Evaluation of the Centers for Independent Living Program

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If it weren’t for the services the CIL provides, I’d be in a nursing home.

The CIL helped me obtain the services of a personal assistant. I am in college. Without the personal assistant, I would not have been able to go to college.

? Quotes from Consumer Survey respondents.

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EXECUTIVE SUMMARY

E.1 Introduction

This report presents findings from a comprehensive two-year evaluation of title VII, chapter 1, Part C of the Centers for Independent Living (CIL) program, funded by the Rehabilitation Services Administration (RSA), in the Office of Special Education and Rehabilitative Services (OSERS), U.S. Department of Education. CIL programs promote a philosophy of independent living—consumer control, peer support, self-help, self-determination, equal access, and individual and systems advocacy—the goal of which is to maximize the leadership, empowerment, independence, and productivity of individuals with disabilities, and enhance the integration and full inclusion of individuals with disabilities into the mainstream of American society. The results of the study will be used to: complement Section 704 Annual Performance Report data; support RSA Government Performance and Results Act (GPRA) reporting requirements; assist CILs to identify successful service and advocacy strategies; and inform advocates and policymakers about the Independent Living Programs.

E.2 Research Questions and Study Issues

The research questions and study issues fell under two major categories: center operations and consumer services. Under each category, issues were divided into access measures, process measures, and outcome measures. Access measures included such issues as physical accessibility of the center, whether the center is located near public transportation, whether consumers can easily reach staff by telephone, and whether services and activities are scheduled at convenient times for consumers. Process measures included the ways in which centers conduct their systems change activities, how they promote empowerment and consumer control at their centers, the services they provide, and relationships between center staff and consumers. Outcome measures included changes in consumers' lives, community changes that occurred as a result of center activities, and acquisition of funding sources beyond title VII, chapter 1, Part C of the Rehabilitation Act. We also included a feedback section under center operations, which includes how centers obtain community input on the services and systems change they provide, and a satisfaction section for the consumer surveys, which explores consumer satisfaction with center services.

This study also explored whether the types of services received, satisfaction with those services, and consumer outcomes varied by consumer demographics, or characteristics of the center. We explored potential differences by consumer race, gender, age, type of disability, income, and residence (rural, suburban, or urban). We examined any potential differences by the size (based upon FY 1999 budget) and location (urban, suburban, and rural) of the centers.

E.3 Methodology

The research team collected data for this study from two principal sources. First, we conducted a mail survey of all CILs that receive federal funding under the title VII, chapter 1, Part C Program. Second, we selected a random sample of 104 centers and conducted telephone surveys with a random sample of 569 current and former consumers. We used information from the Section 704 Report required under title VII of the Rehabilitation Act to describe the centers and the characteristics of center consumers. We also examined the range of national surveys on persons with disabilities and selected questions from the National Health Interview Survey-Disability Supplement (NHIS-D) for inclusion in the consumer survey. This data allowed comparisons between consumer survey responses and those with similar disabilities and other characteristics who are not participating in CIL Programs.

E.4 Results

E.4.1 Overall Findings

The study found that CILs are providing a wide variety of beneficial services and systems advocacy in their communities. Consumers report a high level of satisfaction with the services they receive and report significant life changes as a result of CIL services. Consumers gained knowledge and skill from center services, and credited the center with significant life changes, including positive changes in housing, employment, getting around in the community, and overall improvements in independence. It is noteworthy that, according to the FY 2000 704 Reports, CILs helped 1,380 consumers leave nursing homes or other institutions to live in the community. In other words, almost 1,400 people live in the community rather than in institutions because of Centers for Independent Living! Moreover, CILs are providing these services and advocacy in accordance with the independent living philosophy—consumer empowerment and control, peer support, systems change, and cross-disability services. Additionally, centers made significant changes in their communities. Centers enabled consumers to access community facilities and services in a wide variety of areas, including personal assistance, transportation, housing, employment, and deinstitutionalization. During FY 2000, centers served about 136,000 individuals, at a cost to the federal budget of $48 million—a federal cost of about $353 per individual served.

E.4.2 Access Measures

The Access Measures questions examined the efforts centers are making to reach out to multicultural communities and consumers from traditionally underserved disability groups. These questions also assessed director and consumer perceptions of center accessibility, including access to the main office, availability of interpreters and materials in alternative formats, and the ease of using center services.

Underserved Communities: Centers are serving minorities with disabilities in at least the same percentages that minorities are present among people with disabilities in the United States. For example, 17 percent of center consumers are Black/Non-Hispanic; Black/Non-Hispanic people represent 16 percent of the U.S. disability population. Ten percent of center consumers are Hispanic; Hispanics comprise 9 percent of the disability population. Consumers from minority backgrounds who participated in the survey felt that the centers provided services in a culturally appropriate manner. Similarly, consumers with disabilities that have been traditionally underserved by centers who received services felt that the centers were doing a good job in addressing their disability-related needs; many center directors surveyed were not satisfied with their efforts to reach out to specific multicultural communities or underserved disability communities, particularly people with Multiple Chemical Sensitivity (MCS) and psychiatric disabilities. We conclude that centers are doing an adequate job of serving these communities; however, center directors said they would like to be doing more in this area.

CIL Accessibility: Centers received high marks on most measures related to access. Between 80 and 90 percent of consumers said they could get into and around the center and could easily reach a center staff person by telephone. Consumers felt that adequate accessible parking was provided (78%) and that the center was accessible by public transportation (85%), a finding corroborated by 93% of directors. While center directors said they provided information in alternative formats, such as Braille or audiotape, and used sign language interpreters, 35 percent of consumers who needed alternative formats said that they did not receive them from the center. Of those who need a sign language interpreter or cart reporter to communicate, only 43 percent said that their center always provided one.

E.4.3 Process Measures

Process measures document how staff delivers services to consumers and how they provide advocacy to their community. These measures include the number and types of consumers served, the services they receive, and whether consumers are receiving information about available options and services. We also include measures of whether the executive directors understand and implement the independent living philosophy and the steps they take to promote community change.

Independent Living Philosophy: Most center directors were familiar with the tenets of the philosophy on which CILs are based: consumer control, peer support, community change, serving a cross-disability population, integration, and consumer empowerment. When asked to list the components of the independent living philosophy, 87 percent of directors identified "consumer control" as an important component. Center directors frequently identified integration, inclusion, and participation in the community, removal of barriers, and other tenets of the independent living philosophy. Almost half of center consumers said they had been told about the IL philosophy, 57 percent said they had been told about peer support groups, and 62 percent said that center staff encouraged consumers to advocate for themselves. These responses show that high percentages of directors and consumers understand the independent living philosophy and that this philosophy is being implemented within the CILs. This philosophy is a strong component of center programs.

Consumer population: CILs serve consumers who tend to be poor, unemployed, and unmarried. Among CIL consumers between the ages of 25 and 64, 84 percent had total household incomes below $20,000 per year. About 77 percent of working-age consumers were unemployed and 80 percent were unmarried. All of these factors are risk factors for loss of independence. CILs are serving consumers who can purchase few services to promote their independence.

Services provided by CILs: Over 98 percent of centers are providing the four core services required by title VII, chapter 1, Part C of the Rehabilitation Act: information and referral, independent living skills training, peer support, and individual and systems advocacy. They provide an array of additional independent living services. Over 98 percent of centers also provided housing referral and assistance; over 90 percent provided ADA training, group support, personal assistance service or referral, assistance acquiring technology or adaptive equipment, technical assistance on access, and advocacy training. In addition, over 85 percent provided benefits advisement and assistance with home modifications.

Consumer decision-making: Consumers appear to have a positive working relationship with the center staff person they see most frequently. Seventy-seven percent said they were presented with a variety of options and services to meet their goals. We noted that only thirty-four percent of the consumers stated that they decided on the services they would receive in order to reach their goals; another 22 percent reported that they decided on the services in consultation with a staff member at the CIL, for a total of 56 percent. Over one-fourth of consumers (27%) said the IL staff person decided on the IL services, and the rest said that someone else decided or helped them decide. This finding is surprising, given the emphasis on consumer control in the independent living philosophy and the relatively high number of consumers who said the center gave them information about different options that would help them reach their goal. This issue may warrant further exploration.

Services consumers receive: Consumers receive an array of services to support their independent living goals from their centers. It was not uncommon for a consumer to receive information and referral, peer support, housing referral, personal assistance, and other services from the center. The types of services a center offered did not differ significantly between centers located in urban, rural, or suburban communities. Except in a few cases, types of services received did not vary by CIL size or location, or by consumer demographics, such as residence, race, ethnicity, income, or type of disability. We did note that consumers under age 18 received the full array of IL services less frequently than older consumers, presumably because they are still in school and living with parents. Centers may wish to consider providing more IL skills training, employment services, ADA training, and benefits advisement to transition age youth while they are still in school so that they may move to independence and employment more easily at the appropriate time.

We found that Hispanics were less likely to receive assistance with technology or equipment than were other consumers. We also found that consumers with mental disabilities received employment advisement services less often than people with physical or sensory disabilities. Centers may wish to review their consumer records to insure that employment and technology services are readily available to all consumers.

Advocacy issues and process: A striking finding of the Director Survey was the number and complexity of advocacy issues in which centers were involved and the variety of techniques used to achieve advocacy goals. Over 70 percent of the directors reported involvement over the past year in each of the nine issues listed on the survey: transportation, deinstitutionalization, enforcement of civil rights laws, housing, personal assistance services, youth transition, education, employment, and health care. Centers involve a wide variety of constituencies, including consumers, board and staff members, and representatives of other agencies; they engage in an array of strategies to achieve their goals. Years of effort are sometimes necessary to pass one piece of legislation, achieve one policy change, or acquire a new service, and centers within a state often work together to achieve these goals. The vast majority of the center's activities are collegial—working on committees, meeting with administrators—rather than adversarial—engaging in demonstrations or taking legal action. We also found a high level of consumer involvement in systems advocacy and community change activities; over 80 percent of directors reported consumer participation in almost all of the advocacy issues in which their center was involved. Although the level of consumer involvement seems relatively high, directors feel that the advocacy agenda could be advanced more quickly with more consumer support.

Relationships with other agencies: We asked center directors about the center's relationships with other agencies, including the Designated State Unit (DSU)--generally the state vocational rehabilitation (VR) agency, the agency for the blind, and the Statewide Independent Living Council (SILC). About one third (33%) said that the DSU was very supportive, about 19 percent said the agency for the blind was very supportive, and about 38 percent felt that the SILC was very supportive. Although very low percentages of directors felt that these relationships were adversarial, they recommended the following: (1), the cross training of agency staff, (2), increases in referrals between the state VR agency, the agency for the blind, and the CIL, and, (3), clarification of the roles of CILs and the SILC.

E.4.4 Consumer Satisfaction

We asked center consumers how satisfied they were with center services overall and then asked how satisfied they were with each particular service. When asked about services overall, 64 percent said they were "very satisfied" and 23 percent said they were "somewhat satisfied" with center services. They rated the CIL as "very helpful" (65%) or "somewhat helpful" (25%) in assisting them to achieve their goals. Overall satisfaction levels did not vary much by gender, age, race, disability, center office location, or consumer location. For comparison purposes, we examined a study conducted by the Research Triangle Institute (RTI, 1996) that asked the same question to recipients of VR services. Their study found that 47 percent of participants were very satisfied and an additional 28 percent were somewhat satisfied, for a total of 75 percent of VR consumers who were very or somewhat satisfied.

We then asked consumers how satisfied they were with each specific service they had received. Consumers were most satisfied with the transportation services they received (87% said they were very satisfied). Over 70 percent of consumers were very satisfied with home modifications, personal assistance services, transition from school to work services, technology assistance and ADA training. Satisfaction levels with other services clustered around the overall satisfaction level of 65 percent. Seventeen percent of consumers were somewhat or very dissatisfied with employment referral or assistance and 11 percent were somewhat or very dissatisfied with housing referral or assistance.

E.4.5 Outcomes

Outcomes are the most difficult, but often the most critical aspects of a program to measure. Outcome measures for CIL operations include the community changes that have occurred because of the center's activities, and what resources, other than federal funding, centers have captured. We asked consumers whether they gained skills or knowledge as a result of center services and whether they achieved the goal or solved the problem they had originally approached the center to solve. We also asked consumers what life changes they had made as a result of their contact with the center.

Funding: Centers have been extremely successful in raising funds beyond those provided under title VII, chapter 1, Part C of the Rehabilitation Act. For example, over 80 percent of centers received individual donations and funds from state government; 60 percent received local governmental funding; and over 70 percent received foundation or corporate funds, title VII, chapter 1, Part B funds and fee-for-service funding.

Community change outcomes: We found that centers are achieving a significant level of community change in areas as diverse as transportation, housing, deinstitutionalization, education, employment, and civil rights. Centers are making this change by successfully advocating for passage of legislation, working with administrators to change policies, insuring that governmental agencies and private companies remove physical and communication barriers, advocating for increased services or preventing service cutbacks, and assuring that compliance with civil rights laws is being monitored. Below are some examples excerpted from the FY 2000 704 reports CILs submitted to RSA:

> Passage of HB1197, which requires the state to apply for a Medicaid waiver for publicly funded assisted living, adult foster care, and expanded day care.

Advocacy for qualified interpreters for individuals with hearing impairments with the Walker Baptist Medical Center.

Creation of a fund to assist people with disabilities to make their homes accessible. The program is coordinated through the Idaho Housing and Finance Association with CILs assisting consumers with the application process.

The Center placed two ramps at a local school that will allow students who have disabilities to access a project garden. Until the ramps were placed, these students could not accomplish the hands on study required in their science studies. With a cooperative agreement with the school administration, these students now can enjoy the same outside activities as their classmates.

City building inspection officials and center staff visit all buildings that do not meet the ADA requirements. We do this, so that inspectors can get a first hand understanding of how important it is to pay close attention to all the provisions of the accessibility guidelines and that no accommodation, regardless of how small, should be overlooked.

Advocacy was done at the US Census Bureau, to provide a temporary TTY phone line for consumers to call for job placement.

The Center organized a May, 2000 March to City Hall in support of City funding for public transportation. Despite cuts in funding for fixed route transit, the City Council maintained funding for evening and weekend paratransit services.

Consumer outcomes: Consumers said they benefited significantly from the services that they received from the CIL. For example, over 90 percent of consumers who received independent living skills training and transition services said they gained knowledge or skill. Over 80 percent said that knowledge and skill was gained from ADA training, benefits advisement, information and referral, and peer support; over 70 percent said it was gained from technology assistance, housing referral or assistance, home modifications, and transportation; and over 65 percent said it was gained from personal assistance or employment services. According to consumers, the constellation of services that centers provided, rather than any one particular service, was essential to achieving their independent living goals.

The majority of consumers also reported concrete changes in their lives as a result of these services. Independent living skills training and personal assistance services produced the most change: 82 percent of consumers who received independent living skills training and 77 percent of people who received personal assistance services said the service had made a positive change in their lives. About one quarter of consumers who received peer counseling, technology assistance, and transportation services said the service had made a positive change in their life. Not surprisingly, consumers who received a particular service reported change in that area of life. For example, consumers who received housing assistance often reported a change in housing; those who received employment assistance often reported that they were now working. Additionally, consumers indicated that services received from CILs improved their self-perception, general independence, independent living skills, and level of knowledge about other services and programs.

Improved quality of life: CILs also helped to improve the quality of consumers' lives. Almost half (47%) said their lives were "much better," and over one-fourth (29%) said their lives were "somewhat better" since their contact with the CIL. Forty-three percent of consumers reported that their experience with the CIL had helped them to develop a positive view of themselves. Another 47 percent said they "already had a positive view of themselves" before they came to the CIL.

E.4.6 Feedback

Finally, we asked center directors some questions related to the feedback mechanisms they employ to obtain reactions to their center and its services from consumers, board members, RSA and the DSU. We asked directors about good sources for identifying new board members and about the relationships between their center's board and staff members. We also asked the directors to provide feedback on their perception of how well the SILC was fulfilling its legislatively mandated responsibilities. We asked them to comment upon the evaluation and monitoring efforts of RSA and the DSU, including the site visits conducted by these entities and the 704 Reports.

Relationship with board of directors: A positive relationship between a center's board of directors and staff is essential to a successful center. Fifty-nine percent of directors characterized the relationship with their board of directors as very positive and supportive; only 3 percent felt it was adversarial. Most center directors (51%) said they conduct board training using existing board and staff members as trainers, about 31 percent said they bring in an outside expert, and the rest said they conducted some other type of board training or did not conduct board training at all. Only about 26 percent of directors said that the training they conducted was very effective. Additional training materials or resources to bring in outside experts may be beneficial, especially to the 40 percent of centers who characterized the relationship with their board as less than very positive or supportive.

Director feedback on the SILC: The SILC is empowered by title VII, chapter I to develop the State Plan for Independent Living (SPIL), along with the Designated State Unit (DSU). The SPIL determines how independent living funds are spent and what IL priorities are established in the state. The SILC represents a variety of constituencies, including CIL directors, and works with the DSU to conduct needs assessments for IL. Because the SILCs have these powers, we wanted to obtain the executive directors' views on how their SILC meets these mandates. We also asked the directors' to characterize their center's relationship with their SILC.

While 89 percent of directors felt they had some representation on the SILC, they had mixed reactions when asked whether the SILC was meeting the requirements spelled out in Section 705 of the Rehabilitation Act. It is clear that many center directors felt that their SILC is falling short in several areas of representation and responsibility. Only about half of directors agreed that, to a great extent, the SILC provides statewide representation, that the SILC represents a broad range of individuals with disabilities, and that a majority of members are individuals with disabilities who do not work for a state agency or IL center. Only 26 percent felt that individuals are knowledgeable about CILs and IL services to a great extent. Less than 50 percent of center directors felt the SILC is doing an excellent or very good job of performing the duties outlined in Section 705. It is important to note that the study did not include a survey of the SILCs, or of entities besides center directors that are represented on the SILC. A more in-depth study is needed to evaluate how well the SILCs are meeting their legislative mandates.

DSU and RSA site reviews: On the whole, center directors felt positively about the site reviews conducted by RSA and the DSU. About 73 percent of directors said that the RSA review was very or somewhat helpful, and 69 percent said the DSU review was either very or somewhat helpful. They found the reviews helpful to the center's operation and especially appreciated the involvement of peer reviewers in the process.

704 Reports: We asked centers about the utility and the burden of evaluation and monitoring conducted by the DSU and RSA, including the Section 704 reporting requirements. Only about a quarter of the directors surveyed said that the Section 704 Report was very helpful in assessing the quality of center services and advocacy, although another 44 percent said it was somewhat helpful. We noted other problems with the 704 Reporting process during the course of the evaluation. First, the report is focused upon process rather than outcome measures. For example, the report asks centers to provide the number of consumers served and their characteristics, the number and types of services provided to these consumers, and the number of goals set in each goal area (e.g., housing, transportation, employment, etc.). The report, however, does not ask centers to provide much meaningful outcomes data. Centers are asked to report the number of goals consumers achieve in each area, but there is no clear guidance on how a goal is defined or what constitutes a goal. As a consequence, reported goals can be extremely global or very specific. There are also no consistent definitions for "goals set" or "goals achieved." It is therefore difficult to attach meaning to the number of goal achievements centers report. The exception is "deinstitutionalization," where centers report the number of individuals they have assisted in moving from an institution into the community because of services they received from the center. The number of consumers who leave a nursing home can be readily identified. Centers can readily track consumers who have left nursing homes for independence, with provision of personal assistance services and other community supports. This is an extremely valuable measure of a center's accomplishments. Centers are also asked to report the number of individuals who remain out of nursing homes and in the community due to center services. It is difficult to gauge the reliability of this data because there is no consistent understanding of how this data should be collected.

We noted significant differences in the way centers report community outcomes data, which makes it difficult to quantify community outcomes or draw additional conclusions about center achievements. A review of the data also makes clear that centers do not have a consistent understanding of a "community outcome". Some centers provided several pages of narrative in reporting the process they used to produce the community change, but never then made it clear whether or not the change was achieved. Others reported the outcome but did not describe the process that led to its attainment. This makes it difficult to draw meaningful conclusions about community change activities.

E.5 Recommendations

E.5.1 Training and Technical Assistance

Directors reported a need in their centers for training and technical assistance in several areas. The study also identified some areas where additional technical assistance might enhance center operations or improve center services. These areas include:

- Board roles and responsibilities, to improve the relationships between each center and its board of directors: Although very few center directors described the relationship with their board of directors as somewhat or very adversarial, 40 percent of centers characterized the relationship as less than very positive or supportive and only about one-quarter felt that the board training they provided was very effective.

- Consumer participation: Although we found the level of consumer involvement in systems change activities to be high, center directors felt community change could be achieved more quickly with more consumer participation. They mentioned volunteer organizing and systems advocacy techniques as their top training need.

- Accessible computer applications, such as web design and data base management.

- Outreach and services to consumers from diverse multicultural communities: Although centers are serving people with disabilities from minority groups at or above their percentage in the population, center directors felt they could be doing more to reach ethnic minorities. We also noted lower levels of satisfaction with center services among Hispanic consumers.

- Outreach and services to consumers from underserved disability constituencies, particularly those with sensory and psychiatric disabilities and multiple chemical sensitivity. Again, consumers from these disability groups report that centers are doing a good job of serving them, but center directors would like to be doing more.

- Cross training of staff at the state VR agency, the state blind agency, and the CIL.

The Department of Education funds a variety of training and technical assistance programs, including a Research and Training Center on IL Management, a Research and Training Center on Rural Rehabilitation and IL, the Regional Rehabilitation Continuing Education Programs (RRCEP), and IL Net. Some of the training offered by these organizations addresses the above issues, but centers are still expressing needs or experiencing deficits in these areas.

Recommendation 1: RSA should insure that its funding priorities and the applications it funds to provide training and technical assistance to CILs address the training and technical assistance needs highlighted in this study. We recommend that organizations that provide training emphasize hands-on technical assistance activities, which enable an "expert" to work closely with a center. One option might be to link centers that have been successful with multicultural outreach or providing services to a particular disability constituency to those who are still struggling with these issues. The RRCEPs would be an appropriate vehicle for the cross training of VR, CIL, and blind staff.

E.5.2 Statewide Council on Independent Living (SILC)

Center directors had mixed reactions when asked whether the SILC was meeting the requirements spelled out in Section 705 of the Rehabilitation Act. It is clear that many center directors felt that their SILC is falling short in several areas of representation and responsibility. This study did not include a survey of the SILCs or of entities besides CILs that are represented on the SILCs. However, the executive directors surveyed in this study raised concerns that warrant additional exploration.

Recommendation 2: RSA should conduct a more in-depth study to evaluate how well the SILCs are meeting their legislative mandates. The study should examine the extent to which the SILCs represent the various constituencies specified in the Rehabilitation Act, including: whether it provides statewide representation; whether it is comprised of individuals who represent a broad range of individuals with disabilities; whether it is comprised of a majority of individuals with disabilities who do not represent a state agency or CIL; and whether it is comprised of individuals who are knowledgeable about independent living centers and services. The study should also examine the extent to which the State Independent Living Plans (SPILs) address the needs of unserved and underserved populations. In addition, it should assess community needs and the extent to which SILCs obtain consumer input, develop, monitor, and evaluate the SPIL. This study should also assess the extent to which the SILCs work with the DSU in order to measure consumer satisfaction and to develop a network of centers across the state.

E.5.3 Evaluation and Monitoring

We noted significant problems with the 704 Reporting process during the course of the evaluation. We discovered problems through our own review of the data and also in the responses to the Executive Directors Survey. First, only 22 percent of directors felt the report was “very helpful” in assessing the center’s services and advocacy. Almost half said it took over 14 working days to complete. Additionally, we found the report to be focused upon process rather than outcome measures. Centers are asked to report the number of goals consumers achieve in each area, but there is no clear guidance on how a goal is defined or what constitutes a goal. There are also problems with consistency in the “Community Outcomes” portion of the 704 Report, which makes it extremely difficult to measure a center’s performance or gauge its effectiveness in creating community change.

Recommendation 3: We recommend that RSA modify the 704 Report to respond to the concerns identified in this report. Some modifications may require changes in the regulations governing the report 34 CFR 366.50(i). RSA should obtain significant input from Centers for Independent Living, CIL consumers, and the organizations that represent them. We provide the following suggestions:

1. The 704 Report should gather information on access measures, process measures, outcome measures, and satisfaction with services. Access measures should include the extent to which the center provides the following: (1), outreach to multicultural communities and underserved disability groups, (2), physical access to the centers, and, (3), communication access, including sign language interpreters and alternatives to print formats. Process measures should include the number and types of consumers served, types of services provided, and consumer control in goal setting and decision-making. Satisfaction measures should include consumers' overall satisfaction with center services, and with the center's overall helpfulness in reaching desired goals. Outcome measures should include increasing funds from alternative sources, community outcomes, and positive life changes by consumers.

2. The consumer survey used in the 704 Report should be significantly abbreviated into a two- to three-page survey. This should be provided to centers, in addition to training materials on survey administration, for centers that wish to collect the above data. Those who wish to collect data using this instrument should do so no more than once every three years. Other alternatives to collect this data, such as the center's own survey or a review of consumer records, should also be considered.

3. Community outcomes should be defined as, "Any change in legislation, policy, practice, service, or action that results in increased community access or services for consumers." Specific categories of outcomes should be developed (such as the categories used to sort community outcomes in this report) for centers to use in reporting outcomes data.

E.5.4 Consumer Services

This study shows that CILs are providing a high quality service to its consumers. Centers are assisting consumers in making positive changes in their lives, and are enabling consumers to increase their knowledge, skills, and quality of life. The study found a few areas where services to consumers could be improved. These areas are highlighted below:

Recommendation 4: We make the following recommendations to CILs:

- **We recommend that centers ensure that alternative formats, such as Braille, large print, audiotape, and sign language interpreters are provided to all consumers who need them.**

- **We noted that only 56 percent of consumers stated that, in order to reach a goal, they decided on the services they would receive either by themselves or in conjunction with another staff person. The rest said that a staff member or someone else decided on the services the consumer should receive. Centers should take steps to insure that consumers are empowered to make their own decisions, or to have a voice in decisions, about the independent living services they receive.**

- **CILs should provide more independent living skills training, employment services, ADA training, and benefits advisement to transition age youth while they are still in school so that they may move to independence and employment more easily at the appropriate time. One option is to establish a comprehensive summer program for this population.**

- **Centers should take actions to insure that consumers from Hispanic backgrounds receive culturally appropriate, high quality independent living services. Centers should review consumer service records to determine whether people of Hispanic origin are offered equipment and technology assistance with the same frequency as other center consumers; if Hispanics are offered equipment and technology less often, centers should take any necessary steps to correct the situation.**

- **Centers should review consumer service records to determine whether people with mental disabilities are offered employment assistance with the same frequency as other center**

consumers; if people with mental disabilities are offered employment less often, centers should take any necessary steps to correct the situation.

E.5.5 Services to rural residents

In its study, *Centers for Independent Living: Rural and Urban Distribution of Centers for Independent Living,*[1] the RRTC: Rural found that about 40 percent of U.S. counties--mostly rural--lack access to CILs. They examined the location of CILs funded under title VII, chapter 1, Part C as well as those funded only with state, local, and other dollars. Federal funding has increased significantly since this study was conducted and many new CILs have been added. We do not know the urban/rural distribution of these new centers or the extent to which rural consumers are being served.

Recommendation 5: We recommend that the CIL coverage of rural areas be re-examined in light of the increase in numbers of centers since the original study was conducted.

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[1] Rehabilitation Research and Training Center on Rural Rehabilitation. *Centers for Independent Living: Rural and Urban Distribution of Centers for Independent Living: Fact Sheet.* http://rtc.ruralinstitute.umt.edu/IL/Ruralfacts/RuCILfacts.htm.

CHAPTER 1
BACKGROUND ON INDEPENDENT LIVING

1.1 Introduction

The Rehabilitation Services Administration (RSA), in the Office of Special Education and Rehabilitative Services (OSERS), U.S. Department of Education, funded a comprehensive two-year evaluation of title VII, chapter 1, Part C of the Centers for Independent Living (CIL) program.

CIL programs promote a philosophy of independent living—consumer control, peer support, self-help, self-determination, equal access, and individual and systems advocacy—the goal of which is to maximize the leadership, empowerment, independence, and productivity of individuals with disabilities, and enhance the integration and full inclusion of individuals with disabilities into the mainstream of American society.

This evaluation included questionnaire surveys of all CIL directors and a nationally representative sample of consumers of CIL services. (See Appendix C: Consumer Survey and Appendix D: Executive Director Survey.) The study examined several areas: (1), systems advocacy and change; (2), consumer satisfaction with services; (3), consumer change as a result of IL services; (4), center operations; (5), relationships with other agencies; and (6), evaluation and monitoring.

The results of the study will be used in the following ways: to complement Section 704 Annual Performance Report data; to support RSA Government Performance and Results Act (GPRA) reporting requirements; to assist CILs in identifying successful service and advocacy strategies; and to inform advocates and policymakers about the Centers for Independent Living Program.

Integral to the success of this evaluation was the Panel of Experts (POE). This panel consisted of representatives of Centers for Independent Living and their national organizations, Statewide Independent Living Councils (SILCs), the Council of State Agencies of Vocational Rehabilitation (CSAVR), consumers, and disability rights advocates. The POE held three face-to-face meetings in Washington, DC and two teleconferences during the course of the study, providing specific guidance on the study issues and questions, sample selection, participant recruiting, questionnaire design, and other methodological issues. A list of POE members is provided in Appendix A.

