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**An Assessment of Service Needs  
for Developmental Disability Services  
in St. Charles County**

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Part 1

Conducted for  
**The Developmental Disabilities Resource Board of  
St. Charles County**

Conducted by the  
**Institute of Applied Research  
St. Louis, Missouri**

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## **1. Introduction**

This is a report on an assessment of service needs of St. Charles County residents with developmental disabilities. The project was conducted for the Developmental Disabilities Resource Board (DDRB) of St. Charles County and supported by the St. Charles Office of the St. Louis Regional Center. The DDRB was established under Senate Bill 40 to distribute county tax dollars to fund programs and services for residents with developmental disabilities. The Regional Center Office in St. Charles County is a satellite office of the Missouri Division of Mental Retardation and Developmental Disabilities and provides assessment and case management services.

Developmental disabilities are chronic intellectual or physical impairments that are manifested before age 22. They include “mental retardation, cerebral palsy, epilepsy, head injury, autism, or a learning disability related to a brain dysfunction or any mental or physical impairment.”<sup>1</sup> To be eligible for services funded by the DDRB, residents with such conditions must experience “substantial functional limitation in two or more of the following areas of major life activities: self care, receptive and expressive language development and use, learning, mobility, self direction and capacity for independent living or economic self-sufficiency.”<sup>2</sup>

### **Purpose and Goals of the Project**

It is the mission of the DDRB “to support people with developmental disabilities by partnering in the development and provision of programs and supports that encourage full participation in the community.”<sup>3</sup> This needs assessment project was designed to provide quantitatively accurate and reliable data that can guide the Board as it carries out this mission, providing a rational and informed frame of reference for its policy and decision making.

There were three specific and interrelated goals of this needs assessment:

1. Determine the support needs of county residents with developmental disabilities and their families. This includes immediate service needs as well as anticipated future needs

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<sup>1</sup> DDRB 2000 Annual Report, page 2.

<sup>2</sup> Ibid

<sup>3</sup> Ibid

in the short-term and longer-term. It also includes services that are currently available in the county as well as those needed services that may not now be offered.

2. Estimate the level and assess the nature of future service needs among persons with developmental disabilities in the county through the demographic analysis of available census projections and special education data.

3. Develop a database in electronic format that integrates the results of the needs assessment and demographic projections to allow updated estimates of service needs as more current data becomes available on the county's population.

## **Study Population**

The study population of this needs assessment consisted of the “visible” portion of the service-eligible population in the county. The visible population consists of people who are known to the service system in place in the county. The service-eligible population consists of persons with developmental disabilities who meet eligibility criteria of county and state service systems.

There will always be persons who may be eligible for services but who remain “hidden” and not known by the service system. This hidden group includes those who do not seek out assistance either from choice or ignorance about available services as well as those whose needs are being met in other ways, such as through informal family networks, churches or other support groups. In general, prevalence estimates tend to include both visible and hidden populations and, therefore, tend to reflect a level of service need that exceeds actual demand (or requests for services). One of the first decisions in any needs assessment is whether to attempt to include all residents eligible for services (including hidden populations) or whether to restrict the study to the subgroup of eligible people likely to knock on the service system's door. The chief argument for the latter approach is that rational planning is best served by information about the needs of those persons who actually seek assistance from the service system. In addition, it is reasonable to expect that decades of mandated special education programs and individual curriculum and transition planning have significantly reduced the size of the hidden population mostly to those who prefer to remain hidden. It is also the case that service systems always operate from a deficit, with limited budgets and resources, and are rarely in a position to provide all the assistance even the visible and eligible population requests.

Operationally, the study population in this needs assessment consisted of two groups: 1) county residents who have been determined eligible by the Regional Center and were in the database of that agency; and 2) county residents served by a provider agency funded by DDRB. At the time of the study there were approximately 2,000 unduplicated persons in St. Charles County that met one or both of these conditions.

## Research Design and Methodology

The centerpiece of the study was a survey instrument mailed to families or guardians of each person in the study population. The major steps involved in this were:

1. Instrument Construction. In consultation with an advisory committee established by the Executive Director of the DDRB, a questionnaire was developed. The instrument consisted mostly of questions about the service needs of consumers but also included a few background questions on the consumer and the respondent needed for statistical analysis. The process of development involved an initial draft of an instrument designed by the researchers and submitted to the committee. Feedback was provided by the committee in an active work meeting and a second draft was made. This was resubmitted to committee members and final modifications made based on their feedback. A copy of the survey instrument along with the cover letter that accompanied it is provided in the appendix of this report.

2. Identifying Consumers Served by Community Agencies. The names and addresses of persons with developmental disabilities served by agencies funded by the DDRB were solicited from these agencies. Certain background information on these service consumers was also requested (such as their age and disabling conditions) along with the names and addresses of their parents and/or guardians.

Eighteen agencies agreed to participate in the study and furnished some or all of the information requested. These agencies were:

- Boone Center, Inc.
- Child Day Care Association
- Children's Home Society
- Community Living, Inc.
- Emmaus Homes
- Epilepsy Foundation of Greater St. Louis
- Family Advocacy and Community Training
- Family Support Services
- Job & Employment Support Services
- Judevine Center
- Life Skills Foundation
- Metropolitan Employment & Rehabilitation Service
- Rainbow Village, Inc.
- Show Me Aquatics
- St. Louis Society
- United Services, Inc.
- Willows Way
- YMCA

3. Regional Center Database. The Regional Center provided a copy of its database for St. Charles County. It included the names and addresses of consumers and their parents and/or guardians, the age, sex, race and disabling conditions of consumers.

4. Project Database. A project database was created into which data were merged from the community agencies and the Regional Center. A number of consumers appeared on more than one of the lists supplied by the various agencies and these duplicates were identified. The final form of the database consisted of 2,008 unduplicated records, each representing an individual and each indicating on which agency list or lists his or her name appeared along with the background information that had been provided.

6. Piloting. A small number (20) of consumers were randomly selected for a pilot of the survey instrument. Half of these were returned. They were reviewed for any signs that the questions on the instrument had been misunderstood or misinterpreted or that options for responding were confusing or did not produce useable answers. No problems were found in the returned questionnaires that prompted any changes in the instrument or cover letter that had been prepared

5. Survey Process. Copies of the questionnaire and cover letter were printed. The questionnaires were mailed to the addresses of the parents or guardians of consumers, and when such an address had not been provided, questionnaires were sent to the consumer's address in care of his or her guardian. A business reply return envelope was enclosed that did not require a stamp. On the back of the cover letter the following statement was printed: "If for any reason you would prefer to be interviewed by telephone rather than completing the questionnaire, please write in your name and telephone number below and the best time for us to call you. Then mail this back to us in the enclosed envelope and someone from IAR will contact you. Thanks again."

6. Survey Response. A total of 619 survey responses were received, 592 in time to be included in the analysis. Seven of these 7 were incomplete and could not be used, leaving 585 for analysis. This included 14 individuals who requested they be contacted and interviewed by telephone. They were.

There were 67 questionnaires returned by the Post Office as undeliverable as addressed. Another 9 were returned unopened with an indication that the person was deceased. Excluding these there were 1,932 surveys that, presumably, reached their intended target, although it is generally the case in large scale surveys, such as this one, that some do not.

The response rate at the time of the analysis, therefore and excluding late returns, was 30.6 percent, a very acceptable figure for this type of survey—that is, one in which 1) the entire study population was surveyed rather than a subset or sample only, 2) there was a single mailing, 3) no stipend was included, 4) some of the recipients of the surveys were known to be quite elderly, and 5) the names and addresses of some of the survey targets, parents and guardians, were not known.

7. Analysis. A series of analyses were conducted on the responses and are included and discussed in this report.

In addition to the survey, the most recent general population census data and special education data were obtained and analyzed. These data were primarily needed so that projections could be made of the future service-eligible population and their needs. These data and their sources are explained in the report.

## **Organization of the Report**

Chapters 2 through 6 pertain to findings related to the needs assessment survey. Chapter 2 includes an analysis of what is known of the study population and survey respondents. Chapter 3 describes characteristics of consumers and their families. Chapter 4 discusses findings related to the service needs of consumers. Chapter 5 addresses residential living needs and needs related to employment. Chapter 6 details services currently received by consumers and their families and identifies unmet service needs.

Chapters 7 through 10 cover various issues related to projecting service needs into the future. Chapter 7 reviews recent prevalence literature applicable for such a projection, reviews current special education data for the county, discusses the value of service system data and reaches conclusions about the prevalence of developmental disabilities in St. Charles County. Chapter 9 summarizes the most current census data and population growth projections for the county. Chapter 10 provides projections of service needs through the end of the decade based on the results of the needs assessment, conclusions reached about prevalence, and current population projections for the county.

## 2. Study Population and Survey Respondents

### Study Population

The study population consisted of 1,932 persons whose families or guardians received a survey questionnaire. What we know about these individuals varies depending on which agency list they were included. Some lists included disabling condition, for example, while others did not. However, all included a useable address with a zip code and most included the age of the consumer.

**Affiliation with Regional Center and Community Agencies.** Of the 1,932 consumers, 1,401 (72.5 percent) were included in the database of the Regional Center while 1,258 (65.1 percent) were included on the client list of one or more community agencies. Thus, over one-third (37.6 percent) were included in both the Regional Center database as well as at least one of the community agencies. The following table provides a summary of this information.

Table 2.1. Study Population and Agency Affiliation

| Type of Agency                            | Frequency | Percent |
|---|-----------|---------|
| Regional Center                           | 1401      | 72.5%   |
| Community Agency                          | 1258      | 65.1%   |
| Both Regional Center and Community Agency | 727       | 37.6%   |
| Regional Center Only                      | 674       | 34.9%   |
| Community Agency Only                     | 531       | 27.5%   |

**Age of Consumers.** The age distribution of the consumers in the study population is shown in Figure 2.1. As can be seen, a significant portion of them were quite young; over one-fourth were under the age of 5. While the mean age of the consumers was 20 (19.9), the median age was just 14 and a better indicator of the nature of the population. Sixty-one percent were younger than 20; 39 percent were 20 or older. On the other hand, 4.2 percent were aged 60 or older.

Consumers in the Regional Center database tended to be slightly younger. The average age of this group was 21.0. The average age of consumers in lists received from community agencies was 23.6. Much of this difference was due to the somewhat larger proportion of Regional Center children under the age of 5, 26.5 percent of all consumers in this database. This youngest group made up 17.9 of all consumers in lists from community agencies. The bar graph in Figure 2.2 shows the difference in the age distribution between the two consumer groups.

Figure 2.1. Age Distribution of Consumers in the Study Population

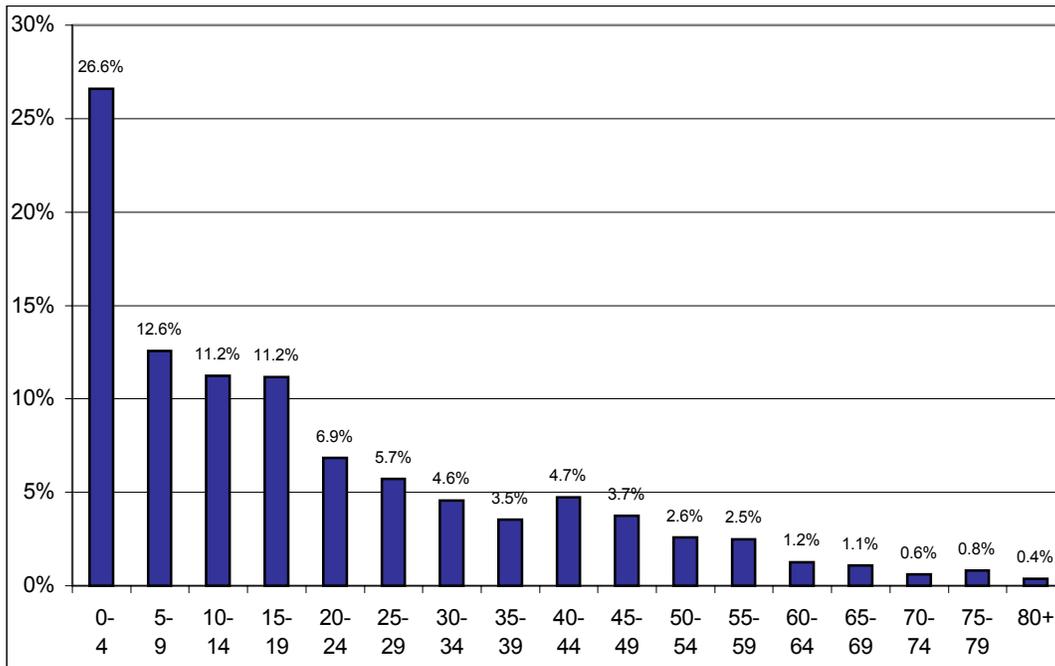
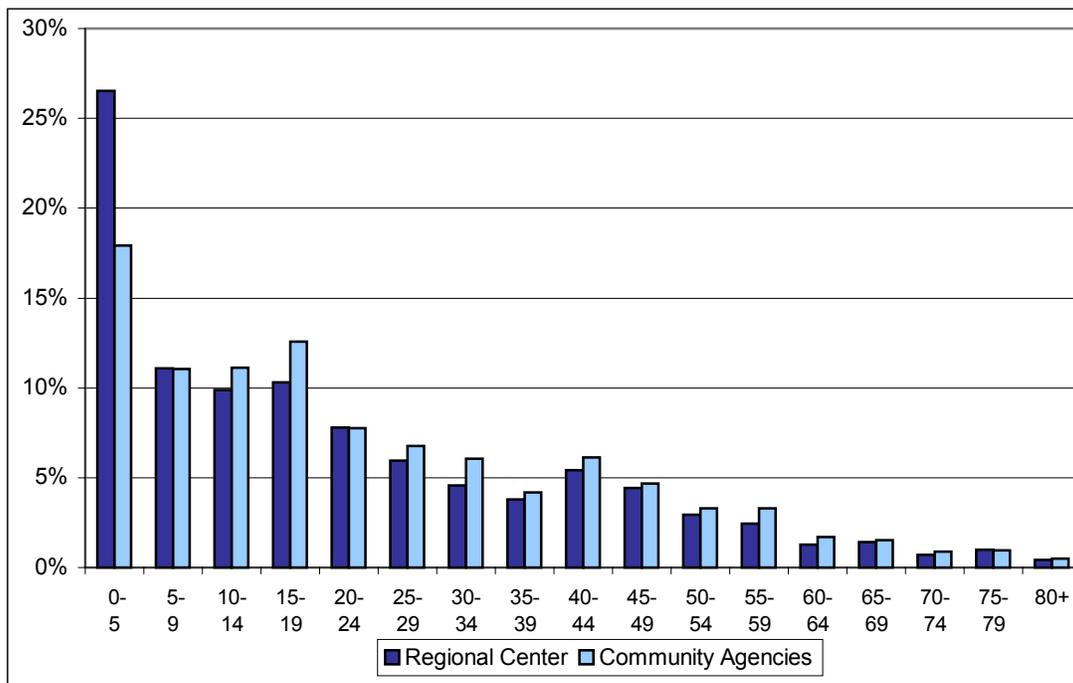
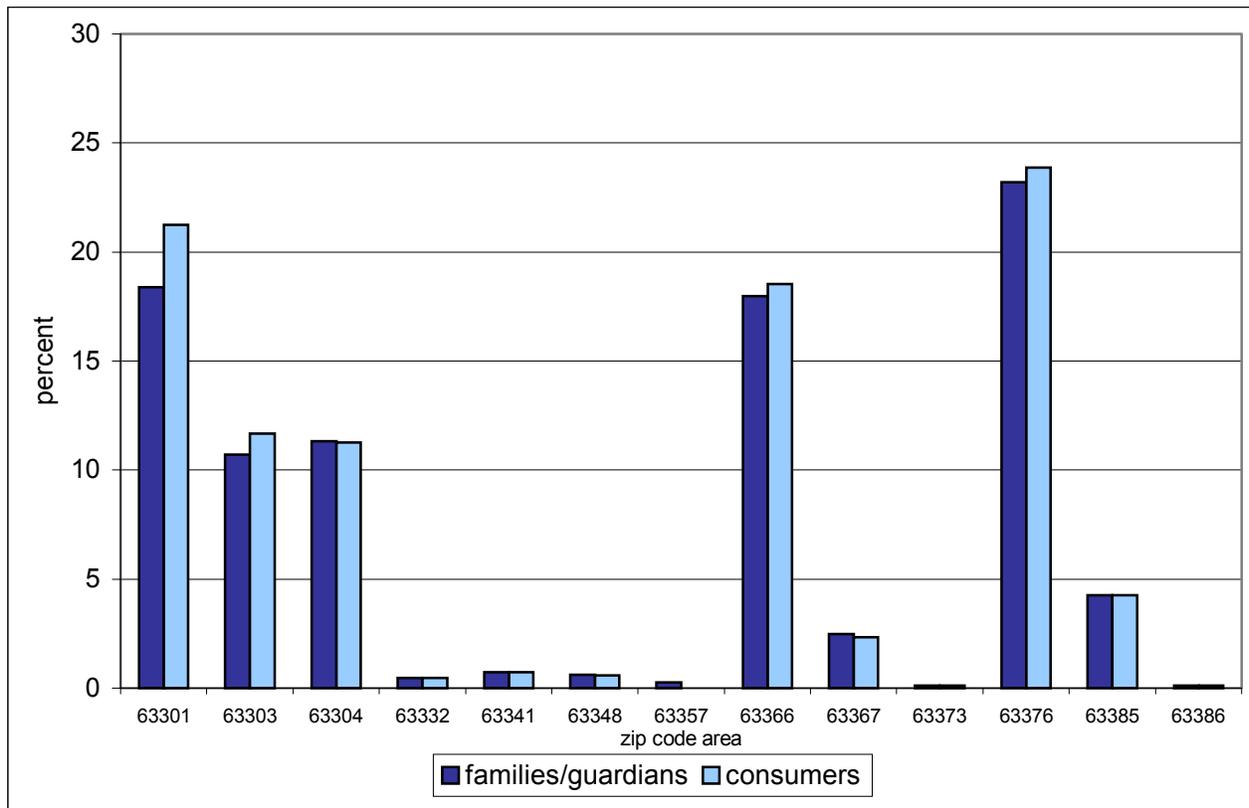


Figure 2.2. Age Distribution of Consumers Affiliated with Regional Center and Community Agencies



**Geographical Distribution.** Most (90.4 percent) of the parents/guardians had an address within St. Charles County. Some (8.5 percent) lived in another Missouri county, generally one adjacent to St. Charles, such as Warren, Lincoln or St. Louis County. A small number (1.1 percent) lived in another state. Figure 2.3 shows the distribution of families and guardians within St. Charles County zip code areas. It also shows the percentage of consumers in the study population with addresses within these zip code areas. (The overall percentage of families accounted for in the figure is somewhat lower than consumers' figure because not all families resided in the county.)

Figure 2.3. Zip Code Address of Families and Consumers



## Survey Respondents

A total of 585 useable survey responses were received. In most cases (82 percent) the respondent was the parent of the consumer, most often his or her mother (69 percent of all respondents). Consumers themselves responded in a few instances (3 percent), sometimes in collaboration with their parents. Other relatives, most often sisters of the consumers, were respondents 7.4 percent of the time. Stepparents, foster parents and other legal guardians returned 1.5 percent of the surveys. Agency staff, providers of care and support, completed the survey for consumers in some instances (5.8 percent). This information is summarized in the following table.

Table 2.2. Survey Respondents

| <i>respondent type</i> | <i>n</i> | <i>%</i> |
|------------------------|----------|----------|
| parent                 | 480      | 82.1%    |
| other relative         | 43       | 7.4%     |
| agency staff           | 34       | 5.8%     |
| consumer               | 17       | 2.9%     |
| step/foster parent     | 9        | 1.5%     |
| friend                 | 2        | 0.3%     |
| total                  | 585      | 100.0%   |

**Affiliation with Regional Center and Community Agencies.** Of the 585 survey respondents, 81.5 percent were included in the Regional Center database and 65.6 percent were included on one or more lists received from community agencies. Nearly half, 47.3 percent, were included in both the Regional Center database and at least one community agency. The following table compares the survey respondents with the study population on their affiliation with the Regional Center and community agencies. As can be seen, Regional Center clients have a somewhat higher representation in the survey group than they had in the study population. Respondents served by community agencies were represented among survey respondents in the same proportion as they appeared in the study population. In terms of general agency affiliation, the survey respondents adequately reflect the study population.

Table 2.3. Agency Affiliation among Survey Respondents and the Study Population

|   | survey respondents | study population |
|---|--------------------|------------------|
| Regional Center                         | 81.5%              | 72.5%            |
| Community Agency                        | 65.6%              | 65.1%            |
| Both Regional Center & Community Agency | 47.3%              | 34.9%            |

**Age of Consumers.** The age distribution of consumers represented in survey responses is shown in Figure 2.4. Nearly one-quarter of these consumers was under the age of 5 and 57.9 percent were less than 20. The age distribution of these consumers closely matched that of consumers in the entire study population as can be seen in Figure 2.5. The mean age of consumers represented in survey responses was 21.2 years and their median age was 15.8. The mean age of consumers in the study population was 19.9 and the median age was 14.0.

