

Core Service Report

Independent Living Skills Instruction

Consumer Category:
With / At Risk of Health Conditions

Primary Consumer Group:
**Persons with Physically
Disabling Conditions**



February 2007

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COMPANION REPORTS

In addition to the information included in this report, a report of the other core services (80 in total), community leader key informant interviews, United Way - First Call for Help staff focus groups, consumer snapshots, and e-survey of United Way funded executive directors, board presidents, and United Way Community Investment staff are available at <http://www.uws.org>.

ACKNOWLEDGEMENTS

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This report was written by a team under contract with MCS Consulting Service, LLC including the following in alphabetical order:

- Renee Aten, Aten Enterprises
- Edwin A. Balcerzak, Strategic Consultants
- Carey Wiant Nyberg
- Marlene C. Stoiber, MCS Consulting Service, LLC.

This report reflects the comments from reviewers and United Way Community Investment Committee cluster volunteers.

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SNAPSHOT

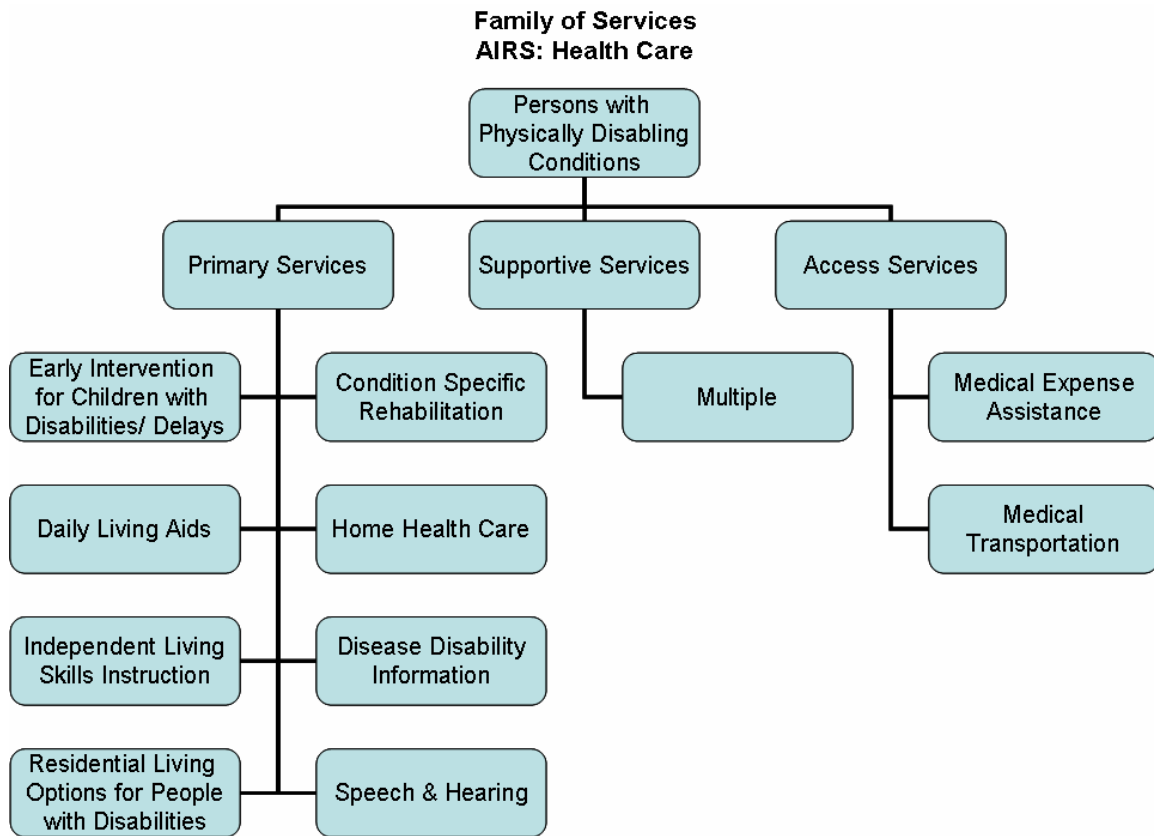
AIRS Code Level I: Health Care (L)
AIRS Code Level II: Rehabilitation/Habilitative Services (LR)
Core Service: Independent Living Skills Instruction (LR-320)

Investment Committee: Health & Caring for All
Cluster: Rehabilitation/Specialized Treatment

AIRS Definition: Programs that assist people who have disabilities to learn the basic skills of daily living through individual and group counseling and instruction, experience and practice in coping with real or simulated life situational demands; or through the use of assistive devices, special equipment and specialized assistants. Services include, but are not limited to, training in the ability to travel about the community alone; to live independently in a private residence; to maintain health through self-care and use of medical services; to live within personal income; to maintain acceptable grooming and appearance; to deal with legal, family or social problems; and to cope with other requirements for successful independent living.

Special Note: There are eight core services related to persons with physical disability conditions. The core services are organized as a continuum across the services along two dimensions: rehabilitation services (early intervention for children with disabilities/delays, condition-specific rehabilitation, daily living aids, independent living skills instruction, and speech and hearing) and long term care services (home health care and residential living options for people with disabilities). Disease/disability information is primarily related to rehabilitation services, but crossed into other physical disease categories that are not considered disabilities. To avoid duplication, early Intervention for children with disabilities/delays addresses the needs of children birth to three years and condition-specific rehabilitation goes from ages 4 to 20 years.

Independent Living Skills is one of eight core services in a family of services persons with physically disabling conditions. In addition, medical expense assistance and medical transportation help consumers access those services. (See figure below.)



Core Service Environment

The emphasis of independent living skills instruction is the teaching and acquisition of knowledge and specific skills that will enable a disabled person to live as independently as possible. There are two sets of skills that an adult disabled person needs to acquire. First, there are the normative skills that any adult needs to master to live independently in the community (activities of daily living, self care, money management, work, housing, etc.), and second, the adaptation of their disability to the accomplishment of these activities to manage their independence in a community.

In recent years, a new paradigm for viewing persons with disabilities has emerged. It recognizes the dynamic interaction between individual and environment over a lifespan (The Center for an Accessible Society, n.d.).

The independent living model/movement was developed during the 1970s as persons with disabilities began to assert their rights to be integrated into mainstream society. The basic premise of this movement is that persons with disabilities are hindered or impaired by barriers in their environment rather than by their physical or mental disabilities. If these barriers or obstacles were removed, then the disabled person could function more “normally.” Within this model, persons with disabilities are viewed as independent, autonomous consumers who are able to manage and direct their own services as well as their own lives (Batavia, DeJong, & McKnew, 1991).

Policy decisions and legislation over the decades have paved the way for the shift toward community-based independent living. The civil rights movement of the 1960s inspired the subsequent disability rights movement that greatly influenced the legislation of the 1970s, 1980s, and 1990s. New laws were created to prohibit discrimination against people with disabilities and made education, telecommunications, public accommodation, and transportation accessible to and usable by disabled individuals.

The Americans with Disabilities Act of 1990 (ADA) has a uniform nationwide mandate that ensures accessibility regardless of local attitudes. The Architectural and Transportation Barriers Compliance Board issued accessibility guidelines for design in 1991. These guidelines were adopted with modifications by the U.S. Department of Justice and became the enforceable ADA Standards for Accessible Design (The Center for Universal Design, 2006).

In June 1999, the U.S. Supreme Court ruled that it was a violation of the ADA for states to provide services in institutions when disabled individuals could be served more appropriately in community-based settings (*Olmstead vs. L.C.*, 119 S. Ct. 2176, 1999). This landmark ruling called for the integration of services within local communities and had a major impact on the services available to older and disabled Americans.

The most recent policy affecting independent living is the New Freedom Initiative of 2001, a comprehensive plan that represents an important step in working to ensure that all Americans have the opportunity to learn and develop skills, engage in productive work, make choices about their daily lives and participate fully in community life.

Ohio ACCESS called for a new vision of a service delivery system for persons with disabilities. This vision emphasizes consumer choice, control, and autonomy. The cornerstone of the vision is consumer self-determination and a person-centered planning approach with assistance from family, friends and caregivers (Johnson et al, 2001).

Core Service Consumers

The target population addressed in this core service report is adults 16 to 64 years with cognitive, physical, or multiple disabilities and who are seeking to live as independently as possible.

Today, there are more than 54 million Americans living with a disability, representing a full 20 percent of the U.S. population. Almost half of these individuals have a severe disability that affects their ability to see, hear, walk or perform other basic functions of life. In addition, there are more than 25 million family caregivers, and millions more who provide aid and assistance to people with disabilities (New Freedom Initiative, 2001).

The 1994 National Health Interview Survey estimated that 15 percent of the non-institutionalized civilian population—some 38 million people—were limited in activity due to chronic conditions (Adams & Marano, 1995 in *Chartbook on Disability*, 1996). The Institute of Medicine interpolated the NHIS data to indicate that 38 percent of disabilities were associated with mobility limitations, followed by chronic disease (32 percent); sensory limitations (8 percent); intellectual limitations (7 percent); and all other conditions (15 percent) (Pope & Tarlov, 1991 in *The Center for an Accessible Society*, n.d.).

Nationwide, independent living programs served over 131,726 individuals with disabilities, according to the U.S. Department of Education, Office of Special Education and Rehabilitation

Services, Rehabilitation Services Administration (2000), which is the most current report available (FY 2000). This is a small proportion of the 50 million persons with disabilities (0.24 percent).

In 2000, 71,791 persons 16 to 64 years in Cuyahoga County with two or more disabilities were estimated to need independent living skills instruction. This number is projected to decrease to 70,829 by 2015 because of population shifts.

Core Service Delivery

The definition of independent living skills for this report is: programs that focus on professional instruction and assistance to learn the skills to achieve or maintain self-sufficiency, use assistive living devices, live productively and independently (Independent Living Institute, 2005). Services include, but are not limited to, training in the ability to travel about the community alone; to live independently in a private residence; to maintain health through self-care and use of medical services; to live within personal income; to maintain acceptable grooming and appearance; to deal with legal, family or social problems; and to cope with other requirements for successful independent living.

Centers for independent living (CILs) are supported by federal legislation and focus on enabling and assisting persons with severe disabilities to achieve independent living.

Putting the independent living concept into practice requires three ingredients: community option development, consumer services, and management. The community option development is achieved through public awareness, technical assistance and advocacy at all levels. The consumer service methodology includes peer counseling, advocacy, information and referral, skills training, and general assistance. CILs also provide services for particular needs: housing assistance, transportation, personal care management; benefit acquisition; employment assistance. The heart of the CIL is sound management with substantial consumer involvement to make sure that the CIL is designed for consumer needs. (Budde and Bachelder, 1986)

Independent living centers were developed under Title VII Part C of the Rehabilitation Act and have geographic service mandates. They are non-residential community-based organizations providing services and advocacy by and for persons with all types of disabilities. Usually they are controlled by a board of directors, the majority of whom have disabilities themselves (The Center for an Accessible Society, n.d.).

Based on United Way - First Call for Help's (FCFH) database (February 2005), there were 12 providers of independent living skills instruction located in Cuyahoga County, all of which are nonprofit. One agency was funded by United Way. According to FCFH data, persons requesting independent living skills instruction in the county increased from 17 in 2000 to 25 by year 2004, representing about a 147 percent increase. Between the years 2000 and 2004, there were 113 requests for independent living skills instruction and 100 percent of them were met.

Centers for independent living receive all or at least part of their funding from the Rehabilitation Services Administration (RSA) of the U.S. Department of Education.

The federal budget for centers for independent living has been increasing between fiscal years 2000 and 2005. The amount was decreased slightly in fiscal year 2006 and the president's proposed budget keeps it flat.

As of May 11, 2006, \$132,155 in revenues for independent living skills instruction has been identified countywide. Seventy-two percent of the identified revenues are from foundations and the remaining 28 percent come from United Way of Greater Cleveland's funds.

What Works; What Doesn't

The Rehabilitation Services Administration of the U.S. Department of Education's trend data from FY 2000 to FY 2003 suggests that centers for independent living successfully increased (by about 10 percent per year) the number of individuals moving from long term care facilities or other institutions to community-based housing. Future performance targets have been increased to 10 percent per year (U.S. Department of Education, 2004).

In 2002, the average annual cost for a person in a community setting served under the home and community based services program (flexible Medicaid funding) was \$37,816. (Costs may vary based on characteristics of client or array of client services.) In 2002, the annual average cost per resident in large state-run institutions averaged \$85,746.

The Rehabilitation Act establishes a set of standards and assurances that centers for independent living must meet and requires the department to develop and publish indicators of minimum compliance with the standards. Each year, the department must conduct compliance reviews of at least 15 percent of the centers and one-third of the designated state units funded under this part (U.S. Department of Education, 2004).

Gap Analysis

The intention of the independent living movement is that all persons with disabilities are entitled to services to be as independent as they can be. Thus, all persons estimated in need are assumed to be the universe of possible consumers, 71,791, including both realized access (467) and those who would be consumers, unrealized access (71,324).

I. FOREWORD

INTRODUCTION

United Way of Greater Cleveland (UW), in partnership with the Cuyahoga County Board of Commissioners, has initiated a large scale core service planning process to generate data and engage in community-wide dialogue about the community's safety net of core service and consumer needs in the Greater Cleveland area. In addition, UW envisions this process as an opportunity to better understand its role in the community and its long term capacity to improve the lives of Greater Clevelanders.

