


# Children with Special Health Care Needs in Madison County



*Madison County Department of Health*



*“Children are one third of our population  
and all of our future”<sup>1</sup>*

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## INTRODUCTION

The foundation of a population's health, well-being, and productivity throughout life is established in early childhood. The beginning years of all children's lives are critical for building the early foundations of learning and wellness needed for success in school and later in life.

During these years, children's brains develop rapidly, influenced by the experiences they share with their families, teachers, peers, and in their communities. More and more, we are learning that biological, social, and environmental exposures in the early stages of life determine people's long-term health and developmental status. Most of the architecture of the brain and the body's core systems are established during pregnancy and in the early years. Negative factors during pregnancy, infancy, and early childhood have long-lasting consequences on health and development outcomes into adulthood.

## BACKGROUND

Young children learn and develop differently. One child may walk earlier than another, while another child might talk first. Often these

differences will even out, but sometimes children need extra help due to developmental delays or disabilities. Developmental delays can involve a learning difficulty, social or communication/language-related problem, movement impairment, adaptive delay or some combination of these.

Enacted in 1975, the federal Education for All Handicapped Children Act Public Law 94-142 (now the Individuals with Disabilities Act (IDEA)) requires that all students, ages 3 to 21 years, with disabilities be provided with a free appropriate education in the least restrictive environment possible. In 1986, The Infants and Toddlers with Disabilities program (Part C) of the Individuals with Disabilities Act was created to enhance the development of Infants and Toddlers with disabilities ages birth through 2 years.

The Global Disease Control Priorities Project estimates that 10% to 20% of individuals worldwide have a developmental disability of some kind. In the United States it is estimated that 9% of children younger than 36 months of age have a possible developmental delay while 14% of children 3 to 17 years of age have a developmental delay.<sup>2</sup>



# Risk Factors

Possible causes for developmental delays are many which include genetic influences inherited from biological parents and environmental influences such as accidents, exposure to toxins, illnesses, and poor living conditions. Delays based on genetic influences are estimated to account for 15 to 25 percent of developmental disorders. About 75 to 85 percent of these are linked to effects of the environment or an unknown reason for developmental de-

lay.<sup>3</sup> While children from all socioeconomic groups are known to have developmental delays, children who live in environments believed to lower the likelihood of reaching maximum levels of development are referred to as at risk. Such children have a higher than normal probability of having a developmental delay. An awareness and understanding of factors that place children at risk may help to address and prevent developmental delays.



## PRENATAL CARE

Early prenatal care is defined as pregnancy-related health care received by the mother in the first three months (first trimester) of her pregnancy. Early high quality prenatal care can help to prevent poor birth outcomes by enabling early identification and, where possible, treatment of health problems. Such care can also provide an opportunity to educate or counsel pregnant women about the adverse effects of behaviors

such as alcohol, tobacco, or other drugs that increase the risks of poor outcomes for their baby. Women who receive late or no prenatal care are at a significantly higher risk of having children who are low birth weight, stillborn, or die within the first year of life.<sup>4</sup> A much higher proportion of Madison County mothers (about 80%) received adequate prenatal care in 2014 compared to New York State (NYS) (about 68%).

# Risk Factors

## LOW BIRTH RATE & PREMATURITY

Short gestation (<37 weeks gestational age) and low birth weight (infants weighing < than 2500 grams or 5.5 pounds) are among the leading causes of neonatal death. Preterm births and low birth weight account for 34% of all infant deaths in the United States and are also the leading cause of severe neurological disorders in childhood.<sup>5</sup> Low birth rate infants are at risk for health problems such as blindness, deafness, cerebral palsy, mental illness and mental retardation as well as other developmental disabilities.<sup>6</sup>

In 2015, about 8% of births in Madison County were premature (<37 weeks gestation). This is slightly lower than the state proportion (about 9%). The proportion of births that were low birthweight (about 8%) was similar between NYS and Madison County.



## BIRTH DEFECTS

Every year, approximately 3%-6% of infants worldwide are born with a serious birth defect. Birth defect is defined as abnormal development of the fetus resulting in death, malformation, growth retardation, and functional disorders. Birth defects can affect an infant regardless of birthplace, race, or ethnicity.

Those infants who survive and live with birth defects are at an increased risk for lifelong disabilities.<sup>7</sup> While some types of birth defects have decreased, mainly through preventive methods, many have increased. According to the CDC, types of birth defects that had increased over the period 1979-89 include cardiac defects, chromosomal defects such as trisomy 18 (Edwards Syndrome), and fetal alcohol syndrome. The medical costs of care for children in the US with disabilities resulting from birth defects have estimated to exceed \$1.4 billion annually.<sup>8</sup>

Between the years 2010-2012 about 267 out of every 10,000 live births in Madison County were diagnosed with a birth defect. This compares to a NYS rate of 258 birth defects per 10,000 live births.



## DRUG USE

The developing brain is vulnerable to neurotoxins including alcohol, drugs, and illegal substances. The presence of neurotoxins during prenatal development can have a negative effect on the developing central nervous system. Alcohol has the most impact on the developing brain and is one of the leading preventable causes of intellectual disabilities in the United States.<sup>9</sup> Nationally, maternal alcohol consumption results in up to 10 per 1,000 live births, or about 42,000 infants, born annually in the United States with fetal alcohol spectrum disorders, which include physical, mental, behavioral, and learning disabilities with lifelong implications.<sup>10</sup>

The use of any illicit drug such as heroin or cocaine is dangerous to the fetus and newborn; increasing the chance of premature birth, low birth weight, and withdrawal syndromes in an infant.

**It is estimated that 1 in 5 pregnant women, approximately 740,000 women, use one or more illegal substances during pregnancy.**

Studies have found that cocaine use among pregnant women ranges from 8-18 percent. Nationally, the additional medical expenses for infants who have been exposed to cocaine in utero total an estimated \$504 million dollars per year.<sup>11</sup>

Newborns born addicted to drugs are treated with methadone to ease symptoms of withdrawal. The long term impact of methadone on infants is unknown at this time.<sup>12</sup>

The rate of a drug related diagnosis at birth has been increasing, with the most recent data showing that in Madison County, between the years 2012-2014, 177 of every 10,000 births had a drug related diagnosis.<sup>13</sup> This rate is higher in Madison County than it is in NYS, which is 147 out of 10,000 births with a drug related diagnosis.

## SMOKING

The U.S. Department of Health and Human Services has indicated that smoking during pregnancy can result in spontaneous abortion, low birth weight, and sudden infant death syndrome. It has been associated with infertility, miscarriages, tubal pregnancies, infant mortality, and childhood morbidity. If smoking during pregnancy were eliminated, infant mortality could be reduced by 10 percent and low birth weight by 25 percent. Women who smoke double the risk of having a low birth weight baby. The health care costs during the first year of life for infants born of low birth weight attributable to maternal smoking totals more than \$1 billion dollars.<sup>14</sup>

Cigarette smoke contains certain toxins that keep the fetus from getting the proper supply of oxygen that he or she needs to grow. Smoking during pregnancy can increase the chance of developmental delays and behavioral and learning problems.<sup>15</sup> Similarly, women who are exposed to second-hand smoke during pregnancy have a higher rate of premature births. Columbia Center for Children's Environmental Health, part of the Mailman School of Public Health at Columbia University, found that children whose mothers are exposed to second-hand smoke during pregnancy have reduced scores on tests of cognitive development at age two, when compared to children from smoke-free homes.<sup>16</sup>

About 25 % of all pregnant women in the US smoke throughout their pregnancies. In 2016 16.4% of women smoked during pregnancy in Madison County which is higher than New York State which was 8.9% in 2016. Smoking-cessation programs remain a crucial strategy for preventing poor birth outcomes and decreasing the social and financial costs of smoking during pregnancy.





# Risk Factors



Madison County has lower rates of teen pregnancy and births compared to the rest of New York State

## TEEN PREGNANCY

Child bearing during adolescence negatively affects the parents, their children, and society. Adolescent mothers are less likely than their non-parenting peers to complete high school; more likely to rely on public assistance; and more likely to have children who have poorer educational, behavioral, and health outcomes over the course of their lives than do children born of older parents.<sup>17</sup> Their children are at greater risk of infant mortality, poor health, lower cognitive development, poor educational outcomes, higher rates of behavior problems,

and higher rates of adolescent childbearing themselves. Poor outcomes affecting the health of infants born to teens include poor eating habits, smoking, drinking alcohol, and taking drugs. Teen birth rates in the United States have declined almost continuously since the 1990's however; teen birth rate is still higher than many other developed countries, including Canada and the United Kingdom.<sup>18</sup> Madison County has lower rates of teen pregnancy and births compared to the rest of New York State as seen in Table 1 (page 11).



## TOXIC STRESS & TRAUMA

Childhood experiences, both positive and negative, can have an immediate and long-lasting impact. Young children are the most frequent victims of maltreatment with 70% of child maltreatment fatalities occurring in children under three years of age. Children with disabilities/delays are at a higher likelihood for experiencing abuse, and children who experience abuse are at a higher likelihood for developing a disability or delay.

Children who live with “Toxic Stress” are at a disadvantage in terms of overall development in their early years and school readiness, as well as dealing with later life challenges. Harvard University’s Center on the Developing Child defines toxic stress as “when a child experiences trauma, strong, frequent, and/or prolonged adversity – such as physical or emotional abuse, chronic abuse, caregiver substance abuse or mental illness, exposure to violence, and/or the accumulated burdens of family economic hardship – without adequate adult support.”<sup>19</sup> Children who develop under such constant stress have increased risks for stress-related disease and cognitive impairment, well into the adult years. Children who experience routine adversity are more likely to be developmentally delayed, have chronic health problems, and be at risk for depression. The Center on the Developing Child also emphasizes that significant neglect – the ongoing disruption or significant absence of caregiver responsiveness – can cause more harm to a young child’s development than overt physical abuse including cognitive delays, and impairments to self-regulation and immune response systems.<sup>20</sup>

Early childhood trauma occurs when a child experiences an event that causes actual harm or poses a serious threat to the child’s emotional and physical well-being. These events range from experiencing abuse and neglect to having a

parent with substance abuse or being separated from a parent. Trauma has been shown to negatively impact early brain development, cognitive development, learning, social-emotional development, the ability to develop secure attachments to others, and physical health.<sup>21</sup>

Research in this area has been referred to Adverse Childhood Experiences (ACEs). Adverse Childhood Experiences have been linked to risky health behaviors, chronic health conditions, low life potential, and early death. As the number of ACEs increases, so does the risk for these outcomes.<sup>22</sup> Child abuse/maltreatment and placement in foster care can be considered adverse childhood experiences. The percent of child/abuse maltreatment in Madison County decreased for children birth to age 17 years from 25.2% in 2005 to 20.0% in 2011. This compares to 16.9% in New York State as a whole for 2011. The rate of children placed in foster care for children birth to age 17 years in Madison County was 2.6 per 1,000 in 2010 compared to 4.0 per 1,000 in New York State as a whole.<sup>23</sup>

Trauma-informed care is an approach that looks at the whole child and person to better understand his or her behaviors before trying to fix any problems. Using a trauma-informed approach, providers recognize the signs and symptoms of trauma and work to prevent re-traumatization.<sup>24</sup>

# Risk Factors

## BREAST FEEDING

Breastfeeding can play a significant role in a child's health and development. Breastfed infants typically need fewer sick care visits, prescriptions, and hospitalizations. According to the Office of Women's Health, US Department of Health and Human Services, breastfeeding may help prevent babies from growing up to be overweight children.<sup>25</sup> Research has indicated that breastfeeding at birth is associated with increased probabilities of being in good health at nine months, and improved cognitive outcomes at 24 months and 54 months.

