

Children with Disabilities: A hidden health care crisis

**Findings of the
Children's Task Force
of the
Milwaukee Center for Independence**



Task Force Staff:

Marc Voyvodich
Stroudwater Associates

TASK FORCE MEMBERS

Vivian Chen, MSW, SCD

Health Operations Director, City of Milwaukee

Joe Dannecker

President, Milwaukee Public Schools (MPS) School Board

Rob Henken

Director, Milwaukee County Health & Human Services

Mark Keane

Associate Professor, UWM School of Architecture & Urban Planning

Randall Lambrecht, Ph.D.

Dean, UWM College of Health Sciences

H. Carl Mueller

Mueller Communications

Eric Schenker, Ph.D.

E.S. Consulting Inc.

Mark Simms, M.D., MPH

Professor & Medical Director, Children's Hospital

Michelle Urban, M.D.

Chief Medical Officer, Division of Health Care Financing

Thank you for your assistance. We appreciate your ongoing support.

MCFI Consultant Report

Executive Summary

Prepared by: H. Carl Mueller, Mueller Communications Inc.

ADDRESSING A GROWING EPIDEMIC

Sounding the alarm

A growing crisis of epidemic proportions is threatening the most vulnerable children in our community. For the first time, this report sounds the alarm for our community and state and offers realistic solutions to help manage the crisis. We have the choice to respond with rational and effective strategies, or we can choose not to respond, to ignore this epidemic and watch the cost to society and our community grow even greater.

This community-based report documents an alarming increase of children who are either born with disabilities or who have been diagnosed with disabling conditions later in childhood in Southeastern Wisconsin.

Simply put, even though the population of school-aged children is declining in the seven-county area, the number of special needs kids continues to increase every year.¹ Today's special needs kids have already cost Wisconsin taxpayers \$15 billion in lifetime costs.² A 2% to 5% reduction in that number can result in savings between \$300 million and \$650 million.

If left unchecked, this is an issue that threatens to bankrupt government programs, agencies and school districts struggling to cope with the challenge. The shockingly large and increasing numbers of children with disabilities represent a huge and growing burden on families, schools, taxpayers and society.

¹ National survey data and the Wisconsin Department of Instruction

² Methodology used to generate this estimate can be found in the Kakalik and Brewer, 1979, Rand Technical report

Call to action

Our community and state must act now or suffer increasingly overwhelming costs and human tragedy that we simply can't afford. We recommend a family-centric approach designed to facilitate improved diagnosis, coordinated treatment, and referral.

To meet this goal, we envision a regional diagnostic, treatment and resource center that would provide cost-effective, cross-disciplinary strategies for diagnosis, care and longitudinal treatment planning for children with disabilities and would offer families in Milwaukee and surrounding counties the education, advocacy and other supportive resources they so desperately need.

We're not seeking to reinvent existing care systems, nor are we seeking additional funding. We want to organize existing systems in a way that is more effective.

Initial momentum has already been generated to address the needs of children and families in the region that currently go unmet. There is a commitment by Milwaukee Center for Independence to provide leadership and planning resources and strong leadership has been shown by a task force representing Milwaukee Public Schools, City of Milwaukee Health Department, Milwaukee County Health and Human Services, University of Wisconsin-Milwaukee, and the State of Wisconsin Department of Health and Family Services, as well as a volunteer board of visitors composed of local and state elected officials committed to solving this crisis. We must now augment this initial momentum with strong leadership to see this vision through to reality.

Meeting the needs of children

The proposed diagnostic center concept focuses on the needs of children and families to effectively coordinate diagnostics, treatment, outcomes, monitoring, research, and reporting in

one geographic location, making the center more “user-friendly” and more efficient and effective.

The vision for a community-based diagnostic and treatment center for children would ideally emphasize three features. Underscoring those features would be facilitated access to a comprehensive expert diagnostic resource that could be leveraged on behalf of families to meet the recommended treatment for their child.

1. **A new children’s diagnostic resource anchored by an interdisciplinary service program.** This would provide families and children with disabilities a single, one-stop portal for accessing the diagnostic assessment, treatment planning, and functional outcomes monitoring services required to maximize the level of function and independence for the child.

2. **Coordinated program of diagnostic assessment services.** This might include any of the following depending on the presenting concerns and individual needs of the child:
 - Psychological assessment
 - Physical therapy assessment
 - Occupational therapy assessment
 - Speech therapy assessment
 - Audiology assessment
 - Recreational therapy assessment
 - Financial/life planning assessment
 - Vision assessment
 - Educational assessment
 - Dental assessment
 - Benefits counseling

3. Access to and coordination of treatment planning services.

- These would be based upon an inter-disciplinary compilation of diagnostic assessment findings for each child;
- Services would be laid out by a team meeting with all diagnosticians and the family for a prescribed period, including establishing initial appointments for each service needed, and ensuring follow through.

The goal of the treatment planning service component will be set to specific treatment and outcome objectives for a specified period for each child diagnosed with a behavioral, cognitive, or communication related disability.

AVERTING THE CATASTROPHE

Solving the crisis – the next step.

Developing and implementing a system as described above is an integral first step to turn the tide in favor of Wisconsin children and families born with disabilities, and the government programs, agencies and school districts that help care for them.

The concept of a model program and center that can show the measurable results outlined in this report is the first step to addressing this vital need in the community. The creation of a Diagnostic Center for Children to provide early diagnosis and a coordinated, integrated and measured program of services is a critical next step. This will take a partnership between the state, local medical and educational institutions and the private sector.

The initial momentum generated for the Diagnostic Center is important and sets the stage to develop and execute the next critical components of the plan. Next steps include:

1. Securing grant funding for detailed planning of the service, education and research programs, their associated facility requirements and the operating and financial models that will support them.
2. Applying these planning resources to:
 - a. Convene potential services, education and research providers to collaboratively define service volumes, staffing and space needs at a level of detail required to support implementation level planning.
 - b. Develop a detailed facility plan and related project cost estimates.
 - c. Specify the corporate structure that will be used for supporting development of the initiative.
 - d. Specify case funding systems and processes, including “Memorandum of Understanding” documentation of prospective eligibility criteria, including how children will be referred for services.
 - e. Establish sources and uses of funds estimate for capital funding.
 - f. Establish an operating budget that defines specific revenue sources and realistic fund flow estimates, as well an expense projection including staffing, facility costs and other operating costs.
 - g. Explore options for establishing an interface between the children’s long-term care waivers, the Children with Special Health Care Needs SE Regional Center and this center.
3. Integrating these data into a strategic business plan for guiding the implementation and funding of the center.

The case for action to improve the futures of children with disabilities is compelling. The professional, institutional and financial resources can be found. The only missing ingredient is an investment in and commitment to execution. MCFI and its partners on the DCC Task Force and Board of Visitors are dedicating to making this vision a reality.

Report on Children with Disabilities: A hidden health care crisis

Findings of the
Children's Task Force

Marc Voyvodich
Stroudwater Associates

INTRODUCTION

Approximately a half-million children under 18 years old live in the seven-county¹ Milwaukee region of Wisconsin. More than 28,000 children are born in the region each year, and a conservative estimate is that 2,700 children will develop a lifetime disability. Using a conservative assumption of a 40-year lifespan, each annual “class” of disabled children in this seven county region will generate cumulative economic net present value costs of more than \$15 billion in 2003 constant dollars. Almost a quarter of these costs will be related to direct medical, educational, and home/vehicle modification costs^{2,3}. There is spirited debate among knowledgeable professionals regarding what specific conditions should be included in this count, but where there is no debate is that these are depressingly large numbers representing a huge burden on families, schools, taxpayers and society, and the problem is growing.

The problem is growing both because the incidence of disability is growing and because the needs of children with a disability are going unmet and their cost is increasing. There are many resources but little coordination on behalf of children and families with a disability. New and better knowledge of health technology competes with second-hand information and charlatanism. The Milwaukee Center for Independence recommends the development of a coordinating accessible expert resource for the community that will put a primary focus on the needs of children and their families where there is a disability. This proposal details the extent of the problem in Milwaukee and the surrounding counties. MCFI has undertaken a planning exercise to develop a strategy that focuses on the growing problem of disability and to recommend an approach to dealing with the problem.

¹ See Table 4. The region includes Milwaukee, Kenosha, Ozaukee, Racine, Walworth, Washington, and Waukesha counties.

² The methodology resulting in an estimated 48,800-49,000 disabled children 0-17 years old living in the seven county area combines Wisconsin Public School data with B-3 enrollment data. This incidence rate of just under 10% is well below the 13.4% number of children and youth with special health care needs reported for Wisconsin by the National Survey of Children with Special Needs, 2001.

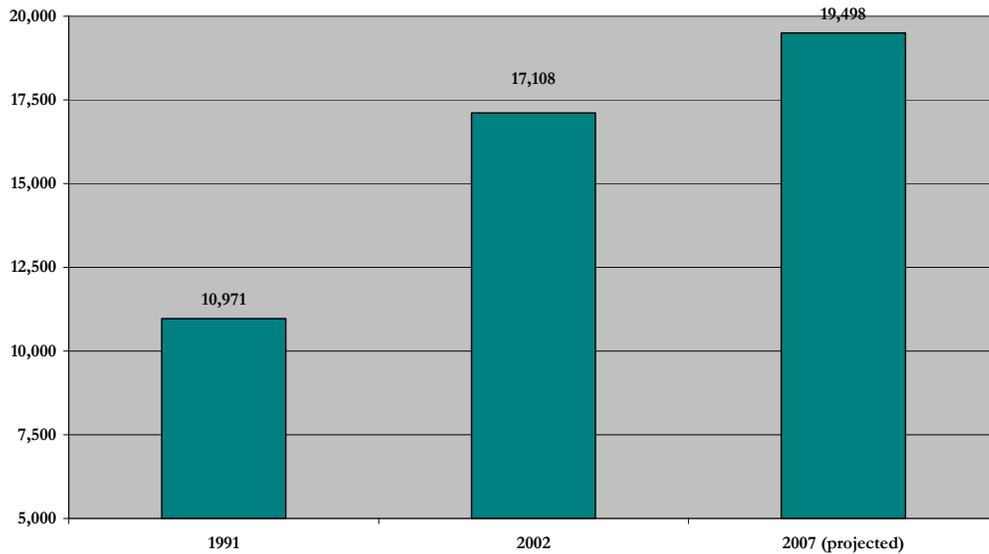
³ See Footnote 24 for a presentation of the methodology used to generate this estimate.

DISABILITY AND DEMOGRAPHICS

In the past 25 years, the number of young people graduating from special education programs has doubled. The rate of special education placement is increasing. About 70 percent of those graduates are unemployed.

Table 1

**MPS Students Enrolled
in Special Education**



School system data from the region shows that between FY 2001 and FY 2004, the number of school children with disabilities increased by 1,388 or 3.26 percent.⁴ The above table (Table 1) details this change by disability/impairment category. For example, the rate of autism among school children in southeastern Wisconsin increased 67.3 percent between 2001 and 2004.⁵ In Milwaukee, the percentage of children who have special health care needs is 23.5 percent, nearly double the national average (12.8 percent) and the state average (13.4 percent).⁶

⁴ Wisconsin Department of Public Instruction

⁵ Wisconsin Department of Public Instruction

⁶ Center for Urban Populations Health, UW Medical School

Table 2
Public School Children with a Disability
in the Seven County Region including Milwaukee

Disability/Impairment	FY 2001	FY2004	Difference	3% Year Change
Cognitive Disability	4,714	4,369	(344)	(7.30%)
Emotional Disturbance	4,919	4,801	(119)	(2.41%)
Specific Learning Disability	16,661	15,490	(1,171)	(7.03%)
Speech or Language Impairment	9,490	10,110	620	6.54%
Autism	943	1,582	639	67.73%
Deaf - Blind	45	44	(1)	(2.48%)
Hearing Impairment	674	703	29	4.36%
Orthopedic Impairment	719	615	(104)	(14.41%)
Other Health Impairment	3,009	4,569	1,560	51.84%
Significant Developmental Delay	988	1,186	198	20.26%
Traumatic Brain Injury	135	176	41	30.46%
Visual Impairment	180	220	40	22.20%
All Disabilities*	42,477	43,865	1,388	3.26%
Total Enrollment	380,755	382,699	1,944	0.51%

Source: Wisconsin Department of Public Instruction

*Note: Disability category numbers were calculated from reported rates by individual school districts and then aggregated by county, causing a <2.0% variance from the reported All Disabilities count, due to rounding.

** Low incidence disabilities of autism, deaf – blind, hearing impairment, orthopedic impairment, other health impairment, significant developmental delay, traumatic brain injury and visual impairment were calculated by applying the respective state-wide prevalence rates as school district prevalence rates were unavailable, to protect the confidentiality of students.

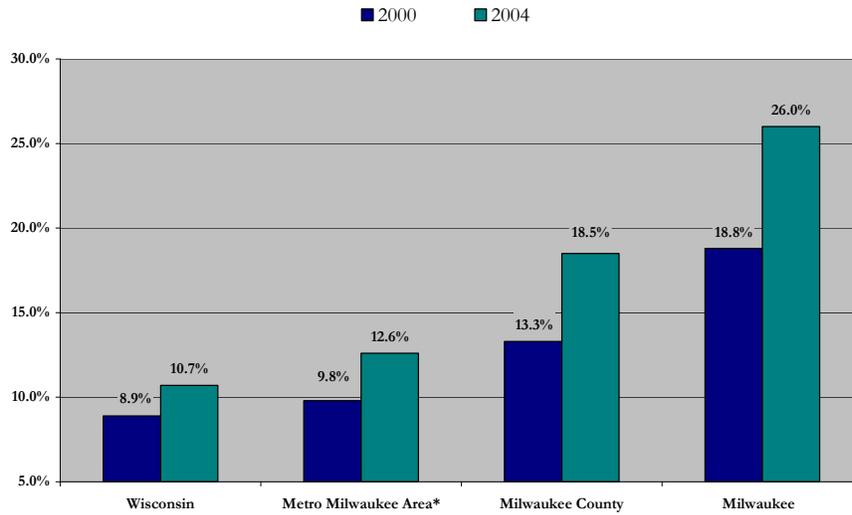
By 2007, it is projected that one in five students in the Milwaukee Public Schools district – or 19,500 children⁷ – will be enrolled in special education.

