



A PROFILE OF OHIO'S
PUBLICALLY FUNDED
SERVICES FOR
CHILDREN WITH
AUTISM SPECTRUM
DISORDERS

2003

Prepared By Capital Partners for Columbus Children's Hospital

A Message from Columbus Children's Hospital

December 2003

Children's Hospital is committed to serving Ohio's children with autism and their families. Through our Autism Center we are dedicated to early diagnoses, high-quality, evidence-based interventions, community support, research, advocacy, and professional education.

In our efforts to advocate on behalf of children with autism and their families, we found that there is no one document that fully describes the current state of Ohio's services and funding for this population. Thus, we asked Capital Partners to create a report documenting the various publicly funded services for children with autism and related disorders (ASD) in Ohio. Out of that request was borne this report, *A Profile of Ohio's Publicly Funded Services for Children with Autism Spectrum Disorders (ASD)*.

The report demonstrates that the system for services for children with autism is highly complex, with many state and local agencies playing some part in the provision of funding and services. The majority of spending takes place through state and local support for special education. Systems are strikingly diverse across the state and often depend on the county in which a child resides.

In addition, options for families and children with autism are limited. There is a tremendous need for increased access to evidence-based practices as well as for more research to improve our standards of care.

The good news is that there have been some significant advances since Capital Partners' report was completed earlier this year. In June, as the Ohio General Assembly was completing work on Ohio's 2004-2005 biennial budget, State Representative Jon Peterson (R-Delaware) won support for amendments that (1) created a pilot scholarship program for autistic students, providing parents with \$15,000 a year to seek services outside their own school districts; and (2) gave permissive authority to the Department of Job and Family Services to seek Medicaid waivers for intensive services for young children with autism.

State legislators also directed the Governor to create the Ohio Autism Task Force to study the growing incidence of the disease and to find ways to improve the delivery of services to individuals suffering from autism. On November 21, 2003, Governor Bob Taft named 21 members to serve on this task force.

This foundational document should provide support to those trying to navigate the systems currently in place and to those working to effect change to those systems. It is our hope that it will serve as a springboard for better futures for Ohio's children with autism and their families.

For more information about the Children's Hospital Autism Center or about current advocacy efforts within Ohio, please call 614-839-2860 and ask to speak to an autism resource coordinator. Or write to the Children's Hospital Autism Center at 433 N. Cleveland Avenue, Westerville, Ohio 43082.

**A Profile of Ohio's Publicly Funded Services for Children
with Autism Spectrum Disorders**

March 2003

**Prepared by
Capital Partners**

A Profile of Ohio's Publicly Funded Services for Children with Autism Spectrum Disorders

Executive Summary

The centerpiece of this report is a program inventory of publicly funded programs available to children with Autism Spectrum Disorders (ASD) in Ohio. The inventory is divided into six parts as outlined below. The report begins with an introduction, which is followed by a brief statistical profile of children with ASD in Ohio. The third section outlines primarily state funded programs for which children with ASD may be eligible. The Ohio Departments of Education, Health, Job and Family Services and Mental Retardation and Developmental Disabilities provide these programs. The fourth section focuses on county-based services provided by County Boards of Mental Retardation and Developmental Disabilities with financial assistance from the State of Ohio and the federal government.

It is important to note at the outset that ASD-related education programs listed as state programs are implemented with significant programmatic and financial support from local school districts. In fact, in FY 2002, local school districts outpaced the state in spending on children with ASD. During that year, pupils with ASD received \$63 million in funding through the Ohio Department of Education's core special education program. This includes \$26.3 million in state aid plus an additional \$36.5 million in local funding. This investment represents the most significant category of public spending in Ohio for ASD-related services.

The fifth section of the report is a selected look at promising ASD-related programs offered in other states. The report ends with proposed policy recommendations.

The centerpiece of the report is the state and county program inventory. The inventory includes special education and related programs; Medicaid waivers designed to facilitate the provision of essential health services to people with ASD and other disabilities living in non-institutional settings; and nine other health and social service related programs, two of which are county-based. These programs are listed below.

State Based ASD-Related Programs

Ohio Department of Education (ODE)

- **Special Education (State, Local and Federal Funding)**

Other ASD Related Education Programs

- Special Education Program Enhancements (including Preschool Special Education)
- Federal Special Education (IDEA) Funding
- Special Education Regional Resource Centers (SERRCs)
- Ohio Regional Center for Low Incidence and Severe Handicapped (ORCLISH)
- Educational Service Centers (ESCs)

Ohio Department of Health (ODH)

- Child and Family Health Services
- Help Me Grow

Ohio Medicaid Waivers

Medicaid is the major state/federal program providing health care services to low-income individuals; however, there are also Medicaid waivers that provide health services tailored to the unique needs of eligible individuals, including, in certain cases, children with ASD. These Medicaid waivers are listed below.

Ohio Department of Mental Retardation and Developmental Disabilities (ODMRDD) Waivers:

- Residential Facilities
- MRDD Waiver

Ohio Department of Job and Family Services (ODJFS) Medicaid Waivers:

- Ohio Homecare Waiver
- Ohio Transitions Waiver

Ohio Department of Mental Retardation and Developmental Disabilities (MRDD)

- Family Resources;
- Community Alternative Funding Systems (CAFS);
- Early Intervention (in connection with ODH)
- County Board Schools
- Supported Living

County-Based, ASD Related Programs

While County Boards of MRDD implement nine state assisted programs on the local level, two programs are targeted specifically at serving children with disabilities, including those with ASD. Both programs are education related and are funded using state and county funds:

- Early Childhood Programs
- County MRDD Board Schools

Policy Recommendations

The document ends with a brief discussion of the report's initial policy and program ramifications and recommendations related to improving services to children with ASD and their families. The recommendations are as follows:

1. Adequately Fund Special Education Needs of Children With ASD
2. Emphasize and Encourage Evidence-Based Early Identification and Intervention Programs
3. Create Statewide ASD Resource Directory
4. Improve Data Management and Analysis
5. Review and Analyze Funding Alternatives
6. Improve Inter-Agency Coordination and Information Sharing
7. Improve Collaboration and Coordination Within Regional Service Delivery
8. Strengthen ASD Related Teacher Professional Development
9. Support Parent Education and Advocacy
10. Support ASD Related Research and Analysis

A Profile of Ohio's Publicly Funded Services for Children with Autism Spectrum Disorders

I. Introduction

In Ohio, those in search of governmental services for children with Autism Spectrum Disorder (ASD) and their families often face complex and confusing challenges in both understanding and accessing appropriate social, educational, and health-related services. One of the first problems encountered is the lack of a statewide inventory of programs and services for children with ASD. Another problem is that most of these programs were designed for children with a wide range of disabilities and do not address the unique needs of children with ASD exclusively. To determine eligibility for services, children with autism must move through an identification and assessment process, though being declared eligible does not always guarantee access to services.

It is apparent that a clearer understanding of publicly funded, autism-related services would help Ohio families, practitioners, and policy makers determine how best to obtain and enhance services for children with ASD. The need for easier access to improved information on resources available is real and growing because of the substantial increase in the identification of children with a primary diagnosis of ASD. Nationally, this number has increased substantially in the past two decades. Ohio has also experienced a large and growing increase. According to the December 2001 Ohio Department of Education Child Count, Ohio schools are now serving nearly 3,000 children with ASD. In 1992, this same survey found only 22 children with ASD. To what degree this trend is rooted in growing incidence rates and to what degree to greater skill in, and attention to, identification is currently under investigation nationally. In any case, being able to understand the array of services provided to children with ASD is of growing practical importance.

This report contributes to such an understanding by providing a comprehensive program inventory of autism-related services funded by state and county government and local school districts in Ohio. By looking across multiple service delivery systems, it allows consumers, professionals, and policy makers to look beyond today's information silos to gain a broader and deeper understanding of services to children with ASD in Ohio. The report begins with a brief, data profile showing current realities and historic trends. The next section of the report, which is its centerpiece, provides a program inventory. It is divided into two parts. The first part outlines primarily state funded programs. The Ohio Departments of Education, Health, Job and Family Services and Mental Retardation and Developmental Disabilities provide these programs. The second part of this section is devoted to a listing of programs provided primarily by County Boards of Mental Retardation and Developmental Disabilities (MRDD).

To a limited degree, the program inventory will be rounded out with a financial profile. Unfortunately, except for special education-related services, which (at \$52 million state/local in FY 2002) represent the largest single category of public spending for children with autism, and Medicaid, public expenditure information is not tracked by disability. Even special education and Medicaid funding require further analysis in order to estimate accurately spending for children with a primary diagnosis of ASD.

The next section of the report places Ohio in a broader context; it is instructive in the sense that it focuses on a selection of relevant autism-related developments in other states that show potential for improving services to children with ASD in Ohio.

The document ends with a discussion of the report's policy and program ramifications related to improving and enhancing services to children with ASD and their families. These are Ohio-focused issues that relate directly to conditions and circumstances in the state of Ohio.

II. A Statistical Profile of Children with ASD in Ohio

According to the National Institute of Mental Health, ASD affects an estimated 1 to 2 persons per 1,000. It is about 4 times more common in boys than girls, though girls tend to have more severe symptoms and greater cognitive impairment. ASD is a developmental disability that typically appears during the first three years of life. ASD interferes with the normal development of the brain in the areas of reasoning, social interaction and communication skills, and is characterized by restricted repetitive patterns of behavior as well as delays in imaginative play. Individuals with ASD may also resist any changes in routines, and may display aggressive and/or self-injurious behavior.

According to the Autism Society of America, it is estimated that nearly 400,000 people in the United States have some form of ASD. Its prevalence rate now places it as the third most common developmental disability -- more common than Down's syndrome. Yet the majority of the public, including many professionals in the medical, educational and vocational fields, are still largely unaware of how ASD affects people and how to effectively work with individuals with ASD.

Ohio's ASD incidence rates are generally consistent with these national estimates. The December 2001 Child Count conducted by the Ohio Department of Education (ODE) reveals that 1 in 597 students, or 2,858 out of approximately 1.8 million students, is identified as having a primary diagnosis of ASD and that fewer than 10 percent of these students is served full time in regular classrooms.

What is particularly concerning is that these numbers have grown substantially in the past decade. As previously stated, in 1992, according to ODE, Ohio identified a total of only 22 students with autism and related disorders. By 1997, this number had grown to 501. Only three years later, in 2000, the number with a primary diagnosis of ASD had grown to 2,159. While it appears likely that at least a portion of this growth spiral can be attributed to better methods of identification and a broader definition of autism, it may also be the case that incidence rates are growing in substantial ways.

Indeed, state and national observers and ASD advocates believe that incidence rates are growing and that the reason lies beyond better identification efforts. This issue has been under intense investigation, and during this investigation, growth in ASD incidence rates has been attributed to many sources. No matter to what investigators ultimately attribute incidence rate increases, it is troublesome that, in Ohio, public agencies at the state level, other than Medicaid and education, do not have a clearer picture of the number of children with ASD served by their respective organizations. Nor do they have clarity about the number of public dollars provided for services to these children. This omission, and the lack of a case registry, focus on service provision to a broad range of children, families, and adults, and, with limited resources and information technology capacity, they have chosen to focus on services rather than on keeping detailed records. This focus does not mean, however, that more could not and should not be done to gain greater understanding of the consumers of these services.

III. State Funding ASD-Related Programs

Outlined below is a program inventory of state funded, ASD-related programs. The programs are grouped by state agency starting with the Ohio Department of Education.

Ohio Department of Education: Special Education Funding for the ASD Population

Bottom Line: *Nearly 3,000 school-aged students with ASD receive ODE funded special education services through the following funding components:*

- **Basic Aid** - *the basic amount of funding guaranteed to every student through a combination of state and local funds.*
- **Weighted Aid** - *the additional amount of formula aid special education pupils receive above base cost funding for the provision of services required by state and federal rules.*
- **Catastrophic Aid** - *aid provides the state's most profoundly disabled pupils extra funding beyond weighted and base cost formula aid.*

In FY 2002 (school year 2001-2002), the Ohio Department of Education provided education and related services to 2,858 ASD pupils ages 6-21. ASD pupils represent 1.24% of the total special education population ages 6-21, but generate 3.43% of state special education formula funding, or \$26.3 million. ASD pupils generate 7.11% of state special education weighted funding. Additionally, ASD pupils receive an unknown amount of additional ODE state and federal funding through a variety of general special education programs, including: parent mentoring, classroom aides, and ASD demonstration projects. Parents of ASD pupils may access this funding through the individualized education plan (IEP) process. Parents may also inquire with their child's local schools as to the other state and federal funding programs referenced in this report.