In 2015, it was estimated that 69% of Madison County babies were ever breastfeed, 22% were at 6+ months, and 12% were at 12+ months. These are all lower than the estimated proportions throughout NYS as reflected in Table 1.



Breastfeeding for six months or more increases a child's motor scores at 9 months.<sup>26</sup>



## LEAD EXPOSURE

Childhood lead poisoning is a serious health problem that can have a devastating effect on a child. The long-term effects of elevated blood lead levels in children include delays in development, reduced IQ scores, learning disabilities, hearing loss, reduced height and hyperactivity.<sup>27</sup> The most common source of lead exposure for children today is lead paint in older housing and the contaminated lead dust and soil it generates. Lead-based paint was banned in 1978 therefore, homes built before 1978 are most likely to contain lead-based paint. In Madison County about 60 % of homes were built before 1970. Furthermore, about 5 out of every 1,000 children in Madison County tested between 2012 and 2014 had very elevated blood lead results ( $\geq 10 \mu\text{g/dL}$ ). This rate was similar to NYS rate for the same time period of 2012-2014.

Overall, these data reveal that Madison County may differ in regards to a few risk factors for birth defects, complications, and/or developmental delays compared to the state. On the beneficial side, we see that Madison County mothers are more likely to have adequate prenatal care and the county has lower teen birth and pregnancy rates. However, it appears Madison County mothers are more likely to smoke during pregnancy and less likely to breastfeed. Furthermore, Madison County babies may be at an increased risk of a drug diagnosis at birth compared to NYS.

**TABLE 1—RISK FACTORS FOR DEVELOPMENTAL DELAYS**

	<b>Madison County (2015)</b>	<b>NYS (2015)</b>
<b>Percent of births by payment type</b>		
Medicaid/Family Health Plus	46.9%	52.1%
Private Insurance	44.3%	43.1%
Self-pay	1.5%	1.1%
Other	6.1%	2.7%
Not stated	1.2%	1.0%
<b>Pregnancy factors</b>		
Maternal smoking during pregnancy	16.4% (2016)	8.9% (2016, NYS excl. NYC)
Adequate prenatal care, (beginning in the first trimester and 80% expected prenatal visits completed)	80.1% (2014)	67.6% (2014)
Teen pregnancy rate (per 1,000 females 15-19 years of age)	18.3 (2012-2014)	37.1 (2012-2014)
Teen birth rate (per 1,000 females 15-19 years of age)	13.6 (2012-2014)	17.8 (2012-2014)
<b>Birth outcome factors</b>		
Percent of births that were premature (<37 weeks gestation)	7.5%	8.7%
Percent of births that were low birthweight (<2,500 grams)	7.6%	7.8%
Drug-related diagnosis at birth (rate per 10,000 newborn discharges)	177.4 (2012-2014)	147.6 (2012-2014)
Any birth defect (rate per 10,000 live births)	267.2 (2010-2012)	257.6 (2010-2012)
<b>Early life/environmental factors</b>		
<b>Percent of mothers breastfeeding</b>		
Ever	69.4%	83.4%
6+ months	21.9%	39.5%
12+ months	12.0%	22.8%
<b>Lead exposure</b>		
Homes built before 1950	38.8%	41.2%
Elevated blood lead levels (incidence of confirmed high blood lead level ( $\geq 10$ $\mu\text{g/dL}$ ) - rate per 1,000 tested children <72 months)	4.8 (2012-2014)	5.1 (2012-2014)

Table 1 Sources unless otherwise noted:

NYSDOH, Vital Statistics of New York State; Maternal smoking during pregnancy: NY Statewide Perinatal Data System  
Prenatal care, drug diagnosis at birth: NYSDOH, New York State Community Health Indicator Reports - Maternal and Infant Health Indicators; Teen birth data: KWIC, Adolescent Pregnancy and Births; Birth defects: NYSDOH, Environmental Public Health Tracking Network – Birth Defects; Breastfeeding: NYSDOH, The Pediatric Nutrition Surveillance System (PedNSS)  
Homes built before 1950: U.S. Census Bureau, 2011-2015 American Community Survey 5-Year Estimates; Elevated blood lead levels: NYSDOH, New York State Community Health Indicator Reports - Child and Adolescent Health Indicators



# Demographics

## POPULATION

In 2015, the U.S. Census Bureau estimated that about 5% of the Madison County population was between 0-5 years of age, equaling approximately 3,305 children. The estimated proportion of women of childbearing age (15-44 years of age) was about 38%, equaling approximately 27,700 women. Both of these proportions of the Madison County population are less than the proportions of these age groups among the overall New York State (NYS) population, as seen in Table 2. Both the fertility and birth rates have slightly increased in Madison County from 2010 to 2015. These rates are both lower in Madison County compared to NYS.

## SOCIOECONOMIC

Research shows that Socioeconomic status (SES) is associated with a wide array of health, cognitive, and social emotional outcomes in children, with effects beginning prior to birth.<sup>28</sup> Potential negative health and development outcomes for children result from unhealthy environments which are substantially associated with socioeconomic disparities.<sup>29</sup> Several ways of measuring SES include family income, parental

education, and occupational status. Lower socioeconomic status including family income and parental education may increase the risk of a child having birth defects and/or developmental disabilities. The socio-economic status of a family has been shown to have an association with the number of words a child learns. The “30 million word gap by age three” was identified by researchers Betty Hart and Todd Risley after they recorded and analyzed more than 1,300 conversations between children and their parents. In 2003 they published their findings in “The Early Catastrophe”.<sup>30</sup> The researchers found that while all families played, nurtured and talked with their children, the families of lower socio-economic incomes used fewer words, and therefore, their children learned fewer words, and learned words more slowly. The average child on welfare was having half as much experience per hour (616 words per hour) as the average working class child (1,215 words per hour) and less than one-third that of the average child in a professional family (2,153 words per hour).<sup>31</sup> As seen in Table 2, Madison County residents have lower educational attainment, but a lower proportion is below 100% of the poverty level when compared to NYS.



The socio-economic status of a family has been shown to have an association with the number of words a child learns.



# Demographics

**TABLE 2 - DEMOGRAPHICS**

	<b>Madison County (2015)</b>	<b>NYS (2015)</b>
<b>Population</b>		
Percent 0-5 years of age	4.7%	5.7%
Percent of women 15-44 years of age	38.1%	40.0%
<b>Race</b>		
<i>American Indian/Alaska Native</i>	0.6%	0.4%
<i>Asian</i>	0.8%	8.0%
<i>Black or African American</i>	2.0%	15.6%
<i>White</i>	94.9%	64.6%
<i>Some other race, and/or multiple races</i>	1.7%	11.4%
<b>Ethnicity</b>		
<i>Hispanic or Latino origin (of any race)</i>	2.0%	18.4%
<i>Non-Hispanic White</i>	93.5%	56.8%
<b>Population characteristics</b>		
Percent below 100% of the poverty level	12.2%	15.7%
Percent of families whose income is below the poverty level	7.8%	12.0%
<b>Educational attainment (among population 25 years and over)</b>		
<i>Less than high school graduate</i>	9.6%	14.4%
<i>High school graduate (includes equivalency)</i>	33.7%	26.7%
<i>Some college or associate's degree</i>	30.5%	24.7%
<i>Bachelor's degree or higher</i>	26.3%	34.2%
<b>Health insurance coverage</b>		
<i>Percent of civilian noninstitutionalized population insured</i>	94.3%	90.3%
<i>Percent of children 0-5 years of age insured</i>	96.5%	96.8%
<b>Fertility rate (per 1,000 female population 15-44)</b>	<b>47.1</b>	<b>58.5</b>
<b>Birth rate (per 1,000 population)</b>	<b>9.1</b>	<b>11.9</b>

Sources:

Population data: U.S. Census Bureau, 2015 American Community Survey 5-Year Estimate  
 Birth and fertility rates: NYSDOH, Vital Statistics of New York State

# Demographics



## POVERTY

Poverty affects many aspects of a child's life. Developmental science shows a strong association between poverty and compromised child development. A child's earliest years are a period of tremendous brain development influenced predominantly by the family context. Exposure to poverty during this rapid brain development can lead to significant short and long term consequences for the development of young children.<sup>32</sup>

The estimated proportion of individuals below 100% of the poverty level has increased from about 10% to 12% in Madison County from 2010 to 2015. This proportion also increased among all NYS residents during that timeframe. The proportion of individuals below 100% of the poverty level is estimated to be higher among all of NYS compared to Madison County. About 8% of families in Madison County are below the poverty level. This is also lower than the state as a whole.

## EDUCATION

Women with less education are more likely to have unintended pregnancies. Unplanned pregnancies are associated with delayed prenatal care, smoking during pregnancy, not breastfeeding, and poorer health during childhood.<sup>33</sup>

As shown in Table 2, NYS residents are more likely than Madison County residents to have a bachelor's degree or higher. A larger proportion of Madison County residents have graduated high school (or equivalent), as compared to NYS residents.

## HEALTH INSURANCE

Women who have health insurance are far more likely to obtain early prenatal care. As previously noted, early prenatal care can help to prevent poor birth outcomes by enabling early identification and treatment of health problems as well as educate pregnant women about the adverse effects of the use of alcohol, tobacco, or other drug use that increase the risk of poor outcomes for the baby.

About 97% of children 0-5 years of age and 94 % of all Madison County residents have health insurance. The proportion of children 0-5 years of age who have insurance coverage in Madison County is similar to NYS; whereas Madison County has a higher proportion of individuals overall who have health insurance coverage.

In summary, the data show that Madison County has a lower proportion of its population who is 0-5 years of age and of women of childbearing age (15-44 years of age) compared to the state. In general, Madison County residents have high health insurance coverage, and the socioeconomic status of the county appears to be better than the state as a whole.



