

# Core Service Report

## Early Intervention for Mental Illness

Consumer Category:  
**Behavioral Health Conditions**

Primary Consumer Group:  
**Persons With or At Risk of  
Mental Illness**



February 2007

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## COMPANION REPORTS

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

## ACKNOWLEDGEMENTS

We are grateful to the multiple public and private funders, provider agencies, experts in the various fields of interest, external reviewers, United Way Community Investment Committee clusters, and staff of United Way for their assistance, support, information, and insight. We would like to acknowledge the substantial contributions of the Cuyahoga County Community Mental Health Board.

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Suggested Citation: MCS Consulting Service. (2007). Core service report: Early intervention for mental illness. United Way of Greater Cleveland. Available at <http://uws.org>

## SNAPSHOT

**AIRS Code Level I: Mental Health Care & Counseling (R)**  
**AIRS Code Level II: Psychiatric Support Services (RR)**  
**Core Service: Early Intervention for Mental Illness RR-180**

**Investment Committee: Strong Families = Successful Children**  
**Cluster: Mental Health/Counseling**

**AIRS Definition:** Programs that identify and provide treatment for individuals whose personal condition and social experiences could potentially produce mental, emotional, or social dysfunctions with the objective of preventing their development; or that conduct general screening efforts to achieve early identification and treatment of children who have incipient problems to ensure the best possible prognosis.

**Special Note:** There are six core services related to persons with or at risk of mental illness. In order to avoid as much duplication as possible across reports, the core services were organized as a continuum across the mental health services. The table below distinguishes the services by age, severity and service description. Certain sections of the reports are necessarily common across each report, such as the public policy and accreditation sections. Other sections such as the core service environment, service delivery, and what works sections are customized to that population. Some sections will be mixed because of the way funding is reported. For instance, it is not always possible to break out mental health funding by age, as opposed to a core service area such as general counseling. Where possible, every effort was made to make each of the mental health core service reports unique to its population.

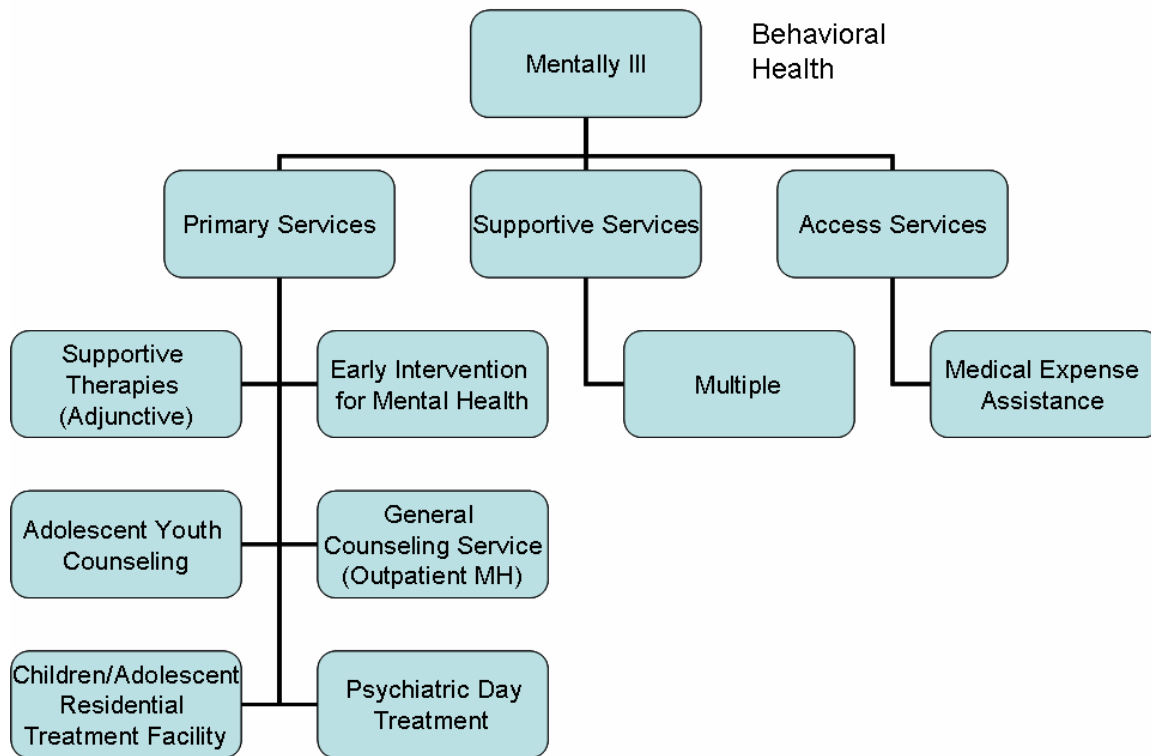
Core Service	Consumers		Service Description
	Age	Severity	
Early Intervention for Mental Illness	Children 0-5 years	Have or are at risk for psychiatric disorders.	Programs that conduct general screening efforts for early identification of children 0-3 who have incipient problems to ensure the best possible prognosis; and programs that provide treatment for individuals ages 0-5 whose personal condition and social experiences could potentially produce mental, emotional, or social dysfunctions, with the objective of preventing their development.
Adolescent Youth Counseling	Children and youth 5-17 years	Any mental disorder or serious emotional disturbance	Programs that specialize in the treatment of adolescents through services that are provided in traditional settings (offices and clinics) as well as in the client's natural environment (home, school, or community)
Children's/Adolescent Residential Treatment	Children and youth 5-17 years	Serious emotional disturbances (SED)	Programs that provide a therapeutic living environment in a community-based facility

Core Service	Consumers		Service Description
	Age	Severity	
General Counseling Service (Outpatient Mental Health Facilities)	Adults ages 18+ years	Moderate to severe mental illness who do not need twenty-four hour care	Programs that provide mental health services in outpatient settings
Psychiatric Day Treatment	Children, youth and adults ages 5+ years	Any severe mental disorder that does not require full-time hospital care, but can benefit from a structured environment for some portion of the day or week	Programs that provide therapeutic services in a structured outpatient setting for several hours of each day and multiple times per week
Supportive Therapies	Children, youth and adults ages 5+ years <sup>1</sup>	A mental disorder	Programs that utilize guided expressive or recreational activities or other specialized interventions as auxiliary forms of treatment to improve the adjustment of individuals with mental, emotional, or social problems; and to facilitate other forms of therapy. Supportive therapies may be used for diagnostic purposes and are, on occasion, utilized as primary treatment modalities.

<sup>1</sup> Supportive therapies are utilized for individuals of all ages, including children under 5. However, most of the important sources utilized in this report (specifically the Cuyahoga County Mental Health Assessment report of 2003 produced by the Center for Community Solutions and the Cuyahoga County Community Mental Health Board) did not provide information for individuals younger than 5. The report on Early Intervention for Children with Mental Illness focuses on this population.

The Early Intervention for Mental Illness Program is part of a family of services for persons who are at risk of or are mentally ill. It is one of six services targeting this consumer group. Medical expense assistance is also a service that helps those who are uninsured or under-insured access mental health services.

**Family of Services  
AIRS: Mental Health Care & Counseling**



*Core Service Environment*

Understanding mental illness in young children is challenging because of the ongoing development process. The normally developing child hardly stays the same long enough to make stable measurements. Criteria for adult illness can be difficult to apply to children when the signs and symptoms of mental disorders are also often the characteristics of normal development. At some point, however, it becomes clearer that certain symptoms and behaviors cause great distress and may lead to dysfunction of children, their families, and others in their social environment. At these points, it is helpful to consider serious deviations from expected cognitive, social, and emotional development as “mental disorders.” Specific treatments and services are available for children with such mental disorders, but one cannot forget that these disorders emerge in the context of an ongoing developmental process and shifting relationships within the family and community. These developmental factors must be carefully addressed if one is to maximize the healthy development of children with mental disorders, promote remediation of associated impairments, and enhance their adult outcomes (Surgeon General, 1999).

Highly significant public policy issues that impact early intervention for infants and toddlers is reimbursement for services from third parties such as private insurance, Medicaid, and the federal Individuals with Disabilities Education Improvement Act (IDEA) of 2004. This has several dimensions including an institutional bias to reimbursement schemes that include hospitals and inpatient facilities, but exclude community-based organizations; third party insurers are disallowing reimbursement for certain diagnoses such as autism; and there is no payment differentiation for the greater time it takes to work with a child than with an adult (Nobili, 2005).

IDEA in particular is a key law that affects early intervention services. Part C of IDEA specifically addresses services for infants and toddlers with disabilities. Part C is a federal grant program that assists states in operating a comprehensive statewide program of early intervention services for infants and toddlers with disabilities, ages birth through 3, and their families. The current statute and regulations for Part C contain many requirements states must meet, including specifying the minimum components of comprehensive statewide early intervention system. States have some discretion in setting the criteria for child eligibility, including whether or not to serve at risk children. In addition, IDEA requires states to refer for early intervention services any child under the age of 3 who: (a) is involved in a substantiated case of child abuse or neglect; or (b) is identified as affected by illegal substance abuse, or withdrawal symptoms resulting from prenatal drug exposure.

#### *Core Service Consumers*

The target population addressed in this core service report is the population of children 0-5 who have or are at risk for psychiatric disorders.

Estimates of national prevalence rates of young children with psychosocial problems are between 10 percent and 21 percent, while rates specifically for externalizing problems can be as high as 25 percent (Powell, Fixsen, and Dunlap, 2003). In infants and toddlers, these problems can manifest themselves as an inability to regulate emotions and form secure attachments (e.g., strong, enduring affective bonds with caregivers). Children who are abused or neglected are particularly at risk.

According to the report of the President's New Freedom Commission on Mental Health (2003), early childhood is a critical period for the onset of emotional and behavioral impairments (Shonkoff and Phillips, 2000). In 1997, the latest data available, nearly 120,000 preschoolers under the age of six—or 1 out of 200—received mental health services (Pottick and Wagner, 2002).

Several biological and environmental circumstances can adversely impact neurobehavioral functioning, making a child more susceptible to emotional disturbances. If not addressed, the emotional disturbance can be worsened or can become compounded by multiple risk factors. These include low birth weight; developmental delays, disabilities, and chronic illness; inadequate nutrition; drug and lead exposure; exposure to violence; maltreatment; stress; and out-of-home placements.

In Cuyahoga County, 2 percent of children 0-4 years were told they had a learning disability; 0.7 percent that they had an attention deficit disorder; and 7 percent had taken prescription medication regularly for at least 3 months.

For children aged 3–17, the rate of having any mental health service use varied from 6.0 percent to 7.5 percent. Rates of preschool children ranged

from (2 percent to 3 percent for children 3–5 years old). Across data sets, a higher percentage of children with public insurance used services than did the uninsured and privately insured children. In these unadjusted analyses, ethnic minority status was significantly associated with lower rates of use; male children had higher rates of mental health use than did female children. Weighted estimates of unmet need for children under age 6 were available only in the National Health Interview Survey. Of 1,499 children 4–5 years old, 131 were estimated to have mental health problems, but of the 131 children in need, only nine used any mental health services in the preceding year. (Kataoka et al., 2002)

Based on findings from the National Survey of Children with Special Health Care Needs (2001), a certain percentage of children 0-5 years will need mental health services. In Cuyahoga County, this total is 10,060 children. This number is projected to decrease to 8,600 in 2015 because of population shifts.

*Core Service Delivery*

The definition of the core service for this report is: programs that conduct general screening efforts for early identification of children 0-3 who have incipient problems to ensure the best possible prognosis; and programs that provide treatment for individuals ages 0-5 whose personal condition and social experiences could potentially produce mental, emotional, or social dysfunctions, with the objective of preventing their development.

There are two primary phases in early intervention services: (1) evaluation, assessment, diagnosis and linkage to services; and (2) early intervention depending on the service need(s) of each child. Some of these are related to need for mental health interventions. In addition, there are consultations and training services available for those who provide the direct services to children identified (e.g. early childhood providers, mental health agencies, and schools.)

There is no data available from United Way - First Call for Help for this core service.

The majority of funding for early intervention for mental illness comes from Medicaid and the Children’s Health Insurance Program (CHIP) and IDEA.

As of May 11, 2006, \$833,535 in revenues for the early intervention for mental illness programs has been identified countywide, excluding Medicaid dollars. Eighty-four percent of the revenues are from contracts or grants from government organizations. United Way of Greater Cleveland accounts for 13 percent of revenue through both Investment Committee allocations and designations.

*What Works; What Doesn’t*

Welcome Home is effectively identifying families at highest risk for abuse/neglect and referring them to Early Start (now Help Me Grow) and other services; in total, almost 24 percent of families who receive a Welcome Home visit are linked with on-going support from Early Start or early intervention services. Almost 99 percent of families visited by Welcome Home reported the experience as helpful (Invest in Children Cuyahoga County, 2005).

Most psychotherapies are deemed effective for children and adolescents because they improve more than they would with no treatment (Casey & Berman, 1985; Hazelrigg et al., 1987; Weisz et

al., 1987; Kazdin et al., 1990; Baer & Nietzel, 1991; Grossman & Hughes, 1992; Shadish et al., 1993; Weisz & Weiss, 1993; Weisz et al., 1995). But it is not clear which therapies are best for which conditions.

Child and adolescent therapy that is carefully defined (usually by a treatment manual) and delivered under carefully controlled, research-oriented conditions is usually found to be effective at reducing mental health problems. Overall, outcome research has not indicated marked differences in treatment effectiveness as a function of client gender, age, ethnic group, or diagnostic category.

Behavioral and cognitive therapies have accumulated much more empirical support than any other type of intervention (Chambless & Ollendick, 2001). Meta-analyses of family systems therapy have produced substantial support for this approach to treatment (Shadish et al., 1993; Stanton & Shadish, 1997). There is particularly strong support for structured forms of family therapy that include cognitive-behavioral elements (e.g., multisystemic therapy, functional family therapy).