The primary goal of the Cuyahoga County core service research is to identify consumer needs and assess whether there are service gaps/duplications on a community-wide level. The findings from this research will guide future funding decisions at UW, and they will also be used to stimulate dialogue with other funders and groups in the community. United Way intends to continue to fund a broad array of "safety net" services that are important to the Greater Cleveland area. But it is hoped that the research findings will inform how UW dollars may be dispersed to have the greatest impact on current realities, needs, and priorities in the Greater Cleveland community.

METHODOLOGY

United Way contracted with MCS Consulting Service, LLC, to conduct the core service research, which focuses on both the consumers served and services provided. (See Attachment 1 for list of members of the research team.) The research team has obtained information about each core service from multiple data sources. At the end of the research process there will be substantial information available for some services and less for others, which will provide a clearer picture of what information *is* available and where there are *significant gaps*.

The questions addressed are:

- Including public policies, what are the environmental influences that are impacting both service consumers and the capacity for service delivery?
- Who are the service consumers? What are the factors that lead to a need for services? How many consumers are there? How many have there been in the past several years and what factors influenced the historic trend line? What are the projected numbers for the future? What is their demographic profile? Where do they reside? How many are receiving services funded by government and/or United Way?
- What is the philosophy that drives service delivery? Has it changed? What does the service consist of? Who provides the service?
- What are the funding sources? What are the annual revenues from government sources, federated fund raising organizations, foundations, and United Way of Greater Cleveland? What are the historic government funding trends and what is projected for the future? What is the reimbursement amount?
- What works and what doesn't work in service delivery?
- Are there service gaps, duplication, under-utilization?

The primary information sources used for this report are:

- Results of 20 focus groups with 159 direct service staff of United Way member agencies and non-members, and key informant interviews with 93 experts in the respective service areas (February 2005). Participants were asked about consumer populations that are increasing and those with unmet needs; they provided insight about specific service gaps and duplication, as well as services they perceive to be outdated or under-utilized.
- United Way Program Report data for FY 2004 (July 2003 to June 2004). Each year United Way member agencies submit information to their respective investment committees on each funded core service they provide. Among other things, this information includes a demographic profile of the consumers served, the zip codes where the consumers reside, and all revenue sources that support the service. The research team has aggregated this information for each core service.
- United Way - First Call for Help call data (2000 to 2004) - United Way - First Call for Help provides a 24/7 information and referral service through its 211 telephone line. The research team analyzed data from its large database, which includes the names of service providers for most core services, the activities they provide and the zip codes in which they and those they serve are located, the number of calls received, and whether the need was met or unmet. Unmet needs are those for which there was no resource to reference.
- Literature reviews on service trends and issues as well as best practices (i.e., what works/ what doesn't work in service delivery), including impact on the individual/family and on the community.
- Searches for information on public policies that are currently impacting consumers or service delivery.
- U.S. Census and American Community Survey data for various time periods.
- Data from funders on actual consumer populations and funding levels.

(See Attachment 2 for technical notes on the research methodology as well as limitations of the data.)

II. THE CORE SERVICE ENVIRONMENT

CORE SERVICE ENVIRONMENT

At the beginning of the 20th century, older adults and people with disabilities were true minorities. The average human lifespan was only 47 years, and people who received spinal cord injuries had only a 10 percent chance of survival. Most people with chronic conditions lived in nursing institutions. (The Center for Universal Design, 2006)

People are living longer today. In addition, more people are now living with disability. Two world wars created a huge population of veterans with disabilities, and antibiotics and other medical advances enabled people to survive accidents and illnesses which were previously fatal. Demographic changes are resulting in a population that is older and more disabled than many realize, and these trends continue. (The Center for Universal Design, 2006)

The deinstitutionalization movement has decreased the numbers of persons with disabilities living in institutional settings and has increased the pressure for community-based living and services. Individuals with disabilities are losing their long-term family caregivers through death or their inability to continue caring for them, at the same time that disabled individuals are also living longer. Since January 2000, Ohio's capacity to serve people with disabilities in the community has grown by more than 12,000 through its Medicaid home- and community-based services (waiver) program. Since 1989, Ohio's state-run institutional census has shrunk from 2,700 residents to fewer than 1,800. While community-based long-term care is not the focus of this report, it certainly is a corollary to independent living skills instruction services.

In recent years, a new paradigm for viewing persons with disabilities has emerged. The "old" paradigm presents "disability as the result of a deficit in an individual that prevented the individual from performing certain functions or activities. This underlying assumption about disability affected many aspects of research, rehabilitation, and services." The new paradigm recognizes the contextual aspect of disability—the dynamic interaction between individual and environment over a lifespan (The Center for an Accessible Society, n.d.).

The majority of Federal definitions of disability, including those in the Rehabilitation Act, the ADA (Americans with Disabilities Act), and the National Health Interview Survey (NHIS), derive from the old paradigm. These definitions all attribute the cause of limitations in daily activities or social roles to characteristics of the individual, that is, 'conditions' or 'impairments.' Even the ADA, which promotes accessibility and accommodations, locates the disability with the individual. This is understandable not only because of the time involved in changing a paradigm, but because of the lack of a system to define, classify, and measure the environmental components of disability and the absence of a model to describe and quantify the interaction of environmental and individual variables. (The Center for an Accessible Society, n.d.)

The need for a change in definitions must be addressed by activities such as the attempt to revise the International Classification of Impairments, Disabilities, and Handicaps (ICIDH) (1980), to better define and measure the factors external to the individual that contribute to disability. Under the new paradigm, questions about employment status, for example, should focus on the need for accommodations as well as on the existence of an impairment. (The Center for an Accessible Society, n.d.)

Measures must enable researchers to predict and understand changes in the prevalence and distribution of disabilities—the emerging universe of disability—which illustrates the link between underlying social and environmental conditions such as poverty, race, culture, isolation, the age continuum, and the emergence of new causes of disability, new disability syndromes, and the differential distribution of disability among various population groups in our society. (The Center for an Accessible Society, n.d.)

The construct of disability is located on a continuum from enablement to disablement. Personal characteristics, as well as environmental ones, may be enabling or disabling, and the relative degree fluctuates, depending on condition, time, and setting. Disability is a contextual variable, dynamic over time and circumstance. For example, on a societal level, institutions and the built environment were designed for a limited segment of the population. Researchers should explore new ways of measuring and assessing disability in context, taking into account the effect of physical, policy, and social environments, and the dynamic nature of disability over the lifespan and across environments. (The Center for an Accessible Society, n.d.)

In the context of the new paradigm, the independent living model/movement was developed during the 1970s as persons with disabilities began to assert their rights to be integrated into mainstream society. The basic premise of this movement is that persons with disabilities are hindered or impaired by barriers in their environment rather than by their physical or mental disabilities. If these barriers or obstacles were removed, then the disabled person could function more “normally.” Within this model, persons with disabilities are viewed as independent, autonomous consumers who are able to manage and direct their own services as well as their own lives (Batavia, DeJong, & McKnew, 1991).

The emphasis of independent living skills instruction is the teaching and acquisition of knowledge and specific skills that will enable a disabled person to live as independently as possible. Organizations that effectively teach disabled persons to acquire these skills have specialized knowledge about disabilities and the social-psychological issues of disability, as well as knowledge about assistive devices and techniques.

There are two sets of skills that an adult disabled person needs to acquire. First, there are the normative skills that any adult needs to master to live independently in the community (activities of daily living, self care, money management, work, housing, etc.), and second, the adaptation of their disability to the accomplishment of these activities to manage their independence in a community.

Some disabled persons can learn these skills and live alone, others chose to live with others and share tasks and life together, some require caregivers, and others remain with family members. All can benefit from learning the skills that enable them to be as independent as possible. Disabilities affect persons of all ages, although this service may be focused more on young adults with physical and cognitive deficits rather than on children and older adults. For the most part, disabilities are lifelong conditions, even though some may be managed by learning the skills to handle tasks of daily living. For the older adult, a disability can be a decline in their physical ability to manage tasks due to aging or disease.

There are five dimensions to independent living for a disabled person:

- *Independent Community-based Living*: “More than 3 million people in the U.S. need help from another person to live independently and many of them face going hungry, falling or other problems that increase the risk of institutionalization and death.”
- *Education*: Over 100,000 students with multiple disabilities were enrolled in public school year 2000-2001. Effective educational programs must also incorporate required related services: therapy, medications, special equipment or technology and integration with non-disabled peers (National Dissemination Center for Children with Disabilities, n.d.). Twenty-two percent of Americans with disabilities fail to complete high school, compared to 9 percent of those without disabilities (National Organization on Disability, 2000).
- *Employment*: In 2003, nationally, 35 percent of people with disabilities reported being employed full or part time, compared to 78 percent of people without disabilities (U.S. Department of Labor, n.d.). People with disabilities are almost twice as likely to start a business as non-disabled individuals. Fourteen percent of working persons with disabilities are self-employed, while only 8 percent of non-disabled working persons are self-employed. (U.S. Department of Census)
- *Transportation*: Access to transportation is vital to independence; it affects the employment, political participation, entertainment, socializing, and religious attendance of all people with disabilities. Thirty percent of Americans with disabilities have a problem with inadequate transportation, compared to only 10 percent of those without disabilities.
- *Technology* is considered “the great equalizer,” giving people with disabilities better opportunities to communicate, learn, participate, and achieve greater overall levels of independence and to perform competitively in the workplace. Only 28.4 percent of Americans with disabilities have access to the Internet at home or work, compared to 56.7 percent of those without disabilities.

In Ohio, Medicaid-eligible persons with disabilities are able to participate in the standard Medicaid plan and, if enrolled, waiver services. Persons with disabilities may also use services from other sources such as the Rehabilitation Services Commission and the Bureau of Vocational Rehabilitation. Persons with disabilities may avail themselves of services through advocacy organizations such as the Ohio Development Disabilities Council, the Governor’s Council for People with Disabilities, and Traumatic Brain Injury Community Support Network. Additionally, a person with disabilities typically has income from Supplemental Security Income or Supplemental Security Disability Income (Johnson et al, 2001).

PUBLIC POLICY ISSUES

NATIONAL

Federal Acts and Regulations

Several policy decisions over the decades have paved the way for the shift toward community-based independent living.

The Civil Rights Movement of the 1960s inspired the subsequent Disability Rights Movement that greatly influenced the legislation of the 1970s, 1980s, and 1990s. These new laws prohibited discrimination against people with disabilities and provided access to education, places of public accommodation, telecommunications, and transportation. (The Center for Universal Design, 2006)

The barrier-free movement in the 1950s began a process of change in public policies and design practices. The movement was established in response to demands by disabled veterans and advocates for people with disabilities to create opportunities in education and employment rather than institutionalized health care and maintenance. Physical barriers in the environment were recognized as a significant hindrance to people with mobility impairments. (The Center for Universal Design, 2006)

Efforts of the Veterans Administration, The President's Committee on Employment of the Handicapped, and the National Easter Seals Society, among others, resulted in development of national standards for "barrier-free" buildings. In 1961, the American Standards Association (later known as The American National Standards Institute, or ANSI), published the first accessibility standard titled, "A 117.1 — Making Buildings Accessible to and Usable by the Physically Handicapped." These standards were not enforceable, however, until adopted by state or local legislative entities. (The Center for Universal Design, 2006)

A number of states responded with their own accessibility standards, and by 1966, 30 states had passed accessibility legislation; by 1973, the number was up to 49 states. Individual federal agencies attempted to provide minimum access through additional regulations and standards. This resulted in numerous, often differing accessibility guidelines. An attempt to "standardize" these federal guidelines occurred in 1984 when the ANSI specifications were incorporated into the Uniform Federal Accessibility Standard (UFAS). (The Center for Universal Design, 2006)

Significant federal legislation began to be passed in the late 1960s, including the following:

The Architectural Barriers Act of 1968 mandated the removal of what was perceived to be the most significant obstacle to employment for people with disabilities: the physical design of the buildings and facilities they had to use on the job. The Act required all buildings designed, constructed,

altered, or leased with federal funds to be made accessible. (The Center for Universal Design, 2006)

Section 504 of the Rehabilitation Act of 1973 was the first civil rights law for people with disabilities. This Act made it illegal to discriminate on the basis of disability and applied to federal agencies, public universities, federal contractors, and any other institution or activity receiving federal funds. The promulgation of regulations was initially stalled by the U.S. Department of Health, Education and Welfare. In protest, disability rights advocates held numerous demonstrations. As a result, regulations were finally issued in 1977. (The Center for Universal Design, 2006)

The Education for Handicapped Children Act of 1975 (now called the Individuals with Disabilities Education Act, or IDEA) guaranteed a free, appropriate education for all children with disabilities. This Act had an effect on educational programs as well as on the facilities in which they were conducted. (The Center for Universal Design, 2006)

The Fair Housing Amendments Act of 1988 expanded the coverage of the Civil Rights Act of 1968 to include families with children and people with disabilities. The Act required accessible units be created in all new multi-family housing with four or more units, both public and private, not just those that received federal funds. Accessibility Guidelines were issued by the U.S. Department of Housing and Urban Development in 1991 to facilitate compliance. (The Center for Universal Design, 2006)

The Americans with Disabilities Act of 1990 (ADA) awakened widespread public awareness of the civil rights of people with disabilities. Discrimination in employment, access to places of public accommodation, services, programs, public transportation, and telecommunications is prohibited by this law. Physical barriers that impede access must be removed wherever they exist. The ADA has a uniform nationwide mandate that ensures accessibility regardless of local attitudes. The Architectural and Transportation Barriers Compliance Board (Access Board) issued Accessibility Guidelines for accessible design in 1991. These guidelines were adopted with modifications by the U.S. Department of Justice and became the enforceable ADA Standards for Accessible Design. (The Center for Universal Design, 2006)

The Telecommunications Act of 1996 mandates that telecommunications services and equipment and customer premises equipment be "designed, developed, and fabricated to be accessible to and usable by individuals with disabilities, if readily achievable." It applies to all types of telecommunications devices and services, from telephones to television programming to computers. (The Center for Universal Design, 2006)

Federal legislation began as requirements for minimum accessibility to small percentages of facilities and features, which lawmakers felt was sufficient. It has progressed to providing full access to public and private

programs and facilities and has begun to affect devices and services in the home. (The Center for Universal Design, 2006)

The Olmstead Decision of 1999 also influenced the trend toward independent living. In June 1999, the U.S. Supreme Court ruled that it was a violation of the Americans with Disabilities Act (ADA) for states to provide services in institutions when disabled individuals could be served more appropriately in community-based settings (Olmstead vs. L.C., 119 S. Ct. 2176, 1999). This landmark ruling called for the integration of services within local communities and had a major impact on the services available to older Americans. However, the ruling does not create an entitlement or call for a fundamental alteration of public programs; it applies only if the provision of community services represents a reasonable accommodation (Koffman, Raphael, & Weiner, 2004).