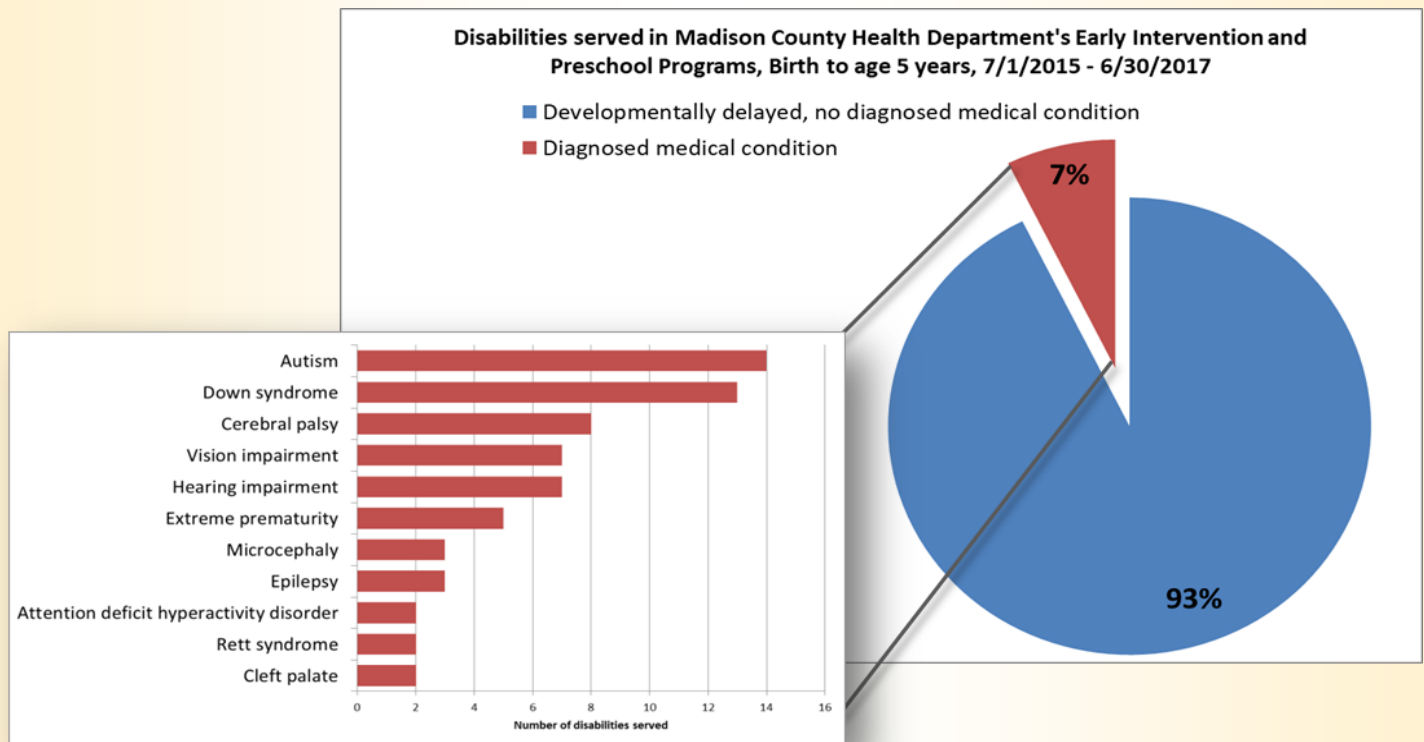
# Disabilities

After decades of steady increases, the population of children with disabilities peaked in 2004-2005 with 6.72 million children, comprising 13.8 percent of the nation's student population. The Special-Education population has steadily declined falling to 6.48 million students by 2009-2010, or 13.1 percent of all students nationwide. The population of students identified as having "specific learning disabilities" declined considerably between 2000 and 2010 falling from 6.1 to 4.9 % of all students nationwide. Mental retardation category dropped from 1.3 to .09 percent, and emotional disturbances fell from 1.0 to .8 percent. The autism population increased

dramatically with the number of autistic students quadrupling from 93,000 to 378,000, or 1.5 to 5.8 percent. Even so, the autistic student population constituted only .8 percent of all students in 2009-10.

Nationally the category of developmental delay, which serves as a general disability category for young students (typically ages three to nine), grew as well, from 213,000 students in 2000 to 368,000 in 2010.<sup>34</sup> In 2010 the percentage of children ages 3-5 years in NYS with developmental delays was 65.4 % compared to 37.2 % nationwide. In 2014 this percentage decreased to 56.92 % in NYS and to 36.96 %

**Figure 1—Disabilities Served by Madison County Health Department's Early Intervention and Preschool Programs  
Birth to age 5 years, 7/1/2015— 6/30/2017**





# Disabilities

nationwide. In 2010 the percentage of children ages 3-5 years in NYS with autism was 3.3% compared to 6.9% nationwide. In 2014 this percentage increased to 4.50% in NYS and 8.85% nationwide.<sup>35</sup>

In New York State the percentage of children ages birth to three with disabilities has remained steady with an average of 4% between 2012 and 2014. However, the percentage of children ages three to five in NYS with disabilities has risen from 9.42 % in 2012 to 9.9% in 2014. New York State had a higher percentage of young children in 2014 with disabilities than the US average, which had 3% percent of children ages birth to three and 6 % of children ages three to five with disabilities in 2014. In 2014 9.2% of the children between the ages of birth to five years were identified as having disabilities in the US compared to 13.9% in New York State.<sup>36</sup>

A number of factors may have influenced the

prevalence of developmental disabilities over the past years, including improved survival of the growing number of children born prematurely, with birth defects, or genetic disorders, whose improved survival may be offset by a disproportionate burden of neurologic and other impairments. Increased awareness and improved diagnosis, particularly for conditions such as autism may have contributed to changes over time. As the number of children with diagnosed disabilities and developmental delays increase, there is a direct bearing on the need for health, education, and social services, including the need for more specialized health services such as mental health, medical specialists, and therapists. Also, the consequent burden on families and caregivers need to be considered. In Madison County the vast majority of children served age's birth to five years for the 2015-2017 school years were developmentally delayed as reflected in figure 1.



In 2014, New York State had a higher percentage of young children with disabilities than the US average





## Services

A child's early years are a critical time for growth and development. Like all children, it is extremely important for children with disabilities and developmental delays to be exposed to a variety of rich experiences and interventions. A disability or established developmental delay as defined by New York State impacts one or more of the following areas of development: physical (large and small motor

detection and services can significantly improve functioning and reduce the need for lifelong interventions.<sup>37</sup> The sooner a child gets help the better chances of their success in school and later in life. The Madison County Department of Health administers Early Intervention and Education and Transportation of Disabled Children programs for children birth to age five years. Services are provided by a network of



skills including walking and use of hands); cognitive (early learning and thinking skills); communication (use and understanding of language); social-emotional (interactions with others); and/or adaptive (beginning self-care skills). Services for young children with disabilities and developmental delays aims to reduce and remove physical and social barriers as well as promoting growth, development, and well-being through therapeutic and educational interventions. Many children with behavioral or developmental disabilities are missing vital opportunities for intervention as they are not being identified early. Research shows that early

New York State approved individual and agency providers. While in NYS counties are mandated to administer Early Intervention and Education and Transportation of Disabled Children, placement of these programs vary from county to county. Madison County elected to place both of these programs within the Health Department to ensure continuity of care and transitions for children who age-out of Early Intervention and move onto Preschool Special Education services. Both the Early Intervention and Education and Transportation of Disabled Children programs are voluntary, whereby parents can decline



# Services



services at any time. Approximately 10% of Madison County referred families decline services annually. Frequently, parents who initially decline services will re-refer their children for services after some time has passed. The Early Intervention Program is a state mandated program that provides family centered services to infants and toddlers with developmental delays and disabilities ages

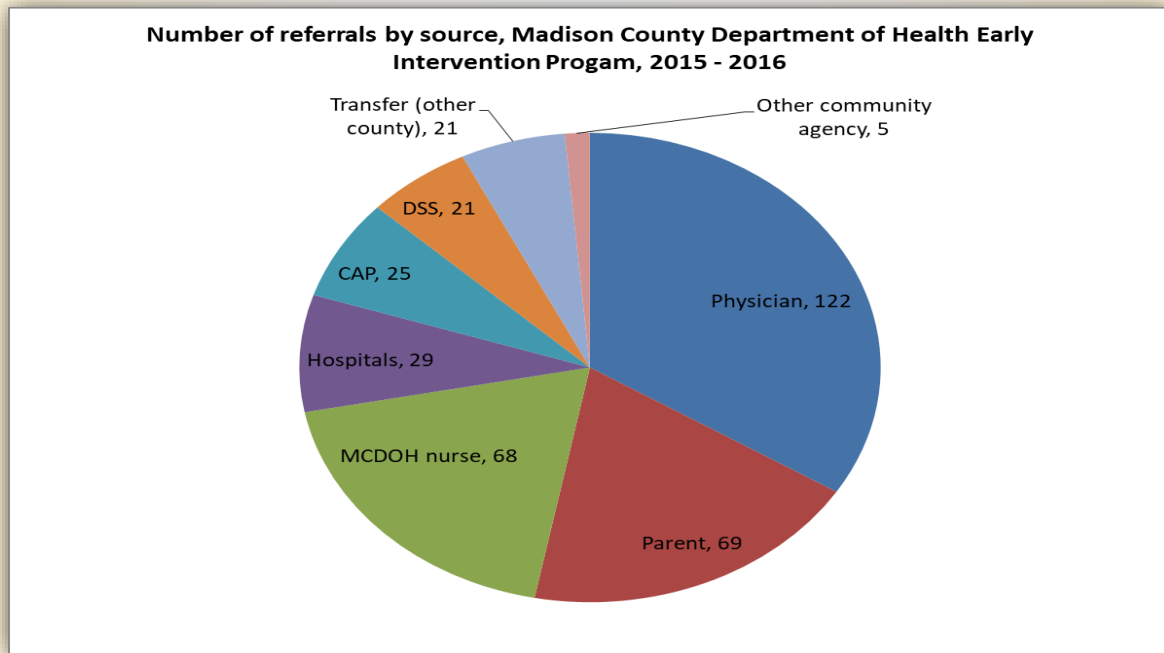
Birth to 2 years. To be eligible for services, children must be less than 3 years of age and have a confirmed disability or established developmental delay. Services include Evaluation, Screening, Special Education Teacher services, Occupational, Physical, and Speech therapies. Through the Child Find Program, children who are at risk for developmental delays are monitored and screened.

Staff works closely with a child's primary care provider to monitor a child's developmental progress. The Education and Transportation of Disabled Children is a state mandated program that provides special education services to three and four year old children with developmental delays and disabilities according to provisions under Section 4410 of the New York State Education Law. The Preschool Program provides services to disabled and developmentally delayed children ages 3-5 years.



