

Core Service Report

Condition Specific Rehabilitation

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>.

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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: Condition Specific Rehabilitation Services (LR-157)

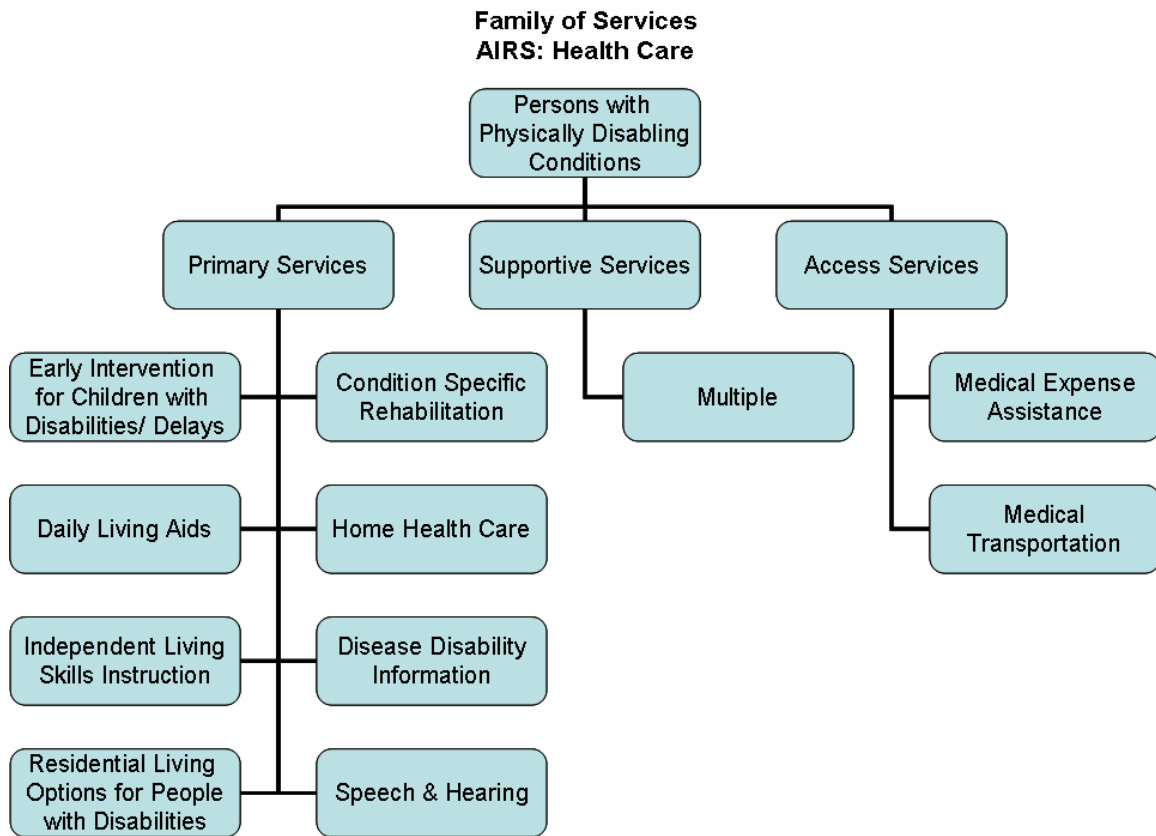
Investment Committee: Health & Caring for All

Cluster: Rehabilitation/Specialized Treatment

AIRS Definition: Programs that provide comprehensive rehabilitation services that help people who have specific types of injuries or other impairments to achieve their maximum level of functioning. Rehabilitation at early ages or stages of a disease or injury process is the focus of such programs/services. The goal of these early rehabilitation programs is to optimize the individual's level of functioning and promote self-sufficiency.

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 3 years and Condition Specific Rehabilitation goes from ages 4 to 20 years.

Condition-specific rehabilitation is for persons with physical disability conditions. It is one of eight services for the population. In addition, medical expense assistance and medical transportation help consumers access these services. (See figure below.)



Core Service Environment

Programs that provide comprehensive rehabilitation services can have the greatest success with early assessment and intervention directed toward young children and their families. Comprehensive early intervention can enable age-appropriate development and facilitate a maximum level of functioning.

The principal public policy issue identified by the American Physical Therapy Association (APTA) and the American Occupational Therapy Association (AOTA) is the reimbursement cap for services from Medicare and Medicaid. Physical and occupational therapists are among the primary providers of rehabilitation services to children who are in non-hospital and non-nursing home settings that tend to be “outpatient or day” treatment programs.

Medicaid and Medicare regulations are key public policy issues and one of the largest and most rapidly growing expenses for federal and state governments. In 2005, Ohio passed a Medicaid budget that significantly limited the projected increase in Medicaid spending mainly by reducing benefits, eligibility, and reimbursements. The Ohio Department of Job and Family Services (ODJFS) estimates that 27,000 patients will lose coverage through this policy action.

Many families are unable to obtain needed health care for their children with severe mental or physical disabilities because they either earn too much to qualify for Medicaid, are without employer health coverage, or have private insurance with inadequate benefits to meet their children’s needs. Private insurers want to avoid risks, and individuals with developmental disabilities often run into issues of insurers excluding payment for pre-existing conditions. The



Family Opportunity Act enacted in 2006 addresses this issue. The purpose of the bill is to allow middle-income families with children who have severe mental or physical disabilities to purchase health care coverage through the Medicaid program.

In June 2000, a gubernatorial executive order created a task force known as Ohio ACCESS to undertake a comprehensive review of Ohio's systems of care for people with disabilities, and recommend improvements by 2006 (Fox-Grage, Folkemer, Straw, & Hansen, 2002). The taskforce 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).

Core Service Consumers

The target population addressed in this core service report is persons ages 4-20, with one or more congenital or acquired physical disability. Acquired disabilities are induced as a result of a birth injury, accident, brain trauma or a physical injury. Disabilities include birth defects, developmental delays, autism, head/brain injuries or other physical trauma, learning disabilities, spinal cord injuries, congenital heart disease, neuromuscular conditions such as cerebral palsy or stroke, spina bifida, mental retardation, acquired brain injury, muscular dystrophy (MD), and fragile X syndrome. There may be children with complex chronic and/or multiple problems.

Children in Cuyahoga County affected by one of the nine categories of disability described in this report are amenable to condition-specific rehabilitation. These children are best served by a rehabilitation team approach. Many of the children affected with these problems or conditions have multiple and complex problems and varying degrees of severity. There appears to be an increase in the incidence of autism and related disorders.

In 2000, an estimated 76,156 persons ages 4 to 20 needed condition-specific rehabilitation in Cuyahoga County, which was 23.5 percent of children and youth, the percent found to be in need of specialized services by the National Survey of Children with Special Health Needs (National Center for Health Statistics, 2001). In 2015, this number is expected to decline to 64,606 due to shifts in population.

Core Service Delivery

For this report, the definition of condition-specific rehabilitation services is as follows: programs that provide comprehensive rehabilitation services that help children and youth with specific types of injuries or other impairments to achieve their maximum level of functioning at early ages or stages. Specifically, the intervention consists of physical, occupational, or speech-hearing therapies or a combination of them. A variety of techniques can be employed.

Rehabilitation services in the broadest sense may also include social work and psychological interventions. In addition, mechanical and electronic assistive devices are being used and developed along with biomedically engineered strategies to facilitate children's appropriate physical, cognitive, verbal, and social development to maximize independent functioning. The development of new interventive strategies to assist these children is an ongoing, evolving process.

There are two major issues that affect the provision of services to these children: the availability of financial resources to provide the necessary interventions in a comprehensive manner to a child to meet the treatment/rehabilitation needs while at an early stage; and the availability of trained professionals and care providers to deliver the critical service needed.



Disabling conditions or injuries often have lifelong consequences. The continuum of care for the disabled child begins with rehabilitation programs and may end with need for further care or assistance to remain independent.

There is no data available from United Way – First Call for Help for this core service. Few calls requesting information about condition-specific rehabilitation are received and, in those instances, callers are referred to their primary care physician.

Medicaid and private insurance are major funders of condition-specific rehabilitation services. Families above Medicaid eligibility have difficulty acquiring services for their children with identified delays and disabilities. The Medicaid recipient increase has been faster in Cuyahoga County than any other urban county.

As of May 11, 2006, \$730,488 in revenues for condition-specific rehabilitation programs has been identified countywide. Over 59 percent of funding came from foundations and the remainder from United Way of Greater Cleveland. Medicaid funding was not included in this number as it includes more than one core service.

What Works; What Doesn't

The measurement of a child's progress in rehabilitation programs includes use of the WeeFIM and Pediatric Evaluation of Disability Inventory (PEDI) for Inpatient Rehabilitation. PEDI is a standardized pediatric assessment designed to serve as a descriptive measure of the child's current functional performance, as well as a method for tracking change across time (Kothari et al, 2003).

Collaboration between public and private organizations and funders is critical to the optimal use of resources for children in need of rehabilitation services. The Help Me Grow program and the Children and Family First Council in Cuyahoga County are collaborations between agencies and governmental entities that work well.

Doman Delcato Patterning, formerly used by physical therapists in the 1960s, is now considered obsolete and dangerous. Psychomotor patterning, a treatment modality for people with mental retardation, brain injury, learning disabilities, and other cognitive maladies, was subjected to controlled trials and found to be of no value (Novella, 1996).

The Joint Commission on Accreditation of Healthcare Organizations (JCAHO) and the Commission on Accreditation of Rehabilitation Facilities (CARF) are two organizations that accredit rehabilitative programs and services for children. The type of accreditation depends on the types of services provided and the nature of the organization.

Gap Analysis

The estimated universe of possible consumers is 2,469, including both realized access (489) and unrealized access (1,980).

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

Programs that provide comprehensive rehabilitation services can have the greatest success with early assessment and intervention directed toward young children and their families. Comprehensive early intervention can enable age-appropriate development and facilitate a maximum level of functioning.

