2008 Evaluation of People with Developmental Disabilities Moving from Developmental Centers into the Community

Volume 1: Report

Submitted by:

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June 30, 2008

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This study was conducted in response to SB 391, Chapter 294, Statutes of 1997
(Welfare and Institutions Code Section 4418.1 (a) through (j)) by
Sacramento State University, California – College of Continuing Education
under Interagency Agreement HD029004

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Executive Summary

EXECUTIVE SUMMARY

The *2008 Mover Study* was conducted in response to SB 391, Chapter 294, Statutes of 1997 (Welfare and Institutions Code Section 4418.1 (a) through (j)). This evaluation documents the annual tracking and monitoring of the quality of life of persons with developmental disabilities who moved from a state developmental center (DC) into the community as a result of the *Coffelt v State Department of Developmental Services* (DDS) settlement agreement (Superior Court, San Francisco City and County, No. 916401). A total of 2,787 persons with developmental disabilities who integrated into the community during or prior to FY2006/07 as defined by section 4418.1 (b) of the Welfare and Institutions Code were evaluated in the *2008 Mover Study*. The evaluation population was divided into two groups: (1) the Total Community Population (TCP) which was comprised of 2,765 consumers and (2) consumers currently residing in a developmental center (IDC Sample) which was comprised of 22 consumers. The TCP was further subdivided into the following five subgroups:

- The Original Community Population (OCP) comprised of 1,743 consumers. The OCP was defined as those consumers who moved from a developmental center into the community during or prior to FY2001/02[1].
- The Newcomer (NC) Sample comprised of 111 consumers. The NC sample was defined as those consumers who moved from a developmental center into the community during FY2006/07.
- The Continuing Consumers (CC) comprised of 580 consumers. The CCs were defined as those consumers who were previously interviewed by CSUS *and* who moved from a developmental center into the community between FY2002/03 and FY2006/07.
- The Not Interviewed (NI) comprised of 264 consumers. The NIs were defined as those consumers who were in the current evaluation population but were not available for an interview.
- The Declined to Participate (DTP) comprised of 67 consumers. The DTPs were defined as those consumers who declined to participate in the current evaluation or who asked to be permanently removed from the *Mover Study*.

THE EVALUATION OBJECTIVE

The objective of this evaluation was to assess: (1) the quality of care and services for consumers provided in the community; (2) the consumers' response to the levels of care and services they received in the community; and (3) the level of consumer and advocate satisfaction with community services for consumers who moved from a DC into the community during or prior to FY2006/07[2].

METHODS

Data were collected by in-person interviews with consumers and staff members at their places of residence and their day programs. When contact information was available, phone interviews were conducted to collect the opinions of the consumers' advocates. The advocates included family members, friends, guardians, and conservators. Additional phone interviews were conducted with the consumers' regional center (RC) service coordinators to gather additional qualitative data on the consumers that were not available for an interview.

SUMMARY OF FINDINGS

For the *2008 Mover Study*, the data were analyzed and reported for each of the following: the TCP, the OCP, the NC Sample, and the IDC Sample. A synopsis of the major findings for each group is given.

[1] As defined in §4418.1 (b)

[2] As defined in §4418.1 (b).

Total Community Population (TCP)

The TCP was comprised of all the consumers who moved from a DC into the community during or prior to FY2006/07[3]. The TCP provides a "snapshot" of the current community evaluation population.

TCP Demographics and the Living Environment. The average consumer age was 48.5 years and the consumers ranged in age from 13 to 89 years. The TCP was comprised of more males (62.4%) than females (37.6%) and was predominantly Caucasian (69.9%). The majority (64.3%) of consumers reported a diagnosis of severe or profound intellectual disability with an additional third reporting mild or moderate diagnoses of intellectual disability.

The majority of the consumers lived in community residences with six or fewer beds (83.9%) and approximately 13% of the consumers were living independently with or without independent living services (ILS) or supported living services (SLS). The average number of persons per household was 5.9. Of the consumers living in community homes, an average of 5.0 inhabitants were persons with developmental disabilities. On average, the consumers had lived in their present homes 7.5 years with the majority (66.2%) of the consumers moving into their community residence directly from a DC.

Just under half (43.6%) of the staff respondents reported having earned a college degree. Staff respondents reported working an average of 10.3 years with people with developmental disabilities and 4.2 years with the specific consumer for whom the interview was being conducted. Staff respondents reported a high degree of job satisfaction, which is consistent with the fact that 87.0% reported they would recommend their job to someone else.

TCP Client Development Evaluation Report (CDER). The CDER is comprised of two sections: (1) Skills demonstrated in daily life (SDD) and (2) challenging behaviors (CB). A composite score was calculated for each section and categorized into low, moderate, and high categories. Consumers had an average SDD composite score of 36.7, indicating that on average, the consumers had a moderate level of adaptive functioning with respect to skills demonstrated in daily living as defined by the CDER. As for the average CB composite scores, consumers had an average CB composite score of 10.7, indicating that on average, the consumers had low challenging behaviors as defined by the CDER.

TCP Health. Staff members reported the majority of the consumers (86.3%) were in good to excellent health. During the past year, the majority of the consumers (59.9%) experienced no fluctuation in their weight. Additionally, three quarters of the consumers reported no change in their medications. Of the remaining 25.0% who experienced a change in medication, staff members reported that the medication change resulted in positive change in symptoms for 73.2% of those consumers. The majority of the consumers (88.5%) did not require an overnight hospital stay. Of those consumers that required overnight hospitalization, the most common reasons cited for hospitalization were pneumonia (21.0%) and seizures (20.0%). Furthermore, the majority of the consumers did not visit an emergency room over the past year for either a medical emergency (80.2%) or a non-emergency medical issue (94.0%).

TCP Relationships. The majority of the consumers (85.7%) had one or more individuals they considered a close friend, with most consumers reporting that their friends consisted of other people with developmental disabilities. In addition to friendship, the majority (53.6%) of the consumers reported having one or more relatives they were close to. Contact with individuals outside the consumers' residences were also measured and the data showed that: (1) 27.1% of the consumers received mail each month, (2) 39.3% of the consumers received telephone calls each month, and (3) 48.9% of the consumers received visits each month.

TCP Individual Program Plan (IPP). IPPs were present at more than 90% of the residences and 82.3%

[3] As defined in §4418.1 (b).

of the IPPs were current. Further, approximately 95% of the consumers were present for at least part of the IPP planning meeting and just over a third (34.3%) of the consumers were reported to have contributed at least somewhat in planning their goals.

The majority (87.4%) of the consumers were working on goals pertaining to independent living and self care skills, with an average of 2.3 IPP goals related to independent living and self care skills per consumer. The second most commonly reported IPP goal category involved the reduction in behavior problems with just under two-thirds (60.7%) of the consumers working on behavioral issues and an average of 2.1 behavior related goals per consumer. Furthermore, the data showed that the consumers were making at least some progress on all IPP goal categories.

TCP Community Integration and Services.

When asked about the consumer's activities during the week, 1.0% of the consumers attended an academic institution and 0.5% of the consumers were employed by a private company or public agency. Most (90.0%) of the consumers attended a day program for an average of 28.9 hours per week. The majority of day programs were site-based (59.3%) or community based (30.2%) programs. The most common academic activities involved reading, storytelling, letters, and numbers. The most common non-academic or non-vocational activities involved community integration, exercise and weight training, music and art, tabletop activities, personal grooming skills, and social skills.

Consumers were asked about their participation in community activities during the past year. These activities included running errands, participating in social gatherings, eating at restaurants, volunteering in the community, and going to the park or other outdoor recreation areas. The results indicated that nearly half of the consumers participated in at least weekly or daily errands (47.4%) and/or went to a park for some type of outdoor recreation (49.7%). Additionally, over half of the consumers participated in a social outing (55.5%) or went out to a restaurant (52.2%) once or twice a month. For those consumers who participated in community activities, the majority of consumers did so as a member of a group consisting of staff and people with developmental disabilities.

TCP Health Care. The health care needs of 99.1% of the consumers and the dental care needs of 91.8% of the TCP were fully met. Respondents were also asked to rate the access and quality of the primary medical care, specialist care, and dental care during the past year. The results indicated that the majority of respondents (84.1%) rated primary medical care as easy to very easy to find. Also, quality of medical care was considered satisfactory by the vast majority of the staff respondents (93.8%).

For the majority of respondents (81.9%), access to specialist care was also reported as easy to very easy to find. For those consumers requiring specialist care, respondents noted that specialists treating neurological and gynecological issues are the most difficult to find. The quality of specialist care was considered satisfactory by 93.5% of the staff respondents.

Dental care was rated as easy to very easy to find by 72.2% of the staff respondents, which was lower than the ratings observed for primary medical and specialist care access. Further, the difficult to very difficult access ratings for dental care were two to six times higher than observed for primary medical care and specialist care. The quality ratings for dental care were slightly lower than those observed for primary care and specialist care, with only 90.2% of the staff respondents considering the quality as satisfactory. The most common reasons given for difficulty in finding dental care were lack of anesthesia services (60.5%) and Medi-Cal/Medicare not accepted by the dental office (63.3%).

TCP Mental Health and Crisis Intervention.

With respect to accessing mental health services, more than 80% of the staff respondents rated access as easy or very easy and more than 90% rated the quality of mental health care as good or very good. Crisis episodes were defined as the use of physical restraints, use of chemical restraints, one or more nights away from home at a psychiatric facility, harm to self or others, or

attempted suicides during the past year. The largest percentage of crises involved harm to self or others which accounted for 3.6% of consumers. The most commonly used community crisis intervention services were police interventions (2.4%), psychiatric facilities (1.6%), emergency rooms (1.6%), and additional people or teams called to the residence (1.4%). On average, these services received quality ratings of good to very good.

TCP Legal Concerns. Fifteen consumers (0.6%) were involved with the criminal justice system as a perpetrator of a crime during the past year. Of those involved with the criminal justice system, the reasons for involvement were: (1) assault that could result in serious injury to another (six consumers); (2) purchase, sale, or use of an illegal substance (five consumers); (3) illegal sex acts (two consumers); and (4) stealing, theft, or shoplifting (one consumer).

Eleven consumers (0.5%) were victims of a crime in the past year. Specifically, 10 consumers were victimized by assault and one consumer's residence was burglarized.

TCP Consumer Interview. Consumers were interviewed regarding satisfaction with their community placement, day program, staff, opportunities to make choices, learning to be independent, and their RC service coordinators. The majority of consumers responded positively to all aspects of community living. The largest percentage of positive responses (more than 90.0%) were in response to: asking for what they want, having people in their lives that help them get into the community, choosing the activities they like to do for fun, and liking the people that help them in their homes and day programs.

TCP Advocate Survey. When available, advocate contact information listed in the consumer's records was collected and phone interviews were conducted. The majority of the advocates interviewed (87.7%) were immediate relatives: mothers, fathers, and siblings. The advocates were asked to rate their satisfaction with the consumer's residence, the staff members at the consumer's residence, and the RC case manager. Over 80% of advocates responded with the highest satisfaction rating to all questions. However, the two issues that had the highest percentage of poor ratings were (1) residence staff listening to the advocate's opinions and concerns (5.0%) and (2) communication between the advocate and residence staff (5.9%).

Even though some advocates admittedly expressed initial feelings of apprehension about community living, an overwhelming majority of advocate comments were positive in nature. The most common themes about community living were: high quality of care, the consumer's improved level of functioning (skills and behavior), gratitude for community living options, positive consumer-staff relationships, and personalization of care. Despite the advocates' high ratings, they also expressed concerns regarding communication with the staff; dissatisfaction with the RC services or service coordinator; high staff turnover; diet and nutrition; and dental care.

Finally, advocates were asked whether they would have the consumer move back to a DC if it was possible. Just under 95% of the advocates responded no, they would not recommend the consumer return to a DC. This is consistent with the high satisfaction ratings for community living and the large number of positive comments regarding the consumers' well being and community placement.

TCP Not Interviewed and Declined to Participate. Consumers not included in the evaluation were divided into two groups: Not interviewed (NI) and declined to participate (DTP). NIs were defined as consumers who have (1) died within the last year, (2) had their case closed within the last year, (3) returned to a DC within the last year, (4) were residing in an acute care hospital, (5) were residing in a psychiatric hospital or drug rehabilitation center, (6) were unable to be located (UTL), (7) were incarcerated in a jail or prison, or (8) were residing in a skilled nursing facility (SNF). The majority of consumers not interviewed were either in a SNF or deceased. DTPs included consumers living in community living facilities (CLFs) who could not be interviewed because: they (1) personally declined to participate, (2) their parents or house managers chose

not to communicate with evaluation visitors, or (3) the consumer asked to be permanently removed from the *Mover Study*. The NIs (9.6%) and DTPs (2.4%) made up 12.0% (331 consumers) of the TCP.

Continuing Original Community Population (OCP)

The *2003 Mover Study* started with a list of 2,320 consumers provided by DDS, and this year, 1,743 consumers from that original cohort were located in a community residence. Of these, 94.9% (n=1,654) have lived in the community uninterrupted and have been interviewed each year since the initiation of the CSUS *Mover Study* in 2002. For the *2008 Mover Study*, these 1,654 consumers were referred to as the Continuing OCP and a separate analysis was included for this group. The Continuing OCP is an important subset of consumers because they are the only group of consumers that can provide a longitudinal analysis of change over the past six years.

Continuing OCP Demographics. The mean consumer age was 49.2 years with a range of ages from 15 to 89 years. Just under two-thirds of the consumers were male (62.2%). Consumers were predominantly Caucasian (69.0%), followed by Hispanic (16.3%), African American (9.9%), Asian (2.2%), Pacific Islander (1.3%), Middle Eastern (0.8%), and Native American (0.5). Two-thirds of the consumers were reported to have a diagnosis of severe (15.2%) or profound (51.6%) intellectual disability

Continuing OCP Living Situation and Residence History. More than 84% of the consumers have lived in a CCF or ICF with six or fewer beds over the past six years. Furthermore, there has been an approximate 1.1% increase in the number of consumers living independently with or without independent ILS or SLS since 2002. Nearly 97% of the consumers moved twice or less over the past six years with the two-thirds of those consumers (66.8%) indicating no change in residence during the same time period.

Continuing OCP Client Development Evaluation Report (CDER). Although there have been slight variations during the past five years with respect to SDD composite score categories, at least 40.0% of the consumers had moderate SDD composite scores every evaluation year. When the statistical differences in average SDD composite scores were examined over the past five years the results indicated that the average SDD composite score for 2003-04 was significantly higher than the average SDD composite score observed in 2004-05. However, the average SDD composite scores over the past four years have not significantly changed.

The distribution of the CB composite score categories over the past five years showed slight variations across years with the largest proportional difference observed between interviews conducted in 2003-04 and 2004-05; a 3.1% change in the number of consumers with moderate CB composite scores. Statistical tests indicated that the average CB composite score for 2003-04 was significantly higher than all other years. Data collected between 2004-05 and 2007-08 did not significantly differ, which means the average CB composite scores showed an initial decline (less challenging behaviors) in 2004-05 and have not changed over the past four years.

Continuing OCP Health. The proportion of consumers rated in good to excellent health has fluctuated slightly over the years. In particular, the percentage of consumers rated to be in excellent health has dropped considerably, 27.1% in 2002-03 to 13.3% in 2007-08. When the average health ratings (4-point scale with higher scores reflecting better health) were examined over the past six years, statistical tests indicated that consumers had significantly higher general health ratings during 2002-03 (M[4] = 3.1) than all other years (M = 3.0 for all other evaluation years). This significant difference in health ratings may be indicative of the increasing age of the population; however, it should be noted that following an initial drop in the general health ratings between 2002-03 and 2003-04, the ratings have remained relatively stable over the past five years with most consumers' health rated in the good to excellent range.

[4] M = Mean.

The average number of overnight hospital stays and emergency room visits was less than one visit per consumer for all CSUS evaluation years. Results from the statistical analyses indicated: (1) hospital stays were significantly higher during 2003-04 than all other years; (2) emergency room visits for medical emergencies were significantly higher during 2003-04 than 2004-05, 2005-06, and 2006-07; (3) emergency room visits for non-emergency issues were significantly lower in 2007-08 than 2003-04 and 2006-07. No other years significantly differed.

Continuing OCP Community Integration and Services. Activities in the community were examined over the past five years. Activities included running errands, participating in social gatherings, eating at restaurants, volunteering in the community, and going to the park. The results indicated that approximately forty percent of the consumers ran errands at least weekly or almost daily with an additional third of the consumers running errands biweekly or monthly. Further, during each evaluation year the majority of consumers participated in social outings, restaurant outings, and park outings biweekly or monthly. Results further indicated that most (90% or more) consumers did not participate in volunteer work over the past five years. For all community activities, the majority of consumers participated as a member of a group of staff and people with developmental disabilities.

Continuing OCP Health Care. More than 94% of the consumers reported that primary medical care was at least average to obtain each of the past six years. Access to specialist care was above average for 58.3% in 2002-03. Since then, there has been a 36.5% overall increase in the above average access ratings. Since the *2005 Mover Study* access to dental care has been an increasing issue of concern. Results indicated there has been a decline in positive dental care access ratings over the past six years. Of particular note is that the percentage of consumers rating the access to dental care as difficult or very difficult has more than doubled between 2002-03 (7.3%) and 2007-08 (15.4%). Irrespective of the access to primary medical care, specialist care, or dental care, the quality ratings of health services have remained exceptionally high over the past five years[5]. Nearly 99% of the consumers have consistently rated health care as average or satisfactory.

Continuing OCP Crisis Intervention. Results indicated that for all types of crisis episodes examined (i.e., physical restraints, chemical restraints, nights spent away from residence due to a crisis, harm to self, and suicide attempts) there were no significant differences for the number of incidents per consumer across the evaluation years. In general, the percentage of consumers experiencing a crisis has declined for each crisis type, with the lowest percentages observed in this year's evaluation; however, these differences were not statistically significant.

Continuing OCP Legal Concerns. An overall decline in the percentage of consumers involved with the criminal justice system as a perpetrator or a victim was observed between 2002-03 and 2007-08. The highest percentage of consumers reported to have been involved in criminal activity or to have been a victim of a crime was observed during interviews conducted in 2002-03. The lowest percentages of consumers reported to have criminal justice system involvement as a perpetrator were found in 2006-07 and as a victim in 2005-06.

Continuing OCP Consumer Satisfaction. Consumer satisfaction was analyzed by evaluating five items from the consumer survey portion of the *Residential Survey*. The items were: (1) Are you happy most of the time, (2) Do you like living in your home, (3) Do you like the people who help you at home, (4) Do you like going to your day program, and (5) Do you like the people who help you at the day program. Consumer satisfaction was evaluated only for those consumers who had responded to a given item for all evaluation years[6].

The results indicated there has been little variation in consumer satisfaction for each of the five items over the past five years. In general, the consumers were observed to be most satisfied with their residence in the current

[5] Quality ratings were not asked during interviews conducted in 2002-03.

[6] Consumer survey items for Interviews conducted in 2002-03 had different response options and are therefore not appropriate to be included in longitudinal comparisons.

evaluation year (2007-08); however they appear to have been most satisfied with their day programs in 2004-05.

An additional analysis was conducted to evaluate overall consumer satisfaction across time. Specifically, the responses for the five consumer survey items described above were summed to create a composite score for consumer satisfaction. Higher scores reflect higher satisfaction with a maximum score of 15.0. Only those consumers who had answered all five of the satisfaction items for all five years were included (17.1% of the Continuing OCP or 282 consumers). There was little variability in satisfaction scores and the statistical tests showed that there was not a significant difference in overall satisfaction scores across the past five evaluation years. This suggests that the Continuing OCP consumers have been and continue to be happy and highly satisfied in their homes, their day programs, and with the people helping them in the community.

Newcomer Sample (NC)

At the initiation of each evaluation year, DDS provides CSUS with a list of the consumers who have integrated into the community from a DC during the previous fiscal year. A Newcomer (NC) is defined as any consumer that has not previously been in the CSUS *Mover Study* evaluation. This year, CSUS identified 139 consumers new to the *Mover Study* from the FY2006-07 list. Of the 139 consumers identified as NCs, 111 consumers were visited in the community as part of the *2008 Mover Study*. The remaining 28 consumers were not visited and are included in the NIs.

The NC sample is presented as a separate subset of consumers because they provide insight into community integration during the first year after leaving a DC. Additionally, comparisons between the NC sample and the Continuing OCP may indicate how the needs of the consumers currently integrating in to the community differ from the original population and may provide insight into how the TCP is changing over time.

NC Demographics. The mean age was 48.7 years with a range of 17 to 82 years. On average, the consumers in the NC sample were six months younger than the Continuing OCP. The demographics further show that the NC sample had a slightly higher male to female ratio (2:1) then the Continuing OCP (3:2). With respect to the ethnic composition of the groups, the NC sample was fairly well matched with the Continuing OCP in ethnic diversity.

The NC sample had a higher percentage of consumers with diagnoses of severe or profound intellectual disability than the Continuing OCP; however, for both groups the majority of consumers had been diagnosed with a severe or profound intellectual disability.

NC Living Situation. Consumers in the NC sample lived in similar types of residences as the consumers in the Continuing OCP with the majority of consumers living in a CCF or ICF with six or fewer beds; 90.0% of the NC sample and 85.1% of the Continuing OCP. Moreover, the next largest proportion of consumers in the NC sample (8.2%) and the Continuing OCP (10.2%) were found to be residing in an independent living situation (with or without services) or in supported living

NC Client Development Evaluation Report (CDER). SDD and CB composite scores were calculated and categorized into low, moderate, and high categories. The NC sample had a higher percentage of consumers in the low (34.9%) and moderate (43.4%) categories than the Continuing OCP (28.3% and 42.4%, respectively). Further analyses indicated the average SDD composite score for the NC sample (M = 32.9) was significantly lower than the average SDD composite score for the Continuing OCP (M = 35.8). This is not surprising given that the NC sample had a higher proportion of consumers diagnosed with profound or severe intellectual disability. The diagnosis of severe or profound intellectual disability means that, by definition, these consumers may require a greater need of support for daily living activities (adaptive skills).

The NC sample had a lower percentage (by 3.0%) of consumers in the low CB range than the Continuing OCP; however the NC sample had a higher percentage (by 3.0%) of consumers in the moderate CB range.

When the average CB composite scores were tested, the results indicated there was not a significant difference in the average CB composite scores (NC = 10.7; Continuing OCP = 10.5) between the two groups.

NC Health. A higher proportion of consumers in the NC sample (91.9%) were rated in good to excellent health than of consumers in the Continuing OCP (84.7%). Health was measured on a four-point scale with higher numbers representing better health. Statistical analyses indicated that the average health rating for the NC sample (*M* = 3.0) did not significantly differ from the Continuing OCP (*M* = 2.9).

The average number of overnight hospital stays and emergency room visits for all consumers in either the NC sample or the Continuing OCP was less than one visit per consumer. Statistical analyses showed that there were no significant statistical differences in the average number of overnight hospital stays, emergency room visits for medical emergencies, or emergency room visits for non-emergency medical issues between the NC sample and the Continuing OCP

NC Community Integration and Services. Activities in the community were examined for both the NC sample and the Continuing OCP. Activities included running errands, participating in social gatherings, eating at restaurants, volunteering in the community, and going to the park. The results indicated that approximately 45% of consumers in both groups participated in errands weekly or almost daily. However, a larger percentage of consumers in the NC sample reported attending social outings and the park more frequently than the Continuing OCP. For the NC sample, 43.2% reported going out once a week to almost daily for a social outing as compared to 35.4% of the Continuing OCP. For park activities, 50.4% of the NC sample attended the park weekly to daily whereas 44.6% of the Continuing OCP reported the same attendance frequency. The results also indicated that a larger percentage of the Continuing OCP reported going out to eat weekly to almost daily (32.3%) and monthly to biweekly (55.7%) than in the NC sample (29.7% and 53.1%, respectively). Results further indicated that most (90% or more) consumers in both groups did not participate in volunteer work. For all community activities, the majority of consumers participated as a member of a group of staff and people with developmental disabilities.

NC Health Care. With respect to health care, a larger percentage of consumers in the NC sample (87.4%) reported access to primary medical care as easy or very easy as compared to those in the Continuing OCP (84.1%). Access to specialist care was above average for 80% of the consumers in both the NC sample and the Continuing OCP. Further, almost twice the percentage of consumers in the Continuing OCP (5.2%) reported access to specialist care as difficult or very difficult than the percentage of consumers in the NC sample (2.8%). Access to dental care was again found to be a concern with 17.9% of consumers in the NC sample reporting access to dental care as difficult or very difficult, which was 2.5% higher than observed for the Continuing OCP (15.4%).

As seen in the longitudinal analyses, when consumers do find primary medical care, specialist care, or dental care, the quality ratings were exceptionally high for both groups. Over 99% of the consumers in the NC sample and the Continuing OCP rated health care as average or satisfactory.

NC Crisis Intervention. The results indicated that no consumers in the NC sample experienced a physical restraint, a chemical restraint, a night away from their residence, or a suicide attempt this past year. However, 1.8% (two consumers) of the NC sample reported a crisis that involved harm to self as compared to 3.3% of the Continuing OCP. Results indicated no significant differences between the groups in the frequency of crisis events.

NC Legal Concerns. Consumers in the NC sample were not involved in with the criminal justice system as a perpetrator or a victim this past year. No significant differences between the groups were found.

NC Consumer Satisfaction. Consumer satisfaction was analyzed by evaluating five items from the consumer portion of the *Residential Survey*. The

items were: (1) Are you happy most of the time, (2) Do you like living in your home, (3) Do you like the people who help you at home, (4) Do you like going to your day program, and (5) Do you like the people who help you at the day program. Consumer satisfaction was evaluated only for those consumers who responded to a given item.

Analyses found that: (1) A larger percentage of consumers in the NC sample liked living in their current residence (92.0%), liked the people at their residence (96.2%), and liked their day program (95.7%) than in the Continuing OCP (86.8%, 91.5%, and 88.4%, respectively); (2) a larger percentage of consumers in the Continuing OCP (91.4%) reported liking the people at their day programs than was reported by the NC sample (76.9%); and (3) approximately the same proportion of consumers reported being happy most of the time (85%).

An additional analysis was conducted to evaluate overall consumer satisfaction by summing the responses to the five satisfaction items with higher numbers representing higher satisfaction. Statistical tests found no significant differences between consumers in the NC sample (M = 14.6) and consumers in the Continuing OCP (M = 14.3) in consumer satisfaction. These results indicate that the consumers in the NC sample report similar levels of satisfaction in the community as the Continuing OCP

In a Developmental Center (IDC)

Each evaluation year DDS provides CSUS with a list of consumers who currently reside in a DC (IDC) that have been identified by DDS as likely to enter the community during the current fiscal year. For the *2008 Mover Study*, IDC list included 29 consumers of which 22 were visited and interviewed while still in a DC. The other seven consumers included on the DDS list had moved into a community living arrangement before a visitor arrived at the DC.

IDC Demographics. The average age was 45.6 years with a range from 24 to 76 years of age. The IDC sample was comprised of more males (16) than females (6) and was predominantly Caucasian (15 of the 22 consumers).

The majority of consumers in the IDC sample reported a diagnosis of profound intellectual disability (seven consumers) or mild intellectual disability (eight consumers).

IDC Client Development Evaluation Report (CDER). Consumers had a mean SDD composite score of 36.7, indicating that on average, the consumers had a moderate level of functioning with respect to skills demonstrated in daily living as defined by the CDER. Further, consumers had a mean CB composite score of 12.6, indicating that on average, the consumers had low challenging behaviors as defined by the CDER.

IDC Health. Staff members reported that 17 of the 22 IDC consumers were in good to excellent health. During the past year, the majority of the consumers in the IDC sample had no change in their weight (12 consumers). In addition, the majority of consumers (18 consumers) reported no change in medications.

Three consumers required overnight hospitalization and two consumers reported a visit to the emergency for a medical emergency during the past year.

IDC Relationships. Eighteen of the consumers in the IDC sample had one or more individuals they considered a close friend and most were friends with developmental disabilities. In addition to friendship, 16 of the consumers reported having one or more relatives with whom they considered having a close relationship.

For contacts outside the residence, (1) ten of the consumers received mail each month; (2) eleven of the consumers received telephone calls each month; and (3) fourteen of the consumers received visits each month.

IDC Individual Program Plan (IPP). Nineteen of the 22 of the consumers worked on goals pertaining to independent living and self care skills. The second most commonly reported IPP goal category involved the reduction in behavior problems (13 consumers). Additionally, half of the consumers were working on goals related to employment. The data further showed that the consumers were making progress on all IPP goal categories.

IDC Physical and Social Environment. None of the consumers attended school or were employed during the past year. However, 16 of the 22 consumers attended a day program. Fifteen of the consumers attended a site-based day program and one attended a community based program. The most commonly observed day program activities were exercise and weight training, music and dance, vocational training, and computer training.

For community activities, the majority of consumers participated in errands, social outings, restaurants, and park activities biweekly to monthly. Only one consumer participated in volunteer work.

IDC Health Care. Staff respondents rated access to primary medical care, specialist care, and dental care as average or better, and they rated the quality for each as satisfactory.

IDC Mental Health and Crisis Intervention. All but five consumers required mental health services. Staff respondents reported that all mental health needs had been met during the past year and the quality of those services was average or better.

IDC Legal Concerns. None of the consumers reported being involved in the criminal justice system as a perpetrator or a victim during the past year.

IDC Consumer Interview. For consumers who responded to the consumer survey for themselves (n = 11) the majority: Felt safe most of the time, asked for what they want, did not feel lonely most of the time, liked the people who help them in their residence, decided how to spend their money, picked the things they do for fun, had people in their lives that help them get out into the community, were learning to do things for themselves, liked their RC case manager, and felt as if they had a case manager that helped them with their problems. Less than half of the consumers reported they liked living in the DC or wanted to continue living in the DC.

Follow-Up With Last Year's IDC Consumers. CSUS interviewed 35 consumers in a DC for the *2007 Mover Study*; 14 of those consumers integrated into the community during 2006-07 and follow-up interviews were conducted for the *2008 Mover Study*. These consumers are referred to as the DC Movers. For this group of consumers, responses to key indicators were compared between when they resided in the DC and the community. Statistical tests were not conducted because of the small number of consumers in the sample. Results indicated that: (1) SDD composite scores slightly increased in the community and CB composite scores decreased in the community; (2) general health ratings were approximately the same in the community and in the DC; (3) the frequency of community activities increased in the community; (4) access to health care ratings slightly decreased in the community; and (5) consumer satisfaction ratings in the community were higher in the community than in the DC.

CONCLUSIONS

The *2008 Mover Study* found:

- The majority of consumers living in the community were satisfied with their residence, enjoyed the people working in their residence and day program, were making choices for themselves, had people in their lives helping them go out into the community, and were learning to live more independently. These results are similar to those in the *2007 Mover Study.*
- The majority of consumers were rated in good to excellent health.
- The majority of consumers were working on independent living and self-care skills.
- On average, the majority of consumers participated in community activities twice a month.
- The majority of consumers received quality health care and mental health services.
- Even though the qualities of services were rated high, access to dental care continues to be a concern for

consumers and advocates. Lack of anesthesia and insurance (Medi-Cal and Medicare) were identified as the most common issues responsible for difficulties in access to dental care.

- Advocates were more satisfied with community living than living in a DC. Further, even advocates who expressed initial feelings of apprehension reported higher satisfaction ratings for community living.
- The majority of advocates were satisfied with services, however some advocates expressed concerns regarding communication with the staff; dissatisfaction with the RC services or service coordinator; high staff turnover; diet and nutrition; and dental care.

While the majority of findings reported this year were similar to those reported in the *2007 Mover Study*, there were a few notable differences:

- The current evaluation found that 2.6% of the TCP reported a weight gain of more than ten percent, which is a decrease from the *2007 Mover Study*where 4.4% of consumers reported a gain of more than ten percent.
- A higher proportion of consumers reported a diagnosis of osteoporosis (15.2%) than was reported in the *2007 Mover Study* (11.1%).
- A 4.2% increase in the percent of consumers residing in a community residence with six or fewer beds was observed in the current evaluation (83.9%) as compared to the *2007 Mover Study* (79.7%).
- The current evaluation found that 14.3% of the consumers reported having no close friends, which was lower than observed in the *2007 Mover Study* (17.4%).
- Finally, the following differences in the distribution of consumers across the NI categories were found: (1) a 4.4% increase in the percent of consumers residing in a SNF was reported for the *2008 Mover Study* (29.9%) as compared to the *2007 Mover Study* (25.5%), (2) a 2.2% decrease in the percent of consumers in jail or prison was reported for the *2008 Mover Study* (7.6%) as compared to the *2007 Mover Study* (9.8%), and (3) a 1.8% decrease in the percent of consumers returning to a DC was reported for the *2008 Mover Study* (7.2%) as compared to the *2007 Mover Study* (9.0%).
- Finally, the longitudinal analyses suggest that the following key indicators remain stable over time: (1) CDER scores (i.e., SDD and CB composite scores), (2) general health, (3) hospital admissions, (4) emergency room visits, (5) residence types, (6) community activities, (7) access and quality of health care in the community, (8) mental health crises, (9) consumer involvement with the criminal justice system as a perpetrator or a victim, and (10) consumer satisfaction.

FUTURE DIRECTIONS

In conjunction with DDS, CSUS has identified and recommended the following changes to the evaluation methodology for the *2009 Mover Study*:

- Consumers residing in a skilled nursing facility (SNF) be interviewed in person and that a separate annotated survey instrument be developed to collect data specific to consumers living in a SNF.
- An annotated survey instrument be developed for phone interviews conducted with regional center service coordinators regarding the status of consumers that can not be interviewed directly. The annotated survey will be used specifically for consumers residing in jail, prison, acute care hospitals, drug rehabilitation facilities, or psychiatric facilities.
- Adaptations be made to the current consumer survey portion of the *Residential Survey* in order to maximize consumer participation.
- Pre and post questions be developed for the consumer survey portion of the *Residential Survey* for all Newcomers, which focuses on community consumer satisfaction with their living arrangement in the developmental center and the community.

ACKNOWLEDGEMENTS

The CSUS Mover Study Research Team would like to acknowledge and thank:

- All of the consumers, families, community care staff, and day program staff for their cooperation and participation in the 2008 Mover Study. We are sincerely grateful of your time and willingness to share your lives with our visitors.
- The Regional Center Service Coordinators who also take time out of their busy schedules to provide tremendous support to our research staff.
- The Mover Study Task Force for their comments and continued support.
- The California State Department of Developmental Services for their support and cooperation.

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ABBREVIATIONS

Abbreviation	*Term*
ANOVA	Analysis of Variance
CB	Challenging Behaviors
CCE	College of Continuing Education
CCF	Community Care Facility
CDER	Client Development Evaluation Report
CLA	Community Living Arrangement
CSUS	California State University, Sacramento
DC	Developmental Center
DDS	Department of Developmental Services
DTP	Declined to Participate
IA	Interagency Agreement
DSPT	Direct Support Professional Training
ID	Intellectual Disability
ICF	Independent Care Facility
IDC	In-DC
ILS	Independent Living Services
IPP	Individual Program Plan
ISP	Individual Service Plan
M	Mean/Average
N or n	Number of Consumers
NC	Newcomers
NI	Not Interviewed
OCP	Original Community Population
RC	Regional Center
QMRP	Qualified Mental Retardation Professional
SD	Standard Deviation
SDD	Skills Demonstrated in Daily Life
SLS	Supported Living Services
SNF	Skilled Nursing Facility
TCP	Total Community Population

Abbreviation	*Regional Center*
ACRC	Alta California
CVRC	Central Valley
RCEB	East Bay
ELARC	Eastern Los Angeles
FNRC	Far Northern
FDLRC	Frank D. Lanterman
GGRC	Golden Gate
HRC	Harbor
IRC	Inland
KRC	Kern
NBRC	North Bay
NLACRC	North Los Angeles County
RCOC	Orange County
RCRC	Redwood Coast
SARC	San Andreas
SDRC	San Diego
SGPRC	San Gabriel/Pomona
SCLARC	South Central Los Angeles
TCRC	Tri-Counties
VMRC	Valley Mountain
WRC	Westside

APPENDICES

(Contained on the enclosed CD)

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Chapter

1

Introduction

Chapter One

INTRODUCTION

BACKGROUND

The Welfare and Institutions Code, Division 4.1 was amended in 1997 as a result of the *Coffelt v State Department of Developmental Services (DDS)* (Superior Court, San Francisco City and County, No. 916401) settlement agreement on January 19, 1994. The amendment (SB 391, Chapter 294, Statutes of 1997, Welfare and Institutions Code Section 4418.1 (a) through (j)) outlines the legislature's special obligation to ensure the well-being of persons with developmental disabilities who are relocated from a developmental center (DC) into the community as a result of the *Coffelt v DDS* settlement agreement and any persons moved after the terms of the settlement have been fulfilled. As described in the legislation, a contractor shall meet with each person selected for inclusion in the evaluation and:

- Track the quality of the community programs, including outcome-based measures such as health and safety, quality of life, integration, choice, and consumer satisfaction.
- Track the quality and appropriateness of community placements for persons moving from large institutions into community placements.
- Measure consumer and family satisfaction with services provided, including case management and quality of life, health and safety, independence, productivity, integration, opportunities for choice, and delivery of needed services.

In order to meet the requirements of the Welfare and Institutions Code 4418.1 (a) through (j) as described above, the following evaluation was conducted by the California State University, Sacramento (CSUS), College of Continuing Education (CCE) under Interagency Agreement (IA) HD029004 with DDS. Under the IA, CSUS is responsible for the delivery of the final evaluation to DDS and the California State Legislature. The evaluation is commonly referred to as the *Mover Study.*

EVALUATION OBJECTIVE

The objective of this evaluation is to assess: (1) the quality of care and services for consumers provided in the community; (2) the consumers' response to the levels of care and services they have received in the community; and (3) the level of consumer and advocate satisfaction with community services for consumers who moved from a DC into the community during or prior to FY2006/07[7]. The data were collected during FY2007/08; therefore this evaluation shall be referred to as the *2008 Mover Study*.

EVALUATION POPULATION

The current evaluation reports the findings for 2,787 persons with developmental disabilities. The evaluation population is divided into: the Total Community Population (TCP) and consumers currently residing in a developmental center (IDC sample). The TCP is further subdivided into five subgroups defined as:

- Original Community Population (OCP): Consumers who moved from a developmental center into the community during or prior to FY2001/02[8].
- Newcomers (NC): Consumers who moved from a developmental center into the community during FY2006/07.
- Continuing Consumers (CC): Consumers who were previously interviewed by CSUS *and* moved from a developmental center into the community between FY2002/03 and FY2006/07.
- Not Interviewed (NI): Consumers who are in the current evaluation population but were not available for an interview.
- Declined to Participate (DTP): Consumers who declined to participate or who have asked to be permanently removed from the *Mover Study*.

[7] As defined in §4418.1 (b). Unless otherwise noted, all references are to the Welfare and Institutions Code and the symbol "§" denotes the section.

[8] As defined in §4418.1 (b)

The IDC sample is comprised of consumers who currently reside in a DC and are identified as likely to enter the community during FY2007/08. Table 1.1 provides a summary of the number of consumers in the evaluation population by evaluation groups and subgroups.

EVALUATION METHODS

CSUS maintains a master database that includes the records of all consumers who have entered the community from a DC as specified in §4418.1 (b). Each evaluation year, consumer records are assigned an active or inactive status. All active consumer records are transferred into an annual tracking database for follow-up during the current evaluation year. A consumer record is considered inactive and not included in the current evaluation year if during prior evaluation periods:

- The consumer was reported deceased.
- The consumer's case was closed by the regional center.
- The consumer asked to be permanently removed from the *Mover Study*.
- The consumer returned to a DC during a prior evaluation period *and* has not returned to the community.

DDS then provides CSUS with a list of consumers that have moved from a DC into the community during the prior fiscal year (defined as NCs; see Table 1.1), and these consumers are added to the annual tracking database for the current evaluation. Lastly, DDS provides a list of consumers residing in a DC (defined as the IDCs) to be added to the annual tracking database for the current evaluation. Once the location of all the consumers has been identified, surveys are assigned to the project visitors and data collection begins.

Project visitors collect the data through:

- In-person interviews with the consumers in the community. As stated in the legislation[9], two staff members are interviewed in instances where consumers cannot respond for themselves.
- In-person interviews with primary staff members responsible for the consumer's care and well-being.
- In-person interviews with the consumers currently living in DCs and expected to enter the community within FY2007/08.
- Telephone interviews with parents, relatives, conservators, or guardians of the consumers as identified from the consumer records.

[9] §4418.1 (f).

Table 1.1
Summary of Evaluation Population

Evaluation Population	*Number of Consumers*	*Percentage of the Total Population*
Original Community Population (OCP)	1,743	62.5
Newcomers (NC)	111	4.0
Continuing Consumers (CC)	580	20.8
Not Interviewed (NI)	264	9.5
Declined to Participate (DTP)	67	2.4
Total Community Population (TCP)	**2,765**	**99.2**
In a Developmental Center (IDC)	22	0.8
TOTAL	**2,787**	**100.0**

- Telephone interviews with the regional center (RC) service coordinators to gather additional qualitative data on consumers that were not interviewed.

EVALUATION INSTRUMENTS

Three separate evaluation instruments were used: (1) the *Residential Survey* entitled: *The Quality of Life for Persons with Developmental Disabilities Moving from Developmental Centers into the Community Instrument*, (2) the *Advocate Survey* entitled: *Views of Family and Friends of Individuals with Developmental Disabilities Who Moved from Developmental Centers into the Community Instrument*, and (3) the *Residential Survey Validation Instrument*, all of which are contained in Appendix A, B, and C, respectively. A brief description of each instrument is provided below.

Residential Survey: The Quality of Life for Persons with Developmental Disabilities Moving from Developmental Centers into the Community Instrument

This instrument is used during in-person interviews with staff members and consumers. The instrument is divided into the following sections: (1) Staff characteristics, (2) consumer descriptive information, (3) living situation and history, (4) relationships, (5) individual program plan and case management, (6) skills demonstrated in daily life, (7) challenging behaviors, (8) physical and social environment, (9) health and safety, (10) mental health and crisis intervention services, (11) legal concerns, (12) home physical assessment, (13) interviewer's subjective impressions, (14) the consumer survey, (15) day programs, and (16) alerts. Each section is comprised of items constructed to collect either qualitative or quantitative data. In general, the qualitative items collect information regarding specification or clarification of responses and the quantitative variables collect information regarding frequency of behaviors and services, the quality of services, satisfaction, community integration, and consumer choice.

Advocate Survey: The Views of Family and Friends of Individuals with Developmental Disabilities Who Moved from Developmental Centers into the Community Instrument

This instrument is used during phone interviews with parents, relatives, conservators, or guardians of the consumers as identified from the consumer records. Variables are constructed to collect qualitative and quantitative data. In general, the qualitative items collect information regarding specification or clarification of responses and quantitative variables collect information regarding the advocate's relationship to the consumer, the advocate's perception of the consumer's satisfaction, the frequency of visitation and communication, the advocate's involvement, and the quality of community services. For all consumers in the NC sample, advocates are additionally asked to rate the quality of services for the consumer before and after leaving the DC.

Residential Survey Validation Instrument

This instrument is used during phone interviews with *Residential Survey* respondents to validate visitor interviews and visitor adherence to interview protocols, as well as to confirm responses to two pre-selected items and one randomly selected item from the *Residential Survey*.

VISITOR EXPERIENCE AND TRAINING

For the *2008 Mover Study*, all but one project visitor had previously worked on the evaluation. On average, project visitors had: (1) 5.7 years of experience working on the *Mover Study*; (2) 10.4 years of experience working with the target population; and (3) 7.5 years of survey research experience.

Project visitors are required to attend an annual eight-hour training session. In addition to providing authorization materials and logistical information, training emphasized contact protocols, coding schemes for survey items, alert reporting (i.e., Level 1 and Level 2 Alerts, see *Alert Reporting* below), sensitivity to respondent availability and programmatic needs of the staff, and general methods to improve data collection. For example, project visitors

have historically reported some difficulties in collecting complete data sets for consumers living independently[10]. While visitors are asked to always respect the right of the consumer to decline participation, if the consumer agrees to the interview, visitors are trained to meet the consumer in a location and at a time convenient for the consumer. If the consumer requests that the project visitor not conduct the interview at the consumer's residence, then the visitor is instructed to drive by the residence in order to complete the Home Physical Quality Assessment section of the *Residential Survey*. Further, when interviewing consumers who live independently and do not receive services, visitors are instructed to *not* ask survey items that are sensitive in nature, evoke feelings of embarrassment, or that can be gathered through observation alone.

Alert Reporting. The Level 1 Alert and Level 2 Alert systems remain in place. Project visitors are legislatively obligated to immediately report any suspected violation of legal, civil, or service rights of an individual or if the project visitor determines that the health and welfare of the consumer is at risk[11]. Such violations are considered Level 1 alerts. Data for Level 1 Alerts are reported directly to DDS, RCs, and the clients' rights advocates.

The Level 2 Alert system reports pre-selected criteria listed in the *Residential Survey*. The Level 2 Alert reports are forwarded to DDS and appropriate RCs once a month. An analysis of the Level 2 Alerts is contained in the related sections of this evaluation.

DATA PREPARATION, VALIDATION, AND ANALYSIS

The completed interviews were edited for errors and omissions. In cases where the respondent did not have access or know the answer to key survey items (e.g., the community living arrangement (CLA) housing code), the research staff contacted the *Residential Survey* respondent, corresponding CLA administrator, or the appropriate RC service coordinator for the information.

Once the interviews were edited, a minimum of eight percent of each visitor's surveys were randomly selected for validation. Additionally, for any instance where a visitor reported the consumer had died; returned to a DC; entered a skilled nursing facility (SNF), acute care hospital or psychiatric hospital; or was serving time in jail or prison; the research staff contacted the appropriate RC service coordinator for validation. Together, these criteria resulted in a total validation rate of 13.4%.

After completing the editing and validation processes, all data were input and prepared for data analysis. All analyses were performed in SPSS[12]. Separate analyses were performed on:

- The TCP, which provides a "snapshot" of the current community evaluation population.
- The OCP, which provides a longitudinal overview of community experiences over the past six years.
- The NC sample, which examines the most recent consumers entering the community as a separate subgroup.
- The IDC sample, which provides consumer data prior to entering the community.

EVALUATION REPORT OUTLINE

The evaluation report is organized in the following fashion:

- **Executive Summary.** This section provides a summary of the *2008 Mover Study* evaluation.
- **Chapter One: Introduction.** This chapter provides background information, defines the evaluation population, and describes the evaluation methodology, the evaluation instruments, the project visitor training, data editing, survey validations, and data analyses.
- **Chapter Two: The Total Community Population (TCP).** This chapter contains data from the *Residential Survey* for all consumers who moved

[10] In the *2008 Mover Study*, 71.6% of the consumers who declined to participate live independently with or without independent or supported living services.

[11] As defined in §4418.1 (g).

[12] SPSS 15 (2006). SPSS Inc., Chicago, IL.

from a DC into the community prior to FY2006/07[13], data from the *Advocate Survey*, and information about consumers not interviewed under the current evaluation. The TCP provides a "snapshot" of the current community evaluation population.