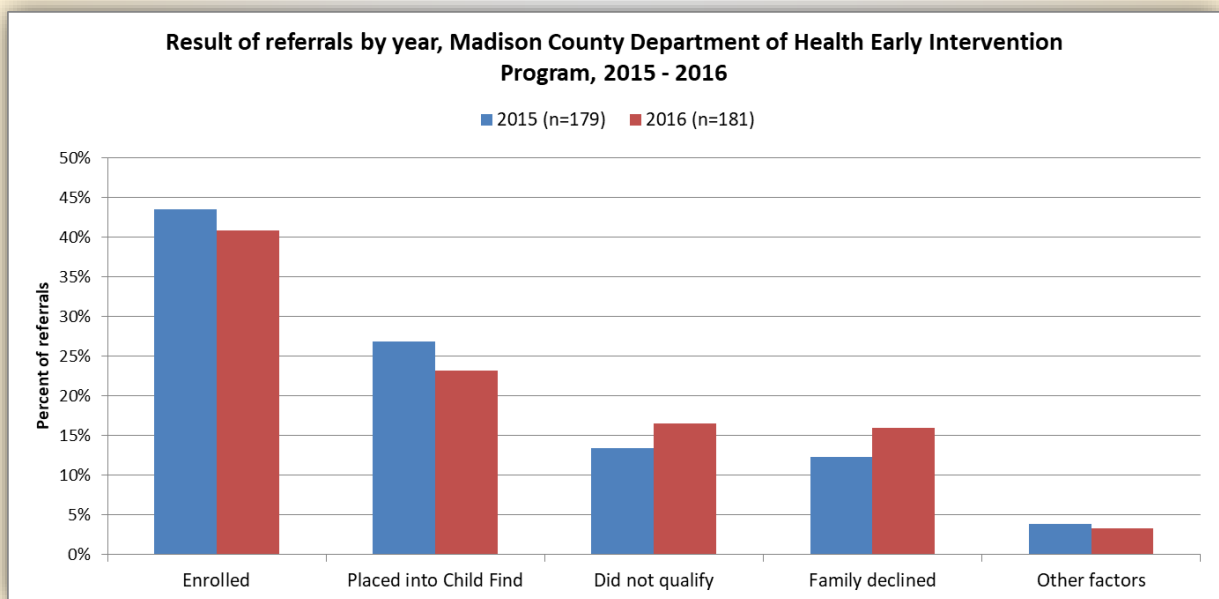
The Early Intervention Program is a state mandated program that provides family centered services to infants and toddlers with developmental delays and disabilities ages birth to 2 years.

## FIGURE 2 - EARLY INTERVENTION REFERRALS 2015-2016



**Figure 1** DSS: Department of Social Services CAP: Community Action Partnership MCDOH: Madison County Department of Health Other community agency Daycare (2), Upstate Cerebral Palsy (1), WIC (1), BOCES (1)

## FIGURE 3 - RESULTS OF REFERRALS 2015 - 2016



**Figure 2** other factors: referred to school due to age, or family moved out of county



Services include Evaluation, Special Education Teacher services, Occupational, Physical, and Speech therapies. Services are provided at home or in integrated preschool settings comprised of children with and without disabilities. The Preschool Special Education Program works closely with School Districts, Head Start, community wide therapeutic agencies and licensed individual professionals. The Preschool Special Education Program fosters an early partnership between the child, family and school district. This early partnership sets the stage for a positive transition from preschool to school age services.

Commitment to a family-centered strength based approach provides the foundation for maximum growth and potential.

Referrals for Preschool services are received and coordinated by the child's school district of residence. Referrals for Early Intervention services are received and coordinated by the Madison County Department of Health. A multidisciplinary team of NYS approved providers, using standardized assessment tools, evaluate referred children in order to determine eligibility for Early Intervention or Preschool services. Once a child has been determined eligible, approved services can be delivered through the Early Intervention or Education and Transportation of Disabled Children public programs at no out of pocket cost to families. An average of 75 % of all referred children are found eligible for services. Families may elect to seek services privately at their own expense if a child is not found eligible for services, or if a family desires additional services beyond what has been approved.

With parent permission, anyone can make a referral for Early Intervention services. Primary care providers are knowledgeable of available services and readily make the majority of referrals as reflected in figure 2. Parents are also aware of available services and often times refer their children. Early Intervention referrals have remained steady over the past five years between 2012-2016, averaging 175 referrals annually. The majority of children referred for Early Intervention services over the two years of 2015-2016 were either enrolled for direct services or placed into the Child Find monitoring program as seen in figure 3. A smaller percentage of children were found not eligible for services or the family declined services. These results indicate that children are appropriately referred for Early Intervention services due to the large percentage of children who are found eligible for either direct services or child find monitoring.

Services for Early Intervention and Preschool children with developmental delays are provided to overcome barriers and foster the healthy development of children and families within the community. Through collaboration with Health Care, Education, Therapeutic and Social Service providers, resources are accessed to meet identified child and family needs.

# Services



As seen in figures 4 & 5, between 2014 and 2016 the top three Early Intervention services provided were speech therapy, special education teacher services, and physical therapy. The top three preschool services provided were speech therapy, special education teacher services, and occupational therapy.

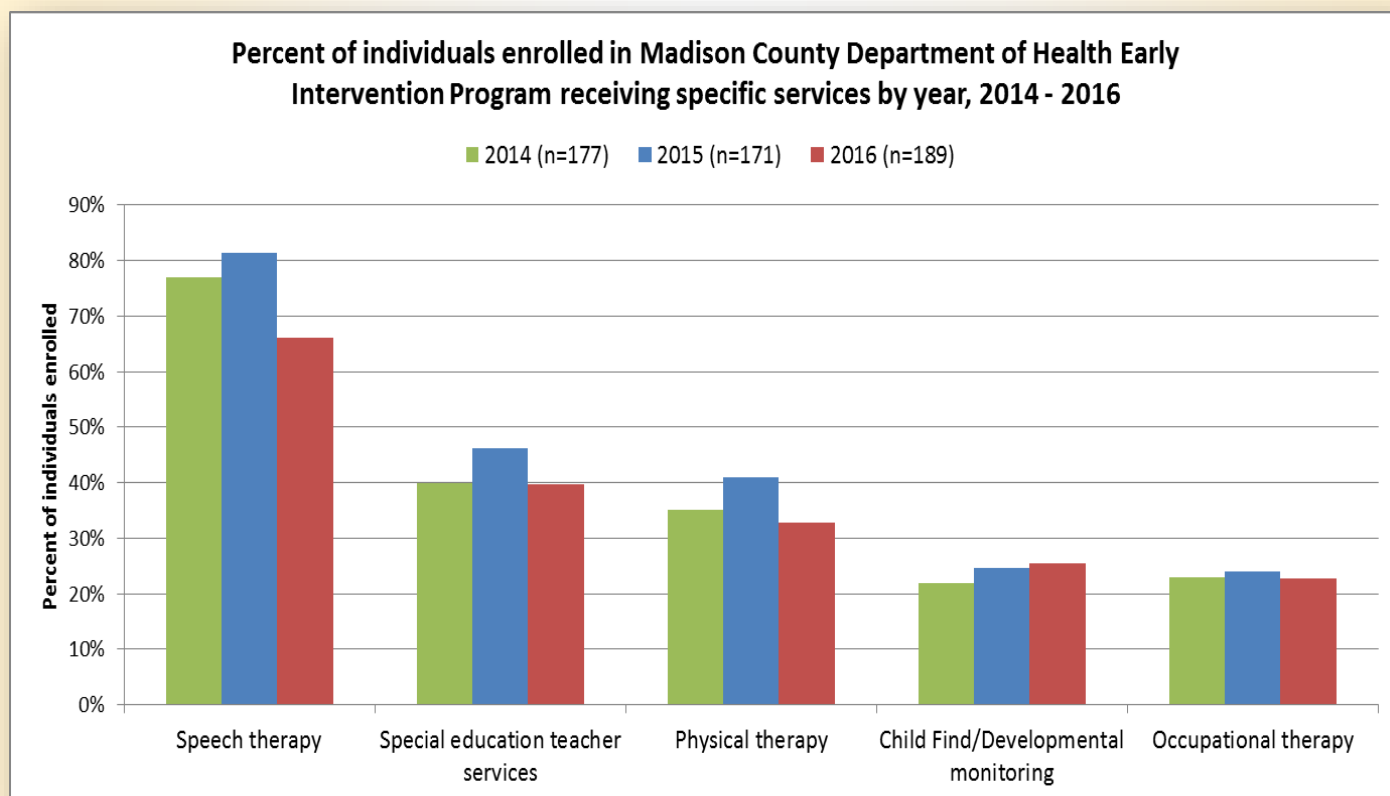
Early Intervention services are primarily provided in the child's home environment with the direct involvement of the child's parents. Preschool services are provided at home as well as at daycare and preschool programs. Additionally, preschool children may be

transported to Special Education Center-based programs to receive services. The majority of preschool children (more than 50%) approved to attend Special Education Center-based programs are transported to programs outside of Madison County.

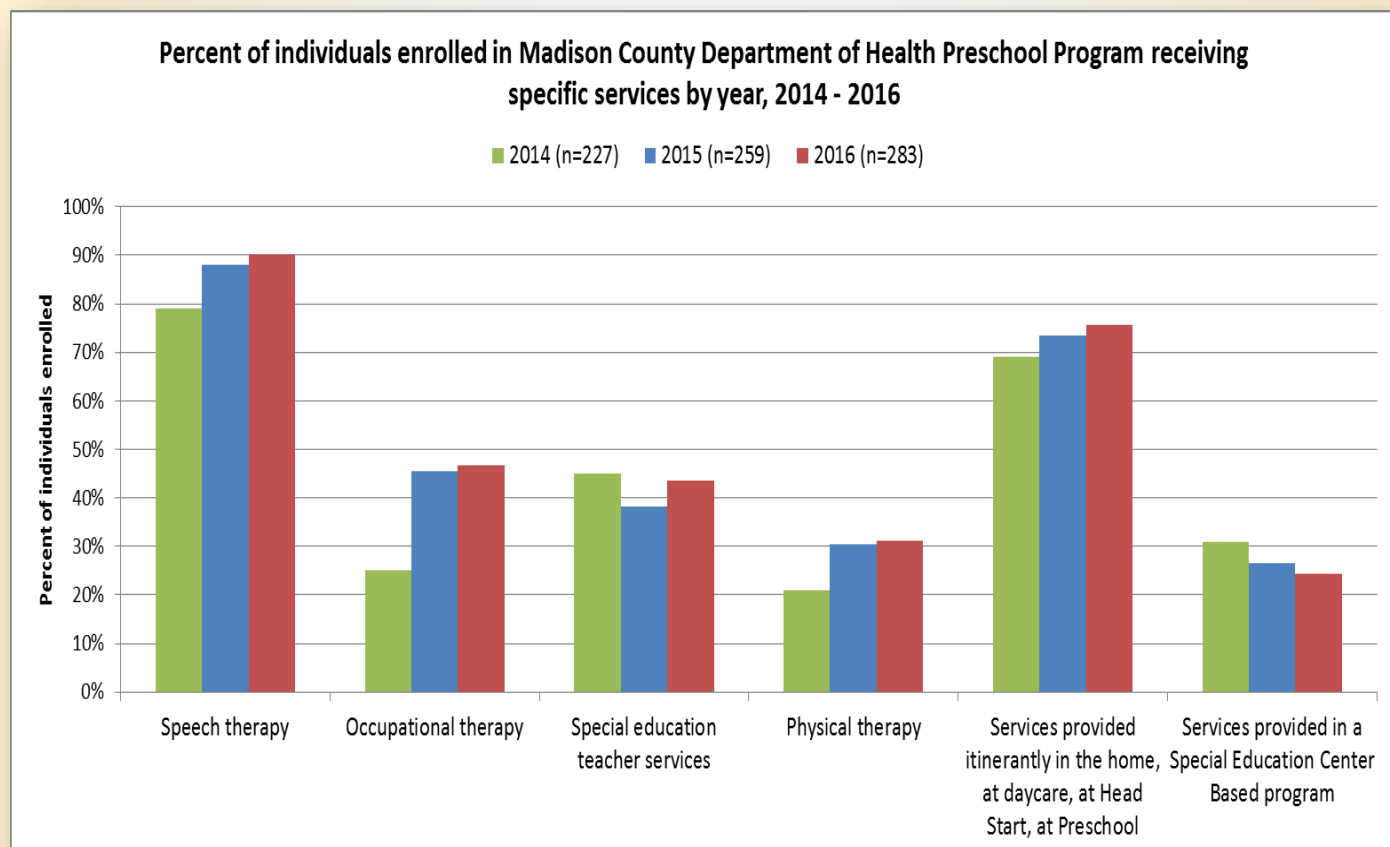
Of the thirteen New York State approved Preschool Special Education Center-based programs in contract with Madison County Health Department only two are currently located in Madison County resulting in long travel times for children (up to 90 minutes one way) and high transportation costs (\$576,560 in 2016).