In light of these data, it is clear the prevalence of disability is rising. The contributions to the increase come from several sources. Research has shown that the more economically stable a family is, the more successful are children academically, socially, and physically. Therefore, this rise is not counter-intuitive, given that Wisconsin’s poverty rate has been growing and children in our state have an uphill battle in those three areas.

⁷ Milwaukee Public Schools

Table 3

Individuals Living In Poverty



The growth of poverty in Wisconsin and Milwaukee can be seen above. During this five-year period, Wisconsin’s poverty rate increased by nearly 20 percent, which is the fastest rate of increase in the country. Poverty in Milwaukee increased 38 percent during this period of time. The number of Wisconsin families living below the federal poverty line – which in 2004 was defined as \$18,850 for a family of four – rose from 74,930 in 2000 to 101,140 in 2003. Without adequate food, housing, health care and other basic necessities, the probability that a child will experience healthy development is diminished.

Another contributing factor to the increase in prevalence is the rising incidence of disability for children born prematurely. In 2004, 7,703 Wisconsin infants were born prematurely, representing about 11 percent of all births. Certainly, premature births are related to factors of severe poverty. Higher percentages of low-birth-weight infants were born to:

- Mothers who received no prenatal care (23.1%)
- Mothers less than 15 years old (14.3%)
- Non-Hispanic black women (13.7%)
- Women who smoked during pregnancy (11.2%)
- Women who were unmarried (9.6%)
- Women with less than a high school education (9%)

The challenges of poverty, poor prenatal care, low birth weight and lack of access to adequate health care have greatly increased the number of children with disabilities such as Down syndrome, autism, diabetes, asthma and depression. This correlates with increased health and social service needs, special education requirements and welfare dependency. U.S. Census Bureau statistics indicate that about 70 percent or more of the people with disabilities are unemployed. When coupled with the opportunity costs associated with reductions in workforce productivity, the costs of this failure are amplified approximately four-fold.

With the risk of development for individual growth, there is not only an increasing probability that these children will not work in the community, but worse, will have a low probability of finishing high school and an increased probability of prison.

This statistic presents a depressingly large number and represents a huge burden on families, schools, taxpayers and society. By coordinating the expert resources of this community and focusing on the needs of children and families at risk with an accessible and well-configured system of care and treatment, the costs can be reduced. In the process of saving money it is fully expected that there will be a significant increase in children who are able to integrate into the community.

Using a conservative assumption of a 40-year lifespan, each annual “class” of disabled children in this seven county region of Wisconsin will generate cumulative economic net present value costs of more than \$15 billion⁸ in 2003 constant dollars. Almost 24 percent or \$3.5 billion of these costs will be related to direct medical, education, and home/vehicle modification costs.

The 0-17 age cohort of disabled children in this region currently consumes \$1.51 billion in direct healthcare, education and adaptation costs annually. Indirect costs, such as lost productivity of these children and the families who care for them, are much higher.

The inability to slow the rate of disability increase and significantly enhance the development of children with a disability belies the extent of knowledge our society possesses.

⁸ See Footnote 24 for a presentation of the methodology used to generate this estimate.

More than 40 years of research shows that a child with a properly structured system of resources based on expert diagnosis of the disability and an expertly prescribed program of treatment monitored over time can show significantly improved development. The problem then is not as much what we know but how to transfer this knowledge into a community setting under the pressure of a growing health problem of considerable urgency and, potentially, of epidemic proportions.

The Milwaukee Center for Independence, a community-based social institution serving more than 10,000 people with disabilities, proposes the development of a community-based Diagnostic Center for Children. This facility would serve as an expert resource by working with institutions such as the University of Wisconsin-Milwaukee and the Medical College of Wisconsin to coordinate resources and focus on the growing problem of disability. That coordination of care and treatment would effectively transfer knowledge into clinical application and create a system for support and guidance to the family and child with a disability.

NATIONAL SURVEY DATA

The special needs population is defined as those who have “a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally”.⁹ The estimated number of children from birth to age 17 with special health care needs in Kenosha, Milwaukee, Ozaukee, Racine, Walworth, Washington and Waukesha counties is projected to be between 60,000 and 70,000, according to the *National Survey of Children with Special Health Care Needs* and the Maternal and Child Health Bureau (a bureau of the Health Resources and Services Administration, U.S. Department of Health and Human Services).¹⁰

About 12.8 percent of children in the United States have special health care needs. Wisconsin exhibits a greater prevalence with 13.4 percent of its children having special health care needs. When applied to the estimated population of children ages 0 to 17 in southeastern Wisconsin (a population of 500,410 in 2005), the resulting market size is 67,058 special needs children. (See Table 4) By 2010, this population is projected to decrease by 1,674 or 2.5 percent to 65,381. Based on national estimates of incidence and prevalence, the national data indicates a small decrease in children with disabilities consistent with the small population decrease. However, local data for Milwaukee has shown a sharp and significant increase of children with special health care needs among the population of children with disabilities to 23.5 percent. This is clearly greater than either national or state estimates and signals an increasing number of children with a disability, and along with other data, a growing complexity in the rising incidence of disability. (See attachment 3 for county population trend and county by age incidence data, 2005 – 2010)

National data has significant limitations in that projected changes in the number of children with special health care needs is determined by multiplying the current incidence rate as a percentage of the projected population of children. This methodology does not reflect health issues occurring within the population, especially mothers living in poverty with poor housing

⁹ *Exhibit 1 WDPI, [State definition]*

¹⁰ *Maternal and Child Health Bureau, July 1998*

and/or environmental conditions and lacking prenatal care. Consequently, if the population is projected to decrease, the projected number of children with disabilities would be expected to decrease.

Table 4
Estimated Market Size By County for Children with Special Needs
Ages 0 -17 for all Special Needs Categories, 2005 and 2010

	2005 Population	2005 expected number w/ disability	2010 Population	2010 expected number w/disability	# change	% change
Kenosha	40,853	5,475	40,852	5,475	0	0.00%
Milwaukee	245,305	32,872	239,228	32,057	(815)	-2.48%
Ozaukee	20,575	2,757	19,111	2,560	(197)	-7.15%
Racine	49,528	6,637	48,030	6,435	(202)	-3.04%
Walworth	22,106	2,963	22,326	2,992	29	0.98%
Washington	30,459	4,082	29,828	3,997	(85)	-2.08%
Waukesha	91,584	12,272	88,548	11,865	(407)	-3.32%
Total	500,410	67,058	487,923	65,381	(1,677)	-2.50%

Source: Population data from Claritas. Size calculated by KCG using National Survey of Children with Special Health Care Needs Wisconsin prevalence of children with special needs (13.40%) and the service area population.

The national survey found that 12.5 percent of Children with Special Health Care Needs (CSHCN) in Wisconsin have one or more unmet needs for specific health services. When applied to the number of service area special needs children in 2005, 8,384 are receiving insufficient care. Other important survey findings were:

- 18.4 percent of children with special health care needs needing specialty care in Wisconsin had problems getting a referral, or 12,339 children in the seven-county service area
- 29.5 percent of children with special health care needs in Wisconsin have inadequate health insurance coverage, or 19,783 service area children
- 14.1 percent of children with special health care needs missed 11 or more school days as a result of illness (9,455 in the service area) and 23.3 percent had health needs that caused family members to cut back or stop working (15,623 in the service area)

A summary of *National Survey of Children with Special Health Care Needs* findings, in relation to the center’s service area, is included in Table 5.

Table 5
Summary of findings from National Survey of Children with Special Health Care Needs

	Wisconsin %	Nation %	Milwaukee	Other 6 counties	Service area total
Access to care					
% of children with one or more unmet needs for specific health care services	12.5	17.7	4,109	4,275	8,384
% of children whose families needs but did not get all respite care, genetic counseling, and/or mental health services	19.8	23.10	6,508	6,769	13,277
% of children needing specialty care who had problems getting a referral	18.4	21.9	6,048	6,291	12,339
% of children without a usual source of care (or who rely on the emergency room)	13.10	9.30	4,306	4,479	8,785
% of children without a personal doctor or nurse	8.4	11	2,761	2,872	5,633
Health insurance coverage					
% of children without insurance at some point during the past year	7	11.6	2,302	2,392	4,674
% of children currently uninsured	2.4	5.2	789	819	1,608
% of children currently insured with coverage that is not adequate	29.5	33.8	9,697	10,086	19,783
Impact on child’s quality of life					
% of children whose health conditions consistently and often greatly affect their daily lives	24.6	23.2	8,086	8,411	16,497
% of children with 11 or more days of school absences due to illness	14.10	15.8	4,635	4,820	9,455
Impact on family					
% of children whose families pay \$1,000 or more in medical expenses per year	10.7	11.2	3,518	3,658	7,176
% of children whose families experienced financial problems due to child’s health needs	18	20.9	5,917	6,151	12,068
% of children whose families spend 11 or more hours per week providing and/or coordinating health care for child	9.4	13.5	3,089	3,213	6,302
% of children whose health needs caused family members to cut back or stop working	23.3	29.8	7,659	7,964	15,623

Source: KCG calculated market size using Claritas population data and the percentage of children and youth with special health care needs, 0-17 years old, for the state of Wisconsin (13.4 percent). Percentages from the National Survey of Children with Special Health Care Needs, 2001

POPULATION SIZE BY DISABILITY

There are a number of diagnoses that define children with special health care needs. The Centers for Disease Control’s National Center of Birth Defects and Developmental Disabilities examined¹¹ the national rate per 1,000, children ages 3 to 10, for autism, autism spectrum disorders (ASD), mental retardation, cerebral palsy, hearing loss, vision impairment, and Tourette’s syndrome. Child Trends, a 26-year-old nonprofit, nonpartisan research organization dedicated to improving the lives of children, determined the prevalence of ADHD and learning disabilities in children ages 3 to 17. Table 6 shows the prevalence rates for each of these diagnoses, as well as the cumulative size of the population in 2005 when applied to the combined 5 to 9 age cohort (for the CDC provided rates) and the 5 to 17 cohorts (for the Child Trends provided rates)¹².

Table 6
Estimated Service Area Disabilities Based on National Rates for Select Conditions, Population Ages 5 – 9 (for CDC rates) and 5 – 17 (for Child Trend rates)

Condition	National rate per 1,000	Milwaukee (2005)	Other 6 counties (2005)	Total (2005)
Autism	3.4	227	229	456
ASD	4.0	981	1,022	2,003
Mental Retardation	9.7	648	654	1,302
Cerebral Palsy	2.8	187	190	377
Hearing Loss	1.1	73	74	147
Vision Impairment	0.9	60	61	121
Tourette Syndrome	1.0	176	191	367
Subtotal	--	2,352	2,421	4,773
ADHD	72.0	12,620	13,818	26,438
Learning Disability	81.0	14,198	15,541	29,739
Speech Impairment	--	--	--	--
Behavioral Health	--	--	--	--
Congenital Anomalies	--	--	--	--
Total	--	29,170	31,780	60,950

Source: National rate of autism, ASD, mental retardation, cerebral palsy, hearing loss, vision impairment, and Tourette syndrome from the CDC National Center of Birth Defects and Developmental Disabilities (NCBDDD) Metropolitan Atlanta Developmental Disabilities Surveillance Program, 1991-1994. National rate of ADHD and learning disability from Child Trends Databank, 2002. KCG calculated market size using national rates and the service area population as defined by the age cohorts from Census data.

¹¹ CDC National Center of Birth Defects and Developmental Disabilities (NCBDDD) Metropolitan Atlanta Developmental Disabilities Surveillance Program was conducted from 1991-1994. Findings were released in 1996.

¹² Age cohorts vary from the referenced study age cohorts due to limitations of census data.

BIRTH TO 3 PROGRAM

Wisconsin’s Birth to 3 Program is an early intervention program that provides case management services for children with special needs and refers these children and their families to appropriate service providers. The federally-mandated program provides services for children up to 3 years of age who show developmental delays of 25 percent or more in such factors as vision, speech or walking.

On Dec. 1, 2004, the program was serving 5,756 children across Wisconsin, with 2,594 children residing in the seven county service area¹³. This is a conservative estimate of the number of children enrolled in the program that year. It is a reasonable snapshot given the difficulty in tracking turnover on an annual basis, as children may leave the program and then return and be double counted in annual counts.

Table 7
Number of Children Enrolled in Birth to Three by County,
Dec. 1, 2000 & Dec. 1, 2004

County	12/1/00	12/1/04	# change	% change
Kenosha	161	168	7	4.35%
Milwaukee	1,403	1,472	69	4.92%
Ozaukee	82	115	33	40.24%
Racine	197	248	51	25.89%
Walworth	73	97	24	32.88%
Washington	79	105	26	32.91%
Waukesha	327	389	62	18.96%
Total	2,322	2,594	272	11.71%
Wisconsin	5,072	5,756	684	13.48%

Source: Wisconsin Birth to Three Program

Footnote: A detailed summary of the Birth to Three disability conditions for the seven county service area and by county is provided in Attachment 5. These summaries also show the services provided to these children by disability.

Table 7 above shows that there is an overall increase of 272 children or 11.71 percent in enrollments from 2000 to 2004 for the seven-county area. Overall, Wisconsin’s program increased the number of children served by 684 or 13.5 percent. While Kenosha and Milwaukee counties experienced moderate enrollment increases of 4.35 percent and 4.92 percent,

¹³ Point in time count provided by Donna Miller, Birth to 3 Program and Policy Specialist/Special Education Coordinator, Wisconsin Department of Health and Family Services, Division of Disability and Elder Services, Bureau of Developmental Disabilities Services (BDDS).

respectively, the other five counties saw significant relative growth with Ozaukee showing the largest relative increase at 40.24 percent. However, despite Milwaukee’s low relative rate increase compared to other service area counties, it experienced the largest numerical growth in disabilities with an increase of 69 children over the four-year period.