- **Chapter Three: The Original Community Population (OCP).** This chapter contains data from the *Residential Survey* for consumers who moved from a DC into the community prior to FY2001/02[14] and were interviewed by CSUS over the past six years. The OCP provides a longitudinal overview of community experiences over the past 6 years.
- **Chapter Four: The Newcomer Sample (NC).** This chapter contains data from the *Residential Survey* for consumers moving from a DC into the community during FY2006/07. The NC sample represents the most recent consumers entering the community, and this chapter examines them as a separate subgroup.
- **Chapter Five: Consumers Currently Residing in a DC (IDC).** This chapter contains data from the *Residential Survey* for consumers currently residing in a DC and are likely to move into the community FY2007/08, in addition to pre and post data for consumers previously interviewed in a DC who moved into the community during FY2006/07. The IDC sample provides consumer data prior to entering the community.
- **Appendix A: Contains a copy of the *Residential Survey*.**
- **Appendix B: Contains a copy of the *Advocate Survey*.**
- **Appendix C: Contains a copy of the *Residential Survey Validation Instrument*.**
- **Appendix D: Descriptive statistics for the Total Community Population (TCP).**
- **Appendix E: Descriptive statistics for the Continuing Original Community Population (OCP).**
- **Appendix F: Descriptive statistics for the Newcomer Sample (NC).**
- **Appendix G: Descriptive statistics for the Consumers Residing in a Developmental Center (IDC).**

In general, each chapter discusses:

- First, the consumer (i.e., demographics, skills demonstrated in daily life, challenging behaviors, and health),
- Second, the consumer's environment and services (i.e., living situation, staff characteristics, home quality and visitor impressions, community integration, health care, and alerts),
- And concludes with consumer satisfaction (i.e., the consumer interview).

[13] As defined in §4418.1 (b).
[14] As defined in §4418.1 (b).

Chapter 2

The Total Community Population

Chapter Two

THE TOTAL COMMUNITY POPULATION

This chapter contains data collected from the *Residential Survey* used during interviews with the Total Community Population (TCP). The TCP included all consumers currently residing in the community as defined in the Welfare and Institutions Code, Division 4.1[15]. The TCP was comprised of 2,765 consumers and was divided into:

1) Original Community Population (OCP): Consumers who moved from a developmental center into the community during or prior to FY2001/02[16].

2) Newcomers (NC): Consumers who moved from a developmental center into the community during FY2006/07.

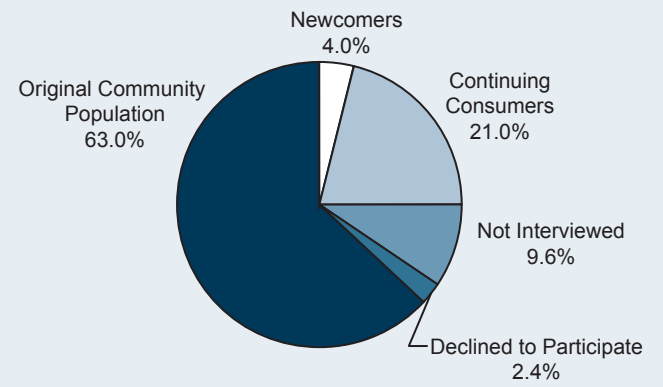
3) Continuing Consumers (CC): Consumers who were previously interviewed by CSUS *and* moved from a developmental center into the community between FY2002/03 and FY2006/07.

4) Not Interviewed (NI): Consumers who are in the current evaluation population but were not available for an interview.

5) Declined to Participate (DTP): Consumers who declined to participate or who have asked to be permanently removed from the *Mover Study*.

For the consumers not interviewed in the community, research staff contacted the corresponding regional center service coordinators for follow-up information. Therefore, the NIs and DTPs are discussed separately from the TCP in the *Not Interviewed* section of this chapter. Figure 2.1 provides a breakdown of the TCP into the defined subgroups.

Figure 2.1
TCP Subgroups



Unless otherwise noted, differences between the data reported for the TCP in the *2007 Mover Study* and the *2008 Mover Study* were negligible or comparisons were not appropriate due to changes in methodology.

CONSUMER CHARACTERISTICS

This section contains data regarding consumer demographics, CDER scores, and health issues for the TCP.

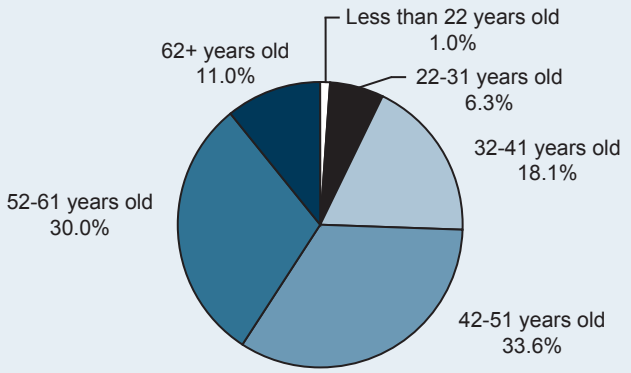
Consumer Demographics

Age, Sex of Consumer, Ethnicity, and Marital Status

The average age for the TCP was 48.5[17] years and the consumers ranged in age from 13 to 89 years of age. Figure 2.2 indicates that nearly two-thirds of the TCP were between 42 and 61 years of age.

[15] §4418.1 (b)
[16] As defined in §4418.1 (b)
[17] Descriptive statistics for the TCP are contained in Appendix D.

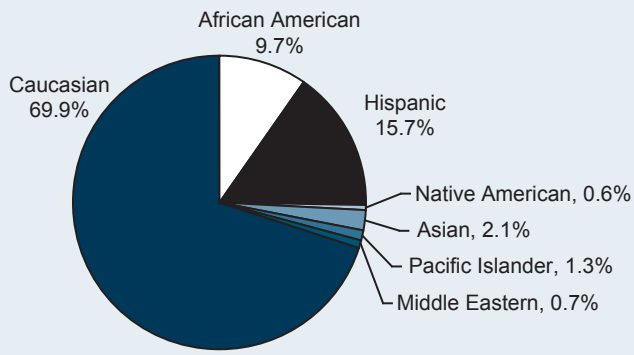
Figure 2.2
Age Distribution



The TCP was comprised of 62.4% males and 37.6% females.

The largest ethnicity group for the TCP was Caucasian (69.9%). The second largest ethnicity group was Hispanic (15.7%) followed by African American (9.7%). Native American, Asian, Pacific Islander, and Middle Eastern collectively represented 4.7% of the TCP (See Figure 2.3).

Figure 2.3
Ethnicity

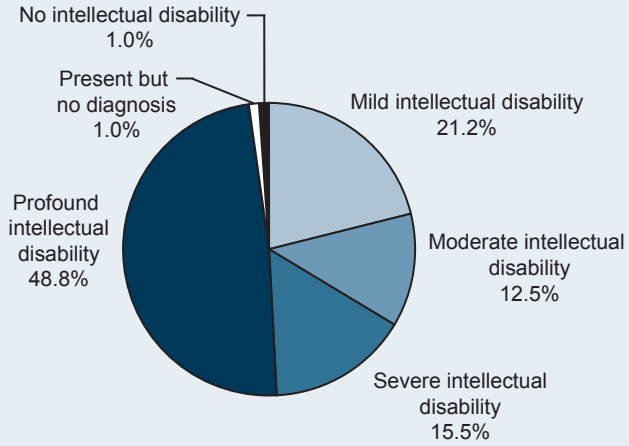


Most consumers had never been married (97.6%), whereas a total of 2.4% of the consumers reported having been previously married at some point in their life or currently being in a long-term relationship.

Diagnosis of Intellectual Disability (formerly referred to as Mental Retardation[18],[19])

As shown in Figure 2.4, nearly two-thirds of the TCP reported a diagnosis of profound or severe intellectual disability. Two percent of the consumers in the TCP reported having no diagnosis of intellectual disability or staff members reported the presence of intellectual disability but no diagnosis had been made. The remaining consumers were reported to have a diagnosis of mild or moderate intellectual disability.

Figure 2.4
Diagnoses of Intellectual Disability



Consumer Diagnoses

The majority of diagnoses specifically referenced in the *Residential Survey* are those that can be clearly diagnosed as congenital, genetic, or hormonal disorders. These have been retained in this section to be consistent with past evaluation reports.

The most common diagnoses included epilepsy and seizures (43.4%), mental illness[20] (40.2%), cerebral palsy (18.6%), and autism (13.9%). Additionally, 15.8% of the

[18] Schalock, R.L. (2007). The renaming of *Mental Retardation*: Understanding the change to the term *Intellectual Disability*. *Intellectual and Developmental Disabilities*, 45 (2), 116-124.

[19] American Association on Intellectual and Developmental Disabilities (2008). *The AAIDD Definition*. Retrieved April 2, 2008, from http://www.aaidd.org/Policies/faq_mental_retardation.shtml.

[20] The category of mental illness was defined as including schizophrenia, bipolar disorder, depression, panic disorders, anxiety disorders, and personality disorders.

TCP reported being diagnosed with para- or quadriplegia. Each of the following diagnoses represents less than 4.0% of the evaluation population: Down syndrome (3.5%), sexual disorders (3.2%), traumatic brain syndrome (3.5%), substance abuse (2.0%), Alzheimer's or chronic brain syndrome (1.2%), and Prader-Willi Syndrome (1.1%).

Client Development Evaluation Report (CDER)

For the *Residential Survey*, the CDER is comprised of two sections: Skills demonstrated in daily life and challenging behaviors. Skills demonstrated in daily living include physical capabilities (i.e., walking and talking), as well as the consumers' ability to care for themselves, their capability of focusing, safety awareness, and social interaction. Challenging behaviors include behaviors that interfere with daily activities such as running away, disruptions, aggression, and emotional outbursts.

Skills Demonstrated For Daily Living (SDD)

For each item in the SDD section of the *Residential Survey*, the percent of consumers who reported having the highest level of functioning is given below.

- **Hand Use** - 76.4% of the consumers used fingers from both hands to manipulate objects.
- **Walking** - 62.2% of the consumers could walk alone at least 20 feet with good balance.
- **Wheelchair Use** - Of the 728 consumers who used a manual or motorized wheelchair, 9.6% used the wheelchair independently and smoothly in nearly all situations.
- **Taking Medications** - Of the 2,389 consumers that take medications, 1.7% of the consumers always self-administered medications without reminders.
- **Eating** - 46.5% of the consumers ate with at least one utensil without spillage.
- **Toileting** - 41.0% of the consumers toileted independently without assistance.
- **Bladder and Bowel Control** - 46.4% of the consumers had complete control of their bladder and bowel.
- **Personal Care** - 15.7% of the consumers performed all personal care activities independently without reminders.
- **Dressing** - 24.7% of the consumers dressed themselves independently without reminders.
- **Safety Awareness** - 8.2% of the consumers did not require supervision to prevent injury/harm.
- **Focus on Tasks** - 16.3% of the consumers focused on a preferred task or activity for more than 30 minutes.
- **Verbal Communication** - 26.7% of the consumers used sentences of three words or more and had a vocabulary of more than 30 words.
- **Nonverbal Communication** - Of the 1,323 consumers that used nonverbal communication, 10.4% of the consumers used and understood signs/gestures and facial expressions in communication.
- **Social Interactions** - 18.6% of the consumers initiated and maintained interactions in familiar and unfamiliar situations/settings.

Challenging Behaviors (CB)

For each item in the CB section of the *Residential Survey*, the percent of consumers who reported having the least challenging behaviors is given below:

- **Disruptive Social Behavior** - 46.8% of the consumers never displayed disruptive social behavior.
- **Aggressive Social Behavior** - 61.1% of the consumers never displayed aggressive social behavior.
- **Self-Injurious Behavior** - 59.3% of the consumers never displayed self-injurious behaviors.

- **Property Destruction** - 74.4% of the consumers never displayed property destruction.
- **Running Away** - 85.5% of the consumers never ran/ wandered away.
- **Emotional Outbursts** - 53.1% of the consumers never displayed emotional outbursts.

CDER Composite Scores

CDER composite scores were developed for the skills demonstrated in daily living (SDD) and challenging behaviors (CB). For the calculation of the composite SDD scores, items regarding wheelchair use and non-verbal communication were excluded because (1) they are questions for a specific subset of the consumers and are not relevant to the whole population and (2) inclusion would have decreased the total number of cases that could be analyzed since the composite scores are based on data points for each variable contained in the composite score. As wheelchair use and non-verbal communication exclude individuals that can walk and can speak, the inclusion of those variables would have excluded all consumers who could walk and talk from the composite score analysis. For the calculation of the CB composite scores, no variables were excluded from the calculation. The composite scores were divided into three categories: low, moderate, and high.

The SDD composite score has a possible minimum score of 11 and a maximum score of 60. The SDD composite score categories were defined as:

- The low category contained SDD composite scores between 11 and 27. The low SDD category was comprised of 26.2% of the TCP.
- The moderate category contained SDD composite scores between 28 and 43. The moderate SDD category was comprised of 41.4% of the TCP.
- The high category contained SDD composite score between 44 and 60. The high SDD category was comprised of 32.4% of the TCP.

In this scheme, the low SDD category describes the consumers with the lowest level of functioning whereas the high SDD category describes the consumers with the highest level of functioning. Consumers in the TCP had an average SDD composite score of 36.7, indicating that on average, the consumers had a moderate level of functioning with respect to skills demonstrated in daily living as defined by the CDER.

The CB composite score has a possible minimum score of 6 and a maximum score of 30. The CB composite score categories were defined as:

- The low category contained CB composite scores between 6 and 14. The low CB category was comprised of 79.3% of the TCP.
- The moderate category contained CB scores between 15 and 23. The moderate CB category was comprised of 18.8% of the TCP.
- The high category contained CB scores between 24 and 30. The high CB category was comprised of 1.9% of the TCP.

In this scheme, low CB category describes the consumers that exhibit the least challenging behaviors whereas the high CB category describes the consumers that exhibit the most challenging behaviors. Consumers in the TCP had an average CB composite score of 10.7, indicating that on average, the consumers had low challenging behaviors as defined by the CDER.

When examining the interaction between the SDD and CB composite scores for the TCP, the percentage of consumers with low CB composite scores was distributed fairly evenly across the three levels of the SDD composite scores (See Table 2.1). While very few consumers had moderate to high CB composite scores, the majority of those that did also had moderate SDD composite scores.

Table 2.1
Cross-tabulation SDD and CB Composite Score Categories
(Percent of the TCP)

	CB Composite Score Category		
SDD Composite Score Category	*Low*	*Moderate*	*High*
Low	24.1	2.2	0.2
Moderate	30.7	9.8	1.2
High	24.2	7.2	0.4

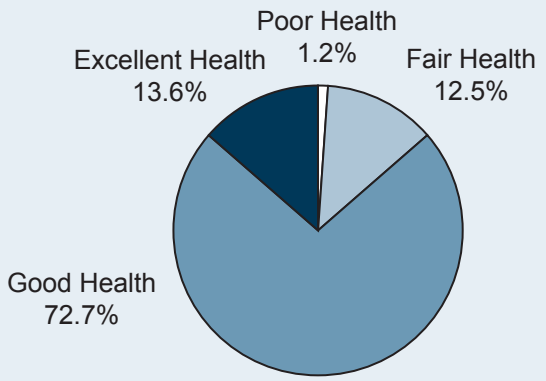
Health

This section includes information covering the general health of the consumers, reported medication changes, chronic ailments, required in-home medical support, hospital stays, emergency room visits, and accidental injuries that required medical attention.

General Health Information

In the current evaluation, staff members reported the majority of the consumers were in good to excellent health (86.3%), which is slightly higher than the percent of consumers reported in the *2007 Mover Study* (84.9%; See Figure 2.5).

Figure 2.5
General Health Ratings



During the past year, the majority of the consumers in the TCP experienced no fluctuation in their weight (59.9%) and slightly more consumers (3.0%) were reported to have gained rather than lost weight. Specifically, the data showed that:

- Eighteen percent of the consumers reported a weight gain, and only 2.6% reported a gain of more than ten percent, which is a decrease in the percent of consumers who reported a gain of more than ten percent in the *2007 Mover Study* (4.4%). Overall, the weight gain reported for the current evaluation was viewed as:
  - Positive for 31.4% of the consumers.
  - Neutral for 38.5% of the consumers.
  - Negative for 30.1% of the consumers.
- Fifteen percent of the consumers reported a weight loss, and only 3.1% reported a loss of more than ten percent as similarly reported in the *2007 Mover Study* (3.2%). Overall, the weight loss reported for the current evaluation was viewed as:
  - Positive for 67.6% of the consumers.
  - Neutral for 24.3% of the consumers.
  - Negative for 8.1% of the consumers.

Medication Changes

Three quarters of the consumers reported no change in the medications that were taken for neurological disorders or maladaptive behaviors. Of the remaining 25.0%, staff members reported that the medication change resulted in:

- Positive change in symptoms for 73.2% of the consumers.
- No change in symptoms for 24.0% of the consumers.
- Negative change in symptoms for 2.8% of the consumers.

Chronic Ailments

The most commonly diagnosed chronic ailments were:

- Bowel disorders (38.9%).
- Visual disorders (22.7%).
- Allergies (22.6%).
- Skin disorders (18.9%).
- Gastrointestinal problems (18.1%).
- High cholesterol (16.9%).
- Thyroid problems (15.9%).
- Osteoporosis (15.2%)[21].
- High blood pressure (13.6%).

Staff members reported that less than ten percent of the TCP consumers have been diagnosed with the following chronic ailments: hearing disorders (9.4%), obesity (8.7%), anemia (6.4%), hepatitis (5.7%), arthritis (6.1%), diabetes (5.6%), respiratory issues (4.9%), cardiovascular issues (4.7%), asthma (4.5%), a hernia (2.7%), a blood-related disorder (2.0%), significantly underweight (1.2%), cancer/leukemia (1.2%), Parkinson's disease (0.9%), or multiple sclerosis (0.2%).

In-Home Medical Supports and Special Health Care Requirements

The most commonly used or needed in-home medical supports were:

- **Wheelchair** - 29.9% of the TCP consumers used a wheelchair. All had adequate access to the equipment except for five consumers who were reported to have the need for a wheelchair but did not have access to one, and six consumers who had an inadequate wheelchair.
- **Special chair/belt** - 25.8% of the TCP consumers used a special chair or belt. All had adequate access to the equipment except for five consumers who were reported to have the need for a special chair/belt but did not have access.
- **Special beds and lifts** - 18.5% of the TCP consumers used a special bed and lift. All had adequate access to the equipment except for three consumers who were reported to have the need for a special bed/lift but did not have access.
- **Special eating utensils** - 14.1% of the TCP consumers used special eating utensils. All had adequate access to the equipment except for three consumers who were reported to have the need for special eating utensils but did not have access, and one consumer who had inadequate eating utensils.
- **Glasses or magnifiers** - 13.1% of the TCP consumers used glasses or magnifiers. All had adequate access to the equipment except for nine consumers who were reported to have the need for glasses or magnifiers but none were provided, and seven consumers who reported using inadequate eyewear.

The staff members were also asked about each consumer's special health care requirements. The most common health care requirement was a special diet (39.8%). Other special health care requirements included:

- Enemas/Suppositories (6.1%).
- Diabetes testing (3.4%).
- Decubitus care (3.1%).
- Oxygen (1.9%).
- Sterile dressings (1.3%).
- Colostomy bag, bee sting kit, and tracheotomy care (less than 1% each).

Hospital Stays and Emergency Room Visits

The majority of the consumers (88.5%) did not require an overnight hospital stay. Of those consumers that required overnight hospitalization, the average number of admissions was 1.4 per consumer. The most common reasons cited for hospitalization were pneumonia (21.0%)

[21] A higher proportion than reported in the *2007 Mover Study* (11.1%).

and seizures (20.0%). The following reasons were also mentioned in relation to hospital admissions for less than 6% of the consumers:

- Constipation, diarrhea, or bowel obstruction/ impaction (5.7%).
- Gastrointestinal problems (5.7%).
- Diabetes related complications (5.0%).
- Urinary tract infections (3.2%).
- Respiratory distress (2.5%).
- Injuries due to a fall (2.1%).
- Cellulitis (2.0%).
- Vomiting (2.0%).

Other miscellaneous reasons mentioned for less than 2% of the consumers included anemia, bladder infection, boil treatment, broken bone, cancer treatment, cardiovascular problems, dehydration, edema, fever, hernia, pain (undiagnosed), stroke, suicidal observation, surgery, ulcer, and weight loss. Over 80% of the respondents rated the hospital care as good to excellent.

The majority of the consumers did not visit an emergency room over the past year for either a medical emergency (80.2%) or a non-emergency (94.0%). Of the 19.8% of the consumers that visited an emergency room for a medical emergency, the average number of visits was 1.8 visits per consumer. Further, the remaining 6.0% of the consumers that visited the emergency room for non-emergency issues had an average of 1.5 visits per consumer.

Accidents and Injuries

During the past year, 8.5% of the TCP experienced an accident that required medical attention. The number of accidents ranged between one and fifty. Of those consumers involved in accidents that required medical attention, the average per consumer accident rate was 1.5.

According to the staff respondents, 1.1% of the consumers (n = 26) were victims of abuse that resulted in an injury during the past year. Of those who experienced abuse, five consumers experienced a life threatening incident.

LIVING ENVIRONMENT

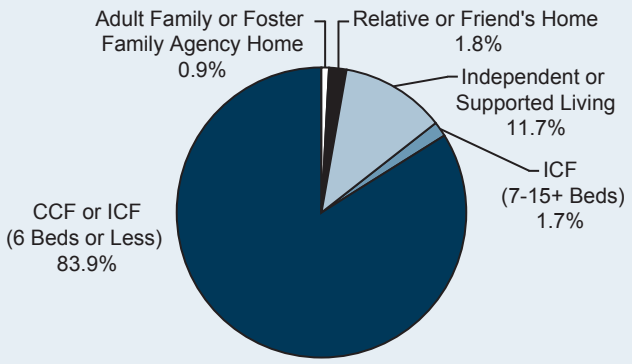
This section contains information about the consumers' living environment including community residence types, circumstances under which the consumers moved to their present community residence, staff member characteristics, relationships, and visitor assessments of the living environment.

Living Situation

Just under two-thirds of the consumers (64.8%) lived in one of three types of community living situations: A Community Care Facility (CCF) Level 4-I (29.8%), an Intermediate Care Facility Developmentally Disabled-Habilitative (ICF/DD-H) (20.9%), or an ICF/DD-Nursing (ICF/DD-N) facility (14.1%). Figure 2.6 shows that the majority of the consumers lived in community residences with six or fewer beds (83.9%)[22] and approximately 13% of the consumers were living independently with or without independent living services (ILS) or supported living services (SLS). A 4.2% increase in the percent of consumers residing in a community residence with six or fewer beds was observed in the current evaluation as compared to the *2007 Mover Study* (79.7%).

[22] The total residences with one to six beds include CCFs, ICF-DD-N, and ICF-DD-H facilities.

Figure 2.6
Community Living Situation



With respect to home ownership, the data indicate that 88.5% of the consumers lived in residences owned by an agency or a private vendor. Of the remaining consumers, 8.7% rented their home, 2.6% lived in a home that the family or an advocate owns, and less than 0.2% of the consumers lived in a house purchased in their own name.

Staffing and Household Composition

On average, the consumers' homes were staffed with 4.9 persons employed full time and 2.1 persons employed part-time. The average number of persons per household was 5.9. Of the consumers living in community homes, an average of 5.0 inhabitants were persons with developmental disabilities, 0.1 were unpaid persons without developmental disabilities, and 0.7 persons were paid staff members.

Residence History

On average, the consumers had lived in their present homes 7.5 years with the majority (66.2%) of the consumers moving into their community residence directly from a DC. Of the remaining consumers who did not move into the community from a DC, 33.8% moved to their present home from another CCF[23] with 28.3% of those moves occurring within the last year. The majority of moves within the last year were requested by the RC (49.3%) for the following reasons: the previous CCF home closed (40.6%), an increase in challenging behaviors (22.9%), in search of better facilities or neighborhoods (13.5%), improved challenging behaviors (8.3%), declining adaptive behaviors or health (8.3%), improved adaptive behaviors or health (5.2%), or to be closer to loved ones (1.2%). Consumer move requests over the past year accounted for 17.9% of the moves within the community. The most common reasons a consumer requested to move were: in search of better housing (43.9%), improved challenging behaviors (21.9%), to be closer to loved ones (17.1%), improved adaptive behaviors or health (7.3%), an increase in challenging behaviors (4.9%), or previous home closed (4.9%). The consumers' relative or the CCF requested the remainder (32.8%) of the moves.

[23] As noted in *Chapter One: The Introduction*, each year the TCP evaluation is a "snapshot" of where the consumer resides at the time of the interview. Therefore, not all residence moves are captured by the *Residential Survey*.

Staff Member Characteristics

For the *2008 Mover Study*, 1,149 staff members were interviewed. Staff members were interviewed for all consumers except those that lived independently or with family and did not receive independent living services, which was 2.2% (n = 53) of the TCP.

Staff Demographics

The majority of the staff respondents were an owner, manager, or administrator (44.3%) of the consumer's CCF or the consumer's direct care staff person (36.6%). Other staff respondents included independent or supported living service workers (12.5%), qualified mental retardation professionals (QMRP) (6.0%), and relatives (0.6%).

The average age of the staff respondents was 43.3 years. The staff respondents were predominantly female (71.4%). Most respondents were Pacific Islander (28.1%), followed by: Caucasian (26.2%), African American (24.1%), Hispanic (15.7%), Asian (4.1%), Native American (1.0%), Middle Eastern (0.6%), and not specified (0.2%).

The majority of the staff respondents (99.2%) spoke the same language as the consumer for whom they worked. Although 19 consumers spoke a language not spoken by the staff members interviewed, 13 of the community facilities employed at least one person who could communicate with the consumers in their own language. On a five-point scale (one being not proficient and five being very proficient), the average visitor rating of the staff respondent's ability to speak English was 4.8.

Most staff respondents worked full time (93.9%). On average, staff respondents reported working 14.6 hours per week directly with the consumers and 9.4 hours per week on administrative tasks.

Staff Member Education and Credentials

Over one-third (35.5%) of the staff respondents reported having earned some college credits with an additional 43.6% having earned a college degree (i.e., an Associate of Arts or Science degree (7.3%), a Bachelor of Arts or Science degree (27.6%), or a graduate degree (8.7%)). Additionally, staff respondents reported other credentials or licenses in addition to their academic education. The most commonly earned licenses or credentials included:

- Administrative (30.7%).
- QMRP (8.7%).
- Certified Nursing Assistant (CNA) (8.0%).
- Licensed Vocational Nurse (LVN) (3.5%).
- Psychiatric Technician (PT) (3.4%).
- Other credentials or job related certifications (45.7%) (i.e., certified medical assistant, teaching credential, emergency medical technician (EMT), CPR, first aid, family home care provider, home health aide, Direct Support Professional Training (DSPT) I and II, California Psychological Inventory (CPI) instructor, and nutrition).

Salary Satisfaction and Benefits

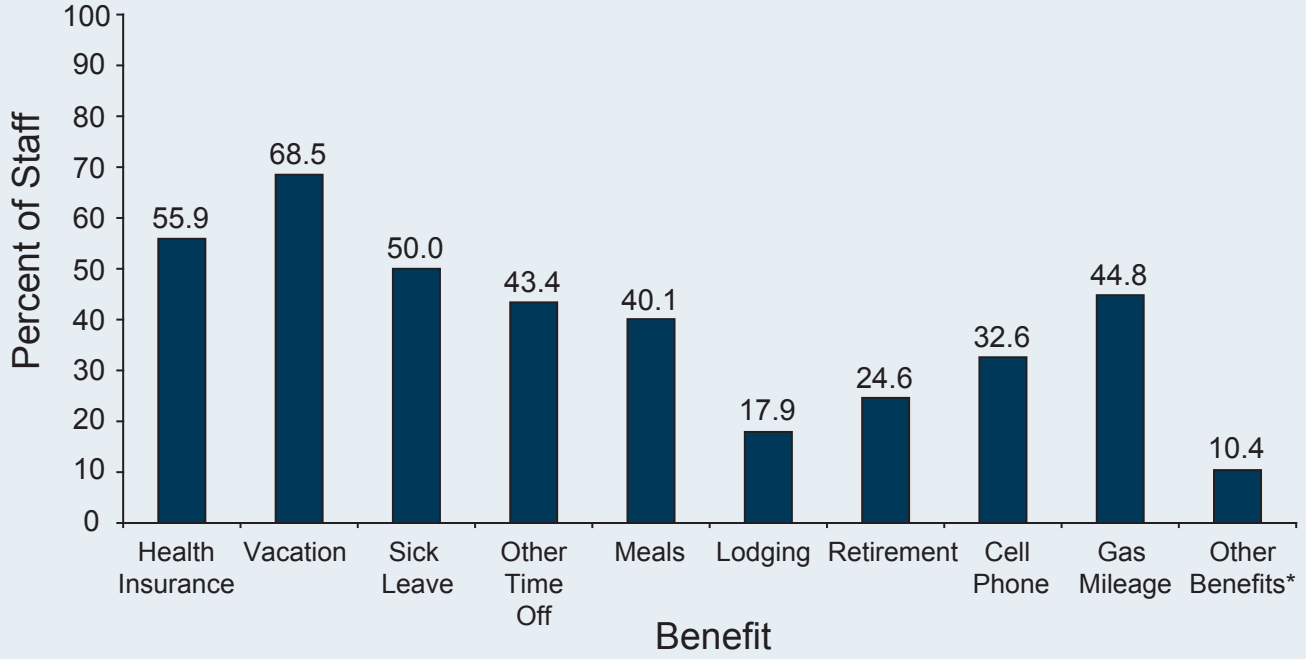
Over half of the staff respondents (60.4%) reported being satisfied with their salary. Of the 23.0% of staff respondents dissatisfied with their current salary, the most common reason given was the disproportionate pay-to-responsibility ratio. In addition, over half (56.1%) of the staff respondents reported satisfaction with their benefits. Figure 2.7 shows the proportion of staff respondents who receive the selected types of benefits. When asked about other benefits staff respondents would like to have, among the most commonly mentioned were health insurance, more affordable health premiums, retirement benefits, and paid vacation.

Staff Member Training

Over 95% of the staff respondents reported that they had received sufficient training. Of those who would like additional training, the most frequently mentioned training topics included:

- **Nursing/Residential Care (39.4%).** Examples were: first aid, CPR, DSPT I and II, QMRP, consumer safety, sensory stimulation, weight management and nutrition, emergency drills and crisis intervention, advanced SLS training, consumer health (autism, dementia, G-tubes, brain injuries, and seizures), consumer quality of life, nursing (RN, LVN), geriatrics, grief counseling, and group dynamics.
- **Administrative (33.8%).** Example were: accounting, agency integration and services, report writing, computer skills, community and consumer resources, communication, grants, medical and medication training, laws and regulations, license processing and preparation, management training, new ideas and opportunities, policies and procedures, stress management, SSI benefits and training, staff training, and motivation issues.
- **Working with Behaviors (22.6%).** Examples were: psychology, psychiatric diagnosis and medications, behavior management, physical aggression, mental health issues, criminal justice, and forensics.

Figure 2.7
Benefits Received by Staff Members



* Other Benefits includes dental insurance, company automobile or van, job related training, life insurance, pager, profit sharing, tuition reimbursement, and vision insurance.

- **Communicating with the Consumers (4.2%).** Examples were: sign language, English as a second language (ESL), and special education.

Staff Member Satisfaction

Staff respondents reported working an average of 10.3 years with people with developmental disabilities and 4.2 years with the specific consumer for whom the interview was being conducted. Staff respondents reported a high degree of job satisfaction with an average job satisfaction rating of 4.7 and an average rating of 4.8 when asked about their satisfaction with working with the consumer for whom the interview was about (a rating of 5 represented the highest level of satisfaction). Staff member job satisfaction is consistent with the fact that 87.0% reported they would recommend their job to someone else, and another 11.5% reported they would recommend their job if the candidate was right for the job. Although nearly a quarter of staff respondents expressed dissatisfaction with their salary, the high proportion of staff respondents that would recommend their job to another person in conjunction with the high degree of job satisfaction, indicates that the intangible rewards of the job outweigh the dissatisfaction with salary and benefits.

Consumer Relationships

This section describes the relationships the consumers had with staff members, friends, and family. Also, the data provide insights into the consumers' contacts with persons outside their residence through the mail, telephone, and in-person visits.

Friends and Relatives

The majority of the consumers (85.7%) had one or more individuals they considered a close friend and 14.3% reported having no close friends, which was lower than the percent of respondents who reported no close friends in the *2007 Mover Study* (17.4%). Further, 64.4% of the consumers had friends with developmental disabilities

and 12.6% of the consumers had friends without developmental disabilities. In addition to friendship, the majority (53.6%) of the consumers reported having one or more relatives they were close to.

Contacts with Individuals Outside the Consumers' Residences

Contacts with individuals outside the consumers' residences are measured by the number of telephone calls, pieces of mail, and visits received each month. These data are the least accurate for the consumers who lived independently and are based solely on the recall of staff members and the consumers. Therefore the numbers may serve as conservative estimates.

The data showed that during the past year:

- 27.1% of the consumers received mail each month.
- 39.3% of the consumers received telephone calls each month.
- 48.9% of the consumers received visits each month.

Visitor Assessments of the Living Environment

This section contains the visitors' ratings of the physical quality of the 1,384 homes visited for the *2008 Mover Study*. The ratings take into consideration the interior and exterior condition of the home, the cleanliness of the interior, and the degree of personalization in the consumers' surroundings.

Home Physical Quality

According to the visitors' assessments regarding the consumers' homes, the data showed:

- 83.9% of the homes were rated as nice and 12.1% were rated more attractive than the surrounding homes in the neighborhood.
- 81.6% of the front yards were rated as having an average appearance with an additional 12.5% rated as more attractive than the surrounding homes.
- 63.2% of the back yards were rated as having an average appearance with an additional 30.6% rated attractive.
- 83.8% of the building exteriors were rated as average and 12.7% were rated exceptional.
- 76.5% of the building interiors were rated as having an average appearance 19.5% were rated exceptional.
- 54.2% of the neighborhoods were rated as having average appearance and 39.1% were considered attractive.
- 94.7% of the neighborhoods were rated safe or neutral.

Quality of the Consumers' Rooms

The visitors rated the orderliness, cleanliness, condition of the furniture, windows, and odors of the consumers' rooms on a three-point scale with three representing the most positive condition. The data showed that the consumers' rooms had an average of:

- 2.8 for orderliness.
- 2.8 for cleanliness.
- 2.8 for the condition of the furniture.
- 2.9 for windows.
- 2.9 for odors.

Visitors also reported that the majority (90.4%) of consumer rooms had some or distinct variation and personalization.

Quality of the Consumers' Homes

The consumers' homes were rated on the same characteristics and on the same three-point scale as the consumers' rooms. The data show that the consumers' homes were rated:

- 2.8 for orderliness.

- 2.8 for cleanliness.
- 2.7 for the condition of the furniture.
- 2.9 for windows.
- 2.9 for odors.

Evidence of pests was observed at 0.5% (n = 7) of the homes visited. The types of pests observed were ants, fleas, flies, and roaches.

Visitors' Subjective Impressions

The visitors were asked to rate their subjective impressions of the homes they visited for consumer-to-consumer interactions, consumer-to-staff interactions, and the visitors' assessment of the home as a placement alternative for a relative of their own.

On average, the visitors rated:

- The friendliness of consumer-to-consumer interactions as 3.6 on a five-point scale with five representing very friendly.
- The personalization of the consumer-to-staff interactions as 3.5 on a four-point scale with four representing very warm and personal.
- Their feelings about the residence as a placement option for a close relative as 3.2 on a four-point scale with four representing extremely positive.

Visitors' Observations

Visitors were asked to indicate whether or not they felt the home could be considered exceptional on the following dimensions:

- Respect for the consumer – 53.3% responded yes.
- Staff-consumer relationship – 44.7% responded yes.
- Family-like environment – 40.5% responded yes.
- Home well run and well organized – 35.6% responded yes.
- Cleanliness, nicely decorated, and well furnished – 35.5% responded yes.
- Good relationship between the staff and owner – 22.3% responded yes.
- Excellent backyard – 19.1% responded yes.
- Innovative leisure or work activities – 14.9% responded yes.

Visitors were also asked to indicate whether or not they felt negative about the following aspects of the residence:

- 4.4% of residences were in unpleasant neighborhoods.
- 4.0% of homes were not clean, poorly decorated, and/or in poor repair.
- 3.9% of homes and yards were in poor condition.
- 3.0% of staff members were not familiar with the consumers' records.
- 2.0% of homes were disorganized with poorly kept records.
- 1.7% of the facilities were large and impersonal.
- 1.1% of staff members did not speak the consumers' primary language.
- 0.4% of the consumers appeared to be in poor health.
- 0.3% of the consumers needed medical insurance.

INDIVIDUAL PROGRAM PLAN (IPP) AND CASE MANAGEMENT

Staff respondents were asked to provide the consumers' Individual Program Plans (IPP). This section contains information gathered from the IPP documents and staff member responses regarding the IPP planning process, staff member opinions about the IPP, consumer goals within the IPP, and case management.

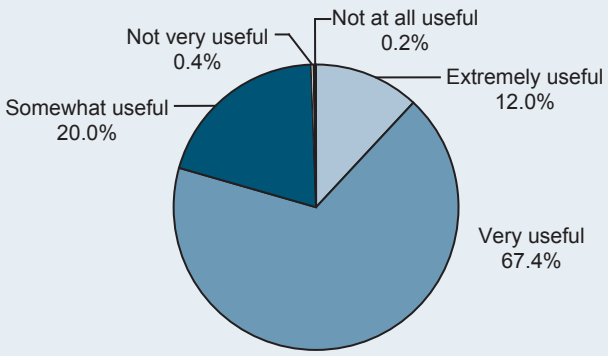
IPP Documentation and Planning

Of the residences visited, IPPs were present at 92.6% of the residences and, of the IPPs present in the residence, 82.3% were current[24]. Further, 94.8% of the consumers were present for at least part of the IPP planning meeting and 34.3% of the consumers were reported to have contributed at least somewhat in planning their goals. Relatives attended 22.1% of the IPP planning meetings and were at least somewhat involved to very involved (96.9%) in planning the IPP goals.

Staff Member Opinions

Almost all (99.5%) staff respondents felt the IPP was a person-oriented document and, as shown in Figure 2.8, approximately two-thirds of the staff respondents felt that the IPP was a very useful source of guidance for day-to-day programmatic planning.

Figure 2.8
Usefulness of the IPP



According to the staff respondents interviewed, 60.3% said they had access to a plan other than the IPP and for most (97.5%), that additional plan was part of the IPP. Almost two-thirds (62.2%) of the staff respondents felt the additional plan was more useful than the IPP. The most commonly mentioned alternative plan was the Individual Service Plan (ISP) (83.4%). Other plans mentioned included nursing plans, behavior treatment plans, individual care plans, facility treatment plans, and individual health plans.

[24] Current IPP included plans on a three-year planning cycle.

Consumers' Goals

Figure 2.9 indicates that the majority (87.4%) of the consumers worked on goals pertaining to independent living and self care skills. On average, the consumers had 2.3 IPP goals related to independent living and self care. The second most commonly reported IPP goal category involved the reduction in behavior problems with just under two-thirds (60.7%) of the consumers working on behavioral issues and an average of 2.1 behavior related goals per consumer. Additionally, a third of the consumers were working on goals related to the development of sensory, motor, and communication skills with an average of 1.5 goals per consumer. Furthermore, the data showed that the consumers were making at least some progress on all IPP goal categories (See Figure 2.10).

Ninety-eight percent of the staff respondents said that the IPP goals met the consumers' needs. The majority of IPP goals that were not addressed in a consumer's current IPP were concerned with independent living and self care skills (i.e., banking, community safety, money management, and paying bills) or reducing challenging behaviors (i.e., anger management, compliance with rules and regulations, and verbal threats).

Another method to assess the consumers' IPP goals was to measure the number of goals added, amended, or dropped from the plan. Of the IPP goals added and dropped, more goals were added or amended (21.0%) than dropped (9.4%). On average, 2.4 goals were amended or added as opposed to an average of 1.5 goals dropped over the past year. Of the goals dropped, the majority (63.8%) were dropped because they were achieved by the consumer with an average rate of 1.5 goals achieved per consumer. The remaining goals (36.2%) were dropped because they were unattainable by the consumer with an average of 1.2 unattainable goals per consumer.

Figure 2.9
IPP Goals

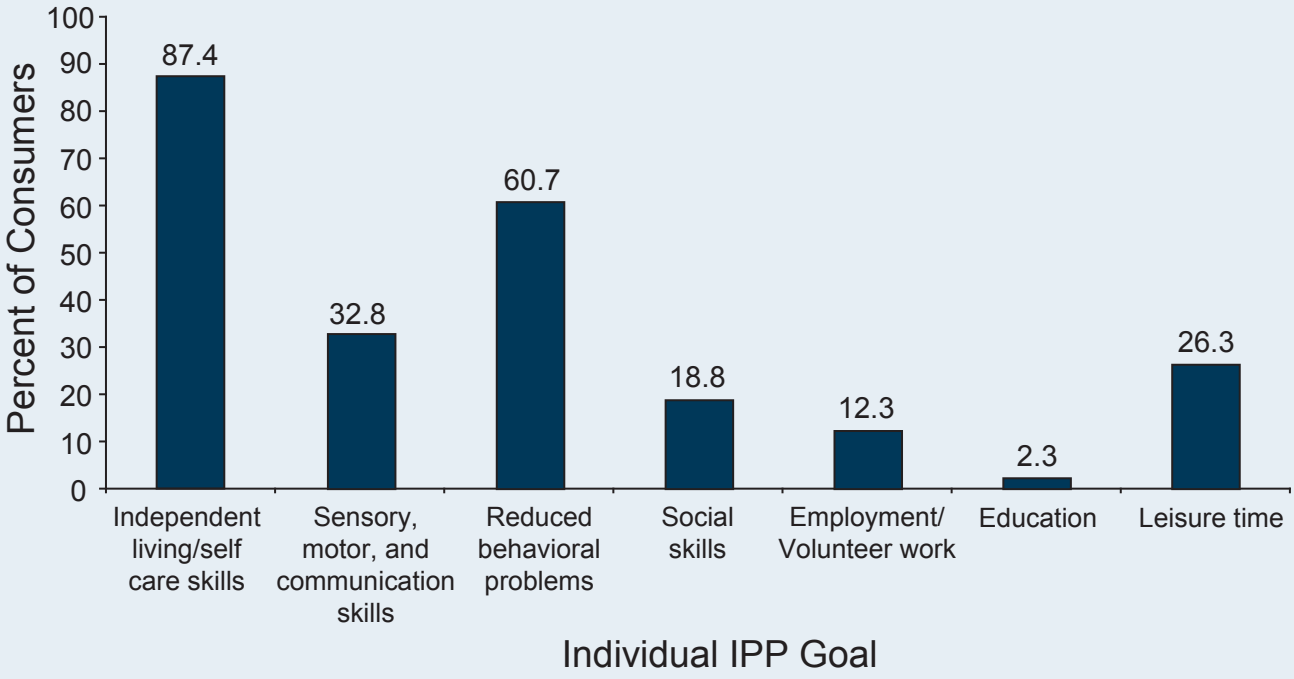
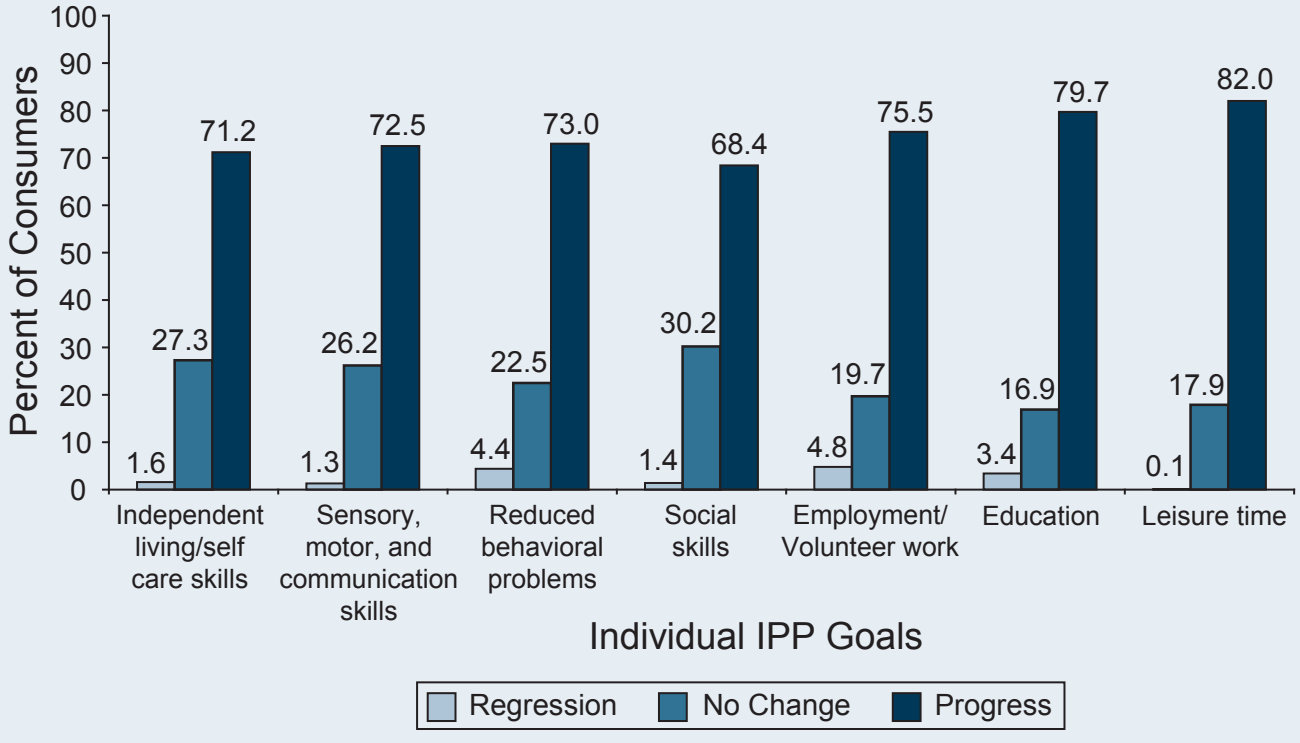


Figure 2.10
IPP Goal Progress



Case Management

About one-third of the consumers experienced a change in their RC case manager this past year with an average of less than one change (*M* = 0.4). On average, the case managers visited each consumer 4.4 times during the past year. Four percent of the staff respondents expressed dissatisfaction with the case manager services. Of those who expressed an opinion, the majority mentioned case manager turnover, lack of communication, and non-responsiveness as a reason for their dissatisfaction.

COMMUNITY INTEGRATION AND SERVICES

This section contains information regarding the indicators of community integration, services received in the community, and issues that may arise in the community for a person with developmental disabilities. Community issues include: the physical and social environment of the community, day program information, health care services, mental health services, crisis intervention data, legal concerns, and the alert reporting data collected during this evaluation.

Physical and Social Environment

The physical and social environment section addresses data collected regarding the consumers' educational opportunities, employment, and community experiences.