**Figure 4 - Percent Receiving Early Intervention Special Services 2014-2016**



**Figure 5 - Percent Receiving Health Preschool Special Services 2014-2016**





# Services

The number of children served by the Early Intervention and Preschool Programs has remained steady between 2014-2016 with an average of 179 Early Intervention and 256 Preschool children. Madison County served 404 children in 2014 with developmental delays between the ages of birth to five years, equating to 12.24% of the approximately 3,305 children in Madison County within this same age group; which is a higher percentage of both the US and NYS for 2014. As seen in figures 4 & 5 the numbers of children served in Madison County have increased between 2014 and 2016 which indicates that children with developmental delays in Madison County are being identified and referred for needed services.

Children leave the Early Intervention and Education and Transportation of Disabled Children programs for various reasons. If families move out of Madison County a referral is made and services are transferred to their new county of residence. Some Early Intervention children transition to local programs such as Head Start or

daycare centers. Often time's children enrolled in the Early Intervention program transition onto continued preschool services through the Education and Transportation of Disabled Children program. Likewise, many preschool children enrolled in the Education and Transportation of Disabled Children program transition onto continued kindergarten school age services through their school district of residence. As seen in tables 3 & 4, for school years 2015-2017, the majority of children (64%) continued to need services beyond Early Intervention and 61% of Preschool children continued to need services when entering Kindergarten.

The ultimate goal of service provision is for children to overcome developmental delays and no longer be in need of continued services; 23% of Preschool children were no longer in need of services once in Kindergarten and 21% of Early intervention children were no longer in need of services beyond Early Intervention for the combined 2015-2017 school years.

**Table 3 - Early Intervention 2015-2017  
(July 1, 2015 – June 30, 2017) 360 total enrollment**

Reason for Discharge 162 discharged	Number/percentage
Transition to Preschool IEP services	103/64%
No longer in need of services	34/21%
Moved out of Madison County	13/8%
Transition to Head Start, Daycare	12/7%

**Table 4 – Preschool 2015-2017  
(July 1, 2015 – June 30, 2017) 542 total enrollment**

Reason for Discharge 240 discharged	Number/percentage
Transition to Preschool IEP services	146/61%
No longer in need of services	56/23%
Moved out of Madison County	34/14%
Family declined services	4/2%

# Evidenced-Based & Best Practices

Evidenced-based practices are strategies shown by science to be effective ways to teach new behaviors or skills. In order to be considered an evidence-based practice, an instructional strategy must be shown to be effective in multiple high-quality research studies across multiple settings with many participants. To be considered high quality, a research study should show that the intervention - and only the intervention - is the reason for any changes in behavior.

Best practices are techniques or methodologies that, through experience and research, have proven reliably to lead to a desired result. A commitment to using best practices in any field is a commitment to using all the knowledge and technology at one's disposal to ensure success.

The following are examples of evidenced - based and best practices in early childhood.

which state that "correct" behaviors can be taught through a system of rewards and consequences. One specific application of these techniques is intensive behavioral intervention for children with Autism Spectrum Disorder (ASD). It is important to note that the techniques of ABA are not just for children with ASD, although it has the most established evidence for this population. One definition of the technique describes ABA as follows:

Applied
principles applied to socially significant behavior
Behavioral
based on scientific principles of behavior
Analysis
progress is measured and interventions modified <sup>38</sup>

Research has shown ABA to be effective in reducing disruptive behaviors typically observed in individuals with ASD, such as self-injury, tantrums, non-compliance, and self-stimulation. ABA has also been shown to be effective in teaching commonly deficient skills such as communication, social, play, academic and self-help skills in individuals with ASD.<sup>39</sup>

ABA services are available to eligible Madison County children ages birth – five years through the Madison County Early Intervention and the Education and Transportation of Disabled Children's Programs New York State approved providers.

## DEVELOPMENTAL SURVEILLANCE

Early identification of developmental disorders is critical to the well-being of children and families and an integral function of the primary care medical home and pediatric health care professionals. Early childhood screenings provide parents, health care and other early



## APPLIED BEHAVIORAL ANALYSIS (ABA)

Applied Behavioral Analysis is a field of psychology that focuses on applying learning theories to different people and situations. ABA is a treatment based on behaviorist theories

## Evidenced-Based & Best Practices

childhood professionals with a standardized way to assess child development and identify concerns as early as possible. Developmental monitoring/surveillance and use of a standardized developmental screen are recommended by The American Academy of Pediatrics during well-child visits at 9, 18, 24,

evaluation to determine diagnosis and treatment.

The Centers for Disease Control's "Learn the Signs. Act Early." program encourages parents and providers to learn the signs of healthy development, monitor every child's early development, and take actions when there is a concern. The program offers free research based checklists and other tools for developmental monitoring intended to aid in the identification of children with developmental delays and disabilities. Materials are available to parents, early childhood providers, healthcare providers, and others who work with young children.<sup>41</sup>

### DEVELOPMENTAL INDIVIDUAL RELATIONSHIP-BASED (DIR) MODEL OR FLOOR TIME

Also known as *Floor Time*, the Developmental, Individual-Difference, Relationship-Based (DIR) Model is an intervention developed by the child psychiatrist Dr. Stanley Greenspan. Floor time is an evidence-based intervention that research has demonstrated strengthens fundamental communication and relationship abilities for children with autism and other special needs.<sup>42</sup> DIR/Floor time is most commonly utilized with children with educational, social-emotional, mental health, and/or developmental challenges. The objectives of the DIR Model are to build healthy foundations for social, emotional, and intellectual development by creating a warm interactive relationship with the child and by meeting the child at his or her developmental level. DIR focuses on emotional development rather than on targeted speech, motor, or cognitive skills in isolation. By following the child's lead, the parent or therapist helps the child to develop social interactions and communication skills. Floor time can be used with children of all ages, and it is often used in

or 30 months. Also, a screen for autism, like the MCHAT (Modified Checklist for Autism in Toddlers) is recommended at the 18 and 24 month visits.<sup>40</sup> Madison County primary care physicians use various screening tools for developmental surveillance including the reliable and valid tools of The Ages & Stages Questionnaire and Modified Checklist for Autism in Toddlers. Additionally, the Madison County Early Intervention Child Find Program monitors the development of children at risk for developmental delays through periodic screening utilizing The Ages and Stages Questionnaire. Early identification of developmental delays leads to further





combination with behavioral, speech, and occupational therapy.

DIR/Floor time services are available to eligible Madison County children ages birth – five years through the Madison County Early Intervention and the Education and Transportation of Disabled Children's Programs New York State approved providers.

## HOME VISITING

Home visiting programs bridge the gaps between health, early learning, family support, and parenting interventions. High-quality home visitation programs - particularly those that teach parenting skills and healthy behaviors along with the social and cognitive needs of young children - have been shown to be effective at supporting families. The Maternal, Infant, and Early Childhood Home Visiting Program builds upon decades of research showing that home visits by a nurse, social worker, early childhood educator, or other trained professional during pregnancy and in the first years of life improve the lives of children and families by promoting maternal child health, preventing child abuse and neglect, supporting positive parenting, and promoting child development.<sup>43</sup>

Home visiting has shown to improve birth outcomes, including reducing the number of low birthweight babies born to mothers in home visiting programs and reducing language delays among toddlers. Longer-term outcomes for children of families that participate in home visiting programs include stronger school performance; fewer behavioral problems; improved reading and math test scores; and improved high school graduation rates.<sup>44</sup>

Early Head Start is an evidenced-based federal grant program available to children and families in Madison County through Community Action Partnership. Early Head Start provides low-income pregnant women and families with children from birth to age

three family-centered services that facilitate and promote self-sufficiency. Early Head Start provides an array of services including home visits and screenings to assess child development, health, and mental health. Activities support families in parenting, child development, school readiness, health, nutrition, and family development.

Healthy Families New York is an evidenced-based program available to children and families in Madison County through Community Action Partnership. Healthy Families New York targets expectant parents and parents with an infant less than three months of age who are considered at risk for child welfare involvement. Home visits are provided to participating families until the child reaches five years of age. Screenings are also provided to monitor child development.<sup>45</sup>

Madison County Health Department's Maternal & Child Health & Home Visitation Program provides nursing home visits and breastfeeding support to pregnant and parenting women and families. Services include prenatal education, newborn health assessment, newborn teaching, and well-child care. Education and information is provided regarding maternal and child health including Sudden Infant Death Syndrome and Shaken Baby Syndrome. International Board Certified Lactation Consultants are available to provide breastfeeding resources and support.

Nurse-Family Partnership (NFP) is an evidenced-based community health program that provides home visits to at-risk, first-time mothers. Each mother is partnered with a registered nurse to receive home visits from pregnancy through the baby's second birthday. The program goals are to improve pregnancy outcomes, improve child health and development, and improve the economic self-sufficiency of the family. Established in New York State in 2003, there are twelve counties served by a Nurse-Family Partnership program, Madison County is not a provider. The cumulative positive outcomes

# Evidenced-Based & Best Practices

for New York state include 17,508 families served, and of those 95% of babies received all immunizations by 24 months, 90% of mothers initiated breastfeeding, and 78% of mothers had no subsequent pregnancies at program completion.<sup>46</sup>

## INCLUSION

Every child and his or her family have the right, regardless of ability, to participate in a broad range of activities as full members of families, communities, and society. The desired results of inclusive experiences for children with and without disabilities and their families include a sense of belonging, positive social relationships and friendships, and development and learning to reach their full potential. Inclusion in early childhood programs refers to including children with disabilities in early childhood programs, together with their peers without disabilities. This applies to all young children with disabilities, from those with the mildest disabilities, to those with the most significant disabilities.