Chapter One of this report provides a background on Independent Living Programs, including Centers for Independent Living. Chapter Two describes the study methodology. Chapter Three describes the operations of CILs, including outreach to underserved populations, efforts to promote community accessibility, relationships with other agencies, funding, and evaluation/monitoring. Chapter Four describes center consumers, their level of satisfaction with services, and the life changes they have achieved. The final chapter contains the report's conclusions and recommendations.

1.2 The Independent Living Movement History and Philosophy

The origination of the Independent Living (IL) movement coincided with other significant social reform movements in the 1960s, most notably, the civil rights movement. Based on their common personal experiences of being excluded from full participation in society, the activists in the early IL movement shared the belief that people with significant disabilities experienced exclusion because of societal and institutional barriers. Only through successfully advocating for changes in federal, state, and local laws, and through changes in society's attitudes toward people with disabilities, can this full participation in society occur. This advocacy approach has served as the cornerstone of the IL movement since its beginnings in the 1960s.

The independent living philosophy represents a shift from the traditional medical and rehabilitation models. Those who hold with traditional models locate the problem within the individual and define the problem as the individual's physical or mental impairment. The solution to the problem is professional intervention and treatment for the patient or client. The professional controls the process and the desired outcomes are seen as maximum function and/or gainful employment. On the other hand, those who hold with the IL model locate the problem within the physical inaccessibility of the environment and within attitudinal and societal barriers. Solutions include advocacy, barrier removal, self-help, peer role models and counseling, and consumer control over options and services. Within this model, the individual with a disability is viewed as a consumer of services, rather than a service recipient; as such, the consumer controls the process. The desired outcome is independence through control over acceptable options for every day living in an integrated community.[1, 2, 3]

Brown[4] points out that IL philosophy includes the notion that each individual is different and unique, that people with disabilities are the most knowledgeable experts about their own needs and issues, and that programs serving disabled people should be designed to serve all disability groups. In addition to emphasizing the uniqueness of each person and each disability group, he also emphasizes the commonalities between people and groups. The predominant theme of the independent living movement is the creation of opportunities for people with disabilities with regard to optimal control over programs, services, and physical settings that influence capabilities to perform in school, job, family, and social roles.

The Centers for Independent Living (CILs) were originated through the work of two early activists in the IL movement, the late Ed Roberts and Judith Heumann, former Assistant Secretary of the Office of Special Education and Rehabilitative Services (OSERS) in the U.S. Department of Education. In April 1972, these two IL leaders helped found the first CIL, which was located in Berkeley, California. Local resources initially funded the center, but a $50,000 grant from the Rehabilitation Services Administration (RSA) supplemented this funding three months after the center opened. The grant's purpose was to examine how to establish a community-based services program for people with significant disabilities. CILs sprang up in other parts of the country supported by local dollars during the early 1970s.

1.3 Federal Support for Independent Living Programs

Federal support for independent living programs began in earnest in 1978 when Congress added title VII, Comprehensive Services for Independent Living, to the Rehabilitation Act of 1973.

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[1] Scotch, R. K. (1984). From Good Will to Civil Rights: Transforming Federal Disability Policy. Philadelphia: Temple.

[2] Shapiro, J. P. (1993). No Pity: People with Disabilities Forging a New Civil Rights Movement. New York: Times Books.

[3] Nosek, M. A., Marcus J. F., and Howland, C.A. (1992). Independence Among People with Disabilities: II. Personal Independence Profile, *Rehabilitation Counseling Bulletin*, 36(1), 21-36.

[4] Brown, S. (2002). *Freedom of Movement: IL History and Philosophy*. Independent Living Research Utilization, Houston TX.

People with severe disabilities viewed the passage of title VII as a significant step toward obtaining options and control over their lives.

Title VII mandated that each Designated State Unit (DSU), generally the state vocational rehabilitation (VR) agency, offer programs for people with disabilities who may not have the immediate potential for employment. The legislation provided funding to state VR agencies for independent living services and created the Centers for Independent Living (CIL) Program. During the 1980s, title VII was changed to require that CILs be non-profit agencies and that at least 51 percent of their board members be individuals with disabilities. Title VII mandates that CILs provide information and referral, peer counseling, individual and systems advocacy, and independent living skills training. Beyond these basic services, CILs developed quite differently, based upon community needs.

1.4 Current Federal Legislation and Funding

The values and principles of the founders of the independent living movement resonate in the current federal legislation dedicated to independent living. Title VII, chapter 1 of the Rehabilitation Act states that the purpose of the programs is to "promote a philosophy of independent living, including a philosophy of consumer control, peer support, self-help, self-determination, equal access, and individual and system advocacy, in order to maximize the leadership, empowerment, independence, and productivity of individuals with disabilities, and the integration and full inclusion of individuals with disabilities into the mainstream of American society." With this commitment, title VII, chapter 1 provides a structure for creating and maintaining the organizational framework intended to accomplish this purpose.

Title VII, chapter 1 consists of three parts. Part A includes definitions, planning requirements for states, and provisions for Statewide Independent Living Councils (SILCs). Part B provides for DSUs to furnish a variety of resources to support independent living services under a State Plan for Independent Living (SPIL). Part C addresses the Centers for Independent Living (CILs) program. Key provisions of title VII, chapter 1 are summarized below.

1.4.1 State Plan for Independent Living (SPIL)

To receive federal assistance, each state's SILC and DSU must jointly develop and submit a three-year plan for providing independent living services. The SPIL must identify the state's overall objectives of its IL program and the timelines for achieving these objectives. The SPIL should identify a state's design for establishing a statewide network of CILs, the priorities for services and populations to be served, the types of IL services to be provided, and plans for outreach to unserved or underserved populations. In addition, it should determine how the state is pursuing coordination and cooperation among the Independent Living program, the SILC, the state VR agency, and other federal, state, and local programs serving those with disabilities.

The legislation also requires that the SILC, the DSU, or both entities hold public hearings regarding the content of the plan during the plan's formulation and after its completion. The plan itself also must provide for periodic review and revision to ensure its appropriateness to the IL needs of the state as these needs evolve over the three-year period. Methods used to periodically evaluate the effectiveness of the plan with regard to meeting the plan's objectives must include evaluation of satisfaction by individuals with disabilities. Additionally, the state must maintain records and submit reports to the Commissioner of RSA that detail state progress in achieving the plan's objectives.

1.4.2 Statewide Independent Living Councils (SILCs)

The statute ensures that the SILC functions as an independent entity by requiring that the SILC "shall not be established as an entity within a state agency." This provision also is intended to facilitate the SILC's functioning as a full partner with the DSU in the development and implementation of IL activities. The governor appoints members of the SILC, which must include at least one CIL director, a representative of the state VR agency, and representatives of other state agencies that provide services for people with disabilities. Other SILC members may include other CIL representatives, parents of individuals with disabilities, advocates for individuals with disabilities, representatives of local businesses and other people who, in the aggregate, provide statewide representation. Each SILC member serves a three-year term, and no member may serve more than two consecutive full terms. The SILC has the following five duties set forth in the enabling legislation:

- Jointly develop and sign (in conjunction with the designated State Unit) the State Plan required in section 704;
- Monitor, review, and evaluate the implementation of the State Plan;
- Coordinate activities with the State Rehabilitation Advisory Council and other councils that address the needs of specific disability populations and issues under other federal law;

- Ensure that all regularly scheduled meetings of the SILC are open to the public and that sufficient advance notice is provided; and
- Submit to the commissioner such periodic reports as the commissioner may reasonably request, keep such records, and afford such access to such records, as the commissioner finds necessary to verify such reports.

Legislation also directs the SILC to develop, in conjunction with the Designated State Unit, a resource allocation plan. The resource allocation plan is to identify how funds made available, through all sources, will be used to carry out the SILC's functions.

1.4.3 The Role of the Designated State Unit (DSU)

In implementing the State Plan, the Designated State Unit (DSU) has the role of receiving, accounting for, and disbursing funds received under title VII, Chapter 1 as designated in the SPIL, providing administrative support services to IL programs, and maintaining suitable records. Under chapter 1, a DSU receives funds including Part B funding and, in only two states (Minnesota and Massachusetts), Part C funding. In all other states, the centers receive their Part C funding directly from RSA. In many states, the DSU receives state funding, which is passed on to the centers.

The following eight specific uses for Part B funds are identified in the legislation:

- Provide resources to carry out the functions of the SILC;
- Provide independent living services;
- Demonstrate ways to expand and improve independent living services;
- Support the operation of CILs that comply with the standards and assurances set forth in Title VII, chapter 1;
- Support activities to increase the capacities of public or nonprofit agencies and organizations and other entities to develop comprehensive approaches or systems for providing independent living services;
- Conduct studies and analyses, gather information, develop model policies and procedures, and present information, approaches, strategies, findings, conclusions, and recommendations to policymakers in order to enhance IL services for individuals with disabilities;

- Train individuals with disabilities and individuals providing services to individuals with disabilities and other people regarding the IL philosophy; and
- Provide outreach to populations that are unserved or underserved by title VII programs, including minority groups and urban and rural populations.

1.4.4 Definition of Centers for Independent Living (CILs)

The definition of a CIL as contained in title VII is, "a consumer-controlled, community-based, cross-disability, nonresidential private nonprofit agency that is designed and operated within a local community by individuals with disabilities, and provides an array of independent living services." A number of federal funding criteria are established by this definition. These criteria ensure that all CILs receiving Part C money share certain essential features. A majority of board members must be individuals with disabilities; they must provide services on a cross-disability basis; they must assist consumers to develop individual IL goals; they must advocate for increased community options; they must build community capacity to serve people with disabilities; and they must obtain resources beyond those provided by title VII.

1.4.5 Current Federal Funding for Independent Living Programs

Funding for IL programs has generally increased incrementally since the early 1980's. A cadre of well-established centers has operated since that time; a few new centers were added to the program each year. In fiscal year 2002, RSA funded 306 centers under title VII, chapter 1, Part C. Funding levels for title VII programs are shown in Table 1-1.

Table 1-1

Funding levels for title VII programs

Programs	FY 2001	FY 2002
Independent Living State Grants (Part B)	$22.3	$22.3
Centers for Independent Living (Part C)	58.0	62.5
Services for Older Blind (Chapter 2)	20.0	25.0
TOTAL	100.3	109.8

1.5 CIL Consumers' Characteristics

Section 704 of the Rehabilitation Act requires that centers compile statistics on the characteristics of the consumers they serve and the services they provide. These reports, typically referred to as "the 704 Reports," reveal that during the year ending September 30, 2000, the Centers for Independent Living served approximately 136,000 consumers. While the program served consumers across the spectrum, the majority were between the ages of 23 and 64. In addition, 25 percent were aged 65 and over, while 14 percent were children and young adults aged 22 or younger. Among this latter group, 1 percent were preschoolers under 6 years of age, 5 percent were school-aged children between ages 6 and 17, and another 8 percent were between the ages of 18 and 22. This latter group is important because they can obtain an array of services from the centers that will prepare them for a lifetime of independence and employment. These breakdowns provide important contextual information for the analysis that follows in the subsequent chapters.

Approximately two-thirds (66%) of consumers were White/non-Hispanic; 17 percent were Black/non-Hispanic; 10 percent were of Hispanic origin; and 6 percent were Native Americans, Asians, or other races. CILs served slightly more males than females (55% vs. 45%).

CILs serve consumers with an array of disabilities, including cognitive, physical, sensory, and mental/emotional. Nearly half (44%) of consumers had physical disabilities, while 22 percent had either cognitive or mental/emotional disabilities. About 14 percent had sensory disabilities, including hearing, visual, or communication disabilities. Table 1-2 presents the distribution of demographic characteristics for consumers.

Table 1-2. Distribution of demographic characteristics for consumers

Centers for Independent Living Consumer Characteristics	Number	%
Age Profile		
Under 6	1,693	1
6 to 17	6,611	5
18 to 22	10,354	8
23 to 64	74,368	57
65 and over	31,955	25

Centers for Independent Living Consumer Characteristics	**Number**	**%**
Unknown	4,935	4
Gender		
Male	72,010	55
Female	59,329	45
Unknown	81	0
Race/Ethnicity		
American Indian/Alaska Native	2,665	2
Asian	3,435	3
Black	22,197	17
Hispanic/Latino	12,655	10
Native HI/Pacific Islander	1,601	1
White	83,655	66
Unknown	1,472	1
Disability		
Cognitive	14,903	11
Mental/Emotional	15,419	11
Physical	60,392	44
Hearing	9,089	7

Table 1-2. Distribution of demographic characteristics for consumers (cont.)

Centers for Independent Living Consumer Characteristics	**Number**	**%**
Vision	8,280	6
Sensory	1,615	1
Multiple	23,202	17
Unknown	3,886	3
TOTAL	136,786	100

1.6 Training for CILs

The Executive Director Survey asked questions related to CIL board and staff training; we provide recommendations related to training based upon the results. This section briefly reviews federally funded training for CILs as background for the reader.

The National Institute on Disability and Rehabilitation Research (NIDRR) and RSA fund several training and technical assistance resources for CILs through a competitive grant process. These efforts are described below.

1.6.1 IL NET

The IL NET (www.ilru.org) is the national training and technical assistance project working to strengthen the independent living movement by supporting CILs and SILCs. Title VII mandates that between 1.8 and 2 percent of the IL program budget is designated for training and technical assistance for title VII, chapter 1 programs. The Independent Living Research Utilization (ILRU) and the National Council on Independent Living (NCIL) operate this project. The IL NET advances CIL and SILC management and programming in the following ways: by conducting large-scale training seminars and on-line and teleconference training; by publishing articles, manuals, FAQs, and other materials; and by providing technical assistance by phone or on location. IL NET activities include workshops, national teleconferences, technical assistance, on-line information, training materials, fact sheets, and other resource materials on operating, managing, and evaluating centers and SILCs. Current course offerings include IL philosophy, IL board development, heroic leadership, orientation for new IL personnel (levels I and II), financial management, and ethics and values. On-site topics include grant writing, development of youth leadership, designing a CIL to support its mission, mobilizing resources, financial management, strengthening board leadership, and marketing. Teleconference training includes innovative programs on serving consumers with psychiatric disabilities, working with consumers with multiple chemical sensitivity (MCS), introduction to IL, using housing Section Eight vouchers, developing youth leadership, VR and IL relations, advocacy, and managing personal assistance services (PAS) programs. SILC training includes how to become a private non-profit organization and CIL and SILC relationships.

1.6.2 Research and Training Center on Independent Living Management

The Rehabilitation Research and Training Center on Independent Living Management (RRTC-ILM) (www.wnyilp.org/rrtcilm) is funded by NIDRR and located at the Western New York Independent Living Project, one of the first CILs in New York State. The RRTC-ILM strives to be a leader in assisting Independent Living Centers in becoming viable through strong programs, management, and funding. It conducts research and provides training and information for the national network of CILs, policy makers, administrators, and advocates in their efforts to improve the quality of life for people with disabilities in their communities. During its first year, the Center on IL Management has published two newsletters, conducted five training programs, developed a website and created a national directory of independent living centers. The RRTC-ILM participated in two national IL conferences and conducted management research focus groups at both. It has also provided technical assistance to RSA and developed a customized training program for the New York State Independent Living Council.

1.6.3 Research and Training Center on Rural Rehabilitation Services

NIDRR also funds the Research and Training Center on Rural Rehabilitation Services (RTC: Rural) (www.ruralinstitute.umt.edu/rtcrural) located at the Rural Institute, University of Montana in Missoula. This RTC provides research and training on rural disability and rehabilitation issues and CILs. The 12.5 million rural Americans with disabilities and those who serve them experience problems with access to transportation and housing, employment and self-employment, independent living services, health and wellness facilities, and inclusion in community planning and activities. The goal of this center is to use scientific methods to develop solutions to these wide-ranging problems.

Several of the RTC: Rural's projects relate specifically to CILs. For example, the RTC: Rural reported on five major models CILs use to provide services to rural areas, including "standard CILs," "satellites," "branch offices," "outreach offices," and "other approaches." Additionally, the RTC: Rural is developing and evaluating strategies to increase the participation of rural people with disabilities in local planning and community development. The RTC has also developed a curriculum to promote health and wellness for people with severe disabilities and has piloted the curriculum with rural centers. Additionally, the RTC has studied the rural and urban distribution of CILs and has estimated the cost of insuring that every county throughout the U.S. has a CIL.

1.6.4 Regional Rehabilitation Continuing Education Programs

RSA funds 22 Regional Rehabilitation Continuing Education Programs (RRCEPs). According to title III of the Rehabilitation Act, the RRCEPs are mandated to accomplish the following: (1), ensure that skilled personnel are available to provide rehabilitation services to people with disabilities through a variety of rehabilitation programs, including CILS; (2), maintain and upgrade basic skills and knowledge of personnel employed in such programs; and (3), provide training and information to people with disabilities and others to develop skills necessary for people with disabilities to access the rehabilitation system.

Ten of the RRCEPs provide training programs for vocational rehabilitation and CIL staff. Training programs vary between regions. In some cases, training for CIL staff is conducted in conjunction with training for VR staff (e.g., training regarding a specific disability population). Other training, such as management skills development, is oriented more specifically to CIL staff. Because of the growing understanding of the interrelationship between CILs and state rehabilitation agencies, some RRCEPs are conducting cross training for staff.

1.7 Evaluation of Independent Living and Vocational Rehabilitation

Prior research studies have used varying approaches to examine the efficacy and operations of CILs. Three studies of the centers commissioned by the federal government are discussed in this section, along with relevant portions of a study of the Vocational Rehabilitation (VR) program, conducted by Research Triangle in 1996. We also provide a brief overview of RSA reporting requirements and evaluation.

1.7.1 Berkeley Planning Associates, 1986

In 1986, Berkeley Planning Associates conducted a comprehensive evaluation of the title VII, Centers for Independent Living Program. The evaluation included mail surveys of IL centers and consumers as well as site visits, which entailed interviews of consumers and community agencies. The evaluation found that the CIL Program was successful in assisting large numbers of disabled people in maintaining or improving their ability to live independently within their communities. Consumers benefited from direct services, referrals to other resources, and community change activities. The study found great diversity among centers in their target populations, the services they offered, their management systems and practices, and level of consumer involvement in center planning and management. The report recommended more guidance and technical assistance from RSA, information exchanges between centers, and increased amount and stability of funding. The study also found that the information that centers collect about the services they provide and the consumers they serve would be more valuable to policymakers and program planners if definitions and measures were made uniform across the IL program.

1.7.2 Research Triangle Institute, 1996

In 1996, the Research Triangle Institute (RTI) produced The Second Interim Report: Characteristics and Perspectives of VR Consumers. This report was part of a longitudinal study of the Vocational Rehabilitation Service Program. We discuss the evaluation of VR because we will later compare our findings with those of the RTI report. One chapter in the RTI report focused on consumers' perspectives of their VR experiences, including their perspectives on how decisions were made about their VR services. RTI examined consumers' perceptions of their degree of choice in selecting their vocational goals, services, and service providers; the nature, frequency, and quality of consumers' interactions with their VR counselors; and consumers' perspectives on specific VR services and on the overall VR experience. Consumers reported a high level of satisfaction with the available choices of a VR goal, VR services, and VR providers. We used some of these questions in this study so we could compare choice and satisfaction between VR and IL consumers.

1.7.3 Research Triangle Institute, 1998

In 1998, RTI conducted an analysis of the federally supported independent living program, including an assessment of the title VII, chapter 1 and title VII, chapter 2 (IL services for Older Individuals who are Blind) programs. The study had three purposes: (1), to clarify the relationship among the three IL programs, other IL service providers, and statewide IL Councils; (2), to describe how IL programs obtain information needed to measure program outcomes; and (3), to identify statutory or regulatory changes, if any, that may be necessary to remove impediments to effective service delivery and program management. The study examined organizational staffing and structure, program planning and coordination, independent living funding and resource allocation, the consumers of independent living services, the independent living services and activities, outcomes and performance measurements, and respondents' recommendations for improvements. RTI conducted a comprehensive review of available program documentation and site visits to nine states that included meetings with representatives of the statewide IL Councils, Designated State Units, IL coordinators, and CIL directors. The 1998 study was a descriptive one that did not produce national data on consumer satisfaction and other outcomes. However, it did report the following: (1), a recent trend toward increased reliance on grants and contracts with CILs and commensurate decreases in DSU delivered services; (2), the belief by most respondents that the planning process is working well but that CILs needs are often inadequately reflected in the final plan, particularly true for CILs in rural areas; (3), the largest percentage of IL consumers were those with significant physical disabilities; (4), a variety of IL services were provided including advocacy/legal services, recreation, peer counseling, IL skills training, and housing and shelter; and (5), most CIL staff relied primarily on consumer satisfaction data in assessing CIL effectiveness.

1.7.4 RSA Monitoring and Evaluation

In fiscal year 1995, statutory evaluation standards and compliance indicators for the CIL Program became effective. These indicators further reinforce and expand the requirements for CILs provided in the title VII legislation. They measured center compliance regarding the areas of IL philosophy, provision of services on a cross-disability basis, support for the development of individual IL goals, advocacy to increase community options, community capacity building, and resource development. The indicators also reinforce the definition of what constitutes a CIL by requiring that individuals with disabilities represent a majority of the governing board and a majority of management staff. They also require that all CILs serve consumers with any significant disability and provide the four core services of information and referral, peer counseling, individual and system advocacy, and IL skills training. The indicators also help ensure that federally funded centers reflect the basic principles upon which the IL movement was founded.

RSA obtains information on whether the CILs are meeting the standards set forth in the legislation and indicators through the “704 Reports” required annually of CILs. These reports collect information on numbers and demographics of individuals served, types of services provided, number of goals set and attained in each service area, types of community change achieved, the percent of individuals with disabilities on the board of directors and in management, and other data. Elements of the 704 data are used to establish and measure program performance under the Government Performance and Results Act (GPRA). RSA must annually report progress in meeting the GPRA performance objectives to Congress. The performance objectives and indicators are shown in Table 1-3.

Table 1-3: Government Performance and Results Act
Performance Objectives and Indicators

Program Performance

Objective 1: Increase the number of individuals with significant disabilities who are served by and benefit from the Title VII, Chapter 1 programs.

Indicator 1.1 Number of individuals with significant disabilities served grouped by age: The number of individuals who receive individual independent living services will increase in all age categories.

Targets and Performance Data

The number of individuals receiving individual independent living services

Year	Actual Performance					Performance Targets
	Under 6	6-17	18-22	23-54	55-older	
1998	2,390	7,028	11,755	81,012	53,045	
	Total: 185,000*					
1999:	Total: No Data Available					Total: 142,301
2000:	No Data	No Data	No Data	No Data	No Data	Total: 146,486
2001:						Total: 220,000
2002:						Total: 220,000

*__Note:__ Additional 30,000 with ages unknown.

Indicator 1.2: Number of goals set and achieved by consumers: The number of consumer goals set and achieved will increase in all service areas measured.

Targets and Performance Data

Actual Performance

The FY 1998 Goals	Set	Met	Rate
Self-care:	44,617	31,004	69.4%
Communication:	21,785	15,985	73.3%
Mobility:	20,301	13,928	68.8%
Residential:	24,318	13,102	53.8%
Educational:	17,295	11,436	66.1%
Vocational:	17,261	8,104	46.9%
Other:	44,403	30,035	67.6%
Total:	**189,980**	**123,594**	**65.0%**

Year	Actual Performance	Performance Targets
1997:	62.3% total	
1998:	65.0% total	
1999:	No Data Available	62.5% total
2000:	No Data Available	63% total
2001:		63% total
2002:		63% total

OBJECTIVE 2: INCREASE THE SATISFACTION OF CONSUMERS WHO RECEIVE CHAPTER 1 INDEPENDENT LIVING (IL) SERVICES.

Indicator 2.1 Consumer satisfaction with IL services: A consistently high proportion of consumers will report satisfaction with IL services.

Targets and Performance Data

FY 1997 New York State survey: Percentage of consumers who are very or mostly satisfied with services

Year	Actual Performance	Performance Targets
1997:	85%	
1998:	No Data Available	
1999:	No Data Available	No target set
2000:	No Data Available	87%
2001:		87%
2002:		87%

OBJECTIVE 3: IMPROVE ACCESS TO PERSONAL ASSISTANCE SERVICES (PAS), HOUSING, TRANSPORTATION, AND COMMUNITY-BASED LIVING THROUGH INCREASED ADVOCACY EFFORTS.

Indicator 3.1: Number of Centers for Independent Living (CILs) using effective advocacy techniques: All CILs will have an advocacy program to address at least two of the following areas: (a) community-based personal assistance services (b), accessible/affordable housing (c), accessible/affordable transportation, and (d) options for moving people from nursing homes and other institutions to the community.

Targets and Performance Data			Assessment of Progress
Preliminary results FY 1997, New York State: Percentage of CILs with programs in two areas			**Status:** Progress toward target is likely. **Explanation:** Data is in but analysis is not yet completed. Projecting analysis will be completed by end of second quarter.
Year	**Actual Performance**	**Performance Targets**	
1997:	25%		
1998:	No Data Available		
1999:	No Data Available	30%	
2000:	No Data Available	50%	
2001:		80%	
2002:			

Indicator 3.2: Increased Community-based Living: The number of individuals who leave nursing homes and other institutions for community-based housing and the number of individuals at risk of entering nursing homes and other institutions who are receiving IL services and can remain at home will increase.

Targets and Performance Data

Year	Actual	Target	Actual	Target
	Number of Individuals who Left Nursing Homes/Institutions		Number of Individuals who Remained in the Community	
1998:	1,671		18,343	
1999:	No Data Available	850	Data not yet available	8,500
2000:	No Data Available	850		8,500
2001:		900		9,000
2002:		950		9,500

* As estimated by RSA staff interviews of CIL executive directors

OBJECTIVE 4: INCREASE THE AMOUNT OF FUNDS IN ADDITION TO TITLE VII THAT SUPPORT CHAPTER 1 GRANTEES.

Indicator 4.1: Increased funding from alternative sources: Up to 76 percent of CILs will have greater than 25 percent of their budget from sources other than title VII, chapter 1, and 80 percent of states will contribute more than the required minimum match for title VII, chapter 1, Part B.

Targets and Performance Data

Year	**Actual**	**Target**	**Actual**	**Target**
	Percent CILs > 25%		Percent States Overmatch Part B	
1997:	74 %		80 %	
1998:				
1999:	No Data Available	No target set	Data not yet available	No target set
2000:	No Data Available	75 %		80 %
2001:		76 %		80 %
2002:		76 %		80 %

In addition to collection of the 704 data, RSA conducts site reviews on CILs that receive funding under title VII chapter 1, Part C. Each RSA regional office randomly selects 15 percent of the centers in its region per year for review. These site reviews consist of interviews with staff and consumers, review of relevant documents and review of a random selection of case records. These site reviews are unique in that current and former CIL directors and disability advocates often serve on the review team.

1.8 Current Issues

1.8.1 Rural Coverage

In its study, *Centers for Independent Living: Rural and Urban Distribution of Centers for Independent Living*[5] the RRTC: Rural found that about 40 percent of U.S. counties--mostly rural--lack access to CILs. They examined the location of CILs funded under title VII, chapter 1, as well as those funded only with state, local, and other dollars. This research indicated that in 1996-1997, a total of 336 CILs served people with severe disabilities across the nation; only 88 CILs were located in non-metropolitan counties; forty percent of rural areas were unserved. Although it was found that many metropolitan CILs also provide services to non-metropolitan, rural areas, their catchment areas often include a number of counties. Research Triangle Institute (RTI, 1998) found that a vast majority of consumers live in the county where the CIL is located. Outreach programs to reach rural residents become

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[5] Rehabilitation Research and Training Center on Rural Rehabilitation. *Centers for Independent Living: Rural and Urban Distribution of Centers for Independent Living: Fact Sheet.* http://rtc.ruralinstitute.umt.edu/IL/Ruralfacts/RuCILfacts.htm.

very important. Federal funding has increased significantly since this study was conducted and many new CILs have been added. We do not know the urban/rural distribution of these new centers or the extent to which rural consumers are being served.

1.8.2 Services to Additional Populations

A major issue for the next few years is inclusion of underserved populations in the IL movement. People with disabling conditions not traditionally included in the IL movement are clamoring for inclusion, especially people with psychiatric disabilities, mental retardation, multiple chemical sensitivities, and AIDS[6]. CIL directors, center staff, and SILC representatives also identified outreach to underserved populations as a major issue during annual focus groups conducted by ILRU since 1998. CIL directors identified the difficulty of providing service to multicultural populations, specifically, serving several diverse populations, conducting outreach in ways that foster trust, and finding and retaining a diverse cadre of staff. Similarly, directors identified outreach to rural populations, individuals who are deaf, and those with non-physical disabilities as a concern. Directors also noted an increased demand for youth services due to the new emphasis on transition from school to work. Line staff and SILC representatives identified outreach to minority populations, rural areas, and youth leadership as concerns.

1.8.3 Other Issues

ILRU reports that the concerns of CIL directors, line staff, and SILC members have remained relatively constant since 1998. For example, participants in the 1998 and 2001 focus groups raised CIL management issues, including leveraging of additional resources, low salaries, burnout, and high staff turnover, board training, improving board and SILC relations, and strategies to accurately and easily assess and report consumer and community outcomes. The service issues they raised included integrating the IL philosophy into service settings and trying to balance systems advocacy and direct services activities. Participants were also concerned about outreach to specific populations, including people with psychiatric disabilities and youth.

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[6] Brown, S. (2002). *Freedom of Movement: IL History and Philosophy*. Independent Living Research Utilization, Houston TX.

A number of these issues have been ongoing concerns of CILs for many years and seem intractable. For this evaluation, an understanding of these problems was essential in order to design an objective, useful survey and to appropriately interpret the findings.