School

For the purposes of the *Mover Study*, schools are defined as those institutions outside the academic and vocational offerings in the consumers' day programs. They include public and private institutions where students with developmental disabilities are enrolled in special education classes or in fully or partially integrated classrooms. All academic and vocational training experiences carried out as part of a day program are reported in the *Day Program* section of this chapter.

Twenty-five consumers (1.0%) were enrolled in a public or private school not associated with a day program. Of the consumers attending school:

- Nine consumers were enrolled in an adult or vocational training program; seven consumers were enrolled in special education institutions; seven were enrolled in mainstream schools that provided classes for students with developmental disabilities; one was home-schooled; and one consumer attended a school with fully integrated classrooms.
- Eleven consumers had all-day contact with students without developmental disabilities. Nine consumers had contact with students without developmental disabilities outside classroom hours or very little in classes during the day. Five of the consumers did not come in contact with students without developmental disabilities at any time during the school day.
- Almost all of the consumers going to school come in contact with persons that speak the consumers' primary language at least once per day (5 consumers) or all day (20 consumers).

Work

Work is defined as employment in the community that is paid for by private companies or public agencies. The consumers may have had help from a day program or the RC in obtaining the job, may have a job coach that meets with the employer periodically or is on-call for special circumstances, or may have assistance with transportation to and from work, but the consumers negotiate their employment experience by themselves. Other work experiences, such as work training programs, day program-related jobs, or sheltered workshop employment are reported in the *Day Program* section of this chapter.

Twelve consumers (0.5%) of the TCP are employed in jobs as defined above.

Of those 12 consumers who were employed:

- Two consumers work less than 10 hours per week.

- Four consumers work between 10 and 25 hours per week.
- Four consumers work between 26 and 39 hours per week.
- Two consumers work 40 hours or more per week.

Nine of the 12 working consumers were paid minimum wage or higher. The majority of the consumers used public transportation or walked to work.

Community employers included:

- Albertsons
- Burger King
- Camp Pendleton
- Community-Based Wrestling Entertainers (as an announcer)
- Food Maxx
- Macy's
- Motor City
- Oakland Day Activities Center
- Safeway
- Target
- Work Creatives

Community Experiences

Community experiences include running errands, participating in social gatherings, eating at restaurants, volunteering in the community, and going to the park or other such community gathering places. The data are summarized below.

- **Errands (Figure 2.11).** Almost half (47.4%) of the consumers ran errands at least once a week. Eighteen and a half percent of the consumers either declined or were unable to participate in errands. The majority (70.4%) of the consumers that participated in running errands participated as a member of a group consisting of staff members and persons with developmental disabilities.
- **Social Outings (Figure 2.12).** Social outings were defined by examples such as church, parties, museums, and shopping. Just over a third (38.6%) of the consumers participated in social outings and 5.9% either declined or were unable to participate. The majority of the consumers who participated in social outings were in a group of staff members and persons with developmental disabilities.
- **Restaurants (Figure 2.13).** Thirty-six percent of the consumers went out to restaurants at least once a week and 11.7% either declined or were unable to participate. The majority (77.9%) of the consumers who went to restaurants did so in a group of staff members and persons with developmental disabilities.
- **Volunteer (Figure 2.14).** Few of the consumers (3.3%) participated in volunteer activities with 1.8% of the consumers participating at least weekly. Of those that did volunteer, 65.0% went with a group that consisted of staff members and persons with developmental disabilities.
- **Park or Other Outdoor Recreation (Figure 2.15).** Half of the consumers went to the park or participated in some other outdoor recreation activity at least once per week and 5.0% either declined or were unable to participate in park activities. Eighty-three percent of the consumers participated in park activities as a member of a group that consisted of staff members and persons with developmental disabilities.

Day Programs

The visitors were asked to conduct the day program interviews in two parts: (1) observation and (2) in-person interviews. First, visitors observed the day program and coded questions regarding the structure of the program, the activities in which all the consumers were involved, the level of activities, and day program staff member involvement. Second, the visitor gathered information

Figure 2.11
Errands in the Community

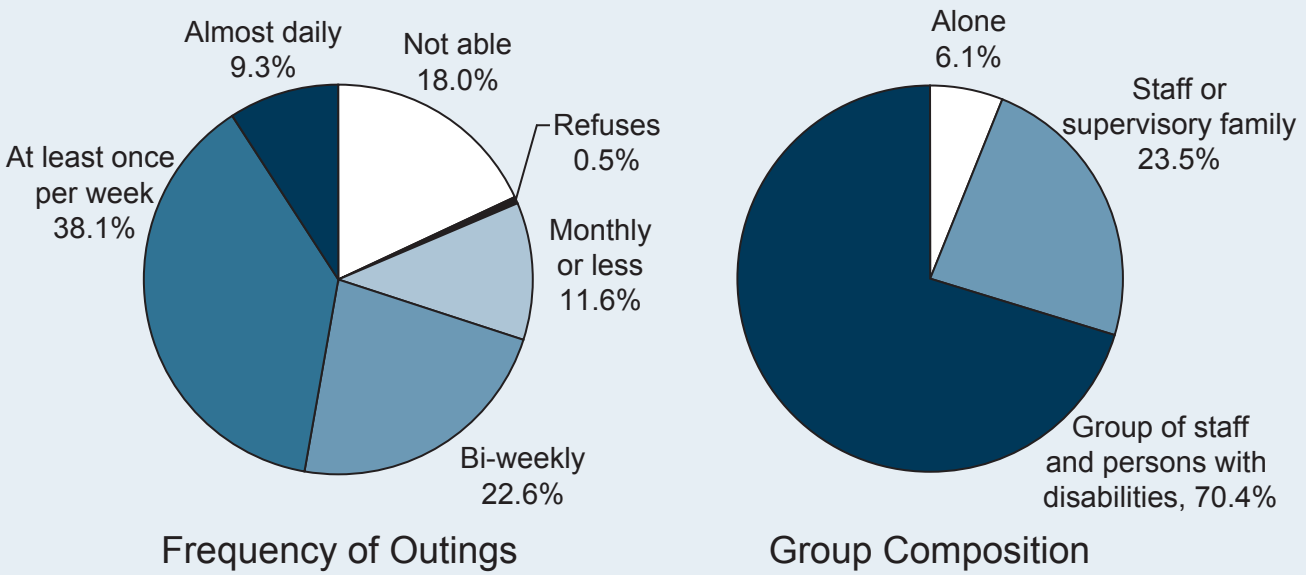


Figure 2.12
Social Outings

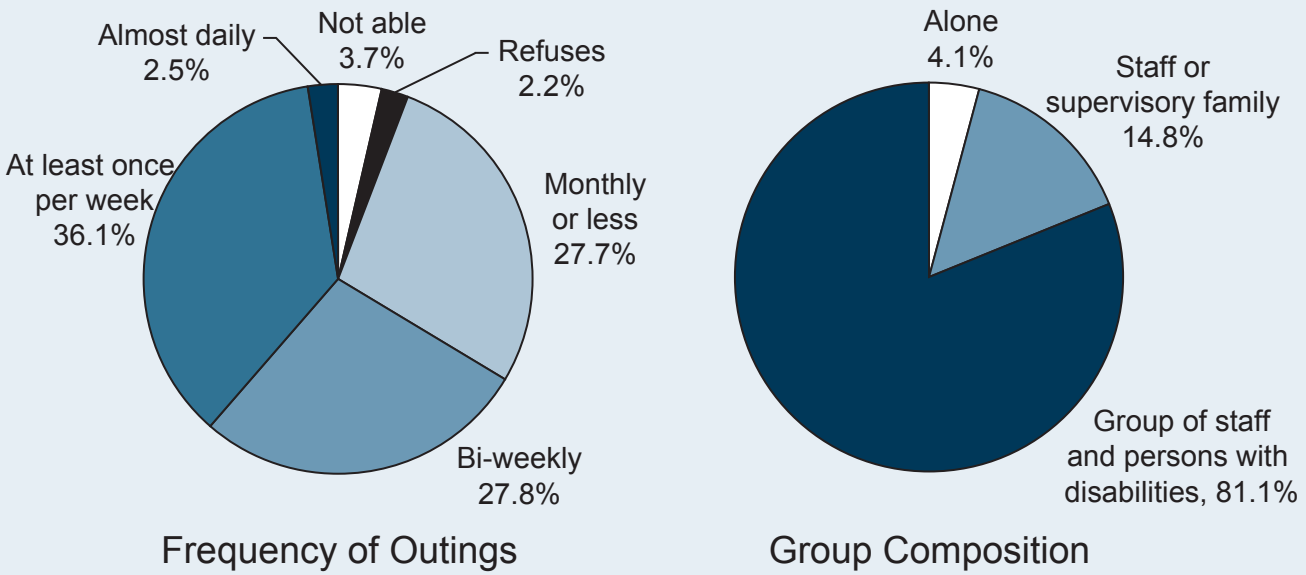
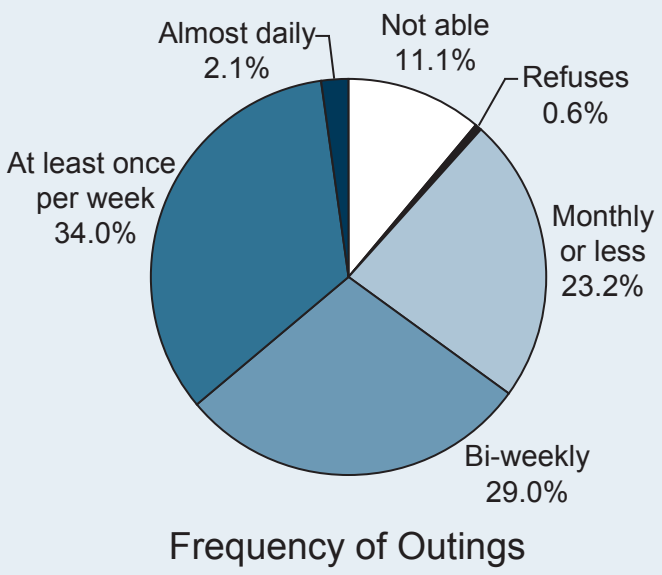


Figure 2.13
Restaurants



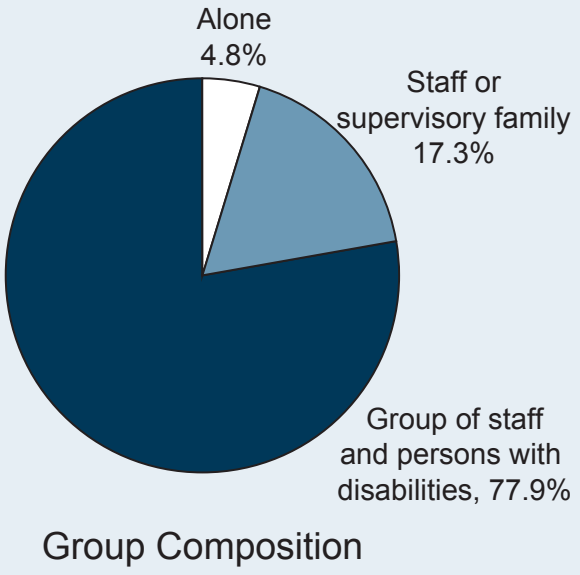
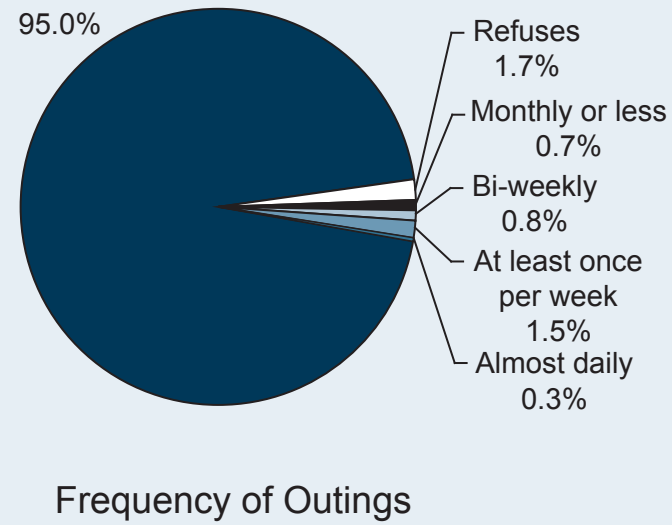


Figure 2.14
Volunteer Work



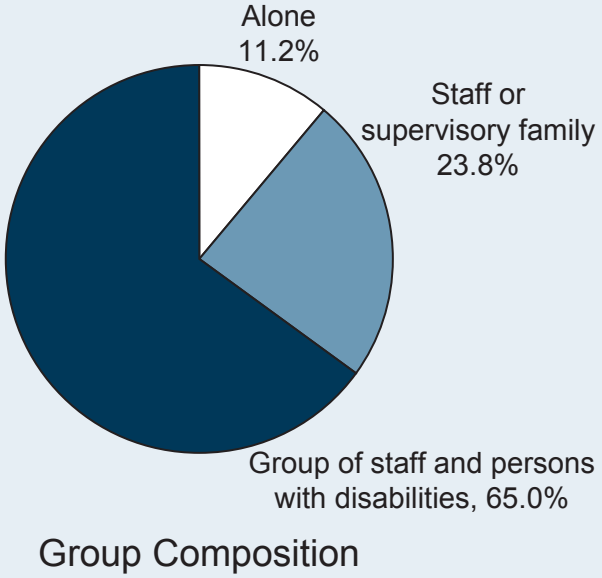
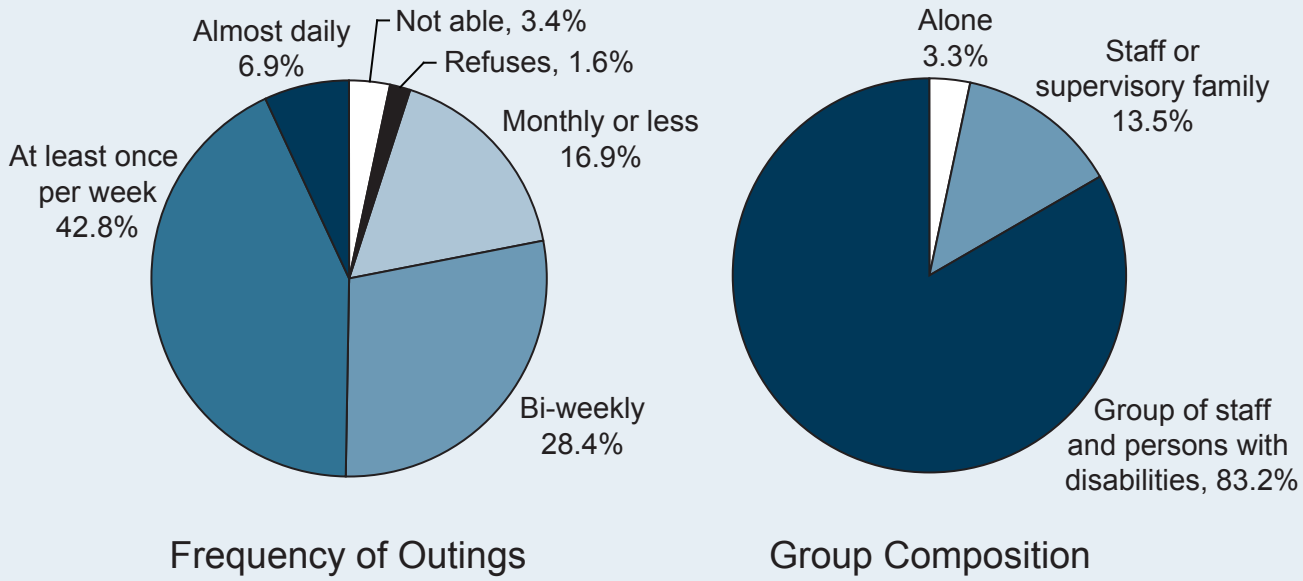


Figure 2.15
Parks and Outdoor Recreation



about the specific consumer for whom the interview was being conducted (i.e., attendance hours per week, travel time to and from the day program, day program related employment, and consumer activities).

Ninety percent of the consumers attended a day program for an average of 28.9 hours per week and traveled an average of 23.4 minutes per day to get to the day program. The reasons why the remaining 10.0% did not attend a day program included refusals, long-term illnesses, and disruptive behaviors.

Visitors reported that 95.8% of the consumers observed at the day programs enjoyed their activities. When the day program staff were asked to rate the level of cooperation between the residence staff and the day program staff on a five-point scale, the average cooperation rating was 4.6 indicating a high level of cooperation between day program and residence staff.

Day Program Observations[25]

[25] Visitors completed observations at 545 day program sites throughout California.

This section contains the visitors' observations of the day program and the activities that the staff members and the consumers were engaged in during their visits. For community-based day programs, the visitors met the staff members and the consumers at a prescheduled place in the community.

The majority of day programs were site-based programs (59.3%). Almost a third of the day programs were community based (30.2%) and approximately 10.0% were conducted at the consumer's residence (6.1%) or at a workshop (4.4%). Most site-based programs were conducted in different rooms within a facility (78.3%).

At the day programs, the most commonly observed activities included: exercise/sensory stimulation activities (57.7%), tabletop games/puzzles (52.8%), shopping/eating exercises (48.9%), music/dance activities (48.7%), and art projects (46.9%). Other activities that were not on the observation checklist but were observed included watching movies or television[26], money management, pet

[26] Watching movies and/or television were the most commonly mentioned "other" activities observed at the visited day programs.

therapy, gardening, and relaxation techniques.

The visitors were asked to assess the ambience of the day program with respect to the level of activities, the consumers' participation, and the staff engagement. The visitors found that:

- Sophisticated, high tech, or highly creative levels of activities were found in only 6.1% of the day programs. The majority (69.5%) of day programs was rated as having some creativity and about a quarter (24.4%) employed simple techniques predominately performed by staff.
- Consumers were observed to be very active in 28.5% of the day programs, interested and somewhat active in 55.6% of the day programs, and passive or exhibiting limited participation in 15.9% of the day programs.
- Staff members were observed to have time and patience for all of the consumers in 89.9% of the day programs.

Consumer Day Program Employment

Just under a third (31.1%) of the consumers attending a day program were engaged in one of the following employment activities:

- Work in a non-sheltered workshop off-site (37.0%).
- On- or off-site sheltered workshop (35.0%).
- Work in a non-sheltered workshop on-site (28.0%).

The types of jobs at which the consumers were employed included janitorial, landscaping, recycling, creating art for sale, and mailing. Several consumers participated in day program associated volunteer activities at senior citizen centers, plant nurseries, animal shelters, and a community environmental organization.

Of those who received pay for their day program related work activities, 38.0% of the consumers earned less than minimum wage, 13.5% earned minimum wage, 1.6% earned more than minimum wage, 8.0% were paid on a piece-work basis, and 4.2% were paid via incentives. Over one-third (34.7%) of the consumers participating in day program work activities were not paid.

Day Program Classroom Activities

Consumers were observed participating in their classroom activities. Visitors were asked to record participation in a list of academic and non-academic/ non-vocational activities. As shown in Figure 2.16, the most common academic activities were those involving reading, storytelling, letters, and numbers. Further, the most common non-academic or non-vocational activities involved community integration, exercise and weight training, music and art, tabletop activities, personal grooming skills, and social skills. Other non-academic and non-vocational classes that were reported include: money management, advocacy, pet therapy, attend an on-site hair salon, and aquatic therapy.

Community Health Care

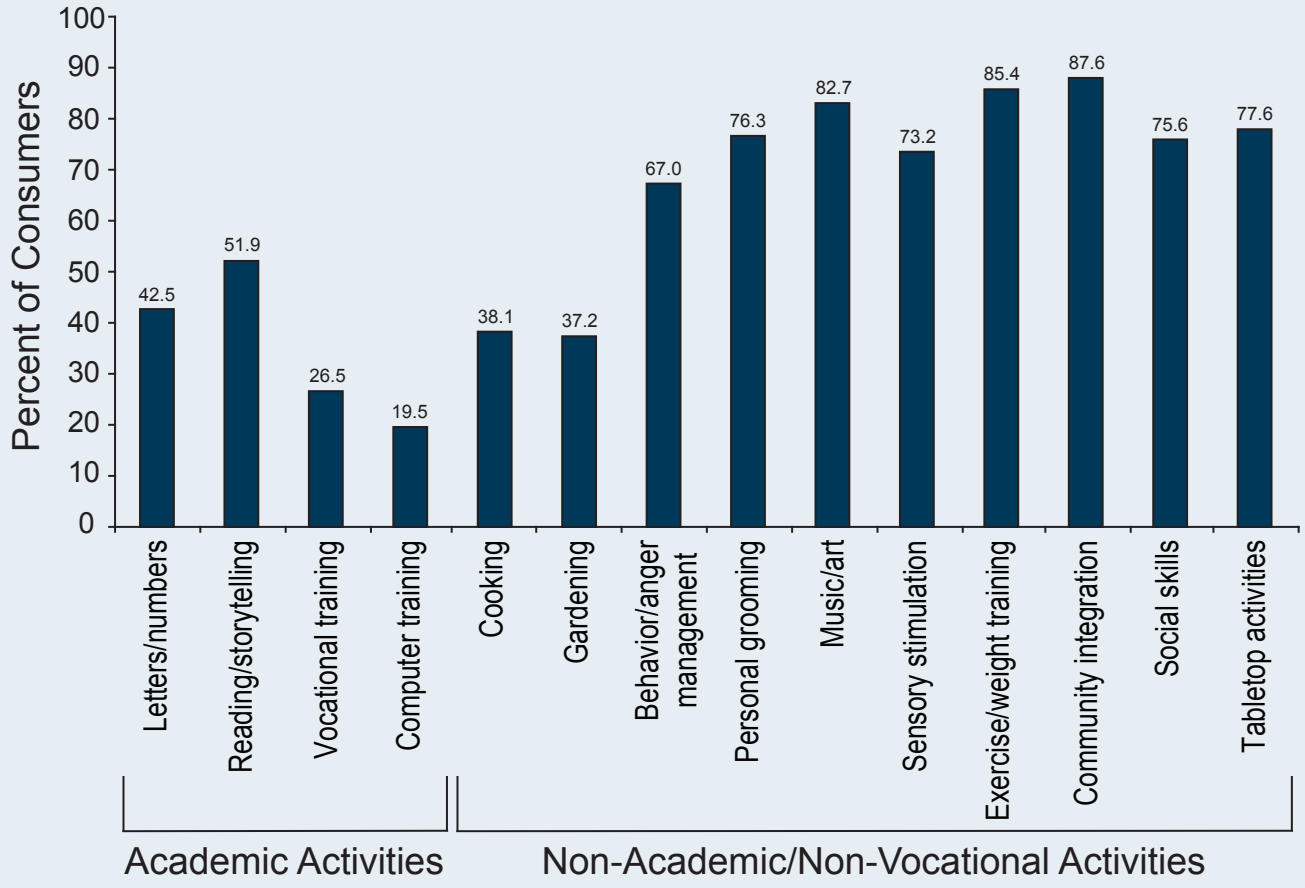
This section includes information regarding the access to and quality of health care services received in the community for the consumers in the TCP. An additional analysis was conducted this year, which examined access to health care disaggregated by RC.

Health Care

The primary health care needs of 99.1% of the consumers were fully met; the health care needs were partially met for 0.4%; health care was not available or not met for 0.2%; and 0.3% of the consumers refused medical treatment. As for dental care, the dental needs of 91.8% of the consumers were fully met; the dental needs were partially met for 1.0%; dental care was not available or not met for 0.4%; and 0.9% of the consumers declined dental care.

Staff respondents were also asked if the consumer had any medical or dental needs over the past year for which appropriate care was *not* provided. Nearly ninety-eight percent of the consumers received all the appropriate medical and dental care needed, however there were a

Figure 2.16
Day Program Activities



few cases in which care was not provided and:

- The health issue was not serious (1.4%).
- The health issue was serious (0.7%).
- The health issue was life threatening (0.2%).

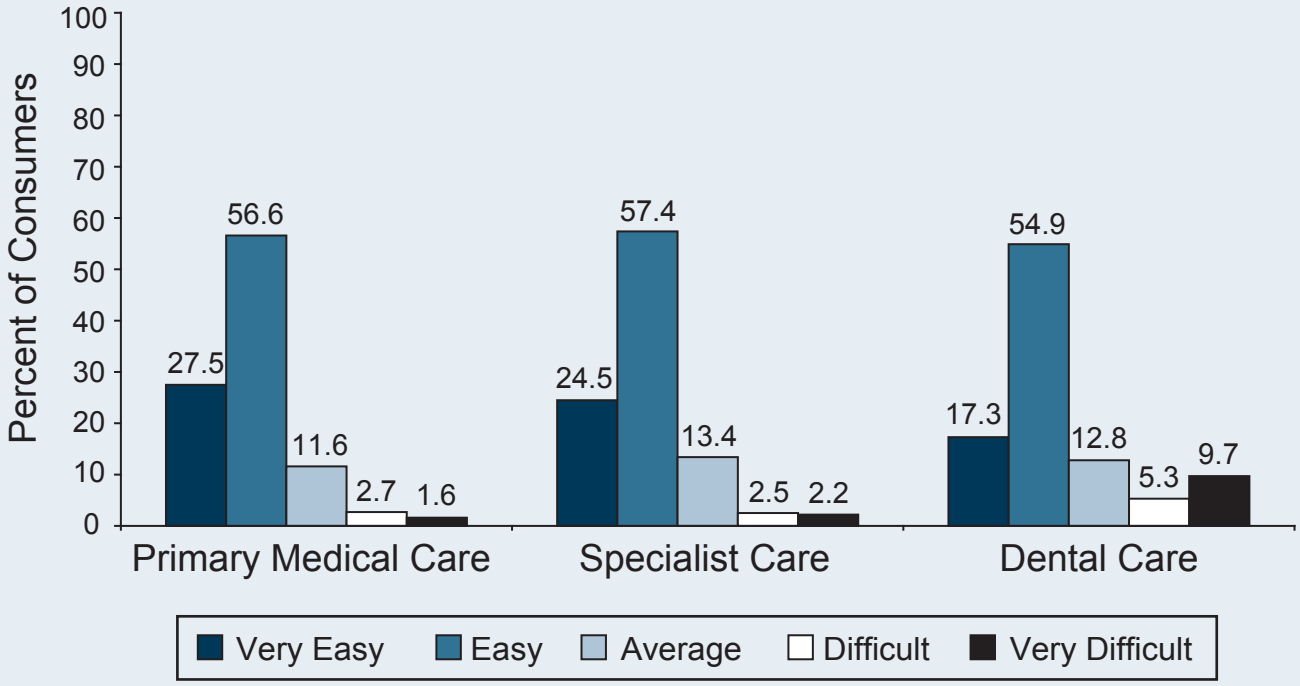
Access to Medical Care

Figure 2.17 indicates that the majority of staff respondents rated primary medical care as easy or very easy to find (84.1%), which is approximately the same as reported in the *2007 Mover Study* (84.6%). Additionally, the quality of medical care was considered satisfactory by the vast majority of the staff respondents (93.8%).

Also shown in Figure 2.17, specialist care was rated very easy or easy to find by over eighty percent (81.9%) of the staff respondents, which is 2.5% higher than the same ratings reported in the *2007 Mover Study* (79.4%). According to staff respondents, specialists treating neurological and gynecological issues are the most difficult to find. The quality of specialist care was considered satisfactory by 93.5% of the staff respondents.

Dental care was rated as very easy or easy to find by 72.2% of the staff respondents, which, as seen in Figure 2.17, was lower than the observed primary care and specialist care access ratings. Further, the difficult to very difficult access ratings for dental care were 2-6 times higher than observed for primary medical care and

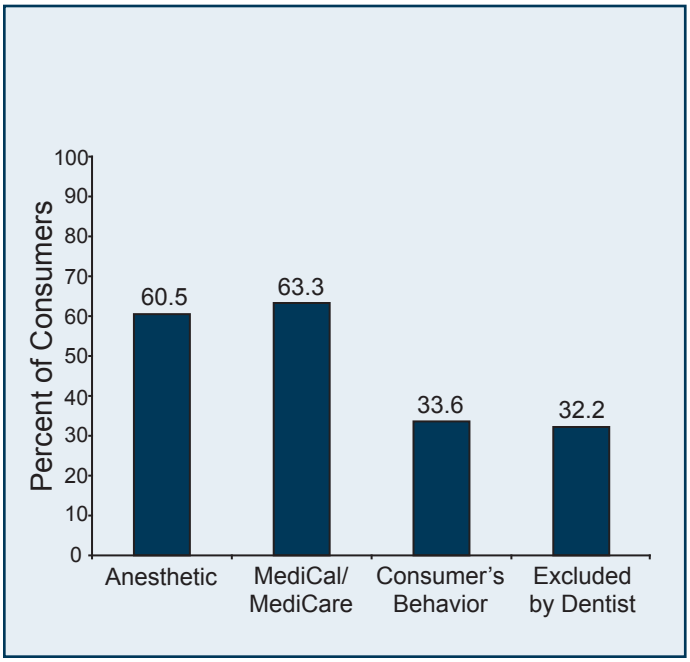
Figure 2.17
Access to Health Care



specialist care. Furthermore, the difficult to very difficult ratings increased by one percent in the *2008 Mover Study* (15.0%) as compared to the *2007 Mover Study* (14.0%). The quality ratings for dental care were slightly lower than those observed for primary care and specialist care this year with 90.2% of the staff respondents considering the quality as satisfactory. Even though the access to dental care continues to be an issue of concern, the percentage of respondents reporting satisfactory quality in dental services increased this year (90.2%) as compared to the *2007 Mover Study* (87.4%).

This year the *Residential Survey* asked four follow-up questions of respondents who rated the access to dental care as difficult or very difficult to identify the causes of the difficulty in finding dental care. These were: (1) anesthesia services, (2) acceptance of MediCal or Medicare, (3) the consumer's behavior, and (4) the dental practice did not accept clients with developmental disabilities. Figure 2.18 shows that the most common reasons reported by staff respondents were lack of anesthesia services and MediCal/Medicare not accepted by the dental office.

Figure 2.18
Reasons for Difficulty in Finding Dental Care



Regional Center (RC) Analysis

Access to health care and quality of health care data were disaggregated by RC to more closely examine health care issues specific to each RC. It is important to note that this analysis is descriptive in nature only and that there are several limitations to consider before drawing conclusions: (1) These data do not necessarily reflect the quality of health care in terms of outcomes but rather do represent the respondents' perceived access to and quality of health care in their area; (2) as stated in the introduction, this evaluation is a "snapshot" in time, which means these opinions are subject to change over time and experience; and (3) no weighting or control measures were used in this data set (i.e., caseloads were not matched across RCs). Additionally, one must keep in mind that the dissatisfaction with access to or quality of health care may not directly reflect RC services but rather the community in which the consumer lives. Given these limitations, the data do provide insight into where funding and resources might be needed. The reader is strongly encouraged to evaluate each RC as a separate analysis and refrain from making comparisons between RCs, even though RCs are presented together on each figure and table[27].

Staff respondents reported that the access to primary medical care was at least average or satisfactory for most RCs (See Figure 2.19 and Table 2.2). A few (2.9% of the TCP) notable[28] exceptions expressed higher levels of difficulty in finding primary medical care:

- ACRC
- KRC
- NLACRC
- RCOC
- SARC

Over 95.0% of respondents rated the quality of primary medical care received as average or satisfactory for all RCs.

Staff respondents reported that the access to specialist care was at least average or better for most RCs (See Figure 2.20 and Table 2.3). A few (2.4% of the TCP) notable exceptions expressed higher levels of difficulty in finding specialist care:

- ACRC
- RCEB
- FNRC
- KRC
- NLACRC
- RCOC
- RCRC

Over 95.0% of respondents rated the quality of specialist care received as average or satisfactory for all RCs. In contrast to primary medical care and specialist care, few respondents rated the access to dental care as average or satisfactory (See Figure 2.21 and Table 2.4). The responses of staff respondents living in the following RC service areas expressed higher levels of difficulty in finding dental care (13.9% of the TCP):

- ACRC
- CVRC
- RCEB
- FNRC
- HRC
- KRC
- NBRC
- RCOC
- RCRC
- SARC
- TCRC
- VMRC

[27] Figures and tables are presented to provide the frequency of responses in addition to the percentages of responses which is of particular importance when examining small data sets.

[28] "Notable" is defined as more than or equal to 5.0% of the respondents from the RC service area.

Figure 2.19
Access to Primary Medical Care by Regional Center

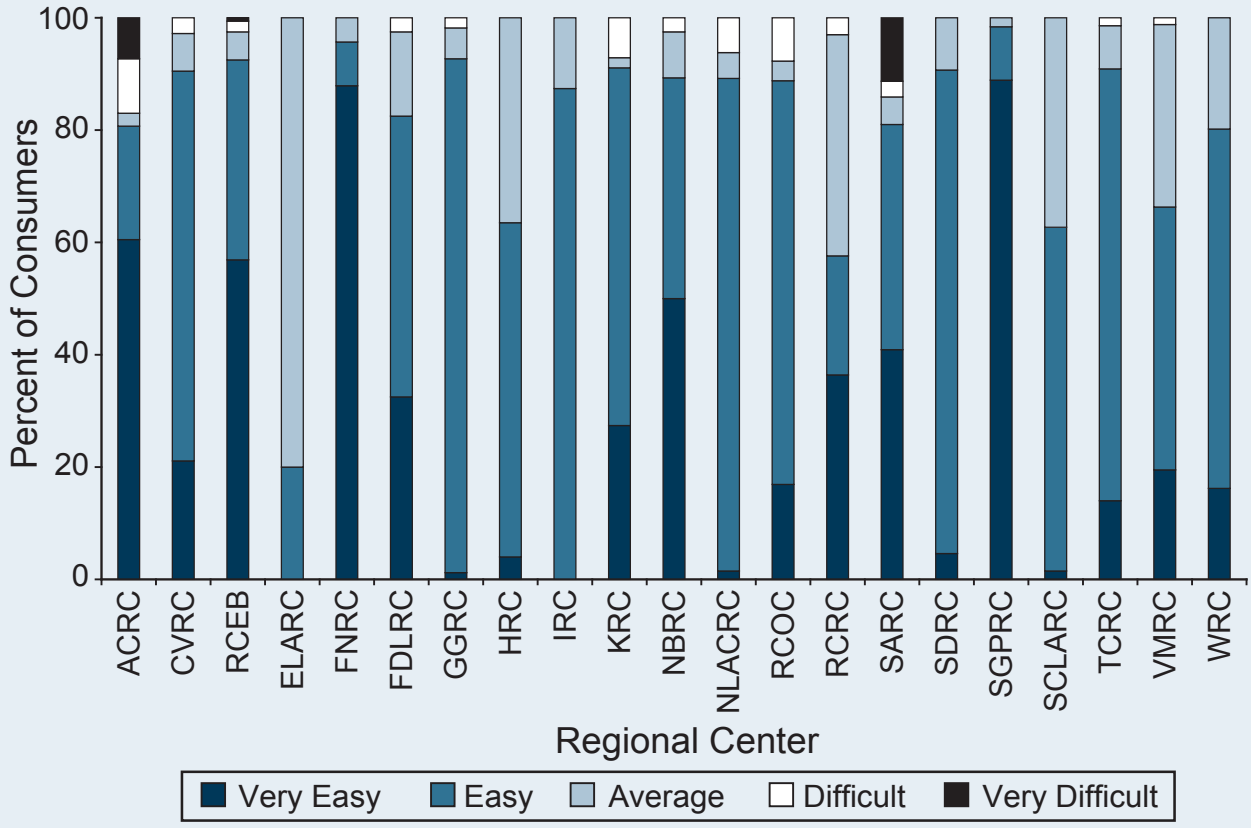


Table 2.2
Access to Primary Medical Care by Regional Center

	Very Easy		*Easy*		*Average*		*Difficult*		*Very Difficult*	
	n	*%*	*n*	*%*	*n*	*%*	*n*	*%*	*n*	*%*
ACRC	75	60.5	25	20.2	3	2.3	12	9.7	9	7.3
CVRC	44	21.1	145	69.4	14	6.7	6	2.8	0	0.0
RCEB	91	56.9	57	35.6	8	5.0	3	1.9	1	0.6
ELARC	0	0.0	13	20.0	52	80.0	0	0.0	0	0.0
FNRC	79	87.9	7	7.8	4	4.3	0	0.0	0	0.0
FDLRC	13	32.5	20	50.0	6	15.0	1	2.5	0	0.0
GGRC	2	1.2	150	91.5	9	5.5	3	1.8	0	0.0
HRC	3	4.0	44	59.5	27	36.5	0	0.0	0	0.0
IRC	0	0.0	146	87.4	21	12.6	0	0.0	0	0.0
KRC	46	27.4	107	63.7	3	1.8	12	7.1	0	0.0
NBRC	61	50.0	48	39.3	10	8.2	3	2.5	0	0.0
NLACRC	1	1.5	57	87.7	3	4.6	4	6.2	0	0.0
RCOC	24	16.9	102	71.9	5	3.5	11	7.7	0	0.0
RCRC	12	36.4	7	21.2	13	39.4	1	3.0	0	0.0
SARC	101	40.9	99	40.1	12	4.9	7	2.8	18	11.3
SDRC	5	4.6	93	86.1	10	9.3	0	0.0	0	0.0
SGPRC	56	88.9	6	9.5	1	1.6	0	0.0	0	0.0
SCLARC	1	1.5	41	61.2	25	37.3	0	0.0	0	0.0
TCRC	20	14.0	110	76.9	11	7.7	2	1.4	0	0.0
VMRC	15	19.5	36	46.8	25	32.5	1	1.2	0	0.0
WRC	14	16.2	55	64.0	17	19.8	0	0.0	0	0.0

Figure 2.20
Access to Specialist Care by Regional Center

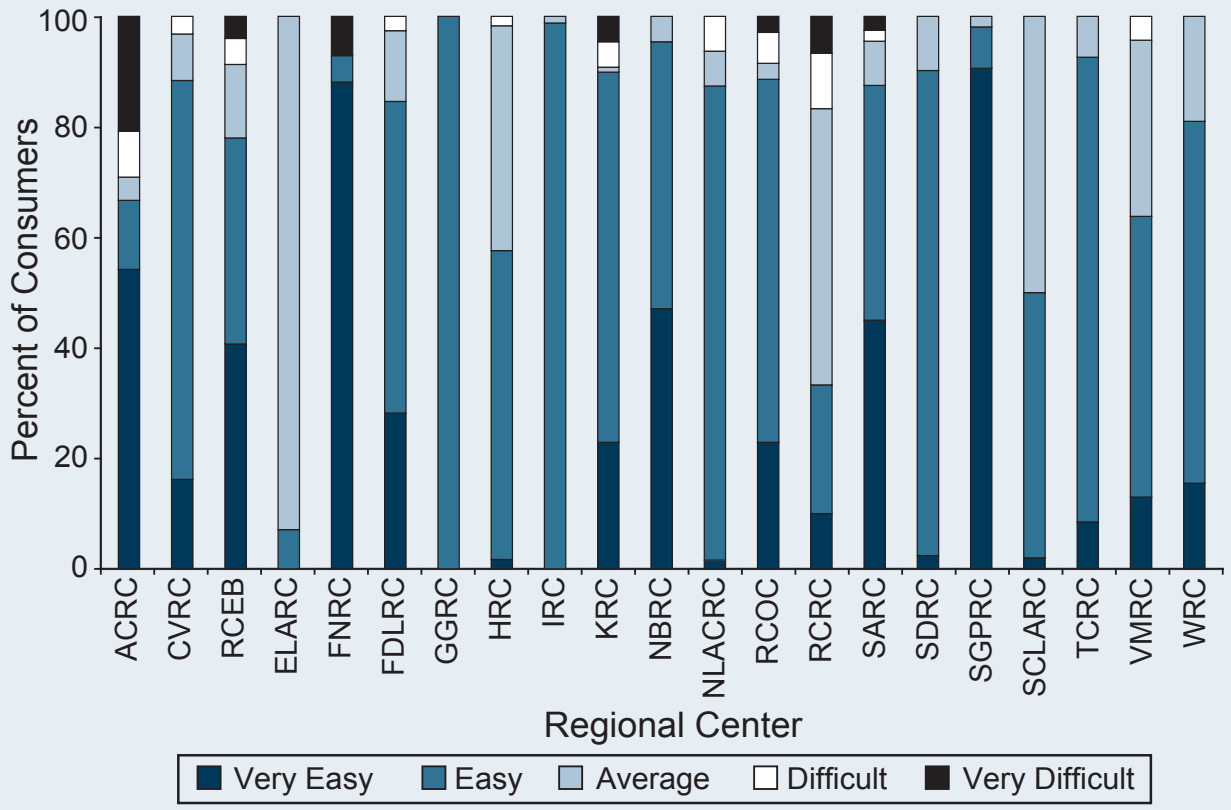


Table 2.3
Access to Specialist Care by Regional Center

	Very Easy		*Easy*		*Average*		*Difficult*		*Very Difficult*	
	n	*%*	*n*	*%*	*n*	*%*	*n*	*%*	*n*	*%*
ACRC	39	54.2	9	12.5	3	4.2	6	8.3	15	20.8
CVRC	25	16.2	111	72.2	13	8.4	5	3.2	0	0.0
RCEB	61	40.7	56	37.3	20	13.3	7	4.7	6	4.0
ELARC	0	0.0	4	7.1	52	92.9	0	0.0	0	0.0
FNRC	37	88.1	2	4.8	0	0.0	0	0.0	3	7.1
FDLRC	11	28.2	22	56.4	5	12.8	1	2.6	0	0.0
GGRC	0	0.0	143	100.0	0	0.0	0	0.0	0	0.0
HRC	1	1.7	33	55.9	24	40.7	1	1.7	0	0.0
IRC	0	0.0	85	98.8	1	1.2	0	0.0	0	0.0
KRC	25	22.9	73	67.0	1	0.9	5	4.6	5	4.6
NBRC	41	47.1	42	48.3	4	4.6	0	0.0	0	0.0
NLACRC	1	1.6	54	85.8	4	6.3	4	6.3	0	0.0
RCOC	16	22.9	46	65.7	2	2.9	4	5.6	2	2.9
RCRC	3	10.0	7	23.3	15	50.0	3	10.0	2	6.7
SARC	90	45.0	85	42.5	16	8.0	4	2.0	5	2.5
SDRC	1	2.4	36	87.8	4	9.8	0	0.0	0	0.0
SGPRC	48	90.6	4	7.5	1	1.9	0	0.0	0	0.0
SCLARC	1	2.0	24	48.0	25	50.0	0	0.0	0	0.0
TCRC	8	8.5	79	84.1	7	7.4	0	0.0	0	0.0
VMRC	9	13.0	35	50.8	22	31.9	3	4.3	0	0.0
WRC	13	15.5	55	65.5	16	19.0	0	0.0	0	0.0

Figure 2.21
Access to Dental Care by Regional Center

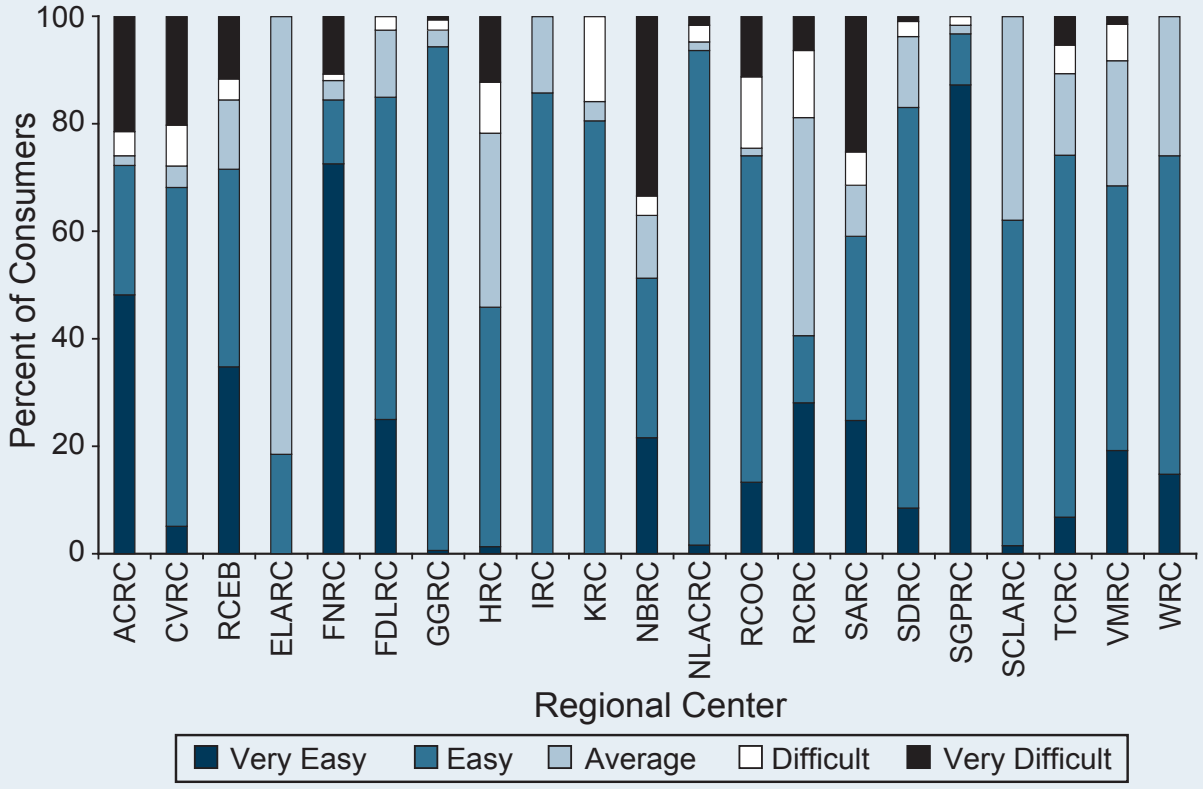


Table 2.4
Access to Dental Care by Regional Center

	Very Easy		*Easy*		*Average*		*Difficult*		*Very Difficult*	
	n	*%*	*n*	*%*	*n*	*%*	*n*	*%*	*n*	*%*
ACRC	54	48.2	27	24.1	2	1.8	5	4.5	24	21.4
CVRC	10	5.1	125	63.1	8	4.0	15	7.6	40	20.2
RCEB	54	34.8	57	36.8	20	12.9	6	3.9	18	11.6
ELARC	0	0.0	12	18.5	53	81.5	0	0.0	0	0.0
FNRC	61	72.6	10	11.9	3	3.6	1	1.2	9	10.7
FDLRC	10	25.0	24	60.0	5	12.5	1	2.5	0	0.0
GGRC	1	0.6	152	93.8	5	3.1	3	1.9	1	0.6
HRC	1	1.3	33	44.6	24	32.4	7	9.5	9	12.2
IRC	0	0.0	145	85.8	24	14.2	0	0.0	0	0.0
KRC	0	0.0	133	80.6	6	3.6	26	15.8	0	0.0
NBRC	24	21.6	33	29.7	13	11.7	4	3.6	37	33.4
NLACRC	1	1.6	59	92.1	1	1.6	2	3.1	1	1.6
RCOC	19	13.3	87	60.8	2	1.4	19	13.3	16	11.2
RCRC	9	28.1	4	12.5	13	40.6	4	12.5	2	6.3
SARC	60	24.8	83	34.3	23	9.5	15	6.2	61	25.2
SDRC	9	8.5	79	74.6	14	13.2	3	2.8	1	0.9
SGPRC	55	87.3	6	9.5	1	1.6	1	1.6	0	0.0
SCLARC	1	1.5	40	60.6	25	37.9	0	0.0	0	0.0
TCRC	9	6.8	89	67.4	20	15.2	7	5.3	7	5.3
VMRC	14	19.2	36	49.3	17	23.3	5	6.8	1	1.4
WRC	12	14.8	48	59.3	21	25.9	0	0.0	0	0.0

For the 15.0% of respondents in the TCP that reported dental care was difficult or very difficult to find, Figure 2.22[29] shows that across RCs, the most common issues in finding dental care were lack of anesthesia services and Medical/Medicare not accepted by the dental office. Respondents within the service areas of a few RCs also cited behavioral concerns (e.g., RCOC) and the exclusion of people with developmental disabilities from the dental practice (e.g., SARC and CVRC) as a difficulty in finding dental care. The exclusion of people with developmental disabilities in dentistry has been anecdotally reported to be due to behavioral concerns and the need for anesthesia during dental procedures. Thus, it may be that the exclusion is not solely based on the diagnosis of a developmental disability but rather the lack of dental practices that offer anesthesia services in the area.