***“All children should be a part of society, not apart from society”<sup>47</sup>***

Research supports the benefits of inclusion for young children with and without disabilities. Studies have shown that individualized evidence-based strategies for children with disabilities can be implemented successfully in inclusive early childhood programs. Children with disabilities, including those with the most significant disabilities and the highest needs, can make significant developmental and learning progress in inclusive settings. Research also suggests that children’s growth and learning are related to their peer’s skills, and the effects are most pronounced for



children with disabilities.<sup>48</sup> Children birth to age five years with developmental delays and disabilities in Madison County are able to receive services in inclusive settings including Head Start programs, Universal Pre-Kindergarten programs, daycare centers, and Special Education Center-Based Inclusive programs.

## PYRAMID MODEL

Through The New York State Pyramid Model Partnership, training is available statewide in efforts to advance professional competencies and training to support children’s social and emotional development. The Pyramid Model is an evidenced based prevention/intervention training framework that provides early childhood professionals with concrete teaching practices and intervention approaches that prevent and address challenging behaviors in addition to promoting healthy social and emotional development.

The Pyramid Model consists of training modules for Infants and Toddlers( birth to age three years), Preschool children( three to six years), and Families( staff who work with families). The Pyramid Model is New York State’s preferred social-emotional curriculum for those who work in childcare and early



## Evidenced-Based & Best Practices



education settings.<sup>49</sup> Pyramid Model trainings are available to Madison County early childhood professionals through Madison-Oneida BOCES. In Madison County Head Start, Preschool, Daycare Teachers and Teacher Aides have participated in Pyramid Model Trainings.

### TOUCHPOINTS

Touchpoints is an evidence-based theory of child development based on more than sixty years of research by the late Dr. T. Berry Brazelton and his colleagues at Children's Hospital in Boston. Touchpoints is a way of looking at child development that can make parent-child relationships stronger, starting before a child is born and continuing through early childhood. The Touchpoints model helps parents and caregivers to understand a child's behaviors, strengths, and growing capacities. It provides common language of child behavior and development enabling families, providers, and professionals to work together and collaborate in the best interest of the child. The Touchpoints model contains a valuable

cultural competency component that can be adapted to engage a community's heritage and assets on behalf of its young children.

Research has found that home visits based on the Touchpoints Model are associated with better maternal-infant interaction, increased well-child treatment, improved child developmental outcomes and longer breastfeeding. In an evaluation of Touchpoints training and reflective coaching of early care and educational professionals serving young children and their families, it was found that trained professionals made significant gains in both developmental and relational knowledge and skill application immediately following training. Trained professionals also maintained their new knowledge and continued to demonstrate that they can apply it to practice situations after six months of reflective coaching.<sup>50</sup> While there are not any Touchpoint trainers located in Madison County, there are Touchpoint trainers located in Onondaga County.



# Costs & Benefits

## COSTS & BENEFITS

Early intervention consists of the provision of services to children of school age or younger who have or are at risk of developing a disabling condition or other special need that



***“In 2017, 64% of the Health Department’s cost to the county (\$1.7 Million) are attributed to the Early Intervention and Preschool Programs”***

may affect their development. After nearly 50 years of research, there is evidence both quantitative (data-based) and qualitative (reports from parents and teachers), that early intervention increases the developmental and educational gains for the child, improves functioning of the family, and reaps long-term benefits for society. Analysis by economists has shown that education and development investments in the earliest years of life produce the greatest returns. Most of the returns, ranging from \$4 to \$9 per dollar invested, benefit the community through reduced crime, welfare, and educational remediation, as well as increased tax revenues on higher incomes for the participants of early childhood programs when they reach adulthood.<sup>51</sup>

Often cited research projects include the High/Scope study of the Perry Preschool in Ypsilanti Michigan which examined the lives of 123 children born in poverty and at high risk of

failing in school.<sup>52</sup> The Syracuse Family Development Research Program (FDRP) was a comprehensive early childhood program that aimed to develop child and family functioning through home visitation, parent training, and individualized day care.<sup>53</sup> The Abecedarian Project is synonymous with positive, long-term effects of high-quality early care and education. The Carolina Abecedarian Project was a controlled experiment that was conducted in North Carolina by the Frank Porter Graham Development Institute to study the potential benefits of early childhood education for disadvantaged children to enhance school readiness.<sup>54</sup>

Results of these research projects indicate that early childhood interventions can yield measurable benefits and some of these benefits endure for some time after the program has ended. Advantages for program participants included improved educational processes and



outcomes for the child. Increased emotional or cognitive development for the child and improved parent-child relationships. Enhanced economic self-sufficiency, initially for the parent and later for the child, through increased participation in the labor force, decreased participation in welfare, and higher incomes. Decreased criminal activity was also a documented benefit. While these findings are most pronounced among disadvantaged

populations, early childhood interventions benefit children of all abilities, across all races and income brackets. When targeted to children and families who will benefit the most, some early childhood interventions have generated savings that exceed program costs.<sup>55</sup> Many of the benefits from early childhood interventions can be translated into dollar figures and compared with program costs. For example, if child outcomes improve, fewer resources may be spent on grade repetition or special education services. If improvements in school performance lead to higher educational attainment and subsequent economic success and self-sufficiency in adulthood, the government may benefit from higher tax revenues and reduced costs for social welfare programs and the criminal justice system.

New York State's Early Childhood Advisory Council (ECAC) Finance Work Group developed a Fiscal Analysis Model for Early Childhood Services. The Early Learning Domain of the fiscal analysis spans child care programs and early interventions as well as Head Start and Preschool Special Education. In New York State funding for Early Intervention Programs is approximately \$623,000,000 and funding for Preschool Special

Education full day programs is approximately \$386,133,54.<sup>56</sup> The fiscal model includes estimates of the return on investment (ROI) of programs. According to the ECAC fiscal analysis, the return on investment of the New York early childhood system is approximately \$27 billion, which is generated by a total annual system cost of \$7.4 billion. The ROI of \$27 billion represents a return of approximately \$3.36 for each dollar invested. The system savings were spread across categories with a ROI of \$108,000,000 for New York States Special Education Kindergarten to grade 12 systems.<sup>57</sup>


In 2016 the Madison County share of the cost for the provision of services in the Early Intervention and The Education and Transportation of Disabled Children's programs following reimbursement from Medicaid, Grants, NYS Department of Education and NYS Department of Health equaled \$1,890,553. Utilizing the ECAC's ROI formula of \$3.36 for every dollar invested, the ROI for Madison County Health Departments Early Intervention and The Education and Transportation of Disabled Children's program's in 2016 was \$635,225, 80.

***“By investing now in these critical programs  
- and therefore our children -  
our future and theirs will be greatly enriched.”<sup>58</sup>***





# Child Outcomes



skills, knowledge skills, and adaptive skills. All children are required to be evaluated upon entry into the Early Intervention and Preschool Special Education programs. The evaluation results along with input from the evaluators and parents are utilized to determine an entry rating for each of the three child outcomes. The rating scale is from 1 (skills not yet attained) to 7 (skills completely attained). When the child leaves the Early Intervention or Preschool Special Education program input from the current service providers, along with input from the parent, are utilized to determine an exit rating for each of the three same child outcomes that were rated upon entry into the program. Children are not required to be evaluated when they leave Early Intervention or Preschool services, such that the child outcome exit ratings are not based on evaluation results.

New York State compares entry and exit ratings to determine child progress in the three outcomes. Results for Early Intervention services are summarized for New York State, as well as by municipality where results for Preschool Special Education are only summarized for New York State. As reflected in table 6, more than half of the children sampled state-wide demonstrated a substantial increase (received a rating of 6 or 7 upon exiting the program) in their rate of growth for all three measured child outcomes for both years of 2010 and 2014. The greatest percentage of children demonstrating substantial increase in their rate of growth was for 2014 New York State Preschool Special Education outcome B (language) at 88.6%. The lowest percentage of children demonstrating substantial increase in their rate of growth was for 2010 Madison County Early Intervention outcome B (language) at 59%. There was an overall increase in the percentage of children demonstrating a substantial increase in their

## CHILD OUTCOMES

Annually, New York State requires municipalities and school districts to report progress data on three specific early childhood outcomes from a representative sample of children receiving Early Intervention and Preschool Special Education services. The three child outcome areas are social-emotional



rate of growth from 2010 to 2014, with the exception of Outcome C (adaptive skills) for New York State Early Intervention which decreased 1.5%. Madison County Early Intervention had a higher percentage of children demonstrating substantial increase in their rate of growth for 2010 and 2014 in outcome A (social- emotional skills) and outcome C ( adaptive skills) than New York State . However, Madison County Early Intervention had a lower percentage than New York State of children demonstrating substantial increase in their rate of growth in outcome C (language skills). All three outcomes increased between 2010- 2014 for Madison County Early Intervention.

While these outcomes are overall positive, with a large percentage of children demonstrating substantial increase in their rate of growth, the results should be taken with careful consideration. In the absence of consistent pre- and post- testing, the rating scale determination is subjective. Children's developmental delays and disabilities along with family demographics are diverse. There will always be children that have severe delays or disabling conditions who may not demonstrate significant developmental growth, and children who overcome their delays and only need services for a short period of time. The measured outcomes are only for a sampling of children, such that the population sampled from year to year is variable.

**Table 6 - Child Outcomes - 2010 vs. 2014**

Outcome A		
Federal Fiscal Year	2014	2010
New York State Early Intervention	67.3%	64%
Madison County Early Intervention	80%	78%
New York State Preschool Special Education	87%	84.5%
Percent of children who entered or exited the program below age expectations in positive social-emotional skills (including social relationships) that substantially increased their rate of growth by the time they exited the program.		
Outcome B		
Federal Fiscal Year	2014	2010
New York State Early Intervention	74.5%	71%
Madison County Early Intervention	60%	59%
New York State Preschool Special Education	88.6%	86%
Percent of children who entered or exited the program below age expectations in the acquisition and use of knowledge and skills (including language/communication and literacy) that substantially increased their rate of growth by the time they exited the program.		
Outcome C		
Federal Fiscal Year	2014	2010
New York State Early Intervention	71.5%	73%
Madison County Early Intervention	83.3%	80%
New York State Preschool Special Education	87.6%	83.5%
Percent of children who entered or exited the program below age expectations in the use of appropriate adaptive behaviors to meet their needs (including self-help and motor development) who substantially increased their rate of growth by the time they exited the program.		