CHAPTER 2
EVALUATION DESIGN

2.1 Research Design

2.1.1 Conceptual Framework for the CIL Evaluation

Figure 2-1 presents the conceptual framework for evaluating Centers for Independent Living. The model builds on the performance measurement work of the United Way of America[1] and divides the Centers for Independent Living Program into several major domains of operation for the purpose of analysis, from program inputs to consumer outcomes. This model, which can be used to examine any non-profit agency, was adapted to fit CIL operations. It examines inputs, process, outcomes, and feedback related to CIL operations.

Inputs

The term "inputs" refers to the resources dedicated to, or consumed by, Centers for Independent Living, including funding, staffing, volunteers, facilities, equipment and supplies, and the host of other capital (human, monetary, or otherwise) available to the Centers for Independent Living. The size and characteristics of the staff, the education and experience of these center personnel, and the cultural and philosophical perspectives of the center director are among the key inputs for measurement of the CIL Program. The physical facility and the related equipment available to support the program are key inputs as well. This includes not only the buildings in which the centers operate, but also the technology the center provides to its consumers and staff. Supporting all of this is the size and composition of the center budgets, especially beyond the formula allocations from RSA. Many of these program inputs can be examined in terms of access; for example, whether consumers have access to the center's physical facilities, whether they can easily use center services, and whether materials are provided in alternative formats, such as Braille or audio-tape.

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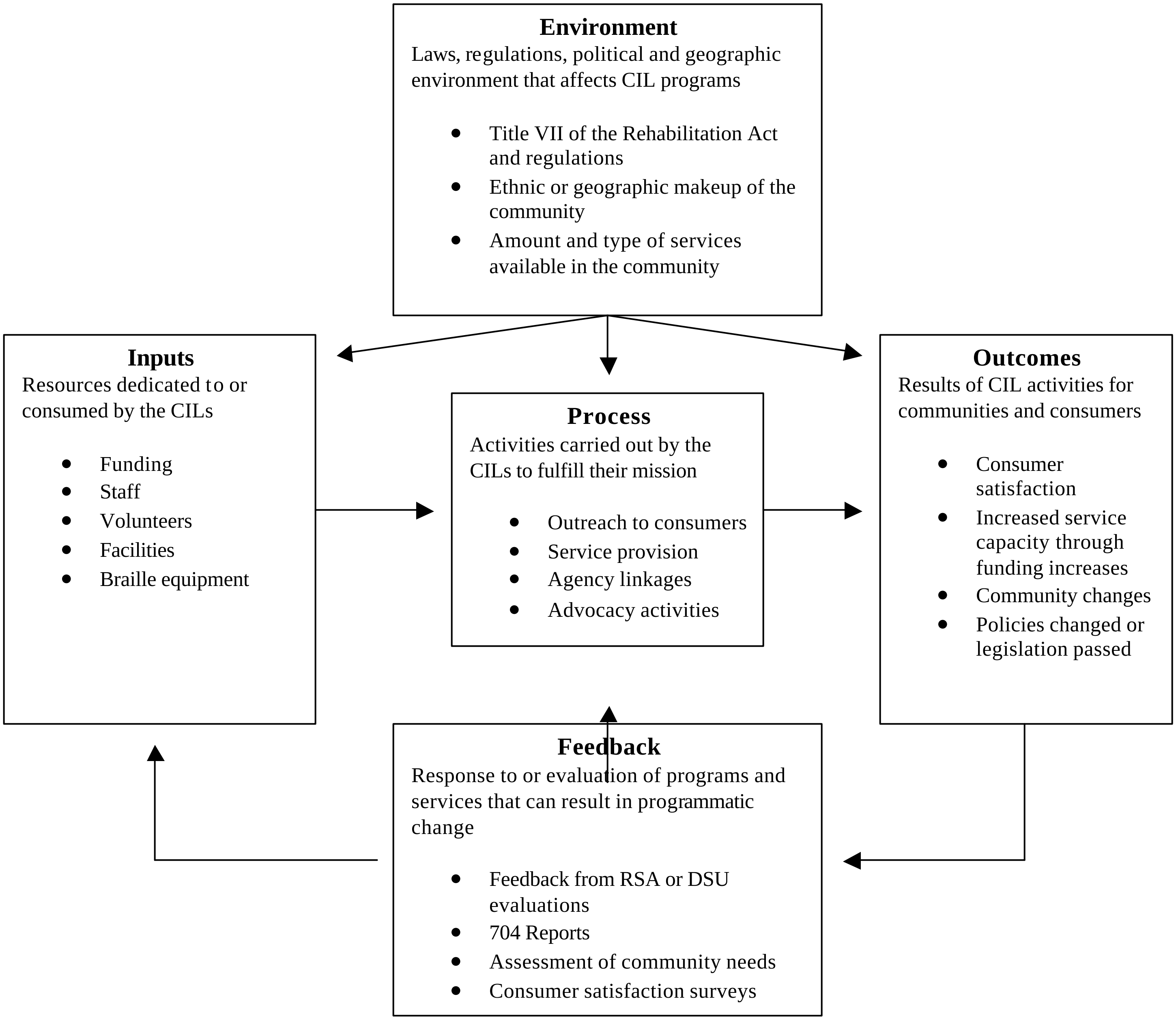
[1] Easton, D. (1996). *Measuring Program Outcomes: A Practical Approach*. Alexandria, VA: United Way of America.

Examples of topic areas that address inputs from the Executive Director Survey include:

- Access to center facilities;
- Alternative communication methods;
- Public transportation; and
- Financial resources.

Figure 2-1

Centers for Independent Living Program Evaluation Model



Environment

Laws, regulations, political and geographic environment that affects CIL programs

- Title VII of the Rehabilitation Act and regulations
- Ethnic or geographic makeup of the community
- Amount and type of services available in the community

Inputs

Resources dedicated to or consumed by the CILs

- Funding
- Staff
- Volunteers
- Facilities
- Braille equipment

Process

Activities carried out by the CILs to fulfill their mission

- Outreach to consumers
- Service provision
- Agency linkages
- Advocacy activities

Outcomes

Results of CIL activities for communities and consumers

- Consumer satisfaction
- Increased service capacity through funding increases
- Community changes
- Policies changed or legislation passed

Feedback

Response to or evaluation of programs and services that can result in programmatic change

- Feedback from RSA or DSU evaluations
- 704 Reports
- Assessment of community needs
- Consumer satisfaction surveys

Process

The process component of the evaluation documents how center staff delivers services to consumers and how staff advocates for system changes to remove barriers and enhance opportunities for persons with disabilities. It documents the steps that center staff take to identify consumers and deliver specific independent living services to them, the activities staff undertake to build linkages with other community agencies on behalf of persons with disabilities, and the specific ways in which centers promote systemic change through advocacy. While all centers share common goals and approaches, the evaluation design assumes that there are substantial variations in the organization and functional make-up of the centers that may help explain differences in consumer and systems outcomes.

Executive Director Survey process measures include:

- Selecting and training the board of directors;
- Types of services provided;
- Methods for conducting systems advocacy; and
- Methods for multicultural outreach.

Process measures from the Consumer Survey include:

- Alternative formats for communication;
- Procedures for making decisions about services; and
- Types of relationships with center staff.

Outcomes

Perhaps the most difficult but most important outcomes to measure are the consumer and systemic changes attributable to the Independent Living Program. These go beyond the levels of effort and services rendered by showing the impact of the programs on the lives of people with disabilities. Examples of possible outcomes include: the levels of consumer satisfaction and perception of life changes or increases in the quality of life; increased service capacity through the development of new programs within or outside the center; documented reduction of barriers to full participation in various aspects of community life; and increased access to services by persons with disabilities, including employment, housing, income support, and other programs attributable to the CILs.

Outcome measures on the Director Survey include:

- Community access resulting from center activities; and
- Additional funds raised by the center.

Outcome measures on the Consumer Survey include:

- Consumer satisfaction with services, knowledge or skill attainment, and life changes;
- Goal achievement; and
- Improved quality of life.

Feedback

The model shown in Figure 2-1 is not necessarily linear because all of the components of the system interrelate. For example, while inputs affect process, the reverse may be true as well (e.g., a center may choose to advocate for another agency to provide a service rather than to provide that service itself, which influences the size and functions of center staffing). Also, data on the outcome or impact of the CIL Program on consumer well-being will affect decision-making by the center director on the overall design and management of the program. For example, the RSA and State DSU site reviews contain recommendations for program changes that can be implemented by centers. The Executive Director Survey asked how centers assess community needs and how centers select board members. The Consumer Survey asked what consumers would do if they perceived a problem with the center.

Environment

Centers for Independent Living do not operate in a vacuum. Each must tailor its program to the realities of the local environment. For example, centers located in service-rich areas may focus on facilitating access to existing community resources and programs, while those in other areas may deliver many services directly, either with RSA funding or using additional resources raised through successful leveraging efforts. Any evaluation must consider the political, economic, and social settings in which the centers operate. For example, we gathered information on the geographic location of the center and the racial and ethnic composition of the service area.

2.1.2 Research Questions and Study Issues

Based upon the elements we identified in the above model, we developed detailed study questions and divided them into access, process, outcome, and feedback measures. These study issues and research questions appear in Table 2-1. These are shown under two major categories: center operations and consumer services. Under each category, issues are divided into access measures, process measures, and outcome measures. We also included a feedback section under center operations and a satisfaction section for the consumer surveys. For each research question we have listed the data elements used to address it and the data collection methodology.

Table 2-1 Research Questions and Study Issues

Research Issue 1. CIL Operations	Data Elements	Data Sources
Access Measures		
What efforts are centers making to reach out to multicultural communities and consumers from disability groups that have been traditionally underserved?	704 Reports and information from center directors and consumers	Center directors Consumers 704 Reports
Does center meet physical access requirements?	Director and consumer perception of facility accessibility	Center directors Consumers
Does the center provide information for all its activities in alternative formats? Do centers use sign language interpreters at all center functions?	Director and consumer perception of formats of communication provided by center	Center directors Consumers
Is the center accessible by public transportation?	Director and consumer perception of accessibility to public transportation	Center directors Consumers
How accessible is the center by telephone?	Consumer perception of accessibility by telephone	Consumers
Process Measures		
Are centers able to articulate the IL philosophy? What are the elements of this philosophy?	Director and consumer perception of the center's application of IL philosophy	Center directors Consumers
In what areas of advocacy has the center engaged during the past year? Was this at the federal, state, or local level?	Systems advocacy efforts of CIL	Center directors
What activities were conducted in each area of advocacy?	Systems advocacy efforts of CIL	704 Reports
Who was involved--consumers, board, staff, other agencies?	Systems advocacy efforts of CIL	CIL directors Consumers

Table 2-1 Research Questions and Study Issues (Continued)

Research Issue 1. CIL Operations	Data Elements	Data Sources
Process Measures (contd.)		
What do center directors feel are the most significant needs for community/systems change during the coming year?	Director perceptions of community needs	Center directors
What are the primary barriers to achieving systems change faced by the center?	Director perceptions of impediments to systems advocacy	Center directors
What is the nature of the relationships between the CIL, the state VR, and the state Blind agency?	Director assessment of agency relationships	Center directors
Outcomes		
What community changes have taken place as a result of center advocacy activities?	Director reports of community changes	704 Reports
What resources (other than federal funding) have centers captured?	Director listings of other resources captured by centers	Center directors 704 Reports
What benefits and/or problems, including effects on service delivery, do center directors feel are associated with the acquisition and use of leveraged resources?	Director perception of problems resulting from funding	Center directors
What factors have facilitated or impeded the acquisition of other resources?	Director perception of factors that facilitate and impede acquisition of other resources	Center directors
Feedback		
How are community needs (both service and system change) identified?	Director description of the process used in identifying community needs	Center directors 704 Reports
How do directors perceive that SILCs are meeting their Title VII, Chapter 1 mandates?	Director assessment of SILC performance	Center directors

Table 2-1 Research Questions and Study Issues (Continued)

Research Issue 2. IL Services	Data Elements	Data Sources
Access Measures		
Do consumers perceive that center services and facilities are accessible (both physically and programmatically) to them?	Consumer perception of center accessibility	Consumers
Do consumers perceive that center services are readily available (e.g., a reasonable wait time for appointments and a reasonable paperwork burden, etc.)?	Consumer perception of timeliness and availability of center services	Consumers
Process Measures		
Who are centers serving? How do center consumers compare to VR consumers and the U.S. disabled population?	Comparison of consumers' demographic information and household surveys	Consumers 704 Reports SIPP NHIS-D
Do consumers believe that they are receiving complete information about options and services?	Consumer perception of completeness of information provided by the centers	Consumers
What services do/did consumers receive? Do type and frequency of service vary by age, gender, race, and type of disability?	Comparison of consumers' demographic information and types of services received by consumers	Consumers
Do consumers feel that centers are teaching and encouraging empowerment?	Consumers perception of center's effectiveness in teaching and encouraging empowerment	Consumers
Do consumers feel that staff are respectful of them and their specific disability or culture?	Consumer perception of respect by center staff of their disability and/or culture	Consumers
Do staff members demonstrate competence in assisting people with various disabilities or from various cultures?	Consumer perception of staff competency in assisting people with various disabilities and cultures	Consumers
Was information about due process, laws, and regulations provided?	Consumer perception of center provision of information on laws, regulations, and due process	Consumers

Table 2-1 Research Questions and Study Issues (Continued)

Research Issue 2. IL Services	Data Elements	Data Sources
Satisfaction		
Do consumers feel they have control in decision making at the center?	Consumer perception of control over decision making at the center	Consumers
Do consumers feel they have control in decisions made about their lives?	Consumer perception of control over decisions affecting their lives	Consumers
How satisfied are consumers with the services (peer support, advocacy, skills training, etc.) they have received?	Consumer satisfaction with services received from the center	Consumers
Outcomes		
What skills do consumers perceive they have gained as a result of their participation with the center?	Consumer perception of skills gained as a result of participation with the center	Consumers
What knowledge do consumers feel they have gained as a result of their participation with the center?	Consumer perception of knowledge gained as a result of participation with the center	Consumers
Did consumers perceive that they achieved the goals they set or solved the problem that needed resolution when they first contacted the center?	Consumer perception of goal achieved or problem solved	Consumers
What life changes have been obtained as a result of their participation?	Consumer perception of life changes obtained as a result of their participation	Consumer responses compared to those in national surveys
Are there correlations between satisfaction with services and gains in knowledge, skills, empowerment, and life changes?	Consumer perceptions correlated	Consumers
Are any services more effective than others in helping consumers make these gains?	Consumer perception of effectiveness of services: correlation of gains made and types of services provided	Consumers

2.2 Methodology

2.2.1 Data Sources

The research team collected data for this study from two principal sources. First, we conducted a mail survey of all CILs that receive federal funding under the title VII, chapter 1, Part C Program. Second, we selected a random sample of centers and conducted telephone surveys with a random sample of their current and former consumers. These surveys captured a range of quantitative and qualitative data covering each aspect of the model shown in Figure 2-1.

Additionally, we examined the Section 704 Reports that each center prepares and submits to RSA on an annual basis. This information is useful for describing the centers, individually and collectively. Based upon feedback from the study's Panel of Experts (POE), the Executive Director Survey was constructed to minimize duplication of the Section 704 Report. We also examined the range of national surveys on persons with disabilities and selected questions from the National Health Interview Survey-Disability Supplement (NHIS-D) for inclusion in the Consumer Survey. This large, comprehensive study contains a wealth of data on such important outcomes for persons with disabilities as access to care, satisfaction with services, capacity for independent living, and a range of quality-of-life measures. Using these existing questions not only builds on valid and reliable measures of well-being, but also allows comparisons between the Consumer Survey responses and the responses of those with similar disabilities and with other characteristics who are not participating in CIL programs.

2.2.2 Questionnaire Design

We designed two data collection instruments for this study: the CIL Executive Director Survey and the CIL Consumer Survey. (Copies of the survey instruments can be found in Appendixes C and D.) To address the research questions and study issues in Exhibit 1-1, we relied primarily upon rating or multiple choice questions, but included some short answer, open-ended questions to explore more complex issues. Both of the questionnaires were designed in a user-friendly format so that they could be self-administered, if necessary. All questions and directions were pilot-tested for clarity, simplicity, and ease of use.

The Executive Director Survey consisted of 45 questions, divided into eight sections:

- Independent Living Philosophy;
- Services and Community Change/Impact;
- Diversity;
- Board of Directors;
- Staff Training;
- Relationships with Other Agencies/Organizations;
- Evaluation and Monitoring; and
- Resources and Funding.

The Consumer Survey consisted of 69 questions. The survey began with questions about the timeframe in which consumers received services. We asked about physical access to the center, access to services and information, the specific services consumers received, and their satisfaction with each service. We asked what life changes consumers made as a result of each service and whether or not their quality of life had improved as a result of center services. We asked about relationships with center staff and how helpful the center was in achieving consumers' personal IL goals. We concluded with questions to assess service needs, type of disability, and other demographic questions.

2.2.3 The Executive Director Respondents

We mailed surveys to the executive directors of all centers that had received federal funding under title VII, chapter 1, Part C of the Rehabilitation Act for at least one year. Approximately 238 centers had received funding for at least one year when we mailed the surveys in the spring of 1999. It should be noted that there are approximately 450 CILs throughout the country, but many do not receive federal funding and were not included in the survey. There is no centralized repository of information on CILs that do not receive federal funding, so we do not know if these non-federal centers differ in any significant way from federal centers.

Many of the federally funded centers operate satellite or branch offices to serve remote portions of their service area, or specific inner-city communities. These satellite offices usually have a director or coordinator, but lack a separate board of directors and operate under the auspices of the parent center's grant. Satellite centers do not receive title VII, chapter 1, Part C funds directly from RSA, but are funded as part of their parent center's grant. Therefore, we did not survey these centers separately, but asked the directors to include the satellite office staff and consumers in their survey responses.

2.2.4 Drawing the Consumer Sample

The consumer sample selection consisted of two parts. First, we drew a random sample of CILs from which the consumer sample would be drawn. Second, we developed a procedure to draw the consumer sample from these centers. These methods are described below.

To determine the optimal number of centers to be used in collecting the consumer sample, we assessed the likely extent of intra-class correlation in the following way. The study team reviewed the 1998 Section 704 Report figures on individual CILs to determine the similarity of consumers across centers. We found that each center's consumers were quite similar with respect to age, gender, and type of disability. However, the percent of African American consumers each center serves varies substantially. The vast majority of minority populations live in the urban areas, with rural areas second and suburban areas third. We accommodated this variation by selecting CILs in proportion to size within each of three urbanization categories, covering center cities, suburban locations, and rural areas.

Because it is the goal of this study to provide national estimates rather than CIL-level analyses, we adopted a design entailing approximately seven completed consumer interviews per CIL. Based on the scale of the IL program itself and the cost of consumer interviews, our design called for interviews of 728 consumers spread across 104 CILs.

Using the total 1999 budget for each eligible CIL as reported on the Section 704 Report, we selected a stratified sample with probability proportionate to size (PPS) for the 104 centers. (Seventeen of these centers or 16% refused to cooperate; we selected an additional 17 centers to compensate for this non-participation.) In addition, we sorted the centers into urban, suburban, and rural categories based upon the zip code of the main office of each center. We sampled CILs within each domain to allow separate analysis for urban, suburban, and rural CILs.

We contacted the directors of selected centers by telephone to elicit their cooperation and explain the study and their role in sampling and data collection. We assured them that individual centers were not being evaluated and that all center and consumer identifying information would be removed before the data was analyzed.

Members of the POE were extremely concerned about protecting the confidentiality of the centers' consumers and their records. They expressed their strong preference that the centers contact their consumers directly to obtain their permission, then forward contact information to the research team. Following this guideline, we provided explicit instructions to each center, allowing them to draw their own random sample. (See Appendix F.)

Of the final 121 centers selected (104 plus 17), 87 (72%) participated in identifying consumers for the Consumer Survey. We provided detailed instructions and worked closely with each center's designated staff person to draw the random samples of consumers. Each CIL prepared a list of consumers, using both open and closed Consumer Service Records (CSRs). There was significant record-keeping variation among the CILs—some had hardcopy lists, others had computerized lists, and others had only case folders. We provided ongoing telephone technical assistance to each sampled CIL irrespective of their record-keeping systems.

We asked each center to number its consumer cases consecutively and provided software to select the case numbers to be sampled. The centers were asked to list consumers who had received services within the last 6 months including cases both open and closed.

Once the samples were selected, the CIL staff contacted all sampled consumers to elicit their cooperation, based upon explicit directions (e.g., number of contact attempts, record keeping, commonly asked questions, etc.). We also provided the CIL with a script to ensure that all key study points were mentioned when speaking with the consumer to reduce bias when recruiting consumers to participate. The script explained the purpose of the study, guaranteed the confidentiality of the consumer and their responses (i.e., not even the center would be aware of an individual's responses), and requested their permission to send contact information to the research team so that an interviewer could contact them.

2.2.5 Pretest

An essential part of survey research is the administration of a pretest, in order to test the sampling strategy, recruiting plan, survey instruments, and data collection procedures. The research team devoted significant time and energy to this task.

We selected a purposive sample of six CILs representing a range of environments, including urban, rural, large, medium, and small centers in order to test the instruments and procedures. These centers were also selected to represent a diversity of federal regions. Test locations were approved by RSA and pilot tests were conducted in April and May of 2000.

The sampling procedures for the Consumer Survey were tested at each center. Centers selected their samples, contacted consumers, and obtained their consent to be interviewed. We conducted interviews with nine consumers. Five executive directors completed and returned the Executive Director Survey.

The pretest taught significant lessons about the operational aspects of the sampling plan. Out of the 40 consumers selected, 16 resulted in non-contact. We took two steps to overcome this problem: we increased the number of consumers the centers attempted to contact for the main study and we contacted by mail those consumers with disconnected or incorrect telephone numbers.

We made one significant change based upon the results of the pilot. “Individual advocacy” is a core IL service required under title VII, chapter 1, Part C. However, when we asked consumers if they had received “individual advocacy services,” they did not comprehend the meaning of the term “advocacy” when used in this way. Although they received individual advocacy services, they didn’t refer to them as such because these services were imbedded in the constellation of services the center provided on any particular issue. For example, an individual who received individual advocacy related to a housing problem tended to think about the individual advocacy they received as a housing service. We eliminated the question about receiving advocacy services and asked other more specific questions to find out if centers provided individual advocacy. We also eliminated and modified other questions as a result of the pretest.

We dropped and revised several questions on the Executive Director Survey as a result of pilot test comments. We also developed more specific instructions and modified the electronic version of the survey.

2.2.6 Data Collection

Executive Director Survey

In March 2001, we mailed 238 surveys to directors of centers that had received title VII, chapter 1, Part C funding for at least one year. We obtained contact information from the RSA/IL Program Office, matched it with contact information from the Independent Living Research Utilization (ILRU), and made telephone calls where we found discrepancies. Centers were offered the opportunity to complete the questionnaire by mail, e-mail, or through an in-person interview. Four centers completed the survey by telephone, approximately 30 completed the survey by e-mail, and the rest mailed in their completed surveys. At 6 to 8 week intervals, we mailed reminder notices and telephoned center directors who failed to return the surveys. Of the 238 surveys we mailed, 173 were completed, for a 72 percent completion rate.

Using the 704 Report, we compared characteristics of respondents and non-respondents on several variables, including total annual budget, center location (urban, suburban and rural), center size (small medium and large), and consumer profiles on age, disability, gender, and race. All differences between respondents and non-respondents were small (between 0 and 4%) with the exception of the location of the center's main office. Respondents were slightly more likely to be located in rural and suburban areas and less likely to be located in an urban area than non-respondents; thus, the sample has proportionally slightly more rural and suburban CILs (see Table 2-2).

Table 2-2
Comparison of CIL Executive Director Respondents and Non-Respondents

	Responding CILs	Non-Responding CILs
Rural	18%	11%
Suburban	13%	8%
Urban	69%	81%

Consumer Survey

The Consumer Survey was conducted by telephone. Interviewers received approximately 12 hours of training, including disability sensitivity, background on CILs, and question-by-question review. We conducted telephone surveys from July 15 to September 30, 2001. Each consumer was offered $10 as an incentive to complete the survey. Of the total initial sample of 1,305 individuals contacted by the centers, 666 (52%) agreed to be interviewed. Of the 666 consumers referred by their centers, a total of 569 interviews were completed, for an 85 percent completion rate or a 43 percent completion rate of the original sample. (See Table 2-3 for a breakdown of the sample members who agreed to be interviewed.)

Table 2-3
Consumer Sampling Results

Total Initial Sample	1305
Total Consumers Who Refused	156
Total Consumers Who Could not be Reached	468
Total Consumers Who Died.	15
Total Consumers Who Agreed to Be Surveyed	666
Total Consumers Who Refused	26
Total Consumers Who Could Not be Reached	60
Total Consumers Who Died or Were Ineligible	11
Total Consumers Interviewed	569

We compared the characteristics of consumer respondents to characteristics of the CIL consumer population from the 704 Report. There were few differences between consumers served by CILs and participants in the Consumer Survey. Survey respondents were working age (ages 18 to 64) more often than overall consumers. Fewer of the survey respondents were aged 65 and over than the overall consumer population (13% vs. 25%). The respondents to the Consumer Survey, therefore, tended to under-represent consumers who were aged 65 and older and tended to over-represent consumers who were aged 18 to 64 years. There may, however, be other important characteristics that affected response rates. Since respondents and non-respondents may have differed significantly in characteristics other than age, employment status, or gender, the survey results may not reflect the CIL consumer population in general and should be interpreted with caution.

Respondents also differed by gender from the CIL population. According to the 704 Report, 55 percent of CIL consumers were male and 45 percent were female. Respondents to the survey were almost the opposite: 44 percent male and 56 percent female (standard error = 2.3%).

The 704 Report collected information on consumer disabilities by the following categories:

- Cognitive,
- Mental/Emotional,
- Physical,
- Hearing,
- Vision,
- Sensory,
- Multiple, and
- Unknown.

To assure a large enough sample in each category, we coded the primary disability of the consumers who responded to the survey into three categories: physical, mental, and sensory/communication, and collapsed the categories from the 704 Report in like manner. Physical includes Physical and Multiple; Mental includes Cognitive and Mental/Emotional; and Sensory/Communication includes Hearing, Vision, and Sensory. When the data were compared in this way, there were very small differences (7 percent or less) between the disabilities of respondents and the overall CIL population.

2.3 Data Analysis

The research team weighted the data to ensure a representative sample of large versus small centers and urban versus rural centers. This process ensured that rural consumers, those from diverse racial and ethnic backgrounds, and large and small centers were represented in appropriate percentages. We conducted several types of analysis, which are described below.

Descriptive Analysis

We analyzed the characteristics of consumers and the range of services provided by CILs. We noted age, race, gender, income, education level, employment, severity of disability, and other characteristics. We also considered degree of urbanization of the CIL that served the consumer and degree of urbanization of the consumer's residence. We noted the types of services received and any differences by socio-economic status.

Bi-variate Analysis

We compared the types of services received with service satisfaction and outcomes. We examined satisfaction with services and outcomes by socio-economic status and by the degree of urbanization of the center and the consumer. We also examined access and process measures by goal attainment, to ascertain whether consumers who were satisfied with their experience with the center (e.g., could go to the center easily and had a positive relationship with the center staff) had higher satisfaction and outcomes.

Consumer Comparisons

We contrasted the characteristics of the CIL consumer population with those of the total U.S. population, using the Survey of Income and Program Participation (SIPP) Disability Topical Module. We also compared the consumers' responses to the National Health Interview Survey–Disability Supplement (NHIS-D). These surveys have a number of variables on the type and severity of disability among a representative sample of the U.S. population. In addition, the NHIS-D includes several variables on access to care, unmet need for services, and quality-of-life indicators, such as degree of choice and control over one's life. This enabled us to compare outcomes from the national sample with those of CIL consumers.

Center Characteristics and Consumer Outcomes

We explored the relationship between characteristics of the centers and the outcomes of consumers, for example, the relationship between CIL size and consumer outcomes. This analysis also allowed us to explore the relationship between Executive Director Survey and Consumer Survey responses. For example, the extent to which the perceptions of the center director and consumers were consistent on facility accessibility.

Qualitative Analysis

The survey contained a number of short-answer questions for qualitative analysis. The qualitative, narrative responses constituted a rich source of information. We sorted the responses into coding categories that emerged from an analysis of the data. This enabled us to report responses by percentages. In addition, we developed running lists of those responses that did not lend themselves to categorization, but still contained important data. We also analyzed the narrative portions of the 704 Reports to draw conclusions about the types of community changes centers had achieved.

2.4 Limitations of the Study

Readers should be aware that this study called for examination of only centers that receive title VII, chapter 1, Part C of the Rehabilitation Act funding. ILRU estimates that there are approximately 650 organizations across the country that consider themselves a CIL; most, but not all of them, meet the criteria for a CIL established by title VII.[2] Because there is no repository of information on centers that do not receive federal funding, we do not know whether the federally funded centers that participated in this study adequately represent non-federally funded centers. Federal funding for CILs has increased by 25 percent since fiscal year (FY) 1999 and about 30 new centers were funded in FY 2000 and FY 2001. Because we drew the sample in FY 2000 from centers that had received federal funding for at least one year, these centers are not included in this study.

This study included telephone surveys of past or current recipients of CIL services. We did not attempt to assess the unmet needs of people with severe disabilities, either within or outside of CIL catchment areas, who had not received CIL services. Because of this limitation, we are not able to assess the unmet need among people with disabilities for CIL services, either within or outside existing CIL service areas.

We obtained a 72 percent response rate to the Executive Director Survey. When comparing characteristics of centers that responded to their non-responding counterparts, we noted that respondents were slightly more likely to be located in rural and suburban areas and less likely to be located in an urban area. Therefore, survey results represent proportionally slightly more rural and suburban CILs and under represent large, urban centers.