A recent Colorado study contrasted the \$1,020 cost for two days of psychiatric hospitalization with the \$987 cost for an entire year of intervention by a behavioral specialist to prevent expulsion from child care. The \$5,000 cost of early intervention services in Maryland were also contrasted with the following: \$35,000 per child per year for therapeutic foster care; \$55,000 to \$75,000 for a year in a therapeutic group home; and \$100,000 to \$120,000 for a year in a residential treatment center (Maryland Committee for Children, 2006).

#### *Gap Analysis*

The assumption is that all children birth to three years need screening for mental health issues. The estimated universe of possible consumers for early intervention services is 7,814 persons including both realized (2,784) and unrealized (5,030) access.

Unfortunately, most children with mental disorders do not receive appropriate treatment. Only about one fifth of these young people receive specialty mental health services. About twice that number receive some type of service from the education, medical, child welfare, or juvenile justice systems, but these services probably do not address clients' mental health problems as directly and effectively as specialized mental health treatments.

This report also notes that one serious constraint on the effective operation of the mental health system, both private and public, is the chronic shortage of psychiatrists with specialized expertise in psychotropic medications.

## 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

Childhood is marked by dramatic changes in physical, cognitive, and social-emotional skills and capacities. Mental health in childhood is defined by the achievement of expected developmental cognitive, social, and emotional milestones and by secure attachments, satisfying social relationships, and effective coping skills. Mentally healthy children enjoy a positive quality of life; function well at home, in school, and in their communities; and are free of disabling symptoms of psychopathology (Hoagwood et al., 1996).

Understanding mental illness in young children is challenging because of the ongoing development process. The normally developing child hardly stays the same long enough to make stable measurements. Criteria for adult illness can be difficult to apply to children when the signs and symptoms of mental disorders are often also the characteristics of normal development. For example, a temper tantrum could be an expected behavior in a young child, but not in an adult. At some point, however, it becomes clearer that certain symptoms and behaviors cause great distress and may lead to dysfunction of children, their families, and others in their social environment. At these points, it is helpful to consider serious deviations from expected cognitive, social, and emotional development as “mental disorders.” Specific treatments and services are available for children with such mental disorders, but one cannot forget that these disorders emerge in the context of an ongoing developmental process and shifting relationships within the family and community. These developmental factors must be carefully addressed to maximize the healthy development of children with mental disorders, promote remediation of associated impairments, and enhance their adult outcomes (Surgeon General, 1999).

Supposed differences between normal and abnormal behavior may be better understood by taking into account the differences in the amount or degree of a particular behavior, or the degree of exposure to a particular risk factor. Frequently, no sharp distinctions can be made. The virtue of these developmental considerations when applied to children is that:

- They enable a broader, more informed search for factors related to the onset of, maintenance of, and recovery from abnormal forms of child behavior;
- They help move beyond static diagnostic terms that tend to reduce the behaviors of a complex, developing, adapting, and feeling child to an oversimplified diagnostic term;
- They offer a new perspective on potential targets for intervention, whether child-focused or directed toward environmental or contextual factors; and
- They highlight the possibility of important timing considerations—windows of opportunity during a child’s development when preventive or treatment interventions may be especially effective (Surgeon General, 1999).

Risk factors for developing a mental disorder or experiencing problems in social-emotional development include prenatal damage from exposure to alcohol, illegal drugs, and tobacco; low birth weight; difficult temperament or an inherited predisposition to a mental disorder; external risk factors such as poverty, deprivation, abuse, and neglect; unsatisfactory relationships; parental mental health disorder; or exposure to traumatic events.

Increasing consensus has emerged that biologic factors exert especially pronounced influences on several disorders in particular, including pervasive developmental disorder (Piven & O’Leary, 1997), autism (Piven & O’Leary, 1997), and early-onset schizophrenia (McClellan & Werry, in press). It is also likely that biological factors play a large part in the etiology of social phobia (Pine, 1997), obsessive-compulsive disorder (Leonard et al., 1997), and other disorders such as Tourette’s disorder (Leckman et al., 1997). Two important points about biological factors should be borne in mind. The first is that biological influences are not necessarily synonymous with those of genetics or inheritance. Biological abnormalities of the central nervous system that influence behavior, thinking, or feeling can be caused by injury, infection, poor nutrition, or exposure to toxins such as lead. These abnormalities are not inherited. Mental disorders most likely to have genetic components include autism, bipolar disorder, schizophrenia, and attention-deficit/hyperactivity disorder (ADHD) (National Institute of Mental Health, 1998).

Environmental factors also influence specific mental disorders in young children. For instance, child abuse is a very widespread problem; it is estimated that over 3 million children are maltreated every year in the United States (National Committee to Prevent Child Abuse, 1995). Physical abuse is associated with insecure attachment (Main & Solomon, 1990), psychiatric disorders such as post-traumatic stress disorder, conduct disorder, ADHD (Famularo et al., 1992), depression (Kaufman, 1991), and impaired social functioning with peers (Salzinger et al., 1993). Psychological maltreatment is believed to occur more frequently than physical maltreatment (Cicchetti & Carlson, 1989); it is associated with depression, conduct disorder, and delinquency (Kazdin et al., 1985) and can impair social and cognitive functioning in children (Smetana & Kelly, 1989).

The consequences of maternal depression vary with the state of the child’s development, and some of the effects are quite subtle (Cicchetti & Toth, 1998). For example, in infancy, a withdrawn or unresponsive depressed mother may increase an infant’s distress, and an intrusive or hostile depressed mother may lead the infant to avoid looking at and communicating with her (Cohn et al., 1986). Other studies have shown that if infants’ smiles are met with a somber or gloomy face, they respond by showing a similarly somber expression and then by averting their eyes (Murray et al., 1993). During the toddler stage of development, research shows that the playful interactions of a toddler with a depressed mother are often briefer and more likely to be interrupted (by either the mother or the child) than those with a non-depressed parent (Jameson et al., 1997). Research has shown that some depressed mothers are less able to provide structure or to modify the behavior of excited toddlers, increasing the risk of out-of-control behavior, the development of a later conduct disorder, or later aggressive dealings with peers (Zahn-Waxler et al., 1990; Hay et al., 1992). A depressed mother’s inability to control a young child’s behavior may result in the child failing to learn appropriate skills for settling disputes without reliance on aggression.

It seems likely that the roots of most mental disorders lie in some combination of genetic and environmental factors—the latter may be biological or psychosocial (Rutter et al., 1999). Therefore, childhood is an important time to prevent mental disorders and to promote healthy development, because many adult mental disorders have related antecedent problems in childhood. Thus, it is logical to try to intervene early in children’s lives before problems are established and become more refractory. The field of prevention has now developed to the point that reduction of risk, prevention of onset, and early intervention are realistic possibilities. Scientific methodologies in prevention are increasingly sophisticated, and the results from high-quality research trials are as credible as those in other areas of biomedical and psychosocial science. There is a growing recognition that

prevention does work; for example, improving parenting skills through training can substantially reduce antisocial behavior in children (Patterson et al., 1993).

The wider human services and law enforcement communities, not just the mental health community, have made prevention a priority. Policymakers and service providers in health, education, social services, and juvenile justice have become invested in intervening early in children's lives. They have come to appreciate that mental health is inexorably linked with general health, child care, and classroom success and inversely related to involvement in the juvenile justice system. It is also perceived that investment in prevention may be cost-effective (Mrazek, 1998).

Mental disorder results from the interaction of a child and his or her environment. Thus, mental illness often does not lie within the child alone. Within the conceptual framework and language of integrative neuroscience, the mental disorder is an "emergent property" of the transaction with the environment. Proper assessment of a child's mood, thought, and behaviors demands a simultaneous consideration of nature and nurture, genes and environment, and biology and psychosocial influences. As with adults, assessment of the mental function of children has important goals: to learn the unique functional characteristics of each individual and to diagnose signs and symptoms that suggest the presence of a mental disorder. Case formulation helps the clinician understand the child in the context of family and community. Diagnosis helps identify children who may have a mental disorder with an expected pattern of distress and limitation, course, and recovery. Both processes are useful in planning for treatment and supportive care. Both are helpful in developing a treatment plan.

Even with the aid of widely used diagnostic classification systems such as DSM-IV, diagnosis and diagnostic classification present a greater challenge with children than with adults for several reasons. Children are often unable to verbalize thoughts and feelings. Clinicians by necessity become more reliant on parents, teachers, and other professionals who may be unable to assess these mental processes in children. Children's normal development also presents an ever-changing backdrop that complicates clinical presentation. As previously noted, some behaviors may be quite normal at one age but suggest mental illness at another age. Finally, the criteria for diagnosing most mental disorders in children are derived from criteria for adults, even though relatively little research attention has been paid to the validity of these criteria in children. Expression, manifestation, and course of a disorder in children might be very different from adults'. The boundaries between normal and abnormal are less distinct and those between one diagnosis and another are fluid. Thus, the field of childhood mental health historically downplayed diagnosis. When conducted by a mental health professional, the evaluation process usually consists of gathering information from several sources: the child, parents, teachers, pediatricians, and hospital records. The mental health professional also makes observations of the child's behavior and speech patterns (Surgeon General, 1999).

## PUBLIC POLICY ISSUES

### ***NATIONAL***

The most significant public policy issue that impacts early intervention for infants and toddlers is reimbursement for services from third parties such as private insurance, Medicaid, and the federal Individuals with Disabilities Education Improvement Act (IDEA) of 2004. This has several dimensions including:

- There is an institutional bias to reimbursement schemes that include hospitals and inpatient facilities, but exclude community-based organizations even though the cost of service may be lower and of the same quality;
- Third party insurers are disallowing reimbursement for certain diagnoses such as autism while at the same time that there is an explosion in the numbers of children diagnosed with the disorder; and
- There is no payment differentiation for the greater time it takes to work with a child than with an adult (Nobili, 2005).

Below is further explanation of several of the major federal regulations that affect early intervention for mental illness programs.

#### Individuals with Disabilities Education Improvement Act (IDEA) of 2004

Historically, there has been an evolution in the definition of developmental disabilities. A new definition emerged through the Developmental Disabilities Assistance and Bill of Rights Act of 1999 (P.L. 88-164). Essentially the term included any number of conditions oriented to functional abilities and was also sensitive to family issues (Malone et al, 2000). The act defined the concept of “young children with developmental concerns” functionally, i.e., children birth to five years with substantial functional limitations in three or more major life activities, including self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency if services are not provided. *Early intervention services* were defined in the act to mean:

- Services provided to an infant, toddler, young child, and his or her family
- Services intended to enhance the child’s development
- Services intended to enhance the capacity of the family to meet the special needs of the child

The Individuals with Disabilities Education Improvement Act of 2004 (IDEA) went into effect July 1, 2005, and further expanded the definition of infants and toddlers with disabilities to mean children under age three who need early intervention services because they are either experiencing delays in cognitive, physical, communicative, social or emotional, or adaptive development, or have a diagnosed physical or mental condition with a high probability of resulting in developmental delay. Thus, IDEA includes children at risk of delay, highlights the need for consideration of families, and includes a comprehensive system of services that are multi- and interdisciplinary.

There are two parts to IDEA that provide funding to states: Part B, Assistance for Education of All children with Disabilities, and Part C, Infants and Toddlers with Disabilities. Part C is a federal grant program that assists states in operating a comprehensive statewide program of early intervention

services for infants and toddlers with disabilities, ages birth through 3, and their families. The current statute and regulations for Part C contain many requirements states have to meet, including specifying the minimum components of comprehensive statewide early intervention system. States have some discretion in setting the criteria for child eligibility, including whether or not to serve at risk children. As a result, definitions of eligibility differ significantly from state to state (National Early Childhood TA Center, 2005).

According to the Council for Exceptional Children (2004), Part C has not been fully funded at the federal level, which places great burden on state and local governments. The new bill includes a new *optional* state program that must be developed and implemented jointly by the Part C lead agency and the state education agency (SEA). If the state elects to apply for this program, parents of children eligible for preschool services under section 619, and who were previously receiving services under Part C, may choose to continue early intervention services under Part C until their children enter, or are eligible under state law to enter, kindergarten. The state policy must ensure that these Part C services for preschoolers with disabilities include an educational component that promotes school readiness and incorporated pre-literacy, language, and numeracy skills. While this is a desirable component of the service package, the problem is that there is no new funding available and it appears that there will be a negative impact on the availability of funds to continue services to eligible children under Part C. The new language calls for 15 percent of any appropriation in excess of \$460 million to be diverted to the preschool option. These diverted funds then are no longer available for children birth through three.

The purpose of services funded through IDEA Part C is to enhance the development of infants and toddlers with disabilities and to minimize the potential for developmental delay. The services are provided through a coordinated network of providers, driven by the needs of the family and documented through an individualized family service plan (IFSP). Not all services available through early intervention are free to families (Ohio Legal Rights Services, 2005).

IDEA has special requirements for abused and neglected children. IDEA requires that states must have policies and procedures in place that require the referral for early intervention services of a child under the age of 3 who: (a) is involved in a substantiated case of child abuse or neglect; or (b) is identified as affected by illegal substance abuse, or withdrawal symptoms resulting from prenatal drug exposure (National Early Childhood TA Center, 2005). See section below addressing the Child Abuse Prevention and Treatment Act.

In Ohio, IDEA Part C is administered through the Ohio Department of Health's Bureau of Early Intervention Services. Ohio's birth to three program, Help Me Grow, integrates the Early Intervention Part C program for infants and toddlers with developmental delays and disabilities with their program, which makes home visits to new families with newborns to provide a seamless delivery system to newborns, infants, and toddlers.

#### Child Abuse Prevention and Treatment Act

The Child Abuse Prevention and Treatment Act (CAPTA) was originally enacted in 1974. CAPTA provides federal funding to states in support of Child Protective Service Agencies. In June 2003, the Child Abuse Prevention and Treatment Act (CAPTA) provisions were amended by the Keeping Children and Families Safe Act of 2003. CAPTA requires that states that receive CAPTA have provisions and procedures for the referral of a child under the age of 3 who is involved in a

substantiated case of abuse or neglect to Early Intervention Services funded under Part C of IDEA (National Early Childhood TA Center, 2005).