ASD Funding (1975-2002)

Bottom Line: *The ASD pupil population has exploded in Ohio and nationally, from 22 students in 1992 to 2,858 students in 2001. This represents nearly a 13,000% increase and an average annual increase of 87%. In 2001, ASD pupils represent one out of every 597 pupils in the state.*

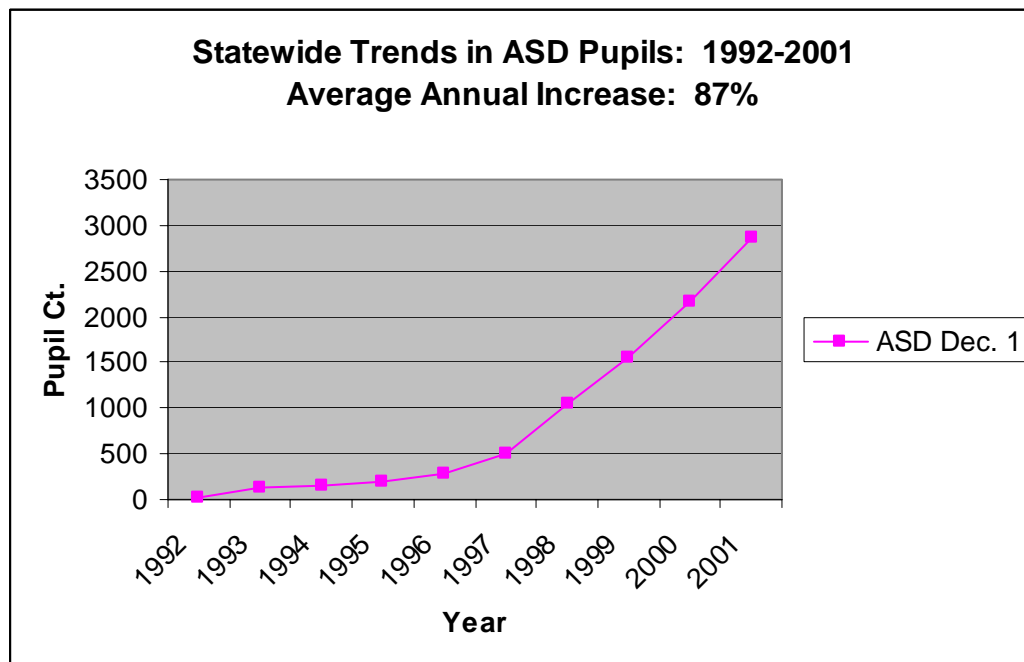
ASD pupils received an additional \$11.6 million in state education aid under a new, cost-based system of funding system implemented during the 2001-2002 school year—an increase of 78.4%. ASD pupils also generated \$11.4 million in new local funding over this time period—an increase of 45.2%. The new funding formula also allows for more flexible use of catastrophic funding (discussed below) for the most profoundly disabled pupils. This funding provides ASD pupils an academic curriculum and needed related services to grow and develop. Most of these services are provided in-school, as opposed to a medical facility or alternative provider. Parents of ASD pupils may access this funding through the individualized education plan (IEP) process, which is mandated by state and federal law.

The Ohio Department of Education (ODE) appropriates the majority of ASD funding in the state, despite the fact it is limited to citizens age three through twenty-one. Although federal and state special education law only recently recognized ASD, the basis for ODE’s large role in funding ASD children evolved from the federal Education of All Handicapped Children Act, passed in 1975, which required all states to provide a free and appropriate public education (FAPE) to disabled children. This act also provided some federal funding to pay for the additional services beyond the state’s provision of FAPE.

Seven years later, the state of Ohio established Rules for the Education of Handicapped Children, otherwise known as the “Blue Book,” which established the state’s FAPE regulations. Neither the 1975 Act, nor the state’s rules recognized ASD. As a result, many families and districts failed to identify ASD children and it is difficult to know if these students met other disability criteria that might have qualified them for funding and services; however, it is possible that many of these children fell through the cracks of the public education system.

Today, twenty-one years later, the “Blue Book” still provides the basis for the majority of ODE funding of ASD students despite the passage of the federal Individuals with Disabilities Act (IDEA) and a newly minted set of state rules (2002). IDEA expanded the scope of federal special education law to require that all disabled children be placed in the “least restrictive environment,” and recognized ASD for the first time for purposes of funding and the federal (December 1) pupil count. IDEA paved the way for state recognition and funding for ASD pupils aged three to twenty-one, even if the state rules did not. Not surprisingly, the number of pupils identified with ASD increased rapidly in the years following IDEA.

Table 1: Pupils with ASD (1998-2002)



In response to the *DeRolph vs. State of Ohio* school funding case, which found Ohio's system of public education unconstitutional, the state started to fund services for ASD children through its then new "weighted" funding formula in fiscal year 1999. Weighted funding provides individual disabled pupils the same amount of funding as non-special education pupils, plus additional support based on the severity of the child's disability. The first weighted aid formula separated disabled pupils into three funding categories. The least severe category provided minimal funding above that received by non-special education pupils. The second and third categories provided additional funding of the same amount. Students in the latter, most severe category were also eligible for additional aid through an application process.

The weighted funding formula classified ASD in the most severe disability category. This funding was given in addition to base cost funding of \$3,851 in state and local dollars for ASD pupils in FY 1999. All pupils, disabled or non-disabled, receive base cost funding. As a supplement to base cost funding, ASD students received an amount of additional state and local aid equal to the base cost amount multiplied by 3.02, or \$11,630, for a total of \$15,481. Under the weighted funding formula, ASD pupils also qualified for "catastrophic aid," a supplemental aid program for the most profoundly disabled pupils. Districts could apply for catastrophic aid for those pupils who exceeded \$25,000 in education and related services costs. Although the state allocated \$14 million for this program in fiscal year 1999, districts used less than \$1 million. This lack of use was largely attributed to the fact that few districts knew about the program.

Many special education stakeholders heralded the weighted funding system for the new money it promised—state officials estimated it would generate up to \$200 million in additional state funding for special education. Two years later, however, there was little new funding despite the state's best intentions. In fact, incorporating special education funding into non-special education funding caused confusion and led many school treasurers and district administrators to think they had actually lost funding.

An Ohio Coalition for the Education of Children with Disabilities (OCECD) analysis of funding from fiscal year 1998 (the last year of unit funding) to fiscal year 2001 indicated that special education funding increased modestly over that time period, but substantially lagged funding increases for non-disabled pupils. In short, the new formula provided nowhere near \$200 million in additional funding. An ODE analysis supported this finding, but also indicated that per pupil funding for special education actually dropped. Furthermore, the new system compounded local "confusion" over special education dollars because districts received one check from the state for both disabled and non-special education pupils, as opposed to separate unit funding.

Concerned that the current system of weights provided inadequate funding and accountability, OCECD conducted a cost-based analysis of state special education rules (the Blue Book) to determine the actual costs of providing services to special education pupils in eleven categories, including ASD. The cost-based analysis, *Special Education Finance in Ohio: Analysis and Recommendations* (SEFO) confirmed the belief that the two weight, three category system fell substantially short of meeting the costs of the state's rules for providing a

free and appropriate public education. The study also found that the two weight system did not adequately distinguish between the costs of serving students with disabilities. For example, severely behavior handicapped pupils received the same amount of funding as ASD children despite the latter's need for a wider and more expensive array of services. SEFO also confirmed the weighted system lacked accountability at both the state and local levels.

Using the study, the state legislature in 2001 established a new cost-based, weighted system of funding for the current state budget (FY 2002-03). The new system increases the number of weights from two to six and the number of categories from three to six, better distinguishing the costs of serving various disabled pupils. The new system provides \$200 million in new state and local funding (\$100 million state) for special education and improves accountability over these dollars.

The cost-based six weight funding system classifies ASD pupils in the most severe disability and corresponding funding category (category six). The new funding system works in exactly the same way as the old funding system, but provides substantially more funding. Category six pupils, including those with ASD, received \$4,814 in state and local base cost funding in FY 2002. As a supplement to base cost funding, ASD pupils generate an additional amount of state and local aid equal to the base cost amount multiplied by 4.7342, or \$22,790, for a total of \$27,604. ASD pupils receive more than \$12,120 in additional state and local funding under the new system than they did in 1999. Under the new system, ASD pupils receive a total of \$11.6 million in additional state funding (and another \$11.4 million in local funding). The new system also maintains a more flexible system of catastrophic funding.

This section first discusses the new weighted funding system and how it impacts ASD children. The remainder of the section describes other ODE funding sources for ASD pupils, including: catastrophic aid, special education enhancements (including pre-school funding); and federal special education funding sources.

The School Foundation Formula: Weighted, Base Cost & Catastrophic Aid

Bottom Line: *The school foundation formula generated a total of \$62.8 million in aid for ASD pupils during the 2001-2002 school year. The state provided \$26.3 million (41.9%) and local school districts \$36.5 million (58.1%) of this funding.*

The school foundation formula, otherwise known as the SF-3 or line 501, provides the great majority of funding for the state's primary and secondary education system by guaranteeing a basic amount of funding for every pupil. The SF-3 provides more than \$4 billion in state funding for primary and secondary education, but also requires local districts to provide a portion of the basic per pupil costs. The state provides most of the per pupil costs for property poor districts (lower property values) and less of the per pupil costs for wealthy districts. Typically, this means that rural districts receive most of their basic per pupil costs from the state, and urban and suburban districts receive less, necessitating meaning they must pay more locally.

This concept is known as state share and districts can receive anywhere between zero percent of their basic per pupil funding from the state to near one hundred percent, with the local district responsible for the rest (although this latter extreme is rare). Thus, a district with a 65 percent state share has a 35 percent local share. In other words, there is a local match dynamic to the state funding formula. On an aggregate basis, state share accounts for just over half of the total base cost funding. As a result, the formula also generates \$4 billion in local base cost funding.

The school foundation formula generates over \$800 million in state funding and approximately the same amount of local funding for special education pupils in kindergarten through grade twelve. More specifically, the formula provides funding for ASD and other special education pupils in three ways:

- **Base cost funding:** Base cost funding is the basic amount of funding guaranteed to every student for the provision of a “thorough and efficient” education through a combination of state and local funds. In school year 2001-2002, the per pupil base cost amount was \$4,814, meaning the state guaranteed every student (including ASD pupils) this amount of aid through state and local resources. (\$504.9 million)
- **Weighted aid:** Weighted funding is the additional amount of formula aid special education pupils receive above base cost funding for the provision of services required by state and federal rules. Only special education pupils generate weighted funding. (\$294 million)
- **Catastrophic aid:** Catastrophic aid provides the state’s most profoundly disabled pupils extra funding beyond weighted and base cost formula aid. The state allocates catastrophic aid using a formula that recognizes a local district’s property wealth; however, all districts receive at least half of the additional costs (above \$30,000). Only special education pupils receive catastrophic funding. (\$15 million)

Although the formula provides substantial dollars for special education, these huge sums of money beg one fundamental policy question: what services do pupils with ASD receive from the state and local school districts? This programmatic question is answered in more detail in the following sections which further explain the three funding pools contained in the formula.

Base Cost Funding

Bottom Line: *In fiscal year 2002, the base cost funding formula generated \$5.4 million in state funding and \$7.4 million in local funding for 2,659 full-time enrollment ASD pupils counted in the formula, or, as previously stated, \$4,814 in funding per pupil on average.*

Base cost funding is the minimum amount of funding guaranteed to every student for the provision of a “thorough and efficient” education through a combination of state and local funds. The state determines the base cost amount using a complex formula based on the average per pupil costs of a set of districts that meet 25 of the state’s 27 academic

performance criteria. Although state aid typically equals local aid, the discrepancy indicates that more ASD pupils live in districts with a less than 50% state share.

Although base cost funding provides minimal classroom-based services to all pupils, including ASD students, the cost-based methodology is clearly not limited to base cost funding for disabled children. In fact, the classroom-based costs of serving ASD students (\$12,388) far exceed the base cost amount. The cost-based methodology determines what the cost is to serve students with disabilities and then provides this amount through a combination of base cost and weighted funding. The weights provide the difference between the base cost and the total cost. In the case of ASD pupils, the base cost funding provides the first \$4,814 (17.4% of the total cost) and the weighted funding provides the remainder, \$22,790 (82.6%).

Weighted Aid: The Primary Source of Funding for Pupils with ASD

Bottom Line: *In fiscal year 2002 (school year 2001-02), the weighted funding formula generated \$21 million in state funding and \$29 million in local funding for 2,659 full-time enrollment ASD pupils counted in the formula, or \$18,802 in funding per pupil on average (not including state and local base cost and catastrophic funding).*

The weighted funding formula generates additional funding for individualized education plan services contained in the 1982 Rules for the Education of Handicapped Children (the Blue Book) that cost more than what base cost funding provides to educate a non-disabled pupil. In short, weighted funding recognizes that special education pupils have unique needs, as outlined in each pupil's individualized education plan, and pays for these extra costs through a combination of state and local money.

At its most basic, weighted aid generates additional dollars for special education by multiplying the base cost amount every pupil receives by a weight (or multiple) which reflects the reality that it is more costly to educate and support a disabled pupil. ASD students are in category six. Category six students include the most profoundly disabled pupils: ASD, traumatic brain injured, and visually and hearing impaired. The formula multiplies the base cost amount received by the highest weight, 4.7342, thereby generating the most per pupil funding for category six disabilities: \$4,814 (base cost funding) + [\$4,814 x 4.7342 (the weight)] = \$4,814 (base cost funding) + \$22,790 (weighted funding) = \$27,604 per pupil in total state and local funding.