In the seven county area within southeastern Wisconsin, the nearly 12 percent increase in children enrolled in Birth to Three programs occurs across a variety of disability categories. Specific conditions/disabilities identified by the Birth to Three Program are shown below in Table 8.

Table 8
Children in the Birth to Three Program with Disabilities
Seven County Service Area – 2004

Condition/Disability	Number
Vision impaired	46
Hearing impaired	50
Physical disability	111
DD Brain	21
DD Cerebral	11
DD Autism	5
DD Retarded	53
DD Epilepsy	4
DD Other	4,458
Blind Deaf	2
Health Impairment	39
Emotional Disturbance	10
Total	4,810

Source: Wisconsin Birth to Three Program

The state data indicates that the seven county service area has approximately 4,800 birth to three disabled children and 44,000 disabled school children. A reasonable estimate of the total number of disabled children in the seven county service area, then, approximates 49,000 disabled children.

GROWING INCIDENCE AND PREVALENCE

The incidence of disability is rising at a rate that counters the corresponding projected decline in the birth to age 17 child population. As was noted, this rise is not counter-intuitive. The more economically stable a family is, the more successful children are academically, socially, and physically; however with the growing rate of poverty, children in our state and especially in Milwaukee, have an uphill battle in those three areas.

The expectation of a decline in the absolute numbers of children to offset the increase in children with a disability, and somehow reduce the economic impact of disabled children (and their dependency as adults) over time is not likely. In fact, the financial resources required to support the current need is inadequate and should increase over time¹⁴. In addition, the number of children from birth to age 17 in the seven county greater Milwaukee region with a disability can be expected to increase even though the population *is* projected to continue to decline by 2.5 percent or by nearly 12,500 children during the next five years. This is according to national survey data. School system data from the region shows that between 2001 and 2004, the number of school-age children with disabilities increased by 1,388 or 3.2 percent, and there appears to be no subsidence of that trend.

The definition of a school-aged child with a disability¹⁵ is someone between the ages of 3 and 21 who has not yet graduated from high school and who requires special education and related services in accordance with the Individuals with Disabilities Education Act. For reporting purposes, the school system groups these children into the following categories: Cognitive Disability, Emotional Disturbance, Specific Learning Disability, Speech or Language Impairment and Low Incidence Disability (when the identified disability for a given school district is five or fewer students). All of the disability terms are defined in Wisconsin's Administrative Code Chapter PI 11 and can be found in Exhibit 2.

¹⁴ MR, V44, #1, 2006

¹⁵ For the cohort of school-aged children with disabilities, information was gathered on those students enrolled in special education. **Table 13** provides a statewide summary as well as breakdown of these children according to primary disability by county.

Table 9
Number of School Children with Disability by County
2000 –2004

County	2000-2001	2003-2004	# Change	% Change
Kenosha	3,586	3,807	221	6.16%
Milwaukee	21,576	21,822	246	1.14%
Ozaukee	1,437	1,570	133	9.26%
Racine	4,549	4,903	354	7.78%
Walworth	1,711	1,993	282	16.48%
Washington	2,381	2,324	(57)	(2.39%)
Waukesha	7,235	7,447	212	2.93%
Total	42,477	43,865	1,388	3.26%
Total Enrollment	380,755	382,699	1,944	0.51%

Source: Wisconsin Department of Public Instruction

Total student enrollment increased by 1,944 children or 0.51% from 380,775 to 382,665. Consequently, the prevalence of children with disabilities increased from 11.1 percent to 11.5 percent over the four-year period. Due to lifetime economic costs associated with any increase in the number of children with disabilities, this change is significant. For example, the lifetime economic cost for one child with mental retardation exceeds \$1 million (see discussion on economic impact).

Low incidence disabilities from the service area were reallocated to other disability categories, based upon the relative relationship of these conditions reported on a statewide basis, to better understand the prevalence of disability conditions. Table 8 shows the estimated number of school children within each disability condition.

Since 2000-2001, the number of students with a cognitive disability, emotional disturbance, specific learning disability, and orthopedic impairment has decreased (deaf-blind decreased by 1). All other disability conditions have shown an increase.

Similarly, it can be seen that the number of children ages birth to three with disabilities increased. Statewide enrollment in Wisconsin's Birth to Three program has increased 15 percent since 2001 (see Table 10).

Table 10

	2001	2002	2003	2004	2005
Total # of children served in Wisconsin's Birth to Three program	10,368	10,534	10,846	11,514	11,922

Source: Wisconsin Birth to 3 Interagency Coordinating Council 2003 annual report (based on 2002 and 2003 calendar years) and Wisconsin Birth to Three Program (2004 and 2005 statistics)

The number of school-age children with special health care needs has also increased over the past four years. Indicating therefore, not only has the number of children with a disability increased, but so have the complexity of their needs. The most significant disability increase for school-age children has occurred in the category of other health impairments. This category means having limited strength, vitality, or alertness due to chronic or acute health problems. Health problems include asthma, sickle cell anemia, epilepsy, diabetes, brain injuries, and degenerative conditions.

Conclusion

The need for services for children with disabilities and their families is growing: in the past 25 years, the number of students needing special education has more than doubled and now represents nearly 12 percent of the state's public school population and by 2010 will verge on 15 percent. Depending on how data are cumulated these figures could well be on the low side. The trend is expected to continue as the rate of placement in special education programs is two times the rate of placement in regular education.

The continuing increase in disabilities among children of all ages and the related lifetime economic costs indicate that the health system needs not only a more cost-effective treatment approach but also an improved capability to help children with disabilities become more productive as they age through and eventually out of the school system.

MEDICAID, THE DISABLED POPULATION AND REIMBURSEMENT TRENDS

Medicaid is the nation’s largest health and long-term coverage program for low-income Americans. In 2004, state and Medicaid spending totaled \$298.2 billion. Since 1999, Medicaid spending has increased by \$117.4 billion or 64.9 percent. The average annual increase in spending was 13 percent. Average spending per enrollee increased as well, but more slowly than average costs in the private insurance market.

Medicaid covers four primary groups of low-income people: the elderly, people with disabilities, children and pregnant women, and parents. The federal government matches funds allocated by states at rates based on each state’s per capita income. The federal financing share was roughly 57 percent nationally in 2003 and ranged from 50 to 77 percent across the states.

States administer Medicaid within federal guidelines, which mandate coverage for certain groups of individuals. The eligibility of these individuals is considered mandatory because federal guidelines require coverage as a condition of a state’s participation in Medicaid and the receipt of federal matching funds. The eligibility of other individuals is considered optional because federal guidelines allow, but do not require, states to cover these groups and receive federal matching funds.

Table 11
Medicaid Beneficiary Groups

Mandatory Populations	Optional Populations
Children under age 6 and older below 100% FPL	Low income children above 100% FPL who are not mandatory by age
Children under age 6 below 133% FPL	Low income parents with income above state’s 1996 AFDC level Pregnant women greater than 133% FPL Disabled and elderly below 100% FPL
Parents below state’s AFDC cutoffs from July 1996 (median = 42% FPL)	Nursing home residents above SSI levels, but below 300% of SSI
Pregnant women less than or equal to 133% FPL	Individuals at risk of needing nursing facility or ICF-MR care
Elderly and disabled SSI beneficiaries with income less than or equal to 74% FPL	Certain working disabled
Certain working disabled	Medically needs
Medicare buy-in groups	

Above federal minimums, states have flexibility to choose to cover other individuals and receive federal matching funds for the cost of their coverage. These groups are referred to as optional groups. Mandatory and optional coverage items and services are shown below.

Table 12
Medicaid Mandatory and Optional Items and Services

Mandatory	Optional
Physicians services	Prescription drugs
Laboratory and X-ray services	Medical care or remedial care furnished by other licensed practitioners
Inpatient care	Rehabilitation and other therapies
Outpatient hospital services	Clinic services
Early and Periodic screening, diagnostic, and treatment services for individuals under 21	Dental services, dentures
Family planning and supplies	Prosthetic devised, eyeglasses, durable medical equipment
FQHC services	Primary care case management
Rural health care clinics	TB-related services
Nurse midwife services	Other specialist or remedial care
Certified pediatric and family nurse practitioner services	

Generally, private health care insurance coverage for children is limited. And, individuals with disabilities who can obtain private health insurance often find that the benefits do not cover the full spectrum of their needs. Private health insurance plans are structured around providing health benefits to relatively healthy working populations, and rarely take into account the needs of people with disabilities. Core disability services including prescription drugs, mental health services, rehabilitation services, and personal care services frequently have annual or lifetime limits or are excluded altogether.

Medicaid provides the majority of coverage for poor (less than 100 percent FPL) children. The percentage of Medicaid coverage decreases significantly for the near poor (100-200 percent FPL) and the non-poor (200+ percent FPL).

Table 13
Medicaid Coverage of Individuals with a Specific Chronic Disability
By Poverty Level and Age – Yr. 1994

Poverty Level	Age 0 – 4	Age 5 – 17
Non-poor	41%	15%
Near Poor	47%	27%
Poor	77%	69%

Source: Economic and Social Research Institute based on data from the 1994 National Health Interview Survey, Phase I, April 1999.

Data from the National Health Interview Survey shows that, overall, coverage for the non-elderly provided by Medicaid is about 20 percent of all coverage. Medicaid is clearly the major payer for poor children ages birth to 17.

In Wisconsin, programs and services for the disabled are administered by the Wisconsin Department of Health and Family Services. Federal agencies and Wisconsin’s Department of Health and Family Services have significantly increased the number of disabled covered under managed care.

Table 14
Wisconsin Medicaid Managed Care Enrollment
June 30, 2000 – 2004

Enrollment	June 30, 2000	June 30, 2004	Number Change	Percent Change
Total Enrollment	477,167	792,177	+315,010	+66.0%
Managed Care	210,423	374,005	+163,582	+77.7%
Percent of Total	44%	47.2%	-	-

Source: Kaiser State Health Facts, 2005

While total Medicaid enrollment increased by two-thirds, the number of enrollees in managed care plans increased by almost 78 percent. The growth in managed care is seen as a direct indicator of the interest in both federal and state government in programs that offer the opportunity to control increasing costs while maintaining quality of care. While overall Medicaid data shows 47 percent of enrollees are in managed care, 70 percent of low-income family recipients are enrolled in managed care plans. Managed care capitation payments are 58 percent of expenditures for low-income families (DHFS).

The State Children's Health Insurance Program in Wisconsin had 37,839 children enrolled in 2003 (Urban Institutes, Assessing the New Federalism). Only two states increased cost sharing under the program in 2004. Wisconsin raised its premium from 3 percent of family income – already the highest in the nation – to 5 percent, the maximum allowed under federal law. Due to this and other policy changes, the state witnessed a significant drop in enrollment in the months that followed – over 18 percent by December 2004.

The Wisconsin managed care program for low-income working families with children is BadgerCare. This program is for non-Medicaid children and parents up to 185 percent of the federal poverty level.

Much of the growth in state Medicaid enrollment in the past few years has been from the creation of BadgerCare and SeniorCare prescription drug coverage. The caseload for family Medicaid and BadgerCare grew rapidly beginning with the economic downturn of 2001-2003 as people lost their jobs and fewer employers offered health insurance. The percentage of Wisconsin residents covered by employer-sponsored group plans declined from 77 percent to 69 percent from 2001 to 2003 (May 2005, DHFS).

In FY 2004, the state spent \$207 million for 94,000 enrollees or \$2,202 per enrollee in BadgerCare. Overall budgeted expenditures in FY 2004 for Wisconsin Medicaid was \$5,205 per enrollee. The state FY 2004 budgeted expenditures of \$4.2 billion shows a decrease of \$600 million over actual FY 2003 expenditures of \$4.8 billion (Wisconsin DHFS).

In July 1999, the Supreme Court issued the *Olmstead v. L. C.* decision. The Court's decision in that case clearly challenges federal, state, and local governments to develop more opportunities for individuals with disabilities through more accessible systems of cost-effective community-based services. Medicaid can be an important resource to assist states in meeting these goals.

However, the scope of the ADA and the Olmstead decision are not limited to Medicaid beneficiaries or to services financed by Medicaid. The ADA and the Olmstead decision apply to all qualified individuals with disabilities regardless of age.

The Centers for Medicare and Medicaid Services (CMS), formerly the Health Care Financing Administration, has begun consultation with states and with people with disabilities. CMS plans to review relevant federal Medicaid regulations, policies and previous guidance to assure that they are compatible with the requirements of the ADA and Olmstead decision, and facilitate states' efforts to comply with the law. CMS is working closely with other involved federal agencies to ensure that these reviews are consistent with the requirements of the statute and are focused on the needs of persons with disabilities.

Key facts regarding Medicaid spending in Wisconsin:

- Total Medicaid budget in FY 2004 was \$4.2 billion
- Wisconsin Medicaid budgeted payments per enrollee were \$5,205 in FY 2004. These payments are based upon a total of 807,000 enrollees or 15 percent of Wisconsin's population.
- The level of federal match for Wisconsin has decreased over the past three years:

FY 2004	61.38%
FY 2005	58.32%
FY 2006	57.65%
- There is an average of 8,717 children under 18 with disabilities on Medicaid. For most of them, Medicaid covers what their parent's group plan does not cover.
- In order to control Medicaid costs, Wisconsin has adopted the following measures: paying less for prescription drugs, negotiating better discounts for services; increasing premiums for BadgerCare; freezing insurance for BadgerCare; requiring verification of income and insurance for BadgerCare; and tightening payment and coverage policies.