Children with disabilities are at higher risk for maltreatment than children without disabilities. Conversely, research shows that children—especially infants and very young children—who have experienced abuse or neglect are at high risk for a variety of developmental problems, including attachment disorders, social and emotional disturbances, cognitive deficits, neurobiological changes in the brain, and failure to thrive (Shaw & Goode, 2005).

#### Early Start (now Help Me Grow)

Early Start (ES) (now Help Me Grow) provides ongoing in-home parent education and support, developmental screenings, and aid in locating resources for at-risk families with a child under three years of age. It began as a voluntary program in 1996 and the Cuyahoga County Early Intervention Collaborative (CCEIC) contracted with community-based providers to deliver ES. All referrals came through Interlink (the county's resource and referral site) at the CCEIC and were then sent out to a provider based on the geographic location and need of the family. Passage of federal welfare reform legislation in 1996, followed in 1997 by Ohio Works First (OWF), led to ES expansion in 1998. ES became one of the support programs for Ohio Works First. All OWF families with children under one year of age were contacted by ES, and all families with children 0-3 years of age were offered ES home visiting (Urban Poverty Center, 2003).

#### Early Periodic Screening, Diagnosis, and Treatment (EPSDT) Program

The Early Periodic Screening, Diagnosis, and Treatment (EPSDT) Program is the child health component of Medicaid. All eligible children are entitled to periodic screening services, including comprehensive physical examinations, and vision, dental, and hearing screens. Also, all eligible children are entitled to any medically necessary service within the scope of the federal program that is to correct or ameliorate defects, and physical and mental illnesses and conditions, even if the state in which the child resides has not otherwise elected to include that service in its state Medicaid plan (Department of Health and Human Services, 1999). Ohio's program is known as HEALTHCHEK and it provides a group of services to children and teens (birth through age 20) that include prevention, diagnosis, and treatment. Per ODJFS, the purpose of HEALTHCHEK is to discover and treat health problems early. HEALTHCHEK services are marketed to parents as a set of preventive health screenings with follow-up diagnosis and treatment (ODJFS, n.d.).

#### Managed Care

Managed care is a large environmental factor in all health-related services, and specifically in the area of services for special needs children because many of the specialized early intervention services for infants and toddlers with disabilities are supported by insurance. While managed care could help children with special needs and their families by improving access and coordination of services, it also provides barriers in obtaining the full range of services needed to promote the child's well-being and development.

#### Medicaid

Medicaid funding for young children with mental health problems is an issue. In Cuyahoga County, according to Help Me Grow (2006), current programs have been able to provide services to fewer than 170 of the children in need. The services these children need are generally not Medicaid-eligible because Medicaid neither accepts results of the most appropriate diagnostic tool for young children's mental health nor pays to treat parents and children together, which is essential to a

family's chance for long-term success. The agencies currently providing early childhood mental health services in Cuyahoga County are struggling for private funding in an increasingly shrinking pool of funds, and are still unable to serve most of the children who can benefit from help.

#### Medicaid and the Family Opportunity Act

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

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

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

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

### ***STATE***

#### State Investment in Early Intervention

A recent study of government funding for education and development of Ohio youth conducted by the Center for Community Solutions shows that public investment is lowest during the time of children's most rapid brain growth. The study found that for every \$1.00 invested in a school-aged child, 40.1 cents is invested in college-aged youth (19-23), 19.9 cents is invested in a pre-school aged child (3-5), and only 7 cents is invested in an infant or toddler (birth to 2). The study also determined that the Ohio per-child investment for 0-2 year olds was \$569.27 (only 18 percent from state and local sources, the remainder federal sources) and for preschoolers was \$1,423.37 (38 percent of funding from state local sources, the remainder from federal). These amounts are compared to \$7,119.56 (91 percent state and local, the remainder federal) for school-age children (6-18) and \$2,846.76 (65 percent state and local, the remainder federal) for college-aged youth (19-23) (Center for Community Solutions, 2005).

### III. THE CORE SERVICE CONSUMERS

#### DEFINITION OF TARGET POPULATION

The target population addressed in this core service report is the population of children 0-5 who have or are at risk for psychiatric disorders.

#### DEMOGRAPHIC CHARACTERISTICS

Millions of children experience behavioral and emotional problems, with early childhood being a critical time for onset of these problems. Estimates of national prevalence rates of young children with psychosocial problems are between 10 percent and 21 percent, while rates specifically for externalizing problems can be as high as 25 percent (Powell, Fixsen, and Dunlap, 2003). In infants and toddlers, these problems can manifest as an inability to regulate emotions and form secure attachments (e.g., strong, enduring affective bonds with caregivers), while in preschoolers, problems often manifest as challenging behaviors such as disruptiveness in child care or school settings.

According to the report of the president's New Freedom Commission on Mental Health (2003), early childhood is a critical period for the onset of emotional and behavioral impairments (Shonkoff and Phillips, 2000). In 1997, the latest data available, nearly 120,000 preschoolers under the age of six—or 1 out of 200—received mental health services (Pottick and Wagner, 2002). Each year, young children are expelled from preschools and child care facilities for severely disruptive behaviors and emotional disorders. Since children develop rapidly, delivering mental health services and supports early and swiftly is necessary to avoid permanent consequences and to ensure that children are ready for school. Emerging neuroscience highlights the ability of environmental factors to shape brain development and related behavior. Consequently, early detection, assessment, and links with treatment and supports can prevent mental health problems from worsening.

Without intervention, child and adolescent disorders frequently continue into adulthood. For example, research shows that when children with co-existing depression and conduct disorders become adults, they tend to use more health care services and have higher health care costs than other adults (Knapp et al., 2002). If the system does not appropriately screen and treat them early, these childhood disorders may persist and lead to a downward spiral of school failure, poor employment opportunities, and poverty in adulthood. No other illnesses damage so many children so seriously (National Advisory Mental Health Council Workgroup on Child and Adolescent Mental Health Intervention and Deployment, 2001).

The hallmarks of a positive developmental trajectory and early childhood mental health are evident in the young child's capacity to:

- Develop enduring relationships with primary caregiver.
- Initiate, discover, play and learn.
- Persist when discouraged and attend when distracted.
- Cope with disappointment and recover from disruption.

- Develop self-regulation and a range of emotional responses that match the social-cultural developmental expectations of the situation. (Poulsen, 2002)

All behaviors noted can be normal ways of responding. Behaviors are concerns only when they are intensive, extensive and pervasive and/or when parents feel overwhelmed to the extent that they are unable to cope with their child's behavior. Infant mental health addresses infants and young children's emotional and behavior disturbances through the lens of parent-child relationships within the context of social and cultural expectation and the child's level of neuron-developmental functioning. (Poulsen, 2002)

One of the many factors that can affect the emotional health of young children is the mental health status of their parents. For example, depression among young mothers has been shown to influence the mental health of their young children (Goodman and Gottlieb, 2002; Hammen and Brennan, 2003). These findings are significant because mental disorders that occur before the age of six can interfere with critical emotional, cognitive, and physical development, and can predict a lifetime of problems in school, at home, and in the community (Lynch et al., 1996).

"Charles Zeanah (1997) emphasizes that in infancy and toddler periods, psychiatric disorders are less clearly differentiated and less well validated, and that...much is to be gained by focusing instead on risk and protective factors for infant development." Babies are born with certain temperamental/neurobehavioral characteristics that can influence how they initiate and respond to nurturing care. A child's capacity to manage stress and regulate emotions stems from interactions among temperamental/neurobehavioral status, early experiences and the quality of attachments. (Poulsen, 2002)

There is considerable new understanding relating to brain-behavior relationships. Behavior, such as impulsiveness, distractibility, aggression and a lack of responsiveness to ordinary disciplinary and socialization guidance, is thought to stem from insufficient inhibitory or over-reactive mechanisms in the brain and/or insufficient ability to process and organize information. This research has underscored the notion of neurobiological vulnerability that holds that biological factors can make one susceptible to developing emotional disturbance, but does not itself cause such an outcome. (Poulsen, 2002)

When an infant's neurobehavioral functioning is compromised, infant emotional availability and the attachment process can be in jeopardy. Abnormal sensory threshold, intensity of reaction, and poor self-regulation are neurobehavioral characteristics that can interfere with the development of a healthy stress management system, leading to increased tantruming, aggression and oppositional responses to behavioral expectations. (Poulsen, 2002)

A highly sensitive over-reactive nervous system sets the young child up for non-adaptive ways of dealing with the world if caregivers are not aware that protective care giving strategies are needed to calm down an over-reactive nervous system. A neurobiological vulnerability may be mild enough to require severe environmental influences in order for dysfunction to arise. Conversely, an actual neurobiological deficit may be serious enough for behavioral disorders to occur, even in the presence of nurturing care giving. In fact, children with neurological damage evidence a 2 to 3 times higher incidence of behavioral disorders than other children. The question remains how much of the behavioral disturbance is due to biological deficit and how much is due to biological vulnerability that has been compounded by negative environmental and/or ineffective care giving influences. The task of the mental health professional is to sort out and address the differences. (Poulsen, 2002)

Several biological and environmental circumstances can adversely impact neurobehavioral functioning making the child more susceptible to emotional disturbances. The emotional disturbance can be worsened if not addressed or can become compounded by multiple risk factors:

- **Low Birth Weight** - Tiffany Field's (2002) research indicates that low birth weight babies (1600 grams) are at increased risk for a variety of behavioral difficulties at two and five years as measured by parental response to the Behavior Problem Checklist. Increased risk is due to neurobehavioral immaturities that may not be appropriately addressed.
- **Developmental Delays, Disabilities and Chronic Illness** - Infants, toddlers and young children with delays, disabilities and chronic illness may be at increased risk for social, emotional and behavioral disorders due to vulnerabilities related to reactivity, intensity of response and other neurobehavioral sensitivities that require special care giving strategies.

The mental health disorders are not due to the disability or illness directly. When the need for special care giving strategies go unaddressed, the child can be set on a negative developmental trajectory that later requires mental health treatment in addition to developmental services. It is important to note that there are neurodevelopmental disabilities of such severity that dyadic/environmental regulation supports play only a small part of the total intervention plan.

- **Nutrition** - Inadequate nutrition and iron deficiency anemia can seriously interfere with brain development leading to neurological and behavioral vulnerabilities. Malnourished children and iron deficient children may evidence more irritability, emotional unresponsiveness, fearfulness, lethargy, and mental apathy resulting in decreased sustained attention and a lack of persistence in task completion and interpersonal

engagement. Nutrition/iron deficiency screening must be considered in the assessment process.

- **Drug and Lead Exposure** - Prenatal drug, cigarettes and alcohol exposure and pre and postnatal lead exposure can lead to low birth weight and central nervous system compromise that effect neurobehavioral functioning and child resilience. Hundreds of thousands of babies are born annually prenatally exposed to toxic substances. The impact on infant outcome will depend on the extent of maternal use, resiliency of the fetus, general health, nutrition and lifestyle of the mother, and, most importantly, postnatal care and special care giving supports.
- **Exposure to Violence** - Exposure to community violence is taking its toll. A study by Taylor and Zuckerman (1994) reported that 47 percent of the mothers using a community hospital recounted that their children heard gunshots in their neighborhoods and one in ten of these young children had witnessed a knifing or shooting before the age of six, half in the streets and half at home. With repeated exposures to violence, children are in danger of becoming accustomed to and emotionally dead to its impact, leaving them to feel hopeless or to identify with the aggressor.
- **Maltreatment** - Maltreatment including neglect, abuse, separation and loss can result in central nervous system dysfunction. Annually, 140,000 children are seriously physically injured by caregivers, with the vast majority being under four years of age and 1,500 of that group being victims of “Shaken Baby” syndrome. One of three physical abuse reports is about a baby less than one year. Many times the inconsolable crying of a distressed infant unleashed the torrent of rage of the caregiver—described as distressed fathers, stepfathers and boyfriends. When any baby is described as an inconsolable crier, there needs to be assurance that the family is able to tolerate it and that the baby will be protected from harm via family support, care giving strategies, respite care, and so forth.
- **Stress** - Evidence suggests that high levels of stress can actually undermine brain development. Extremes of experience from trauma or neglect can result in prolonged elevated stress hormone (e.g., high cortisol levels) which increases activity in the brain structures involved in vigilance and arousal. Patterns of hyperarousal develop, including affective lability, behavioral impulsivity, increased anxiety and sleep abnormalities. As a result, the brain becomes wired to be on “hair-trigger” alert. Everyday events that do not initiate a stress response from a robust child may elicit an exaggerated one in the vulnerable child. Regions of the brain that were activated by trauma are immediately reactivated when a potential threat is perceived. This unleashes a new surge of the stress hormone, leading to behavioral difficulties in intensity of reaction and self-regulation. This can set up the child to repeatedly experience events as catastrophic, leading to surges of stress

hormones, patterns of arousal and lingering distress behaviors. And thus potentially begins a negative chain reaction. The rationale for early intervention for reactivity and self-regulation difficulties is to break the cycle before it becomes “hard wired” and perpetuates the risk effects. Infants and young children at biological risk are more vulnerable to adverse environmental influences than are non-risk children. Thus, these young children are in double jeopardy.

- **Out of Home Placements** - Out of home placement is always a traumatizing event and has escalated in the last decade. Multiple placements within the foster care system is leaving thousands of young children without rich attachments, and without a history of self, memory of family rituals, and persons to whom they really belong. (Poulsen, 2002)

There are several circumstances that can interfere with a mother’s (or father’s) capacity to be emotionally available for the child. Some of these are depression, limited parenting skills, lack of social support, poverty, domestic violence, teen parents, and substance abuse. If preventive intervention community supports are not accessible for these parents, the child may later require mental health treatment (Poulsen, 2002).