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[2] D. Heinson, Independent Living Utilization (personal communication, January 17, 2003)

Due to concern among the Panel of Experts about the confidentiality of center consumers and their records, CIL staff contacted the sample of consumers and requested their permission before sending contact information to the research team. Although the CIL staff made their contacts based on a random sample of consumers, only half of the original sample agreed to be contacted by the survey team. Among the 666 consumers who agreed to be contacted, interviews were actually completed with only 569 consumers, for a response rate of 43 percent of the total random sample.

This low response rate triggers concerns about possible response bias. Without more information on those consumers that either the CIL staff or the survey team were unable to contact, we cannot determine if the non-response reflected some dissatisfaction with the CIL or the services they received. It is quite possible that the CILs are not as successful with those for whom they are not able to obtain or retain accurate contact information, the more transient population. The same is true when the contractor could not find the respondent. It is also quite possible that many people without contact information did not find their initial contact with the CILs helpful or useful and, therefore, did not return. In order to draw meaningful conclusions about the effectiveness of the CIL program, we need to know why some clients do not return and are no longer in contact with a CIL. Because of this possible response bias, readers should use caution when drawing conclusions about CIL consumers in general from the sample in the consumer survey.

This study assessed the CIL executive directors' perspectives on the Statewide Councils on Independent Living (SILCs). We did not study the SILCs independently of the executive director survey, therefore, this study's perspective on the SILCs is limited.

Finally, the study design called for telephone interviews of 7 consumers per CIL. This number of consumers provides a sample of consumers in the CIL program, but is insufficient to draw conclusions about each individual CIL. In general, our conclusions about specific center policies and practices that produce higher satisfaction levels and stronger outcomes are limited, due to the small per center sample size.

The next two chapters describe the results of this evaluation. Chapter 3 is an analysis of the CIL directors' responses; it reports the results of the evaluation related to CIL operations. Chapter 4 describes the demographics of the consumers who participated in this study; it reports their level of satisfaction with center services and the outcomes and life changes they achieved. Chapter 5 contains a discussion of the evaluation and presents the study's recommendations.

CHAPTER 3
CIL OPERATIONS

3.1 Introduction

This chapter answers the question, “How do CILs operate?” Using information taken primarily from responses to the Executive Director Survey and supplemented with responses from the Consumer Survey, we describe the components of centers and how they provide services to their communities and their consumers. Where possible, we highlight differences between rural, urban, and suburban centers.

After providing some demographic data from the centers, we provide directors’ descriptions of the Independent Living philosophy that is so critical to CIL operations. We then discuss how centers recruit and work with their boards of directors and what elements promote positive working relationships between staff and board. We then turn to a discussion of how CILs assess community needs and determine what services and advocacy they will provide to their communities. We follow with a description of the issues in which centers are most involved and how they accomplish their advocacy goals. We use the Section 704 Reports to provide examples of community changes that have resulted from centers’ advocacy efforts. We then list the services provided by centers, how they make those services accessible, and how they reach populations that have been traditionally underserved by centers. Next, we examine staffing issues, particularly what directors feel are the most acute needs for training and technical assistance. We then provide a discussion of CIL relationships with other entities, including the Statewide Independent Living Council (SILC), the State Vocational Rehabilitation (VR) agency, and the State Blind VR agency. We discuss directors’ reactions to the evaluation and monitoring by RSA and the State VR agency and close with a discussion of funding issues.

3.2 Characteristics of the Centers and their Directors

Directors who completed the survey represented a mix of geographic settings. When asked about the geography of their service area, about 61 percent said their service area was a mix of urban, rural, and suburban communities. About 13 percent said they served an urban area, 3 percent said they served a suburban area, and 23 percent said they served a rural area. We also examined the geographic location of each center’s main office according to that center’s zip code. Based upon the zip code of the main center office, 75 percent of centers were located in urban areas, 10 percent in suburban areas, and 15 percent in rural areas. This is important because most consumers of center services are located in the same county as the center office (RTI, 1998). Many consumers who live in counties without centers do not have access to services.

3.3 Independent Living Philosophy

The most significant element of CILs that sets them apart from other human service agencies is the philosophy upon which they are based. This philosophy includes consumer control, serving a cross-disability population, self-help, and empowerment of individuals with disabilities. Because the study's Panel of Experts (POE) felt strongly that center directors should be able to articulate this philosophy for a center to be successful, it was the first question on the Executive Director Survey.

We asked center directors to articulate the center's beliefs about the basic components of the independent living philosophy in a short-answer format and sorted their responses into broad categories. Most centers provided multiple answers. Not surprisingly, consumer control, including control over one's life and decision making, was mentioned most often by almost 87 percent of directors. Forty eight percent mentioned integration, inclusion, and participation in the community; 41 percent cited accessibility and the removal of barriers. The directors' answers to this question are provided in Table 3-1.

Table 3-1. Components of Independent Living Philosophy Listed by Center Directors

Component	Count	%
Consumer control, directing their own lives, making decisions	146	87
Integration, inclusion, and participation in the community	80	48
Accessibility, removal of barriers that prevent integration in society	69	41
System advocacy	59	35
Self-advocacy	54	32
Peer support	49	29
Consumer independence	46	27
Community advocacy	45	27
Education, information, and referral regarding resources	27	16
Cross-disability services	23	14
Take risks and be allowed to fail	17	10
Consumer self-help	14	8
Least restrictive setting by consumer choice	11	7
Consumer responsibility	10	6
Rejection of medical model	9	5
Other*	36	21
Total number of centers	168	

*Each center director may have listed more than one “other” component.

Consumers should also understand the basics of the independent living philosophy. When asked, “Did the center tell you about the independent living movement or about its philosophy on independent living?” almost half of the consumers (46%) said “yes.” We asked center consumers questions about peer support, self-advocacy, and systems advocacy to ascertain whether the tenets of the independent living philosophy influenced the services they received. We asked center consumers if they have been told about groups of people with disabilities with whom they could share problems, sometimes known as peer support groups; 57 percent said “yes.” Approximately 62 percent said that center staff encouraged the consumers to advocate for themselves, and 41 percent said the center had provided them with training or information about federal, state, or local advocacy issues. These responses show that the independent living philosophy is a strong component of center programs.

3.4 Board of Directors

A significant component of the independent living philosophy is the ongoing involvement of the board of directors, with its requirement that a majority of board members be individuals with disabilities. Because the recruitment of good board members is crucial, we asked center directors how useful various sources were in finding center board members. Almost 60 percent of directors said that referrals from members of the board were an excellent or very good source of recruitment for other board members, about 58 percent said consumers were an excellent or very good source of board members, and 55 percent said that recommendations of staff were an excellent or very good source. Elected officials were not considered a good source of board members (see Table 3-2).

Table 3-2. Sources of Recruiting for CIL Board Members

Source	Excellent	Very Good	Good	Fair	Poor
Recommendations of Board	26%	34%	25%	9%	6%
Consumers	25%	33%	23%	13%	6%
Recommendations of Staff	20%	35%	27%	13%	5%
Disability Organization	11%	19%	28%	32%	10%
Relatives of Consumers	7%	19%	19%	29%	25%
Former Staff	6%	10%	20%	25%	40%
Private Business	4%	19%	19%	28%	29%
Human Service Agencies	4%	11%	30%	32%	24%
Representatives of Center Funding Sources	1%	5%	10%	25%	58%
Elected Officials	0%	1%	10%	31%	59%
Other (please specify)	40%	25%	35%	0%	0%

When asked how board training is conducted, 51 percent of directors said they conducted board training using the center's board and staff members, 31 percent said they bring in an expert on board development or independent living to conduct the training, and about 10 percent said they conducted some other type of training. Eight percent said they do not conduct formal board training. About 26 percent said the training they conducted was very effective, 42 percent said it was somewhat effective, 23 percent said it was neutral, and the remaining 8percent said it was somewhat or very ineffective.

When we asked center directors about the relationship between the center's board and staff members, 59 percent said it was very positive or supportive, 27 percent said it was somewhat positive, 10 percent characterized it as neutral, and under 3 percent characterized it as somewhat or very adversarial. When asked what factors contribute most to a positive relationship between the center's board and staff members, 33 percent of centers mentioned board involvement in center activities and 28 percent mentioned good communication. Other factors listed by directors included clear roles, boundaries, a chain of command, a common vision (understanding the center's mission and the IL philosophy), and a team approach. When asked what factors contributed to an adversarial relationship, unclear roles, boundaries, and no chain of command topped the list. Centers also mentioned poor communication, micro-management, and lack of board involvement in center activities.

3.5 Assessing Community Needs and Establishing the Advocacy Agenda

Centers are community-based organizations—one of their primary missions is to respond to the disability issues raised in their communities. An important process measure concerns the way in which centers assess community needs and plan the services and advocacy they provide. When directors were asked which methods to assess community needs were most useful, they rated contact with disability consumer groups as the most helpful, with 85 percent rating it somewhat or very useful. The next most useful process was a consumer needs survey, with about 68 percent rating it somewhat or very useful. Directors rated contacts with community agencies third (66%), and rated board and staff assessments of community needs fourth (63%). Expectations of funding sources were less useful (41%), as were community forums (53%) and analysis of census or other data (24%). (See Table 3-3.)

Table 3-3. Methods Used to Assess Community Needs
Rated from 1 (not at all useful) to 5 (very useful)

Methods	Useful & Very useful	Neutral	Not useful & Not at all useful
Contacts with disability/consumer groups	85%	10%	5%
Consumer needs survey	68%	22%	10%
Contacts with community agencies	66%	25%	9%
Board/staff assessments	63%	32%	5%
Community forum	53%	29%	18%
Expectations/availability of funding sources	41%	37%	22%
Analysis of census or other existing data	24%	44%	32%

3.6 Systems Advocacy--Process

About 99 percent of center directors reported that they conducted systems advocacy activities at their center. An important finding of the Executive Director Survey was the number of advocacy issues in which centers were involved and the variety of techniques used to achieve advocacy goals. Over 70 percent of the directors reported involvement over the past year in each of the nine issues listed on the survey. Transportation and deinstitutionalization had the highest percentage of involvement. Over 92 percent of centers were involved in these issues (93% and 92% respectively) and over 40 percent of centers that worked on these issues said they spent significant amounts of time on them (rating them 4 or 5 on a 1-5 scale). Almost 90 percent of directors said they were involved in the passage of or enforcement of federal, state, or local civil rights laws, 89 percent were involved in integrated housing, and almost 87 percent were involved in personal assistance services (PAS). Centers were less involved in employment (76%), education and youth transition (74%), and health care (70%), although over 70 percent of directors reported involvement in these issues.

Although many centers are involved in advocacy at the federal level, centers focused most of their energy at the state and local levels of government. For example, almost 48 percent of centers who worked on PAS did so at the federal level, as compared to 83 percent at the state and 81 percent at the local levels (see Table 3-4). It is clear that centers were fulfilling their mission of local community involvement. For example, of the centers that worked on youth transition issues, 97 percent were involved locally. In addition, 95 percent of centers that worked on integrated community housing and transportation did so locally. Centers were also involved at the state level. For example, 86 percent of centers working for deinstitutionalization and 83 percent of those working on PAS were involved at the state level.

Table 3-4. Level of Advocacy--Federal, State, and Local

Issue	Worked on: YES	Federal	State	Local
Transportation	93%	24%	55%	95%
Deinstitutionalization	92%	52%	86%	86%
Federal, state, or local civil rights laws, including physical and program access	90%	62%	75%	87%
Integrated community housing	89%	28%	57%	95%
Personal assistance services	87%	48%	83%	81%
Employment	76%	34%	59%	90%
Youth transition	74%	16%	42%	97%
Education	74%	31%	56%	93%
Health care	70%	40%	85%	70%
Other	26%	44%	70%	91%

The results revealed small differences between centers whose main offices were in either rural, suburban, or urban communities. Enforcement of federal, state, and local civil rights laws was the top issue for rural centers; 93 percent said they were involved. Civil rights was closely followed by deinstitutionalization and transportation, with 90 and 87 percent involved, respectively. Health care had the lowest level of involvement among rural centers, with only 58 percent of rural centers involved in this issue. All suburban centers surveyed said they were involved in transportation, deinstitutionalization, and PAS. Only 65 percent were involved in health care and only 60 percent in education. (See Table 3-5.)

Center Directors rated the amount of time they spent working on each advocacy issue on a 1 (a little) to 5 (a lot) scale. As shown in Table 3-6, center directors spent more time on personal assistance, civil rights, and transportation advocacy than on other issues.

Table 3-5. Involvement in Advocacy Issues by Urban, Suburban, and Rural Centers

Issue worked on by CIL location				
Issue	Overall	Rural	Suburban	Urban
Deinstitutionalization	92%	90%	100%	91%
Integrated community housing	88%	83%	86%	90%
Transportation	93%	87%	100%	93%
Personal assistance services	86%	77%	100%	86%
Federal, state, or local civil rights laws including physical and program access	89%	93%	91%	88%
Health care	70%	58%	65%	74%
Education	74%	74%	60%	77%
Employment	76%	74%	69%	78%
Youth transition	74%	71%	82%	73%
Other	26%	29%	17%	27%

Table 3-6. Level of Time and Involvement in Advocacy Issues of Centers Involved in the Issue

	Worked on: YES	Worked on: YES	% of centers that spent from a little to a lot of time on each issue				
Issue	Count	%	5 (A lot)	4	3	2	1 (A little)
Personal assistance services	146	87	27	30	23	14	6
Federal, state, or local civil rights laws, including physical and program access	151	90	19	31	33	16	1
Transportation	156	93	16	26	40	14	5
Youth transition	125	74	16	16	27	27	14
Deinstitutionalization	155	92	15	28	37	14	5
Education	125	74	13	26	31	19	11
Employment	128	76	13	20	33	23	10
Integrated community housing	148	89	12	23	41	20	3
Health care	118	70	11	18	30	33	8
Other	44	26	26	35	30	7	2

Centers engaged in a variety of actions to move the advocacy agenda forward. Most centers focused their efforts on participating in committees or working groups, working with agency or organizational representatives, working with decision makers, or providing in-service training (see Table 3-7). They were less likely to train grassroots organizations, work with the media, take legal action, or conduct demonstrations, although a sizable number of centers undertook these activities. For example, almost 54 percent of centers working on deinstitutionalization worked with the media and almost 24 percent conducted demonstrations. Almost 15 percent of centers working on housing took legal action and 34 percent trained grassroots organizations.

Center staff, consumers, board members, and representatives of disability and non-disability agencies were usually involved in these advocacy efforts. Staff had the highest percentage of involvement, with consumers next, on all advocacy issues. Board members or representatives of disability organizations and agencies had the third highest percentage of involvement and representatives of non-disability agencies the fourth (see Table 3-8).

It is interesting to note that 41 percent of center consumers said they received training about federal, state, or local advocacy issues while they were involved with the center; 28 percent said they actually got involved and 8 percent said they were still involved at the time the survey was conducted. This tends to support the high level of consumer involvement in advocacy issues claimed by directors.

When asked what are the most significant advocacy issues that will be faced by CILs in the next 5 years, directors rated deinstitutionalization as the top advocacy issue. About 58 percent rated it as 5 on a one to five scale of importance. This issue was closely followed by transportation and PAS (each were rated by 52% as a 5), and civil rights enforcement and housing (each were rated by 50% as a 5). Employment, health care, and education were less significant (see Table 3-9).

Table 3-7. Type of Activity by Advocacy Issue

		Worked with/action taken							
Issue	Overall worked on	Agency or organizational representatives	Decision makers	Media	Legal action	Committees or working groups	Demonstrations	In-service training, accessibility surveys, or provided technical assistance	Trained grassroots organizations or organizers
Deinstitutionalization	92%	87%	84%	54%	13%	82%	24%	66%	38%
Integrated community housing	89%	92%	79%	33%	15%	81%	12%	70%	34%
Transportation	93%	95%	84%	47%	8%	85%	14%	61%	35%
Personal assistance services	87%	92%	83%	39%	9%	82%	24%	59%	33%
Federal, state, or local civil rights laws, including physical and program access	90%	85%	87%	64%	25%	74%	32%	71%	46%
Health care	70%	84%	76%	25%	10%	75%	19%	46%	28%
Education	74%	89%	74%	29%	8%	79%	18%	65%	34%
Employment	76%	94%	67%	27%	5%	71%	10%	57%	25%
Youth transition	74%	89%	57%	18%	4%	77%	5%	54%	23%
Other (please specify)_____	26%	93%	88%	60%	9%	88%	23%	74%	49%

Table 3-8. Participants Involved in Each Advocacy Issue

ISSUE	Worked on: YES	Consumers	Board	Staff	Other disability organizations or agencies	Non-disability organizations or agencies
Deinstitutionalization	92%	91%	63%	96%	84%	37%
Integrated community housing	89%	82%	45%	97%	74%	59%
Transportation	93%	91%	60%	97%	76%	58%
Personal assistance services	87%	87%	57%	97%	81%	40%
Federal, state, or local civil rights laws, including physical and program access	90%	87%	69%	97%	77%	52%
Health care	70%	81%	50%	97%	69%	40%
Education	74%	85%	45%	99%	65%	47%
Employment	76%	76%	38%	94%	68%	43%
Youth transition	74%	74%	32%	97%	65%	38%
Other	26%	86%	60%	98%	77%	65%

Table 3-9. Most Significant Advocacy Issue in Next 5 Years

ISSUE	Rating scale: 5 = Very important 1 = Not at all important				
	5	4	3	2	1
Deinstitutionalization	58%	22%	14%	4%	2%
Integrated community housing	50%	30%	14%	4%	1%
Transportation	52%	31%	13%	3%	1%
Personal assistance services	52%	28%	15%	4%	1%
Civil rights, including physical and program access	50%	38%	9%	1%	2%
Health care	23%	42%	22%	12%	1%
Education	21%	37%	32%	9%	1%
Employment	34%	32%	24%	6%	4%
Other	48%	44%	8%	0%	0%

When asked what was the most significant barrier to achieving community change, 84 percent of center directors identified the lack of resources to hire staff as a very or somewhat significant barrier and about 69 percent felt that the lack of time was a very or somewhat significant barrier. Directors also felt that barriers within service or governmental agencies were a problem. About 61 percent said that agency resistance was a very or somewhat significant problem; 81 percent identified lack of agency resources as a very or somewhat significant barrier. Less significant barriers were concerns about IL funding sources (48%), lack of knowledgeable staff (28%), board concerns (17%), and center reputation (11%). It is interesting that about 50 percent of directors identified consumer involvement as a problem (see Table 3-10). Although the level of consumer involvement seems relatively high, directors feel that the advocacy agenda could be advanced more quickly with increased consumer involvement.

Table 3-10. Perceived Barriers to Community Change

	Rating scale: 1 = Not at all important 5 = Very important		
	Rated 4 or 5	Rated 3	Rated 1 or 2
Not enough center resources to hire staff	84%	10%	6%
Lack of knowledgeable staff	28%	33%	39%
Not enough time to devote to the issue	69%	21%	11%
Lack of involvement from consumers	50%	32%	19%
Board concerns	17%	30%	54%
Concern about center reputation	11%	14%	74%
Concern about funding	48%	22%	29%
Resistance of the agency or entity you are trying to change	61%	23%	16%
Lack of agency funding to implement the service or program	81%	11%	8%
Other	89%	6%	6%

3.7 Systems Advocacy--Outcomes

To ascertain the results or outcomes of CIL systems advocacy efforts, the research team reviewed the FY 2001 704 Reports. These reports include a narrative section, in which centers are asked to describe the activities they have undertaken to increase access or create community change.

We reviewed the narrative portions of the 704 Report and sorted the narratives into "process" and "outcome" segments. We defined "process" as "any activity with the intended result of producing increased community access." A "process" activity would include participating in an advisory council or coalition, organizing a rally, conducting a public education campaign, holding a meeting or forum, etc. We defined an "outcome" as "any change in legislation, policy, practice, service, or action that results in increased community access or services for consumers."

We imported the 704 narrative data into NVivo qualitative research software which is used to categorize and sort large quantities of narrative data. We sorted the narrative data into the advocacy areas contained in Table 3.7 (employment, transportation, housing, etc). (Deinstitutionalization and PAS were combined into one category, due to the similarity of outcomes.) Under each area, we subdivided the data into the following types of changes that occurred as a result of center activities:

- Change in policy: Any change in administrative policy or procedure of a governmental or private entity.

- Physical access: Modifications that have been made in the physical environment, such as, ramps, building entrances, parking, paths of travel, etc.

- Communication access: Modifications that have been made in communication access, such as, TTY, Braille information, etc.

- Service increase or improvement: An increase or improvement in services, including increases in personal assistant wages, additions of lift equipped buses, an increase or improvement in paratransit service, etc.

- Maintenance of current funding or service levels: Fighting to keep levels of service the same, for example, advocating against a decrease in service or a fare increase for transportation services, etc.

- Passage of legislation: Any legislation passed as a result of CIL advocacy.

- Monitoring: Obtaining agreement from an agency, such as a department of state or local government, to monitor enforcement of civil rights legislation, physical access, etc.

Appendix E presents examples of each type of change, for example, legislation passed or policy changed, in each advocacy area. This list should not be considered exhaustive; the appendix merely provides a snapshot of the types of community changes resulting from CIL activities.

We draw several conclusions from our review of this data. First, the 704 Reports support the conclusions drawn in Section 3.7 above. Centers are involved in a wide range of advocacy issues; they involve a wide variety of constituencies, including consumers, board and staff members, and representatives of other agencies; and they engage in an array of strategies to achieve their goal. A second conclusion is that years of effort are sometimes necessary to pass one piece of legislation, achieve one policy change, or acquire a new service. A third conclusion is that the vast majority of the center's activities are collegial, such as, working on committees and meeting with administrators—rather than adversarial, such as engaging in demonstrations or taking legal action.

We also noted important differences in the way centers report community outcomes data. Some centers furnish several pages of narrative, which provides a detailed description of their systems advocacy efforts, while others furnish a bulleted list or chart that presents their community outcomes. A review of the data also makes clear that centers do not have a consistent understanding of what constitutes a "community outcome." Some centers report the steps they have undertaken to produce community change, but never make it clear whether the change was achieved. Others report the outcome but do not describe the process that led to its attainment. Therefore, it is difficult to draw further conclusions from this data.

3.8 Services Provided

The survey presented directors with a list of possible services that centers provide and asked each director to specify which services his or her center provided. One hundred percent of directors said they provided information and referral; 99 percent said they provided independent living skills training, individual advocacy, and systems advocacy. Over 98 percent of directors said they provided peer counseling as well as housing referral and assistance. Over 90 percent said they provided ADA training, group support, personal assistance service or referral, assistance acquiring technology or adaptive equipment, technical assistance on access, and advocacy training. Over 85 percent said they provided benefits advisement and assistance with home modifications. (See Table 3-11.)

Table 3-11. Services Provided by Centers with Main Offices in Rural, Urban, and Suburban Communities

Service	Service provided - %			
	Overall	Rural	Suburban	Urban
Information and referral	100	100	100	100
IL skills training	99	100	100	99
Individual advocacy	99	97	100	100
Systems advocacy	99	97	100	99
Peer counseling	98	100	100	97
Housing referral or assistance	98	97	100	98
Technical assistance on access	97	94	100	97
Advocacy training	96	94	95	97
Assistance acquiring technology or adaptive equipment	93	100	87	93
ADA training	93	90	100	93
Group support	92	87	96	92
Personal assistance services or referral	92	90	100	90
Benefits advisement	89	94	78	90
Assistance with modifications at home	87	87	91	87
Employment training or referral	80	81	65	83
Transition from school to work or independent living	77	90	83	72
Services for specific disability groups (please specify group)*	47	32	48	50
Interpreter services	45	36	61	45
Transportation (other than to and from the center)	33	36	26	34
Education/Literacy/GED	29	40	27	27
Legal advisement	25	28	23	25

*17.3 percent said they provide specific services to deaf or hard-of-hearing consumers, 11.9 percent provide specific services to blind or low-vision consumers, and 8.3 percent provide specific services to consumers with traumatic brain injury.

We noted few significant differences between the types of services provided by centers with main offices in rural, suburban, or urban locations. Suburban centers appeared to provide employment training and referral services less often and interpreter services more often than their urban and rural counterparts. Urban centers provided transition from school to work or independent living less often than rural or suburban centers. Rural centers provided literacy/GED services more often and services to specific disability groups less often than urban or suburban centers.

3.9 Outreach to Underserved Constituencies

3.9.1 Multicultural Communities

During the last 10 years, CILs have paid significant attention to reaching out to constituencies that have traditionally been underserved by CILs. It is important to ascertain what efforts centers are making to reach out to multicultural communities and to evaluate how well they are doing in this area. We note that centers are serving minorities in equal or greater proportion than they are present among people with disabilities in the United States (See Chapter 4, Section 3.9). The consumers surveyed rated their centers quite favorably in terms of minority sensitivity. The survey asked consumers, "How sensitive to your cultural or ethnic customs was the IL staff you worked with the most?" Although 40 percent responded that their culture "was not relevant," 44 percent replied that the IL staff was "very sensitive," 11 percent replied "somewhat sensitive," with 2 percent responding "somewhat insensitive." When asked, "Did the IL staff person you saw the most often communicate with you in your preferred language," 96 percent replied "yes" and only 2 percent replied "no."

However, center directors judged their center's own performance more harshly. Many believed they were not adequately serving various minority groups. Table 3-12 lists the minority groups we considered, the percentages of directors who believed their center was not adequately serving each group, and the primary barrier to which they attributed this failure.

Table 3-12. Outreach to Minority Populations

Minority Group	Centers That Do Not Adequately Serve the Group	Primary Barrier
African American	30%	lack of funding and staff
Hispanic/Latino	42%	lack of funding and staff
Asian/Pacific Islander	62%	weak outreach and communication
Native American	39%	cultural issues related to seeking services

Directors also rated their degree of success on a number of strategies used to reach out to ethnic minorities. The strategy most commonly used and deemed most successful overall is employment of staff from the constituency the center is trying to reach. Seventy-seven percent used this strategy and 63 percent found it successful. In terms of outreach to African Americans, directors told us that they had achieved the most success by working with social service agencies. For outreach to Native Americans and Alaska Natives, they rated working with community organizations to develop a common advocacy agenda as most successful. In terms of outreach to Hispanics, Latinos, Asian Americans, and Pacific Islanders, directors found the most success by developing satellite or branch offices in those communities.

3.9.2 Assisting People with Various Disabilities

We also asked center directors if they felt they were adequately serving disability populations that have been traditionally underserved by centers. About 40 percent said they were not adequately serving the deaf and hard of hearing community, 38 percent felt they were not adequately serving consumers who were blind or low vision, 35 percent felt they were not adequately serving people with psychiatric disabilities, 22 percent felt they were not adequately serving people with cognitive disabilities, and 52 percent felt they were not adequately serving people with multiple chemical sensitivity (MCS). Centers appeared to have mixed success with the strategies they used for reaching the various consumer populations that we suggested. When asked which of the following strategies were successful, no more than 26 percent of directors rated any of the strategies as “very successful.” The strategies suggested were:

- Provide written information in alternative formats (Braille, audio-tape, simple language, etc);
- Employ staff from the constituency you are trying to reach;
- Access specialized resources, such as sign language interpreters or Braille teachers, in order to meet specific needs;
- Work with disability specific agencies that serve a particular constituency; and
- Work with disability organizations to develop a common advocacy agenda.

In order to be effective, center staff must demonstrate competence in assisting people with various disabilities. Eighty-two percent of consumers told us that the CIL staff person they worked with the most understood their disability “very well,” while 13 percent said their disability was understood “somewhat.” Only 4 percent replied that their disability was understood “poorly” or “not at all.”

3.10 Accessibility of Centers and the Services They Provide

We asked a series of questions to consumers and directors about the accessibility of the center and its services. We included accessibility of the center’s office, transportation access to the center, access by telephone, and some general questions about how easy it was to receive services from the center. Eighty-nine percent of consumers stated that they were able to enter and leave the building where the center is located and could easily use the telephone security system to enter the building; only 7 percent disagreed. Ninety-one percent of consumers said that once inside the center, they could easily move around individual offices.

Another important question is whether CILs are accessible by public transportation or paratransit services. Twenty-eight percent of consumers told us that they used either regular route transit or a door-to-door transportation service to get to their centers. Fortunately, public transportation is available to most centers. Ninety-three percent of center directors stated that their center was accessible by public transportation and only 4 percent of consumers told us that their center was not.

Accessible parking is necessary for the 61 percent of consumers who either drive or get a ride to their centers. Seventy-eight percent said that accessible parking was located close to the entrance that they use.

To serve people with sensory disabilities, it is vital to provide alternative communication methods. More than 88 percent of center directors told us that they provided materials in the following formats: large print, Braille, audio-cassette, and computer disk, and that they used sign language interpreters. In addition, 82 percent of consumers said that they could read and understand all of the written materials that they were given. However, it is somewhat unclear just how successful centers are in providing alternative formats to all who need them. Of the 22 percent of consumers who need printed materials in an alternative format, 35 percent said that they did not receive them from the center. Of the 6 percent who need a sign language interpreter or cart reporter to communicate, only 43 percent said that their center always provided one.

Using complex and cumbersome telephone answering systems to reach the right person has become an increasingly frustrating experience for most Americans. To ensure that centers are not placing barriers in consumers' paths by employing complex telephone systems, we asked consumers about their experience in contacting their centers. CILs performed extremely well regarding telephone access. In terms of reaching someone at the center, 85 percent told us that they could easily contact their center on their first attempt. In addition, 80 percent said that if they needed to leave a message for someone, they were called back by the next day that the center was open. Of the 27 percent who requested a telephone call to remind them of their appointment, 92 percent received that call. Finally, 73 percent explained that, at least in one instance, they did not have to visit the center because of the help they had received on the telephone. This is especially important for consumers with multiple chemical sensitivity or other disabilities that make travel outside the home difficult.