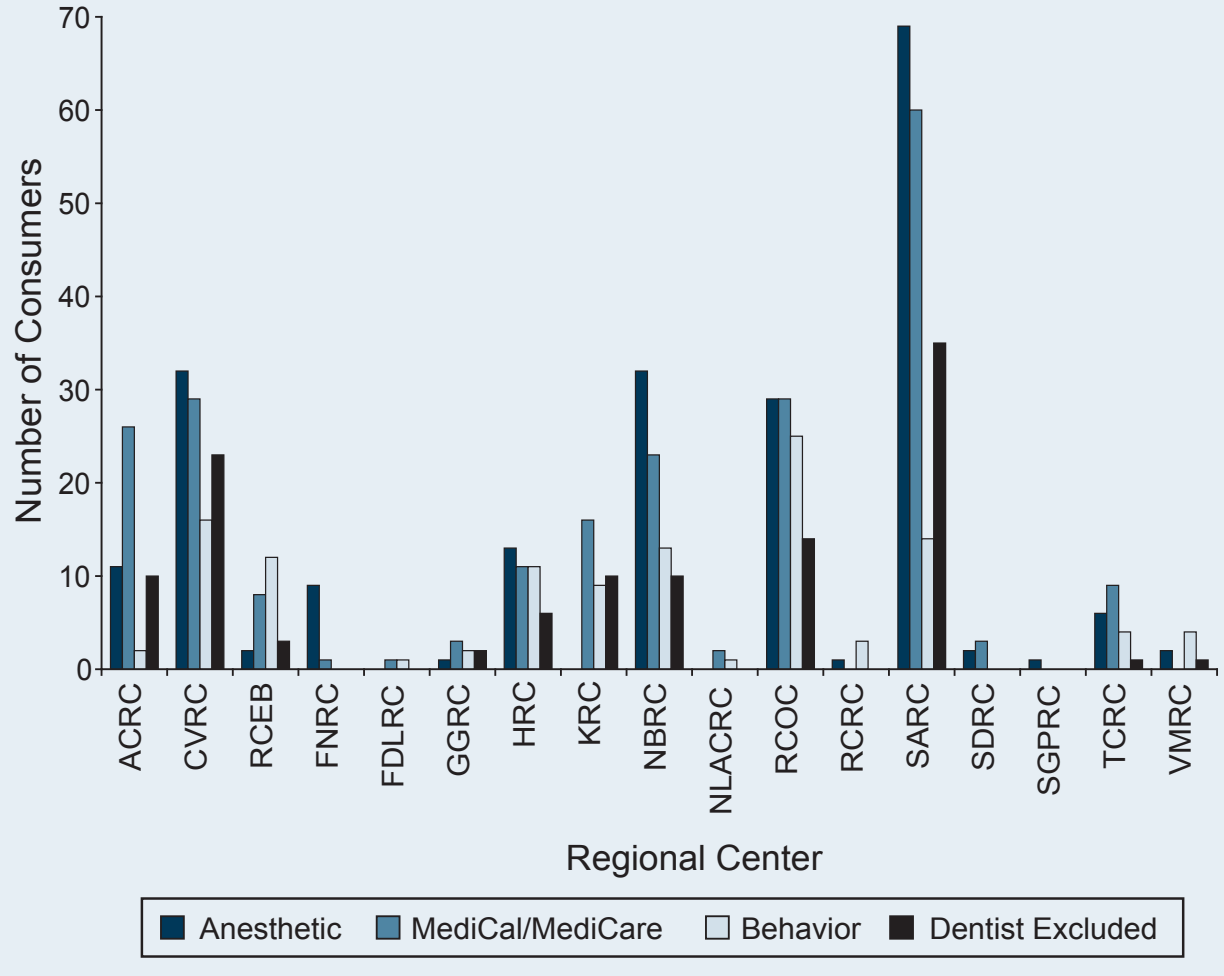
Over 95.0% of respondents rated the quality of dental care received as average or satisfactory for all RCs.

Mental Health and Crisis Intervention

This section contains information about the mental health services required by the consumers, the quality of the mental health services, the crises the consumers have experienced, and the frequency and quality of crisis intervention services utilized in the community.

[29] The frequency of consumers is presented because of the small number of respondents.

Figure 2.22
Reasons for Difficulty in Finding Dental Care by Regional Center



Mental Health Services

The data show that of the consumers for whom information was available (2,427 consumers), 35.2% received medications monitoring, 2.7% received therapy and counseling only, and 27.2% received medications monitoring and therapy. Furthermore, staff respondents reported that 0.5% of the TCP consumers needed mental health services but did not receive them. When asked to specify the mental health needs not received, 1.5% of the TCP staff respondents expressed a need and specified the following areas of concern:

- Anxiety
- Depression
- Impulse control
- Obsessive-compulsive disorder

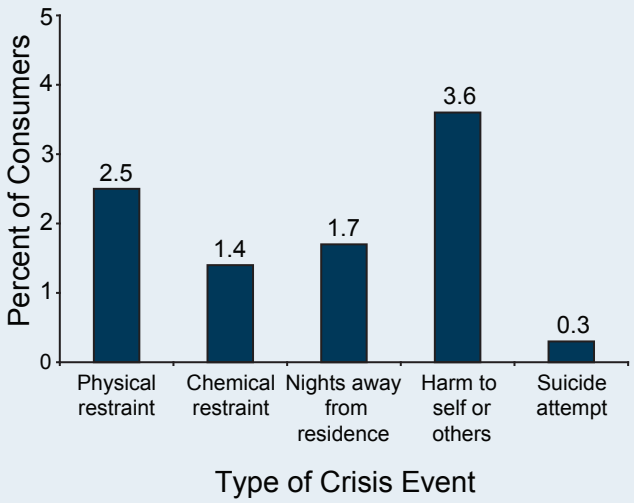
With respect to accessing mental health services, 86.5% of the staff respondents said it was easy or very easy to find someone to monitor the consumers' medications. The majority of the staff members (93.2%) rated the medication monitoring services received by the consumers as good or very good. With respect to access to therapeutic services,[30] 82.9% of the staff members reported that it was easy or very easy to find. The majority of the staff members (94.8%) rated the quality of therapeutic services as good or very good.

Crisis Episodes

Crisis episodes were defined as the use of physical restraints, use of chemical restraints, one or more nights away from home, harm to self or others, or attempted suicides. Figure 2.23 shows that the most frequent crisis episode involved harm to self or others. Specifically, during the past year:

- For the 2.5% of the consumers that experienced crises involving physical restraints, the average was 12.0 per consumer in crisis.
- For the 1.4% of the consumers that experienced crises involving chemical restraints, the average was 15.4 per consumer in crisis.
- For the 1.7% of the consumers that experienced crises involving a one or more nights away from the residence at a psychiatric facility, the average was 1.7 per consumer in crisis.
- For the 3.6% of the consumers that experienced crises resulting in harm to self or others, the average was 7.5 per consumer in crisis.
- For the 0.3% of the consumers that experienced crises involving a suicide attempt, the average was 2.4 per consumer in crisis.

Figure 2.23
Crisis Episodes



Crisis Intervention Services

Table 2.5 contains information about the crisis interventions services utilized in the community. The data were collected for the following types of crisis intervention services: people or teams called to a consumer's residence, supplemental supports called to the residence, RC crisis facilities, RC after-hours calls, emergency room visits, psychiatric facility visits, police interventions, and incarcerations. The most commonly used crisis

[30] Therapeutic services may or may not include medication monitoring.

Table 2.5
Community Crisis Intervention Services

Type of Intervention	Frequency of Consumers n	Frequency of Consumers %	Intervention Services per Consumer in Crisis Average	Intervention Services per TCP Consumer Average	Quality Rating of Intervention Services (Very Good = 5) Average
People/team to the residence	33	1.4	1.7	0.02	4.2
Supplemental supports to the home	13	0.5	1.9	0.01	4.5
RC crisis facility	2	0.1	1.0	0.00	3.0
RC after-hours call	12	0.5	2.1	0.01	4.2
Emergency room visits	38	1.6	1.6	0.02	3.8
Psychiatric facility	40	1.6	2.1	0.03	3.5
Police interventions	59	2.4	2.1	0.05	3.9
Incarceration	4	0.2	1.5	0.00	4.3

intervention services used in the community were police interventions, psychiatric facilities, emergency rooms, and additional people or teams called to the residence. The community intervention services that received, on average, good to very good quality ratings were supplemental supports to the home, incarceration, RC after-hours calls, and additional people or team called to the residence.

Legal Concerns

This section contains information about the consumers' involvement with the criminal justice system and data regarding the consumers who were victims of a crime.

Criminal Justice Involvement

Fifteen consumers (0.6%) in the TCP were involved with the criminal justice system as a perpetrator of a crime during the past year. Of those involved with the criminal justice system, the reasons for involvement were:

- Assault that could result in serious injury to another (six consumers).
- Purchase, sale, or use of an illegal substance (five consumers).
- Illegal sex acts (two consumers).
- Stealing, theft, or shoplifting (one consumer).
- Other criminal activity reported included filing false charges, loitering, and panhandling (two consumers).

Of the 15 consumers involved with the criminal justice system, four were detained in jail overnight or longer with one consumer jailed on more than one occasion.

Victims of a Crime

Eleven consumers (0.5%) in the TCP were victims of a crime in the past year. Specifically, 10 consumers were victimized by assault and one consumer's residence was burglarized. One of the ten consumers was assaulted twice during the past year.

Denial of Rights

A Denial of Rights Report was filed for two consumers during the past year. According to staff respondents, the reports were issued for physical restraints (to prevent self injury) and for the removal of consumer property (consumer diagnosed with Pica).

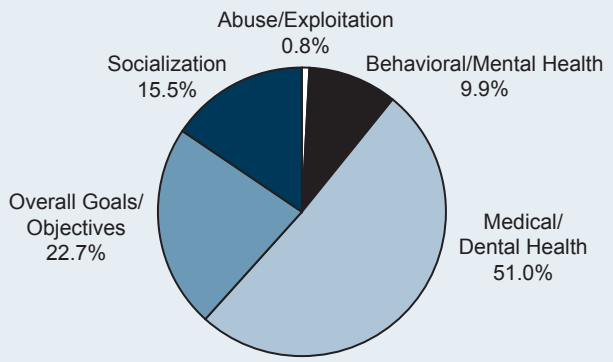
Alerts

The Level 1 Alert system requires visitors to immediately report any suspected violation of legal, civil, or service

rights of an individual or if the project visitor determines that the health and welfare of the consumer is at risk. Data for Level 1 Alerts are reported directly to DDS, RCs, and the clients' rights advocates. For the *2008 Mover Study*, no Level 1 Alerts were reported.

The Level 2 Alert system requires visitors to report violations of pre-selected criteria variables. Upon notification, CSUS is required to notify DDS and the appropriate RC. Alerts fall within one of the following five categories: Abuse or exploitation risk; behavioral and mental health; medical and dental health; overall goals and objectives; and socialization. For the TCP, 2,214 alerts were filed for 1,168 consumers. Figure 2.24 indicates that the majority of alerts filed (51.0%) involved medical and dental health, with the most common reasons being: (1) difficulty in finding medical and dental care and/or the lack of dental services, (2) three or more visits to the emergency room, and (3) a negative weight change. Just under a quarter of the Level 2 Alerts filed involved overall goals and objectives, with most of the alerts due to the lack of day program services.

Figure 2.24
Level 2 Alerts



As discussed in the *2007 Mover Study*, visitors reported two Level 1 Alerts and 2,259 Level 2 Alerts during last year's evaluation.

CONSUMER INTERVIEW

The consumers were interviewed to determine their satisfaction with their home and day program, their sense of independence, and their relationships with friends and staff members. Consumers who could respond for themselves were interviewed by the visitors. As stated in the Welfare and Institutions Code,[31] two staff members familiar with the consumer of interest completed the interview when a consumer could not respond for themselves. Staff member interviews were conducted separately. Proportions were:

- 30.2% of the consumers completed the interview themselves.
- 1.5% of the consumers started the interview but did not finish.
- 1.6% of the consumers declined to participate.
- 66.7% of the interviews were conducted with two staff members.

Consumer Responses

Most items had a majority of positive responses, Table 2.6 indicates that:

More than 90% of the consumers:

- Ask for what they want.
- Have people in their lives that help them get into the community.
- Pick the things they like to do for fun.
- Like the people that help them in their homes.
- Like the people that help them in their day programs.

Consumers felt the most ambivalent about:

- Their case manager's help.
- Liking their case manager.

[31] §4418.1 (f).

Table 2.6
Consumer Responses

Interview Question	Response (Percent of Consumers) Yes	Ambivalent	No
Feeling safe most of the time	87.3	9.5	3.2
Feeling happy most of the time	84.2	11.1	4.7
Asking for what you want	95.9	3.2	0.9
Feeling lonely	42.8	13.9	43.3
Like living in your home	86.9	8.8	4.3
Like the people who help you at home	91.7	6.7	1.6
Like the others living in your home	83.7	12.5	3.8
Want to keep living in your home	83.1	7.2	9.7
Like going to your day program	89.1	6.8	4.1
Like the people who help you at the day program.	91.3	6.9	1.8
Like others at your day program	86.2	10.1	3.7
Want to keep going to your day program	88.4	5.3	6.3
Decide to spend your money	88.3	8.8	2.9
Friends come to visit you at home	85.2	9.6	5.2
Friends visit as often as you like	79.1	12.6	8.3
Pick the things you want to do	92.8	5.9	1.3
Anyone help you go out into the community	93.4	2.9	3.7
Learning to do things for yourself	89.8	6.7	3.5
Like your case manager	83.0	14.1	2.9
Case manager helps you with your problems	80.7	15.2	4.1

- Whether or not they felt lonely at times.
- If their friends could visit as often as the consumer liked.
- Other people living in the home.

More than 5.0% but less than 10.0% of consumers:

- Did not want to keep living in their present home.
- Reported their friends did not come visit them at home.
- Did not want to keep going to their present day program.

When consumers were asked if they felt lonely at times, approximately the same number of consumers responded yes as did no.

Comments to the Consumers' Interview

Consumers were asked if they had any additional comments upon the completion of the consumer interview portion of the *Residential Survey*. Responses were categorized into: wants and wishes (the majority of comments), satisfaction, general comments, and negative in nature. The most common responses to each category were:

Wants and Wishes

- Desire to move closer to family and/or significant others.
- Live independently in their own home.
- More privacy in their home.
- Learn more and do more at their day program.

- Have a job or get a better paying job.
- To be married.
- More visits with their family and friends.
- Continue to live in supported living.
- Take responsibility for their money.
- More help from their case manager.

Satisfaction

- Very happy and like living in their present home.
- Enjoy having friends and good coworkers.
- Like their job.
- Feel as if they have shown improvements in their behavior.

General Comments

- Reported on community outings.
- Discussed their significant relationships.
- Discussed their social activities (e.g., birthday celebrations).
- Discussed their job.

Negative

- Did not like their current living situation and wanted to move.
- Did not like their current job.
- Missed their family.
- Had dental insurance problems.
- Staff and other residents were perceived as abusive.

Staff Responses

As stated above, two staff members were independently interviewed when the consumer was unable to respond. Inter-rater reliability analyses were performed to assess the extent to which staff members agreed in their assessments. All items were significantly correlated, with the majority (15) of the items being strongly correlated (*rho* ≥ 0.5)[32] and the remaining items[33] being moderately correlated (*rho* ≥ 0.3) indicating that most staff members agreed in their responses.

Figure 2.25 shows the percentage of consumers that responded yes for themselves versus the percent of staff members that both responded yes to the items on the consumer survey. As has been historically reported, staff member responses tended to be more positive than those given by the consumers. In fact almost all staff members (≥98%) responded yes to:

- The consumer felt safe in their current home.
- The consumer liked living in their current home.
- The consumer wanted to continue living in their current home.

However, there were four items in which the consumers responded more positively than the staff members:

- The consumers asked for what they wanted.
- The consumers decided how to spend their money.
- The consumers chose the activities they liked to do for fun.
- The consumers were learning to do things for themselves.

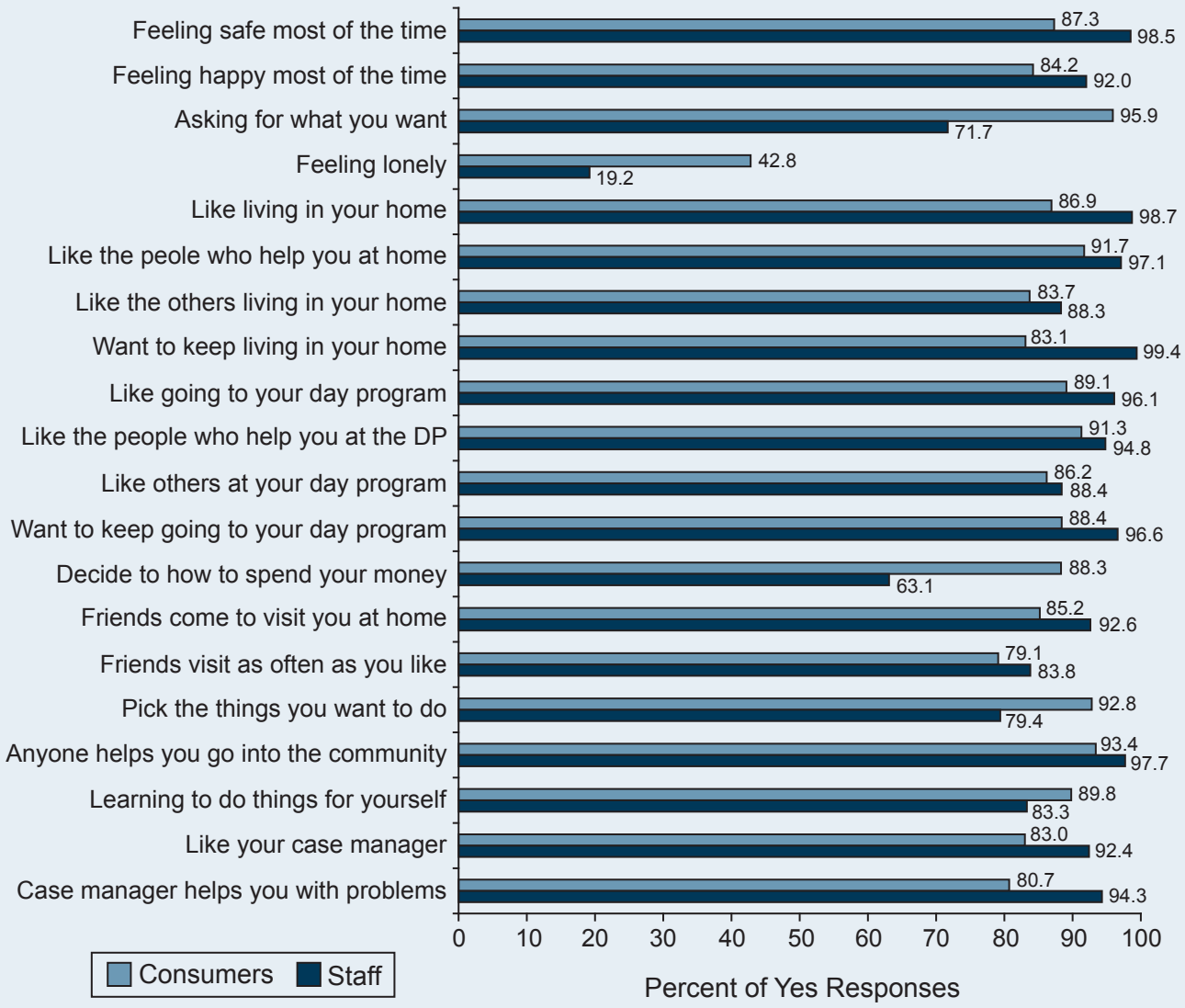
The differences observed between staff and consumer responses may be due to differences in the perceptions of the community environment. Alternatively, these differences may reflect a disparity between consumer

[32] Cohen, J. (1988). *Statistical Power Analysis for the Behavioral Sciences, 2nd Edition*. New Jersey: Erlbaum.

[33] Items included: Safety, happiness, liked their present home, continue to live in their present home, and liked the people who helped them at their day program.

groups with differing levels of intellectual disability diagnoses. Specifically, the majority of consumer respondents (85.5%) were not diagnosed with an intellectual disability or were diagnosed with a mild to moderate intellectual disability. In contrast, the majority of consumers in which staff members were interviewed (89.1%) were diagnosed with severe or profound intellectual disability. Staff perceptions may differ from the consumers' but it may be more probable that the behaviors actually do differ between the groups. For example, for the responses to the item "Do you ask for what you want," 71.7% of staff members responded yes as opposed to 95.9% of the consumer respondents. Given the dramatic difference in the levels of intellectual disability between the groups (consumer respondents versus consumers unable to respond), consumers who were able to respond for themselves may actually ask for what they want more frequently than the consumers who were unable to respond.

Figure 2.25
Consumer Survey



ADVOCATE INTERVIEWS

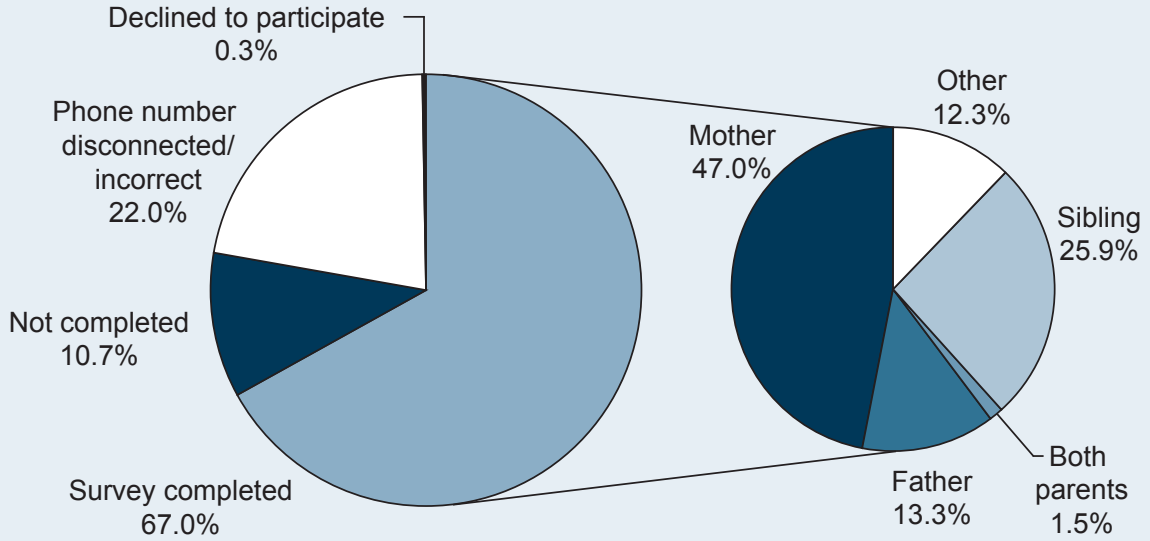
The *Advocate Survey* was conducted via telephone interviews with relatives, friends, guardians, or conservators of the consumers in the TCP. In this section, the respondents are collectively referred to as advocates because of the diversity of the relationships between the consumers and the respondents. Names and contact information of the advocates were found in the records of 1,188 (48.4%) of the 2,434 consumers in the TCP.

Telephone interviews were conducted using industry-standard methods. Visitors attempted to contact each advocate a minimum of three times. In an effort to accommodate the advocates' schedules, the contact calls were made mornings, afternoons, evenings, and/or weekends. The interviews were conducted over a three-month period. The responses were recorded, entered into a database, and analyzed for this evaluation. The percentages reported in this section are for the proportion of the advocates with whom contact was made and who agreed to participate in the study.

Figure 2.26 shows that of the 1,188 telephone calls attempted:

- 67.0% were completed.
- 10.7% were not completed because there was no answer, the visitor reached a voice mailbox, the line was busy, or the visitor reached a dedicated facsimile line.
- 22.0% of the telephone numbers were disconnected or incorrect.
- 0.3% of advocates were reached but declined to participate.

Figure 2.26
Advocate Interviews



Further, Figure 2.26 indicates that the majority of the advocates (87.7%) were immediate relatives: mothers, fathers, and siblings. Over half of the advocates (54.7%) reported being the consumer's legal conservator.

Life in a Developmental Center (DC)

Of the advocate respondents, 87.4% provided information about the length of time the consumers had resided in a DC. The remaining respondents could not remember the dates the consumer had been admitted into a DC or integrated into the community. On average, advocates reported that the consumers had been in a DC for 19.5[34] years and 59.1% of the respondents rated the quality of the consumer's life at the DC as Good.

Life in a DC Compared to the Community

Respondents were asked to rate their perceptions of various aspects of life in a DC and in the community on a three-point scale, with three being the most positive rating. These items were only asked of the advocates of consumers who were integrated into the community within the last year, FY2006/07. The sample was limited to this group because many of the advocates of consumers who have been in the community more than one year have expressed difficulty in remembering (or did not know about) the consumer's life in a DC. Figure 2.27 and Table 2.7 contain the results of the advocate responses to the DC and community comparison questions.

Paired sample t-tests were used to evaluate the differences between the DC and community ratings for each DC versus community question. All perceptions were rated significantly higher for community living than for living in a DC. Specifically, the overall quality of life in the community (M = 3.0) was rated more positively than the overall quality of life in a DC (M = 2.2). In addition, advocates were asked to rate their feelings about community integration before the consumer was in a DC and how they feel now. Ratings for community living were much higher now that the consumer was in the community (M = 2.8) than when the consumer was still residing at a DC (M = 2.1).

Consumer-Advocate Contacts

All respondents were asked about their contacts with the consumer over the past year in the community. On average advocates reported that they:

- Visited the consumer in person 24.0 times.
- Made 104.8 telephone calls.
- Wrote 5.1 letters and/or cards.

Forty percent of the advocates attended the consumers' IPP meetings this past year.

Advocates' Satisfaction with Community Services

The advocates were asked to rate their satisfaction with the consumer's residence, the staff members at the consumer's residence, and the RC case manager. Figure 2.28 shows that for all rated residence and staff characteristics, over 80.0% of advocates reported their satisfaction as good (the highest rating). The two characteristics that had the highest percentage of poor ratings were (1) listening to the advocate's opinions and concerns (5.0%) and (2) communication between the advocate and residence staff (5.9%).

Advocates were asked about their satisfaction with the consumer's RC service coordinator. The data showed that 82.4% of the advocates were satisfied with the consumer's service coordinator, 6.7% were dissatisfied, and 10.9% felt neutral.

When asked how much attention was given to the advocate's opinions about planning services for the consumer, three-quarters of the advocates felt at least some attention was given to their opinions. The remaining quarter felt as if none to very little attention was given to their opinion when it came to planning service for the consumer (Figure 2.29).

[34] Descriptive statistics for the Advocate Survey data are contained in Appendix D.

Figure 2.27
Advocate Response to DC and Community Comparison

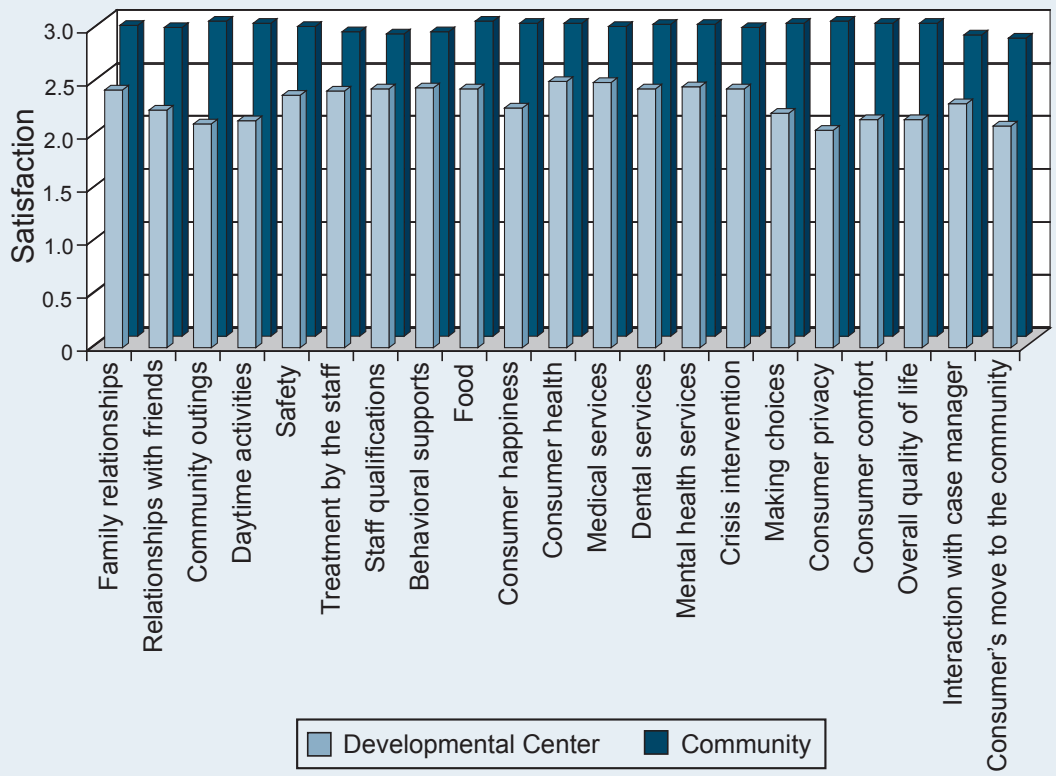


Table 2.7
Comparison of Respondents' Perceptions of the Consumers' Welfare in Developmental Centers and the Community

	Ratings			
	DCs	Community		
*Perceptions***	*Average*	*Average*	*t*	*df*
Family relationships	2.4	2.9	-4.4	39
Relationships with friends	2.2	2.9	-5.8	33
Community outings	2.1	3.0	-8.1	37
Daytime activities	2.1	3.0	-7.0	36
Safety	2.4	2.9	-4.1	36
Treatment by the staff	2.4	2.9	-3.6	37
Staff qualifications	2.4	2.9	-3.4	38
Behavioral supports	2.5	2.9	-3.4	37
Food	2.4	3.0	-5.0	33
Consumer happiness	2.3	3.0	-7.1	38
Consumer health	2.5	3.0	-4.3	38
Medical services	2.5	2.9	-3.2	35
Dental services	2.4	2.9	-4.6	35
Mental health services	2.5	2.9	-4.4	34
Crisis intervention	2.4	2.9	-4.1	33
Making choices	2.2	3.0	-6.2	38
Consumer privacy	2.1	3.0	-7.9	37
Consumer comfort	2.2	3.0	-7.1	38
Overall quality of life	2.2	3.0	-7.1	38
Interaction with case manager	2.3	2.8	-4.8	36
Consumer's move to the community	2.1	2.8	-5.5	42

**All ratings were significant at $p < .01$.

Figure 2.28
Advocate Ratings of Residence and Residence Staff

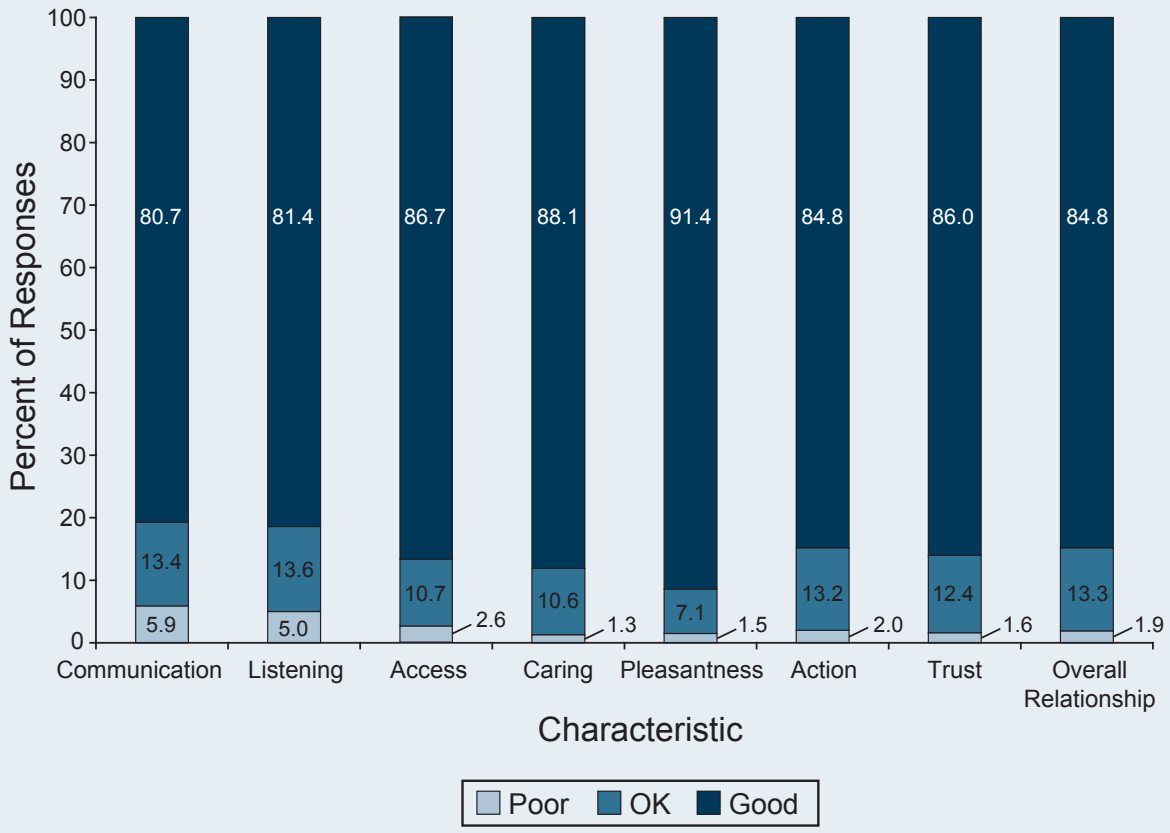
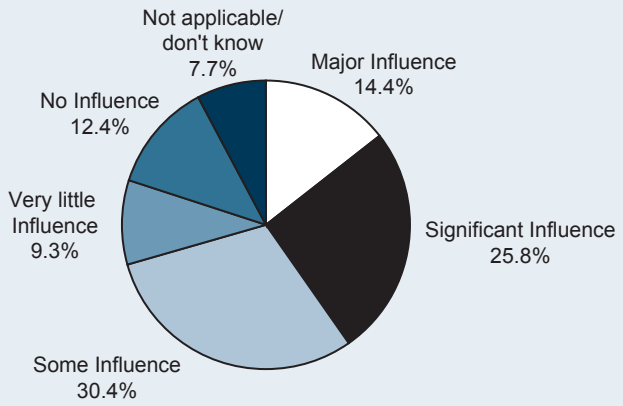


Figure 2.29
How Much Attention was Given to the Advocate's Opinion



An overwhelming majority of advocate comments were positive in nature, which was consistent with the high satisfaction ratings. The most common themes about community living were:

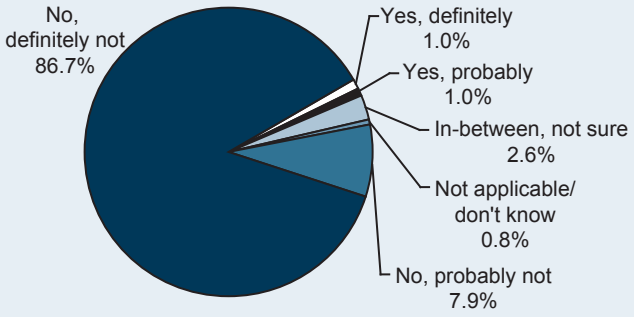
- High quality of care.
- Improved level of functioning (skills and behavior).
- Gratitude for community living options.
- Positive consumer-staff relationships.
- Personalization of care.
- Advocates initially expressed tentative to resistant feelings about community living but have been extremely pleased with the consumer's community placement.
- Cleanliness of the residence.

Despite the advocates' high ratings for the staff members and the consumers' life in the community, they also expressed some concerns. Concerns revolved around the following themes:

- Care for the consumer after the parents are deceased.
- Lack of communication between the residence staff and the advocate.
- Dissatisfaction with the RC and/or RC service coordinator.
- Distance between consumers' residences and the advocates' homes.
- High staff member turnover.
- Staff members who do not speak the consumers' primary language.
- Diet and nutrition.
- Disappearance of the consumers' money and personal possessions.
- Dental care.

Finally, advocates were asked whether they would have the consumer move back to a DC if it was possible. Given the satisfaction ratings with community living and the dramatically large number of positive comments regarding the consumers' well being and community placement, it is not surprising that just under 95% of the advocates responded no, they would not recommend the consumer return to a DC (Figure 2.30).

Figure 2.30
Recommend Return to a DC



CONSUMERS NOT INCLUDED IN THE TCP DISCUSSION

This section contains information about the consumers for whom data were not collected for during the *2008 Mover Study*. These consumers are divided into two groups: Not interviewed (NI) and declined to participate (DTP). NIs are defined as consumers who have (1) died within the last year, (2) had their case closed within the last year, (3) returned to a DC within the last year, (4) were residing in an acute care hospital, (5) were residing in a psychiatric hospital or drug rehabilitation center, (6) were unable to be located (UTL), (7) were incarcerated in a jail or prison, or (8) were residing in a SNF. DTPs include consumers living in community living arrangements (CLAs) who could not be interviewed because: they (1) personally declined to participate, (2) their parents or house managers chose not to communicate with evaluation visitors, or (3) the consumer asked to be permanently removed from the *Mover Study*. The NIs and DTPs consisted of 331 consumers, which made up 12.0% of the TCP: 9.6% of the consumers were NIs and 2.4% were DTPs.

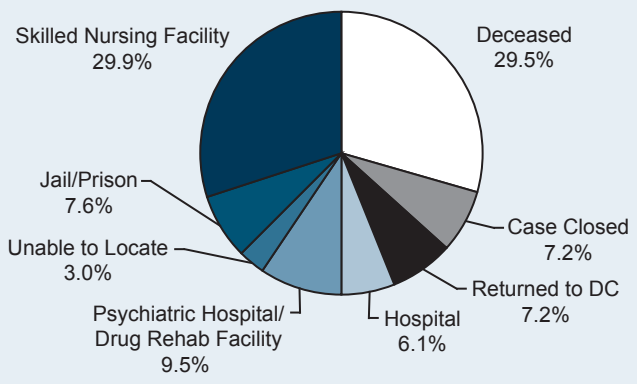
Not Interviewed

Figure 2.31 indicates that the majority of consumers not interviewed were either in a SNF or deceased. The total percent of NIs for the *2008 Mover Study* (9.6%) was similar as reported in the *2007 Mover Study* (9.3%). However, the distribution of the consumers among the NI categories showed the following notable differences:

- A 4.4% increase in the percent of consumers residing in a SNF was reported for the *2008 Mover Study* (29.9%) as compared to the *2007 Mover Study* (25.5%).
- A 2.2% decrease in the percent of consumers in jail or prison was reported for the *2008 Mover Study* (7.6%) as compared to the *2007 Mover Study* (9.8%).
- A 1.8% decrease in the percent of consumers returning to a DC was reported for the *2008 Mover Study* (7.2%) as compared to the *2007 Mover Study* (9.0%).

Each group within the NI category is described in further detail below.

Figure 2.31
Not Interviewed Categories



Deceased

The visitors found that 78 (29.5%) of the NI consumers had died since the last evaluation interview period. The ages of the deceased ranged between 26 and 86 years of age with an average age of 53.8 years. More males (64.1%) than females (35.9%) died this past year. The breakdown of ethnicities was as follows: 77.9% Caucasian, 14.3% Hispanic, 5.2% African American, 1.3% Asian, and 1.3% identified as other. With respect to the level of intellectual disability, 2.6% had no diagnosis of an intellectual disability, 10.4% were diagnosed with a mild intellectual disability, 7.8% were diagnosed with a moderate intellectual disability, 18.2% were diagnosed with a severe intellectual disability, and 61.0% were diagnosed with a profound intellectual disability.

The research staff attempted to verify the cause of each death with the RC service coordinator. Table 2.8 shows that the majority of NI consumers died from pneumonia and respiratory related complications.

Table 2.8
Cause of Death Summary

Cause of Death	*Number of Consumers*	*Percent of Consumers*
Pneumonia and respiratory related complications	17	21.8
Cardiopulmonary arrest	8	10.2
Choking	3	3.8
Unspecified ongoing health issues	3	3.8
Cancer	2	2.6
Diabetes-related complications	2	2.6
Seizure-related complications	2	2.6
Sudden Death Syndrome	2	2.6
Cerebral palsy-related complications	1	1.3
Excited delirium	1	1.3
Sleep apnea complications	1	1.3
Stroke	1	1.3
Information not available	35	44.8

Cases Closed

The cases of 19 (7.2%) of the NIs were closed. The ages of these consumers ranged from 12 to 68 years of age with an average age of 41.7 years. More males (78.9%) than females (21.1%) had their cases closed during the past year. Over half of the consumers were Caucasian (53.4%), followed by African American (33.3%), and Hispanic (13.3%). Just over 50% had been diagnosed with a mild to moderate intellectual disability, and approximately a quarter of the consumers had been diagnosed with a severe to profound intellectual disability. The remaining 25% had no diagnosis of an intellectual disability.

Of the closed cases, the majority of cases (84.2%) were closed by the RC. Reasons for closing a case cited by RC service coordinators were: file inactivity, the consumer moved out of state, or the whereabouts of the consumer was not known. The remaining cases (15.8%) were closed at the request of the consumer or the consumer's family.

Returned To A DC

This year 19 (7.2%) of the consumers returned to a DC. Of the consumers returning to a DC during the past year, twelve consumers were male (63.2%) and seven were female (36.8%). The majority of consumers returning to a DC were Caucasian (five consumers, 26.3%), two consumers (10.5%) were African American, one consumer (5.3%) was Hispanic, and the ethnicity of 11 consumers was not specified (57.9%). Three consumers had a diagnosis of mild intellectual disability, one consumer each had been diagnosed with a moderate, severe, or profound intellectual disability. Three consumers had not been diagnosed with an intellectual disability. The intellectual disability diagnosis of the remaining ten consumers was not specified. The most common reasons for returning to a DC were acts related to the criminal justice system, challenging behaviors, or health issues. One consumer preferred to be returned to a DC.

Acute Care Hospital

Sixteen (6.1%) consumers were in an acute care hospital. These consumers had an average age of 45.7 years and an age range of 22 to 71 years. More males (11 consumers; 68.8%) than females (five consumers, 31.2%) were in acute care hospitals. The majority of consumers in acute care hospital were Caucasian (seven consumers, 43.8%) and the remaining consumers were either African American (three consumers, 18.8%), Hispanic (three consumers, 18.8%), or specified as other (one consumer, 6.3%). The ethnicity of the remaining two consumers was not specified. Six consumers had been diagnosed with a mild or moderate intellectual disability and five consumers had been diagnosed with a moderate intellectual disability. Two consumers had not been diagnosed with an intellectual disability. The intellectual disability diagnosis of the remaining three consumers was not specified. The most common reason for hospitalization was respiratory related issues.

Psychiatric Hospital and Drug Rehabilitation Centers

Twenty-five (9.5%) consumers were found to be in psychiatric hospitals or drug rehabilitation centers. The average age was 40.2 years old with a range of 21 to 74 years. More males (16 consumers, 64.0%) than females (9 consumers, 36%) were in treatment. The majority of consumers in psychiatric hospitals or drug rehabilitation centers were African American (nine consumers, 36.0%) followed by Caucasian (seven consumers, 28.0%), Hispanic (five consumers, 20.0%), and Asian (one consumer, 4.0%). The ethnicity of three consumers was not specified (12.0%). Eighteen of the 25 consumers had been diagnosed with a mild intellectual disability with the remaining diagnosed with either a moderate (three consumers) or profound (one consumer) intellectual disability and three consumer had not been diagnosed with an intellectual disability. Most of these consumers were in a psychiatric hospital or locked psychiatric facility due to challenging behaviors and three consumers were in drug treatment.

Unable To Locate

Eight (3.0%) consumers were not located. Of the UTL consumers, four were male (50.0%) and four were female (50.0%). Four consumers (50.0%) were African American, one consumer (12.5%) was Native American, three consumers (37.5%) were not specified. One consumer had not been diagnosed with an intellectual disability, three consumers had been diagnosed with a mild intellectual disability, one consumer had been diagnosed with a moderate intellectual disability, and one was not specified. The intellectual disability diagnosis of the remaining two consumers was not specified. When the RCs were contacted the following reasons were given as to why the consumer could not be located: Homeless, ran away, or known to have moved into a residence but the location was not known.

Jail or Prison

Twenty (7.6%) of the NIs were in jail or prison at the time of the visit. Of those, 18 (90.0%) were in jail and two (10.0%) were in a state prison. The average age for the consumer in jail was 34.9 years and the average age of the two consumers in prison was 52 years. All incarcerated consumers were male. Sixty percent of the consumers were either African American (six consumers, 30.0%) or Hispanic (six consumers, 30.0%), and the remaining were Caucasian (three consumers, 15.0%), not specified (five consumers, 5.0%), or not known (four consumers, 20.0%). Twelve of the incarcerated consumers had been diagnosed with a mild intellectual disability, one consumer had no level of an intellectual disability assigned and seven were not specified. The reasons cited for incarceration were: not following court ordered drug treatment, drug-related offenses, robbery, arson, rape or attempted rape, assault, parole violations, and unspecified misdemeanors.

Skilled Nursing Facility

Seventy-nine (29.9%) consumers resided in a SNF during the past year. The average age for consumers residing in a SNF was 56.1 years with an age range of 22 to 80 years. Over half of these consumers were male (65.8%). The majority of the consumers were Caucasian (65.8%) followed by 15.2% Hispanic, 6.3% African American, 2.5% Asian, and 1.3% Pacific Islander. The ethnicity of seven consumers was not specified (8.9%). Two-thirds of the SNF consumers were diagnosed with a profound or severe intellectual disability and 15.2% were diagnosed with a mild or moderate intellectual disability. The remaining consumers had no intellectual disability (two consumers, 2.5%), an intellectual disability had not been diagnosed, or was not specified (15 consumers, 19.0%). Half of the consumers residing in a SNF had been placed for long term care. Reasons given for the SNF placement included burns, hospice care, tracheotomy, and hip replacement.