The most recent policy affecting independent living is the New Freedom Initiative of 2001, initiated on February 1, 2001, as part of a nationwide effort to remove barriers to community living for people with disabilities. The initiative is a comprehensive plan that represents an important step toward working to ensure that all Americans have the opportunity to learn and develop skills, engage in productive work, make choices about their daily lives, and participate fully in community life. The initiative's goals are to:

- Increase access to assistive and universally designed technologies;
- Expand educational opportunities;
- Promote homeownership;
- Integrate Americans with disabilities into the workforce;
- Expand transportation options; and
- Promote full access to community life.

There are a number of current legislative policies that have been introduced in Congress.

- The Section 811 program entitled “Supportive Housing for People with Disabilities” presently allocates 25 percent of its funds for Section 8 mainstream vouchers with the remaining 75 percent allocated by HUD for supportive housing programs. The goal is to allocate 70-80 percent of the 811 funds for tenant-based housing vouchers to better serve disabled persons who seek independent living (NCIL, 2005).
- Public housing and community development block grants legislation introduced in Congress will make cuts in housing programs for the disabled easier to make under the proposed legislation—State and Local Housing Flexibility Act of 2005, S. 771 (NCIL, n.d.).
- Title II of the Americans with Disabilities Act (ADA) requires public transit agencies to make their systems fully accessible to people with disabilities. A major part of this requirement calls for all new buses and rail cars to be accessible to wheelchair users. Until a system's entire fleet of vehicles is accessible, it must provide alternatives that allow equal access for riders with disabilities (SIL, n.d.).

Family Opportunity Act

On February 8, 2006, the Family Opportunity Act (FOA) was enacted as part of the final federal budget law, the Deficit Reduction Act (DRA). Supported by many organizations that advocate for children and adults with disabilities, the purpose of the FOA is to allow middle-income families with children who have severe mental or physical disabilities to purchase health care coverage through the Medicaid. Under the legislation, individual states:

- can create a new *optional* Medicaid eligibility group for children with disabilities under age 19:
 - a) who meet the severity of disability required under SSI without regard to any asset or eligibility requirements under SSI for children, and
 - b) whose family income does not exceed 300 percent of the federal poverty level (approximately \$58,500 for a family of four).
- can require cost-sharing (premiums and co-pays) on a sliding scale based on income, but cannot exceed five percent of family income up to 200 percent of the federal poverty level, and 7.5 percent of family income from 200-300 percent of federal poverty. The state may waive payment of a premium in any case where the state determines that requiring a payment would create an undue hardship. (Ohio Legal Rights Services, 2006)

The provision goes into effect on January 1, 2007. The federal law includes a phase-in approach. In the first year, states can offer Medicaid services to families with incomes up to \$60,000 for a family of four if their child is under the age of 6. In the next year, children up to age 12 can participate and in the third year, children under the age of 18 can participate. (Ohio Legal Rights Services, 2006)

States now need to pass legislation to implement the Family Opportunity Act. Ohio currently does not have a Medicaid buy-in program for children with disabilities. The Ohio Disabilities Council is actively advocating for this provision, and it is a component of their 2007 Public Policy Platform (Ohio Developmental Disabilities Council, 2006).

STATE

Ohio Task Forces

Ohio ACCESS. In June 2000, a gubernatorial executive order created a task force (Ohio ACCESS) to undertake a comprehensive review of Ohio's systems of care for people with disabilities, and to make recommendations for improvements by 2006 (Fox-Grage, Folkemer, Straw, & Hansen, 2002). The task force—comprised of representatives from a number of state departments, consumers, and consumer representatives—focused on people with physical and developmental disabilities, with the priority goal of ensuring that people live with dignity in the setting they prefer (Mehdizadeh & Applebaum, 2005).

A review of the system as it exists today, coupled with feedback from consumers and their advocates, lead the agencies involved in Ohio ACCESS to call for a new vision of a service delivery system for persons with disabilities. This vision emphasizes consumer choice, control, and autonomy. The cornerstone of the vision is consumer self-determination and a person-centered planning approach with assistance from family, friends and caregivers. Consumers will be given more control over the funds available for their care and will be integrally involved in their choice of services and caregivers that comprise their individual service plan. A holistic approach to person-centered planning and care will ensure consideration of each consumer's physical, mental, emotional and spiritual needs (Johnson et al, 2001).

Ohio Regulations

The Ohio Personal Assistance Services Act (OPASA) along with the federal Medicaid Community Attendant Services and Supports Act (MiCASSA) would create a system of community attendant services and supports to be provided in the home or at school or work. These services would be consumer-oriented, managed by the recipient and selected from several service delivery models. By allowing the money for long-term care to “follow the individual,” OPASA and MiCASSA would finance the community attendant services and support systems without budget increases or unfunded mandates. Approximately 25 percent of the Medicaid dollars that currently go to nursing homes would be redirected to home and community based services (SIL, n.d.).

III. THE CORE SERVICE CONSUMERS

DEFINITION OF TARGET POPULATION

The target population for this core service is adults 16 to 64 years with cognitive, physical, or multiple disabilities and who are seeking to live as independently as possible. The focus is not on children because child rehabilitation programs may focus more on developmental tasks, language, communication, motor skills, self care, etc. than on independent living, which is a developmental task of the young adult. The Rehabilitation Act states that eligibility of funding is for individuals with significant physical, mental-cognitive, or sensory impairments that substantially limit the ability to function independently in the family or community or to obtain, maintain, or advance in employment. Eligibility is not to be based on the presence of any one or more specific significant disabilities.

DEMOGRAPHIC CHARACTERISTICS

Today, there are more than 54 million Americans living with a disability, representing a full 20 percent of the U.S. population. Almost half of them have a severe disability affecting their ability to see, hear, walk, or perform other basic functions of life. In addition, there are more than 25 million family caregivers, and millions more who provide aid and assistance to people with disabilities (New Freedom Initiative, 2001).

Some disabilities are easy to see, such as when a person uses a wheelchair or when someone has lost an arm. Other disabilities, like intellectual disability (mental retardation) or a chronic condition like arthritis, may not be as easy to see. Some people may live with a disability all their lives. Others may have a disability when they are young or as an older adult. (Chartbook on Disability in the U.S., 2006)

The National Health Interview Survey (NHIS) and the Survey of Income and Program Participation (SIPP) are the two most widely used sources of survey data to describe the population of individuals with disabilities. Note that this is the most current comprehensive data on persons with disabilities available.

- The 1994 National Health Interview Survey estimated that 15 percent of the non-institutionalized civilian population—some 38 million people—were limited in activity due to chronic conditions (Adams & Marano, 1995). The Institute of Medicine interpolated the NHIS data to indicate that 38 percent of disabilities were associated with mobility limitations, followed by chronic disease (32 percent); sensory limitations (8 percent); intellectual limitations (7 percent); and all other conditions (15 percent). (Pope & Tarlov, 1991)
- The SIPP identified 48.9 million persons who reported themselves as limited in performing functional activities or in fulfilling a socially defined role or task. Of these, 24.1 million persons were identified as having a “severe disability.” (Kraus, L. E., Stoddard, S. & Gilmartin, D.

[1996]. Chartbook on Disability in the United States, 1996. An InfoUse Report. Washington, DC: National Institute on Disability and Rehabilitation Research.)

- Both surveys excluded persons in nursing homes or institutions, who would be expected to have a high rate of disability. Including that population through extrapolation has led to the commonly cited figures of 43 to 48 million Americans with disabilities (now 50+ million).” (The Center for an Accessible Society, n.d.)

Both the NHIS and SIPP focus on limitations in major life activities, due to a physical or mental condition, but also provide data on persons who are limited in or unable to perform activities of daily living (ADLs)—such as eating, bathing, dressing, toileting, or transferring--without assistance or devices, or to perform instrumental activities of daily living (IADLs)—such as basic home care, shopping, meal preparation, telephoning, and managing money. Approximately eight million people reported difficulty with ADLs, and approximately four million with one or more ADLs needed the assistance of another person. (McNeil, 1993; Americans with Disabilities: 1991-92. U. S. Bureau of the Census. Current Population Reports, Washington, DC: U.S. Government Printing Office; The Center for an Accessible Society, n.d.)

The range of these estimates—from approximately 4 million people who need help simply to sustain their lives to the nearly 40 million who report any kind of activity limitation—illustrates the danger in discussing the disabled population or its needs as a homogeneous group. More refined data are needed to assess the needs for medical and health care, vocational rehabilitation and employment assistance, supports for living in the community, and assistive technology. (The Center for an Accessible Society, n.d.)

Disability is distributed differently in the population according to characteristics of age, gender, race, and ethnicity, and both region and size of locality in which a person resides. Educational level is inversely correlated with the prevalence of disability. Poverty is a key factor both as a contributing cause and a result of disability. (The Center for an Accessible Society, n.d.)

Of all non-institutionalized persons age 15 and over in the United States, 17.5 percent have a functional limitation (34.2 million people). The SIPP asked respondents about their ability to perform the following specific sensory and physical activities: (1) seeing ordinary newspaper print (with glasses or contacts if normally used); (2) hearing normal conversation (using aid if normally used); (3) having speech understood; (4) lifting or carrying 10 lbs.; (5) walking a quarter of a mile without resting; (6) climbing a flight of stairs without resting; (7) getting around outside; (8) getting around inside; or (9) getting into and out of bed. Difficulty in performing any of these activities is classified as a functional limitation in the SIPP. (Chartbook on Disability in the U.S., 1996)

Many people have more than one limitation. For 17.5 million, it is going up a flight of stairs without resting; for 17.3 million people the limitation is in walking a quarter of a mile; for 16.2 million it is lifting or carrying something as heavy as a bag of groceries; for 10.9 million, it is hearing what is said in normal conversation; for 9.7 million, it is seeing words or letters in ordinary newsprint, even when wearing glasses or contact lenses; for 7.8 million, it is getting around outside the home; for 5.3 million, it is getting into and out of bed; for 3.7 million, it is getting around inside the home; and for 2.3 million, it is having one's own speech understood. (Chartbook on Disability in the U.S., 1996)

People have a physically severe functional limitation if they are unable to perform a physical function or if they need the help of another person to perform the function. An estimated 7.8 percent of those age 15 and older (15.2 million people) are severely limited in the functions of seeing, hearing, having speech understood, lifting or carrying, walking, or using stairs. A quarter of the population over 15 years old has some functional limitation, and nearly one-third of them has a severe limitation. (Chartbook on Disability in the U.S., 1996)

As can be seen, the range of persons with disabilities who need assistance in managing independent living tasks is very broad and includes persons with genetic or inherited disabilities as well as those with acquired disabilities due to injury or disease. Consumers of independent living skills instruction may have cognitive disabilities such as mental retardation, physical disabilities as a result of a birth, brain or traumatic injury or genetic condition, or multiple impairments. They may also be unable to live alone without some form of support and services to maintain their independence. But the common denominator is that they have the will and the ability to live independently and are motivated to develop the skills needed to live independently and productively.

Some additional facts (Mauro, 2005):

- Ten thousand persons (or 1 out of 250 persons) each year suffer spinal cord injuries that require them to use a wheelchair for the remainder of their lives. Eighty-two percent (82 percent) of them are male.
- The ADA (Americans with Disabilities Act) Committee reports that 8.2 million persons with disabilities want to work.
- Over 20 percent of persons with disabilities live in poverty and have more than twice as high a poverty rate as other Americans.
- About half of the disabled live in households with \$15,000 income or less—double the proportion of people without disabilities.
- Only 12 percent of persons with disabilities live in families with incomes higher than \$35,000 (annually).
- The overall rate of disability is 20.2 percent for whites, 24.9 percent for blacks, and 19.2 percent for Hispanics.
- In a long-term study of quadriplegics, it was found that they live for an average of 15 years when independent while those in a nursing home live 18 months on average.

Persons with disabilities who strive to live independently may face economic problems in addition to the challenges of managing their disabilities. For example, many people with mental retardation exist at the economic and social margins of American society (Edgerton, 2001, in Tymchuk, Lakin, & Luckasson, 2001). They are much more likely to live in poverty and have substantially lower employment rates than do people in the general population. Approximately one third of adults with mental retardation lived below the federal poverty level in 1994, as compared with 13 percent of adults without mental retardation (Larson, Lakin, Anderson, Kwak, & Lee, 2001).