The state "phased-in" weighted funding in the FY 2002-03 budget (2001-02 school year, 2002-03 school year) at 82.5% and 87.5% respectively, for budgetary reasons. As a result, all disabled pupils received only 82.5% of their weighted funding amounts during the 2001-02 school year. ASD pupils received \$23,616 in state and local funding during this same year (\$4,814 + (.825*\$22,790), or nearly \$4,000 less than what they would have received if the state had not phased-in weighted funding. [Note: The weighted funding methodology is discussed in more detail in Appendix #1.]

Catastrophic Aid

Bottom Line: *In the current school year, 2002-03, 87 category six pupils (ASD, traumatic brain injury, and visually and hearing impaired) have received \$1.29 million in state catastrophic funding, or an average of \$14,825 in additional aid per pupil. Local districts spent an additional \$586,812 in catastrophic funding for these pupils. Unfortunately, it is difficult to determine how much of this funding was actually spent on ASD pupils for what services. Parents of ASD pupils may access this funding by demonstrating that the needs of their children exceed \$30,840 through the IEP process.*

After the state established catastrophic aid in the 1998-1999 school year to provide an additional pool of money for the state's most profoundly disabled pupils, it expanded catastrophic aid for the 2001-2002 school year to all disabled pupils (specific learning disabled to ASD) and assumed a larger percentage of these costs. [Note: The history and mechanics of catastrophic funding are discussed in more detail in Appendix #2.]

Districts may use catastrophic aid to pay for any services mandated by an IEP if costs exceed \$30,840. These services include, but are not limited to, instruction, related services, other support services (i.e. psychological services), and assistive technology. During the current school year, the state has spent \$5.9 million in catastrophic aid across all disabilities of the \$15 million in total funding available. Category six pupils (including ASD) have received \$1.29 million. Although it is impossible to know with exact precision how much of the \$1.29 million is being spent on ASD, it is likely that ASD pupils received the bulk of this money when considering proportionality.

ASD pupils account for nearly 85% of category six pupils. Assuming ASD pupils receive a proportional share of the \$1.29 million that the state is spending, catastrophic aid for ASD totals: \$1.1 million. Applying this same rationale to local catastrophic aid, districts are spending an additional \$493,509 on ASD pupils. Of course, these calculations are estimates assuming proportionality. There are two category six pupils who each receive more than 10% of the total catastrophic aid for category. If either of these pupils, or other exceedingly high cost pupils was in another disability classification (i.e. traumatic brain injury), then the proportionality assumption overstates what ASD pupils receive from the state in catastrophic aid.

Because districts have applied for only \$5.9 million of catastrophic aid in the current school year, it is conceivable that districts will receive additional catastrophic aid in the second half of the school year; however it is doubtful, even with the strides that ODE has made in publicizing the availability of this funding, that the remaining \$9 million will be spent. This probably reflects that many school districts and families of pupils with disabilities are unaware of this funding source.

Other ODE Programs, Services and Funding Sources for ASD

Bottom Line: *There are numerous other ODE funding sources for ASD pupils, including:*

- *Special Education Program Enhancements,*
- *Federal IDEA funding, and*
- *Special Education Regional Resource Centers (SERRCs).*

Given data limitations, it is currently impossible to determine precisely how much of this funding is received by ASD pupils. Many of the state and federal programs in question serve a broad array of disabled pupils (i.e. school psychology interns). Parents of ASD pupils and other service providers may access this funding by inquiring with their local districts and schools to create tangible ASD programs (or demonstration projects)

Other ODE programs providing aid to students with ASD (local/state/federal), include:

- **Special Education Enhancement Programs (state):** The state allocated \$139 million for special education enhancements in FY 2002, and \$142 million in FY 2003. The bulk of enhancement funding is used to pay for pre-school special education for children ages 3-5 per federal IDEA law. The state earmarked \$78.6 million in pre-school special education funding for the state’s 19,075 eligible pre-school special education pupils in both fiscal years 2002-03 [Note: pre-school special education is discussed in more detail in the next bullet, even though it is an enhancement program.]

In addition to pre-school special education, the enhancements line item funds the following programs:

Table 2: Special Education Enhancement Programs (FY 2002-03)

Program/Earmark	FY 2002	FY 2003
County Boards of MR/DD	\$45,295,000	\$47,809,750
Institutional Units	2,500,000	2,500,000
Home Instruction	3,293,959	3,425,717
Parent Mentoring	1,500,000	1,500,000
School Psychology Interns	2,744,966	2,854,764
Special Education Aides	3,852,160	4,006,246
Pre-school Special Education Units	78,623,506	78,623,506
Reading Mentoring	808,081	832,323
<i>Wood Co. ASD Demonstration Project</i>	<i>86,000</i>	<i>86,000</i>
Language & Literacy Demonstration Project	303,030	312,121
Total	139,006,702	141,950,427

The goal of the Wood County ASD Demonstration Project, a collaborative effort on behalf of many local education entities, is to develop best educational practices for ASD children. The collaborative effort involves the Wood County Board of Mental Retardation and Developmental Disabilities, Wood County Educational

Services Center, Children's Resource Center of Wood County, and the Family and Children First Council of Wood County. The primary area of focus is to increase the effectiveness of the summer ASD program and expand the number of school personnel being trained to work with students with ASD.

Although the enhancement line item provides very little direct funding for ASD pupils, aside from the Wood County ASD Demonstration Project, it is likely that many of the other programs either directly or indirectly serve students with ASD. Unfortunately, there is no detailed data showing how much these pupils receive through pre-school special education, county board of MR/DD funding or home instruction.

- **Pre-school Special Education (state & federal):** The state funds pre-school special education through classroom-based and related services units. The state determines the number of units each district receives on the basis of a pupil-to-staff ratio. For example, if there are fifty students in a school district requiring adapted physical education, the state may fund one adapted physical education unit that includes personnel salary, benefits, and any supplies or administrative support required by the unit. Although the state provided full and partial units to 18,600 students in FY 2001, it did not fully fund the number of units required.

ODE reported 334 ASD pupils aged 3-5 in its December 2001 child count (FY 2002). Similar to enhancement funding, it is not known how many ASD pupils actually received funding. Furthermore, it is likely that numerous ASD pupils are yet to be identified by this age for purposes of receiving funding. Assuming proportionality, each pre-school special education pupil (19,075) would have received \$4,121 in state funding and an unknown amount of local funding.

In addition to state pre-school special education units, the state allocates some federal dollars for pre-school special education. In FY 2002, the state allocated \$9,913,538 in federal IDEA funding (grant money received by the state) for special education. Once again, assuming proportionality, each pre-school special education pupil would have received \$520 in federal funding. Combined with state special education units, pre-school special education pupils received an average of \$4,641 in state and federal dollars. If ASD pupils received this average amount, ODE would have allocated a total of \$1.55 million in funding (\$1.38 million in state funding, \$.17 million in federal).

- **IDEA Funding (federal):** The federal government allocated \$186,000,000 for special education in Ohio in FY 2002, and \$206,000,000 in FY 2003. The majority of this funding flows to the district and can be used for any special education expense or service as long as it does not supplant local funds used to provide a free and appropriate education (FAPE). Federal law requires states to provide and fund a free and appropriate education. Federal funding is intended to supplement FAPE services as opposed to supplant. Therefore, the state cannot use

federal dollars to pay for FAPE. In short, federal funding is intended to buy progress through the provision of added services.

The state spent \$1,000,000 of its IDEA allotment in grant year 2000 on ASD projects. This money was intended to “provide statewide leadership, advocacy, technical assistance, and...collaboration among stakeholders to ensure all children with ASD have a free and appropriate public education.” Although there is no data indicating how much IDEA money the state is currently spending towards this specific purpose, Ohio continues to fund many ASD “projects” using IDEA money, and more specifically, federally-funded state improvement grants (SIGs). SIG funding totaled \$584,175 in grant year 2000. These projects and grants are discussed in more detail in the following bullet.

In grant year 2000, the last year for which there is local data, federal flow through money totaled \$129.3 million or \$559 per student with disability. This amount accounted for 81.9% of federal special education funding, which totaled \$157.8 million. Federal flow through funding is intended to buy direct services for students with disabilities, as opposed to administrative services. Flow-through funding is allocated on a proportional basis. The more students enrolled in a district, the more money that district receives and vice versa. Local districts spent a substantial amount of flow-through funding on special education classroom and related services aides. Other districts spent IDEA money on assistive technology and other supplemental personnel, such as counselors, psychologists and additional teachers.

After flow-through funding, the next largest category was aid to the state’s Special Education Regional Resource Centers (SERRCs). SERRCs provide resources to local districts to improve the quality of instruction for disabled pupils. SERRCs received \$16.1 million in IDEA funding or 10.2% of the total.

- **Other Federal Programs (federal):** In addition to federal IDEA funding, the U.S. Department of Education funds additional state programs, such as the State Parent Training and Information Projects. These projects provide information, advocacy, and training to parents regarding the educational rights of their children. State University Affiliated Programs are authorized by federal legislation to help states and local communities respond to the needs of people with developmental disabilities and their families; these programs serve as a liaison between the academic world and the developmental disabilities service delivery system.
- **ASD Successful Models and Demonstration Projects/State Improvement Grants (federal):** The state currently funds 26 “Successful Models and Demonstration Projects” for ASD through state improvement grants (included in federal IDEA funding). These models or projects are located in all areas of the state, and “the purposes and outcomes of the projects are to identify and support current resources and programs that implement successful models and to build

capacity of knowledgeable, qualified service providers through demonstration projects for the education of students with ASDs.”

The projects span collaborative efforts with other educational and health entities (i.e. the Wood County project), non-traditional education approaches, and community schooling. Local districts and other educational and health entities may apply for state improvement grant funding to start a successful model and demonstration project through the ODE. [Note: Existing demonstration projects are discussed in more detail in Appendix #3.]

- **Ohio Resource Center for Low Incidence and Severely Handicapped (ORCLISH) And Special Education Regional Resource Centers (SERRCs)**

Ohio’s SERRCs fulfill a critical role in providing timely and specialized assistance to families and school personnel by:

- *Assisting school district personnel in providing appropriate services to children with disabilities, including those with ASD, through technical assistance and cooperative planning;*
- *Providing regular and special education teachers, support personnel, administrators, and families with resources designed to improve the quality of instruction for children with disabilities, through the delivery of instructional materials and methodologies designed to meet the individual needs of children with special needs; and*
- *Providing staff development to local school district personnel and families, on an individual and team basis, to improve the quality of instruction for children with disabilities.*

Ohio’s school districts and families of children with ASD can access limited resources through Ohio’s special education regional resource centers (SERRCs). The Office for Exceptional Children, a division of the Ohio Department of Education, recognized in 1968 that a state agency alone could not successfully relate to individual teachers, supervisors, and school districts. Therefore, federal funds were used to create a new linkage between the state and the school districts of Ohio.

Under Ohio's State Plan submitted in accordance with P.L. 101-476, part of the discretionary portion of Title VI-B is to be used to fund the SERRC system. This statewide mechanism was designed to develop and implement services and priorities in keeping with the Individuals with Disabilities Education Act (IDEA).

Currently, there are sixteen (16) SERRCs that provide services to all school districts, county boards of mental retardation and developmental disabilities, and institutions in the state of Ohio. Each SERRC has the following four components: Identification and Program Development Project (IPD); Educational Assessment Project (EAP); Instructional Resource Center Project (IRC); and Early Childhood Services Project (ECS).

Additionally, the Ohio Resource Center for Low Incidence and Severely Handicapped (ORCLISH) provides technical assistance to SERRC personnel, educators, and families on adaptive and assistive devices and other specialized instruction, materials, and technology that can be used to assist children with severe disabilities, including those with deaf-blindness, to meet desired educational outcomes.

ORCLISH is a statewide federally funded project under the direction of the Ohio Department of Education, Division of Special Education. ORCLISH serves parents and educators of school-age students with low incidence and severe disabilities including:

- autism
- deaf-blindness
- deafness and hearing impairments
- multiple disabilities
- orthopedic and other health impairments
- traumatic brain injuries
- visual impairments

Each SERRC functions through a participatory management system based on a governing board composed of superintendents of schools; special and general education personnel; at least two parents of children with disabilities; and representatives from nonpublic schools, county boards of mental retardation and developmental disabilities, regional institutions, and universities in the region. Governing boards may include student representatives and persons with disabilities.

As regional entities, the SERRCs attempt to identify local needs and design and deliver services in ways that are responsive to local and regional constituents. At the same time, the SERRC system assists the ODE's Office for Exceptional Children, playing a role in statewide networking activities, advocacy on behalf of students with disabilities, and state and national outreach and information dissemination. These efforts provide an opportunity for school districts to learn better methods for working with students impacted by ASD.

Educational Service Centers (ESCs)

Bottom Line: *Ohio's 60 county-based Educational Service Centers are regional special education service providers, providing the majority of direct special education services to Ohio's school districts. ESC services that students with ASD can access may include:*

- *Speech-language Pathologist Services*
- *Occupational Therapy*
- *Physical Therapy*
- *School Psychology Services*
- *Special Education Preschool*

- *CAFS Administration*
- *Head Start/Early Start Programs*

ESCs are funded through a combination of local, state, and federal dollars. Seventy-five to ninety percent of the program budget for ESCs, however, is generated by direct contracts on a fee-for-service basis with school districts. In most instances, therefore, school districts will contract with an ESC to provide services to children with ASD. ESCs also administer Community Alternative Funding Systems (CAFS) reimbursements for Ohio's school districts – funds that are used to partially reimburse districts for the provision of services to special needs students. Additionally, many ESCs operate programs specifically for children with ASD.