Figure 2.4. Age Distribution of Consumers in Survey Responses

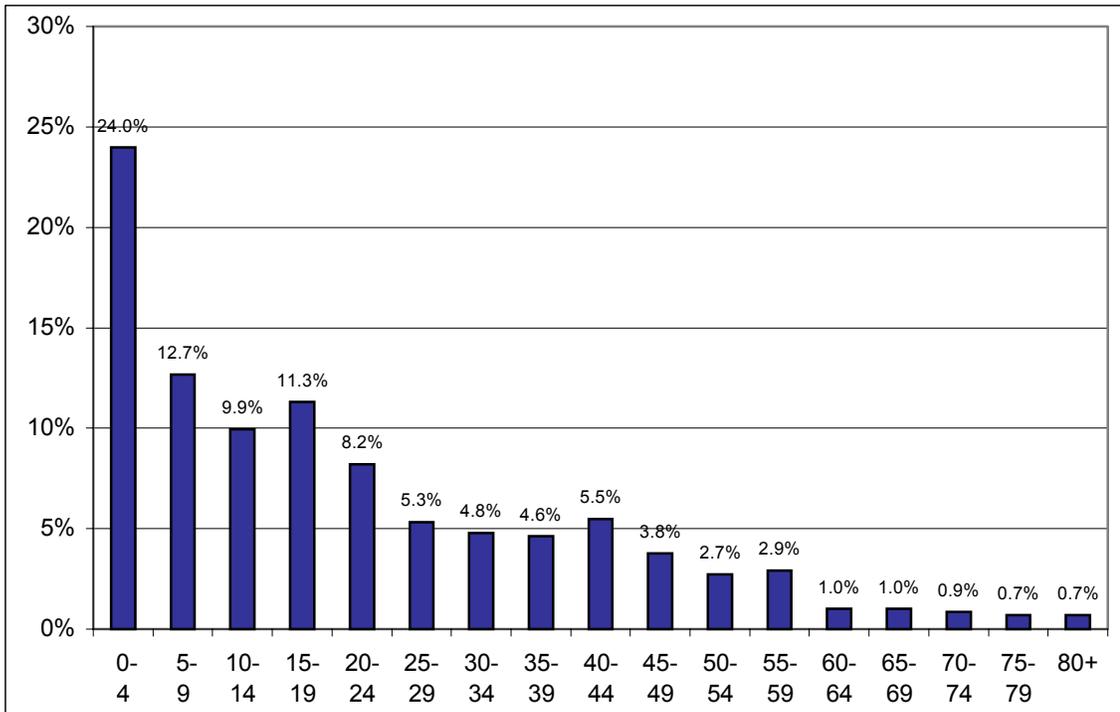
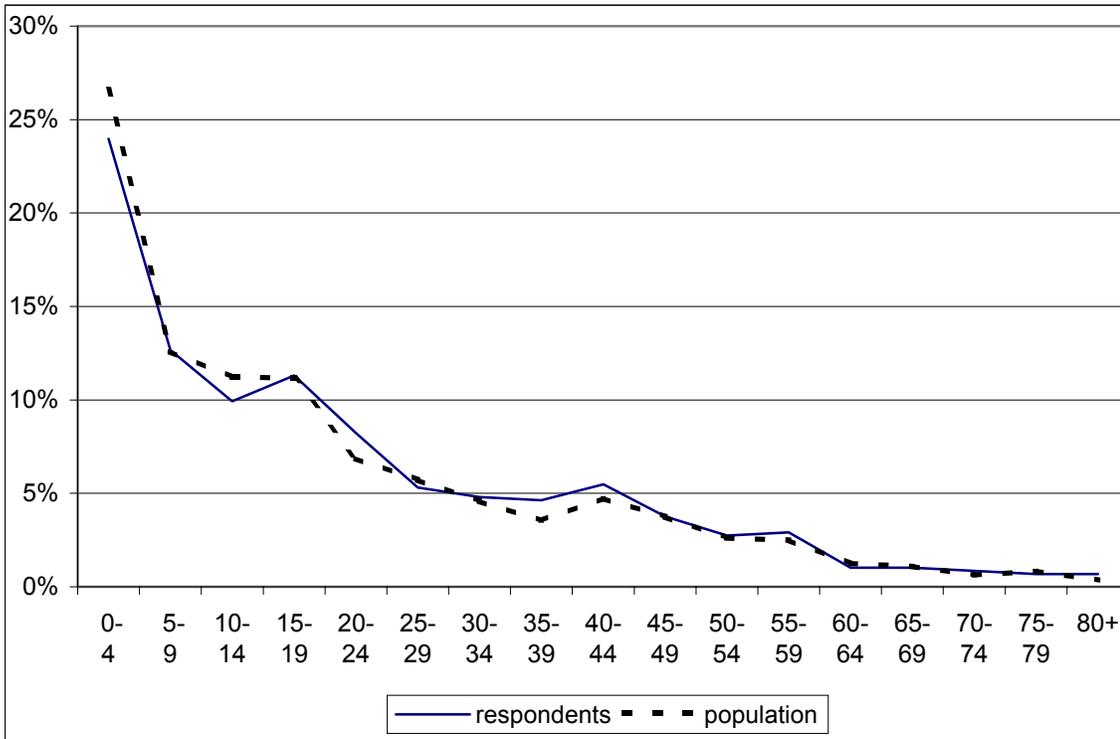


Figure 2.5. Age Distribution of Consumers in Survey Responses and the Study Population

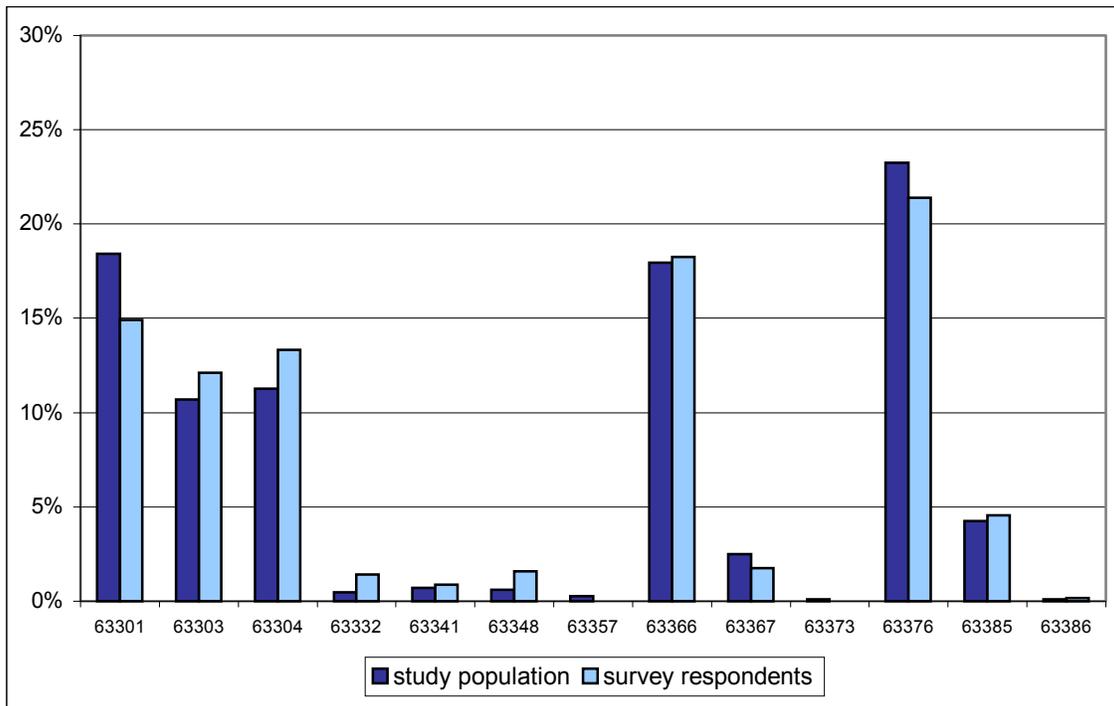


The level of similarity between the survey responses and the entire study population in those areas where the two groups can be compared—agency affiliation, geographic distribution, and age of consumers—indicates an acceptable correspondence between the two. This, coupled with the level of response in a survey that did not involve

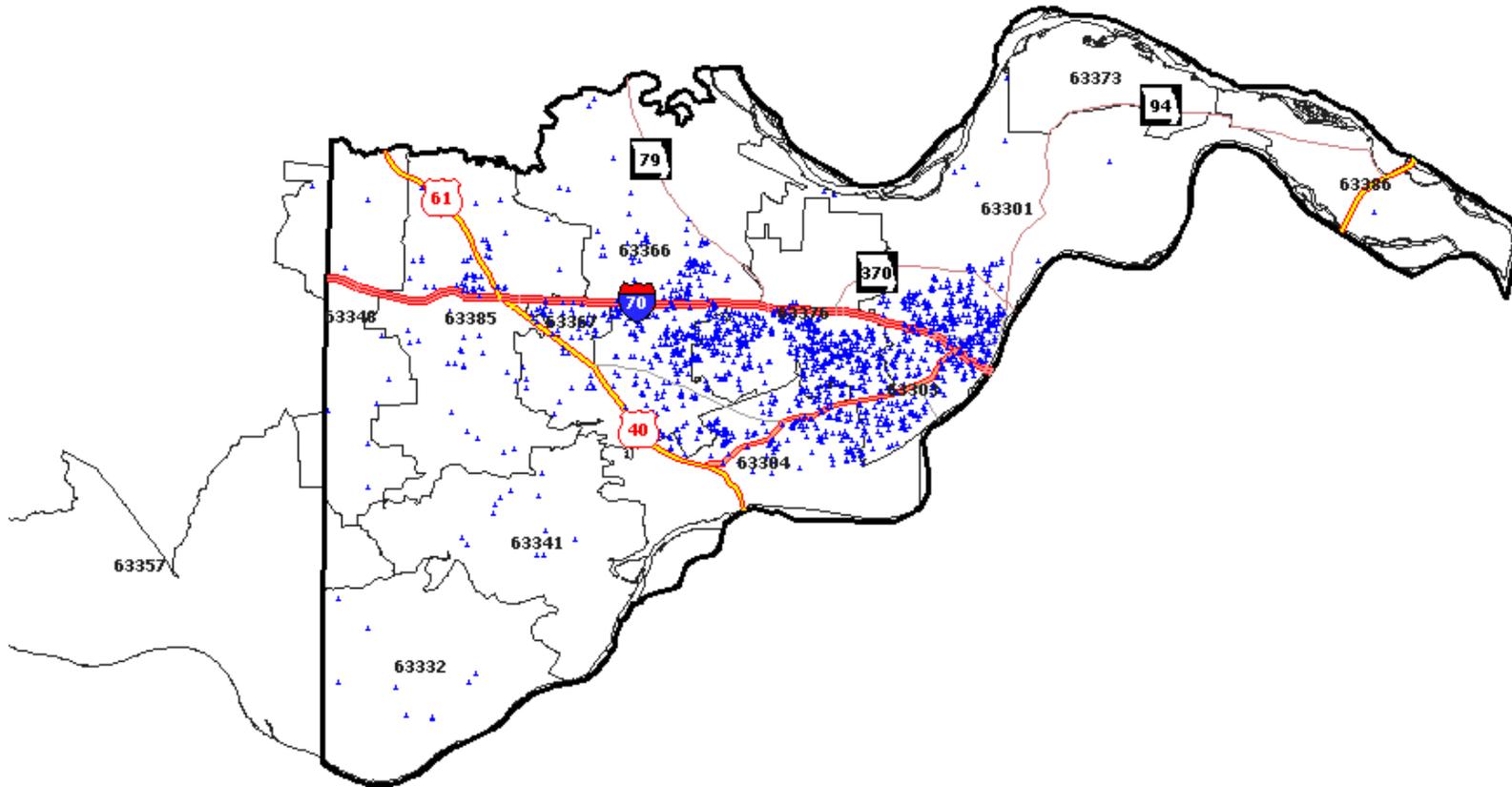
sampling, indicates that the response set is adequately representative of the entire population and that statistical weighting of responses is not necessary for the integrity of the results.

**Geographical Distribution.** The geographical distribution of survey respondents closely reflected that of the study population as a whole. Ninety percent of both groups resided in St. Charles County. Nearly all of the other survey respondents were living in adjacent counties. The proportion of respondents who resided in specific St. Charles County zip code areas also closely matched the proportions for the study population as a whole, as can be seen in Figure 2.6 and the two maps that follow. The first map plots the residences of the study population in St. Charles County. The second map plots the addresses of survey respondents. The zip code areas within the county are shown on both maps.

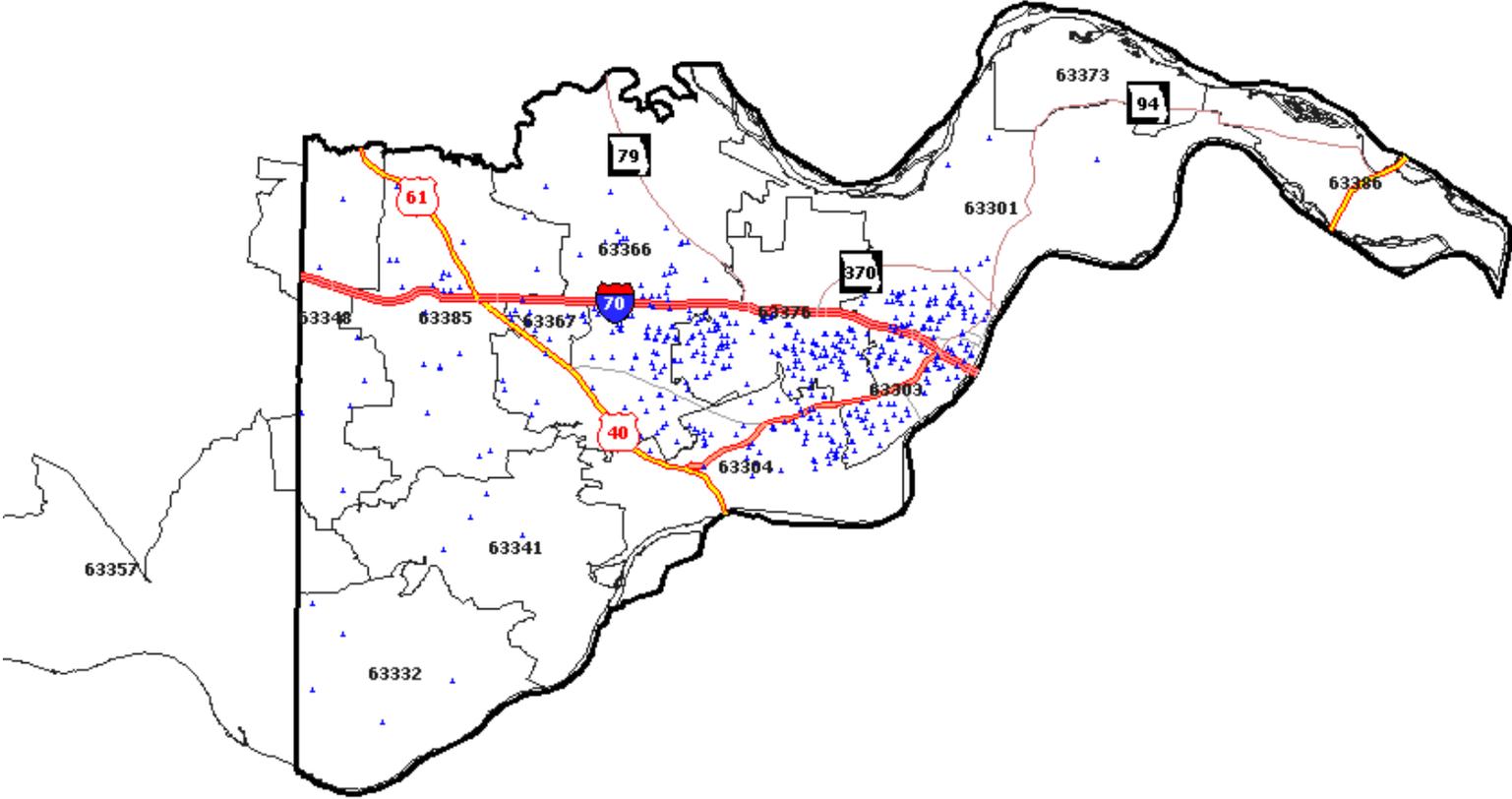
Figure 2.6. Zip Code Addresses of the Study Population and Survey Respondents



# Study Population



# Survey Respondents



### 3. Characteristics of Consumers and their Families

#### Consumers

**Age.** The age distribution of consumers represented in survey responses was given in the previous chapter. For the sake of a detailed understanding of the population, the ages of consumers were given in 5-year groupings. However, in most analyses conducted for this project consumers were broken into four distinct groups by age: 1) preschool children, ages from birth through 5 years; 2) children in school, ages 6 through 18; 3) consumers about to leave school or no longer in school, ages 18 and over; and 4) consumers aged 55 and over. A review of responses showed that all consumers in the survey population up to the age of 17 were in school. At age 18, some consumers were in school and others were not. In our age groupings, therefore, we took age 18 to be the dividing point and placed 18 year olds who were in school in the second, in-school age category (ages 6-18) and placed those 18 year olds not in school in the third or adult age category (18 and over). This gives us the following age groupings for the study:

Table 3.1. Study Age Groups

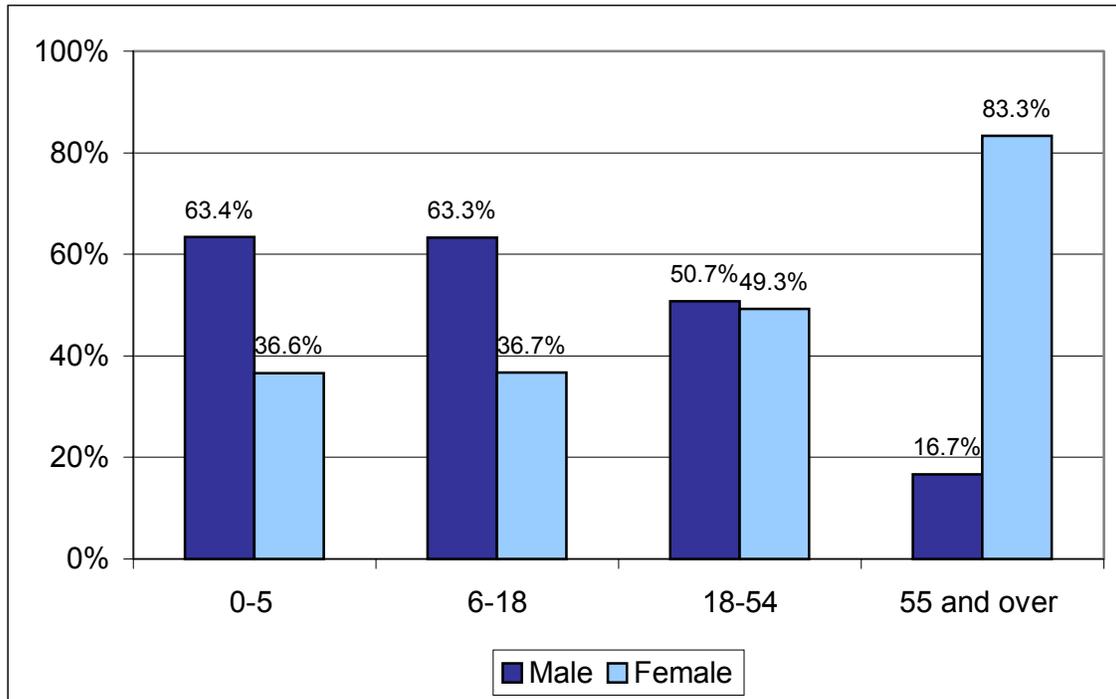
| <i>Age Group</i> | <i>n</i> | <i>%</i> |
|------------------|----------|----------|
| 0-5 (preschool)  | 161      | 27.6     |
| 6-18 (in school) | 168      | 28.8     |
| 18-54 (adult)    | 214      | 36.6     |
| 55 and over      | 42       | 7.2      |
| Total            | 585      | 100.0    |

**Sex.** There were more males (55 percent) than females (45 percent) in the surveyed population overall. This imbalance is most pronounced in younger children, as Figure 3.1 shows. Among consumers between the ages of 18 and 54 about equal numbers are male and female. Among older consumers, there were many more females.

**Race.** The large majority (94.5 percent) of consumers in the surveyed population were white. The largest minority group represented was Black/African American, 2.9 percent, followed by Hispanic/Latino, 1.2 percent, and Asian, 1.0 percent.

**Disabling Conditions.** Table 3.2 shows the percentage of consumers in the survey population with specific disabling conditions as reported by respondents. Half of the consumers were persons with mental retardation. Cerebral Palsy or other orthopedic impairments were indicated for 16 percent and neurological impairments for 10 percent.

Figure 3.1. sex by age group



Thirteen percent of the consumers were persons with autism; 2 percent had experienced traumatic brain injuries. There were also 5 percent with psychiatric disorders and another 5 percent with some emotional disturbance, among other conditions as can be seen in the table. Across the population, one in five experienced multiple disabling conditions, often mental retardation combined with a second or third impairment.

Table 3.2. Percent of Consumers with Specific Disabling Conditions

| Disabling Condition           | %    |
|-------------------------------|------|
| Mental Retardation            | 49.5 |
| Autism                        | 13.3 |
| Cerebral Palsy                | 11.2 |
| Deafness/Blindness            | 3.1  |
| Obsessive Compulsive Disorder | 3.1  |
| Epilepsy                      | 2.2  |
| Brain Injury                  | 2.0  |
| Spina Bifida                  | 0.9  |
| Other Orthopedic Impairment   | 4.4  |
| Other Neurological Impairment | 3.9  |
| Speech/Language Impairment    | 12.7 |
| Emotional Disturbance         | 5.5  |
| Psychiatric Condition         | 5.2  |
| Developmental Delay           | 2.4  |
| Other Health Condition        | 1.7  |
| Multiple Disabling Conditions | 21.2 |

**Living Arrangements.** Over three-quarters (77.3 percent) of all the consumers lived in their natural home with their families, 12.2 percent lived in a group home or other supervised facility, 7.7 percent lived in a supported living arrangement, 1.9 percent lived independently without support, and .9 percent lived in other situations (e.g., with a spouse or another person).

Nearly all (98.9 percent) consumers under the age of 21 lived in their homes. For consumers aged 21 and older, 45.1 percent lived in their homes, 29.6 percent were in group homes or supervised facilities, 18.5 percent were in supported living situations, and 4.7 lived independently. (See Figure 3.2).

Figure 3.2. Living Situations of Consumers

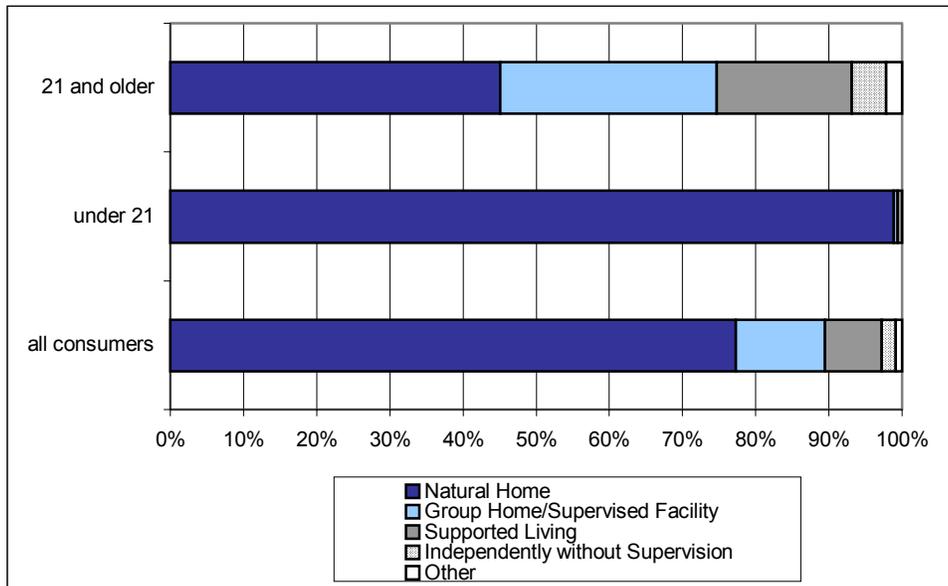


Table 3.3 shows the current living arrangements of consumers of different ages. (Note that age is broken down more finely here and in traditional decade units due to the nature of the issue.) Those consumers who leave home as they get older tend to move into either some type of supervised group setting or a supported living situation.