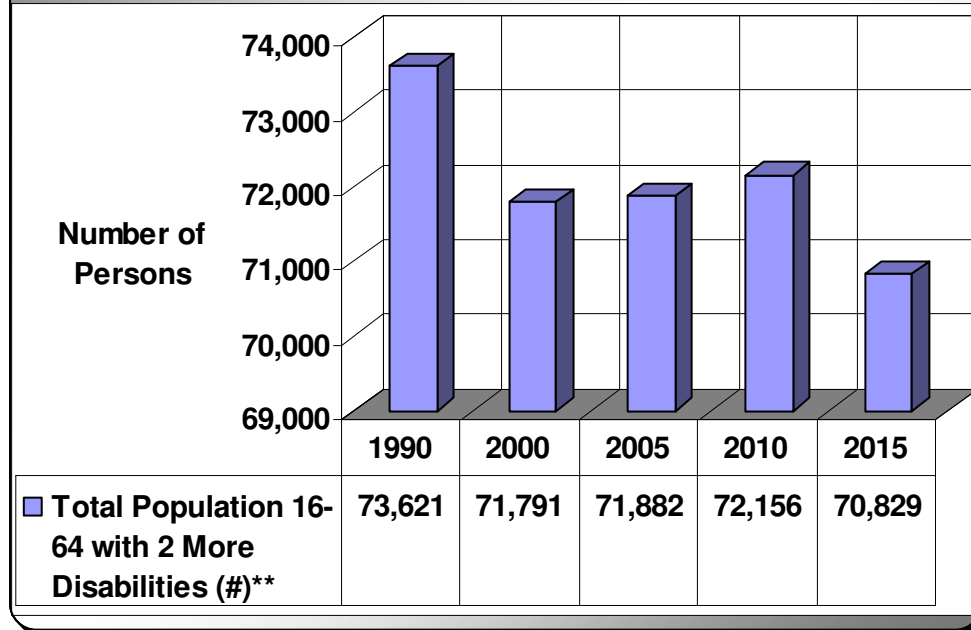
Nationwide, independent living programs served over 131,726 individuals with disabilities, according to the U.S. Department of Education, Office of Special Education and Rehabilitation Services, Rehabilitation Services Administration (2000), which is the most current report available (FY 2000). This is a small proportion of the 50 million persons with disabilities (0.24 percent). Those individuals received services in one or more of the following areas:

- 1,372 individuals were relocated from nursing homes or other institutions to community-based living arrangements.
- 18,036 individuals were reported as having received services that prevented the necessity of their entering into nursing homes or other institutions.
- 52,883 individuals received independent living skills training and life skills training.
- 33,270 individuals received independent living services related to securing housing or shelter.
- 35,322 individuals received services related to transportation.
- 36,594 individuals received personal assistance services.

Estimated Persons in Need

In 2000, an estimated 71,791 persons 16 to 64 years in Cuyahoga County with two or more disabilities needed independent living skills instruction. This number is projected to decrease to 70,829 by 2015 because of population shifts. (See Figure 1.)

**Figure 1: Independent Living Skills Instruction
Estimated Persons in Need
Cuyahoga County, 1990-2015**



Sources:

* U.S. Census 1990, STF 1 (P11); 2000, SF3 (P8); 2005-2015, Ohio Department of Development, (July, 2003).

**2000, U.S. Census SF3 (PCT26); other years estimated using 2000 rate of 8.3 percent total population 16-64

This estimate begins to give some clarity about the need for this service in Cuyahoga County.

REALIZED ACCESS TO SERVICE

Realized access to service is represented by the number of consumers actually served. It includes the actual number of consumers reported by agencies funded by United Way and by government funders from which it was possible to obtain data. Thus, it is an underestimate of actual numbers of consumers receiving service.

In FY 2004, United Way funded 467 persons for independent living skills instruction. (See Attachment 3.) No other funders were identified.

Racially, according to the 2000 U.S. Census, 52 percent of the county's population 16-64 years with two or more disabilities was Caucasian, 41 percent African American, and 2 percent Asian. Five percent of the county's 16-64 cohort with two or more disabilities was Hispanic. United Way funded 16 percent white, 73 percent African American, 0 percent Asian, and 8 percent Hispanic.

Seventy-six percent of the consumers funded by United Way were between 15 and 19 years; 9 percent were 20 to 34; 10 percent 35 to 54; and 2 percent 55 to 64.

Household income was unreported.

Geographically, 47 percent of the county's population 16-64 years with two or more disabilities resided in Cleveland and 53 percent in the suburbs. Eighty-three percent of consumers funded by United Way were in Cleveland and 17 percent in the suburbs. The largest proportions were in two zip codes: 20 percent in 44108 (Cleveland/Bratenahl) and 14 percent in 44104 (Cleveland). The rest were scattered around the county. (See Attachment 4.)

IV. CORE SERVICE DELIVERY

CORE SERVICE DEFINITION

Independent living skills focus on professional instruction and assistance to learn skills needed to achieve or maintain self-sufficiency, use assistive living devices, and live productively and independently. All persons with disabilities are guided to explore alternatives and make their own decisions. Independent living is a philosophy and a movement of people with disabilities who work for self-determination, equal opportunities, and self-respect (Independent Living Institute, 2005).

As stated in the AIRS definition, methods include individual and group counseling and instruction, experience and practice in coping with real or simulated life situational demands; or through the use of assistive devices, special equipment, and specialized assistants. Services include, but are not limited to, training in the ability to travel about the community alone; to live independently in a private residence; to maintain health through self-care and use of medical services; to live within personal income; to maintain acceptable grooming and appearance; to deal with legal, family or social problems; and to cope with other requirements for successful independent living.

BACKGROUND ON CORE SERVICE

Independent living centers were developed under Title VII Part C of the Rehabilitation Act and have geographic service mandates. While it is difficult to estimate the number of disabled persons in Cuyahoga County who are entitled to services from an independent living center, it is estimated that 1 in 5 persons in the population has a disability. This covers the entire spectrum from the severely disabled to the less visible or less severe disabilities. However, all these persons are entitled to some form of independent living assistance and/or training in how to be independent, live on their own, be in the workforce, and take care of themselves.

Centers for independent living (CILs) are a byproduct of the civil rights movement of the 1960's and supported by federal legislation in the 1970's and most recently by the Americans with Disabilities Act of 1990 and the New Freedom Initiative of 2001. Centers for independent living (CILs) are focused on enabling and assisting persons with severe disabilities to achieve independent living.

The independent living concept, model and methodology were developed for persons with severe disabilities and now serve a variety of disabilities. The term "independent living" is one that emphasizes direct consumer control, assistive service, and improvement in the community environment. Putting the independent living concept into practice requires three ingredients: community option development, consumer services, and management. No matter how the community option development is organized, it is achieved through public awareness, technical assistance and advocacy at all levels. The second ingredient in a CIL is the consumer service methodology, which includes peer counseling, advocacy, information and referral, skills training, and general assistance. CILs also provide services for particular needs: housing assistance,

transportation, personal care management; benefit acquirement; employment assistance. The heart of the CIL is sound management with substantial consumer involvement to make sure that the CIL is designed for consumer needs. (Budde and Bachelder, 1986)

Independent Living Centers are non-residential community-based organizations providing services and advocacy by and for persons with all types of disabilities. Usually they are controlled by a board of directors the majority of whom have disabilities themselves.... They are private, nonprofit organizations. Many independent living centers serve as a strong advocacy voice on a wide range of national, state and local issues. They work to assure physical and programmatic access to housing, employment, transportation, communities, recreational facilities, and health and social services. There are nearly 500 independent living centers nationwide. Most belong to the National Council on Independent Living. (The Center for an Accessible Society, n.d.)

One of the distinguishing characteristics of centers for independent living (CILs) is that services are available throughout a disabled person's life. Services typically offered by all CILs include independent living skills training, advocacy, information and referral, and peer counseling. Other available services include independent living skills evaluation, one-to-one and group individual skills training, TTY training, adaptive equipment loans, personal care assistance, peer support, and support groups.

An independent living skills evaluation involves assessing a person's need and abilities as they relate to living an independent self-directed lifestyle. Independent living skills training teaches persons with disabilities the skills that are necessary for creating and maintaining an independent lifestyle. (Talikka, 2004)

In addition, CILs can facilitate the securing of other resources such as the personal care assistance (PCA) program.

Ohio's PCA program provides financial resources for personal assistance services to Ohioans with severe physical disabilities. Personal assistance services help a person with a severe physical disability perform activities of daily living. Eligibility is that a person is severely physically disabled and requires assistance in a minimum of three activities of daily living. (Ohio Rehabilitation Services Commission, n.d.)

CILs can also assist others whose work and focus are supportive to independent living for persons with disabilities, e.g., information about compliance with the Americans with Disabilities Act of 1990, architects, builders, building and facility managers, as well as commercial and corporate businesses.

Two additional sources of information on independent living are:

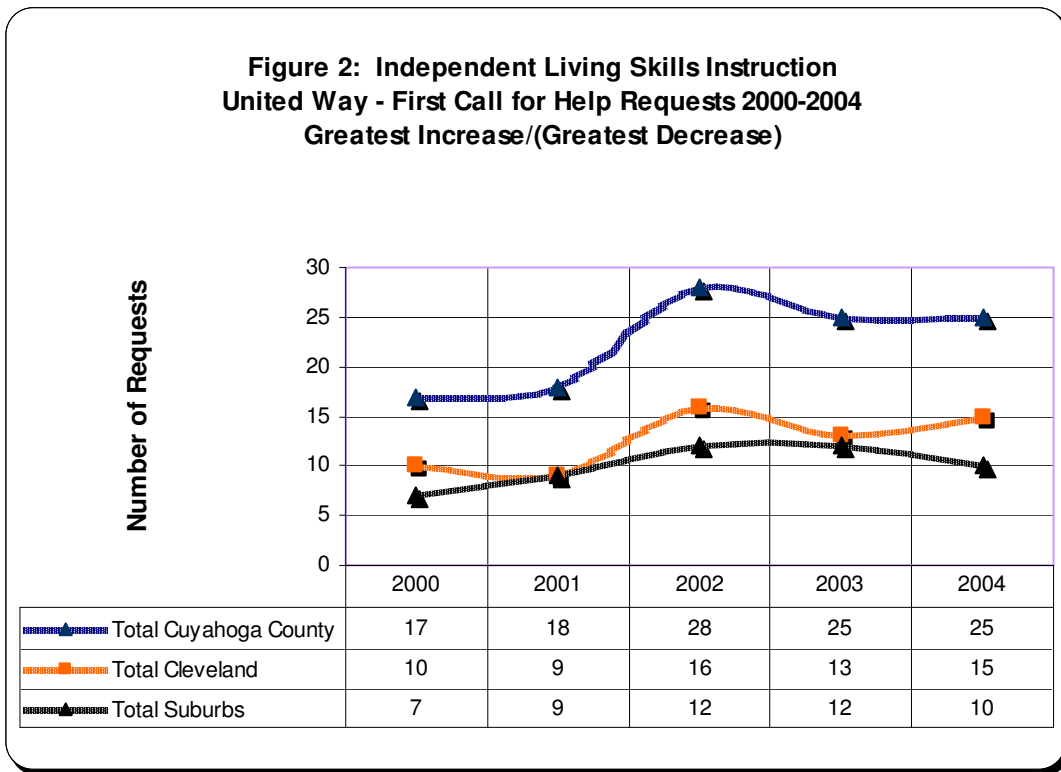
- The Independent Living Institute in Stockholm Sweden operates a virtual library website that offers resources for persons with extensive disabilities and develops consumer-driven policies for self-determination, self respect and dignity in regard to independent living. [<http://www.independentliving.org>]

- The Research and Training Center on Independent Living at the University of Kansas is another resource for information on independent living. Core areas for the Research and Training Center on Independent Living (RTC/IL) include independent living, health promotion, and disability policy. The independent living core addresses advocacy, services and interventions that enhance IL in the community. The health promotion core addresses interventions that promote good health and reduce the risk of health problems that impede IL. The disability policy core addresses policy issues at various levels that impede or facilitate IL. [<http://www.rtcil.org>]

United Way - First Call for Help Call Data

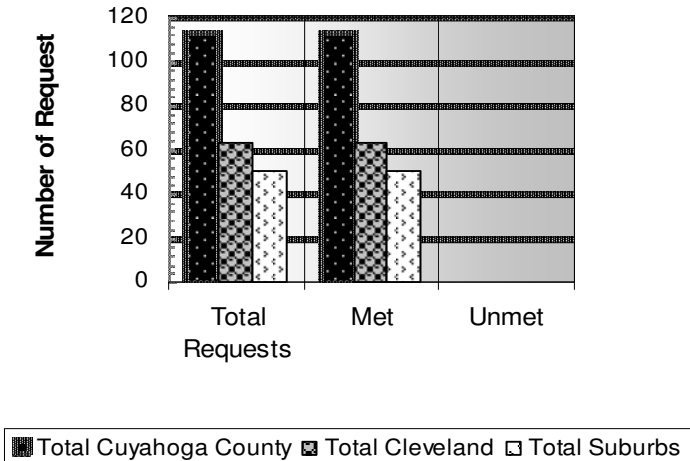
In 2005, there were 12 providers of independent living skills instruction located in Cuyahoga County. Five sites were located in the City of Cleveland and 7 in the surrounding suburbs. All were operated by nonprofit providers. One nonprofit agency was funded by United Way and located in a suburban area. (See Attachments 5 and 6.)

According to FCFH data, persons requesting independent living skills instruction in the county increased from 17 in 2000 to 25 by 2004, representing about a 147 percent increase. Calls from persons in Cleveland increased from 10 to 15, while those in the suburbs went from 7 to 10. Note that percentages are inflated because of small numbers. (See Figure 2 and Attachment 7.)