Centers also ranked high on access to center programs and services. For consumers, it is vital that programs are scheduled at convenient times and that appointments are timely, otherwise, they simply will not make use of center services. Over three-quarters of consumers surveyed told us that their center scheduled programs and services at convenient times so that they could attend without missing work or school. Eighty-four percent told us that they received center services as soon as they needed them and 86 percent said that they had gotten an appointment within the period of time that they wanted. Once they arrived at the center for an appointment, almost three-quarters said that they were able to see a center staff person within 15 minutes. And almost half told us that they did not need to schedule an appointment ahead of time in order to receive services, but were able to simply "walk in." Only 6 percent felt that the paperwork they had to complete in order to obtain services was a burden.

3.11 Training and Technical Assistance Needs

Centers must maintain a highly qualified cadre of staff to ensure first class services and advocacy to consumers and the community. When asked to describe the three most pressing training needs of the center, directors most often mentioned advocacy, volunteer organizing, or systems advocacy techniques (19%). Fundraising and development came next (17%), followed by independent living philosophy (15%). Center directors also mentioned board training, technical assistance with computers and web pages, and deinstitutionalization related to implementation of the Olmstead decision of the U.S. Supreme Court. The most pressing technical assistance needs of centers were computer skills and web page assistance (29%), database design and data collection (24%), and fundraising and development (16%).

3.12 Relationships with Other Agencies

Because relationships with the Statewide Independent Living Council (SILC), the state agency for the blind, and the Designated State Unit (DSU) or state vocational rehabilitation agency are vital to center operations, we asked center directors about the centers' relationships with these agencies. For example, the DSU conducts site reviews of CILs and often passes funds from the state legislature through to the CIL. The DSU and the state agency for the blind refer consumers to the centers and the centers, in turn, refer consumers who need employment services to these agencies. In some cases, the state agency for the blind administers title VII, chapter 2 funds, which provide services to older blind individuals, and in other cases, the CIL administers these funds. In either case, cross-referrals between the two entities are important. The SILC jointly develops the State Plan for Independent Living (SPIL) along with the DSU; the SPIL determines how independent living funds are spent in the state. Additionally, the CIL directors elect a representative to the SILC.

3.12.1 Designated State Unit (DSU)

When asked to what extent the DSU was supportive of the center, 33 percent of directors said that the DSU was very supportive; 34 percent said it was somewhat supportive; 13 percent said it was neutral toward the center; 13 percent said it was somewhat adversarial; and 5 percent said it was very adversarial. Center directors said that open communication between the DSU and the CIL contributed the most toward a supportive relationship, along with DSU staff involvement in the CIL. Understanding of and commitment to the independent living philosophy were also very important. When asked what contributed to an adversarial relationship, responses included lack of support from the DSU in raising funds from the state legislature or other funding issues, too much control of the center by DSU staff, disputes about services to consumers, lack of understanding of the independent living philosophy, lack of respect for independent living, and too few staff with disabilities at the DSU. Directors suggested that RSA could encourage cross training of DSU and CIL staff, clarify roles of CILS and the DSU, encourage DSUs to contract with CILs for services, and foster increases in referrals between CILs and the DSU.

3.12.2 State Agency for the Blind

About 75 percent of CILs said that they had a separate state agency for the blind in their states. Of those centers, 19 percent said the state agency for the blind was very supportive; 34 percent said it was somewhat supportive; 21 said it was neutral toward the center; and about 8percent said the relationship was somewhat or very adversarial. When directors were asked what contributed to a positive working relationship, their responses included the following: open communication, involvement of the agency for the blind staff members on the center’s board of directors, collaboration on services to the elderly blind, CIL support of blindness consumer groups, collaboration on the SILC, and a shared commitment to high-quality services. When asked what contributed to an adversarial relationship, directors gave the following responses: the perception that CILs do not serve blind consumers, the perception of a separate culture and service needs for blind people, lack of communication, and lack of support for CILs.

3.12.3 Statewide Independent Living Council (SILC)

We asked center directors if they had some representation on the SILC; the vast majority of center directors stated that they had. About one-third of directors (33%) said they serve on the SILC, 18 percent said that a member of their staff serves, 20 percent said that a member of the center's board of directors serves, and 24 percent said that a consumer serves on the SILC. About 40 percent said they elect someone to serve on the SILC and 17 percent replied "other." About 11 percent stated they had no representation on the SILC. This is a surprising finding because legislation requires the CIL directors to elect a representative to serve on the SILC. (Directors could select more than one response, therefore, summed percentages equal more than 100.)

We asked to what extent representation on the SILC met each of the criteria outlined in Section 705 of title VII of the Rehabilitation Act (see Table 3-13). It is clear that many center directors felt that their SILC falls short in several areas of representation. Only about 53 percent of directors felt that the SILC provided statewide representation to a great extent, 50 percent felt it represented a broad range of individuals with disabilities, and 55 percent felt that, to a great extent, a majority of members are individuals with disabilities who do not work for a state agency or CIL. Only 27 percent felt that individuals were knowledgeable about CILs and independent living services to a great extent.

Table 3-13. CIL Director Perception of How SILC Meets Its Representation Mandates

The extent to which SILC meets each of the following…	Not at All	To Some Extent	To a Great Extent
Provides statewide representation	6%	41%	53%
Represents a broad range of individuals with disabilities from diverse backgrounds	4%	47%	50%
Individuals are knowledgeable about centers for independent living and independent living services	14%	59%	27%
A majority of members are individuals with disabilities who do not work for any state agency	9%	36%	55%

Center directors also had mixed reviews about whether SILCs were adequately fulfilling the responsibilities outlined under Section 705. The SILC works jointly with the DSU to develop the SPIL. The SPIL must address outreach to unserved and underserved communities. The SILC must also work with the DSU to assess community needs, obtain consumer input on the SPIL, evaluate consumer satisfaction, and develop a network of centers across the state. Additionally, the SILC conducts oversight and evaluation of the SPIL. Less than 50 percent rated the SILC as excellent or very good on any of its responsibilities. For example, only about 41 percent said the SILC was excellent or very good at working with the DSU to develop the State Plan for Independent Living, only 34 percent felt it was excellent or very good at monitoring the plan, and only 29 percent felt it was excellent or very good at evaluating it. Directors rated the SILC as performing less well on its other responsibilities, including assessing community needs, obtaining consumer input in developing the state IL plan, assessing consumer satisfaction with IL services, developing a network of CILs, or outreach to underserved populations. (See Table 3-14.)

Table 3-14. CIL Director Perception of How SILC Meets Its Mandated Responsibilities

SILC Purposes…	Poor	Fair	Good	Very Good	Excellent
Outreach to unserved and underserved populations	26%	33%	23%	12%	6%
Assessment of community needs	19%	27%	31%	15%	9%
Obtaining consumer input on the state IL plan	15%	19%	28%	22%	16%
Development of the state IL plan	10%	20%	27%	27%	16%
Oversight and monitoring of the state IL plan	12%	21%	33%	24%	10%
Evaluation of the state plan	17%	23%	31%	21%	8%
Evaluation of consumer satisfaction	21%	25%	30%	14%	10%
Development of a network of centers across the state	19%	21%	24%	15%	21%

Only 38 percent of directors felt that the SILC was very supportive of their center, about one third (33%) felt it was somewhat supportive, 14 percent felt the SILC was neutral toward the center, about 8 percent felt the SILC was either somewhat or very adversarial, and about 4 percent felt there was no relationship.

We asked what factors had contributed most to a positive relationship between the center and the SILC. The most common response was center representation on the SILC. Other common responses included open communication between the two organizations, a SILC that understood the independent living philosophy, collaboration on specific projects, including increased funding for CILs, a competent SILC staff, and an autonomous SILC (e.g., one that has obtained non-profit status). Factors contributing to an adversarial relationship included lack of understanding by SILC members of the day-to-day operations of centers, multiple agendas and lack of trust, lack of understanding of independent living philosophy, and too much control by the DSU.

Center directors suggested that RSA should clarify roles of the center, the SILC, and the DSU, specifically noting the advocacy role of CILs, and provide training on roles and responsibilities of each entity. Several directors felt the minimal representation of CIL directors was problematic and that RSA should require the SILC to make it optional for every CIL director in the state to have a seat on the SILC. Others felt that RSA should mandate that the SILCs become a 501(c)(3) incorporated entity. Still others felt that RSA should provide greater specificity on the requirements and credentials needed to serve on the SILC and ensure that minorities are represented adequately.

3.13 Evaluation and Monitoring

Evaluation and monitoring of CILs has become critical, as the centers grow in size, resources, and influence. We asked questions about the evaluation and monitoring of centers conducted by RSA and the Designated State Unit (DSU), which is generally the state vocational rehabilitation agency. We asked centers about the usefulness of the evaluation report required under Section 704 of the Rehabilitation Act and how much time it took to prepare for and complete this report. When asked how helpful to the director and the staff information gathered for the Section 704 Report is in assessing the quality of the services and advocacy provided by the center, only 22 percent reported that it was very helpful. About 44 percent reported that it was somewhat helpful, 16 percent were neutral about the helpfulness of the report, 5 percent reported that it was somewhat unhelpful, and 12 percent reported that it was very unhelpful. When asked how many days it took to prepare for the report, 27 percent of directors said it took between 0 and 7 days, 25 percent said it took between 8 and 14 days, 34 percent said it took between 15 and 30 days, and 14 percent said it took over 30 days. When asked what RSA could do to improve the Section 704 Report, directors suggested that RSA should provide information about reporting changes before centers need to begin collecting the data. They also suggested that RSA should provide additional training, better definitions of terms, standardized software for data collection, and should measure outcomes rather than numbers of people served. Directors also felt that they should have input into the Section 704 Report questions and that the report should be simplified. (Some alterations in the 704 Reports will require regulatory changes—34 CFR 366.50(i)).

RSA and the DSUs conduct periodic site reviews of each center. Of the directors surveyed, almost 40 percent had been reviewed by RSA and 46 percent had been reviewed by a DSU within the past 3 years. On the whole, directors felt that the reviews by RSA and the DSU were helpful in assessing the services and advocacy the center provides. About 42 percent said the RSA review was very helpful and an additional 31 percent said it was somewhat helpful. About 10 percent were neutral about the review, 1 percent said it was somewhat unhelpful, and 8 percent said it was very unhelpful. Although the majority of center directors felt that review by the DSU was either very or somewhat helpful, they felt it was less helpful than the RSA review, with only 32 percent saying it was very helpful, and 37 percent saying it was somewhat helpful. About 14 percent were neutral concerning the DSU review, 4 percent said it was somewhat unhelpful, and 12 percent said it was very unhelpful. About 41 percent of directors said it took 0 to 7 days to prepare for the RSA's visit, as compared with 61 percent for the DSU visit. About 12 percent said it took over 30 days to prepare for the RSA site review, as compared with 5 percent for the DSU visit. Based upon these responses, it appears that directors feel that the RSA site visits are more useful, but more burdensome to prepare for than the DSU reviews.

A number of directors made positive comments about the DSU and the RSA review process. They found the reviews helpful to the center's operation and especially appreciated the involvement of peer reviewers in the process. There were only a few suggestions on how the RSA site review could be improved. One person suggested that a "best practices" monograph be distributed to assist CILS in complying with RSA requirements. Others suggested that the site review requirements be provided to new CILs when they open so they can establish procedures to comply. With respect to the DSU review, center directors suggested training on the independent living philosophy, more emphasis on consumer outcomes rather than on case records and internal policies (paperwork), and more similarity between the RSA and DSU reviews. A few directors suggested that the DSU provide the review format with clear expectations well in advance of the review and write a written report of the review results.

3.14 CIL Funding

Since the inception of the CIL Program, CILs have been expected to raise state, local, and private dollars to supplement their federal funding. One measurement of success is the extent to which they have been able to leverage resources beyond funding under title VII, chapter 1, Part C. Table 3-15 shows that centers have been extremely successful in doing so. For example, 87 percent of centers received individual donations, 84 percent received funds from state government, and 60 percent received local governmental funding. Approximately 75 percent received foundation or corporate funds and about 72 percent received title VII, chapter 1, Part B funds. About 71 percent received fee-for-service funding, which means they were successful in selling their services to community or government agencies. Forty percent of centers received income from investments, to augment their initial "shoestring" budgets.

Suburban centers were less likely to be funded with "other federal funds" but more likely to receive funds from state and local government, most likely because suburban governments tend to have a higher tax base than rural or urban areas. Rural centers were less likely to receive local government funds, with only 39 percent of rural centers receiving these funds, compared with 78 percent of suburban centers and 63 percent of urban centers. Rural centers were less likely to receive private funds in all categories (Table 3-15).

Table 3-15. Type of Funding Source Received by Rural, Suburban, and Urban Centers

Source of funding by CIL location				
Source	Overall	Rural	Suburban	Urban
Federal funds				
Title VII, chapter 1, Part B	72%	68%	65%	75%
Title VII, chapter 1, Part C	92%	94%	100%	90%
Title VII, chapter 2	8%	7%	4%	10%
Other federal funds	41%	36%	30%	44%
Other government funds				
State government funds	84%	81%	91%	83%
Local government funds	60%	39%	78%	63%
Private funds				
Foundations, corporations, or trust grants	75%	68%	74%	77%
Donations from individuals	87%	81%	87%	89%
Memberships	27%	23%	30%	27%
Investment income	40%	32%	48%	40%
Fee for service (program income)	71%	65%	78%	71%
Other income/resources (in-kind, etc.)	61%	58%	65%	61%

We asked the CIL directors whether they had experienced problems or difficulties that arose as a result of acquiring any of these resources (e.g., with regard to a record-keeping burden, eligibility rules, or inconsistencies with independent living philosophy, etc.). Title VII, chapter 2, which provides funds to serve older blind people, was most problematic. About 24 percent of those receiving these funds cited problems, including data collection and other administrative issues. Over one-fifth of centers receiving state and local funds experienced problems (21%), including excessive data collection and reporting requirements for the level of funding received and conflicts with independent living philosophy. Directors cited the least amount of difficulty with foundation, corporate, or investment income; less than 5 percent of directors experienced problems with this type of funding.

About 22 percent of directors mentioned funds their center no longer received because of difficulties related to the funding source. They cited a variety of funding sources they no longer received, including HUD, VR, or state Development and Disabilities (DD), or education funds. Again, they most often cited administrative issues, including paperwork burden, reimbursement and reporting requirements for relatively low levels of funding, and conflicts with independent living philosophy as problems.

When center directors were asked to list the factors that facilitated the acquisition of funding, they most often mentioned aggressively exploring funding sources, writing grant proposals, and maintaining a high level of visibility and leadership in the community. When asked what factors impeded resource acquisition, directors most often mentioned the lack of time and the deadlines for grant proposals.

This chapter has provided an overview of center operations, including the philosophy under which they operate, recruitment and relationships with their board of directors, the services and advocacy they provide, their relationships with other agencies, and the funds they have garnered to continue their work. In the next chapter, we will review the demographics of the consumers we surveyed, the services they received, and their satisfaction with these services. We will also present the life changes and outcomes they attribute to CIL services.

CHAPTER 4
CONSUMERS

4.1 Introduction

This chapter describes the 569 consumers we interviewed. We describe the services they received, the outcomes they achieved as a result, and their satisfaction with those services. We begin by presenting the demographics of the consumers who participated in the study. We note differences between CIL consumers and respondents of other studies, including the Survey of Income and Program Participation (SIPP) National Health Interview Survey--Disability Supplement (NHIS-D). We also note the similarities and differences between CIL consumers and NHIS-D respondents who received vocational rehabilitation (VR) services. We define the variables upon which we based our analysis. These include center location (urban, rural, and suburban) and center size (based upon size of budget), as well as consumer location (urban, rural, and suburban), race, gender, age, type of disability, and income. We briefly discuss some of the process measures centers use to ensure consumer control and empowerment, such as presentation of options, education about civil rights laws, and information about the Client Assistance Program (CAP).

The following section of this chapter describes the services consumers received and their satisfaction with those services, noting any differences based upon the variables listed above. We conclude by presenting the outcomes of these services, including gains in knowledge and skills, changes in particular areas of life, and overall life changes.

4.2 Consumer Characteristics and Study Variables

The consumer interviews were conducted in the summer and the early fall of 2001. Most of the consumers had begun receiving services within the year prior to the interview (29% had begun receiving services in 2000 and 22% in 2001). Seventeen percent started receiving services in 1999; another 26 percent had first contacted the CIL sometime earlier in the 1990s; 4 percent had first contacted the CIL in the 1980s, and the remaining 2 percent in the 1970s. Sixty-eight percent were still receiving services at the time of the interview.

The consumers surveyed exhibited a range of involvement with their centers. In the past year, 19 percent of consumers had face-to-face contact with someone from their center once or more per week, 40 percent had contact from 1 to 3 times per month, 29 percent had contact from 1 to 4 times per year, and 12 percent did not visit the center at all. About 28 percent actually became involved in advocacy issues in order to change systems or programs for people with disabilities.

Of the 32 percent no longer receiving services, 13 percent had stopped services within the 3 months prior to the interview; another 30 percent within 3 to 6 months of the interview, 21 percent between 7 months and 1 year, and 36 percent had not received services for more than a year. Thirty-six percent of the consumers who were no longer receiving services told the interviewer they stopped receiving services because their goals had been met. Nineteen percent felt there was nothing more the CIL could do for them and 9 percent were dissatisfied with the services. Of the 36 percent who gave other reasons, 8 percent said they had personal problems with staff; 5 percent cited a change in their living situation (i.e., they moved); 10 percent stated that the CIL did not offer the services they needed; and 10 percent stated that they were not eligible for services. Sixteen percent said they chose not to follow through with the CIL and an additional 16 percent noted that the CIL staff stopped contacting them.

Of the consumers who completed this survey (and were over the age of 18), 23 percent had not completed high school; another 29 percent had a high school diploma or GED. Twenty-one percent had some college. Three percent completed an associate’s degree; 12 percent completed a bachelor's degree, and 7 percent had an advanced degree (e.g., a master’s or doctorate degree). Another 5 percent completed vocational or technical school. Seventy-seven percent of the consumers were not working at the time of the survey. Of the 23 percent who were employed, 39 percent told us they worked full-time and 61 percent said they worked part-time. Over 80 percent of the consumers we interviewed were not married. Thirty-seven percent had never been married, 11 percent were widowed, and 33 percent were separated or divorced. Other demographic characteristics of the consumers and the CILs who serve them are shown in Table 4-1. The table also presents the definitions used for analysis of the data by demographic characteristic.

Table 4-1. Consumer Variable Definitions

Variable Name	Variable Definition	% in Each Category	Rationale
CIL Location	Urban	75%	CIL location was determined by matching the CIL's ZIP code to Census metropolitan statistical areas (MSAs).
	Suburban	10%	
	Rural	15%	
Consumer Location	Urban	53%	Consumer location was determined by matching the consumers' home zip codes to Census MSAs.
	Suburban	12%	
	Rural	35%	
Size of CIL	Small-Budget of $121,945 to $476,662 per year	28 CILs	Centers were divided into terciles by annual budget. These categories were reviewed by project personnel familiar with CILs.
	Medium-Budget of $495,294 to $1,181,727 per year	28 CILs	
	Large-Budget of $1,210,260 to $7,388,855	29 CILs	
Consumer Race	White	73%	Race categories were collapsed into White and non-White, because there were very few consumers in the study who were not either White or African American. Respondents were asked to identify their race by using categories presented during the interview.
	Non-White (combined Black, African-American; Asian; Native Hawaiian or Pacific Islander; Native American or Alaskan Native; and Other)	27%	
Hispanic	Hispanic	9%	Respondents were asked if they were of Hispanic origin.
	Non-Hispanic	91%	
Income	< $8,000	39%	There were so few consumers whose incomes were above $40,000, that all categories above that level were combined.
	$8,001-$10,000	17%	
	$10,001-$20,000	25%	
	$20,001-$40,000	14%	
	$40,001+ (combine 40,001-60,000, 60,001-80,000, and 80,000+)	6%	
Gender	Male	44%	
	Female	56%	

Table 4-1. Consumer Variable Definitions (continued)

Variable Name	Variable Definition	% in Each Category	Rationale
Disability	Physical: Physical Impairment and all disabilities originally coded as “other” except speech disabilities or speech impairments	68%	Categories were collapsed into Physical, Mental, and Communication. These are categories that have been used in prior disability studies. Respondents were asked to indicate their primary disability. Disabilities that were originally coded as “other” were re-coded, then collapsed into the three categories, so that no respondent was excluded from these categories.
	Mental: Cognitive impairment Mental health or substance abuse problem	20%	
	Sensory/Communication: Visual impairment Hearing impairment Speech impairment and disabilities listed under “other” as “speech disability or speech impairment”	13%	
Consumer Age	< 18 yrs.	5%	Consumers were asked to verify or provide their birth date. Categories were initially determined, then combined to provide useful categories for comparison. For instance, although there are few children (<18 yrs. and young people (18-24 yrs.), it was felt these consumers might be different enough from the 25 to 44 year olds to be kept as separate categories. There were also very few people over the age of 64, so those people were combined into one group: 65 and over.
	18-24 yrs.	8%	
	25-44 yrs. (combined 25-34 yrs. and 35-44 yrs.)	36%	
	45-64 yrs. (combined 45-54 yrs. and 55-64 yrs.)	39%	
	65+ yrs. (combined 65-74, 75-84, and 85+ yrs.)	13%	

4.3 Disability Profile of CIL Consumers

This section of the report describes the activity limitations, needs for accessible housing and home modifications, and need for and use of accessible transportation of the consumers we surveyed. We also asked CIL consumers about their overall life satisfaction. In conducting the survey, we included questions from the National Health Interview Survey–Disability Supplement in order to collect comparable data. We used this data to compare the CIL population to the general population of people with disabilities in the United States. We briefly discuss these findings.

4.3.1 Home Accessibility Features

Table 4-2 describes the home modifications or other accessibility features needed and available in the homes of CIL consumers. About half of CIL consumers (51-52%) said they needed alerting devices, accessible parking, and bathroom modifications, followed by railings (46%) and ramps or street-level entrances to their homes (42%). Of those needing alerting devices and bathroom modifications, between 65 and 83 percent reported having them. Most persons needing accessible parking said they had it (83%), and about three-quarters of those reporting a need for railings and ramps or street-level entrances said they had them. Between 27 and 38 percent of consumers reported needing other special features, such as automatic easy-to-open doors, widened doorways, kitchen modifications, or an elevator, stair, or stair glide. Between 46 and 59 percent of consumers who needed these features said they had them available in their homes. Conversely, among CIL consumers who required these home accessibility features, unmet needs ranged from a low of 17 percent for accessible parking to a high of 54 percent for kitchen modifications.

Table 4-2. Home Accessibility Features

		Of those who need the feature	
Special features	% needing feature	% having	% not having
Alerting devices	52	66	34
Accessible parking or drop-off site	51	83	17
Bathroom modifications	51	65	35
Railings	46	76	24
Ramps or street level entrances	42	73	27
Automatic easy-to-open doors	38	56	44
Widened doorways or hallways	36	59	41
Kitchen modifications	33	46	54
Elevator, chair lift, or stair glide	27	50	50

4.3.2 Difficulty Getting Around the Home

CIL consumers reported various difficulties in getting around the home. Twenty-nine percent of CIL consumers reported having difficulty entering or leaving their home and 27 percent reported difficulty opening or closing doors. Forty-one percent said they had difficulty reaching or opening cabinets, and 26 percent had difficulty using the bathroom.

4.3.3 Use of Special Transportation Services

Transportation is essential for ensuring access by persons with disabilities to a range of community facilities and resources, such as one's place of employment, essential shopping, doctor's offices, and social and recreational activities. Special transportation services are often necessary when a person's disability makes it difficult or impossible to get to and from a fixed-route bus stop or otherwise use mass transit. The Americans with Disabilities Act requires that any fixed-route transit program also have a parallel service that provides special transportation for persons with disabilities, such as door-to-door van service.

As Table 4-3 shows, most (85%) of CIL consumers reported having this type of special transportation service available to them, and nearly half of those who did (43%) had used this service within the past 12 months. For those who had not used the service, the vast majority (76%) said they did not need it. However, over one-quarter (28%) said that they did not use the special transportation service because they needed the help of another person, while 22 percent said they could not use it alone. Nearly one-fifth (19%) of those not using the special transportation said they did not do so because of unreliable or inconvenient service. Only 14 percent of CIL consumers said they did not ride on the special transportation service because they did not know how to use it.

Table 4-3. Use of Special Transportation Services

	% Yes	% No
Is such a service is available in your area?	85	15
If yes, have you used this service in the past 12 months?	43	57
If service is available but not used it is because:		
Service not needed/wanted	76	24
Need help from another person	28	72
Cannot use alone	22	78
Pickup unreliable/inconvenient	19	81
Illness	17	83
Do not know how to use service	14	86
Hours of service inadequate	13	87
Cost	8	92
Cannot use telephone	7	93
Cannot get reservation for service	7	93
Denied use of service	6	94
Cannot read	5	95
Other reason	5	95
Do not have a telephone	2	98

4.3.4 Use of Regular Public Transit

Consumers were also asked about their use of regular public transit, including bus, rail, and subway service. About one-third (32%) of CIL consumers reported using public transit during the past 12 months. Of these, about one-third (32%) used it every day or almost every day, while approximately half (47%) used it occasionally, and 22 percent reported only seldom use. In addition, of those who had used public transit services in the past 12 months, about one-quarter (28%) said that they were limited in doing so by an impairment or health problem.

4.3.5 Telephone Availability

Table 4-4 shows the percent of CIL consumers who have been without telephone service for various lengths of time. Nine percent of consumers reported being without telephone service some time during the past 12 months. Of these, most reported only brief periods without service. For example, 15 percent (of the 9% without a telephone) had no service for only 1 day, 27 percent for 2 days, and 25 percent for 3 days. About one-fifth (21%) of those with some interruption were without telephone service for between 4 and 10 days, and 13 percent of these consumers reported being without telephone service more than 10 days.

Table 4-4. Telephone Availability

Has your household been without telephone service at any time during the past 12 months?	
	%
Yes	9
No	91

For how long was your household without telephone service in past 12 months?	
	%
1 day	15
2 days	27
3 days	25
4-10 days	21
More than 10 days	13

4.3.6 Life Satisfaction

CILs are concerned about more than just physical functioning and health status; they are concerned about the overall quality of life their consumers experience. The following questions cover several such dimensions including anxiety, depression, psychological well-being, quantity and quality of social activities, vitality, and other measures of social well-being.[1] Over one-quarter (27%) of consumers reported being very satisfied with their lives, while 51 percent were somewhat satisfied, and 23 percent were not satisfied.

Nearly half (48%) of consumers reported they were very confident with their ability to deal with daily living, while another 45 percent said they were somewhat confident. Only eight percent said they were not confident with their ability to deal with daily living.

Nearly one-fifth (19%) of consumers said they worried a lot about not knowing who to turn to for help, while 44 percent reported worrying some of the time. Another 37 percent said they did not worry at all about who to turn to for help.

During the past 12 months, 10 percent of consumers said they felt sad or depressed all the time, while nearly half (45%) said they felt that way some of the time. About one-third (32%) reported feeling this way a little of the time, and 14 percent said they were sad or depressed none of the time. (See Table 4-5.)

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[1] Ware, J.E. (1993*). SF-36 Health Survey, Manual and Interpretation Guide.* Boston, MA: The Health Institute, New England Medical Center.

Table 4-5. Life Satisfaction

In general, how satisfied are you with the way your life is going these days? Would you say…	
	%
Very satisfied	27
Somewhat satisfied	51
Not satisfied	23

How confident are you in your ability to deal with daily living? Would you say you feel…	
	%
Very confident	48
Somewhat confident	45
Not confident	8

How much do you worry about not knowing who to turn to for help? Would you say you worry…	
	%
A lot	19
Some	44
Not at all	37

In the past 12 months, how often did you feel sad or depressed?	
	%
All of the time	10
Some of the time	45
A little of the time	32
None of the time	14

Compared to your own level of physical activity 1 year ago, would you say you are now more active, less active, or about the same as you were then?	
	%
More active	28
Less active	30
About the same	43

4.3.7 Types of Disabilities of CIL Consumers

Consumers reported having a range of physical, cognitive, and emotional disabilities (see Table 4-6). Approximately half (49%) of the consumers reported a non-orthopedic physical disability, 37 percent reported a visual disability, and 31 percent reported an orthopedic disability, including amputations. Twenty-eight percent of consumers reported having a mental illness or psychiatric disability, and 25 percent reported having a learning disability. One-fifth (20%) of consumers reported having a hearing impairment, and about the same number (19%) said they had a traumatic brain injury. The least frequently reported disabilities among CIL consumers were substance abuse (2%), mental retardation (6%), and environmental illness (8%). Thirty-eight percent of consumers reported some other type of disability, including multiple sclerosis, cerebral palsy, epilepsy, or a spinal cord injury.

Table 4-6. Types of Disabilities of CIL Consumers

Disability	%
Non-orthopedic physical disability	49
Visual disability	37
Orthopedic, including amputations	31
Mental illness/psychiatric disability	28
Learning disability	25
Hearing disability	20
Traumatic brain injury	19
Environmental illness	8
Mental retardation	6
Substance abuse	2
Something else	38

4.3.8 Activity Limitations

Table 4-7 shows the types and severity of several types of activity limitations among CIL consumers. The first category covers functional limitations, including a range of sensory and mobility activities. The activities that CIL consumers were most able to do without assistance included reading ordinary newsprint (72%), writing (66%), and using public transportation (51%). The activities that CIL consumers were least able to do without assistance were walking a quarter mile (36%), driving (36%), and walking up one flight of stairs (41%).