In summary, Medicaid is the primary payer for poor children (less than 100% of the FPL). As the income level of the child and family increases, the Medicaid coverage provided decreases significantly. Wisconsin has emphasized managed care program enrollment and both

the state and federal government have a strong interest in programs that will help reduce cost and maintain or improve quality.

Although Medicaid has made great strides in enrolling low-income children, significant numbers of children remain uninsured. From 1988 to 1998, the proportion of children insured through Medicaid increased from 15.6 percent to 19.8 percent. At the same time, however, the percentage of children without health insurance increased from 13.1 percent to 15.4 percent. The increase in uninsured children is mostly the result of fewer children being covered by employer-sponsored health insurance.

With heightened cost consciousness for Medicaid expenditures, coverage requirements have been tightened resulting in a reduction of the number of children covered by BadgerCare.

Despite the aggressive trend to control costs, CMS and Medicaid do have an expressed interest in programs that would integrate services within a setting to provide cost-effective community-based services.

MEDICAID AND DISABILITY REIMBURSEMENT

- Medicaid provides the significant majority of payment for disability services for poor children - less than 100 percent Federal Poverty Level (FPL).
- As children/families move above the FPL, the importance of Medicaid in reimbursement decreases. Overall, Medicaid provides about 20 percent of reimbursement for those with disabilities.
- As the poverty rate has risen over the past four years, the Wisconsin Medicaid enrollment has increased by two-thirds or 315,010.
- In an effort to control costs and provide quality care, the state has encouraged Medicaid managed care enrollment, which has increased by 77.7 percent or 163,582 people from 210,423 to 374,003.
- Medicaid managed care now represented 47.2 percent of total enrollment.
- The financial pressure on the program continues as the level of federal match for Wisconsin Medicaid has decreased from 61.38 percent in 2004 to 57.06 percent in FY 2006.
- With heightened cost consciousness for Medicaid expenditures, the results has been that coverage requirements have been tightened and forced a reduction in the number of children covered by BadgerCare.
- A child may also qualify for disability benefits under Social Security or SSI Title XVI. Benefits are payable to disabled children under age 18 who have limited income and resources or who come from homes with limited income and resources.

As part of the aggressive trend to control costs, CMS expressed interest in Medicaid programs that would integrate services within a setting to provide more cost-effective community-bases services. This is based upon the Olmstead court case decision that interpreted Title II of the Americans with Disabilities Act (ADA) and the regulation requiring States to administer their services, programs, and activities “in the most integrated setting appropriate to the needs of qualified individuals with disabilities.” CMS cost concerns therefore have generally supported implementation of managed care programs to achieve more cost effectiveness.

The strategy of developing a community-based clinic to recommend an effective treatment for a child with a disability bridges expert resources into an accessible program into the long term goal of enhance development of children with a chronic health care need, The expectation, in turn, is an increased probability that this child will be more likely able to participate in their community.

ECONOMIC COSTS AND THEIR IMPACT

We have used the seven-county service area cost data based upon the national data survey applied to service area births for a selected year and then extended those data estimating lifespan of 40 years to develop the economic impact of those costs over time.

There are many disability conditions, but the discussion includes eight conditions which were identified from a review of industry research for which lifetime economic disability costs have been projected. These include mental retardation, Cerebral palsy, hearing loss, vision impairment, cleft lip or palate, lower limb reduction, upper limb reduction and Down syndrome.

Assuming a life expectancy of 40 years, the lifetime economic cost to the system (federal, state, county) will exceed \$15.5 billion for those conditions from the seven county service area. What is clear is the system can not be expected to sustain these costs into the future.

Individuals with significant developmental disabilities require a variety of direct medical support and non-medical support services like home and vehicle modification, special education, and services arising from their disability condition. As individuals age, their inability to actively participate in the workforce adds a lost productivity cost to the system and to the individual lifetime economic cost for support. The following discussion focuses on costs for selected disabilities and the potential economic return from development of more effective treatment plans and an increased opportunity for the disabled to actively participate in the workforce.

In 2003, the Centers for Disease Control and Prevention (CDC) studied the estimated lifetime economic costs for persons with mental retardation, cerebral palsy, hearing loss, and vision impairment. Other developmental disabilities like autism were not studied due to major gaps in cost data.

Estimated lifetime costs for the United States in 2003 dollars were expected to total \$51.2 billion for persons born in 2000 with mental retardation; \$11.5 billion for persons with Cerebral

palsy; \$2.1 billion for persons with hearing loss; and, \$2.5 billion for persons with vision impairment.

Lifetime economic costs are those over and above “ordinary costs incurred by unaffected persons in the U.S. population.” These very significant costs highlight the need for effective prevention measures to reduce the numbers of disabled children, more efficient treatment plans for individuals with developmental disabilities, and an increased ability to move disabled individuals into gainful employment whenever possible.

CDC estimated lifetime costs segmented by direct medical costs, direct non-medical costs, and indirect costs. This data is shown in Table 15.

Table 15
Individual Lifetime Economic Costs
Selected Disability Conditions – 2003

Developmental Disability	Direct Medical Costs (millions)	Direct Non-Medical Costs (millions)	Indirect Costs (millions)	Total Costs (millions)
Mental Retardation	\$7,061	\$5,249	\$38,927	\$51,237
Cerebral Palsy	\$1,175	\$1,054	\$9,241	\$11,470
Hearing Loss	\$132	\$640	\$1,330	\$2,102
Vision Impairment	\$159	\$409	\$1,915	\$2,484
Total	\$8,257	\$7,352	\$51,413	\$67,293

Source: Morbidity and Mortality Weekly Report (MWWR Weekly) January 30, 2004/53(03); 57-59. KCG calculated Indirect Costs as a % of Total Costs and Average Indirect costs per Person.

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

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

(c) Includes costs of home and vehicle modifications for persons aged <76 years and costs of special education for persons aged 3-17 years.

(d) Includes productivity losses from increased morbidity (i.e. Inability to work or limitation in the amount or type of work performed) and premature mortality for person aged <35 years with mental retardation, aged <25 years with cerebral palsy, and aged <17 years with hearing loss and vision impairment.

Individual lifetime economic costs for the four conditions above are shown below in Table 16.

Table 16
Individual Lifetime Economic Costs
Selected Disability Conditions – 2003

Developmental Disability	Direct/Non-Direct Medical Costs	Indirect Costs	Average Total Costs Per Person
Mental Retardation	\$243,664	\$770,336	\$1,014,000
Cerebral Palsy	\$178,950	\$742,050	\$921,000
Hearing Loss	\$153,164	\$263,836	\$417,000
Vision Impairment	\$129,671	\$436,329	\$566,000

Source: Morbidity and Mortality Weekly Report (MWR Weekly) January 30, 2004/53(03); 57-59. KCG calculated Indirect Costs as a % of Total Costs and Average Indirect costs per Person.

Note (a): Includes productivity losses from increased morbidity (i.e. inability to work or limitation in the amount or type of work performed) and premature mortality for person aged <35 years with mental retardation, aged <25 years with cerebral palsy, and aged <17 years with hearing loss and vision impairment.

Using the incidence rate for each disability, the seven-county service area births of 27,645 in year 2000 (base year for the study) were converted to an estimated case volume for each condition. This volume was multiplied by the per person cost in Table 16 to estimate the service area cost for each disability. This information is shown in Table 17.

Table 17
Projected Service Area Lifetime Economic Costs
Selected Disability Conditions

Disability	National Rate Per 1,000 (a)	Average Medical Costs	Average Indirect Costs	Total Costs
Mental Retardation	9.7	\$64,914,648	\$205,225,599	\$270,140,247
Cerebral Palsy	2.8	\$13,761,613	\$57,065,129	\$70,826,742
Hearing Loss	1.1	\$4,627,315	\$7,970,881	\$12,598,196
Vision Impairment	0.9	\$3,205,273	\$10,785,398	\$13,990,671
Total		\$86,508,849	\$281,047,007	\$367,555,856

Source: National incidence data from CDC National Center of Birth Defects and Developmental Disabilities. Incidence rates applied to year 2000 births.

Note: (a) Incidence data applied to age cohorts from available population data. These cohorts differ slightly from CDC age cohorts.

Data in Table 17 shows that the disability system (federal, state, county) could benefit significantly from investing in opportunities to develop new treatment models that will provide significant economic savings from more cost-effective medical care and treatment plans. In

addition, an increased ability to improve the functional capability of disabled children would reduce the societal cost of productivity losses.

Assuming a lifespan of 40 years, lifetime economic costs would be \$14.7 billion. If just a one percent reduction in costs could be achieved, the system would save \$147 million per year.

Disability costs are impacted by the dysfunctional nature of the health care system. Research conducted by Special Olympics documented that individuals with neurological disabilities face widespread health problems and they are not addressed in the total care of the disabled individual. In addition, primary care physicians, dentists and other health professionals do not receive adequate training to treat individuals with disabilities. The poor overall health of people with neurological disabilities and the serious gaps in provider health care training and availability constitute serious gaps in the care of the disabled child.

In regards to training for doctors and dentists, the Special Olympics study found that:

- Fifty two percent of medical school deans, 53 percent of dental school deans, 56 percent of students and 32 percent of medical residency program directors responded that graduates were “not competent” to treat people with intellectual disabilities.
- Eighty one percent of medical school students say they are not receiving any clinical training regarding individuals with intellectual disabilities.
- Two-thirds of medical students say they are not receiving enough classroom instruction.

Existing treatment models for individuals with disabilities have serious deficiencies because:

1. Most primary care providers are not adequately trained in the total needs of the disabled person and their family; and
2. The overall poor health of those individuals with disabilities and a lack of treatment knowledge among non-specialists in children’s disabilities limits attainment of a high level of cost effectiveness in treatment planning and total care of the disabled individual.

In addition, environmental and societal conditions impact the lifetime economic disability costs. A population segment where social and environmental change would help reduce the name of children born with a disability is improved prenatal care, especially for low-income mothers.

Studies have reported the following regarding low birth weight babies:

“A now substantial literature documents that school-aged children born low birth weight are at excess risk for mental retardation and borderline intelligence, and do not perform as well as their peers on tests of language, visual-perceptual organization and memory, even when IQ is in the normal range.”¹⁶

An international study of 436 children stated that:

“This large, international, population-based study indicates that early low birth weight children at school age experience a substantial burden of childhood disability, school-related difficulties, and increased utilization of special educational resources. These difficulties, which cannot be identified at younger ages, become steadily more apparent as the children face increasingly complex tasks in school.”¹⁷

Health services research conducted in 2004¹⁸ that studied profiles of annual medical charges for children by health status group and severity level in a Washington State Health Plan found that those with one or more chronic conditions incurred mean and median charges significantly greater than healthy children. Children classified as healthy had mean and median annual charges of \$485 and \$191, respectively. Children with one or more chronic conditions and had mean and median charged increasing by status and severity group from \$2,303 to \$76,143 (mean charges) and from \$1,151 to \$19,456 (median charges).

¹⁶ Pinto-Martin, Whitaker, Feldman, Cnaan, Zhao, Rosen-Bloch, McCulloch and Paneth. Special education services and school performance in a regional cohort of low-birth weight infants at age nine. *Pediatric and perinatal epidemiology* 2004, 18. pp, 120-129

¹⁷ Saigal, Ouden, Wolke, Hoult, Paneth, Streiner, Whitaker, and Pinto-Martin. School-Age Outcomes in Children who Were Extremely Low Birth Weights From Four International Population-Based Cohorts. *PEDIATRICS*. Vol. 112, No. 4. October 2003.

¹⁸ John M. Neff, Virginia L. Sharp, John Muldoon, Jeff Graham, and Kristin Myers. 2004. “Profile of Medical Charges for Children by Health Status Group and Severity Level in a Washington State Health Plan.” *HSR: Health Services Research* 39:1:73-89.

Key findings from this study were:

- Children who are classified as having a chronic condition of any kind represent only about 10 percent of the population, yet account for nearly 50 percent of total medical service charges;
- To decrease the cost of high cost hospital services and improve health status, careful long-term coordination of care, identification of community services, and access to appropriate specialty services is required; and
- Services might be able to be rearranged in a more cost effective way.

Intuitively, more effective treatment planning and use of medical resources for those children with significant developmental disabilities will reduce health and disability support system costs. In addition, the opportunity for a child to have a more productive economic life will reduce current system economic support costs resulting from loss of productivity.

In addition to the cost of \$368 million noted in Table 17 for mental retardation, cerebral palsy, vision and hearing impairment, another study¹⁹ projected lifetime economic costs related to the conditions of cleft lip or palate, upper and lower limb reduction, and Down syndrome. Based upon individual lifetime cost data from this study, the system for the seven-county service area would incur an additional \$20 million in lifetime economic costs. This data is shown below in Table 18.

Table 18
Estimated Service Area Economic Support Cost for Selected Disabilities
for Service Area Children Born in 2002

Condition	(Thousands) Medical Direct Costs	(Thousands) Non-medical Costs	(Thousands) Indirect Costs	(Thousands) Total Costs	(Thousands) Cost per New Case
Cleft lip or palate	\$650	\$134	\$4,013	\$4,797	\$101
Lower-limb reduction	\$119	\$84	\$972	\$1,175	\$199
Upper-limb reduction	\$76	\$165	\$928	\$1,169	\$99
Down syndrome	\$1,918	\$2,675	\$8,114	\$12,707	\$451
Total	\$2,763	\$3,058	\$14,027	\$19,848	n/a

Source: Calculations by KCG. Reported cost per case by cost element allocated among cost categories based upon relative relationship of total cost elements to total costs. All dollar values in thousands.

¹⁹ Economic Costs of Birth Defects and Cerebral Palsy – United States, 1992. *The Morbidity and Mortality Weekly Report*. September 22, 1995. Vol. 44/No.37. Pp. 694-699.

The eight disability conditions discussed above have been projected to result in lifetime economic costs of \$388 million for 491 individuals or an approximate \$790,000 average lifetime economic cost per disabled person. Assuming the number of individuals with disabilities continues to increase, the projected system cost burden will also grow. Without change to current treatment models, as well as environmental and social changes, these system costs are likely unsustainable in the future.

