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AUTISM
TASK FORCE REPORT

A Report to the 1999 Minnesota Legislature

Minnesota Department of Human Services
Minnesota Department of Children, Families & Learning
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LEGISLATIVE DIRECTIVE

The task force was assembled according to the following mandate of the 1997 Legislature:

The Commissioner of Human Services and the Commissioner of Children, Families and Learning shall establish a task force to study the treatment of autism. The task force shall consist of providers, advocates, and consumers of services to children affected by autism. The terms and compensation of the members shall be described under Minnesota Statutes, Section 15.059, subdivision 6.

Subd. 2. [Duties.] The advisory task force shall meet on a regular basis to study the following:

(1) the spectrum of autistic disorders;

(2) treatment options for autism, including behavioral therapy, and outcome data on these treatment options;

(3) the role of the schools, appropriate state agencies, and counties in providing services to children with autism;

(4) Funding flexibility options for services to children with autism, including the use of state funds to provide behavioral therapy; and

(5) the use of behavioral therapy day treatment programs and the use of school and medical assistance funds for these programs.

Subd. 3. [REPORT.] The task force shall provide the commissioner of human services with the findings of the study by December 15, 1998. The commissioner of human services shall submit a preliminary report to the legislature by January 15, 1998, on the progress of the task force study. The commissioner shall submit a final report to the legislature by January 15, 1999, on recommendations to improve the treatment options available to children with autism within the current available funding. The final report must include recommendations on how to inform and educate families with autistic children on available expertise and resources on the treatment of autism. The task force expires upon submission of its report.

EXECUTIVE SUMMARY

A legislatively mandated task force was formed to study issues pertaining to treatment options, the roles of schools, counties and state agencies and the funding of services for children with autism. The membership consisted of a diverse group of representatives from throughout Minnesota that included state and local public agency personnel, parents, providers and advocates (Appendix 1). The task force convened in September, 1997 and met monthly through January, 1999 to complete its charge. The results of the second phase of study, completed in 1998, are reflected in this report. This summary contains recommendations to improve the treatment options available to children with autism within currently available funding and recommendations which relate to informing and educating providers of service and families on available expertise and resources are also presented.

Based upon literature reviews and presentations by national and state experts, the task force determined that autism is better defined and understood when viewed as a spectrum disorder. This approach acknowledges that the symptoms and characteristics of autism can present themselves in a wide variety of combinations from mild to severe. The critical characteristics include significant impairments in social interaction and communication, as well as a restricted range of interests or repetitive behaviors, with an onset before three years of age. Although autism is defined by a certain set of behaviors, children and adults can exhibit any combination of the behaviors in any degree of severity. Two children, both with a diagnosis of autism, can act very differently from one another. The term autism is represented throughout this report with the term Autism Spectrum Disorder (ASD).

Dr. Greenstein, a national expert in the diagnosis of ASD, highlighted for the task force the increase in the incidence of ASD and defined the qualitative difference in learning and behavior for those with the diagnosis. Dr. Greenstein identified the hallmarks of methods that have been proven effective for children with ASD. These include engagement in activity, activities that are reproducible in other settings, a focus on linguistic abilities, and methods that explicitly address social needs. Research and professional experience support that accurate, early identification of the disability and the specific needs of each child lead to individualized and more effective intervention.

A majority of the task force efforts were directed toward the analysis of treatment options. Research conducted in the last two decades in the area of ASD intervention has indicated (a) significant acceleration of development rates, resulting in significant IQ gains; (b) significant language gains; and, (c) improved social behavior and decreased symptoms of ASD. These outcomes were accomplished during one to two years of intensive preschool intervention.

Following the study of various treatments available to children with ASD, the task force agreed that there are common elements of effectiveness regardless of the methodology of intervention.

The most common elements of effectiveness include family involvement, intensity of intervention and appropriately trained staff.

Historically, public education and social service programs have supported a philosophy that services should facilitate families in rearing children with disabilities within their homes. This has prompted social service agencies to develop respite care and in-home services and support. This philosophy has required both public schools and social service providers to identify methodologies to help children with ASD reach their potential and live in the community.

Multiple agencies and programs have roles and responsibilities in the provision and payment of services for children with ASD and their families. The agencies and programs discussed by the task force provide and pay for a significant amount of services for this population. They also share a focus on services to children with disabilities (eligibility is disability based) and have missions that promote self-sufficiency and independence. Self-sufficiency for children with ASD involves supporting the family's ability to keep the child in the home as well as supporting independence in the context of development and health.

The array of funding sources and options is complex. The task force found that a variety of services are accessed from multiple programs and agencies. Data demonstrates that funding for necessary services is categorical and program based, which negatively impacts access and management of funds and resources. The data demonstrates that children can access multiple sources and combinations of programs and payment sources to meet their needs. This process, however, is cumbersome, difficult to navigate and time consuming to manage. Most children with ASD meet the criteria for eligibility in multiple categories of Medical Assistance (MA) funding, but may actually access reimbursement through only one funding stream.

Services vary throughout the state due to the lack of resources for such things as personnel, experts and funding. For example, while day treatment services are available, there are few providers of day treatment that focus on young people with ASD. These children frequently require individualized training and support in the home and throughout the community. The needs of children with ASD conflict with the current day treatment model of intervention. It is apparent that enhanced interagency coordination must occur to effectively meet the complex needs of children with ASD.

The task force generated a variety of recommendations including the expansion of interagency coordination and the intensity of services. They also recommend that funding be coordinated, family support and education be increased and educational outreach be established.

The Commissioners of the Departments of Human Services (DHS) and Children, Families and Learning (CFL) endorse the recommendations that can be accomplished within current and proposed budget expectations. The legislative directive requires recommendations be implemented "within the current available funding." Therefore, recommendations which are not budget neutral and/or which will require significant policy considerations, are noted separately in the body of the report and identified as additional task force recommendations.

- A single intake process should be developed and used by all agencies serving children with Autism Spectrum Disorder (ASD).
- The Department of Children, Families and Learning's entrance criteria for Autism eligibility should be revised to reflect current research and practice.
- Access to Child and Teen Check-Up funding (EPSDT) should be clarified by the Department of Human Services to enhance treatment options.
- Training and technical assistance on Autism Spectrum Disorder and how to access available funding should be provided to county personnel by the Department of Human Services.
- A jointly convened state work group which includes family, advocate and professional representation should be formed to develop best practices and personnel standards relating to services and treatments for children with Autism Spectrum Disorder.
- The efforts of the Minnesota Autism Network should continue to be supported by the Department of Children, Families and Learning.

INTRODUCTION

This report presents the work and findings of the Autism Task Force. The report highlights recommendations addressing the legislative charge to improve the treatment options available to children with Autism Spectrum Disorder (ASD) and to inform and educate families on available expertise and resources for the treatment of ASD. The task force generated recommendations that are within currently available funding resources, and recommendations that will require additional funds and policy considerations.

The report addresses the scope of the task force efforts and provides an in-depth explanation on the spectrum of autism to clarify the range and variety of conditions that are included in the study and recommendations. Treatment options are presented and distinct methodologies are summarized.

The report presents an overview of the role of schools, state agencies and counties in the funding and delivery of services for children with ASD. This explanation is followed by an overview of the multiple funding mechanisms available for treatment. The treatment modality, behavioral day treatment, and the critical need for information and education are addressed as legislatively mandated.

The body of the report concludes with the presentation of recommendations developed by the task force. Recommendations focus on the need to:

- ✦ Improve treatment options including
    - Expanding the quality and intensity of services; and
    - Expanding interagency responsibilities and improving coordination between agencies and providers.
- ✦ Provide information and education including
    - Coordinating funding and improving access to resources;
    - Increasing opportunities for family support; and
    - Disseminating information.

The task force recommendations presented in the Executive Summary Section meet the legislative requirement for budget neutrality. Recommendations which require policy consideration and additional funding to implement are also included in the text of the report. Within the report, recommendations are divided into two categories: (1) "Recommendations from the Commissioner", and (2) "Additional Task Force Recommendations." Each recommendation is presented within the section pertaining to the subject matter that generated the recommendation. Task force members feel strongly that implementation of all recommendations will have a positive effect on children with ASD and their families. Therefore, recommendations in entirety are outlined at the conclusion of the report.

SCOPE OF THE TASK FORCE: 1998

The 1997 Legislature authorized the Commissioners of Human Services and of Children, Families & Learning to establish a task force to study the treatment of autism. The legislation was prompted by:

- The increase in the number of children diagnosed with autism in Minnesota;
- The complexities of the diagnosis;
- The multitude of treatment options and funding sources;
- The lack of coordination among services and funding;
- Increased concern among parents that children with autism receive appropriate services.

The legislative directive specified a two-stage process, the first to be completed in 1997 and the second in 1998. The first stage of the process was completed in December 1997 and resulted in a February 15, 1998 report to the legislature entitled the "Autism Task Force Report." This report reviewed the current status of ASD, treatment options and methods, the scope of funding resources and the role of education, state, county and private agencies in providing services to children with ASD.

The task force determined that autism is better defined and understood when viewed as a spectrum disorder. The term autism is therefore represented throughout this report with the term Autism Spectrum Disorder (ASD). The task force concurred that there are three critical elements in services to children with ASD: early intervention; high intensity treatment; and the need for parent and agency involvement. The task force focused their study and recommendations toward young children with ASD ages birth through eight years. The second stage of the task force was devoted to further study and development of recommendations. The group met monthly in 1998 in order to accomplish its charge.

The 1997 legislature also established a task force to study and design flexible funding options for personal care services, a service frequently used in the care of children with ASD. The Department of Human Services staff person for the Autism Task Force served as a member of the PCA Task Force which met concurrently with the Autism Task Force. The PCA Task Force is addressing how personal care services can be more responsive to better meet needs and preferences.

Programs and Methods

The task force conducted an in-depth study of ASD and the various treatment methodologies and programs employed to meet the complex needs of children diagnosed with ASD. A wide variety of information was studied and discussed prior to the development of recommendations. Program and methodologies studied included:

- Applied Behavior Analysis, Discreet Trial Training and Variations (Lovaas);
- Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH);

- Picture Exchange System (PECS);
- Sensory integration;
- Developmental;
- Relationship based approaches;
- Educational programs based in county and school settings.

Autism Spectrum Disorder

Dr. Greenstein, an expert in the diagnosis of ASD, provided a presentation regarding the spectrum of the disorder which focused on the increase in the incidence of ASD and the qualitative differences in learning and behavior for those with the diagnosis. Dr. Greenstein identified the hallmarks of methods that have proven effective with children with ASD. These hallmarks include: engagement in activity, activities that are reproducible in other settings, a focus on linguistic abilities, and methods that explicitly address social needs.

Data Collection

The task force reviewed data from education and human services regarding the number of persons identified with the diagnosis of ASD, the number of persons served and the costs and variety of services. This information was utilized to develop recommendations to better meet the needs of children with ASD.

The task force, with the assistance of Fraser Child & Family Center, completed a survey of families with children with ASD in 1997-1998. The purpose of the survey was to gather information regarding the services available, desired and received by persons with ASD (Appendix 7). The survey was returned by 345 respondents. Four of the surveys were excluded due to the age of the child with ASD.

The survey was completed primarily by parents. The average age of the children of respondents was 5.6 years with 83% being male and 17% being female. Residents of 60 counties in Minnesota responded, with Dakota, Ramsey and Hennepin providing 43% of the responses. Results of the survey indicated:

- Psychologists are the primary source of first identification.
- The majority of children were diagnosed with autism (57%) or PDD (31%). Other diagnoses included Aspergers, bi-polar with Pervasive Developmental Disorder (PDD), complex language disorder, etc.
- Many children were receiving early intervention service when they were identified.
- Early intervention services were provided at 2.7 years on average compared to the average identification age of 3.17 years.
- Early childhood special education was the primary category used to identify children for special education services.
- The majority of children attended a special education classroom with other special education students and spent a portion of the day in regular education sites.
- The primary instruction methods reported were sensory integration, social skills training and use of picture exchange systems.

- Approximately half of the respondents reported receiving services from county social services and having a county case manger.
- Teachers were the primary contact for parents to locate and learn about services.
- The majority of families (64%) had a financial worker and approximately half were enrolled in MA.
- The services most frequently accessed by families included respite care, home care, rehabilitation services, psychological assessment and home-based skills training.

Task Force Subgroup Reports

A number of subgroups of the task force were formed to study multiple topics and prepare recommendations for task force consideration. Each subgroup's work and recommendations were reviewed by the task force and components on which consensus was obtained are incorporated into this report. The primary activities of the subgroups were:

- State Reports: Review of reports from other states on ASD to determine a method for addressing the array of treatment methodologies and intervention strategies in this report.
- Funding: Identification of issues regarding funding for services in Minnesota. The Department of Children, Families & Learning (CFL), Minnesota Department of Health (MDH) and Department of Human Services (DHS) data regarding the costs of services were reviewed. Recommendations for funding options available to children with ASD were identified.
- Services and agencies: Services available by agency were reviewed. Services unique to children with ASD were identified.

Assumptions

The task force agreed upon parameters surrounding the scope of their charge. The legislation specified that recommendations should be provided within current available funding and limits. The task force members developed recommendations that utilize current funding streams in ways not previously accessed but within current funding limits. The task force further agreed that maximum use of complete MA programs and funds, private and public health plan benefits, and state and local funding is necessary to meet the needs of children diagnosed with ASD. The following assumptions and broad-based statements were utilized in developing recommendations.

- Autism is a complex and treatable disorder. The identification of ASD, whether made medically or educationally, should be shared with the parent and/or guardian and Individualized Family Service Plan (IFSP) team members as soon as possible. Early diagnosis is critical for appropriate intervention and meaningful outcomes for children with ASD.

- ASD has a biological basis which falls within the purview of both health care plans and mental health subsidiaries.

- All financial resources must follow the child's needs - versus a category of service or diagnosis - and should reinforce efforts to improve diagnostic schemes to better match developmental needs of children.

- Necessary year-round services should be available from a variety of providers.
- The determination of intervention methods for each child should be made using a team process.
- Early intervention and in-home care can result in a vast cost savings over the costs of institutionalized care. Early intervention and in-home care build capacity and skills in a parent rearing a child with a complex disorder.
- An interagency coordinated system of outreach, assessment, treatment/services, case management and evaluation is necessary for children with ASD and their families.
- Coordinated efforts between families, agencies, and providers should include the family at the center of the planning process, support which is sensitive to the varying needs of individual families, information sharing and data collection.
- Social service personnel, including county case mangers and financial workers, require comprehensive training in the complexities surrounding ASD as well as available resources. Agency and cross-discipline training on collaboration will insure more appropriate service delivery.
- Home based services are an important component of a child's comprehensive service plan.
- Informed consent regarding costs, outcomes, equal rights and advocacy is required to enable parents to make choices based on options available.
- Families should know that choosing to limit the use of public payment resources and options may in turn limit the range of services and options for their child.
- The recommendations made by this task force will only occur as a result of system change.

REPORT ON THE SPECTRUM OF AUTISM

Introduction

The task force studied current information regarding the spectrum of autism as directed by the legislation. It was agreed that a common description of the children under discussion was essential to begin understanding the complex issues related to identification and subsequently to intervention methods and funding.

Historical Perspective

Since 1943 when autism was first described, the professional and public understanding of this complex disorder has grown. Leo Kanner first described this condition in a small group of young children. At the same time, Hans Asperger was describing a similar and seemingly related condition in a different group of children. Kanner coined the term "autism" to describe his group; Asperger's group carried his name. Children in both groups demonstrated difficulties in their ability to communicate, play or relate to others, and had a narrow range of interests. In the years that followed, professionals have attempted to more clearly understand the differences and similarities in the types of children that Kanner and Asperger had described. While assessment and diagnostic methods have improved, the following difficulties remain in identification.

Identification Issues

- The terms used to identify the condition often change. Efforts to more clearly describe and identify these children have resulted in various terms and criteria being established and revised, and subgroups being added. Various terms used historically in medicine, psychiatry and education have included Childhood Autism, Atypical Autism, Pervasive Developmental Disorder: Not Otherwise Specified (PDD:NOS), Autistic Disorder, Childhood Schizophrenia, High Functioning Autism, Low Functioning Autism, Asperger's Syndrome, and others.

- Individual differences occur along a continuum or spectrum. Research and professional experience supports the fact that the clinical picture of autism varies across individuals, especially in preschool years. There is often a lack of understanding or misidentification of the disability. The parents of these children are often told that their child is oppositional, defiant, emotionally disturbed, obsessive compulsive, learning disabled, speech delayed or mentally retarded.

- Autism can occur in association with other disorders and disabilities such as mental retardation, sensory impairments, Fragile X Syndrome, obsessive-compulsive disorders, epilepsy or other medical conditions, making proper identification critical.

- Effective interventions may be delayed without proper identification. Diagnosticians lacking experience may not identify the critical features and needs associated with the disorder and thus delay effective early interventions.

Autism as a Spectrum Disorder

It is widely believed today that autism is better understood as a spectrum disorder, meaning the symptoms and characteristics of autism can present themselves in a wide variety of combinations from mild to severe. Although autism is defined by a certain set of behaviors, children and adults can exhibit any combination of the behaviors in any degree of severity. Two children, both with a diagnosis of autism, can act very differently from one another. One child may demonstrate average cognitive development and some academic success yet still have significant functional, social and communication needs, while another child may experience extreme difficulties and inconsistencies with learning. Research and professional experience support that accurate, early identification of the disability and the specific needs of each child leads to individualized and more effective intervention.

- The term "Autism Spectrum Disorders" generally refers to the five diagnostic categories described in the current Diagnostic and Statistical Manual (DSM4) under the section Pervasive Developmental Disorders. These individual disorders are Autistic Disorder, Childhood Disintegrative Disorder, Asperger's Disorder, Rett's Disorder, and Pervasive Developmental Disorder: Not Otherwise Specified (PDD:NOS). For purposes of clarity, the use of the term "autism" in this report refers to the Autism Spectrum Disorders (ASD), unless specifically stated otherwise.

- In light of the numerous terms, definitions (see Appendix 2) and complex nature of this disability, the task force agreed that the term "Autism Spectrum Disorders" (ASD) most clearly defines the critical features in the group of children under discussion. The critical features occur before three years of age and include significant impairments in social interaction, communication and a restricted range of interests or repetitive behaviors.

- Autism is currently understood as a developmental disability. Current research suggests it is a neurologically based syndrome described by a pattern of behavioral characteristics. The syndrome is not caused by poor parenting or any other psychological influences in a child's life.

- Research summarized by Mark Greenstein, M.D., developmental pediatrician and geneticist, indicates that scientists have not yet found a specific cause for autism. Evidence indicates that there are genetic factors involved and that there are biological and/or neurological differences in the brains of individuals with autism.

- Autism is considered a "low incidence" disability but it is the third most common developmental disability, after cerebral palsy and mental retardation. It is four times more common in boys than girls and occurs more frequently than Down's syndrome, blindness or childhood cancer.

- The National Institute of Child Health and Human Development (NICHHD) reported new incidence figures in 1998. Considering the broader spectrum of the disorder,

projected incidence rates range anywhere from 7 to 48 per 10,000 births.
Marie Bristol-Powers, Ph.D., NICHHD Director, reported the following figures to the Autism Society of America in July, 1998:

- Less than 1 in 666 individuals with "classic" Autism;
- Less than 1 in 500 individuals when combining Autism and Pervasive Developmental Disorders: Not Otherwise Specified (PDD:NOS); and
- Less than 1 in 200 individuals when combining Autism, PDD:NOS and Asperger's Disorder.

- The most recent child count data reported by school districts to CFL on December 1, 1997 indicates that 1283 children (birth-22 years of age) meet the educational criteria for the Autism category (see Appendix 4). These students receive special education services as determined by their Individualized Educational Plan (IEP) or Individualized Family Service Plan (IFSP) teams. This figure does not reflect a complete count due to several factors. Young children with Autism may be counted and receive services when they meet criteria under Early Childhood Special Education (see Appendix 4). Very young children are sometimes difficult to identify; others may be incorrectly identified.

- Applying the most recent NICHHD rates to Minnesota, estimates can be projected regarding the number of individuals with this disability in the state. Based on the total student enrollment reported December 1, 1997, Minnesota is home to 933,516 individuals birth-22 years. Applying an estimated rate of 1 in 666 to this total, there are potentially 1402 students with Autism. If we consider the incidence rate of 1 in 500, the potential number of students identified with autism and PDD:NOS increases to 1867. When we also include individuals with Asperger's Syndrome and use the 1 in 200 incidence rate, the estimated number reaches 4667 students from birth to 22 years.

- When considering a population estimate of 420,000 for the birth-8 year old age group and applying the rate of 1 per 500 births, there are possibly 840 young children with Autism and PDD:NOS in Minnesota. The actual child count reported for this age group was 587 children.

- In Minnesota the incidence rate for the autism category has increased by approximately 20% in each of the last six years. While it is impossible using current data systems to determine a true incidence rate of Autism Spectrum Disorders in Minnesota, this rate of increase is consistent with national figures/trends and is expected to continue as this has been an under-identified disorder.

- While there is general agreement that Autism Spectrum Disorders are on the rise, it is unclear why. Better identification methods and better-trained professionals certainly contribute to this increase but some speculate that there may be some undetermined factors that continued research may identify.

Eligibility and Agency Issues

There are different eligibility criteria established by various state agencies and private insurance providers for children with ASD. The process for accessing services and funding mechanisms available for these children is complex. This adds to the confusion of parents and staff who are already faced with a multitude of challenges in providing for a child with an ASD.

- Access to public and private services may be delayed due to the lack of understanding of the multiple access points and variable eligibility criteria utilized by various agencies.

- Understanding of ASD by some schools, counties, private providers, the medical community and the general community is also limited. Institutes of higher education do not currently have training programs that prepare staff to better understand and address the needs of these individuals. CFL has begun initial efforts to collaborate with institutes of higher education.

Recommendation from the Commissioner

- The Department of Children, Families and Learning's entrance criteria for Autism eligibility should be revised to reflect current research and practice.

  The revised criteria should be consistent with the current research and understanding in the field, should recognize the range and spectrum of autism and pervasive developmental disorders (i.e. Autism Spectrum Disorders), should be consistent with the broader federal definition and should establish criteria for special education eligibility in Minnesota under the category of autism.

TREATMENT METHODOLOGIES

Introduction

Since PL 94-142 assured the education of children with autism in 1975 and PL 99-457 mandated early intervention for young children with autism in 1994, public education services have led community service delivery for children with ASD in Minnesota. Historically, public education programs have supported a philosophy that services should facilitate families in raising children with disabilities within their homes. This belief prompted social service agencies to develop in-home support, respite care, and living services. This philosophy has required both public schools and social service providers to find methodologies which could help children with ASD to reach their potential and to grow up living in the community. Prior to 1975, approximately 95% of individuals with autism were institutionalized.

Throughout the 1980's and 1990's, information on effective intervention methodologies came from research centers at universities throughout the United States. The published findings have refuted the commonly held view that children with ASD are not treatable and cannot be expected to improve. In fact, all the children with ASD showed improvement with effective treatment and some improved so significantly that they were able to attend regular education classes without support. Efforts are underway to replicate some of these encouraging findings. The message from this research is one of hope and challenges current public policy and service delivery in Minnesota.

Research Findings

Research conducted over the last two decades in the area of early intervention in ASD was reported by Sally Rogers, Ph.D., University of Colorado, Health Sciences Center, at a working conference on the State of Science in Autism held at the National Institutes of Health in 1995. The summary of six comprehensive early intervention studies reported (a) significant acceleration of developmental rates, resulting in significant IQ gains, (b) significant language gains, and (c) improved social behavior and decreased symptoms of autism. These gains were accomplished within one to two years of intensive preschool intervention. The majority of treated children (73%) had useful speech by the end of the intervention period (generally age five). [Fenske, et al (1985); Lovaas (1987); and McEachlin, Smith, and Lovaas (1993); Hoyson, Jamieson, and Strain (1984); Rogers and Lewis (1989) and Rogers and DiLala (1991); Harris, Handleman, Kristoff, Bass, and Gordon (1990); and Anderson, Avery, Dipietro, Edwards, and Christian (1987)]

Eight clinical program models of intensive early intervention for children with ASD in the United States have been active since 1980. In 1997, Dawson and Osterling provided a review of these programs and summarized common elements reported by these effective programs. The programs are: the Douglass Developmental Disabilities Center, Rutgers University; Health Sciences Center, University of Colorado; May Institute, Boston; Princeton Child Development Institute, Princeton, New Jersey; Treatment and Education of Autistic and Communication-Handicapped Children (TEACCH), University of North Carolina; Young Autism Program, (Lovaas) University of California; Learning Experiences

- An Alternative Program for Preschoolers and Parents; and Walden Preschool, Emory University School of Medicine. [The Effectiveness of Early Intervention, edited by M. Guralnick, Ph.D.; chapter by Geraldine Dawson and Julie Osterling (1997)]

These programs reviewed the overall progress of 150 young children with ASD. Of the six programs that reported placement data, four reported that approximately 50% of the children were able to be integrated into a general classroom by the end of the intervention. All children made, on average, an IQ gain of approximately 20 points. Although no study has been completed comparing two or more intensive programs and methods with each other, the findings were impressive and underscore the need for continuing scientific studies.

Additional research studies in the past fifteen years have provided evidence for the biological basis for ASD as reported at the National Institutes of Health's (NIH) Autism State-of-the-Science Conference (Bristol, et.al., 1996). Information from neuropathology indicated that there may be abnormalities in the amygdala, hippocampus, septum, mamillary bodies, and the cerebellum. These findings were linked to studies that revealed problems in ASD with certain aspects of higher order cognitive functions, encoding of complex information, and attention functioning. In addition, there is now general agreement that sharing attention and emotions with others is specifically and universally impaired in children with ASD (Sigman).