Table 3.3. Living Arrangement of Consumers of Different Ages

| Type of living arrangement        | 0-5    | 6-19  | 20-29 | 30-39 | 40-49 | 50+   |
|-----------------------------------|--------|-------|-------|-------|-------|-------|
| Natural Home                      | 100.0% | 98.3% | 70.9% | 61.8% | 38.9% | 10.3% |
| Group Home/Supervised Facility    | 0.0%   | 1.1%  | 6.3%  | 18.2% | 37.0% | 58.6% |
| Supported Living                  | 0.0%   | 0.6%  | 15.2% | 12.7% | 16.7% | 27.6% |
| Independently without Supervision | 0.0%   | 0.0%  | 5.1%  | 1.8%  | 7.4%  | 3.4%  |
| Other                             | 0.0%   | 0.0%  | 2.5%  | 5.5%  | 0.0%  | 0.0%  |

**School.** About 4 in 10 consumers (43 percent) were in some type of educational program at the time of the survey. (See Table 3.4). This includes those children in pre-school programs (11 percent) as well as those in a vocational school program (.5 percent) and programs affiliated with a community college or other college program (1.2 percent). In addition, 6 percent (not shown in Table 3.4) were in some other special adult program that the respondent considered educational or vocational, such as a day program or sheltered workshop and .9 percent were in the “state school.”

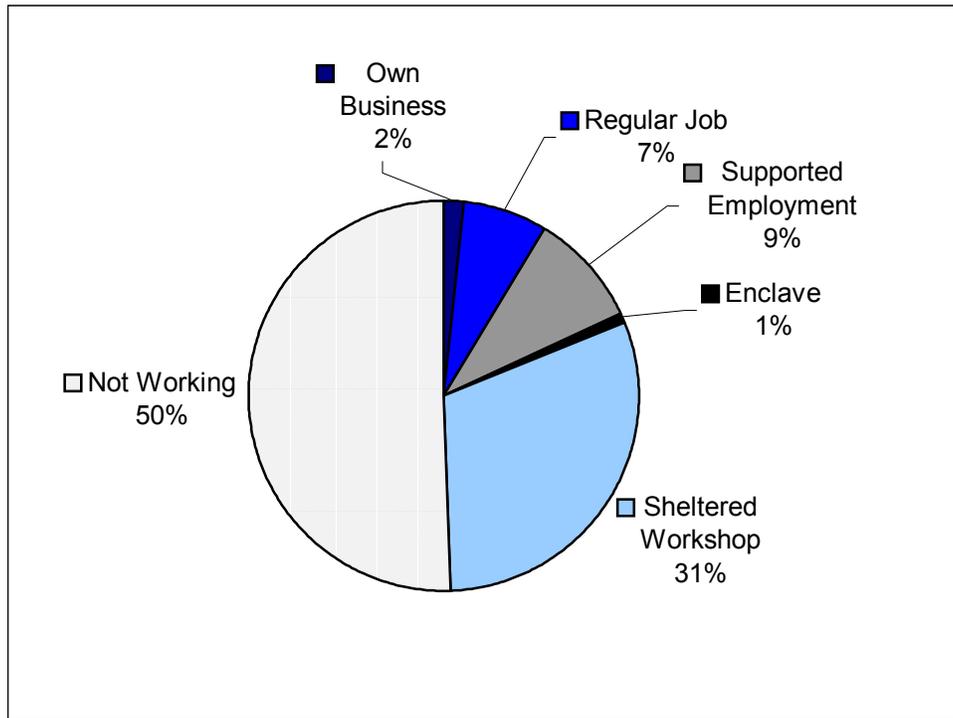
Table 3.4. Percent of Consumers in Different Types of Educational Programs.

| Type of Educational Program          | %    |
|--------------------------------------|------|
| Pre-School                           | 11.3 |
| Elementary School                    | 20.1 |
| High School                          | 10.1 |
| Vocational School Program            | 0.5  |
| College or Community College Program | 1.2  |

Respondents were asked if the consumer would like to become a student in an educational or vocational program now or in the future. In response, 8 percent said the consumer would like to enroll in a college or community college program—even though very few now are—and one in four said they would like to begin such a program this year. Similarly, 16 percent indicated an interest in enrolling in a vocational or skill training program with one-third saying they would like to begin within the year.

**Employment/Work.** Altogether, 22 percent of the consumers in the survey population had a paid job. Of those aged 21 and over, 50 percent had a paid job and 50 percent did not. Figure 3.3 is a pie chart showing the types of jobs held by consumers aged 21 and over. The most common form of employment for consumers with a job was in a sheltered workshop. Thirty-one percent of all consumers 21 and older worked in sheltered workshops, while 10 percent worked in supported employment situations. Seven percent worked in regular jobs without support. A small number, as can be seen in the figure, worked in some form of enclave setting, that is, along side other persons with disabilities, but not in a workshop. A very small percentage were being assisted to operate their own business enterprises.

Figure 3.3. Types of Jobs Held by Consumers Aged 21 and Over



Consumers who had jobs, worked an average of 28.4 hours per week. Their average weekly earnings were \$104.00 and their average hourly wage was \$3.66. Hours worked and wages earned varied with the type of work situation, as can be seen in Table 3.6. While consumers who worked in sheltered workshops worked more hours on average than other consumers, earnings were highest for consumers who worked in regular jobs without support followed by those in supported employment.

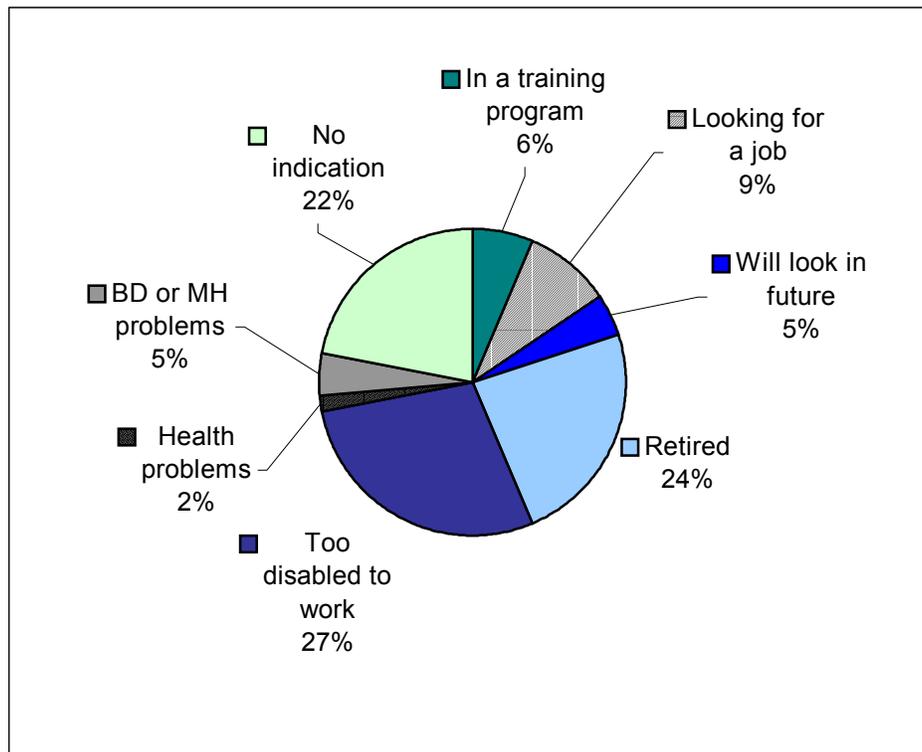
Table 3.5. Hours Worked and Wages Received

| Type of Work         | Avg Hours/Week | Avg Wages/Week | Avg Hourly Wage |
|----------------------|----------------|----------------|-----------------|
| Own Business         | 23.3           | \$21.72        | \$0.93          |
| Regular Job          | 26.6           | \$176.95       | \$6.66          |
| Supported Employment | 21.5           | \$121.44       | \$5.64          |
| Enclave              | 24.5           | \$91.75        | \$3.74          |
| Sheltered Workshop   | 33.2           | \$80.17        | \$2.41          |
| Total                | 28.4           | \$104.00       | \$3.66          |

Figure 3.4 shows the reasons given for why consumers over 21 and without jobs were not working. The most common reason was that they were considered too disabled. This was the case with 28.2 percent of consumers over 21 who were not working. Some (23.6 percent) were retired or were considered too old to work. Some of those without a job were currently looking for one (9.1 percent) or planned to do so in the future (4.5

percent). A few had health problems (1.8 percent) or mental health or behavioral problems (4.5 percent) that kept them from working.

Figure 3.4. Reasons Given for Why Consumers Aged 21 and Over and Without Jobs were not Working



**Other Income Sources.** According to respondents, 41 percent of the consumers received financial support from their families, 36 percent received SSI (Supplemental Security Income), and 12 percent received SSDI (Social Security Disability Insurance). A small number (.5 percent) received a pension through a parent. Less than 1 percent of the families received adoption subsidies for the consumer and 2.2 percent received public assistance. One in five responses (19.5 percent) involving a consumer aged 21 or over reported that the consumer received financial support from his or her family.

## Families

The large majority (82.1 percent) of survey respondents were the parents of consumers. A small percentage (1.5 percent) were the step or foster parents of consumers. A few respondents (7.4 percent) were related to consumers in other ways—grandparents, brothers or sisters—and represented the natural family of the consumers. Altogether, 91 percent of respondents were related to the consumers in one of these ways. A large majority (78.6 percent) of the consumers lived with the person responding to the

survey. When the respondent was a parent, the percentage living with the respondent was 86.7.

The characteristics of the households of respondents related to consumers (who were the parents, step parents or foster parents of consumers (representing 91 percent of all respondents) are shown in Table 3.6. The table summarizes this information for all of these households combined (“total”) and by the age group of the consumers. (It should be noted that for the oldest group of consumers, some family member other than a parent often responded to the survey. As these were often siblings, the characteristics of this group reflects someone closer in age to the consumer versus someone a generation older.)

For the entire response set, there were many more two-parent households than single households. The mean number of persons living in these households was 3.25, including an average of 1.5 younger than 18 and 1.7 who were 18 and older. As would be expected, the average household size was largest in households of the youngest consumers and decreased with the age of the consumer.

One household in six (17 percent), had another household member with developmental disabilities. Among households represented by the 0-5 consumer age group, the figure was 29 percent.

The mean age of family respondents was 44.7. Thirty-nine percent were younger than 40. Seventeen percent were age 60 or older.

Forty-four percent of family respondents had college degrees and another 27 percent had attended college. Just 4 percent had not completed high school. The educational attainment of respondents was closely related to the age-grouping of the consumers (which in turn was related to the age of the respondents). Thus, 54 percent of the respondents representing the 0-5 consumer age group had completed college, and fully 8 out of 10 had attended college, whether or not they graduated.

Over one-third of the respondents (38 percent) had family incomes over \$60,000, 26 percent reported an income between \$40,000-59,999, and 22 percent reported an income between \$20,000-\$39,999, while 14 percent had incomes below \$20,000. Income, like education, tended to be inversely related to the age of the consumer. That is, the younger the consumer, the higher the income and educational attainment of the family and respondent.

Importantly for the purposes of the study, responses representing consumer families in St. Charles County included households across the full dimensions of age, education, income and structure.

Table 3.6. Family Characteristics by Age of Consumer

|  | Total       | Age of Consumer |             |             |             |
|--|-------------|-----------------|-------------|-------------|-------------|
|  |             | 0-5             | 6-18        | 18-54       | 55+         |
| Household Type   | %           | %               | %           | %           | %           |
| Two Parents  | 73.9        | 83.0            | 77.2        | 65.2        | 14.3        |
| Single Parent  | 20.8        | 15.1            | 20.4        | 26.4        | 14.3        |
| Other  | 5.3         | 1.9             | 2.5         | 8.4         | 71.4        |
|  |             |                 |             |             |             |
| Persons in Household   | <i>mean</i> | <i>mean</i>     | <i>mean</i> | <i>mean</i> | <i>mean</i> |
| under 18   | 1.51        | 2.29            | 2.24        | 0.33        | 0.13        |
| over 18  | 1.74        | 1.75            | 1.62        | 1.83        | 1.87        |
| Total  | 3.25        | 4.04            | 3.86        | 2.16        | 2.00        |
|  |             |                 |             |             |             |
|  | %           | %               | %           | %           | %           |
| Households with Another Person with Developmental Disabilities | 17.0        | 28.5            | 9.9         | 15.4        | 18.0        |
|  |             |                 |             |             |             |
| Age of Respondent  | %           | %               | %           | %           | %           |
| less than 40   | 38.6        | 80.1            | 36.5        | 5.4         | 0.0         |
| 40-49  | 28.7        | 16.6            | 50.0        | 22.6        | 0.0         |
| 50-59  | 15.9        | 2.6             | 10.9        | 32.2        | 10.0        |
| 60-69  | 10.1        | 0.7             | 2.7         | 22.6        | 50.0        |
| 70+  | 6.7         | 0.0             | 0.0         | 17.3        | 40.0        |
| mean age   | 44.7        | 34.5            | 42.0        | 54.8        | 69.7        |
|  |             |                 |             |             |             |
| Education Level of Respondents                                 | %           | %               | %           | %           | %           |
| Did not finish high school                                     | 4.4         | 0.6             | 1.8         | 8.9         | 33.3        |
| High school / GED  | 25.0        | 18.6            | 19.0        | 36.9        | 22.2        |
| Some college   | 26.6        | 26.9            | 28.8        | 25.6        | 0.0         |
| College Degree   | 44.0        | 53.8            | 50.3        | 28.6        | 44.4        |
|  |             |                 |             |             |             |
| Family Income  | %           | %               | %           | %           | %           |
| Under \$20,000   | 13.9        | 7.9             | 13.8        | 18.7        | 42.9        |
| \$20,000 - \$39,999  | 22.1        | 16.4            | 17.8        | 32.0        | 28.6        |
| \$40,000 - \$59,999  | 26.2        | 27.6            | 22.4        | 30.0        | 0.0         |
| \$60,000+  | 37.7        | 48.0            | 46.1        | 19.3        | 28.6        |

## 4. Service Needs

The major objective of this study was to determine the service needs of persons with developmental disabilities in St. Charles County who are currently in contact with the service system. Because such consumers are unique individuals and their family circumstances vary considerably, their service needs and the support needs of their families can differ markedly. In recognition of this, the developmental disabilities service system has become increasingly individualized in its focus—from the special education plan of the young child at school, to the transition plan to bridge the move from school, to adult case management and services that put a premium on consumer choice. The result of this, however, is that there is no generally accepted list of services for consumers and families that should be provided by the service system. The initial problem for this study was to develop such a list that could be used in this study. As discussed in the introduction, this was done in consultation with a special project committee assembled by the DDRB.

The resulting taxonomy of services that was used in the development of the survey questionnaire is shown in Table 4.1. The list has 10 major service categories. Five of them might be considered “core” family support services. These are respite and day care, home assistance, recreational services, systemic and planning services, and other support services. They are core in the sense that they are characterized by their focus on supporting the family as a whole and they tend to show up on lists of family support services enumerated in the literature or funded by states under this rubric. At the same time, many of the services listed within these general categories are often available for and appropriate for the consumer who is no longer living with his or her family of origin. Some, in fact, such as those included under systemic and planning services, may be seen to be as crucial to the individual consumer whether or not he or she is still at home. Traditional developmental services, group D in the table, are individually centered clinical interventions commonly identified in an individualized plan of service. Medical services likewise are highly individualized but may, like developmental services be provided either inside or outside the consumer’s natural home. Employment services likewise may be provided to the consumer still at home or living in a more independent or separate setting, but the primary beneficiary is the consumer. Finally, residential services listed here apply only to situations in which the consumer is no longer living at home.

In this chapter we examine the expressed service needs for the entire population and for each of the four age groups. We look at the proportion of the population which expressed a need and the relative criticality of the need.

Table 4.1. Taxonomy of Services

A. RESPITE AND DAY CARE

- Day care while working or in school
- Extended day care
- Day care on weekends/nights
- Out-of-home respite care
- In-home respite care

B. MEDICAL SERVICES

- Out-of-home medical respite
- In-home medical respite
- Medical services
- Dental services
- Nursing services

C. HOME ASSISTANCE

- Daily in-home personal care assistance
- Occasional in-home personal care assistance
- Special equipment or assistive devices
- Home modification
- Vehicle modification

D. TRADITIONAL DEVELOPMENTAL SERVICES

- Counseling services
- Behavior management services
- Adult development services
- Special therapies (occupational, speech, physical, etc)
- Training for living in the community
- Adult day programming services

E. TRANSPORTATION

F. RECREATIONAL SERVICES

- Weekend recreational/leisure time activities
- Summer recreational/leisure time activities
- Summer camp
- Camp during school breaks
- Group recreational/leisure time activities
- Individual supported recreational/leisure time activities

G. RESIDENTIAL LIVING SERVICES

- Supported living services
- Group home or other supervised residential setting
- Other residential services

Table 4.1., cont.

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#### H. EMPLOYMENT AND VOCATIONAL SERVICES

- Vocational/job skill program
- Supported employment
- Sheltered workshop
- Entrepreneurial services
- Other employment services

#### I. SYSTEMIC AND PLANNING SERVICES

- Case management services
- Information about available services for persons with disabilities
- Planning for future service needs
- Learning about options for his/her out-of-home living arrangements
- Learning more about his/her employment options
- Planning for his/her financial needs/security

#### J. OTHER SUPPORT SERVICES

- Family support groups
  - Advocacy services
  - Legal services and guardianship information
  - Getting financial assistance from government agencies
  - Other family support services
- 

Table 4.2 on the following page lists the services from the taxonomy in the order they appeared in the survey instrument. They are presented with the item identifier (a through nn) to make it easier to compare some of the later tables of findings where the items are sorted by frequency of expressed need. Not included in this list are items related to employment and vocational services and residential services except for those included under systemic and planning services in the taxonomy. Questions about employment and residential services in the survey instrument were somewhat more complex and the analysis results are, for the most part, presented separately here.

Table 4.2. Listing of Services from the Survey Instrument

|  |
|--|
| a. Day care while working or in school                                 |
| b. Extended day care   |
| c. Day care on weekends/nights   |
| d. Occasional out-of-home respite care                                 |
| e. Occasional in-home respite care                                     |
| f. Out-of-home medical respite   |
| g. In-home medical respite   |
| h. Medical services  |
| i. Dental services   |
| j. Nursing services  |
| k. Daily in-home personal care assistance                              |
| l. Occasional in-home personal care assistance                         |
| m. Special equipment or assistive devices                              |
| n. Home modification   |
| o. Vehicle modification  |
| p. Legal services and guardianship information                         |
| q. Advocacy services   |
| r. Counseling services   |
| s. Behavior management services  |
| t. Adult development services  |
| u. Special therapies (occupational, speech, physical, etc.)            |
| v. Training for living in the community                                |
| w. Adult day programming services                                      |
| x. Weekend recreational/leisure time activities                        |
| y. Summer recreational/leisure time activities                         |
| z. Summer camp   |
| aa. Camp during school breaks  |
| bb. Group recreational/leisure time activities                         |
| cc. Individual supported recreational/leisure time activities          |
| dd. Getting financial assistance from government agencies              |
| ee. Transportation services  |
| ff. Case management services   |
| hh. Family support groups  |
| ii. Information about available services for persons with disabilities |
| jj. Planning for future service needs                                  |
| kk. Learning about options for his/her out-of-home living arrangements |
| ll. Learning more about his/her employment options                     |
| mm. Planning for his/her future financial needs/security               |
| nn. Other services for the family                                      |

## Expressed Needs

Table 4.3 shows the percentage of consumers seen as needing various services according to respondents. The table shows the percentages for all consumers included in the survey. It also shows the percentages for each of the four age groups: ages 0 to 5, 6 to 18, 18 to 54, and 55 and over. The percentages vary both by the type of service and by the age of consumers.

There are some services needed by relatively large numbers of consumers across the entire population. Special therapies (which included many different types of treatments such as occupational therapy, speech therapy, physical therapy, etc.) was seen as needed by 59 percent of all consumers. Systemic and planning services were likewise needed by many consumers. This included a need for case management services (51 percent), assistance in planning for future service needs (45 percent), information about available services (42 percent), and help planning for future financial needs (37 percent). Medical (42 percent) and dental services (44 percent) were also needed by many consumers. The same was true for transportation services (39 percent) and recreation services on weekends (37 percent). And 3 respondents in 10 indicated a need for respite care.

Special therapies was marked by many respondents partly because it is judged to be a need for many consumers but also because it is not a single service but rather a category of services. The general category recreation, on the other hand, was presented in the survey instrument broken into six different types. If these had been combined, and a count taken of those who were seen as needing any type of recreation, the percentage would have been nearly as high as it was for special therapies. Altogether, 55 percent of all consumers were reported to need one or more types of recreation services. Similarly, services listed under systemic and planning services involve a set of highly related issues, often associated with case management. Altogether, 73 percent of all consumers were reported to need one or more services in this category. Interpretation of survey results, particularly the comparison of results that apply to specific services and service areas, must be done cautiously and with an understanding of how questions were asked and how items might have been combined or kept apart.

As would be expected, and as can be seen in Table 4.3, service needs vary by age. Need for special therapies, for example, was the highest rated need for consumers under 18 but fewer older consumers were perceived to have this need. On the other hand, need for case management increased with age. To help sort through the variation in needs for consumers of different ages, the list of needs were ranked in order of importance and provided in succeeding tables. Table 4.4 lists the services ranked for all consumers from highest to lowest, that is, the service judged to be needed by the largest percentage of consumers to the service judged to be needed by the smallest percentage of consumers.