ESCs provide a wide array of services to more than 93% of Ohio's 612 public school districts. Services include, but are not limited to, special education supervision and related services, special education preschool, general supervision, assistive technology, and teacher professional development. While ESCs no longer receive direct state funding for special education and related services, they do contract directly with local school districts and county boards of MR/DD to provide those services.

Educational Service Centers are also partners at the county-level with Ohio's Family and Children First Councils and Help Me Grow, and are particularly involved with early intervention services as a result of their expertise in this area. Several ESCs also collaborate with other service providers in the ODE demonstration projects. As indicated previously, the 2002 Successful Models and Demonstration Projects in Autism Spectrum Disorders are projects funded through the Ohio Department of Education, Office for Exceptional Children. The purposes and outcomes of the projects are to identify and support current resources and programs that implement successful models. Further the goal is to build capacity of knowledgeable, qualified service providers through demonstration projects for the education of student with autism spectrum disorders. Of the 26 funded projects, ESCs are directly involved in 8, and serve as a resource in several others. The Lucas County ESC operates 3 community schools directly for the purpose of providing services to children with ASD. One of those schools, M.O.D.E.L community school, is funded through an ODE's demonstration project grant.

ESCs are also involved in other collaboratives. For instance, Warren County ESC and other providers formed a consortium in 2000 to organize and disseminate information around the Cincinnati area regarding ASD. The organization is called The Regional Autism Advisory Council (RAAC). The primary function of ESCs, however, is to directly deliver services to children with autism on a contractual basis.

Ohio Department of Health: ASD Funding

Bottom Line: *There are only two ODH health programs that provide services to Ohio citizens with ASD: Child and Family Health Services (CFHS) and Help Me Grow. Both programs are of modest size and have limited resources. The former program is screening oriented, while the latter serves at-risk children age 0-3. Neither program is specifically*

designed to serve children with ASD. There is no data indicating the number of ASD children and families served by ODH or how much money the programs or individuals receive. Parents of ASD children may access funding and services from these programs by contacting the Ohio Department of Health.

Child and Family Health Services

The CFHS program provides funding for community-based health services, including diagnosis, treatment, and case management for eligible children. The program is designed to serve the state's medically underinsured, uninsured, Medicaid-eligible women, infants and children, and under-served populations in Ohio through grants to local public health clinics and health care providers overseen by ODH. In FY 1998, the last year for which there is public data, the state provided funding to 284 health clinics to provide prenatal and child and family planning services for approximately 94,100 clients. It is unknown how many children with ASD received services.

The program also funds medical specialty clinics in 52 of Ohio's 88 counties. These clinics, spanning seven different health risks, include developmental and neurological clinics. Last year, the clinics held 560 sessions and had 11,000 individual client visits. According to ODH, a team of health professionals, including a developmental pediatrician, speech language pathologist, physical therapist, occupational therapist, and psychologist, staffs developmental clinics. In order for a child to be referred to additional specialists for continued testing, he or she must display "developmental delays documented by screenings which show failure to reach age appropriate milestones in areas of speech, gross motor, fine motor, and social skills; inadequate weight gain or other obvious problems which may cause a delay in development." The developmental delay clinics are located in Adams, Clinton, Coshocton, Hocking, Muskingum and Pike counties.

Help Me Grow

The Help Me Grow program consolidates three Ohio Department of Health birth to three programs: Welcome Home, Early Start, and Early Intervention (EI). Of these three programs, EI would potentially provide the most services to children with ASD. EI is intended to identify and treat infants and toddlers with disabilities early in life. The program's goal is to minimize developmental delay and reduce the need for special education later in life, even if it is unlikely pupils with ASD will not require special education. Early Intervention serves disabled Ohioans aged birth to three years and their families; all newborns; and individuals with genetic disease and their families.

Ohio Medicaid Waivers: ASD Funding

Bottom Line: *Ohio's Medicaid system, which is funded with state and federal funds and provides health care services to nearly 1.5 million low income Ohioans, offers eligible recipients, including people with ASD, the opportunity to apply for a limited number of Medicaid waiver "slots" through the following waiver programs: Residential Facilities, MRDD and Ohio Home Care. Another waiver, the Transition Waiver, has been created on a temporary basis to serve individuals with significant habilitation needs and an Intermediate*

Care Facility-Mentally Retarded (ICF-MR) level. According to the Ohio Department of Job and Family Services (ODJFS), the number of people age 21 and under with a reported diagnosis of autism (though not necessarily in all cases a primary diagnosis of autism) served on Ohio Medicaid waivers in FY 2001 totaled over 600. 595 were served through the Ohio Homecare Waiver; 42 were served by the MRDD Waiver (which includes people served by the former OBRA and Individual Options Waivers); and the Residential Facility Waiver served 6. These individuals are among a broader group totaling 1500 children age 21 and under with autism related diagnoses who were served by the Medicaid program in FY 2001. Family members of ASD citizens may access these services through the state agencies (and local-level entities) that administer these waivers, though waiting lists currently exist for each of these waivers.

ODJFS allows a limited number of Medicaid eligible persons, including people with ASD, to apply for Medicaid waivers. These Home and Community-Based Service (HCBS) waivers allow eligible individuals to receive Medicaid funding for health-related services in non-traditional, non-institutional, home and community-based settings. HCBS serve financially eligible Aged, Blind, and Disabled Medicaid consumers and some other citizens with disabling conditions. Home and Community-Based Service waivers provide three levels of care (or benefits) to consumers: Core, Core Plus and Ohio Homecare Waiver. All three levels of care include: nursing, daily living, and skilled therapy (physical, occupational and speech/language therapy). The core benefit package serves the home care needs of citizens who require 14 hours or less of living services each week. The Core Plus level of care serves those citizens who require more than 14 hours. The Homecare Waiver serves the most fragile aged and disabled citizens who require the most care.

ODMRDD manages two of these waivers despite the fact that Medicaid provides most of the funding for these services. The other Home and Community-based Medicaid waiver programs are administered by ODJFS.

Ohio Department of Job and Family Services (ODJFS) Medicaid Waivers

- **Ohio Home Care Waiver (OHCW):** This waiver serves Medicaid consumers age 60 and under whose medical condition or functional abilities would normally require nursing home or hospital/institute services. In FY 2001, the number of Home Care waivers was capped at 8,208. The waiver provides “core” services including: nursing, daily living, and skilled therapy (physical, occupational and speech/language therapy). The waiver makes payments to ODJFS-approved providers for services. Children with ASD can receive intensive behavioral intervention services through this waiver, though judgments are made on a case-by-case basis.

As noted previously, the Transition Waiver was created in 2001 to serve children with ASD and others who were on the Home Care Waiver, but needed more habilitation services (i.e., training and self-care) and had an ICF-MR level of nursing home care. These people were placed on the Transition Waiver for up to three years so that they could receive these additional services not otherwise

available under the Home Care Waiver. However, because the Transition Waiver is a closed waiver to all individuals who were not on the Home Care Waiver at the time the Transition Waiver was created, there are no new openings.

Children who were on the waitlist for the Home Care Waiver were switched over to the waitlist for the Individual Options waiver. The state purchased more Individual Options slots to accommodate those citizens on the waitlist and distributed these to counties—by request. Although many counties took no action, Franklin County requested and received a number of slots for children with ASD.

There are still slots available for children with ASD; however, there is currently a hold on distributing these slots.

Ohio Department of MRDD Medicaid Waivers

- **Residential Facilities:** This waiver serves Ohioans age 18 and over who require an ICF-MR level of care. The waiver provides an alternative to an intermediate care facility and was limited (capped) at 3,434 slots in FY 2001. In FY 2001, the program received \$68.2 million from the state, and \$42.7 million from the federal government for a total of \$110.9 million. Families of ASD citizens should contact ODMRDD's Eligibility Services office to determine whether or not a consumer is eligible for a waiver on the basis of an assessment packet submitted by the county board of MRDD. The waiver provides a number of services, including: homemaker personal care, adaptive assistive technology, and supported employment. The Residential Facility waiver makes payments to ODJFS-approved providers for services.
- **MRDD Waiver:** This waiver is designed to provide support in an individualized setting as an alternative to an ICF-MR for Ohioans of any age and was capped at 2,821 citizens in FY 2001. In FY 2001, the program received \$19 million in state general revenue funding, \$12.5 million in state special revenue, and \$74.1 million in federal funding for a total of \$105.6 million. Although ODMRDD manages the program, ODJFS ultimately determines whether or not a consumer is eligible for the individual options waiver. Families of ASD citizens should contact both ODMR/DD and ODJFS to determine eligibility.

ODMRDD is currently petitioning the federal Centers for Medicare and Medicaid Services to increase the cap. The waiver provides federal financial reimbursement for certain Medicaid services, including: supported employment, adaptive and assistive technology, home modifications, home-delivered meals, homemaker and personal care, interpretive services, nutritional education, respite care, social work and transportation. Room and board is provided using state funds because it is not a reimbursable service under the federal waiver. The waiver makes payments to ODJFS-approved providers for services.

Ohio Department of Mental Retardation and Developmental Disabilities (MRDD)

Bottom Line: *The Department of Mental Retardation and Developmental Disabilities (MR/DD) ensures the availability of programs, services, and supports to assist individuals affected by mental retardation and developmental disabilities, including ASD. Programs are delivered primarily through the regionally based county MRDD board system. Primary programs under which children with ASD might receive services are:*

- *Family Resources;*
- *Community Alternative Funding Systems (CAFS);*
- *Early Intervention (in connection with the Ohio Department of Health)*
- *County Board Schools; and*
- *Supported Living*

While the state does do some tracking of individuals by specific disabilities, it is by no means a unified, comprehensive system. Currently, there is no way to completely validate the data to ensure an accurate count, by program, of the individuals receiving services for autism spectrum disorder. This is a problem that is apparent in other state agencies and not just in the ODMRDD.

ODMRDD provides funding assistance to Ohio's 88 county boards of mental retardation and developmental disabilities for residential and support services. Currently, over 10,200 individuals receive residential services through funding from the MR/DD and approximately 56,700 individuals receive other support services through programs provided by Ohio's County Boards of MRDD, including those impacted by ASD.

History. Prior to the 1950s, children and adults with mental retardation or other developmental disabilities had little opportunity to become educated or trained for jobs. Public school systems and local businesses excluded them. This began to change in 1967 when, in concert with a national thrust to improve the lives of these individuals, the state passed Senate Bill 169 creating the County Boards of Mental Retardation. This measure placed community-based services for persons with mental retardation and other developmental disabilities on more solid ground. The county board names were later changed to County Boards of Mental Retardation and Developmental Disabilities (Am SB 160, 1980).

Family Resources. The Family Resources program supports families in their efforts to care for family members with mental retardation and developmental disabilities in their homes and avoid placement outside of the home. In fiscal year 2001, nearly 11,200 families received reimbursements from the state, with average reimbursements falling in the \$1,000 range. The program provides state funds to county boards of MRDD that then make payments to families for certain costs associated with the care of family members with mental retardation and developmental disabilities. Payments under this program may be made for respite care, special diets, home modifications, lease or purchase of special equipment, and other services that are consistent with the purposes of this program and the plan developed by the county board. As stated previously, however, data collection methods make it difficult to determine the number of individuals directly affected by ASD being served by this program.

Supported Living – Developmental Centers. The Developmental Centers program series operates 12 centers throughout the state, serving approximately 2,000 citizens with mental retardation. Each center, as an ICF/MR facility, is Medicaid certified signifying compliance with mandated standards governing the care, training, and environment provided to residents. In addition, the department provides direct residential care for persons with mental retardation in these 12 developmental centers. Certain individuals with ASD would qualify for services through the developmental centers program. The mission of these centers is to serve individuals who require comprehensive program, medical, and residential services.

In these centers, an individual with ASD would have professional staff, consisting of physical, occupational and speech therapists; behavioral specialists; medical and nursing personnel and others who work as interdisciplinary team members to design individual habilitation plans for residents based on individual health care needs. The plans address such areas as training in activities of daily living; communication and social skills; pre-vocational and vocational training; occupational, physical, and recreational therapies; and attention to necessary health care needs.

IV. County Funded ASD-Related Programs

Outlined below are primarily county funded ASD-related programs.

County Boards Of MRDD

Funding. Revenue for county board operations and programs is generated from Local, State and Federal sources. Local funds are generated primarily by local tax levies and these funds represent the largest source of income. State funds are primarily reimbursements from the ODMRDD and the Ohio Department of Education. Federal funds are generated from various grants, the National School Lunch Program and Medicaid. State funds are allocated to county boards and may be matched by local tax levies as indicated above. County boards operate a series of nine (9) programs, of which the Community Alternative Funding Systems (CAFS) receives the most funding. Some services administered through the county board system overlap and as a result these services often have multiple funding sources.

Function. County boards of MR/DD early childhood programs provide early diagnosis of developmental delays. Once a child is found to have a developmental delay, service providers and the family work together to develop an Individual Family Services Plan (IFSP), identifying the child and family's strengths and needs. County board early intervention programs, often delivered through programs such as Help Me Grow, offer services in the home or an early intervention center that include language stimulation and communication skills training, self-help skills training, physical development, social and emotional development, cognitive and sensory development, transportation, family support, and other services designed specifically for each child and family.