Sources for New York State data:

[https://www.health.ny.gov/statistics/community/infants\\_children/early\\_intervention/local\\_program\\_performance/madison.htm](https://www.health.ny.gov/statistics/community/infants_children/early_intervention/local_program_performance/madison.htm)

<https://www2.ed.gov/fund/data/report/idea/partcspap/2014/ny-acc-statedatadisplay-part-c-12-13-2.pd>

# Initiatives & Resources

There are numerous national, state, and local initiatives and resources that support children and families of all abilities to maximize the potential of every child and family. The following are a selection of initiatives and resources.

## NATIONALLY

### **Birth to Five Watch me Thrive**

A federal effort to encourage healthy child development, universal developmental and behavioral screening for children, and support for the families and providers who care for them. Providers can access tailored guides online, and a compendium of research based developmental screening tools appropriate for use across a wide range of settings.

<https://www.acf.hhs.gov/ecd/child-health-development/watch-me-thrive>

### **Early Intervention Program (EIP)**

Part of the National Early Intervention Program for Infants and Toddlers with Disabilities and their families. To be eligible for services, children must be under 3 years of age and have a confirmed disability or established developmental delay. A variety of therapeutic and support services are provided to eligible children and families. The EIP is administered by the New York State Department of Health through the Bureau of Early Intervention. The municipality/county administers the EIP locally; in Madison County the EIP is administered through The Department of Health.

[https://www.health.ny.gov/community/infants\\_children/early\\_intervention/](https://www.health.ny.gov/community/infants_children/early_intervention/)  
<https://www.madisoncounty.ny.gov/448/Early-Intervention>

### **Head Start & Early Head Start**

US Department of Health and Human Service programs providing early childhood education, health, and nutrition services for low income families and their children. Head Start and Early

Head Start promote school readiness and family well-being through home visits and center-based services. Early Head Start serves expectant and new parents with children under the age three; Head Start serves children from 3-5 years of age and their families. In Madison County, Early Head Start services are provided through Community Action Partnership Agency (CAP) and Head Start services are provided through Mohawk Valley Community Action Agency (MVCAA).

<https://capmadco.org/>

<https://www.mvcaa.com/>

### **Dolly Parton's Imagination Library**

A book gifting program that mails free books to children from birth to age five in participating communities in the United States, United Kingdom, Canada, and Australia. Madison County is a participant in this book gifting program through the Literacy Coalition of Madison County. There are no income restrictions and families can sign up at any public library within a Madison County School District.

<http://literacycoalitionmadisoncountyny.org/free-books-for-children/>

### **Learn the Signs. Act Early**

A program through The Centers for Disease Control that encourages parents and providers to learn the signs of healthy development, monitor child development, and take action when there is a concern. The program offers free research based checklists, tools for developmental monitoring and training modules. Materials are available to parents, early childhood providers, healthcare providers, and others who work with young children and can be found online.

<https://www.cdc.gov/ncbddd/actearly/index.html>

## **Preschool Special Education**

Also known as The Education and Transportation of Disabled Children is a federal and state mandated program for three and four year old children who have a confirmed disability or established developmental delay, whereby educational and therapeutic services are provided to eligible children. In New York State the Preschool Special Education Program is overseen by the State Education Department (SED), Office of Special Education. School Districts are responsible for the approval and oversight of preschool special education services while municipalities/counties are responsible for the administration of the program. In Madison County, the Preschool Special Education program is located at The Department of Health.

<http://www.p12.nysed.gov/specialed/preschool/home.html> <https://www.madisoncounty.ny.gov/1501/Pre-Kindergarten-Program>

## **NEW YORK STATE**

### **Child Care Resource and Referral Agencies (CCRRs)**

Provide services to parents and day care providers in every county of New York State. CCRR's assist parents in identifying and locating the most appropriate child care or early childhood education program for their children. CCRR's also provide technical assistance and training for child care providers. The CCRR for Madison County is coordinated through Cornell Cooperative Extension of Oneida County.

<http://cceoneida.com/child-care-council>

### **Early Childhood Direction Centers (ECDC)**

Provide information, assistance, and workshops related to programs and services for children birth to age 5 who have special needs or are suspected of having a developmental delay. Services are available free of charge to parents, providers, and community agencies. The Early Childhood Direction Center covering Madison County is coordinated through the Resource Center for Independent Living (RCIL) Utica, NY

office.

<https://www.rcil.com/ecdc>

### **Healthy Families**

New York is a home visiting program providing information and support to expectant and new parents. Services include helping families' access community resources and services, educating families on parenting and child development, connecting families with medical providers, and assessing children for developmental delays. In Madison County, the Healthy Families program is provided through Community Action Partnership Agency (CAP).

<https://capmadco.org/>

### **Parent to Parent of New York State**

Provides emotional support and information for parents of children and young adults with disabilities or special healthcare needs. Through a telephone network, support parents share their experiences of having a child with a disability or special health care need with other parents. Regional Coordinators connect parents from a local or statewide roster. Regional Coordinators also provide parents and professionals with information on specific disabilities, referral resources and available support groups. Parent to Parent services for Madison County are coordinated through The North Central Parent to Parent office .

<http://parenttoparentnys.org/offices/North-Central/>

### **Universal Prekindergarten (UPK)**

Overseen by the New York State Education Department, provides center based services to four year olds with an emphasis on preparing children to be successful when entering Kindergarten. The curriculum is aligned with the New York State Common Core Learning Standards and connected to the kindergarten and early elementary curricula. UPK programs are optional for states and school districts. In New York State 443 out of 675 school districts provide UPK. In Madison County 16 out of 18 school districts provide UPK.

<http://www.p12.nysed.gov/upk/>



## MADISON COUNTY

### Early Childhood Committee

Focuses on the social emotional and behavior development of young children in Madison County. Representatives from Health, Education, and Human Service agencies meet regularly to identify available mental health services and supports for children and families. The Early Childhood Committee has coordinated free parent learning opportunities at various Madison County locations. Contact the Madison County Department of Mental Health for more information.

<https://www.madisoncounty.ny.gov/390/Mental-Health>

### Early Intervention Coordinating Council

A group of professionals, parents, and community members that discuss the needs and services for young children with disabilities and developmental delays and their families in Madison County. The forum shares available services and how to access those services. Gaps in service delivery are discussed along with strategies to address identified gaps. Contact the Madison County Health Department for more information

[health@madisoncounty.ny.gov](mailto:health@madisoncounty.ny.gov)

### Healthy Moms and Babes Provider Network

A group of community organizations and health providers serving pregnant and new moms and their infants and children. Focus of the network has been to promote early and adequate prenatal care, breastfeeding support, parent education, and networking among health and human service providers serving this population. Activities have included community baby showers and breast feeding support through community breast feeding cafes and baby weigh stations. Contact the Madison County Health Department for more information.

[health@madisoncounty.ny.gov](mailto:health@madisoncounty.ny.gov)

### Lead Poisoning Prevention Program

Through the Madison County Health Department provides education and information on how to reduce lead levels. Evaluation and education on lead hazards in homes and guidance to fix or mitigate a lead problem is provided. Lead screening is available for uninsured or underinsured children up to six years of age along with nursing and environmental home visits for children with elevated blood lead levels.

<https://www.madisoncounty.ny.gov/460/Lead-Poisoning-Prevention>

### Maternal Child Health Program

Through the Madison County Health Department provides nursing home visits and breastfeeding support to pregnant and parenting women and families. Education and information is provided regarding maternal and child health including Sudden Infant Death Syndrome and Shaken Baby Syndrome. International Board Certified Lactation Consultants are available to provide breastfeeding resources and support.

<https://www.madisoncounty.ny.gov/1497/Maternal-Child-Health-Program-Home-Visit>

### Mental Health Department

Madison County services children and adults providing individual and family therapy in addition to care coordination and referral assistance.

<https://www.madisoncounty.ny.gov/390/Mental-Health>

### Social Services Department

Madison County provides an array of services for families including parenting skills classes, child care assistance, emergency assistance, assistance in obtaining WIC and health insurance.

<https://www.madisoncounty.ny.gov/233/Social-Services>

# Recommendations

## Recommendations

The following recommendations result from our review of the current data, national and state trends, and services. These recommendations highlight gaps and identify potential strategies.

### Overarching Goal:

Decrease the number of children in need of services beyond Early Intervention and Preschool by 3%.

2017 Baseline
Early Intervention 79%
Preschool 77%

2020 Target
Early Intervention 76%
Preschool 74%

### Focus Area: Developmental Screening

100% of children will be screened for developmental delays by their physician during well child visits.

- ◆ As part of the 2019 Madison County Health Departments comprehensive Community Health Assessment, survey Madison County physicians to identify any gaps in well child visit developmental screenings.
- ◆ Re-survey physicians every three years to assess and assist with identified needs for continued developmental screenings.
- ◆ Conduct a community education campaign in 2019 emphasizing early screening, identification, and referral of children with diagnosis and/or suspected developmental delays.

- ◆ In 2020, conduct public health detailing in provider's offices regarding early screening, identification and referral of children with diagnosis and/or suspected developmental delays.

### Focus Area: Prevention

Reduce the rate of smoking in women of child bearing age by 3%

2016 Baseline 16.4%
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2020 Target 13.4%
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- ◆ In 2018 survey providers regarding the questions they ask their women of child-bearing aged patients about smoking status and how/if they are referring to cessation programs.  
-OR-
- ◆ In 2018, survey Madison County providers, not surveyed by St. Joseph Hospital's CNY Regional Center for Tobacco Health Systems, to determine the percentage of providers who are screening their patients, specifically women of child bearing age, regarding smoking status.
- ◆ Conduct detailing campaign in 2019 with Madison County providers regarding risk factors of smoking in women of child bearing age and screening women of child bearing age for smoking status.
- ◆ In 2019 conduct a health education and awareness campaign on the harmful effects of smoking in women of child bearing age.
- ◆ In 2019 conduct evidenced based smoking cessation campaign for women of child bearing age.

# Recommendations

- ◆ In 2018, establish baseline data on the number of women of child bearing age enrolled in smoking cessation programs in Madison County.

- ◆ In 2019 re-survey providers to determine if there is an increase in the percentage of providers who are screening their patients, specifically women of child bearing age, regarding smoking status.

- ◆ In 2020, gather data on number of women of child bearing age enrolled in smoking cessation programs in Madison County to determine if enrollment increased from 2018.

## Focus Area: Outreach Education & Training

Provide training and resources related to children with special needs, family centered services, and other early childhood related topics.

- ◆ In 2019 offer training on Adverse Childhood Experiences (ACES) to Madison County Early Intervention and Preschool providers, and MCDOH Maternal and Child Health Staff.
- ◆ In 2019 offer a training for parents on Early Literacy.
- ◆ In 2020 offer evidence based practice training to Madison County Early Intervention and Preschool providers.
- ◆ By 2020 expand Madison County Health Department Children with Special needs webpage to include internet links and resources for providers and families related to child development, developmental screening, evidenced based and best practices, trainings and workshops.