There has been a surge of national attention on the impact of experience on brain development and on child outcome. This in part stems from the 1996 University of Chicago Conference on Brain Development in Young Children. Neuroscientists, having used research tools such as brain imaging technologies, provided insights on the influences of early experience on brain development and neurobehavioral competence. Not only was there validation that early experience influences developmental trajectories, but also they provided evidence that early experience actually affects how the intricate circuitry of the brain is wired. Infant brain research data have reinforced the role of early interactive nurturing experience between mother and child as a significant cornerstone to the development of self-regulation in early childhood. (Poulsen, 2002)

Research has indicated that as many as 30 percent of our children receive emotionally inadequate care that puts them at risk for later social, emotional and behavioral disturbances. The pediatric literature has labeled the behavior and developmental problems of children as the “new morbidity.” Pediatricians are reporting that they are seeing more social, emotional and behavior problems among their patients than instances of infectious diseases. (Poulsen, 2002)

Young children are telling us by their behavior that the world they are experiencing is overwhelming to them. Their “SOS” signals are demonstrated through tantrums, non-compliance to adult requests, frequent anger, fear of being alone, poor attention, sleeping problems, over-activity and “too easily falls apart” that are beyond the typical expected behaviors of children. (Poulsen, 2002)

*Cuyahoga County*

Table 1 below provides estimates of child mental health status in Cuyahoga County. Two percent of children 0-4 years were told they had a learning disability; 0.7 percent that they had an attention deficit disorder; and 7 percent had taken prescription medication regularly for at least 3 months.

**Table 1: Estimates of Child Mental Health Status in Cuyahoga County\***

Population by Age	Total Population	Estimated Total with Disorder	% Total
Total county population 3-17 years, 2000			
<b>3-4 years</b>	<b>37,569</b>		
5-11 years	143,029		
12-17 years	113,438		
Ever told had "learning disability"			
<b>3-4 years</b>		<b>751</b>	<b>2.0%</b>
5-11 years		10,155	7.1%
12-17 years		10,890	9.6%
Ever told had "Attention Deficit Hyperactivity Disorder"			
<b>3-4 years</b>		<b>263</b>	<b>*0.7%</b>
5-11 years		9,011	6.3%
12-17 years		9,415	8.3%
Total county population <18 years, 2000			
<b>0-4 years</b>	<b>90,912</b>		
5-11 years	143,029		
12-17 years	113,438		
Prescription medication taken regularly for at least 3 months			
<b>0-4 years</b>		<b>6,818</b>	<b>7.5%</b>
5-11 years		18,022	12.6%
12-17 years		19,398	17.1%

\*Estimate has a relative standard error of greater than 30 percent and should be used with caution as it does not meet the standard of reliability or precision.

Source: Dey AN, Bloom B. Summary Health Statistics for U.S. Children: National Health Interview Survey, 2003. National Center for Health Statistics. Vital Health Stat 10(223). 2005.

\*Computed using age-adjusted percentages (with standard errors) of ever having been told of having a learning disability or ADHD or having a problem for which prescription medication has been taken regularly for at least 3 months among for children 3-17 years, or under 18 years: United States, 2003

*Estimated Persons in Need*

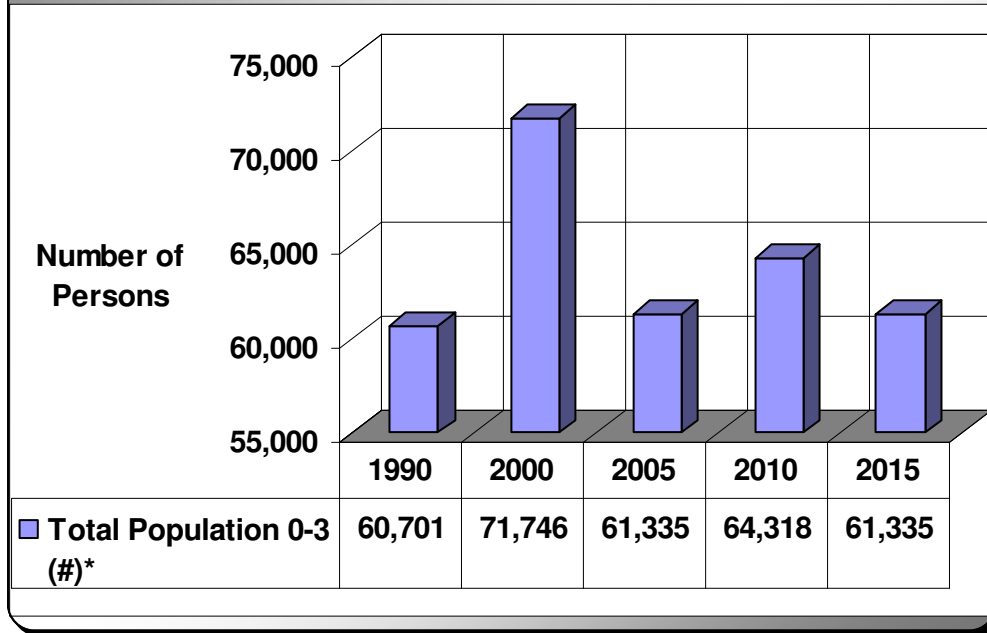
For children aged 3–17, the rate of having any mental health service use varied from 6.0 percent (both National Survey of American Families and National Health Interview Survey) to 7.5 percent (Community Tracking Survey). Rates were lower for preschool children (2 percent–3 percent for children 3–5 years old). Across data sets, a higher percentage of children with public insurance used services (9 percent–13 percent) than did the uninsured (4 percent–5 percent) and privately insured (5 percent–7 percent) children. In these unadjusted analyses, ethnic minority status was significantly associated with lower rates of use in the Community Tracking Survey and National Health Interview Survey data sets, but not in the American Families data. Across data sets, male children had higher rates of mental health use than did female children. Weighted estimates of unmet need for children under age 6 were available only in the National Health Interview Survey. Of 1,499 children 4–5 years old, 131 (8.5 percent) were estimated to have mental health problems, but of the 131 children in need, only 9 (6.0 percent) used any mental health services in the preceding year. (Kataoka et al., 2002)

The research provided only a first sketch of national mental health care among preschoolers, who are referred most often for behavioral problems such as aggression, defiance, and over-activity (Campbell, 1990; Lavigne, et al., 1998). The descriptive findings suggest that the vast majority of preschool children with mental health needs in the United States do not receive services for those problems. The more talked-about public concern is the high rate of psychotropic medication use in young children (Minde, 1998; Zito, et al., 2000), but an even greater problem may be the lack of any evaluation or care for children with mental health problems. Further research is needed to confirm these findings on larger samples of young children and to determine whether unmet need is due to parent preference, unavailability of services, or problems in recognizing problems or identifying specialists for this age group. (Lavigne, 1998; Kataoka et al., 2002)

In estimating the number of persons in need of early intervention for mental illness in Cuyahoga County, we made the following assumptions:

- All children birth through 3 years need an evaluation or assessment to determine if there is need for early intervention mental health (or other) services. In Cuyahoga County in 2000, this was 71,746 children. This number is projected to decrease to 61,335 by 2015 because of shifts in the population. (See Figure 1.)

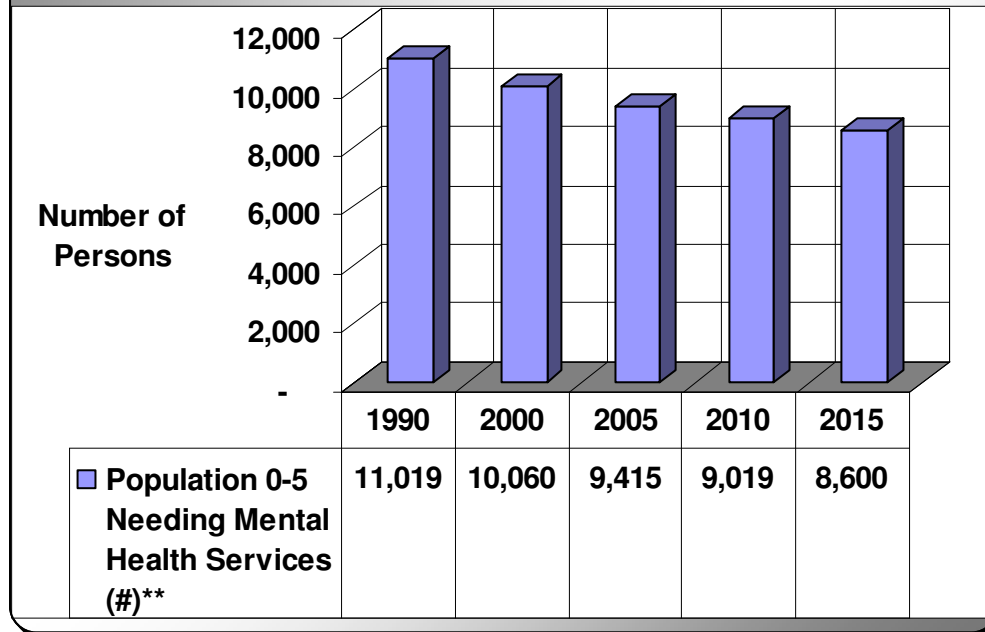
**Figure 1: Early Intervention for Mental Illness  
Estimated Persons in Need of Assessment  
Cuyahoga County, 1990-2015**



Sources:  
\* US Census: 1990, STF 1 (P11); 2000, SF3 (P8); 2005-2015, Ohio Department of Development, (July, 2003). Note: Age 0-5 in 1990, 2005-2015 was prorated from ages 0-4 using ratios from 2000 age group data.

- A certain percentage of children 0-5 years will need mental health services. Based on findings from the National Survey of Children with Special Health Care Needs (2001), this percent is 9.2 percent of children 0 to 5 years. In Cuyahoga County, this total is 10,060 children. This number is projected to decrease to 8,600 by 2015 because of population shifts. (See Figure 2.)

**Figure 2: Early Intervention for Mental Illness  
Estimated Persons in Need, Early Intervention  
Cuyahoga County, 1990-2015**



Sources:  
 \* US Census: 1990, STF 1 (P11); 2000, SF3 (P8); 2005-2015, Ohio Department of Development, (July, 2003). Note: Age 0-5 in 1990, 2005-2015 was prorated from ages 0-4 using ratios from 2000 age group data.  
 \*\* National Survey of Children with Special Health Needs (2001) by the U.S. Department of Health and Human Services, Health Resources and Services Administration estimates that 9.2 percent of children 0 to 5 years needs mental health services.

These estimates of persons in need of early intervention for mental illness begin to offer some clarity about the extent of need in Cuyahoga County.

**REALIZED ACCESS TO SERVICE**

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

In FY 2004, United Way funded 65 Cuyahoga County residents between 2 and 5 years for early intervention for mental illness programs. Invest in Children provided early intervention for 2,784. We assume duplication across these two funding sources.

In FY 2004 in Cuyahoga County, 51 percent of the county in the total 0 to 5 population was male and 49 percent female. Invest in Children funded 57 percent male and 43 percent female while United Way funded consumers were 20 percent male and 80 percent female.

(See Attachment 3.)

In 2000, according to the U.S. Census, 57 percent of the county's total 0 to 5 population was Caucasian, 36 percent African American, and 3 percent Asian. Consumers funded by United Way for early intervention for mental illness were 9 percent Caucasian, 18 percent was African-American, and under 1 percent Asian. The rest were unreported. Invest in Children funded approximately 42 percent Caucasian and 42 percent African American children.

Four percent of consumers funded by United Way reported an annual household income between \$0-\$9,999, 2 percent reported a household income between \$10,000-\$14,999, 2 percent reported a household income between \$15,000-\$19,999, and 3 percent reported a household income between \$20,000-\$29,000. The rest were unreported. No income data was received from Invest in Children.

Geographically, 38 percent of the county's total 0 to 5 population resided in Cleveland and the remaining 62 percent in the suburbs. (See Attachment 4.) Fifty-two percent of consumers funded by United Way were from Cleveland and 48 percent from the suburbs, while Invest in Children consumers were 38 percent from Cleveland and 59 percent from the suburbs.

## IV. CORE SERVICE DELIVERY

### CORE SERVICE DEFINITION

The definition of the core service for this report is: programs that conduct general screening efforts for early identification of children 0-3 who have incipient problems to ensure the best possible prognosis; and programs that provide treatment for individuals ages 0-5 whose personal condition and social experiences could potentially produce mental, emotional, or social dysfunctions, with the objective of preventing their development.

### BACKGROUND ON CORE SERVICE

The congressional Joint Commission on the Mental Health of Children (1969) made the first major national statement of the problem of unmet mental health needs in children. The Joint Commission reported that many children of all ages suffered from significant mental health problems but were either unable to adequately access services or were served in excessively restrictive settings. Critically, the Joint Commission also emphasized that many children have complex needs that would require a coordinated response across multiple systems in the health and social service sectors. (Lourie, 2003; Behan and Blodgett, n.d.)

Nevertheless, children’s mental health treatment as a field of study received scant attention in the professional literature prior to the early 1980s and even less attention in the practice field. In the landmark study of children’s mental health, *Unclaimed Children*, Knitzer and Olson (1982) reported some three million US children had significant mental health needs and two-thirds either received no or inappropriate services; further, fewer than half the states had even one mental health professional devoted to serving children (Duchnowski, Kutash, & Friedman, 2002; Knitzer & Olson, 1982; Lourie, 2003). This study significantly raised public awareness and concern regarding children’s mental health, and contributed to a significant increase in national attention from researchers and policymakers alike. Subsequently, the advent of the Children and Adolescent Service System Project (CASSP) movement in 1984 gave rise to the system of care concept (SOC) (Duchnowski, et al., 2002; Neill, 1997; Stroul, 1996; Lourie, Stroul, & Friedman, 1998) and the development of the first national effort to create a system of care around children with mental health needs. To a great degree, system of care principles forms the framework in which the development of public mental response to children is defined. (Behan and Blodgett, n.d.)