Declined to Participate

Fifty-one consumers for whom no interview data are available this year declined to participate (DTP) in the *2008 Mover Study* and 16 consumers requested to be permanently removed from the evaluation population. The average age for DTPs was 38.4 years and ranged in age from 16 to 80 years of age. More males (37.2%) than females (32.8%) declined this year. The reported ethnicities were as follows: 46.7% Caucasian, 21.3% African American, 21.3% Hispanic, 4.3% Native American, 2.1% Asian, and 4.3% not specified. With respect to the diagnosis of intellectual disability, 14.9% had no level assigned, 38.3% were diagnosed as mild, 12.8% were diagnosed as moderate, 4.3% were diagnosed as severe, 10.6% were diagnose as profound, and 19.1% were not specified. Consumers in the DTP group either personally declined to participate or their parents or house managers chose not to allow the consumer to participate.

CONCLUSIONS

For the TCP, the *2008 Mover Study* found:

- The majority of consumers living in the community were satisfied with their residence, enjoyed the people working in their residence and day program, made choices for themselves, had people in their lives helping them go out into the community, and were learning to live more independently.
- The majority of consumers were rated in good to excellent health.
- The majority of consumers were working on independent living and self-care skills.
- On average, the majority of consumers participated in community activities twice a month.
- The majority of consumers received quality health care and mental health services.
- Even though the qualities of services were rated high, access to dental care continued to be a concern for consumers and advocates. Lack of anesthesia and insurance (Medi-Cal and Medicare) were identified as the most common issues responsible for difficulties in access to dental care.
- Advocates were more satisfied with community living than living in a DC. Further, even advocates who expressed initial feelings of apprehension reported higher satisfaction ratings for community living.
- The majority of advocates were satisfied with the services received in the community, however some advocates expressed concerns regarding communication with the staff; dissatisfaction with the RC services or service coordinator; high staff turnover; diet and nutrition; and access to dental care.

While the majority of findings reported this year were similar to those reported in the *2007 Mover Study*, there were a few notable differences:

- The current evaluation found that 2.6% of the TCP reported a weight gain of more than ten percent, which is a decrease from the *2007 Mover Study* where 4.4% of consumers reported a gain of more than ten percent
- A higher proportion of consumers reported a diagnosis of osteoporosis (15.2%) than was reported in the *2007 Mover Study* (11.1%).
- A 4.2% increase in the percent of consumers residing in a community residence with six or fewer beds was observed in the current evaluation (83.9%) as compared to the *2007 Mover Study* (79.7%).
- The current evaluation found that 14.3% of the consumers reported having no close friends, which was lower than observed in the *2007 Mover Study* (17.4%).
- Finally, the following differences in the distribution of consumers across the NI categories were found: (1) a 4.4% increase in the percent of consumers residing in a SNF was reported for the *2008 Mover Study* (29.9%) as compared to the *2007 Mover Study* (25.5%), (2) a 2.2% decrease in the percent of consumers in jail or prison was reported for the *2008 Mover Study* (7.6%) as compared to the *2007 Mover Study* (9.8%), and (3) a 1.8% decrease in the percent of consumers returning to a DC was reported for the *2008 Mover Study* (7.2%) as compared to the *2007 Mover Study* (9.0%).

Chapter

3

The Continuing Original Community Population

Chapter Three

THE CONTINUING ORIGINAL COMMUNITY POPULATION

Over the past six years CSUS has tracked and monitored the consumers who relocated from a DC into the community as defined in the Welfare and Institutions Code Section 4418.1(b). The *2003 Mover Study* started with a list of 2,320 consumers provided by DDS, and this year, the *2008 Mover Study* collected data on 1,743 consumers from that original cohort, referred to in this evaluation as the Original Community Population (OCP). Of these 1,743 consumers, 94.9% (n=1,654) have lived in the community uninterrupted since the initiation of the CSUS Mover Study in 2002-03. The remaining 5.1% (n=89), while initially interviewed in the community in 2002-03, have been in and out of community residences over the past five years due to any one of the following circumstances: returned to a DC; hospitalized in an acute care facility, psychiatric hospital, or drug rehabilitation center; resided in a SNF; declined to participate, was unable to be located, or was incarcerated in a prison or county jail.

Figure 3.1 shows how the OCP has changed since the *2003 Mover Study*. Between the *2003 Mover Study* and the *2007 Mover Study*, 216 OCP consumers had died, 72 consumers had their cases closed, 49 consumers had returned to a DC and have not re-entered the community, 12 consumers were incarcerated in a state prison, and 15 consumers asked to be removed from the *Mover Study*, which means a cumulative total of 15.7% of the OCP has been permanently assigned an inactive status in the CSUS Master Database. Additionally, a cumulative total of 3.8% of the OCP (89 consumers) were assigned an inactive status at one time (reasons listed above) and have since re-entered the study. Finally, Figure 3.1 shows that at the beginning of this year's evaluation, 1,654 consumers (71.3%) of the OCP have been continuously interviewed in the community since the *2003 Mover Study*. This chapter takes a longitudinal look at how this group of 1,654 consumers has changed over the last six years. This group of consumers who have continuously been interviewed in the community since CSUS began the *Mover Study* in 2002 will be referred to as the Continuing OCP.

The Continuing OCP is an important subset of consumers because it is the only group that can provide a longitudinal overview of the key variables of interest as identified in discussions with DDS and stakeholders in the community. In addition to describing the demographics of the Continuing OCP, this chapter examines how the following variables change over time: (1) CDER scores (i.e., SDD and CB composite scores), (2) general health, (3) hospital admissions, (4) emergency room visits, (5) residence types, (6) community activities, (7) access and quality of health care in the community, (8) mental health crises, (9) consumer involvement with the criminal justice system as a perpetrator or a victim, and (10) consumer satisfaction.

CONSUMER CHARACTERISTICS

In this section, the following Continuing OCP demographics are examined[35]: Age, sex of consumers, ethnicity, diagnoses of intellectual disability, CDER composite scores, and general health ratings.

Consumer Demographics

Age, Sex of the Consumer, and Ethnicity

The mean age for the Continuing OCP this year was 49.2 years[36] with a range of 15 to 89 years. Figure 3.2

[35] The Continuing OCP accounts for 70.0% of the TCP so although the demographics slightly differ between the Continuing OCP and the TCP, these differences are negligible.

[36] Descriptive statistics for the Continuing OCP are contained in Appendix E.

Figure 3.1
History of the OCP
(N = 2,320 Consumers)

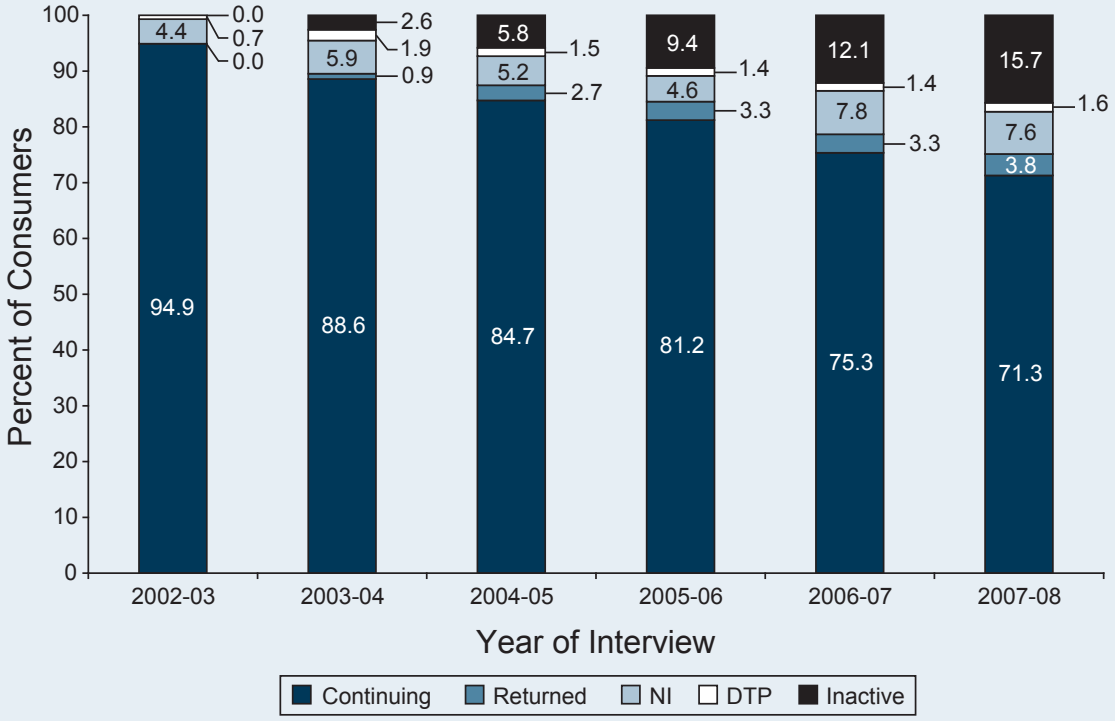
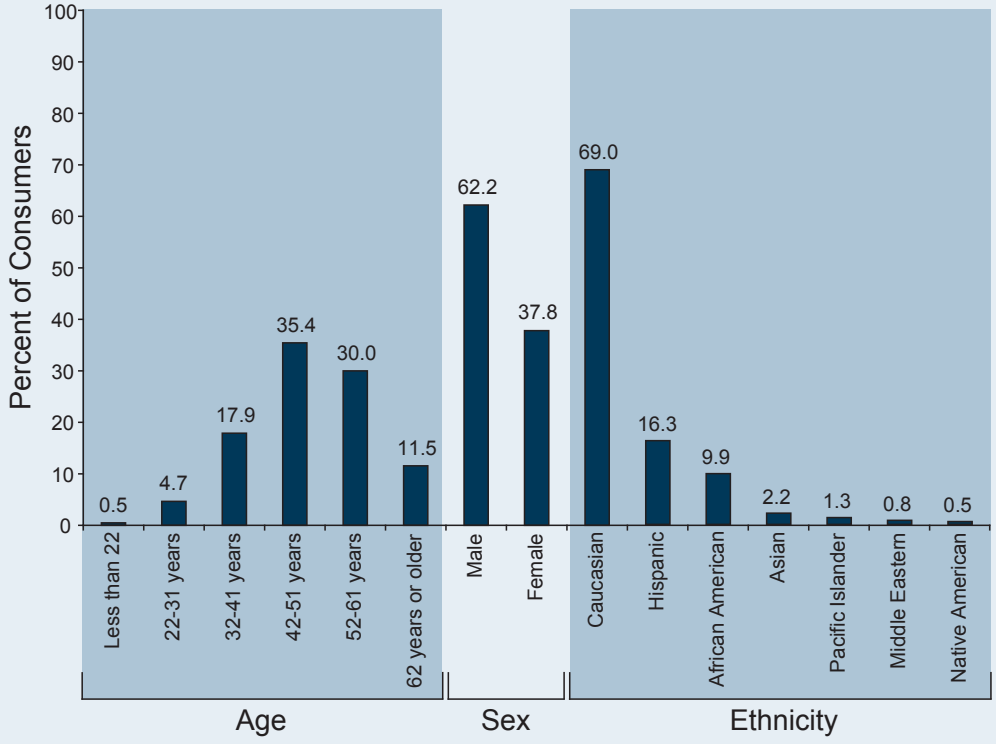


Figure 3.2
Continuing OCP Demographics

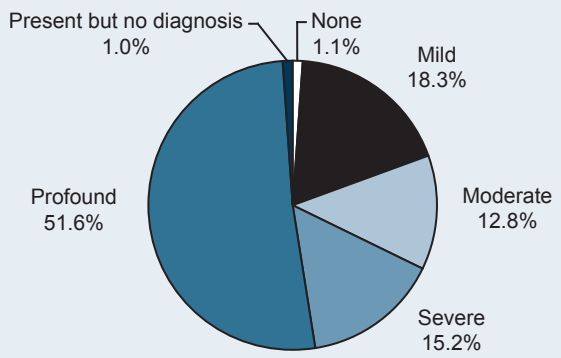


indicates that three quarters (76.9%) of the consumers were over 42 years of age. Additionally, just under two-thirds of the Continuing OCP was male (62.2%). The largest ethnicity group for the Continuing OCP was Caucasian, followed by Hispanic, African American, Asian, Pacific Islander, Middle Eastern, and Native American, listed in order of prevalence.

Diagnoses of Intellectual Disability

Two-thirds of the Continuing OCP was reported to have a diagnosis of severe or profound intellectual disability (Figure 3.3) and just under one third had a diagnosis of mild or moderate intellectual disability. The remaining 2.1% of the Continuing OCP consumers had no diagnosis of intellectual disability.

Figure 3.3
Continuing OCP Diagnoses of Intellectual Disability



Client Development Evaluation Report (CDER)

As described in Chapter 2, CDER composite scores were developed for the skills demonstrated in daily living (SDD) and challenging behaviors (CB). Higher SDD composite scores represent higher levels of functioning and higher CB composite scores represent more challenging behaviors as defined by the CDER portion of the *Residential Survey*. The composite scores have been categorized into the following groups:

SDD Composite Scores

- Low – composite scores between 11 and 27.
- Moderate – composite scores between 28 and 43.
- High – composite scores between 44 and 60.

CB Composite Scores

- Low – composite scores between 6 and 14.
- Moderate – composite scores between 15 and 23.
- High – composite scores between 24 and 30.

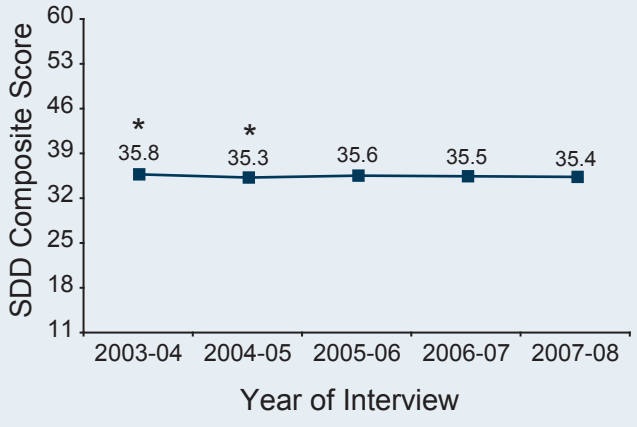
Figure 3.4 shows the distribution of the SDD composite score categories over the past five years[37]. Although there have been slight variations across the years with respect to SDD composite score categories, at least 40.0% of the Continuing OCP consumers had moderate SDD composite scores. The greatest proportional difference in the moderate category was observed between interview years 2005-06 and 2006-07.

Further analyses were used to evaluate the statistical differences in average SDD composite scores over the past five years (Figure 3.5). A repeated measures one-way analysis of variance (ANOVA)[38] indicated there was a statistical difference in the average SDD composite scores between evaluation years[39]. Specifically, the average SDD composite score for 2003-04 was significantly higher than the average SDD composite score observed in 2004-05. However, the average SDD composite scores over the past four years have not significantly changed.

[37] The response choices for the SDD items in the 2002-03 *Residential Survey* were different and therefore are not comparable or appropriate for comparison.
[38] A statistical method used to determine whether two or more means are significantly/statistically different.
[39] $F(4,1519) = 4.3$, $p<.01$.

Figure 3.4
Continuing OCP SDD Composite Score Categories

Figure 3.5
Continuing OCP Average SDD Composite Scores



* Significant differences at $p<0.01$

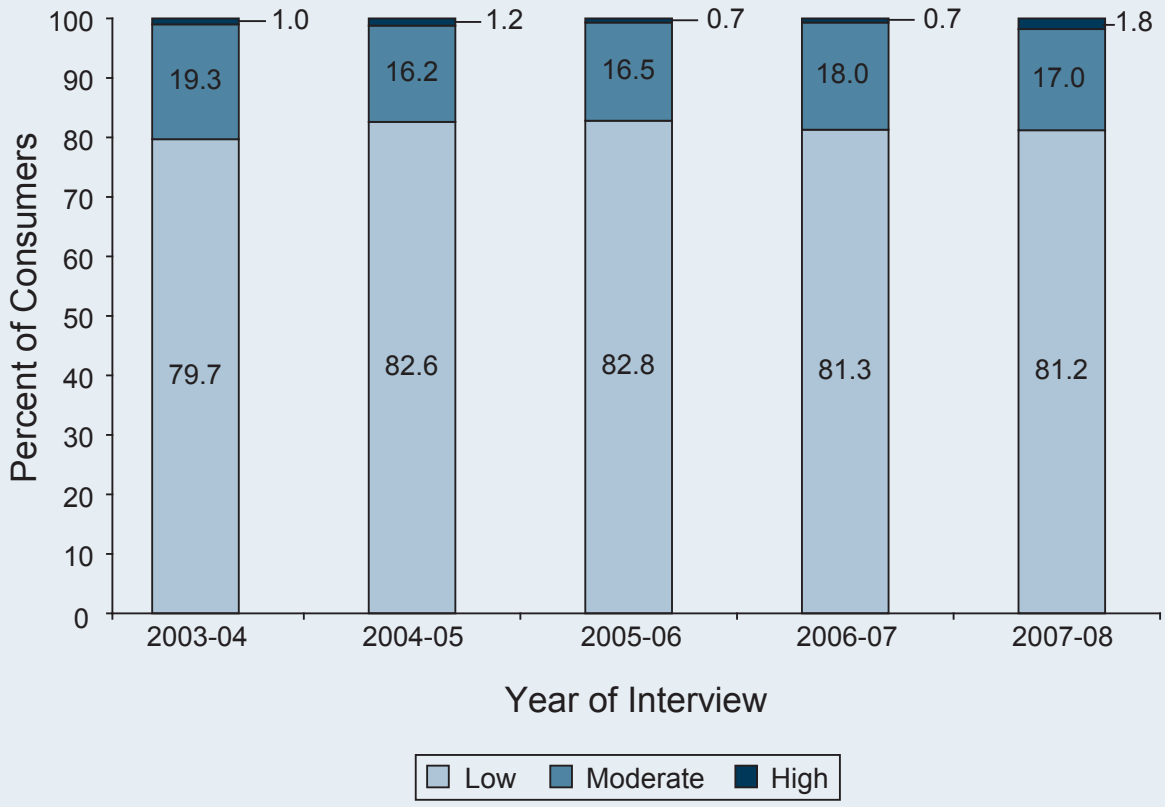
Figure 3.6 shows the distribution of the CB composite score categories over the past five years[40]. Again, slight variations were observed across years with the largest proportional difference observed between interviews conducted in 2003-04 and 2004-05; a 3.1% change in the number of consumers with moderate CB composite scores.

A repeated measures one-way ANOVA was used to more closely examine the average CB composite scores over time. The results indicated there was a significant difference in average CB composite scores between evaluation years.[41] Specifically, the average

[40] The response choices for the CB items in the 2002-03 Residential Survey were different and therefore are not appropriate for comparison.

[41] $F(4, 1595) = 7.4$, $p<.01$.

Figure 3.6
Continuing OCP CB Composite Score Categories

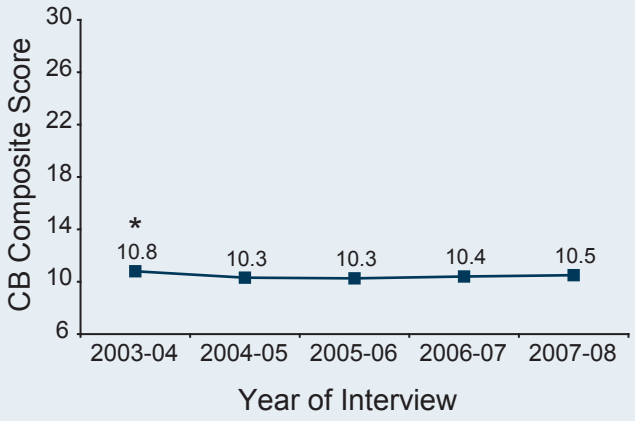


CB composite score for 2003-04 was significantly higher than all other years. Data collected between 2004-05 and 2007-08 did not significantly differ, which means the average CB composite score dropped (less challenging behaviors) in 2004-05 and have not changed for the Continuing OCP consumers over the past four years (Figure 3.7).

Health

This section includes data for the Continuing OCP consumers from the past six years describing the general health ratings, visits to the emergency room for a medical emergency, and visits to the emergency for a non-emergency issue.

Figure 3.7
Continuing OCP Average CB Composite Scores



* Significant differences at $p<0.01$

General Health Ratings

Figure 3.8 shows that the proportion of consumers rated in good to excellent health has fluctuated slightly over the years but, in general, has decreased by 2.6% between the interviews conducted in 2002-03 and 2007-08. In particular, the percentage of consumers rated to be in excellent health has dropped considerably. Since health was measured on a four-point scale with higher numbers representing better health, a repeated measures one-way ANOVA was used to examine the difference in average health ratings over the past six years. The results indicated that consumers in the Continuing OCP had significantly different health ratings between evaluation years[42]. Specifically, Continuing OCP consumers had significantly higher general health ratings during 2002-03 (M^{43} = 3.1) than all other years (M = 3.0 for all other evaluation years). This significant difference in health ratings may be indicative of the increasing age of the population; however, it should be noted that following an initial drop in the general health ratings between 2002-03 and 2003-04, the ratings have remained relatively stable over the past five years with most Continuing OCP consumers' health rated in the good to excellent range.

Overnight Hospital Stays and Emergency Room Visits

The average number of overnight hospital stays and emergency room visits for the Continuing OCP was less than one visit per consumer for all CSUS evaluation years. Table 3.1 and Figure 3.9 show (1) the number of consumers (n) who required medical treatment in a hospital or emergency room and (2) the average number of visits for only those consumers who required medical treatment. Since it was not the same consumers that experienced visits to the hospital or emergency room each year, an independent-groups one-way ANOVA was used to examine the statistical differences in the average number of overnight hospital stays, emergency room visits for medical emergencies, and emergency room visits for non-emergency medical issues across the past six years. For the Continuing OCP the analysis indicated:

- Hospital stays were significantly higher during 2003-04 than all other years[44].
- Emergency room visits for medical emergencies were significantly higher during 2003-04 than 2004-05, 2005-06, and 2006-07.[45] No other years significantly differed.
- Emergency room visits for non-emergency issues were significantly lower in 2007-08 than 2003-04 and 2006-07.[46] No other years significantly differed

LIVING ENVIRONMENT

This section examines the types of residences the Continuing OCP consumers have lived in over the past six years and the number of moves they have experienced within the community.

Living Situation

As shown in Figure 3.10, more than 84% of the Continuing OCP consumers have lived in a CCF or ICF with six or fewer beds over the past six years. There was a slight decline (1.6%) in the percentage of consumers residing in one to six bed facilities between 2002-03 and 2005-06. However, there has been a gradual increase (0.9%) over the past two years. In 2007-08, 85.1% of the Continuing OCP resided in CCFs with one to six beds. Furthermore, there has been an approximate 1.1% increase in the number of Continuing OCP consumers living independently with or without independent ILS or SLS since 2002-03.

Residence History

In addition to the history of residence types, the number of times the Continuing OCP moved within the community was examined. These data were taken from the address information at the time of interview for each of the last six years. While it is possible that a consumer could move

[42] F(5, 1617) = 17.4, p<.01.
[43] M = Average.
[44] F(5, 1024) = 9.5, p<.01. Tukey HSD post hoc analyses were used to assess pairwise comparisons.
[45] F(5, 1856) = 3.1, p<.01. Tukey HSD post hoc analyses were used to assess pairwise comparisons.
[46] F(5, 504) = 3.9, p<.01. Tukey HSD post hoc analyses were used to assess pairwise comparisons.

Figure 3.8
Continuing OCP General Health Ratings

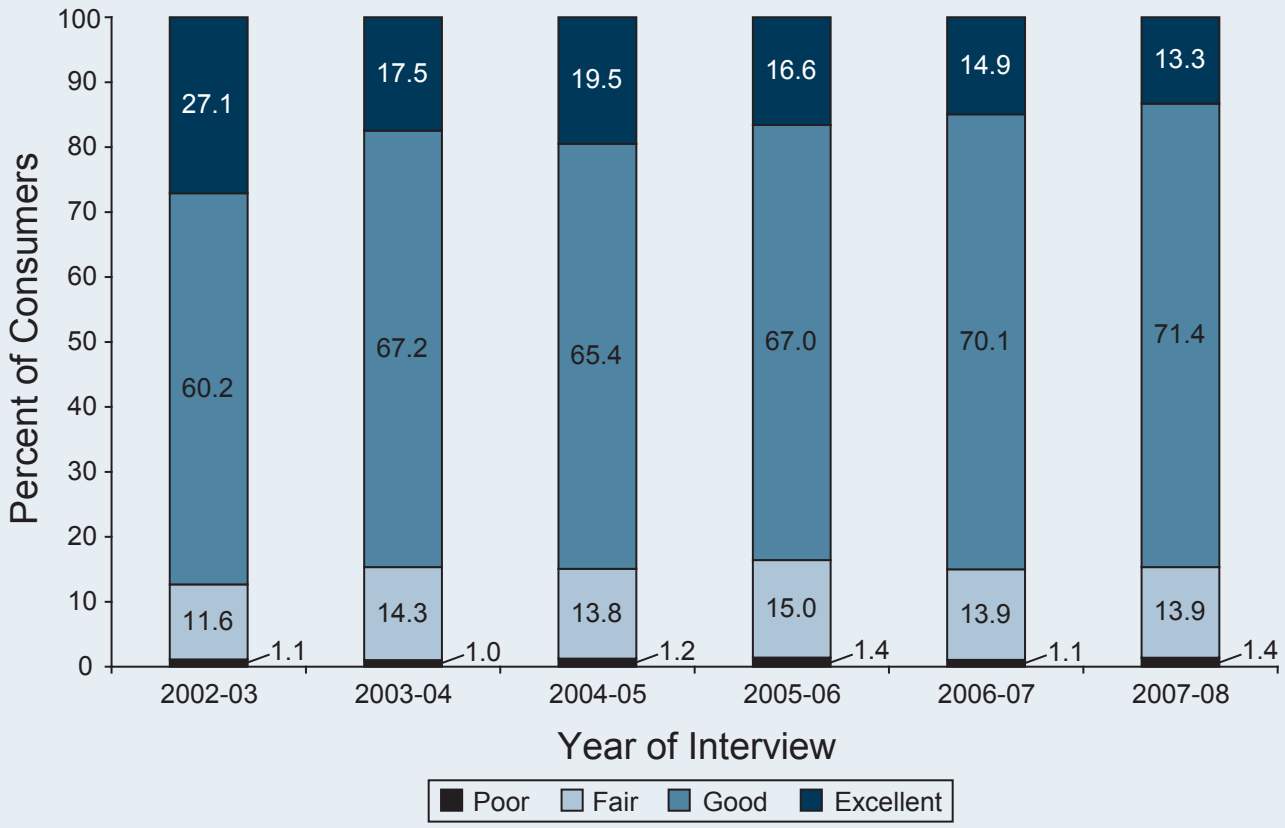
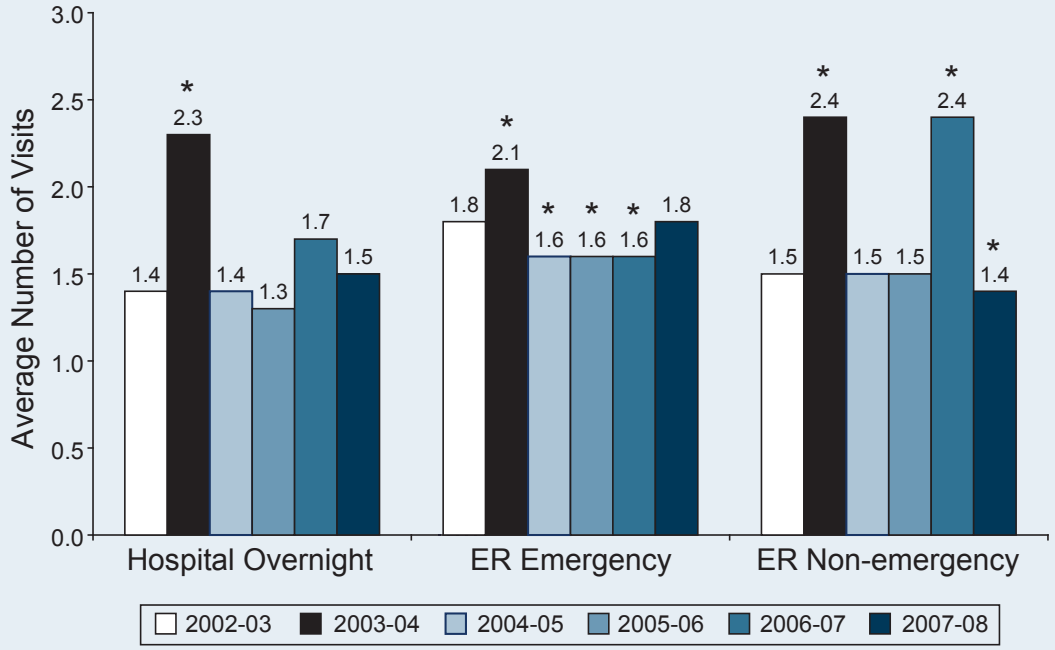


Table 3.1
Continuing OCP Overnight Hospital Stays and Emergency Room Visits

	Overnight Hospital Stays		ER Emergency Visits		ER Non-Emergency Visits	
Year of Interview	*n*	*Average*	*n*	*Average*	*n*	*Average*
2002-03	185	1.4*	356	1.8	39	1.5
2003-04	162	2.3*	305	2.1*	102	2.4*
2004-05	160	1.4*	284	1.6*	78	1.5
2005-06	178	1.3*	298	1.6*	92	1.5
2006-07	155	1.7*	299	1.6*	99	2.4*
2007-08	185	1.5*	315	1.8	95	1.4*

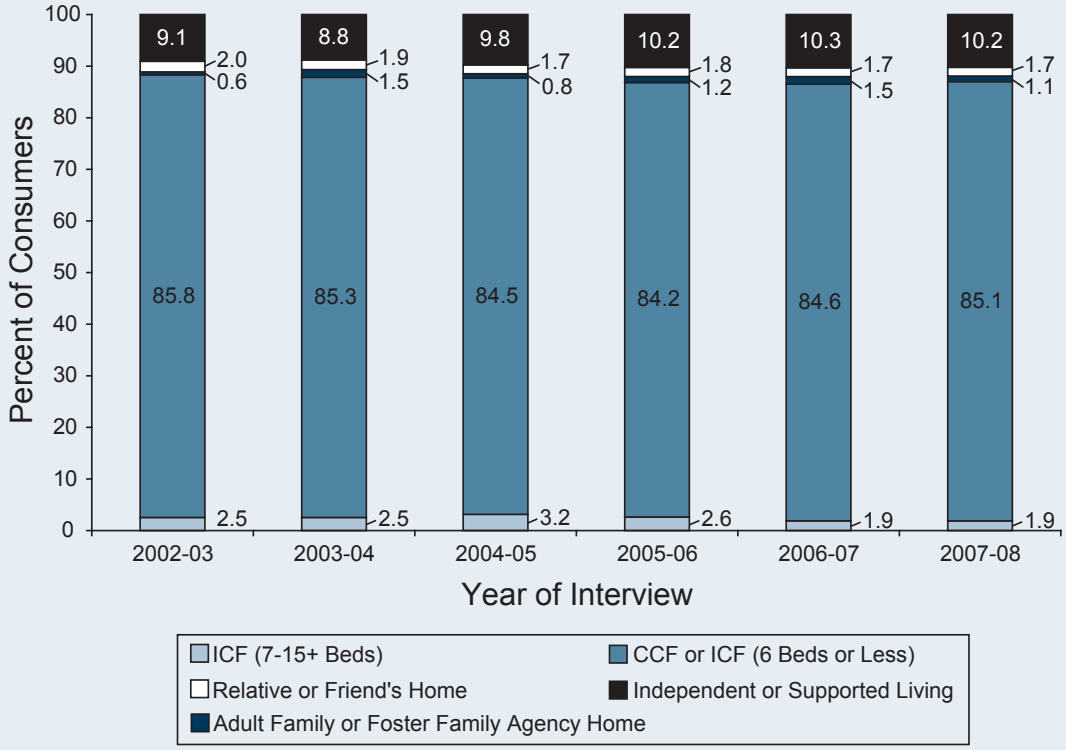
*Significant differences at p<.01.

Figure 3.9
Continuing OCP Overnight Hospital Stays and Emergency Room Visits



* Significant differences at $p<0.01$

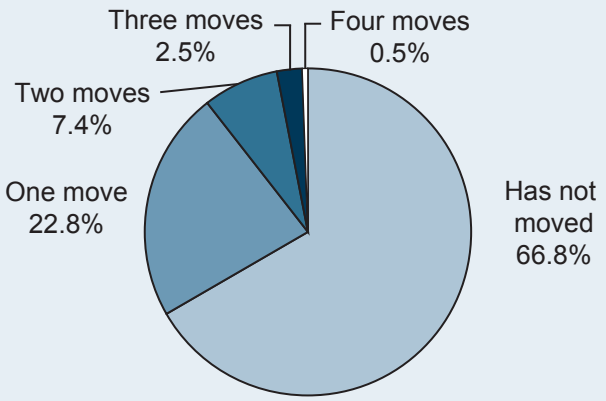
Figure 3.10
Continuing OCP Community Living Situation



between data collection time points, these data provide at minimum a conservative estimate of movement within the community for the Continuing OCP consumers.

Figure 3.11 shows nearly 97% of the Continuing OCP consumers moved twice or less over the past six years with the majority of consumers (66.8%) indicating no change in residence. The remaining 3.0% of Continuing OCP consumers moved three to four times during the last six CSUS evaluation years. The data indicated that for the majority of the consumers that moved three to four times, the move was requested by the consumer or the RC because the consumer was looking for better housing and/or a better neighborhood. Further, four of the nine consumers who moved four times, moved from a CCF into independent living and then returned to a CCF. The requests for a change in residence to a more structured environment (i.e., from independent living to a CCF) had been made by either the RC or the consumer's family due to a decline in health or adaptive behaviors, or an increase in challenging behaviors.

Figure 3.11
Continuing OCP Residence History



COMMUNITY INTEGRATION AND SERVICES

The following section discusses data collected regarding the community activities, services received in the community, crises, and involvement with the criminal justice system.

Community Experiences

The community experiences examined were errands, social outings, restaurants, volunteer work, and parks and other outdoor recreation. The first year of the CSUS *Mover Study* did not ask the same questions about community activities that the later years did and have therefore been omitted from this analysis. Thus, only the past five years of data are presented in this section

Errands

Figure 3.12 shows that the frequency of consumers in the Continuing OCP participating in errands in the community has varied over the years. The percentage of consumers who were reported to be unable to participate in community errands increased during 2005-06 but declined this year to the lowest rate (19.6%) observed over the five evaluation years. At least weekly community errand participation was the highest in 2003-04 (48.7%) with a steady decline until 2005-06 (42.2%). Over the past two evaluation years there has been a slight increase in at least weekly participation (45.3% in 2006-07 and 43.6% in 2007-08).

Social Outings

Social outings include such activities as going to church, parties, museums, and shopping malls. Figure 3.13 shows that the percentage of Continuing OCP consumers reported to be unable to participate has overall declined from 2003-04 to 2007-08 by 5.7%. As for consumers participating in social outings daily or at least once a week, there was an initial decline of 3.3% between 2003-04 and 2004-05, however there was an increase of 2.5% in 2005-06 which has remained relatively constant over the past three years. Interviews conducted this year

Figure 3.12
Continuing OCP Errands in the Community

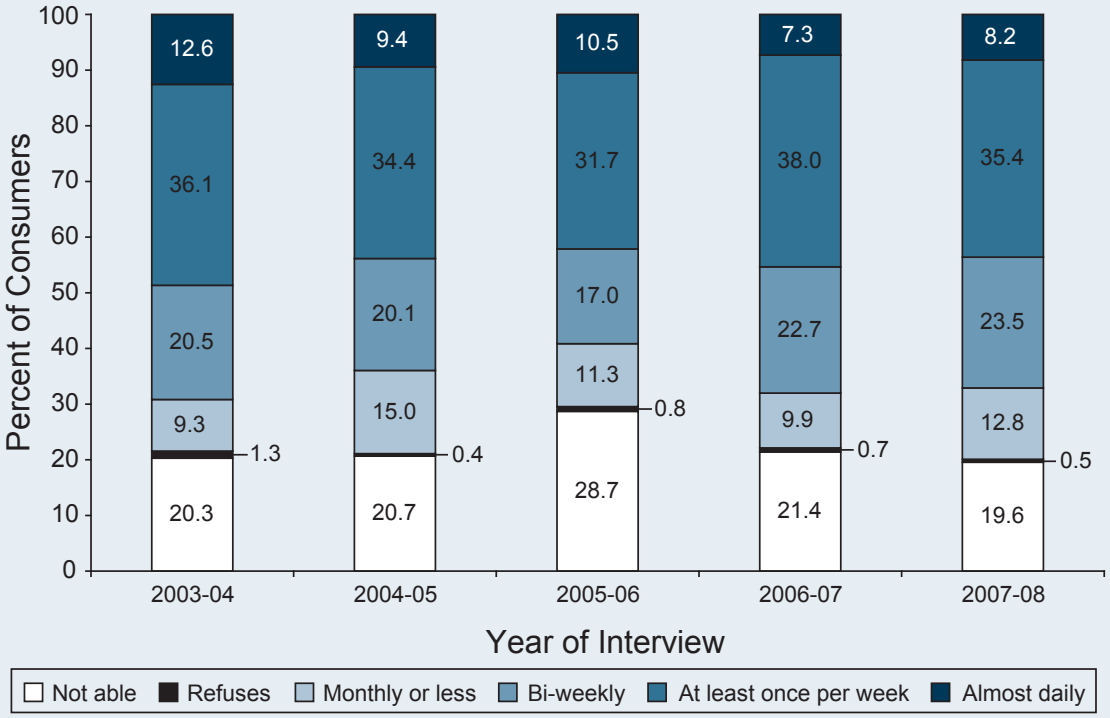
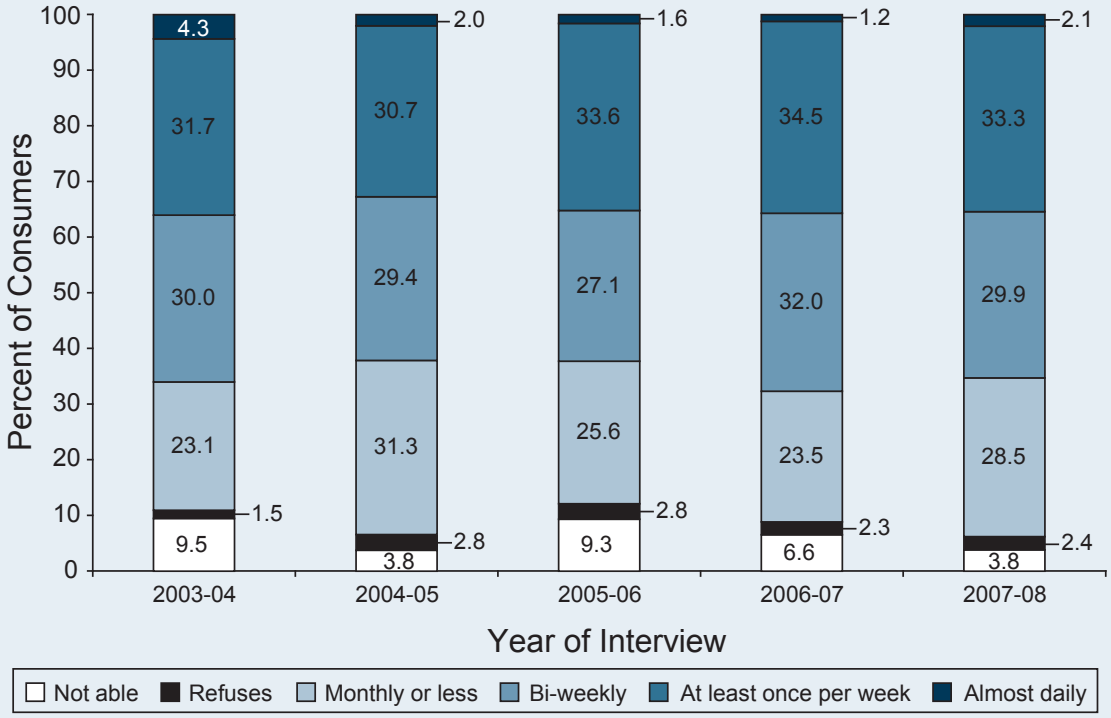


Figure 3.13
Continuing OCP Social Outings in the Community



indicated that just over one third of the Continuing OCP consumers participated at least weekly in a social outing. This year's data further showed that approximately 65% of the Continuing OCP participated in a social outing at least once a month.

Restaurants

The percentage of Continuing OCP consumers reported as unable to go out to a restaurant to eat has fluctuated over the years as shown in Figure 3.14. The percentage of consumers who participated monthly or less also fluctuated. In contrast, those who go out to eat bi-weekly accounted for approximately 30% of the Continuing OCP over the past evaluation years. Also, the percentage of consumers who went out to eat at least weekly or daily has remained around a third throughout the CSUS evaluation years.

Volunteer Work

Each year the overwhelming majority of Continuing OCP consumers were reported to be unable to participate in volunteer work with the percentage increasing over the past five years to the current 95.9% (see Figure 3.15). A steady decline was also observed for consumers who participated bi-weekly or more in volunteer work from 7.5% in 2003-04 down to 2.0% for the current evaluation.

Park or Other Outdoor Recreation

The percentage of Continuing OCP consumers considered unable to participate in park and other outdoor recreational activities increased threefold from 1.1% in 2003-04 to 4.7% in 2005-06 (see Figure 3.16). Since then there has been a slight decline in the consumers considered unable to participate down to 3.1% this past year. While there was a slight decrease in the percentage of consumers who participated at least weekly in park activities, approximately 45% of the consumers over the past two evaluation years have attended parks or other outdoor recreational activities weekly or almost daily.

Community Health Care

This section discusses Continuing OCP consumer data collected over the past six years regarding the access to and quality of health care services received in the community.

Access to Primary Medical Care

Figure 3.17 indicates that over the past six years, more than 94.0% of the consumers reported that primary medical care was at least average to obtain. There was a peak of access to primary medical care in 2005-06 with 97.1% of the Continuing OCP consumers reporting access as average or better, which is slightly lower than this year's evaluation showing 96.7% of the consumers reporting similar access ratings. Given the rise in the ease of access to primary medical care, there has been a corresponding decrease in the percentage of consumers reporting difficulties in finding primary care over the past six years.

Access to Specialist Care

Figure 3.18 shows that access to specialist care was at least average for 58.3% of the Continuing OCP in 2002-03. Since then, there has been a 36.5% overall increase in the above average access ratings between 2002-03 and 2007-08. This year 94.8% of the Continuing OCP consumers rated the access to specialist care as average or above.

Access to Dental Care

Since the *2005 Mover Study* access to dental care has been an increasing issue of concern. Figure 3.19 shows the decline in positive dental care access ratings over the past six years. Of particular note is that the percentage of Continuing OCP consumers rating the access to dental care as difficult or very difficult has more than doubled between 2002-03 (7.3%) and 2007-08 (15.4%).