Between 2000 and 2004, there were 113 requests for independent living skills instruction and 100 percent of them were met. Sixty-three requests were from Clevelanders and 50 from persons in suburbs. (See Figure 3 and Attachment 8.)

**Figure 3: Independent Living Skills Instruction
United Way - First Call for Help Requests 2000-2004
(TOTAL REQUESTS: n=113,
TOTAL UNMET NEED: n=0)**



FUNDING OF CORE SERVICES

Major Government Funders

The major sources of government funding for independent living skills instruction programs are:

- Centers for Independent Living Program
- Independent Living - State Grants Program
- Ohio General Revenue Fund

Centers for Independent Living Program

Enabled by the Rehabilitation Act of 1973, as amended, Title VII, Chapter 1, Part C, and administered through the Rehabilitation Services Administration within the Office of Special Education and Rehabilitative Services within the U.S. Department of Education, the Centers for Independent Living program provides grants for consumer-controlled, community-based, cross-disability, nonresidential, private nonprofit agencies that are designed and operated within a local community by individuals with disabilities and provide an array of independent living services. At a minimum, centers are required to provide the core services of information and referral, independent living skills training, peer counseling, and individual and systems advocacy. Most centers are also actively involved in one or more of the following activities: community planning and decision making; school-based peer counseling, role modeling, and skills training; working with local governments and employers to open and facilitate employment opportunities; interacting with local, state, and federal legislators; and staging recreational events that integrate individuals with disabilities with their non-disabled peers. A population-based formula determines the total amount available for discretionary grants to centers in each state (U.S. Department of Education, 2004). Amounts available for discretionary programs have fluctuated somewhat from \$73.6 million in FY 2005 to \$74.6 million in FY 2006. The range of grants made is about \$1000 to \$795,000 with the average award being \$210,000 (U.S. Department of Education, n.d.). Specific allocations available to organizations within Cuyahoga County from this source were not available at the time this report was written.

Independent Living – State Grants Program (Title VII, Part B)

Enabled by the Rehabilitation Act of 1973, as amended, Title VII, Chapter 1, Part B, and administered through the Rehabilitation Services Administration within the Office of Special Education and Rehabilitative Services within the U.S. Department of Education, the Independent Living – State Grants Program offers formula grants to states. The program’s purpose...

...[is] to maximize the leadership, empowerment, independence, and productivity of individuals with disabilities and to integrate these individuals into the mainstream of American society. Independent living programs provide financial assistance to provide, expand and improve independent living services; develop and support statewide networks of centers for independent living; and improve working relationships among state independent living rehabilitation programs, centers for independent living, statewide Independent Living Councils (SILCs), Rehabilitation Act programs outside of Title VII, and other relevant federal and non-federal programs. (U.S. Department of Education, 2004)

A state match is required: the state provides 10 percent and the federal government provides 90 percent of program costs. Per the State of Ohio Executive Budget for FY 2006 and 2007, Ohio received \$894,662 in FY 2006, and \$686,520 in FY 2007. Specific allocations available to organizations within Cuyahoga County from this source were not available at the time this report was written.

Ohio General Revenue Fund

The Ohio General Revenue fund provides state matching funds for the federal Independent Living, Title VII, Part B grant program. GRF matching funds have fluctuated, but have decreased. In 2001, the state allocated \$61,319, and in 2005 \$50,000 was appropriated. Specific amounts available from this source allocated for Cuyahoga County were not available at the time this report was written.

Trends of Identified Government Funders in Cuyahoga County

Total allocations from identified major government sources to organizations within Cuyahoga County were not available at the time this report was written.

IDENTIFIED REVENUES

As of May 11, 2006, \$132,155 in revenues for independent living skills instruction has been identified countywide. This includes information from foundations; federated fundraising organizations; regional, county and municipal government; and United Way of Greater Cleveland. (See Table 1.)

Seventy-two percent of the identified revenues are from foundations and the remaining 28 percent come from United Way of Greater Cleveland’s funds.

Table 1: Identified Annual Revenue for Core Services: Countywide and United Way of Greater Cleveland Independent Living Skills, 2003/2004.

Funder	Period	A		B	
		Identifiable Total Dollars County-wide		Total Dollars UW-Funded Agencies (Actual FY2004)	
		Amount	% of Total (A)	Amount	% of Total (B)
Total - Contributions and dues (less UW designations)			0.00%	5,400	1.32%
Britton Fund	2004	10,000			
Deaconess Community Foundation	2004	23,000			
Other Private Foundations - Not Elsewhere Classified	2004	7,500			
Kulas Foundation	2004	55,000			
Total - Foundations & Trusts		95,500	72%	0	0.00%
Ohio Rehabilitation Services Commission				26,600	
State Department of Education				287,300	
Subtotal State of Ohio		0	0.00%	313,900	76.76%
Community Development Block Grant				20,000	
Subtotal City of Cleveland Funding Sources		0	0.00%	20,000	4.89%
Cleveland Board of Education				25,000	
All Other Funding - Not Elsewhere Classified				4,500	
Subtotal Other Govt Funding Sources		0	0.00%	29,500	7.21%
Total - Contracts/grants from government organizations		0	0.00%	363,400	88.86%
Total - Investment Income			0.00%	1,500	0.37%
Total - All Other Revenue			0.00%	2,000	0.49%
Subtotal Non - UWGrCle Support		95,500	72.26%	372,300	91.04%
Total - UWGrCle designations applied to program		7,300	5.52%	7,300	1.79%
Total - UWGrCle investment committee allocation		29,355	22.21%	29,355	7.18%
Subtotal UWGrCle Support - 4001, 4701 & 4703		36,655	27.74%	36,655	8.96%
Total Support/Revenue		132,155	100%	408,955	100%

REIMBURSEMENT/COST

No information was found.

V. WHAT WORKS; WHAT DOESN'T

IMPACT ON INDIVIDUALS/FAMILIES

What Works

Caring for a disabled family member can be—and is—a source of stress in a family. When an individual is able to demonstrate self-sufficiency, and live independently, some of the family's stress can be relieved. People with disabilities will have greater control over the resources that are spent on them. There will be more “self-determination,” meaning that more time will be spent with the individual and his or her family to determine necessary services. This should be a more efficient and effective model for service delivery because it shifts control to the individual and the family instead of an institution.

An example of best practices in this service area would be models of interconnected health care systems.

The Rehabilitation Services Administration of the U.S. Department of Education, which administers funding for independent living centers, has established a program goal of supporting individuals with significant disabilities in the achievement of their independent living goals, including older blind individuals served by independent living programs. The objective is to increase the number of disabled individuals living independently in community-based housing. The indicator is increased numbers of individuals leaving long-term care facilities and other institutions for community-based living because of the independent living services provided by a CIL. RSA's trend data from FY 2000 to FY 2003 suggest that CILs have been successful in increasing the number of individuals moving from long term care facilities or other institutions to community-based housing by about 10 percent per year. Future performance targets have been increased to 10 percent per year (U.S. Department of Education, 2004).

What Doesn't Work

Research must develop new methods to focus on the interface between person and society. It is not enough simply to shift the focus of concern from the individual to the environment. What is needed are studies of the dynamic interplay between person and environment; of the adapting process, by the society as well as by the individual; and of the adaptive changes that occur during a person's lifespan. Research must focus on the development and evaluation of environmental options in the built environment and the communications environment, including such approaches as:

- Universal design;
- Modular design; and
- Assistive technology. (The Center for an Accessible Society, n.d.)

All of these enable individuals with disabilities and society to select the most appropriate means to accommodate or alleviate limitations. Research must lead to a better understanding of the context and trends in our society that affect the total environment in which people with disabilities will live and in which disability will be manifested:

- Economy and labor market trends;
- Social, cultural, and attitudinal developments; and
- New technological developments. (The Center for an Accessible Society, n.d.)

Research must develop ways to enable individuals with disabilities to compete in the global economy, including education and training methods, job accommodations, and assistive technology. Research must develop an understanding of the public policy context in which disability is addressed, ignored, or exacerbated. General fiscal and economic policies, as well as more specific policies on:

- Employment,
- Delivery and financing of health care,
- Income support,
- Transportation,
- Social services,
- Telecommunications,
- Institutionalization,
- Education, and
- Long-term care

...are critical factors influencing disability and disabled persons. Their frequent inconsistencies, contradictions, and oversights can inhibit the attainment of personal and social goals for persons with disabilities. (The Center for an Accessible Society, n.d.)

IMPACT ON COMMUNITY

Over the last 35 years, there has been an 81 percent reduction in numbers of people with intellectual and developmental disabilities living in state institutions. In 2002, the average annual cost for a person in a community setting served under the home- and community-based services program (flexible Medicaid funding) was \$37,816. (Costs may vary based on characteristics of client or array of client services.) The annual average cost per resident in large, state-run institutions in 2002 averaged \$85,746.

An estimated 80 percent of Medicaid money spent annually on long-term care goes to institutions, with community and at-home services getting the remaining 20 percent. All states have a Medicaid home- and community-based waiver program for younger persons with disabilities (HCBS). HCBS allows states flexibility in rules and types of service and support provided. In FY 2002, the federal, state, and local governments spent almost 35 billion on non-educational services for persons with intellectual and developmental disabilities. The cost for community-based living has increased over the last several years because of: (1) a 36 percent increase in individuals receiving service and a 19 percent increase in service utilization rate; (2) 60,000 people on waiting list (reflecting concerns in equity/access to service); and (3) federal cost sharing (unmatched state expenditures) and increased life expectancy of individuals (especially for individuals with mental retardation/developmental disabilities and the elderly not at a high risk of institutionalization) (Lakin, Prouty, Pollister & Coucouvanis, 2003).

ACCREDITATIONS/STANDARDS/CERTIFICATIONS

There are a number of national organizations focused on improving services to persons with disabilities and independent living, although none are specifically focused on standards, certification, or accreditation. The Statewide Independent Living Council (SILC) Congress developed a set of draft standards and indicators in January 2004. The intent of these standards is to assist the states in fully implementing the requirements outlined in Title VII of the Rehabilitation Act of 1992. These standards were presented in the SLIC Congress meeting in January 2005, but there is no information about their adoption or implementation. [<http://www.ilru.org>] There are, however, some national organizations that are focused on service delivery funding for disabled persons.

The Association for Persons with Severe Handicaps (TASH) “is a civil rights organization for, and of, people with mental retardation, autism, cerebral palsy, physical disabilities, and other conditions that make full integration a challenge” (The Association of Persons with Severe Handicaps, n.d.). TASH is engaged in advocacy, public awareness and the dissemination of knowledge and information about services that enable the severely handicapped to be fully included in society. TASH publishes a journal that promotes sound and effective practices.

The National Council on Independent Living (NCIL) is the oldest cross disability, grassroots organization run by and for people with disabilities. Founded in 1982, NCIL is a public policy advocacy organization representing over 700 organizations and individuals including: Centers for Independent Living (CILs), Statewide Independent Living Councils (SILCs), individuals with disabilities, and other organizations that advocate for the human and civil rights of people with disabilities throughout the U.S. (National Council on Independent Living [NCIL], n.d.)

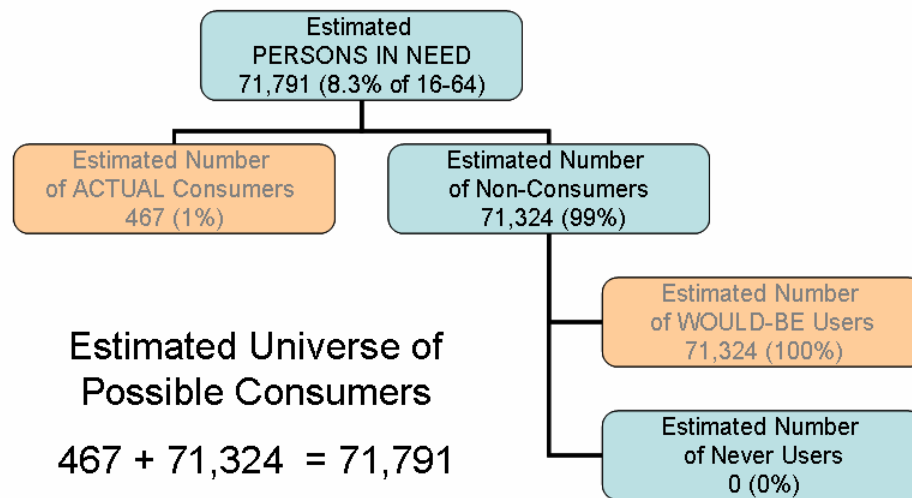
The Rehabilitation Act establishes a set of standards and assurances that centers for independent living must meet and requires the Department to develop and publish indicators of minimum compliance with the standards. These standards and assurances are used in evaluating compliance in the following areas: philosophy, including consumer control and equal access; provision of services on a cross-disability basis; support of the development and achievement of the independent living goals chosen by consumers; advocacy to increase the quality of community options for independent living; provision of independent living core services; resource development; and community capacity-building activities, such as community advocacy, technical assistance and outreach. Each year, the Department must conduct compliance reviews of at least 15 percent of the centers and one-third of the designated state units funded under this part. (U.S. Department of Education, 2004)

VI. GAP ANALYSIS

The following is the formula for arriving at the estimated universe of possible consumers for Independent Living Skills Instruction:

- A conservative estimate of 71,791 persons need independent living skills instruction, which is the number of individuals 16-64 years with two or more disabilities in Cuyahoga County, based on the 2000 Census.
- Realized access is 467, based on the number of consumers funded by United Way.
- The intention of the independent living movement is that all persons with disabilities are entitled to services to be as independent as they can be. Thus, all persons estimated in need are assumed to be the universe of possible consumers, 71,791, including both realized access (467) and those who would be consumers, unrealized access (71,324). (See Figure 4.)