While prevention and safety programs can limit some disabilities, causal evidence to decisively eliminate them is insufficient and much research is still needed. Some are a result of accidents or birth injuries, while others are inherited or genetic. There are some useful medical strategies that can limit the extent of some disabling conditions and problems, but the rehabilitative process is important for most, if not all, of these conditions and problems that are lifelong and often require ongoing intervention or support.

Physical medicine and rehabilitation (PM&R) or physiatry is a branch of medicine dealing with functional restoration of a person affected by physical disability. A physician who has completed training in this field is referred to as a physiatrist. PM&R is a relatively young specialty. Among the early pioneers of the field include Dr. Frank Krusen who developed the Department of Physical Medicine at the Mayo Clinic in 1936. PM&R was recognized as a medical specialty by the American Board of Medical Specialties and the American Medical Association in 1947. The field expanded rapidly, owing in large part to World War II, when many soldiers with severe disability returned to the United States and physicians were necessary to treat and manage chronic debilitating conditions. The polio epidemic in the early 1950s also helped establish the value of physiatrists in management of neuromuscular disorders. Advances that allowed longer survival from disorders as varied as spinal cord injury and stroke led to greater role of physiatrists in managing these chronic conditions. This specialty's research base is still evolving. (Wikipedia.com, 2006)

Physical medicine and rehabilitation involves the management of disorders that alter the function and performance of the patient. Emphasis is placed on the optimization of function through the combined use of medications, physical modalities, and experiential training approaches. Electrodiagnostics are used to diagnose and provide prognosis for various neuromuscular disorders. (Wikipedia.com, 2006)

Common conditions that are treated by physiatrists include amputation, spinal cord injury, sports injury, stroke, and traumatic brain injury. Cardiopulmonary rehabilitation involves optimizing function in those afflicted with heart or lung disease. Chronic pain management is achieved through multidisciplinary approach involving psychologist, physical therapist, occupational therapist, and interventional procedures when indicated. (Wikipedia.com, 2006)

The major concern of the field is the ability of the person to function optimally within the limitations placed upon them by a disease process for which there is no known cure. The general emphasis is not on the full restoration to the pre-morbid level of function, but rather the optimization of the quality of life for those who may not be able to achieve full restoration. A team approach to chronic conditions is emphasized, using trans-disciplinary team meetings to coordinate care of the patients. (Wikipedia.com, 2006)

Three formal sub-specializations are recognized by the field in the United States: pain medicine (in conjunction with anesthesiology, neurology and psychiatry), pediatric rehabilitation, and spinal cord injury (SCI) medicine. A new formal sub-specialty based on post-residency fellowship training in neuromuscular medicine is set to commence in 2008, in conjunction with neurology. Many in the field also sub-specialize in areas of amputee care, musculoskeletal medicine, electrodiagnostics, traumatic brain injury (TBI), cardiopulmonary rehabilitation and neuromuscular disorders. (Wikipedia.com, 2006)

The problems or conditions addressed in this condition-specific rehabilitation services and programs report are those that are recognized at early stages of development (i.e. infancy and early childhood) in the pediatric rehabilitation specialty. Because the effects of these diseases, injuries and conditions can be lifelong, rehabilitation aims to limit the effects of the condition or problem and, as such, the strategic focus of these programs is early intervention with children.

Prevention is the optimal process of limiting the incidence of these conditions and diseases. However, there is insufficient evidence of causation for many of these conditions. Medical research is working on these problems with support from disease/condition specific national associations dedicated to finding cures. There are some useful strategies that can be employed to limit the extent of the problems. These include corrective surgery, genetic counseling and testing, screening of newborns and early intervention, sound nutrition and prenatal care from the beginning of a pregnancy, smoking cessation and drug counseling for pregnant women, and improvements in the variety of rehabilitative interventions. Safety programs aimed at preventing accidents and physical trauma also may be useful in limiting brain injuries.

Agencies have difficulty retaining qualified staff with enough certified professionals to perform the range of therapeutic services. As a result, there is a large group of children requiring specialized services such as speech and hearing who are being underserved.

Federal budget cuts for health and social services affect the availability of services at state and local levels. As a consequence of these budget cuts, states and localities are left to decide how to allocate budgetary resources to an array of services, including rehabilitation services for young children. Medicaid is a primary source of revenue for a variety of services such as nursing home care, medical care, and rehabilitation services—and budget cutting is creating competition for scarce dollars. In addition, voters may be involved in making these decisions with state budget limiting initiatives. It is not clear to the average citizen that local philanthropic efforts alone cannot provide sufficient financial revenue to provide the essential resources to rehabilitate these children.

Locally, service delivery is principally affected by the availability of financial resources from public sources such as Medicaid because private philanthropic support is a supplemental resource that enables only the provision of a comprehensive service program.

PUBLIC POLICY ISSUES

Shared Federal-State Regulations

Medicaid

Medicaid and Medicare regulations are key public policy issues and one of the largest and most rapidly growing expenses for federal and state governments. According to a report by Begala (2005) of the Center for Community Solutions:

Medicaid spending through the Ohio Department of Job and Family Services has increased 78 percent over the past 7 years. While spending increases per recipient are increasing at a rate of only slightly above the rate of medical inflation, annual Medicaid spending is increasing at almost twice the rate of growth in the state's general revenues.

Medicaid costs are determined by only three factors: 1) *eligibility*, the number of participants, 2) *utilization*, the services which are covered and rates at which they are prescribed, and 3) *prices*, the amounts paid for these services. Today, one in six Ohioans are covered by Medicaid through two broad eligibility categories – aged, blind, and disabled (ABD), of whom there are about 420,000, and low-income families and children, of whom there are about 1.3 million.

Medicaid was established as a federal-state program in 1965 (at the same time as Medicare) through Title XIX of the Social Security Act. Medicaid is the largest of the federal-state partnerships for low-income Americans. Medicaid provides matching federal funds to states for certain health care services for eligible parents, children, seniors, and people with disabilities. Each state administers its own Medicaid program. The federal Centers for Medicare and Medicaid services (CMS) monitor state-run programs and establish requirements for service delivery, quality, funding, and eligibility standards. State participation is voluntary, but all states have participated.

The mission of Ohio's Medicaid program is to assure access to comprehensive health care services for targeted populations in order to improve the health status of Ohioans and their communities and to support the self-sufficiency and care of covered populations. Medicaid acts as a value purchaser in the health care market place, seeking improvements in access, cost, and quality while being accountable to consumers and taxpayers. Ohio Medicaid is structured so that services are provided under two benefit plans; acute care services (such as physician, hospital, laboratory, and prescription drugs), and long-term care services (including home- and community-based care, waivers, and services obtained through long-term care facilities.)

The Ohio Medicaid program, as mandated by federal law, provides services such as inpatient hospital, outpatient hospital, prescription drugs, durable medical equipment, physicians, laboratory and x-ray, nursing facility, home health, and early periodic screening and diagnostic treatment (EPSDT) services. These are mandatory services that all state-operated Medicaid programs must provide to eligible consumers. Each state also chooses optional services to include in its state plan. In Ohio, optional covered services include pharmacy, dental, private duty nursing, physical therapy, occupational therapy, speech and hearing, psychology, podiatry, community behavioral health care services, and others. Also, federal law requires these state plan services to be available statewide. Medicaid may offer additional services to persons with disabilities who are

enrolled in a home- and community-based waiver. Ohio covers waiver services such as emergency response systems, home-delivered meals, supplementary equipment/adaptive devices, home modification, out-of-home respite, adult day care, supported employment, and homemaker/personal care services.

Persons with disabilities who are eligible for Medicaid 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.

The federal budget reconciliation legislation in the U.S. Congress session in 2005-06

...gives the states broad and sweeping powers to limit benefits, charge premiums and force cost sharing on the elderly, persons with disabilities, children and others. Federal rules must be issued to guide how states can exercise the options, and states then must decide, by administrative and legislative action, how to exercise them. (These proposed changes) represent the most far-reaching changes in the program since its inception 40 years ago. . . States would be able to establish a new Medicaid eligibility group for children with disabilities under age 19 who meet the severity of disability required under the Supplemental Security Income (SSI) program whose families earn incomes that exceed SSI financial standards but below the 200 percent federal poverty level. (Corlett, 2006)

In 2005, Ohio passed a Medicaid budget that significantly limited the projected increase in Medicaid spending, mainly by reducing benefits, eligibility, and reimbursements. The Health Policy Institute of Ohio published a thorough analysis of the bill. Per their findings, among the many provisions the budget calls for to limit spending, the budget eliminates coverage for patients with incomes between 90 and 100 percent of poverty (100 percent of poverty in 2006 was \$20,000 for a family of four). The Ohio Department of Job and Family Services (ODJFS) estimates that 27,000 patients will lose coverage through this policy action. Total amount of money for the adult dental benefit is reduced by about 50 percent. ODJFS must restructure its adult dental benefit into a smaller package of covered services, affecting around 800,000 adults. The budget cut spending for the Disability Medical Assistance (DMA) program by \$80 million over the two years of the budget, reducing it from \$140 million to \$60 million. Changes in the state Medicaid budget will also affect providers, who in many cases will need to pass on the effects to patients. For example, except for children's hospitals and pharmacies, hospitals will have their payment rates frozen at the SFY 2005 level. Children's hospitals will get a rate increase while pharmacies will receive a rate cut. Hospitals will experience two other actions that will reduce their payments from Medicaid. First, ODJFS is in the process of recalibrating the payment rates for all hospital services. Second, ODJFS is changing its policy for paying cost-sharing payments for people on Medicaid and Medicare (these individuals are known as "dual-eligibles" and the cost sharing is known as "crossover payments"). This change will make sure that Medicaid pays no more than the maximum amount it would pay if the consumer did not have Medicare coverage. The hospital or nursing home will have to seek the rest of the money it is owed from Medicare. The budget bill also requires ODJFS to increase the use of consumer cost sharing. The rules for cost sharing are currently in the clearance review process and

open for public comment. The hope is that cost sharing will make consumers more careful in their use of health services (and reduce use of services) (Hayes, 2005).

Participants in focus groups conducted for United Way of Greater Cleveland’s core service planning (2005) indicated that the number of underserved individuals and families will increase because of diminishing financial resources. Specifically, participants indicated a concern with funding cuts with respect to Ohio’s budget, with particular emphasis on cuts in Medicaid. Families above Medicaid eligibility also have difficulty acquiring services for their children with identified delays and disabilities.