Effective Methodologies

The results of the research findings on early intervention for young children with ASD lead one to ask what methods were effective. Although it is true that services for young children must be tailored to individual abilities, interests, and needs, there were some specific methods which effectively addressed the difficulty in autism of sharing attention and emotion with others. Without utilizing these effective methods, young children with ASD do not learn to pay attention and to relate to others. Communication and learning are compromised. Behavior problems are exacerbated. While there are some exemplary public and private services provided in Minnesota, there is a critical need for development of more comprehensive programming and training across all agencies.

Intensive Behavior Therapy

Intensive Behavior Therapy, also known as discrete trial training or applied behavior analysis, involves teaching a child how to perform a particular activity by breaking it down into simple components which can be rehearsed individually and chained into a complete sequence. This approach addresses the difficulty in ASD with attention, orienting, shifting, and maintaining joint attention, which is critical to learning. Intensive behavior therapy has been documented as effective in teaching linear skill sequences which can be chained together. The child is systematically rewarded for performing learned responses. In time, skills are generalized to new places and people. A behavioral approach may include instruction in designated sessions and in everyday life situations (Lovaas 1980, 1987).

Developmental Approach

The developmental approach is based on the observation that children with ASD have patterns of development characterized by uneven skills. There are delays in the areas of communication, interaction, play, and particularly in social development. The developmental approach emphasizes the emergence of joint attention, engagement, and the ability to use others to self-regulate using the child's intrinsic interests. Effective techniques support and encourage the child to interact and communicate (Greenspan, 1997).

Structured Teaching

Structured teaching is a method which supports children's independent functioning in home, school and community. The method uses techniques such as portable work stations, student schedules, and color-coded materials. This structure addresses the problems in autism with motor planning and verbal comprehension. Children are taught self-management and self-care, building on strengths that they already possess, such as the ability to follow routines, visual cues, and rehearsal techniques. Structured teaching methods stress the building of independent routines (Lord and Schopler, 1994).

Common Elements of Effectiveness

Each of these methods is documented to be effective; all eight programs share certain critical common elements. The following are the common elements that were the keys to the gains noted by Dawson and Osterling (1997).

Element one: intensity of intervention

Intensity refers to the time engaged in systematic instruction and frequency of learning opportunities in the home, school and community. Programs involved an average of 27 hours of direct intervention per week for a period of two years.

Element two: family involvement

Programs recognized that parents are a critical component in early intervention and they devoted time and resources to parent training.

Element three: curriculum content

All of the curricula emphasized five basic skills that are fundamental to children with autism spectrum disorders advancing to less supported settings. They are as follows:

- the ability to attend to elements of the environment;
- the ability to imitate others;
- the ability to comprehend and use language;
- the ability to play appropriately with toys; and
- the ability to socially interact with others.

Element four: one-to-one teaching by a trained person

The basic skills were taught in a very structured situation where the child interacted directly with a trained teacher or therapist. Generalization strategies were systematically introduced.

__Element five:__ ***strict adherence to specific routines and predictability***
This adherence helped children become more socially responsive and attentive with their behavior more controlled.

__Element six:__ ***a functional approach to problem behaviors***
Programs sought to prevent the development of problem behaviors by increasing the child's interest and social engagement.

__Element five:__ ***transition from the preschool classroom***
All programs taught children to function as independently as possible so that they could succeed in future classrooms.

While the task force did not make specific judgements regarding each of the methodologies reviewed, it was agreed that the earlier the intervention is initiated the better prognosis for the child. There are essential elements for an effective program regardless of the methodology utilized. No specific methodology was endorsed but the task force supports the research that indicates that a minimum range of hours (20 - 40) of engaged time produces the best outcomes for children with ASD.

The task force discussed the research regarding intensity of intervention and there is agreement that the intensity of intervention is critical and that appropriate programming for these children may include a high number of hours in intervention. However, specifying a discrete numerical range of hours is inconsistent with federal (IDEA) and state legislation that insures that the decisions regarding the individualization of programming for each child will be made by the team who knows the child best and provides for due process protection.

Additional Task Force Recommendation

➤ Early intervention should be provided with sufficient intensity to meet the individual needs identified for each child. Progress must be monitored by a team on a routine and frequent basis. Adjustments to the intervention plan should be based on objective data.

> *Based upon current research and promising practices, the condition of autism in young children often requires intense intervention strategies (intense meaning number of hours of engaged time, number of instructional opportunities, number of settings in which intervention occurs, quality of provider training, etc.). In many cases this may require an increase in services provided to a child and additional training for providers as demonstrated and supported by current research and summarized in this report in the Methodology Section. These services must be provided and paid for through interagency shared responsibility among private insurance, state and county human services, school districts, health departments and families. This recommendation makes use of all available funding resources to assure that the young child with autism has an intervention plan that is intense enough to meet the child's needs.*

ROLE OF SCHOOLS, STATE AGENCIES AND COUNTIES

Multiple agencies and programs have roles and responsibilities in the provision and payment of services for children with ASD and their families. The agencies and programs discussed by the task force provide and pay for a significant amount of services to this population. The programs and agencies share a focus on children with disabilities and have missions that promote independence and self sufficiency. Eligibility is disability based. Self-sufficiency for children with ASD means supporting the family's ability to keep the child in the home and community and supporting independence in the context of development and health.

Schools are a major provider of services to children with ASD. School districts are responsible for providing these children with a Free and Appropriate Public Education (FAPE). Special education services are provided based on a determination of eligibility. Decisions regarding services, based on identified child needs, are designed to assist the child to gain access to and benefit from, educational opportunities.

Educational resources alone should not be expected to fund the complete intensive program for children with ASD. Educational agencies should provide services in conjunction with families, county, state, and private resources.

Local social service agencies provide case management, allocate services and funding from the Family Support Fund, facilitate child protection activities and oversee in-home support services as well as out-of-home placement activities. County public health agencies play a key role in health related activities and, in particular, have the responsibility to evaluate the need for and authorize personal care assistant services. County Boards (health and social services) are responsible for administering as well as providing and paying for a variety of services for eligible children with ASD. For example, social services is responsible for administering Minnesota's Home and Community-based Services for Persons with Mental Retardation and Related Conditions waiver program.

Health plans provide reimbursement for health care. Consumers in Minnesota have access to a variety of commercial health plan structures, including indemnity insurance plans, managed care organizations and employers' self-insured plans. Covered services are reimbursed and/or provided when medically necessary. According to the "Caring for our Children: A Study of TEFRA in Minnesota" (a report done by the Minnesota Department of Health, August 1998) seventy-nine percent of the survey respondents have private health care coverage. Managed care coverage is two times more common than indemnity insurance. TEFRA, the Tax Equity Fiscal Responsibility Act, is a mechanism used to deem children with disabilities eligible for MA benefits regardless of parental income.

Parents have a responsibility to provide and pay for services for their children and to access and coordinate services for their child. The TEFRA report noted that families of children eligible for

TEFRA spend more than 11% of their adjusted gross income on medical care, excluding out-of-pocket expenses for non-disabled family members. Minnesota families in general spend about 5.5% of their income on medical care for the entire family. The family circumstances in this study are fairly reflective of average Minnesota families in terms of income, education and geographic distribution.

Services offered through various agencies and programs are often not coordinated. Each agency or program has an intake, assessment and case management system. The allocation of services and resources is based on differing criteria and expertise. There is no mandated team process that would facilitate the coordination and collaboration of multiple agencies and programs nor assigned lead responsibility by any state agency. This lack of coordination frequently prevents the development of an appropriate package of services or the assurance of expert input into key decisions regarding a child's program intensity and program methodology.

Recommendations from the Commissioner

- A single intake process should be developed and used by all agencies serving children with Autism Spectrum Disorder.

  This process will reduce the current burden of multiple assessments and intake procedures necessary to obtain funds and services. A uniform process should not reduce or eliminate a family's right of appeal.

Additional Task Force Recommendations

- Appropriate medical providers should be included in the interagency process of assessment and services for children with ASD.

  The child's primary medical provider (child's medical home) is a key participant in the process of assessment and service delivery. Other pediatric specialists, such as developmental pediatricians, psychologists, pediatric neurologists and child psychiatrists may also be involved in a child's care and should be included in a coordinated interagency process.

- A mechanism to assign an interagency case manager/service coordinator at the point of identification should be developed.

  This interagency case manager could be chosen from a variety of providers. The role of the case manager would be to facilitate interagency intake and assessment, to coordinate the development of an interagency plan and to assist the family in navigating the system.

- A single plan of care/service should be developed.

- An appropriately trained and licensed person should be available to coordinate and facilitate services for children diagnosed with ASD.

- Legislation which requires public and private agencies to collaborate and assume responsibility for service provision should be enacted.

FUNDING

OVERVIEW

The array of funding sources and options for children with ASD is complex. This section reviews current available data reflecting the funding of services and programs used by children with autism. The task force held a strong belief that providing earlier and intensive programming for children with ASD yields savings in future costs for this population. The task force attempted to engage in a statistical analysis of cost benefit ratios for increasing funding and services to younger children with ASD. Current Minnesota data was not available to address this issue. Other states and other research supported this cost benefit scenario. Appendix 6 provides an example of a cost benefit analysis done by Philadelphia in 1996.

The task force found that a variety of services are accessed from multiple programs and agencies. The data demonstrates that funding for necessary services is presently categorical and program based, which makes both access and management of funds and resources difficult. What the data fails to demonstrate are the multiple combinations of programs and payment sources that individual children must access. Most children with ASD meet the criteria for eligibility in both the developmentally disabled and mental health categories of service. This enables access to services across categories of eligibility in order to meet their unique needs. For example, a child with ASD may be enrolled in a special education program and have a personal care assistant (PCA), use the services of a county case manager, obtain a psychological evaluation and access family support funds. The services the child receives may be reimbursed by education entitlement funds, MA, private health insurance, county funds and funding by families.

While an array of services may be available, there are barriers to funding the services. Children and families who do not qualify for public funding may have increased difficulty accessing the necessary array of services to meet their needs due to restrictions in coverage or policy limitations of third party payers and managed care organizations. Private insurers often exclude and/or limit coverage for services through policy exclusions for persons diagnosed with developmental delay or mental health issues. Employers who choose to self insure employees determine the scope of benefits and can limit benefits that appear costly.

Services vary dramatically throughout the state due to lack of such resources as funding, personnel and experts. Funding in-home services, especially programs targeting behavioral interventions at the level of intensity of services recommended for children with ASD, has been difficult. Additionally, the access and management of the services which come from multiple sources can be burdensome.

The task force reviewed data from three sources to evaluate the trends, the services most utilized by the ASD population and the funds allocated and reimbursed for services. Data sources were: CFL child count statistics; MA Minnesota Medical Information System (MMIS) screening and paid claims files; and, data gathered in the task force survey.

The data from the MMIS source provided information on paid claims for those individuals qualifying for MA services with a primary diagnosis of autism. The task force reviewed the claims reimbursed for services received by individuals who met the category of service entitled Developmentally Disabled (DD) and/or Mental Health (MH). **The MMIS data did not include all children with ASD who were MA eligible and submitted claims for service.** The data did not include information for children who received services from schools or counties and were not eligible for either the DD or MH category, or who were not eligible for MA services. The data from the task force survey captured information about children with ASD who access MA services. The data sources utilized for this summary are found in Appendix 4. An analysis of the data is summarized by statistical trends, service and reimbursement access data and funding.

STATISTICAL TRENDS

- All agencies have seen an increase in the numbers of children accessing services.
    - **Education**: In 1997 the total number of children, ages 0-8 years, meeting the autism criteria was 587. This is an increase. In fact, education has realized a 20% increase in each of the last six years (for children 0-22).
    - **Medical Assistance***: Children ages 0-8 years old accessing MA reimbursement in the categories of DD and MH services has increased. The number of children in 1995 was 172. In 1997, the number of MA eligible children with paid claims had increased to 237 (numbers are not unduplicated counts). MA expenditures for children with a diagnosis of autism, who meet the mental health category, have increased from $300,00 in 1995 to $520,000 in 1997. *MA mental health service expenditures for children with a primary diagnosis of Autism have increased from $280,000 in 1995 to $470,000 in 1997. (However, the 1997 claims data is not complete.)* The MA expenditures for children with autism in the DD category have also increased every year.
    - **Social Services**: The task force did not have historical data on families who receive services reimbursed by local and state funds. Informal reports indicate counties have been asked to provide more services to increasing numbers of children with autism. The task force survey reported that half of the respondents were receiving services from their host county. Currently, 1.6 million state dollars are allocated to local counties to provide services through Family Support Grants. The Family Support Grant supports families of children with developmental disabilities which includes ASD.

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*Note: Medical Assistance data used in this report should be interpreted with caution. The Task Force reviewed claims data from the MMIS system for individuals who met the category of service entitled Developmentally Disabled and/or Mental Health. This data did not include all children with ASD who were eligible for and submitted claims for service.

Many children with ASD receive services funded by MA. The Autism Task Force Survey reported that approximately half of the 345 respondents received services reimbursed for by MA.

- Special education has provided services to the largest number of children diagnosed with ASD, with its numbers increasing annually. Most of the children served by special education receive all their services through the special education program. It appears that approximately 25% of children, with the primary diagnosis of Autism, are receiving services and payment for services from other sources.

SERVICE AND REIMBURSEMENT ACCESS DATA

Medical Assistance Access for Children with ASD in the Developmental Disabilities Service Category**. Children (ages 0-8) who receive services through the DD service category are reimbursed by MA access for a number of services. The top three accessed services/programs by children with ASD in this category were the DD waiver plan and services, home care (mostly personal care assistants (PCA services)), and assessment and therapies. The trend between 1995 and 1997 for such services is demonstrated in Table 1 below. Costs related to these services are demonstrated in Table 2.

Table 1: SELECTED MA SERVICES FOR CHILDREN WITH ASD WITHIN THE CATEGORY OF DEVELOPMENTAL DISABILITIES (DD)

	1995	1996	1997
Total # of Recipients	57	62	87
DD Waiver	9	11	13
Home Care	37	37	48
Assessment/Therapies	91	84	119

Table 2: COST OF SELECTED SERVICES FOR CHILDREN WITH ASD WITHIN THE CATEGORY OF DEVELOPMENTAL DISABILITIES (DD)

	1995	1996	1997
DD Waivers	$110,492	$133,369	$198,004
Home Care	17,440	21,639	21,115
Assessment/Therapies	6,559	8,267	4,858

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*Note: Medical Assistance data used in this report should be interpreted with caution. The Task Force reviewed claims data from the MMIS system for individuals who met the category of service entitled Developmentally Disabled and/or Mental Health. This data did not include all children with ASD who were eligible for and submitted claims for service.

Medical Assistance Access for Children with ASD in the Mental Health Service Category*. The top three services reimbursed by MA for children (ages 0-8) with ASD who received services through the MH category between 1995 and 1997 were: mental health diagnostic assessment, day treatment and individual and family psychotherapy, as demonstrated in Table 3. Costs related to these services are demonstrated in Table 4.

Table 3: SELECTED MA SERVICES FOR CHILDREN WITH ASD WITHIN THE CATEGORY OF MENTAL HEALTH (MH)

	1995	1996	1997
Total # Recipients	115	129	149
Diagnostic Assessment	55	54	57
Day Treatment	40	59	75
Individual & Family Psychotherapy	47	32	49

*NOTE: * 94% of the clients receiving day treatment services, do so from one day treatment site in the metro area.*

Table 4: COST OF SELECTED SERVICES FOR CHILDREN WITH ASD WITHIN THE CATEGORY OF MENTAL HEALTH (MH)

	1995	1996	1997
DD Waivers	$110,492	$133,369	$198,004
Home Care	17,440	21,639	21,115
Assessment/Therapy	6,559	8,267	4,858

Special Education Costs Related to Children with ASD. Exact special education expenditure figures for children with ASD are not available. First, children with autism may be included under other categories of disability such as mental retardation or early childhood learning disabled.

For the 1996-97 school year, Minnesota school districts claimed personnel expenditures of $5,446,108 for children ages birth to 21 served within the category of autism. Of this amount, districts were reimbursed $3,901,217 in calculated state aid. The amount included all special education funding sources. These amounts are conservative due to the lack of a license requirement and teacher category for an autism teacher and the variety of diagnostic categories children with

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*Note: Medical Assistance data used in this report should be interpreted with caution. The Task Force reviewed claims data from the MMIS system for individuals who met the category of service entitled Developmentally Disabled and/or Mental Health. This data did not include all children with ASD who were eligible for and submitted claims for service.

autism may be labeled in education, e.g. mental retardation, early childhood, learning disabled, etc. Over 90% of the special education expenditures reported were for special education teachers and para professionals (teacher assistants). Special education costs are not broken down into service assistance for children with varied disabilities.

Education: Clearly children with ASD utilize special education services. The total number of children ages 0-11 years old with a primary disability of Autism was 879. The types of services accessed within special education were: special education services, speech-language pathology services, occupational and physical therapy, the use of teacher assistants and extended school-year.

FUNDING DISCUSSION

Education and Funding

Almost all children with ASD are involved with the educational system. Educational services are funded through a combination of state, federal and local sources. Special education and related services become entitled for children who meet eligibility criteria and require such services in order to benefit from educational opportunities. Educational programs are individually designed by a team to meet a child's needs. The educational program appropriate to the child's needs is detailed in an Individualized Educational Plan (IEP) for children ages 3-22 and on an Individualized Family Service Plan (IFSP) for children birth to age three. In general, service provisions for older preschoolers and school age children are typically designed within the school day and school calender.

Many of the related services children with ASD require may be necessary beyond the school day or calender. They may be interpreted as being more medical and/or health related than educational in nature. Presently schools are being directed to bill other sources such as MA and other third party payers for these services, if appropriate, and with the permission of the families. This policy is an attempt to recognize the joint responsibility for payment of services. The policy also recognizes that arbitrary decisions are made regarding medical and education funding of services for younger children. Access to all funding sources can maximize resources which may then better meet the needs of children with ASD.

Additional Task Force Recommendation

➤ The development and implementation of the interagency coordinated service system as defined in the 1997 K-12 bill should be supported by the Department of Human Services and the Department of Children, Families and Learning.

> *This will serve the three to twenty-two year old age group of children with disabilities. The task force specifically supports any plans to enhance the ability of local areas to provide interagency service coordination.*

Medical Assistance (MA)

Many children with ASD access services reimbursed through Medical Assistance. MA is funded through a formula match of state and federal dollars. MA is a "benefit,"a payment package available to categorically and/or financially eligible populations. The Federal Health Care Administration (HCFA) mandates certain medically necessary services that must be reimbursed by the state's MA program for eligible populations. Each state then determines what optional, medically necessary, services they choose to reimburse. Both mandated and optional services are outlined within the state's Medical Assistance Plan. Persons meeting MA eligibility, specific categories of service, and authorizing requirements are entitled to these services. Minnesota MA currently reimburses medically necessary optional services with the exception of Christian Science Nursing. Eligible children with ASD have access to MA benefits for a variety of services designed to meet medical needs.

MA eligibility and service reimbursements are administered through a variety of management and funding structures. Although funding is available, access to service may be difficult for a variety of reasons. These include a lack of understanding on the part of staff regarding a child's eligibility for services in the multiple categories of service, limitations by prepaid medical plan providers of MA services, licensing requirements, site of care restrictions, lack of adequate supervision and training and lack of provider availability.

Medical Assistance Funding Programs

Children with ASD may access MA funding through a variety of access programs. Five major entry points into MA eligibility are presented below.

- **TEFRA:** TEFRA is a mechanism for disabled children to gain eligibility for MA benefits without consideration of family income and assets. Parents in Minnesota are required to pay a monthly contribution, determined by a sliding fee scale, toward the costs of medical care.

- **Fee-for-Service**: Providers may be reimbursed for services provided to MA eligible recipients on a fee-for-service basis. MA enrollment of eligible recipients for this type of reimbursement mechanism is facilitated by the local county and enrolled providers bill DHS for services rendered. There are amounts of services (thresholds) outlined and a system in place for authorizing services amounts beyond base thresholds. The providers of services are responsible for meeting individual professional standards and licensing requirements, for maintaining appropriate documentation and for billing services to DHS.

- **Prepaid Medical Plan**: The full array of MA benefits are available for eligible populations from a managed care organization. The state, through contracts with managed care organizations (MCO), assures that the services are available and establishes payment rates to the MCO. Contracts with prepaid medical plans assure a set payment amount and allow the MCO to manage the services through the MCO system of thresholds, authorization, definitions and personnel/provider structure.

- **Waivers**: Waivers are written permission from the federal government to provide and reimburse services normally not covered or reimbursed through MA, or to develop an alternative method of providing and reimbursing services for a target population(s). Individual consumer waivers must be approved and a limited number of waivers and waiver slots are granted by HCFA to the state.

  Families who receive services through a waiver program, which is administered by the County, report more functional and easier access to a wide range of services. The task force survey data substantiated the ease of access and wide array of service options available through the waiver option. However, there is considerable concern regarding the limit on the number of waiver slots available. There is a current waiting list for the DD/MR waiver.

- **Child & Teen Check Up (Early, Periodic Screening, Diagnosis & Testing (EPSDT))**: The EPSDT option, entitled Child & Teen Check Up in Minnesota, is a federally mandated component of the MA program. The program is designed to identify and treat all children from birth to age 21 who are MA eligible. State MA programs may not apply limits to the amount, duration, and scope of services that meet the state plan definitions of medically necessary treatment for a condition identified in a screening and provided by a MA provider.

Recommendations from the Commissioner

➤ Access to Child and Teen Check-Up funding (EPSDT) should be clarified by the Department of Human Services to enhance treatment options.

> *These funds could then potentially be used to enhance treatment options for children with ASD.*

Additional Task Force Recommendations

➤ Access to the Department of Human Services' programs and funding should be ensured for children with either mental retardation/related conditions and/or mental health categories of care.

➤ Service coordination and/or case management shall be afforded to all children with ASD.

> *Service coordination can be supported by combining state, local and Medical Assistance funding (for example, Community Social Services Act (CSSA), Individualized Education Plan (IEP), Rule 185).*

- Legislation to provide increased funding to DHS for the Family Support Grant program to expand the number of grants available and the number of persons served should be enacted.

- DHS should create a category of PCA services that provides a behavioral aide who is trained and supervised by a mental health provider.

  PCA services are inadequate for young learners with ASD are inadequate due to availability, training, level of pay and supervision factors.

- DHS should expand reimbursement for services provided by mental health practitioners.

  The Rehabilitation Option in the Minnesota Medicaid State Plan should be changed to allow Mental Health Providers to bill for skills training provided by mental health practitioners. DHS should expand reimbursement for services provided by mental health practitioners through the Rehabilitation Option in the Minnesota Medicaid State Plan by allowing Mental Health Providers to bill for skills training provided by mental health practitioners.

County Services

Children with ASD and their families may access services and programs that are administered by local county boards. County boards often administer state or federally funded programs. Some services and programs are funded through a combination of state and local funds. Counties generally contract with local service providers for many of the services provided.

Generally, children with ASD meet eligibility requirements for either or both categories of MA services entitled under Mental Retardation/Related Conditions or Children's Mental Health. Counties are responsible for meeting the programmatic and fiscal needs of both program categories. The dual eligibility for these two programs presents opportunities and challenges. The knowledge base of county workers and the history of cooperation between the category of service areas are significant variables in the effectiveness of program access. Counties fund services via the Community Social Services Act Plan and manage services for children in foster care and in intermediate care facilities for persons with mental retardation and related conditions.

Additional Task Force Recommendation

- Legislation increasing funding to DHS for MR/RC (mental retardation/related conditions) waiver slots to eliminate waiting lists should be enacted.

Families of Children with ASD

As previously noted, families have a funding responsibility for their children with ASD. One would assume that families would avail themselves to whatever assistance they need to facilitate access to services and payment for those services. Families are not always aware of their eligibility for a wide variety of programs.

Occasionally families are hesitant to participate in publicly funded programs, such as MA and county social services. Families report that one of the major barriers to participation is the stigma of asking for and receiving help from government sources. The parental fee required for participation in MA through the TEFRA option is often too great to make MA benefits worthwhile. Lack of awareness regarding program eligibility and the enrollment process deter families. Assistance with the application process and providing and maintaining necessary documentation can make access to publicly funded programs easier and less confusing.

FUNDING AND SERVICES SCENARIO

A four-year-old child with ASD receives an array of educational services outlined on an Individualized Education Plan (IEP). IEP services are provided in the educational setting and include special education and related services such as speech therapy and occupational therapy. The child is covered by the family's private health care insurance and is enrolled in MA through the TEFRA eligibility option. The parent pays a monthly fee to MA to be enrolled. The child receives the following services in providers' offices and within the child's home: speech-language pathology, occupational and physical therapy, psychological assessment and treatment, personal care assistant services, consultation from a mental health practitioner, medical visits and public health nursing services. The family receives social work services from their county of residence. The family arranges and facilitates all the child's services outside of school. The county social worker provides information on service availability and facilitates access to MA. In this scenario MA will reimburse for all of the medically necessary services the child receives except those of the mental health practitioner (behavior analyst). The burden of coordination of care is significant to the family. This family, due to the child's diagnosis, is eligible for additional services through the county in the form of "case management." Even though the family has accessed some public programs and funds, without knowledge of the full array of services and resources it is difficult to access all the services necessary to meet the child and family's needs. Appendix 5 outlines the multitude of program development issues the families, programs and agencies must consider.