- ◆ In 2019, provide training on Touchpoints program to Madison County Early Intervention and Preschool providers, and MCDOH Maternal and Child Health Staff.

## Focus Area: Program Evaluation

Continuously assess and evaluate effectiveness of services.

- ◆ In 2018 develop an internal system to track child progress by measuring the rate of child development and rate of child progress based on entrance and exit developmental evaluations.
- ◆ In 2018 revise Early Intervention parent surveys with satisfaction ratings.
- ◆ Measure parent satisfaction survey ratings quarterly with goal of 80% customer satisfaction.

## Focus Area: Surveillance

- ◆ Gather and track social determinants of children with special needs and their families in Madison County.
- ◆ In 2018 develop an internal system to gather data by locality for disability, education, ethnicity, health insurance.



# References

- <sup>1</sup> Select panel for the Promotion of Child Health, 1981.
- <sup>2</sup> Caring For Kids New to Canada. A Guide for Health Professionals working with immigrant and refugee children and youth: Prenatal Risk Factors for Developmental Delay in Newcomer Children, July, 2014; [www.kidsnewtocanada.ca/mental-health/prenatal-risk](http://www.kidsnewtocanada.ca/mental-health/prenatal-risk)
- <sup>3</sup> An Introduction to Early Childhood Special Education, Possible Causes for Developmental Delays, by L.L. Dunlap; [www.education.com/reference/article/possible-causes-developmental-delays](http://www.education.com/reference/article/possible-causes-developmental-delays)
- <sup>4</sup> U.S. Department of Health and Human Services, Prenatal Care: Frequently Asked Questions. 2009
- <sup>5</sup> Centers for Disease Control, Healthy Infants & Toddlers-Healthy People in Every Stage of Life, 2007
- <sup>6</sup> Madison County Community Health Improvement Plan, 2013
- <sup>7</sup> US Department of Health and Human Services/Centers for Disease Control, Morbidity and Mortality Weekly Report/February 24, 2017/Vol.66/No.7
- <sup>8</sup> Physicians Committee for Responsible Medicine; [www.Pcrm.org/research/resch/reschethics/birth-defect-Statistics](http://www.Pcrm.org/research/resch/reschethics/birth-defect-Statistics)
- <sup>9</sup> Center for Disease Control, 2006
- <sup>10</sup> Centers for Disease Control, Healthy Infants & Toddlers-Healthy People in Every Stage of Life, 2007
- <sup>11</sup> Physicians Committee for Responsible Medicine; [www.Pcrm.org/research/resch/reschethics/birth-defect-statistics](http://www.Pcrm.org/research/resch/reschethics/birth-defect-statistics)
- <sup>12</sup> Division for Early Childhood, Promoting the Health, Safety and Well-Being of Young Children with Disabilities and Developmental Delays, September 2012
- <sup>13</sup> NYSDOH, New York State Community Health Indicator Reports - Maternal and Infant Health Indicators
- <sup>14</sup> Physicians Committee for Responsible Medicine; [www.Pcrm.org/research/resch/reschethics/birth-defect-statistics](http://www.Pcrm.org/research/resch/reschethics/birth-defect-statistics)
- <sup>15</sup> Winickoff, J., Van Cleave, J., Oreskovic, N. (2010) Tobacco Smoke Exposure and Chronic Conditions of Childhood. Pediatrics, 126 (1), 251-252.
- <sup>16</sup> Columbia Center for Children's Environmental Health, Mailman School of Public Health, Columbia University; <http://ccceh.org/our-research/research-studies/secondhand-smoke>
- <sup>17</sup> US Department of Health & Human Services/Office of Adolescent Health , Teen Pregnancy and Childbearing; <https://www.hhs.gov/ash/oah/adolescent-development/reproductive-health-and-teen-pregnancy/teen-pregnancy-and-childbearing/index.html>
- <sup>18</sup> US Department of Health & Human Services/Office of Adolescent Health, Teen Pregnancy and Childbearing; <https://www.hhs.gov/ash/oah/adolescent-development/reproductive-health-and-teen-pregnancy/teen-pregnancy-and-childbearing/index.html>
- <sup>19</sup> Toxic Stress: The Facts Center on the Developing Child at Harvard University; <https://developingchild.harvard.edu/science/key-concepts/toxic-stress/>
- <sup>20</sup> The Science of Neglect: Center on the Developing Child at Harvard University; <https://developingchild.harvard.edu/resources/inbrief-the-science-of-neglect-video/>
- <sup>21</sup> Helping Young Children Who Have Experienced Trauma: Policies and Strategies for Early Care and Education: National Center for Children in Poverty; [http://nccp.org/publications/pub\\_n80.html](http://nccp.org/publications/pub_n80.html)
- <sup>22</sup> [https://www.cdc.gov/violenceprevention/acestudy/about\\_ace.html](https://www.cdc.gov/violenceprevention/acestudy/about_ace.html)
- <sup>23</sup> Madison County Community Health Assessment, 2013
- <sup>24</sup> <https://hfwcny.org/view-trauma-informed-care-helps-children-families-build-resilience>
- <sup>25</sup> Madison County Community Health Assessment, 2013
- <sup>26</sup> Clive R. Belfield and Inas Rashad Kelly (October 2010) National Bureau of Economic Research; The Benefits of Breast feeding Across the Early Years of Childhood, <http://www.nber.org/papers/w16496.pdf>
- <sup>27</sup> Center for Disease Control; [https://www.cdc.gov/nceh/lead/acclpp/final\\_document\\_030712.pdf](https://www.cdc.gov/nceh/lead/acclpp/final_document_030712.pdf)
- <sup>28</sup> Socioeconomic Status and Child Development, Annual Review of Psychology Vol. 53:371-399, February 2002
- <sup>29</sup> Centers for Disease Control, Healthy Infants & Toddlers-Healthy People in Every Stage of Life, 2007
- <sup>30</sup> Hart, Betty and Todd R. Risley. "The Early Catastrophe." Education Review 17.1, 2003; [https://www.aft.org/ae/spring2003/hart\\_risley](https://www.aft.org/ae/spring2003/hart_risley)
- <sup>31</sup> Hart, Betty and Todd R. Risley. "The Early Catastrophe." Education Review 17.1, 2003; [https://www.aft.org/ae/spring2003/hart\\_risley](https://www.aft.org/ae/spring2003/hart_risley)
- <sup>32</sup> Madison County Community Health Assessment, Healthy Infants and Toddlers, 2013
- <sup>33</sup> Madison County Community Health Assessment, Healthy Infants and Toddlers, 2013
- <sup>34</sup> Thomas Fordham Institute, Shifting Trends in Special Education, May 2011
- <sup>35</sup> Part C and Part B 619 Data Display: [www.ideadata.org](http://www.ideadata.org)

# References

- <sup>36</sup> Part C and Part B 619 Data Display: [www.ideadata.org](http://www.ideadata.org)
- <sup>37</sup> Center on the Developing Child at Harvard University (2008). In Brief: The Science of Early Childhood Development; <https://developingchild.harvard.edu/resources/inbrief-the-impact-of-early-adversity-on-childrens-development/>
- <sup>38</sup> <http://nationalautismassociation.org/>
- <sup>39</sup> <http://nationalautismassociation.org/>
- <sup>40</sup> <http://pediatrics.aappublications.org/>
- <sup>41</sup> <https://www.cdc.gov/ncbddd/actearly/index.html>
- <sup>42</sup> The Interdisciplinary Council on Development and Learning; <http://www.icdl.com/>
- <sup>43</sup> U.S. Department of Health and Human Services, Administration for Children and Families. Home Visiting Evidence of Effectiveness; <https://homvee.acf.hhs.gov/>
- <sup>44</sup> Expanding Home Visiting to Strengthen all of New York's Families, Schuyler Center for Analysis and Advocacy; [http://www.scaany.org/wp-content/uploads/2016/08/Home\\_Is\\_Where\\_the\\_Start\\_Is-Expanding\\_HV-06-2016.pdf](http://www.scaany.org/wp-content/uploads/2016/08/Home_Is_Where_the_Start_Is-Expanding_HV-06-2016.pdf)
- <sup>45</sup> Expanding Home Visiting to Strengthen all of New York's Families, Schuyler Center for Analysis and Advocacy; [http://www.scaany.org/wp-content/uploads/2016/08/Home\\_Is\\_Where\\_the\\_Start\\_Is-Expanding\\_HV-06-2016.pdf](http://www.scaany.org/wp-content/uploads/2016/08/Home_Is_Where_the_Start_Is-Expanding_HV-06-2016.pdf)
- <sup>46</sup> <https://www.nursefamilypartnership.org/locations/New-York/>
- <sup>47</sup> United Nations International Children's Emergency Fund (unicef)
- <sup>48</sup> US Department of Health and Human Services U.S. Department of Education: Policy Statement on Inclusion of Children with Disabilities in Early Childhood Programs, September 14, 2015; <https://www2.ed.gov/policy/speced/guid/earlylearning/joint-statement-full-text.pdf>
- <sup>49</sup> New York State Department of Health Early Intervention Program, Meeting the Social-Emotional Development Needs of Infants and Toddlers: Guidance for Early Intervention Providers and Other Early Childhood Professionals; <https://www.health.ny.gov/publications/4226.pdf>
- <sup>50</sup> <https://www.brazeltontouchpoints.org/about/evidence-based-research>
- <sup>51</sup> Center on the Developing Child at Harvard University. In Brief: Early Childhood Program Effectiveness (2007); [www.developingchild.harvard.edu](http://www.developingchild.harvard.edu)
- <sup>52</sup> Perry Preschool Study; <https://highscope.org/research-and-evaluation>
- <sup>53</sup> Syracuse Family Development Research Program; <http://www.promisingpractices.net/program.asp?programid=133>
- <sup>54</sup> The Carolina Abecedarian Project; <http://abc.fpg.unc.edu/>
- <sup>55</sup> Costs and Benefits of Early Childhood Intervention U.S. Department of Justice Office of Juvenile Justice and Delinquency Prevention; <https://www.ncjrs.gov/pdffiles1/fs9994.pdf>
- <sup>56</sup> A look at New York State's Early Childhood Fiscal Model – Return on Investment Brief March 2015; [http://nysecac.org/files/8714/2842/6914/Returnon\\_Investment\\_Brief.pdf](http://nysecac.org/files/8714/2842/6914/Returnon_Investment_Brief.pdf)
- <sup>57</sup> A look at New York State's Early Childhood Fiscal Model – Return on Investment Brief March 2015; [http://nysecac.org/files/8714/2842/6914/Returnon\\_Investment\\_Brief.pdf](http://nysecac.org/files/8714/2842/6914/Returnon_Investment_Brief.pdf)
- <sup>58</sup> Save the Children









*“Our greatest natural resource is the  
minds of our children.”*



*~ Walter Elias Disney*



## Madison County Department of Health

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