Findings

Opportunities for decreasing the prevalence of disabilities exist. System cost reduction opportunities through improvements in medical knowledge, treatment plans, and functional capabilities to enhance productivity of disabled individuals will benefit the health system.

A treatment model focused upon improvement in information coordination, improved treatment plans, and system cost reduction does not currently exist in the seven county service area. However, if current medical and social technologies could be brought to an appropriate focus on disability, significant improvement to the health care of these children could be obtained. By developing an approach toward improved coordination, diagnosis, treatment, and referral through a partnership of community-based institutions, we can provide a significant benefit to the system economics as well as to the health of area children and their families.

In the seven county service area, it was estimated that children with disabilities from eight conditions have a lifetime economic cost to the system approximating \$388 million. Assuming a life expectancy of 40 years, the economic cost to the system from the identified eight conditions exceeds \$15.5 billion.²⁰ The system will likely not be able to sustain this enormous cost. Changes in the transfer of medical and social knowledge for more effective treatment could probably achieve a one percent savings, saving the system roughly \$155 million annually.

²⁰ Represents \$14.7 billion from Table 12 data times 40 years plus Table 13 data for 40 years rounded to \$800 million. Total of two estimates is \$15.5 billion.

“How can I help my child?”

The problem faced by most families when they first understand that their child has a disability is they have no expert resource to help them. The issues go far beyond immediate medical care and include social and psychological development as well as support of the family system. Those resources are scattered throughout the community and are not readily accessible. Concern about the effectiveness of those resources and the quality of service that they can provide the family does not encourage confidence. Even when care is available for a child, it is often short-term and narrowly assigned to the child or family’s immediate needs.

Nearly 3,000 families in Southeastern Wisconsin will learn that their child has a significant disability this year alone – and that number is growing. Imagine the plight of a family that has learned that their child has been diagnosed with a disability that will affect his/her life, and the lives of everyone in their family, forever. Soon, the questions become overwhelming:

- What community resources are available for my child and our family?
- How can I be sure my child has access to proper medical treatment and effective therapies?
- How can I provide the best education for my child?
- Will my child someday be able to work?
- What will my child’s life be like in 20 years?

The child’s family will need to navigate a complex, confusing maze of health care providers, educational systems and social service agencies to find answers to those important questions. What we have clearly come to understand is that the effective application of medical, educational and social treatment can significantly enhance development for most children and greatly increase their probability for community independence.

So the question that remains, after all is said and done, demographic analysis notwithstanding, is the parent’s question: “How can I help my child?” The resources are not

readily accessible, not configured as a system and the focus is not on enhancing development of children with a disability.

There is no organized clearinghouse offering families affected by a disability with information on proper care for their dependents; on measuring the extent of the disability; on planning for future needs; on accessing expert treatment resources nor on addressing other needs. Dissemination of best practices developed through the United States is not routinely available to Milwaukee families.

What is needed is a community-based, accessible expert resource that families in Milwaukee County and the surrounding counties, who are faced with the problems of a disability, can use to connect them to advocacy and other supportive resources.

The need for Diagnostic Center for Children (DCC) services has grown tremendously and has brought us to a critical stage where a community-based resource is essential in order to focus on the growing community problem of disability and to provide early intervention and treatment services. Not only are the numbers of children with disabilities increasing, so too are the complexities of their needs. By coordinating expert resources, we can provide easier access to services and have the greatest impact on addressing the problem.

The DCC model represents a powerful strategy for dispersing what research has shown works for helping children with disabilities achieve their highest potential. At the heart of this proposal is the design of a multi-institutional task force to plan how to configure existing community resources in order to facilitate a cross-disciplinary strategy for diagnosis and treatment planning for children with disabilities. The hypothesis, guided by significant research and comparisons to clinical models elsewhere in the country, will guide the creation of this center and facilitate access to services that would be offered by the most competent resources within the medical and educational community.

RESOURCES FOR CHILDREN WITH DISABILITIES

The Milwaukee region is blessed with a broad spectrum of institutional and professional care resources, augmented and supported by professional education and research capabilities relevant to the needs of children with disabilities. These include the following:

- **Milwaukee Center For Independence (MCFI):** This 68 year old community-based private agency provides specialty services to more than 10,000 individuals with disabilities annually in southeastern Wisconsin. MCFI has grown its children's services figures significantly in response to growing community needs. MCFI is assuming the role of facilitator for the DCC.
- **The University of Wisconsin-Milwaukee's College of Health Sciences:** The capacity of this entity to educate nurses, therapists, and other health service professionals is an indispensable resource that is augmented by the services available and provided by both students and faculty. It is a significant resource for research knowledge and planning methodology. Its direct service capacity is established and is growing.
- **Children's Health System:** With the Children's Hospital of Wisconsin (CHW) recognized as one of the top three children's hospitals in the country, this is a major resource, particularly for children with physical disabilities. It is also developing a new Medicaid HMO for children in Wisconsin.
- **Medical College of Wisconsin:** The combined basic science education and research capabilities and clinical practice capacities, linked as they are with Children's Hospital, represents a significant dimension to the ability to address questions and challenges related to caring for children with disabilities.
- **Schools:** All of the school districts, as well as charter schools in the region have federally-mandated special education services and are required to provide mainstream educational services to children with disabilities. This represents a major challenge for most school organizations, particularly in terms of assembling, managing, and monitoring the myriad of specialty services needed to serve children with disabilities in a manner that optimizes their functional potential.

- Private Practitioners: There are many physician, psychologist, therapy, and other private practice resources that combine to fill service need gaps with varying levels of success. By definition, access to and coordination of these services occurs in a manner that is fragmented to the point of being nearly random from a regional perspective.
- Other agencies: There are dozens of other agencies throughout southeastern Wisconsin that provide various social, recreational, and other support services to children both with disabilities and at risk for acquiring them.

The seven county service providers to children with special health care needs include:

- | | |
|---------------------------------------------------|---------------------------------------|
| – Center for Blind and Visually Impaired Children | – Lutheran Social Services |
| – Rehab Resources | – Center for Deaf and Hard of Hearing |
| – Medical Support Services Inc. | – St. Francis Children’s Center |
| – Children’s Hospital of Wisconsin | – New Berlin Therapies |
| – St. Rose Youth and Family Center Inc. | – Curative Care Network |
| – Next Door Foundation | – The Threshold Inc. |
| – Easter Seals Child Development Center | – Ozaukee Therapy Services |
| – WI Facets | – Health Reach Rehab Services Inc. |
| – Penfield Children’s Center | – Kenosha Achievement Center |
| – Racine County Opportunity Center | |

Source: Information from individual organization Web sites.

NOTE: The providers do not include MCFI nor mandated school district programs.

CHW is the largest provider of children’s services. It services more than 200,000 outpatient visits and more than 70 clinics. It operates social service agencies and has five service contracts with the state. It operates Children’s Health Education Center and a Children’s Medical Group with 60 employed physicians. It has a transitions program from pediatrics to adult providers (medical model). CHW is working on development of a case management program.

Services frequently provided by other organizations are summarized in Table 19 below:

Table 19
Summary of Frequently Provided Services

Service	Number of Providers	Percent of Total
Birth to three program	15	79
Case management	13 (8 of 13 are for the birth to three program)	68
In home services	11	58
Parent support	10	53
Therapies (PT/SP/OT)	16	84

Source: Prepared by KCG for individual website data information

OTHER DISABILITY PROVIDERS AND AGENCIES

The following providers represent clinical models useful to the design of the DCC and are potential resources for the exchange of clinical information or referrals.

- **The Waisman Center in Madison** has a University Center for Excellence in Developmental Disabilities. Programs and services are organized into early childhood, community inclusion, and clinical services. It has a comprehensive set of services for children with disabilities. It does have a public policy and system change section and does provide follow-up services. It does not appear to have a clinical research component for documentation of outcomes and the refinement of treatment strategies. The Waisman Center is a significant Wisconsin resource in the provision of services and information to children with special health care needs and their families. However, it is located outside of the MCFI service area.
- **The Gunderson Lutheran Teen Health Service** is a comprehensive program based in La Crosse that provides mental health, education, and counseling services to adolescents and their families. It provides a multi-disciplinary team comprised of a pediatric physician, director, social workers, dietitian, nurses, and health educators. This program also is located outside of the MCFI service area.
- **The Respite Care Association of Wisconsin** provides respite care for temporary relief of caregivers and families who are caring for people with disabilities or other special needs such as chronic or terminal illnesses; or are at risk of abuse and neglect. The association was organized in 1987 and supports and advocates for quality systems of respite care for Wisconsin families. Several entities throughout the service area provide respite care through this agency.
- **DAWN** is a statewide grassroots cross-disability network of people who care about disability issues. DAWN supports legislative change in the programs and systems affecting people with all disabilities, as well as parent education.

- **State of Wisconsin Department of Health and Family Services (DHFS)** is the primary state agency responsible for the development and implementation of statewide policy, services and supports for people with developmental disabilities. It provides a wide range of services and programs including:
 - Autism Services
 - Birth to 3 Program
 - Brain Injury Waiver Program
 - Children’s Long-Term Care Redesign
 - Community Integration Program
 - Community Supported Living Arrangements
 - Developmental Disabilities Network
 - Family Support Program
 - Katie Beckett Program-Special Medicaid Eligibility
 - Person-Centered Planning
 - Self-Determination Project
 - Supported Employment
 - Supported Housing Specialist

- **Regional Centers for Children With Special Health Care Needs** - There are five regional centers in Wisconsin that provide free and confidential assistance to providers and children with special health care needs and their families. The southeastern Region Center is located in the foyer of the Reiman Foundation at Children’s Hospital. The center is staffed by parents of children with disabilities.

SERVICE GAPS

Although there is a rich array of service providers, there remains a significant gap in needed services. Families have difficulty accessing services, lack the confidence in service when found and usually have no resource to guide them over the longer course of development.

Programs not frequently provided and/or offered by one-third or less of area providers include:

- After school program for children with special needs
- Peer monitoring for high school students with disabilities
- Summer camp and other life experience activities
- Preschool child care
- Psychological and educational diagnostics
- Referral and care coordination
- Transportation
- Vision assessments
- Vision and sensory training
- Auditory-verbal therapy
- Transition to independence after high school
- Orientation and mobility monitoring
- Parent training

The school systems in each county are mandated to provide special education services to children with disabilities. Accordingly, the county school systems are significant service providers in the area of special education and therapies. An example of the significant school system commitment is shown in the Milwaukee Public School (MPS) district where 1,475 full-time equivalent employees (FTE) are in the district's special education program. This staffing level includes 138 FTE psychologists and 163 FTE speech and language staff.

In FY 2003-04, MPS reported that more than one third of students with disabilities were suspended. In the state, 13.96 percent of students with disabilities were suspended. An

opportunity may exist for the new center to work with the school system in training suspended students with significant emotional or other severe disabilities.

The single greatest service area deficiency is a single entry point for patient entry and coordination of all disability and health information, diagnosis, treatment plan development, assessment of family needs, referral out, reassessment, and subsequent documentation of outcomes through clinical research. Without information coordination and outcomes documentation, very little progress can occur in the development and implementation of more effective and cost efficient treatment strategies.

It would be the center's goal and that of the proposed partnership to meet the area's service need through a single point of access as a one stop comprehensive service that effectively coordinates all health care information, provides diagnostic services, treatment, referral, and, importantly, follow-up for children that are not achieving their potential, as well as meet family needs for information and referral. In addition, its goals would be to transfer new knowledge to application, create new knowledge and disseminate that information and in turn leverage existing resources as an effective system of services focused on disability outcome.

SUMMARY OF SERVICE AVAILABLE

We have identified 19 providers of disability services in the seven county service area for children with special health care needs, excluding the county school systems and MCFI. The services most frequently provided are birth to three program services; in home services including nursing care, durable medical equipment and therapies; physical, speech and language, and occupational therapy, and parent training in the birth to three program. Fifteen providers or 79 percent serve the birth to three population.

However, children with disabilities have a significant range of needs and either are not served or must search for service. Programs offered by one-third or less of area providers include psychological and educational diagnostics, referral, vision assessment, auditory-verbal therapy, orientation and mobility monitoring, and parent training. School systems are the largest provider of special education services and certain therapies are mandated to be offered to the school-age population.

There are several crucial services not identified in the service area market including:

- Care coordination
- Long term follow up
- Long term life planning
- Research to identify more effective treatment models

The state has five regional planning areas for disability services. MCFI is located in the Southeastern region. The Waisman Center, which has a significant disability service for children, is located in the South region in Madison and is not a comprehensive provider of services.

The single greatest service area deficiency is a single site entry point for the diagnosis, treatment plan development, assessment of family needs, referral out, coordination of information, reassessment of the treatment plan, and subsequent documentation of outcomes through clinical research. Without information coordination and outcomes documentation, very

little progress can occur in the development and implementation of more effective and efficient treatment strategies, which properly administered can help provide disabled children with the potential for a more productive life.

INFORMING VALUE ENHANCEMENT STRATEGIES

While the existing compendium of resources for children with disabilities in Southeastern Wisconsin is impressively robust, it is also shackled by several shared deficiencies. Fundamentally, it represents a set of services organized, provided, and evaluated from the perspective of independent institutional and professional practice structures. Services for children with disabilities are not organized from the perspective of children with disabilities and their families.

This is not a trivial distinction. From an empirical standpoint, it is a key contributor to performance gaps within Wisconsin related to children with special healthcare needs, including²¹:

- A reported 12.5 percent have one or more of their needs unattended.
- A reported 19.8 percent needed but did not get respite care, genetic counseling, and/or mental health services.
- A reported 18.4 percent needing specialty care had problems getting a referral.
- A reported 13.1 percent have no routine source of care other than a hospital emergency room.
- A reported 9.4 percent of families spend 11 or more hours per week providing and/or coordinating health care for their disabled child.
- A reported 23.3 percent of families have members who have cut back or stopped working to care for their disabled child.