The scenario assumes the family has access to all the services necessary to meet the child's needs. However, the needs of a child with ASD are complex and service requirements are variable. Access to services is dependent upon the parent's knowledge of ASD, service availability and resources. The program a child receives can vary daily, dependent upon the availability of care givers and staff. This variability can be very detrimental for children with ASD who require consistency in care, treatment and programs.

BEHAVIORAL DAY TREATMENT

Children with ASD may be eligible to access behavioral day treatment programs. They are structured programs consisting of individual and group psychotherapy and other intensive therapeutic services. Services are provided by a multidisciplinary team of professionals and are designed to stabilize the child's mental health status, provide mental health services, and develop and improve the child's independent living and socialization skills. In order to be eligible to access these services, the child must have a diagnosis of emotional disturbance or severe emotional disturbance. This service is funded through Medical Assistance.

Day treatment services are provided by a multidisciplinary team. Services may be provided by a mental health professional or under the clinical supervision of a mental health professional who must be on site 50% of the time. Services must be provided in a community mental health center, outpatient hospital or in an entity that is under a contract with the county board, which could include a school setting. There is nothing to preclude a school district from establishing a day treatment program and billing MA for those services provided to Medicaid eligible children.

There are limitations on the number of hours covered in a year and the services must be available at least one day a week for a minimum of three contact hours. At least one hour, but no more than two hours, of individual or group psychotherapy must be provided within those contact hours. The day treatment model of services was developed for group treatment settings. Children with ASD frequently require individualized training and support in the home and throughout the community; this need conflicts with the current day treatment model in implementing a child's treatment plan.

Services available through MA in the mental health category of service may provide children with ASD a broader base of mental health treatment options. Appendix 3 delineates the MA mental health benefits available to persons with ASD.

Day treatment services are a recognized, important component under the Children's Mental Health Act and have become the most utilized psychological service for all age groups. There is one primary provider of day treatment services in the metropolitan area which receives reimbursement from MA for children with a primary diagnosis of autism. The concept of a day treatment program for children with ASD may appear appropriate conceptually. However, the program, staff and service requirements as established for reimbursement by MA are cumbersome and have not been proven cost effective.

INFORMATION AND EDUCATION

The task force discussed the dramatic need for information and education to support the work of professionals and parents. While highly trained personnel and well informed parents are essential to meet the needs of any child with a disability, both are especially important in the area of ASD. The diagnosis of children with ASD has increased at a phenomenal rate. The treatment methodologies for this area of disability are many and specific. The amount of information on this topic is tremendous. Programming for children with ASD is complex; many agencies are being asked to provide more intense services than they have historically provided for either a given age group or a disability area.

Families have a need for current, unbiased, credible information and resources. The increases in the scope of ASD research and treatment methodologies make it difficult for families to locate information that will assist them in making informed decisions for their child. The Internet and other technology resources enable families access to a vast amount of information. However, his information is often unreliable, and is sometimes without the necessary interpretations and/or cautions (e.g., relevance to individual child, efficacy of data in general practice, etc.). The need for an unbiased source of information is essential as individual programs champion their own treatment methodologies.

Professionals need opportunities to obtain current and credible information and to enhance their skills and knowledge. Professionals working with children with autism should have expertise in ASD. With the explosion of information in ASD, expertise is difficult to maintain without regular access to education and training opportunities. Knowledge of resources across agency and program boundaries is also critical when developing a program for children with ASD.

To address the need for ongoing education, training and information support, the task force developed the following recommendations:

Recommendations from the Commissioner

➤ Training and technical assistance on Autism Spectrum Disorder and how to access available funding should be provided to county personnel by the Department of Human Services.

> *The Department of Human Services should facilitate specific training on ASD to social services personnel (e.g., county case managers, health care and financial workers). DHS should also schedule training and technical assistance to help counties identify and access mental health Medical Assistance (MA) dollars, Rehabilitation Option services, Home and Community-Based Services, and Day Treatment. This will also assist county personnel to access local providers to meet necessary treatment needs.*

- A jointly convened state work group which includes family, advocate and professional representation should be formed to develop best practices and personnel standards relating to services and treatments for children with Autism Spectrum Disorder.

  This work group should include representation from CFL, DHS and MDH. The practices and standards should reflect research findings regarding identification criteria, curricula content, intensity, staff to child ratios, parent training and services and funding protocols. This recommendation should be the first step toward development of a training institute and provide valuable material for a central clearinghouse on ASD in Minnesota.

- The efforts of the Minnesota Autism Network should continue to be supported by the Department of Children, Families and Learning.

  The Department of Children, Family and Learning's support of this Network, as well as continuing support of the Regional Low Incidence Projects, should build the capacity of all school districts in Minnesota to provide an array of educational options and services for students with ASD living throughout Minnesota.

Additional Task Force Recommendations

- The legislature should appropriate state funds for a central clearinghouse of extensive ASD resources.

  Resources exist in the state but efforts to coordinate these have been sparse. Information should be dispersed in an unbiased manner designed to get all information to the public in the broadest manner. The use of a statewide toll free number, an Internet web site or other cost effective methods of information dissemination should be included. The clearinghouse should be neutral in its sharing of information to parents and hold as its primary goal the provision of the most current information regarding services and therapies available for children. Information regarding advocacy agencies and statewide experts should be available. All parents and care givers upon receipt of a diagnosis of ASD would be able to access these resources. An additional focus would be outreach to economically disadvantaged or culturally diverse families to assist them in accessing and understanding the information.

- Allocate funds to establish an ongoing Autism Institute.

  An institute would allow CFL, in collaboration with DHS, MDH, families and institutes of higher education, to build and maintain competent and qualified personnel to address the unique needs of these children and their families. This institute would provide systematic, ongoing training and technical assistance regarding current promising practices in the field of ASD for educators, community service providers and families in Minnesota.

RECOMMENDATIONS

The task force has generated a variety of recommendations which include the expansion of interagency coordination and the intensity of services. They also recommend that funding be coordinated, family support and education be increased and educational outreach be established.

The Commissioners of the Departments of Human Services (DHS) and Children, Families and Learning (CFL) endorse the recommendations that can be accomplished within current and proposed budget expectations. Listed below are all the recommendations generated by the task force. It is anticipated that those cited under the Commissioner's recommendations can be accomplished within currently available funding. Supplemental funding would be required to accomplish the recommendations listed under "Additional Recommendations from the Task Force."

RECOMMENDATIONS FROM THE COMMISSIONER

- A single intake process should be developed and used by all agencies serving children with Autism Spectrum Disorder.

  This process will reduce the current burden of multiple assessments and intake procedures necessary to obtain funds and services. A uniform process should not reduce or eliminate a family's right of appeal.

- The Department of Children, Families and Learning's entrance criteria for Autism eligibility should be revised to reflect current research and practice.

  The revised criteria should be consistent with the current research and understanding in the field, should recognize the range and spectrum of autism and pervasive developmental disorders (i.e. Autism Spectrum Disorders), should be consistent with the broader federal definition and should establish criteria for special education eligibility in Minnesota under the category of autism.

- Access to Child and Teen Check-Up funding (EPSDT) should be clarified by the Department of Human Services to enhance treatment options.

  These funds could then potentially be used to enhance treatment options for children with ASD.

- Training and technical assistance on Autism Spectrum Disorder and how to access available funding should be provided to county personnel by the Department of Human Services.

  The Department of Human Services should facilitate specific training on ASD to social services personnel (e.g., county case managers, health care and financial workers). DHS should also schedule training and technical assistance to help counties identify and access available mental health Medical Assistance (MA) dollars, Rehabilitation Option services, Home and Community-Based Services, and Day Treatment. This will also assist county personnel to access local providers to meet necessary treatment needs.

- A jointly convened state work group which includes family, advocate and professional representation should be formed to develop best practices and personnel standards relating to services and treatments for children with Autism Spectrum Disorder.

  This work group should include representation from CFL, DHS and MDH. The practices and standards should reflect research findings regarding identification criteria, curricula content, intensity, staff to child ratios, parent training and services and funding protocols. This recommendation could be the first step toward development of a training institute and provide valuable material for a central clearinghouse on ASD in Minnesota.

- The efforts of the Minnesota Autism Network should continue to be supported by the Department of Children, Families and Learning.

  The Department of Children, Family and Learning's support of this Network, as well as continuing support of the Regional Low Incidence Projects, should build the capacity of all school districts in Minnesota to provide an array of educational options and services for students with ASD living throughout Minnesota.

ADDITIONAL TASK FORCE RECOMMENDATIONS:

- Access to the Department of Human Services' programs and funding should be ensured for children with either mental retardation/related conditions and/or mental health categories of care.

- Appropriate medical providers should be included in the interagency process of assessment and services for children with ASD.

  The child's primary medical provider (child's medical home) is a key participant in the process of assessment and service delivery. Other pediatric specialists, such as developmental pediatricians, psychologists, pediatric neurologists and child psychiatrists may also be involved in a child's care and should be included in a coordinated interagency process.

- The development and implementation of the interagency coordinated service system as defined in the 1997 K-12 bill should be supported by the Department of Human Services and the Department of Children, Families and Learning.

  This will serve the three to twenty-two year old age group of children with disabilities. The task force specifically supports any plans to enhance the ability of local areas to provide interagency service coordination.

- Legislation which requires public and private agencies to collaborate and assume responsibility for service provision should be enacted.

- Early intervention should be provided with sufficient intensity to meet the individual needs identified for each child. Progress must be monitored by a team on a routine and frequent basis. Adjustments to the intervention plan should be based on objective data.

  Based upon current research and promising practices, the condition of autism in young children often requires intense intervention strategies (intense meaning number of hours of engaged time, number of instructional opportunities, number of settings in which intervention occurs, quality of provider training, etc.). In many cases this may require an increase in services provided to a child and additional training for providers as demonstrated and supported by current research and summarized in this report in the Methodology Section. These services must be provided and paid for through interagency shared responsibility among private insurance, state and county human services, school districts, health departments and families. This recommendation makes use of all available funding resources to assure that the young child with autism has an intervention plan that is intense enough to meet the child's needs.

- A mechanism to assign an interagency case manager/service coordinator at the point of identification should be developed.

  This interagency case manager could be chosen from a variety of provider. The role of the case manager would be to facilitate interagency intake and assessment, to coordinate the development of an interagency plan and to assist the family in navigating the system.

- A single plan of care/service should be developed.

- An appropriately trained and licensed person should be available to coordinate and facilitate services for children diagnosed with ASD.

- Service coordination and/or case management shall be afforded to all children with ASD.

  Service coordination can be supported by combining state, local and Medical Assistance funding (for example, Community Social Services Act (CSSA), Individualized Education Plan (IEP), Rule 185).

- Legislation mandating increased health care industry participation in funding both early interventions and the long term needs of children with ASD and their families should be enacted.

  Expenses for necessary treatment should not be precluded under mental health or developmental delay exclusion clauses.

- Legislation increasing funding to DHS for MR/RC (mental retardation/related conditions) waiver slots to eliminate waiting lists should be enacted.

- Legislation to provide increased funding to DHS for the Family Support Grant program to expand the number of grants available and the number of persons served should be enacted.

- DHS should expand reimbursement for services provided by mental health practitioners.

  The Rehabilitation Option in the Minnesota Medicaid State Plan should be changed to allow Mental Health Providers to bill for skills training provided by mental health practitioners.

- DHS should create a category of PCA services that provides a behavioral aide who is trained and supervised by a mental health provider.

  PCA services are inadequate for young learners with ASD are inadequate due to availability, training, level of pay and supervision factors.

- The legislature should appropriate state funds for a central clearinghouse of extensive ASD resources.

  Resources exist in the state but efforts to coordinate these have been sparse. Information should be dispersed in an unbiased manner designed to get all information to the public in the broadest manner. The use of a statewide toll free number, an Internet web site or other cost effective methods of information dissemination should be included. The clearinghouse should be neutral in its sharing of information to parents and hold as its primary goal the provision of the most current information regarding services and therapies available for children. Information regarding advocacy agencies and statewide experts should be available. All parents and care givers upon receipt of a diagnosis of ASD would be able to access these resources. An additional focus would be outreach to economically disadvantaged or culturally diverse families to assist them in accessing and understanding the information.

- Allocate funds to establish an ongoing Autism Institute.

  An institute would allow CFL, in collaboration with DHS, MDH, families and institutes of higher education, to build and maintain competent and qualified personnel to address the unique needs of these children and their families. This institute would provide systematic, ongoing training and technical assistance regarding current promising practices in the field of ASD for educators, community service providers and families in Minnesota.

AUTISM
TASK FORCE REPORT

APPENDICES

March, 1999

Autism Task Force Report

Appendix 1: Task Force Members

Appendix 1: Task Force Members

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Autism Task Force Report

Appendix 2 - Part I: Definitions of Autism

·Appendix 2 - Part I: Definitions of Autism

Federal Definition of Autism (1997)
IDEA Reauthorization 1997
"Autism" means a developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age three, that adversely affects a child's educational performance. Other characteristics often associated with autism are engagement in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences. The term does not apply if a child's educational performance is adversely affected primarily because the child has an emotional disturbance.

Minnesota Definition from Educational Criteria for Eligibility (1992)
MN. 3525.1325 AUTISM
Subpart 1. Definition. "Autism" is a lifelong developmental disability with onset usually in the first three years of life. It is a behaviorally defined syndrome characterized by an uneven developmental profile and disturbances in interaction, communication, and perceptual organization. Autism occurs on a continuum from mild to severe. It occurs by itself or in association with other disorders such as mental retardation or fragile X syndrome. It may include the diagnosis of pervasive developmental disorder. Because of the low incidence and complexity of this disability, professionals with experience and expertise in the area of autism need to be included on the team determining the disability and educational program.

Autism Society of America Definition (1998)
Autism is a complex developmental disability that typically appears during the first three years of life. The result of a neurological disorder that affects functioning of the brain, autism and its associated behaviors have been estimated to occur in as many as 1 in 500 individuals. Autism is four times more prevalent in boys than girls and knows no racial, ethnic, or social boundaries. Family income, lifestyle, and educational levels do not affect the chance of autism's occurrence.

Autism interferes with the normal development of the brain in the areas of social interaction and communication skills. Children and adults typically have deficiencies in verbal and non-verbal communication, social interactions, and leisure or play activities. The disorder makes it hard for them to communicate with others and relate to the outside world. They may exhibit repeated body movements (e.g., hand flapping, rocking), unusual responses to people or attachments to objects, and they may resist changes in routines.

Over one half million people in the United States today have some form of autism. Its prevalence rate now places it as the third mos the majority of the t common developmental disability - more common than Downs Syndrome. Yet most of the public, including many professionals in the medical, education, and vocational fields, are still unaware of how to effectively work with individuals with autism.

Autism Task Force Report

Appendix 2 - Part II:
State & Federal Rules & Statutes

Appendix 2 - Part II: State & Federal Rules & Statutes

Categorical model references: Minn. Rule 3525.1325 AUTISM.

Subpart 1. Definition. "Autism" is a lifelong developmental disability with onset usually in the first three years of life. It is a behaviorally defined syndrome characterized by an uneven developmental profile and disturbances in interaction, communication, and perceptual organization. Autism occurs on a continuum from mild to severe. It occurs by itself or in association with other disorders such as mental retardation or fragile X syndrome. It may include the diagnosis of pervasive developmental disorder. Because of the low incidence and complexity of this disability, professionals with experience and expertise in the area of autism need to be included on the team determining the disability and educational program.

Subp. 2. Criteria. The team shall determine that a pupil meets criteria for autism according to the Diagnostic and Statistical Manual, Third Revision (DSM-III-R) of the American Psychiatric Association, the current accepted standard in the field. The criteria for autism in (DSM-III-R) are incorporated by reference, DSM-III-R is subject to frequent change and is available through the Minitex interlibrary loan system. Consider a criterion to be met only if the behavior is abnormal for the person's developmental level. DSM-III-R states that a pupil meets criteria when at least eight of the following 16 items are present, these to include at least two items from item A, one from item B, and one from item C.

A. qualitative impairment in reciprocal social interaction (the examples within parentheses are arranged so that those first listed are more likely to apply to younger or more disabled, and the later ones, to older or less disabled) as manifested by the following:

(1) marked lack of awareness of the existence or feelings of others (for example, treats a person as if that person were a piece of furniture; does not notice another person's distress; apparently has no concept of the need of others for privacy);
(2) no or abnormal seeking of comfort at times of distress (for example, does not come for comfort even when ill, hurt, or tired; seeks comfort in a stereotyped way, for example, says "cheese, cheese, cheese" whenever hurt);
(3) no or impaired imitation (for example, does not wave bye-bye; does not copy parent's domestic activities; mechanical imitation of others' actions out of context);
(4) no or abnormal social play (for example, does not actively participate in simple games; prefers solitary play activities; involves other children in play only as mechanical aids); and
(5) gross impairment in ability to make peer friendships (for example, no interest in making peer friendships; despite interest in making friends, demonstrates lack of understanding of conventions of social interaction, for example, reads phone book to uninterested peer);

B. qualitative impairment in verbal and nonverbal communication and in imaginative activity, (the numbered items are arranged so that those first listed as more likely to apply to younger or more disabled, and the later ones, to older or less disabled) as manifested by the following:

(1) no mode of communication, such as communicative babbling, facial expression, gesture, mime, or spoken language;
(2) markedly abnormal nonverbal communication, as in the use of eye-to-eye gaze, facial expression, body posture, or gestures to initiate or modulate social interaction (for example, does not anticipate being held, stiffens when held, does not look at the person or smile when making a social approach, does not greet parents or visitors, has a fixed stare in social situations);
(3) absence of imaginative activity, such as play acting of adult roles, fantasy characters, animals; lack of interest in stories about imaginary events;
(4) marked abnormalities in the production of speech, including volume, pitch, stress, rate, rhythm, and intonation (for example, monotonous tone, question-like melody, or high pitch);
(5) marked abnormalities in the form or content of speech, including stereotyped and repetitive use of speech (for example, immediate echolalia or mechanical repetition of a television commercial); use of "you" when "I" is meant (for example, using "You want cookie?" to mean "I want a cookie"); idiosyncratic use of words or phrases (for example, "Go on green riding" to mean "I want to go on the swing"); or frequent irrelevant remarks (for example, starts talking about train schedules during a conversation about sports); and
(6) marked impairment in the ability to initiate or sustain a conversation with others, despite adequate speech (for example, indulging in lengthy monologues on one subject regardless of interjections from others);

C. markedly restricted repertoire of activities and interests, as manifested by the following:
(1) stereotyped body movements (for example, hand flicking or twisting, spinning, head-banging, complex whole-body movements);
(2) persistent preoccupation with parts of objects (for example, sniffing or smelling objects, repetitive feeling of texture of materials, spinning wheels of toy cars) or attachment to unusual objects (for example, insists on carrying around a piece of string);
(3) marked distress over changes in trivial aspects of environment (for example, when a vase is moved from usual position);
(4) unreasonable insistence on following routines in precise detail (for example, insisting that exactly the same route always be followed when shopping);
(5) markedly restricted range of interests and a preoccupation with one narrow interest (for example, interested only in lining up objects, in amassing facts about meteorology, or in pretending to be a fantasy character);

D. onset during infancy or early childhood;

E. other symptoms that may occur with the syndrome:
(1) sensory disturbances as evidenced by atypical responses to stimuli (for example, touch, sound,

light, movement, smell, taste). Responses may include overreaction, indifference, or withdrawal; and
(2) uneven acquisition of skills, and/or difficulty in integrating and generalizing acquired skills; and

F. the pupil's need for instruction and services must be supported by at least one documented systematic observation in the pupil's daily routine setting by an appropriate professional and verify the criteria categories in items A to D. In addition, corroboration of developmental or medical information with a developmental history and at least one other assessment procedure that is conducted on a different day must be included. Other documentation should include parent reports, functional skills assessments, adaptive behavior scales, intelligence tests, criterion-referenced instruments, language concepts, developmental checklists, or an autism checklist.

STAT AUTH: MS s 120.17
HIST: 16 SR 1543

Code of Federal Regulations (CFR) 300.7 (b)(1)
(b) The terms used in this definition are defined as follows:

(1) "Autism" means a developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age 3, that adversely affects a child's educational performance. Other characteristics often associated with autism are engagement in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences. The term does not apply if a child's educational performance is adversely affected primarily because the child has a serious emotional disturbance, as defined in paragraph (b)(9) of this section.

<u>Non-categorical model references</u>: Mn Rule 3525.1350 EARLY CHILDHOOD SPECIAL EDUCATION.

Subpart 1. Definition. Early childhood special education must be available to pupils from birth to seven years of age who have a substantial delay or disorder in development or have an identifiable sensory, physical, mental, or social/emotional condition or impairment known to hinder normal development and need special education.

Subp. 2. Criteria for birth through two years of age. The team shall determine that a child from birth through the age of two years and 11 months is eligible for early childhood special education if:
A. the child meets the criteria of one of the disability categories; or
B. the child meets one of the criteria in sub item (1) in addition to criteria in subitems (2) and (3):

(1) the child: (a) has a medically diagnosed syndrome or condition that is known to hinder normal development including, but not limited to, cerebral palsy, chromosome abnormalities, fetal alcohol syndrome, maternal drug use, neural tube defects, neural muscular disorders, cytomegalovirus, grades III and IV intracranial hemorrhage, and bronchopulmonary dysplasia (BPD);

(b) has a delay in overall development demonstrated by a composite score of 1.5 standard deviations or more below the mean on an assessment using at least one technically adequate, norm-referenced instrument that has been individually administered by an appropriately trained professional; or the child is less than 18 months of age and has a delay in motor development demonstrated by a composite score of 2.0 standard deviations or more below the mean on an assessment using technically adequate, norm-referenced instruments. These instruments must be individually administered by an appropriately trained professional;

(2) the child's need for instruction and services is supported by at least one documented, systematic observation in the child's daily routine setting by an appropriate professional. If observation in the daily routine setting is not possible, the alternative setting must be justified;

(3) corroboration of the development or medical assessment with a developmental history and at least one other assessment procedure that is conducted on a different day than the medical norm-referenced assessment. Other procedures may include parent report, language sample, criterion-referenced instruments, or developmental checklists.

Subp. 3. Criteria for three through six years of age. The team shall determine that a child from the age of three years through the age of six years and 11 months is eligible for early childhood special education when:

A. the child meets the criteria of one of the disability categories; or

B. the child meets one of the criteria in subitem (1) in addition to criteria in subitems (2) and (3):

(1) the child:

(a) has a medically diagnosed syndrome or condition that is known to hinder normal development including cerebral palsy, chromosome abnormalities, fetal alcohol syndrome, maternal drug use, neural tube defects, neural muscular disorders, cytomegalovirus, grades III and IV intracranial hemorrhage, and bronchopulmonary dysplasia (BPD); or

(b) has a delay in each of two or more areas of development that is verified by an assessment using technically adequate, norm-referenced instruments. Subtests of instruments are not acceptable. The instruments must be individually administered by appropriately trained professionals and the scores must be at least 1.5 standard deviations below the mean in each area;

(2) the child's need for special education is supported by at least one documented, systematic observation in the child's daily routine setting by an appropriate professional. If observation in the daily routine setting is not possible, the alternative setting must be justified;

(3) corroboration of the developmental or medical assessment with a developmental history and at least one other assessment procedure in each area that is conducted on a different day than the medical or norm-referenced assessment.

Other procedures may include parent report, language sample, criterion-referenced instruments, or developmental checklists.

STAT AUTH: MS s 121.11; L 1994 c 647 art 3 s 23
HIST: 19 SR 2432

34 CFR 300.7 (a)(2)
Sec. 300.7 Children with disabilities

(a)(1) As used in this part, the term "children with disabilities" means those children evaluated in accordance with Secs. 300.530-300.534 as having mental retardation, hearing impairments including deafness, speech or language impairments, visual impairments including blindness, serious emotional disturbance, orthopedic impairments, autism, traumatic brain injury, other health impairments, specific learning disabilities, deaf-blindness, or multiple disabilities, and who because of those impairments need special education and related services.

(2) The term "children with disabilities" for children aged 3 through 5 may, at a State's discretion, include children--and

"Infants and toddlers with disabilities" birth- age two ...
IDEA at 20 U.S.C. 1472 (1)-Part H

20 U.S.C. Chapter 33
SUBCHAPTER VIII--INFANTS AND TODDLERS WITH DISABILITIES

Sec. 1472 Definitions
As used in this subchapter--
(1) The term "infants and toddlers with disabilities" means individuals from birth to age 2, inclusive, who need early intervention services because they--

(A) are experiencing developmental delays, as measured by appropriate diagnostic instruments and procedures in one or more of the following areas: cognitive development, physical development, language and speech development (hereafter in this subchapter referred to as "communication development"), psycho social development (hereafter in this subchapter referred to as "social or emotional development"), or self-help skills (hereafter in this subchapter referred to as "adaptive development"), or
(B) have a diagnosed physical or mental condition which has a high probability of resulting in developmental delay.

Such term may also include, at a State's discretion, individuals from birth to age 2, inclusive, who are at risk of having substantial developmental delays if early intervention services are not provided.

34 CFR 303.16-Part H
EARLY INTERVENTION PROGRAM FOR INFANTS AND TODDLERS WITH DISABILITIES
34 C.F.R. Part 303
SUBPART A--GENERAL Definitions

Sec. 303.16 Infants and toddlers with disabilities
(a) As used in this part, infants and toddlers with disabilities means individuals from birth through age two who need early intervention services because they--

(1) Are experiencing developmental delays, as measured by appropriate diagnostic instruments and procedures, in one or more of the following areas:

(I) Cognitive development.
(ii) Physical development, including vision and hearing.
(iii) Communication development.
(iv) Social or emotional development.
(v) Adaptive development; or

(2) Have a diagnosed physical or mental condition that has a high probability of resulting in developmental delay.