The principal public policy issue identified by the American Physical Therapy Association (APTA) and the American Occupational Therapy Association (AOTA) is the reimbursement cap for services from Medicare and Medicaid. Physical and Occupational therapists are among the primary providers of rehabilitation services to children who are in non-hospital and non-nursing home settings which tend to be outpatient or day treatment programs.

Medicaid reimbursement for home- and community-based care is becoming an increasingly important issue. In 1981, Congress enacted legislation that allowed states to request a waiver from the federal government in order to use Medicaid funds for individuals with chronic disability in non-institutional settings. Prior to this legislation, Medicaid long-term care funds could only be used for nursing home care. To be eligible for Medicaid-funded services under the new home- and community-based waiver, an individual had to meet the nursing home admission criteria as established by each state. Because there were nursing home residents who could be served in non-institutional settings, the popularity of the waiver programs around the United States has increased substantially in the past two decades. Currently every state in the nation has at least one waiver program and in fact there are nearly 300 waivers in operation serving individuals with disabilities of all ages. More than 800,000 participants are being served through this array of waiver programs. The \$19 billion spent on home care waiver programs in 2003 represented nearly 22 percent of all Medicaid long-term care expenditures (Mehdizadeh & Applebaum, 2005).

Specifics of funding policy will be discussed in Section IV of the report.

Medicaid and the Family Opportunity Act

Many families are unable to obtain needed health care for their children with severe mental or physical disabilities. They might earn too much to qualify for Medicaid, be without employer health coverage, or have private insurance with inadequate benefits to meet their children’s needs. The commercial market place operates differently from Medicaid. Private insurers want to avoid risks, and individuals with developmental disabilities often run into issues of insurers excluding payment for pre-existing conditions. The Family Opportunity Act enacted in 2006 is aimed at addressing this issue. The purpose of the bill is to allow middle-income families with children who have severe mental or physical disabilities to purchase health care coverage through the Medicaid program. The bill enables states to allow eligible families to buy-in to the Medicaid program by enabling states to:

- Create a new optional Medicaid eligibility group for children with disabilities under age 19 who meet the severity of disability required under SSI without regard to asset or eligibility requirements and 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 on a sliding scale based on income, but cannot exceed five percent of family income up to 200 percent of the federal poverty level (Ohio Development Disabilities Council, 2006).

Families of children with special health care needs face significant family strains and barriers in securing health coverage. Children with disabilities are more likely to live with single parents, especially their mothers. Parents of children with special needs are less likely to marry and more likely to divorce. And families with children with special health care needs have high levels of finance-related problems, including issues with securing and maintaining employment and employer sponsored health care (Ohio Development Disabilities Council, 2006).

As of 2005, more than 32 states offer a Medicaid buy-in type of system; however, Ohio is not one of these states. Many organizations, including the Ohio Developmental Disabilities Council, are advocating for adoption of a Medicaid buy-in program for Ohio families with children with special health care needs (Ohio Development Disabilities Council, 2006).

Ohio

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 taskforce—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).

The ACCESS task force made several recommendations; however, most were focused on improving long-term care services for Ohioans with disabilities rather than on rehabilitation services. Below are the task force's key recommendations:

- *Match capacity with demand.* Put simply, expenditures for publicly funded care in Ohio is misaligned with the expectations and desires of Ohio's consumers. Adjustments to the current Medicaid reimbursement system for institutional care are needed to slow the growth in the cost of these services, while at the same time investing an additional \$145 million dollars to expand home- and community-based services for persons with disabilities.
- *Generate and sustain the necessary resources to expand community services.* Without a shift of some funding to community settings, alternative community services will not grow and be sustained.
- *Overcome federal policy constraints.* Ohio must work with the National Governors' Association and other national groups to lobby for more flexible regulations. At the same time, state policy makers must continue to be responsive to the Health Care Financing Administration and the federal Office of Civil Rights to assure Ohio's compliance with the mandates of the Americans with Disabilities Act (ADA), allowing consumers to choose the most integrated settings for services.



- *Address the health care workforce shortage.* Good management techniques and the adoption of best practices can create a work environment in which people are treated fairly and professionally. More emphasis should be placed on training and supporting supervisors who make the transition from direct care. The state should encourage the creation of demonstration projects to increase workforce efficiency.
- *Overcome policy constraints on self-sufficiency and personal responsibility.* There are currently far too many policy barriers that inhibit persons with disabilities from achieving self-sufficiency. To the extent that such barriers exist, the state has an important role in developing mechanisms to remove them. Also, while the state plays an important role in financing and organizing long-term care services, the vast majority of long-term care services and supports is given informally by relatives, neighbors, and friends. Ohio has an important role in supporting, not replacing, this informal network.

III. THE CORE SERVICE CONSUMERS

DEFINITION OF TARGET POPULATION

The target populations addressed in this core service report are persons age 4 to 20 years old who have congenital or acquired disabilities.¹ Acquired disabilities are induced as a result of a birth injury, accident, brain trauma, or a physical injury. Such disabilities include birth defects, developmental delays, autism, head/brain injuries or other physical trauma, learning disabilities, spinal cord injuries, congenital heart disease, neuromuscular conditions such as cerebral palsy or stroke, spina bifida, mental retardation, acquired brain injury, muscular dystrophy (MD), and fragile X syndrome. There may be children with complex chronic and/or multiple problems.

DEMOGRAPHIC CHARACTERISTICS

For this analysis, prevalence and incidence numbers will be used to describe the persons affected by a condition, illness or disease. *Prevalence* quantifies the proportion of individuals in a population who have a condition during a specific time period. *Incidence* refers to the number of new cases that develop in a population of individuals at risk during a specific time period. While both prevalence and incidence rates have similar denominators (that is, the population at risk) and include new cases in their numerator, prevalence rates also contain existing cases in the numerator.

Some diagnoses of persons who would benefit from condition-specific rehabilitation are referred to as (1) conditions, and (2) illnesses or diseases. Conditions are usually caused by damage to one or more areas of the brain; illness is a state of being ill or in an unhealthy state; and a disease is a defined state with specific symptoms, location, and/or causes. Conditions, illnesses, and diseases can be acute, temporary, progressive, and/or chronic. What follows is a list of children’s conditions (not all inclusive) or injuries and illnesses that are amenable to rehabilitation.

- **Birth Defects.** A birth defect occurs while the baby is developing in the mother’s body. Most birth defects happen during the first 3 months of pregnancy. A birth defect may affect how the body looks, works, or both. It can be found before birth, at birth, or any time after birth. Most defects are found within the first year of life. Birth defects can vary from mild to severe. Some birth defects can cause the baby to die. Babies with birth defects may need surgery or other medical treatments, but, if they receive the help they need, these babies often lead full lives. Birth defects include congenital heart disease and other heart defects, cleft palate, spina bifida, and brain anencephaly. About 3 percent of babies are born with birth defects annually (Department of Health and Human Services [DHHS] & the Centers for Disease Control and Prevention [CDCP], n.d.).
- **Genetic Syndromes.** Genetic disorders are medical conditions caused by mutations in a gene or a set of genes. Mutations are changes in the DNA sequence of a gene. There are four categories of genetic disorders: (1) chromosome abnormalities (e.g. Down syndrome), (2)

¹ The U.S. Census does not track disability for individuals younger than 5 years old, and provides a significant amount of information organized by the age cohort 4-20 years old.

single-gene disorders (e.g. sickle cell anemia), (3) multi-factorial disorders (e.g. diabetes), and (4) mitochondrial disorders (Genetic Science Learning Center, University of Utah, 2005).

- **Neuromuscular Conditions** (such as cerebral palsy, stroke, spina bifida, and mental retardation). Cerebral palsy is a term used to describe a group of chronic conditions affecting movement and muscle coordination. It is caused by damage to one or more specific areas of the brain, usually occurring during fetal development. The annual incidence of cerebral palsy is 2 to 2.5 per 1,000 births. The incidence rate is approximately 1 in 34,000 or 0.00 percent or 8,000 people in the US (WrongDiagnosis.com, 2005).

It is estimated that some 764,000 children and adults in the United States manifest one or more of the symptoms of cerebral palsy. Currently about 8,000 babies and infants are diagnosed with the condition each year. In addition, some 1,200 – 1,500 preschool age children are recognized each year to have cerebral palsy (United Cerebral Palsy, 2001).

- **Head/Brain Injuries** or other physical trauma that result in loss of muscle and/or cognitive functioning. Traumatic brain injury (TBI) is defined in the Individuals with Disabilities Education Act (IDEA) as

...an acquired injury to the brain caused by an external physical force, resulting in total or partial functional disability or psychosocial impairment, or both, that adversely affects a child's educational performance. The term applies to open or closed head injuries resulting in impairments in one or more areas, such as cognition; language; memory; attention; reasoning; abstract thinking; judgment; problem solving; sensory, perceptual, and motor abilities; psycho-social behavior; physical functions; information processing; and speech.

More than 1 million children sustain brain injuries each year, and more than 30,000 of these children have lifelong disabilities as a result (National Dissemination Center for Children with Disabilities, 2004).

- **Developmental Delays.** A developmental delay occurs when a child does not reach his or her developmental milestones at the expected times. It is an ongoing, major delay in the developmental process rather than a temporary developmental lag as may be experienced by many children. Developmental delay is usually diagnosed by a doctor based on strict guidelines and may require an assessment by a developmental specialist (Boyse, 2005). A developmental delay may affect a child's speech and language, fine and gross motor skills, and/or personal and social skills.

It is possible that a child with a developmental delay who receives services will not develop a disability; whereas if the same child did not receive services, the delay would become a disability ... The 1997 reauthorization of Individuals with Disabilities Education Act (IDEA) added that for children 3 through 9, the state and local education agency (LEA) may define a child with a disability as a child who is experiencing developmental delays and needs special education and related services. (Valdivia, 1999)

Developmental milestones are determined by the average age at which children attain each skill; therefore, statistically, about 3 percent of children will not meet them on time, but only about 15-20 percent of these children will actually have abnormal development. The rest (temporary lagging) will eventually develop normally over time, albeit a little later than expected (Keep Kids Healthy, 2005).