Other research suggests that the more than 18 percent of families noted above who have trouble getting a referral is actually the tip of the iceberg. By one RAND Report²², out of more than 80 percent of families who are referred, only 47 percent follow through with the referral, and only 17 percent receive a treatment or care recommendation provided at the visit. By this estimate, the efficiency of the system is 10 percent. This is not the result of any malice of intent

²¹ See Appendix E for detail by county and age cohort from the National Survey of Children with special Health Care Needs, 2001

by either the providers or the families involved. Instead, it is a system failure of massive proportions that can and must be remedied.²²

Qualitative data gathered from provider interviews recently completed by MCFI reinforces the above data. For example, a physician with a focus on caring for children with disabilities noted that his periodic consult visits are typically uninformed by what medical, social service, and education services, problems, achievements, and unfulfilled opportunities occurred since the prior visit. This confounds the diagnostic process, as well as informed treatment recommendations. It is a barrier to coordination of services and oversight related both to other care provided and family compliance with the treatment plan. In other words, lack of coordination and oversight degrades performance of the system.

Similarly, parents utilizing MCFI services routinely express their frustration about how they find themselves by default serving in the role of care coordinator. This is a responsibility that most are understandably unprepared to effectively execute. Leaving parents responsible for coordinating medical, behavioral, and functional assessments, cobbling together a multi-disciplinary care plan that straddles medical care, educational services, and social agency-based care, and determining the effectiveness of the plan on an ongoing basis is unfair and unrealistic.

There is research evidence that strongly suggests that a system that effectively organizes services around the child and the family will be more successful. A study published in 2005 by the RAND Corporation²³ investigated the expected return on investment related to focused interventions for disadvantaged children ages 2 to 5 in California. The study also included a meta-analysis of prior studies focused on this issue. The study concluded that an annual rate of return of 10 percent was achievable, or \$2.62 for every dollar invested.

Another study completed by Yale University on a population in Waterbury, Connecticut measured the return on organizing and providing coordinated multi-disciplinary services to foster care children.

²² Kakalik and Brewer, 1979, Rand Corp Technical report

²³ "The Economics of Investing in Universal Preschool Education in California," Lynn A. Karoly, James H. Bigelow.

Intervention early on in a child's life is more effective than interventions later in life. According to the National Survey of Children with Special Health Care Needs – which was conducted in 2001 by the U.S. Maternal and Child Health Bureau – there is a higher prevalence of special health care needs among older children either because their disability or delay was not diagnosed early or because they did not develop until later in childhood. In Wisconsin, 6.1 percent of children birth to five years old had special health care needs. However, 16.6 percent of Wisconsin children six to 11 had special health care needs, compared to 14.6 percent nationally.

SOLVING THE PROBLEM

The relative contribution of genetics, poverty, dysfunctional families, substance abuse, poor nutrition, etc. constitutes an immediately irresolvable debate, in fact it has raged for more than a half century. Underlying etiology is important. Theories regarding etiology have spawned a myriad of primary prevention interventions ranging from Women, Infants and Children (WIC) to Head Start. Despite all of these important program responses, the reality is that the actual number of children with disabilities continues to rise. Secondary prevention aimed at optimizing the functional capacity of children with disabilities remains a major challenge and societal responsibility not being addressed at anywhere close to an optimal cost/benefit ratio.

Predicting future child population levels, associated disability incidence rates, and service and opportunity costs related to this population for the seven county area 25 years from now is a worthy exercise. However, it is an exercise that is inherently speculative and has not been completed. Whether the “wave” of accruing liabilities is 80 feet or 90 feet high is important, but the negative implications only vary in cost and acuity. What is far less speculative is the \$15 billion in lifetime costs to be accrued as a result of today’s disabled children. The challenge is minimizing existing, as well as future, accrued liabilities.

The first step in addressing this problem, complexity notwithstanding, is to acknowledge the existence of a problem that is negatively affecting thousands of individual’s lives and growing. This is the most essential precursor to effectively dealing with this problem. Wisconsin citizens, not unlike people in other communities, have a problem rooted in the service systems and associated costs related to the effectiveness of how we care for children with disabilities. With this acknowledgement comes the opportunity and responsibility to respond.

Wisconsin is at a crossroads. It can choose to assume control over the trajectory of service effectiveness and costs for caring for children with disabilities. Alternatively it can allow the growing wave of need to force a devil’s choice between spending ever greater resources – or comprising its responsibilities to this vulnerable population by rationing services.

We can envision a **system** for effectively managing the needs of disabled children that responds to the following design criteria:

- It is unwaveringly and unapologetically focused on achieving the highest possible functional capacities of every disabled child in southeastern Wisconsin, knowing that this is in the long-term best interest of every citizen in Wisconsin.
- Services and the information required to inform them, are organized within a family/child-centric model rather than a provider-centric model.
- It is committed to a coordinated, multi-disciplinary service model that applies medical services, educational services, and social services in a synergistic manner.
- It is based upon a distributed service delivery model that utilizes the many existing service delivery resources currently available within the region.
- It actively promotes the dispersion of best practice approaches to treatment and care throughout all regional service resources.
- The service delivery model actively supports, and in turn is improved by, the incorporation of professional training and translational research elements into its mission.
- It routinely reviews processes and outcomes and empowers service providers with this information as a performance improvement strategy.
- It periodically calculates return-on-investment and other performance variables of the new model against performance levels achieved via the current system. The economic and service imperative is to extract more economic and social value from existing resources via performance improvement.

These design criteria are not utopian in their ambition and are quite achievable, given the existing resources. Achieving a system based on them will require modest risk, but capital coupled with a commitment will achieve the best outcomes for our most vulnerable citizens.

THE SYSTEM VISION

Families, providers, and taxpayers in southeastern Wisconsin would directly benefit from an expert, accessible, community-based diagnostic (assessment) and treatment planning resource that can coordinate the necessary services and supports for children with special needs, their families and schools, with the ultimate goal of enhanced development and increased probability of community integration. These children will require coordinated medical, psychological, social and behavioral diagnostic assessments along with a routinely updated treatment plan for maximizing the performance and value generation of the wealth of resources that already exist in many organizations through the regions.

The effectiveness of early treatment of special needs has been primarily demonstrated in controlled settings (i.e. university or hospital programs). However, the coordination of expertise involved in successful treatment has been limited in Milwaukee by the unavailability of a community-based setting where interdisciplinary assessment resources can be applied. Effectively, this would require moving disaggregated resources into a common inter-institutional setting to focus on disability and provide an accessible entry to necessary resources for families with a disabled child.

A center focused on children with disabilities would provide a resource in southeastern Wisconsin that provides and coordinates both medical and social services. Clinical models exist elsewhere outside the area (i.e. the Waisman Center; the Rehabilitation Institute in Chicago) that will need to be translated as a community program with facilitated access to a system in which there is a mechanism for coordinated service. Families and professionals in Milwaukee deserve access to resources that compare in quality to institutes such as the Kennedy-Krieger Institute-Johns Hopkins in Baltimore, the Neuropsychiatric Institute-UCLA in Los Angeles and the Children's Medical Center in Boston.

The need for this service system has grown tremendously and brought us to a critical stage where a facility to house the resource is essential to provide early intervention and

treatment services. The center would also be a powerful strategy for transferring new research in a timely manner to help children with disabilities achieve their highest potential.

The vision for a community-based diagnostic and treatment center for children ideally would emphasize three features, including facilitated access to a comprehensive expert diagnostic resource that could be leveraged on behalf of the families to meet the recommended treatment for their child.

1. A new children's diagnostic resource anchored by an **interdisciplinary service program**:
 - It would provide families/children with disabilities a single, one-stop portal for accessing the diagnostic assessment, treatment planning, and performance monitoring services required to maximize the level of function and independence for this child.

2. A program of **diagnostic assessment** services might include:
 - Psychological assessment
 - Physical therapy assessment
 - Occupational therapy assessment
 - Speech therapy assessment
 - Audiology assessment
 - Recreational therapy assessment
 - Financial/life planning assessment
 - Vision assessment
 - Educational assessment
 - Dental assessment

The initial service mix provided to a new client will be based upon presenting symptoms and/or a prior diagnosis. Depending upon service volumes for each category, services could be available on a full-time or part-time clinic basis.

The goal of the diagnostic assessment services is to recommend a treatment plan for the child. The diagnostic work-up would include routine period re-assessments as input for up-to-date treatment planning for all children once having been diagnosed with a behavioral, cognitive, or communication related disability.

3. **Treatment planning** services:

- They would be based upon an inter-disciplinary compilation of diagnostic assessment findings for each child.
- A team meeting with all diagnosticians and the family would lay out a treatment plan for a prescribed period, including establishing initial appointments for each service needed.

The goal of the treatment planning service component will be to provide services to every child who has had a diagnostic work-up, and to set specific treatment and outcome goals for a specified period for each child diagnosed with a behavioral, cognitive, or communication related disability.

TURNING THE VISION INTO REALITY

Converting the vision of a diagnostic center into a reality that successfully positions children with disabilities to achieve their highest functional potential will require an adroit fusion of political support, administrative flexibility and creativity at the state, county and municipal levels, collaboration among key healthcare providers and educational community resources, a successful case for philanthropic support, and a tenacity that accepts nothing short of achieving the vision.

Initial momentum has already been generated. First, there is a commitment by MCFI to provide leadership and planning resources, as well as real estate to support a facility plan. It includes the articulation of the case for action and a responsive vision. Second, there is an initial effort to collaborate in a planning process that includes a task force with representation from the MPS board of directors, City of Milwaukee Health Department, Milwaukee County Health and Human Services, Milwaukee School of Architecture, UWM-College of Health Sciences, and the state of Wisconsin Division of Health Care Financing. A listing of task force members is appended.

This initial momentum is important and sets the stage to develop additional components of the plan. Next steps include:

1. Securing grant funding for detailed planning of the service, education, and research programs, their associated facility requirements, and the operating and financial models that will support them.
2. Applying these planning resources to:
 - a. Convene potential service, education and research providers to collaboratively define service volumes, staffing, and space needs at a level of detail required to support implementation level planning.
 - b. Develop a detailed facility plan and related project cost estimates.

- c. Specify the corporate structure that will be used for supporting development of the initiative.
 - d. Specify case finding systems and processes, including “Memorandum of Understanding” documentation of under what circumstances and how children will be referred for services.
 - e. Establish sources and uses of funds estimate for capital funding.
 - f. Establish an operating budget that defines specific revenue sources and realistic fund flow estimates, as well as an expense projection including staffing, facility costs, and other operating costs.
3. Integrating these data into a strategic business plan for guiding the implementation and funding of the center.

The case for action to improve the destinies of children with disabilities is compelling. The professional, institutional, and financial resources can be found. The only missing ingredient is an investment in and commitment to execution. We invite you to join us in the creative process of achieving this vision for brightening what collectively our children represent – the future.

Attachment 1
Summary of school children with disabilities in the seven-county area of Wisconsin

Source: Wisconsin Department of Public Instruction. Prevalence data derived from www2.dpi.state.wi.us/leareports. Disability definitions from www.dpi.state.wi.us/dpi/dlsea/een/pi11_0701.html#Id

Notes: A child with a disability is a child who needs special education and related services. The child must be at least 3 years old, but not yet 21, and not yet graduated from high school. The term includes a person who becomes 21 during the school term for the remainder of the school term, not including summer classes. Students with disabilities are the number of students identified on the December 1 Federal Child Count, of that particular school year, for whom the district has educational responsibility. The number of children with a particular Disability was calculated by multiplying the Prevalence Percentage with Total Enrollment for the same school year and then rounding to the nearest whole number. Prevalence represents the percentage of the district enrolled children identified with particular disability and is determined by dividing the number of students identified by the primary disability by the total public/non-public enrollment for the district. Pupil confidentiality prohibits the reporting of prevalence for a particular disability when the identified student count is five or fewer students. To protect pupil confidentiality, district prevalence is reported in the categories of Cognitive Disability, Emotional Behavior Disturbance, Specific Learning Disability, Speech or Language Impairment, and Low Incidence Disabilities. Total enrollment represents the number of children attending public and private schools within the district's boundaries as of the third Friday in September of the appropriate school year. Private school students may or may not be residents of the district. The Low Incidence category may include the disabilities of Other Health Impairment, Orthopedic Impairment, Autism, Visual Impairment, Hearing Impairment, Orthopedic Impairment, Autism, Visual Impairment, Hearing Impairment, Deaf-Blind, Traumatic Brain Injury, and Significant Developmental Delay. In addition, the Low Incidence Category may include the disabilities of Cognitive Disability, Emotional Behavioral Disability, Specific Learning Disability, and Speech or Language Impairment when the identified student count is five or fewer students.