(b) The term may also include, at a State's discretion, children from birth through age two who are at risk of having substantial developmental delays if early intervention services are not provided.

(Authority: 20 U.S.C. 1472(1))

Note 1: The phrase "a diagnosed physical or mental condition that has a high probability of resulting in developmental delay," as used in paragraph (a)(2) of this section, applies to a condition if it typically results in developmental delay. Examples of these conditions include chromosomal abnormalities; genetic or congenital disorders; severe sensory impairments, including hearing and vision; inborn errors of metabolism; disorders reflecting disturbance of the development of the nervous system; congenital infections; disorders secondary to exposure to toxic substances, including fetal alcohol syndrome; and severe attachment disorders.

Note 2: With respect to paragraph (b) of this section, children who are at risk may be eligible under this part if a State elects to extend services to that population, even though they have not been identified as disabled.

Under this provision, States have the authority to define who would be "at risk of having substantial developmental delays if early intervention services are not provided." In defining the "at risk" population, States may include well-known biological and environmental factors that can be identified and that place infants and toddlers "at risk" for developmental delay. Commonly cited factors include low birth weight, respiratory distress as a newborn, lack of oxygen, brain hemorrhage, infection, nutritional deprivation, and a history of abuse or neglect. It should be noted that "at risk" factors do not predict the presence of a barrier to development, but they may indicate children who are at higher risk of developmental delay than children without these problems.

Autism Task Force Report

Appendix 3: Medical Assistance Mental Health Benefits for Persons with Autism

Appendix 3: Medical Assistance Mental Health Benefits for Persons with Autism

Services children with autism could access through the medical assistance mental health benefit.

Child with emotional disturbance: An organic disorder of the brain or a clinically significant disorder of thought, mood, perception, orientation, memory, or behavior that:

A. is listed in the clinical manual of the International Classification of Diseases (ICD-9-CM), current edition, code range 290.00 to 302.99 or 306.0 to 316.0 or the corresponding code in the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (DSM-MD), current edition, Axes I, II, or III; and
B. seriously limits a child's capacity of function in primary aspects of daily living such personal relations, living arrangements, work, and recreation.
"Emotional disturbance" is a generic term and is intended to reflect all categories of disorder described in DSM-MD, current edition as "usually first evident in childhood or adolescence."

Child with severe emotional disturbance: For purposes of eligibility for case management and family community support services, "child with severe emotional disturbance" means a child who has an emotional disturbance and who meets one of the following criteria:

A. The child has been admitted within the last three years or is at risk of being admitted to inpatient treatment or residential treatment for an emotional disturbance; or
B. The child is a Minnesota resident and is receiving inpatient treatment or residential treatment for an emotional disturbance through the interstate compact; or
C. The child has one of the following determined by a mental health professional:
  1. psychosis or a clinical depression; or
  2. risk of harming self or others as a result of an emotional disturbance; or
  3. psychopathological symptoms as a result of being a victim of physical or sexual abuse or of psychic trauma with the past year; or

D. The child, as a result of an emotional disturbance has significantly impaired home, school, or community functioning that has lasted at least one year or that, in the written opinion of a mental health professional, presents risk of lasting at least one year.
The term "child with severe emotional disturbance" shall be used only for purposes of county eligibility determinations. In all other written and or communications, case managers, mental health professionals, mental health practitioners, and all other providers of mental health services shall use the term "child eligible for mental health case management" in place of "child with severe emotional disturbance."
The second part of the discussion concerned recognized provider qualifications through the medical assistance mental health area. These basically involves two provider types-mental health professionals and practitioners.

Mental health professionals. The following staff persons providing clinical services in the treatment of mental illness are eligible for enrollment as providers of outpatient mental health services:

- **Licensed Psychologist (LP)** licensed under Minnesota Statues, sections 148.88 to 148.98, who has stated to the Board of Psychology competencies in the diagnosis and treatment of mental illness.
- **Licensed Psychological Practitioner (LPP)** granted a waiver by the Board of Psychology from the supervision requirements as listed in Minnesota Statutes, section 148.925.
- **Licensed Independent Clinical Social Worker (LICSW)** licensed as an independent clinical social worker, under Minnesota Statutes, section 148B.21, subdivision 6.
- **Psychiatrist**--a physician licensed under Minnesota Statutes, chapter 147 and certified by the American Board of Psychiatry and Neurology or eligible for board certification in psychiatry.
- **Clinical Nurse Specialist-Mental Health.** A registered nurse licensed under Minnesota Statutes, sections 148.171 to 148.285, and certified as a clinical specialist in psychiatric or mental health nursing by the American Nurse's Association with at least 4,000 hours of post-master's supervised experience in the delivery of clinical services in the treatment of mental illness.
- **Marriage and Family Therapist**--licensed under Minnesota Statutes, sections 148B.29 to 148B.39 who is employed by a community mental health center under Minnesota Rules, part 9505.0260.

Mental health practitioners who provide services in the treatment of mental illness, under supervision of a mental health professional, must be qualified in at least one of the following ways:

- Bachelor's degree in one of the behavioral sciences or related fields from an accredited college or university and 2,000 hours of supervised experience in the delivery of clinical services in the treatment of mental illness;

- Completed 6,000 hours of supervised experience in the delivery of clinical services in the treatment of mental illness;

- Enrolled as a graduate student in one of the behavioral sciences or related fields formally assigned to the center for clinical training by an accredited college or university; or• Obtained a master's or other graduate degree in one of the behavioral sciences available to a child determined to have a severe emotional disturbance. These services include:

    1. Targeted Mental Health case management;
    2. Home-Based Mental Health Services;
    3. Therapeutic Support for Foster Care; and
    4. Family Community Support Services.

Autism Task Force Report

Appendix 4:
Data from DHS and CFL

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*Note: Medical Assistance data used in this report should be interpreted with caution. The Task Force reviewed claims data from the MMIS system for individuals who met the category of service entitled Developmentally Disabled and/or Mental Health. This data did not include all children with ASD who were eligible for and submited claims for service.

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Data on Autistic Students

1996-97 School Year

Tables

Data in these tables were originally collected via MARSS (Minnesota Automated Reporting Student System) for the 1996-97 school year. The data were compiled by Data Management, Office of Information Technologies during June and July, 1998 at the request of Robyn Widley and Michael Eastman.

Only students reported as having a primary disability of Autistic is included in the tables. Prekindergarten students who had either an IFSP or IEP but whose primary disability was identified as other than Autistic, e.g., early childhood special education, are excluded. Each student is included only once; irrespective of the number of different schools/districts in which the child may have been enrolled during the school year. The age used in these reports is determined as of September 1, 1996. Prekindergarten students are those reported in *grade* level "EC" early childhood (not *disability* early childhood). School age students are those reported in kindergarten or older grade level.

Percentages may not always total 100.0 percent due to rounding.

Autistic Students by Gender, FY97

Gender	Number of Students	Percent
F	186	17.4%
M	881	82.6%
Grand Total	1,067	

Tuesday, July 07, 1998

Autistic Students by Gender, FY97

Gender	Number of Students	Percent
F	186	17.4%
M	881	82.6%
Grand Total	1,067	

Autistic Students by Age, FY97

Age as of September 1, 1996	Number of Students	Percent
1	1	0.1%
2	2	0.2%
3	13	1.2%
4	26	2.4%
5	49	4.6%
6	121	11.3%
7	123	11.5%
8	114	10.7%
9	104	9.7%
10	71	6.7%
11	91	8.5%
12	68	6.4%
13	61	5.7%
14	58	5.4%
15	35	3.3%
16	32	3.0%
17	34	3.2%
18	30	2.8%
19	16	1.5%
20	10	0.9%
21	7	0.7%
22	1	0.1%
Grand Total	1,067	

Autistic Students By Race/Ethnicity, FY97

Race/Ethnicity	Number of Students	Percent
American Indian/Alaskan	12	1.1%
Asian/Pacific Islander	34	3.2%
Hispanic	14	1.3%
Black, Not Hispanic	96	9.0%
White	911	85.4%
Grand Total	1,067	

Autistic Students by Region, FY97

Service Cooperative	Number of Students	Percent
1	27	2.5%
3	55	5.2%
4	23	2.2%
5	21	2.0%
6	60	5.6%
7	86	8.1%
9	33	3.1%
10	61	5.7%
11	701	65.7%
Grand Total	1,067	

Autistic Students By Region/Race, FY97

Service Cooperative	Race/Ethnicity	Number of Students
1		
	American Indian/Alaskan	2
	Asian/Pacific Islander	1
	White	24
Subtotal for Region		27
3		
	American Indian/Alaskan	2
	Hispanic	1
	White	52
Subtotal for Region		55
4		
	Asian/Pacific Islander	1
	White	22
Subtotal for Region		23
5		
	Hispanic	1
	White	20
Subtotal for Region		21
6		
	Black, Not Hispanic	1
	Hispanic	1
	White	58
Subtotal for Region		60
7		
	Asian/Pacific Islander	2
	White	84
Subtotal for Region		86
9		
	White	33
Subtotal for Region		33

Service Cooperative	Race/Ethnicity	Number of Students
10		
	Asian/Pacific Islander	1
	Black, Not Hispanic	1
	Hispanic	2
	White	57
Subtotal for Region		**61**
11		
	American Indian/Alaskan	8
	Asian/Pacific Islander	29
	Black, Not Hispanic	94
	Hispanic	9
	White	561
Subtotal for Region		**701**
Grand Total		1,067

Autistic Students by Region/Age, FY97

Service Cooperative	Age as of September 1, 1996	Number of Students
1	6	2
	7	5
	8	1
	9	3
	10	1
	11	7
	12	1
	13	1
	16	1
	18	3
	19	2
Subtotal for Region		27
3	5	2
	6	4
	7	3
	8	5
	9	4
	10	4
	11	7
	12	4
	13	6
	14	3
	15	3
	16	1
	17	2
	18	3
	19	3
	20	1

Service Cooperative	Age as of September 1, 1996	Number of Students
Subtotal for Region		55
4	5	1
	6	3
	7	3
	8	3
	10	2
	12	2
	13	5
	14	2
	16	1
	17	1
Subtotal for Region		23
5	6	1
	7	5
	8	2
	9	2
	11	3
	12	2
	13	1
	15	1
	16	1
	18	2
	19	1
Subtotal for Region		21
6	3	1
	4	7
	5	1
	6	10
	7	4
	8	3
	9	2

Service Cooperative	Age as of September 1, 1996	Number of Students
6	10	3
	11	6
	12	1
	13	3
	14	3
	15	1
	16	6
	17	4
	18	2
	19	1
	20	1
	21	1
Subtotal for Region		60
7	3	1
	5	2
	6	8
	7	9
	8	6
	9	14
	10	6
	11	10
	12	7
	13	3
	14	8
	15	4
	16	4
	17	2
	18	1
	19	1
Subtotal for Region		86
9	3	1

Service Cooperative	Age as of September 1, 1996	Number of Students
9	4	5
	5	2
	6	4
	7	3
	8	4
	9	1
	10	3
	11	5
	12	2
	13	1
	18	2
Subtotal for Region		**33**
10	1	1
	3	1
	4	3
	5	2
	6	8
	7	9
	8	10
	9	8
	11	6
	12	1
	13	4
	14	3
	15	1
	16	2
	17	1
	19	1
Subtotal for Region		**61**
11	2	2
	3	9

Service Cooperative	Age as of September 1, 1996	Number of Students
11	4	11
	5	39
	6	81
	7	82
	8	80
	9	70
	10	52
	11	47
	12	48
	13	37
	14	39
	15	25
	16	16
	17	24
	18	17
	19	7
	20	8
	21	6
	22	1
Subtotal for Region		701
Grand Total		1067

Prekindergarten Autistic Students by Setting, FY97

Federal Setting	Number of Students	Percent
1	10	17.2%
2	19	32.8%
3	9	15.5%
4	18	31.0%
8	2	3.4%
Total Prekindergarten Autistic	58	

School Age Autistic Students by Setting, FY97

Federal Setting	Number of Students	Percent
1	390	38.7%
2	247	24.5%
3	336	33.3%
4	31	3.1%
5	2	0.2%
7	1	0.1%
8	2	0.2%
Total School Age	1,009	

K-12 Autistic Students by Age/Setting, FY97

Age	Federal Setting	Number of Students
4	3	1
Age Subtotal		1
5	1	16
5	2	10
5	3	12
Age Subtotal		38
6	1	63
6	2	23
6	3	28
6	4	2
Age Subtotal		116
7	1	58
7	2	30
7	3	31
7	4	2
7	5	1
Age Subtotal		122
8	1	66
8	2	29
8	3	18
8	4	1
Age Subtotal		114
9	1	45
9	2	22
9	3	35
9	4	2
Age Subtotal		104
10	1	25

Age	Federal Setting	Number of Students
10	2	22
10	3	23
10	4	1
Age Subtotal		71
11	1	46
11	2	23
11	3	22
Age Subtotal		91
12	1	19
12	2	18
12	3	28
12	4	3
Age Subtotal		68
13	1	18
13	2	16
13	3	25
13	4	1
13	8	1
Age Subtotal		61
14	1	10
14	2	20
14	3	26
14	4	1
14	8	1
Age Subtotal		58
15	1	10
15	2	8
15	3	15
15	4	2
Age Subtotal		35
16	1	4

Age	Federal Setting	Number of Students
16	2	9
16	3	19
Age Subtotal		32
17	1	4
17	2	6
17	3	21
17	4	2
17	7	1
Age Subtotal		34
18	1	3
18	2	10
18	3	13
18	4	4
Age Subtotal		30
19	1	2
19	2	1
19	3	9
19	4	3
19	5	1
Age Subtotal		16
20	3	5
20	4	5
Age Subtotal		10
21	1	1
21	3	4
21	4	2
Age Subtotal		7
22	3	1
Age Subtotal		1
Total School Age		1,009

PRIMARY DISABILITY INSTRUCTIONAL SETTING
AGES BIRTH TO FIVE
IN AN ECSE PROGRAM

EFFECTIVE FALL FY 96

SETTING

1 Early Childhood Setting. This includes children who received all of their special education and related services in educational programs designed primarily for children without disabilities. This may include, but is not limited to:

- regular Kindergarten classes,
- public or private preschools,
- Head Start centers,
- child care facilities,
- preschool classes offered to an eligible prekindergarten population by the public school system,
- home/early childhood combinations,
- home/Head Start combinations, and
- other combinations of early childhood settings.

2 Early Childhood Special Education Setting. This includes children who received all of their special education and related services in educational programs designed primarily for children with disabilities housed in regular school buildings or other community based settings. This may include, but is not limited to:

- special education classrooms in regular school buildings,
- special education classrooms in child care facilities or other community based settings, and
- special education classrooms in trailers or portables outside regular school buildings.

3 Home This includes children who received all of their special education and related services in the principle residence of the child's family or caregivers.

4 Part-Time Early Childhood/Part-Time Early Childhood Special Education Setting. This includes children who received services in multiple settings, such that:

- a portion of their special education and related services are provided at home or in educational programs designed primarily for children without disabilities, and
- the remainder of their special education and related services are provided in programs designed primarily for children with disabilities. This may include, but is not limited to:

over

◊ home/early childhood special education combinations,

◊ Head Start, child care, nursery school facilities or other community-based settings with special education provided outside of the regular class,

◊ regular Kindergarten classes with special education provided outside of the regular class,

◊ separate school/early childhood combinations, and

◊ residential facility/early childhood combinations.

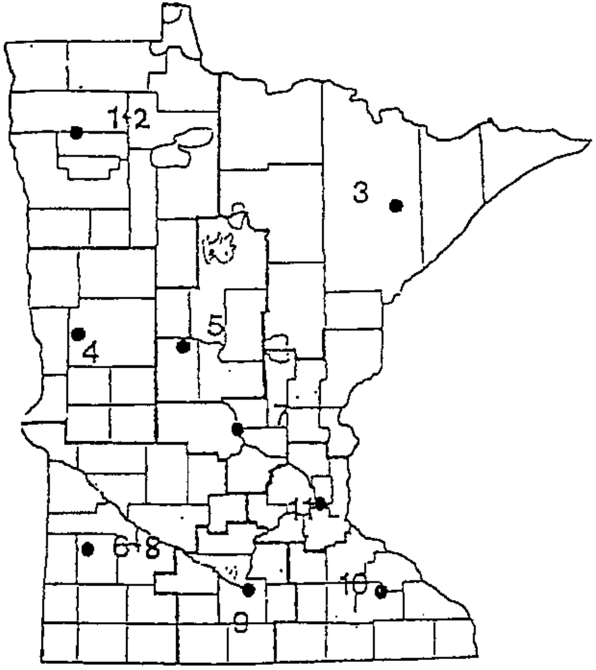
5 Residential Facility This includes children who received all of their special education and related services in publicly or privately operated residential schools, or residential facilities on an in-patient basis.

6 Separate Schools This includes children who received all of their special education and related services in educational programs in public or private day schools specifically for children with disabilities.

7 Itinerant Services Outside the Home This includes children who received all of their special education and related services at a school or other location for a short period of time (e.g., no more than 3 hours per week). *This column does not include children receiving services at home; those children are reported in setting 4.* These services may be provided individually or to a small group of children.

8 Reverse Mainstream Setting (OPTIONAL) This includes children who received all of their special education and related services in educational programs designed primarily for children with disabilities, but that include 50 percent or more children without disabilities

A private institution or school is a school NOT under federal or public supervision or control and may be a non-profit proprietary.



Minnesota Planning Regions

MINNESOTA DEPARTMENT OF

Children, Families & Learning

LOW INCIDENCE CHILD COUNT BY REGION

Region 1 & 2 Total Enroll:
1991=34,484
1993=35,382
1996=36,676
1997=35,168

46 School Districts
9 Directors of Special Education

Dis.	1991	1993	1996	1997
PI	29	30	37	37
D-HoH	34	45	42	46
B-VI	30	25	27	26
OHI	23	57	136	169
Autism	5	10	28	31
D-B	0	0	1	1
TBI	na	0	13	18
	121	167	282	328

Region 3 Total Enroll:
1991=58,334
1993=59,388
1996=58,342
1997=57,995

29 School Districts
7 Directors of Special Education

Dis.	1991	1993	1996	1997
PI	147	106	109	116
D-HoH	107	96	83	91
B-VI	29	21	28	34
OHI	32	98	189	206
Autism	19	34	49	61
D-B	0	0	0	0
TBI	na	0	16	22
	334	368	474	530

Region 4 Total Enroll:
1991=36,851
1993=38,702
1996=39,575
1997=38,866

33 School Districts
8 Directors of Special Education

Dis.	1991	1993	1996	1997
PI	69	72	70	73
D-HoH	47	59	69	77
B-VI	15	11	10	6
OHI	12	79	273	356
Autism	3	5	21	27
D-B	0	0	1	0
TBI	na	3	8	10
	146	229	452	549

Region 5 Total Enroll:
1991=32,155
1993=34,149
1996=31,413
1997=31,279

25 School Districts
3 Directors of Special Education

Dis.	1991	1993	1996	1997
PI	34	36	36	33
D-HoH	30	36	37	41
B-VI	12	10	12	9
OHI	32	72	133	148
Autism	3	9	21	28
D-B	0	0	0	0
TBI	na	5	8	11
	111	168	247	270

Region 7 Total Enroll:
1991=82,232
1993=89,683
1996=96,047
1997=95,905

38 School Districts
9 Directors of Special Education

Dis.	1991	1993	1996	1997
PI	146	117	129	158
D-HoH	118	138	183	201
B-VI	39	46	38	36
OHI	81	262	528	594
Autism	5	37	77	111
D-B	0	0	0	0
TBI	na	5	21	24
	389	605	976	1124

- OVER -

Region 6 & 8 Total Enroll: 1991=59,754
1993=60,269
1996=59,927
1997=59,590

70 School Districts
6 Directors of Special Education

Dis.	1991	1993	1996	1997
PI	69	64	83	79
D-HoH	66	82	111	120
B-VI	12	15	20	15
OHI	57	117	280	306
Autism	14	18	48	56
D-B	2	6	3	3
TBI	na	25	4	19
	220	327	559	598

Region 9 Total Enroll: 1991=41,546
1993=43,407
1996=45,057
1997=44,547

28 School Districts
6 Directors of Special Education

Dis.	1991	1993	1996	1997
PI	48	75	71	77
D-HoH	69	65	70	64
B-VI	6	14	16	14
OHI	29	75	217	213
Autism	4	11	31	45
D-B	0	1	1	2
TBI	na	1	11	9
	156	241	417	442

Region 10 Total Enroll: 1991=81,500
.1993=85,512
1996=84,969
1997=86,916

46 School Districts
12 Directors of Special Education

Dis.	1991	1993	1996	1997
PI	98	133	113	121
D-HoH	163	193	310	332
B-VI	36	29	85	86
OHI	60	164	316	396
Autism	6	24	50	69
D-B	3	3	6	9
TBI	na	8	14	20
	366	554	894	1030

Region 11 Total Enroll: 1991=408,746
1993=426,616
1996=467,890
1997=483,250

49 School Districts
46 Directors of Special Education

Dis.	1991	1993	1996	1997
PI	693	725	853	835
D-HoH	783	892	959	958
B-VI	169	180	197	191
OHI	315	1,040	2,270	2,765
Autism	130	286	631	855
D-B	9	12	10	13
TBI	na	27	102	122
	2,099	3,162	5,022	5,739

LOW INCIDENCE TOTALS (0-22) '97

	1991	1993	1997	[% of H.]
PI	1,233	1,358	835	1.43
D-HoH	1,417	1,606	1,930	1.80
B-VI	343	351	417	.39
OHI	641	1,964	5,171	4.83
Autism	189	434	1,283	1.20
D-B	14	22	25	.02
TBI	na	86	255	.23
T:	3,837	5,821	10,610	9.9

1993 LI TOTAL = 5,821
% of Total SE Child Ct = 6.42

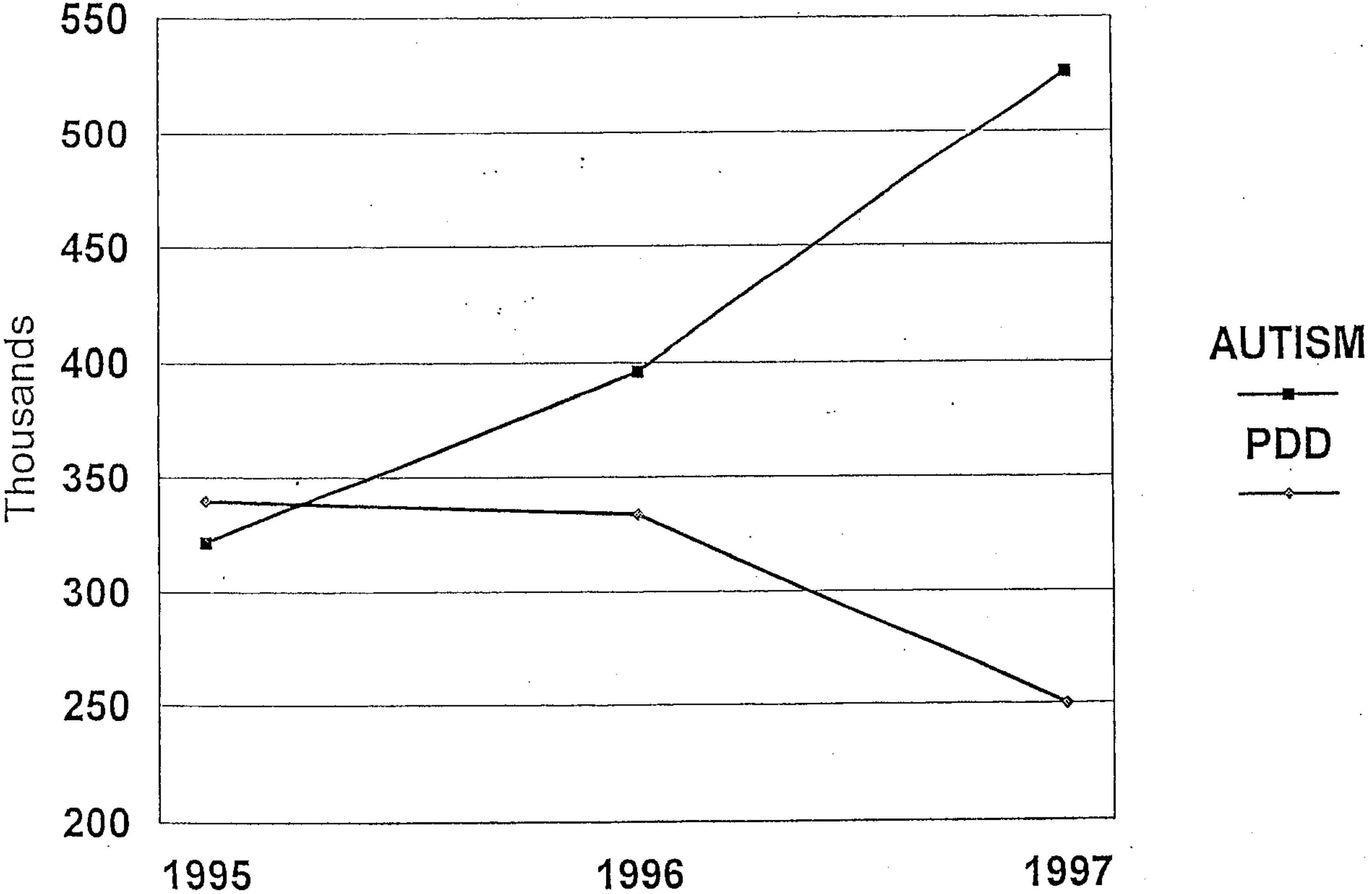
1994 LI TOTAL = 7,158
% of Total SE Child Ct = 7.41

1996 LI TOTAL = 9,325
% of Total SE Child Ct. = 8.93

STATE ENROLLMENT DATA

	(5-18)	Sp. Ed.	(5-18)
Enroll 1993		Pupil	%
Public	791,969	88,857	
Non-P.	81,631	1,694	
Totals:	873,558	90,551	9.39
	(5-18)	Sp. Ed.	(5-18)
Enroll 1996		Pupil	%
Public	843,917	102,231	
Non-P.	74,979	1,842	
Totals:	918,896	104,073	10.16
	(5-18)	Sp. Ed.	(5-18)
Enroll 1997		Pupil	%
Public	849,458	105,126	
Non-P.	83,981	1,772	
Totals:	933,439	106,898	11

Expenditures for Mental Health Services by Primary Diagnosis of Autism or PDD--1995 through 1997*



(*1997 Claims Data is not complete.)