Table 4.5 ranks the services needed by consumers under 6 years of age. The highest ranked services for this preschool group were special therapies (96 percent), planning for future service needs (43 percent), information about available services (41 percent), day care while the caregiver is working or in school (35 percent) and family support groups (30 percent).

Table 4.6 ranks the services needed by consumers aged 6 to 18 (in school). The greatest service needs for this group were special therapies (72 percent), planning for future service needs (64 percent), in-home respite care (61 percent), planning for future financial services (59 percent), and information about available services (58 percent). In addition, over 50 percent of the respondents indicated a need for summer recreation, case management, financial assistance, and out-of-home respite care. Moreover, 16 other services were seen as needed by over one-third of the consumers. Service needs for this group of consumers is driven in part by the fact that most (98 percent) are still living at home.

Table 4.7 ranks the services needed by consumers aged 18 (not in school) to 54. The most frequently reported need for this group was transportation (61 percent), followed by case management services (60 percent), dental services (55 percent), and financial assistance (55 percent). Medical services were also needed by many of these consumers (49 percent), along with various types of recreation services and service planning information and assistance.

Table 4.8 ranks services in order of need for consumers who are 55 and older. The services needed most often by this group were medical services (91 percent) and dental services (85 percent), followed by case management (82 percent), financial assistance (77 percent), nursing services (71 percent), daily in-home personal care assistance (56 percent) and transportation (56 percent).

The rankings of the various services for consumers in different age groups are provided in Table 4.9. It shows, for example, that special therapies was the highest ranked service need for consumers aged 0-5 and 6-18 (that is, more consumers were judged to need special therapies than any other need). At the same time, special therapies ranked 17<sup>th</sup> among service needs for consumers between 18 and 54, and 23<sup>rd</sup> for consumers aged 55 and older.

Table 4.3. Expressed Needs for Services (for entire population and age groups)

| RESPITE AND DAY CARE                     | All  | 0-5  | 6-18 | 18-54 | 55+  |
|--|------|------|------|-------|------|
| Day care while working or in school      | 23.4 | 34.8 | 32.9 | 9.1   | 8.8  |
| Extended day care                        | 12.1 | 5.8  | 25.7 | 7.6   | 0.0  |
| Day care on weekends/nights              | 10.6 | 7.1  | 18.6 | 7.6   | 5.9  |
| Out-of-home respite care                 | 28.1 | 19.4 | 50.3 | 21.2  | 0.0  |
| In-home respite care                     | 31.5 | 21.9 | 60.5 | 19.7  | 2.9  |
| MEDICAL SERVICES                         |      |      |      |       |      |
| Out-of-home medical respite              | 8.3  | 5.2  | 6.6  | 8.6   | 29.4 |
| In-home medical respite                  | 8.5  | 7.7  | 9.0  | 6.6   | 20.6 |
| Medical services                         | 41.4 | 24.5 | 38.9 | 48.5  | 91.2 |
| Dental services                          | 44.1 | 20.6 | 44.9 | 55.1  | 85.3 |
| Nursing services                         | 13.7 | 6.5  | 4.8  | 17.2  | 70.6 |
| HOME ASSISTANCE                          |      |      |      |       |      |
| Daily in-home personal care assist.      | 17.5 | 2.6  | 13.2 | 26.3  | 55.9 |
| Occasional in-home personal care assist. | 12.8 | 5.2  | 16.8 | 14.6  | 17.6 |
| Special equipment or assistive devices   | 22.7 | 21.3 | 24.6 | 20.2  | 35.3 |
| Home modification                        | 11.4 | 6.5  | 14.4 | 12.1  | 14.7 |
| Vehicle modification                     | 9.0  | 7.7  | 6.0  | 10.6  | 20.6 |
| DEVELOPMENTAL SERVICES                   |      |      |      |       |      |
| Counseling services                      | 22.2 | 7.7  | 38.9 | 22.7  | 2.9  |
| Behavior management services             | 27.9 | 11.0 | 46.7 | 27.3  | 17.6 |
| Adult development services               | 17.7 | 0.0  | 21.6 | 27.3  | 11.8 |
| Special therapies                        | 59.1 | 96.1 | 71.9 | 27.3  | 11.8 |
| Training for living in the community     | 24.1 | 3.2  | 35.9 | 29.8  | 29.4 |
| Adult day programming services           | 13.5 | 0.0  | 9.0  | 22.7  | 41.2 |
| TRANSPORTATION                           |      |      |      |       |      |
|  | 38.6 | 15.5 | 29.9 | 61.1  | 55.9 |
| RECREATIONAL SERVICES                    |      |      |      |       |      |
| Weekend recreational/leisure time acts.  | 37.5 | 10.3 | 47.9 | 48.5  | 47.1 |
| Summer recreational/leisure time acts.   | 37.1 | 12.9 | 55.7 | 39.9  | 41.2 |
| Summer camp                              | 27.0 | 13.5 | 49.1 | 21.7  | 11.8 |
| Camp during school breaks                | 16.6 | 11.6 | 36.5 | 6.1   | 2.9  |
| Group recreational/leisure time acts.    | 37.1 | 15.5 | 44.9 | 46.5  | 44.1 |
| Individual supported rec/leisure acts.   | 33.0 | 11.0 | 43.1 | 40.4  | 41.2 |
| SYSTEMIC AND PLANNING SERVICES           |      |      |      |       |      |
| Case management services                 | 50.6 | 27.7 | 54.5 | 60.1  | 82.4 |
| Information about available services     | 41.8 | 41.3 | 58.1 | 34.3  | 8.8  |
| Planning for future service needs        | 45.4 | 42.6 | 64.1 | 38.4  | 8.8  |
| Info about out-of-home living arrangmts. | 29.2 | 12.3 | 45.5 | 32.8  | 5.9  |
| Info about employment options            | 26.5 | 11.0 | 47.3 | 25.8  | 0.0  |
| Planning for future financial needs      | 37.0 | 25.2 | 58.7 | 32.8  | 8.8  |
| OTHER SUPPORT SERVICES                   |      |      |      |       |      |
| Family support groups                    | 26.1 | 30.3 | 36.5 | 17.7  | 5.9  |
| Advocacy services                        | 20.4 | 11.6 | 35.3 | 17.7  | 2.9  |
| Legal servs/guardianship info.           | 20.7 | 8.4  | 34.7 | 19.7  | 14.7 |
| Financial assistance fr govmnt agencies  | 47.2 | 25.2 | 53.3 | 54.5  | 76.5 |
| Other family support services            | 4.9  | 3.9  | 7.2  | 4.5   | 0.0  |

Table 4.4. Ranking of Expressed Needs from Highest to Lowest Need (population)

| Services                                     | %    |
|--|------|
| u. Special therapies                         | 59.1 |
| ff. Case management services                 | 50.6 |
| dd. Financial assistance fr govmnt agencies  | 47.2 |
| jj. Planning for future service needs        | 45.4 |
| i. Dental services                           | 44.1 |
| ii. Information about available services     | 41.8 |
| h. Medical services                          | 41.4 |
| ee. Transportation services                  | 38.6 |
| x. Weekend recreational/leisure time acts.   | 37.5 |
| y. Summer recreational/leisure time acts.    | 37.1 |
| bb. Group recreational/leisure time acts.    | 37.1 |
| mm. Planning for future financial needs      | 37.0 |
| cc. Individual supported rec/leisure acts.   | 33.0 |
| e. In-home respite care                      | 31.5 |
| kk. Info about out-of-home living arrangmts. | 29.2 |
| d. Out-of-home respite care                  | 28.1 |
| s. Behavior management services              | 27.9 |
| z. Summer camp                               | 27.0 |
| ll. Info about employment options            | 26.5 |
| hh. Family support groups                    | 26.1 |
| v. Training for living in the community      | 24.1 |
| a. Day care while working or in school       | 23.4 |
| m. Special equipment or assistive devices    | 22.7 |
| r. Counseling services                       | 22.2 |
| p. Legal services/guardianship inform.       | 20.7 |
| q. Advocacy services                         | 20.4 |
| t. Adult development services                | 17.7 |
| k. Daily in-home personal care assist.       | 17.5 |
| aa. Camp during school breaks                | 16.6 |
| j. Nursing services                          | 13.7 |
| w. Adult day programming services            | 13.5 |
| l. Occasional in-home personal care assist.  | 12.8 |
| b. Extended day care                         | 12.1 |
| n. Home modification                         | 11.4 |
| c. Day care on weekends/nights               | 10.6 |
| o. Vehicle modification                      | 9.0  |
| g. In-home medical respite                   | 8.5  |
| f. Out-of-home medical respite               | 8.3  |
| nn. Other services for the family            | 4.9  |

Table 4.5. Expressed Needs for Services for Consumers 0-5

| Services                                     | %    |
|--|------|
| u. Special therapies                         | 96.1 |
| jj. Planning for future service needs        | 42.6 |
| ii. Information about available services     | 41.3 |
| a. Day care while working or in school       | 34.8 |
| hh. Family support groups                    | 30.3 |
| ff. Case management services                 | 27.7 |
| dd. Financial assistance fr govmnt agencies  | 25.2 |
| mm. Planning for future financial needs      | 25.2 |
| h. Medical services                          | 24.5 |
| e. In-home respite care                      | 21.9 |
| m. Special equipment or assistive devices    | 21.3 |
| i. Dental services                           | 20.6 |
| d. Out-of-home respite care                  | 19.4 |
| bb. Group recreational/leisure time acts.    | 15.5 |
| ee. Transportation services                  | 15.5 |
| z. Summer camp                               | 13.5 |
| y. Summer recreational/leisure time acts.    | 12.9 |
| kk. Info about out-of-home living arrangmts. | 12.3 |
| q. Advocacy services                         | 11.6 |
| aa. Camp during school breaks                | 11.6 |
| s. Behavior management services              | 11.0 |
| cc. Individual supported rec/leisure acts.   | 11.0 |
| ll. Info about employment options            | 11.0 |
| x. Weekend recreational/leisure time acts.   | 10.3 |
| p. Legal services/guardianship inform.       | 8.4  |
| g. In-home medical respite                   | 7.7  |
| o. Vehicle modification                      | 7.7  |
| r. Counseling services                       | 7.7  |
| c. Day care on weekends/nights               | 7.1  |
| j. Nursing services                          | 6.5  |
| n. Home modification                         | 6.5  |
| b. Extended day care                         | 5.8  |
| f. Out-of-home medical respite               | 5.2  |
| l. Occasional in-home personal care assist.  | 5.2  |
| nn. Other services for the family            | 3.9  |
| v. Training for living in the community      | 3.2  |
| k. Daily in-home personal care assist.       | 2.6  |
| t. Adult development services                | 0.0  |
| w. Adult day programming services            | 0.0  |

Table 4.6. Expressed Needs for Services for Consumers 6-18

| Services                                     | %    |
|--|------|
| u. Special therapies                         | 71.9 |
| jj. Planning for future service needs        | 64.1 |
| e. In-home respite care                      | 60.5 |
| mm. Planning for future financial needs      | 58.7 |
| ii. Information about available services     | 58.1 |
| y. Summer recreational/leisure time acts.    | 55.7 |
| ff. Case management services                 | 54.5 |
| dd. Financial assistance fr govmt agencies   | 53.3 |
| d. Out-of-home respite care                  | 50.3 |
| z. Summer camp                               | 49.1 |
| x. Weekend recreational/leisure time acts.   | 47.9 |
| ll. Info about employment options            | 47.3 |
| s. Behavior management services              | 46.7 |
| kk. Info about out-of-home living arrangmts. | 45.5 |
| i. Dental services                           | 44.9 |
| bb. Group recreational/leisure time acts.    | 44.9 |
| cc. Individual supported rec/leisure acts.   | 43.1 |
| h. Medical services                          | 38.9 |
| r. Counseling services                       | 38.9 |
| aa. Camp during school breaks                | 36.5 |
| hh. Family support groups                    | 36.5 |
| v. Training for living in the community      | 35.9 |
| q. Advocacy services                         | 35.3 |
| p. Legal services/guardianship inform.       | 34.7 |
| a. Day care while working or in school       | 32.9 |
| ee. Transportation services                  | 29.9 |
| b. Extended day care                         | 25.7 |
| m. Special equipment or assistive devices    | 24.6 |
| t. Adult development services                | 21.6 |
| c. Day care on weekends/nights               | 18.6 |
| l. Occasional in-home personal care assist.  | 16.8 |
| n. Home modification                         | 14.4 |
| k. Daily in-home personal care assist.       | 13.2 |
| g. In-home medical respite                   | 9.0  |
| w. Adult day programming services            | 9.0  |
| nn. Other services for the family            | 7.2  |
| f. Out-of-home medical respite               | 6.6  |
| o. Vehicle modification                      | 6.0  |
| j. Nursing services                          | 4.8  |

Table 4.7. Expressed Needs for Services for Consumers 18-54

| Services                                     | %    |
|--|------|
| ee. Transportation services                  | 61.1 |
| ff. Case management services                 | 60.1 |
| i. Dental services                           | 55.1 |
| dd. Financial assistance fr govmnt agencies  | 54.5 |
| h. Medical services                          | 48.5 |
| x. Weekend recreational/leisure time acts.   | 48.5 |
| bb. Group recreational/leisure time acts.    | 46.5 |
| cc. Individual supported rec/leisure acts.   | 40.4 |
| y. Summer recreational/leisure time acts.    | 39.9 |
| jj. Planning for future service needs        | 38.4 |
| ii. Information about available services     | 34.3 |
| kk. Info about out-of-home living arrangmts. | 32.8 |
| mm. Planning for future financial needs      | 32.8 |
| v. Training for living in the community      | 29.8 |
| s. Behavior management services              | 27.3 |
| t. Adult development services                | 27.3 |
| u. Special therapies                         | 27.3 |
| k. Daily in-home personal care assist.       | 26.3 |
| ll. Info about employment options            | 25.8 |
| r. Counseling services                       | 22.7 |
| w. Adult day programming services            | 22.7 |
| z. Summer camp                               | 21.7 |
| d. Out-of-home respite care                  | 21.2 |
| m. Special equipment or assistive devices    | 20.2 |
| e. In-home respite care                      | 19.7 |
| p. Legal services/guardianship inform.       | 19.7 |
| q. Advocacy services                         | 17.7 |
| hh. Family support groups                    | 17.7 |
| j. Nursing services                          | 17.2 |
| l. Occasional in-home personal care assist.  | 14.6 |
| n. Home modification                         | 12.1 |
| o. Vehicle modification                      | 10.6 |
| a. Day care while working or in school       | 9.1  |
| f. Out-of-home medical respite               | 8.6  |
| b. Extended day care                         | 7.6  |
| c. Day care on weekends/nights               | 7.6  |
| g. In-home medical respite                   | 6.6  |
| aa. Camp during school breaks                | 6.1  |
| nn. Other services for the family            | 4.5  |

Table 4.8. Expressed Needs for Services for Consumers 55 and Over

| Services                                     | %    |
|--|------|
| h. Medical services                          | 91.2 |
| i. Dental services                           | 85.3 |
| ff. Case management services                 | 82.4 |
| dd. Financial assistance fr govmt agencies   | 76.5 |
| j. Nursing services                          | 70.6 |
| k. Daily in-home personal care assist.       | 55.9 |
| ee. Transportation services                  | 55.9 |
| x. Weekend recreational/leisure time acts.   | 47.1 |
| bb. Group recreational/leisure time acts.    | 44.1 |
| w. Adult day programming services            | 41.2 |
| y. Summer recreational/leisure time acts.    | 41.2 |
| cc. Individual supported rec/leisure acts.   | 41.2 |
| m. Special equipment or assistive devices    | 35.3 |
| f. Out-of-home medical respite               | 29.4 |
| v. Training for living in the community      | 29.4 |
| g. In-home medical respite                   | 20.6 |
| o. Vehicle modification                      | 20.6 |
| l. Occasional in-home personal care assist.  | 17.6 |
| s. Behavior management services              | 17.6 |
| n. Home modification                         | 14.7 |
| p. Legal services/guardianship inform.       | 14.7 |
| t. Adult development services                | 11.8 |
| u. Special therapies                         | 11.8 |
| z. Summer camp                               | 11.8 |
| a. Day care while working or in school       | 8.8  |
| ii. Information about available services     | 8.8  |
| jj. Planning for future service needs        | 8.8  |
| mm. Planning for future financial needs      | 8.8  |
| c. Day care on weekends/nights               | 5.9  |
| hh. Family support groups                    | 5.9  |
| kk. Info about out-of-home living arrangmts. | 5.9  |
| e. In-home respite care                      | 2.9  |
| q. Advocacy services                         | 2.9  |
| r. Counseling services                       | 2.9  |
| aa. Camp during school breaks                | 2.9  |
| b. Extended day care                         | 0.0  |
| d. Out-of-home respite care                  | 0.0  |
| ll. Info about employment options            | 0.0  |
| nn. Other services for the family            | 0.0  |

Table 4.9. Ranking of Expressed Needs for Consumers of Different Ages

| Services                                     | all | 0-5 | 6-18 | 18-54 | 55+ |
|--|-----|-----|------|-------|-----|
| u. Special therapies                         | 1   | 1   | 1    | 17    | 23  |
| ff. Case management services                 | 2   | 6   | 7    | 2     | 3   |
| dd. Financial assistance fr govmnt agencies  | 3   | 7   | 8    | 4     | 4   |
| jj. Planning for future service needs        | 4   | 2   | 2    | 10    | 27  |
| i. Dental services                           | 5   | 12  | 15   | 3     | 2   |
| ii. Information about available services     | 6   | 3   | 5    | 11    | 26  |
| h. Medical services                          | 7   | 9   | 18   | 5     | 1   |
| ee. Transportation services                  | 8   | 15  | 26   | 1     | 7   |
| x. Weekend recreational/leisure time acts.   | 9   | 24  | 11   | 6     | 8   |
| y. Summer recreational/leisure time acts.    | 10  | 17  | 6    | 9     | 11  |
| bb. Group recreational/leisure time acts.    | 11  | 14  | 16   | 7     | 9   |
| mm. Planning for future financial needs      | 12  | 8   | 4    | 13    | 28  |
| cc. Individual supported rec/leisure acts.   | 13  | 22  | 17   | 8     | 12  |
| e. In-home respite care                      | 14  | 10  | 3    | 25    | 32  |
| kk. Info about out-of-home living arrangmts. | 15  | 18  | 14   | 12    | 31  |
| d. Out-of-home respite care                  | 16  | 13  | 9    | 23    | 37  |
| s. Behavior management services              | 17  | 21  | 13   | 15    | 19  |
| z. Summer camp                               | 18  | 16  | 10   | 22    | 24  |
| ll. Info about employment options            | 19  | 23  | 12   | 19    | 38  |
| hh. Family support groups                    | 20  | 5   | 21   | 28    | 30  |
| v. Training for living in the community      | 21  | 36  | 22   | 14    | 15  |
| a. Day care while working or in school       | 22  | 4   | 25   | 33    | 25  |
| m. Special equipment or assistive devices    | 23  | 11  | 28   | 24    | 13  |
| r. Counseling services                       | 24  | 28  | 19   | 20    | 34  |
| p. Legal services/guardianship inform.       | 25  | 25  | 24   | 26    | 21  |
| q. Advocacy services                         | 26  | 19  | 23   | 27    | 33  |
| t. Adult development services                | 27  | 38  | 29   | 16    | 22  |
| k. Daily in-home personal care assist.       | 28  | 37  | 33   | 18    | 6   |
| aa. Camp during school breaks                | 29  | 20  | 20   | 38    | 35  |
| j. Nursing services                          | 30  | 30  | 39   | 29    | 5   |
| w. Adult day programming services            | 31  | 39  | 35   | 21    | 10  |
| l. Occasional in-home personal care assist.  | 32  | 34  | 31   | 30    | 18  |
| b. Extended day care                         | 33  | 32  | 27   | 35    | 36  |
| n. Home modification                         | 34  | 31  | 32   | 31    | 20  |
| c. Day care on weekends/nights               | 35  | 29  | 30   | 36    | 29  |
| o. Vehicle modification                      | 36  | 27  | 38   | 32    | 17  |
| g. In-home medical respite                   | 37  | 26  | 34   | 37    | 16  |
| f. Out-of-home medical respite               | 38  | 33  | 37   | 34    | 14  |
| nn. Other services for the family            | 39  | 35  | 36   | 39    | 39  |

Just as service needs vary depending on the age of consumers, other factors also impact the need for services. Some of these have to do with differences in the characteristics of respondents, such as whether the household of the consumer's family includes one or two parents or the family's income level. Needs, and the perception of needs, also varies depending on whether the consumer is still living in the home of his or her parents. Importantly, expressed needs may also depend on how well informed the respondent is about the service system as well as their views about the nature and consequences of the consumer's disabilities.

**Needs and Household Type.** On many service areas listed in the survey instrument, caregivers in single-parent households were more likely to report a need than their counterparts in two-parent households. This particularly involved four general service areas: 1) systemic and planning service areas (information about available services, planning for future service and financial needs, information about residential and employment options); 2) areas of practical assistance, such as respite care, day care, in-home assistance, family support groups, and legal services; 3) counseling and behavior management; and 4) medical and dental services.

**Needs and Income and Education.** There were some differences in expressed service need based on the income of the respondent. Lower income families were more likely to report a need for medical and dental services, transportation, and financial assistance. Higher income families were more likely to report a need for in-home respite care services and for special therapies. Respondents with more education were also more likely to report a need for special therapies as well as for training for community living. Overall, education and income levels often correlated in the response pattern as they did in the characteristics of families.

**Needs and Living Situation.** For consumers who still lived with their families of origin there was a strong statistical association in two general areas. 1) Needs were much more frequently expressed for systemic and planning services (information about available services, planning for future service and financial needs, information about residential and employment options). 2) Needs were also more frequently reported for day care and respite care services. For consumers who no longer lived with their families—who were also generally older on average—needs were more often expressed for medical and dental services, nursing services, special equipment, vehicle modification, training for community living, recreational services, financial assistance and case management.