**Summary of School Children with Disabilities in the Seven County
Area of Wisconsin**

STATE of WISCONSIN

Disability/Impairment	2000-2001*	2001-2002	2002-2003	2003-2004	# Change	4 Yr % Change
Autism	2,156	2,561	3,068	3,662	1,506	69.83%
Cognitive Disability	13,451	13,110	12,680	12,309	-1,143	-8.50%
Deaf-Blind	103	102	102	102	-1	0.93%
Emotional Behavioral Disability	16,424	16,695	16,566	16,378	-46	0.28%
Hearing Impairment	1,540	1,639	1,636	1,628	87	5.67%
Specific Learning Disability	52,676	52,030	50,414	48,827	-3,849	-7.31%
Other Health Impairment	6,800	8,091	9,203	10,579	3,700	53.77%
Orthopedic Impairment	1,643	1,536	1,534	1,424	-219	-13.32%
Significant Developmental Delay	2,259	2,458	2,557	2,747	488	21.58%
Speech or Language Impairment	27,416	27,691	28,428	29,296	1,880	6.86%
Traumatic Brain Injury	308	307	409	407	99	32.09%
Visual Impairment	411	410	511	509	98	23.83%
All Disabilities	125,267	126,901	127,110	127,867	2,600	2.08%
Total Enrollment	1,026,825	1,024,222	1,022,604	1,017,237	-9,588	-0.93%

Source: State Department of Public Instruction

7 County Summary of School Children

Disability/Impairment	2000-2001*	2001-2002	2002-2003	2003-2004	# Change	4 Yr % Change
Cognitive Disability	4,714	4,610	4,518	4,369	-344	-7.30%
Emotional Disturbance	4,919	4,913	4,809	4,801	-119	-2.41%
Specific Learning Disability	16,661	16,482	16,009	15,490	-1,171	-7.03%
Speech or Language Impairment	9,490	9,560	9,778	10,110	620	6.54%
Low Incidence Disabilities	6,692	7,562	8,328	9,095	2,403	35.90%
All Disabilities*	42,476	43,127	43,441	43,865	1,390	3.27%
Total Enrollment	380,775	382,117	382,868	382,699	1,924	0.51%

Source: State Department of Public Instruction

Attachment 2 Children with Disabilities

PI 11.35 Determination of eligibility

- (1) An evaluation conducted by an IEP team under s.115.782, Stats., shall focus on the consideration of information and activities that assist that IEP team in determining how to teach the child in the way he or she is most capable of learning. Specifically, the IEP team shall meet the evaluation criteria specified under s. 115.782 9(2) (a), Stats., when conducting tests and using other evaluation materials in determining a child's disability.
- (2) A child shall be identified as having a disability if the IEP team has determined from an evaluation conducted under s.115.782, Stats., that the child has impairment under s.PI 11.36 that adversely affects the child's educational performance, and the child, as a result thereof, needs special education and related services.
- (3) As part of an evaluation or reevaluation under s.115.782, Stats., conducted by the IEP team in determining whether a child is or continues to be a child with a disability, the IEP team shall identify all of the following:
 - a. The child's needs that cannot be met through the regular education program as structured at the time the evaluation was conducted
 - b. Modifications, if any, which can be made in the regular education program, such as adaptation of content, methodology or delivery of instruction to meet the child's needs identified under par. (a), that will allow the child to access the general education curriculum and meet the educational standards that apply to all children.
 - c. Additions or modifications, if any, that the child needs which are not provided through the general education curriculum, including replacement content, expanded core curriculum or other supports.

PI 11.36 Areas of Impairment

All provisions in these rules shall be construed consistent with 20 USC 1400 et. Seq. and the regulations promulgated thereunder.

(1) COGNITIVE DISABILITY

- (a) Cognitive disability means significantly sub average intellectual functioning that exists concurrently with deficits in adaptive behavior and that adversely affects educational performance.
- (b) The IEP team may identify a child as having a cognitive disability if the child meets the criteria under subd. 1.a. or b., 2. and 3.a. or b. as follows:
 - 1. a. The child has a standard score of 2 or more standard deviations below the mean on at least one individually administered intelligence test developed to assess intellectual functioning.
 - b. The child has a standard score between 1 and 2 standard deviations below the mean on at least one individually administered intelligence test, the child has been documented as having a cognitive disability in the past, and the child's condition is expected to last indefinitely.
 - 2. The child has deficits in adaptive behavior as demonstrated by a standard score of 2 or more standard deviations below the mean on standardized or nationally-normed measures, as measured by comprehensive, individual assessments that include interviews of the parents, tests, and observations of the child in adaptive behavior which are relevant to the child's age, such as:
 - a. Communication
 - b. Self-care
 - c. Home living skills
 - d. Social skills
 - e. Appropriate use of resources in the community
 - f. Self direction
 - g. Health and safety
 - h. Applying academic skills in life
 - i. Leisure
 - j. Work

3. a. The child is age 3 through 5 and has a standard score of 2 or more standard deviations below the mean on standardized or nationally-normed measures, as measured by comprehensive, individual assessments, in at least 2 of the following areas: academic readiness, comprehension of language or communication, or motor skills.
- b. The child is age 6 through 21 and has a standard score of 2 or more standard deviations below the mean on standardized or nationally-normed measures, as measured by comprehensive, individual assessments, in general information and at least 2 of the following areas: written language, reading, or mathematics. NOTE: Cognitive disabilities typically manifest before age. An etiology should be determined when possible, so that the IEP team can use this information for program planning.

(2) ORTHOPEDIC IMPAIRMENT

Orthopedic impairment means a severe orthopedic impairment that adversely affects a child's educational performance. The term includes, but is not limited to, impairments caused by congenital anomaly, such as a clubfoot or absence of some member; impairments caused by disease, such as poliomyelitis or bone tuberculosis; and impairments from other causes, such as cerebral palsy, amputations, and fractures or burns that cause contractures.

(3) VISUAL IMPAIRMENT

Visual impairment means even after correction a child's visual functioning significantly adversely affects his or her educational performance. The IEP team may identify a child as having a visual impairment after all of the following events occur:

- (a) A certified teacher of the visually impaired conducts a functional vision evaluation which includes a review of medical information, formal and informal tests of visual functioning and the determination of the implications of the visual impairment on the educational and curricular needs of the child.
- (b) An ophthalmologist or optometrist finds at least one of the following:
 - a. Central visual acuity of 20/70 or less in the better eye after conventional correction
 - b. Reduced visual field to 50 degrees or less in the better eye
 - c. Other ocular pathologies that are permanent and irremediable

- d. Cortical visual impairment
 - e. A degenerative condition that is likely to result in a significant loss of vision in the future
- (c) An orientation and mobility specialist, or teacher of the visually impaired in conjunction with an orientation and mobility specialist, evaluates the child to determine if there are related mobility needs in home, school or community environments

(4) HEARING IMPAIRMENT

Hearing impairment, including deafness, means a significant impairment in hearing, with or without amplification, whether permanent or chronically fluctuating, that significantly adversely affects a child's educational performance including academic performance, speech perception and production, or language and communication skills. A current evaluation by an audiologist licensed under ch.459, Stats., shall be one of the components for an initial evaluation of a child with a suspected hearing impairment.

(5) SPEECH OR LANGUAGE IMPAIRMENT

- (a) Speech or language impairment means an impairment of speech or sound production, voice, fluency, or language that significantly affects educational performance or social, emotional or vocational development
- (b) The IEP team may identify a child as having a speech or language impairment if the child meets the definition under par. (a) and meets any of the following criteria:
 - 1. The child's conversational intelligibility is significantly affected and the child displays at least one of the following:
 - a. The child performs on a norm referenced test of articulation or phonology at least 1.75 standard deviations below the mean for his or her chronological age.
 - b. Demonstrates consistent errors in speech sound production beyond the time when 90 percent of typically developing children have acquired the sound.
 - 2. One or more of the child's phonological patterns of sound are at least 40 percent disordered or the child scores in the moderate to profound range of phonological process use in formal testing and the child's conversational intelligibility is significantly affected.

4. The child's voice is impaired in the absence of an acute, respiratory virus or infection and not due to temporary physical factors such as allergies, short-term vocal abuse, or puberty. The child exhibits atypical loudness, pitch, quality or resonance for his or her age and gender.
 5. The child exhibits behaviors characteristic of a fluency disorder
 6. The child's oral communication or, for a child who cannot communicate orally, his or her primary mode of communication, is inadequate, as documented by all of the following:
 - a. Performance on norm referenced measures that is at least 1.75 standard deviations below the mean for chronological age
 - b. Performance in activities is impaired as documented by informal assessment such as language samplings, observations in structured and unstructured settings, interviews or checklists
 - c. The child's receptive or expressive language interferes with oral communication or his or her primary mode of communication. When technically adequate norm references language measures are not appropriate as determined by the IEP team to provide evidence of a deficit of 1.75 standard deviations below the mean in the area of oral communication, then 2 measurement procedures shall be used to document a significant difference from what would be expected given consideration to chronological age, developmental level, and method of communication such as oral, manual, and augmentative. These procedures may include additional language samples, criterion references instruments, observations in natural environments and parent reports.
- (c) The IEP team may not identify a child who exhibits any of the following as having a speech or language impairment:
1. Mild, transitory or developmentally appropriate speech or language difficulties that children experience at various times and to various degrees
 2. Speech or language performance that is consistent with developmental levels as documented by formal and informal assessment data unless the child requires speech or language services in order to benefit from his or her educational programs in school, home, and community environments

3. Speech or language difficulties resulting from dialectical differences or from learning English as a second language, unless the child has a language impairment in his or her native language
 4. Difficulties with auditory processing without a concomitant documented oral speech or language impairment
 5. A tongue thrust which exists in the absence of a concomitant impairment in speech sound production
 6. Elective or selective mutism or school phobia without a documented oral speech or language impairment
- (d) The IEP team shall substantiate a speech or language impairment by considering all of the following:
1. Formal measures using normative data or informal measures using criterion referenced data
 2. Some form of speech or language measures such as developmental checklists, intelligibility ratio, language sample analysis, minimal core competency
 3. Information about the child's oral communication in natural environments
 4. Information about the child's augmentative or assistive communication needs
- (e) An IEP team shall include a department-licensed speech or language pathologist and information from the most recent assessment to document a speech or language impairment and the need for speech or language services.

(6) SPECIFIC LEARNING DISABILITY

- (a) Specific learning disability, pursuant to s. 115.76 (5) (a) 10., Stats., means a severe learning problem due to a disorder in one or more of the basic psychological processes involved in acquiring, organizing or expressing information that manifests itself in school as an impaired ability to listen, reason, speak, read, write, spell or do mathematical calculations, despite appropriate instruction in the general education curriculum. Specific learning disability may include conditions such as perceptual disability, brain injury, minimal brain dysfunction, dyslexia and developmental aphasia.
- (b) The IEP team shall base its decision of whether a child has a specific leaning disability on formal and informal assessment data on intellectual ability, academic achievement, and

learning behavior from sources such as standardized tests, error analysis, criterion referenced measures, curriculum-based assessments, student work samples, interviews, observations and an analysis of the child's response to previous interventions, classroom expectations, and curriculum in accordance with s. 115.782. Stats. The IEP team may identify a child as having a specific learning disability if all of the following are true:

1. Classroom achievement – upon initial identification, the child's ability to meet the instructional demands of the classroom and to achieve commensurate with his or her age and ability levels is severely delayed in any of the following areas:
 1. Oral expression
 2. Listening comprehension
 3. Written expression
 4. Basic reading skill
 5. Reading comprehension
 6. Mathematical calculation
 7. Mathematical reasoning
2. Significant discrepancy – upon initial identification, a significant discrepancy exists between the child's academic achievement in any of the areas under subd. 1.a. to g. and intellectual ability as documented by the child's composite score on a multiple score instrument or the child's score on a single score instrument. The IEP team may base a determination of significant discrepancy only upon the results of individually administered, standardized achievement and ability tests that are reliable and valid. A significant discrepancy means a difference between standard scores for ability and achievement equal to or greater than 1.75 standard errors of the estimate below expected achievement, using a standard regression procedure that accounts for the correlation between ability and achievement measures. This regression procedure shall be used except under any of the following conditions:
 - a. The regression procedure under this subdivision may not be used to determine a significant discrepancy if the IEP team determines that the child cannot attain valid and reliable standard scores for intellectual ability or achievement because of the child's test behavior, the child's language, another impairment of the child

that interferes with the attainment of valid and reliable scores or the absence of valid and reliable standardized, diagnostic tests appropriate for the child's age.

- b. If the IEP team makes such a determination under subd. 2.a., it shall document the reasons why it was not appropriate to use the regression procedure and shall document that a significant discrepancy exists, including documentation of a variable pattern of achievement or ability, in at least one of the areas under subd. 1.a.to g. using other empirical evidence.
 - c. If the discrepancy between the child's ability and achievement approaches but does not reach the 1.75 standard error of the estimate cut-off under subd. 2. (intro.), the child's performance in any of the areas in subd. 1. a. to g. is variable, and the IEP team determines that the child meets all other criteria under subsd. 1. and 3, the IEP team may consider that a significant discrepancy exists.
3. Information processing deficit – the child has an information processing deficit that is linked to the child's classroom achievement delays under subd. 1. and to the significant discrepancy under subd.2. An information processing deficit means a pattern of severe problems with storage, organization, acquisitions, retrieval, expression, or manipulation of information rather than relative strengths and weaknesses. The IEP team shall document the reasons for and data used to make its determination that the child has an information processing deficit.
- (c) 1. The IEP team may not identify a child as having a specific learning disability if it determines that the significant discrepancy between ability and achievement is primarily due to environmental, cultural or economic disadvantage or any of the reasons specified under s. 115.782 (3) (a), Stats., or any of the impairments under s.115.76 (5) Stats., except s.115.76 (5) (a) 10.
2. If the IEP team is concerned that a child has a significant discrepancy in oral expression or listening comprehension, the IEP team shall include a person qualified to assess speech and language impairments.
 3. A child who is found to have a significant discrepancy between ability and achievement in the single area of oral expression or listening comprehension and who meets criteria for speech and language impairment under sub. (5) shall be considered to have a primary impairment in the area of speech and language.

4. At least one observation in the general classroom setting by a team member other than the classroom teacher shall be conducted.
- (d) Upon reevaluation, a child who met initial identification criteria under par. (b) and continues to demonstrate a need for special education under s. PI 11.35 (2), including specially designed instruction, is a child with a disability under this section, unless the provision under par. (c) 1. now applies. If a child with a specific learning disability performs to generally accepted performance expectations in the general education classroom without specially designed instruction, the IEP team shall determine whether the child is no longer a child with a disability.