MENTAL HEALTH SERVICES FOR RECIPIENTS WITH A PRIMARY DIAGNOSIS OF AUTISM (CY 95/96/97)

1995

AGE*	0 to 3	4 to 8	9 to 20	21 and Older	TOTALS
SERVICE	AMOUNT-(CLIENTS)				
Diagnostic Assessment	1,324.10 (6)	8,246.48 (49)	4,149.99 (37)	4,471.23 (41)	18,191.80
Psychological Testing	197.40 (2)	3,217.81 (23)	1,019.90 (6)	2,560.47 (16)	6,995.58
Explanation of Findings	302.78 (6)	3,596.05 (35)	721.24 (8)	782.48 (11)	5,402.55
Individual Psychotherapy	85.98 (3)	1,387.63 (15)	3,922.06 (25)	3,139.14 (15)	8,534.81
Family Psychotherapy	644.00 (8)	2,318.50 (21)	683.78 (12)	313.74 (7)	3,960.02
Group Psychotherapy	0 (0)	594.00 (3)	198.00 (1)	2,164.20 (10)	2,956.20
Medication Management	20.00 (1)	544.00 (12)	2,522.83 (47)	5,289.20 (59)	8,376.03
Day Treatment	10,346.70 (4)	247,162.65 (36)	2,899.35 (1)	0 (0)	260,408.70
Skills Training	0 (0)	0 (0)	0 (0)	0 (0)	.00
Case Management	0 (0)	2,976.25 (2)	3,033.75 (6)	522.50 (2)	6,532.50
TOTALS	12,920.96 (10)	270,043.37 (105)	19,150.90 (89)	19,242.96 (106)	321,358.19 (310)

1996

AGE*	0 to 3	4 to 8	9 to 20	21 and Older	TOTALS
SERVICE	AMOUNT-(CLIENTS)				
Diagnostic Assessment	2,818.90 (9)	7,710.88 (45)	4,498.15 (40)	3,673.06 (30)	18,700.99
Psychological Testing	8.70 (1)	3,378.67 (17)	2,167.11 (11)	1,628.06 (15)	7,182.54
Explanation of Findings	71. 25 (2)	1,852.80 (31)	936.56 (15)	1,332.36 (15)	4,192.97
Individual Psychotherapy	658.00 (0)	1,146.39 (13)	5,547.64 (29)	2,657.97 (16)	10,010.00
Family Psychotherapy	729.00 (5)	2,532.00 (14)	2,440.00 (15)	28.00 (1)	5,729.00
Group Psychotherapy	0 (0)	0 (0)	641.25 (3)	3,438.00 (9)	4,079.25
Medication Management	24.00 (1)	372.00 (8)	2,964.60 (55)	6,016.29(66)	9,376.89
Day Treatment	35,308.56(15)	268,373.07(44)	16,922.36 (3)	0 (0)	320,603.98
Skills Training	0 (0)	3,206.50 (1)	5,420.11 (3)	0 (0)	8,626.61
Case Management	0 (0)	4,196.25 (3)	2,999.50 (9)	332.50 (2)	7,527.25
TOTALS	39,618.41 (21)	292,768.56 (108)	44,537.27 (120)	19, 106.24 (105)	396,030.48 (354)

1997**

AGE*	0 to 3	4 to 8	9 to 20	21 and Older	TOTALS
SERVICE	AMOUNT-(CLIENTS)				
Diagnostic Assessment	1,028.80 (10)	6,513.40 (47)	3,747.38 (35)	3,114.18 (29)	14,403.76
Psychological Testing	1,002.22 (7)	2,796.64 (19)	1,888.25 (9)	484.16 (3)	6,171.27
Explanation of Findings	78.37 (2)	1,072.21 (30)	869.20 (11)	819.30 (10)	2,839.08
Individual Psychotherapy	52.64 (1)	1,246.61 (15)	5,599.91 (32)	3,365.45 (20)	10,264.61
Family Psychotherapy	2,759.72 (8)	5,855.27 (25)	5,324.00 (18)	21.00 (1)	13,959.99
Group Psychotherapy	0 (0)	0 (0)	0 (0)	1,431.00 (1)	1,431.00
Medication Management	0 (0)	1,072.00 (14)	3,122.68(62)	5,214.26 (68)	9,408.94
Day Treatment	32,218.74 (12)	392,713.69 (63)	11,047.85 (2)	0 (0)	435,980.28
Skills Training	0 (0)	14,294.65 (4)	7,965.96 (3)	0 (0)	22,260.61
Case Management	0 (0)	7,537.50 (5)	2,511.75 (4)	0 (0)	10,049.25
TOTALS	37,140.49 (23)	433,101.97 (126)	42,076.98 (127)	14,449.35 (103)	526,768.79 (379)

* Age groupings based on age of recipient as of 12/31 of that year.

** 1997 Claims Data not complete.

***Note:** Medical Assistance data used in this report should be interpreted with caution. The task force reviewed claims data from the MMIS system for individuals who met the category of service entitled Developmentally Disabled and/or Mental Health. This data did not include all children with ASD who were eligible for and submitted claims for service.

DEPARTMENT OF HUMAN SERVICES

DRAFT9/26/98

MENTAL HEALTH SERVICES FOR RECIPIENTS WITH A PRIMARY DIAGNOSIS OF PERVASIVE DEVELOPMENTAL DISORDER (CY 95/96/97)

1995

AGE*	0 to 3	4 to 8	9 to 20	21 and Older	TOTALS
SERVICE	AMOUNT-(CLIENTS)				
Diagnostic Assessment	1,223.10 (6)	7,168.99 (56)	6,608.69 (55)	1,898.10 (13)	16,908.88
Psychological Testing	394.80 (2)	4,420.38 (18)	3,133.25 (21)	444.15 (3)	8,392.58
Explanation of Findings	459.51 (5)	2,739.42 (32)	1,605.77 (22)	541.44 (6)	5,346.14
Individual Psychotherapy	139.03 (2)	9,111.01 (32)	16,645.42 (63)	5,200.82 (14)	31,096.28
Family Psychotherapy	1,121.50 (5)	3,397.10 (19)	8,312.72 (32)	138.60 (3)	12,969.92
Group Psychotherapy	33.75 (1)	168.75 (2)	234.00 (1)	508.50 (3)	945.00
Medication Management	80.00 (1)	1,832.20 (21)	4,171.61 (48)	2,308.97 (24)	8,392.78
Day Treatment	21,716.70 (6)	184,768.87 (29)	21,404.50 (12)	1,819.20 (2)	229,709.27
Skills Training	0 (0)	0 (0)	5,752. 43 (5)	0 (0)	5.752.43
Case Management	0 (0)	5,239.75 (6)	12,302.50 (19)	2,426.00 (3)	19,968.25
TOTALS	25,168.39 (17)	218,846.47 (121)	80,170.89 (151)	15,285.78 (42)	339,471.53(331)

1996

AGE*	0 to 3	4 to 8	9 to 20	21 and Older	TOTALS
SERVICE	AMOUNT-(CLIENTS)				
Diagnostic Assessment	1,534.80 (11)	6,090.29 (48)	5,681.26 (48)	2,248.93 (22)	15,555.28
Psychological Testing	737.35 (5)	4,388.96 (21)	5,478.97 (21)	1,385.39 (9)	11,990.67
Explanation of Findings	14.25 (1)	1,791.82 (26)	1,794.41 (18)	391.85 (6)	3,992.33
Individual Psychotherapy	231.15 (3)	7,718.25 (31)	19,387.78 (47)	7,007.50 (25)	34,344.68
Family Psychotherapy	545.32 (4)	4,966.55 (25)	8,097.84 (29)	172.20 (3)	13,781.91
Group Psychotherapy	0 (0)	249.75 (2)	549.70 (7)	1,074.60 (3)	1,874.05
Medication Management	40.00 (1)	1,965.60 (23)	4,428.00 (61)	4,526.32 (41)	10,959.92
Day Treatment	8,931.65 (4)	170,152.05 (25)	18,358.45 (10)	8,480.54 (4)	205,922.69
Skills Training	0 (0)	2,171.34 (4)	7,128.94 (4)	0 (0)	9,300.28
Case Management	0 (0)	5,115.00 (5)	17,487.50 (24)	3,015.00 (5)	25,617.50
TOTALS	12,034.52 (20)	204,609.61 (120)	88,392.85 (157)	28,302.33 (77)	333,339.31(374)

1997**

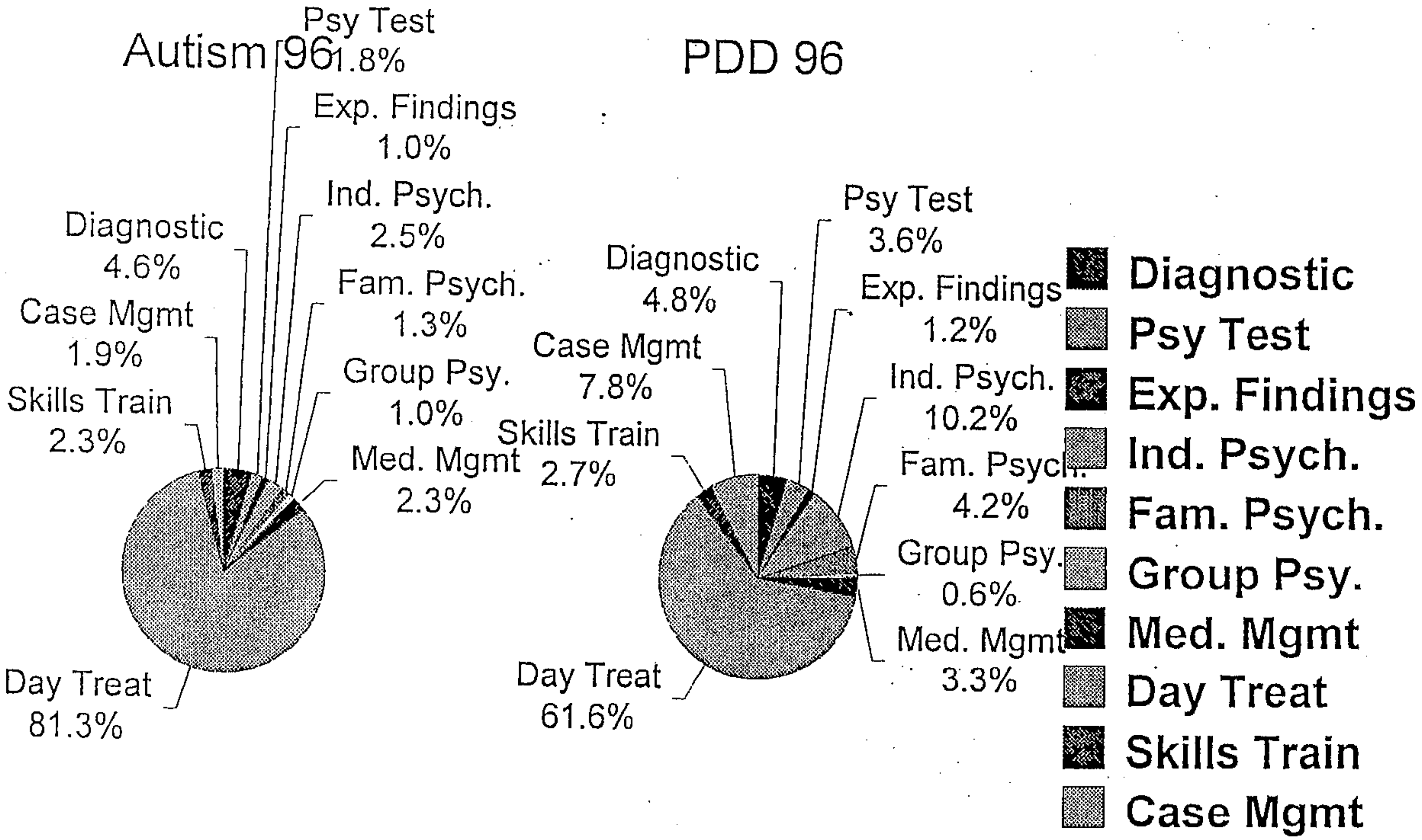
AGE*	0 to 3	4 to 8	9 to 20	21 and Older	TOTALS
SERVICE	AMOUNT-(CLIENTS)				
Diagnostic Assessment	97.20 (3)	7,453.44 (57)	5,215.93 (50)	1,822.41 (19)	14,588.98
Psychological Testing	648.90 (4)	2,621.50 (21)	5,219.64 (24)	928.31 (5)	9,418.35
Explanation of Findings	64.13 (2)	1,011.69 (15)	1,232.50 (17)	776.32 (9)	3,084.64
Individual Psychotherapy	0 (0)	6,118.08 (19)	15,161.20 (56)	8,744.73 (27)	30,024.01
Family Psychotherapy	1,802.50 (2)	5,007.07 (23)	6,180.00 (33)	0 (0)	12,989.57
Group Psychotherapy	0 (0)	270.00 (2)	1,200.37 (3)	2,295.00 (2)	3,765.37
Medication Management	24.00 (2)	1,788.00 (22)	6,117.24 (74)	4,706.22 (51)	12,635.46
Day Treatment	4,974.86 (1)	85,708.52 (15)	14,098.80 (6)	9,845.46 (4)	114,627.64
Skills Training	2,270.02 (2)	5,232.44 (2)	6,505.01 (6)	0 (0)	14,007.47
Case Management	1,102.50 (1)	2,610.00 (5)	24,719.25 (22)	6,596.00 (6)	35,027.75
TOTALS	10,984.11 (9)	117,820.74 (108)	85,649.94 (169)	35,714.45 (82)	250,169.24(368)

* Age groupings based on age of recipient as of 12/31 of that year.

** 1997 Claims Data is not complete.

***Note:** Medical Assistance data used in this report should be interpreted with caution. The task force reviewed claims data from the MMIS system for individuals who met the category of service entitled Developmentally Disabled and/or Mental Health. This data did not include all children with ASD who were eligible for and submitted claims for service.

Composition of Mental Health Services--Autism vs. PDD (1996)



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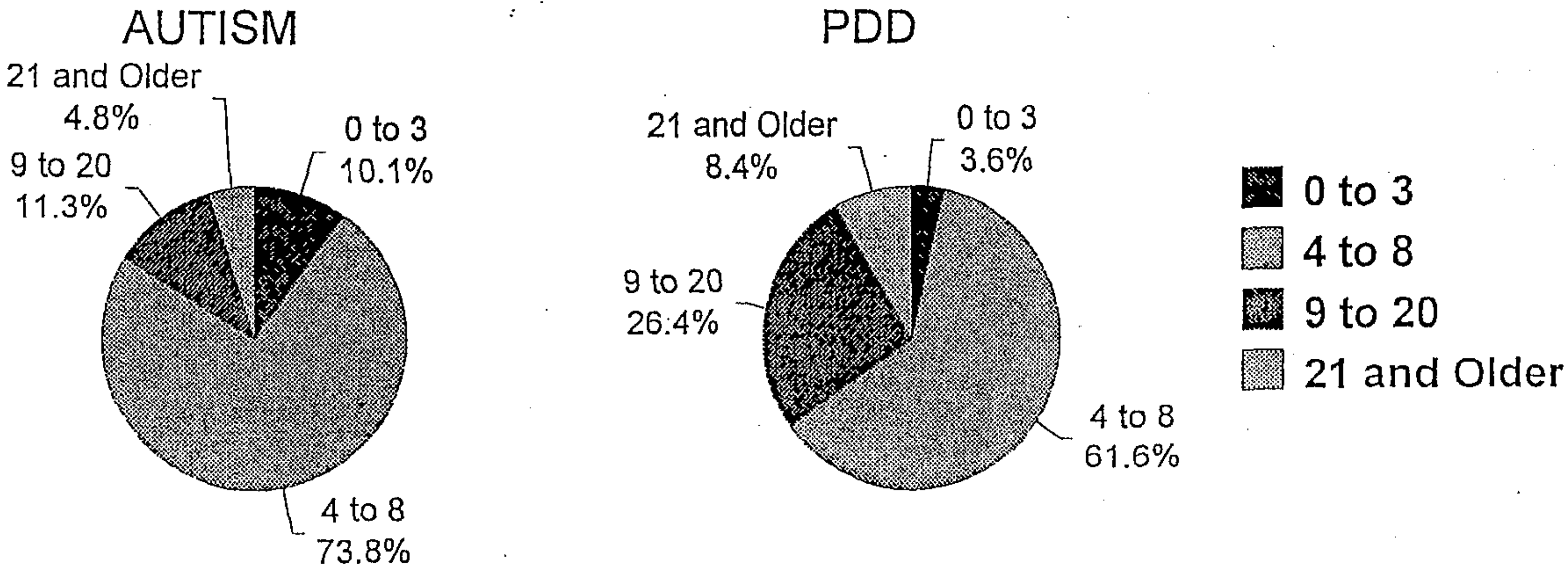
Comparison of Mental Health Reimbursements by Age Groupings and Primary Diagnosis (CY 1996)



DEPARTMENT OF HUMAN SERVICES

Draft 9/28/1998

DAY TREATMENT PROVIDERS
*CALENDAR YEAR 1997**
CLIENTS WITH AUTISM DIAGNOSIS ONLY

NAME	*# Claims*	*% of Claims*	*# of Clients*	*% of Clients*
FRASER COMMUNITY SERVICES	2633	86%	68	94.4%
LIFESPAN	21	1%	1	1.4%
NEIGHBORHOOD COUNSELING CENTER	65	2%	1	1.4%
NORTHWOOD CHILDREN'S HOME	207	7%	1	1.4%
WHIPPLE HEIGHTS	137	4%	1	1.4%
TOTALS	**3063**	**100%**	72	**100%**

* 1997 Claims Data is not complete.

DEPARTMENT OF HUMAN SERVICES

Costs for DD Clients Diagnosed with Autism--Calendar Year 1995

Data from the MMIS Screening and Paid Claims files as they existed on 9/4/1998 and 10/2/1998 (for Non-HC Therapies)

	Age Group	0-3	4-8	9-20	21 and over	Total
	Total # recips.	4	53	68	16	141
	With SILS	0	0	0	0	0
	With FSG	0	0	0	1	1
DD WAIVER	Case Management	$1,462.50	$16,932.50	$43,647.75	$17,701.25	$79,744.00
	DT&H	$0.00	$0.00	$0.00	$60,583.99	$60,583.99
	Homemaker	$0.00	$3,593.35	$14,958.23	$0.00	$18,551.58
	In-Home Support	$1,455.24	$69,441.08	$279,299.55	$4,495.39	$354,691.26
	Modifications	$0.00	$111.00	$13,550.34	$0.00	$13,661.34
	Respite	$1,597.75	$7,052.21	$36,514.56	$1,273.56	$46,438.08
	Crisis Respite	$0.00	$0.00	$0.00	$0.00	$0.00
	Supported Employment	$0.00	$0.00	$0.00	$0.00	$0.00
	Adult SLS	$0.00	$0.00	$1,046.52	$342,598.24	$343,644.76
	Child SLS	$0.00	$0.00	$270,715.45	$0.00	$270,715.45
	Specialist Services	$418.00	$7,820.28	$6,035.56	$0.00	$14,273.84
	Caregiver Training	$0.00	$609.50	$616.12	$0.00	$1,225.62
	Personal Support	$0.00	$0.00	$0.00	$0.00	$0.00
	Assistive Technology	$0.00	$0.00	$0.00	$0.00	$0.00
	Housing Access	$0.00	$0.00	$0.00	$0.00	$0.00
	$ Total	$4,933.49	$105,559.92	$666,384.08	$426,652.43	$1,203,529.92
	# Undup. Recips.	1	8	27	9	45
	Avg. Cost/Recip.	$4,933.49	$13,194.99	$24,680.89	$47,405.83	$26,745.11
D ICF/MR	$ Total	$0.00	$0.00	$18,449.12	$156,837.24	$175,286.36
	# Undup. Recips.	0	0	1	3	4
	Avg. Cost/Recip.	$0.00	$0.00	$18,449.12	$52,279.08	$43,821.59
D RTC	$ Total	$0.00	$0.00	$0.00	$68,956.00	$68,956.00
	# Undup. Recips.	0	0	0	1	1
	Avg. Cost/Recip.	$0.00	$0.00	$0.00	$68,956.00	$68,956.00
TH Non-Waiver	$ Total	$0.00	$0.00	$0.00	$23,391.92	23391.92
	# Undup. Recips.	0	0	0	2	2
	Avg. Cost/Recip.	$0.00	$0.00	$0.00	$11,695.96	$11,695.96
ome Care						
Personal Care	$ Total	$4,606.73	$449,198.92	$400,524.00	$0.00	$854,329.65
	# Undup. Recips.	1	35	33	0	69
	Avg. Cost/Recip.	$4,606.73	$12,834.25	$12,137.09	$0.00	$12,381.59
Other	$ Total	$0.00	$100.56	$77.14	$0.00	$177.70
	# Undup. Recips.	0	1	1	0	2
	Avg. Cost/ Recip.	$0.00	$100.56	$77.14	$0.00	$88.85
C Therapies and ssessments						
Occupational Therapy	$ Total	$0.00	$1,828.56	$1,828.56	$0.00	$3,657.12
	# Undup. Recips.	0	1	1	0	2
	Avg. Cost/Recip	$0.00	$1,828.56	$1,828.56	$0.00	$1,828.56
Physical Therapy	$ Total	$0.00	$0.00	$0.00	$0.00	$0.00
	# Undup. Recips.	0	0	0	0	0

***Note:** Medical Assistance data used in this report should be interpreted with caution. The task force reviewed claims data from the MMIS system for individuals who met the category of service entitled Developmentally Disabled and/or Mental Healt This data did not include all children with ASD who were eligible for and submitted claims for service.

