficult with residence staff. The residence staff is not always well trained. ♦ I wish there were more general information resources, for example, I need more info on [consumer]'s finance and if I need to set up a trust. How do I found out the information? Is there a resource center or person for family members? 		

ACCESS AND DELIVERY OF SUPPORTS

Source: Family Guardian Survey		
Q7. When you ask the service coordinator/case manager for assistance, does he/she help you get what you need?		
Number of surveys		12
	% always or usually	83.3
	% sometimes	16.7
	% seldom or never	0.0
Q8. Does your family member get the services and supports he/she needs?		
Number of surveys		17
	% always or usually	100.0
	% sometimes	0.0
	% seldom or never	0.0
Q9. If your family member does not speak English or uses a different way to communicate (e.g., sign language), are there enough support workers available who can communicate with him/her?		
Number of surveys		11
	% always or usually	72.7
	% sometimes	27.3
	% seldom or never	0.0
Q10. Does your family member have access to the special equipment or accommodations that he/she needs (e.g., wheelchairs, ramps, communication boards)?		
Number of surveys		9
	% always or usually	88.9
	% sometimes	11.1
	% seldom or never	0.0
Q11. Are frequent changes in support staff a problem for your family member?		
Number of surveys		16
	% always or usually	6.3
	% sometimes	6.3
	% seldom or never	87.5

Source: Consumer Survey			
		N	%
Q50. Do you get the services and supports you need?			
	No	1	1.3
	Sometimes	2	2.6
	Yes	73	96.1
	Total	76	

SATISFACTION

Source: Family Guardian Survey	
Q25. Overall, are you satisfied with the services and supports your family member currently receives?	
Number of surveys	17
% yes or most of the time	100.0
% some of the time	0.0
% no or not at all	0.0
Q26. Are you familiar with the process for filing a complaint or grievance regarding services you receive or staff who provide them?	
Number of surveys	17
% yes or most of the time	29.4
% some of the time	11.8
% no or not at all	58.8
Q27. Are you satisfied with the way complaints/grievances are handled and resolved?	
Number of surveys	5
% yes or most of the time	100.0
% some of the time	0.0
% no or not at all	0.0
Q28. Do you feel that services and supports have made a positive difference in the life of your family?	
Number of surveys	17
% yes or most of the time	100.0
% some of the time	0.0
% no or not at all	0.0
Q29 Overall, do you feel that your family member is happy?	
Number of surveys	16
% yes or most of the time	100.0
% some of the time	0.0
% no or not at all	0.0
Related Comments:	
<ul style="list-style-type: none"> ♦ They are doing a really good job. They are being careful and picking good homes. ♦ Our daughter has been treated well and with a lot of consideration. Her case manager is excellent - she saw a need and filled it. ♦ The way everything has been handled during the transition has been great. [Case Manager] does a good job, works hard. Our daughter just blossomed under all the attention. She is in a more stable environment and they are a good influence on her. ♦ This has been a great transition for our son. The residence takes our concerns for his safety into consideration. Changing from Agnews to the community has been really, really positive, even though I was hesitant to do it. Our son has had no complaints since he's lived there. ♦ People have to be willing to try something new even if it's difficult. I've been very pleased. ♦ He seems to be transitioning well. ♦ She's doing very well. I wish I would have done it a long time ago. I wish other parents 	

would be more open to placing their family member in the community. I was scared, too. There are good homes in the community.

- ◆ We are very pleased and satisfied with the service plan. We feel so privileged to have her live where we lives, in a new residence. Services and supports have made an enormous difference in the life our family. Having [consumer] properly cared for is a great comfort.
- ◆ I am so grateful. He is well cared for. While I am alive, it's nice that he is in the county. When I am dead it doesn't matter.
- ◆ The residence staff are exceptional people. We could not have found a better home.
- ◆ The transition was handled very well by the residence staff. It was done gradually to help her acclimate.
- ◆ The day program is not always sufficiently active with worthwhile programs and work. I wish it had more of a work component.