The second category of limitations in the table covers instrumental activities of daily living (IADLs), including various home management activities essential for independent living. The activities that CIL consumers were most able to do without help included using the telephone (83%) and managing money (61%). The activities that consumers were least able to do without assistance were heavy housework (32%), shopping for personal items (52%), and getting around outside the home (53%).

The third category in the table covers the Activity of Daily Living (ADL) Scale, perhaps the most indicative measure of risk for loss of independence. The ADL Scale includes a range of very basic life activities, such as bathing, dressing, and eating. Needing help in performing these activities, or being unable to do them at all, constitutes the most severe disabilities presented in this table.

The ADLs that CIL consumers were most able to do without assistance were eating (86%) and getting in or out of bed (74%). The ADLs that consumers were least able to do without assistance were bathing or showering (61%), dressing (70%), and using the toilet (71%). Another method of measuring ADL limitations is to count the number of persons reporting at least one. Among CIL consumers, nearly half (47%) reported needing help with (or were unable to do) at least one ADL. This demonstrates the substantial level of need among CIL consumers and the effective outreach and targeting by CILs to locate and serve this population with severe disabilities. As a basis for comparison, only 3.8 percent of the total U.S. population reported needing personal assistance with an ADL or IADL limitation.[2]

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[2] McNeil, J. (2001). Americans with Disabilities 1997. *Current Population Reports* (pp. 70-73). Washington, DC: U.S. Census Bureau.

Table 4-7. Activity Limitations

Activity	Can do without assistance (%)	Can do with assistance (%)	Cannot do activity (%)
Functional limitations			
Walking for a quarter of a mile	36	18	46
Walking up a flight of stairs without resting	41	15	44
Reading and understanding the newspaper	72	17	11
Writing	66	21	13
Driving	36	16	48
Using public transportation	51	32	17
Instrumental activity of daily living (IADL) limitations			
Doing heavy housework	32	12	56
Getting around outside the house	53	37	10
Using the telephone	83	13	4
Managing your money	61	28	11
Shopping for personal items	52	36	13
Activity of daily living (ADL) limitations			
Using the toilet, including getting to the toilet	71	23	6
Dressing	70	26	4
Bathing or showering	61	36	3
Getting into or out of bed	74	23	3
Eating	86	14	1

4.3.9 Characteristics of CIL Consumers Compared to the General Population with Disabilities

The study found that CIL consumers were much poorer than others in the general population with a severe disability. The Census Bureau defines a severe disability as having a long-term health condition that requires assistance in performing (or causes an inability to perform) such basic life activities as bathing, dressing, and meals preparation; use of a wheelchair, cane, crutches, or a walker; a serious mental or emotional condition that seriously interferes with everyday activities; or receiving federal disability benefits.[3] Among CIL consumers between the ages of 25 and 64, 84 percent had total household incomes below $20,000 per year, compared to 42 percent for the total household population with a severe disability. For CIL consumers who were age 65 and over, 83 percent had household incomes below $20,000 per year, compared to 53 percent for the total household population with a severe

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[3] Ibid.

disability. This also shows the extent to which Centers for Independent Living have identified and serve a highly vulnerable population with disabilities.

The consumer survey collected data on race and ethnicity to show program participation and service satisfaction levels for members of minority groups. We know from other national studies that disability prevalence rates vary considerably according to many demographic factors, including income and poverty, age, gender, and race and ethnicity. For example, according to the Census Bureau approximately 12 percent of the White/non-Hispanic population in the U.S. reported having a severe disability, compared to nearly 16 percent for the African American population.[4]

As Table 4-8 shows, Centers for Independent Living were serving members of minority groups at or above their proportion in the total population of persons with a severe disability. For example, while 72 percent of the U.S. population with a severe disability is White/non-Hispanic (i.e., not members of a minority group), 66 percent of CIL consumers fell into this category. This means that 34 percent of CIL consumers were members of a minority group, compared to 28 percent of all persons in the U.S. population with a severe disability. CILs served slightly more Black and Hispanic individuals than are found in the general population of people with severe disabilities. But in terms of those minorities that fall into the "other" category in the survey, namely Asian, Native Hawaiian/Pacific Islander, and American Indian/Alaskan Native, CILs served more that twice as many as exist in the general population of people with severe disabilities (see Table 4-1 for specific rates).

Table 4-8. Minority Group Participation Among CIL Consumers Compared to the Total U.S. Population

Race/Ethnicity	CIL Consumers	Total Population with a Severe Disability	Total Population
White, non-Hispanic	66%	72%	72%
Black, non-Hispanic	17%	16%	13%
Hispanic	10%	9%	11%
Other	7%	3%	4%

Source: CIL consumer survey; SIPP Disability Topical Module, 1997

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[4] McNeil, J. (2001). Americans with Disabilities 1997. *Current Population Reports* (pp. 70-73). Washington, DC: U.S. Census Bureau.

4.3.10 Characteristics of CIL Consumers Compared to the NHIS-D

In comparing CIL consumers with the disability population in the NHIS-D, we looked at NHIS-D respondents with one or more limitation in activities of daily living (ADL) and CIL respondents with similar limitations. We found no significant differences between CIL and NHIS-D respondents related to their use of and need for home modification and measures of life satisfaction. We did, however, note a difference in transportation use; CIL consumers were much more likely to use both regular public transit and specialized transportation for persons with disabilities, where they existed, than were members of the general population who had similar levels of disability. This suggests that CIL consumers were better able to avail themselves of transportation services than their counterparts who did not have the benefit of CIL support. One purpose of CIL services is to train and facilitate the use of these transportation services by persons with disabilities; the comparison between the consumer survey and the national NHIS-D suggests that this may very well be occurring.

4.3.11 Vocational Rehabilitation Services

As noted in Chapter 1, the Rehabilitation Act provides funding for several other programs for persons with disabilities, including vocational rehabilitation (VR). VR programs provide equipment and services, such as job training and placement, to improve opportunities for work. While the IL and VR programs operate separately, they often serve the same individuals and provide complementary services. For example, we found that 42 percent of CIL consumers reported receiving equipment or services through a VR agency. This means there is considerable overlap between these two programs.

In addition to documenting the complementary nature of IL and VR programs, the evaluation compared the characteristics of all CIL consumers and all persons receiving services from a VR agency, as reported in the National Health Interview Survey-Disability Supplement (NHIS-D). As Table 4-9 shows, there is considerable similarity according to several demographic and disability characteristics. For example, approximately three-quarters of participants in each program were white, 16 percent were African American, and nearly 10 percent were of Hispanic origin. Slightly more than half of the participants in each program were male. The types of disabilities among participants in both programs were very similar as well. Over two-thirds of the participants had a physical disability, about one-fifth had a mental health or cognitive disability, and about 10 percent had a sensory disability (vision and hearing). Please note that the Vocational Rehabilitation data in this table must be viewed with caution because the VR responses in the National Health Interview Survey on Disability (NHIS-D) may not be representative of all persons in the VR program.[5]

Table 4-9. Comparison between CIL Consumers and Persons Receiving Services from a VR Agency

Characteristics	CIL	VR
Race/ethnicity*		
White (includes white Hispanics)	72%	78%
Black (includes Black Hispanics)	16%	16%
Hispanic (Hispanics can be of any race)	9%	8%
Gender		
Male	55%	53%
Female	45%	47%
Type of Disability		
Physical	68%	71%
Mental health/cognitive	20%	19%
Sensory	11%	10%

* The race/ethnicity figures are not mutually exclusive and cannot be added.
VR Data Source: 1994/5 National Health Interview Survey on Disability in *Analysis of the National Health Interview Survey: the Vocational Rehabilitation Perspective*, Research Triangle Institute for the U.S. Department of Education, December 2000.

4.4 Information about Options, Services, and Laws

Consumer control is an important philosophical component of CIL programs. Consumer control means the extent to which consumers decide about the services they receive, the goals they set, and overall, the path their lives take. Consumer control requires that consumers have a positive and collegial working relationship with staff and a strong voice in the services they receive. Consumers must be presented with a full array of options for services and goals for choice to be a reality.

The majority of consumers stated that CIL staff was helpful, respectful, and listened to their ideas. Seventy-seven percent said the staff person they saw most often "always" listened to their ideas and suggestions and 60 percent said they were "very satisfied" with the CIL's staff's efforts to help them reach their goal.

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[5] *Analysis of the National Health Interview Survey: the Vocational Rehabilitation Perspective*. Research Triangle Institute for the U.S. Department of Education, December 2000.

Seventy-one percent of the consumers said the center gave them information about different options that would help them reach their independent living goals. We noted that only thirty-four percent of consumers stated that they decided on the services they would receive in order to reach their goals; another 22 percent reported they decided on the services in consultation with a staff member at the CIL, for a total of 56 percent. About 27 percent said the IL staff person decide; about 5 percent said a friend or family member decided; and about 12 percent said that someone else decided on their services, usually a social worker, teacher, or another counselor.

The Longitudinal Study of Vocational Rehabilitation Services (RTI, 1996), mentioned in Chapter 1, asked consumers of VR services a series of questions about choosing a goal and about their VR services. A roughly equal number (75%) of VR consumers who responded to this survey said their counselor always listened to their ideas and suggestions, as compared with 77 percent of CIL consumers. About two-thirds of VR consumers (66%) said they had received information about service options through the VR agency, as compared with 71 percent of consumers on the CIL survey. Of the two-thirds of consumers that said they were told about service options by a VR counselor, about 31 percent said that they selected a goal themselves and about 42 percent said they and the counselor selected a goal together, for a total of about 73 percent. Of CIL consumers who said they were presented with service options, 33% said they selected a goal themselves and 26% said they selected it with their counselor for a total of 60%.

CILs are required to provide information to service applicants about the Client Assistance Project (CAP), which provides assistance to consumers of rehabilitation or independent living services who feel they have not been treated fairly, or who wish to resolve a dispute. About 55 percent of CIL consumers had been told how to file a complaint with the CAP at their center if they were unhappy with any of the center's services. While this indicates that a majority of consumers were told about the CAP, the law requires that all consumers be told about this service. The possibility exists that CIL staff are not providing this information as the law requires, or that consumers received the information but did not recall the conversation about the CAP.

Twenty-seven percent of consumers did say they would have liked the staff to have "done something differently." (This compares with about one-third of consumers in the VR study mentioned above.) Their suggestions included:

- Better transportation assistance;

- Better communication between staff and consumers; and
- Less paperwork.

When asked to whom they would turn if they thought the center should be doing something differently, consumers replied that they would:

- Talk to a center staff person (87%);
- Talk to the executive director (77%);
- Talk to a board member (71%);
- Talk to a friend (81%);
- Talk to an advocacy organization (72%); and/or
- Something else (28%).

Of those who said they would do "something else," consumers gave the following responses:

- Talk to a family member or relative (14%);
- Tell a politician, someone in the media, or another public figure (19%);
- Write a letter (5%);
- Do "whatever it takes" and tell "anyone who will listen" (21%); and
- Talk with another professional (13%) (vocational rehabilitation counselor, doctor, social worker, etc.).

4.5 Services and Satisfaction Levels

Consumers were asked about the types of services they received from the CIL, satisfaction with those services, whether knowledge or a skill had been gained from the service, if the service made a change in their lives, and, if so, the type of change. Consumers were asked if they had received the following services:

- Information and referral (I&R): staff person provides the name and telephone number of another agency, or explains where to get a particular service
- Peer support: meeting with one person or a group of people who have disabilities to talk about and solve problems

- Benefits advisement: explaining SSI, SSDI, Medicaid, food stamps, or other benefits
- Independent Living Skills training (IL Skills training): learning how to manage a budget, shop for food, or do other things necessary to live independently
- Housing referral or assistance: locating a place to live
- Personal assistance services or referral: learning how to use a personal assistant or referral to someone who can be a personal assistant
- Help with modifications at home: helping to make homes more accessible
- Employment advisement, training, or referral: assistance with looking for a job or with problems on the job
- Transition from school to work or independent living: planning for work or living independently upon leaving school
- Getting technology or adaptive equipment: such as wheelchairs, adapted computers, or hearing aids
- Transportation: transportation arranged and/or paid for by the center to and from appointments or an activity that is not sponsored by the center
- Americans with Disabilities Act (ADA) training: awareness of consumer rights under the Americans with Disabilities Act

Consumers were asked about each service separately, so they could report receiving more than one of the services. Level of satisfaction for each service was reported on a five-point Likert-type scale. Respondents were given choices of:

- Very dissatisfied,
- Somewhat dissatisfied,
- Neither dissatisfied nor satisfied,
- Somewhat satisfied, and
- Very satisfied.

Consumers were asked a yes/no question to determine if they gained knowledge or a skill from the service and if the service made a change in their lives. If they replied that the service made a change in their lives, they were asked, "What type of change?" This was an open-ended question; response categories were not provided for the participant. The research team grouped consumer responses into categories for analysis.

4.5.1 Services Consumers Received

Fifty-nine percent of CIL consumers received Information and Referral (I&R) services. Another 41 percent of consumers said they received benefits advisement, and 37 percent received peer support services. These were the most frequently reported services.

Twenty-nine percent of the consumers said they received training on the Americans with Disabilities Act (ADA). Twenty-nine percent also said they received personal assistance services (or a referral for personal assistance services). Twenty-six percent of consumers received help getting technology or durable medical equipment, help with home modifications, or assistance obtaining housing (including referrals for housing).

Twenty percent received help finding employment. Twenty percent also received independent living skills training, and 19 percent received transportation services. Nine percent received help making the transition from school to work. Table 4-10 shows these results.

Table 4-10. Services Received by CIL Consumers

Service	Consumers receiving service (%)
Information and referral	59
Benefits advisement	41
Peer support	37
ADA training	29
Personal assistance services or referral	29
Getting technology or adaptive equipment	26
Home modification	26
Housing referral or assistance	26
Employment advisement	20
Independent Living Skills training	20
Transportation	19
Transition from school to work	9

4.5.2 Individual Advocacy

Individual advocacy is one of the center's most important services; it is listed as one of four core services in title VII, chapter 1, Part C. We were unable to ask consumers directly if they had received this service, because the pilot tests revealed that consumers did not comprehend the meaning of the term "individual advocacy" when used in this way. If a consumer had received a service in a particular area, for example, in the area of housing, transportation, or personal assistance, he or she tended to think about the help provided as being within that specific area, rather than thinking of themselves as being recipients of "individual advocacy." Therefore, we asked a series of specific questions to ascertain whether consumers had received individual advocacy services.

Center consumers often need assistance receiving services from agencies other than a CIL and may experience problems because of a disability. When asked if they had ever experienced difficulty receiving services from or gaining access to an agency other than the center because of a disability, 24 percent said they had experienced problems. Of the consumers who said they had experienced problems, 15 percent said the problem was solved, an additional 28 percent said that the problem had been partially solved, and the remaining 57 percent said that the problem remained unsolved. Of those who said the problem had been fully or partially solved, about 63 percent said the center had helped them solve the problem; 37 percent said it had not. When asked what occurred in solving the problem, 36 percent said "The center staff solved the problem for me"; 22 percent said, "Center staff told me how to solve the problem myself"; 27 percent said, "The staff worked with me to solve the problem"; and 16 percent said, "Center staff put me in touch with other people with disabilities and we solved it together." However, when asked how they would handle the problem the next time it occurred, 39 percent of consumers said they would solve the problem themselves; 26 percent said they would work with the center staff to solve the problem; and only 22 percent said they would contact the center and let them solve the problem. About 14 percent said they would get in touch with other people with disabilities to solve the problem together. These responses show that significant numbers of consumers are having problems receiving services from other agencies and are receiving individual advocacy services.

In terms of teaching empowerment, 62 percent of consumers said they had been encouraged by center staff to advocate for themselves and 30 percent of consumers indicated that they had received training on the Americans with Disabilities Act at their center. Forty-six percent of consumers said that their center had told them about the independent living movement or about its philosophy. About 41 percent said that they had been provided with information or training concerning federal, state, or local advocacy issues. Twenty-eight percent of consumers said they actually got involved in advocacy and 8 percent said they were still involved at the time the survey was conducted. Involvement in advocacy issues is an important component of teaching empowerment and advocacy skills. The centers are empowering some consumers to solve their own problems and to get involved in community change, but teaching empowerment and problem-solving skills to consumers may be an area for further concentration.

4.5.3 Consumer Satisfaction with Services Received

As shown in Table 4-11, the vast majority of consumers were either very or somewhat satisfied with the services they received. Consumer satisfaction with services received from the CILs ranged from 59 percent of consumers stating they were very satisfied with the employment advice they received from the CIL to 87 percent reporting they were very satisfied with the transportation services they received. (It should be noted that only 20% of consumers received employment advisement services, and 20% received transportation services.) Levels of consumer dissatisfaction were consistently low. The highest levels of consumer dissatisfaction were reported in the areas of housing referral or assistance (6%) and employment advisement (7%).

Table 4-11. Level of Satisfaction with Services Received

		Consumer satisfaction (%)				
Service	Percent receiving service	Very satisfied	Some-what satisfied	Neither dissatisfied nor satisfied	Somewhat dissatisfied	Very dissatisfied
Transportation	19	87	7	5	2	1
Other services	9	80	11	6	1	1
Home modification	26	75	16	4	3	2
Personal assistance services or referral	29	74	18	1	7	0
Transition from school to work	9	74	21	0	3	2
Technology or adaptive equipment	26	73	15	7	3	2
ADA training	29	71	22	6	1	0
Independent living skills training	20	69	26	4	1	0
Housing referral or assistance	26	65	19	5	5	6
Information and referral	59	64	28	4	1	3
Benefits advisement	41	63	29	3	2	3
Peer support	37	62	28	7	1	1
Employment advisement	20	59	17	7	10	7

4.5.4 Services Received by CIL Location

The location of the CIL (urban, suburban, or rural) did not significantly affect the services consumers received, with only two exceptions:

- Employment advisement, which was reported by 10 percent of rural consumers and 21 percent of consumers served by suburban and urban CILs. This difference was significant ($p \leq .02$); and
- Housing referral and assistance, which was received by 29 percent of consumers from suburban and urban centers, and 9 percent of consumers of rural centers. This difference was also significant ($p \leq .001$).

Table B-1 in Appendix B shows the reported percentages of services received by CIL location.

4.5.5 Consumer Satisfaction and CIL Location

Consumer satisfaction did not vary by CIL location (urban, suburban, and rural) except in one instance. As shown in Table 4-12, 97 percent of consumers served by a rural CIL and who received IL skills training were very satisfied with that service compared to 75 percent of those served by a suburban CIL and 64 percent of those served by an urban CIL. This difference was significant ($p \leq .05$), when consumers served by a rural CIL were compared to the combined satisfaction levels of consumers served by suburban and urban CILs. None of the other differences in reported satisfaction were significant.

Table 4-12. Consumer Satisfaction with Services by CIL Location

Service	CIL location (% consumers served by CIL location) Overall	Rural (15%)	Not rural (85%)	% Difference (% standard error)	
	% very satisfied				
Independent living skills training	69	97	65	32*	(6.75)
ADA training	71	86	69	17	(8.73)
Technology/adaptive equipment	73	85	70	15	(12.94)
Information and referral	64	67	63	4	(7.55)
Transportation	87	86	87	1	(10.21)
Transition from school to work	74	84	73	11	(12.94)
Personal assistance	74	83	72	11	(11.45)
Home modification	75	74	75	1	(12.4)
Peer support	62	64	62	2	(10.19)
Benefits advisement	63	52	65	13	(10.26)
Housing referral	65	50	66	16	(23.43)
Employment advisement	59	46	60	14	(21.53)

* $p \leq .05$

4.5.6 Services Received and Satisfaction by Consumer Location

To examine consumer services and satisfaction based upon the geographic location of the consumer, we classified consumers as urban, suburban, or rural, based upon the zip code of their residence. Table 4-13 shows services received by consumer location.

We noted only three significant differences. A greater proportion of consumers who lived in urban and suburban areas received transportation services ($p = .04$) and ADA training ($p = .05$) than did consumers who lived in rural areas. A greater proportion of consumers who lived in suburban areas received I&R services than did people living in urban or rural areas ($p = .01$).

Table 4-13. Service Received by Consumer Location

		Consumer Location (% of consumers)		
	Overall	Urban (53%)	Suburban (12%)	Rural (35%)
Service	% Consumers receiving service			
Information and referral @	59	58	76	54
Peer support	37	40	49	30
Benefits advisement	41	44	53	32
Independent living skills training	20	24	15	15
Housing referral or assistance	26	30	26	19
Personal assistance services	29	33	29	23
Home modification	26	27	18	28
Employment advisement	20	23	22	14
Transition from school to work	9	10	7	7
Getting technology or adaptive equipment	26	23	27	30
Transportation *	19	22	24	13
ADA training #	29	32	32	23

@ p = .01 Suburban vs. urban/rural
* p = .04 Rural vs. urban/suburban
\# p = .05 Rural vs. urban/suburban

We noted only two differences in satisfaction levels based upon the consumer's geographic location. Proportionately less consumers who lived in urban areas were satisfied with the ADA training they received than consumers who lived in suburban or rural areas (p = .01). Proportionately more consumers who lived in rural areas were satisfied with the personal assistance services they received than consumers in suburban and urban areas (p = .01). Table 4-14 shows the satisfaction levels by consumer location.

Table 4-14. Consumers Who Reported Being Very Satisfied with Services by Consumer Location

Service	Consumer Location (% of consumers)			
	Overall	Urban (53%)	Suburban (12%)	Rural (35%)
Information and referral	64	70	55	58
Peer support	62	61	67	61
Benefits advisement	63	65	54	61
Independent living skills training	69	71	56	69
Housing referral or assistance	65	71	47	61
Personal assistance services #	74	69	59	88
Home modification	75	72	63	77
Employment advisement	59	61	44	63
Transition from school to work	74	78	62	67
Getting technology or adaptive equipment	73	80	69	64
Transportation	87	83	95	89
ADA training*	71	61	77	82

\# $p = .01$ Rural vs. urban/suburban
* $p = .01$ Urban vs. suburban/rural

4.5.7 Services Received and Satisfaction by CIL Size

To determine if large centers provided a different array of services to their consumers than smaller centers, we categorized centers as small, medium, and large. Size was determined by the total annual budget of the CIL as reported in the fiscal year 1999 Section 704 Report (see Table 4-1). Table 4-15 shows differences in the percentages of consumers who received services by size of CIL. Most of these differences are non-significant. There was one significant difference; consumers served by medium-size CILs received housing referral or assistance services more often than consumers served by large and small CILs (36% as compared with 18% and 25% respectively, $p \leq .01$).

Table 4-15. Service Received by CIL Size

	CIL size (Number of CILs)			
	Overall (85 CILs)	Small (28 CILs)	Medium (28 CILs)	Large (29 CILs)
Service	% consumers receiving service			
Transition from school to work	9	11	9	5
Information and referral	59	56	63	59
Peer support	37	35	40	37
Benefits advisement	41	40	44	39
Housing referral or assistance *	26	25	36	18
Personal assistance services or referral	29	23	36	32
ADA training	29	26	33	29
Employment advisement	20	17	26	18
Independent living skills training	20	20	22	17
Home modification	26	23	26	31
Getting technology or adaptive equipment	26	25	23	30
Transportation	19	19	18	20

* $p \leq .01$, Medium vs. large and small CILs.

We next examined consumer satisfaction by CIL size; we looked at satisfaction with each service within small, medium, and large centers. We noted two significant differences. Proportionately more consumers who were served by small CILs reported being very satisfied with independent living skills training than consumers who received independent living skills training services from medium-size CILs ($p \leq .05$). And proportionately more consumers who received benefits advisement from small CILs were highly satisfied than those who received benefits advisement from large CILs ($p \leq .05$). Although these differences were statistically significant, they may or may not reflect meaningful differences in service satisfaction. Given the number of service categories analyzed, we would expect to find a small percentage of random statistical differences (see Table 4-16).

Table 4-16. Percent of Consumers Very Satisfied with Services by CIL Size

Service	Level of satisfaction by CIL size (Number of CILs)				Significant? % Difference (% Standard error)
	Overall (85 CILs)	Small CIL (28 CILs)	Medium CIL (28 CILs)	Large CIL (29 CILs)	
	% very satisfied				
Independent living skills training	69	81	54	67	Small and Medium only 27* (12.74) Small and Large 14 (12.71) Medium and Large 13 (16.91)
ADA training	71	80	66	65	Small and Medium/Large combined 14 (9.7)
Benefits advisement	63	69	69	46	Large and Small/Medium combined 23 # (9.11)
Information and referral	64	69	64	56	Small and Large 13 (11.22)
Peer support	62	68	59	57	Small and Medium/Large combined 9 (10.71)
Employment advisement	59	65	51	63	Medium and Small/Large combined 13 (13.51)
Home modification	75	78	79	69	Large and Small/Medium combined 10 (10.47)
Personal assistance services or referral	74	77	79	63	Large and Small/Medium combined 16 (11.01)
Transition from school to work	74	75	77	63	Large and Small/Medium combined 13 (15.75)
Housing referral or assistance	65	62	68	67	Not large enough to calculate
Transportation	87	89	78	91	Medium and Small/Large combined 11 (9.13)
Getting technology or adaptive equipment	73	66	71	83	Medium and Large 12 (12.34)

* $p \leq .05$ Small vs. medium CILs

\# $p \leq .05$ Large vs. small/medium CILs

4.5.8 Services Received and Satisfaction by Race

The type of service a consumer received did not vary significantly by the race of the consumer. Seventy-three percent of the respondents identified their race as White; the remaining 27 percent said they were non-White. Table 4-17 shows only one significant difference; 28% of non-Whites received transportation services compared to 16% of Whites ($p \le .04$). This may be due to income or the geographic location of minority populations where other transportation options are lacking. The other differences vary between 0 percent (for information and referral services) to 8 percent (for peer support and employment advisement) and were not significant. Non-Whites received slightly more services more often than Whites.

Table 4-17. Service Received by Race

		Race (% consumers)		
	Overall	White (73%)	Non-White (27%)	
Service	% receiving service			% Difference
Information and referral	59	58	58	0
Peer support	37	36	44	8
ADA training	29	28	34	6
Personal assistance services or referral	29	29	32	3
Home modification	26	24	30	6
Transportation	19	16	28	12*
Employment advisement	20	18	24	6
Independent living skills training	20	18	23	5
Transition from school to work	9	8	10	2
Benefits advisement	41	41	39	2
Getting technology or adaptive equipment	26	27	24	3
Housing referral or assistance	26	27	22	5

* $p \le .04$

As shown in Table 4-18, there was only one significant difference in levels of satisfaction by the consumer's race. A higher proportion of Whites who received ADA training were very satisfied with the training than were non-Whites ($p \le .01$).

Table 4-18. Satisfaction with Services by Consumer Race

	Satisfaction by race (% consumers)			
	Overall	White (73%)	Non-White (27%)	% Difference (% standard error)
Service	% very satisfied			P value
Transition from school to work	74	72	79	N/A
Technology/adaptive equipment	73	70	78	N/A
Independent living skills training	69	65	76	11 (10.59)
Employment advisement	59	51	72	21 (12.25)
Housing referral	65	63	70	N/A
Peer support	62	59	69	10 (8.59)
Transportation	87	88	84	N/A
Home modification	75	79	65	14 (9.66)
ADA training	71	79	54	25 (9.08) *
Personal assistance	74	78	66	12 (8.09)
Benefits advisement	63	63	61	N/A
Information and referral	64	66	59	N/A

Note: Significance tests were only run for differences of 10 percent or more in satisfaction level.
* $p \leq 0.01$.

4.5.9 Services Received and Satisfaction by Hispanic and Non-Hispanic Consumers

As shown in Table 4-19, there was only one significant difference in services received by Hispanic and non-Hispanic consumers. A higher percentage of non-Hispanic consumers received help getting technology or equipment than Hispanic consumers ($p \leq .03$).

Table 4-19. Service Received by Hispanic and Non-Hispanic Consumers

		Hispanic/Non-Hispanic (% consumers)		
	Overall	Hispanic (9%)	Non-Hispanic (91%)	% Difference
Service	% receiving service			
Home modification	26	35	25	10
Personal assistance services or referral	29	31	29	2
Housing referral or assistance	26	30	25	5
Transition from school to work	9	12	9	3
Information and referral	59	48	60	12
Benefits advisement	41	33	42	9
Peer support	37	26	38	12
ADA training	29	24	30	6
Getting technology or adaptive equipment	26	14	28	14*
Employment advisement	20	11	20	9
Independent living skills training	20	19	19	0
Transportation	19	18	19	1

* $p \leq .03$

Levels of satisfaction between Hispanic and non-Hispanic consumers differed significantly in only one instance. A higher proportion of Hispanic consumers reported being very satisfied with the ADA training they received ($p \leq .04$) than non-Hispanic consumers (see Table 4-20).

Table 4-20. Satisfaction with Services by Hispanic and Non-Hispanic Origins

Service	Satisfaction by Hispanic/Non-Hispanic (% consumers) Overall	Hispanic (9%)	Non-Hispanic (91%)	% Difference (% standard error)
	% very satisfied			
Transportation	87	94	86	N/A
ADA training	71	89	69	20 (9.56) *
Independent living skills training	69	88	68	20 (12)
Home modification	75	80	74	N/A
Transition from school to work	74	80	73	N/A
Employment advisement	59	80	59	21 (18.45)
Benefits advisement	63	76	62	14 (12.39)
Peer support	62	70	61	N/A
Personal assistance	74	66	74	N/A
Technology/adaptive equipment	73	51	74	23 (32.48)
Housing referral	65	49	66	17 (22)
Information and referral	64	53	65	12 (12.51)

P value not calculated if difference was <10%
* $p \leq .04$

4.5.10 Service Received and Satisfaction by Income Level

Consumer household annual income affected some of the services consumers received. Differences in reporting services received were determined by comparing two income levels: $10,000 per year or less (56% of consumers) and $10,001 or more (44% of consumers). Differences in level of services received by income level were:

- Housing referral: 33% of consumers with incomes of $10,000 per year or less received this service, while only 19% of those with incomes over $10,000 per year received it ($p \leq .01$).
- Independent living skills training: 24% of consumers with incomes below $10,000 per year received this service, while only 13% of those with incomes over $10,000 received it ($p \leq .01$).
- Help obtaining technology or adaptive equipment: 34% of consumers with household incomes at $10,001 or more received this service, while only 20% of consumers whose incomes were $10,000 per year or less received it ($p \leq .02$).