Figure 3.14
Continuing OCP Restaurant Visits

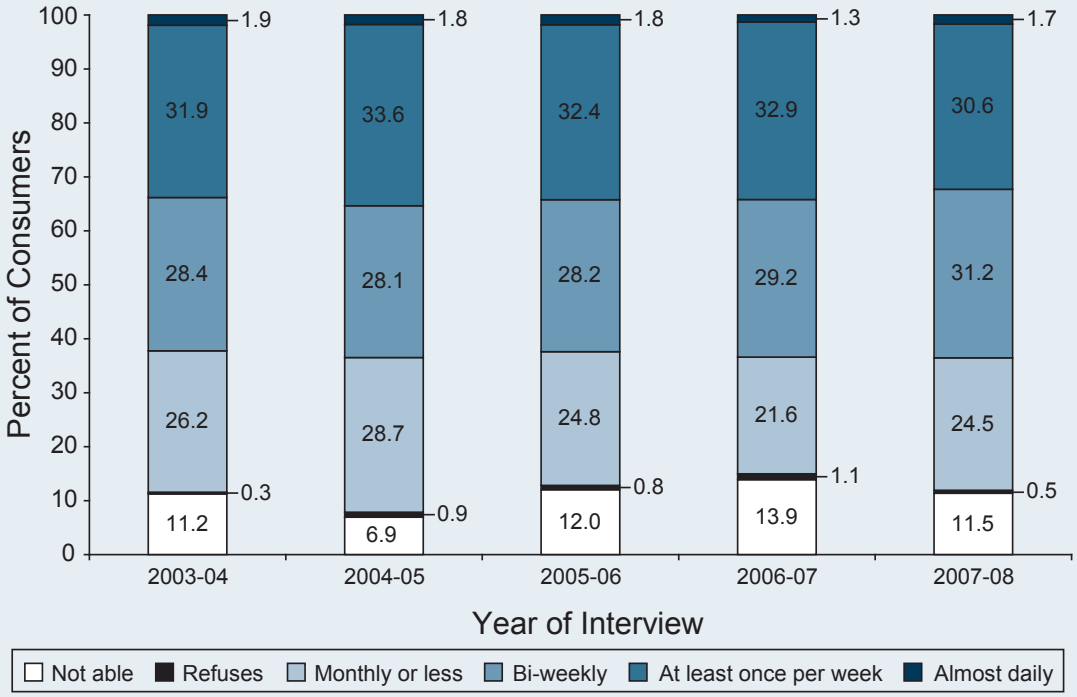


Figure 3.15
Continuing OCP Volunteer Work

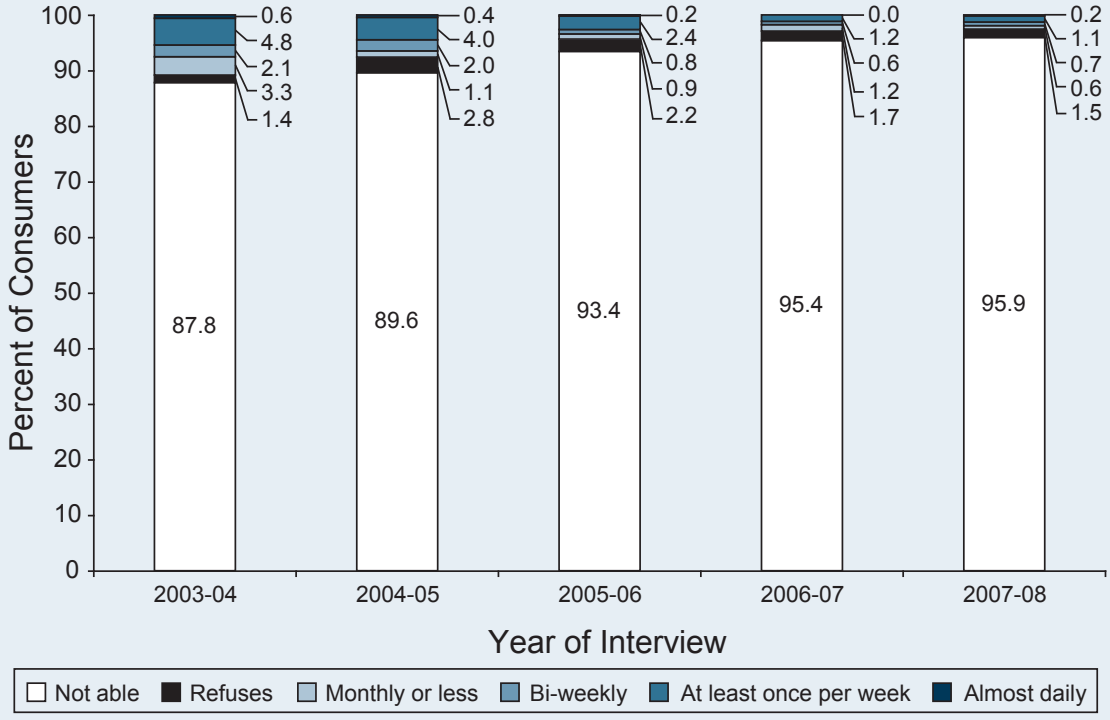


Figure 3.16
Continuing OCP Park and Other Outdoor Recreation

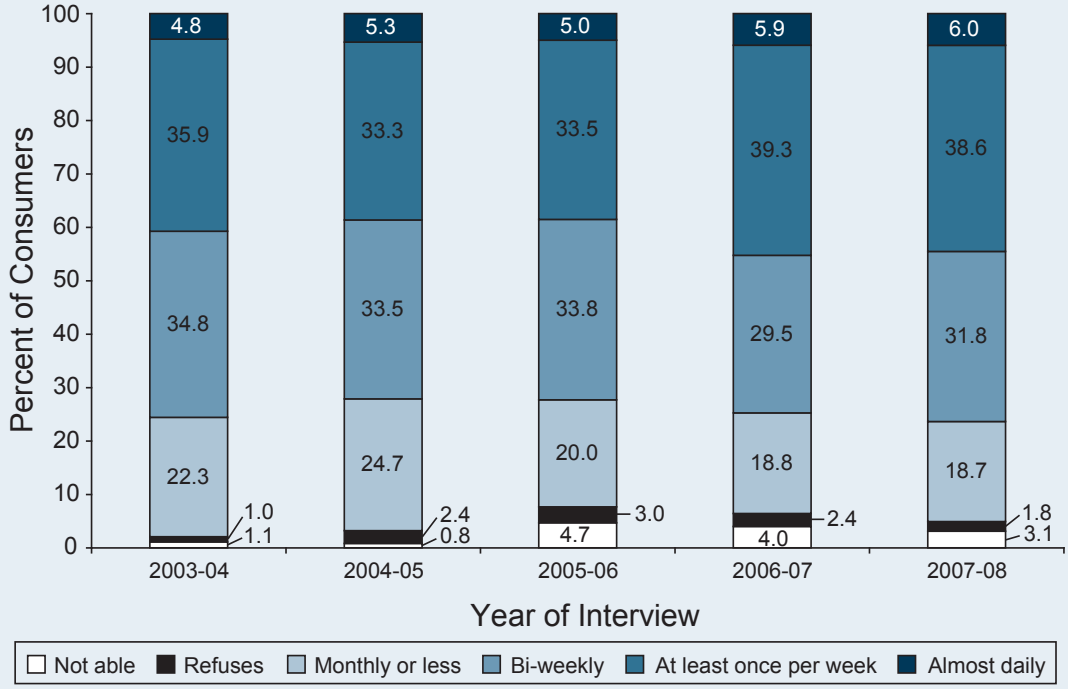


Figure 3.17
Continuing OCP Access to Primary Medical Care

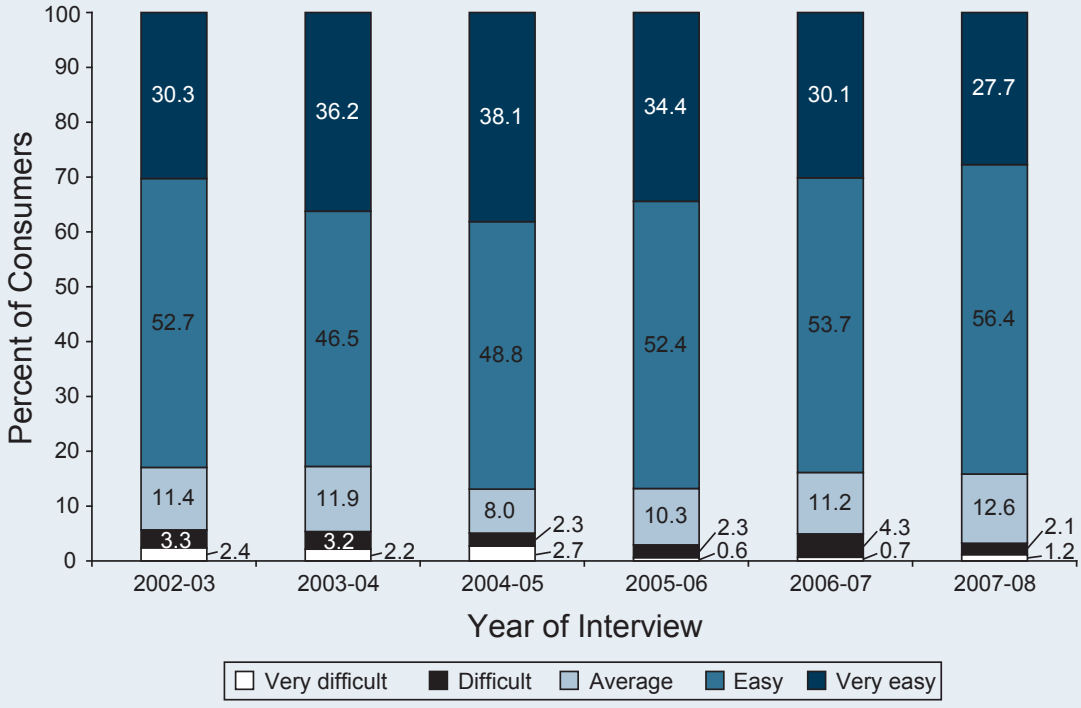


Figure 3.18
Continuing OCP Access to Specialist Care

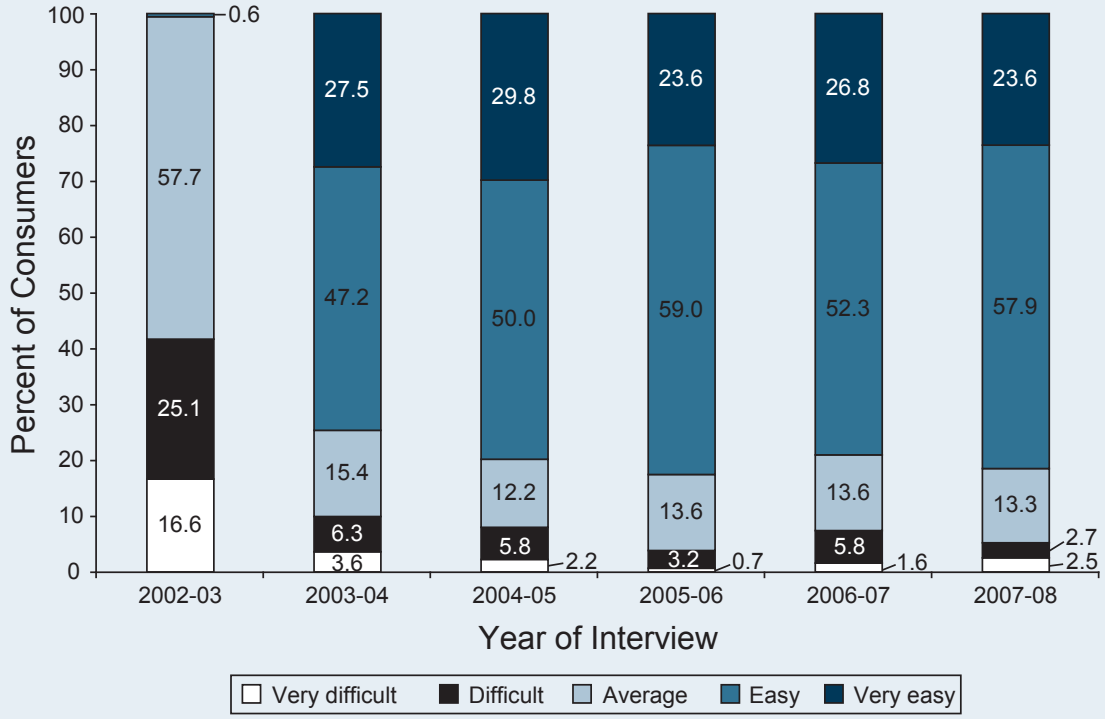
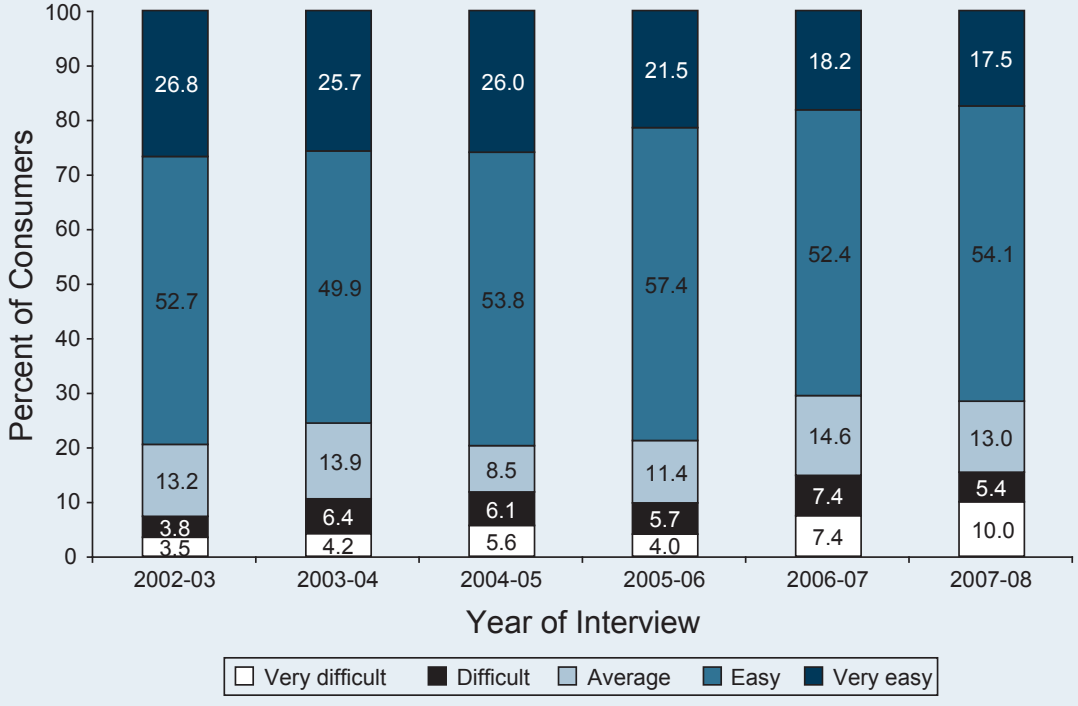


Figure 3.19
Continuing OCP Access to Dental Care



Quality of Medical Care

Irrespective of the access to primary medical care, specialist care, or dental care, the quality ratings of health services have remained exceptionally high over the past five years[47] (Figure 3.20). Nearly 99% of the Continuing OCP consumers have consistently rated health care as average or satisfactory. One exception were quality ratings reported in 2004-05 where 2.3% of consumers rated specialist care as being of lower than average or satisfactory quality. This has since gone down to 0.4% in 2007-08.

Mental Health

Crisis episodes examined in this section include: physical restraints, chemical restraints, nights spent away from residence due to a crisis, harm to self, and suicide attempts. An independent-groups one-way ANOVA was used to analyze the frequency of crisis episodes across years for consumers in the Continuing OCP. No significant differences were found for the number of incidents per consumer across the evaluation years[48]. Figure 3.21 shows the percentage of Continuing OCP consumers who experienced each type of crisis by year of interview[49]. In general, the percentage of consumers experiencing a crisis has declined for each crisis type, with the lowest percentages observed in this year's evaluation.

Legal Concerns

This section examines the Continuing OCP consumers' involvement with the criminal justice system as perpetrator of a crime or as a victim.

Figure 3.22 shows an overall decline in the percentage of consumers involved with the criminal justice system as a perpetrator or a victim between 2002-03 and 2007-08. The highest percentage of consumers reported to have been involved in criminal activity or to have been a victim of a crime was observed during interviews conducted in 2002-03. The lowest percentages of consumers reported to have criminal justice system involvement as a perpetrator were found in data collected in 2006-07 and as a victim in 2005-06.

CONSUMER SATISFACTION

Consumer satisfaction was analyzed by evaluating five items from the consumer survey portion of the *Residential Survey*. The items were: (1) Are you happy most of the time, (2) Do you like living in your home, (3) Do you like the people who help you at home, (4) Do you like going to your day program, and (5) Do you like the people who help you at the day program. Consumer satisfaction was evaluated only for those consumers who responded to a given item each evaluation year[50].

Figure 3.23 shows the percent of Continuing OCP consumers who responded yes to the individual items. As indicated, there has been little variation in consumer satisfaction for each of the five items over the past five years; however:

- The highest percentage of consumers responding yes to feeling happy most of the time was observed during 2007-08 (85.3%).
- The highest percentage of consumers responding yes to liking their current residence was observed during 2007-08 (86.8%).
- The highest percentage of consumers responding yes to liking the people that help them in their residence was observed during 2006-07 (92.3%).
- The highest percentage of consumers responding yes to liking their day program was observed during 2004-05 (92.2%).
- The highest percentage of consumers responding yes to liking the people who help them at their day program was observed during 2004-05 (93.7%).

[47] Quality ratings were not asked during interviews conducted in 2002-03.

[48] Physical restraints: $F(5, 236) = 0.9$, $p>.05$; Chemical restraints: $F(5, 163) = 0.7$, $p>.05$; Nights away: $F(5, 196) = 0.7$, $p>.05$; Harm to self: $F(4, 337) = 0.6$, $p>.05$; and suicide attempts: $F(4, 44) = 1.9$, $p>.05$.

[49] Harm to self and suicide attempts were not asked in the *2002-03 Residential Survey*.

[50] Consumer survey items for Interviews conducted in 2002-03 had different response options and are therefore not appropriate to be included in longitudinal comparisons.

Figure 3.20
Continuing OCP Quality of Medical Care

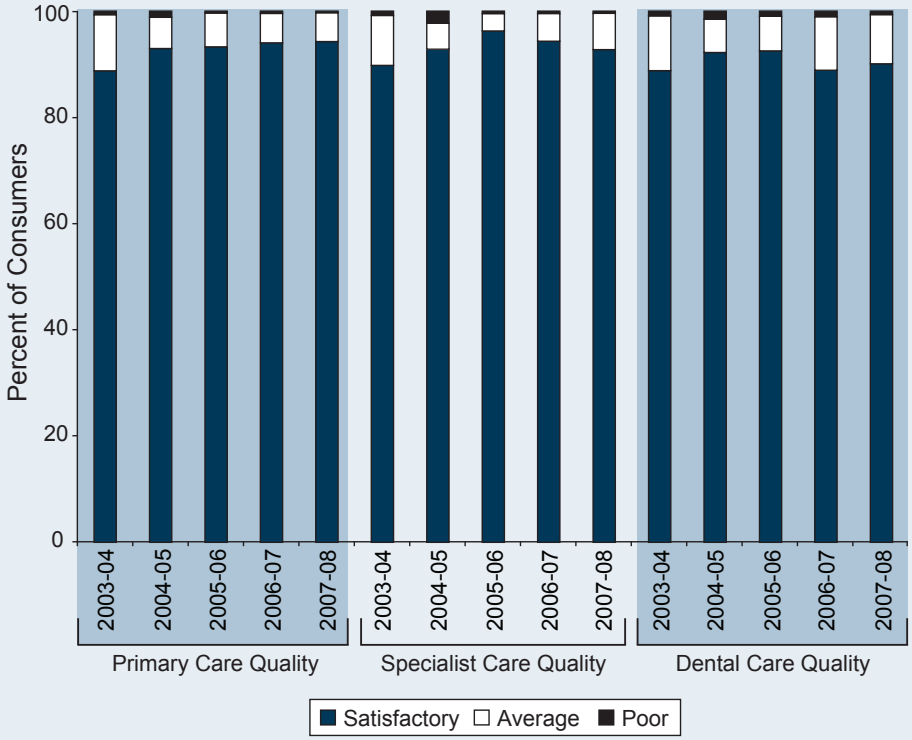


Figure 3.21
Continuing OCP Crisis Episodes

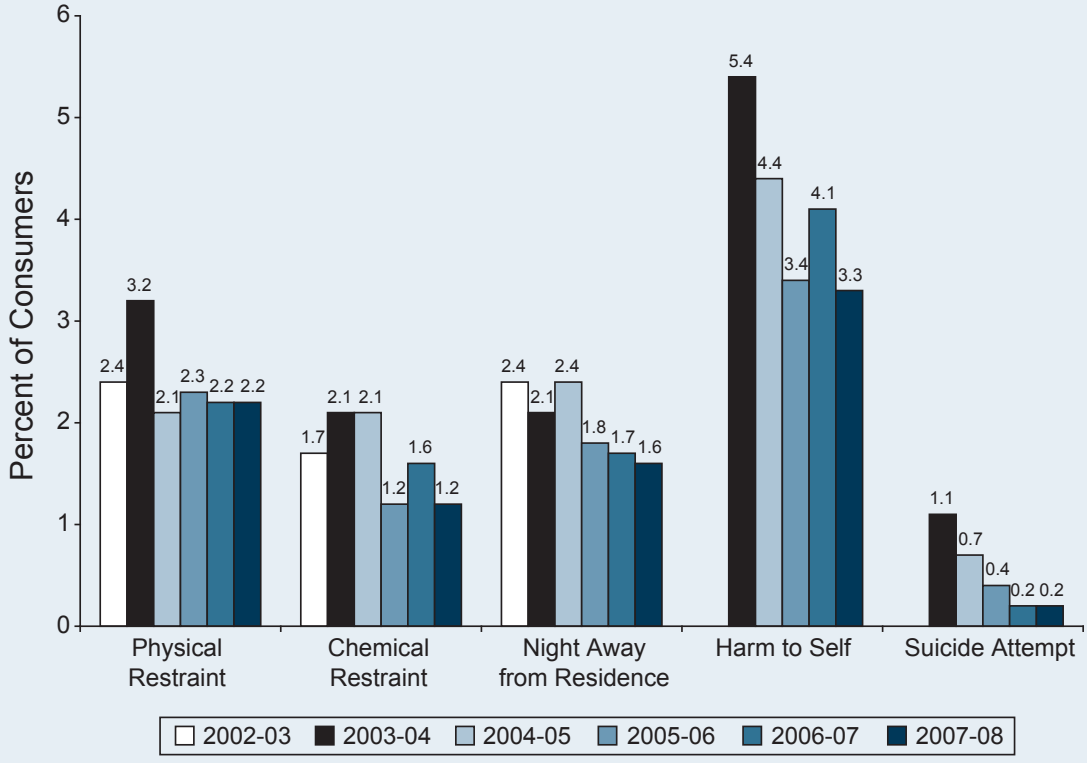


Figure 3.22
Continuing OCP Legal Concerns

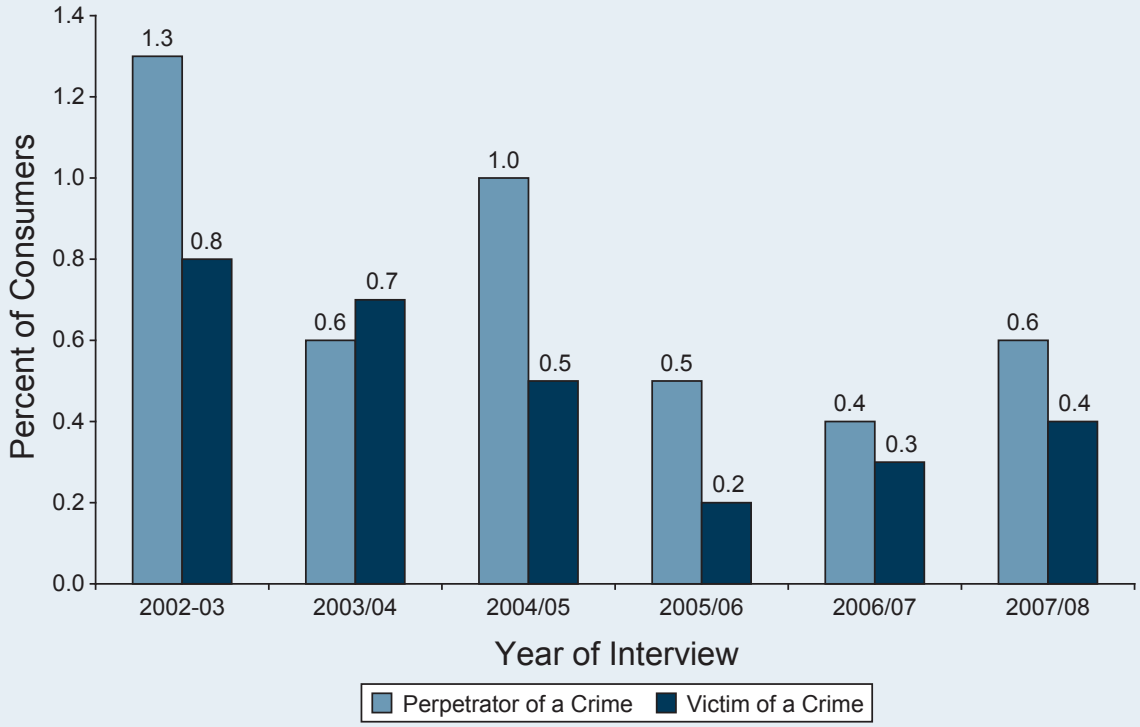
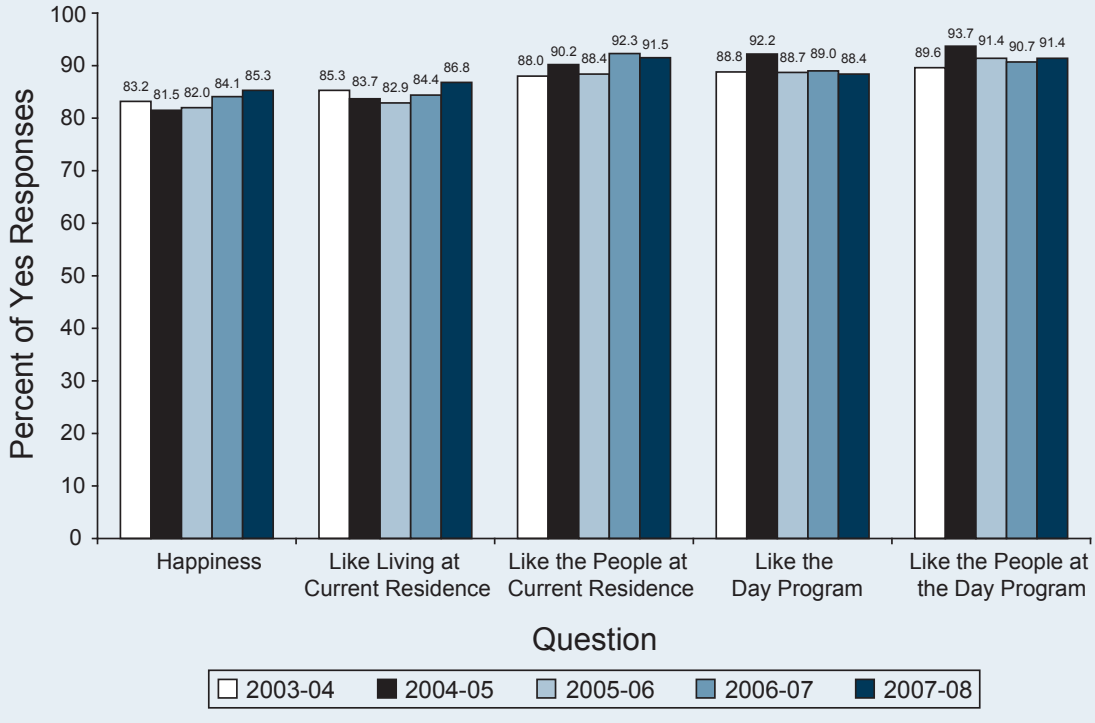


Figure 3.23
Continuing OCP Consumer Satisfaction Items



Thus, Continuing OCP consumers were observed to be most satisfied with their residence in the current evaluation year (2007-08); however they appear to have been most satisfied with their day programs in 2004-05.

An additional analysis was conducted to evaluate overall consumer satisfaction across time. Specifically, the responses for the five consumer survey items described above were summed to create a composite score for consumer satisfaction. Higher scores reflect higher satisfaction with a maximum score of 15.0. For this analysis, only consumers who had answered all five of the satisfaction items for all five years were included so that an overall satisfaction score could be tabulated. Only 17.1% (282 consumers) of the Continuing OCP answered all five items for each of the five evaluation years. Table 3.2 reports the averages (*M*) for overall consumer satisfaction for each evaluation year. There was little variability in satisfaction scores. A repeated measures one-way ANOVA indicated there were no significant differences in overall satisfaction scores over the past five evaluation years.[51] This suggests that the Continuing OCP consumers have been and continue to be happy and highly satisfied in their homes, their day programs, and with the people helping them in the community.

Table 3.2
Continuing OCP Satisfaction Scores

Year of Interview	*Average*
2003-04	14.2
2004-05	14.2
2005-06	14.0
2006-07	14.2
2007-08	14.3

CONCLUSIONS

For the 2008 Mover Study:

- The longitudinal analyses suggested that the following key indicators remain stable over time: (1) CDER scores (i.e., SDD and CB composite scores), (2) general health, (3) hospital admissions, (4) emergency room visits, (5) residence types, (6) community activities, (7) access and quality of health care in the community, (8) mental health crises, (9) consumer involvement with the criminal justice system as a perpetrator or a victim, and (10) consumer satisfaction.

[51] $F(4, 278) = 1.3$, $p > .05$.

Chapter

4

The Newcomer Sample

Chapter Four

THE NEWCOMER SAMPLE

Given the legislative requirements of the *Mover Study*[52], at the initiation of each evaluation year DDS provides CSUS with a list of consumers who have integrated into the community from a DC during the previous fiscal year. The list is then compared to the CSUS Master Database. Consumers identified as previous participants of the *Mover Study* have their files reactivated and become part of the TCP. Any consumer that has not previously been in the CSUS *Mover Study* evaluation is entered into the database and considered a Newcomer (NC) to the evaluation for that year. This year, CSUS identified 139 consumers new to the *Mover Study* from the FY2006-07 list. Of the 139 consumers identified as NCs, 111 consumers were visited in the community as part of the *2008 Mover Study*. The remaining 28 consumers were not visited and are included in the NIs previously described in Chapter 2.

The NC sample is presented as a separate subset of consumers because they provide insight into community integration the first year after leaving a DC. Additionally, comparisons between the NC sample and the Continuing OCP may indicate how the needs of the consumers currently integrating in to the community differ from the original population and may provide insight into how the TCP is changing over time. This chapter describes the NC sample relative to the Continuing OCP data from this evaluation year with respect to demographics and the key variables of interest examined in Chapter 3 which are: (1) CDER scores (i.e., SDD and CB composite scores), (2) general health, (3) hospital admissions, (4) emergency room visits, (5) residence types, (6) community activities, (7) access and quality of health care in the community, (8) mental health crises, (9) consumer involvement with the criminal justice system as a perpetrator or a victim, and (10) consumer satisfaction.

CONSUMER CHARACTERISTICS

In this section, the following NC demographics are examined relative to the Continuing OCP: age, sex of the consumers, ethnicity, diagnoses of intellectual disability, CDER composite scores, and general health ratings.

Consumer Demographics

Age, Sex of the Consumer, and Ethnicity

The mean age for the NC sample was 48.7 years[53] with a range of 17 to 82 years. On average, the consumers in the NC sample were six months younger than the Continuing OCP (*M* = 49.2 years). Figure 4.1 indicates that almost one-half (47.7%) of the consumers in the NC sample were 52 years of age or older as opposed to 41.5% of the Continuing OCP consumers in the same age range. Further, the proportion of consumers less than 22 years of age was higher for the NC sample (5.4%) than the Continuing OCP (0.5%).

The demographics further show that the NC sample had a slightly higher male to female ratio (2:1) then the Continuing OCP (3:2). Lastly, Figure 4.2 shows that the NC sample was fairly well matched with the Continuing OCP in ethnic diversity. The largest ethnicity group for the NC sample was Caucasian (73.0%), followed by Hispanic and African American (11.7% each), and the remaining four consumers were either Asian (0.9%), Pacific Islander (0.9%), Middle Eastern (0.9%), or Native American (0.9%).

[52] §4418.1 (b)

[53] Descriptive statistics for the NC sample are contained in Appendix F.

Figure 4.1
Age Distributions

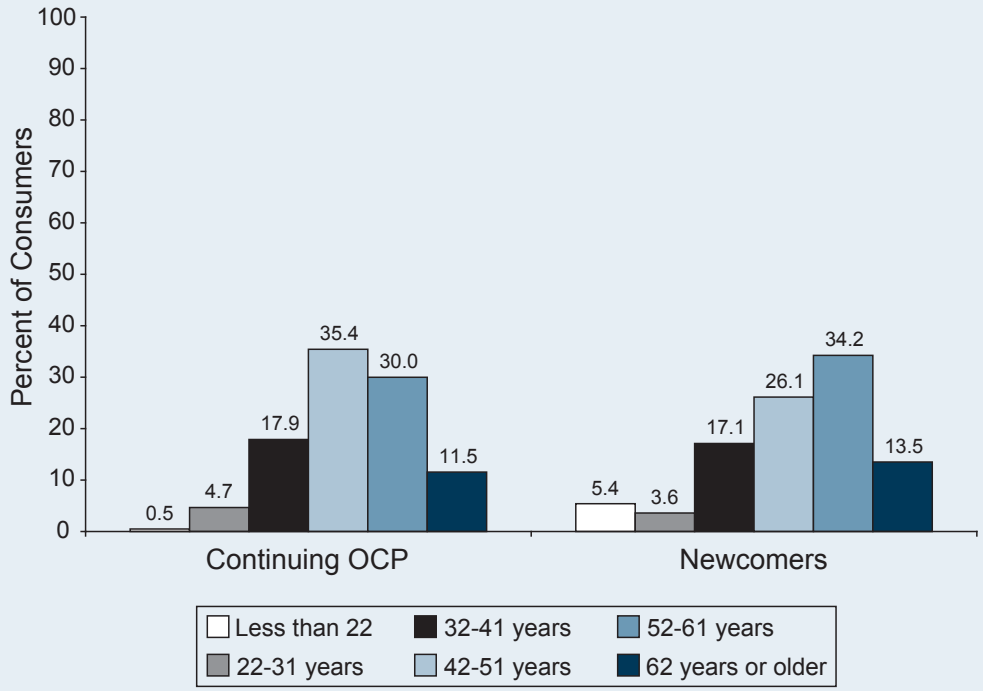
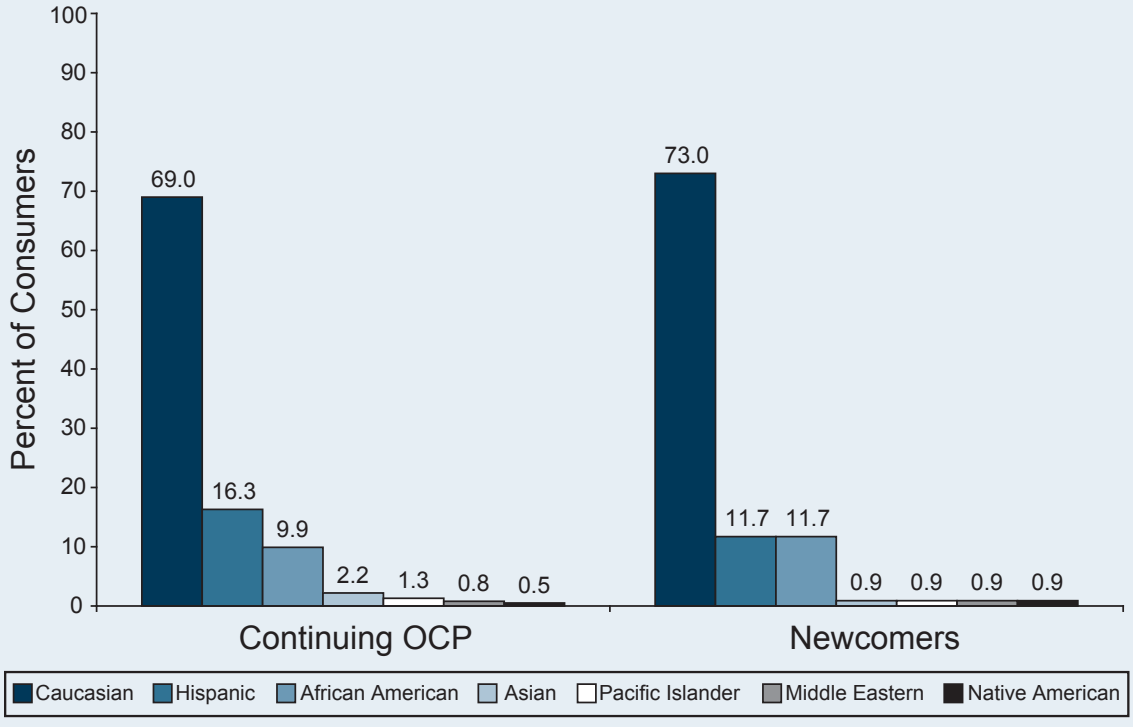


Figure 4.2
Ethnicity



Diagnoses of Intellectual Disability

Just less than three quarters (73.0%) of the NC sample were reported to have a diagnosis of severe or profound intellectual disability (Figure 4.3) with an additional quarter (25.2%) reported to have a diagnosis of mild or moderate intellectual disability. The remaining 1.8% of the consumers in the NC sample had no diagnosis of intellectual disability. Figure 4.3 also shows that the NC sample had a higher percentage of consumers with diagnoses of severe or profound intellectual disability than the Continuing OCP; however, for both groups the majority of consumers had been diagnosed with a severe or profound intellectual disability.

Client Development Evaluation Report (CDER)

CDER composite scores were calculated for the consumers in the NC sample for the skills demonstrated in daily living (SDD) and challenging behaviors (CB). As previously described, higher SDD composite scores represent higher levels of functioning and higher CB composite scores represent more challenging behaviors as defined by the CDER portion of the *Residential Survey*.

Figure 4.4 shows the distribution of the SDD composite score categories for the NC sample and the Continuing OCP. The NC sample had a higher percentage of consumers in the low (34.9%) and moderate (43.4%) categories than the Continuing OCP (28.3% and 42.4%, respectively). Further analyses were used to evaluate the statistical differences in average SDD composite scores between the two groups. An independent-groups t-test indicated there was a statistical difference in the average SDD composite scores between the NC sample and the Continuing OCP[54]. Specifically, the average SDD composite score for the NC sample (*M* = 32.9) was significantly lower than the average SDD composite score for the Continuing OCP (*M* = 35.8). This is not surprising given that the NC sample had a higher proportion of consumers diagnosed with profound or severe intellectual disability. Given the diagnosis of severe or profound intellectual disability, by definition these consumers may require a greater need of support for daily living activities (adaptive skills).[55]

Figure 4.5 shows the distribution of the CB composite score categories for the Newcomers and the Continuing OCP. The NC sample had a lower percentage (by 3.0%) of consumers in the low CB range than the Continuing OCP; however the NC sample had a higher percentage (by 3.0%) of consumers in the moderate CB range. When the average CB composite scores were tested, the results indicated there was not a significant difference in the average CB composite scores (NC = 10.7; Continuing = 10.5) between the two groups[56].

Health

This section includes data for the consumers in the NC sample that describes the general health ratings, visits to the emergency room for a medical emergency, and visits to the emergency for a non-emergency issue. Results are compared to the Continuing OCP.

General Health Ratings

Figure 4.6 shows that a higher proportion of consumers in the NC sample (91.9%) were rated in good to excellent health than of consumers in the Continuing OCP (84.7%). Health was measured on a four-point scale with higher numbers representing better health. An independent-groups t-test was used to evaluate the average health ratings between the two groups. The results indicated that the average health rating for the NC sample (*M* = 3.0) did not significantly differ from the Continuing OCP (*M* = 2.9).[57]

Overnight Hospital Stays and Emergency Room Visits

The average number of overnight hospital stays and emergency room visits for all consumers in either the NC sample or the Continuing OCP was less than one

[54] t(1714) = 2.4, $p<.02$.

[55] Beers, M.H., & Porter, R.S. (Eds.) (2006). *The Merck Manual of Diagnosis and Therapy (18th Edition)*. New Jersey: Merck Research Laboratories.

[56] t(1733) = -0.3, $p>.05$.

[57] t(1762) = -1.1, $p>.05$.

Figure 4.3
Diagnoses of Intellectual Disability

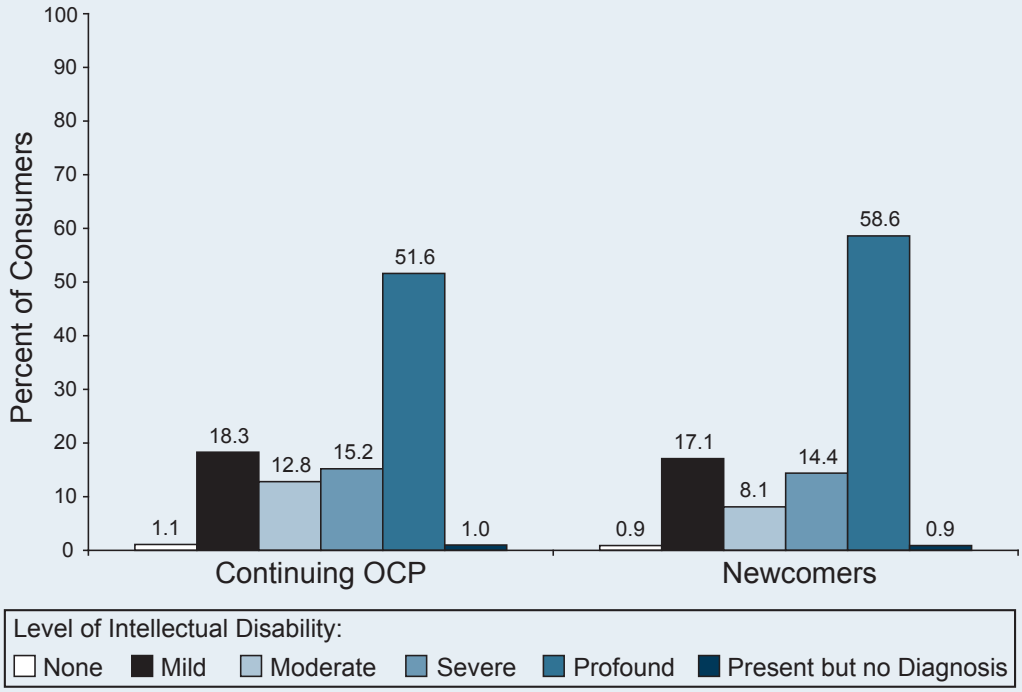


Figure 4.4
SDD Composite Score Categories

Figure 4.5
CB Composite Score Categories

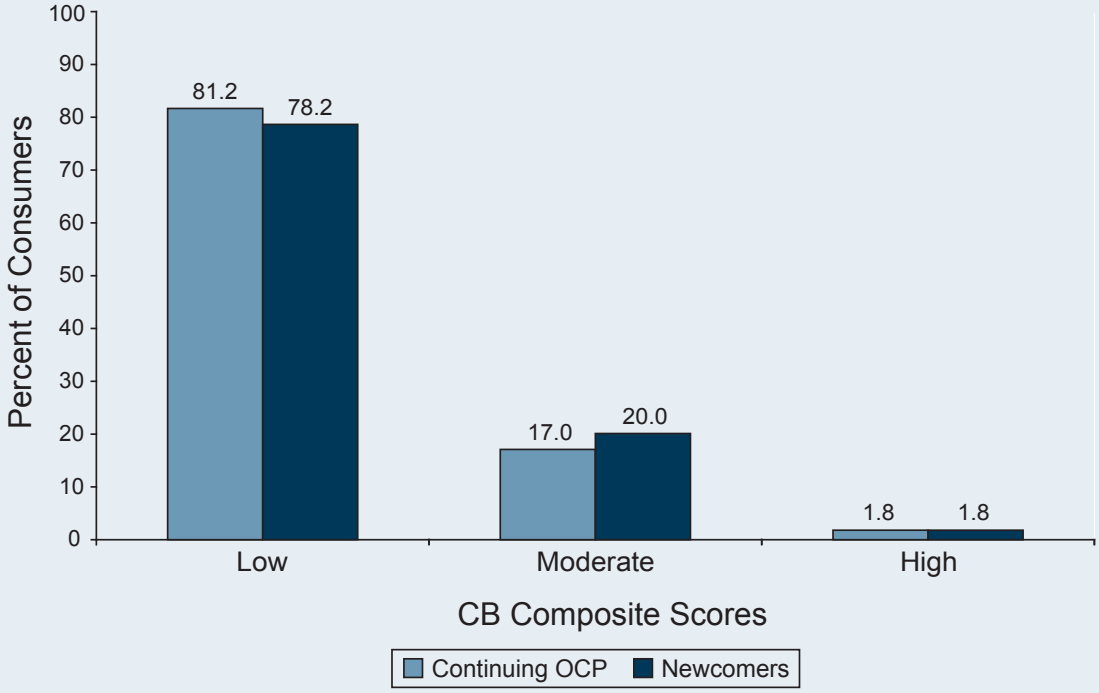
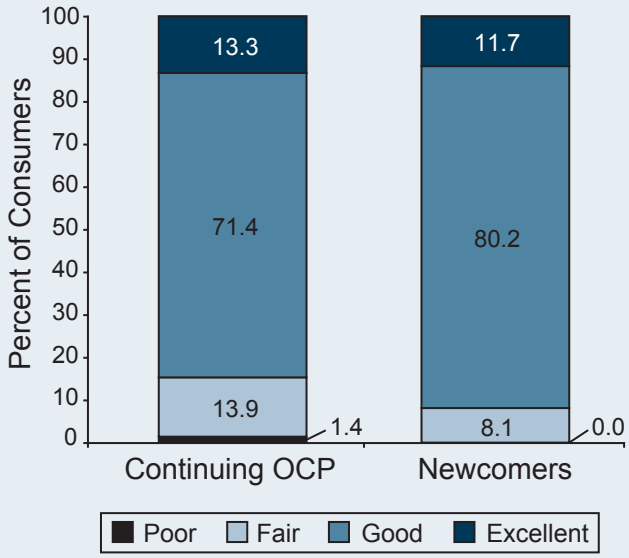


Figure 4.6
General Health Ratings



visit per consumer (Figure 4.7). Table 4.1 shows (1) the number of consumers (n) who required medical treatment in a hospital or emergency room and (2) the average number of visits (*M*) for only those consumers who required medical treatment during the prior year. An independent-groups t-test showed that there were no significant statistical differences in the average number of overnight hospital stays, emergency room visits for medical emergencies, or emergency room visits for non-emergency medical issues between the NC sample and the Continuing OCP[58].

[58] Overnight hospital stays: t(198) = 0.7, *p*>.05; Emergency medical issue ER visit: t(334) = 0.8, *p*>.05; Non-emergency ER visit: t(99) = 0.8, *p*>.05.

LIVING ENVIRONMENT

This section examines the types of residences consumers in the NC sample moved to after leaving the DC. Comparisons are made to the Continuing OCP.

Living Situation

Figure 4.8 shows that the consumers in the NC sample were living in similar types of residences as the consumers in the Continuing OCP with the majority of consumers living in a CCF or ICF with six or fewer beds; 90.0% of the NC sample and 85.1% of the Continuing OCP. Moreover, the next largest proportion of consumers

Figure 4.7
Overnight Hospital Stays and Emergency Room Visits for All Newcomers

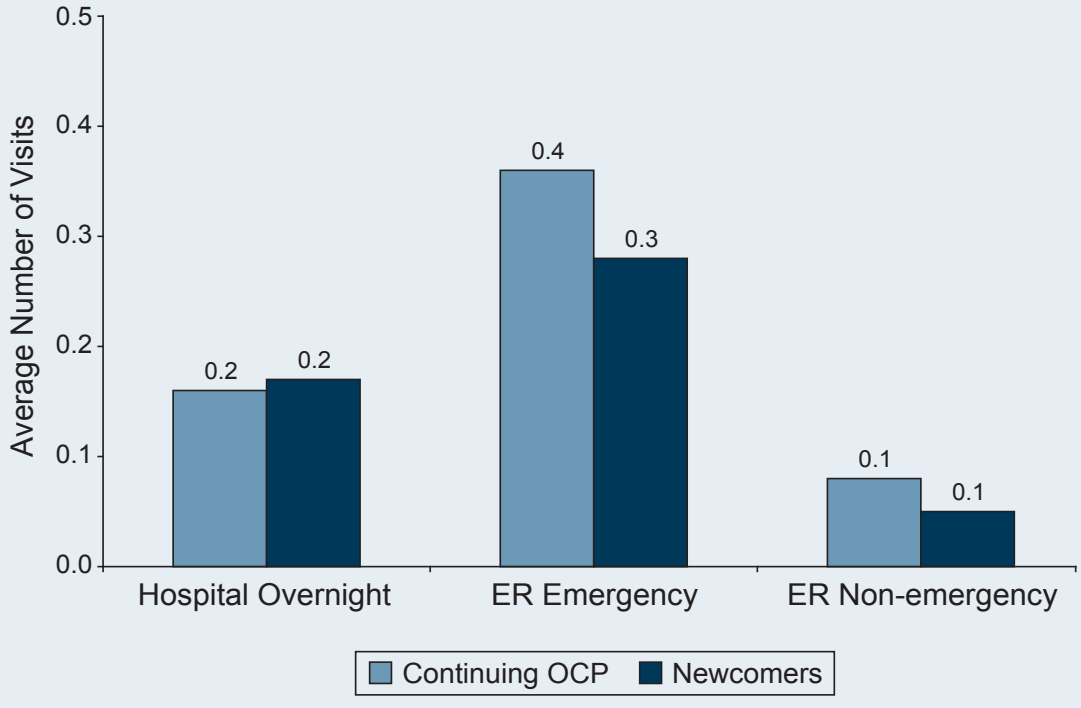


Table 4.1
Overnight Hospital Stays and Emergency Room Visits for Only the Consumers that Experienced a Stay or Visit

	Overnight Hospital Stays		*ER Emergency Visits*		*ER Non-Emergency Visits*	
Group	*n*	*Average*	*n*	*Average*	*n*	*Average*
NC Sample	15	1.3	21	1.5	6	1.0
Continuing OCP	185	1.5	315	1.8	95	1.4

in the NC sample (8.2%) and the Continuing OCP (10.2%) were found to be residing in an independent living situation (with or without services) or in supported living.