A consensus description of the key elements of a “system of care” developed from the CASSP efforts and serves as a guide for most current policies and programs addressing complex needs in children. Rather than prescribing the specific components of care that had to be in place, system of care describes a set of core values and principles that are recommended to guide

communities' and providers' efforts. (Lourie, Stroul & Friedman, 1998; Neill, 1997; Stroul, 1996; Stroul & Friedman, 1996 in Behan and Blodgett, n.d.)

Systems of care concepts define a model for what good services should look like but not what the services should be. Grounded in clinical experience and a democratic humanistic philosophy, public agencies and providers adopted systems of care standards as a “best practice” guide in the absence of an empirically validated service and outcome literature. The system of care concept purports a philosophy built on three core values:

- The inclusion of families in planning services for their children.
- Integration of cultural competence into children’s services.
- The encouragement of cross-system efforts to meet the range of needs experienced in children. (Behan and Blodgett, n.d.)

The model additionally asserts ten guiding principles:

1. Seriously, Emotionally Disturbed (SED) children should have access to services that address their individual physical, emotional, social, and educational needs.
2. Each child should receive individualized services.
3. Services should be the least restrictive available.
4. Family's participation in service planning and delivery is vital.
5. Services should be integrated and coordinated between child-serving agencies.
6. Case management is fundamental to service coordination and integration of services.
7. The system of care should promote early identification to maximize the likelihood of positive outcomes.
8. The system of care should plan for a smooth transition to the adult system if necessary.
9. The rights of SED children should be protected.
10. Children with emotional disturbance should receive services regardless of gender, ethnicity, race, income status, etc. (Paster, 1997; Stroul, 1996; Lourie, Stroul & Friedman, 1998; Winters & Pumariega, 2001). (Behan and Blodgett, n.d.)

Infant and early childhood/family mental health refers to the development of social and emotional well-being in infants and toddlers, including infant health and brain development, family functioning, and the “goodness of fit” in the infant/child-parent relationship. Typically infant mental health refers to children birth to three. Early childhood mental health is the more generic term referring to children birth to five. (Poulsen, 2002)

The field of infant and early childhood/family mental health emphasizes a developmental approach. Infant developmental and neuron-behavioral competencies, as well as the ability of the care giving environment to

regulate the development of the child, are addressed in assessment and treatment processes. (Poulsen, 2002)

There is a shortage of community-based mental health practitioners who feel comfortable working with this age group. It requires attention to primary caregiver “internal working models,” infant neurobehavioral/developmental vulnerabilities and competencies and all relate to rich dyadic relationships.

Infant/family mental health work is qualitatively different and requires practitioners with training and supervised experience. Some of the qualitative differences include a paradigm shift in how treatment services are delivered that include viewing the dyad as the client, providing emotional and instrumental supports and developmental guidance, the need for interdisciplinary perspectives, and a new emphasis on program collaboration and home visiting.

There are two primary phases in early intervention services: (1) evaluation, assessment, diagnosis and linkage to services; and (2) early intervention depending on the service need(s) of each child. Some of these are related to the need for mental health interventions. In addition, there are consultations and training services available for those who provide the direct services to children identified (e.g. early childhood providers, mental health agencies, and schools).

Assessment and diagnostic services are available to children birth through 3 years as part of early intervention for mental illness and up to 5 years for mental health services. Note that the needs of children 6-17 years are addressed in two other reports on adolescent and youth counseling services and children/youth residential treatment services.

*Mental Health Early Intervention Services*

There is both group and individual screening for mental illness issues, as well as psychiatric diagnosis as necessary.

*Evaluation, Assessment, Diagnosis and Linkage to Services*

Early intervention (EI) includes services for infants and toddlers that are designed to identify and help a child with a delay as early as possible. Federal law identifies a wide range of services for early intervention including, but not limited to, hearing and vision services; family training and counseling; nutrition services; occupational, physical, and speech therapy; and social work services and service coordination. The Ohio Department of Health in implementing the federal IDEA legislation required that families with children under the age of three who are eligible for early intervention services be entitled to developmental evaluation, service coordination, and an individualized family service plan (IFSP).

Invest in Children – Cuyahoga County

In 1999, inspired by new research that shows the importance of the first five years of life, 23 private foundations and corporations joined with county government to redesign the face of human services for young children and their families throughout Cuyahoga County. Working together, the founders of Invest in Children (formerly the Early Childhood Initiative) launched a plan to make sure that all children in the county receive the best possible start in life, one that allows them to grow and develop to their full potential.

Through this new network of services, providers reach out to families at the time of birth, offering home visits, enrollment in health insurance, quality child care, and information about the importance of those early years. Families who receive services from one element of Invest in Children are linked to other relevant services, so that they will not face a “wrong door” if they are seeking services. More than 80 public and private agencies came together to deliver these services (Invest In Children, Cuyahoga County, 2005).

Some of the assessment, diagnostic, and linkage services of Invest in Children are provided through the Help Me Grow program. The Help Me Grow program, a communication and public awareness initiative for wellness programs at the Ohio Department of Health, now includes several birth to 3 children’s programs in one consolidated initiative (Welcome Home, Ohio Early Start [now Help Me Grow], and Early Interventions). Help Me Grow is a program that provides prenatal services and newborn home visits along with information about child development. The program helps families with young children connect with resources they need. The program provides service coordination and ongoing specialized services to those families that are eligible.

The following types of early intervention services, provided by Help Me Grow, are aimed at preventing, identifying, or treating mental illness in youth:

- *Family training, counseling, and home visits* refers to services provided, as appropriate, by social workers, psychologists, and other qualified personnel to assist the family of an eligible child in understanding the special needs of the child and enhancing the child’s development.
- *Medical services only for diagnostic or evaluation purposes* refers to services provided by a licensed physician to determine a child’s developmental status and need for early intervention services.
- *Psychological services* address issues related to learning, mental health, and development.
- *Service coordination* refers to the activities carried out by a service coordinator to assist and enable a child and his or her family to receive their rights, procedural safeguards, and services.
- *Social work services* include assessment, providing individual and family group counseling, and coordinating community resources (Help Me Grow of Cuyahoga County, 2005).

Some of the mental health services offered include outpatient and home-based therapy for young children with behavioral and/or developmental problems; individual and group therapy, consultation, and summer programming for young children with regulatory difficulties and/or autistic spectrum disorders; service coordination, home visiting, and early learning and literacy for young children and their families in partnership with the Help Me Grow Collaborative; psychiatric consultation; individual and group therapy; family and multifamily therapy; crisis intervention and safety planning; therapy using play and creative expression; case management; and community support.

An individualized family service plan (IFSP) is required for a child enrolled in an early intervention program. Table 2 describes the number of Cuyahoga County children in 2003 who participated in individualized family service plans (IFSP) required for those enrolled in an early intervention plan, by age at first participation activity and by birth year. The number hovers around 19,000 IFSPs annually.

**Table 2: Number of Children Participating in Individualized Family Service Plans (IFSP), by Age at First Participation Activity and by Birth Year, Cuyahoga County, 2003**

<b>Birth Year/Age at First Participation</b>	<b># Children</b>	<b>% of Total</b>
<b>Births in 1997</b>	<b>19,033</b>	
0-6 months old	145	0.76%
6-12 months old	71	0.37%
12-18 months old	50	0.26%
18-24 months old	80	0.42%
24-30 months old	86	0.45%
30-36 months old	83	0.44%
>36 months old	51	0.27%
<b>Births in 1998</b>	<b>19,002</b>	
0-6 months old	230	1.21%
6-12 months old	92	0.48%
12-18 months old	71	0.37%
18-24 months old	93	0.49%
24-30 months old	161	0.85%
30-36 months old	123	0.65%
>36 months old	14	0.07%
<b>Births in 1999</b>	<b>18,402</b>	
0-6 months old	411	2.23%
6-12 months old	141	0.77%
12-18 months old	108	0.59%
18-24 months old	126	0.68%
24-30 months old	134	0.73%
30-36 months old	41	0.22%
>36 months old		0.00%
<b>Births in 2000</b>	<b>18,904</b>	
0-6 months old	456	2.41%
6-12 months old	192	1.02%
12-18 months old	117	0.62%
18-24 months old	47	0.25%
24-30 months old		0.00%
30-36 months old		0.00%
>36 months old		0.00%

Source: Cuyahoga County Early Childhood Initiative Evaluation: Phase I Final Report, 2003, Center on Urban Poverty and Social Change, MSASS

Cuts in Medicaid can threaten these early intervention strategies. Innovative interventions often include components such as outreach efforts to engage families not eligible for Medicaid reimbursement at the beginning treatment.

*United Way – First Call for Help Call Data*

There is no data available from United Way - First Call for Help for this core service. The United Way - First Call for Help Refer database does not specifically track this area.

## FUNDING OF CORE SERVICES

### *Major Government Funders*

The major sources of government funding for early intervention for mental illness programs are:

- Children's Health Insurance Program
- Cuyahoga County Health and Human Services Levies
- Individuals with Disabilities Education Act (IDEA) Part C
- Medicaid
- State General Revenue Funds
- Temporary Assistance to Needy Families (TANF)
- Title IV-E (family support/family stability)
- Title V/Maternal Child Health Block Grant

The majority of funding for early intervention for mental illness comes from Medicaid and the Children's Health Insurance Program (CHIP). This funding comes from the federal government and is passed through the state to local agencies that provide mental health services for children. However, as noted previously, there are difficulties with young children obtaining Medicaid funding for mental health services because of limitations of diagnosis. For Cuyahoga County, funding comes through the Department of Children and Family Services and the Cuyahoga County Mental Health Board (CCMHB); they do not provide services, but they fund providers through funding received from the Cuyahoga County Health and Human Services levy. IDEA funding is also a primary source of funding through the school districts, as is private insurance.

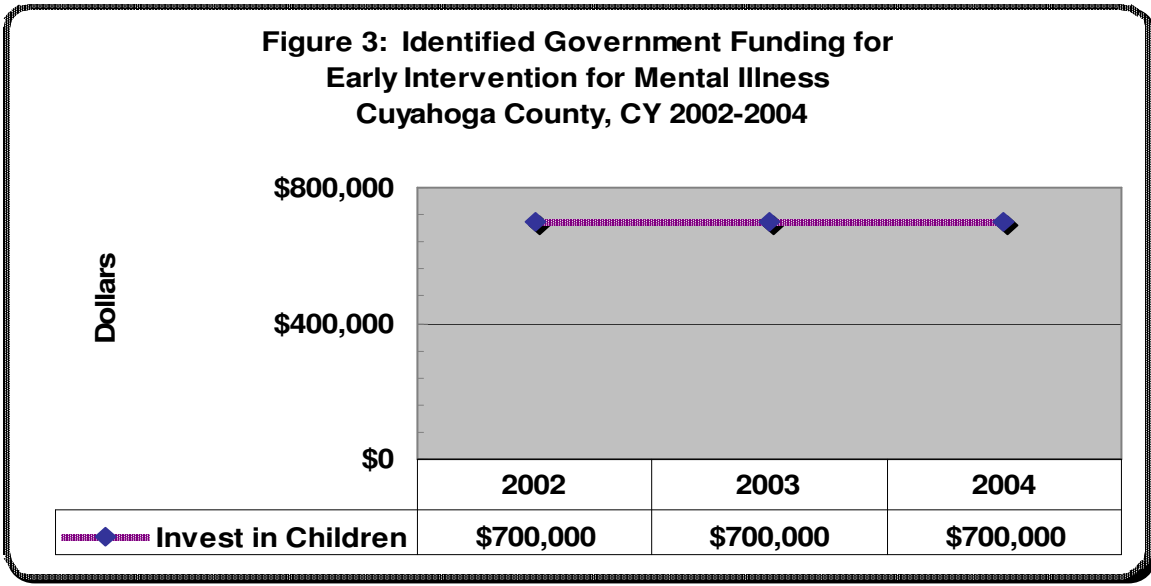
The State of Ohio has prioritized funding for Help Me Grow specialized services in this order:

- Private insurance or CHIP (e.g. EPSDT/HEALTHCHEK)
- Medicaid; Title V/Maternal Child Health (e.g. BCMH)
- Temporary Assistance to Needy Families (TANF)
- Title IV-E (family support/family stability funding through Children's Services)
- Other state and local funding sources
- State funds (GRF)
- Federal Part C Funds (Ohio Department of Health Bureau of Early Intervention Services, 2002).

Cuyahoga County uses these sources plus monies from the Board of Cuyahoga County Commissioners via the Office of Early Childhood to support early intervention services.

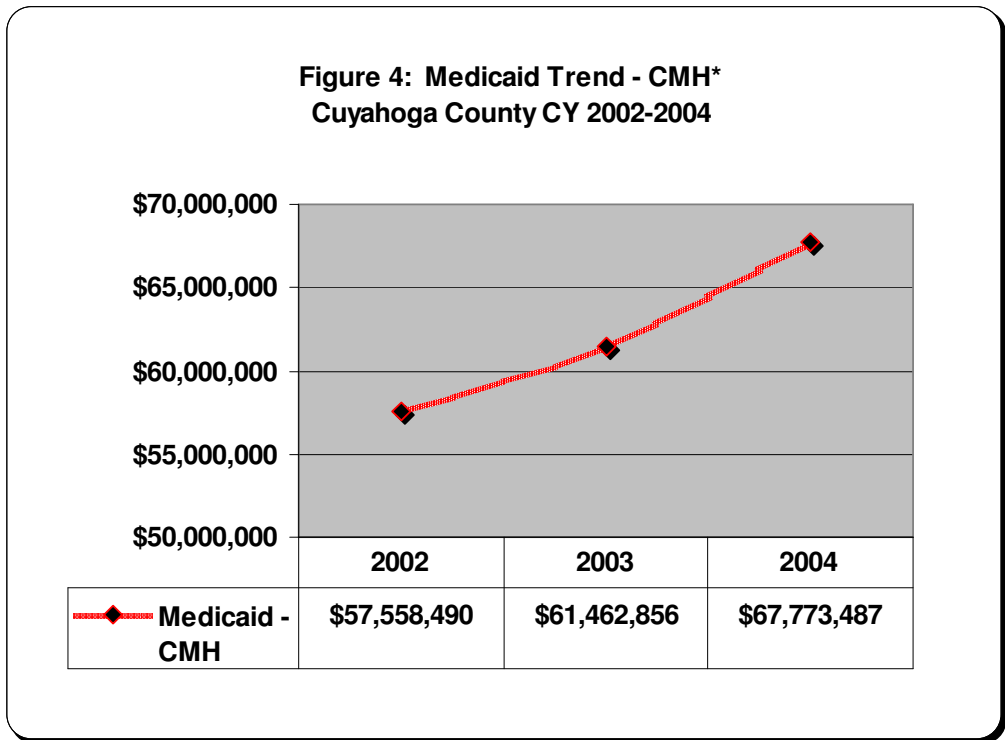
### *Trends of Identified Government Funders in Cuyahoga County*

Between 2003 and 2005, identified government funding for early intervention for mental illness has remained fairly level at \$700,000. (See Figure 3.) In 2007, the amount is \$1 million.