Costs for DD Clients Diagnosed with Autism--Calendar Year 1995

Data from the MMIS Screening and Paid Claims files as they existed on 9/4/1998 and 10/2/1998 (for Non-HC Therapies)

	Avg. Cost/Recip.	$0.00	$0.00	$0.00	$0.00	$0.00
Speech Therapy	$ Total	$0.00	$1,149.12	$0.00	$0.00	$1,149.12
	# Undup. Recips.	0	1	0	0	1
	Avg. Cost/Recip.	$0.00	$1,149.12	$0.00	$0.00	$1,149.12
Assessment	$ Total	$102.18	$814.46	$715.26	$0.00	$1,631.90
	# Undup. Recips.	1	8	6	0	15
	Avg. Cost/Recip.	$102.18	$101.81	$119.21	$0.00	$108.79
Non HC Therapies and Assessments	(therapies, assessments and evaluations combined)					
Occupational Therapy	$ Total	$72.36	$26,922.15	$14,356.76	$2,368.81	$43,720.08
	# Undup. Recips	1	19	8	5	33
	Avg. Cost/Recip.	$72.36	$1,416.96	$1,794.60	$473.76	$1,324.85
Physical Therapy	$ Total	$0.00	$154.56	$144.00	$0.00	$298.56
	# Undup. Recips	0	5	1	0	6
	Avg. Cost/Recip.	$0.00	$30.91	$144.00	$0.00	$49.76
Speech Therapy	$ Total	$0.00	$21,812.36	$4,217.64	$496.88	$26,526.88
	# Undup. Recips	0	19	2	2	23
	Avg. Cost/Recip.	$0.00	$1,148.02	$2,108.82	$248.44	$1,153.34

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DEPARTMENT OF HUMAN SERVICES

Costs for DD Clients Diagnosed with Autism--Calendar Year 1996

Data from the MMIS Screening and Paid Claims files as they existed on 9/4/1998 and 10/2/198 (for Non-HC Therapies)

	Age Group	0-3	4-8	9-20	21 and over	Total
	Total # of Recips.	4	58	91	20	173
	With SILS	0	0	0	0	0
	With FSG	0	0	1	1	2
DD WAIVER	Case Management	$0.00	$14,550.76	$57,695.57	$27,258.68	$99,505.01
	DT&H	$0.00	$0.00	$2,865.04	$72,439.58	$75,304.62
	Homemaker	$0.00	$1,101.00	$12,678.21	$0.00	$13,779.21
	In-Home Support	$0.00	$89,216.62	$456,717.77	$4,211.93	$550,146.32
	Modifications	$0.00	$451.80	$9,284.71	$0.00	$9,736.51
	Respite	$0.00	$20,955.91	$41,088.39	$1,951.03	$63,995.33
	Crisis Respite	$0.00	$0.00	$3,180.00	$81,020.52	$84,200.52
	Supported Employment	$0.00	$0.00	$0.00	$0.00	$0.00
	Adult SLS	$0.00	$0.00	$0.00	$364,052.20	$364,052.20
	Child SLS	$0.00	$0.00	$338,286.12	$0.00	$338,286.12
	Specialist Services	$0.00	$6,713.46	$12,020.87	$0.00	$18,734.33
	Caregiver Training	$0.00	$379.62	$635.60	$0.00	$1,015.22
	Personal Support	$0.00	$0.00	$0.00	$0.00	$0.00
	Assistive Technology	$0.00	$0.00	$2,031.21	$0.00	$2,031.21
	Housing Access	$0.00	$0.00	$0.00	$0.00	$0.00
	$ Total	$0.00	$133,369.17	$933,303.49	$469,913.42	$1,536,586.08
	# Undup. Recips.	0	11	37	11	59
	Avg. Cost/Recip.	$0.00	$12,124.47	$25,224.42	$42,719.40	$26,043.83
DD ICF/MR	$ Total	$0.00	$0.00	$19,128.52	$177,078.69	$196,207.21
	# Undup. Recips.	0	0	1	4	5
	Avg. Cost/Recip.	$0.00	$0.00	$42.00	$44,269.67	$39,241.44
DD RTC	$ Total	$0.00	$0.00	$0.00	$36,801.42	$36,801.42
	# Undup. Recips.	0	0	0	2	2
	Avg. Cost/Recip.	$0.00	$0.00	$0.00	$18,400.71	$18,400.71
DTH Non-Waiver	$ Total	$0.00	$0.00	$0.00	$35,049.76	$35,049.76
	# Undup. Recips.	0	0	0	4	4
	Avg. Cost/Recip.	$0.00	$0.00	$0.00	$8,762.44	$8,762.44
Home Care						
Personal Care	$ Total	$8,984.14	$404,980.17	$452,758.17	$6,713.04	$873,435.52
	# Undup. Recips	1	32	42	1	76
	Avg. Cost/Recip.	$8,984.14	$12,655.63	$10,779.96	$6,713.04	$11,492.57
Other	$ Total	$0.00	$331.98	$0.00	$0.00	$331.98
	# Undup. Recips	0	3	0	0	3
	Avg. Cost/Recip.	$0.00	$110.66	$0.00	$0.00	$110.66
Home Care Therapies and Assessments						
Occupational Therapy	$ Total	$0.00	$1,732.32	$5,726.28	$0.00	$7,458.60
	# Undup. Recips	0	1	3	0	4
	Avg. Cost/Recip.	$0.00	$1,732.32	$1,908.76	$0.00	$1,864.65
Physical Therapy	$ Total	$0.00	$0.00	$0.00	$0.00	$0.00
	# Undup. Recips	0	0	0	0	0
	Avg. Cost/Recip.	$0.00	$0.00	$0.00	$0.00	$0.00
Speech Therapy	$ Total	$0.00	$0.00	$1,053.36	$0.00	$1,053.36
	# Undup. Recips	0	0	1	0	1
	Avg. Cost/Recip.	$0.00	$0.00	$1,053.36	$0.00	$1,053.36
Assessment	$ Total	$306.54	$3,678.48	$4,700.28	$102.18	$8,787.48
	# Undup. Recips	2	25	29	1	57
	Avg. Cost/Recip.	$153.27	$147.14	$162.08	$102.18	$154.17

***Note:** Medical Assistance data used in this report should be interpreted with caution. The task force reviewed claims data from the MMIS system for individuals who met the category of service entitled Developmentally Disabled and/or Mental Health This data did not include all children with ASD who were eligible for and submitted claims for service.

Costs for DD Clients Diagnosed with Autism--Calendar Year 1996

Data from the MMIS Screening and Paid Claims files as they existed on 9/4/1998 and 10/2/198 (for Non-HC Therapies)

	Age Group	0-3	4-8	9-20	21 and over	Total
Non Home Care Therapies and Assessments	(therapies, assessments and evaluations combined)					
OT	$ Total	$1,374.84	$42,267.22	$9,165.61	$6,283.62	$59,091.29
	# Undup. Recips	1	24	9	4	38
	Avg. Cost/Recip.	$1,374.84	$1,761.13	$1,018.40	$1,570.91	$1,555.03
PT	$ Total	$0.00	$695.69	$573.50	$33.00	$1,302.19
	# Undup. Recips	0	4	3	1	8
	Avg. Cost/Recip.	$0.00	$173.92	$191.17	$33.00	$162.77
Speech Therapy	$ Total	$1,121.58	$46,965.20	$4,552.69	$1,768.54	$54,408.01
	# Undup. Recips	1	26	5	1	33
	Avg. Cost/Recip.	$1,121.58	$1,806.35	$910.54	$1,768.54	$1,648.73

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DEPARTMENT OF HUMAN SERVICES

Costs for DD Clients Diagnosed with Autism--Calendar Year 1997

Data from the MMISII Screening and Paid Claims files as they existed on 9/4/1998 and 10/2/1998 (for Non-HC Therapies)

	Age Group	0-3	4-8	9-20	21 and over	Total
	# Undup. Recips.	6	81	121	22	230
	With SILS	0	0	0	0	0
	With FSG	0	3	9	0	13
DD Waiver	Case Management	$0.00	$13,808.84	$69,289.47	$16,814.45	$99,912.76
	DT&H	$0.00	$0.00	$11,292.28	$106,169.27	$117,461.55
	Homemaker	$0.00	$579.20	$9,463.00	$0.00	$10,042.20
	In-Home Support	$0.00	$89,740.77	$593,792.19	$1,549.52	$685,082.48
	Modifications	$0.00	$2,220.21	$13,592.42	$639.28	$16,451.91
	Respite	$0.00	$26,916.45	$34,735.09	$7,104.92	$68,756.46
	Crisis Respite	$0.00	$1,585.60	$24,895.66	$2,160.00	$28,641.26
	Supported Employment	$0.00	$0.00	$0.00	$0.00	$0.00
	Adult SLS	$0.00	$7,409.86	$75,239.94	$485,120.49	$567,770.29
	Child SLS	$0.00	$22,092.68	$378,551.04	$0.00	$400,643.72
	Specialist Services	$0.00	$30,060.17	$12,189.62	$0.00	$42,249.79
	Caregiver Training	$0.00	$229.00	$49.00	$0.00	$278.00
	Personal Support	$0.00	$4,499.62	$971.04	$0.00	$5,470.66
	Assistive Technology	$0.00	$447.95	$1,037.91	$0.00	$1,485.86
	Housing Access	$0.00	$0.00	$0.00	$0.00	$0.00
	$ Total	$0.00	$198,004.75	$1,200,203.00	$617,302.44	$2,015,510.19
	# Undup Recips	0	13	49	12	74
	Avg. Cost/Recip.	$0.00	$15,231.13	$24,493.94	$51,441.87	$27,236.62
DD ICF/MR	**$ Total**	$0.00	$0.00	$40,624.65	$140,557.90	$181,182.55
	# Undup Recips	0	0	4	3	7
	Avg. Cost/Recip.	$0.00	$0.00	$10,156.16	$46,852.63	$25,883.22
DD RTC	$ Total	$0.00	$0.00	$0.00	$46,488.42	$46,488.42
	# Undup Recips	0	0	0	4	4
	Avg. Cost/Recip.	$0.00	$0.00	$0.00	$11,622.11	$11,622.11
DTH Non-Waiver	**$ Total**	$0.00	$0.00	$0.00	$37,177.55	$37,177.55
	# Undup.Recips	0	0	0	4	4
	Avg. Cost/Recip.	$0.00	$0.00	$0.00	$9,294.39	$9,294.39
Home Care						
Personal Care	**$ Total**	$25,000.73	$562,434.95	$561,695.47	$13,405.33	$1,137,535.75
	# Undup.Recips	3	44	50	1	95
	Avg. Cost/Recip.	$8,333.58	$12,782.61	$11,233.91	$13,405.33	$11,974.06
Other	**$ Total**	$0.00	$1,790.43	$50.28	$0.00	$1,840.71
	# Undup.Recips	$0.00	1	1	0	2
	Avg. Cost/Recip.	$0.00	$1,790.43	$50.28	$0.00	$920.36
Home Care Therapies and Assessments						
Occupational Therapy	**$ Total**	$0.00	$555.83	$13,385.15	$0.00	$13,940.98
	# Undup.Recips	0	1	4	0	5
	Avg. Cost/Recip.	$0.00	$555.83	$3,346.29	$0.00	$2,788.20
Physical Therapy	**$ Total**	$0.00	$396.08	$99.02	$0.00	$495.10
	# Undup.Recips	0	1	1	0	2
	Avg. Cost/Recip.	$0.00	$396.08	$99.02	$0.00	$247.55
Speech Therapy	**$ Total**	$0.00	$201.08	$4,170.18	$0.00	$4,371.26
	# Undup.Recips	0	2	2	0	4
	Avg. Cost/Recip.	$0.00	$100.54	$2,085.09	$0.00	$1,092.82
Assessment	**$ Total**	$613.08	$6,437.34	$4,802.46	$306.54	$11,546.34
	# Undup.Recips	3	44	36	2	82
	Avg. Cost/Recip.	$204.36	$146.30	$133.40	$153.27	$140.81

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DEPARTMENT OF HUMAN SERVICES

Costs for DD Clients Diagnosed with Autism--Calendar Year 1997

Data from the MMISII Screening and Paid Claims files as they existed on 9/4/1998 and 10/2/1998 (for Non-HC Therapies)

	Age Group	0-3	4-8	9-20	21 and over	Total
Non Home Care Therapies and Assessments	(therapies, assessments and evaluations combined)					
Occupational Therapy	$ Total	$0.00	$45,175.49	$9,718.80	$6,268.83	$61,163.12
	# Undup. Recips	0	32	8	5	45
	Avg. Cost/Recip.	$0.00	$1,411.73	$1,214.85	$1,253.77	$1,359.18
Physical Therapy	$ Total	$0.00	$1,767.34	$813.60	$0.00	$2,580.94
	# Undup. Recips	0	9	2	0	11
	Avg. Cost/Recip.	$0.00	$196.37	$406.80	$0.00	$234.63
Speech Therapy	$ Total	$0.00	$55,510.43	$14,052.12	$2,465.40	$72,027.95
	# Undup. Recips	0	30	8	1	39
	Avg. Cost/Recip.	$0.00	$1,850.35	$1,756.52	$2,465.40	$1,846.87

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Autism Task Force Report

Appendix 5:
Program Development Issues

Appendix 5: Program Development Issues

The task force attempted to identify program development issues that address the necessary components of services for children with ASD. A completely developed program includes program and personnel standards, appropriate service flow and documentation of care, a wide range of educated and trained providers, method for accountability of quality and coordinated payment by all resources.

A program of services cannot be developed unless a child receives an assessment. Assessment is essential for appropriate intervention and an expert in the area of ASD needs to be identified as the assessment and interagency plan are being developed. A child's team must be aware of and consider the full array of methods that have been supported by research. A comprehensive assessment of the child's abilities, strengths and needs should be used as the basis for initial choice of intervention methodology. Progress toward goals and objectives should be monitored on a frequent and regular basis using systematically collected data. Subsequent maintenance of, or changes in, intensity of service or methods should be based on data. Quality assurance of the single plan of care/service needs to be monitored through systematic evaluation of individual progress.

The program development issues identified under each of the sub categories need further development and range from specific to philosophical.

Program and Personnel Standards

- CFL, DHS & MDH acting under an interagency agreement shall meet regularly to review program and personnel standards (para and professional levels) for children with ASD. This group should decide best practice guidelines for personnel complements and program practices.
- Program is year round and based on the use of a parent and interagency approach to provide intensive early intervention; engaged time can take place across multiple settings.
- ASD component for Early Childhood Special Education (ECSE) and Special Education training program provides a range of information to include research, identification, training in methodology, spectrum, and interventions. This also includes social workers, mental health workers and PCAs.

Service Flow and Documentation

- Public relations outreach and referral - medical home, day care, etc. Local community decides entrance into services; interagency intake process (consent interagency). The ASD expert is accessed and a service coordination assigned. Interagency single plan of care is developed; "model" decision is documented every 3 - 6 months. Continued data collection to review progress and check model effectiveness should occur.
- One stop service delivery that provides user friendly and more appropriate connections, easier access and clearinghouse help to the consumer.
- Document progress to all parties which requires contribution by all and sharing of data.
- Early identification & hassle free entry into services.
- Coordinated service provision including funding with state and local help and clearinghouse support.

Providers

- Services are family centered not provider/program driven.
- Providers exist across a variety of agencies. They have training in the areas of ASD. Services have home based capabilities and work together toward a plan developed across agencies with families at center of team. Services are coordinated through a service coordinator/case manager.
- Providers deliver services across an array of settings, supported by an array of professionals, para-professionals, and behavioral specialists.
- Family centered services is the core concept with interagency service provision planning key to the process. A basic knowledge base is required of all providers. Providers will have training on ASD and will be able to articulate role and outcomes.
- Philosophical shift to a student focus.

Accountability

- Interagency agreements or memorandum of understanding among agencies.
- State mediators trained and available.
- Utilize a Part C, State interagency group system for problem solving and assignment of financial responsibilities if there are disputes at the local level.
- Systems: All agencies involved are responsible for participating in the development of a common plan for children with ASD.
- Implementation of Plan: All agencies are accountable for demonstrating individual child's progress toward the outcomes identified on the child's plan.
- Everyone is involved in the use of data, progress notes, supervision, multi-agency plan.

Payment

- An individual with ASD places them in a specific category which makes them eligible for appropriate services.
- Funding should reflect the increased incidence of ASD.
- Reassessment for eligibility purposes is not necessary on an annual basis. Cost savings could be achieved if reassessments were not required and funding is shifted toward services.
- Use of all current funding systems (parental, public, MA, private) coordinated by a skilled service coordinator, facilitating assessment of financial responsibilities.
- Shared local and state dollars used to pay for joint services (assessment and service coordination).
- Additional funds allocated to enhance program options for child with ASD (intensity, training, etc.).
- Fair and appropriate, easy to access, no red tape, connect with a one step entry.
- Financial package predetermined - individual has an ASD waiver that provides funding for appropriate choices.

Training

- Develop team that could diagnose and/or evaluate programs and children that travels through the state similar to MCSHN.
- Develop provider resources list.

- Establish an ASD training institute coordinated with a central clearinghouse for information.
- Ensure training for families, providers, higher education and diagnostic teams.
- Team training, cross agency training, general information on ASD as well as specific training on behaviors, methods, specific child on-the-job training.

Autism Task Force Report

Appendix 6:
Philadelphia State Report on Autism

Financial Cost and Benefits of Intensive Early Intervention for Young Children with Autism - Pennsylvania Model Achieving Cost Savings

BRIEFING

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Executive Summary

Clinical and educational research and public policy reviews that have emerged in the past several years now make it possible to estimate the cost-benefits of intensive early intervention with infants, toddlers and preschoolers with autism or pervasive developmental disorders (PDD). It is now known that the attainment of intellectual, social, and behavioral functioning within the normal range can be achieved for a signficant proportion of children with autism or PDD when they are served in settings, situations, and learning environments that use principles of applied behavior analysis for teaching. Educational costs and other representative costs from Pennsylvania, including costs for public resources other than those from the educational and adult developmental disabilities services sectors, were used in a cost-benefit analysis. This briefing document presents estimates of cost-benefit assuming average participation for three years between the ages of 2 years old to school entry in such services. The analysis indicates cost-aversion or cost-avoidance, the extent to which cost savings are realized by providing early intervention. Positive dollar values indicate savings.

Autism is a disorder of brain development arising before age 3. Autism has a severe impact upon the development and use of social and communication skills, and is also characterized by stereotyped behavior and highly restricted interests or activities. Children with autism tend to leave school as young adults with these conditions still present. They require lifelong care, services, and supervision. Spontaneous recovery and highly successful rehabilitation through regular educational processes are very rare.

During the past decade research began to demonstrate that significant proportions of children with autism or PDD who participated in intensive early intervention based on the principles of applied behavior analysis achieved normal or near-normal functioning. Applied behavior analysis is a natural science approach to solving socially important problems of behavior, such a building appropriate cognitive, communication, and social skills in children with autism and PDD. Although there have been some criticisms of this research on some philosophical grounds, these philosophical grounds have not generated research results that indicate achievement of normal or near-normal functioning for these children.

The availability of these instructional technologies and approaches has changed the picture and outlook for cost-benefit and cost-aversion analysis of early intervention for these children, particularly in terms of averting education-long and life-long costs for special services. The cost-benefit model applied in this briefing assumes a range of effects of early intervention for these children that will result in some attending regular education, some special education, and some intensive special education.

Fifteen assumptions, reflecting research findings, program evaluation experience, and cost analysis considerations, underpin the cost-benefit analysis and are presented in the main body of the briefing. A brief annotated reference list of research findings and related reviews is also appended. Seven schedules and two appendices provide background information and layouts of findings. The analysis specifies an annual cost for these services of about $33,000, but extrapolations to $50,000 are feasible and noted.

In general, rounded terms for the purposes of summary, for children with autism or PDD who participate in competently delivered intensive early behavioral intervention:

- Cost savings from ages 3-22 years at $33,000 initial annual cost range from $185,000 to $205,000 without inflation and from $275,000 to $300,000 with inflation.
- Cost savings from ages 3-45 years at $33,000 initial annual cost range from $560,000 to $875,000 without inflation and from $1,050,000 to $1,650,000 with inflation.
- Differences in initial costs of $33,000 and $50,000 per year for intensive early behavioral intervention have a modest impact (about $51,000 higher expenditures per child for three years) on savings, but are outweighed by the extent of the savings noted above, even with respect to savings for ages 3-22 years without inflation.
- In terms of most likely levels of savings: based on a rate of normal functioning achieved of from 30% to 40% of children with autism or PDD, with inflation the projected savings would be $285,000 to $295,00 to age 22 and $1,200,000 to $1,350,000 to age 45.
- In terms of most likely levels of savings compared to controls in the UCLA study; based on a rate of normal functioning achieved of from 30% to 40% of children with autism or PDD, with inflation the projected savings would be $61,798 to $68,606 to age 22 and $668,678 to $823,920 to age 45.

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Overview

Background

First identified in the 1940s, autism is a disorder of brain development arising before age three, and often identified by that age or shortly thereafter. Autism has a severe impact upon the development and use of social and communication skills, and is also characterized by stereotyped behavior (e.g., rituals or repetitive behaviors) and highly restricted interests or activities. It has generally been found that between 60% to 75% of all children with autism also have some degree of mental retardation. The relationship between autism and mental retardation is not well understood, because some children with autism have intellectual abilities within the normal--and in a small number of cases, the superior--range. However, research clearly indicates that children with both autism and mental retardation tend to leave school as young adults with these conditions still present. They require lifelong care, services, and supervision. Spontaneous recovery and highly successful rehabilitation through regular educational processes are very rare.

Nationally, however, educational services for children with autism are among the most intensively staffed and expensive forms of special education available under provisions of the Individuals with Disabilities Education Act. The picture is similar for children diagnosed with pervasive developmental disorder (PDD), which has many characteristics in common with autism.

Contemporary Research

During the past decade research began to demonstrate that significant proportions of children with autism or PDD who participated in intensive early intervention based on the principles of applied behavior analysis achieved normal or near-normal functioning. Applied behavior analysis[1] is a natural science approach to solving socially important problems of behavior, such a building appropriate cognitive, communication, and social skills in children with autism and PDD. Here, also, we include both early intervention and preschool services, which are sometimes provided under the auspices of different public agencies in the states under the umbrella term of early intervention. Follow-up research by one group of investigators found that the benefits of early intensive behavioral intervention persisted into adolescence and young adulthood. The most comprehensive research was published by Ivar Lovaas and colleagues at UCLA, but studies by other independent investigators confirmed that it is possible for many children with autism or PDD to achieve normal functioning through early intensive intervention of this type. Of great importance is the fact that many children in the study samples whose skills did not reach normal levels nonetheless made significant, functional gains in core areas, such as everyday living and communication skills. A small proportion (about 10%,

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[1] Applied behavior analysis entails the specific and comprehensive use of principles of human learning, i.e., operant psychology or learning theory; in order to enhance the development, abilities, and self-direction skills of children and adults with disabilities. In the treatment of autism, various applied behavior analytic approaches may be referred to colloquially as discrete trial training, direct instruction, Lovaas therapy, or behavior modification.

across several studies) appeared to continue to need intensive intervention beyond the early childhood years. Research is ongoing to better identify the specific instructional and programmatic practices that enhance outcomes in these children.

Controversy and Criticisms

The research findings just summarized have been controversial, in that they date only from the mid-to-late 1980s and these findings have been the specific focus of research on autism and PDD conducted in only a few locations. For researchers, replication of the original findings has been a major concern and is the focus of ongoing efforts, as noted above. Moreover, these findings have emerged at a time when leaders of some philosophical movements in special education have begun to advocate for apparently incompatible educational practices of unproven efficacy, under the rubrics of total inclusion and "developmental appropriateness." Criticisms of early intensive behavioral intervention by some of these advocates have focused on alleged side effects, such as adverse social consequences. These criticisms are not grounded in sound research or established facts. They are erroneous interpretations of behavioral intervention, reflect incomplete or distorted understanding of behavioral procedures, or are otherwise suppositional and groundless. Among many leading clinicians and researchers concerned with effective intervention for autism and PDD, the question is not whether children with autism or PDD can achieve substantially improved functioning, but what practices lead to the best outcomes for these children.

Prior Cost-Benefit Analysis

Although critics of early behavioral intervention for autism and PDD stress philosophical concerns, from a public policy standpoint, the scientifically validated achievement of normal functioning by many children with autism or PDD has profound implications for analyses of the relative costs and benefits of early intervention for these children. Until recently, benefits could be estimated solely in terms of savings that might be associated with decreased, but still persisting, dependency in later childhood and into adulthood. Considering the high cost of specialized educational services for children with autism or PDD compared to regular education or other forms of special education, potential benefits were confined to relative savings at different levels of care during adulthood. Savings reflected comparison of total educational and adult services costs with and without specialized education. Because no basis existed for projecting these cost differentials, the cost-benefit of early intervention services remained unidentified.

Varying Effects for Different Children

With the emergence of research documenting substantial improvements for large proportions of children with autism or PDD following early intensive behavioral intervention, and confirmatory studies showing that the effects can be long-term, it has become possible to project costs and utilization more specifically. Such projections are aided by the compilation of costs for adult services in the developmental disabilities service sector by contemporary researchers, data that were not previously available. Thus, costs and benefits may be projected with reasonable confidence in terms of:

(1) children who achieve normal functioning, participate in regular education with little or no support, and are vocationally productive as adults;

(2) children who derive sufficient benefit from early intensive intervention that they are then able to participate in nonintensive special education, and evidence persisting but reduced dependency in adulthood; and

(3) children who achieve meaningful functional improvements but still require specialized and intensive educational and adult services.

In the present analyses, costs from the Commonwealth of Pennsylvania are used to develop overall cost comparisons in the calculation of cost-benefit.

Need for Cost-Benefit Analysis

As expenditures for social welfare, public health, and specialized human services have increased dramatically over the past two decades, there has been an increasing impetus for understanding the costs and consequences (i.e., benefits) of the investment of public resources and funding in specific progams and services. Welfare reform, Medicaid reform through such initiatives as managed care and home and community-based services waivers, and scrutiny of the rising costs of Part H early intervention services, preschool services, and related expenditures are all manifestations of the need to contain costs and direct resources in the most efficient and effective ways possible. In the area of intensive early intervention as a whole, including services for young children with autism or PDD, there has been mounting concern regarding cost-benefit. This concern has arisen because of the wide variations in costs for seemingly similar services available through local contractors. There are additional concerns are that possible economies may be lost when substitute financing mechanisms (for example. Medicaid fee-for-service) are used in lieu of system-wide cost-related rates within the educational or other specialized public service sector.

This briefing presents a cost-benefit analysis of early intensive behavioral intervention for autism or PDD based on the three groups of children that were previously identified: Those whose skills improve to within the normal range, those who make large gains but continue to require some special services, and those who will probably require long-term intensive help.

The analysis compares the costs and benefits of services for children with autism or PDD who receive intensive early intervention relative to those of children without disabilities in general, to children who continue to require special education, and those of other children with autism who do not receive effective intervention or who otherwise continue to require intensive supports. The analysis provides a projection of cost-aversion, that is, the costs avoided through provision of intensive early behavioral intevention services. These costs are stated as positive dollar amounts. A number of assumptions required to structure the analysis are detailed below.

Assumptions in the Present Analysis

1. Current research does not identify characteristics of children with autism or PDD that predict their response to early intensive intervention (e.g., initial I.Q. is not a good predictor) during the years before school entry, funded as either early intervention or preschool services. Thus, benefit must be gauged upon outcomes as identified in the literature.

2. The proportion of children who achieve normal functioning in all areas is probably somewhat lower than the proportion reported so far in the behavioral research literature (i.e., just under 50%) because (1) in very young children, when severe or profound mental retardation is present, a conclusive diagnosis of autism or PDD may not be made, and (2) other local or nonspecific factors probably affect whether children are diagnosed or, especially, referred for early intensive behavioral intervention.

3. In any group of children with autism or PDD who receive competently delivered early intensive behavioral intervention, between 20% and 60% will achieve normal functioning. Ten percent (10%) will continue to require intensive special education and intensive adult services, and the remainder will evidence benefit sufficient to reduce the intensity of educational and adult services requirements.

4. For these reasons, cost-benefit should be couched in terms of marginal benefit, in terms of impact of improvement as well as the attainment of normal functioning. Analyses should encompass comparison of costs for children with autism or PDD who achieve normal functioning with costs for serving children without disabilities, and with costs for serving children with autism or PDD who make large gains but do not move into the normal range. The latter group should also be compared with children who make minimal gains.