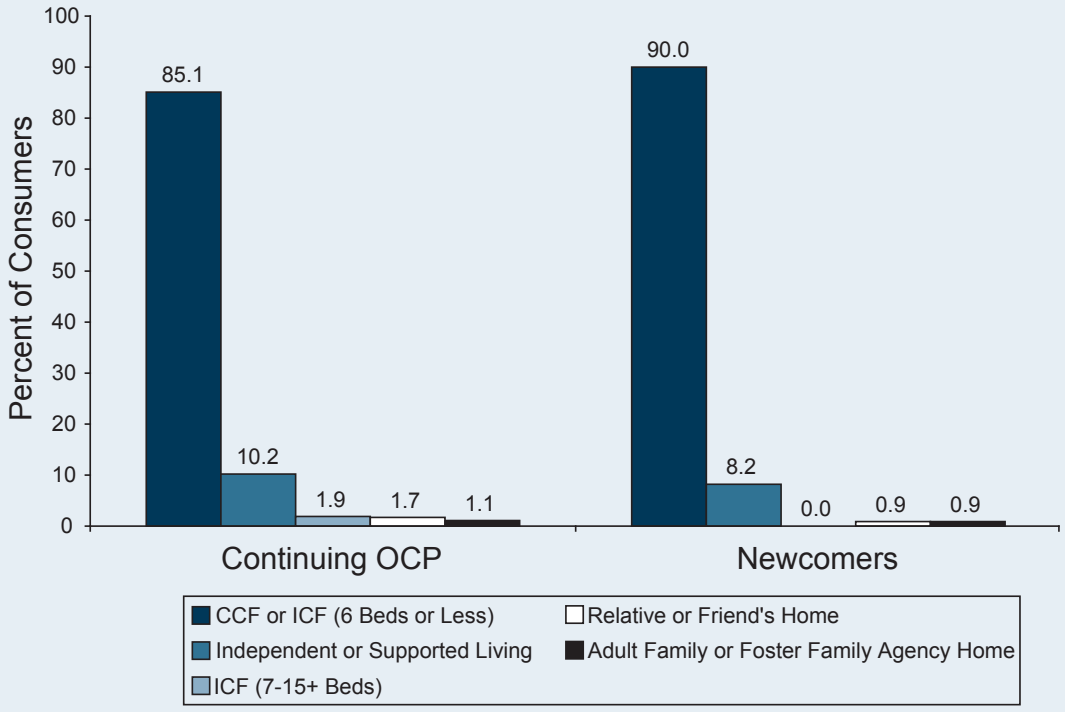
COMMUNITY INTEGRATION AND SERVICES

The following section discusses data collected regarding the community activities, services received in the community, crises, and involvement with the criminal justice system for the NC sample relative to the Continuing OCP.

Community Experiences

The community experiences examined were errands, social outings, restaurants, volunteer work, and parks and other outdoor recreation. For all community activities, the majority of consumers (greater than or equal to 75.0%) in the NC sample participated in these activities with groups of staff and persons with developmental disabilities.

Figure 4.8
Community Living Situation



Errands

Figure 4.9 shows the frequency of consumers in the NC sample and the Continuing OCP who participated in errands in the community during the past year. The percentage of consumers who were reported to be unable to participate in community errands differed by 1.5% between the two groups; 18.1% of the NC sample and 19.6% of the Continuing OCP. Approximately 45% of the consumers in both groups participated in community errands daily or at least once per week. Each group also had approximately a third of the consumers who participated in community errands less than or equal to twice a month.

Social Outings

Figure 4.10 shows that a larger percentage of consumers in the NC sample (43.2%) frequently attended social activities (at least once a week or more) as compared to the consumers in the Continuing OCP (35.4%). Additionally, a lower percentage of consumers in the NC sample were reported to be unable to participate in social outings, 1.0% versus 3.8%, respectively.

Figure 4.9
Errands in the Community

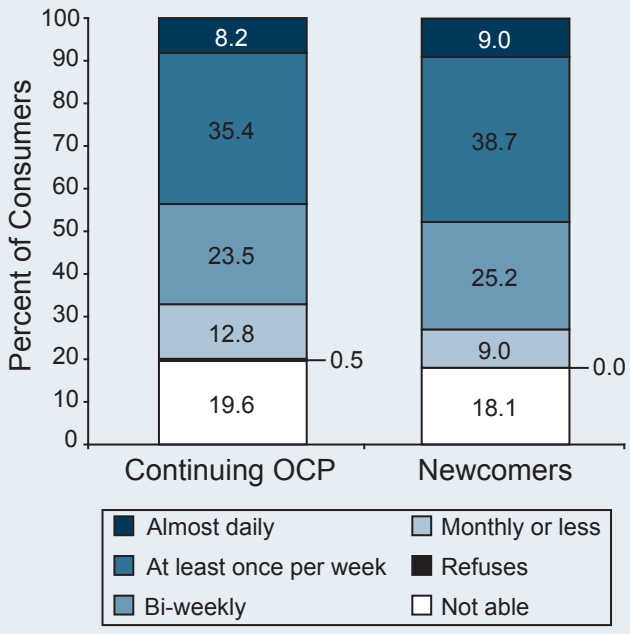
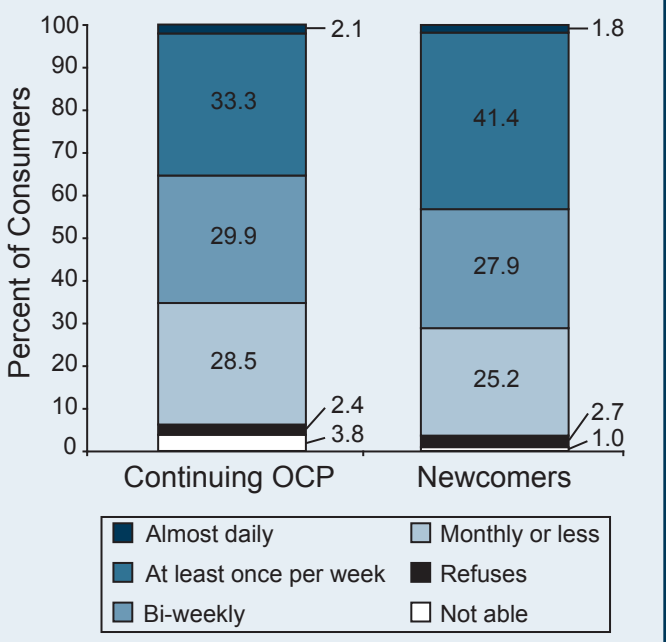


Figure 4.10
Social Outings in the Community



Restaurants

The percentage of consumers that went out to a restaurant to eat weekly to almost daily was higher for the Continuing OCP (32.3%) than the NC sample (29.7%) (see Figure 4.11). The Continuing OCP (55.7%) also had a higher proportion of consumers that ate out monthly to biweekly than those in the NC sample (53.1%). These differences appear to be due to the fact that more consumers in the NC sample (15.4%) were reported to be unable to attend restaurant outings than in the Continuing OCP (11.5%).

Volunteer Work

Both groups reported that more than 90% of consumers were unable to participate in volunteer work (see Figure 4.12). There were only eight consumers in the NC sample and 42 consumers in the Continuing OCP that had participated in volunteer work at any time during the past year.

Figure 4.11
Restaurant Visits

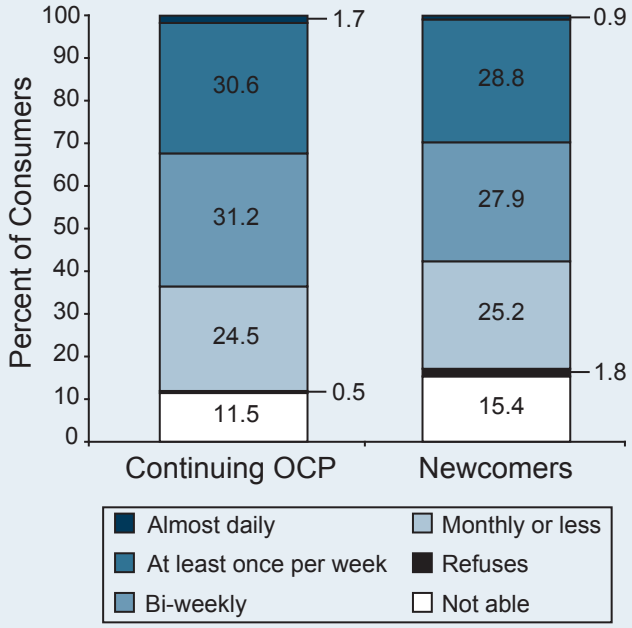
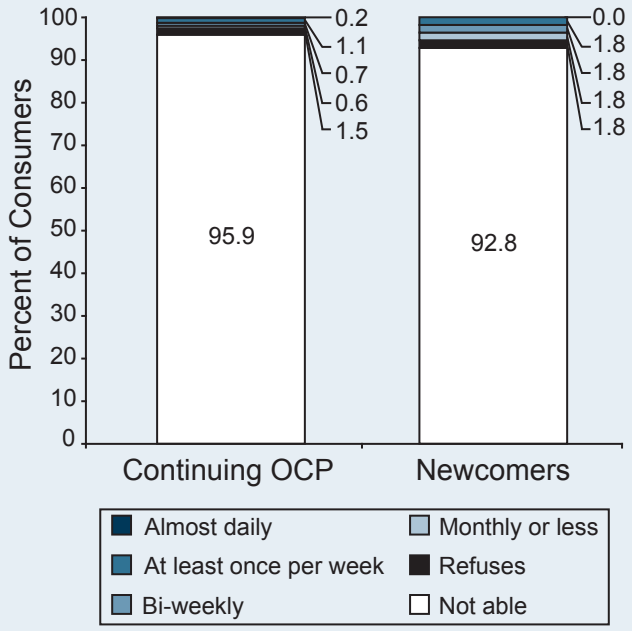


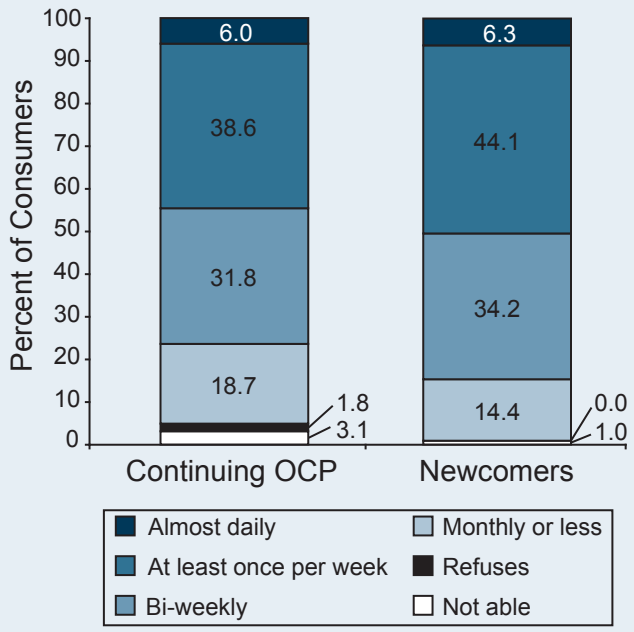
Figure 4.12
Volunteer Work



Park or Other Outdoor Recreation

As shown in Figure 4.13, half of the consumers in the NC sample participated in weekly to almost daily park and outdoor recreation activities, whereas 44.6% of consumers in the Continuing OCP participated with the same frequency. Further, given that only 1.0% of consumers in the NC sample were reported as unable to participate in park activities, this indicates that almost all (99.0%) of these consumers attended the park monthly or more frequently.

Figure 4.13
Park and Other Outdoor Recreation



Community Health Care

This section discusses the NC sample and the Continuing OCP data regarding the access to and quality of health care services received in the community.

Access to Primary Medical Care

Figure 4.14 indicates that a larger percentage of consumers in the NC sample (87.4%) reported access to primary medical care as easy or very easy as compared to those in the Continuing OCP (84.1%). However, in both groups just over 96% of the consumers indicated that access to medical care was considered to be average, easy, or very easy to find. Additionally, the same percentage of consumers (3%) in both groups reported access to medical care as difficult of very difficult.

Access to Specialist Care

Figure 4.15 shows that access to specialist care was above average for 81% of the consumers in both the NC sample and the Continuing OCP. Almost twice the percentage of consumers in the Continuing OCP (5.2%) reported access to specialist care as difficult or very difficult than the percentage of consumers in the NC sample (2.8%). This may partly be due to the fact that proportionately more of the consumers in the Continuing OCP (75%) required specialist care than in the NC sample (66%).

Access to Dental Care

As mentioned in the previous two chapters, access to dental care is of great concern for consumers in the community. Figure 4.16 reiterates this concern by demonstrating that 17.9% of consumers in the NC sample reported access to dental care as difficult or very difficult, which was 2.5% higher than observed for the Continuing OCP (15.4%).

Figure 4.14
Access to Primary Medical Care

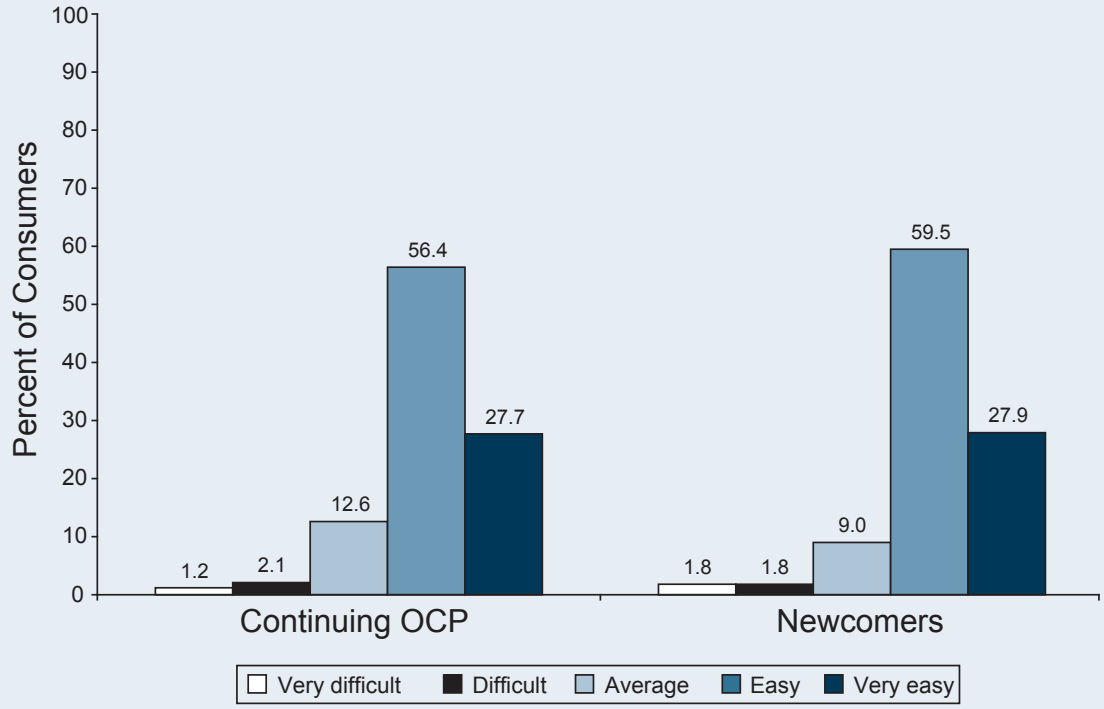


Figure 4.15
Access to Specialist Care

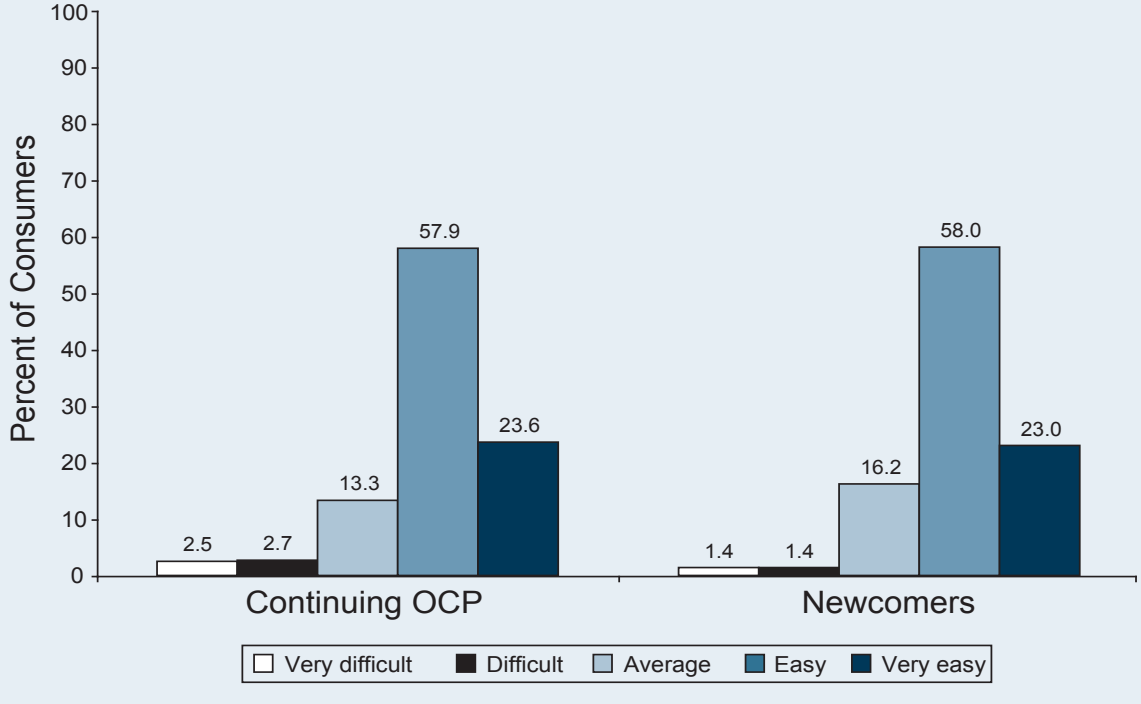


Figure 4.16
Access to Dental Care

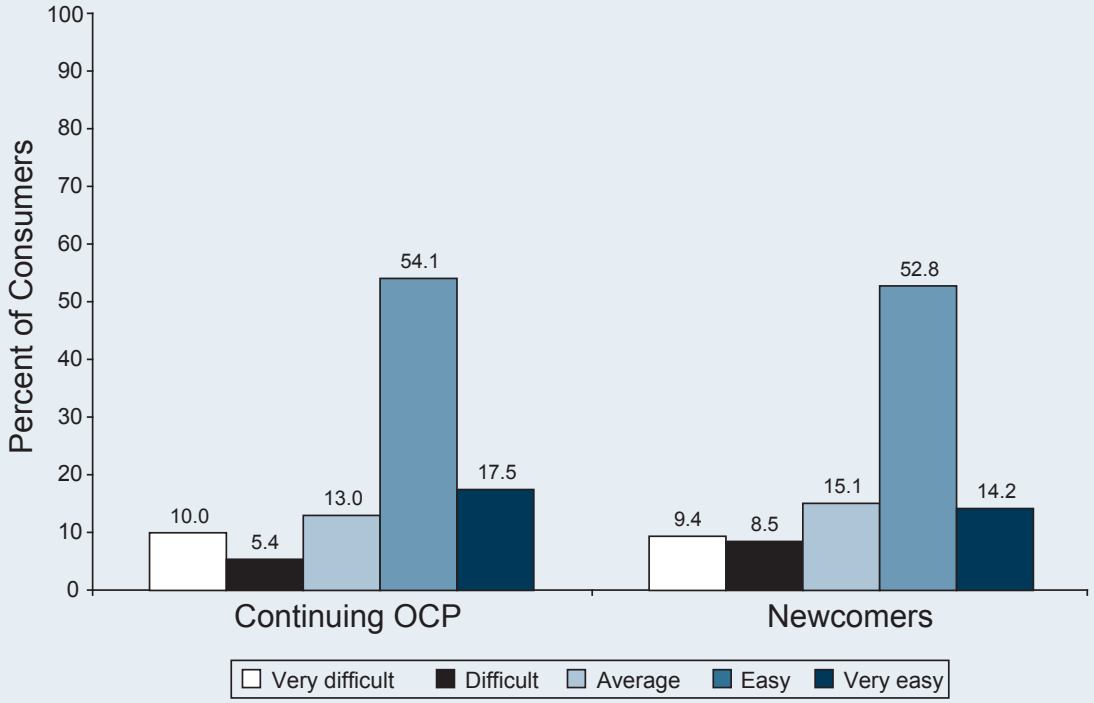
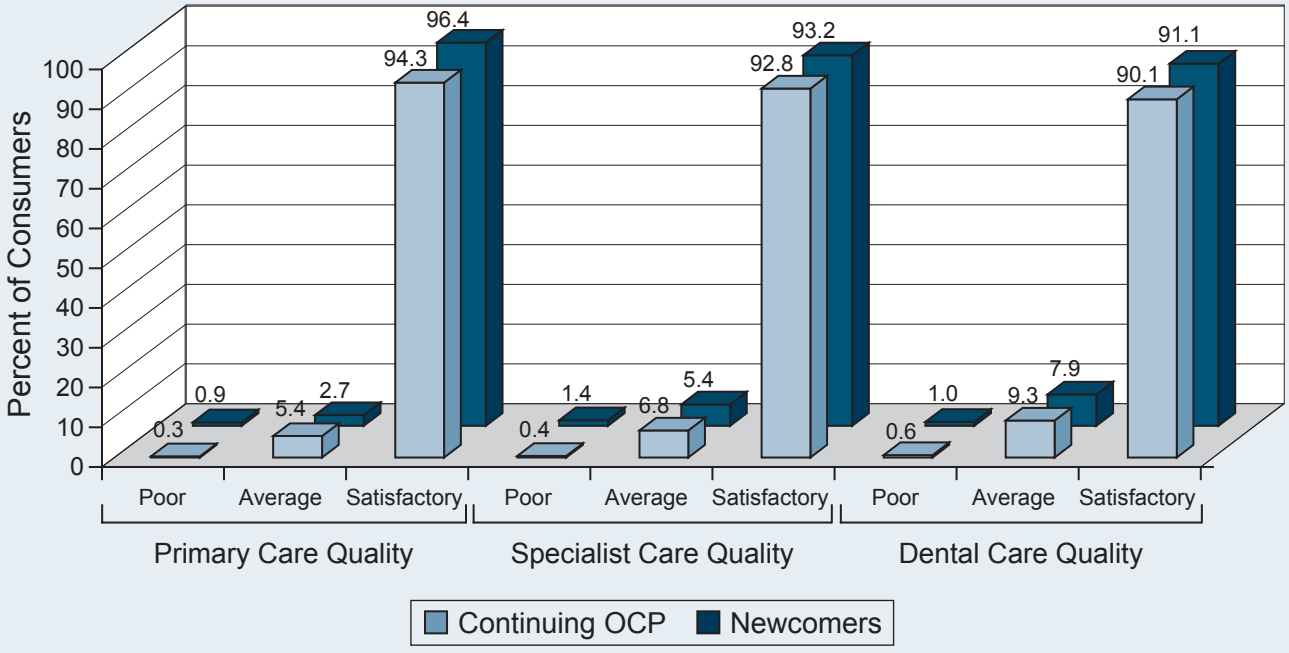


Figure 4.17
Quality of Health Care



Quality of Health Care

As seen in the longitudinal analyses, when consumers do find primary medical care, specialist care, or dental care, the quality ratings were exceptionally high for both groups (see Figure 4.17). Over 99% of the consumers in the NC sample and the Continuing OCP rated health care as average or satisfactory. In general, there was a slightly larger percentage of consumers in the NC sample who rated the quality of all health care services as poor.

Mental Health

Consumers in the NC sample only experienced one type of crisis examined in the *Residential Survey*. The results indicated that no consumers in the NC sample experienced a physical restraint, a chemical restraint, a night away from their residence, or a suicide attempt this past year. However, 1.8% (two consumers) of the NC sample reported a crisis that involved harm to self as compared to 3.3% of the Continuing OCP. An independent-groups t-test was used to examine the average frequency of crises between the NC sample and the Continuing OCP. The results indicated no significant differences between the groups[59].

Legal Concerns

Consumers in the NC sample were not involved in with the criminal justice system as a perpetrator or a victim this past year. From the Continuing OCP, nine consumers were involved as a perpetrator and six consumers were involved as a victim. No significant differences between the groups were found.

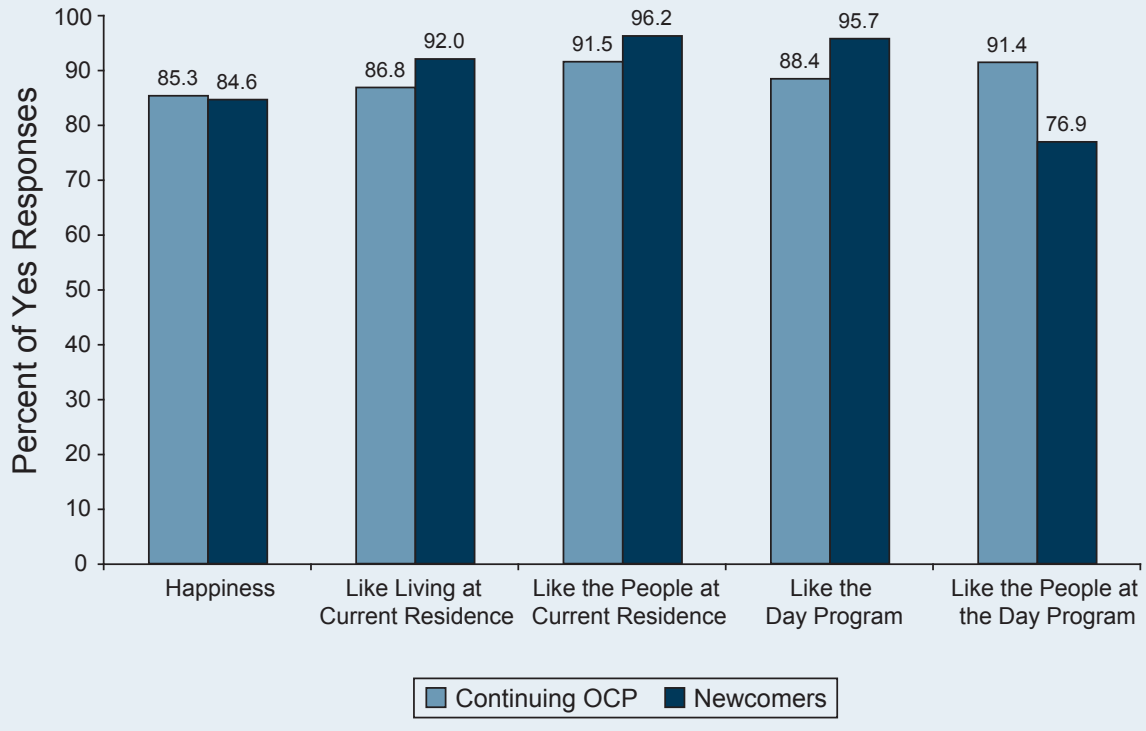
CONSUMER SATISFACTION

Consumer satisfaction was analyzed by evaluating five items from the consumer portion of the *Residential Survey*. The items were: (1) Are you happy most of the time, (2) Do you like living in your home, (3) Do you like the people who help you at home, (4) Do you like going to your day program, and (5) Do you like the people who help you at the day program. Consumer satisfaction was evaluated only for those consumers who responded to a given item.

Figure 4.18 shows the percent of consumers who

[59] t(54) = 0.3, p>.05.

Figure 4.18
Consumer Satisfaction



responded yes to each of the individual consumer satisfaction items. As shown:

- A larger percentage of consumers in the NC sample liked living in their current residence (92.0%), liked the people at their residence (96.2%), and liked their day program (95.7%) than in the Continuing OCP (86.8%, 91.5%, and 88.4%, respectively).
- In contrast, a substantially larger percentage of consumers in the Continuing OCP (91.4%) reported liking the people at their day programs than was reported by the NC sample (76.9%).
- Approximately the same proportion of consumers reported being happy most of the time (85%).

An additional analysis was conducted to evaluate overall consumer satisfaction between the groups. The responses for the five consumer survey items described above were summed to create a composite score of consumer satisfaction. Higher scores reflect higher satisfaction with a maximum score of 15.0. For this analysis, only consumers who had answered all five of the satisfaction items were included so that an overall satisfaction score could be tabulated. Only 20 consumers in the NC sample and 381 of the Continuing OCP answered all five items. An independent-groups t-test resulted in no significant differences between consumers in the NC sample (M = 14.6) and consumers in the Continuing OCP (M = 14.3) in consumer satisfaction.[60] Thus, the consumers in the NC sample report similar levels of satisfaction in the community as the Continuing OCP.

CONCLUSIONS

The 2008 Mover Study found:

- Comparisons between the NC Sample and the Continuing OCP indicated that the two groups did not significantly differ on the following key indicators: (1) Composite CB scores, (2) general health, (3) hospital admissions, (4) emergency room visits, (5) residence types, (6) community activities, (7) access and quality of health care in the community, (8) mental health crises, (9) consumer involvement with the criminal justice system as a perpetrator or a victim, and (10) consumer satisfaction. However, the average SDD composite score for the NC sample (M = 32.9) was significantly lower than the average SDD composite score for the Continuing OCP (M = 35.8).

[60] $t(399) = -0.8$, $p > .05$.

Chapter 5

The Developmental Center Sample

Chapter Five

THE DEVELOPMENTAL CENTER SAMPLE

Each evaluation year DDS provides CSUS with a list of consumers who currently reside in a DC (IDC) that have been identified by DDS as likely to enter the community during the current fiscal year. This year the IDC list included 29 consumers of which 22 were visited and interviewed while still in a DC. The other seven consumers included on the DDS list had moved into a community living arrangement before a visitor arrived at the DC. This chapter contains data collected from the *Residential Survey* used during interviews with the 22 IDC consumers. Also presented in this chapter are data for 14 consumers who were first interviewed in a DC for the *2007 Mover Study* and then in the community during the current evaluation period.

CONSUMER CHARACTERISTICS

This section contains data regarding consumer demographics, CDER scores, and health issues for the IDC consumers.

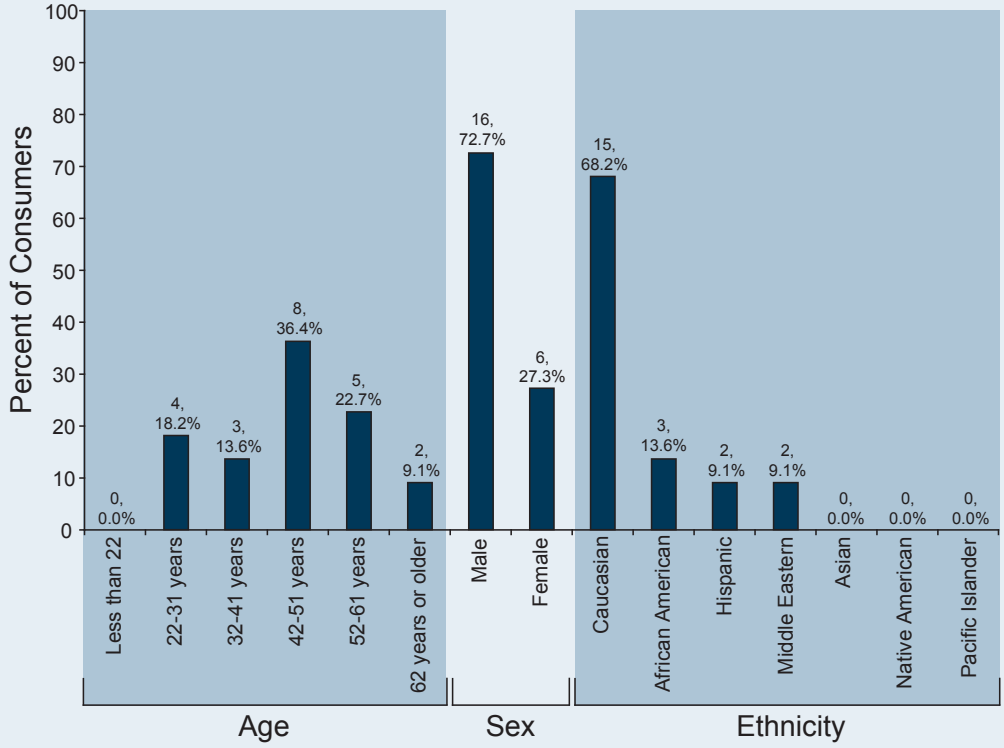
Consumer Demographics

Age, Sex of Consumer, Ethnicity, and Marital Status

The average age for the IDC was 45.6 years[61], and the consumers ranged in age from 24 to 76 years of age. Figure 5.1 indicates that most IDC consumers were between 42 and 51 years of age. The IDC sample was comprised of more males (16) than females (6) and was predominantly Caucasian (15 of the 22 consumers were

[61] Descriptive statistics for the IDC sample are contained in Appendix G.

Figure 5.1
IDC Demographics

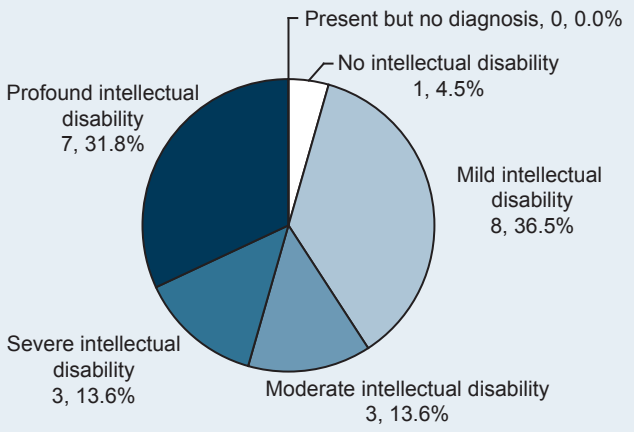


Caucasian). Finally, none of the IDC consumers reported having ever been married or having been in a romantic relationship during the past year.

Diagnosis of Intellectual Disability

As shown in Figure 5.2, the majority of consumers in the IDC sample reported a diagnosis of profound intellectual disability (seven consumers) or mild intellectual disability (eight consumers). One consumer reported no diagnosis of intellectual disability. The remaining six consumers were reported to have a diagnosis of moderate (three consumers) or severe (three consumers) intellectual disability.

Figure 5.2
Diagnoses of Intellectual Disability



Client Development Evaluation Report (CDER)

As described in Chapter 2, the CDER is comprised of two sections: Skills demonstrated in daily life (SDD) and challenging behaviors (CB). Skills demonstrated in daily living include physical capabilities, such as walking and talking, as well as the consumers' ability to care for themselves, their capability of focusing, safety awareness, and social interaction. Challenging behaviors include behaviors that interfere with daily activities such as running away, disruptions, aggression, and emotional outbursts.

Skills Demonstrated For Daily Living (SDD)

For each item in the SDD section of the *Residential Survey*, the number of consumers in the IDC sample who reported having the highest level of functioning is given below.

- **Hand Use** – Sixteen consumers used fingers from both hands to manipulate objects.
- **Walking** – Seventeen consumers could walk alone at least 20 feet with good balance.
- **Wheelchair Use** – Four of the eight consumers who used a manual or motorized wheelchair used the wheelchair independently and smoothly in nearly all situations.
- **Taking Medications** – None of the IDC consumers self-administered medications without reminders. However, nineteen consumers were able to self-administer medication with supervision.
- **Eating** – Thirteen consumers ate with at least one utensil without spillage.
- **Toileting** – Sixteen consumers toileted independently without assistance.
- **Bladder and Bowel Control** – Seventeen consumers had complete control of their bladder and bowel.
- **Personal Care** – Seven consumers performed all personal care activities independently without reminders.
- **Dressing** – Fourteen consumers dressed themselves independently without reminders.
- **Safety Awareness** – One consumer did not require supervision to prevent injury/harm. Almost half (10 consumers) of the IDC sample required constant supervision during waking hours to prevent harm or injury in all settings.
- **Focus on Tasks** – Nine consumers focused on a preferred task or activity for more than 30 minutes.

- **Verbal Communication** – Nine consumers used sentences of three words or more and had a vocabulary of more than 30 words.
- **Nonverbal Communication** - Of the nine consumers that used nonverbal communication, two consumers used facial expressions to communicate but did not understand those of other people.
- **Social Interactions** – Four consumers initiated and maintained interactions in familiar and unfamiliar situations/settings.

Challenging Behaviors (CB)

For each item in the CB section of the *Residential Survey*, the number of consumers who reported having the least challenging behaviors is given below:

- **Disruptive Social Behavior** - Eight consumers never displayed disruptive social behavior.
- **Aggressive Social Behavior** – Thirteen consumers never displayed aggressive social behavior.
- **Self-Injurious Behavior** – Thirteen consumers never displayed self-injurious behaviors.
- **Property Destruction** – Fifteen consumers never displayed property destruction.
- **Running Away** – Seventeen consumers never ran/ wandered away.
- **Emotional Outbursts** – Seven consumers never displayed emotional outbursts.

CDER Composite Scores

CDER composite scores were calculated for the skills demonstrated in daily living (SDD) and challenging behaviors (CB). The SDD composite score has a possible minimum score of 11 and a maximum of 60. As shown in Figure 5.3, for the IDC sample:

- The low SDD category was comprised of 13.6% (three consumers) of the IDC sample.
- The moderate SDD category was comprised of 27.3% (six consumers) of the IDC sample.
- The high SDD category was comprised of 59.1% (13 consumers) of the IDC sample.

The low SDD category describes the consumers with the lowest level of functioning whereas the high SDD category describes the consumers with the highest level of functioning. Consumers in the IDC sample had a mean SDD composite score of 36.7, indicating that on average, the consumers had a moderate level of functioning with respect to skills demonstrated in daily living as defined by the CDER.

The CB composite score has a possible minimum score of 6 and a maximum score of 30. As shown in Figure 5.3, for the IDC sample:

- The low CB category was comprised of 63.6% (14 consumers) of the IDC sample.
- The moderate CB category was comprised of 36.4% (eight consumers) of the IDC sample.
- None of the consumers in the IDC sample were in the high CB category.

The low CB category describes the consumers that exhibit the least challenging behaviors whereas the high CB category describes the consumers that exhibit the most challenging behaviors. Consumers in the IDC sample had a mean CB composite score of 12.6, indicating that on average, the consumers had low challenging behaviors as defined by the CDER.

Health

This section includes information covering the general health of the consumers, reported medication changes, chronic ailments, hospital stays, emergency room visits, and accidental injuries that required medical attention.

General Health Information

Staff members reported that 17 of the 22 IDC consumers were in good to excellent health (Figure 5.4).

Figure 5.3
CDER Composite Scores

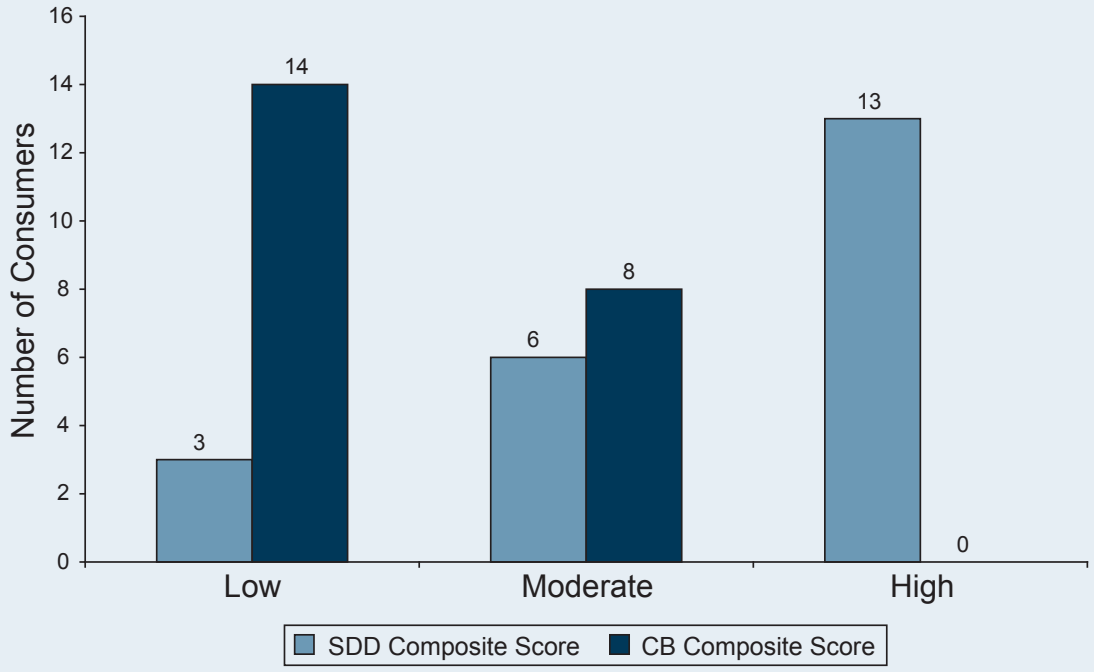
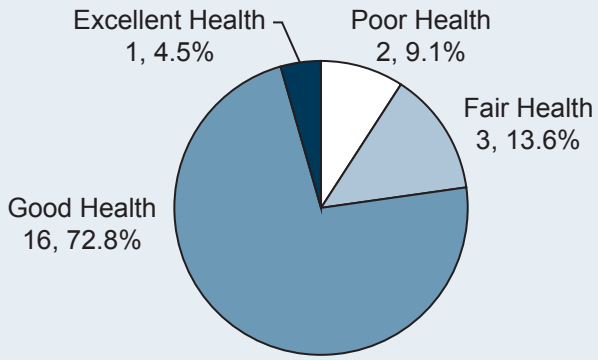


Figure 5.4
General Health Ratings



During the past year, the majority of the consumers in the IDC sample had no change in their weight (12 consumers). Three consumers had a slight weight gain, three consumers fluctuated in their weight, and three consumers had a slight weight loss. One consumer experienced a negative significant weight loss.

Medication Changes

The majority of consumers (18 consumers) in the IDC sample reported no change in the medications that were taken. For the four consumers who had a change in medication, staff members reported that the change resulted in symptoms improving for two of the consumers and no change in symptoms for the other two consumers.

Chronic Ailments

Over half of the consumers were diagnosed with bowel disorders (14 consumers) or skin disorders (13 consumers). Table 5.1 summarizes the number of consumers diagnosed with each chronic ailment.

Table 5.1
Chronic Ailments

Chronic Ailment	*Number of Consumers*	*Percent of Consumers*
Allergies	9	40.9
Obesity	7	31.8
Gastrointestinal	7	31.8
Osteoporosis	6	27.3
High Cholesterol	6	27.3
Visual Disorder	5	22.7
Anemia	4	18.2
Respiratory	4	18.2
Cancer	3	13.6
Thyroid Disorder	3	13.6
Hearing Disorder	3	13.6
High Blood Pressure	3	13.6
Asthma	2	9.1
Cardiovascular	2	9.1
Arthritis	2	9.1
Hepatitis	2	9.1

Hospital Stays and Emergency Room Visits

Three of the IDC consumers required overnight hospitalization. The reasons cited for hospitalization included cellulitus, cancer, and gall bladder issues.

The majority of the consumers did not visit an emergency room over the past year for a medical emergency; however, two consumers had one visit each for a medical emergency. None of the IDC consumers went to the emergency room for a non-emergency.

Accidents and Injuries

During the past year, three consumers experienced an accident that required medical attention. For these consumers, the number of accidents ranged between one and three accidents. Further, staff respondents reported that none of the consumers in the IDC were victims of abuse that resulted in an injury during the past year.

LIVING ENVIRONMENT

This section contains information about the consumers' living environment, average years in a DC, staffing, household composition, and relationships.

Living Situation

All of the consumers resided in one of the following developmental centers at the time of the interview: Agnews, Canyon Springs, Fairview, Lanterman, Porterville, Sierra Vista, or Sonoma. On average consumers had resided in a DC for 18.3 years with a range of 2.8 to 38.5 years.

Staffing and Household Composition

On average, the consumers' homes were staffed with 15.4 persons employed full time and 1.0 persons employed part-time. The average number of persons per residence was 17.5 of which all inhabitants were persons with developmental disabilities. On average consumers in the IDC sample shared a bedroom with 1.5 consumers.

Consumer Relationships

This section describes the relationships the consumers had with staff members, friends, and family. Also, the data provide insights into the consumers' contacts with persons outside their residence through the mail, telephone, and in-person visits.

Friends and Relatives

The majority of the consumers (18 consumers) had one or more individuals they considered a close friend. Further, 16 of the consumers had friends with developmental disabilities and two of the consumers had friends without developmental disabilities. In addition to friendship, 16 of the IDC consumers reported having one relative or more they considered a close relationship.

Contacts with Individuals Outside the Consumers' Residences

Contacts with individuals outside the consumers' residences are measured by the number of telephone

calls, pieces of mail, and visits received each month. The data showed that during the past year:

- Ten of the IDC consumers received mail each month.
- Eleven of the IDC consumers received telephone calls each month.
- Fourteen of the IDC consumers received visits each month.

INDIVIDUAL PROGRAM PLAN (IPP) AND CASE MANAGEMENT

Staff respondents were asked to provide the consumers' Individual Program Plans (IPP). This section contains information gathered from the IPP documents and staff member responses regarding the IPP planning process, consumer goals within the IPP, and case management.

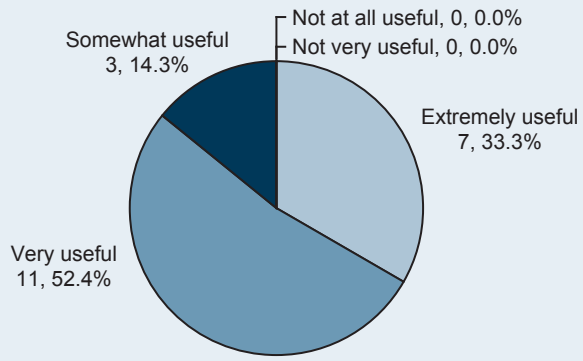
IPP Documentation and Planning

Of the 22 consumers visited in a DC, IPPs were present for all but one consumer and, of the IPPs present, all were current[62]. Fifteen of the IDC consumers were present for all or at least part of the IPP planning meeting and eleven of the consumers were reported to have contributed at least somewhat in planning their goals. Ten of the consumers had a relative, guardian, or conservator who attended the IPP planning meetings and participated at least somewhat in planning the IPP goals.

Staff Member Opinions

All staff respondents felt the IPP was a person-oriented document and, as shown in Figure 5.5, 18 of the staff respondents felt that the IPP was an extremely to very useful source of guidance for day-to-day programmatic planning.

Figure 5.5
Usefulness of the IPP



According to the staff respondents interviewed, four consumers had an additional plan that was part of the consumers' IPP. Staff respondents reported that the additional plans were easier to understand and contained realistic goals. Other plans mentioned included behavior treatment plans, facility treatment plans, and individual support plans.

Consumers' Goals

Figure 5.6 indicates that 19 of the 22 of the consumers in the IDC sample worked on goals pertaining to independent living and self care skills. For IDC consumers working on independent living and self care skills, on average, the consumers had 2.3 related IPP goals. The second most commonly reported IPP goal category involved the reduction in behavior problems with 13 of the consumers working on behavioral issues and an average of 1.8 behavior related goals per consumer. Additionally, half of the IDC consumers were working on goals related to employment with an average of 1.1 employment goal per consumers working on employment. Furthermore, the data showed that the consumers were making progress on all IPP goal categories (Figure 5.7).

[62] Current IPP included plans on a three-year planning cycle.