HEALTH

Source: Consumer Survey			
		N	%
BI-19. When was his/her last physical exam?			
	Within past year	65	100
	Total	65	
BI-20. If female, when was her last OB/GYN exam?			
	Within past year	18	64.3
	Over a year ago	6	21.4
	Never had an exam	1	3.6
	Don't know	3	10.7
	Total	28	
BI-21. When was his/her last dentist visit?			
	Within last six months	35	53.8
	Over six months ago	30	46.2
	Total	65	
BI-22. Is weight a concern for this person?			
	Yes, underweight	1	1.3
	Yes, overweight	10	13.2
	No	65	85.5
	Total	76	
BI-23. Does this person smoke or chew tobacco?			
	No	70	92.1
	Yes	6	7.9
	Total	76	
BI-24. How physically active is this person?			
	Very active	30	39.5
	Moderately active	33	43.4
	Physically inactive	13	17.1
	Total	76	

Source: Family Guardian Survey		
Q12. Do you feel that your family member's residential setting is a healthy and safe environment?		
Number of surveys		17
	% always or usually	100.0
	% sometimes	0.0
	% seldom or never	0.0
Q13. Do you feel that your family member's day/employment setting is a healthy and safe environment?		
Number of surveys		11
	% always or usually	100.0
	% sometimes	0.0
	% seldom or never	0.0

Related Comments:

- ◆ I would like the day program to have more outdoor activities and physical movement.
- ◆ ...The only ongoing concern we have is her weight and her inability to control that on her own.
- ◆ I would like to still have medical services at Agnews.

COMMUNITY ACTIVITIES

Source: Consumer Survey			
		N	%
Q28. Do you go shopping?			
	Yes	76	100
	Total	76	
Q29. Do you go out on errands or appointments?			
	Yes	76	100
	Total	76	
Q30. Do you go out for entertainment?			
	No	2	2.6
	Yes	74	97.4
	Total	76	
Q31. Do you always eat at home or do you sometimes go out to eat?			
	No	5	6.6
	Yes	71	93.4
	Total	76	
Q32. Do you go to religious services?			
	No	37	48.7
	Yes	39	51.3
	Total	76	
Q33. Do you go to other meetings in the community?			
	No	67	88.2
	Yes	9	11.8
	Total	76	
Q34. Do you exercise or play sports?			
	No	8	10.5
	Yes, in non-integrated settings	54	71.1
	Yes, in a community setting	14	18.4
	Total	76	

Source: Consumer Survey – Questions added by Bay Area Project			
		N	%
QRC7. Who do you go with in the community?			
	With staff and other people I live with	22	64.7
	With staff	12	35.3
	Total	34	
QRC8. Are events only for people with disability?			
	Never	0	0.0
	Rarely	2	8.3
	Sometimes	8	33.3
	Most of the time	8	33.3
	Always	6	25.0
	Total	24	

QRC9. If can't always go where you want, why not?			
	Other	14	87.5
	*Transportation unreliable or unavailable	2	12.5
	Total	16	

*The most commonly cited reasons for people not being able to go where they want to go are behavioral and health issues. Other mentioned reasons include having a busy or strict schedule.

QRC11. How often do you get a chance to meet new people?			
	Not often	8	23.5
	In-between	11	32.4
	Often	15	44.1
	Total	34	

Source: Family Guardian Survey			
Q21. If your family member wants to use typical supports in your community (e.g., through recreation departments or churches), do either the staff who help plan or who provide support help connect him/her to these supports?			
Number of surveys			11
	% always or usually		90.9
	% sometimes		9.1
	% seldom or never		0.0
Q22. If your family member would like to use family, friends, or neighbors to provide some of the supports your family needs, do either the staff who help plan or who provide support help him/her do this?			
Number of surveys			8
	% always or usually		75.0
	% sometimes		0.0
	% seldom or never		25.0
Q23. Do you feel that your family member has access to community activities?			
Number of surveys			17
	% always or usually		94.1
	% sometimes		5.9
	% seldom or never		0.0
Q24. Does your family member participate in community activities?			
Number of surveys			14
	% always or usually		92.9
	% sometimes		7.1
	% seldom or never		0.0
Related Comment:			
<ul style="list-style-type: none"> ◆ Community activities tend to be inconsistent and temporary. 			

CHOICE & DECISION-MAKING

Source: Consumer Survey			
		N	%
Q35. Who chose the place where you live?			
Someone else chose		32	44.4
Person had some input		40	55.6
Total		72	
Q37. Did you choose the people you live with (or to live by yourself)?			
Someone else chose		64	86.5
Chose some people		9	12.2
Chose who to live with		1	1.4
Total		74	
Q36. How many places did you visit before moving here?			
Did not visit		7	16.7
One place only		16	38.1
More than one place		19	45.2
Total		42	
Q38. Did you choose who helps you at home?			
No		52	68.4
Can request a change		24	31.6
Total		76	
Q39. Who decides your daily schedule?			
Someone else decides		40	53.3
Has help deciding		30	40.0
Person decides		5	6.7
Total		75	
Q40. Who decides how you spend your free time?			
Someone else decides		24	31.6
Has help deciding		36	47.4
Person decides		16	21.1
Total		76	
Q41. Did you choose the place where you work (or go during the day?)			
Someone else decided		35	54.7
Person had input		29	45.3
Total		64	
Q42. How many places did you visit before working here?			
Did not visit		6	16.2
One place only		15	40.5
More than one place		16	43.2
Total		37	
Q45. Did you choose your case manager/service coordinator?			
Someone else chose		55	73.3
Can request a change		20	26.7
Total		75	