- **Learning Disabilities.** A learning disability (LD) is a neurological disorder that affects the brain's ability to receive, process, store, and respond to information. The term *learning disability* describes the seemingly unexplainable difficulty a person of at least average intelligence has in acquiring basic academic skills. These skills are essential for success at school and work, and for coping with life in general. LD is not a single disorder. It is a term that refers to a group of disorders. Learning disabilities include autism, dyslexia, dyscalculia, dysgraphia, attention deficit disorder (ADD) and attention deficit hyperactivity disorder (ADHD).

The prevalence of Learning Disabilities in children is estimated at 4.6 million children or 1 in 59 persons in the U.S. About 3.3 million children have Attention Deficit Disorder (ADD) or 3 to 5 percent of all children. (WrongDiagnosis.com, 2005)

- **Autism.** While autism may be grouped with learning disabilities, the incidence and prevalence of the diagnosis has risen such that the disorder needs to be examined by itself.

Autism and Asperger Syndrome are two of the five pervasive developmental disorders (PDD), more often referred to today as autism spectrum disorders (ASD). All these disorders are characterized by varying degrees of impairment in communication skills, social interactions, and restricted, repetitive and stereotyped patterns of behavior. The autism spectrum disorders can often be reliably detected by the age of 3 years, and in some cases as early as 18 months. Studies suggest that many children eventually may be accurately identified by the age of 1 year or even younger. The appearance of any of the warning signs of ASD is reason to have a child evaluated by a professional specializing in these disorders. (Strock, 2004)

A report of Ohio Public Schools on the prevalence of autism showed a dramatic rise in the growth of autism from 1992 to 2003. This represents an annual average growth rate of 81 percent. In 2003, there were 5,490 public school children diagnosed with autism (Fighting Autism, 2004). A count of the number of autistic children in 2004 by the Ohio Department of Education showed 600 school districts reporting 6,308 children with autism. In Cuyahoga County 37 districts reported 1,053 children with autism (Ohio Department of Education, 2005).

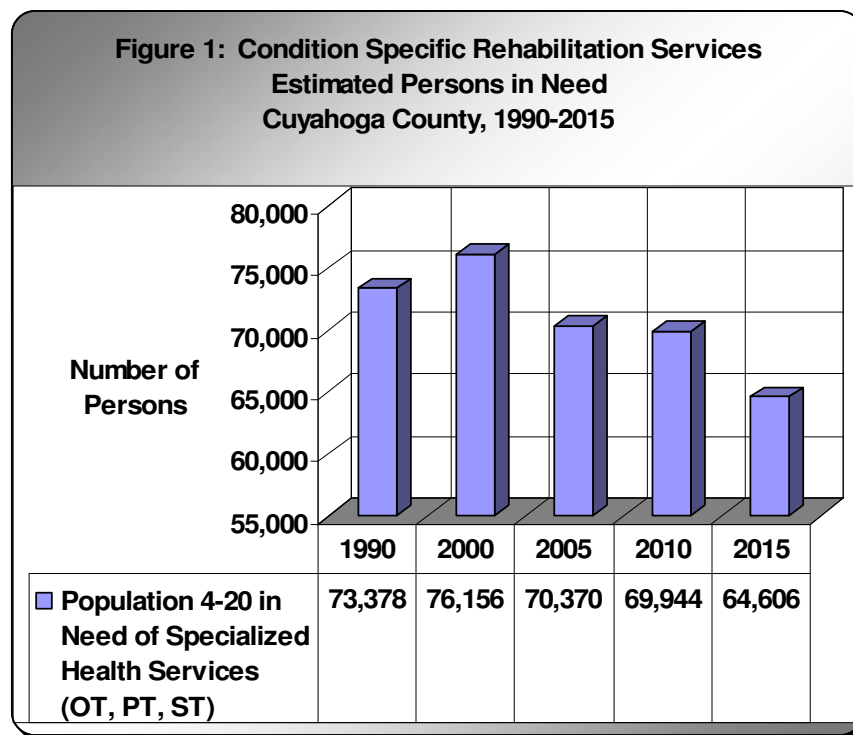
- **Fragile X Syndrome** is a hereditary/genetic condition that includes mental impairments such as severe cognitive or intellectual challenges (mental retardation), and autistic like behaviors. Fragile X syndrome can also include other conditions that affect balance, tremor, and memory in males; and early menopause in females.

- Muscular Dystrophy (MD).** Muscular dystrophy (MD) is a group of rare diseases. They cause muscle fibers to weaken and break down. MD affects the skeletal or voluntary muscles that control movement in the arms, legs and trunk. It also can affect the heart and other involuntary muscles, such as those in the gut. MD passes from parent to child (genetic) and gets worse over time (progressive). There are nine major types of MD affecting people of all ages, from infancy to middle age or later. The two most common types of MD affect children. “The incidence rate of muscular dystrophy in the U.S. is approximately 1 in 651,450 persons, or about 417 persons annually” (WrongDiagnosis.com, 2005).

Local and state data about these conditions and diseases can be estimated utilizing the national prevalence and incidence rates. However, such estimates must be based on the same population age groups and the methodology utilized. These two items of information are not known.

Estimated Persons in Need

In 2000, an estimated 76,156 persons ages 4 to 20 needed condition-specific rehabilitation in Cuyahoga County, which was 23.5 percent of children and youth 4 to 20, the percentage found to be in need of specialized services by the National Survey of Children with Special Health Needs (2001). This number is expected to decline to 64,606 by 2015 due to shifts in population. (See Figure 1.)



Sources:

* US Census: 1990, STF 1 (P11); 2000, SF3 (P8); 2005-2015, Ohio Department of Development, (July, 2003). Note: Age 4-20 in 1990 was prorated from Ages 3-20, and in 2005-2015 was prorated from ages 5-19, both using ratios from 2000 age group data.

** National Survey of Children with Special Health Needs (2001) estimates that 23.5 percent of children needed Occupational Therapy (OT), Physical Therapy (PT), or Speech Therapy (ST) in the past 12 months.

This estimate begins to give clarity to 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 of Greater Cleveland 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 of Greater Cleveland funded 489 Cuyahoga County residents 21 years and younger for condition-specific rehabilitation services. (See Attachment 3.)

Per the 2000 US Census, while 51 percent of the county's total 4-20 population was male and 49 percent female, agencies funded by United Way served 62 percent male and 38 percent female.

In 2000, according to the U.S. Census, 59 percent of the county's total 4-20 population was Caucasian, 36 percent African American, and 2 percent Asian. Agencies funded by United Way of Greater Cleveland served 47 percent Caucasian, 35 percent African American, and 1 percent Asian, with the remaining 18 percent unknown. Three percent were Hispanic, compared to the countywide total of 5 percent.

Thirty-five percent of those funded by United Way of Greater Cleveland reported annual household income below \$10,000, and forty-one percent had income \$30,000 and over.

Geographically, 35 percent of estimated persons 4-20 resided in Cleveland and the remaining 65 percent in the suburbs. (See Attachment 4). Agencies funded by United Way of Greater Cleveland served just over one third in Cleveland (38 percent), with 62 percent in the suburbs.

IV. CORE SERVICE DELIVERY

CORE SERVICE DEFINITION

Building on the AIRS definition of condition-specific rehabilitation services, the definition for this core service report is: programs that provide comprehensive rehabilitation services that help persons 4 through 20 years with specific types of injuries or other impairments to achieve their maximum level of functioning at early ages or stages. Specifically, the intervention consists of physical, occupational, or speech-hearing therapies or a combination of them. A variety of techniques can be employed.

BACKGROUND ON CORE SERVICE

Because developmental disabilities by definition begin during childhood and are expected to persist throughout life, services are generally lifelong—often beginning with early intervention for infants and toddlers and continuing through old age. Advances in medicine and health care have made it possible for many children born with disabilities not only to survive birth and infancy but also to have corrective medical interventions and rehabilitation services that enable them to grow into adulthood and achieve levels of functioning. In adulthood, persons with disabilities may need care and supportive services to enable them to live and work in the community rather than the rehabilitative services provided earlier in their lives. At times, long-term care services such as in-home services or nursing facilities are needed.

For children, rehabilitation services may require hospital or residential care and treatment, day treatment, and/or outpatient treatment. The approach to intervention and management of many of these disabling childhood conditions requires a multi-disciplinary approach—medicine, nursing, social service, rehabilitation, physical, occupational, speech, and other specialty therapists. Mechanical and electronic assistive devices are being developed to facilitate the rehabilitation process and mobility, medical care (implanted medication pumps, stimulation devices), and communication. Services for parents, guardians, and caregivers are also important to ensure that program interventions and techniques are continued in the home setting.

The likelihood of requiring aids and devices increases with the severity of the disability ... The likelihood of requiring an aid or device increases from 51 percent for those with mild disabilities, to 89 percent among those with very severe disabilities ... Among children, the most commonly required aids/devices are those related to learning disabilities: specialized computers ... tutors ... recording equipment ... talking books ... hearing aids. ... Children with disabilities are less likely than adults to have their needs for assistive aids/devices fully met. Just a little over half (54 percent) of children ... have what they need, while just under half (46 percent) have unmet needs. (Canadian Council on Social Development, 2005)

The cost of assistive aids/devices is the principal reason that children do not have them.

Current research suggests that therapy for children with disabilities works better by scheduling intense therapy for short periods of time during bursts of development; for example, 12 weeks spent in a rehabilitation facility followed by 12 weeks of an at-home program. One of the outstanding questions being asked is how to identify the burst of development and how to make sure that service is accessible immediately. A related issue is parental expectations. Parents have typically viewed therapies as a cure, and more are better. Families need to be educated about the new therapy model. This new strategy of intense treatment for short periods of time may be more beneficial to the life of a family. Regular therapy appointments for long periods of time can be stressful.