Figure 4 - Consumer Estimate: Independent Living Skills Instruction



Service Site Index

No Service Site Index was completed for this service because this is a countywide service.

VII. SUMMARY

The following are the major findings from the research on independent living skills instruction:

- In recent years, a new paradigm for viewing persons with disabilities has emerged. It recognizes the dynamic interaction between individual and environment over a lifespan.
- The independent living model/movement was developed during the 1970s. Within this model, persons with disabilities are viewed as independent, autonomous consumers who are able to manage and direct their own services as well as their own lives.
- Policy decisions and legislation over the decades have paved the way for the shift toward community-based independent living. The civil rights movement of the 1960s inspired the subsequent disability rights movement that greatly influenced the legislation of the 1970s, 1980s, and 1990s. New laws were created to prohibit discrimination against people with disabilities and made education, telecommunications, public accommodation, and transportation accessible to and usable by disabled individuals.
- The most recent policy affecting independent living is the New Freedom Initiative of 2001, a comprehensive plan that represents an important step toward working to ensure that all Americans have the opportunity to learn and develop skills, engage in productive work, make choices about their daily lives, and participate fully in community life.
- Centers for independent living receive all or at least part of their funding from the Rehabilitation Services Administration (RSA) of the U.S. Department of Education. A population-based formula determines the total amount available in each state for discretionary grants to centers.
- The federal budget for centers for independent living has been increasing between fiscal years 2000 and 2005. The amount was decreased slightly in fiscal year 2006 and the president's proposed budget keeps it flat.
- As of May 11, 2006, \$132,155 in revenues for independent living skills instruction has been identified countywide.
- The Rehabilitation Services Administration of the U.S. Department of Education's trend data from FY 2000 to FY 2003 suggest that centers for independent living have been successful in increasing by about 10 percent per year the number of individuals moving from long term care facilities or other institutions to community-based housing. Future performance targets have been increased 10 percent per year.
- Research must develop new methods to focus on the interface between person and society. It is not enough simply to shift the focus of concern from the individual to the environment. Studies are needed of the dynamic interplay between person and environment; of the adapting process, by the society as well as by the individual; and of the adaptive changes that occur during a person's lifespan.
- The intention of the independent living movement is that all persons with disabilities are entitled to services to be as independent as they can be. Thus, all persons estimated in need are assumed to be the universe of possible consumers, 71,791, including both realized access (467) and those who would be consumers, unrealized access (71,324).

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ATTACHMENTS

Attachment 1: Researcher List

MCS CONSULTING SERVICE

CORE SERVICE RESEARCH TEAM

Co-Lead Consultants

Marlene C. Stoiber, Ph.D. President, MCS Consulting Service, LLC
Bette S. Meyer, M.A.

Research Team

Renee Aten, CFRE, Aten Enterprises, Associate, MCS Consulting Service, LLC
Edwin A. Balcerzak, Ph.D., Associate, MCS Consulting Service, LLC
Louis B. Burroughs, M.S.U.S., Associate, MCS Consulting Service, LLC
Elsie Day, J.D., Associate, MCS Consulting Service, LLC
Jennifer M. Forshey, M.P.P., IntelliSolve, Inc.

Karen Gillooly, M.Ed., IntelliSolve, Inc.
Sue E. Grant, Ella & Associates, IntelliSolve, Inc.
Gary Harris, B.A., M.B.A., IntelliSolve, Inc.
Jeffry D. Harris, M.P.A., J.D., IntelliSolve, Inc.
Kristen Haskell, M.A., Associate, MCS Consulting Service, LLC

Dion Lau, B.A., Associate, MCS Consulting Service, LLC
Kitty Leung, M.S.S.A., Associate, MCS Consulting Service, LLC
Marcy Hunt- Morse Ph.D., Ella & Associates, IntelliSolve, Inc.
Carey Wiant Nyberg, M.U.P., Associate, MCS Consulting Service, LLC
RNR Consulting, Inc.

Jeremy Shapiro, Ph.D., IntelliSolve, Inc.
Jennifer Slusser, J.D., IntelliSolve, Inc.
Sarah Stilgenbauer, M.N.O., Associate, MCS Consulting Service, LLC
Kola Sunmonu, Ph.D., Associate, MCS Consulting Service, LLC
Jamie Watkins, B.A., IntelliSolve, Inc.

Jacqueline Kirby Wilkins, Ph.D., CFLE - President/Director, IntelliSolve, Inc.
Debra Zanglin, Ella & Associates, IntelliSolve, Inc.

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Attachment 2: Technical Notes

Technical Notes: Methodology, Caveats, Limitations of Data

The following provides descriptions, definitions, methodologies, caveats, or limitations of data for the following components of the core service reports:

- Unit of Analysis
- First Call for Help Data
- Funding Information for Core Services
- Consumer and Financial Data: Caveats
- Gap Analysis Methodology & Limitations
- Service Site Index

Unit of Analysis

The core service is the unit of analysis. United Way of Greater Cleveland either funds or could fund 80 core services. These are the object and subject of the research, specific to Cuyahoga County. A separate report has been developed for each service. It must be noted that the aggregate of any quantifiable data across all of the reports does not comprise a picture of the totality of health and human services in Cuyahoga County because there are many more than 80 services that comprise the community's safety net.

The unit of analysis for estimates of service consumers is the individual, the family, or the household.

United Way - First Call for Help Data

For most core services, United Way First Call for Help (FCFH), the community's resource and referral service data, was used in tables that show the number of service providers and service sites, the geographic location of service providers by zip code, the service area by zip code as reported by providers of the respective services, and to show unmet need and greatest increase/decrease in calls received by FCFH for a particular core service.

It is important to remember that FCFH receives calls from a variety of sources that include people calling on behalf of a prospective consumer such as social workers, provider agencies, relatives, etc. Not all calls come directly from a prospective consumer, so some of the zip codes are for hospitals and business addresses, although the numbers for these zip codes are relatively small.

Calls also may be from people who are not interested in receiving a service, but wish instead to make a contribution to a program such as clothing, household items, food, books, crafts supplies, etc.

Because, in many instances, FCFH codes its data with a different level of core services than the 80 core services identified by the United Way Community Investment staff as fundable services, it was necessary to develop a crosswalk. This crosswalk was used for a number of services,

however, seven services did not have a match in the FCFH database. The staff of United Way - First Call for Help gave explanations which follow each core service):

- Adolescent/Youth Counseling: A caller asking about help with their troubled teenager would be referred by the type of counseling rather than age. (Example: counseling for drugs, family, sexual abuse, etc.)
- Advocacy: FCFH does not receive calls from people about advocacy.
- Child Care: Calls are directed to Starting Point.
- Condition Specific Rehabilitation Services: FCFH would refer caller back to their primary care physician for a referral.
- Early Intervention for Mental Illness: FCFH does not receive calls for this, but if they did, they would refer to the county's Help Me Grow program.
- Family Support Centers: FCFH defines data by specific service rather than type of agency. Depending on the call, the caller may be referred to General Counseling or Early Intervention for Infants and Toddlers with Disabilities, and so on.
- Preschools: Calls are directed to Starting Point.

A different match was used for other services that had no crosswalk.

- Medical Transportation and Senior Ride: FCFH uses "Paratransit" as they do not differentiate between senior transportation, medical transportation, and transportation for the disabled.
- Outpatient Mental Health Facilities: FCFH uses "Mental Health Drop-in Centers."

It must also be noted that, for the most part, the FCFH database does not include for-profit agencies. In the case of home health care providers, we contacted the Long Term Care Ombudsman for a more complete list of provider agencies which includes for-profit organizations.

There were several instances where the FCFH database did not code a United Way-funded agency with the core service for which they were receiving funding. In these instances, the agency was added manually to the Service Provider Table along with their site locations. The core services with the respective United Way of Greater Cleveland agencies that were added are:

- Case/Care Management – Care Alliance, Cystic Fibrosis, Epilepsy Foundation, Golden Age Centers
- Comprehensive Outpatient Substance Abuse Treatment – The Covenant
- Disease/Disability Information – The Muscular Disease Society of Northeastern Ohio
- Early Intervention for Infants and Toddlers with Disabilities – United Cerebral Palsy
- Medical Expense Assistance – North Coast Health Ministry
- Medical Transportation (Paratransit in FCFH) – Kidney Foundation of Ohio
- Senior Centers – Catholic Charities Services Corporation, Jewish Community Center of Cleveland, Jewish Family Service Association of Cleveland, University Settlement House.
- Volunteer Development – Neighborhood Leadership Institute

It must also be noted that when numbers are low for trend data reported, the high percentages are slightly exaggerated.

Funding Information for Core Services

We collected financial information for each core service on a countywide level from multiple sources including major government funders, foundations, federated fund raising organizations, and United Way of Greater Cleveland. While we were successful in gathering a substantial amount of data, there is much that has not been collected. It must also be noted that even if we had all major public and private funding gathered, this would not create a total picture of health and human service funding in Cuyahoga County because there are more than 80 core services provided. The following provide highlights of data collected and some of the limitations for each source. It is important to note that funding in each source is changing and represents point in time amounts. The typical period for trend data, when available, is 2002, 2003, and 2004. Note: some services are funded by private insurance or other self-pay arrangements.

Foundation Funding

We attempted to obtain foundation funding amounts for each core service from the latest annual report or 990 PF (foundation tax return to the IRS) of each major foundation that funds social services in Greater Cleveland. Wherever a description of the grant purpose was given, we used our best judgment to match the grant to the appropriate core service. If the grant fell within more than one core service area, it was not listed. When no description was given, the grant was treated like a general operating grant and assigned to a core service only when the mission of the grant recipient fell mainly within one particular core service. In-kind donations, grants for capital and equipment expenses and administrative salaries were not used. When grants were \$10,000 or greater, they were listed by name of the foundation. All others were placed under Other Foundations and not listed. Typically, we did not attempt to provide trend financial data for foundation funding of core services because of the changing nature of funded programs from year to year.

Federated Funding Sources

We approached the major federated funders of core services in Greater Cleveland for funding and consumer information. Some data provided was for a single point in time; others provided three years of trend data. We often had to do a cross walk of United Way of Greater Cleveland funded core services against those funded by federated agencies to agree on the services.

Government Funding

We approached every major government funder for funding amounts for each core service and also did Internet searches for some federal government sources. Due to the constant state of change in government funding, it is important to note that the data provided is a snapshot in time and that many of the programs funded in 2004 have changed definition, are funded through different revenue sources, or no longer exist at all due to a lack of funding. This is particularly true of Community Development Block Grant dollars which have decreased due to shifting federal priorities.

Every effort was made to appropriately match government funding data to the correct core service area; however, this was not always possible as frequently the service definitions were not a one-to-one match. It was necessary, in some instances, to take the closest match or use the sore service which represented a majority of the services being provided.

In other cases, it was not possible to select a specific core service. An example is Medicaid in which Medicaid-defined services crossed over more than four core services in some instances. In cases where Medicaid is a significant source of revenue, the data was entered as an

aggregate total at the appropriate AIRS level. These aggregates are footnoted under the appropriate funding table.

Every effort was made to include data from municipalities. However, many did not respond after repeated requests for information. We would like to thank those who took the time to help with this project.

Medicaid Funding

A significant portion of Medicaid funding was NOT entered under the countywide total in the core service reports for two reasons: first, because many of the Medicaid services are not a one-to-one match with United Way core services, and second because some Medicaid services fall into more than one AIRS Level 1 categories. In the first instance, Medicaid funding was entered as an aggregate total at the AIRS 1 level, and in the second instance Medicaid funding was entered as an aggregate total under Third Party Payee/Direct Bill in the combined Master Revenue file of funding across all nine AIRS Levels. They are as follows:

Entered as Aggregate Total Under Appropriate AIRS Level

- Medicaid Service - Home Care (\$17,787,703 in 2004) - Falls into AIRS 1 Health Care and includes the following core services: daily living aids and home health care.
- Medicaid Service - CADAS (\$8,522,183 in 2004) - Falls into AIRS 1 Health Care and includes the following core services: comprehensive outpatient substance abuse treatment, residential substance abuse treatment programs, substance abuse education and prevention.
- Medicaid Service - Therapy (\$2,257,394 in 2004) - Falls into AIRS 1 Health Care and includes the following core services: condition specific rehabilitation, and speech & hearing.
- Medicaid Service - CMH (\$67,773,487 in 2004) - Falls into AIRS 1 Mental Health Care & Counseling and includes the following core services: supportive therapies, adolescent/youth counseling, children's residential treatment facilities, early intervention for mental illness, general counseling services (outpatient mental health facilities), and psychiatric day treatment.

Entered as Aggregate Total Under Third Party Payee/Direct Bill

- Medicaid Service - Inpatient Hospital (\$188,329,269 in 2004) - Falls into two different AIRS 1 categories: Basic needs and health care. It includes the following core services: condition specific rehabilitation and medical expense assistance.
- Medicaid Service - Waiver (\$128,921,354 in 2004) – This category included all PASSPORT services. Since we reported PASSPORT separately, in order to avoid duplication, we deducted the PASSPORT total of \$52,676,048 from this number and reported the remaining \$76,245,306. This total falls into AIRS 1 Basic Needs, Health Care and Individual & Family Life and includes the following core services: adult day care, home-delivered meals, home health care and in-home assistance.
- Medicaid Service - Habilitation (\$55,550,307 in 2004) - Falls into AIRS 1 Health Care and Individual & Family Life and includes the following core services: condition specific rehabilitation services, early intervention for infants and toddlers with disabilities/delays, and residential living options for people with disabilities.