Figure 5.6
IPP Goals

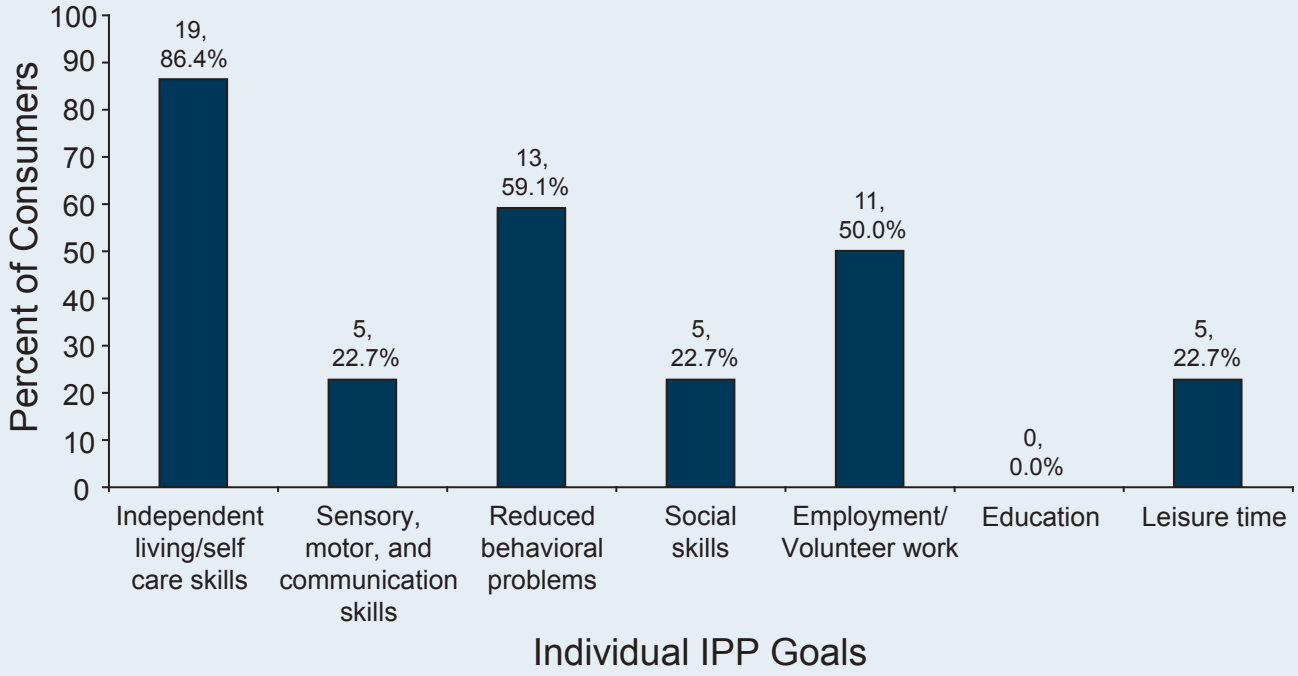
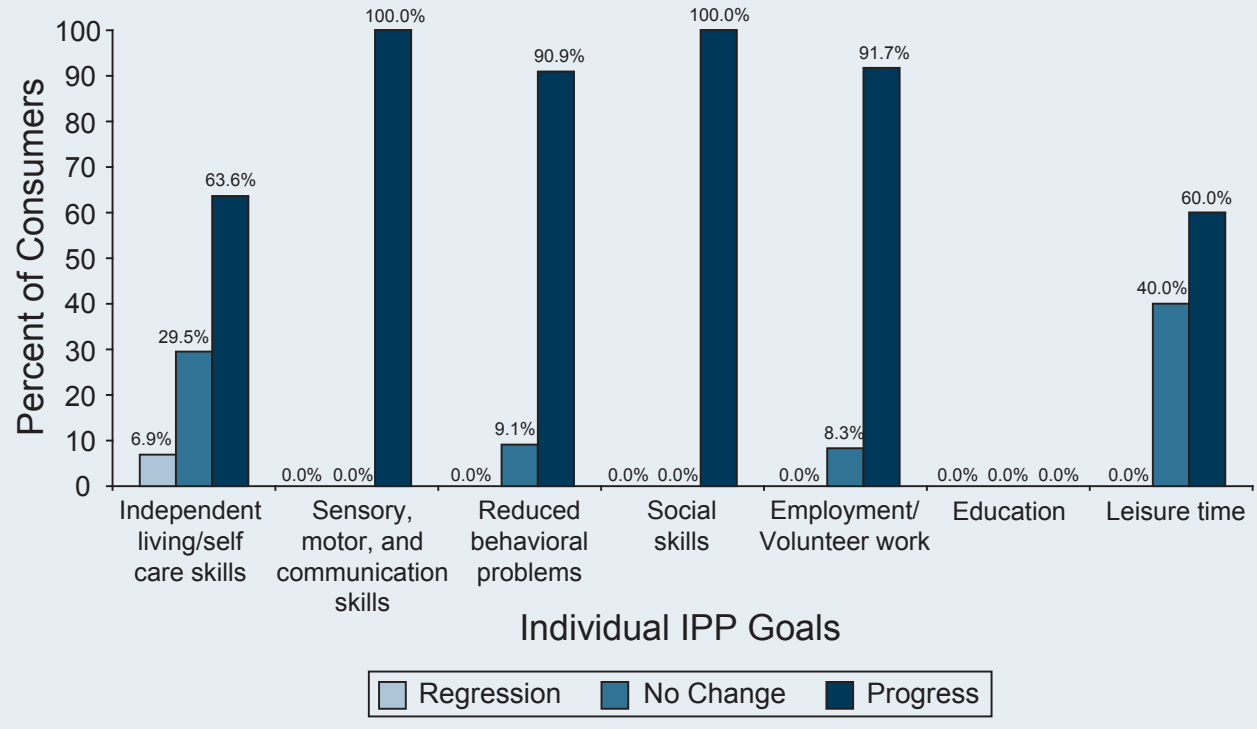


Figure 5.7
IPP Goal Progress



Case Management

Three of the consumers in the IDC sample experienced a change in their RC case manager this past year with each experiencing one change in management. On average, the case managers visited each consumer 3.4 times during the past year. Two of the staff respondents expressed dissatisfaction with the case manager services but did not provide a reason for their dissatisfaction.

COMMUNITY INTEGRATION AND SERVICES

This section contains information regarding activities, day program information, health care services, mental health services, crisis intervention data, legal concerns, and the alert reporting data collected during this evaluation for the 22 consumers interviewed in a DC.

Physical and Social Environment

The physical and social environment section addresses data collected regarding educational opportunities, employment, and community activities.

School[63] and Employment[64]

None of the consumers on the IDC sample attended school or were employed during the past year.

Day Program

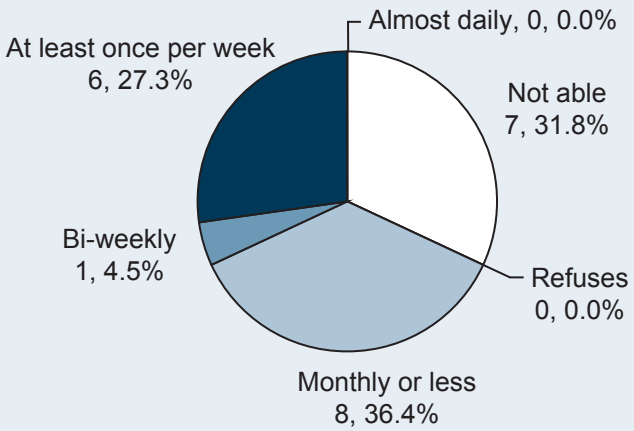
Sixteen of the 22 consumers in the IDC sample attended a day program. Fifteen of the consumers attended a site-based day program and one attended a community based program. The most commonly observed activities were exercise and weight training, music and dance, vocational training, and computer training. Twelve of the consumers were employed as a part of their day program activities and all but one were financially compensated for their work.

Community Experiences

Community experiences include running errands, participating in social gatherings, eating at restaurants, volunteering in the community, and going to the park or other such community gathering places. The data are summarized below.

- **Errands (Figure 5.8).** Six of the consumers ran errands at least once a week and seven consumers were unable to participate in errands. The majority (14 of the 15 consumers who participated in errands) participated as a member of a group consisting of staff members and persons with developmental disabilities.

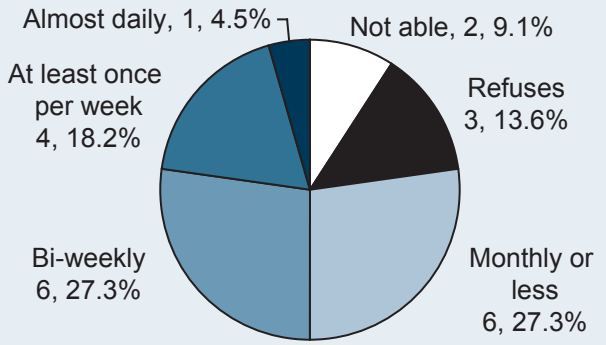
Figure 5.8
Errands in the Community



- **Social Outings (Figure 5.9).** Just over half (12 consumers) of the IDC sample participated in social outings biweekly or monthly and five consumers either declined or were unable to participate. Additionally, five consumers attended social gatherings at least once a week or almost daily. All of the consumers in the IDC sample who participated in social outings were in a group of staff members and persons with developmental disabilities.

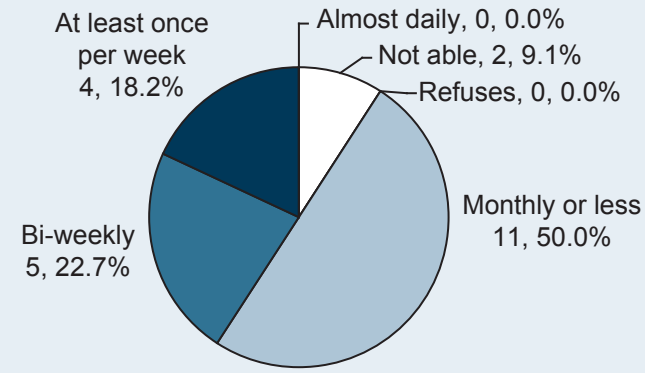
[63] Schools were defined as those institutions outside the academic and vocational offerings in the consumers' day programs.
[64] Employment was defined as a job in the community that is paid for by private companies or public agencies.

Figure 5.9
Social Outings



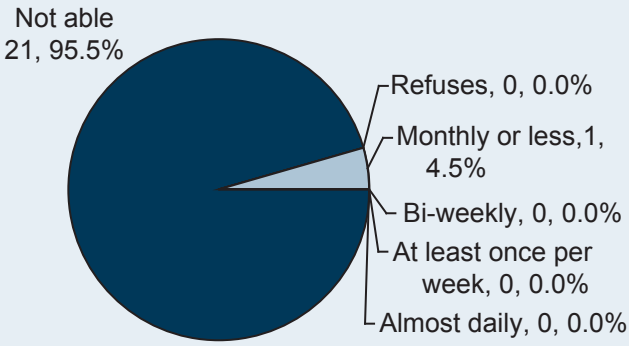
- **Restaurants (Figure 5.10).** The majority of the consumers (16 consumers) in the IDC sample went out to restaurants biweekly or monthly and two consumers were unable to participate. Eighteen of the twenty of the consumers who went to restaurants did so in a group of staff members and persons with developmental disabilities.

Figure 5.10
Restaurants



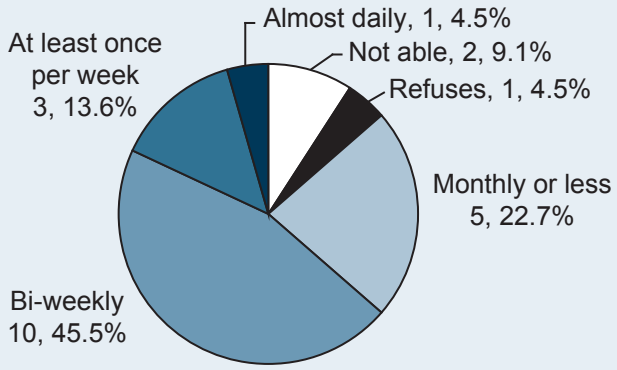
- **Volunteer (Figure 5.11).** Only one consumer participated in volunteer activities and the consumer did so as a member of a group of staff members and persons with developmental disabilities.

Figure 5.11
Volunteer Work



- **Park or Other Outdoor Recreation (Figure 5.12).** Fifteen of the 22 consumers in the IDC sample went to the park or participated in some other outdoor recreation activity biweekly to monthly and four consumers participated at least weekly or daily. Three consumers either declined or were unable to participate in park activities. All but one of the consumers participated in park activities as a member of a group that consisted of staff members and persons with developmental disabilities.

Figure 5.12
Parks and Outdoor Recreation



Health Care

This section includes information regarding the access to and quality of health care services received by the consumers in the IDC sample.

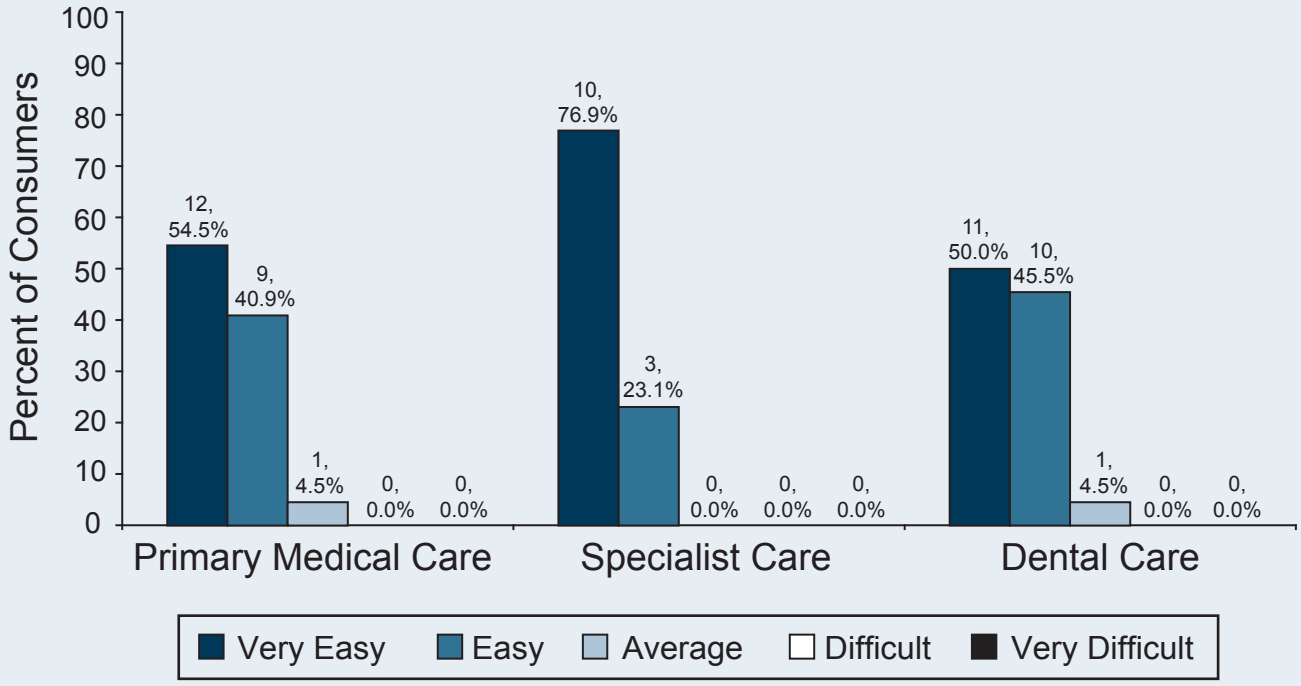
Health Care

The primary health care needs of all of the consumers in the IDC sample were fully met as were the dental care needs. Staff respondents were also asked if the consumer had any medical or dental needs over the past year for which appropriate care was *not* provided and all respondents reported that appropriate care had been received when needed.

Access to Medical Care

Figure 5.13 indicates that all staff respondents rated access to primary medical care, specialist care, and dental care as average or better. Additionally, the quality of medical care, specialist care, and dental care was considered satisfactory by all staff respondents.

Figure 5.13
Access to Health Care



Mental Health and Crisis Intervention

This section contains information about the mental health services required by the consumers in the IDC sample, the quality of the mental health services, the crises the consumers have experienced, and the frequency and quality of crisis intervention services utilized.

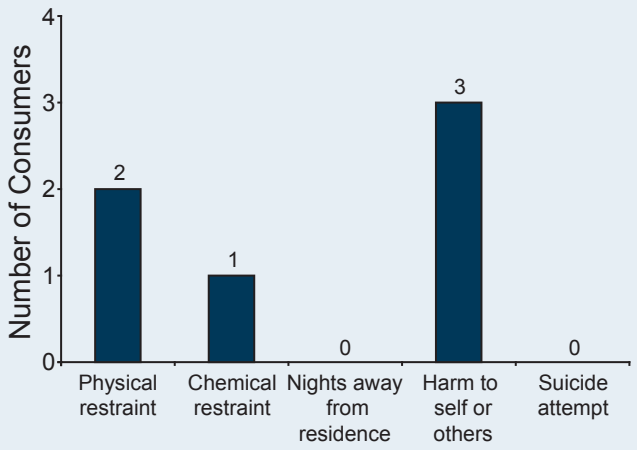
Mental Health Services

The data show that of the 22 consumers in the IDC sample, six received medications monitoring, three received therapy and counseling only, eight received medications monitoring and therapy, and that all mental health needs had been met. Furthermore, with respect to accessing mental health services, all of the staff respondents reported access to mental health care was easy to very easy to find and rated the quality of therapeutic services as average or better.

Crisis Episodes

Crisis episodes were defined as the use of physical restraints, use of chemical restraints, one or more nights away from home at a psychiatric facility, harm to self or others, or attempted suicides. Figure 5.14 shows that the most frequent crisis episode involved harm to self or others for consumers in the IDC sample. Further, two consumers in the IDC experienced physical restraints and one consumer experienced a chemical restraint during the past year. Additional staff and team interventions were the only crisis intervention support used for these three consumers during the past year. The quality of services was rated as very good for the three incidents.

Figure 5.14
Crisis Episodes



Legal Concerns

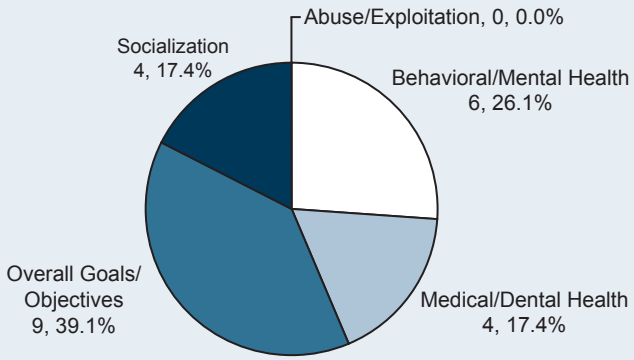
None of the consumers in the IDC sample reported being involved in the criminal justice system as a perpetrator or a victim during the past year.

Alerts

As described in Chapter 1, visitors are legislatively obligated to report any suspected violation of legal, civil, or service rights of an individual or if the project visitor determines that the health and welfare of the consumer is at risk. No Level 1 Alerts were reported for consumers in the IDC sample.

Level 2 Alerts fall within one of the following five categories: Abuse or exploitation risk; behavioral and mental health; medical and dental health; overall goals and objectives; and socialization. For the IDC sample, 23 alerts were filed for 13 consumers. Figure 5.15 indicates that the majority of alerts filed involved overall goals and objectives (nine alerts) or behavioral and mental health issues (six alerts).

Figure 5.15
Level 2 Alerts



CONSUMER INTERVIEW

The consumers were interviewed to determine their satisfaction with their home and day program, their sense of independence, and their relationships with friends and staff members. Consumers who could respond for themselves were interviewed by the visitors. As stated in the Welfare and Institutions Code,[65] two staff members familiar with the consumer of interest completed the interview when a consumer could not respond for themselves. Staff member interviews were conducted separately. The proportion of respondents was:

- Eleven of the consumers in the IDC sample completed the interview themselves.
- Eleven of the interviews were conducted with two staff members.

A minimum of eight out the eleven IDC consumers who responded for themselves indicated that they:

- Felt safe most of the time.
- Asked for what they want.
- Did not feel lonely most of the time.
- Liked the people who help them in their residence.
- Decided how to spend their money.
- Picked the things they do for fun.
- Had people in their lives that help them get out into the community.
- Were learning to do things for themselves.
- Liked their case manager.
- Felt as if they had a case manager that helped them with their problems.

Less than half of the eleven consumers:

- Like living in the DC.
- Wanted to continue living in the DC.
- Felt as if their friends could visit as often as the consumer liked.

FOLLOW-UP WITH LAST YEAR'S IDC CONSUMERS

Last year CSUS interviewed 35 consumers in a DC; 14 of those consumers integrated into the community during 2006-07 and follow-up interviews were conducted for the *2008 Mover Study*. These consumers are referred to as the DC Movers. This section presents data collected from the DC interviews and the community interviews on key variables of interest such as: (1) CDER scores (i.e., SDD and CB composite scores), (2) general health, (3) hospital admissions, (4) emergency room visits, (5) residence types, (6) community activities, (7) access and quality of health care, (8) mental health crises, (9) consumer involvement with the criminal justice system as a perpetrator or a victim, and (10) consumer satisfaction. Due to the small sample size, statistical tests of significance were not used to compare data collected from consumers in the DC and the community, and any conclusions drawn from these data are anecdotal in nature.

[65] §4418.1 (f).

CONSUMER CHARACTERISTICS

In this section, the following demographics are presented: Age, sex of consumer, ethnicity, diagnoses of intellectual disability, CDER composite scores, and general health ratings.

Consumer Demographics

Age, Sex of the Consumer, and Ethnicity

The average age for the DC Movers was 41.4 years with a range of 20 to 68 years. The demographics further show that the DC Movers were comprised of eight males and seven females. Eleven of the consumers were Caucasian, two consumers were African American, and one consumer was Native American.

Diagnoses of Intellectual Disability

Respondents reported that half of the DC Movers had a diagnosis of mild intellectual disability, five had a diagnosis of profound intellectual disability, one consumer had a diagnosis of moderate intellectual disability, and one had a diagnosis of severe intellectual disability.

Client Development Evaluation Report (CDER)

Table 5.2 shows that the average SDD score for the DC Movers slightly increased and the average CB Composite scores decreased between the two interviews. These results indicate that DC Movers' adaptive skills were rated slightly higher by community respondents than DC respondents and that the inverse was observed for challenging behavior (i.e., CDER CB ratings went down in the community).

Table 5.2
Average CDER Composite Scores for the DC Movers

	DC Average	Community Average
SDD	41.2	41.7
CB	12.3	12.0

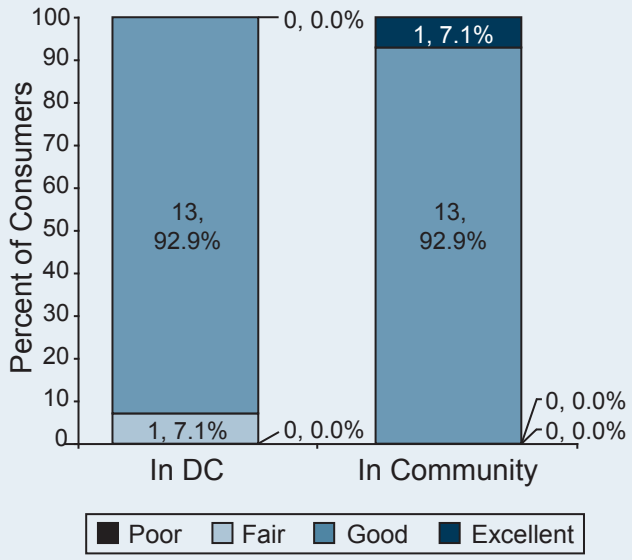
Health

This section includes data for the DC Movers that describes the general health ratings, visits to the emergency room for a medical emergency, and visits to the emergency for a non-emergency issue.

General Health Ratings

Figure 5.16 shows that consumers received approximately the same health ratings in the DC and in the community.

Figure 5.16
General Health Ratings for the DC Movers



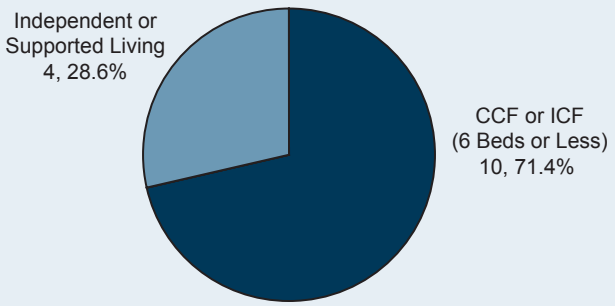
Overnight Hospital Stays and Emergency Room Visits

The average number of overnight hospital stays and emergency room visits for the DC Movers was less than one visit per consumer in the DC and in the community. One consumer had an overnight hospital stay while in a DC and one visit after moving into the community for seizures. As for emergency room visits, none were reported while the consumers resided in a DC but there were three emergency room visits for emergency medical issues and two emergency room visits for non-emergency issues while in the community.

LIVING ENVIRONMENT

Figure 5.17 shows that three quarters of the DC Movers moved from a DC into a CCF or ICF with six beds or less and that the remaining four consumers lived in the community independently with supported living services.

Figure 5.17
Community Living Situation for the DC Movers



COMMUNITY INTEGRATION AND SERVICES

The following section discusses data collected regarding the community activities, services received in the community, crises, and involvement with the criminal justice system for the DC Movers.

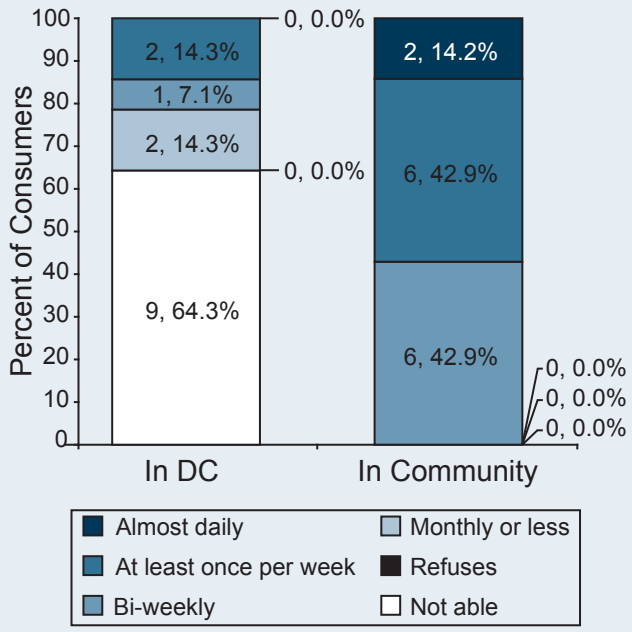
Community Experiences

The community experiences examined were errands, social outings, restaurants, volunteer work, and parks and other outdoor recreation.

Errands

Figure 5.18 shows that the frequency of errand participation increased in the community for the DC Movers. In the DC the consumers were not able to perform errands in the community but once integrated into the community, eight of the fourteen DC Movers participated in errands at least weekly or almost daily.

Figure 5.18
Errands in the Community for the DC Movers



Social Outings

Figure 5.19 shows that the DC Movers participated more frequently in social outings in the community as opposed to a DC. Additionally, in the community fewer DC Movers were reported to be unable to participate in social outings.

Figure 5.19
Social Outings in the Community for the DC Movers

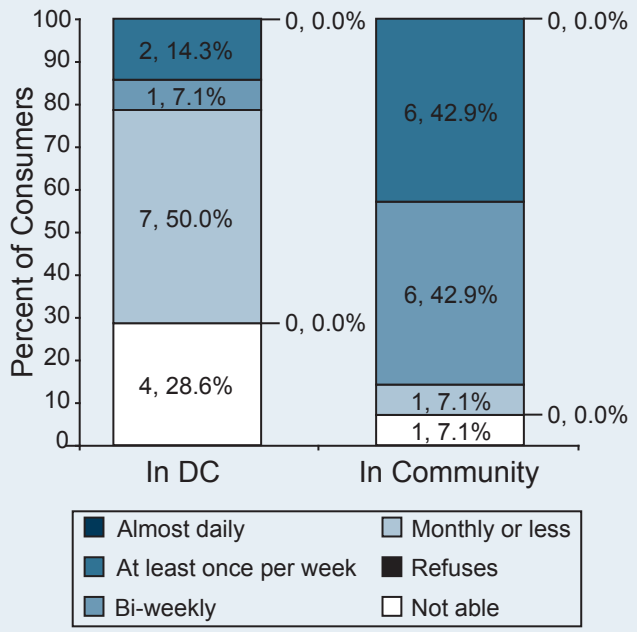
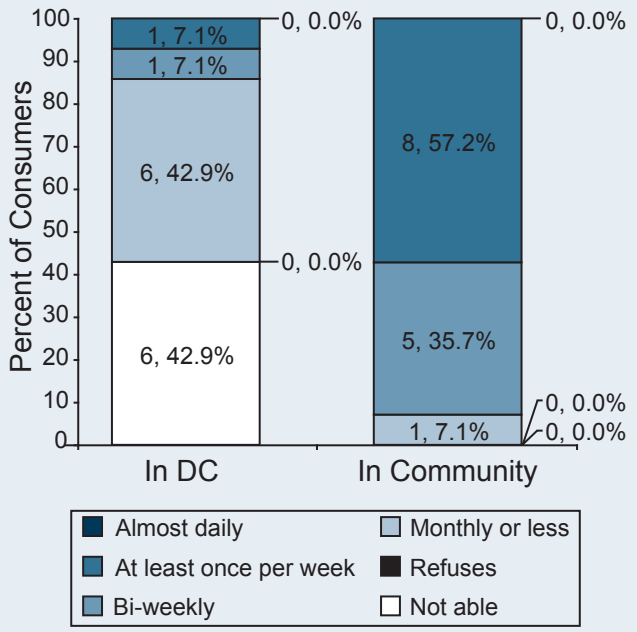


Figure 5.20
Restaurant Visits of the DC Movers



Restaurants

In the community, consumers went out to a restaurant more frequently than while residing in a DC. For example, over half of the DC Movers went out to a restaurant at least once a week as compared to only one consumer who went out at least once a week while in the DC. Also, the number of consumers who were unable to go out to a restaurant dropped from six while in the DC to zero in the community (Figure 5.20).

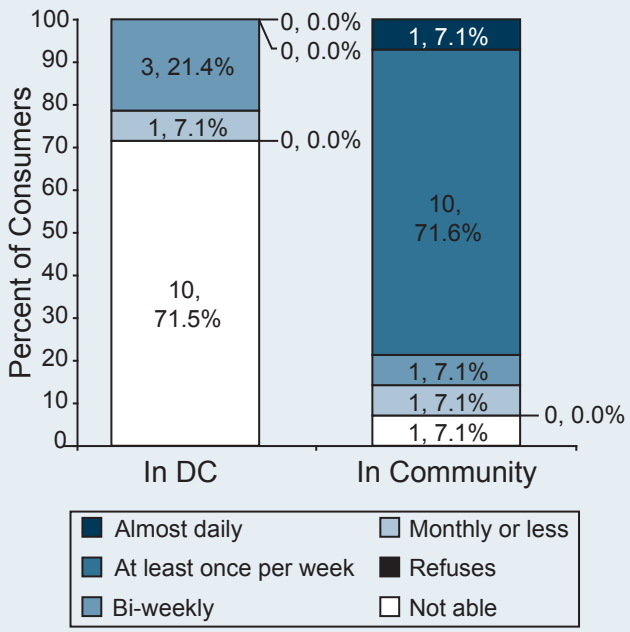
Volunteer Work

All DC Movers were unable to participate in volunteer activities while in a DC and in the community.

Park or Other Outdoor Recreation

Figure 5.21 shows, once in the community, almost all of the DC Movers participate in weekly or almost daily park visits or other outdoor recreation. While in a DC, these same consumers rarely participated in park activities.

Figure 5.21
Park and Other Outdoor Recreation for the DC Movers



Community Health Care

This section discusses data regarding the access to and quality of health care services received in a DC and in the community.

Access to Primary Medical Care

Figure 5.22 indicates that more of the DC Movers rated the access to primary medical care as easy to very easy to find while residing in a DC as compared to the community. While in the community, four of the DC Movers dropped their access ratings from easy and very easy to find to average.

Access to Specialist Care

Figure 5.23 shows that access to specialist care was easier for consumers when residing in a DC. Specifically, of those consumers who required specialist care (10 consumers), 80.0% of the DC Movers rated specialist care as very easy to find while in a DC as compared to one consumer reporting the same rating while in the community. Two consumers dropped their specialist access ratings to average once in the community.

Access to Dental Care

As mentioned in previous chapters, access to dental care is of great concern for consumers in the community. Figure 5.24 reflects, at least for the DC Movers, that access to dental care was average or above in the community. Still, access to dental care was rated much easier to access while in a DC than in the community

Quality of Medical Care

The overwhelming majority of DC Movers rated the quality of health care as satisfactory in the DC and in the community (Figure 5.25). The two exceptions were one rating of “average” for the quality of primary medical care and one for the quality of dental care in the community.

Mental Health

Mental health crisis episodes during the past year were examined for the DC Movers while in a DC and in the community. The results showed that none of the DC Movers experienced any of the following crises while in a DC or in the community: Chemical restraint, night away from residence, or a suicide attempt. One consumer reported a physical restraint while in a DC but none were reported while living in the community. In addition, one incident of harm to self was reported while in a DC but none were reported while in the community.

Legal Concerns

No incidents of criminal justice system involvement was reported for the DC Movers while in a DC or in the community.

Figure 5.22
Access to Primary Medical Care for the DC Movers

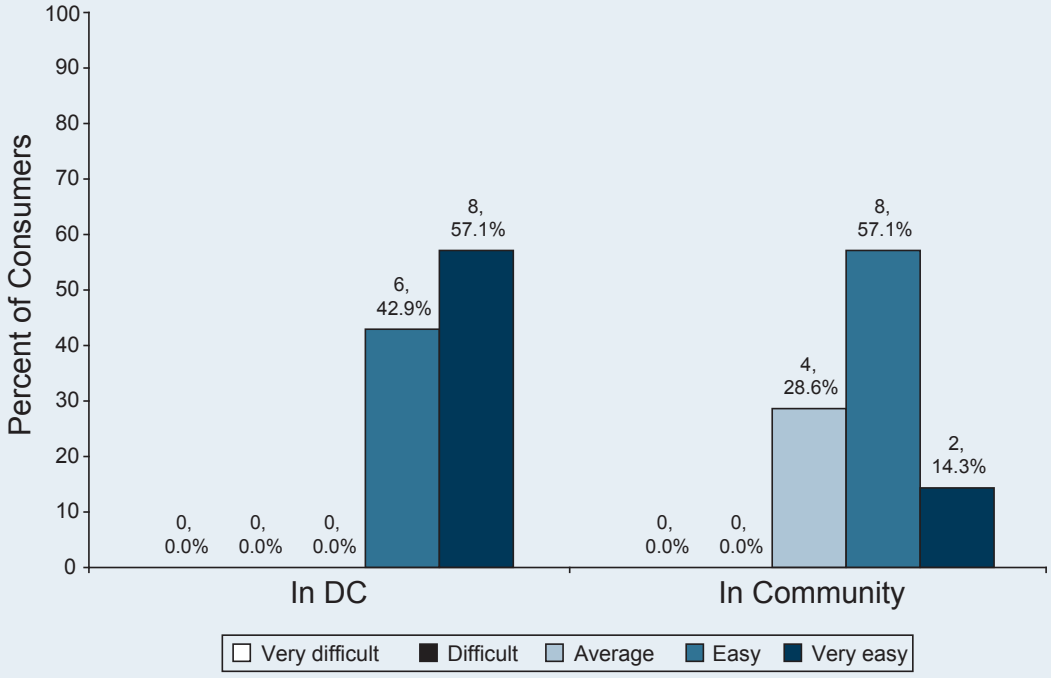


Figure 5.23
Access to Specialist Care for the DC Movers

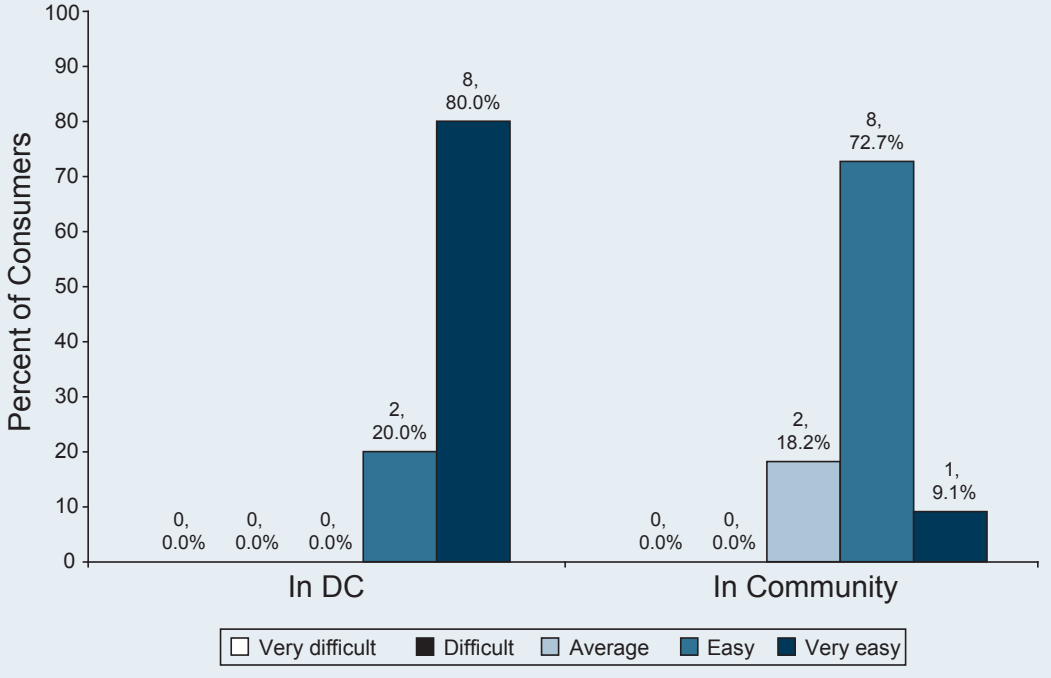


Figure 5.24
Access to Dental Care for the DC Movers

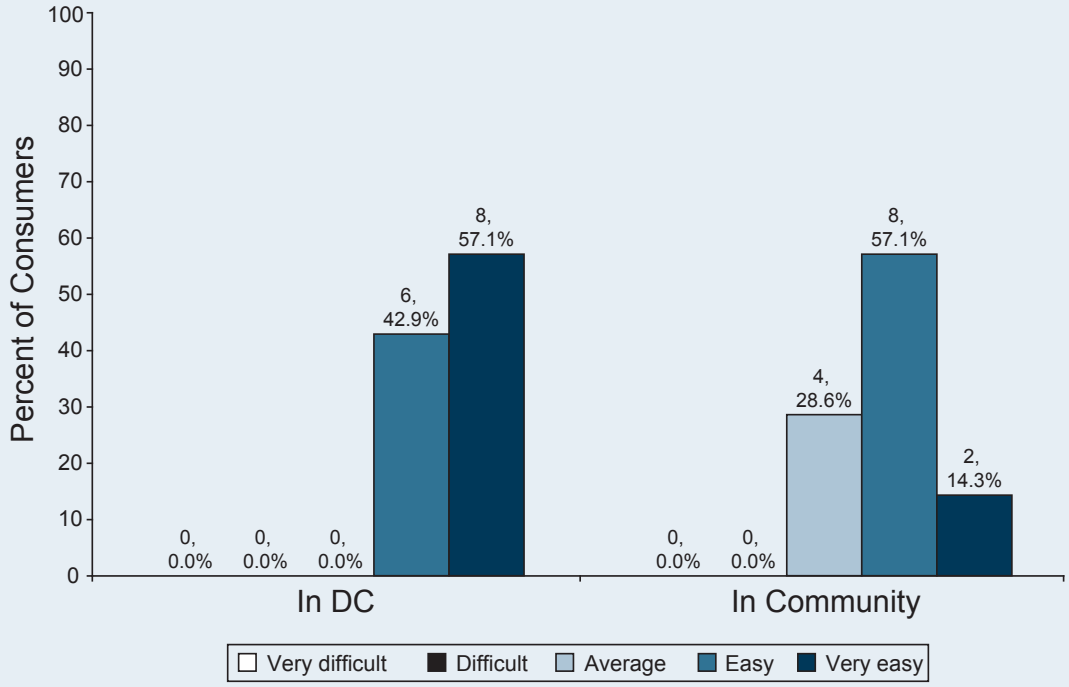
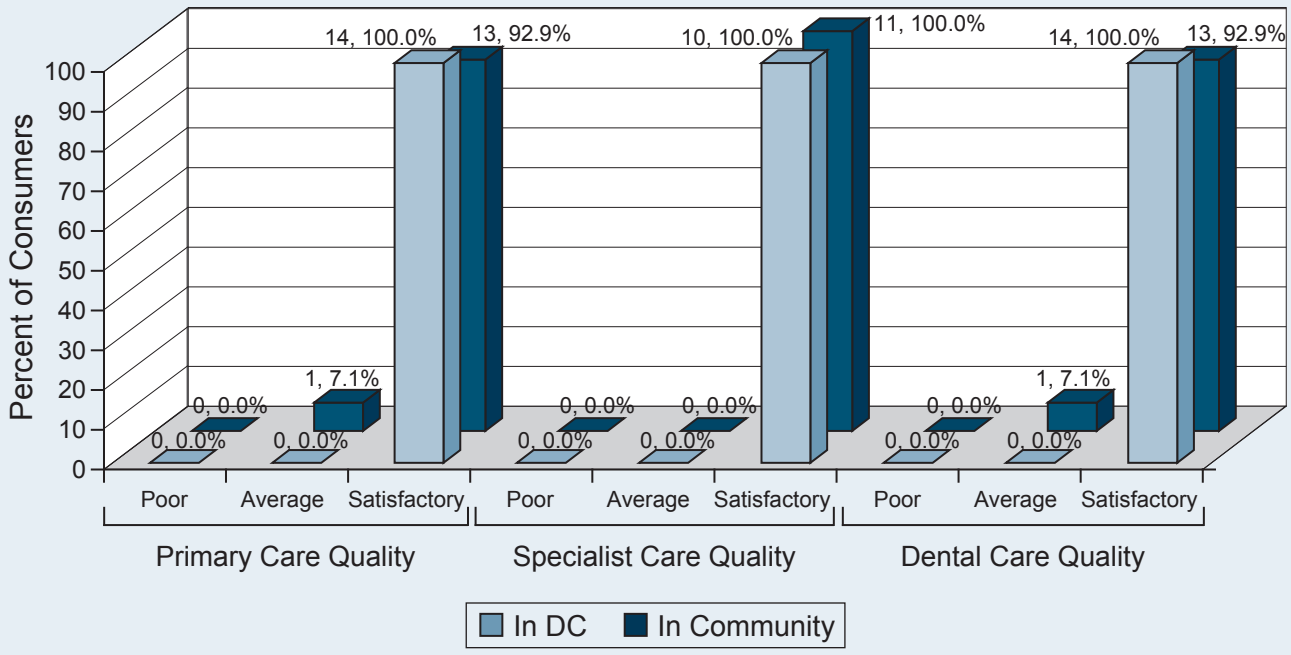


Figure 5.25
Quality of Medical Care for the DC Movers



CONSUMER SATISFACTION

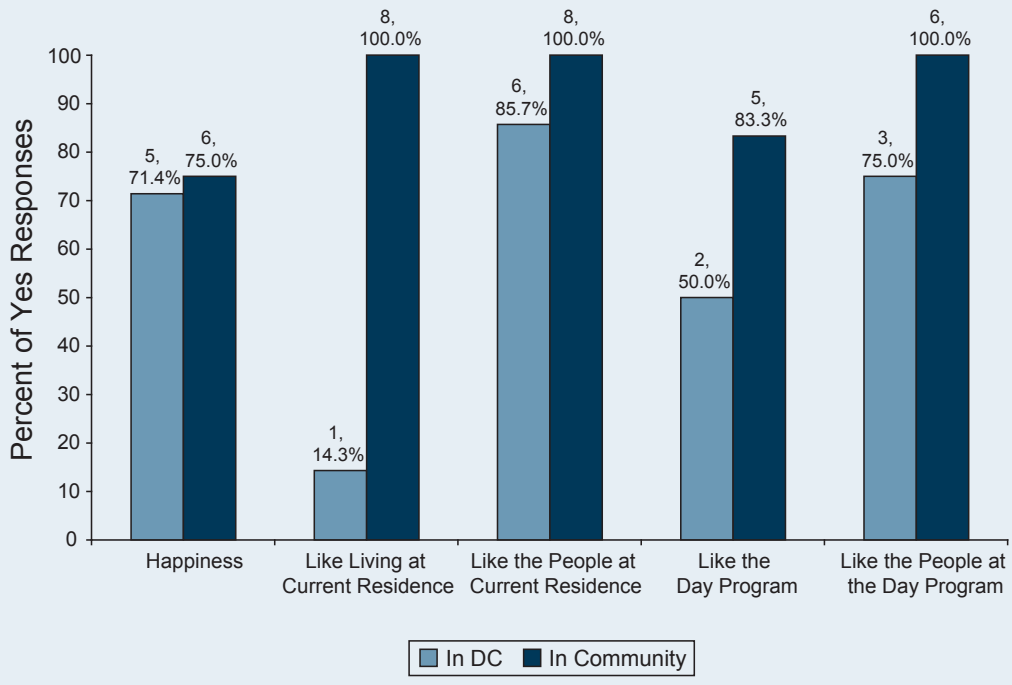
Consumer satisfaction was analyzed by evaluating five items from the consumer survey portion of the *Residential Survey*. The items were: (1) Are you happy most of the time, (2) Do you like living in your home, (3) Do you like the people who help you at home, (4) Do you like going to your day program, and (5) Do you like the people who help you at the day program. Consumer satisfaction was evaluated only for those consumers who responded for themselves (n = 8).

Figure 5.26 shows the percent of consumers who responded yes to each of the individual consumer satisfaction items. As shown:

- A larger percentage of the DC Movers reported being happy most of the time in the community as compared to the DC.
- All of the DC Movers reported they liked living in their current residence while living in the community as compared to only one consumer while living in the DC.
- Most of the DC Movers reported they liked the people they lived with while in a DC and in the community.
- A larger percentage of consumers reported liking their day program in the community as compared to the day program while in a DC.
- A larger percentage of consumers reported liking the people at their day program in the community than while living at a DC.

In summary, for the 14 consumers who were initially interviewed in a DC and subsequently in the community, their satisfaction ratings were higher in the community than in a DC.

Figure 5.26
Consumer Satisfaction Items for the DC Movers



CONCLUSIONS

The 2008 Mover Study found that:

- The DC Movers were given similar general health ratings in the DC and in the community.
- The DC movers participated more frequently in community errands, social outings, and park outings in the community as compared to the DC. Conversely, respondents reported a higher frequency of restaurant outings when the consumers resided in a DC than in the community.
- Access to health care was rated as average or above for both the DC and the community. Further, the quality of health care also received similar ratings of satisfaction in the community and the DC.
- Consumer satisfaction ratings were higher in the community as compared to the DC.