Q43. Did you choose who helps you at work?			
	No	31	46.3
	Can request a change	35	52.2
	Yes	1	1.5
	Total	67	
Q44. Do you choose what to buy with your spending money?			
	Someone else decides	21	27.6
	Has help deciding	46	60.5
	Person decides	9	11.8
	Total	76	

Source: Consumer Survey – Questions added by Bay Area Project			
		N	%
QRC10. If you share a room, did you choose who shares the room with you?			
	No, someone else chose	10	55.6
	Yes, all of them	8	44.4
	Total	18	

Source: Family Guardian Survey			
Q14. Does the agency providing residential services to your family member involve you in important decisions?			
	Number of surveys		17
	% always or usually		82.4
	% sometimes		5.9
	% seldom or never		11.8
Q15. If your family member gets day or employment services, does the agency providing these services involve you in important decisions?			
	Number of surveys		14
	% always or usually		28.6
	% sometimes		7.1
	% seldom or never		64.3
Q16. Do you or your family member choose the support workers that work with your family?			
	Number of surveys		17
	% always or usually		5.9
	% sometimes		5.9
	% seldom or never		88.2
Q17. Do you or your family member have control and/or input over the hiring and management of your family member's support workers?			
	Number of surveys		16
	% always or usually		0.0
	% sometimes		6.3
	% seldom or never		93.8

Q18. Do you or your family member <u>want</u> to have control and/or input over the hiring and management of your support workers?		
Number of surveys		16
	% always or usually	18.8
	% sometimes	18.8
	% seldom or never	62.5
Q19. Do you or your family member know how much money is spent by the MR/DD agency on behalf of your family member with a developmental disability?		
Number of surveys		17
	% always or usually	5.9
	% sometimes	0.0
	% seldom or never	94.1
Q20. Do you or your family member get to decide how this money is spent?		
Number of surveys		17
	% always or usually	23.5
	% sometimes	23.5
	% seldom or never	52.9

RESPECT & RIGHTS

Source: Consumer Survey – Questions added by Bay Area Project			
		N	%
QRC12. Has anyone ever spoken to you about your rights in the past year?			
	Yes	32	100.0
	Total	32	
QRC13. If you haven't voted in the past 5 years, would you like to vote?			
	No	22	95.7
	Yes	1	4.3
	Total	23	

Source: Consumer Survey			
		N	%
Q46. Do people read your mail without your permission?			
	No	57	82.6
	Yes	12	17.4
	Total	69	
Q47. Can you be alone with [guests], or does someone have to be with you?			
	No	13	41.9
	Yes	18	58.1
	Total	31	
Q48. Are you allowed to use the phone when you want to?			
	No	2	7.7
	Yes	24	92.3
	Total	26	
Q49. Have you ever participated in a self-advocacy group?			
	No	65	87.8
	Yes	9	12.2
	Total	74	

IV. DISCUSSION

At the core of an effective quality management strategy is the commitment to measuring success through the perspective of the individuals and families who are being served by the system. By administering the NCI Consumer Survey and Family Guardian Survey to the consumers and families who have made the transition from the Agnews Developmental Center to the community, the Bay Area QMS was able to gather critical information that can help inform Regional Center leaders and Quality Commission members about progress toward meeting their shared goals. These goals are:

- ◆ Support value based outcomes
- ◆ Keep people safe and ensure their well-being
- ◆ Ensure consumer and family satisfaction
- ◆ Identify and close gaps in the community system
- ◆ Develop a system with potential for statewide use
- ◆ Meet the expectations of the Centers for Medicare and Medicaid Services

This report describes in detail the methodology and findings of the study. In summary, the results indicate strong positive outcomes, particularly in the areas of consumer and family satisfaction with the transition planning process and with the services being provided in the community. A few opportunities for quality improvement were also suggested, such as ensuring more consistent access to community activities and expanding the employment emphasis within day programs.

Key findings by topic area are briefly summarized and discussed below.

Information & Planning

Most of the families/guardians had positive responses to questions about the service plan and the staff who facilitated the planning process. A few responses indicated a desire for additional information and general resources on estate planning, for instance. The only weak area identified was that, while 9 respondents reported that they helped develop the person's plan, the remaining 6 respondents reported that they "seldom or never" helped to develop the person's plan.