United Way of Greater Cleveland Funding

Financial data for core services funded by United Way of Greater Cleveland was for FY 2004 (July 2003 to June 2004). It included allocations through the community investment committees

and donor designations that United Way funded agencies applied to the respective core services. It is important to note that not all United Way funded agencies applied donor designated gifts, which are unrestricted, to the core service for which they receive United Way funding. It did not include donor designations that non-United Way funded agencies used for any of the 80 core services.

United Way Agency Revenues

Annually United Way-funded agencies submit revenue budgets to United Way for each funded core service. This information for FY 2004 is reported. However, all of the agency data may not be included in the countywide data as agencies may have assigned dollars from unrestricted grants to a specific core service, or allocated a portion of grant monies that fell within two or more core service areas. It was not always possible to match countywide government or foundation funding with that reported by the agencies and that gathered from other funding sources.

Consumer and Financial Data: Caveats

The following applies to revenue sources on tables and graphs and their corresponding consumer data used in the consumer demographics and zip code tables.

All Core Services

Data was self-verified by the funder/provider. Whenever data provided by a funder appeared to be inconsistent or incorrect, an attempt was made to contact the funder. If the funder responded, the data was either adjusted according to their instructions, or the reason for discrepancies footnoted. If they did not respond, or if they said it was correct, the data was left as submitted.

Demographic and zip code data provided by the funder/provider is frequently taken from consumer intake forms which may have missing or incomplete data, or from provider agency databases which contain data entry errors or incomplete consumer intake forms. Whenever possible, the funder was asked for corrected data. In cases where a correction was not possible, the data was counted as either unknown or missing. The usage of these terms is footnoted at the bottom of each table and is explained more fully in the Gap Analysis section of this attachment.

It was not always possible to get information in the format requested as each funder tracks data differently, using different service definitions, terminology and variables. Wherever possible, data was matched to a consistent report format.

When a funder could not provide consumer demographics, but could provide an estimated percentage of consumers by category, we took the total number of consumers and applied the percentages to come up with estimated numbers for the consumer tables. For example, Medicaid tracks individual recipients throughout the year, entering new data if there is a change, each time a claim occurs. Thus, a consumer who has a birthday between claims will appear in the system for that year with two different ages.

To resolve this, the percentage of consumers in each age range was determined for the total number of duplicated consumer ages. Those percentages were then applied to the total number of unduplicated consumers for the year in order to reach a total number of unduplicated consumers for each age range.

The time periods for both revenue and consumers vary by funder/provider. United Way Program Report data is for FY 2004 (July 2003 to June 2004). Other funder/provider data is for either a January to December or July to June fiscal year.

Gap Analysis Methodology & Limitations

Based on Anderson's (1964) seminal needs assessment model, realized access is defined as the number of consumers who receive service while unrealized access is the estimated number of consumers who need and would utilize a service, but are not currently receiving it. This could be considered the service gap. Unrealized consumer access to services drives the need for change in the social service delivery system. Ensuring unrealized consumer access to services requires new models of service delivery related to access, effective use of resources, data management, and funding. There were multiple steps used to conduct a gap analysis:

- *Estimate of persons in need of the service:* Unless local research was conducted to determine need for a given service, this estimate was obtained by either using U.S. Census data for Cuyahoga County or applying percentages from national studies and reports to the census data. All references and percentages are footnoted in the respective graphs or tables. In most cases this percentage was also applied to actual 1990 Census figures and population projections 2005 through 2015 that were done by the Ohio Department of Development.
- *Estimate of number of ACTUAL consumers in the public systems (realized access):* Data submitted to United Way by funded agencies was aggregated to determine the number of consumers for each core service. The period was FY 2004, which is July 2003 through July 2004.
 - In some cases data was "unknown," defined as data not collected by agency because no tracking system was available or the type of service delivered made it difficult (i.e., group presentations, telephone information and referral, and drop-ins). This also represents data not completed by consumers either deliberately or inadvertently on intake forms.
 - In other cases, data was missing that, for United Way data, represented computational errors or incorrect completion of online reports. For all other data, "missing" represents data funders/providers were unable to provide.
 - There was no check of the accuracy of data submitted by agencies.
 - Major government funders were asked to provide information about the number of consumers for the respective core services that they funded. In most cases, services were not defined in the same way as the United Way core services which are based on the Alliance for Information and Referral Systems (AIRS) taxonomy. To accommodate these differences, customized crosswalks were developed.
 - We assumed that the numbers of consumers across funding sources were not unduplicated and thus made a judgment about which numbers would be the best estimate of an unduplicated number.
 - The estimate of consumers is not inclusive since it does not include numbers of consumers who use their personal resources to pay for services, nor for other private resources such as insurance or agency fundraising. In addition, it was not always possible to obtain information from some government funders.
- *Estimate of number of "unknown/non-consumers":* This is the difference between the estimated number of actual consumers and the estimate of persons in need.

- *Estimate of number of “would-be users” (unrealized access):* This is the estimate of persons who would use a service if it were available, typically based on research.
- *Estimate of number of “never users”:* This is the difference between the estimated number of unknown/non-consumers and would-be users.
- *Estimate of “universe of possible consumers”:* This is the total of those actually receiving the service (realized access) and those would-be users (unrealized access).

We recognize that this is not a perfect method for assessing either realized or unrealized access to core services. However, we opted to use an imperfect method rather than no method to demonstrate both the complexity and the usefulness of quantifying realized and unrealized access to services as a first step toward a more rigorous methodology. In the business sector this would be a form of market analysis. We also recognize that actual consumer numbers are not unduplicated across funders, or across core services. Thus, there is much work yet to be done to gain realistic estimates of needs.

The numbers we provided are on a countywide level. We recognize that there could be, and often are, differences by demographics and geographical area. In the Actual Consumer Demographics attachment, we have identified the profile of the base consumer group from census, but have little on the estimated persons in need. Occasionally, there is information from other research that describes differences among different racial, ethnic, gender, age, or income groups that is discussed in the narrative. There is also inconsistent information for consumers funded by various governmental bodies. In other words, some funders provided demographic data and others did not. In the Actual Consumer Zip Codes attachment, we have also attempted to identify the geographic profile of the estimated persons in need and actual consumers. However, this information has the same limitations as the demographics.

Service Site Index

For many services a service site index was developed. It provides a ratio of estimated consumers per service site on a countywide level and for each zip code within the county. The ratio is based on the number derived from the gap analysis described in the previous section and on the number of providers who reported to United Way – First Call for Help whether a specific service site includes a given zip code in its service area. A provider site is located in a single zip code, but could serve multiple zip codes. The ratio is a measure of potential service accessibility by estimated universe of service consumers per zip code area. This measure does not include the capacity of providers to offer the service, for example, the number of consumers that can be served on a daily basis. It is only capturing whether there is a possibility of being a consumer. The lower the ratio, the greater is the chance of receiving service. The index also gives an indication of which zip codes have higher ratios which means that consumers have a lower probability of receiving a service as well as any patterns in zip codes that have high percentages of African Americans, Asians, or Hispanics. A map is also attached which provides a graphic picture of the estimated consumers by zip code.

Based on the numbers of providers that report to FCFH whether they serve a given zip code, we had assumed that there would be greater variability across zip codes. In reality, many report that they serve the entire county. Thus the variability across zip codes is often primarily because of differences in the population numbers rather than in service sites that offer service in a given zip code.

Specific Service Issues

Senior Services

“Senior Centers” was used as a catch-all category when the funder-defined service covered more than one senior success core service and could not be accurately allocated among the separate core services. Often, funding for transportation and home-delivered meals was not broken out from senior activities and supportive services at the municipal level, so it was placed under Senior Centers. Because the core services for congregate and home-delivered meals and senior ride were tracked separately, funding for these core services was not included under Senior Centers to avoid duplication of resources, even though senior center activities can and do include congregate meals.

Senior Ride includes disabled individuals of all ages as well as seniors for most funders with the notable exception of Western Reserve Area Agency on Aging (WRAAA) that requires an individual to be 60 years of age or older in order to receive services. If the transportation service was not provided by a senior center, the number of consumers reflects the number of riders using the system and contains duplicates (e.g. paratransit).

Home improvement/accessibility data includes programs for low-income families and people of all ages with disabilities, as well as seniors.

References

- Anderson, Ronald M. (1995, March). Revisiting the behavioral model and access to medical care: Does it matter? *Journal of Health and Social Behavior*, 36(1): 1-10.
- Wan, Thomas T. H., Odell, Barbara Gill, & Lewis, David T. (1982). *Promoting the well-being of the elderly: A community diagnosis*. New York: The Halworth Press.

Attachment 3: Actual Consumer Demographics

Core Service: Independent Living Skills Instruction LR: 320				
			Estimated Persons in Need	Actual Number/Percent of Consumers by Funding Source ^{*****}
	Total Population (%) [*]	Total Population 16-64 (%) ^{**}	Total Population 16-64 with 2 or More Disabilities (%) ^{***}	UW Program Report Data Cuy Cnty Only 97.3% (%)
PERIOD	1/1/2000-12/31/2000	1/1/2000-12/31/2000	1/1/2000-12/31/2000	7/1/2003-6/30/2004
16-20 Years	1,393,978	85,377	3,743	
21-64 years		780,987	68,048	
TOTAL		866,364	71,791	467
Percent		62.2%	8.3%	
GENDER				
Male	47.2%	47.2%	N/A	57.9%
Female	52.8%	52.8%	N/A	42.1%
Unknown Data ^{*****}				0.0%
Missing Data ^{*****}				0.0%
RACE^{*****}				
White alone	67.1%	67.7%	52.2%	16.3%
Black or African American alone/combo	27.9%	26.9%	40.7%	73.3%
Asian alone/combo	2.1%	2.5%	2.2%	0.0%
American Indian and Alaska Native alone/combo	0.7%	0.7%	1.5%	0.2%
Native Hawaiian and Other Pacific Islander alone/combo	0.1%	0.1%	0.1%	0.0%
Some other race alone/combo	2.1%	2.1%	3.3%	10.2%
Unknown Data ^{*****}				0.0%
Missing Data ^{*****}				0.0%
HISPANIC^{*****}	3.3%	3.3%	5.3%	7.9%
AGE				
0-4	6.5%			0.0%
5-9	7.3%			0.0%
10-14	7.1%			4.0%
15-19	6.4%	5.0%	N/A	75.6%
20-34	19.1%	19.1%	N/A	8.8%
35-54	29.3%	29.3%	N/A	9.6%
55-64	8.7%	8.7%	N/A	1.9%
65-74	7.8%			0.2%
75+	7.8%			0.0%
Unknown Data ^{*****}				0.0%
Missing Data ^{*****}				0.0%
INCOME^{*****}				
Average Household Size	2.4	N/A	N/A	
\$0-\$9,999	11.3%	N/A	N/A	0.0%
\$10,000-\$14,999	6.9%	N/A	N/A	0.0%
\$15,000-\$19,999	6.7%	N/A	N/A	0.0%
\$20,000-\$29,999	13.6%	N/A	N/A	0.0%
\$30,000 and above	61.5%	N/A	N/A	0.0%
Unknown Data ^{*****}				100.0%
Missing Data ^{*****}				0.0%
Totals	100.0%	N/A	N/A	100.0%

Attachment 3: Actual Consumer Demographics (continued)

* U.S. Census 2000, SF1(P1); SF4 (PCT144)
** U.S. Census 2000 SF3 (PCT26); SF4 (PCT69)
***U.S. Census 2000 SF3 (PCT26); SF4 (PCT 69)
**** Note: Consumers could be funded by more than one funding source; thus the columns are not necessarily mutually exclusive.
*****Unknown Data - Represents data not collected by agency because no tracking system is available or type of service delivered makes it difficult (i.e., group presentations, telephone information and referral, and drop-ins). Also represents data not completed by clients either deliberately or inadvertently on intake forms.
*****Missing Data - For United Way Data - represents computational errors or incorrect completion of online report. For all other data - represents data funder was unable to provide.
*****The race categories and data utilize US Census SF4 "Race Iterations," which allow for multiple races to be selected by census respondents. As a result, totals will add to > 100% of population. Universe is "Total Races Tallied." Except "White Alone", all racial categories are "... alone or in combination with some other race". This method isolates and minimizes the non-minority population ("White alone").
*****Hispanic - Amount in this field is from data provided by clients on intake forms and may not be accurate as clients may either deliberately or inadvertently provide incomplete data, or data may not be collected by the agency.
*****The U.S. Census reports income by household or family, not individuals. Estimates by income category were derived by applying the ratio of total county population (1,393,978) to total households (571,606) = 2.4. The number of households in each income category was multiplied by 2.4 to arrive at an estimate of individuals by income category. The assumption is that the average household size applies to each income category, which may result in more conservative estimates for children and the "old old," which may actually have larger proportions of persons in the lower income categories.