(7) EMOTIONAL BEHAVIORAL DISABILITY

- (a) Emotional behavioral disability, pursuant to s. 115.76 (5) (a) 5., Stats., means social, emotional or behavioral functioning that so departs from generally accepted, age appropriate ethnic or cultural norms that it adversely affects a child's academic progress, social relationships, personal adjustment, classroom adjustment, self-care or vocational skills.
- (b) The IEP team may identify a child as having an emotional behavioral disability if the child meets the definition under par. (a), and meets all of the following:
1. The child demonstrates severe, chronic and frequent behavior that is not the result of situational anxiety, stress or conflict.
 2. The child's behavior described under par. (a) occurs in school and in at least one other setting.
 3. The child displays any of the following:
 - a. Inability to develop or maintain satisfactory interpersonal relationship
 - b. Inappropriate affective or behavior response to a normal situation
 - c. Pervasive unhappiness, depression or anxiety
 - d. Physical symptoms, pains or fears associated with personal or school problems
 - e. Inability to learn that cannot be explained by intellectual, sensory or health factors
 - f. Extreme withdrawal from social interactions
 - g. Extreme aggressiveness for a long period of time

- h. Other inappropriate behaviors that are so different from children of similar age, ability, educational experiences and opportunities that the child or other children in a regular or special education program are negatively affected
- (c) The IEP team shall rely on a variety of sources of information, including systematic observations of the child in a variety of educational setting and shall have reviewed prior, documented interventions. If the IEP team knows the cause of the disability under this paragraph, the cause may be, but is not required to be, included in the IEP team's written evaluation summary.
- (d) The IEP team may not identify or refuse to identify a child as a child with an emotional behavioral disability solely on the basis that the child has another disability, or is socially maladjusted, adjudged delinquent, a dropout, chemically dependent, or a child whose behavior is primarily due to cultural deprivation, familial instability, suspected child abuse or socio-economic circumstances, or when medical or psychiatric diagnostic statements have been used to describe the child's behavior.

(8) AUTISM

- (a) Autism means a developmental disability significantly affecting a child's social interaction and verbal and nonverbal communication, generally evident before age 3, which adversely affects learning and educational performance. Other characteristics often associated with autism are engagement in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences. The term does not apply if a child's educational performance is adversely affected primarily because the child has an emotional disturbance, as defined in sub. (7).
- (b) The results of standardized or norm-referenced instruments used to evaluate and identify a child under this paragraph may not be reliable or valid. Therefore, alternative means of evaluation, such as criterion-referenced assessments, achievement assessments, observation and work samples, shall be considered to identify a child under this paragraph. Augmentative communication strategies, such as facilitated communication, picture boards, or signing shall be considered when evaluating a child under this

paragraph, the criteria under subd.1. and 2. and one or more criteria under subd. 3. through 6. shall be met.

1. The child displays difficulties or differences or both in interacting with people and events. The child may be unable to establish and maintain reciprocal relationship with people. The child may seek consistency in environmental events to the point of exhibiting rigidity in routines.
2. The child displays problems which extend beyond speech and language to other aspects of social communication, both receptively and expressively. The child's verbal language may be absent, or, if present, lacks the usual communicative form which may involve deviance or delay or both. The child may have a speech or language disorder or both in addition to communication difficulties associated with autism.
3. The child exhibits delays, arrests, or regressions in motor, sensory, social or learning skills. The child may exhibit precocious or advanced skill development, while other skills may develop at normal or extremely depressed rates. The child may not follow normal developmental patterns in the acquisition of skills.
4. The child exhibits abnormalities in the thinking process and in generalizing. The child exhibits strengths in concrete thinking while difficulties are demonstrated in abstract thinking, awareness and judgment. Perseverant thinking and impaired ability to process symbolic information may be present.
5. The child exhibits unusual, inconsistent, repetitive or unconventional responses to sounds, sights, smells, tastes, touch or movement. The child may have a visual or hearing impairment or both in addition to sensory processing difficulties associated with autism.
6. The child displays marked distress over changes, insistence on following routines, and a persistent preoccupation with or attachment to objects. The child's capacity to use objects in an age-appropriate or functional manner may be absent, arrested or delayed. The child may have difficulty displaying a range of interests or imaginative activities or both. The child may exhibit stereotyped body movements.

(9) TRAUMATIC BRAIN INJURY

- (a) Traumatic brain injury means an acquired injury to the brain caused by an external physical force resulting in total or partial functional disability or psychosocial

impairment, or both, that adversely affects a child's educational performance. The term applies to open or closed head injuries resulting in impairments in one or more areas, such as cognition; speech and language; memory; attention; reasoning; abstract thinking; communication; judgment; problem solving; sensory, perceptual and motor abilities; psychosocial behavior; physical functions; information processing; and executive functions, such as organizing, evaluating and carrying out goal-directed activities. The terms do not apply to brain injuries that are congenital or degenerative, or brain injuries induced by birth trauma.

- (b) Children whose educational performance is adversely affected as a result of acquired injuries to the brain caused by internal occurrences, such as vascular accidents, infections, anoxia, tumors, metabolic disorders and the effects of toxic substances or degenerative conditions may meet the criteria of one of the other impairments under this section.
- (c) The results of standardized and norm-referenced instruments used to evaluate and identify a child under this paragraph may not be reliable or valid. Therefore, alternative means of evaluation, such as criterion-referenced assessment, achievement assessment, observation, work samples, and neuropsychological assessment data, shall be considered to identify a child who exhibits total or partial functional disability or psychosocial impairment in one or more of the areas described under par. (a).
- (d) Before a child may be identified under this subsection, available medical information from a licensed physician shall be considered.

(10) OTHER HEALTH IMPAIRMENT

Other health impairment means having limited strength, vitality or alertness, due to chronic or acute health problems. The term includes, but is not limited to: a heart condition, tuberculosis, rheumatic fever, nephritis, asthma, sickle cell anemia, hemophilia, epilepsy, lead poisoning, leukemia, diabetes, or acquired injuries to the brain caused by internal occurrences or degenerative conditions, which adversely affects a child's educational performance.

(11) SIGNIFICANT DEVELOPMENTAL DELAY

- (a) Significant developmental delay means children, ages 3, 4 and 5 years old or below compulsory school attendance age, who are experiencing significant delays in the areas of physical, cognition, communication, social-emotional or adaptive development.
- (b) All other suspected impairments under this section shall be considered before identifying a child's primary impairment as significant developmental delay.
- (c) A child may be identified as having significant developmental delay when delays in development significantly challenge the child in two or more of the following five major life activities:
 - 1. Physical activity in gross motor skills, such as the ability to move around and interact with the environment with appropriate coordination, balance and strength; or fine motor skills such as manually controlling and manipulating objects such as toys, drawing utensils, and other useful objects in the environment.
 - 2. Cognitive activity, such as the ability to acquire, use and retrieve information as demonstrated by the level of imitation, discrimination, representation, classification, sequencing, and problem-solving skills often observed in a child's play.
 - 3. Communication activity in expressive language, such as the production of age-appropriate content, form and use of language; or receptive language, such as listening, receiving and understanding language.
 - 4. Emotional activity such as the ability to feel and express emotions, and develop a positive sense of oneself; or social activity, such as interacting with people, developing friendships with peers, and sustaining bonds with family members and other significant adults.
 - 5. Adaptive activity, such as caring for his or her own needs and acquiring independence in age-appropriate eating, toileting, dressing and hygiene tasks.
- (d) Documentation of significant developmental delays under par. (c) and their detrimental effect upon the child's daily life shall be based upon qualitative and quantitative measures including all of the following:
 - 1. A developmental and basic health history, including results from vision and hearing screenings and other pertinent information from parents and, if applicable, other caregivers or service providers.

2. Observation of the child in his or her daily living environment such as the child's home, with a parent or caregiver, or an early education or care setting which includes peers who are typically developing. If observation in these settings is not possible, observation in an alternative setting is permitted.
3. Results from norm-referenced instruments shall be used to document significant delays of at least one and one-half standard deviations below the mean in 2 or more of the developmental areas which correspond to the major life activities. If it is clearly not appropriate to use norm-referenced instruments, other instruments, such as criterion referenced measures, shall be used to document the significant delays.

NOTE: With respect to the eligibility criteria under s. PI 11.36, in September 1991, the U.S. Department of Education issued a memorandum clarifying state and local responsibilities for addressing the educational needs of children with attention deficit disorder (ADD). (See 18 IDELR 116). As a condition of receipt of federal funds under the Individuals with Disabilities Act (IDEA), the state and local school districts are bound to comply with the federal policy outlined in that memo. (See e.g. *Metropolitan School District of Wayne Township, Marion County, Indiana v. Davila*, 969 F. 2d 485 (7th cir. 1992)).

Attachment 3
Service Area Population Estimate (2005) and Projection (2010)

	2005	2010	# change	% change
Kenosha				
0 to 4	10,694	10,886	192	1.80
5 to 9	10,919	10,960	41	.38
10 to 14	12,027	11,223	(804)	(6.68)
15 to 17	7,213	7,783	570	7.9
Total	40,583	40,852	(1)	0
Milwaukee				
0 to 4	70,020	67,646	(2,374)	(3.39)
5 to 9	66,789	67,055	266	.40
10 to 14	68,534	64,236	(4,298)	(6.27)
15 to 17	39,962	40,291	329	.82
Total	245,305	239,228	(6,077)	(2.48)
Ozaukee				
0 to 4	4,481	4,521	40	.89
5 to 9	5,320	4,637	(683)	(12.84)
10 to 14	6,289	5,518	(771)	(12.26)
15 to 17	4,485	4,435	(50)	(1.11)
Total	20,575	19,111	(1,464)	(7.12)
Racine				
0 to 4	12,938	12,807	(131)	(1.01)
5 to 9	13,239	12,875	(364)	(2.75)
10 to 14	14,224	13,255	(969)	(6.81)
15 to 17	9,127	9,093	(34)	(.37)
Total	49,528	48,030	(1,498)	(3.02)
Walworth				
0 to 4	5,639	5,839	200	3.55
5 to 9	5,900	5,886	(14)	(.24)
10 to 14	6,642	6,171	(471)	(7.09)
15 to 17	3,925	4,430	505	12.87
Total	22,106	22,326	220	1.0
Washington				
0 to 4	7,541	7,591	50	.66
5 to 9	8,124	7,821	(303)	(3.73)
10 to 14	8,967	8,432	(535)	(5.97)
15 to 17	5,827	5,984	157	2.69
Total	30,459	29,828	(631)	(2.07)
Waukesha				
0 to 4	21,904	22,077	173	.79
5 to 9	23,967	22,638	(1,329)	(5.55)
10 to 14	27,090	24,910	(2,180)	(8.05)
15 to 17	18,623	18,923	300	1.61
Total	91,584	88,548	(3,036)	(3.31)
All 7 counties				
0 to 4	133,217	131,367	(1,850)	(1.39)
5 to 9	134,258	131,872	(2,386)	(1.78)
10 to 14	143,773	133,745	(10,028)	(6.97)
15 to 17	89,162	90,939	1,777	1.99
Total	500,410	487,923	(12,487)	(2.5)

Source: Claritas

Attachment 4

Estimated Service Area Prevalence of Children with Special Health Care Needs

Child level prevalence	Wisconsin	Nation
% of children and youth with special health care needs (0-17)	13.4	12.8

Source: National Survey of Children with Special Health Care Needs, 2001

	2005	2010	# change	% change
Kenosha 0 to 4	1,433	1,459	26	1.81
5 to 9	1,463	1,469	6	.41
10 to 14	1,612	1,504	(108)	(6.7)
15 to 17	967	1,043	76	7.86
Total	5,475	5,475	0	0
Milwaukee 0 to 4	9,383	9,065	(318)	(3.39)
5 to 9	8,950	8,985	35	.39
10 to 14	9,184	8,608	(576)	(6.27)
15 to 17	5,355	5,399	44	.82
Total	32,872	32,057	(815)	(2.48)
Ozaukee 0 to 4	600	606	6	1.0
5 to 9	713	621	(92)	(12.9)
10 to 14	843	739	(104)	(12.34)
15 to 17	601	594	(7)	(1.16)
Total	2,757	2,560	(197)	(7.15)
Racine 0 to 4	1,734	1,716	(18)	(1.04)
5 to 9	1,774	1,725	(49)	(2.76)
10 to 14	1,906	1,776	(130)	(6.82)
15 to 17	1,223	1,218	(5)	(.41)
Total	6,637	6,435	(202)	(3.04)
Walworth 0 to 4	756	782	26	3.44
5 to 9	791	789	(2)	(.25)
10 to 14	890	827	(63)	(7.08)
15 to 17	526	594	68	12.93
Total	2,963	2,992	29	.98
Washington 0 to 4	1,010	1,017	7	.69
5 to 9	1,089	1,048	(41)	(3.76)
10 to 14	1,202	1,130	(72)	(5.99)
15 to 17	781	802	21	2.69
Total	4,082	3,997	(85)	(2.08)
Waukesha 0 to 4	2,935	2,958	23	.78
5 to 9	3,212	3,033	(179)	(5.57)
10 to 14	3,630	3,338	(292)	(8.04)
15 to 17	2,495	2,536	41	1.64
Total	12,272	11,865	(407)	(3.32)
All 7 counties				
0 to 4	17,851	17,603	(248)	(1.39)
5 to 9	17,992	17,670	(322)	(1.79)
10 to 14	19,267	17,922	(1,345)	(6.98)
15 to 17	11,948	12,186	238	1.99
Total	67,058	65,381	(1,677)	(2.50)

Findings:

The Child trends databanks reported that in 2002, 16.5 percent of children ages 5 to 11 had at least one limitation, while 20.1 percent of children ages 12 to 17 had at least one limitation. The percentage of children (ages 5-17) with at least one limitation stayed relatively constant from 1998 to 2002, going from 17.5 percent to 18.1 percent. Limitations include difficulty seeing, difficulty hearing diagnosed learning disabilities, limitations requiring help with bathing or showering and limitations in normal physical activities due to health conditions and impairments (Source: www.childtrendsdatabank.org)

The number of children with special health care needs served by Title V in Wisconsin has increased from 1,737 in

1999 to 4,161 in 2003 for an increase of 2,424 children or 139.55 percent (Source: Maternal and Child Health Bureau's Web site)