Source: Invest in Children

Medicaid funding has increased from \$57.8 million in 2002 to \$67.7 million in 2004. (See Figure 4.) However, these numbers include a bundle of multiple mental health services as noted in the footnotes below.



\* Includes the following core services: Adjunctive 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.

Foundation funding has increased from \$70,000 in 2002 to \$140,000 in 2004. Many foundations have been contributing to Invest in Children in general and it was not possible to determine how much of the funding was unique to early intervention for mental illness.

## IDENTIFIED REVENUES

As of May 11, 2006, \$833,535 in revenues for early intervention for mental illness programs has been identified countywide, excluding Medicaid dollars. This includes information from foundations; federated fundraising organizations; regional, county and municipal government; and United Way of Greater Cleveland. (See Table 3).

Eighty-four percent of the revenues are from contracts or grants from government organizations. Invest in Children is a primary funder of the service through CCCMHB funds. United Way of Greater Cleveland is a significant funder through Investment Committee allocations and designations.

**Table 3: Identified Annual Revenues for Core Services: Countywide and United Way of Greater Cleveland Early Intervention for Mental Illness Programs, 2003/2004.**

Funder	Period	A		B	
		Identifiable Total Dollars Countywide		Total Dollars UW-Funded Agencies (Actual FY2004)	
		Amount	% of Total (A)	Amount	% of Total (B)
<b>Total - Contributions and dues (less UW designations)</b>			<b>0.00%</b>	69,528	<b>8.26%</b>
Britton Fund				20,000	
Cleveland Foundation, The				10,000	
Reuter Foundation, The		10,000			
Other Private Foundations - Not Elsewhere Classified				98,414	
Cleveland Cavalier's Charities				100,000	
<b>Total - Foundations &amp; Trusts</b>		<b>10,000</b>	<b>1.20%</b>	<b>228,414</b>	<b>27.12%</b>
United Black Fund of Greater Cleveland		19,000			
<b>Total - Federated Fundraising Organizations</b>		<b>19,000</b>	<b>2.28%</b>	<b>0</b>	<b>0.00%</b>
Cuyahoga County Community Mental Health (648 Board)				22,333	
Office of Early Childhood/Invest in Children	2004	700,000			
<b>Subtotal Cuyahoga County Funding Sources</b>		<b>700,000</b>	<b>83.98%</b>	<b>22,333</b>	<b>2.65%</b>
All Other Funding - Not Elsewhere Classified				121,260	
<b>Subtotal Other Govt Funding Sources</b>		<b>0</b>	<b>0.00%</b>	<b>121,260</b>	<b>14.40%</b>
<b>Total - Contracts/grants from government organizations</b>		<b>700,000</b>	<b>83.98%</b>	<b>143,593</b>	<b>17.05%</b>
<b>Total - Investment Income</b>			<b>0.00%</b>	<b>123,500</b>	<b>14.66%</b>
<b>Total - All Other Revenue</b>			<b>0.00%</b>	<b>127,863</b>	<b>15.18%</b>
<b>Total - Prior Period balances/interfund transfers</b>			<b>0.00%</b>	<b>44,790</b>	<b>5.32%</b>
<b>Subtotal Non - UWGrCle Support</b>		<b>729,000</b>	<b>87.46%</b>	<b>737,688</b>	<b>87.59%</b>
<b>Total - UWGrCle investment committee allocation</b>		<b>104,535</b>	<b>12.54%</b>	<b>104,535</b>	<b>12.41%</b>
<b>Subtotal UWGrCle Support - 4001, 4701 &amp; 4703</b>		<b>104,535</b>	<b>12.54%</b>	<b>104,535</b>	<b>12.41%</b>
<b>Total Support/Revenue</b>		<b>833,535</b>	<b>100%</b>	<b>842,223</b>	<b>100%</b>

\*\* 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 - CMH (\$67,773,487 in 2004) - Falls into AIRS 1 Mental Health Care & Counseling and has been entered as an aggregate total for this AIRS Level. CMH includes the following core services: Adolescent/Youth Counseling, Children's/Adolescent Residential Treatment Facilities, Early Intervention for Mental Illness, General Counseling Services, Outpatient Mental Health Facilities, and Psychiatric Day Treatment.

**REIMBURSEMENT/COST**

Screening and evaluation to determine a child’s eligibility for early intervention services and the recommendations for services must be provided free of charge. Parents can choose whether or not to use their insurance for early intervention services that should be at no cost (Ohio Legal Rights Services, 2005).

If funds are available, specialized services can be paid for through the early intervention program if the multi-disciplinary team is in full agreement regarding the services that best support the family and its needs, that there are no alternative sources of payment available, and that the services will be performed in the child's natural environment (Ohio Legal Rights Services, 2005).

Before early intervention funds are considered, other available sources of funding are to be used. As noted previously, other sources of funding include: private insurance or CHIP (e.g. EPSDT),

Medicaid, Title V/Maternal Child Health (e.g., CFHS, Specialty clinics), Title V/Children with Special Health Care Needs (e.g., BCMH), Temporary Assistance to Needy Families (TANF), Title IV-E (family support/family stability funding through Children's Services, other local funding sources (e.g., United Way, local tax levies), and state funds (GRF) (Ohio Legal Rights Services, 2005).

Early intervention funds cannot pay for medical health services that are routinely recommended for all children (e.g. immunizations and “well baby” care), medical services that are surgical in nature (e.g., hospitalizations or the prescription of medications), and devices necessary to control or treat a medical condition (Ohio Legal Rights Services, 2005).

Parents may be asked to pay for specialized services through the IFSP. If payment is requested from the family, their income must be considered and charges are calculated on a sliding fee scale in accordance with the family’s ability to pay. Other sources of funding can be used to pay for services such as family health insurance, Medicaid, or other health benefits (Ohio Legal Rights Services, 2005).

## V. WHAT WORKS; WHAT DOESN'T

### IMPACT ON INDIVIDUALS/FAMILIES

#### *What Works*

##### Invest in Children

Over 35,000 families in Cuyahoga County (more than 86 percent of all infants born to first-time and teen parents in the county) have received a visit from a Welcome Home nurse, with the majority of visits occurring within twenty days of birth. Welcome Home is effectively identifying families at highest risk for abuse/neglect and referring them on to Early Start (now Help Me Grow) and other services; in total, almost 24 percent of families that receive a Welcome Home visit are linked up with on-going support from Early Start or early intervention services. Almost 99 percent of the families visited by Welcome Home report the experience as helpful (Invest in Children Cuyahoga County, 2005).

Early Start (now Help Me Grow) has served 14,765 families and is reaching the families most in need. In fact, families at highest risk of child abuse and neglect are twice as likely to receive a home visit and engage in on-going home-based services. After referral, families are receiving services in a timely manner; within two working days of referral to Early Start, at-risk families are forwarded to a service provider and on average an initial home visit is conducted within three weeks of the referral. The average number of visits has increased by 68 percent since the start of Invest in Children. Early Start participants who received at least 15 visits demonstrated significant improvement in the areas of maternal depression, perceived stress, and parental competence (Invest in Children Cuyahoga County, 2005).

Invest in Children enables early identification of children with special needs. The number of children with developmental delays and disabilities who have been identified and linked up with early intervention services within the first six months of their lives has more than doubled since the start of Invest in Children. An Early Childhood Mental Health (ECMH) framework that entails both system and child/family outcomes is being developed, as well as the preliminary stages of an ECMH evaluation to be utilized in accordance with the Welcome Home and Early Start (now Help Me Grow) visits (Invest in Children Cuyahoga County, 2005).

##### Outcome Research Findings

The major types of psychotherapy for children are supportive, psychodynamic, cognitive-behavioral, interpersonal, and family systemic. With the exception of the latter, these therapies were originally developed for adults and then tailored for use with children. Most psychotherapies are deemed effective for children and adolescents because they improve more than they would with no treatment (Casey & Berman, 1985; Hazelrigg et al., 1987; Weisz et al., 1987; Kazdin et al., 1990; Baer & Nietzel, 1991; Grossman & Hughes, 1992; Shadish et al., 1993; Weisz & Weiss, 1993; Weisz et al., 1995). But despite this strong body of research that compares treatment with no treatment for children, far less attention has been paid to, and guidance provided for, the efficacy of a given psychotherapy for a specific diagnosis (Lonigan et al., 1998). In other words, it is not clear which therapies are best for which conditions.

Outpatient counseling is the most extensively studied intervention for children, with over 300 studies. Reviews of this literature, which often uses the statistical technique of meta-analysis to combine results from numerous studies, have identified several broad themes. First, child and adolescent therapy that is carefully defined (usually by a treatment manual) and delivered under carefully controlled, research-oriented conditions is usually found to be effective at reducing mental health problems. Typically, effect sizes are of moderate magnitude, with the average treated client showing more improvement than approximately three quarters of youth in control groups. Overall, outcome research has not indicated marked differences in treatment effectiveness as a function of client gender, age, ethnic group, or diagnostic category.

The outcome research literature provides varying amounts of support for different therapeutic approaches. In terms of the number of studies that have produced positive results, behavior therapy is the most supported form of intervention, cognitive therapy is second, and there is much support for the various combinations of these interventions—called *cognitive-behavioral therapy*. There is also extensive support for structured forms of family therapy, most of which include prominent cognitive-behavioral elements (e.g., multisystemic therapy, functional family therapy). Outcome research with adolescents exhibiting conduct disorders generally provides stronger support for family therapy than individual treatment. There is little research support for psychodynamic, solution-focused, and narrative interventions for youth, although these strategies are often utilized by therapists.

The contrast between outcomes obtained in research and community clinics indicates a need for stronger emphasis on evidence-based practice (i.e., interventions that have received strong support from outcome research). However, depending on the individual needs and strengths of the client, there are probably cases in which empirically supported strategies that are effective for most youth would not be optimal for a young person in question.

In research on child and adolescent treatment, behavioral and cognitive therapies have accumulated much more empirical support than any other type of intervention (Chambless & Ollendick, 2001). Approximately 80 percent of child and adolescent therapy outcome studies have investigated cognitive-behavioral treatment, and the vast majority of these studies have produced supportive results. A meta-analysis focusing specifically on these therapies found substantial positive effects across a range of client problems (Durlak, Fuhrman, & Lampman, 1991). Weisz et al.'s (1995) broad meta-analysis directly compared the effect sizes produced by behavioral and non-behavioral interventions and found that behavioral therapies had a greater positive impact on clients.

A meta-analysis of cognitive-behavioral therapy outcome studies found that this type of intervention produces stronger positive effects in youth aged 11 and older, compared to younger children (Durlak et al., 1991). Cognitive and cognitive-behavioral techniques are generally inappropriate for children below 8 years old because these strategies require considerable thinking abilities to be beneficial. There are no empirically well-supported therapies for young children whose primary complaint is emotional distress (e.g., anxiety and depression); this sub-population of children represents a gap in the field's repertoire of research-based best practices.

There is a treatment approach for disruptive behavior disorders in young children that does have a strong research base: behavioral parent training. In this treatment modality, the clinician does not provide therapy directly to the child, but instead trains caregivers in parenting techniques that then provide therapeutically beneficial experiences on a day-to-day basis in children's natural environment. Caregivers learn how to give effective directives, praise, rewards, and mildly negative

consequences for misbehavior. Extensive outcome research indicates that this type of therapy reduces disruptive behavior problems, improves parent-child relationships, and also has positive, non-specific effects on children's emotional functioning and self-esteem (Barkley, 1997; McMahon & Forehand, 2003).

There have been four meta-analyses involving comprehensive reviews of the outcome research on child and adolescent therapy (Casey & Berman, 1985; Kazdin, Bass, Ayers, & Rodgers, 1990; Weisz, Weiss, Alicke, & Klotz, 1987; Weisz, Weiss, Han, Granger, & Morton, 1995). The results produced by these meta-analyses were quite similar to each other, and the results were consistently encouraging. In most of the studies reviewed by these meta-analyses, adolescent therapy demonstrated significant positive effects on client symptoms and psychosocial functioning. The effect sizes calculated were in the medium to large range. In the studies summarized by these analyses, the average therapy client achieved more improvement than approximately 75-80 percent of the youngsters in control groups. Most youth who demonstrated improvement continued to show some symptoms of their disturbance at the end of the studies, and only a minority achieved the same level of functioning as average youngsters in non-clinical samples. In the follow-up studies included in these meta-analyses, the positive effects of therapy were usually maintained for at least the 6-month periods typically investigated and sometimes for considerably longer periods. In summary, therapy is somewhat helpful for most youngsters, and its beneficial effects usually last for at least six months.

Behavioral and cognitive therapies have accumulated much more empirical support than any other type of intervention (Chambless & Ollendick, 2001). Approximately 80 percent of child and adolescent therapy outcome studies have investigated cognitive-behavioral treatment, and the vast majority of these studies have produced supportive results. A meta-analysis focusing specifically on these therapies found substantial positive effects across a range of client problems (Durlak et al., 1991). Weisz et al.'s (1995) broad meta-analysis directly compared the effect sizes produced by behavioral and non-behavioral interventions and found that behavioral therapies had a larger positive impact on young clients.