Attachment 4: Actual Consumer Zip Codes

Core Service: Independent Living Skills Instruction LR: 320					
				Estimated Persons in Need	Actual Number/Percent of Consumers by Funding Source ****
	City/Town (% Cleveland)	Total Population (%)*	Total Population 16-64 (%)**	Total Population 16-64 with 2 or More Disabilities (%)***	UW Program Report Data (%)
Period		1/1/2000-12/31/2000	1/1/2000-12/31/2000	1/1/2000-12/31/2000	7/1/2003-6/30/2004
16-20 Years			85,377	3,743	
21-64 years			780,987	68,048	
TOTAL		1,393,978	866,364	71,791	467
Percent			62.2%	8.3%	
44017	Berea	1.4%	1.5%	1.1%	0.2%
44022	Bentleyville	1.3%	0.8%	0.3%	0.2%
44040	Gates Mills/Mayfield Village	0.2%	0.2%	0.1%	0.0%
44070	North Olmsted	2.4%	2.5%	1.5%	0.0%
44101	Cleveland (100%)	0.0%	0.0%	0.0%	0.2%
44102	Cleveland/Brooklyn (95%)	3.7%	3.8%	7.0%	6.6%
44103	Cleveland (100%)	1.8%	1.7%	3.7%	5.1%
44104	Cleveland (100%)	2.1%	1.9%	3.5%	13.5%
44105	Cleveland/NewburghHts/GarfieldHts (75%)	3.9%	3.9%	6.3%	3.6%
44106	Cleveland/Cleveland Hts (60%)	2.3%	2.5%	3.0%	4.9%
44107	Lakewood/Cleveland	4.0%	4.5%	2.8%	0.0%
44108	Cleveland/Bratenah (90%)	2.6%	2.4%	3.8%	20.3%
44109	Cleveland/Brooklyn Hts (98%)	3.3%	3.4%	5.2%	8.1%
44110	Cleveland/East Cleveland (98%)	1.9%	1.8%	3.0%	8.1%
44111	Cleveland (100%)	3.1%	3.2%	3.2%	1.7%
44112	East Cleveland/Cleveland	2.4%	2.3%	3.9%	2.8%
44113	Cleveland (100%)	1.4%	1.6%	2.6%	4.7%
44114	Cleveland (100%)	0.3%	0.3%	0.7%	0.6%
44115	Cleveland (100%)	0.6%	0.6%	0.9%	3.6%
44116	Rocky River	1.5%	1.4%	0.6%	0.0%
44117	Euclid/Cleveland	0.9%	0.8%	1.4%	0.4%
44118	ClevelandHts/UniversityHts/ShakerHts	3.2%	3.5%	2.4%	1.3%
44119	Cleveland/Euclid (50%)	1.0%	1.0%	0.6%	0.0%
44120	Shaker Hts/Cleveland	3.4%	3.3%	3.9%	2.8%
44121	University Hts/South Euclid	2.5%	2.6%	2.0%	1.3%
44122	Beachwood/Highland Hills/ShakerHts	2.5%	2.2%	1.4%	1.7%
44123	Euclid	1.3%	1.3%	0.8%	0.0%
44124	Pepper Pike/MayfieldHts/Lyndhurst	2.9%	2.7%	1.8%	0.4%
44125	Valley View/Garfield Hts	2.1%	2.1%	1.9%	0.2%
44126	Fairview Park/Cleveland	1.2%	1.2%	0.7%	0.0%
44127	Cleveland (100%)	0.6%	0.6%	1.2%	1.5%
44128	Warrensville Hts/Cleveland	2.4%	2.3%	3.2%	0.6%
44129	Brooklyn/Parma/Cleveland	2.1%	2.1%	1.6%	0.6%
44130	Parma/Cleveland	3.8%	3.8%	2.7%	0.6%
44131	Independence/Seven Hills/BrooklynHts	1.5%	1.4%	1.0%	0.0%
44132	Euclid	1.1%	1.1%	1.3%	0.6%
44133	North Royalton	2.0%	2.2%	1.6%	0.0%
44134	Parma/Cleveland	2.9%	2.8%	2.2%	0.2%
44135	Cleveland/Lindale (90%)	2.0%	2.1%	2.4%	0.6%
44136	Strongsville	3.1%	3.3%	1.6%	0.0%
44137	Maple Hts/Cleveland	1.9%	1.8%	1.4%	0.4%
44138	Olmsted Twsp/Olmsted Falls	1.3%	1.3%	0.7%	0.0%
44139	Bentleyville/Glenwillow/Solon	1.6%	1.6%	0.7%	0.2%
44140	Bay Village	1.1%	1.2%	0.3%	0.0%
44141	Brecksville	1.0%	1.0%	0.4%	0.0%
44142	Brookpark/Cleveland	1.5%	1.5%	1.2%	0.4%
44143	Highland Hts/Richmond Heights	1.7%	1.7%	1.2%	0.2%
44144	Brooklyn/Cleveland	1.6%	1.6%	1.3%	0.2%
44145	Westlake	2.3%	2.3%	1.2%	0.2%
44146	Walton Hills/Oakwood/Bedford	2.3%	2.3%	2.3%	0.6%
44147	Broadview Hts	1.1%	1.2%	0.5%	0.0%
44149	Strongsville				0.0%
Unknown Cuyahoga County Zip Codes*****					0.0%
Missing*****					0.0%
Unknown*****					2.8%
Total Cuyahoga County		100.0%	100.0%	100.0%	100.0%
Total Known Cleveland		30.7%	30.6%	47.1%	83.5%
Total Known Suburbs		69.3%	69.4%	52.9%	16.5%
Unknown & Missing					2.8%

Attachment 4: Actual Consumer Zip Codes (continued)

* U.S. Census 2000 SF1 (P1)
** U.S. Census 2000 SF3 (PCT26)
***U.S. Census 2000 SF3 (PCT26)
**** Note: Consumers could be funded by more than one funding source; thus the columns are not necessarily mutually exclusive.
*****Missing Data - For United Way - represents computational errors or incorrect completion of online report. This data may contain zip codes outside of Cuyahoga County so it is not included in the total number served for Cuyahoga County. For all other data - represents data funder was unable to provide.
*****Unknown Data - Represents data not collected by agency because no tracking system is available or type of service delivered makes it difficult (i.e., group presentations, telephone information and referral, and drop-ins). Also represents data not completed by clients either deliberately or inadvertently on intake forms. This data may contain zip codes outside of Cuyahoga County so it is not included in the total number served for Cuyahoga County.
***** Totals vary because of rounding. County total population 1,393,978 does not correspond to the total of zip codes because some zip codes include data from adjacent counties.

Attachment 5: Profile of Core Service Providers – 2005

PROFILE OF CORE SERVICE PROVIDERS - 2005		
Source: United Way - First Call for Help Refer Database February 2005		
	Count	Sub-Count: UW-Affiliated
Total Number of Providers	12	1
Number of Providers by Type		
Nonprofit	12	1
For-profit	-	-
Government	-	-
Other	-	-
Total Number of Sites	12	-
Number of Service Sites per Provider		
1	12	1
2 – 5	-	-
6 – 10	-	-
11+	-	-
Geographical Location of Service Sites, by ZIP Code		
44017 – Berea	2	-
44022 – Bentleyville	-	-
44040 – Gates Mills/Mayfield Village	-	-
44070 – North Olmsted	-	-
44101 – Cleveland	-	-
44102 – Brooklyn/Cleveland	-	-
44103 – Cleveland	-	-
44104 – Cleveland	1	-
44105 – Newburgh Hts/Garfield Hts	-	-
44106 – Cleveland Hts/Cleveland	2	-
44107 – Cleveland/Lakewood	-	-
44108 – Cleveland/East Cleveland	1	-
44109 – Cleveland/Brooklyn Hts	-	-
44110 – Cleveland/Bratenahl	-	-
44111 – Cleveland	-	-
44112 – Cleveland/East Cleveland	1	-
44113 – Cleveland	1	-
44114 – Cleveland	-	-
44115 – Cleveland	-	-
44116 – Rocky River	-	-
44117 – Cleveland/Euclid	1	1
44118 – Euclid/University Hts	-	-
44119 – Cleveland/Euclid	-	-
44120 – Cleveland/Shaker Hts	-	-
44121 – University Hts/South Euclid	-	-
44122 – Orange/Warrensville Hts	1	-
44123 – Euclid	-	-
44124 – Pepper Pike/Mayfield Village	-	-
44125 – Valley View/Garfield Hts	-	-
44126 – Cleveland/Fairview Park	-	-
44127 – Cleveland	-	-
44128 – Cleveland/Warrensville Hts	-	-

Attachment 5: Profile of Core Service Providers – 2005 (continued)

PROFILE OF CORE SERVICE PROVIDERS - 2005		
Source: United Way - First Call for Help Refer Database February 2005		
	Count	Sub-Count: UW-Affiliated
44129 – Cleveland/Brooklyn/Parma	-	-
44130 – Cleveland/Parma	-	-
44131 – Seven Hills/Brooklyn Hts	-	-
44132 – Euclid	-	-
44133 – North Royalton	-	-
44134 – Parma/Cleveland	-	-
44135 – Cleveland/Linndale	-	-
44136 – Strongsville	-	-
44137 – Maple Hts/Cleveland	-	-
44138 – Olmsted Twp/Olmsted Falls	-	-
44139 – Bentleyville/Glenwillow/Solon	-	-
44140 – Bay Village	-	-
44141 – Brecksville	-	-
44142 – Cleveland/Brookpark	-	-
44143 – Highland Hts/South Euclid	-	-
44144 – Brooklyn/Cleveland	-	-
44145 – Westlake	1	-
44146 – Walton Hills/Oakwood/Bedford	1	-
44147 – Broadview Hts	-	-
44149 – Strongsville	-	-
Total Cuyahoga County	12	1
Total Cleveland	5	0
Total Suburbs	7	1

Attachment 6: Providers and Functions – 2005

Service Providers & Functions	
Source: United Way - First Call for Help Refer Database February 2005	
Agency	Services
Berea Children's Home and Family Services	Independent Living - Transitional Housing - Youth
Cleveland Clinic Children's Hospital for Rehabilitation	Inpatient, Outpatient & Intensive Treatment (Main Campus)
Cleveland Sight Center	Recreation And Daily Living Skills For Youth, Daily Living Skills Training, Community Rehabilitation Training, Deaf-Blind Services, Adaptive Diabetes Education
East Cleveland Neighborhood Center	Activities/Camping/Programs For Teens
Far West Center	Support Services - Skills And Support Groups
Hansonhouse TBI Clubhouse	Brain Injury Clubhouse Operations
Jewish Family Service Association of Cleveland	MR/DD - Independent Living
Services for Independent Living	Independent Living Skills Evaluation, Training and Support
Spectrum of Supportive Services	Secondary Community Support Services For Mentally Ill
UHHS Bedford Medical Center	Assistive Technology
United Cerebral Palsy Association of Greater Cleveland	In-Home Supportive Services
Vocational Guidance Services	Independent Living Skills Development

Bold represents agencies funded by United Way for this service.

Attachment 7: United Way - First Call for Help Independent Living Skills Instruction Requests – 2000-2004: Greatest Increase/Greatest Decrease

LR-320 Independent Living Skills Instruction United Way - First Call for Help Requests 2000-2004 Greatest Increase/(Greatest Decrease)								
Zip Code		TOTAL REQUESTS					% Change* 00&04	Avg. # Calls 00-04
		2000	2001	2002	2003	2004		
44120	Shaker Hts/Cleveland	1	1	1	1	4	300%	2
44113	Cleveland	0	1	1	0	3	N/A	1
44115	Cleveland	0	0	0	3	3	N/A	1
44102	Cleveland/Brooklyn	0	3	0	1	2	N/A	1
44125	Valley View/Garfield Hts	0	0	0	0	2	N/A	0
44108	Cleveland/Bratenahl	0	1	0	0	1	N/A	0
44110	Cleveland/East Cleveland	0	2	0	0	1	N/A	1
44143	Highland Hts/Richmond Heights	0	0	0	1	1	N/A	0
44129	Brooklyn/Parma/Cleveland	1	1	0	0	0	(100%)	0
44109	Cleveland/Brooklyn Hts	2	3	1	0	0	(100%)	1
44106	Cleveland/Cleveland Hts	3	2	0	0	0	(100%)	1
44105	Cleveland/Newburgh Hts/Garfield Hts	3	0	1	2	0	(100%)	1
44107	Lakewood/Cleveland	3	0	0	3	1	(67%)	1

**Total Cuyahoga County	17	18	28	25	25	147%	23
**Total Cleveland	10	9	16	13	15	0%	13
**Total Suburbs	7	9	12	12	10	143%	10

* Extremely high percentages are due to low numbers.
 ** These totals do not reflect the sum of the numbers above which are the zip codes reflecting the greatest increase or decrease. Rather, they are the total of calls from ALL zip codes many of which do not appear on this table.

Attachment 8: United Way - First Call for Help Independent Living Skills Instruction 2000-2004: Unmet Need

LR-320 Independent Living Skills Instruction				
United Way - First Call for Help Requests 2000-2004				
Unmet Need				
Zip Code	TOTALS 00-04			% Unmet
	Requests	Met	Unmet	
*Total Cuyahoga County	113	113	0	0%
*Total Cleveland	63	63	0	0%
*Total Suburbs	50	50	0	0%

FCFH DATA NOTES

Met = service request resulting in referral to an organization. (Does not mean agency was able to provide the service.)

Unmet = service request for which there was no referral.

Note: Zip Codes shared by Cleveland and surrounding suburbs whose boundaries fall 50% and greater within the city of Cleveland are highlighted and totaled as Cleveland. Others are totaled as Suburbs.

* These totals do not reflect the sum of the numbers above which are the zip codes reflecting unmet need in 2004. Rather, they are the total of calls from ALL zip codes some of which do not appear on this table.



**United Way of
Greater Cleveland**

1331 Euclid Avenue
Cleveland, Ohio 44115

uws.org/CoreServicesPlanning