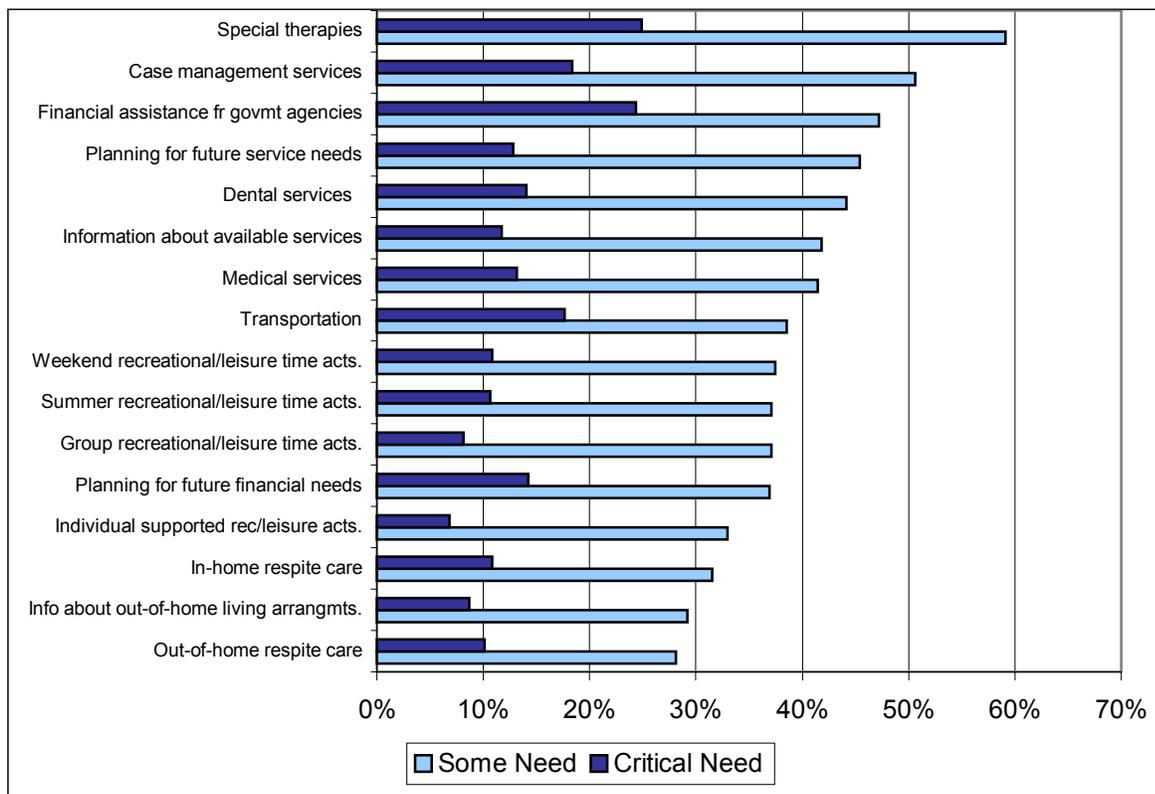
**Needs and Agency Affiliation.** Finally, we examined the data for differences in expressed needs that might be associated with agency affiliation. Specifically, we separated consumers into three groups: those who appeared on lists received from both the Regional Center and one or more community agency, those on Regional Center's list but not that of any community agency, and those on one or more community agency list but not Regional Center's. Differences in reported needs that were statistically significant were found on about half of the items in the service taxonomy. In all cases where differences were found, needs were more likely to be reported for consumers who were included on the lists of both the Regional Center and one or more community agency. This suggests an association between expressed needs and the relative integration of the consumer into the service system.

## Criticality of Needs

In the survey, respondents were asked not simply to indicate whether a need existed for a specific service, but also how serious the need was. If a need was present for a particular service, was it considered to be “minor,” “major,” or “critical”? Table 4.10 shows how respondents reported this. The first column shows the percentage that indicated some need for the service was present. The other columns show what percentage of all persons surveyed reported the need to be minor, major or critical. The sum of the last three columns, therefore, equals the first.

It is noteworthy that services reported as needed by a higher percentage of respondents also frequently tended to be viewed as critically needed. Figure 4.1 lists the 16 services seen as needed by the most respondents. They are ranked by the percentage that indicated some need for them. For 13 of the 16, the percentage who reported the need to be critical was above 10 percent. None of the other services in the taxonomy had as many identify the need to be critical.

Figure 4.1. Services with High Incidence of Need that are Critically Needed



This convergence within the population as a whole of high incidence of need with higher criticality of need, suggests there is a core set of services that require close attention. They involve systemic and planning services, medical and dental services, special therapies, recreation, transportation, and respite care.

Table 4.10. Expressed Criticality of Service Needs (for entire population)

|  | Some Need | Minor Need | Major Need | Critical Need |
|--|-----------|------------|------------|---------------|
| <b>RESPIRE AND DAY CARE</b>              |           |            |            |               |
| Day care while working or in school      | 23.4      | 5.6        | 9.0        | 8.8           |
| Extended day care                        | 12.1      | 4.0        | 3.2        | 4.9           |
| Day care on weekends/nights              | 10.6      | 4.7        | 2.9        | 3.1           |
| Out-of-home respite care                 | 28.1      | 9.0        | 9.0        | 10.1          |
| In-home respite care                     | 31.5      | 10.5       | 10.3       | 10.8          |
| <b>MEDICAL SERVICES</b>                  |           |            |            |               |
| Out-of-home medical respite              | 8.3       | 2.3        | 2.7        | 3.2           |
| In-home medical respite                  | 8.5       | 1.8        | 2.9        | 3.8           |
| Medical services                         | 41.4      | 10.3       | 18.0       | 13.2          |
| Dental services                          | 44.1      | 11.2       | 18.9       | 14.1          |
| Nursing services                         | 13.7      | 3.6        | 5.2        | 4.9           |
| <b>HOME ASSISTANCE</b>                   |           |            |            |               |
| Daily in-home personal care assist.      | 17.5      | 3.8        | 4.3        | 9.4           |
| Occasional in-home personal care assist. | 12.8      | 5.0        | 5.6        | 2.2           |
| Special equipment or assistive devices   | 22.7      | 4.7        | 8.8        | 9.2           |
| Home modification                        | 11.4      | 2.3        | 4.0        | 5.0           |
| Vehicle modification                     | 9.0       | 1.8        | 2.9        | 4.3           |
| <b>DEVELOPMENTAL SERVICES</b>            |           |            |            |               |
| Counseling services                      | 22.2      | 6.5        | 8.3        | 7.4           |
| Behavior management services             | 27.9      | 7.9        | 10.8       | 9.2           |
| Adult development services               | 17.7      | 4.3        | 5.9        | 7.4           |
| Special therapies                        | 59.1      | 10.3       | 24.0       | 24.9          |
| Training for living in the community     | 24.1      | 5.9        | 9.4        | 8.8           |
| Adult day programming services           | 13.5      | 1.3        | 4.3        | 7.9           |
| <b>TRANSPORTATION</b>                    |           |            |            |               |
|  | 38.6      | 6.8        | 14.1       | 17.7          |
| <b>RECREATIONAL SERVICES</b>             |           |            |            |               |
| Weekend recreational/leisure time acts.  | 37.5      | 10.3       | 16.4       | 10.8          |
| Summer recreational/leisure time acts.   | 37.1      | 9.5        | 16.9       | 10.6          |
| Summer camp                              | 27.0      | 7.2        | 11.4       | 8.5           |
| Camp during school breaks                | 16.6      | 5.8        | 5.2        | 5.6           |
| Group recreational/leisure time acts.    | 37.1      | 10.8       | 18.2       | 8.1           |
| Individual supported rec/leisure acts.   | 33.0      | 9.4        | 16.8       | 6.8           |
| <b>SYSTEMIC AND PLANNING SERVICES</b>    |           |            |            |               |
| Case management services                 | 50.6      | 11.7       | 20.5       | 18.4          |
| Information about available services     | 41.8      | 14.1       | 16.0       | 11.7          |
| Planning for future service needs        | 45.4      | 13.9       | 18.7       | 12.8          |
| Info about out-of-home living arrangmts. | 29.2      | 9.7        | 10.8       | 8.6           |
| Info about employment options            | 26.5      | 9.0        | 9.7        | 7.7           |
| Planning for future financial needs      | 36.9      | 9.0        | 13.7       | 14.2          |
| <b>OTHER SUPPORT SERVICES</b>            |           |            |            |               |
| Family support groups                    | 26.1      | 12.6       | 10.5       | 3.1           |
| Advocacy services                        | 20.4      | 7.7        | 7.0        | 5.6           |
| Legal servs/guardianship info.           | 20.7      | 5.9        | 8.6        | 6.1           |
| Financial assistance fr govmt agencies   | 47.2      | 7.9        | 15.0       | 24.3          |
| Other family support services            | 4.9       | 1.6        | 1.6        | 1.6           |

Following is a set of figures that break down the level of need for the different age groups of consumers as assessed by survey respondents. The figures are presented in four series of three graphs each. The first graph in each series presents data on the relative need for family support services and recreational services. The second graph shows the need for developmental and medical services. And the third graph in each series shows the need for systemic and planning services.

**Consumers Aged 0-5.** The first series of graphs shows the level of need for services for the youngest consumers, those under the age of 6. All of these young children live with their families of origin and all respondents were parents. Figure 4.2 shows the relative need expressed for family support services and recreational services. As can be seen, day care and respite care are serious needs for this group, as are special equipment and assistive devices. Nearly a third of these expressed a need for family support groups, and 1 in 10 had a critical need to obtain financial assistance.

Figure 4.3 that follows shows the level of need expressed for developmental and medical services. Here, the need for special therapies can be seen. Finally, Figure 4.4 shows the broad need expressed for systemic and planning assistance.

Figure 4.2. Level of Need for Family Support Services and Recreation Services for Consumers under the Age of 6

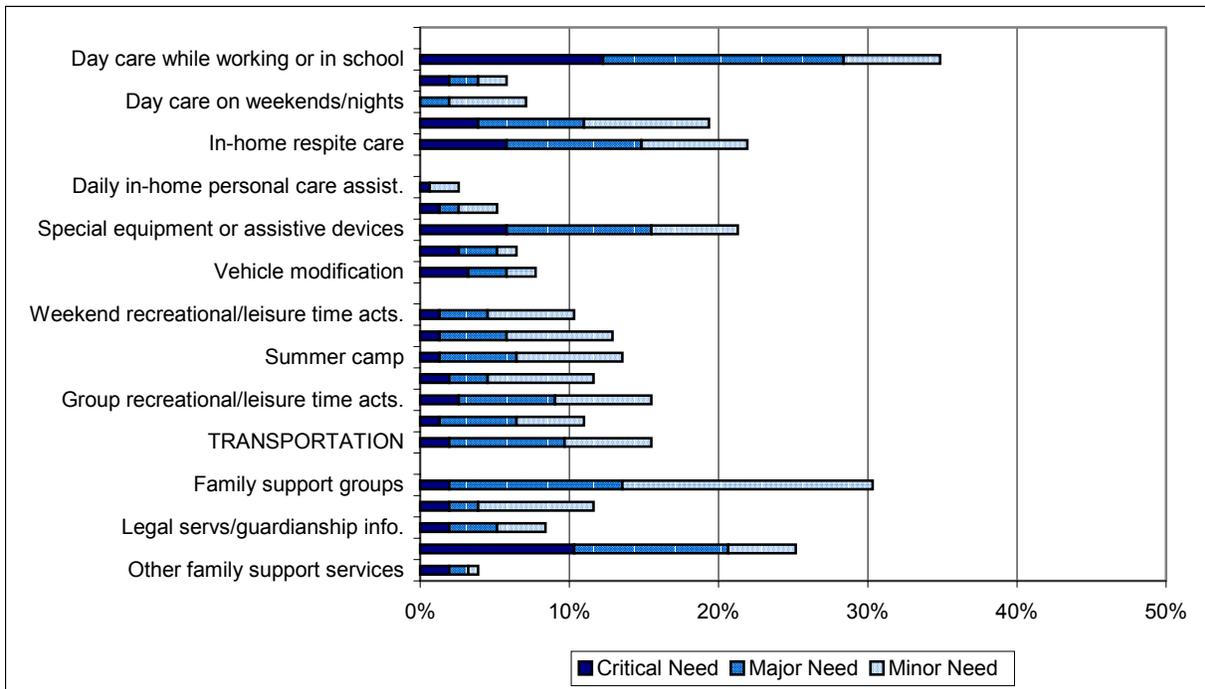


Figure 4.3. Level of Need for Developmental Services and Medical Services for Consumers under the Age of 6

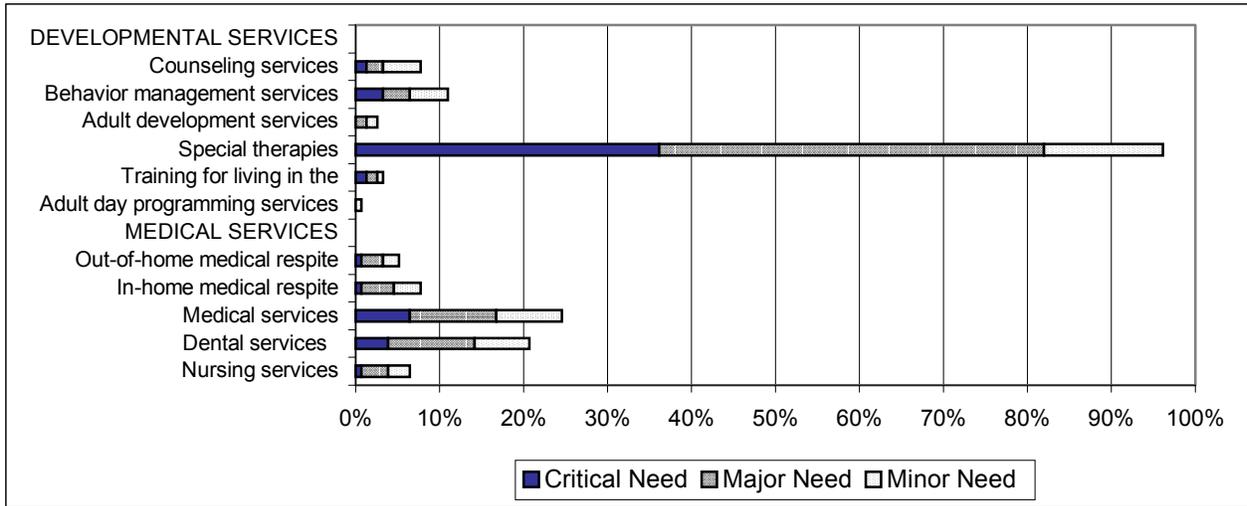
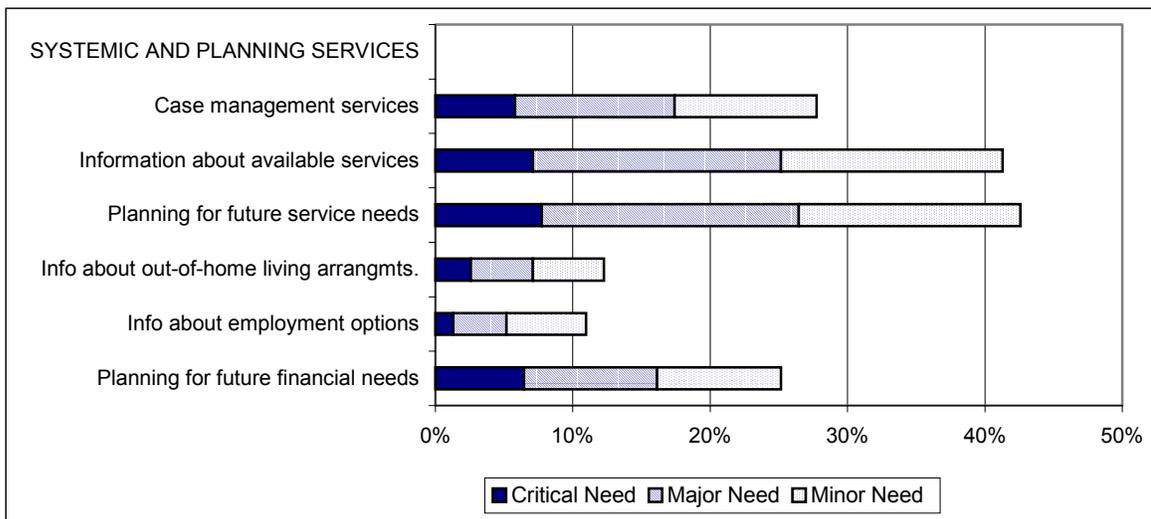


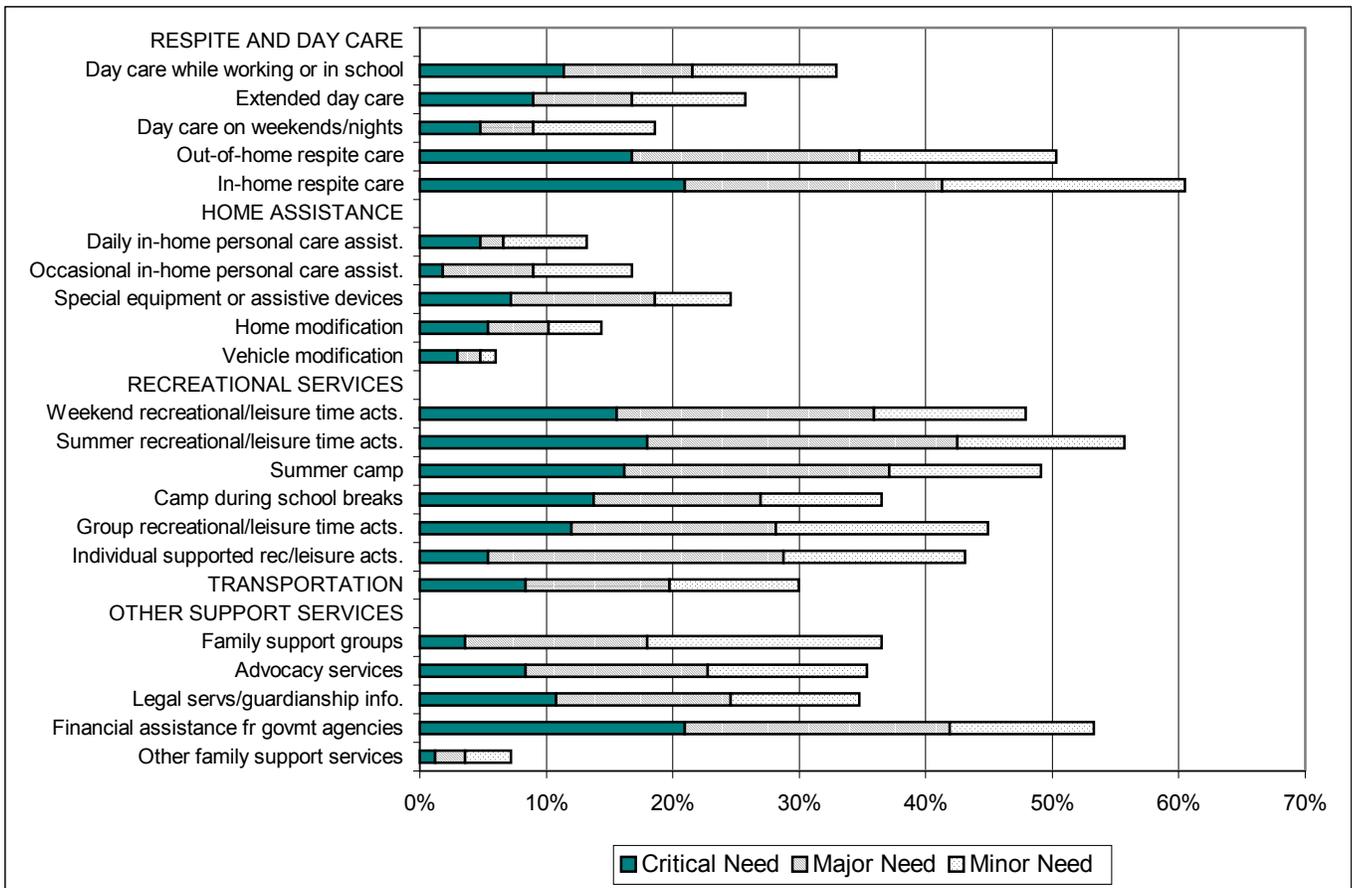
Figure 4.4. Level of Need for Systemic and Planning Services for Consumers under the Age of 6



**Consumers Aged 6-18.** The second series of graphs shows the level of need for services for school-age consumers, ages 6 through 18. Nearly all (98 percent) of these children live at home with their parents who completed the survey.

As can be seen in Figure 4.5, many respondents expressed a need for respite care, recreational services and financial assistance. In addition, over 30 percent reported needs for day care and support services such as family support groups, advocacy services and legal services. Not only did these primarily parent-respondents express a need for these services but often indicated that the need was critical. This was particularly the case regarding financial assistance, respite care and recreation.

Figure 4.5. Level of Need for Family Support Services and Recreation Services for Consumers 6-18



Except for special therapies, needs expressed for these school-age consumers for developmental and medical services were higher than for the pre-school group, as can be seen in Figure 4.6. Expressed needs for case management and informational services related to the service system were quite high for these consumers, many of whom are approaching transition from school (see Figure 4.7).