Services. Fifty-eight county boards of MR/DD provide special education to children 6 years of age and older in board-operated facilities. [Note: The map of service delivery regions is contained in Appendix #4.] Of the thirty counties which no longer have school programs, 6 provide teaching staff who work in classrooms within the public schools in the county. Further, of the same 30 counties that no longer have school programs, 25 provide other supports to public schools, such as behavior management, therapies (speech, occupational, physical), service coordination, recreation, and summer extended school programs. Several county boards which have their own school buildings, including Franklin and Cuyahoga, also operate special education classrooms in public schools. County board schools have decreased in the numbers of students 6 years and older, from around 6,000 in 1991 to less than 3,400 now. County boards of MRDD have shown a modest increase in preschool children served, from around 3,000 in 1991 to nearly 3,300 today.

All 88 county boards offer advocacy and support to school age children and their families through activities such as service coordination, Supported Living, and Family Resource Services.

County boards are the major providers statewide of early intervention, through the ODH funded Help Me Grow initiative, a system of supports for children birth through 2, with disabilities, delays, or at risk for delays, and their families. In the last 11 years, the number of infants and families served has more than tripled from just over 2,000 in 1991 to nearly 7,400 in 2002.

The total number of children served by county boards has gone from around 13,600 in 1991, to nearly 23,000 today. Of these, only 14,000 attend a county board school or education program in a board operated facility. Over 9,000 children attending public schools are benefiting from the related services and supports provided through the county board system. County boards are serving approximately 41,000 adults 16 years of age and over. This is an increase from less than 22,000 in 1991. An estimated 8,000 of the adults served are between the ages of 16 and 21, and are receiving sheltered work or job skills training through the county board rather than attending special education classes in public schools.

Ultimately, county boards serve approximately 1.18% (21,400) of the 1.8 million school-aged children in Ohio.

Community Alternatives Funding System (CAFS)

CAFS provides federal reimbursement to county boards of MRDD, schools, or non-profit organizations for medical and support services provided to persons with mental retardation and developmental disabilities. Reimbursement also is made to schools for the same services provided to Medicaid-eligible children. In a school setting, any Medicaid-eligible child, including those served through Ohio Works First and Healthy Start, may receive services covered by CAFS. In a non-school setting, a person, regardless of age, is eligible if the person has been determined by a county board of MRDD to have a developmental disability.

CAFS providers furnish direct services that include physician, nursing, nursing physical therapy, psychological services (including behavioral intervention services), occupational therapy, speech therapy and audiology, transportation, social work, and counseling. Eligible providers are then reimbursed for these services. Another similar program is Medicaid Administrative Claiming (MAC). The MAC program reimburses a district for administrative services, outreach activities and student identification functions.

Currently, there are over 230 schools in Ohio participating in the CAFS program. Districts receive approximately \$30 to \$40 million per year from the CAFS program. The MAC program has about 220 districts participating in one of two consortiums. **Warren City** leads the northern consortium. **Dayton City** leads the southern consortium. The MAC program should provide these districts with \$20 to \$40 million per year in reimbursements. The state does not track students by disability within these programs. As a result, while it is possible to

identify the number of students impacted by this program, it is currently not possible in all cases to identify the specific disability for which a provider is being reimbursed.

MRDD Data Collection

The state department of MRDD tracks the recipients of its services through the county boards of MRDD, though not by individual disability. The year 2000 report from Individual Information Forms (IIF) indicates a total of 57,503 individuals receiving services through County Boards of MRDD.

The IIF has fields for primary and secondary etiology as determined by medical diagnosis. Autism (code 82) is a choice in this reporting system. However, etiology codes are subject to discrepancies in the validity (and uniformity) of county reporting. Presently, the Ohio Department of MRDD is working on a report linking the autism diagnosis to waiver and other programs; however, this information is not yet available. The IIF database is kept by ODMRDD and the information comes directly from County Boards of MRDD. While there is some limited capability for sorting the information by subgroups of disabilities, the validity of that data remains an issue.

V. ASD Policy and Program Highlights: Stories from Other States and the Non-Profit Sector

In an effort to set Ohio's ASD policies and programs within a broader context, and in so doing, to inform policy making and system reform efforts in Ohio, this section of the report provides a selected look outside of Ohio at non-profit and public efforts at the national and state level to enhance services and outcomes for people with ASD. This profile is meant to be representative of important, and potentially instructive, initiatives to improve public and private services to individuals with ASD -- efforts that either represent advances in public policy or, on the programmatic side, appear to exceed the scope and quality of services provided in Ohio.

Federal Activity and Resources

C.A.R.E.

The Coalition for Autism Research and Education (C.A.R.E.), the Congressional Autism Caucus, was started in 2001 by Representative Chris Smith of New Jersey and is the first Congressional Member Organization to focus on ASDs.

During the 106th Congress, Smith introduced the Autism Statistics, Surveillance, Research and Epidemiology Act (ASSURE). The measure was passed and signed into law in November 1999. Among other provisions, this act mandated the establishment of three to five regional Centers of Excellence for Autism and Developmental Disabilities Research and Epidemiology (CADDRE) to collect and analyze vital information. Smith also submitted House Concurrent Resolution 91 which stressed the need for education intervention and called for full federal funding of the Individuals with Disabilities Education Act (IDEA) rather than the 40% that has been proposed and the 14% of IDEA that is actually funded. In May of 2001, the House approved Smith's resolution thereby recognizing the need to increase resources to train teachers to respond to special needs of children with ASD and increase worker training programs tailored to the needs of developmentally disabled person, including those with ASD.

Smith followed up on House recognition of the need for increased support, particularly in the area of education, by introducing House Resolution 4728 or the Teacher Education for Autistic Children Act of 2002 (TEACH). The TEACH Act would authorize the Department of Education to invest \$20 million each year for five years in programs, grants, and scholarships to train teachers who teach students with autism. Additional funding would be available for states to invest in similar teacher preparation and education programs, and tax

credits would be provided for educators who undertake and pass certified courses on autism education. H.R. 4728 was referred to the House Committee on Education and the Workforce and then to the Subcommittee on Education Reform. The bill did not pass during the 107th Congress because of competing priorities. However, Congressman Smith plans to re-introduce the measure during the 108th congress.

National attention to ASD in recent years has been unprecedented. In the past six years, funding for ASD research at the National Institutes of Health (NIH) has increased from \$10.5 million in 1995 to \$65.1 million in 2001. Likewise, funding at the Center for Disease Control (CDC) for data gathering on ASDs has increased from less than \$300,000 in 1995 to \$9.2 million in 2001. As the number of identified cases of ASD rises, so has the federal investment in research and data collection. This trend will likely broaden to include teacher preparation, education, and early intervention.

The Centers for Disease Control and Prevention (CDC) www.cdc.gov/aboutcdc.htm

CDC is recognized as the lead federal agency for protecting the health and safety of people. It funds projects on autism spectrum disorders (ASDs) in several states. These projects track the number of children who have an ASD, conduct studies to find out what factors make it more likely that a child will have an ASD, and share what is learned with researchers and people affected by ASDs. Current state activities include: Autism and Developmental Disabilities Monitoring Network (ADDM); CADDRE; and Prevention of Secondary Conditions Related to Autism and Pervasive Developmental Disorder. New funding opportunities for ASD-related projects can be found on the National Center for Birth Defects and Developmental Disabilities Funding Opportunities Web page or the CDC Grants and Cooperative Agreements Web page.

CDC's Web-based Autism Information Center www.cdc.gov/ncbddd/dd/ddautism.htm focuses on the activities of federal and federally funded programs and the resources affected by these programs. The information center includes: information about autism spectrum disorders; activities of CDC and other federal agencies; state activities funded by CDC; education, services, and research resources; and activities to help children use the Internet to learn more about autism spectrum disorders.

The Children's Health Act of 2000 required that a committee be formed to coordinate autism-related activities in the Department of Health and Human Services (DHHS). The Interagency Autism Coordinating Committee (IACC) began in 2001 to help agencies share information and to coordinate autism research and related activities in the agencies that are part of DHHS. The IACC includes staff from the following agencies: the National Institutes of Health, the Centers for Disease Control and Prevention, the Administration for Children and Families, the Food and Drug Administration, the Agency for Toxic Substances and Disease Registry, and the Department of Education. The IACC also includes parents of people with ASD.

Nationally Recognized Centers for ASD*

* Recommended by the National Information Center for Children and Youth with Disabilities (NICHCY)

Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH)

TEACCH is located in the School of Medicine at the University of North Carolina at Chapel Hill and has been cited by the National Institute of Mental Health as the most effective statewide program in this country. There are nine regional centers, one at each branch of the University. The state appropriates \$6 million a year for the centers and other financial support is derived from federal grants, services offered, and private donations. This program was founded in 1972 with a strong grass roots effort and has enjoyed a powerful lobby of parents ever since. Parents are co-therapists and are taught strategies for working with their children.

TEACCH's regional Centers provide regular consultation and training to parents, schools, preschools, and daycare centers. There is one demonstration classroom and about 300 classes in public schools that are affiliated with TEACCH. There are 6-8 students in a class. The school systems hire the teachers and TEACCH trains them through a contract with individual TEACCH centers. TEACCH also offers several summer sessions with 25 trainees in each one, many from out of state. TEACCH has conducted training sessions to over half of the states and many foreign countries.

Indiana Resource Center for Autism (IRCA) www.iidc.indiana.edu/irca/

The Indiana Resource Center for Autism conducts outreach training and consultations, engages in research, and develops and disseminates information focused on building the capacity of local communities, organizations, agencies, and families to support children and adults across the autism spectrum in typical work, school, home, and community settings. IRCA does not promote one method or a single approach. Instead, IRCA staff strives to address the specific needs of the individual by providing information and training on a variety of strategies and methods. It trains school teams to enhance programs and build local capacity to better educate and support individuals across the autism spectrum; maintains relevant databases and utilizes them for documentation, research, and evaluation purposes; and serves as a state clearinghouse for information about ASDs by responding to individual requests for information.

Yale Developmental Disabilities Clinic/Autism Yale Child Study Center

The Yale Developmental Disabilities Clinic (<http://info.med.yale.edu/chldstdy/autism/>) offers comprehensive, multidisciplinary evaluations for children with social disabilities, usually focusing on issues of diagnosis and intervention. It is located in the Child Study Center at [Yale University](#), in New Haven, Connecticut. The Center is known worldwide for its research on a variety of child psychiatric and neurological disorders and is affiliated with The Learning Disabilities Association of America (LDA), the largest advocacy organization in the country for families affected by learning disabilities.

Cure Autism Now (CAN) www.canfoundation.org

CAN is an organization of parents, physicians and researchers dedicated to promoting and funding research with direct clinical implications for treatment and a cure for autism. Founded in 1995, the organization is the largest private funder of autism research. CAN works with Congress and the National Institutes of Health to encourage more aggressive funding of biological research in autism.

National, Non-Profits

Outlined below are organizations that lend support to children with ASD and their families in more than one state.

The Autism Society of America (ASA) <http://www.autism-society.org> is the largest autism-related organization in the country. Founded in 1965, the Society has developed into the leading source of information and referral on ASD. Today, over 20,000 members are connected through a working network of over 200 chapters in nearly every state including Ohio. Its mission is to promote lifelong access to services and opportunities for all individuals within the autism spectrum and their families. Education, advocacy at state and federal levels, active public awareness, and the promotion of research form the cornerstones of ASA's efforts to carry forth its mission.

The next largest autism-related organization and the only other one with many nation-wide affiliates is Families for Effective Autism Treatment (FEAT). <http://www.feat.org/> FEAT was founded in California in 1993. FEAT-affiliated organizations have been established in several states, including Ohio. FEATs are non-profit organizations dedicated to providing world-class education, advocacy, and support. Emphasis is placed on connecting families with early intervention services, particularly evidence-based intervention programming, as soon as possible.

The Doug Flutie Jr. Foundation for Autism <http://www.dougflutiejrfoundation.org> is a nationally known foundation that addresses ASD exclusively. The foundation's mission is to aid financially disadvantaged families who need assistance in caring for their children with ASD; to fund education and research into the causes and consequences of childhood ASD; and to serve as a clearinghouse and communications center for new programs and services developed for individuals with ASD. The Foundation is affiliated with WebED, Inc., one of the nation's leading Internet-based education companies. Both organizations work together to provide a comprehensive series of online ASD courses for parents and teachers. WebED will provide professional development credits to educators who take the fee-based ASD courses developed by academics and practicing professionals in the field and makes these courses available free to parents. www.WebED.com/parents.

The John Maxwell Biasco Resource Centers for Autism and Other Special Needs <http://www.maxie.org/> are places for parents, therapists, educators, medical personnel, and concerned individuals from across the country to obtain information that will aid in understanding and improving the lives of those with autism and related developmental disabilities. They are complete resource centers with books on autism and works that deal with sibling issues, family stress, government aid, the IDEA law, medical issues, health

insurance, “special” education, lifelong planning, and job training. Newsletters from autism societies across the country are available along with books, periodicals, journals, videos, audio tapes, and current research papers. There are 15 centers in the U.S., mostly in Florida, and two are in Ohio (Bowling Green and Youngstown*).