Access & Delivery of Supports

Both surveys provide evidence of a high degree of access to needed services. Specifically, all 17 families reported that their family member "always or usually" gets the services and supports he/she needs. One area that could be explored further is whether support workers are adequately prepared to communicate with consumers. Out of the 11 respondents, 3 noted that support workers are only "sometimes" available to communicate with individuals who either do not speak English or who use alternative forms of communication (e.g., signing, adaptive communication devices, etc).

Satisfaction

The results on satisfaction leave no doubt that the families and guardians who responded to the survey were extremely satisfied with the transition process. Without exception, all 17 respondents reported the highest level of satisfaction. Many also took the time to write in additional positive comments, praising case managers and provider staff for their careful consideration and noting that consumers were doing very well in their new homes.

One finding that stood out as a potential area for improvement was that 10 out of 17 family/guardian respondents indicated that they were not familiar with the processes for filing complaints or grievances. This finding suggests that the transition process could include some additional education for families about the avenues available to them for resolving problems.

Although all comments about the residential services were positive, one respondent expressed a desire for the day program to include a stronger work component.

Health

The Consumer Survey collects information on basic health care outcomes, and the data are usually obtained through record review as opposed to direct interview. All of the individuals in the sample reportedly received a physical exam in the past year. About two-thirds of the women had a GYN exam in the last year, and just over half the sample had been to the dentist in the last six months. These results should be considered baseline data and could serve as a starting point for tracking data over time to ensure that all consumers have adequate access to preventative health care services in the community.

Responses from families and guardians about health and safety were generally positive. They consistently reported (100%) that their family members' day and residential settings were healthy and safe environments. One respondent expressed a concern about the consumer's ability to control her weight, and another requested that the day program offer more physical activities. One respondent stated that they would still like to have medical services provided at Agnews, but did not elaborate on this comment.

Community Activities

Findings from both the Consumer Survey and Family Guardian Survey suggest that individuals are generally participating in community activities, most often going with staff and other residents. More than half of the time, the events are specifically geared toward people with disabilities. Very few consumers are reported to participate in community meetings or integrated sports. It appears that while individuals may be experiencing physical integration in the community, more could be done to facilitate true participation and interaction in integrated community settings.

Choice & Decision-Making

Nearly half of the consumers were reported to have been involved in making important decisions about where they live and where they go during the day, and about 45% had looked at more than one option before choosing residential and day settings. In most cases, someone other than the consumer chose the person's housemates. Of those who share a room, about half had their roommate chosen for them as well. It is certainly a positive finding that so many individuals were supported to participate in the decision-making process, but the results suggest that individual choice and control is a potential area for developing improvement strategies. Given that staff answered most of these questions, the results may not reflect how individuals perceived the degree of choice exercised in making these decisions.

Most families (14 out of 17) reported that the agency providing residential services involves them in important decisions, however only 4 out of 14 reported having the same involvement with day service providers. It is not clear from the survey whether families desire more control in this area. The QMS may want to explore this topic further.

Respect & Rights

The results in this area were somewhat difficult to interpret, given that residential staff were responding on the person's behalf. According to their responses, only 58% of consumers can be alone with guests in the home, and very few consumers (12%) had participated in a self-advocacy group.

Process Recommendations

If the Bay Area QMS decides to continue utilizing the NCI tools, a couple of observations should be noted:

- ⇒ The rights questions added to the survey ("Has anyone ever spoken to you about your rights..." and "If you haven't voted in the past 5 years, would you like to vote") may not be reliable since they were answered by a staff person. These items should either be reworded or moved to Section I.
- ⇒ Assuming that proxies respondents will be needed in many cases, the QMS may want to consider specifying the type of proxy allowed for each question. Residential staff may be most familiar with the person's day to day life, but they may be biased when responding to questions about choosing staff or whether people's rights are being respected. This is a topic for further discussion.
- ⇒ Additional items of interest to the QMS could be added to the tools in the future.

In conclusion, the results of this pilot study provide the Bay Area QMS and the Quality Commission with useful data to support and guide the continued transition of consumers from the Agnews Developmental Center to the community. These findings suggest that families and guardians are highly satisfied with the transition process and with the services being provided in the community. More specifically, the NCI measures enable the QMS to examine and track valued outcomes, such as access to health care, choice and community inclusion. Gathering this information from consumers and families on a regular basis is one way for the system to ensure that positive outcomes are not only achieved but maintained over time for the individuals who have made the transition to community and that concerns expressed by families and guardians are addressed at a system level.