5. Without early intensive behavioral intervention the majority of children with autism or PDD will manifest enduring dependency on adult developmental disabilities services. This is consistent with the literature on child, adolescent, and young adult development for people with autism or PDD.

6. The costs of intensive behavior analytic center-based services for children with autism or PDD (including those with a home-based, parent-directed component) may not be comparable or equivalent, on average, with the costs of intensive home-based services, when instruction is comparably intensive, but relative costs and utilization mix are not well-established. The mix of costs for intensive early intervention services is represented here as an average which is assumed to be a represenative average for use of both center-based and home-based services.

7. Children with autism or PDD who ultimately develop normal skills are assumed to participate in regular education; those who make large gains but not sufficient for them to participate successfully in regular education are assumed to participate in special education; and children who make minimal gains Are assumed to participate in intensive special education or the equivalent from a cost perspective Special education alternatives (e.g., intensive special education) are assumed to be

equivalent in cost regardless of whether they are delivered in segregated, partially integrated, related service, and fully inclusive models, based on requisite instructional load requirements for comparable instructional and educational effects. In short, comparable instruction is assumed to cost the same regardless of whether an inclusive approach is used or not.

8. Because no generalizable mortality data exist for people with autism or PDD (owing partially to the advent of the diagnosis in the 1940s and lack of data on several populations), cost-benefit analyses including the adult years are made only to age 45. There is no compelling evidence of marked mortality prior to age 45 years for children surviving to adulthood, and the lifespan of people with autism or PDD may well be similar to that of the general population. Therefore, this cutoff point will tend to underestimate adult income from supported or regular employment, utilization of general public entitlements or benefits during adulthood, utilization costs for adult developmental disabilities services, and costs for utilization of aging services and public retirement or income transfer programs for elders.

9. Present costs are used as indicators of future costs, with recognition that reforms in welfare and public health may either result in decreased per person rates or expenditures, or in substitution of services in the future. To compensate, costs have been trended forward at 3% per annum, except for SSI/ADC(AFDC) or the equivalent such as TANF, which is trended at 1.5%. These trend factors probably represent an underestimate of inflationary factors. The average cost inflator for health related services from 1986 to 1996 was about 4.5%.

10. SSI/ADC costs are used as a summary cost for all utilization of general public benefits outside of the early intervention, educational, and developmental services sectors (e.g., public housing subsidies, food stamps, child care, temporary assistance, all forms of public assistance, higher education grants, vocational assistance, public transportation, Medicaid card services). Although these are not entered as costs for nondisabled children to age 22 years, they are entered as costs for all children with autism or PDD who achieve normal functioning (three years' cost), and partial or minimal effects (18 years' cost). SSI/ADC is also entered as a cost for 23 years to age 45 years for 25% of nondisabled children and children with autism or PDD who achieve normal functioning, and for 100% for children with autism or PDD who make substantial improvements or who benefit minimally. A lower estimate of 15% would not significantly alter relative costs, engendering only a 4% flex in total income or expense for nondisabled children and children with autism or PDD who achieve normal functioning. However, in light of present welfare reform initiatives, reduction to a 15% estimate might well be warranted in further analysis,

11. The average duration of early intensive behavioral intervention is assumed to be three years, a period that is associated in the literature with apparent better benefits from participation in these services. The existing literature suggests that two years of intervention can result in normal functioning, but in this analysis it is recognized that children may participate in from two to four years of early intervention (between the ages of two years old and school entry) and three years is stipulated to be a representative average duration.

12. Children with autism or PDD who achieve normal functioning are assumed to use family support services during participation in intensive early intervention. Children who make substantial gains and those for whom minimal effects are attained are assumed to use 18 years of family support services, to age 22 years.

During adulthood, those who achieve substantial improvements but not normal functioning are assumed to use 18 years of Medicaid waiver (or equivalent) services and 15 years of supported work services. During adulthood, for adults for whom minimal effects are obtained, 80% are assumed to use waiver services for 20 years, 20% are assumed to use intensive community services for 23 years, and 40% are assumed to use supported work services for 15 years. These utilization patterns are a function of variations in individual service needs and delays between requests for services and service enrollment associated with waiting lists. With the possible exception of adults with whom intervention is minimally effective, the cost mixes used are lower than those that are presently typical for intensive comprehensive community services for adults with autism or PDD (e.g., ICF/MR and ambulatory clinic variants or equivalent levels of care).

13. Supported employment wages are projected as comparable for individuals with autism or PDD who achieve substantial or minimal gains, at 20% of the median household annual income. It should be noted that although this probably overestimates income (and thus offset of service costs) for people with minimal benefits, it nonetheless reflects a single-person income level that remains below current poverty level indicators, and a full-time employment (40-hour week) hourly rate of $3.24 hourly in 1996.

14. This analysis uses costs reported in several sources for the Commonwealth of Pennsylvania. Annual Regular education costs are $7,543 per year in 1996, special education is $12,935, and intensive special education is $28,806 (from Schedule 1): The initial annual cost of early intensive behavioral intervention is set at $32,820. To calculate the cost-benefit of this intervention set at a higher level of $50,000, readers may simply subtract $53,100 from inflated benefit totals and subtract $51,540 from uninflated benefit totals.

15. Finally, in composite, the service costs and inflators used will tend to underestimate cost slightly relative to current expenditure patterns, whereas the earnings projected will tend to overestimate income slightly; providing, overall, a relatively conservative estimate of cost-benefit. All saving shown, however, are net of the expense of providing intensive behavioral early intervention.

Findings in the Present Analysis

At $32,820 initial annual cost, the total cost-benefit savings of intensive applied behavior analysis services per child with autism or PDD for ages 3-22 years averages from $187,399 to $205,305 without inflation and from $273,764 to $300,997 with inflation.

The majority of savings to schools accrue from children who achieve partial benefit rather than normal range functioning, and savings decrease slightly (by about 9%) on average with increased rates of children achieving normal range functioning. [Note: See Schedule 6]

At $50,000 initial annual cost, the corresponding cost-benefit savings of intensive applied behavior analysis services per child with autism or PDD ages 3-22 years averages from $135,859 to $153,765 without inflation and from $220,664 to $248,897 with inflation.

At $32,820 initial annual cost, the total cost-benefit savings of intensive applied behavior analysis services per child with autism or PDD for ages 3-45 years averages from $561,933 to $874,446 without inflation and from $1,040,806 to $1,661,774 with inflation.

The majority of savings to the developmental disabilities sector accrue from children who achieve normal range of functioning rather than partial benefit, and savings increase substantially (by about 62%) on average with increased rates of children achieving normal range functioning. [Note: See Schedule 7]

At $50,000 initial annual cost, the corresponding cost-benefit savings of intensive applied behavior analysis services per child with autism or PDD ages 3-45 years averages from $510,906 to $822,906 without inflation and from $987,706 to $1,608,674 with inflation.

Assuming a probable rate of normal functioning achieved of from 30% to 40% of children with autism or PDD who receive early intensive behavioral intervention compared to completely ineffective intervention, cost-benefit savings per child served would be from $287,381 to $294,189 with inflation to age 22 and from $1,196,048 to $1,351,290 with inflation to age 45. [Note: See Schedule 2]

Assuming a probable rate of normal functioning achieved of from 30% to 40% of children with autism or PDD who receive early intensive behavioral intervention compared to benefits shown by the UCLA control group in research studies, cost-benefit savings per child served would be from $61,768 to $68,606 with inflation to age 22 and from $668,678 to $823,920 with inflation to age 45. [Note: See Schedules 8 and 9]

Annotated Bibliography

These sources report outcomes or follow-up outcomes from early intensive behavioral intervention for autism or PDD using the principles of applied behavior analysis:

Anderson, S. R., Avery, D. L., DiPietro, E. K., Edwards, G. L., & Christian, W. P. (1987). Intensive home-based early intervention with autistic children. *Education and Treatment of Children, 10,* 352-366.

Birnbrauer, J. S., & Leach, D. J. (1993). The Murdoch Early Intervention Program after 2 years. *Behaviour Change, 10*(2), 63-74.

Lovaas, O. I. (1987). Behavioral treatment and normal intellectual and educational functioning in autistic children. *Journal of Consulting and Clinical Psychology, 55,* 3-9.

McEachin, J. J., Smith, T., & Lovaas, O. I. (1993). Long term outcome for children with autism who received early intensive behavioral treatment. *American Journal on Mental Retardation, 97,* 359-372.

Perry, R., Cohen, I, & DeCarlo, R. (1995). Case study: Deterioration, autism, and recovery in two siblings. *Journal of the American Academy of Child and Adolescent Psychiatry, 34,* 232-237.

Sheinkopf, S. J., & Siegel, B. (in press). Home based behavioral treatment of young autistic children. *Journal of Autism and Developmental Disorders.* (Available upon request to the authors).

This source exemplifies a cost-benefit analysis of early intervention for at-risk children and briefly addresses early intervention for children with identified disabilities:

Barnett, W. S., & Escobar, C. M. (1990). Economic costs and benefits of early intervention. In S. J. Meisels & J. P. Shonkoff (Eds.), *Handbook of early childhood intervention* (pp. 560-582). New York, NY: Cambridge University Press.

This source identifies the primary characteristics of effective intensive early intervention services for children with autism or PDD based upon the existing clinical research literature:

Green, G. 1996). Early behavioral intervention for autism. What does research tell us? In C. Maurice, G. Green, & S. Luce (Eds.), *Behavioral intervention for young children with autism: A manual for parents and professionals* (pp. 29-44). Austin, TX: Pro-Ed.

This source identifies the basis for claims of effective interventionS for autism or PDD other than those using the principles of applied behavior analysis:

Smith, T. (1996). Are other treatments effective? In C. Maurice, G. Green,& S. C. Luce. (Eds.). *Behavioral intervention for young children with autism: A manual for parents and professionals* (pp. 45-62). Austin, TX: Pro-Ed.

These sources identify the functional and practical skills of adults with autism and their service utilization patterns:

Jacobson, J. W., & Ackerman, L. J. (1990). Differences in adaptive development among persons with autism and mental retardation. *Journal of Autism and Developmental Disorders. 20*, 205-219.

Janicki, M. P., & Jacobson, J. W. (1983). Selected clinical features and service characteristics of autistic adults. *Psychological Reports, 52*,387-390.

This source addresses the issues presented by requirements for appropriate educational practices to address the needs of children with severe or complex disabilities in the context of the movement to full inclusion in educational settings:

Kauffman, J. M., & Hallahan, D. P. (1995). *The illusion of full inclusion: A comprehensive critique of a current special education bandwagon.* Austin, TX: Pro-Ed.

These sources identify research findings from 25 years of research regarding the premise that the use of reinforcement procedures undermines intrinsic motivation to learn and enhance performance, a criticism levied against early intensive behavioral intervention:

Cameron, J., & Pierce, W. D. (1994). Reinforcement, reward and intrinsic motivation. *Review of Educational Research, 64*, 363-423.

Eisenberger, R., & Cameron, J. (1996). Detrimental effects of reward: Reality or myth? *American Psychologist, 51*, 1153-1166.

Summary Tables Identifying Costs and Benefits

Schedule 1: Present (1996) Costs for Services and Income Estimates [This schedule presents a listing of the *1996 costs* used in the analysis.]

Schedule 2: Most Probable Level of Normal Range Achieved or Essential Mainstreaming = 30% - 40% [This schedule presents findings of financial benefits at 30% and 40% rates of normal range achieved, separately for ages 3-22 (top of table), and ages 3-45 years (bottom of table). Values are shown, with inflation and in 1996 dollars, per 100 children and per child.]

Schedule 3: Costs to Age 22 Years [This schedule presents findings regarding costs to age 22 years. These include costs for regular education, family support services, SSI/ADC, intensive early intervention, and regular, special, and intensive special education. Costs are attributed according to whether a child is nondisabled, or achieves functioning in the normal range, partial benefit, or minimal benefit from early intensive intervention. Costs are shown separately with inflation and in 1996 dollars.]

Schedule 4: Costs to Age 45 Years [This schedule presents findings regarding costs from age 22 to 45 years. These include costs for family support services, SSI/ADC, Home and Community Based Services (waiver services), or intensive community services, and income from regular or supported work. Costs are attributed according to whether a person is nondisabled, or achieves normal range functioning, partial benefit, or minimal benefit from early intensive intervention. Costs (expenses) and income are shown separately with inflation and in 1996 dollars.]

Schedule 5: Financial Cost-Benefit of Early Intervention - Ages 3-45 Years and Summary of Benefit Levels (Relative Cost) Ages 3-45 Years [This schedule combines net costs for ages 3-22 and 22-45 years from Schedules 3 and 4. These costs are shown separately with inflation and in 1996 dollars. Simple comparisons of costs among groups with differing levels of benefit are presented at the bottom of the schedule.]

Schedule 6: Service Financial Benefits at Different Levels of Effectiveness, Age 3 to 22 Years, Per 100 Children Served [This schedule presents a comparison of financial benefits at different levels or rates of normal range achievement for children ages 3-22 years, achieved by intensive early intervention, ranging from 20% of children achieving normal range functioning (an assumed minimal rate) to 60% of children achieving normal range functioning (a rate somewhat higher than that justified by the current literature). At each level of effectiveness, differing rates of not only normal range achievement, but also partial benefit, are projected. Costs are shown in terms of the aggregate of 100 children served, and averages per person served, with inflation and in 1996 dollars.]

Schedule 7: Service Financial Benefits at Different Levels of Effectiveness, Age 3 to 45 Years, Per 100 Children Served [This schedule presents a comparison of financial benefits at different levels or rates of normal range achievement for people ages 3-45 years, attained through intensive early intervention, ranging from 20% of children achieving normal range functioning (an assumed minimal rate) to 60% of children achieving normal range functioning (a rate somewhat higher than that justified by the current literature). At each level of effectiveness, differing rates of not only normal range achievement, but also partial benefit, are projected. Costs are shown in terms of the aggregate of 100 children served, and averages per person served with inflation and in 1996 dollars.]

Schedule 8: Service Financial Benefits at Different Levels of Effectiveness, Age 3 to 22 Years, Per 100 Children Served - Pennsylvania Model vs. UCLA Controls [This schedule presents a comparison of financial benefits at different levels or rates of achievement of normal functioning for people ages 3-22 years, achieved by intensive early intervention, versus benefits from regular early intervention. Costs are shown in terms of the aggregate of 100 children served, and averages per person served, with inflation and in 1996 dollars. Bold numbers denote per child inflated and uninflated savings. The summary table at the bottom of the page depicts cost savings adjusted for differences in three-year costs of early intervention and intensive early intervention.]

Schedule 9: Service Financial Benefits at Different Levels of Effectiveness, Age 3 to 45 Years, Per 100 Children Served - Pennsylvania Model vs. UCLA Controls [This schedule presents a comparison of financial benefits at different levels or rates of achievement of normal functioning for people ages 3-45 years, achieved by intensive early intervention, versus benefits from regular early intervention. Costs are shown in terms of the aggregate of 100 children served, and averages per person served, with inflation and in 1996 dollars. Bold numbers denote per child inflated and uninflated savings. The summary table at the bottom of the page depicts cost savings adjusted for differences in three-year costs of early intervention and intensive early intervention.]

Appendix A: Financial Information: Per Recipient Expenditure Estimates [This appendix presents information regarding the sources used in order to develop the estimates used in the cost analysis.]

Appendix B: Values of Primary Estimates: Age 3 to 45 Years [This appendix presents the trend table for the estimates used in the cost analysis for the period 1992 to 2038.The year 1992 was used as a base year in this table because some available data were current to that year. However, costs reported in the schedules were trended from 1996 values.]

Schedule 1:
Present (1996) Costs for Services and Income Estimates--Pennsylvania Model

This schedule presents a listing of the *1996 costs* used in the analysis.

Present Age of the Child with Autism	3 years
Beginning Calendar Year	1996
Early Intervention Annual Cost	3,284
Family Support Services Annual Cost	1,110
Intensive Early Intervention Annual Cost	32,820
Regular Education Annual Cost	7,543
Special Education Annual Cost	12,935
Intensive Special Education Annual Cost	28,806
Home and Community Based Services (Adult) Annual Cost	31,818
Intensive Community Services (Adult) Annual Cost	46,838
Institutional Services (or equivalent, Adult) Annual Cost	56,775
Supplemental Security Income/Aid to Dependent Children Annual Cost (estimate for all generic public support costs)	5,379
Median Household Annual Income	33,714
Supported Wages Annual Value (a % of median income)	6,743

Schedule 2:
Most Probable Level of Normal Range Achieved or Essential Mainstreaming = 30% - 40%; Pennsylvania Model

This schedule presents findings of financial benefits at 30% and 40% rates at which normal functioning is achieved, separately for ages 3-22 (top of table), and ages 3-45 years (bottom of table). Values are shown, with inflation and in 1996 dollars, per 100 children and per child.

Financial Benefits. Age 3-22 Years: Per 100 Children and Per Child

	Inflated Total	1996$ Total	Inflated /Student	1996$ /Student
At 30%Normal Range				
30Norm Range vs. Partial Effect	8,444,670	5,798,970	281,489	193,299
60 Partial vs. Minimal Effect	20,974,200	14,283,900	349,570	238,065
10 Minimal Effect	0	0	0	0
Net	29,418,870	20,082,870	**294,189**	**200,829**
At 40% Normal Range				
40 Norm Range vs. Partial Effect	11,259,560	7,731,960	281,489	193,299
50 Partial vs. Minimal Effect	17,478,500	11,903,250	349,570	238,065
10 Minimal Effect	0	0	0	0
Net	28,738,060	19,635,210	**287,381**	**196,352**

Note: Compare savings with cost of 13 years of public education at $128,731 inflated and $98,061 in 1996 dollars.

Financial Benefits. Ages 3-45 Years: Per 100 Children and Per Child

	Inflated Total	1996$ Total	Inflated /Student	1996$ /Student
At 30% Normal Range				
30 Norm Range vs. Partial Effect	70,916,700	36,961,050	2,363,890	1,232,035
60 Partial vs. Minimal Effect	46,668,080	27,045,060	811,468	450,751
10 Minimal Effect	0	0		
Net	119,604,780	64,006,110	**1,196,048**	**640,061**
At 40% Normal Range				
40 Norm Range vs. Partial Effect	94,555,600	49,281,400	2,363,890	1,232,035
50 Partial vs. Minimal Effect	40,573,400	22,537,550	811,468	450,751
10 Minimal Effect	0	0		
Net	135,129,000	71,818,950	**1,351,290**	**718,190**

Note: Bold numbers denote per child inflated and uninflated savings.

Schedule 3:
Costs to Age 22 Years - Pennsylvania Model

This schedule presents findings regarding costs to age 22 years. These include costs for regular education, family support services, SSI/ADC, intensive early intervention, and regular, special, and intensive special education. Costs are attributed according to whether a child is *nondisabled, or achieves functioning in the normal range, partial benefit, or minimal benefit* from early intensive intervention. Costs are shown separately with inflation and in 1996 dollars.

Note: Table Shows (Expense) Only	Costs with Inflation	Costs in 1996$
NonDisabled Child		
Thirteen Years of Regular Education	128,731	98,061
Net	(128,731)	(98,061)
Autism- with Normal Range Effects of Early Intervention		
Three Years of Family Support Services	3,433	3,330
Three Years of SSI/ADC	16,380	16,137
Three Years of Intensive Early Intervention	101,445	98,460
Thirteen Years of Regular Education	128,731	98,061
Net	(249,989)	(215,988)
Autism- with Partial Effects of Early Intervention		
Eighteen Years of Family Support Services	27,873	19,980
Eighteen Years of SSI/ADC	117,244	96,822
Three Years of Intensive Early Intervention	101,445	98,460
Fifteen Years of Special Education	284,916	194,025
Net	(531,478)	(409,287)
Autism- with Minimal Effects of Early Intervention		
Eighteen Years of Family Support Services	27,873	19,980
Eighteen Years of SSI/ADC	117,244	96,822
Three Years of Intensive Early Intervention	101,445	98,460
Fifteen Years of Intensive Special Education	634,486	432,090
Net	(881,048)	(647,352)

Schedule 4:
Costs from Age 22 to Age 45 Years -Pennsylvania Model

This schedule presents findings regarding costs from age 22 to 45 years. These include costs for family support services, SSI/ADC, Home and Community Based Services (waiver services), or intensive community services, and income from regular or supported work. Costs are attributed according to whether a person is *nondisabled, or ahieves normal functioning, partial benefit, or minimal benefit* from early intensive intervention. Costs (expenses) and income are shown separately with inflation and in 1996 dollars.

Note: Table Shows Income (Expense)	Costs with Inflation	Costs in 1996$
NonDisabled Child		
Twenty-Three Years of SSI/ADC and All Other Public Benefits (25%)	(49,796)	(32,119)
Twenty-Three Years of Wages and Other Income (75%)	564,369	465,250
Net	514,573	433,131
Autism- with Normal Range Effects of Early Intervention		
Twenty-Three Years of SSI/ADC and All Other Public Benefits (25%)	(49,796)	(32,119)
Twenty-Three Years of Wages and Other Income (75%)	564,369	465,250
Net	514,573	433,131
Autism- with Partial Effects of Early Intervention		
Five Years of Family Support Services	(10,331)	(5,550)
Twenty-Three Years of SSI/ADC	(199,184)	(128,476)
Eighteen Years of Waiver Services	(1,559,872)	(572,724)
Fifteen Years of Supported Work	170,662	101,145
Net	(1,598,725)	(605,605)
Autism- with Minimal Effects of Early Intervention		
Five Years of Family Support Services	(10,331)	(5,550)
Twenty-Three Years of SSI/ADC	(199,184)	(128,476)
Twenty Years of Waiver Services (80%)	(1,349,878)	(509,088)
Twenty-Three Years of Intensive Community Services (20%)	(569,495)	(215,455)
Fifteen Years of Supported Work (40%)	68,265	40,458
Net	(2,060,623)	(818,111)

Schedule 5:
Financial Cost-Benefit of Early Intervention - Pennsylvania Model - Ages 3-45 Years

This schedule combines net costs for ages 3-22 and 22-45 years *from Schedules 3 and 4*. These costs are shown separately with inflation and in 1996 dollars. *Simple comparisons* of costs among groups with differing levels of benefit are presented at the bottom of the schedule.

Note: Table Shows Income (Expense)	With Inflation	Costs in 1996$
NonDisabled Child		
Childhood Costs	(128,731)	(98,061)
Adult Cost or Benefit	514,573	433,131
Net	**385,842**	**335,070**
Autism- with Normal Range Effects of Early Intervention		
Childhood Costs	(249,989)	(215,988)
Adult Cost or Benefit	514,573	433,131
Net	**265,584**	**217,193**
Autism- with Partial Effects of Early Intervention		
Childhood Costs	(531,478)	(409,287)
Adult Cost or Benefit	(1,598,725)	(605,605)
Net	**(2,130,203)**	**(1,014,892)**
Autism- with Minimal Effects of Early Intervention		
Childhood Costs	(881,048)	(647,352)
Adult Cost or Benefit	(2,060,623)	(818,111)
Net	**(2,941,671)**	**(1,465,643)**

Note: Bold numbers denote total income or (expense).

Schedule 6:
Service Financial Benefits at Different Levels of Effectiveness, Age 3 to 22 Years, Per 100 Children Served - Pennsylvania Model

This schedule presents a comparison of financial benefits at different levels or rates of achievement of normal functioning for *children ages 3-22* years, achieved by intensive early intervention, ranging from 20% of children achieving normal functioning (an assumed minimal rate) to 60% of children achieving normal functioning (a rate somewhat higher than that justified by the current literature). At each level of effectiveness, differing rates of not only achievement of normal range functioning, but also partial benefit, are projected. Costs are shown in terms of *the aggregate of 100 children served, and averages per person served,* with inflation and in 1996 dollars. Bold numbers denote per child inflated and uninflated savings.

At 20% Normal Range	Inflated Total	1996$ Total	Inflated /Student	1996$ /Student
20 Norm Range vs. Partial Effect	5,629,780	3,865,980	281,489	193,299
70 Partial vs. Minimal Effect	24,469,900	16,664,550	349,570	238,065
10 Minimal Effect	0	0		
Net	30,099,680	20,530,530	**300,997**	**205,305**
At 30%Normal Range				
30Norm Range vs. Partial Effect	8,444,670	5,798,970	281,489	193,299
60 Partial vs. Minimal Effect	20,974,200	14,283,900	349,570	238,065
10 Minimal Effect	0	0		
Net	29,418,870	20,082,870	**294,189**	**200,829**
At 40% Normal Range				
40 Norm Range vs. Partial Effect	11,259,560	7,731,960	281,489	193,299
50 Partial vs. Minimal Effect	17,478,500	11,903,250	349,570	238,065
10 Minimal Effect	0	0		
Net	28,738,060	19,635,210	**287,381**	**196,352**
At 50% Normal Range				
50 Norm Range vs. Partial Effect	14,074,450	9,664,950	281,489	193,299
40 Partial vs. Minimal Effect	13,982,800	9,544,200	349,570	238,065
10 Minimal Effect	0	0		
Net	28,057,250	19,209,150	**280,572**	**192,092**
At 60% Normal Range				
60 Norm Range vs. Partial Effect	16,889,340	11,597,940	281,489	193,299
30 Partial vs. Minimal Effect	10,481,100	7,141,950	349,570	238,065
10 Minimal Effect	0	0		
Net	27,376,440	18,739,890	**273,764**	**187,399**

Schedule 7:
Service Financial Benefits at Different Levels of Effectiveness, Age 3 to 45 Years, Per 100 Children Served - Pennsylvania Model

This schedule presents a comparison of financial benefits at different levels or rates of achievement of normal functioning for *people ages 3-45 years*, achieved by intensive early intervention, ranging from 20% of children achieving normal range functioning (an assumed minimal rate) to 60% of children achieving normal range functioning (a rate somewhat higher than that justified by the current literature). At each level of effectiveness, differing rates of not only normal range functioning, but also partial benefit, are projected. Costs are shown in terms of *the aggregate of 100 children served, and averages per person served*, with inflation and in 1996 dollars. Bold numbers denote per child inflated and uninflated savings.