States

New Jersey

New Jersey offers many programs. These programs are supported by a variety of funding sources. The following are three examples:

The New Jersey Center for Outreach and Services for the Autism Community (COSAC) www.njcosac.org, a non-profit agency that receives approximately 40 percent of its funding from the state, provides a wide variety of information and referral services including lists of special education attorneys, dentists, and pediatricians who understand autism. It holds parent education workshops; provides seminars, workshops, and special training to parents and other professionals; holds an annual “Issues in Autism” conference; publishes a semi-annual magazine and updated legislative information in a monthly newsletter; sponsors ten parent support groups throughout the state; maintains a toll-free number for New Jersey residents; and publishes the National Directory of Programs and Services for the Autism Community.

The Statewide Parent Advocacy Network, Inc. (SPAN) www.spannj.org empowers families, professionals, and others interested in the educational rights of children with a range of disabilities. It does so through individual advocacy and technical assistance. It receives federal, state, county, and foundation funding. SPAN staff and resource parents assist over 170,000 individuals each year in resolving education problems, free of charge. Its special commitment is to those children with the greatest need due to disability, poverty, discrimination based on race, sex, or language, or other special needs.

First Signs <http://www.firstsigns.org>, a relatively new program, is a 501(c)(3) non-profit organization funded by individual donors, foundations, and government agencies, such as Cure Autism Now, the Flutie and Dr. Laura Schlessinger Foundations, and the New Jersey Governor's Council on Autism at the Robert Wood Johnson Medical School University of Medicine & Dentistry of New Jersey (UMDNJ) that receives an annual appropriation of \$1.5 million from the state. *First Signs* is dedicated to educating parents and physicians about the early warning signs of autism and other developmental disorders. It seeks to increase early identification through a simple screening method and to facilitate timely referral of identified children to early intervention programs. It was launched in New Jersey in 2001 in collaboration with COSAC and the UMDNJ-Robert Wood Johnson Medical School. Among other services, it makes available a *First Signs* Screening Kit for physicians that includes an educational video, screening guidelines, screening tools, a wall chart of developmental milestones, and an Early Intervention Referral Guide.

* Parents Resource Center The Wood County Autism wcesc_kr@nwoca.org <http://nwoca.org> (419) 352-5115
The Paula and Anthony Rich Center For the Study and Treatment of Autism Youngstown State University jgbackus@cc.yosu.edu
www.yosu.edu/colleges/coll_edu/rich/index.htm

In June, 2002, this organization launched a mini-pilot in Tallahassee, Florida in collaboration with Florida State University's Center for Autism and Related Disabilities (CARD) that tests the use of *First Sign* materials in training pediatric physicians. *First Signs* is about to launch a statewide pilot in Minnesota in April 2003 and is in discussions with organizations and state agencies from Illinois, California, and a few other states. To date, it has had inquiries from over 30 states about implementing its program. Of those medical practitioners attending the initial hands-on sessions in Minnesota, 100 will be identified to participate in a two-year research study to determine if and how they are improving screening in pediatric practice over time.

California

California is of special interest in that it is served through a statewide system of 21 regional centers that provide a wide array of services for California residents with developmental disabilities, the only state to be so organized. Individuals with ASD represent 11.2% (20,160) of the developmentally disabled population of 180,000. These centers are funded by a \$2.2 billion appropriation from the state including federal flow-through Medicaid funding. The funding to the individual centers is based on caseloads and special projects each handles. A separate contract is drawn up for each center. The Department of Developmental Services (DDS) <http://www.dds.ca.gov/> is responsible for designing, coordinating, and evaluating services, but the centers are private, non-profit corporations with their own governing boards. Some have their own endowments. The centers provide intake and assessments, but no other direct services. Direct services are contracted out and include speech therapy, occupational therapy, behavioral consultation and intensive behavioral services.

California also houses one of the country's five federally funded CADDREs. <http://www.cdc.gov/ncbddd/dd/aic/states/ca.htm> (The other four are in Colorado, Maryland, North Carolina, and Pennsylvania.) The Children's Health Act of 2000 directed the CDC to establish regional centers of excellence for ASDs and other developmental disabilities. California's CADDRE is conducting four major projects: monitoring activities to determine whether ASD is more common in some groups of children than in others, and whether the number is changing over time; finding causes of ASDs or factors that make it more likely a child will have an ASD; studying biomarkers in newborn blood specimens from children who are later diagnosed with autism and how autism is experienced in culturally specific communities; and sharing information about what is learned from these studies through mailings, conferences, scientific publications, and the Center's Web site.

An example of the wide-range of autism-related activity in this state is the collaboration of the California Departments of Education and Developmental Services to identify and promulgate *Best Practices for Designing and Delivering Effective Programs for Individuals with ASD*. <http://www.feap.org/CABP/default.htm> The purpose of the report was to define and clarify issues in providing appropriate and effective interventions for individuals with ASD and autism-related disorders, to identify "best practices" in the processes involved, and to encourage ongoing collaboration among all those responsible for providing services.

California also houses the Medical Investigation of Neurodevelopmental Disorders (M.I.N.D.) Institute at the University of California at Davis (UC Davis) <http://news.ucdmc.ucdavis.edu>, a unique interdisciplinary organization of parents, community leaders, researchers, clinicians and volunteers to study and treat autism and other neurodevelopmental disorders. It is one of two children's centers in the United States funded by the [National Institute of Environmental Health Sciences \(NIEHS\)](#) and the Environmental Protection Agency (EPA) at \$5 million for five years. The M.I.N.D. Institute recently found that the increase in the numbers of children being diagnosed with autism is real and not simply the product of improved identification techniques. http://news.ucdmc.ucdavis.edu/mindepi_study.html A 1999 report by the California DDS found a 273 percent increase in autism cases between 1987 and 1998. The report was the catalyst for the state Legislature and Gov. Gray Davis to direct DDS and the M.I.N.D. Institute to identify factors responsible for the increase, funding the effort with a \$1 million appropriation.

Another well-known institute in California is the Lovaas Institute for Early Intervention <http://www.lovaas.com/services/index.html> which is a research-based institute that specializes in teaching pre-school age children with autism, pervasive developmental disorders, and related developmental disabilities. Their evidenced-based, behavioral intervention program was developed in the Psychology Department of UCLA under the direction of Dr. Ivar Lovaas. It is based on extensive clinical experience and more than 35 years of scientific research.

California's United Autism Alliance (UAA) <http://www.unitedautismalliance.org/family/history.html> has been one of the largest and most active autism organizations in the country. It was founded in 1969 by parents who united to advocate on behalf of their children to prevent them from being placed in state institutions and to advocate for their inclusion in the public school system. UAA served over 6000 families in 2001. It is estimated that between 90,000 to 140,000 individuals are diagnosed with ASD in Los Angeles County.

Wisconsin

Although all states provide limited behavioral health services through Medicaid, Wisconsin has taken a leadership position in the expanded use of Medicaid dollars for mental health services for children, including those with ASDs. <http://www.dhfs.state.wi.us/medicaid7/providers.htm#medicaid> For instance, the state uses the Medicaid program to fund 100% of intensive in-home therapy by certified providers for children with ASDs. Starting with one provider, there are now 17 statewide.

The Wisconsin Early Autism Program (WEAP) <http://www.wiautism.com/index.html>, a non-profit agency begun in 1994, receives Medicaid dollars to fund treatment for any Wisconsin child with ASD three to five years old with an IQ over 35. Children up to the age of 14 are now being served. This service is so popular that parents of children with an ASD have been moving in from out-of-state to take advantage of it, in some cases putting such a heavy burden on school systems that there is now a one-year residency requirement. WEAP operates six clinics in Wisconsin and clinics in London, Vancouver, and Sidney, Australia. It also works

with individual children in other countries and several states. WEAP is linked with the Lovass Institute and has a NIMH program replication grant.

The Wisconsin Department of Instruction (DPI) offers an autism connection <http://www.dpi.state.wi.us/een/autism.html> which contains links to autism data and a booklet on Interventions and Strategies for Success. As a result of a statewide meeting of stakeholders ten years ago to discuss how autistic children could be better served by the educational system, DPI began funding sessions for teachers and administrators. The sessions have continually expanded and become self-sustaining through fee assessments. Also, a K-2 charter school exclusively for children with ASDs was opened a few years ago and the third grade will be added this year. More of these schools may be opened next year.

The Autism Society of Wisconsin maintains a Web site with extensive resources that are updated annually. <http://www.asw4autism.org/index.htm> The site lists 12 advocacy groups, statewide referrals for professional help, and programs such as *Wisconsin First Step*; provides a fact sheet for families; and covers everything from home schooling to travel.

WrapAround Milwaukee,

<http://milwaukeecounty.org/Service/organizationDetail.asp?org=6450&audience=5> serves very few children with ASDs, but is an exemplary model for coordinating services, pooling agency funds, maintaining and utilizing comprehensive data, and improving support needed in a cost-effective manner. The state has granted this organization HMO status, giving them complete flexibility in their treatment options.

Oregon

Caring for Oregon's Children with Autism Spectrum Disorder
Task Force Report, July 1, 2000

<http://www.ode.state.or.us/sped/spedareas/autism/finalrec1.pdf>

From 1991 to 1999, Oregon experienced nearly a 300% enrollment increase of students with autism. In 1999, out of a school-age population of 790,847, Oregon identified 2290 students with autism, representing 0.290 % of the school population and 3.446% of special education students. That same year, Oregon's Legislature established a task force to address issues surrounding services for children with ASD, specifically including: Oregon's Autism Implementation Plan; a state residential school, the implementation of a continuum of educational services, potential funding sources, and curricula.

Task force recommendations stressed the importance of individualization and educators having a full range of choice of effective educational options to meet diverse needs.

Recommendations include:

1. Create a three-level service delivery system:
 - a) A State ASD Development Center (ASDC) – the core of the system – to:
 - conduct and review research;
 - gather, evaluate, and disseminate information;

- provide parent training; and
 - develop and evaluate ASD services to enhance effectiveness;
 - b) Regional Autism Model Centers (RAMCs) to provide intensive training and model educational sites in eight regions of the state; and
 - c) Early Intervention/Early Childhood Special Education (EI/ECSE) and Local Educational Agencies (LEAs).
2. Recruit, train, and retain an adequate number of competent service providers.
 3. Provide appropriate public funding and fiscal accountability.
 4. Identify outstanding issues requiring legislative and administrative follow up including establishing a state residential school for students with ASDs; and improving intergovernmental and interagency cooperation.

Other barriers that the panel identified were: adversarial attitudes between districts and parents; delay in referral by physicians; caseload sizes being too large; special educators leaving the profession; and a lack of: adequate funding, trust in the system, pre-service and in-service training, standards, certification in autism, and agreement on best practices or research.

In summary, this brief look at activities taking place elsewhere in the country not only provides examples of resources that could prove helpful in supplementing Ohio's services to children with ASDs but also offers better insights into what is available in Ohio to meet the needs of those children. Better understanding of the organizations, funding, and infrastructure that exist outside the state can be instructive in putting Ohio's efforts into clearer perspective as next steps to improve services are contemplated.

VI. Concluding Comments and Policy Recommendations

As a result of compiling this program inventory of ASD-related services in Ohio, it is apparent that Ohio provides most of the major services provided by other states (special education, Medicaid and early intervention); however, it is also true that Ohio's service infrastructure is made complicated, and in some cases overly so, by the state's long history of local control. This means that service delivery and quality can be impacted significantly by services provided (or not provided) by local school districts and individual counties. There is also a need for greater ease of operation in terms of accessibility to ASD-related services, and greater accountability in terms of the use of public funds for these services. Finally, Ohio needs to provide consumers of ASD-related services more objective information concerning evidence-based best practice models, including early intensive behavioral intervention services. In addition to these system level insights, this report has highlighted many promising policies and practices being pursued by other states that deserve additional analysis and possible replication.

With these initial thoughts in mind, the following recommendations are provided to help parents, policymakers and practitioners gain greater clarity and understanding regarding effective steps that can be taken to improve publicly funded services to children with ASD in Ohio.

- 1. Address School Foundation Formula Issues Impacting ASD Pupils.** Although the school foundation formula provides substantial fiscal resources for pupils with ASD, it can be strengthened in ways to better fund and serve ASD and other disabled pupils. The state can improve the formula as follows:
 - **Fully fund the new six weight funding system:** In FY 2003, ASD and other disabled pupils receive only 87.5% of the cost-based weighted funding due to them because the state is phasing-in the new funding system. In the preceding year, disabled pupils only received 82.5% of weighted funding. *If the state had fully funded the new weighted system during the preceding school year (fiscal year 2002), ASD pupils would have received an additional \$4.4 million in state funding and \$6.2 million in local funding, for a total of \$10.6 million in increased aid. This total amounts to \$3,988 per ASD pupil in state and local funding.*
 - **Update the weights to account for new state and federal service requirements:** In 1982, neither the federal or state government recognized ASD as a disability. Because the cost-based weights were based on the state's rules in 1982, the new category six ASD weight does not account for state and federal requirements adopted in the past 23 years, including IDEA, which recognized ASD for the first time. The weights also do not account for new state rules adopted in 2002. In

order to ensure that ASD pupils and their families are receiving the full array of services available to them under both federal and state law, the weights need to be continually updated to include new requirements.