Meta-analyses of family systems therapy have produced substantial support for this approach to treatment (Shadish et al., 1993; Stanton & Shadish, 1997). There is particularly strong support for structured forms of family therapy that include cognitive-behavioral elements (e.g., multisystemic therapy, functional family therapy). Outcome research on treatment for youth with disturbances involving overt acting out generally provides stronger support for family therapy than for individual treatment. There is little research support for psychodynamic, solution-focused, and narrative therapies for youth, although these strategies are often utilized by therapists.

Wraparound Services (Grundle, 2002; Van Den Berg, 1993) aim to provide comprehensive, individualized interventions through a combination of case management and flexible funding. Like MST, wraparound services involve an expansive view of mental health treatment that extends beyond traditional professional-client interactions to include virtually any type of relationship or activity with the potential to improve the youth's psychosocial functioning and quality of life. Planning meetings include professional staff and, in addition, other individuals who are important to the youth and who have the potential to provide helpful forms of support and guidance (e.g., neighbors, coaches, relatives). The case manager seeks to arrange for whatever activities he or she thinks would most benefit the client. Outcome research has found that, compared to conventional interventions, youth who receive wraparound services show improved adjustment, reduced behavior problems, and reduced placements outside the community (Grundle, 2002; Hyde, Burchard, & Woodworth, 1996).

Finally, a study by the National Center for Children in Poverty (NCCP) looked at effective programs that promote the emotional health and school success of young children and their families, particularly families that are most vulnerable. Based on their research, NCCP developed “Ten Strategies to Help Infants, Toddlers, and Families at Higher Risk for Poor Outcomes.” These strategies are outlined below:

- Strategy 1: Ensure that ALL low-income families have access to infant and toddler child development and family support programs.
- Strategy 2: Embed research-informed intensive interventions, such as parent therapies, into Early Head Start and home visiting infant and toddler child development and family support programs.
- Strategy 3: Embed intensive interventions for infants and toddlers and their families in settings serving only high-risk families.
- Strategy 4: Organize services by level of family risk.
- Strategy 5: Use basic support programs for families to provide more intensive services.
- Strategy 6: Build partnerships with early intervention and child welfare systems.
- Strategy 7: Screen for and address maternal depression and other risks in health care settings serving women and young children.
- Strategy 8: Implement parenting curricula and informal support groups designed for higher risk families.
- Strategy 9: Build a community approach to prevention and early intervention for groups of babies, toddlers, and families facing special risks.
- Strategy 10: Include more vulnerable families in broader infant, toddler, and early childhood advocacy strategies (Knitzer & Lefkowitz, 2006).

#### *What Doesn't Work*

In survey research coordinated by the Center for Community Solutions (2003), most community agencies reported extensive use of evidence-based practices. Over 90 percent of child agencies reported using cognitive-behavioral therapy with clients suffering from post-traumatic stress disorder. This type of therapy was also reportedly used extensively with anxiety and depressive disorders. However, this study did not ascertain the degree of fidelity with which the agency therapists implemented their evidence-based practices. It is difficult to know whether these therapists carefully followed treatment manuals, merely kept certain principles in mind when conducting therapy, or achieved a level of implementation fidelity lying somewhere in between the two extremes.

The Center for Community Solutions and Cuyahoga County Community Mental Health Board (2003) recently surveyed all CCCMHB-funded agencies about their use of evidence-based practices. Thirty agencies (18 serving adults and 12 serving children) participated in the study. The researchers defined evidence-based practices as interventions that have been supported by studies with well-designed experimental or quasi-experimental methodologies and adequate sample sizes. They searched the literature through a variety of avenues and identified 13 evidence-based mental health practices for children and 30 such practices for adults. Then they administered a brief telephone interview to survey one senior clinical staff member or administrator at each agency about use of these practices. The researchers acknowledged the potential limitations of this self-report method of data collection; respondents might have over-reported use of evidence-based practices in order to portray their agencies in a favorable light, and no attempt was made to assess the fidelity with

which these interventions were implemented. However, the interview utilized probes designed to support the validity of these agency reports of their practices.

The results indicated that Cuyahoga County agencies make extensive use of evidence-based practices. There were a number of specific interventions that 80-90 percent of the agencies reported as using. Given that the researchers inquired about 13 interventions for children and 30 for adult clients, their results indicate that virtually all of the agencies use some evidence-based practices, and most apparently use a number of them.

Over 90 percent of the child agencies reported implementing cognitive behavior therapy for posttraumatic stress disorder in children. Eighty-three percent of these organizations said they utilize cognitive behavior therapy for depression. Two thirds of the agencies reported using cognitive problem solving skills for conduct disorder. Significant proportions of the child-serving organizations reported using many of the 10 other empirically supported practices about which the interview inquired.

Although these results may seem to indicate that Cuyahoga County agencies make extensive use of research-based, empirically supported interventions, there are several considerations that make the results of the survey difficult to interpret. First, as the researchers noted themselves, the self-report nature of the data, coupled with the concern many agencies have about being viewed positively by CCCMHB, might have resulted in inflated estimates of evidence-based practice utilization, especially because there was no independent check on these agency reports.

## IMPACT ON COMMUNITY

A recent Colorado study contrasted the \$1,020 cost for two days of psychiatric hospitalization with the \$987 cost for an entire year of intervention by a behavioral specialist to prevent expulsion from child care. In Maryland, 10 to 20 hours worth of basic consultation services provided by a behavioral specialist working out of a child care resource center costs approximately \$250. For a cost of about \$5,000 per year, a child can receive outpatient services to prevent the development of serious emotional disturbances at a facility such as Montgomery County's Reginald Lourie Center. Contrast those figures with the following: \$35,000 per child per year for therapeutic foster care; \$55,000 to \$75,000 for a year in a therapeutic group home; and \$100,000 to \$120,000 for a year in a residential treatment center. By following the principles of prevention and early intervention, problems can be addressed early so they do not intensify (Maryland Committee for Children, 2006).

Nurse home visitation programs for high-risk (low income and unmarried) mothers and their infants show significant return on investment. Multiple and long-term benefits for both the mother and children at 15-year follow-up have been demonstrated. These benefits include reductions in child abuse and neglect, and fewer arrests among the mothers; fewer arrests and convictions, less substance abuse, and fewer sexual partners among the adolescents. Cost savings for these types of early intervention programs are estimated at \$4 saved for every dollar invested. Savings are from child welfare costs, taxes on increased income, and reductions in criminal justice costs (U.S. Department of Health and Human Services, 1999).

## ACCREDITATIONS/STANDARDS/CERTIFICATIONS

Most non-medical mental health services are provided by members of three professions: psychology, social work, and counseling. There are 3,765 licensed clinical and school psychologists

in the state of Ohio. Based on Cuyahoga County's proportion of Ohio's population and the higher concentrations of mental health professionals in urban and suburban areas, we estimate that there are approximately 1000 licensed psychologists in our county. Ohio has 14,905 licensed social workers (LSWs), who practice under supervision, and 6,472 licensed independent social workers (LISWs), who have accumulated sufficient supervised work experience to practice without supervision. Based on these numbers, we estimate there are approximately 4000 LSWs and 2000 LISWs in Cuyahoga County. Ohio has 3115 licensed professional counselors (LPCs), who practice under supervision, and 3447 licensed professional clinical counselors (LPCCs), who have enough supervised experience to practice independently. We estimate that there are approximately 900 LPCs and 1000 LPCCs in Cuyahoga County. In addition, there are small numbers of licensed psychiatrists, marriage and family therapists, registered nurses, music therapists, art therapists, and pastoral counselors who provide psychotherapy to clients.

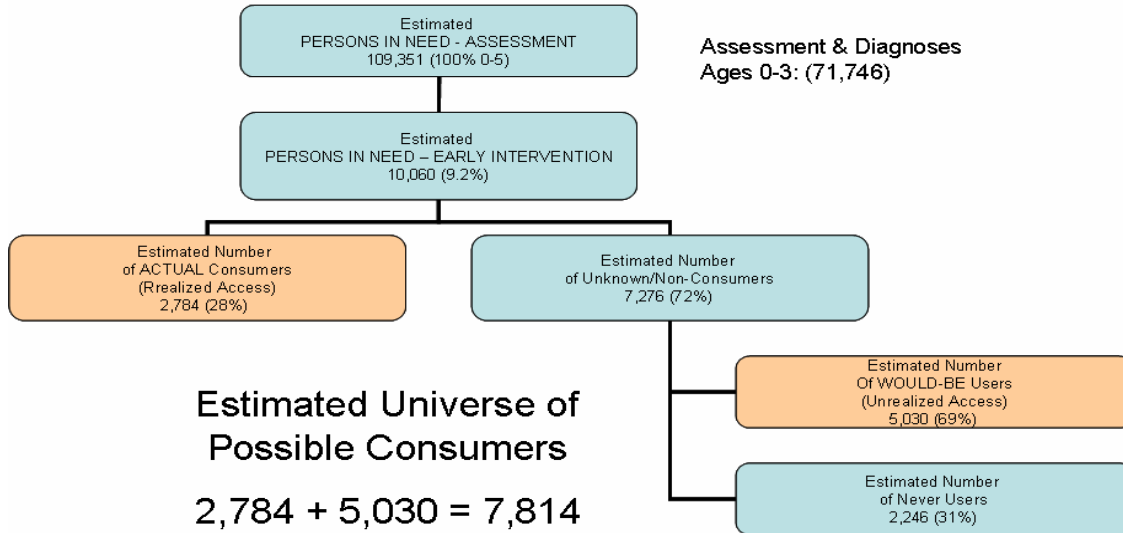
## VI. GAP ANALYSIS

The following is the formula for arriving at the estimated universe of possible consumers for Early Intervention for Mental Illness:

- An estimated 71,746 children need evaluation, assessment, and diagnosis services under the early intervention for mental illness programs, which is the number of all Cuyahoga County children 0-3 years, per U.S. Census 2000.
- Of the 109,351 children ages 0-5 in 2000, 10,060 (9.2 percent) have been identified as in need of mental health services ( $109,351 \times 9.2\% = 10,060$ ). This is based on research from the National Survey of Children with Special Health Care Needs (2001) that found that 9.5 percent of children 0-5 years need mental health services.
- Based on available information about actual consumers, approximately 2,784 children have realized access to early intervention for mental illness programs. This is the sum of children 0-5 estimated to receive early intervention services by Invest in Children (2,784) and assumes duplication with United Way's funded consumers (65).
- This leaves a net estimate of 7,276 children 0-5 who are either receiving services from unaccounted-for sources or are not receiving early intervention for mental illness. ( $10,060 - 2,784 = 7,276$ )
- The National Survey of Children with Special Health Care Needs (2001) found that 4.6 percent of children of all ages needed and did not receive mental health services. Applying this to Cuyahoga County's population 0-5 results in 5,030 would-be consumers if services were available, families knew about them, and could afford them. ( $109,351 \times 4.6\% = 5,030$ )
- Including both realized (2,784) and unrealized (5,030) access, there is an estimated universe of 7,814 children 0-5 who would be possible consumers for early intervention mental health services (See Figure 5.)

The same study found that access to mental health services was even lower for low income and uninsured children of all ages.

## Figure 5 - Consumer Estimates: Early Intervention for Mental Illness



### *Service Site Index*

Because United Way – First Call for Help does not collect data on this service, a Service Site Index was not completed.

### *Service Capacity*

Unfortunately, most children with mental disorders do not receive appropriate treatment. Only about one fifth of these young people receive specialty mental health services. About twice that number receive some type of service from the education, medical, child welfare, or juvenile justice systems, but these services probably do not address clients' mental health problems as directly and effectively as specialized mental health treatments.

This report also noted that one serious constraint on the effective operation of the mental health system, both private and public, is the chronic shortage of psychiatrists with specialized expertise in psychotropic medications. The shortage of child and adolescent psychiatrists is particularly acute. This shortage is a national problem, but it seems to be more pronounced in the Midwest than on the East and West Coasts. The result of the shortage is long waiting lists for psychiatric services, which sometimes results in the deterioration of mental health conditions before needed medication is prescribed.

## VII. SUMMARY

The following are the major findings from research on early intervention for mental illness:

- Specific treatments and services are available for children with mental disorders, but these disorders emerge in the context of an ongoing developmental process and shifting relationships within the family and community. These developmental factors must be carefully addressed to maximize the healthy development of children with mental disorders, promote remediation of associated impairments, and enhance their adult outcomes.
- The most significant public policy issues that impact early intervention for infants and toddlers is reimbursement for services from third parties such as private insurance, Medicaid, and the federal Individuals with Disabilities Education Improvement Act (IDEA) of 2004.
- There is an institutional bias to reimbursement schemes that include hospitals and inpatient facilities, but exclude community-based organizations.
- Medicaid and other insurances are disallowing reimbursement for certain diagnoses such as autism.
- The majority of funding for early intervention for mental illness comes from Medicaid and the Children's Health Insurance Program (CHIP) and IDEA. Medicaid funding has increased from \$57.8 million in 2002 to \$67.7 million in 2004. However, these numbers include a bundle of multiple mental health services.
- Between 2003 and 2005, identified funding for early intervention for mental illness has remained fairly level at \$700,000.
- As of May 11, 2006, \$833,535 in revenues for the early intervention for mental illness programs has been identified countywide, excluding Medicaid dollars.
- Welcome Home is effectively identifying families at highest risk for abuse/neglect and referring them on to Early Start (now Help Me Grow) and other services.
- Most psychotherapies are deemed effective for children and adolescents because they improve more than they would with no treatment, but it is not clear which therapies are best for which conditions.
- There is particularly strong support for structured forms of family therapy that include cognitive-behavioral elements (e.g., multisystemic therapy, functional family therapy).
- The assumption is that all children birth to three years need screening for mental health issues. The estimated universe of possible consumers for early intervention services is 7,814 persons including both realized (2,784) and unrealized (5,030) access.