Figure 4.6. Level of Need for Developmental Services and Medical Services for Consumers 6-18

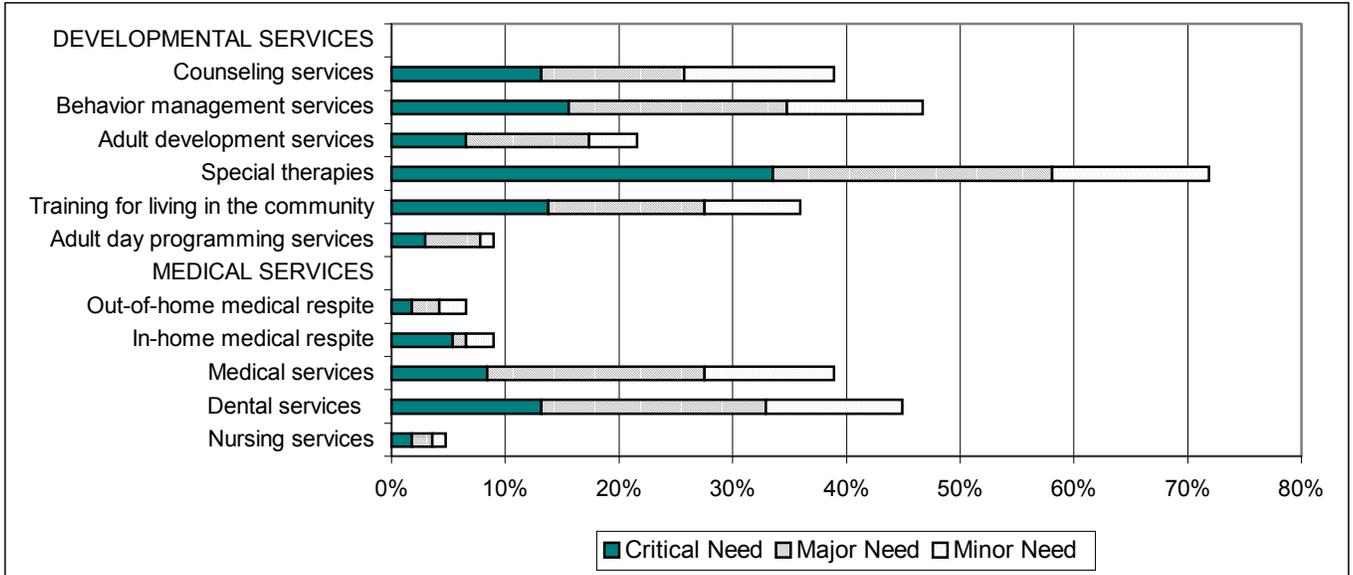
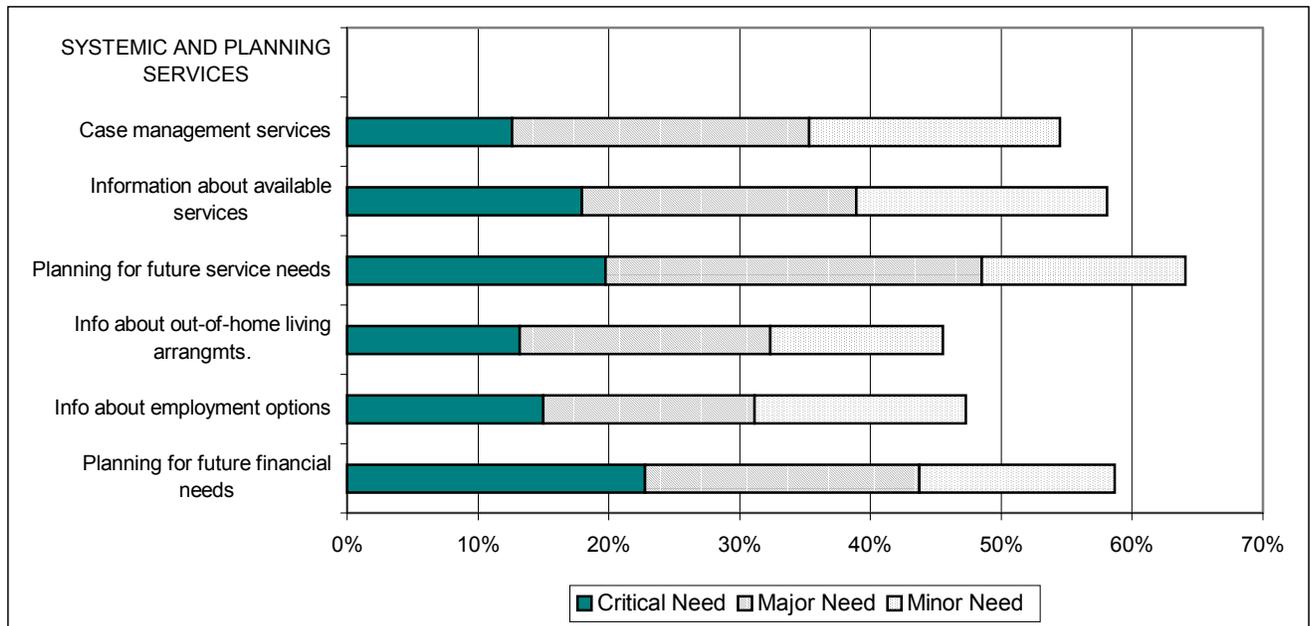


Figure 4.7. Level of Need for Systemic and Planning Services for Consumers 6-18

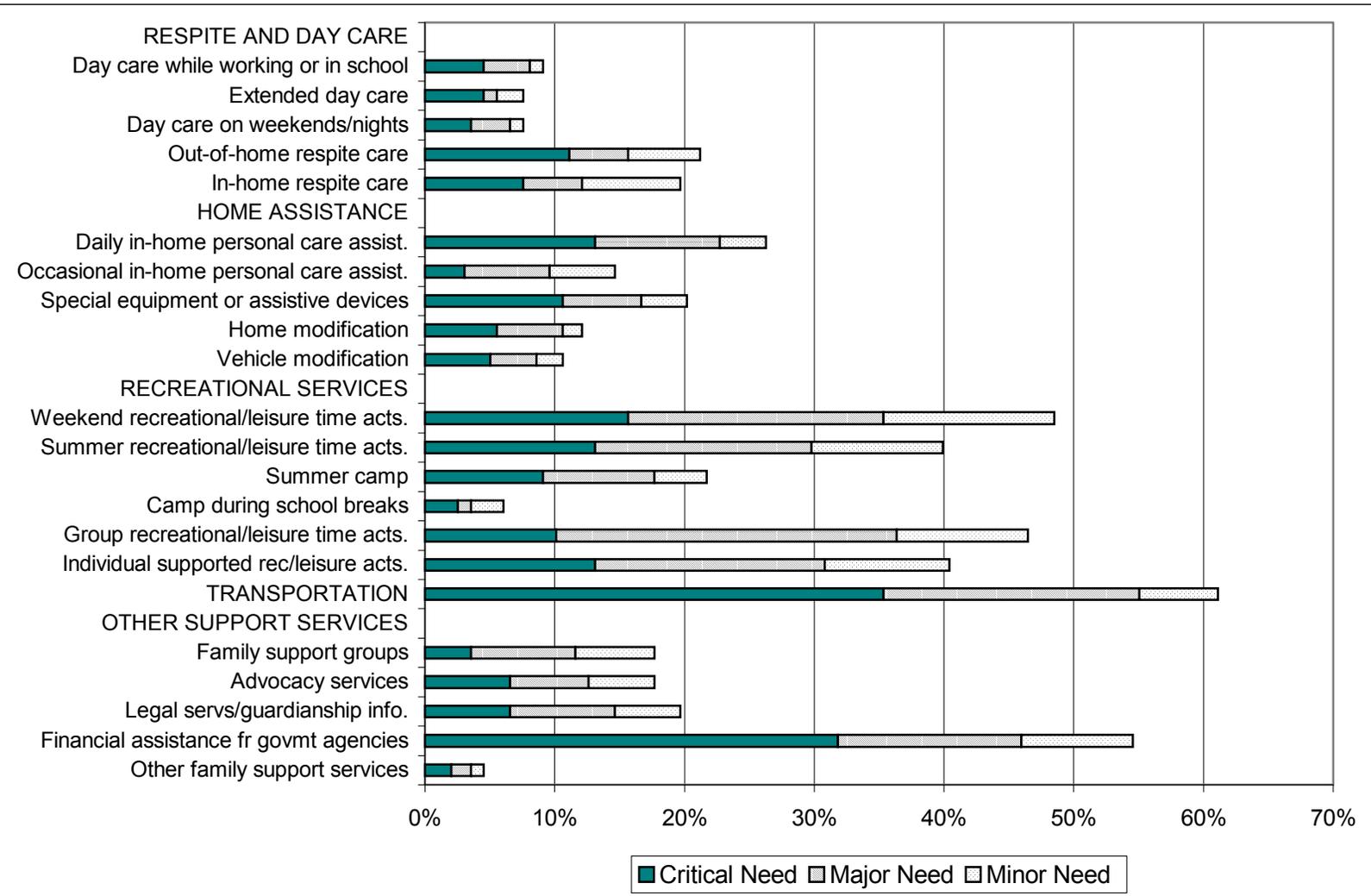


**Consumers Aged 18-54.** The third series of graphs shows the level of need for services for consumers who are between the ages of 18 and 54. For this group as a whole, 58 percent remain living at home with their family of origin, a percentage that is higher for those in their twenties (71 percent) and diminishes with the consumers' age. Respondents for this group were often (87 percent) relatives of the consumers, frequently (78 percent) their parents.

Figure 4.8 shows expressed needs for family support services and recreation services for this age group. Need for transportation and recreational services were high along with a need for financial assistance. Transportation and monetary needs are especially critical.

Need for special therapies was considerably less for this age group than the two younger groups. On the other hand, considerably more of these consumers need medical and dental services. (See Figure 4.9.)

Figure 4.8. Level of Need for Family Support Services and Recreation Services for Consumers 18-54



Except for the continuing need for case management services, which remains high, needs for other systemic and planning services are somewhat lower and can be understood to be generally inversely correlated with age—the older the consumer, the less likelihood there will be for a need for information and planning assistance. (See Figure 4.10.)

Figure 4.9. Level of Need for Developmental Services and Medical Services for Consumers 18-54

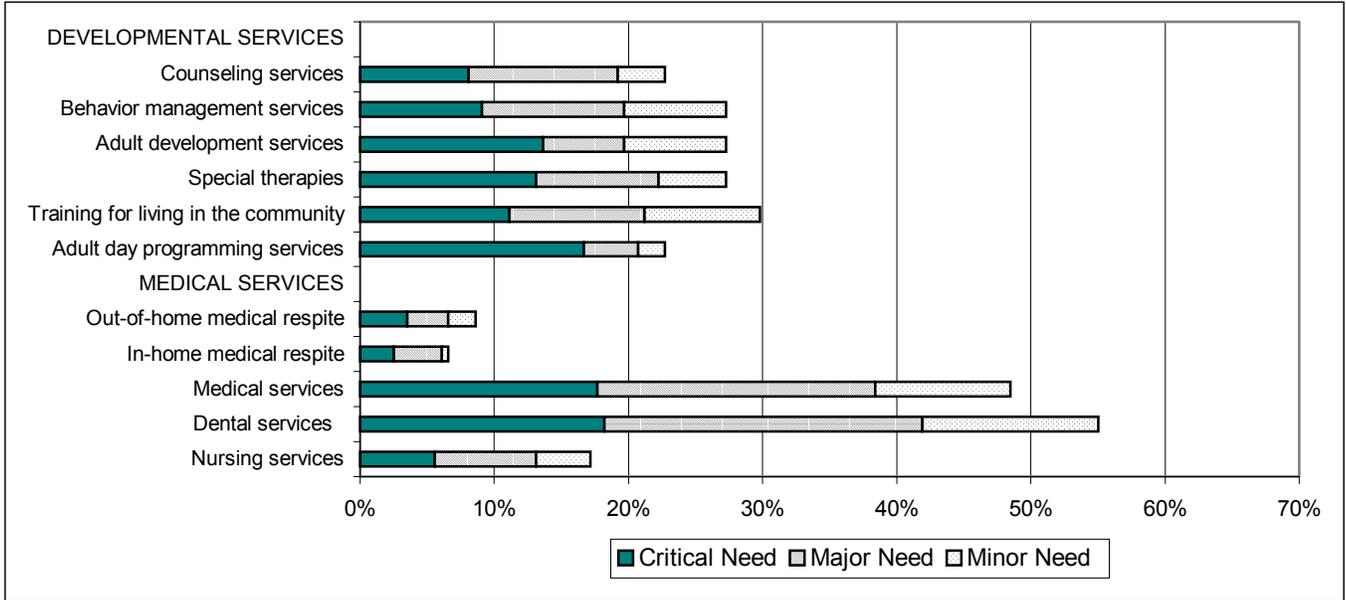
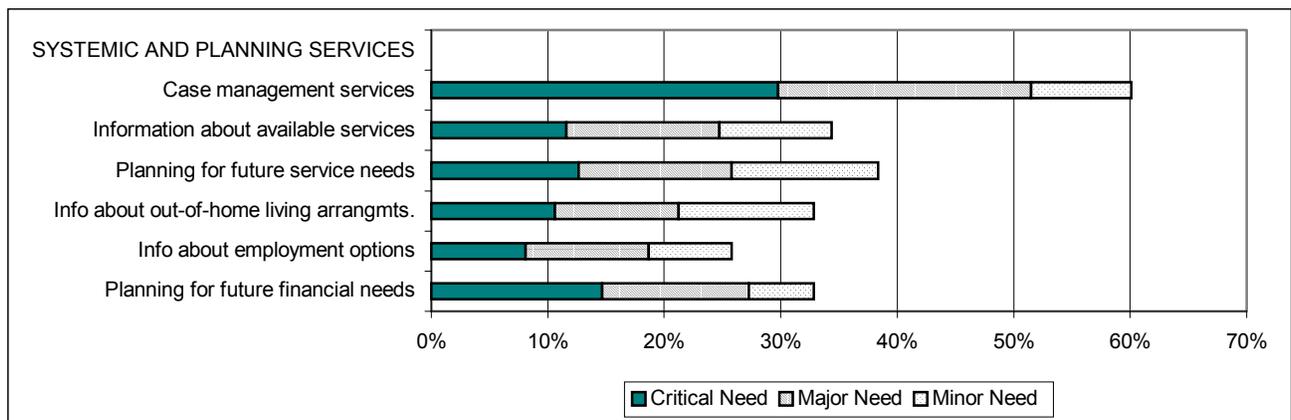


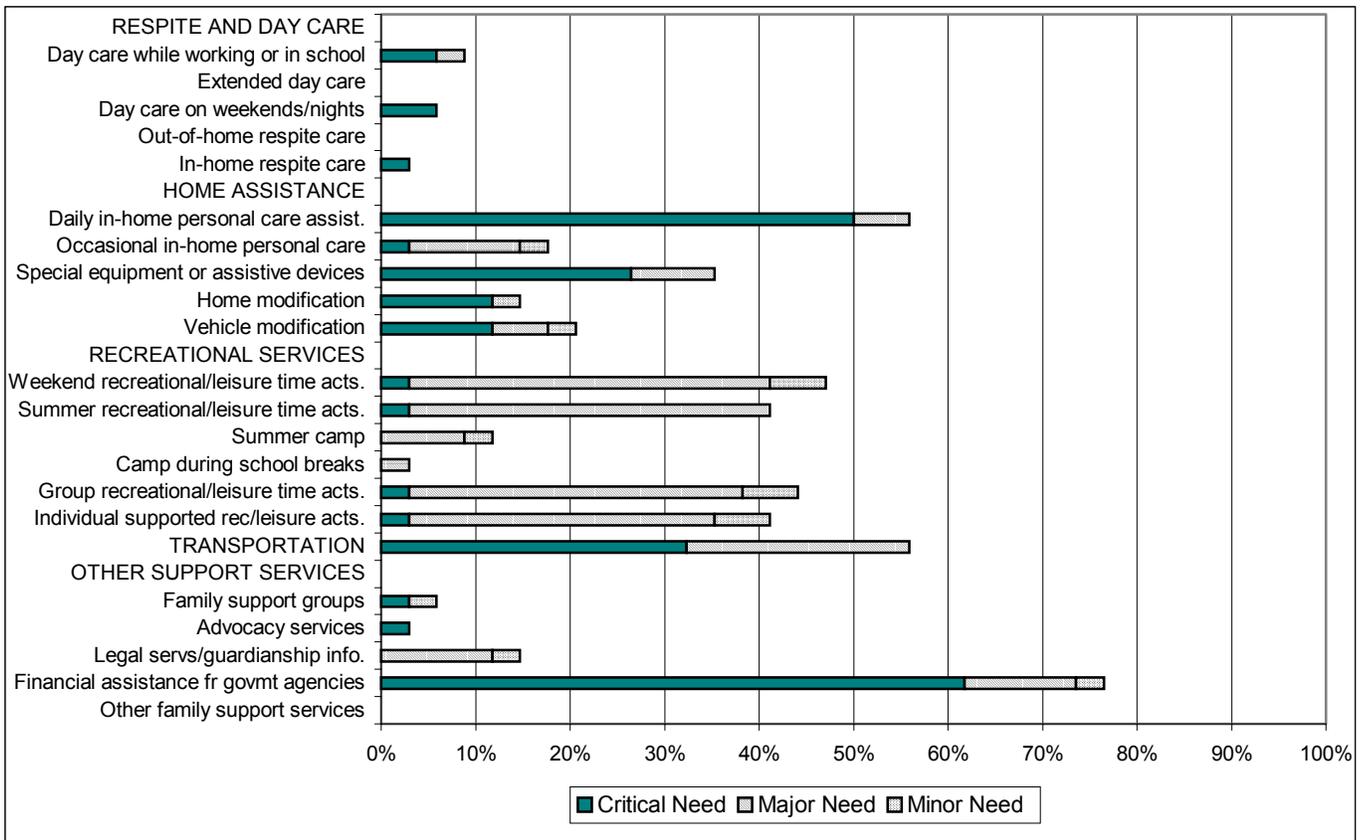
Figure 4.10. Level of Need for Systemic and Planning Services for Consumers 18-54



**Consumers Aged 55 and Older.** The fourth series of graphs shows the level of need for services for consumers who are 55 years old or older. Few (5 percent) of these consumers still live with parents and few parents (5 percent) completed the survey. Respondents tended to be other relatives (36 percent), such as siblings, or staff of community agencies providing services to the consumers.

As can be seen in Figure 4.11, need for certain support services is high for this group. This includes financial assistance, daily in-home personal care assistance, transportation, and special equipment and assistive devices. Many of these consumers also need recreation and leisure time services, but these tend not to be viewed as critical.

Figure 4.11. Level of Need for Family Support Services and Recreation Services for Consumers 55 and Older



Need for developmental services is lowest for consumers in the 55 and older group. On the other hand, need for medical and dental services is very high. (See Figure 4.12.)

Except for case management services, which remains high for this group, need for other systemic and planning assistance is low among this group of consumers. (See Figure 4.13.)

Figure 4.12. Level of Need for Developmental Services and Medical Services for Consumers 55 and Older

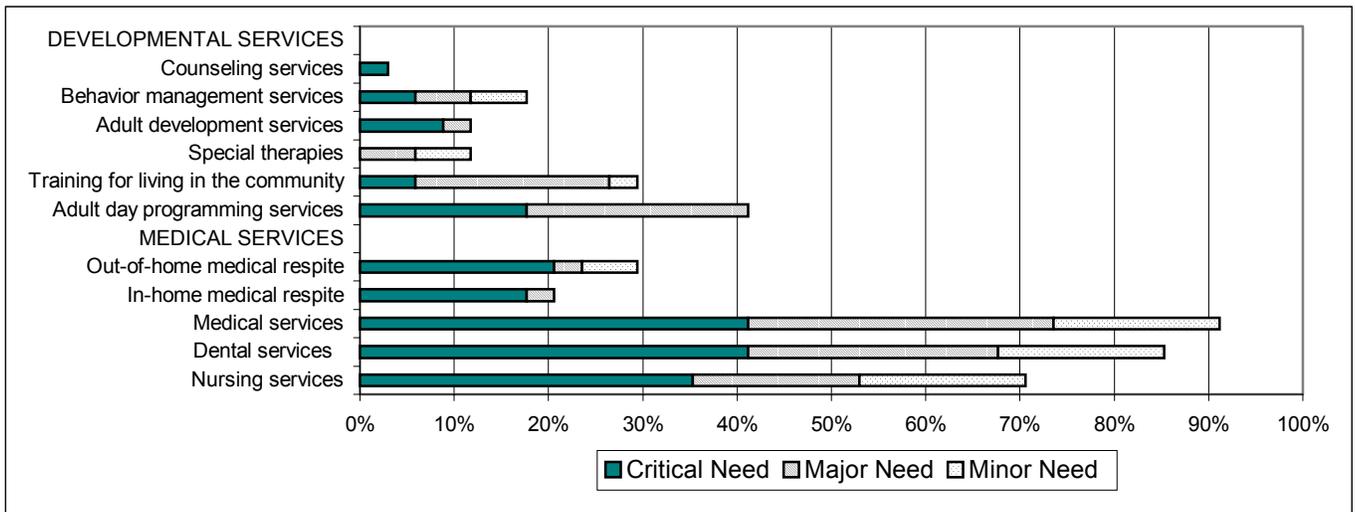
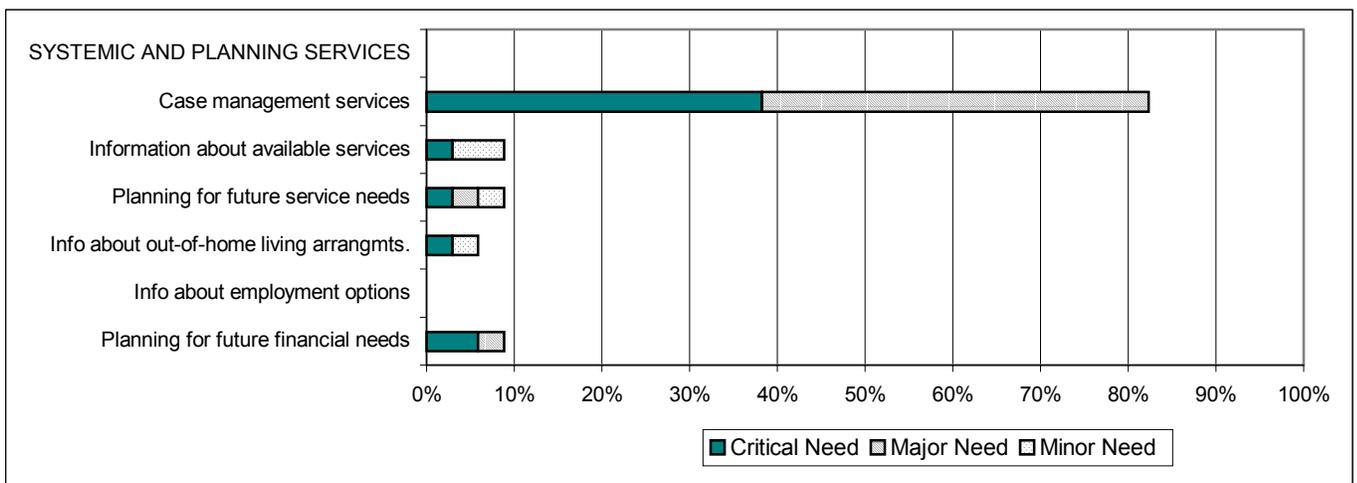


Figure 4.13. Level of Need for Systemic and Planning Services for Consumers 55 and Older



## Future Service Needs

In an attempt to help project service needs into the future, respondents were asked to indicate which services would be needed by the consumer sometime in the future. They were specifically asked to indicate which services would be needed, if not now, then within the next two years, between three and five years from now, or in six or more years.