- **Ensure federal pupil counts are accurately reflected in the formula:** Every December, state departments of education are required to report to the federal Department of Education the number of special education pupils in their respective states. This is known as the “December pupil count.” In December 2001, the last pupil count available, the Ohio Department of Education reported it was serving 2,858 ASD pupils aged 6-21 under IDEA and another 334 pupils aged 3-5. For purposes of the school foundation formula, the state served a total of 2,659 ASD pupils (K-12). Of these pupils, 2,524 were enrolled in grades 1-12.

In school year 2001-2002, the state’s 2,659 ASD pupils generated an average per pupil amount of \$23,616 in state and local funding. According to the December child count however, the state served an additional 199 pupils (3,057 – 2,858). Assuming the state and local districts did serve 199 more ASD pupils, they would require an additional \$1.97 million in state weighted and base cost funding and \$2.73 million in local funding if they received the average per pupil amount of \$23,616. *These additional students would have generated a total of \$4.7 million in state and local funding!*

A potential reason for this discrepancy is that state education officials who “run” the formula must make assumptions about child counts long before the December count because of timing issues. In other words, the state needs to begin paying districts in July for the upcoming school year—five months prior to the December count. The discrepancy between the number of ASD pupils reported in the December child count and the number served through the formula raises important questions that should be answered however. For example, how can state education officials better estimate the number of ASD and other disabled pupils? What are the funding implications of undercounting ASD pupils? Are these additional pupils receiving any additional formula aid? Are these additional pupils being served by other state entities (i.e. County Boards of MR/DD)?

- **Increase utilization of catastrophic aid:** In the current school year, local districts have only applied for only \$5.9 million of \$15 million in available catastrophic aid. Given the profound needs of ASD and other disabled pupils a 39% utilization rate is unacceptable. Although the state has made strides in publicizing the availability of this funding, it needs to do more to ensure that this important money is spent serving the most profoundly disabled pupils in the state. In order to accomplish this goal, the state should do more to publicize this funding or consider revising the formula to provide a greater state share.

2. **Early Identification and Intervention.** Emphasize and provide more support for early diagnosis for children with a possible ASD; inform and educate physician community about ASD and the effectiveness of the CHAT diagnostic test. Provide

information about best practices, including the importance of early identification and the efficacy of intensive behavioral interventions.

- 3. ASD Statewide Resource Directory.** Create a comprehensive directory of publicly funded ASD-related services, programs, agencies and providers in Ohio. Update the directory regularly and make it accessible in hard copy and electronically on an interactive web site.
- 4. Data Management and Analysis.** Accurately track and report the number of children with ASD being served by all publicly funded agencies, the funds expended on their behalf, and the specific services that they are receiving.
- 5. Funding Alternatives.** Thoroughly review the funding sources that other states are able to access to help provide services to children with ASD and make these funds available to people with ASD in Ohio. The possibility of seeking additional federal Medicaid funds should be an important part of this analysis.
- 6. Inter-Agency Coordination.** Improve state agency coordination and collaboration to streamline services, combine resources and improve information sharing.
- 7. Regional Service Delivery.** Explore ways to improve regional delivery of ASD-related services. Review public/private partnership used by California to provide services to people with disabilities, including those with ASD.
- 8. Teacher Professional Development.** Strengthen in-service teacher professional development programs in an effort to enhance teacher understanding of the educational needs of children with ASD.
- 9. Parent Education and Advocacy.** Work with special education professionals and parent and professional advocacy organizations to educate parents regarding their rights and responsibilities (and those of their children) in the IEP (Individualized Education Plan) process, which is central to providing effective special education services for children with disabilities, including those with ASD. This effort should facilitate more productive, less adversarial relations between families and schools and more effective service delivery.
- 10. Further Analysis.** The following analyses would help policymakers, practitioners, and parents to build on this initial program inventory in an effort to improve services to people with ASD in Ohio:
 - Create a state government task force to investigate the growing incidence of ASD in Ohio and to review and make recommendations regarding needed improvements in the state's ASD-related service delivery system.
 - Conduct focus groups and surveys with policy makers, professionals, and practitioners, including ESCs, to identify ASD issues specific to Ohio,

including barriers to improved services and “best practice” models. This effort could be pursued as part of the proposed state task force or done separately (albeit in coordination with) the task force.

- Requesting an independent evaluation of ODE’s ASD pilot projects.
- Identify ASD policy issues that require legislative action and work with appropriate policymakers and ASD stakeholders as necessary to craft legislation.

APPENDICES

Appendix #1: ODE Weighted Funding in Detail

The Ohio Department of Education calculated the weights for the six categories of disabled pupils using a four-step process (formula) that factors in special education personnel salaries and state service levels for providing a free and appropriate public education:

- **Step 1:** Calculate the statewide average salary (plus benefits and a non-personnel allowance) for all personnel serving ASD pupils;
- **Step 2:** Use Blue Book service ratios to calculate the personnel cost per pupil. For example, the Blue Book prescribes a maximum pupil-to-teacher ratio of eight MH pupils per multi-handicapped teacher. Assuming the statewide average salary (plus benefits and a non-personnel allowance) for a MH teacher is \$40,000, the personnel cost per pupil is \$5,000 (\$40,000 cost of one MH teacher divided by eight MH pupils = \$5,000 per pupil). ODE performed this calculation for every personnel type assumed to serve ASD pupils using Blue Book ratios prescribed for MH students.
- **Step 3:** Add all the personnel costs per pupil (i.e. MH teacher, physical therapist, speech/language therapist) to calculate a total cost per pupil.
- **Step 4:** Divide the total cost per pupil by the base cost amount for the year in question. Assuming the total cost of serving an ASD pupil is \$25,000 and the base cost amount is \$5,000, the weight is 4.00 as calculated using the following formula: $\$25,000$ (total cost of ASD pupil) - $\$5,000$ (base cost amount) = $\$20,000$ (total cost of ASD pupil above the base cost amount) \div $\$5,000$ (base cost amount) = 4.00 (weight). Thus, an ASD pupil receives \$5,000 in base cost funding plus an extra amount equal to the base cost amount multiplied by a weight of 4.00, \$20,000.

For purposes of the cost-based analysis, ODE assumed that ASD pupils would benefit from the following classroom-based and related services.

- Classroom based services (teachers);
- Adapted physical education;
- Attendant services;
- Vocational services;
- Occupational therapy;
- Physical therapy;
- Supervisory services;
- Supplemental services;
- Speech/language assistance; and
- Work study services.

Of course, the above list does not comprise the entire range of services that ASD pupils receive as dictated by their individual education plans. The list is not exhaustive for four reasons. First, ODE employed a cost-based methodology in order to achieve legitimacy for enacting a new system. More specifically, the state analyzed the minimum personnel-delivered costs of meeting prescribed service levels for each disability category outlined in the Blue Book. Thus, if the Blue Book stated that districts should provide a MH teacher for every eight students, the cost-based methodology assumed the formula should fund this service level.

Given that there were no prescribed service levels for pupils with ASD, ODE made assumptions based on past experience and research to determine the services these pupils should receive within the parameters of the Blue Book. In some cases, these assumptions increased service levels (i.e. reduced the pupil-to-teacher ratio from 8:1 to 4:1) and decreased service levels (i.e. eliminated teacher aides because of the lower pupil-to-teacher ratio). Despite these minor adjustments, ODE did not contemplate services outside the realm of state rules because it may have undermined credibility for the new system. Alternatively, the state's analysis provides most of the personnel-delivered services available in the Blue Book to ASD pupils (similar to multi-handicapped pupils).

Second, the list only considers personnel costs. An ASD child's IEP may require assistive technology or other supplies. Given the lack of cost data available and near absence of minimum technology or supply standards, it was impossible to include these services in the weight. Instead, ODE asked the state to provide an additional pool of money for assistive technology and other necessary devices. The state did not fund this recommendation.

Third, the list is non-exhaustive because short of evaluating every pupil's IEP, there is no way to know the unique services (and costs) required by every ASD child. Obviously, it is impossible to survey every child's family to determine the services received because of data management and privacy issues. As a result, ODE assumed that all ASD pupils received a uniform level of service as based on the Blue Book even though one ASD child's IEP might require a very different educational program than that required by another. While this approach is imperfect, it is likely that some ASD pupils receive significantly more services than that provided by the baseline and others receive less. The inability to contemplate numerous additional services that ASD pupils may need does not absolve the state from paying these services by virtue of federal law. Where these services exceed \$30,000, ODE hopes that districts will utilize catastrophic aid.

Fourth, ODE recognized the state's rules did not include changes to special education laws and regulations as passed by Congress in 1997's IDEA. Given the substantial impact of IDEA on services provided to all special education pupils, ODE was hesitant to cost-out new federal rules for one pupil classification (i.e. ASD pupils), but not for others. Although the Blue Book should have been updated to reflect federal law changes at the time of the analysis, the state had yet to do so and thus many services that ASD pupils are eligible to receive were not included in the new system of weights.

As a result of these limitations, ODE felt compelled to cost-out traditional special education classroom and related services even though it knew the menu of services was outdated and non-comprehensive, particularly in regard to ASD. ODE recommended the state calculate the costs of classroom-based and related services required by IDEA, including ASD requirements, and any new state rules in subsequent years. ODE recently adopted new rules for the education of disabled pupils, but did not cost out the new rules for the next budget. In light of the cost implications of new state and not-so-new federal rules, the state should utilize the cost-based methodology to revise the weights accordingly.

Appendix #2: Catastrophic Funding

The former two weight, three category funding system instituted catastrophic aid—an additional pool of money designed to pay for the extreme costs of a small percentage of the most severely disabled special education students that cost districts more than \$25,000. Catastrophic aid was also intended to act as a “circuit breaker,” so that one or more extremely expensive pupils do not adversely impact local districts.

The initial system of catastrophic funding was limited to services for category three pupils: ASD, traumatic brain injured, and visually and hearing impaired. Similar to the base cost and weighted funding formulas, the state equalized catastrophic aid to districts. Thus, if a district received thirty percent of its base cost and weighted funding from the state, districts would receive thirty percent of the catastrophic costs exceeding \$25,000 from the state. The local district would be responsible for the remaining 70% of costs exceeding \$25,000. Additionally, districts were required to apply for these dollars by documenting the catastrophic costs of each individual pupil. Despite allocating \$14 million for catastrophic funding, local districts applied for less than \$2 million. According to state and local education officials, many local districts did not apply for aid because they were not familiar with the new funding source.

The new weighted funding system strengthened the catastrophic funding system in two ways. First, it expanded the eligibility for catastrophic funding to all disabled pupil classifications (except speech only disabled). Second, it changed the equalization formula to ensure districts receive a greater share of funding from the state. The new formula assures that the state provides a minimum of 50% of catastrophic aid. The remaining 50% is equalized using the state share percentage. Districts can apply for and receive catastrophic aid by documenting the individualized education plan costs of the student through an application process. If the IEP costs exceed the “threshold catastrophic cost” for the disability classification (i.e. ASD), then the pupil and the district are eligible for catastrophic aid. The threshold catastrophic cost for pupils with ASD is \$30,000 in fiscal year 2002 (school year 2001-02) and \$30,840 in fiscal year 2003 (\$30,000 multiplied by an inflation factor of 1.028).

Under the current catastrophic aid formula, the amount of funding an ASD pupil may receive is largely dependant on the costs of his or her IEP and the district’s state share. Using the example of an ASD pupil with an IEP costing \$50,000, living in a district that receives 50% of its funding from the state, the new formula generates \$15,000 in catastrophic funding in school year 2001-2002. More specifically, the state guarantees a minimum of half of the IEP costs exceeding the threshold catastrophic costs: $\$50,000 - \$30,000 = \$20,000 \times .50 = \$10,000$ state guarantee. In addition to this minimum catastrophic aid, the state provides the district an amount equal to the district’s state share multiplied by the other half of the student’s costs exceeding the threshold: $\$20,000 \text{ (excess)} \times .50 \times .50 = \$5,000$. All told, the pupil and district receive \$15,000 in additional catastrophic aid on top of both base cost and weighted funding.

Appendix #3: Demonstration Project Descriptions

2002 Successful Models and Demonstration Projects in Autism Spectrum Disorders

The 2002 Successful Models and Demonstration projects are funded through the Ohio Department of Education, Office for Exceptional Children. The purposes and outcomes of the projects are to identify and support current resources and programs that implement successful models and to build capacity of knowledgeable, qualified service providers through demonstration projects for the education of students with autism spectrum disorders.