Table 4-21 shows the percentage of consumers who received services by household income ($10,000 or less and $10,001 or more) for all services.

Table 4-21. Service Received by Income

Service	% receiving service			
	Overall	≤ $10,000	> $10,000	% Difference
Information and referral	59	61	59	2
Peer support	37	36	38	2
Benefits advisement	41	46	40	6
Independent living skills training	20	24	13	11*
Housing referral or assistance	26	33	19	14*
Personal assistance services or referral	29	31	30	
Home modification	26	26	27	1
Employment advisement	20	16	19	3
Transition from school to work	9	8	6	2
Getting technology or adaptive equipment	26	20	34	14#
Transportation	19	21	19	2
ADA training	29	33	24	9

* p ≤ .01
\# p ≤ .02

Consumer satisfaction varied only slightly by income level (see Table 4-22). We determined consumer satisfaction by income by comparing the two income levels described above. Significance levels were computed for all the services where there was at least a 10 percent difference in the proportion of consumers who were very satisfied. We found only one significant difference. The proportion of consumers who made less than $10,000 per year and were very satisfied with peer support services was greater than those whose incomes were $10,001 or more (p ≤ .05). None of the other differences were significant. (See Table B-2 in Appendix B for levels of satisfaction by all income categories.)

Table 4-22. Satisfaction with Services Received by Income Level

Service	Income level (% consumers) Overall	<$10,000 (56%)	$10,001 or more (45%)	% Difference (% standard error)
	% very satisfied			
Transition from school to work	74	85	69	16 (18)
Peer support	62	72	50	22* (9)
Benefits advisement	63	68	52	16 (9)
Information and referral	64	67	64	N/A
ADA training	71	68	77	N/A
Personal assistance services or referral	74	73	76	N/A
Home modification	75	79	73	N/A
Transportation	87	88	83	N/A
Getting technology or adaptive equipment	73	68	80	12 (11)
Independent living skills training	69	72	69	N/A
Housing referral or assistance	65	68	56	12 (13)
Employment advisement	59	56	55	N/A

* $p \leq .05$

4.5.11 Services Received and Satisfaction by Gender

As shown in Table 4-23, the consumer's gender did not affect the type of services consumers received. The percentages of consumers receiving services varied between genders only slightly (generally 1 to 5 percentage points).

Table 4-23. Service Received by Gender

	Overall	Gender (%)		
		Male (44%)	Female (56%)	
	% service received			% Difference
Information and referral	59	61	57	4
Benefits advisement	41	43	39	4
Peer support	37	37	37	0
Personal assistance services or referral	29	31	28	3
Getting technology or adaptive equipment	26	31	22	9
ADA training	29	30	28	2
Housing referral or assistance	26	29	24	5
Employment advisement	20	23	17	6
Transportation	19	22	17	5
Independent living skills training	20	21	19	2
Home modification	26	21	30	9
Transition from school to work	9	8	9	1

As shown in Table 4-24, we noted only one significant difference in satisfaction with services by gender. A greater proportion of females than males were very satisfied with housing referral or assistance services ($p \leq .02$). Males and females were equally satisfied with the other services they received.

Table 4-24. Consumer Satisfaction with Services by Gender

	Satisfaction level by gender (% consumers)			
	Overall	Male (44%)	Female (56%)	% Difference (% standard error)
Service	% very satisfied			
Home modification	75	75	75	N/A
ADA training	71	71	71	N/A
Independent living skills training	69	69	69	N/A
Personal assistance services or referral	74	73	74	N/A
Peer support	62	62	63	N/A
Transportation	87	92	81	11 (6.57)
Transition from school to work	74	83	67	16 (23.17)
Information and referral	64	67	61	N/A
Getting technology or adaptive equipment	73	64	82	18 (11.48)
Housing referral or assistance	65	52	77	25* (10.71)
Benefits advisement	63	60	65	N/A
Employment advisement	59	56	62	N/A

* $p \leq .02$ P value not calculated if difference <10%

4.5.12 Service Received and Satisfaction by Disability Type

The type of service the consumer received varied by type of disability in only one instance. Consumers with physical disabilities received employment advisement services significantly more often than consumers with mental disabilities ($p \leq .04$). Table 4-25 shows the percentage of consumers who received each service by type of disability.

Table 4-25. Service Received by Disability Type

Service	Overall	Physical (68%)	Mental (20%)	Sensory/ Communication (13%)
	% service received			
Personal assistance services or referral	29	32	27	26
ADA training	29	31	28	29
Home modification	26	29	20	28
Benefits advisement	41	40	43	37
Housing referral or assistance	26	25	32	18
Transportation	19	19	28	16
Employment advisement*	20	15	26	24
Independent living skills training	20	16	23	21
Transition from school to work	9	6	12	8
Information and referral	59	57	60	68
Peer support	37	33	42	47
Getting technology or adaptive equipment	26	25	27	40

Disability type (% consumers) spans Physical, Mental and Sensory/Communication.

* $p \leq .04$ Physical vs. mental

Consumers with mental disabilities were significantly more satisfied with the housing referral services they received than consumers with physical disabilities ($p \leq .05$) and communication disabilities ($p \leq .01$). None of the other differences in satisfaction level by disability were significant (see Table 4-26).

Table 4-26. Consumer Satisfaction by Disability Type

		Disability type (% consumers)		
		Physical (68%)	Mental (20%)	Sensory/ Communication (13%)
Service	% overall very satisfied	% very satisfied		
Transportation	87	92	81	69
Getting technology or adaptive equipment	73	83	68	54
Home modification	75	78	68	62
Independent living skills training	69	77	62	72
Peer support	62	68	60	54
Personal assistance services or referral	74	72	87	57
Transition from school to work	74	73	84	74
Housing referral or assistance *	65	60	83	32
Information and referral	64	64	71	64
ADA training	71	72	55	78
Benefits advisement	63	63	63	67
Employment advisement	59	59	62	67

* $p \leq .05$ mental vs. physical
* $p \leq .01$ mental vs. sensory/communication

4.5.13 Service Received and Satisfaction by Age

Table 4-27 shows that consumers between the ages of 18 and 64 received some services, such as employment advisement, independent skills training, and transportation, more than consumers of other ages.

Table 4-27. Service Received by Age Group

Service	% service received			
	Overall	<18	18 - 64	65+
Information and referral @	59	46	62	45
Peer support ^	37	31	41	14
Benefits advisement*, ^	41	21	45	23
Independent living skills training#, ^	20	8	23	6
Housing referral or assistance	26	0	29	16
Personal assistance services or referral	29	17	31	26
Home modification	26	28	26	24
Employment advisement	20	7	23	1
Transition from school to work	9	23	9	2
Getting technology or adaptive equipment	26	16	25	39
Transportation	19	11	20	12
ADA training #, ^	29	15	33	7

* p ≤ .02 <18 vs. 18-64
\# p ≤ .03 <18 vs. 18-64
@ p ≤ .03) 18 -64 vs. 65+
^ p ≤ .001 18 -64 vs. 65+,

To test for differences, the respondents were split into the following three categories:

- Less than 18 years old,
- 18 to 64 years old, and
- 65 and older.

Generally, consumers who were under 18 were still at home and probably not looking for a regular full-time job. Consumers between the ages of 18 and 64 were more likely to need services related to working, and consumers who were 65 years old and over were more likely to be out of the work force. The following differences between age groups were found to be significantly related to the type of service consumers received:

Under 18 compared to 18 to 64

- Consumers who were under the age of 18 received benefits advisement services significantly less often than consumers between the ages of 18 and 64 (p ≤ .02).
- Consumers who were under the age of 18 also received independent living skills training less often than consumers who were between the ages of 18 and 64 (p ≤ .03).
- Consumers who were under the age of 18 received ADA training less often than consumers who were 18-64 years of age (p ≤ .03).

18 to 64 compared to age 65 and older

- Consumers who were 18 to 64 years of age received the following services more often than consumers age 65 and over.
  - Information and referral ($p \leq .03$),
  - Peer support ($p \leq .001$),
  - Benefits advisement ($p \leq .001$),
  - Independent skills training ($p \leq .001$), and
  - ADA training ($p \leq .001$).

18 to 64 compared to 18 or less and 65 and over

- 18- to 64-year-old consumers received employment advisement services more often than consumers who were under 18 or age 65 and older ($p \leq .001$).
- 18- to 64-year-old consumers also received help getting technology or equipment more often than consumers in the other age groups ($p \leq .001$).

Consumers who were under the age of 18 (or their parents who served as a proxy for the interview) received services at lower rates. These are consumers who are still living at home, so they did not receive housing referral or assistance services. Consumers in this age group received information and referral services and benefits advisement services most often (46% and 41% respectively) but less often than their older counterparts.

Consumers who were age 65 or older received help obtaining technology or adaptive equipment more often than consumers in other age groups. For other services, they reported very low rates of services (such as employment advisement, independent living skills training, peer support, transition from school to work, etc.). Table B-3 in Appendix B shows services received by each age group.

To test for significance, levels of satisfaction were collapsed into two broad categories, “very satisfied” and “not very satisfied” (which included responses of “somewhat satisfied,” “neither satisfied nor dissatisfied,” “somewhat dissatisfied,” and “very dissatisfied”). We found no significant differences where these tests could be run. Cell sizes were too small to draw conclusions about age and levels of satisfaction.

4.6 Consumer Outcomes

4.6.1 Consumer Gains and Positive Life Changes

Overall, the services CILs provide made a difference in the lives of consumers. For instance, consumers reported gaining skills and knowledge from the services they received. Ninety-six percent of the consumers who received independent living skills training said they gained knowledge or skills from that service. Ninety-four percent of the consumers who received help making the transition from school to work also reported gaining skills and knowledge (see Table 4-28).

Table 4-28. Consumers Reporting Gain in Knowledge or Skills from Services Received

Service	Gained knowledge or skill (%)
Independent living skills training	96
Transition from school to work	94
ADA training	87
Peer support	86
I&R	83
Benefits advisement	80
Technology/adaptive equipment	79
Housing referral	77
Home modification	73
Transportation	72
Personal assistance	68
Employment advisement	65

Not only did consumers report that CIL services helped them gain knowledge and skills, they also reported that these services made a change in their lives. Eighty-two percent of the respondents who received independent living skills training said that the training made a change in their lives, as did 77 percent of those consumers who received personal assistance services. Seventy-six percent of those who received peer support services also said that this service made a change in their lives. Table 4-29 shows the percentage of consumers reporting change by type of service.

Table 4-29. Consumers Stating Service Made a Change in Their Lives

Service	Change in life (%)
Independent living skills training	82
Personal assistance	77
Peer support	76
Technology/adaptive equipment	74
Transportation	74
Information and referral	71
Home modification	71
Transition from school to work	71
Housing referral	69
Benefits advisement	68
ADA training	61
Employment advisement	55

Overall, respondents indicated that the services they received from CILs improved their self-perception, general independence, independent living skills, and their level of knowledge about other services and programs. Consumers also reported changes in their lives directly related to the type of services provided (i.e., housing and housing referral services resulted in housing, employment advisement resulted in employment, etc.). The following reported percentages are "percent of consumers who reported a change in their lives due to the service."

Of the respondents who received information and referral services, and who reported that this service made a change in their lives, 19 percent said it helped to improve their self-perception and adjustment to their disability. Seventeen percent also indicated this service improved their general independence. Ten percent said that the service made a change in their income and benefits and also that they learned about other services.

Forty-one percent of respondents who received benefits advisement (and who said this service made a change in their lives) reported a change in their income and benefits as a result of this service. Fourteen percent said the service improved their self-perception and adjustment to their disability, and 10 percent said they learned about other programs and services.

Of consumers who said peer support made a change in their lives, 42 percent reported this service improved their self-perception and adjustment to their disability. Twelve percent also reported a change in their level of socialization due to this service.

Of consumers who had help with transition from school to work, 21% said that it changed their general independence and 12% said it changed their ability to get around in the community. Transportation also affected the same areas of consumers' lives (15% and 42% respectively), as well as their ability to participate in the community (14%). Consumers who received ADA training said the service improved their self-perception (28%), knowledge of their legal rights (33%), and knowledge of other services and programs (17%).

Independent living skills training made a change in the independent living skills of 68 percent of the consumers who received that service. Fifty-nine percent of consumers who received housing assistance or referral reported a change in their housing situation. Twenty-seven percent of consumers who received personal assistance or referral services said that service made a change in the personal assistance they received, as well as in their general independence (24%) and their self-perception (12%). People who received home modification services reported a change in the home (34%). This service also made a change in the consumers' general independence (25%) and their independent living skills (11%). Thirty-one percent of consumers who received employment advisement services also said that service made a change in their job situation, as well as improving their self-perception (13%). Forty-seven percent of respondents who received help obtaining adaptive equipment and/or technology received assistive devices, and also reported a change in their independence (14%). Table B-4 in Appendix B shows the reported changes by service received.

Consumers were asked early in the survey, "*In which of the following areas of life did you have a problem you wanted to solve or a goal you wanted to achieve?*" and, later in the survey, they were asked if those and other areas of life had improved since their contact with the CIL. Consumers told us that CIL services had improved their lives.

For example, 56 percent of consumers came to the CIL specifically to learn about the availability of disability services. Of these consumers, 36 percent said this area of their life had "improved a great deal," and another 43 percent said this area of their life had "improved somewhat."

As another example, 55 percent of the consumers said they had originally gone to the CIL for help obtaining personal assistance services. Overall, 38 percent of the consumers said this area of their life had "improved a great deal" as a result of their contact with the CIL. Of consumers who came to the CIL to work on this area of their life, 49 percent said that in general, their lives had "improved a great deal."

Table 4-30 presents the results for all consumers and for those who specifically contacted the CIL to work on a particular life area. The table shows the following:

- The percentage of consumers who contacted the CIL to work on a life area
- The percentage of consumers reporting improvement who specifically contacted the CIL for help in that area of their lives
- The percentage of all consumers reporting improvement in their life irrespective of the reason that they came to the center.

Table 4-30. Improvement in Life Area as a Result of CIL Contact

	Response		
Life area	Came to CIL to achieve goal/solve problem (%)	Of those who came to CIL to achieve goal/solve problem, that area of life improved a great deal (%)	Those reporting improvement irrespective of reason they came to center
Knowledge of disability services	56	36	30
Personal assistance services	55	49	38
Knowledge of disability rights laws	50	35	28
Ability to get around in community	44	41	32
Self-esteem	42	45	34
Increased level or number of benefits	40	29	21
Income	37	20	14
Housing	36	33	25
Entertainment or recreational activities	36	37	24
Community Integration	36	29	20
Employment	33	24	14
Education level	32	25	15

4.6.2 Achieving the Goal/Solving the Problem

Most consumers reported the CILs helped them to achieve their independent living goals. Consumers were asked if they achieved their goal or solved the problem for which they came to the CIL for help. They could respond, “Yes,” “No,” or “Partially.” If the respondent said, “No,” they were then asked an open-ended question: “Why have you not achieved your goal or solved the problem?” We analyzed the responses, sorting them into categories that emerged from the data. The categories are as follows:

- Still working on it;
- Changed mind; and
- Other. Other was further coded into:
    - Medical issues (e.g., illness);
    - Service issues (e.g.., CIL did not provide the service they wanted);
    - Resistance from others (e.g., family did not want the person to have the service); and
    - Other.

Fifty percent of consumers said they had achieved their goal/solved the problem that prompted them to contact the CIL. Another 35 percent said they had partially done so. Almost 15 percent said they had not achieved their goal.. Of this 15 percent, 34 percent were still working on it, 7 percent had changed their mind, and 59 percent gave other reasons. These other reasons included medical issues (6%), service issues (48%), and resistance from others (1%). Another 46 percent gave disparate reasons.

There were no significant differences in consumers' responses by CIL location, CIL size, consumer race, ethnicity (Hispanic/non-Hispanic), income, gender, disability type, or age.

4.6.3 Overall Satisfaction

Most consumers rated CILs as "very helpful" or "somewhat helpful" in assisting consumers to achieve their independent living goals. Sixty-five percent of the consumers found the CIL to be very helpful. Another 25 percent said the CIL was somewhat helpful, for a total of 90 percent. Perception of how helpful the CIL was did not vary by gender, type of disability, CIL size or location, consumer race, or income. We noted only two variations: 76 percent of consumers who were under 18 rated the CILs as very helpful and 9 percent rated them somewhat helpful. Hispanic consumers rated the CIL as less helpful than did consumers in general. Only 46 percent of Hispanics rated CILs as very helpful and 27 percent rated them somewhat helpful; 20 percent of Hispanics rated the CILs as very unhelpful.

Consumers were asked, "*Overall, how satisfied were you with your experience at the center? Would you say . . . very satisfied, somewhat satisfied, neither satisfied nor dissatisfied, somewhat* *dissatisfied, or very dissatisfied?*" Overall, 64 percent were very satisfied with their experience with the CIL; 23 percent were somewhat satisfied, 6 percent were neither satisfied nor dissatisfied, 4 percent were somewhat dissatisfied, and 3 percent were very dissatisfied. Response rates were very similar, and did not vary by gender, type of disability, CIL size or location, age group, race, or income.

The RTI 1996 study asked the same question to recipients of VR services. Their study found that 47 percent of participants were very satisfied and an additional 28 percent were somewhat satisfied, for a total of 75 percent of VR consumers who were very or somewhat satisfied. This compares with 83 percent of CIL consumers.

To compare satisfaction of services between IL and vocational rehabilitation, we asked consumers about their experience with the state vocational rehabilitation (VR) agency. About 42 percent of consumers said they had received services from the state VR agency and 58 percent had not received services. Of those who had received services, 54 percent said they were very satisfied, 25 percent said they were somewhat satisfied, 3 percent said they felt neutral about their experience, 8 percent said they were somewhat dissatisfied, and 11 percent said they were very dissatisfied. These figures are roughly comparable with the RTI 1996 study, which found that 47 percent of participants were very satisfied and an additional 28 percent were somewhat satisfied.

CILs also helped to improve the quality of consumers' lives. Forty-seven percent of the consumers we surveyed said their lives were "much better" and 29 percent said their lives were "somewhat better" since their contact with the CIL, for a total of 76 percent reporting some life improvement. There were not any differences in responses based on gender, disability type, CIL size and location, age group, race, ethnicity, and income. Table B-5 in Appendix B shows the percentages of consumer perceptions of life quality by gender, disability type, CIL size and location, age group, race, ethnicity, and income.

Forty-three percent of consumers reported that their experience with the CIL had helped them to develop a positive view of themselves. Forty-seven percent also reported they "already had a positive view" of themselves before they came to the CIL.

Consumers were also asked if they would refer a friend who had a similar problem to the CIL. Ninety-six percent of consumers said they would refer a friend to the CIL. Of this 96 percent, 47 percent had already done so.

4.7 Summary

CILs are providing services consumers need. Overall, consumers in the survey are very satisfied with those services. However, since respondents to the survey may not have reflected CIL consumers in general, the survey results should be interpreted with caution. Except in rare cases, types of services received, and satisfaction with those services, did not vary by CIL size or location, or consumers' residence, race, ethnicity, income, or type of disability. Significant differences in services received and satisfaction level are summarized below. We recommend that these results be interpreted judiciously. When provision of and satisfaction with eleven services are compared on a high number of CIL and consumer demographics, some differences are bound to occur. To interpret these data, the reader should look for patterns of service delivery and satisfaction levels.

Age

We noted a number of different service patterns based upon the consumer's age. Individuals between the ages of 18 and 64 received some services more often than younger or older consumers, specifically, information and referral, independent living skills training, employment and benefits advisement, ADA training, peer support, and technology. This discrepancy is likely due to the greater number of individuals in the 18 to 64 year age group who are in need of independent living services because they are establishing their own independent households, identifying careers, and learning to live independently.

Income

Consumers whose income was $10,000 or less received independent living skills training and housing more frequently than did consumers with higher incomes. In addition, a greater proportion were highly satisfied with peer support services than were consumers with higher incomes. The greater use of housing services by the low income group probably relates to the need for subsidized housing. The other differences are interesting, but we can identify no discernable pattern to them.

Center size and location

Rural and small CILs had greater proportions of consumers who were very satisfied with the independent living skills training they received than did other centers. Small CILs had greater proportions of consumers who were highly satisfied with the benefits advisement they received than did large CILs. Consumers from urban and suburban centers received housing and employment services more often than consumers from rural centers. The higher satisfaction levels for IL skills training and benefits advisement may be because rural and smaller centers provide these services on an individual, rather than a group basis.

Race

Greater proportions of Whites and Hispanics were highly satisfied with the ADA training they received than were Non-Whites and Non-Hispanics. Hispanic consumers received technology and equipment services less often than Non-Hispanics, whereas Non-Whites received transportation services more often than Whites. Centers may wish to review their consumer records to insure that they are offering technology and equipment to Hispanic consumers as frequently as to others.

Disability

Consumers with mental disabilities received employment services less often than consumers with physical and sensory disabilities. Greater proportions of consumers with mental disabilities were highly satisfied with the housing referral services they received than consumers in other disability categories. Centers should examine their consumer files to ascertain whether employment is offered to consumers with mental disabilities as often as to consumers with physical and sensory disabilities. See Tables B-6 and B-7 in Appendix B for a summary of the services consumers received and satisfaction with those services.

Consumers' lives are positively affected by the CILs. Consumers credit CILs with helping them achieve their independent living goals and making positive changes in their lives and self-perception. Consumers were pleased enough with the services they received to state they would refer a friend to the CIL (and almost half had already done so).

CHAPTER 5
DISCUSSION AND CONCLUSIONS

5.1 Introduction

This chapter answers the study research questions and provides discussion and recommendations for the CIL Program. We base our discussion and recommendations on the background information presented in Chapter 1, on, on the CIL directors' responses to the mail survey presented in Chapter 3, on the responses of 569 consumers to the telephone survey presented in Chapter 4, and on the CIL 704 Reports and other national data. In this chapter, we combine the responses of consumers and directors to provide a holistic picture of center activities. We begin with the overall findings and follow with a discussion of the access, process, and outcome questions raised in Chapter 2.

5.2 Overall Findings

The study found that CILs are providing a wide variety of beneficial services and systems advocacy in their communities. Consumers report a high level of satisfaction with the services they receive and report significant life changes as a result of CIL services. Consumers gained knowledge and skill from center services, and credited the center with significant life changes, including positive changes in housing, employment, getting around in the community, and overall improvements in independence. Moreover, CILs are providing these services and advocacy in accordance with the independent living philosophy, which includes consumer empowerment and control, peer support, systems change, and cross-disability services.

Additionally, centers made significant changes in their communities. Centers enabled consumers to access community facilities and services in a wide variety of areas, including personal assistance, transportation, housing, employment, and deinstitutionalization. Centers insure that systems are in place and funds are available to support community living. They are working with state and local Medicaid agencies to implement the Olmstead Supreme Court decision, which requires that individuals who are institutionalized have equal access to community services. They are working with state and local housing authorities to provide accessible, affordable housing to their consumers, and advocating with transit authorities to make sure low-income consumers can afford to use transportation services. CILs are increasing the availability of personal assistants by advocating with departments of human services to insure that personal assistants are paid a fair, living wage. The 704 Reports reveal that, during fiscal year 2000, CILs helped 1,380 consumers leave nursing homes or other institutions to live in the community. In other words, almost 1,400 people live in the community rather than in institutions because of Centers for Independent Living. During fiscal year 2000, centers served about 136,000 individuals, at a cost to the federal budget of $48 million—a federal cost of about $353 per individual served.

Chapter 2 of this report sets forth the research design and methodology for the Evaluation of the Centers For Independent Living Program. The chapter presents a set of research issues and study questions that provide the framework for this study. The study research questions are divided into two domains: CIL Operations and CIL Services. We consider access, process, and outcome measures under each domain. We include a feedback section under CIL Operations and a satisfaction section under CIL Services. The following sections respond to the research questions we initially proposed in order to assess the access, process, outcome, satisfaction, and feedback measures.

5.3 Access Measures

The Access Measures questions examined the efforts centers are making to reach out to underserved constituencies, including multicultural communities and consumers from disability groups that have been traditionally underserved by centers. These questions also assessed director and consumer perceptions of center accessibility, including access to the main office, availability of interpreters, availability of materials in alternative formats, and ease of using center services.

5.3.1 Outreach to Underserved Constituencies

During the last several years, CILs have made concerted efforts to serve multicultural communities. National data compared with data from the 704 Reports indicates that these efforts are paying off. Centers are serving minorities with disabilities in at least the same percentages that minorities are present among people with disabilities in the United States. For example, 17 percent of center consumers are Black/Non-Hispanic; Black/Non-Hispanic people represent 16 percent of the U.S. disability population. Ten percent of center consumers are Hispanic; Hispanics comprise 9 percent of the disability population. Consumers from minority backgrounds who participated in the survey reported that the centers provided services in a culturally appropriate manner.

Despite these statistics, center directors felt they could be doing a better job in serving multicultural communities. Thirty percent of center directors felt they were not adequately serving the African American community, 42 percent felt they were not adequately serving the Hispanic community, 62 percent felt they were not adequately serving Asians and Pacific Islanders, and 39 percent felt they were not adequately serving Native Americans. Directors reported that the most successful strategy was hiring staff from the community the center was trying to reach, but explained that lack of funding and staff, weak communication and outreach, and cultural issues related to seeking services were primary barriers to serving multicultural communities. We conclude that centers are doing an adequate job of serving these communities; however, center directors would like to be doing more in this area.

We found a similar pattern for consumers with disabilities that have been traditionally underserved by centers. Those who received services reported that the centers were doing a fairly good job in addressing their disability-related needs. However, only about 60 percent of directors felt they were adequately serving deaf and hard of hearing, blind and low vision, and psychiatric constituency groups. A higher percentage (76%) reported that they were adequately serving people with cognitive disabilities, but only 44 percent reported that they were adequately serving people who have multiple chemical sensitivity. Again, directors felt that hiring staff from the group the center was trying to reach was the most successful strategy, but no more than 26 percent of center directors rated any particular strategy for serving these groups as "very successful." Centers could be doing more to serve these communities, particularly consumers with psychiatric disabilities and multiple chemical sensitivity.

5.3.2 Center Accessibility

Centers received high marks on most measures related to access. Between 80 and 90 percent of consumers said they could get into and around their centers and could easily reach center staff by telephone. Consumers who drove to the center felt that adequate accessible parking was provided. About 85 percent said the center was accessible by public transportation, a finding corroborated by 93 percent of executive directors. Only 6 percent of consumers felt that center paperwork was a burden.

While center directors said they provided information in alternative formats, such as Braille or audiotape, and used sign language interpreters, 35 percent of consumers who needed alternative formats said that they did not receive them from the center. Of those who need a sign language interpreter or cart reporter to communicate, only 43 percent said that their center always provided one.

Communication access is equally as important to consumers with sensory disabilities as physical access is to people with physical disabilities. Centers should ensure that these accommodations are provided to all consumers who need them.

5.4 Process Measures

Process measures document how staff delivers services to consumers and how they provide advocacy to their community. These activities consist of the steps that center staff take to identify consumers and deliver specific independent living services to them, the activities staff undertake to build linkages with other community agencies on behalf of persons with disabilities, and the specific ways in which centers promote systemic change through advocacy.

The process portion of the evaluation examined whether directors were able to articulate the independent living philosophy and whether this philosophy carried through to the center's interactions with consumers. Because a significant element of the independent living philosophy is consumer choice in the services they receive and in control over their lives, we asked consumers if they had received information about the many options and services available to them and if CIL staff were teaching and encouraging empowerment. The independent living philosophy also promotes peer support and systems advocacy, so we asked consumers if they were told about peer support groups and if they were given information about pertinent laws, due process, and regulations.

The process component of the evaluation also compared the demographics of center consumers with the demographics of the U.S. population of people with disabilities. We studied the services center consumers received and whether these services differed by age, gender, race, center location, consumer residence (rural, suburban, or urban), and type of disability. Relationships with staff are an important process element of service provision, so we asked consumers if they perceived staff to be respectful of them and their specific disability or culture and if they were presented information about the range of options available to meet their independent living goals.

This section also included questions about the process by which advocacy was conducted. We asked in what areas of advocacy the center had engaged during the last year, whether the advocacy was conducted at the federal, state, or local level, what activities were conducted in each area of advocacy, and who was involved in the center's advocacy efforts.

Relationships with other entities that receive funding under the Rehabilitation Act are crucial to the center's success. Consumers benefit from strong working relationships between the state vocational rehabilitation (VR) and blind rehabilitation agencies; 42 percent of CIL consumers we surveyed reported receiving service or equipment through a state VR agency. The state VR agency and the Statewide Independent Living Council (SILC) have joint responsibility for development of the State Plan for IL centers and services. A positive relationship between the CIL, the VR agency and the SILC is vital to the planning process. We questioned center directors extensively on the extent and quality of these relationships.