Other effective rehabilitation treatment strategies include:

- Neurodevelopmental treatment (NDT)
- Therapeutic listening
- Activity analysis
- Sensory processing/integrations therapy
- Oral motor therapy
- Augmented communication: picture exchange communication system (PECS), voice output systems (electronic speech devices), sign language
- Oral motor apraxia treatment. (This is the dis-coordination of oral movements and planning of speech production.)
- Oral motor exercises for awareness and strengthening, followed by the Kaufman method of teaching sound production and home program to practice
- Cochlear implants, especially implanted prior to age two and follow- up training
- Language therapy (separated into *comprehension* and *expression*): comprehension—understanding questions, directions; expression—verbally communicating or using augmented communication to express needs
- Feeding therapy (based on individual needs of child)
- Serial casting
- Splinting: hand made splits used to avoid contractures in children with high muscle tone and to facilitate functional use of limb

Finally, occupation therapists, physical therapists, and speech therapists are beginning to develop rehabilitation protocols for some specific disabilities.

Rehabilitation treatment teams are comprised of licensed and certified professionals in physical occupational and speech therapy, social workers, physiatrists, pediatricians, and nurses who carry out a plan of treatment and intervention with both the child and the family.

The field of pediatric rehabilitation has grown since the 1980's due to a number of factors, namely deinstitutionalization, greater awareness of the capabilities of disabled persons, advocacy, and public policy changes (ADA, IDEA).

The definition of pediatric rehabilitation has expanded to include the care and treatment of children with congenital and acquired disabilities ... Complete assessment of the child with a disability includes a parent-child interview and physical assessment, with particular focus on the child's developmental age, movement patterns, and functional activities of daily living ... Cerebral palsy and spina bifida are the two most common childhood

disabilities. With advanced technological equipment and refined surgical techniques, the child’s potential for independence is reaching new heights (Burkett, 1989).

United Way - First Call for Help Call Data

There is no data available from United Way – First Call for Help for this core service. Few calls requesting information for condition-specific rehabilitation are received, and in those instances callers are referred to their primary care physician.

FUNDING OF CORE SERVICES

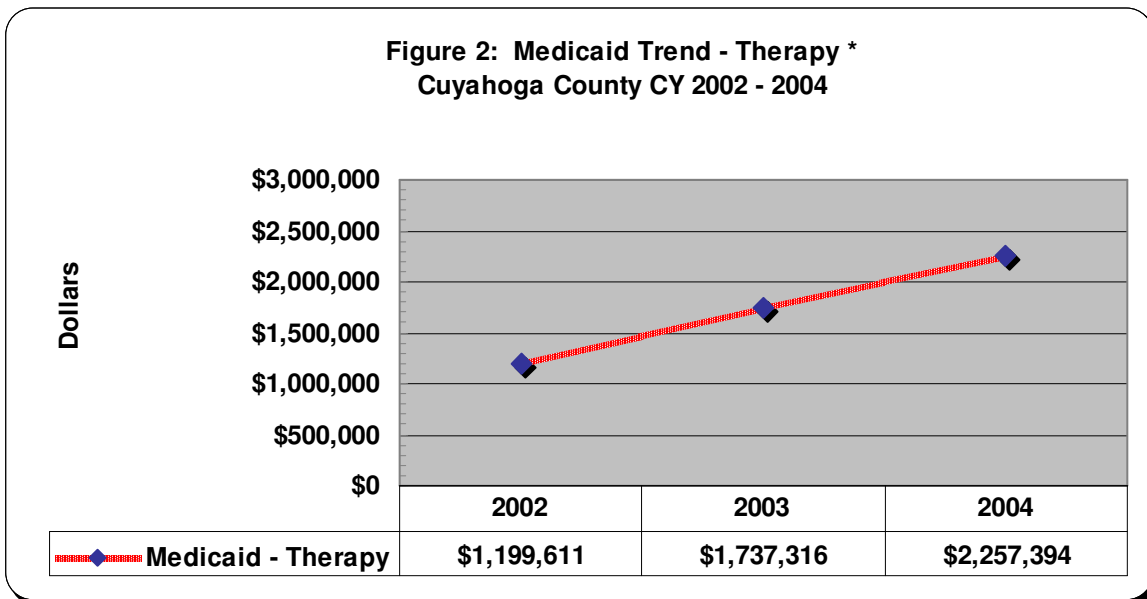
Major Government Funders

The major sources of government funding for condition-specific rehabilitation are:

- Medicaid
- Medicare

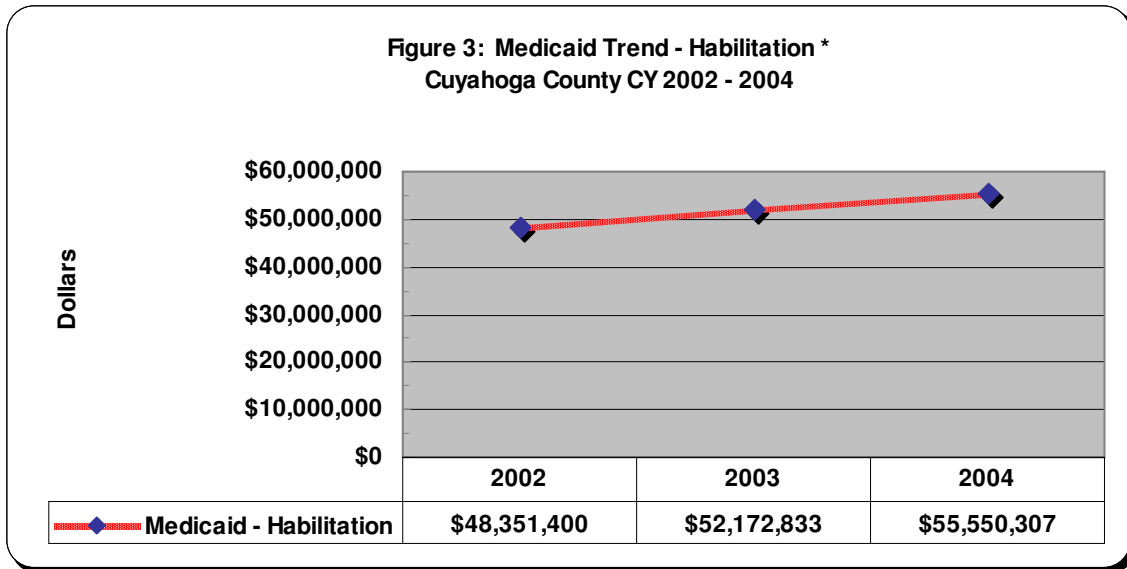
Medicaid

In the last ten years, the number of Medicaid recipients has increased by 120 percent. The Medicaid cost in the same time has increased 78 percent. The Medicaid recipient increase has been faster in Cuyahoga County than any other urban county. Between 2002 and 2004, Medicaid funding for therapy in Cuyahoga County increased from \$1.2 million to \$2.25 million. Note that multiple therapeutic services fall into this category. (See Figure 2.)



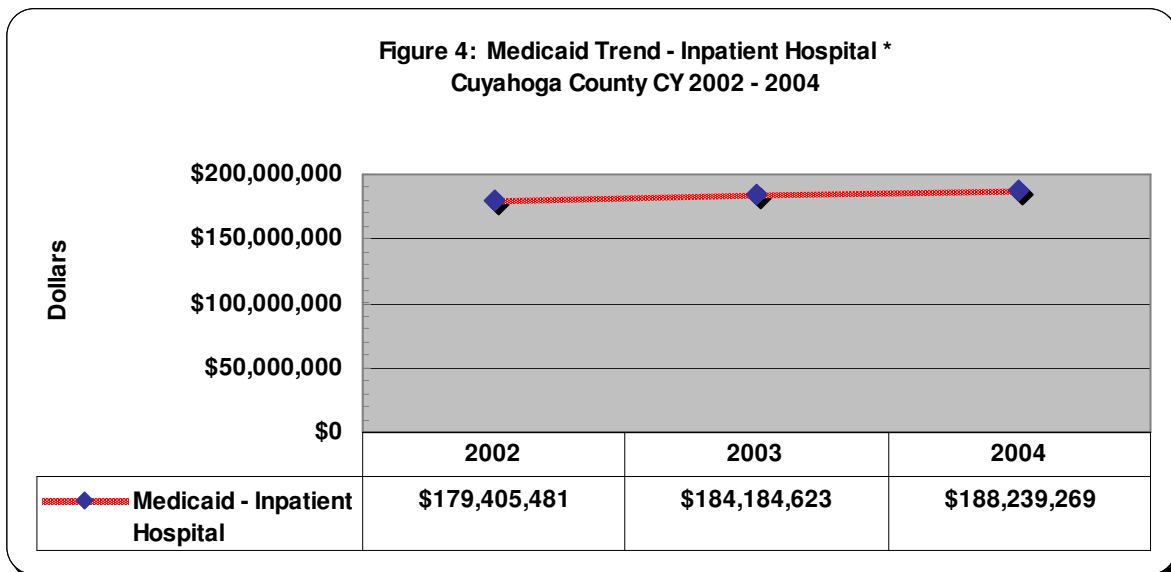
* Includes the following core services: Condition Specific Rehabilitation, Early Intervention for Children with Disabilities/Delays, and Speech & Hearing

Between 2002 and 2004, Medicaid funding for habilitation in Cuyahoga County increased from \$48.3 million to \$55.5 million. Note that multiple therapeutic services fall into this category. (See Figure 3.)



* Includes the following core services: Condition Specific Rehabilitation, Early Intervention for Children with Disabilities/Delays, and Residential Living Options for People with Disabilities

Between 2002 and 2004, Medicaid funding for inpatient hospitalization in Cuyahoga County increased from \$179 million to \$188 million. Note that multiple therapeutic services fall into this category. (See Figure 4.)



* Includes the following core services: Condition Specific Rehabilitation and Medical Expense Assistance

IDENTIFIED REVENUES

As of May 11, 2006, \$730,488 in revenues for condition-specific rehabilitation programs has been identified countywide. This includes information from foundations; special events; regional, county and municipal government; and United Way of Greater Cleveland. (See Table 1.)

In 2004, Medicaid provided about \$2.5 million in reimbursement for the two condition-specific rehabilitation programs funded by United Way of Greater Cleveland (UW). This represented only 54 percent of the costs of services, the balance being provided by UW, program service fees, foundations and trusts, charitable donations, and other sources.