Agency	Area of Focus	Collaborative Partners	Project Contact
Berlin – Milan Local (Erie Co)	Implement non-traditional approaches to improve academic expectations for achievement of students with ASD. Collaborate with local Autism Spectrum Kids Disorders support group to expand staff and parental knowledge base and understanding of autism	Berlin-Milan Elementary Berlin-Milan Middle School	Linda Moon Principal, Berlin-Milan Elementary
Bowling Green City Schools (Wood Co)	Increase the effectiveness of the summer autism program and expand the number of school personnel being trained to work with individuals with autism	Wood Co Autism Project BGSU Wood Co ESC Wood Co MR/DD	Belinda Rhoades Director, Special Needs Wood Co ESC
Buckeye Local (Medina Co)	Establish 1-2 ASD IAT teams from each of 4 local schools (up to 8 teams) to be comprised of parent, general and special education teacher, SLP, OT, guidance counselor, psychologist and paraprofessional ASD IATs will act as resources to parents and support to other districts	Highland Local Cloverleaf Local Black River Local	Margo Gibson-Costello Director, Special Education Buckeye Local
Canfield Local (Mahoning Co)	Increase parent and school collaboration. Establish educational support opportunities for parents as a group to address integration of communication/schedule systems within daily routines and support children behaviorally by development of appropriate communication systems/schedules	Hilltop Elementary	Christine Jackson Director, Special Services Canfield Local

Agency	Area of Focus	Collaborative Partners	Project Contact
Cardinal Local (Geauga Co)	Contract with consultant at Rich Center for Autism at Youngstown State University Conduct a comprehensive evaluative study of existing classroom clusters Encourage parents to become active partners to assist them in developing their skills and knowledge. Implement a comprehensive, intentional systematic data collection method	Berkshire Local Ledgemont Local Geauga Co MR/DD Youngstown State University	Sharon Knotek Special Education Director Geauga Co ESC
Cleveland Municipal (Cuyahoga Co)	Systematic use of daily communication notebooks across all service domains Monthly newsletter focused on information and updates related to ASD Parent training and support groups to enhance carry-over of learned skills Demonstrations of positive efforts of sensory movement activities and social language activities that promote calming, attending and communication to both general and special education students	District wide program	Carol Hanna Manager, Autism Program Cleveland Municipal
Cuyahoga Falls City (Summit Co)	Increase the number of children served in home district in LEA. Provide itinerant in-home service to support transference of skills to all environments Provide the community, other school districts, child-care providers, related service agencies with a "model center" for identification, strategy building, implementation and transference opportunities Increase our ability to support a student to transfer newly acquired skills to community settings	Woodridge School Tallmadge City Summit Co ESC MEO SERRC Kent State University	Drew Hinkle Director, Pupil Services Cuyahoga Falls City

Agency	Area of Focus	Collaborative Partners	Project Contact
Delaware/Union Co ESC (Delaware, Union Co)	Internship training opportunity with Children's Center for Developmental Enrichment Improve transition services provided to children and families moving from pre-K to kindergarten; and kindergarten to first grade	Children's Center for Developmental Enrichment	Marie Ward Delaware/Union Co ESC
Firelands Local (Lorain Co)	Increase related services 1:1 for individual students and training for general education teachers in meeting sensory needs of students Teachers will make home visits to coordinate school and home programs Increased emphasis on collection of data and improvement of students social skills	Firelands Elementary	Jean Hays Special Education Supervisor Firelands Local Barbara Harris School Psychologist Firelands Local
Hamilton Local (Franklin Co)	Increase access to and quality of participation in the general education learning environment for children with ASD Increase support and services to families of children with ASD Increase social and play skill development for students with ASD	Groveport-Madison Local Westerville City Worthington City	Judy Dymond Title/Grants Coordinator Hamilton Local
Howland Local (Trumbull Co)	Ongoing opportunities for professional development, expanding opportunities for networking among school district IEP teams, establish procedures for communication among service providers and between service providers and families	20 Trumbull Co LEAs Trumbull Co MR/DD	Dale Lennon Director, Pupil Personnel Trumbull Co ESC

Agency	Area of Focus	Collaborative Partners	Project Contact
Huron City (Erie Co)	Training teams of professionals, paraprofessionals and parents to serve as resource and support team. Provide a library of sensory, motor, communication and curricular materials Offer a social skills training series in collaboration with a local mental health provider	Woodlands Elementary McCormick Middle	Carol Janik Director, Special Education Huron City
Kenston Local (Geauga Co)	On-site therapists to work collaboratively with teachers, parents and paraprofessionals Provide opportunities for students with ASD and typically developing peers to interact in social and recreational settings to enhance life skills	West Geauga Local Chardon Local Newburg Local Geauga Co MR/DD	Rita Pressman Special Education Supervisor Kenston Local
Lakota Local (Butler Co)	Foundation of summer day camp to make substantial positive change in the communication skills of students with ASD Multi-media training presentation will be produced using interactions videotaped during the summer program	Adena Elementary	Vicki Curtis Director, Special Services Lakota Local
Louisville City (Stark Co)	Develop and train multidisciplinary support teams in 4 districts Provide intensive services to 5 students per district with consultative support Provide advanced training for teams in designing effective programs for children and youth with ASD Develop parent education and support meetings and resources	Perry Local Jackson Local Plain Local	Karen Best Director, Special Programs Louisville City

Agency	Area of Focus	Collaborative Partners	Project Contact
Lynchburg-Clay Local (Highland Co)	Increase capacity of local early childhood providers to serve students with ASD Increase capacity and knowledge general ed staff, special ed support staff and aides currently serving students with ASD and those projected to serve next school year. Increase knowledge of transition service providers regarding autism. Develop a forum on Hopewell SERRC website to address instructional issues for students with ASD	Hopewell SERRC Miami Trace Local Washington Court House City Schools	Nikki Green Autism Consultant Hopewell SERRC
Madison Local (Richland Co)	Create and provide ESY to preschool and school age students with autism Integrate components of structured teaching Increase the percentage of children with autism served in general education classes Assist parents and schools to work collaboratively	Jesse Beer Elementary Mifflin Elementary Eastview Elementary Wooster Heights Middle School South High School	Toni Miller Director, Special Services Madison Local
Mentor EV (Lake Co)	All substitute teachers and paraprofessionals will have a basic understanding of autism Promote greater independence of students with autism by decreasing the amount of assistance needed by paraprofessionals in the regular classroom. Provide resources for parents and teachers to make materials and adapt materials by students with autism. Provide on-going professional development and opportunities for collaboration with educators and families	Hopkins Elementary Sterling Morton Elementary Shore Junior High Memorial Junior High	Patricia Cronin Coordinator, Special Education Mentor EV

Agency	Area of Focus	Collaborative Partners	Project Contact
M.O.D.E.L. Community School (Lucas Co)	Increase awareness of functional communication techniques that assist with behavior management and prevention of severe behaviors Increase knowledge and practical application techniques for visual and multi-sensory teaching to students with ASD Seamless transitions for students with ASD from separate facilities with typical peers	Autism Academy of Learning Community School Lucas Co ESC	Mary Walters Director M.O.D.E.L. Community School
Northwestern Local (Clark Co)	Link activities and efforts of education providers, family members and community service providers throughout Clark County. Analyze behaviors which impact student learning and social interaction to formulate positive behavior interventions and address behavioral concerns Select and utilize technology/assistive technology to facilitate individual goal attainment Build capacity in students to interact in social settings through social skills instruction Build teams of parents and school personnel capable of creating appropriate learning plans designed to assist students in the development of academic and social skills	Tecumseh Local Greenon Local Clark-Shawnee Local Northeastern Local Southeastern Local	Fred Breyer Superintendent Northwestern Local Phil Fraley Clark Co ESC
Ohio Valley Local (Adams Co)	Study group for parents, professionals, paraprofessionals, community stakeholders Workshops on social skills development, behavior management, technology	Woodland Elementary West Union Elementary West Union High School Oliver School Hopewell SERRC	Laurel Hamilton Low Incidence Coordinator Ohio Valley Local

Agency	Area of Focus	Collaborative Partners	Project Contact
Pymatuning Valley Local (Ashtabula Co)	Professional development for teachers and teacher aides in communication and assistive technology Provide students with ASD effective classrooms where instructional activities enable them to participate fully	Pymatuning Valley Primary Pymatuning Valley Middle	Patricia Kloosterman Supervisor, Special Education Services Ashtabula Co ESC
Revere Local (Summit Co)	Focused opportunities for smooth transition from integrated preschool setting to kindergarten. 5 week summer social skills camp for maintenance of skills and the prevention of objective regression	Hillcrest Elementary	Cynthia Ratkovich Director, Student Services Revere Local
Teays Valley Local (Pickaway Co)	Establish child-centered communications between home and school. Promote collaboration among all stakeholders for the enhancement of service delivery and instruction. Increase community awareness of ASD	Ashville Preschool Ashville Elementary Scioto Elementary Teays Valley Middle School	Anne Wisniowski Supervisor, Special Needs Programs Teays Valley Local
Tri-County ESC (Ashland, Wayne, Holmes Co)	Expand and strengthen preschool program Circle of Sharing that has 3 components - a play therapy group, parent support group and resource center.	Tri-Co Cooperative Preschool – Ashland & Wayne Counties	Irma Hardesty Director of Preschool for Ashland County Tri-County ESC
Warren Local (Washington Co)	Pilot project to compare methodologies DTT and social stories with sound field application	Barlow-Vincent Elementary Little Hocking Elementary Cutler Elementary Warren Elementary Marietta College Washington Co ESC, SE Ohio SERRC BitterSweet Farms Autism Society of NW Ohio	Bill Bauer Director, Special Education Warren Local

Appendix #4: Educational Entity Service Delivery Regions

Educational Service Centers



Appendix #4: Educational Entity Service Delivery Regions (continued)

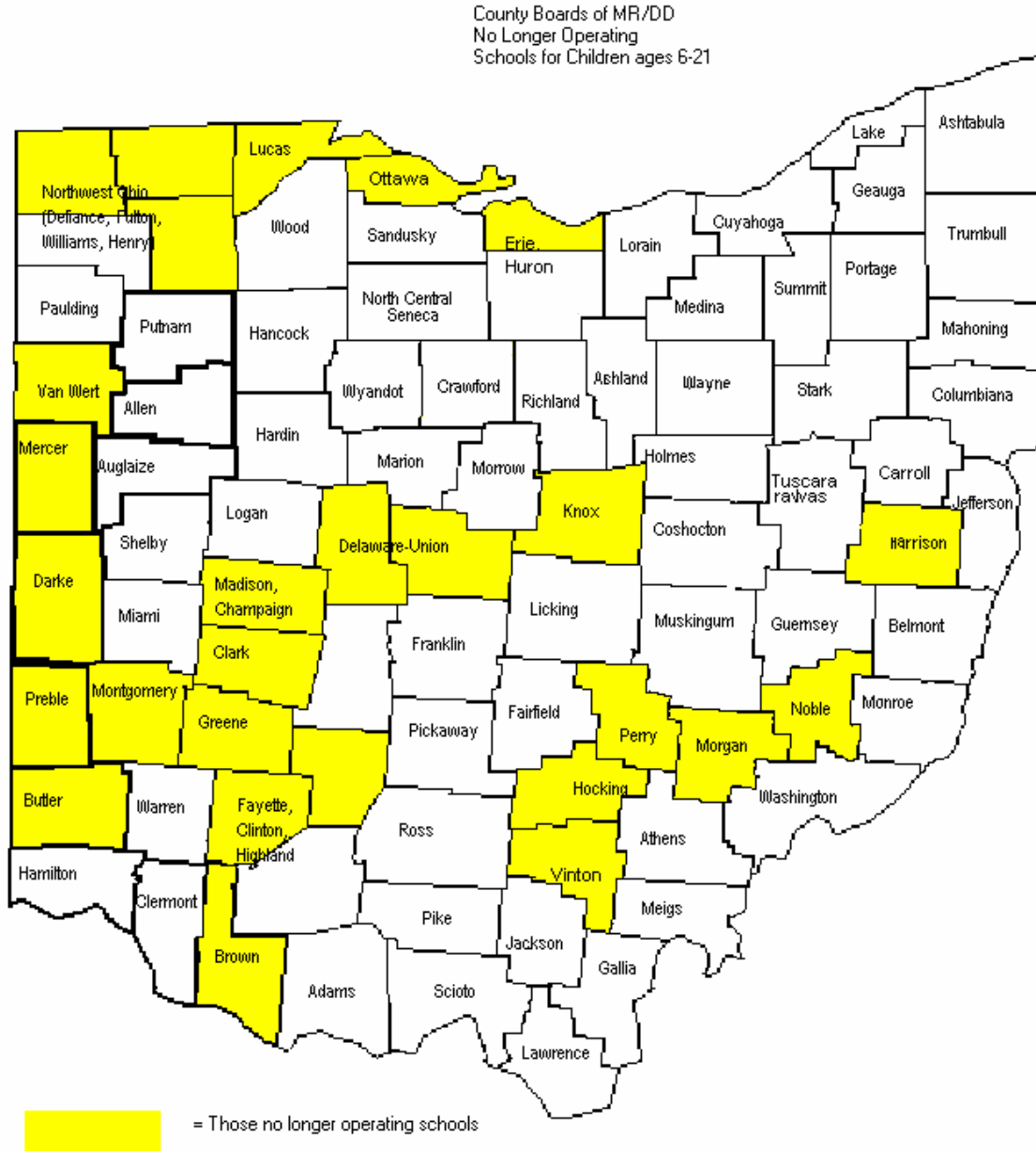
Special Education Regional Resource Centers (SERRCs)

State Map



Appendix #4: Educational Entity Service Delivery Regions (continued)

Children’s Services in Ohio County Boards of MR/DD



August 2002