The percentages of all respondents that reported a need in these timeframes can be seen in the Table 4.11. The first data column in the table shows the percentage of respondents that reported a need for each of the services listed in the survey instrument. The second data column shows the percentage who indicated that while the consumer or family did not have an immediate need for a service, they expected a need would arise within the next two years. The third column presents the percentages of those who indicated a need would arise in three to five years from now. The last column contains the percentages of respondents who reported a need would exist in six or more years.

This table lets us see how respondents perceive future service needs. We do not consider it particularly useful data for planning purposes, however. Families are not all able to make such projections, and a number left the questions blank. At the same time, while providing some information on the possible numbers of new consumers who may need various services, we cannot tell how many may cease to need certain services. This is more the case with some services than others - those that are more tied to the age of the consumer. Needs for planning assistance is highest for consumers around times of transition and needs for day care are greater for younger consumers; etc.

Considering the results of the survey, we believe the best predictor of future service needs are expressed needs for services right now. To forecast what future service needs may be, we have used population projections for the county and have applied them to the results of the needs assessment survey. These can be found in Chapter 8 and have also been put into electronic spreadsheets. What is most likely to affect changes in service needs other than population growth are factors beyond the control of the study. These include changes in special education programs, IEP's and transition planning efforts within county school districts. Changes in these can be expected to change how consumers themselves and their families view the subsequent services they need, as such changes have already greatly impacted these views. This can be seen in the results of this study in which younger consumers and their parents tend to favor supported employment more than older consumers. Similarly, any changes instituted by the Regional Center in its case management procedures or practices, outreach or public communication activities of the DDRB itself, or efforts to integrate community agencies into a more cohesive and integrated system can be expected to shape or reshape how consumers and families think about the service system and how they assess consumer service needs. Because of these factors, which will always be at work, there will be no escaping the need to conduct future needs assessments of this kind to appreciate subjective shifts that will take place. In the interim, however, the results of this study can be tied to changes in the population as the best way of keeping these data relevant.

Table 4.11. Future Service Needs for Total Population

| RESPITE AND DAY CARE                     | Need Now | Next Two Years | 3-5 Years | 6+ Years |
|--|----------|----------------|-----------|----------|
| Day care while working or in school      | 23.4     | 4.8            | 2.1       | 1.6      |
| Extended day care                        | 12.1     | 4.1            | 2.5       | 1.9      |
| Day care on weekends/nights              | 10.6     | 2.5            | 0.7       | 1.2      |
| Out-of-home respite care                 | 28.1     | 4.1            | 0.5       | 1.8      |
| In-home respite care                     | 31.5     | 4.8            | 0.4       | 0.9      |
| MEDICAL SERVICES                         |          |                |           |          |
| Out-of-home medical respite              | 8.3      | 1.9            | 0.5       | 1.4      |
| In-home medical respite                  | 8.5      | 2.3            | 0.9       | 1.4      |
| Medical services                         | 41.4     | 4.8            | 1.2       | 1.8      |
| Dental services                          | 44.1     | 5.5            | 2.3       | 1.8      |
| Nursing services                         | 13.7     | 1.6            | 1.2       | 1.8      |
| HOME ASSISTANCE                          |          |                |           |          |
| Daily in-home personal care assist.      | 17.5     | 2.8            | 1.4       | 2.5      |
| Occasional in-home personal care assist. | 12.8     | 2.7            | 1.1       | 2.8      |
| Special equipment or assistive devices   | 22.7     | 1.4            | 1.4       | 1.8      |
| Home modification                        | 11.4     | 1.6            | 1.4       | 1.8      |
| Vehicle modification                     | 9.0      | 1.8            | 1.2       | 0.7      |
| DEVELOPMENTAL SERVICES                   |          |                |           |          |
| Counseling services                      | 22.2     | 3.7            | 1.1       | 0.9      |
| Behavior management services             | 27.9     | 4.1            | 0.9       | 1.2      |
| Adult development services               | 17.7     | 5.3            | 1.6       | 5.3      |
| Special therapies                        | 59.1     | 3.4            | 0.7       | 0.7      |
| Training for living in the community     | 24.1     | 5.0            | 1.8       | 6.4      |
| Adult day programming services           | 13.5     | 3.9            | 2.3       | 6.4      |
| TRANSPORTATION                           | 38.6     | 5.8            | 1.6       | 3.0      |
| RECREATIONAL SERVICES                    |          |                |           |          |
| Weekend recreational/leisure time acts.  | 37.5     | 6.9            | 1.6       | 2.3      |
| Summer recreational/leisure time acts.   | 37.1     | 5.3            | 1.4       | 1.4      |
| Summer camp                              | 27.0     | 3.7            | 3.0       | 1.9      |
| Camp during school breaks                | 16.6     | 2.7            | 2.1       | 1.4      |
| Group recreational/leisure time acts.    | 37.1     | 5.7            | 1.6       | 1.9      |
| Individual supported rec/leisure acts.   | 33.0     | 6.2            | 0.9       | 1.1      |
| SYSTEMIC AND PLANNING SERVICES           |          |                |           |          |
| Case management services                 | 50.6     | 3.9            | 0.2       | 0.4      |
| Information about available services     | 41.8     | 4.6            | 0.5       | 1.1      |
| Planning for future service needs        | 45.4     | 5.5            | 1.9       | 1.2      |
| Info about out-of-home living arrangmts. | 29.2     | 3.4            | 1.9       | 5.5      |
| Info about employment options            | 26.5     | 2.7            | 1.8       | 6.4      |
| Planning for future financial needs      | 37.0     | 3.4            | 1.9       | 3.0      |
| OTHER SUPPORT SERVICES                   |          |                |           |          |
| Family support groups                    | 26.1     | 3.2            | 0.2       | 0.5      |
| Advocacy services                        | 20.4     | 3.9            | 0.9       | 1.6      |
| Legal servs/guardianship info.           | 20.8     | 4.1            | 1.8       | 2.1      |
| Financial assistance fr govmnt agencies  | 47.3     | 5.5            | 1.6       | 1.6      |
| Other family support services            | 4.9      | 1.9            | 0.2       | 0.2      |

## 5. Residential Living Arrangements and Employment

### Residential Living

**Assistance Related to Current Living Situation.** According to survey respondents, a little more than half (54.9 percent) of the consumers were receiving some type of support or assistance from some source outside their family related to their current living situation. For a majority of this group (70 percent of those receiving outside support; 38 percent of all consumers), the assistance they received was judged to be sufficient to meet their current needs. The others (30 percent of those receiving some outside support and 17 percent of all consumers) were seen as needing more living assistance than they were receiving.

Less than half of the consumers (39.6) were not receiving any outside support or assistance related to their living situation. Two-thirds of these (67 percent; 27 percent of all consumers) did not need any outside support or assistance related to their residential living situation according to respondents. One-third (33 percent; 13 percent of all consumers) were seen as needing some assistance from a source outside the family. (A small number (5.5 percent) of the respondents were not sure of the adequacy of the supports received or the need for them.)

The following table shows the breakdown of the responses on this issue.

Table 5.1. Percent of Consumers Judged to Need or Not Need Outside Support Related to their Living Situation

|   |       |
|---|-------|
| Not now receiving any outside support but needs some        | 13.1% |
| Not now receiving any outside support and does not need any | 26.5% |
| Currently receiving some outside support but needs more     | 16.7% |
| Currently receiving about as much outside support as needed | 38.2% |
| Not sure  | 5.5%  |

The following table breaks down responses on this issue by the current living situation of the consumer. As can be seen at the bottom of the table, a solid majority of consumers in each type of living arrangement were receiving adequate living assistance or did not need any. On the other hand, a sizeable minority of consumers were judged to need more living-related support than they were currently receiving.

Table 5.2. Percent of Consumers Judged to Need or Not Need Outside Support Related to their Living Situation by the Type of Current Living Arrangement

|   | Natural Home | Supported Living | Group Home /Supervised Facility | Living Independently | Other Living Situation |
|---|--------------|------------------|---------------------------------|----------------------|------------------------|
| Not now receiving any outside support but needs some      | 14.9%        | 8.9%             | 5.6%                            | 0.0%                 | 20.0%                  |
| Not now receiving any outside support & does not need any | 32.1%        | 2.2%             | 8.5%                            | 27.3%                | 0.0%                   |
| Currently receiving some outside support but needs more   | 16.7%        | 15.6%            | 11.3%                           | 27.3%                | 80.0%                  |
| Currently receiving as much outside support as needed     | 30.1%        | 73.3%            | 69.0%                           | 45.5%                | 0.0%                   |
| Not sure  | 6.2%         | 0.0%             | 5.6%                            | 0.0%                 | 0.0%                   |

|                                |       |       |       |       |       |
|--------------------------------|-------|-------|-------|-------|-------|
| Not receiving outside support  | 47.0% | 11.1% | 14.1% | 27.3% | 20.0% |
| Receiving some outside support | 46.8% | 88.9% | 80.3% | 72.7% | 80.0% |

|                                 |       |       |       |       |        |
|---------------------------------|-------|-------|-------|-------|--------|
| Does not need any/more services | 62.1% | 75.6% | 77.5% | 72.7% | 0.0%   |
| Needs some/more services        | 31.6% | 24.4% | 16.9% | 27.3% | 100.0% |

**Changes Needed in Living Arrangements.** Respondents were asked if and when changes might be needed in the living arrangement of consumers. A total of 4.4 percent of respondents reported a need for an immediate change, and 5.6 percent indicated a change would be necessary within the next two years. Another 8.7 percent of the respondents indicated that a change would be needed in the next 3 to 5 years, while 20.3 percent said a change would not be needed for at least 6 or more years. Many respondents did not foresee the need for a change (38.5) or did not know when one might be needed (22.6). (See Figure 5.1.)

Respondents were asked what type of living arrangement would be needed if and when a change was necessary. Table 5.3 summarizes their responses. The percentages in this table are based on the total number of consumers represented in the survey. Thus, for example, of all consumers studied, 2.1 percent desired an immediate change to a supported living arrangement, while another 2.3 percent were looking for a move into a supported living arrangement within two years. Whenever the time frame for change might be viewed as needed, more respondents tended to see supported living as the preferred arrangement. (It should be noted that because not all respondents were sure what type of arrangement might be most appropriate nor when a move from the home be needed, the percentages showing preferences for particular arrangements within specific time frames must be taken as minimum figures.)

Figure 5.1. When Changes Will be Needed in Current Living Arrangements

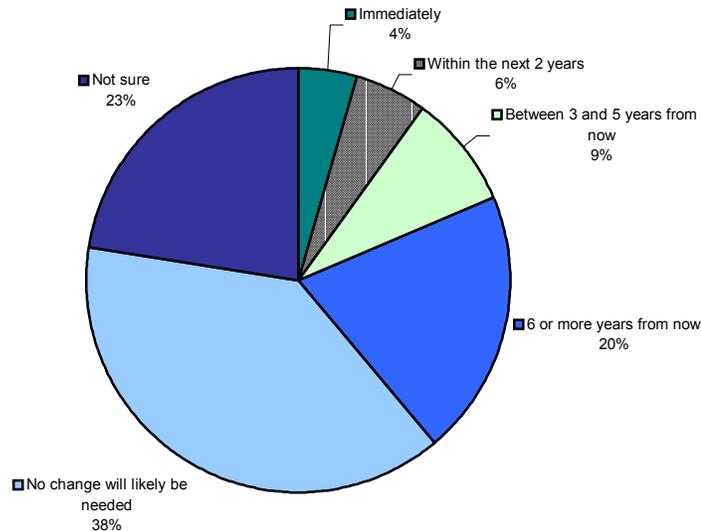


Table 5.3. Type of Living Arrangement Needed When Change is Necessary

| Percent of All Consumers       | When a change is needed |                 |               |              | Total |
|--------------------------------|-------------------------|-----------------|---------------|--------------|-------|
|                                | Imme-<br>diately        | Within<br>2 yrs | In<br>3-5 yrs | In<br>6+ yrs |       |
| Independent Living             | 0.2%                    | 0.2%            | 1.0%          | 2.1%         | 3.5%  |
| Supported Living               | 2.1%                    | 2.3%            | 3.0%          | 2.6%         | 10.0% |
| Group Home/Supervised Facility | 0.7%                    | 1.0%            | 1.7%          | 3.3%         | 6.8%  |
| Nursing Home                   | 0.2%                    | 0.2%            | 0.0%          | 0.3%         | 0.7%  |
| Not Sure                       | 1.2%                    | 1.9%            | 3.0%          | 11.9%        | 18.0% |
| Total                          | 4.4%                    | 5.6%            | 8.7%          | 20.3%        | 39.0% |

Preference for supported living can be seen more clearly in Table 5.4. Here the percentages are based on column totals where the columns represent all respondents who reported a change to be needed within a particular time frame. For example, of all respondents who indicated a change was needed immediately, 48 percent were looking for a supported living arrangement, while 16 percent thought a group home or some type of supervised facility was appropriate. For respondents who thought a change would be needed within two years, 41 percent preferred supported living and 19 percent a group home. (As above, percentages for particular types of arrangements are conservative and should be taken as minimums.)

Table 5.4. Type of Living Arrangement Needed When Change is Necessary

| Percent of those Needing Change | Imme-<br>diately | Within<br>2 yrs | In<br>3-5 yrs | In<br>6+ yrs |
|---------------------------------|------------------|-----------------|---------------|--------------|
|                                 |                  |                 |               |              |

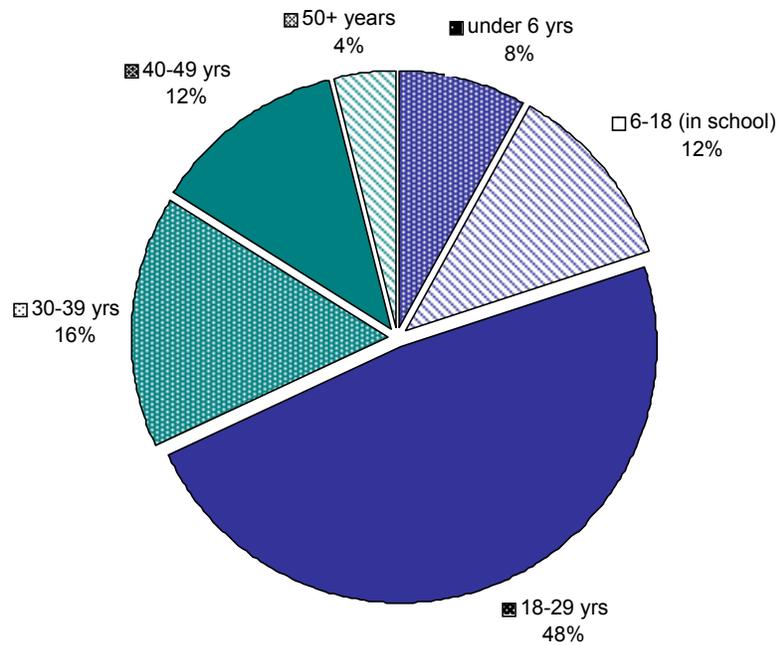
|                                |        |        |        |        |
|--------------------------------|--------|--------|--------|--------|
| Independent Living             | 4.0%   | 3.1%   | 12.0%  | 10.3%  |
| Supported Living               | 48.0%  | 40.6%  | 34.0%  | 12.9%  |
| Group Home/Supervised Facility | 16.0%  | 18.8%  | 20.0%  | 16.4%  |
| Nursing Home                   | 4.0%   | 3.1%   | 0.0%   | 1.7%   |
| Not Sure                       | 28.0%  | 34.4%  | 34.0%  | 58.6%  |
| Total                          | 100.0% | 100.0% | 100.0% | 100.0% |

Table 5.5 breaks down the time frame for a change in living arrangement by the age of the consumer. The first pie chart that follows shows the age distribution of consumers who were seen as needing an immediate change in their living arrangements. A couple of parents with preschool children were included in this group. Most of these youngest consumers, as well as those school-age consumers who were in school, were receiving some services, but needed more according to the parents. Nearly all of the respondents in these cases indicated that they would be able to keep their children at home if some additional support services were provided. Of those consumers needing an immediate change who were between the ages of 18 and 29 and not in school, half were currently receiving some outside support related to their living situation and half were not. A majority said they would not be able to keep their children at home longer if additional support services were provided, although some (40 percent) said they would be able to. Regarding consumers 30 and older, half were said to be receiving some support services while half were not. Additional support services could help lengthen the time they could remain home, according to about one-third of the respondents.

Table 5.5. Time Frame within which a Change in Living Arrangement was Viewed as Needed by Age of Consumer

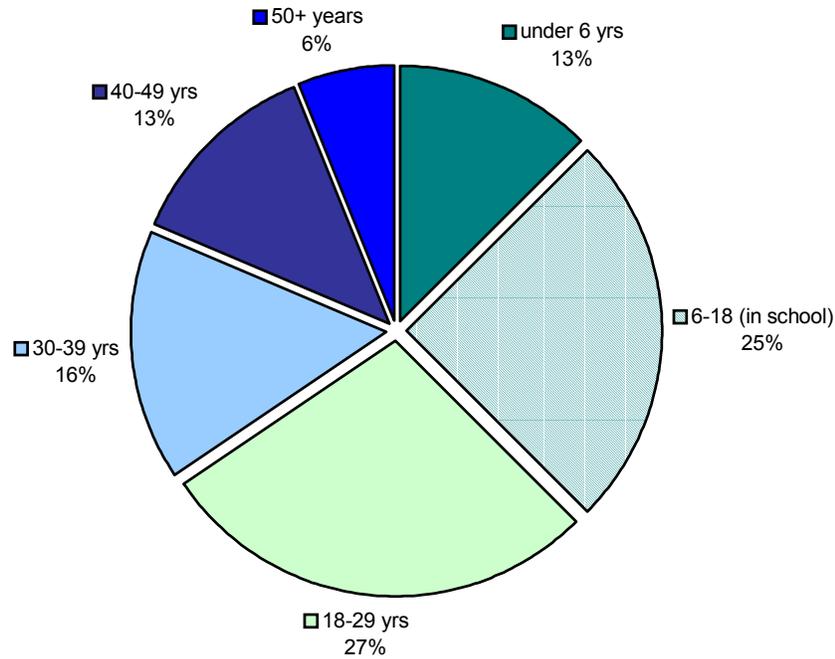
|                                | Population | 0-5    | 6-18   | 18-54  | 55+    |
|--------------------------------|------------|--------|--------|--------|--------|
| Immediately                    | 4.4%       | 1.3%   | 1.8%   | 9.1%   | 2.6%   |
| Within the next 2 years        | 5.6%       | 2.5%   | 4.8%   | 9.1%   | 2.6%   |
| Between 3 and 5 years from now | 8.7%       | 1.3%   | 16.9%  | 7.7%   | 10.3%  |
| 6 or more years from now       | 20.3%      | 15.2%  | 41.0%  | 10.0%  | 7.7%   |
| No change seen as needed       | 38.5%      | 71.5%  | 13.3%  | 29.7%  | 59.0%  |
| Not sure                       | 22.6%      | 8.2%   | 22.3%  | 34.4%  | 17.9%  |
| Total                          | 100.0%     | 100.0% | 100.0% | 100.0% | 100.0% |

Figure 5.2. Age Distribution of Consumers Who Need an Immediate Change in Living Arrangements



The following pie chart provides an age breakdown for consumers who will need a change in living arrangement within the next two years according to respondents. All of the pre-school children were receiving some support services, but most (75 percent) respondents said additional services would not make a difference. A majority (75 percent) of school-age consumers were not receiving support services and most said additional services would not make a difference in lengthening the time the consumers could remain at home. Under half (46 percent) of the consumers between the ages of 18 and 29 who were not in school were receiving support services. About half of the respondents said additional services would enable them to keep the consumer at home longer, while half said such services would not make a difference. About two-thirds of the consumers over the age of 30 were receiving some support services. According to respondents, additional services would allow about one of these consumers in five to remain at home longer.

Figure 5.3. Age Distribution of Consumers Who Will Need a Change in Living Arrangements within the Next Two Years



**Impact of Support Services.** As indicated above, we asked respondents whether consumers who were currently living in their natural homes (with parents or relatives) could remain at home longer if necessary support services were provided to the family. Their responses are shown in the following table, broken down by the age of the consumer. It should be noted that the response category “more services would not make a difference,” does not mean a change is necessary, it also includes families who do not foresee a need to change in living arrangements at the present time.