Table 1: Partial Identified Annual Revenue for Core Services: Countywide and United Way of Greater Cleveland Condition-Specific Rehabilitation 2003/2004.

Funder	Period	A		B	
		Identifiable Total Dollars Countywide		Total Dollars UW-Funded Agencies (Actual FY2004)	
		Amount	% of Total (A)	Amount	% of Total
Total - Contributions and dues (less UW designations)			0.00%	83,235	1.81%
Cleveland Foundation, The	2004	76,665		22,964	
Eaton Charitable Fund	2003	2,000			
Hershey Foundation, The	2004	14,500			
Key Foundation	2003	7,850			
Kulas Foundation	2004	15,000			
Mt. Sinai Health Care Foundation, The	2003	220,000			
Murphy Foundation, The John P	2004	5,000			
O'Neill Foundation, The William J. and Dorothy K.	2003	11,000			
Other Corporate Foundations - Not Elsewhere Classified	2003	5,200			
Other Private Foundations - Not Elsewhere Classified				158,306	
Prentiss Foundation, Elisabeth Severance	2003	55,000		20,819	
Sherwin-Williams Foundation, The	2004	11,500			
White Foundation, The Thomas H.	2004	10,000			
Total - Foundations & Trusts		433,715	59.37%	202,089	4.39%
Total - Special Events - Growth			0.00%	205,339	4.46%
Board of Mental Retardation and Developmental Disabilities (169 Board)				62,993	
Subtotal Cuyahoga County Funding Sources		0	0.00%	62,993	1.37%
Medicaid *				2,429,687	
Medicare				2,218	
Other Private Insurer				779,245	
Subtotal Third Party Payee/Direct Bill		0	0.00%	3,211,150	69.79%
Total - Contracts/grants from government organizations		0	0.00%	3,274,143	71.16%
Private Pay/Fee for Service				212,969	
Total - Program Service Fees		0	0.00%	212,969	4.63%
Total - Investment Income			0.00%	86,400	1.88%
Total - Prior Period balances/interfund transfers			0.00%	240,177	5.22%
Subtotal Non - UWGrCle Support		433,715	59.37%	4,304,352	93.55%
Total - UWGrCle designations applied to program		21,829	2.99%	21,829	0.47%
Total - UWGrCle investment committee allocation		274,944	37.64%	274,944	5.98%
Subtotal UUWGrCle Support - 4001, 4701 & 4703		296,773	40.63%	296,773	6.45%
Total Support/Revenue		730,488	100%	4,601,125	100%

* Medicaid dollars have not been entered under countywide total for this core service because not all Medicaid services are a one-to-one match with United Way core services. 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. Medicaid Service - Inpatient Hospital (\$188,329,269 in 2004) - Falls into AIRS 1 Basic Needs and Health Care and includes the following core services: Condition Specific Rehabilitation Services and Medical Expense Assistance. Medicaid Service - Therapy (\$2,257,394 in 2004) - Falls into AIRS 1 Health Care and includes the following core services: Condition Specific Rehabilitation, Early Intervention for Children with Disabilities/Delays, and Speech & Hearing.

REIMBURSEMENT/COST

Not Available.

V. WHAT WORKS; WHAT DOESN'T

IMPACT ON INDIVIDUALS/FAMILIES

What Works

As in all health and human services, rehabilitation providers are facing increasing pressure to show evidence of improved functioning as part of meeting rehabilitation goals. The measurement of a child's progress in rehabilitation programs includes use of the WeeFIM and Pediatric Evaluation of Disability Inventory for Inpatient Rehabilitation.

WeeFIM IISM is:

- A standardized process that allows credentialed clinicians across the country and around the world to measure and document functional performance in children and adolescents with either acquired or congenital disabilities in a consistent manner.
- A reliable outcomes measurement instrument that can be applied uniformly across inpatient, outpatient, and community-based settings.
- A benchmarked outcomes management system that provides a method of evaluating outcomes for individual patients, groups of patients (population-based), and overall medical rehabilitation/habilitation programs (Uniform Data System for Medical Rehabilitation [UDSMR], 2005).

The WeeFIM IISM System has been accepted by the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) to provide performance measures for the ORYX® Initiative. The WeeFIM IISM System can also be used to meet accreditation standards for the Commission on Accreditation of Rehabilitation Facilities (CARF) (UDSMR, 2005).

The Pediatric Evaluation of Disability Inventory (PEDI) for Inpatient Rehabilitation is a standardized pediatric assessment tool that quantifies changes during rehabilitation through test scores. PEDI was developed to provide a comprehensive clinical assessment of key functional capabilities and performance in children between the ages of six months and seven years. The PEDI was designed primarily for the functional evaluation of young children; however, it can also be used to evaluate older children if their functional abilities fall below those expected of seven-year-old children without disabilities. The assessment was designed to serve as a descriptive measure of the child's current functional performance, as well as a method for tracking change across time. The PEDI measures both capability and performance of functional activities in three content domains: 1) self-care, 2) mobility, and 3) social function (Kothari et al, 2003).

General best practices of service delivery to individuals with disabilities include the following:

- Provide comprehensive and coordinated service delivery of a broad range of services with a single-entry point for access;
- Are consumer driven, consumer friendly, based on self-determination, and utilize person-centered planning;
- Are culturally competent;

- Support caregivers by providing such services as respite and information and referral to enable them to not be “burned out”; and
- Utilize multi-disciplinary approaches.

In addition, there are some best practices for the distinct needs of specific populations. Leading programs for infants and toddlers with disabilities are characterized by the following: the earlier the intervention the better, high levels of parental involvement, and well-defined curriculums (as opposed to less structured programs). For aging MR/DD individuals whose caregivers are also aging (a situation termed *double-jeopardy*), pre-planning for the time when caregivers will no longer be able to be responsible is essential. For individuals who are acquiring living skills, programs should focus on helping the individual adapt to his/her environment, engage in meaningful work, and develop satisfying, lasting relationships. All program activities need to emphasize personal empowerment and offer constant opportunities to learn, develop, and exercise increasing levels of self-determination, recovery, and control. Program activities need to flow with the natural rhythms of daily life (i.e. work/study in the daytime, recreation and play after work and on weekends). Additionally, programs should not look exclusively at “medical impairment” to determine work eligibility, but should also focus on functional limitations and consider utilizing situational assessments.

Cultural competence in treatment of individuals with disabilities is a leading practice. The significance of culture in the understanding of disability and the rehabilitation process is of paramount importance. An individual’s culture has been shown to serve as both a barrier to recovery as well as a facilitator for recovery (Stodden, Stodden, Kim-Rupnow, Thai, & Galloway, 2002). The following practices are recommended to train personnel that provides services to individuals with disabilities:

- Understand diverse cultural backgrounds and preferences of culturally and linguistically diverse (CLD) persons with disabilities;
- Participate as a team member in service, training, and research settings,
- Implement inclusive practices;
- Incorporate person-centered practices that includes relationship-building with CLD persons with disabilities; and
- Focus on successful strategies for the particular CLD groups they serve (Stodden, Stodden, Kim-Rupnow, Thai, & Galloway, 2002).

What Doesn’t Work

Doman Delcato Patterning, formerly used by physical therapists in the 1960s, is now considered obsolete and dangerous.

In the 1960s, psychomotor patterning was proposed as a new treatment modality for people with mental retardation, brain injury, learning disabilities, and other cognitive maladies. The method was subjected to controlled trials and found to be of no value. It was debated in the scientific literature up until the early 1970s, when the scientific medical community arrived at the consensus that it should be discarded as a false concept with no therapeutic role. Its use, however, has not stopped (Novella, 1996).

The concept of patterning was invented by Glenn Doman and C. Delacato and is therefore often referred to as the Doman-Delacato technique. Their

theories are primarily an extension of the outdated concept that ontogeny (the stages through which organisms develop from single cell to maturity) recapitulates phylogeny (the evolutionary history of the species). Thus the neuron-developmental stages of crawling, creeping, crude walking, and mature walking through which normal children develop is directly related to the amphibian, reptilian, and mammalian evolutionary human ancestors. (Novella, 1996)

Doman and Delacato postulated that mental retardation represents a failure of the individual to develop through the proper phylogenetic stages. Their treatment modality supposedly stimulates proper development of these stages, each of which must be mastered before progress can be made to the next stage. This stimulation is done through what they call "patterning," in which the patient moves repeatedly in the manner of the current stage. (Novella, 1996)

Medical treatments are evaluated on two criteria, their theoretical basis and their empirical value. The scientific community has rejected patterning on both counts. By the 1960s, it became clear that recapitulation it is based on an incorrect linear concept of evolution. Evolutionary lines continuously branch and deviate, forming a complex bush of relationships, not a linear ladder of descent. Embryological development does not reflect the mature stages of other distant branches of this evolutionary bush. Studying the embryology of the developing fetus also does not reveal any evidence of successive stages reflecting past evolutionary ancestors. (Novella, 1996)

According to participants in United Way’s core service planning (2005), there is no centralized location where all agencies can post or share information about what is happening within their particular program or to access data about available services for their clients. It is difficult for some service providers to navigate existing sources of information and determine which program should be selected for a particular client.

IMPACT ON COMMUNITY

The Economic Costs of Disabilities

In 2003, RTI International (Research Triangle Park, North Carolina) and the Center for Disease Control (CDC) analyzed data from multiple surveys and reports to estimate the direct and indirect economic costs associated with four DD’s [Developmental Disabilities] in the United States. On the basis of that analysis, estimated lifetime costs in 2003 dollars are expected to total \$51.2 billion for persons born in 2000 with mental retardation, \$11.5 billion for persons with cerebral palsy, \$2.1 billion for persons born with hearing loss, and \$2.5 billion for persons with vision impairment. (Centers for Disease Control, 2004)

The same study estimated average costs per person for the developmental disabilities of mental retardation, cerebral palsy, hearing loss, and vision impairment. The types of costs estimated were direct medical costs (including physician visits, prescriptions, therapy, rehabilitation, etc.), direct

non-medical costs (including home and vehicle modifications and special education), and indirect costs (including costs resulting from increased morbidity and premature mortality). Mental rehabilitation had the highest average cost per person. Indirect costs accounted for the largest percentage of costs for each developmental disability. The table below outlines these findings.