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## ATTACHMENTS

### Attachment 1: Researcher List

# MCS

## CONSULTING SERVICE

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Thanks to *The Center for Community Solutions* for providing multiple sources of information.

## 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 core 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: Early Intervention for Mental Illness RR-180						
	Total Population (%) <sup>*</sup>	Total Population 0-5 (%) <sup>**</sup>	Estimated Persons in Need		Actual Number/Percent of Consumers by Funding Source <sup>****</sup>	
			Assessment (0-3) <sup>***</sup>	Service (0-5) <sup>***</sup>	Program Report Data Cuy Cnty Only 28.6%	Invest in Children (%)
PERIOD	1/1/2000-12/31/2000	1/1/2000-12/31/2000	1/1/2000-12/31/2000	1/1/2000-12/31/2000	7/1/2003-6/30/2004	7/1/2003-6/30/2004
<b>Age 0-3</b>		71,746	71,746	6,601		
<b>Age 4-5</b>		37,605	-	3,460		
<b>TOTAL Age 0-5</b>	1,393,978	109,351	71,746	10,060	65	2,784
<b>Percent</b>		7.8%	100.0%	9.2%		
<b>GENDER</b>						
Male	47.2%	50.7%	N/A	N/A	20.3%	56.5%
Female	52.8%	49.3%	N/A	N/A	8.4%	43.1%
Unknown Data <sup>*****</sup>					71.4%	0.4%
Missing Data <sup>*****</sup>					0.0%	0.0%
<b>RACE<sup>*****</sup></b>						
White alone	67.1%	56.5%	N/A	N/A	8.8%	41.7%
Black or African American alone/combination	27.9%	36.3%	N/A	N/A	18.1%	41.5%
Asian alone/combination	2.1%	2.6%	N/A	N/A	0.4%	1.5%
American Indian and Alaska Native alone/combination	0.7%	0.8%	N/A	N/A	0.0%	0.3%
Native Hawaiian and Other Pacific Islander alone/combination	0.1%	0.1%	N/A	N/A	0.0%	0.0%
Some other race alone/combination	2.1%	3.7%	N/A	N/A	1.3%	2.5%
Unknown Data <sup>*****</sup>					71.4%	12.6%
Missing Data <sup>*****</sup>					0.0%	0.0%
<b>HISPANIC<sup>*****</sup></b>						
	3.3%	5.7%	N/A	N/A	0.0%	0.0%
<b>AGE</b>						
0-4	5.3%	67.8%	N/A	N/A	21.1%	0.0%
5-9		93.0%	N/A	N/A	7.5%	0.0%
10-14			N/A	N/A	0.0%	0.0%
15-19			N/A	N/A	0.0%	0.0%
20-34			N/A	N/A	0.0%	0.0%
35-54			N/A	N/A	0.0%	0.0%
55-64			N/A	N/A	0.0%	0.0%
65-74			N/A	N/A	0.0%	0.0%
75+			N/A	N/A	0.0%	0.0%
Unknown Data <sup>*****</sup>					71.4%	0.0%
Missing Data <sup>*****</sup>					0.0%	100.0%
<b>INCOME<sup>*****</sup></b>						
<b>Average Household Size</b>	2.4	N/A	N/A	N/A	N/A	N/A
\$0-\$9,999	11.3%	N/A	N/A	N/A	3.5%	0.0%
\$10,000-\$14,999	6.9%	N/A	N/A	N/A	2.2%	0.0%
\$15,000-\$19,999	6.7%	N/A	N/A	N/A	1.8%	0.0%
\$20,000-\$29,999	13.6%	N/A	N/A	N/A	3.1%	0.0%
\$30,000 and above	61.5%	N/A	N/A	N/A	3.5%	0.0%
Unknown Data <sup>*****</sup>					85.9%	0.0%
Missing Data <sup>*****</sup>					0.0%	0.0%
<b>Totals</b>	<b>100.0%</b>	<b>N/A</b>	<b>N/A</b>	<b>N/A</b>	<b>100.0%</b>	<b>100.0%</b>

### Attachment 3: Actual Consumer Demographics (continued)

* U.S. Census 2000, SF1 (P1); SF4 (PCT 144)
** U.S. Census SF3 (P8); SF4 (PCT3); SF4 (PCT144).
*** Assumes that 100 percent of children 0-3 years need assessment and 9.2 percent of children 0-5 years need mental health services. The latter is based on an estimate in the National Survey of Children with Special Health Needs (2001) by the U.S. Department of Health and Human Services, Human Resources and Services Administration.
****Note: Consumers could be funded by more than one funding source; thus the columns are not necessarily mutually exclusive.
*****Unknown Data - Represents data not collected by agency because no tracking system is available or type of service delivered makes it difficult (i.e., group presentations, telephone information and referral, and drop-ins). Also represents data not completed by clients either deliberately or inadvertently on intake forms.
*****Missing Data - For United Way Data - represents computational errors or incorrect completion of online report. For all other data - represents data funder was unable to provide.
*****The race categories and data utilize US Census SF4 "Race Iterations," which allow for multiple races to be selected by census respondents. As a result, totals will add to > 100% of population. Universe is "Total Races Tallied." Except "White Alone", all racial categories are "... alone or in combination with some other race". This method isolates and minimizes the non-minority population ("White alone").
*****Hispanic - Amount in this field is from data provided by clients on intake forms and may not be accurate as clients may either deliberately or inadvertently provide incomplete data, or data may not be collected by the agency.
*****The U.S. Census reports income by household or family, not individuals. Estimates by income category were derived by applying the ratio of total county population (1,393,978) to total households (571,606) = 2.4. The number of households in each income category was multiplied by 2.4 to arrive at an estimate of individuals by income category. The assumption is that the average household size applies to each income category which may result in more conservative estimates for children and the "old old" which may actually have larger proportions of persons in the lower income categories.

### Attachment 4: Actual Consumer Zip Codes

Core Service: Early Intervention for Mental Illness RR-180							
						Actual Number/Percent of Consumers by Funding Source *****	
	City/Town (% Cleveland)	Total Population (%) <sup>*</sup>	Total Population 0-5 (%) <sup>***</sup>	Assessment (0-3) <sup>***</sup>	Service (0-5) <sup>***</sup>	UW Program Report Data (%)	Invest in Children(%)
Period		1/1/2000-12/31/2000	1/1/2000-12/31/2000	1/1/2000-12/31/2000	12/31/2000	7/1/2003-6/30/2004	7/1/2003-6/30/2004
<b>Age 0-3</b>			71,746	71,746	6,601		
<b>Age 4-5</b>			37,605	-	3,460		
<b>TOTAL</b>		1,393,978	109,351	71,746	10,060	65	2,784
<b>Percent</b>			7.8%	100.0%	9.2%		
44017	Berea	1.4%	1.1%	N/A	N/A	0.0%	0.4%
44022	Bentleyville	1.3%	0.7%	N/A	N/A	0.0%	0.6%
44040	Gates Mills/Mayfield Village	0.2%	0.1%	N/A	N/A	0.0%	0.0%
44070	North Olmsted	2.4%	2.1%	N/A	N/A	0.0%	1.8%
44101	Cleveland (100%)	0.0%	0.0%	N/A	N/A	0.0%	0.0%
44102	Cleveland/Brooklyn (95%)	3.7%	4.8%	N/A	N/A	1.5%	5.2%
44103	Cleveland (100%)	1.8%	2.3%	N/A	N/A	3.1%	2.6%
44104	Cleveland (100%)	2.1%	3.5%	N/A	N/A	6.2%	3.7%
44105	Cleveland/NewburghHts/GarfieldHts (75%)	3.9%	4.9%	N/A	N/A	7.7%	4.7%
44106	Cleveland/Cleveland Hts (60%)	2.3%	2.0%	N/A	N/A	12.3%	1.1%
44107	Lakewood/Cleveland	4.0%	3.7%	N/A	N/A	0.0%	3.6%
44108	Cleveland/Bratenahl (90%)	2.6%	3.2%	N/A	N/A	1.5%	4.2%
44109	Cleveland/Brooklyn Hts (98%)	3.3%	4.2%	N/A	N/A	4.6%	4.5%
44110	Cleveland/East Cleveland (98%)	1.9%	2.5%	N/A	N/A	3.1%	2.6%
44111	Cleveland (100%)	3.1%	3.5%	N/A	N/A	3.1%	2.8%
44112	East Cleveland/Cleveland	2.4%	2.7%	N/A	N/A	3.1%	3.3%
44113	Cleveland (100%)	1.4%	1.5%	N/A	N/A	3.1%	1.4%
44114	Cleveland (100%)	0.3%	0.2%	N/A	N/A	0.0%	0.0%
44115	Cleveland (100%)	0.6%	1.2%	N/A	N/A	3.1%	1.3%
44116	Rocky River	1.5%	1.2%	N/A	N/A	0.0%	1.2%
44117	Euclid/Cleveland	0.9%	0.6%	N/A	N/A	0.0%	0.8%
44118	ClevelandHts/UniversityHts/ShakerHts	3.2%	3.4%	N/A	N/A	4.6%	4.1%
44119	Cleveland/Euclid (50%)	1.0%	0.9%	N/A	N/A	1.5%	1.1%
44120	Shaker Hts/Cleveland	3.4%	3.9%	N/A	N/A	9.2%	3.9%
44121	University Hts/South Euclid	2.5%	2.4%	N/A	N/A	3.1%	2.7%
44122	Beachwood/Highland Hills/ShakerHts	2.5%	1.9%	N/A	N/A	6.2%	1.7%
44123	Euclid	1.3%	1.5%	N/A	N/A	0.0%	0.9%
44124	Pepper Pike/MayfieldHts/Lyndhurst	2.9%	2.2%	N/A	N/A	0.0%	2.2%
44125	Valley View/Garfield Hts	2.1%	1.9%	N/A	N/A	0.0%	1.7%
44126	Fairview Park/Cleveland	1.2%	1.1%	N/A	N/A	1.5%	0.9%
44127	Cleveland (100%)	0.6%	0.8%	N/A	N/A	1.5%	0.6%
44128	Warrensville Hts/Cleveland	2.4%	2.3%	N/A	N/A	9.2%	3.2%
44129	Brooklyn/Parma/Cleveland	2.1%	2.0%	N/A	N/A	1.5%	1.5%
44130	Parma/Cleveland	3.8%	2.9%	N/A	N/A	0.0%	2.2%
44131	Independence/Seven Hills/BrooklynHts	1.5%	1.0%	N/A	N/A	1.5%	0.7%
44132	Euclid	1.1%	1.0%	N/A	N/A	1.5%	1.4%
44133	North Royalton	2.0%	1.7%	N/A	N/A	0.0%	1.0%
44134	Parma/Cleveland	2.9%	2.6%	N/A	N/A	0.0%	2.0%
44135	Cleveland/Lindale (90%)	2.0%	2.3%	N/A	N/A	0.0%	2.5%
44136	Strongsville	3.1%	3.1%	N/A	N/A	0.0%	1.3%
44137	Maple Hts/Cleveland	1.9%	1.8%	N/A	N/A	0.0%	2.6%
44138	Olmsted Twp/Olmsted Falls	1.3%	1.2%	N/A	N/A	0.0%	1.5%
44139	Bentleyville/Glenwillow/Solon	1.6%	1.5%	N/A	N/A	0.0%	1.5%
44140	Bay Village	1.1%	1.1%	N/A	N/A	0.0%	0.9%
44141	Brecksville	1.0%	0.7%	N/A	N/A	0.0%	0.7%
44142	Brookpark/Cleveland	1.5%	1.2%	N/A	N/A	0.0%	1.4%
44143	Highland Hts/Richmond Heights	1.7%	1.3%	N/A	N/A	4.6%	1.4%
44144	Brooklyn/Cleveland	1.6%	1.4%	N/A	N/A	1.5%	1.1%
44145	Westlake	2.3%	1.9%	N/A	N/A	0.0%	1.4%
44146	Walton Hills/Oakwood/Bedford	2.3%	1.8%	N/A	N/A	0.0%	1.5%
44147	Broadview Hts	1.1%	1.2%	N/A	N/A	0.0%	1.0%
44149	Strongsville	0.0%				0.0%	1.0%
Unknown Cuyahoga County Zip Codes*****						0.0%	2.7%
Missing*****						0.0%	0.0%
Unknown *****						0.0%	0.0%
<b>Total Cuyahoga County*****</b>		<b>100.0%</b>	<b>100.0%</b>	<b>N/A</b>	<b>N/A</b>	<b>100.0%</b>	<b>100.0%</b>
<b>Total Known Cleveland</b>		<b>30.5%</b>	<b>37.9%</b>	<b>N/A</b>	<b>N/A</b>	<b>52.3%</b>	<b>38.2%</b>
<b>Total Known Suburbs</b>		<b>69.5%</b>	<b>62.1%</b>	<b>N/A</b>	<b>N/A</b>	<b>47.7%</b>	<b>59.1%</b>
<b>Unknown &amp; Missing</b>						<b>249.2%</b>	<b>0.0%</b>

Attachment 4: Actual Consumer Zip Codes (continued)

* U.S. Census 2000, SF1 (P1)
** U.S. Census SF3 (P8), SF4(PCT3); SF4 (PCT144)
*** Assumes that 100 percent of children 0-3 years need assessment and 9.2 percent of children 0-5 years need mental health services. The latter is based on an estimate in the National Survey of Children with Special Health Needs (2001) by the U.S. Department of Health and Human services, Human Resources and Services Administration.
**** 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 zipcodes because some zipcodes include data from adjacent counties

### Attachment 5: Providers and Functions – 2005

Service Providers & Functions	
Source: United Way - First Call for Help Refer Database February 2005	
Agency	Services
<b>Beech Brook/Family Health Program</b>	
<b>Hanna Perkins School</b>	

**Bold** represents agencies funded by United Way for this service. United Way - First Call for Help does not collect data on this service.



**United Way of  
Greater Cleveland**

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