Table 5.6. Question: Could the Consumer Remain at Home Longer if Necessary Support Services were Provided to the Family?

|   | 0-5   | 6-19  | 20-29 | 30-39 | 40-49 | 50+    |
|---|-------|-------|-------|-------|-------|--------|
| Yes, with a few additional services       | 36.4% | 54.6% | 53.1% | 42.9% | 28.6% | 100.0% |
| Yes, but only with many more services     | 4.5%  | 10.8% | 14.3% | 0.0%  | 28.6% | 0.0%   |
| More services would not make a difference | 54.5% | 31.5% | 30.6% | 57.1% | 42.9% | 0.0%   |
| Not sure                                  | 4.5%  | 3.1%  | 2.0%  | 0.0%  | 0.0%  | 0.0%   |

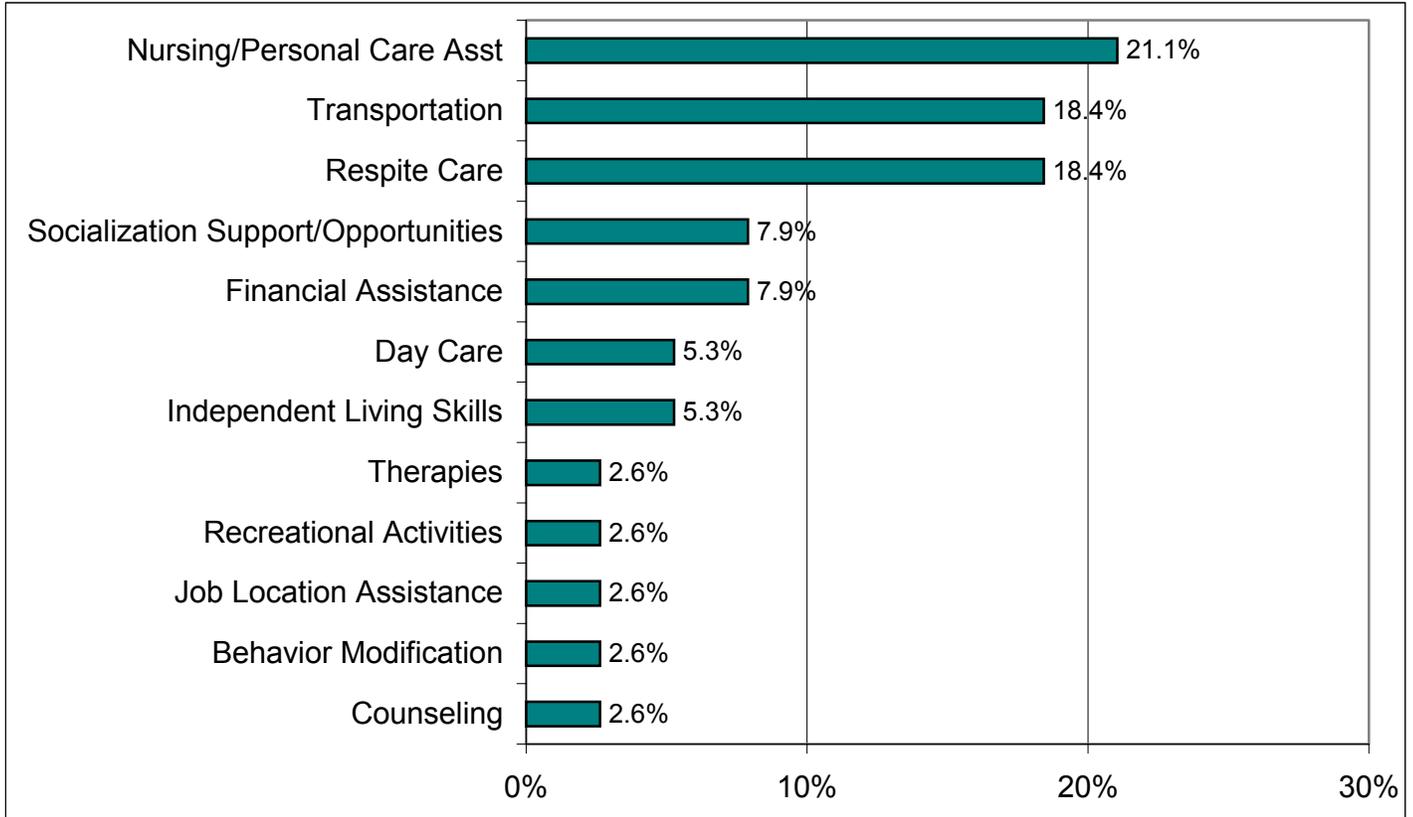
When respondents indicated that consumers could remain at home longer with more services, they were asked to tell us the kind of services that would help the most. Respite care was mentioned most frequently—by 20 percent of those who said some services would make a difference. Transportation was also mentioned frequently, by 16 percent, and in-home nursing or personal care assistance was mentioned by 11 percent. A variety of other services were mentioned – often in combination with the first three. Table 5.7 lists the services that respondents said would enable them to keep the consumer in his or her natural home longer. The table provides the percentage for all respondents as well as for consumers of different ages.

Table 5.7. Services that Would Enable Consumers to Remain in Their Natural Homes Longer (as a percent of those who said some services would make a difference)

| Service                             | % Total | % 0-5 | % 6-19 | % 20-29 | %30+ |
|-------------------------------------|---------|-------|--------|---------|------|
| Respite Care                        | 19.5    | 19.2  | 17.3   | 25.0    | 21.4 |
| Transportation                      | 16.1    | 11.5  | 18.5   | 14.3    | 14.3 |
| Nursing/Personal Care Asst.         | 10.7    | 7.7   | 7.4    | 25.0    | 7.1  |
| Independent Living Skills           | 6.7     | 0.0   | 8.6    | 3.6     | 14.3 |
| Day Care                            | 5.4     | 7.7   | 4.9    | 3.6     | 7.1  |
| Financial Assistance                | 5.4     | 0.0   | 3.7    | 10.7    | 14.3 |
| Home Modifications                  | 4.7     | 15.4  | 3.7    | 0.0     | 0.0  |
| Therapies                           | 4.0     | 7.7   | 3.7    | 3.6     | 0.0  |
| Socialization Support/Opportunities | 4.0     | 3.8   | 4.9    | 3.6     | 0.0  |
| Recreational Activities             | 3.4     | 3.8   | 4.9    | 0.0     | 0.0  |
| Equipment                           | 2.7     | 11.5  | 1.2    | 0.0     | 0.0  |
| Job Location Assistance             | 2.7     | 0.0   | 2.5    | 3.6     | 7.1  |
| Job Training                        | 2.7     | 0.0   | 4.9    | 0.0     | 0.0  |
| Behavior Modification               | 2.7     | 0.0   | 3.7    | 3.6     | 0.0  |
| Counseling                          | 2.0     | 0.0   | 2.5    | 3.6     | 0.0  |
| Vehicle Modifications/Lift Vans     | 1.3     | 7.7   | 0.0    | 0.0     | 0.0  |
| Supervision                         | 1.3     | 0.0   | 2.5    | 0.0     | 0.0  |
| Parental Support                    | 1.3     | 0.0   | 2.5    | 0.0     | 0.0  |

The question of the consumer remaining at home becomes an increasingly critical issue for families with consumers who are nearing transition from their Special Education program as it already is for many with children who have recently completed school and have entered the adult service system. The following figure shows the types of services families with consumers between the ages of 18 and 25 mentioned most frequently as making a difference. In-home nursing or personal care assistance, transportation and respite care again top the list of services that would most make a difference to these families.

Figure 5.4. Services that Would Enable Consumers to Remain in Their Natural Homes Longer  
According to Parents of Consumers between 18 and 25  
(as a percent of those who said some services would make a difference)



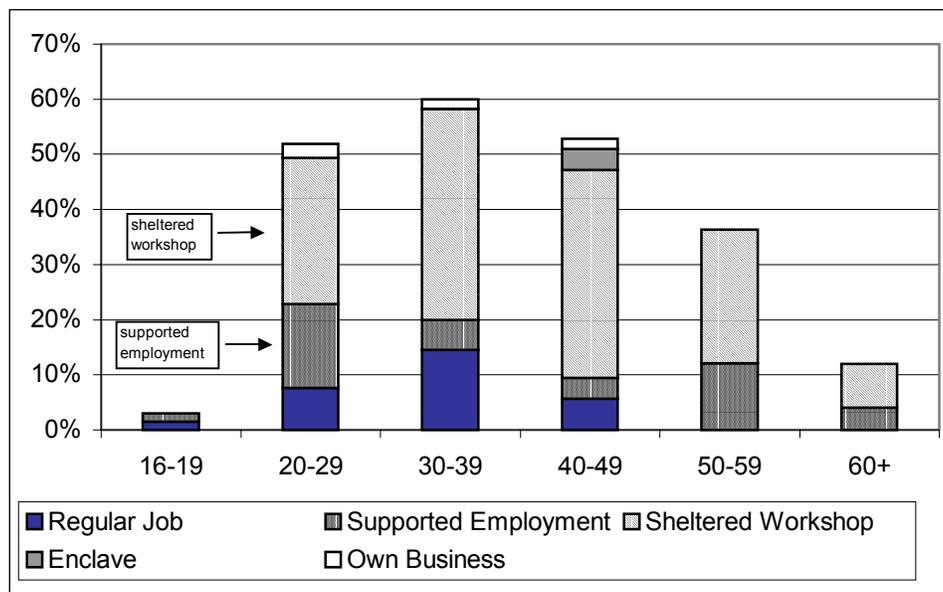
## Employment Services

Table 5.8 shows the percentage of consumers of different ages who were working and not working, as well as the types of jobs held by those consumers who were working. This same data is also shown in graphic form in Figure 5.5. As can be seen, 60 percent of consumers in their thirties held jobs of some kind, and over 50 percent of consumers in their twenties and forties held paid jobs. Sheltered workshop employment was the most common type of work for consumers in each age group. Over 20 percent of consumers in their twenties and thirties held some type of more integrated job, however. And the increase in supported employment for consumers in their twenties and those transitioning from school suggests a trend in that direction. The average age of consumers in sheltered workshops was 37.1; the average for consumers in supported employment was 31.4; and the average for those working in competitive jobs without support was 27.0.

Table 5.8 Types of Jobs Held by Consumers of Different Ages

|                      | 16-19 | 20-29 | 30-39 | 40-49 | 50-59 | 60+   |
|----------------------|-------|-------|-------|-------|-------|-------|
| Regular Job          | 1.5%  | 7.6%  | 14.5% | 5.7%  | 0.0%  | 0.0%  |
| Supported Employment | 1.5%  | 15.2% | 5.5%  | 3.8%  | 12.1% | 4.0%  |
| Sheltered Workshop   | 0.0%  | 26.6% | 38.2% | 37.7% | 24.2% | 8.0%  |
| Enclave              | 0.0%  | 0.0%  | 0.0%  | 3.8%  | 0.0%  | 0.0%  |
| Own Business         | 0.0%  | 2.5%  | 1.8%  | 1.9%  | 0.0%  | 0.0%  |
| Not Working          | 97.1% | 48.1% | 40.0% | 47.2% | 63.6% | 88.0% |
| Working Some Job     | 2.9%  | 51.9% | 60.0% | 52.8% | 36.4% | 12.0% |

Figure 5.5. Types of Jobs Held by Consumers of Different Ages



Consumers who were working were asked if they were currently seeking a change in jobs or work settings and, if so, what type of job they wanted. A majority of working

consumers (about 3 in 4) were not looking to change jobs, while 1 in 4 were. From this it was possible to gauge the type of jobs preferred by those now working and the results are shown in Figure 5.6. As can be seen, while sheltered workshops remain the choice of the majority, preference for it drops to 50 percent while preference for supported employment rises to above 30 percent. These data are broken down by age group in Table 5.7.

Figure 5.6. Types of Jobs Held and Preferred by Consumers

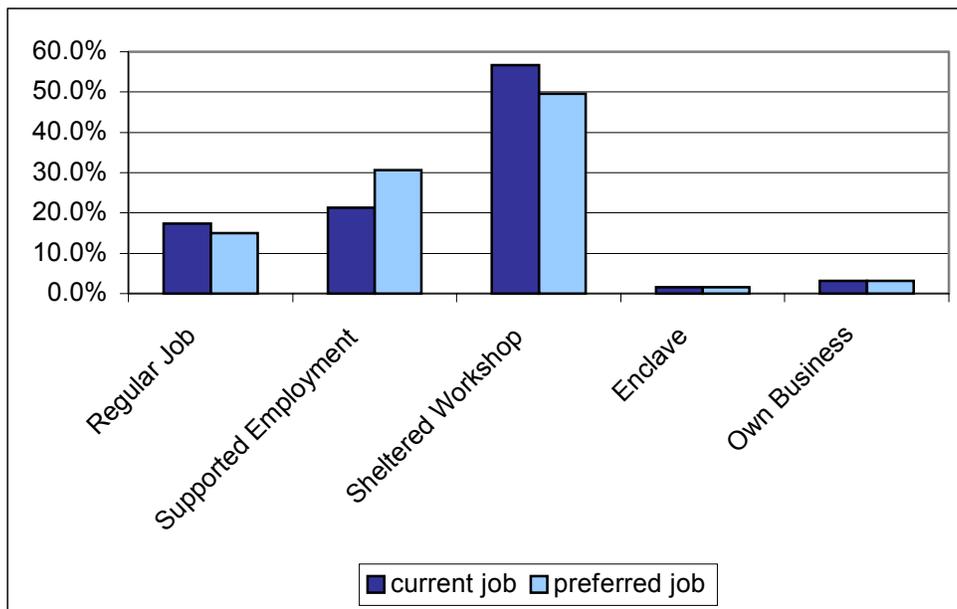


Table 5.7. Types of Jobs Held and Preferred by Consumers of Different Ages

| Current Job          | 16-19  | 20-29  | 30-39  | 40-49  | 50-59  | 60+    |
|----------------------|--------|--------|--------|--------|--------|--------|
| Regular Job          | 50.0%  | 14.6%  | 24.2%  | 10.7%  | 0.0%   | 0.0%   |
| Supported Employment | 50.0%  | 29.3%  | 9.1%   | 7.1%   | 33.3%  | 33.3%  |
| Sheltered Workshop   | 0.0%   | 51.2%  | 63.6%  | 71.4%  | 66.7%  | 66.7%  |
| Enclave              | 0.0%   | 0.0%   | 0.0%   | 7.1%   | 0.0%   | 0.0%   |
| Own Business         | 0.0%   | 4.9%   | 3.0%   | 3.6%   | 0.0%   | 0.0%   |
| Total                | 100.0% | 100.0% | 100.0% | 100.0% | 100.0% | 100.0% |
| Preferred Job        | 16-19  | 20-29  | 30-39  | 40-49  | 50-59  | 60+    |
| Regular Job          | 40.0%  | 14.6%  | 18.2%  | 10.7%  | 0.0%   | 0.0%   |
| Supported Employment | 60.0%  | 41.5%  | 21.2%  | 14.3%  | 33.3%  | 33.3%  |
| Sheltered Workshop   | 0.0%   | 39.0%  | 57.6%  | 64.3%  | 66.7%  | 66.7%  |
| Enclave              | 0.0%   | 0.0%   | 0.0%   | 7.1%   | 0.0%   | 0.0%   |
| Own Business         | 0.0%   | 4.9%   | 3.0%   | 3.6%   | 0.0%   | 0.0%   |
| Total                | 100.0% | 100.0% | 100.0% | 100.0% | 100.0% | 100.0% |

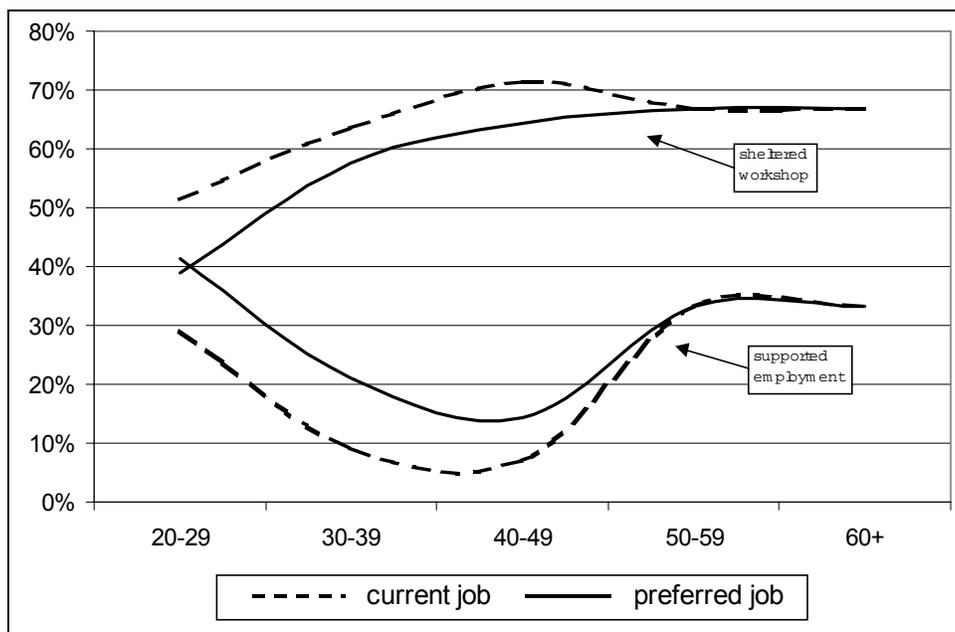
The trends in job preference can be more fully appreciated in Table 5.7. A majority of workers under age 30 prefer something other than sheltered workshops. Many would prefer supported employment. None of the workers holding competitive jobs in integrated settings with or without support were seeking work in sheltered workshops. On the other hand, 1 in 8 sheltered workers wanted to change to jobs working alongside

persons without disabilities. The average age of these sheltered employees seeking a change was 30.6 versus 38.4 for those not seeking a change.

This rising preference for supported employment and work in integrated settings may be the result of transition programs in place in schools and vocational experiences students are receiving. It is likely that part of the preference of older workers in sheltered workshops is correspondingly shaped by the more limited experience many of them and their parents have had with any alternative. This conclusion is reinforced by the data on workers in the 50-59 age group. Interestingly, there appears to be a small group of workers in their fifties who hold supported employment jobs and, as the data shows, they tend to like these jobs.

This trend of rising interest in supported employment among younger consumers can be seen again in Figure 5.7. This graph shows the relationship between age and both the type of job consumers hold and the type they prefer. It also suggests that the adult service system will need to be attentive to these trends to remain responsive to entering consumers.

Figure 5.7. Percent of Consumers of Different Ages Who Held and Preferred Supported Employment and Sheltered Workshop Jobs



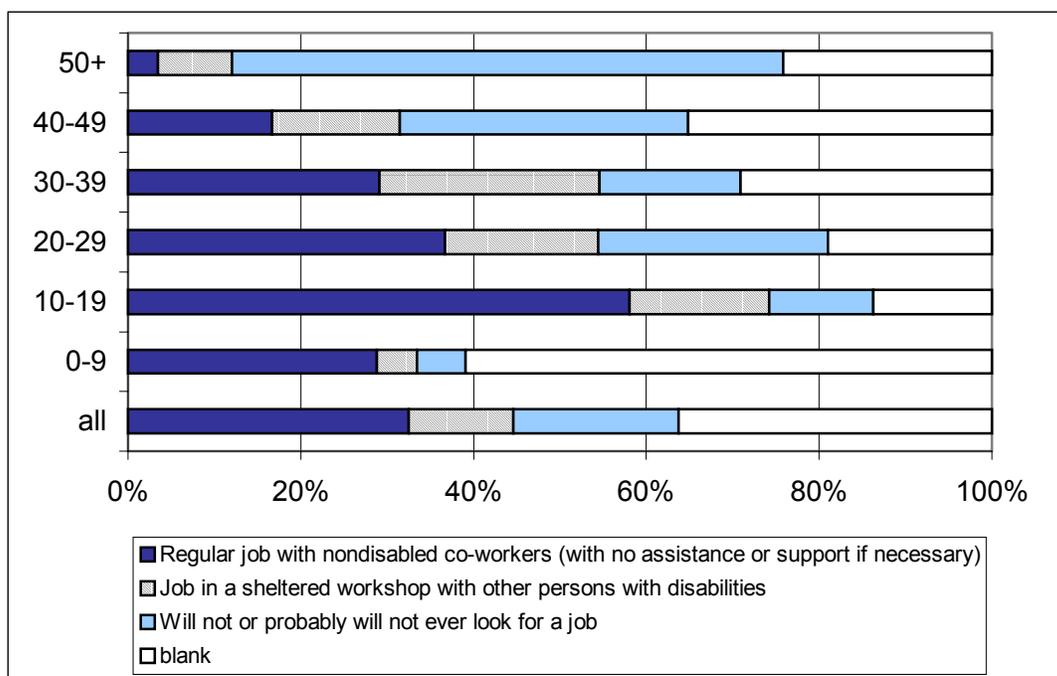
Respondents were asked, whether or not a consumer was currently working: When this person next looks for a job, which of the following will he or she want?

- A regular job with nondisabled co-workers (with no assistance or support if necessary).
- A job in a sheltered workshop with other persons with disabilities.
- Will not or probably will not ever look for a job.

Overall, 32.5 percent of the respondents indicated the first response: a regular job in an integrated setting with support if needed. Sheltered employment was selected by 12.1 percent, while 19.1 percent indicated that the consumer would probably not ever look for a job. Over a third, 36.2 percent, did not answer the question. Some, particularly those with young or very young children, may not have answered because they did not know which the consumer might eventually choose for himself or herself. Some others might have refrained from answering because they believed the consumer was currently satisfied with his or her job and unlikely to seek another one. (Respondents with consumers currently in sheltered workshops versus integrated employment left this item blank in equal proportions.)

Figure 5.8. shows how this question was answered for consumers of different ages. The response pattern reinforces again the trend toward competitive and supported employment. Very few parents of young children think in terms of sheltered workshops for them. And even for consumers over 30 years of age, sheltered workshops drop into the minority on this question.

Figure 5.8. Type of Job Consumer Will Want the Next Time He/She Looks for a Job (whether or not the consumer is currently working)



These data clearly show a need for employment services that increasingly involve integrated and competitive situations.

Finally, respondents were asked whether the consumer needed help starting his or her own business. As a percentage of the study population, the percentage answering yes who were age 21 and older was 2.5 percent. The percentage was higher for consumers in their twenties and thirties, and lower for those aged 40 or more. It was not clear whether all those who indicated an interest in getting such help wanted more information about such an enterprise or actually wanted to start a business.

**Current Service Needs Related to Employment.** We can get an idea of the current level of service needs related to employment by combining certain data already discussed. First there are those consumers now working in jobs that require some assistance or ongoing support. This includes those in sheltered workshops, supported employment and enclave settings and those operating their own businesses—a total of 18 percent of the study population. Secondly, there are those with jobs currently who are seeking a change, either in moving into a different work setting or in changing to a different job in the same type of work setting. This includes those working independently without support who are seeking a new job, those who are seeking a new supported employment job, those working in a sheltered workshop who would like a new workshop job, and those who would like help starting a business. Finally, there are those not currently working but looking for work who need help finding a supported employment or independent, competitive job or who want help starting a business.

Table 5.8. shows the percentages of consumers in these various groups who require some employment-related services. In totaling these figures there is some duplication among consumers—for example, those working in a sheltered workshop and currently receiving support but who also want help locating a job outside the workshop setting. Removing such duplication, 55 percent of the consumers in the study population between the ages of 20 and 64 have some employment-related service needs.

Table 5.8. Percent of Consumers with Current Service Needs Related to Employment

| Service   | %     |
|---|-------|
| <i>assistance with current jobs</i>                       |       |
| Supported Employment                                      | 4.6%  |
| Sheltered Workshop  | 12.4% |
| Enclave   | 0.3%  |
| Own Business  | 0.7%  |
|   |       |
| <i>assistance with job changes for those working</i>      |       |
| Finding new independent job                               | 0.9%  |
| Finding supported employment job                          | 4.0%  |
| Changing to different sheltered workshop job              | 0.7%  |
| Starting own business                                     | 0.4%  |
|   |       |
| <i>assistance obtaining new job for those not working</i> |       |
| Regular job with or without support                       | 3.1%  |
| Sheltered workshop job                                    | 0.9%  |
| Help starting own business                                | 2.1%  |
|   |       |
| Total of study population (some duplication)              | 27.9% |
| Total of consumers aged 20-64 (no duplication)            | 55.0% |