TABLE. Estimated prevalence and lifetime economic costs* for mental retardation, cerebral palsy, hearing loss, and vision impairment, by cost category — United States, 2003

Developmental disability	Rate [†]	Direct medical costs [§] (millions)	Direct nonmedical costs [¶] (millions)	Indirect costs ^{**} (millions)	Total costs (millions)	Average costs per person
Mental retardation	12.0	\$7,061	\$5,249	\$38,927	\$51,237	\$1,014,000
Cerebral palsy	3.0	1,175	1,054	9,241	11,470	921,000
Hearing loss	1.2	132	640	1,330	2,102	417,000
Vision impairment	1.1	159	409	1,915	2,484	566,000

* Present value estimates, in 2003 dollars, of lifetime costs for persons born in 2000, based on a 3% discount rate.

[†] Per 1,000 children aged 5–10 years, on the basis of Metropolitan Atlanta Developmental Disabilities Surveillance Program data for 1991–1994.

[§] Includes physician visits, prescription medications, hospital inpatient stays, assistive devices, therapy and rehabilitation (for persons aged < 18 years), and long-term care (for persons aged 18–76 years), adjusted for age-specific survival.

[¶] Includes costs of home and vehicle modifications for persons aged ≤76 years and costs of special education for persons aged 3–17 years.

^{**} Includes productivity losses from increased morbidity (i.e., inability to work or limitation in the amount or type of work performed) and premature mortality for persons aged ≤35 years with mental retardation, aged ≤25 years with cerebral palsy, and aged ≤17 years with hearing loss and vision impairment.

Source: Centers for Disease Control (CDC). (2004). Economic costs associated with mental retardation, cerebral palsy, hearing loss and vision impairment. Morbidity and Mortality Weekly Report. United States.

ACCREDITATIONS/STANDARDS/CERTIFICATIONS

Program Accreditation

The Joint Commission on Accreditation of Healthcare Organizations (JCAHO) and the Commission on Accreditation of Rehabilitation Facilities (CARF) are two organizations that accredit rehabilitative programs and services for children. The type of accreditation depends on the types of services provided and the nature of the organization.

Professional Staff Licensure and Certification

Physical therapists, occupational therapists, and speech-language pathologists are the three main providers of condition-specific rehabilitation services.

The American Physical Therapy Association (APTA) is a national professional organization. Its goal is to foster advancements in physical therapy practice, research, and education. The APTA has standards of practice and criteria for membership (The American Physical Therapy Association, 2005).

The American Occupational Therapy Association (AOTA) is the nationally recognized professional association of occupational therapists, occupational therapy assistants, and students of occupational therapy. Occupational therapy practitioners can be credentialed at either the professional (occupational therapist) or technical (occupational therapy assistant) level. The occupational therapist completes a baccalaureate, entry-level master's, or entry-level doctoral degree; and the occupational therapy assistant completes a 2-year associate degree (OTA) program at one of more than 300 accredited programs at colleges and universities throughout the United States. Beginning January 1, 2007, occupational therapists will be credentialed at the post baccalaureate degree level. Occupational therapy and occupational therapy assistant students must also complete a supervised fieldwork program and pass a national certification exam. All 50 states, the District of Columbia, and Puerto Rico regulate the practice of occupational therapy. Many of these jurisdictions mandate periodic continuing education requirements. AOTA's accrediting body,

the Accreditation Council for Occupational Therapy Education (ACOTE) has established standards for the profession that have been adopted by many states in their laws and regulations (The American Occupational Therapy Association, Inc, 2005).

The American Speech Language Association (ASLA) certifies speech language personnel. Audiologists and speech-language pathologists must be licensed to practice by the State of Ohio. They may be certified by the American Speech Language Association, which is considered in the licensure process. A master's degree is the entry level to practice in both pathology fields.

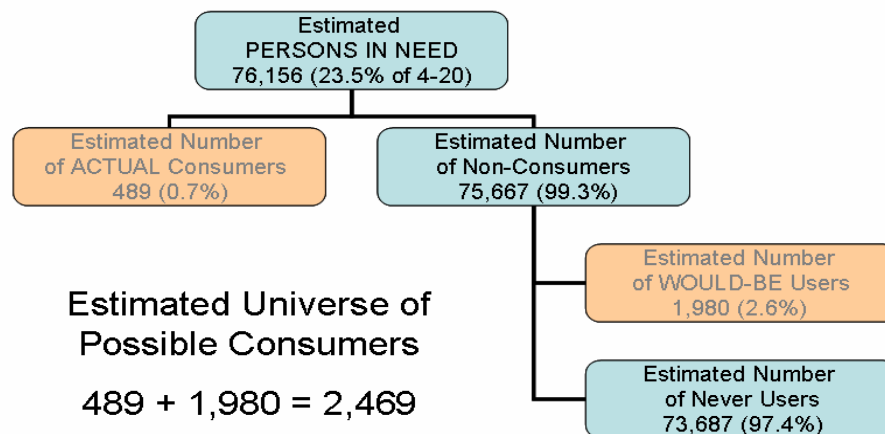
The Ohio Occupational Therapy, Physical Therapy, and Athletic Trainers Board regulates the professions of occupational therapy, physical therapy, and athletic training and licenses practitioners. The Ohio Board of Speech-Language Pathology and Audiology licenses speech-language pathologists.

VI. GAP ANALYSIS

The following is the formula for arriving at the estimated universe of possible consumers for Condition Specific Rehabilitation:

- An estimated 76,156 persons need condition-specific rehabilitation services, which is 23.5 percent of persons 4-20 in Cuyahoga County, the percentage found to be in need of specialized services by the National Survey of Children with Special Health Needs (2001).
- Based on available information about actual consumers, approximately 489 persons have realized access to condition-specific rehabilitation, which is the number of individuals funded by United Way of Greater Cleveland for this service.
- This leaves a net estimate of 75,667 persons 4-20 who are either receiving services from unaccounted-for sources or are not receiving services ($76,156 - 489 = 75,667$).
- The National Survey of Children with Special Health Care Needs (U.S. Department of Health and Human Services, 2001) found that 2.6 percent of children that needed specialized health services (occupational therapy, physical therapy, or speech therapy) did not get them. Applying this percentage figure to the estimated number of persons in need ($76,156 \times 2.6\%$) results in 1,980 children and youth who would use the service if they knew about it, it was available, and was affordable.
- Including both realized and unrealized access ($489 + 1,980$), the estimated universe of possible consumers for condition-specific rehabilitation is 2,469. (See Figure 5.)

Figure 5 - Consumer Estimate: Condition Specific Rehabilitation



Note that many of those who are actual consumers are under-served primarily because of funding limitations. Furthermore, there are trends (e.g. the increasing number of children with autism as well as medical advancements that save more at risk infants) that are likely to increase the future numbers of children needing early intervention services.

Service Site Index

Because United Way-First Call for Help does not track requests for this service, we do not have sufficient information on number of sites to provide a service site index.

Service Capacity

Waiting lists for service indicate the lack of duplication even for clients who apparently have the same condition or problem and have applied for rehabilitative services with different program providers. The current condition-specific rehabilitation providers treat an ever-growing variety of childhood conditions and disabilities. The geographic absence of a program is not a sufficient reason to develop similar programs given the capabilities of these agencies to provide rehabilitative services, their facility capacities and the necessary professional staff complement to serve the populations in need.

There are financial and non-financial barriers to health care service. Financial barriers principally have to do with insurance and increasing out-of-pocket costs even for a family with insurance. If the legislature implements changes in the Medicaid system, the poor will be faced with co-pays and other costs that will cause them to avoid the rehabilitation services needed for their child, or will require financial assistance from the care providers. Non-financial barriers include cultural barriers. The issue may reflect the cultural competency of the health care provider and the provider systems; these barriers may include language barriers and/or social barriers with regard to ethnic and cultural differences.

The working poor are “underserved and un-served,” and entirely dependent on the “system” to receive health care. This population may work for minimum wage, live “day to day,” and usually does not receive employee benefits. So the burden of paying for the rehabilitation of their children falls entirely on them. Ineligibility for Medicaid assistance and lacking the resources to pay for services may mean that a child will not receive treatment.

One condition-specific rehabilitation agency has a waiting list for physical therapy with a wait time as long as 3 months. Limited funding makes it difficult for this organization to increase capacity to shorten the waiting time.

Interconnecting health records was identified as additional collaboration that could make services more effective. Electronic health records could be interconnected throughout the region, although this would require an enormous amount of work and cooperation.

Participants in focus groups for United Way of Greater Cleveland’s core service planning (2005) identified the following gaps regarding their service populations:

- Services for the target populations will only be available to persons who have insurance; generally this would be persons who qualify for Medicaid/Medicare or upper income persons who are highly insured. Moderate and middle-income persons without extensive insurance will be left out.
- There will be an increase in the underserved. Funding will not support persons receiving the full set of services, which optimal treatment for their condition would call for.
- Individuals will be burdened with the responsibility of health care, including attention to extraordinary services because of their condition throughout their life span.
- Individuals will increasingly have to make greater contributions toward their health care costs, as insurers increase co-pays if/when Medicaid eligibility shrinks.
- Poor people are not being served adequately.