5.4.1 Independent Living Philosophy

Most center directors were familiar with the tenets of the philosophy on which CILs are based: consumer control, peer support, community change, serving a cross-disability population, integration, and consumer empowerment. When asked to list the components of the independent living philosophy, 87 percent of directors identified "consumer control." Center directors frequently identified integration, inclusion, and participation in the community, removal of barriers, and other tenets of the independent living philosophy. We asked consumers a number of questions to assess whether the independent living philosophy was integral to the services CIL consumers received. Almost half of center consumers said they had been told about the independent living philosophy, 57 percent said they had been told about peer support groups, and 62 percent said that center staff encouraged consumers to advocate for themselves. About 41 percent said the center had provided them with training or information about federal, state, or local advocacy issues. These responses show that high percentages of directors and consumers understand the independent living philosophy and that this philosophy is being implemented within the CILs. This philosophy is a strong component of center programs.

5.4.2 Consumers Served and Services Provided

CILs serve consumers who tend to be poor, unemployed, and unmarried. Among CIL consumers between the ages of 25 and 64, 84 percent had total household incomes below $20,000 per year; the Survey of Income and Program Participation (SIPP) reports that 42 percent of households with a disabled member had a household income below this level. For CIL consumers who are age 65 and over, 83 percent had household incomes below $20,000 per year, compared to 53 percent for the total household population with a severely disabled member. Nine percent of CIL consumers reported being without telephone service at some time within the last 12 months. Seventy-seven percent of the consumers who were 18 years of age or older were unemployed. Of the 23 percent who did work, almost two-thirds worked only part time. Of consumers 18 years and older, over 80 percent were not married. All of these factors—low income, unemployment (or under employment) and single status—are risk factors for loss of independence. CILs are serving consumers who are highly vulnerable and have few options for purchasing services to promote their independence.

CIL consumers we spoke with said they had a significant level of impairment and a high level of unmet need. For example, 29 percent of CIL consumers reported having difficulty entering or leaving their home and 27 percent reported difficulty opening or closing doors. Forty-one percent said they had difficulty reaching or opening cabinets and 26 percent had difficulty using the bathroom. These difficulties create a need for home modifications that are not being met; among CIL consumers who required home accessibility features, unmet needs ranged from a low of 17 percent for accessible parking to a high of 54 percent for kitchen modifications. In terms of the instrumental activities of daily living (IADLs), including shopping, money management, house cleaning and other home management activities, consumers needed assistance doing heavy housework (32%), shopping for personal items (52%), and getting outside the home (53%). Unfortunately, over one-quarter (28%) of consumers we surveyed said that they did not use paratransit service because they needed the help of another person. Nearly one-fifth (19%) of consumers said they worried a lot about not knowing who to turn to for help, while 44 percent reported worrying some of the time. In other words, many consumers feel they need assistance that is unavailable to them for major IL activities.

Over 98 percent of centers are providing the four core services required by title VII, chapter 1, Part C of the Rehabilitation Act: information and referral (100%), independent living skills training (99%), peer support (98%), and individual and systems advocacy (99% and 98% respectively). Centers provide an array of additional independent living services; over 98 percent also provide housing referral and assistance, and over 90 percent provide ADA training, group support, personal assistance service or referral, assistance acquiring technology or adaptive equipment, technical assistance on access, and advocacy training. Over 85 percent said they provided benefits advisement and assistance with home modifications.

5.4.3 Consumer Control in Goal Setting and Decision Making

Consumer control is an important philosophical component of CIL programs. Consumer control means the extent to which consumers decide about the services they receive, the goals they set, and overall, the path their lives take. Consumers must be presented with a full array of options for services and goals for choice to be a reality. Seventy-seven percent said the staff person they saw most often "always" listened to their ideas and suggestions and seventy-one percent of the consumers said the center gave them information about different options that would help them reach their independent living goals. We noted that only thirty-four percent of the consumers stated that they decided on the services they would receive in order to reach their goals; another 22 percent reported they decided on the services in consultation with a staff member at the CIL, for a total of 56 percent. Over one-fourth of consumers (27 percent) said the IL staff person decided on the IL services; the rest said that someone else decided or helped them decide. This finding is surprising, given the emphasis on consumer control in the independent living philosophy as well as the relatively high number of consumers who said the center gave them information about different options that would help them to reach their goals. This issue may warrant further exploration.

5.4.4 Variations in Services

Consumers receive an array of services from their centers to support their independent living goals. It was not uncommon for a consumer to receive information and referral, peer support, housing referral, personal assistance, and other services from the center.

We were not able to ask consumers directly if they received individual advocacy, because most did not comprehend the meaning of the term, "individual advocacy" when used in this way. However, from their responses to numerous other questions, it was clear that they were receiving individual advocacy services. For instance, center consumers often needed assistance receiving services from agencies other than a CIL; 24 percent had experienced problems receiving these services because of a disability. Of the consumers who said they had experienced problems, 15 percent said that the problem had been solved, an additional 28 percent said that the problem had been partially solved, and the remaining 57 percent said that the problem remained unsolved. Of those who said the problem had been fully or partially solved, about 63 percent said that the center had helped them solve the problem; 37 percent said that it had not. When asked what occurred in solving the problem, 36 percent said "The center staff solved the problem for me," 22 percent said, "Center staff told me how to solve the problem myself," 27 percent said, "The staff worked with me to solve the problem," and 16 percent said, "Center staff put me in touch with other people with disabilities and we solved it together." These responses show that almost 25 percent of consumers are having problems receiving services from other agencies and are receiving individual advocacy services from the center to help them solve problems. They also show that the center is teaching problem solving and empowerment skills to many of its consumers.

The types of services a center offered did not differ significantly between centers located in urban, rural, or suburban communities. Except in a few cases, types of services received did not vary by CIL size or location, or by consumer demographics, such as age, race, ethnicity, income, or type of disability. Some of the differences in the types of services we did find can be readily explained. For example, consumers between ages 18 and 64 received information and referral, independent living skills training, ADA training, technology assistance, employment assistance, and benefits advisement more frequently than those who were under age 18 or over age 64. Presumably, consumers under age 18 would request these services less frequently because they are still in school and living with parents. They may not be as aware of access barriers addressed by the ADA as consumers who have already begun to work and live independently. They probably receive some of their technology through the school system. Consumers over age 64 are probably not interested in employment and have learned independent living skills already. They would likely receive Social Security retirement benefits, or have learned about the benefits system through their life experience.

Centers may wish to consider providing more independent living skills training, employment services, ADA training, and benefits advisement to transition age youth while they are still in school so that they may move to independence and employment more easily at the appropriate time. Benefits advisement and employment are vital if transition age consumers are to leave the benefit rolls for work. These consumers should be educated about the ADA while they are still in school, so they can take full advantage of its protections. One option is to establish a comprehensive summer program for this population.

We noted that rural consumers received housing referral and assistance less frequently than their urban and suburban counterparts. Rural centers were also less likely to provide employment advisement.

We noted that consumers with annual incomes of $10,000 or less received independent living skills training more frequently than those with higher incomes. They also received more housing referral and less assistance acquiring technology. Their need for housing assistance relates to their low-income status, with the commensurate need for housing subsidy. The other differences are not as readily explained; perhaps these consumers acquired their disability as children and did not learn the skills necessary to live independently. Perhaps they are receiving Medicaid due to their income level and receive their technology through this agency.

We found that Hispanics were less likely to receive assistance with technology or equipment than other consumers. We also found that consumers with mental disabilities received employment advisement services less often than people with physical or sensory disabilities. Centers may wish to review their consumer records to insure that employment and technology services are readily available to all consumers.

5.4.5 Advocacy

A striking finding of the Executive Directors Survey was the number and complexity of advocacy issues in which centers were involved and the variety of techniques used to achieve advocacy goals. Over 70 percent of the directors reported involvement over the past year in each of the nine issues listed on the survey: transportation, deinstitutionalization, enforcement of civil rights laws, housing, personal assistance services, youth transition, education, employment, and health care. Transportation and deinstitutionalization had the highest percentage of involvement. Rural centers mentioned involvement in the enforcement of federal, state, and local civil rights laws at even higher levels than involvement in transportation. The Executive Directors and narrative portions of the 704 Reports reveal that centers are involved in a wide range of advocacy issues; they involve a wide variety of constituencies, including consumers, board and staff members, and representatives of other agencies; and they engage in an array of strategies to achieve their goals. Years of effort are sometimes necessary to pass one piece of legislation, achieve one policy change, or acquire a new service; centers within a state often work together to achieve these goals. The vast majority of the center’s activities are collegial, such as, working on committees and meeting with administrators--rather than adversarial, such as, engaging in demonstrations or taking legal action.

Another important finding was the level of consumer involvement in systems advocacy and community change activities. Although staff had the highest percentage of involvement, over 80 percent of directors reported consumer participation in almost all of the advocacy issues in which their center was involved. This finding supports the above assertion that centers are implementing an important tenet of the independent living philosophy—empowering consumers to change their communities. It is interesting to note that about 50 percent of directors identified lack of consumer involvement as a barrier to change in their communities. Although the level of consumer involvement is high, directors feel that the advocacy agenda could be advanced more quickly with more consumer support. Training materials or technical assistance on how to heighten consumer involvement in systems change activities may be warranted. Center directors appear to corroborate this conclusion. When asked to describe the three most pressing training needs of the center, directors most often mentioned training in advocacy, volunteer organizing, or systems advocacy techniques.

Lack of resources was the most significant barrier in achieving community change. Directors expressed the need for additional resources in terms of inability to hire sufficient staff or the lack of time to work on advocacy issues. Directors felt they needed more financial resources in order to facilitate change in their community, given the number and complexity of advocacy issues in which CILs are involved.

5.4.6 Relationships with Other Agencies

When we asked center directors about the center's relationships with other agencies, including the Designated State Unit (DSU--generally the state VR agency), the agency for the blind, and the Statewide Independent Living Council (SILC), about one third said that the DSU was very supportive, about 19 percent said the agency for the blind was very supportive, and about 38 percent felt that the SILC was very supportive. Although very low percentages of directors felt that these relationships were adversarial, they recommended cross-training of agency staff, increases in referrals between the state VR agency, the state blind agency, and the CIL, and clarification of the roles of CILs and the SILC. Some of the Regional Rehabilitation Continuing Education Programs (RRCEPs) provide cross-training for the staff of these respective agencies. We do not know, however, whether staff who attended this training found it useful, or the extent to which this training improved services to consumers.

5.5 Consumer Satisfaction

This study raises some interesting issues about service satisfaction; for example, what is considered a high level of satisfaction with services? At what point do centers and policy makers conclude that centers are providing services that satisfy their consumers? One option is to compare satisfaction levels with those reported in other, similar surveys, such as the RTI 1996 study of vocational rehabilitation consumers. These comparisons are provided below.

We asked center consumers how satisfied they were with center services overall and then asked how satisfied they were with each particular service. When asked about services overall, 64 percent said they were "very satisfied" and 23 percent said they were "somewhat satisfied." Sixty-five percent rated the CIL as "very helpful" and 25 percent as "somewhat helpful" in assisting them to achieve their goals. Overall satisfaction levels did not vary by gender, age, race, disability, center location, or consumer location, with only two exceptions: Transition age youth (or their parents) rated the CIL as "very helpful," at a higher rate (76%) than did the general population of CIL consumers. And Hispanics rated CILs as "very helpful," at lower rates (46%) and rated them "very unhelpful," at higher rates (20%) than did the general population of CIL consumers.

The RTI 1996 study asked the same question to recipients of VR services. Their study found that 47 percent of participants were very satisfied and an additional 28 percent were somewhat satisfied, for a total of 75 percent of VR consumers who were very or somewhat satisfied. This compares with 83 percent of CIL consumers.

We then asked consumers how satisfied they were with each specific service they had received. Consumers were most satisfied with the transportation services they received (87 percent said they were very satisfied with this service), but it should be noted that only 20 percent of consumers received transportation assistance from the center. Over 70 percent of consumers were very satisfied with home modifications, personal assistance services, transition from school to work services, technology assistance, and ADA training. Satisfaction levels with other services clustered around the overall satisfaction level of 65 percent. Consumers were somewhat or very dissatisfied with both employment referral or assistance (17 percent) and housing referral or assistance (11 percent).

We noted only a few differences in satisfaction levels and there seemed to be no particular pattern to these differences. (See Chapter 4, Section 4.5). These differences should be interpreted judiciously. When comparing 12 types of services on a high number of socio-economic and center variables, it is expected that a small percentage of statistically significant differences will be found by chance alone. A review of the statistically significant differences identified in Chapter 4 reveals no specific pattern. For example, consumers with a certain disability or served by a certain size center were not likely to be more or less satisfied with a number of services. We therefore conclude that satisfaction levels across services are relatively uniform.

5.6 Outcomes

Outcomes are the most difficult, but often the most critical aspects of a program to measure. Outcome measures for CIL operations include the community changes that have occurred because of the center activities and the resources, other than federal funding, centers have captured. In terms of consumer outcomes, we asked consumers whether they have gained skills or knowledge as a result of center services and whether they had achieved the goal or solved the problem they had originally approached the center to solve. We also asked consumers about the life changes they have made as a result of their contact with the center. We looked for correlations between service satisfaction and gains in skill and knowledge. We also explored whether any services were more effective than others in helping consumers make life changes.

5.6.1 Community Change

Centers are achieving legislative and policy changes, removing physical and communication barriers, and creating additional services. They are also bringing about the monitoring of civil rights laws in areas as diverse as transportation, housing, deinstitutionalization, education, employment, and civil rights. We found important differences in the ways in which centers report community outcomes data in the 704 Reports, which makes it difficult to quantify community outcomes or draw additional conclusions about center achievements. A review of this data also makes clear that centers interpreted the term “community outcomes” in a number of ways. Some centers provided several pages of narrative outlining the steps they had taken to produce community change, but then never made it clear whether the change was achieved. Others reported the outcome, but did not describe the process that led to its attainment. This makes it difficult to draw meaningful conclusions about community change activities.

5.6.2 Acquisition of Financial Resources

We found that centers have been extremely successful in raising funds beyond those provided under title VII, chapter 1, Part C of the Rehabilitation Act. For example, over 80 percent of centers received individual donations and funds from state government and 60 percent received local governmental funding. Over 70 percent received foundation or corporate funds, title VII, chapter 1, Part B funds, and fee-for-service funding. We asked centers if they had experienced problems, such as excessive paperwork, service delivery issues, impediments to advocacy, or other difficulties related to receipt of funding from any of these sources. Over one-fifth (21%) of directors receiving state and local funds for their centers said they experienced problems. The same percentage said their center had experienced problems with a variety of funding sources from which they no longer received funding. Problems most often cited were administrative issues. These included paperwork burdens, reimbursement problems, extensive reporting requirements for relatively low levels of funding, and conflicts with the funding source regarding independent living philosophy.

5.6.3 Consumer Outcomes

Consumers said they benefited significantly from the services they received from the CIL. For example, over 90 percent of consumers who received independent living skills training and transition services said they gained knowledge or skills; over 80 percent gained knowledge or skills from ADA training, benefits advisement, information and referral, and peer support; over 70 percent gained knowledge or skills from technology assistance, housing referral or assistance, home modifications, and transportation; and over 65 percent gained knowledge or skills from personal assistance or employment services. According to consumers, the constellation of services centers provided, rather than any one particular service, was essential to their independent living goal.

The majority of consumers also reported concrete changes in their lives as a result of these services. Independent living skills training and personal assistance services produced the most change; 82 percent of consumers who received independent living skills training and 77 percent of people who received personal assistance services said the service had made a positive change in their life. About one quarter of consumers who received peer counseling, technology assistance, and transportation services said the service had made a positive change in their life. Not surprisingly, consumers who received a particular service reported change in that area of life. For example, consumers who received housing assistance often reported a change in housing, and those who received employment assistance often reported that they were working. Other examples include the following:

- Of the 76 percent of consumers who said peer support made a change in their lives, 42 percent reported this service improved their self-perception and adjustment to their disability and 12 percent said this service had changed their level of socialization.

- Of the 69 percent of consumers who said housing referral and assistance had made a change in their lives, 59 percent reported a change in their housing situation.

- Of the 82 percent of consumers who said independent living skills training had made a change in their lives, 68 percent said it had improved their independent living skills.

- Of the 55 percent of consumers who said employment services had made a change in their lives, 31 percent said the service had made a change in their job situation and 13 percent said it improved their self-perception.

Additionally, consumers indicated that services received from CILs improved their self-perception, general independence, independent living skills, and level of knowledge about other services and programs.

CILs also helped to improve the quality of consumers' lives. Almost half said their lives were "much better," and over one-fourth said their lives were "somewhat better" since their contact with the CIL. Forty-three percent of consumers reported that their experience with the CIL had helped them to develop a positive view of themselves. Another 47 percent said they "already had a positive view" of themselves before they came to the CIL.

Consumers who went to the center to solve a particular problem generally reported that the problem had been fully or partially solved. Fifty percent of consumers who came to the center with a particular problem said that the problem had been solved and an additional 35 percent said the problem had been partially solved. Consumers reported that other areas of their lives had also improved. Evidence from the consumer interviews shows that, once consumers make contact with the CIL, they use an array of services to reach their goals and change their lives.

5.7 Feedback

Finally, we asked center directors some questions related to the feedback mechanisms they employ to obtain reactions to their center and its services from consumers, board members, RSA and the DSU. We asked center directors how they assess community needs and establish their service and advocacy agenda. We asked them about good sources for identifying board members and about the relationships between their center's board and staff members. We also asked them to provide feedback on their perception of how well the SILC was fulfilling its legislatively mandated responsibilities. In addition, we asked them to comment upon the evaluation and monitoring efforts of RSA and the DSU, including the site visits conducted by these entities and the 704 Reports.

5.7.1 Assessing Community Needs

Centers are community-based organizations; one of their primary missions is to respond to the disability issues raised in their communities. We found that centers are using a variety of methods to assess community needs. Directors said that contact with disability consumer groups was the most helpful way to assess community needs, with 85 percent rating it somewhat or very useful. The next most useful strategy reported was a consumer needs survey, with about 68 percent rating it somewhat or very useful. About two thirds of directors found contacts with community agencies as well as board and staff assessments of community needs as very or somewhat helpful.

5.7.2 Board of Directors

A positive relationship between a center's board of directors and staff is essential to a successful center. Fifty-nine percent of directors characterized the relationship with their board of directors as very positive and supportive; only 3 percent felt it was adversarial. Most center directors (51%) said they conduct board training using existing board and staff members as trainers, about 31 percent said they bring in an outside expert, and the rest said they conducted some other type of board training or did not conduct board training at all. Only about 26 percent of directors said that the training they conducted was very effective. Additional training materials or resources to bring in outside experts may be beneficial, especially to the 40 percent of centers who characterized the relationship with their board as less than very positive or supportive.

5.7.3 Statewide Independent Living Council (SILC)

The SILC is empowered by title VII, chapter 1 to develop the State Plan for Independent Living, which determines how independent living funds are spent and what IL priorities are established in the state. The SILC represents a variety of constituencies, including CIL directors, and conducts needs assessments for independent living services. Because the SILCs have these powers, we wanted to obtain the executive directors' views on how their SILC meets these mandates. We also asked the directors to characterize their center's relationship with their SILC.

While almost 90 percent of directors felt they had some representation on the SILC, they had mixed reactions when asked whether the SILC was meeting the requirements spelled out in Section 705 of the Rehabilitation Act. It is clear that many center directors felt that their SILC is falling short in several areas of representation and responsibility. Only about half of directors agreed that the SILC provided statewide representation, that the SILC represented a broad range of individuals with disabilities, and that a majority of members are individuals with disabilities who do not work for a state agency or CIL. Only 26 percent felt that SILC members were knowledgeable about CILs and independent living services to a great extent. Less than 50 percent of center directors felt the SILC was doing an excellent or very good job of performing the duties outlined in Section 705. Center directors suggested that RSA should clarify the roles of the CIL, the SILC, and the DSU, specifically noting the advocacy role of CILs. They also suggested that RSA provide training on the roles and responsibilities of each entity. It is important to note that the study did not include a survey of the SILCs or of entities besides center directors that are represented on the SILC. A more in-depth study is needed to evaluate how well the SILCs are meeting their legislative mandates.

5.7.4 Evaluation and Monitoring

We asked centers about the utility and the burden of evaluation and monitoring conducted by the DSU and RSA, including the Section 704 reporting requirements. Only about a quarter of the directors surveyed (22%) said that the Section 704 Report was very helpful in assessing the quality of center services and advocacy, although another 44 percent said it was somewhat helpful. They had a number of suggestions for RSA: that RSA provide information about future changes prior to the collection of data, that it provide better definitions of terms, and that it measure outcomes rather than numbers of people served. Once these changes have been implemented, they felt that RSA should provide or fund additional training on Section 704 reporting requirements. Directors also suggested that they should have input into the Section 704 Report questions and that the report should be simplified.

We noted other problems with the 704 Reporting process during the course of the evaluation. First, the report is focused upon process rather than upon outcomes measures. For example, the report asks centers to provide numbers of consumers served and their characteristics, the number and types of services provided to these consumers, and the number of goals set in each goal area, such as, housing, transportation, employment, etc. Centers are asked to report the number of goals consumers achieve in each area, but there is no clear guidance on how a goal is defined or what constitutes a goal. It is therefore difficult to attach meaning to the number of goal achievements centers report. The exception is "deinstitutionalization," where centers report the number of individuals they have assisted in moving from an institution into the community as well as the number of consumers that have remained in the community because of services they received from the center. The number of consumers who leave a nursing home or remain in the community can be readily identified. Centers can readily track consumers who have left nursing homes for independence and can monitor those who remain in the community with the provision of personal assistance services and other community supports. This is an extremely valuable measure of a center's accomplishments. We note problems with the "Community Outcomes" section of the 704 Report in Section 5.4.4 above. It is extremely difficult to measure a center's performance or gauge its effectiveness in creating community change from these reports.

On the whole, center directors felt positively about the site reviews conducted by RSA and the DSU. About 73 percent of directors said that the RSA review was very or somewhat helpful; 69 percent said the DSU review was either very or somewhat helpful. They found the reviews helpful to the center's operation and especially appreciated the involvement of peer reviewers in the process. One person suggested that a "best practices" monograph be distributed to assist CILs in complying with RSA requirements; this would be particularly helpful to new CILs.

5.8 Recommendations

5.8.1 Training and Technical Assistance

Directors reported a need in their centers for training and technical assistance in several areas. The study also identified some areas where additional technical assistance might enhance center operations or improve center services. These areas include:

- Board roles and responsibilities, to improve the relationships between each center and its board of directors: Although very few center directors described the relationship with their board of directors as somewhat or very adversarial, 40 percent of centers characterized the relationship as less than very positive or supportive and only about one-quarter felt that the board training they provided was very effective.

- Consumer participation: Although we found the level of consumer involvement in systems change activities to be high, center directors felt community change could be achieved more quickly with more consumer participation. They mentioned volunteer organizing and systems advocacy techniques as their top training need.

- Accessible computer applications, such as web design and data base management.

- Outreach and services to consumers from diverse multicultural communities: Although centers are serving people with disabilities from minority groups at or above their percentage in the population, center directors felt they could be doing more to reach ethnic minorities. We also noted lower levels of satisfaction with center services among Hispanic consumers.

- Outreach and services to consumers from underserved disability constituencies, particularly those with sensory and psychiatric disabilities and multiple chemical sensitivity. Again, consumers from these disability groups report that centers are doing a good job of serving them, but center directors would like to be doing more.

- Cross training of staff at the state VR agency, the state blind agency, and the CIL.

The Department of Education funds a variety of training and technical assistance programs, including a Research and Training Center on IL Management, a Research and Training Center on Rural Rehabilitation and IL, the Regional Rehabilitation Continuing Education Programs (RRCEP), and IL Net. Some of the training offered by these organizations addresses the above issues, but centers are still expressing needs or experiencing deficits in these areas.

Recommendation 1: RSA should insure that its funding priorities and the applications it funds to provide training and technical assistance to CILs address the training and technical assistance needs highlighted in this study. We recommend that organizations that provide training emphasize hands-on technical assistance activities, which enable an "expert" to work closely with a center. One option might be to link centers that have been successful with multicultural outreach or providing services to a particular disability constituency to those who are still struggling with these issues. The RRCEPs would be an appropriate vehicle for the cross training of VR, CIL and the state blind agency staff.

5.8.2 Statewide Council on Independent Living (SILC)

Center directors had mixed reactions when asked whether the SILC was meeting the requirements spelled out in Section 705 of the Rehabilitation Act. It is clear that many center directors felt that their SILC is falling short in several areas of representation and responsibility. This study did not include a survey of the SILCs or of entities besides centers that are represented on the SILC. However, the executive directors surveyed in this study raised concerns that warrant additional exploration.

Recommendation 2: RSA should conduct a more in-depth study to evaluate how well the SILCs are meeting their legislative mandates. The study should examine the extent to which the SILCs represent the various constituencies specified in the Rehabilitation Act, including: whether it provides statewide representation; whether it is comprised of individuals who represent a broad range of individuals with disabilities; whether it is comprised of a majority of individuals with disabilities who do not represent a state agency or CIL; and whether it is comprised of individuals who are knowledgeable about independent living centers and services. The study should also examine the extent to which the State Independent Living Plans (SPILs) address the needs of unserved and underserved populations. In addition, it should assess community needs and the extent to which SILCs obtain consumer input, develop, monitor, and evaluate the SPIL. This study

should also assess the extent to which the SILCs work with the DSU in order to measure consumer satisfaction and to develop a network of centers across the state.

5.8.3 Evaluation and Monitoring

We noted significant problems with the 704 Reporting process during the course of the evaluation. We discovered problems through our own review of the data and also in the responses to the Executive Directors Survey. First, only 22 percent of directors felt the report was "very helpful" in assessing the center's services and advocacy. Almost half said it took over 14 working days to complete. Additionally, we found the report to be focused upon process rather than outcome measures. Centers are asked to report the number of goals consumers achieve in each area, but there is no clear guidance on how a goal is defined or what constitutes a goal. There are also problems with consistency in the "Community Outcomes" portion of the 704 Report, which makes it extremely difficult to measure a center's performance or gauge its effectiveness in creating community change.

Recommendation 3: We recommend that RSA modify the 704 Report to respond to the concerns identified in this report. Some modifications may require changes in the regulations governing the report 34 CFR 366.50(i). RSA should obtain significant input from Centers for Independent Living, CIL consumers, and the organizations that represent them. We provide the following suggestions:

1. The 704 Report should gather information on access measures, process measures, outcome measures, and satisfaction with services. Access measures should include the extent to which the center provides the following: (1), outreach to multicultural communities and underserved disability groups, (2), physical access to the centers, and (3), communication access, including sign language interpreters and alternatives to print formats. Process measures should include number and types of consumers served, types of services provided, and consumer control in goal setting and decision-making. Satisfaction measures should include consumers' overall satisfaction with center services and with the center's overall helpfulness in reaching desired goals. Outcome measures should include increasing funds from alternative sources, community outcomes, and positive life changes by consumers.

2. The consumer survey used in the 704 Report should be significantly abbreviated into a two- to three-page survey. This should be provided to centers, in addition to training materials on survey administration, for centers that wish to collect the above data. Those who wish to collect data using this instrument should do so no more than once every three years. Other alternatives to collect this data, such as the center's own survey or a review of consumer records, should also be considered.

3. Community outcomes should be defined as, "Any change in legislation, policy, practice, service, or action that results in increased community access or services for consumers." Specific categories of outcomes should be developed (such as the categories used to sort community outcomes in this report) for centers to use in reporting outcomes data.

5.8.4 Consumer Services

This study shows that CILs are providing a high quality service to its consumers. Centers are assisting consumers in making positive changes in their lives, and are enabling consumers to increase their knowledge, skills, and quality of life. The study found a few areas where services to consumers could be improved. These areas are highlighted below:

Recommendation 4: We make the following recommendations to CILs:

- **We recommend that centers ensure that alternative formats, such as Braille, large print, audiotape, and sign language interpreters are provided to all consumers who need them.**

- **We noted that only 56 percent of consumers stated that, in order to reach a goal, they decided on the services they would receive either by themselves or in conjunction with another staff person. The rest said that a staff member or someone else decided on the services the consumer should receive. Centers should take steps to insure that consumers are empowered to make their own decisions, or to have a voice in decisions, about the independent living services they receive.**

- **CILs should provide more independent living skills training, employment services, ADA training, and benefits advisement to transition age youth while they are still in school so**

that they may move to independence and employment more easily at the appropriate time. One option is to establish a comprehensive summer program for this population.

- **Centers should take actions to insure that consumers from Hispanic backgrounds receive culturally appropriate, high quality independent living services. Centers should review consumer service records to determine whether people of Hispanic origin are offered equipment and technology assistance with the same frequency as other center consumers; if Hispanics are offered equipment and technology less often, centers should take any necessary steps to correct the situation.**

- **Centers should review consumer service records to determine whether people with mental disabilities are offered employment assistance with the same frequency as other center consumers; if people with mental disabilities are offered employment less often, centers should take any necessary steps to correct the situation.**

5.8.5 Services to Rural Residents

In its study, *Centers for Independent Living: Rural and Urban Distribution of Centers for Independent Living,*[1] the RRTC: Rural found that about 40 percent of U.S. counties--mostly rural--lack access to CILs. They examined the location of CILs funded under title VII, chapter 1, Part C as well as those funded only with state, local, and other dollars. Federal funding has increased significantly since this study was conducted and many new CILs have been added. We do not know the urban/rural distribution of these new centers or the extent to which rural consumers are being served.

Recommendation 5: We recommend that the CIL coverage of rural areas be re examined in light of the increase in numbers of centers since the original study was conducted.

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[1] Rehabilitation Research and Training Center on Rural Rehabilitation. Centers for Independent Living: Rural and Urban Distribution of Centers for Independent Living: Fact Sheet. http://rtc.ruralinstitute.umt.edu/IL/Ruralfacts/RuCILfacts.htm.