VII. SUMMARY

The following are the major findings from the research on this service:

- Programs that provide comprehensive rehabilitation services can have the greatest success with early assessment and intervention directed toward young children and their families.
- There are two major issues that affect the provision of services to disabled children: the availability of financial resources to provide the necessary interventions in a comprehensive manner to a child who meets the treatment/rehabilitation needs while at an early stage; and the availability of trained professionals and care providers to deliver the critical service needed.
- Disabling conditions or injuries often have lifelong consequences. The continuum of care for the disabled child begins with rehabilitation programs and may end with need for further care or assistance to remain independent.
- Many families are unable to obtain needed health care for their children with severe mental or physical disabilities because they either earn too much to qualify for Medicaid, are without employer health coverage, or have private insurance with inadequate benefits to meet their children's needs. The purpose of the Family Opportunity Act, enacted in 2006, is to allow middle-income families with children who have severe mental or physical disabilities to purchase health care coverage through the Medicaid program.
- The reimbursement cap for services from Medicare and Medicaid is an important public policy issue. Physical and occupational therapists are among the primary providers of rehabilitation services to children who are in non-hospital and non-nursing home settings that tend to be "outpatient or day" treatment programs.
- In 2005, Ohio passed a Medicaid budget that significantly limited the projected increase in Medicaid spending mainly by reducing benefits, eligibility, and reimbursements.
- As of May 11, 2006, \$730,488 in revenues for condition-specific rehabilitation programs has been identified countywide. This excludes Medicaid.
- The measurement of a child's progress in rehabilitation programs includes use of the WeeFIM and Pediatric Evaluation of Disability Inventory for Inpatient Rehabilitation.
- Collaboration between public and private organizations and funders is critical to the optimal use of resources for children in need of rehabilitation services.
- Doman Delcato Patterning, formerly used by physical therapists in the 1960s, is now considered obsolete and dangerous.
- The estimated universe of possible consumers is 2,469, including both realized access (489) and unrealized access (1,980).

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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: Condition Specific Rehabilitation Services LR-157				
			Estimated Persons in Need	Actual Number/Percent of Consumers by Funding Source ****
	Total Population (%)*	Total Population 4-20 (%)**	Population 5-20 in Need of Specialized Health Services (OT, PT, ST) (%) ***	UW Program Report Data Cuyahoga County Only (90.7%)
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
TOTAL	1,393,978	324,068	76,156	489
Percent		23.2%	23.5%	
GENDER				
Male	47.2%	51.1%	N/A	61.8%
Female	52.8%	48.9%	N/A	38.2%
Unknown Data*****				0.0%
Missing Data*****				0.0%
RACE*****				
White alone	67.1%	58.7%	N/A	46.6%
Black or African American alone/combination	27.9%	36.1%	N/A	34.5%
Asian alone/combination	2.1%	2.0%	N/A	0.9%
American Indian and Alaska Native alone/combination	0.7%	0.8%	N/A	0.0%
Native Hawaiian and Other Pacific Islander alone/combination	0.1%	0.0%	N/A	0.0%
Some other race alone/combination	2.1%	3.1%	N/A	0.9%
Unknown Data*****				17.1%
Missing Data*****				0.0%
HISPANIC*****	3.3%	4.8%	N/A	3.0%
AGE				
0-4	6.5%			48.1%
5-9	7.3%	31.4%	N/A	34.9%
10-14	7.1%	30.6%	N/A	13.2%
15-19	6.4%	27.4%	N/A	3.3%
20-34	19.1%	10.6%	N/A	0.6%
35-54	29.3%			0.0%
55-64	8.7%			0.0%
65-74	7.8%			0.0%
75+	7.8%			0.0%
Unknown Data*****				0.0%
Missing Data*****				0.0%
INCOME*****				
Average Household Size	2.4	N/A	N/A	N/A
\$0-\$9,999	11.3%	N/A	N/A	35.4%
\$10,000-\$14,999	6.9%	N/A	N/A	3.3%
\$15,000-\$19,999	6.7%	N/A	N/A	3.9%
\$20,000-\$29,999	13.6%	N/A	N/A	6.1%
\$30,000 and above	61.5%	N/A	N/A	40.8%
Unknown Data*****				10.4%
Missing Data*****				0.0%
Totals	100.00%	N/A	N/A	100.0%

Attachment 3: Actual Consumer Demographics (continued)

* U.S. Census 2000, SF1(P1); SF4 (PCT 144)
** U.S. Census 2000, SF1 (P1); SF4 (PCT 144)
*** National Survey of Children with Special Health Needs (2001) estimates that 23.5 percent of children needed Occupational Therapy (OT), Physical Therapy (PT), or Speech Therapy (ST) in the past 12 months.
****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." 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: Condition Specific Rehabilitation Services LR-157					
				Estimated Persons in Need	Actual Number/Percent of Consumers by Funding Source ****
	City/Town (% Cleveland)	Total Population (%)*	Total Population 4-20 (%)**	Population 4-20 in Need of Specialized Health Services (OT, PT, ST) (%)***	UW Program Report Data Known Cuyahoga County Zip Codes (%)
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
TOTAL		1,393,978	324,068	76,156	489
Percent			23.2%	23.5%	
44017	Berea	1.4%	1.5%	1.5%	0.6%
44022	Bentleyville	1.3%	0.8%	0.8%	0.4%
44040	Gates Mills/Mayfield Village	0.2%	0.2%	0.2%	0.0%
44070	North Olmsted	2.5%	2.4%	2.4%	1.2%
44101	Cleveland (100%)	0.0%	0.0%	0.0%	0.2%
44102	Cleveland/Brooklyn (95%)	3.8%	4.3%	4.3%	6.3%
44103	Cleveland (100%)	1.8%	2.3%	2.3%	1.0%
44104	Cleveland (100%)	2.1%	3.0%	3.0%	4.1%
44105	Cleveland/NewburghHts/GarfieldHts (75%)	4.0%	4.8%	4.8%	5.7%
44106	Cleveland/Cleveland Hts (60%)	2.3%	2.5%	2.5%	1.0%
44107	Lakewood/Cleveland	4.1%	3.4%	3.4%	12.3%
44108	Cleveland/Bratenahl (90%)	2.6%	3.3%	3.3%	1.8%
44109	Cleveland/Brooklyn Hts (98%)	3.3%	3.5%	3.5%	2.9%
44110	Cleveland/East Cleveland (98%)	1.9%	2.3%	2.3%	1.2%
44111	Cleveland (100%)	3.1%	2.9%	2.9%	6.3%
44112	East Cleveland/Cleveland	2.4%	2.8%	2.8%	2.9%
44113	Cleveland (100%)	1.4%	1.3%	1.3%	0.6%
44114	Cleveland (100%)	0.3%	0.1%	0.1%	0.0%
44115	Cleveland (100%)	0.6%	0.8%	0.8%	0.8%
44116	Rocky River	1.5%	1.2%	1.2%	1.4%
44117	Euclid/Cleveland	0.9%	0.7%	0.7%	0.0%
44118	ClevelandHts/UniversityHts/ShakerHts	3.3%	3.5%	3.5%	3.7%
44119	Cleveland/Euclid (50%)	1.0%	0.8%	0.8%	0.4%
44120	Shaker Hts/Cleveland	3.4%	3.6%	3.6%	5.7%
44121	University Hts/South Euclid	2.5%	2.5%	2.5%	3.1%
44122	Beachwood/Highland Hills/ShakerHts	2.5%	2.2%	2.2%	3.5%
44123	Euclid	1.3%	1.2%	1.2%	0.8%
44124	Pepper Pike/MayfieldHts/Lyndhurst	2.9%	2.1%	2.1%	0.4%
44125	Valley View/Garfield Hts	2.2%	2.1%	2.1%	0.6%
44126	Fairview Park/Cleveland	1.2%	1.1%	1.1%	1.4%
44127	Cleveland (100%)	0.6%	0.8%	0.8%	1.8%
44128	Warrensville Hts/Cleveland	2.4%	2.4%	2.4%	2.9%
44129	Brooklyn/Parma/Cleveland	2.1%	1.9%	1.9%	1.4%
44130	Parma/Cleveland	3.9%	3.0%	3.0%	2.0%
44131	Independence/Seven Hills/BrooklynHts	1.5%	1.2%	1.2%	0.8%
44132	Euclid	1.1%	1.0%	1.0%	0.2%
44133	North Royalton	2.1%	2.1%	2.1%	0.6%
44134	Parma/Cleveland	2.9%	2.5%	2.5%	1.4%
44135	Cleveland/Linddale (90%)	2.1%	2.0%	2.0%	3.9%
44136	Strongsville	3.2%	3.3%	3.3%	2.5%
44137	Maple Hts/Cleveland	1.9%	2.0%	2.0%	2.5%
44138	Olmsted Twp/Olmsted Falls	1.3%	1.2%	1.2%	1.2%
44139	Bentleyville/Glenwillow/Solon	1.6%	2.0%	2.0%	0.4%
44140	Bay Village	1.2%	1.1%	1.1%	0.8%
44141	Brecksville	1.0%	0.9%	0.9%	0.4%
44142	Brookpark/Cleveland	1.5%	1.4%	1.4%	0.8%
44143	Highland Hts/Richmond Heights	1.7%	1.5%	1.5%	0.2%
44144	Brooklyn/Cleveland	1.6%	1.2%	1.2%	1.2%
44145	Westlake	2.3%	2.1%	2.1%	0.6%
44146	Walton Hills/Oakwood/Bedford	2.3%	1.9%	1.9%	0.8%
44147	Broadview Hts	1.2%	1.1%	1.1%	1.2%
44149	Strongsville				1.4%
Unknown Cuyahoga County Zip Codes*****					0.2%
Missing*****					0.0%
Unknown*****					10.2%
Total Cuyahoga County *****		100.0%	100.0%	100.0%	100.0%
Total Known Cleveland		40.3%	34.7%	34.7%	38.2%
Total Known Suburbs		59.7%	65.3%	65.3%	61.6%
Unknown & Missing					10.2%

Attachment 4: Actual Consumer Zip Codes (continued)

* U.S. Census 2000, SF1 (P1)
** U.S. Census 2000, SF1 (P1)
*** National Survey of Children with Special Health Needs (2001) estimates that 23.5 percent of children needed Occupational Therapy (OT), Physical Therapy (PT), or Speech Therapy (ST) in the past 12 months.
**** 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: Providers and Functions – 2005

Service Providers & Functions	
Source: United Way	
Agency	Services
Achievement Centers for Children	
Cleveland Clinic Children's Hospital for Rehabilitation	

Bold represents agencies funded by United Way for this service. First Call for Help does not collect data on this service; thus this is not an inclusive list of providers.



**United Way of
Greater Cleveland**

1331 Euclid Avenue
Cleveland, Ohio 44115

uws.org/CoreServicesPlanning