	Inflated Total	1996$ Total	Inflated /Student	1996$ /Student
At 20% Normal Range				
20 Norm Range vs. Partial Effect	47.277.800	24,640,700	2,363,890	1,232,035
70 Partial vs. Minimal Effect	56.802.760	31.552.570	811,468	450,751
10 Minimal Effect	0	0		
Net	104.080.560	56.193.270	**1,040,806**	**561,933**
At 30% Normal Range				
30 Norm Range vs. Partial Effect	70,916.700	36.961,050	2,363,890	1,232,035
60 Partial vs. Minimal Effect	46,668.080	27.045,060	811,468	450,751
10 Minimal Effect	0	0		
Net	119.604.780	64.006,110	**1,196,048**	**640,061**
At 40% Normal Range				
40 Norm Range vs. Partial Effect	94.555.600	49.281.400	2,363,890	1,232,035
50 Partial vs. Minimal Effect	40.573.400	22.537.550	811,468	450,751
10 Minimal Effect	0	0		
Net	135.129.000	71.818.950	**1,351,290**	**718,190**
At 50% Normal Range				
50 Norm Range vs. Partial Effect	118.194.500	61.601.750	2,363,890	1,232,035
40 Partial vs. Minimal Effect	32.458.720	18.030.040	811,468	450,751
10 Minimal Effect	0	0		
Net	150.653.220	79.631.790	**1,506,532**	**796,318**
At 60% Normal Range				
60 Norm Range vs. Partial Effect	141.833.400	73.922.100	2,363,890	1,232,035
30 Partial vs. Minimal Effect	24.344.040	12.522.530	811,468	450,751
10 Minimal Effect	0	0		
Net	166.177.440	87.444.630	**1,661,774**	**874,446**

Schedule 8:
Service Financial Benefits at Different Levels of Effectiveness, Age 3 to 22 Years, Per 100 Children Served - Pennsylvania Model vs. UCLA Controls

This schedule presents a comparison of financial benefits at different levels or rates of achievement of normal functioning for people ages 3-22 years, achieved by intensive early intervention, versus benefits from regular early intervention. Costs are shown in terms of the aggregate of 100 children served, and averages per person served, with inflation and in 1996 dollars. Bold numbers denote per child inflated and uninflated savings. The summary table at the bottom of the page depicts cost savings adjusted for differences in three-year costs of early intervention and intensive early intervention.

At 30% Normal Range	Inflated Total	1996$ Total	Inflated /Student	1996$ /Student
30 Norm Range vs. Partial Effect	8,444,670	5,798,970	281,489	193,299
60 Partial vs. Minimum Effect	20,974,200	14,283,900	349,570	238,065
10 Minimal Effect	0	0		
Net	30,099,680	20,530,530	**294,189**	**200,829**
At 40% Normal Range				
40 Norm Range vs. Partial Effect	11,259,560	7,731,960	281,489	193,299
50 Partial vs. Minimum Effect	17,478,500	11,903,250	349,570	238,065
10 Minimal Effect	0	0		
Net	28,738,060	19,635,210	**287,381**	**196,352**
At 50% Normal Range				
50 Norm Range vs. Partial Effect	14,074,450	9,664,950	281,489	193,299
40 Partial vs. Minimum Effect	13,982,800	9,544,200	349,570	238,065
10 Minimal Effect	0	0		
Net	28,057,250	19,209,150	**280,572**	**192,092**
UCLA Controls				
3 Norm Range vs. Partial Effect	844,467	579,897	281,489	193,299
45 Partial vs. Minimum Effect	12,584,520	8,589,780	349,570	238,065
52 Minimal Effect	0	0		
Net	13,428,987	9,169,677	**134,290**	**91,697**

Summary: Savings at Different Levels of Benefit vs. UCLA Controls, Age 3 to 22:

Level of Benefit	Inflated /Student	1996$ /Student
At 30% Normal Range	68,606	17,839
At 40% Normal Range	61,798	13,362
At 50% Normal Range	54,989	9,102

(Taking into account difference between costs of early intervention, for UCLA controls, and intensive early intervention)

Schedule 9

Service Financial Benefits at Different Levels of Effectiveness, Age 3 to 45 Years, Per 100 Children Served - Pennsylvania Model vs. UCLA Controls

This schedule presents a comparison of financial benefits at different levels or rates of achievement of normal functioning for people ages 3-45 years, achieved by intensive early intervention, versus benefits from regular early intervention. Costs are shown in terms of the aggregate of 100 children served, and averages per person served, with inflation and in 1996 dollars. Bold numbers denote per child inflated and uninflated <u>savings</u>. The summary table at the bottom of the page depicts cost savings <u>adjusted</u> for differences in three-year costs of early intervention and intensive early intervention.

	Inflated <u>Total</u>	1996$ <u>Total</u>	Inflated <u>/Student</u>	1996$ <u>/Student</u>
<u>At 30% Normal Range</u>				
30 Norm Range vs. Partial Effect	70,916,700	36,961,050	2,363,890	1,232,035
60 Partial vs. Minimum Effect	46,668,080	27,045,060	811,468	450,751
10 Minimal Effect	0	0		
Net	119,604,780	64,006,110	**1,196,048**	**640,061**
<u>At 40% Normal Range</u>				
40 Norm Range vs. Partial Effect	94,555,600	49,281,400	2,363,890	1,232,035
50 Partial vs. Minimum Effect	40,573,400	22,357,550	811,468	450,751
10 Minimal Effect	0	0		
Net	135,129,000	71,818,950	**1,351,290**	**718,190**
<u>At 50% Normal Range</u>				
50 Norm Range vs. Partial Effect	118,194,500	61,601,750	2,363,890	1,232,035
40 Partial vs. Minimum Effect	32,458,720	18,030,040	811,468	450,751
10 Minimal Effect	0	0		
Net	150,653,220	79,631,790	**1,506,532**	**796,318**
<u>UCLA Controls</u>				
3 Norm Range vs. Partial Effect	7,091,670	3,696,105	2,363,890	1,232,035
45 Partial vs. Minimum Effect	36,516,060	20,283,795	811,468	450,751
52 Minimal Effect	0	0		
Net	43,607,730	23,979,900	**436,077**	**239,799**

Summary: Savings at Different Levels of Benefit vs. UCLA Controls, Age 3 to 45:

<u>Level of Benefit</u>	Inflated <u>/Student</u>	1996$ <u>/Student</u>
At 30% Normal Range	668,678	309,691
At 40% Normal Range	823,920	387,820
At 50% Normal Range	979,162	465,948

(Taking into account difference between costs of early intervention, for UCLA controls, and intensive early intervention)

Appendix A:
Financial Information: Per Recipient Expenditure Estimates - Pennsylvania Model

This appendix presents information regarding the sources used in order to develop the estimates used in the cost analysis.

Sources:

Source for EI, FSS, HCBS, Institutional, and SSI/ADC is Braddock et al. (1995). *State of the states in developmental disabilities.* Washington, DC: American Association on Mental Retardation.

Source for Intensive Community Services is annual expenditures for 6 person or less ICF/MR plus one half of the difference between this amount and the annual institutional expenditure, from Braddock et al. (1995), as above.

Source for Special Education expenditures is average for all special education types from Barnett & Escomar (1990). Economic costs and benefits of early intervention. In Meisels & Shokoff (Eds.), *Handbook of early childhood intervention* (pp. 560-582). New York: Cambridge University Press. Source for Intensive Special Education expenditures is multihandicapped rate, p. 566.

Source for Regular Education expenditures is U.S.D.O.E. (1992). *The condition of education* (NCES 92-096), p. 334.

Source for Intensive Early Intervention is the average cost of 7 model programs reported in Harris & Handleman (1994). *Preschool education programs for children with autism.* Austin, TX: Pro-Ed.

Source for Median Household Income is the 1990 federal census. Supported wages indexed at 20% average of median household income for Pennsylvania.

All amounts are trended at 3%, except SSI/ADC which is trended at 1.5%.

Appendix B:
Values of Primary Estimates: Age 3 to 45 Years - Pennsylvania Model

This appendix presents the trend table for the estimates used in the cost analysis for the period 1992 to 2038. The year 1992 was used as a base year in this table because some available data were current to that year. However, costs reported in the schedules were trended from 1996 values.

Age	Year	EI	FSS	Int EI	Reg Ed	SpecEd	Int SpcEd	HCBS	Int Com	Institutl	SSI	Mdn Inc	Supp Wages
	1992	2918	986	29161	6702	11493	25594	28270	41615	50444	5068	31764	6353
	1993	3006	1016	30035	6903	11838	26362	29118	42863	51957	5144	32241	6448
	1994	3096	1046	30936	7110	12193	27153	29992	44149	53516	5221	32725	6545
	1995	3189	1077	31865	7323	12559	27967	30891	45474	55122	5299	33215	6643
3	1996	3284	1110	32820	7543	12935	28806	31818	46838	56775	5379	33714	6743
4	1997	3383	1143	33805	7769	13324	29670	32773	48243	58478	5460	34219	6844
5	1998	3484	1177	34819	8003	13723	30561	33756	49690	60233	5542	34733	6947
6	1999	3589	1213	35864	8243	14135	31477	34769	51181	62040	5625	35254	7051
7	2000	3696	1249	36940	8490	14559	32422	35812	52717	63901	5709	35782	7156
8	2001	3807	1287	38048	8745	14996	33394	36886	54298	65818	5795	36319	7264
9	2002	3922	1325	39189	9007	15446	34396	37993	55927	67793	5882	36864	7373
10	2003	4039	1365	40365	9277	15909	35428	39132	57605	69826	5970	37417	7483
11	2004	4160	1406	41576	9555	16386	36491	40306	59333	71921	6059	37978	7596
12	2005	4285	1448	42823	9842	16878	37586	41515	61113	74079	6150	38548	7710
13	2006	4414	1491	44108	10137	17384	38713	42761	62946	76301	6243	39126	7825
14	2007	4546	1536	45431	10441	17906	39875	44044	64835	78590	6336	39713	7943
15	2008	4683	1582	46794	10755	18443	41071	45365	66780	80948	6431	40309	8062
16	2009	4823	1630	48198	11077	18996	42303	46726	68783	83376	6528	40913	8183
17	2010	4968	1679	49644	11410	19566	43572	48128	70847	85878	6626	41527	8305
18	2011	5117	1729	51133	11752	20153	44879	49572	72972	88454	6725	42150	8430
19	2012	5270	1781	52667	12105	20758	46226	51059	75161	91107	6826	42782	8556
20	2013	5428	1834	54247	12468	21380	47612	52591	77416	93841	6928	43424	8685
21	2014	5591	1889	55875	12842	22022	49041	54168	79739	96656	7032	44075	8815
22	2015	5759	1946	57551	13227	22682	50512	55793	82131	99556	7138	44736	8947
23	2016	5932	2004	59277	13624	23363	52027	57467	84595	102542	7245	45407	9081
24	2017	6110	2064	61056	14032	24064	53588	59191	87133	105619	7353	46089	9218
25	2018	6293	2126	62887	14453	24786	55196	60967	89747	108787	7464	46780	9356
26	2019	6482	2190	64774	14887	25529	56852	62796	92439	112051	7576	47482	9496
27	2020	6676	2256	66717	15334	26295	58557	64680	95212	115412	7689	48194	9639
28	2021	6876	2324	68719	15794	27084	60314	66620	98068	118875	7805	48917	9783
29	2022	7083	2393	70780	16268	27897	62123	68619	101011	122441	7922	49650	9930
30	2023	7295	2465	72904	16756	28733	63987	70677	104041	126114	8041	50395	10079
31	2024	7514	2539	75091	17258	29595	65907	72798	107162	129897	8161	51151	10230
32	2025	7740	2615	77344	17776	30483	67884	74982	110377	133794	8284	51918	10384
33	2026	7972	2694	79664	18309	31398	69920	77231	113688	137808	8408	52697	10539
34	2027	8211	2774	82054	18859	32340	72018	79548	117099	141942	8534	53488	10698
35	2028	8457	2858	84515	19424	33310	74179	81934	120612	146201	8662	54290	10858
36	2029	8711	2943	87051	20007	34309	76404	84392	124230	150587	8792	55104	11021
37	2030	8972	3032	89662	20607	35338	78696	86924	127957	155104	8924	55931	11186
38	2031	9241	3123	92352	21225	36399	81057	89532	131796	159758	9058	56770	11354
39	2032	9519	3216	95123	21862	37491	83489	92218	135750	164550	9193	57621	11524
40	2033	9804	3313	97977	22518	38615	85991	94984	139822	169487	9331	58486	11697
41	2034	10098	3412	100916	23194	39774	88573	97834	144017	174571	9471	59363	11873
42	2035	10401	3515	103943	23889	40967	91230	100769	148337	179808	9613	60253	12051
43	2036	10713	3620	107062	24606	42196	93967	103792	152787	185203	9758	61157	12231
44	2037	11035	3729	110273	25344	43462	96786	106906	157371	190759	9904	62075	12415
45	2038	11366	3841	113582	26105	44766	99690	110113	162092	196482	10053	63006	12601

Estimates to Age 45 years

Note Some estimates were based on 1992 data and all estimates are trended forward from that year or, for later estimates, back to that year.

Autism Task Force Report

Appendix 7: Minnesota AutismTask Force Survey Findings

FINDINGS OF THE MINNESOTA AUTISM TASK FORCE NEEDS SURVEY

The Minnesota Autism Task Force Survey was mailed to families on January 23, 1998. 345 respondents returned the survey. Four of the surveys were excluded from analysis due to the children's ages not fitting within the birth to nine age bracket established by the task force.

DEMOGRAPHICS

The surveys were completed primarily by parents (97%) with grandparents, guardians, social workers, sisters and therapists completing the remaining surveys. White/Caucasian children were represented at a 90% rate, while a least 1% of each of the races/ethnic groups including in the survey were represented. The average age of the children was 5.6 years with 83% male and 17% female children.

A number of Minnesota counties (60) were included in the responses. Hennepin County had the highest rate (18%) of respondents with Dakota (15%) and Ramsey (10%) following close behind.

The average age of the children when they were first identified with autism or a related disorder was 3.17 years of age. Psychologists (29%) were the primary source of first identification. However, identification was fairly evenly distributed between medical teams (22%), school teams (20%), and multiple sources (23%). The majority of the children were initially diagnosed with autism (57%) or PDD (31%). Other diagnosis included aspergers (5%), bi-polar with PDD, complex language disorder, severe sensory defensiveness, global developmental delay, autistic behaviors and Fragile-X syndrome.

Many children were already receiving early intervention services when they were identified with autism or a related disorder. Early intervention services were provided at the age of 2.7 years on average compared to the average identification age of 3.17 years. Services specifically for autism were first provided at a later date at an average age of 3.8 years.

CURRENT EDUCATIONAL INFORMATION

Early Childhood Special Education (34%) was the primary criteria used to identify children for special education services. Autism (30%) and speech/language (27%) criteria were also often used for this purpose. A number of respondents chose more than one category making it difficult to ascertain which category was the primary special education criterion used for services.

The service received by families from their school district is reported in the following chart. Some surveys were excluded from this section of the survey due to the fact that the services received may have been indicated, but the number of hours received were not recorded and therefore could not be analyzed.

Service	# Respondents	Average # Direct Hours	Average # Indirect Hours	Range of hrs. – Direct	Range of hrs.- Indirect
Special ed w/ special ed. students	143	11	2.2	1-40	.5 – 9
Special ed w/ 1-1 teacher	67	4.25	1.4	.5 - 14	.16 – 4
Special ed w/ 1-1 TA	64	5	1.1	2 - 35	.16 - .5
Speech/Language Therapy	185	1.7	.6	.16 - 10	.16 – 1.25
Occupational Therapy	142	1.1	.3	.16 - 4	.08 - .75
Physical Therapy	32	1.4	.2	.08 - 6	.16 - .5
Reg. K w/ sp. ed. teacher	15	9.8		2 - 27	
Regular K w/ TA	44	14.7	.3	1 - 30	.16 - .5
Regular preschool w/ TA	39	7.5	.6	2 - 16	.3 – 1
Home program w/ teacher	20	2	.4	.25 - 2	.25 - 1
Home program w/ TA	19	14		1 - 30	
Extended school year	72 families*				
Parent training/support	25 families*				

**Extended school year and parent training/support were counted as yes/no responses rather than number of service hours.*

The majority of children attended a special education classroom with other special education students with a portion of their day spent in a regular preschool or Kindergarten with support from a special education teacher and/or a teacher's aide. Speech/language therapy and occupational therapy were also provided to a number of the families. During their time in the classroom and/or home, children were instructed using the following methods:

Sensory Integration – 62%
Social Skills Training - 42%
Unspecified education support in the classroom – 37%
Picture Exchange System – 35%
Applied Behavioral Analysis – 27%
Incidental Teaching – 17%
Discrete Trial Training – 16%
TEACCH – 9%
Lovaas – 8%
LEAP – 1%

In addition, 18% of respondents didn't know which methods were used for instruction. All children received more than one type of instructional method. Gentle Teach. Son Rise. High Scope, Edmark, Circle of Friends, Greenspan, Play Therapy and AIT were other methods mentioned by respondents.

Most children (84%) had a professional on their IEP team who has knowledge and experience in the area of autism. However, a number of families indicated that in some cases the extent of knowledge in this area was somewhat limited. Some of the families were appreciative that there was such a willingness to learn more information with the families. Special education teachers (60%) tended to fill this role with school (24%) and outside (16%) consultants serving in this capacity in the remaining cases.

CURRENT COUNTY AND HEALTH CARE SERVICE INFORMATION

Approximately half of the families reported receiving services from the county and having a county case manager. Many of the written comments on the surveys expressed frustration with accessing services. Families reported confusion regarding what services were available and who to contact to access the services. Teachers (42%) were the primary contact for parents to find out about services. Parents (35%) often researched information on their own and by networking with other parents.

The majority of families (64%) did have a financial worker. Approximately half of the families were enrolled in medical assistance but only 17% received medical assistance through TEFRA. The families receiving TEFRA were provided service through home and community based services. A small percentage of families (8%) had been denied medical assistance or TEFRA. However, a number of families wrote that they had to refuse or "drop" TEFRA because of the substantial parental fee. In addition, 17% of the families were on a waiting list for the above services. Many families were unfamiliar with the term "waivered services" with only 15% of the families receiving services under this umbrella.

Only 31% of the families reported attending a parent support group. A number of families wrote that they would be interested in attending but there were no groups in the area or their schedules did not correspond to the available support group meeting times.

The services currently being received by families is outlined below:

Service	**% of families receiving service**	**Source of payment**	**Denial of services**	**Service location**	**Waiting list**
Respite Care	32%	County 52% Parent 22% M.A. 14%	8 county denials 2 M.A. denials	Home 78% Other 18%	22 families
Home Care	27%	M.A. 72% County 18%	3 county denials 3 M.A. denials	Home 93%	10 families
Nursing	2%	County and M.A.	2 county denials 1 M.A. denial	Home	
Assistive Technology	2%	Parent	2 county denials 1 M.A. denial	Home	
Home Modification	9%	Parent	4 county denials	Home	
Rehab Services	58%	Insurance 35% M.A. 34% Parent 15%	2 county denials 4 M.A. denials	Other 48% M.H. facility 37% Home 13%	
Medication Eval.	27%	Insurance 50% M.A. 30% Parent 18%	1 county denial	M.H. facility	
Psych. Assessment	58%	Insurance 45% M.A. 33% Parent 17%	2 county denials 2 M.A. denials	M.H. facility – primary location	
Day Treatment	12%	M.A. 42% Insurance 23%	1 county denial	M.H. facility – primary location	
Individual Psychotherapy	11%	M.A. 36% Insurance 36%	1 county denial	M.H. facility – primary location	
Group Psychotherapy	2%	Parent, M.A. and County	1 county denial	M.H. facility – primary location	
Parent Guidance/ Family Therapy	12%	Insurance 30% Parent 25% M.A. 20%	1 county denial 1 M.A. denial	Home – primary location	
Home-Based Skills Training	18%	Parent 38% M.A. 20% County 19% Insurance 11%	2 county denials 2 M.A. denials	Home – primary location	

In addition to the above covered services; families were asked to indicate any additional expenses that were not reimbursed through any of the programs in which they participate or they have chosen to pay due to difficulty accessing reimbursement. All of the expense categories were paid "out-of-pocket" by at least a portion of the families. The categories most likely to be additional expenses included; educational materials/publications, training/information seminars, diapers, educational toys/teaching aids, association membership fees and non-prescription drugs. However, the highest expense items were behavior therapy and auditory training with some families paying $6,000 to $13,000 per year. Families did not indicate that they paid expenses due to difficulty accessing services. However, a number of families wrote comments that many of the categories were significant financial burdens and they would appreciate assistance in easier access and better reimbursement for some of the services. The other issue which was often mentioned, was the difficulty families had in finding suitable daycare for their children. Lack of daycare often resulted in one of the parents having to stay home and provide care for the child.

MINORITY REPORT OF THE AUTISM TASK FORCE

Supplemental Report

of the

Autism Task Force

A Report to the Minnesota Legislature

February 5, 1999

Introduction

The members of the Autism Task Force worked diligently for 18 months to construct recommendations for Minnesota's decision-makers concerning ways to optimize the outcomes for autistic[1] children and minimize the public costs associated with the disability of autism. While much of the Task Force's work is included in the Commissioners' Task Force Report on Treatment of Autism (Commissioner's Report), specific recommendations were excluded at the direction of the Commissioner of Human Services (DHS) and the Commissioner of Children, Families and Learning (DCFL). The members of the Autism Task Force identified at the conclusion of this Supplemental Report felt strongly that the Commissioners' deletions critically compromised the important work of the Task Force. As a result, these members join in the following Supplemental Report which represents the views of the majority[2] of the public members of the Autism Task Force.

The Supplemental Report is not in conflict with the bulk of the recommendations included in the Commissioners' Report. Instead, this report addresses three critical findings not adequately addressed in the Commissioners' Report, as follows:

- Early intervention dramatically improves the long-term prognosis for children with autism.
- Sufficiently intensive intervention is required to assure the best outcomes for autistic children.
- Early, intensive intervention results in long-term savings in treatment and social costs.

The Supplemental Report includes recommendations related to these identified topics following a brief description of the realities facing Minnesota families raising a child with autism.

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[1] Consistent with the Commissioners' Report, this Supplemental Report uses the terms "autism" or "Autism Spectrum Disorders" to refer to the five diagnostic categories that comprise the complete spectrum of the disorder, including: Autistic Disorder, Childhood Disintegrative Disorder, Asperger's Disorder, Rett's Disorder, and Pervasive Developmental Disorder: Not Otherwise Specified.

[2] The Autism Task Force membership included ten individuals representing four state agencies. Excluding these state agency members, the Task Force consisted of 20 members representing the public. Twelve of these members join in this Supplemental Report.

The Reality of Autism for Minnesota Families.

Autism is currently regarded as a developmental disability that results most often from biological and/or neurological differences in the brain. The critical features of the disability include a significant impairment in social interaction, communication and attention, with onset before 3 years of age.

Autism is a "spectrum disorder", meaning that the symptoms or characteristics of the disorder can present themselves in various combinations, from mild to severe, in each affected person. No two children diagnosed with autism will have difficulties in the same areas of function to the same degree. As a result, no two autistic children will act exactly alike, and no two autistic children need the same supports from family, friends, teachers and members of their communities to maximize their outcomes.

Since diagnosis often hinges on a practitioner's observation of abnormal or uneven language development, attention functioning and/or motor abnormalities in the child, it is a very difficult disability to diagnose with certainty earlier than age 2. According to the survey completed by the Task Force, Minnesota children with Autism Spectrum Disorders are diagnosed at approximately 3.17 years of age, on average.

The information provided to families upon diagnosis varies greatly across the State and across the service delivery systems. Once presented with the diagnosis, families must marshal the economic and personal resources to educate themselves about: the condition of autism; the potential treatment strategies; the availability of treatment options in the family's geographic area; the State's special education system; the federal and state laws defining eligibility for services; the county public health system; the complicated eligibility criteria and funding options administered through the county social service system;[3] and the private health care system. The enormity of this task is often overwhelming, and always exhausting, for the parents and families of Minnesota's autistic children. No state or local public agency is statutorily charged with the responsibility to assist families navigate these identified systems in their efforts to meet the needs of their children with autism.

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[3] Even after 18 months of study, many of the public members of the Autism Task Force remain confused about the varying eligibility criteria for the services administered by DHS and described in the Commissioners' Report. The fact that this confusion exists even after the Task Force's intense study of the relevant systems is evidence of the level of difficulty that the typical parent of an autistic child faces in their quest to decipher and navigate the social service delivery system in Minnesota.

Early Intervention Dramatically Improves The Long-Term Prognosis for Children with Autism.

Twenty years ago, over 95% of the individuals diagnosed with autism were institutionalized for life. Families of children with autistic children were routinely advised that their children would never learn to talk, to control impulsive behavior, to interact independently in the world or be productive members of their communities.

That bleak message has changed. Academic research conducted throughout the last two decades has proven that early, intensive intervention can and does result in improved outcomes for autistic children. Based upon this research, we now know that early, intensive intervention can result in the following differences for autistic children:

- Significant acceleration of developmental rates resulting in IQ gains averaging 20 points.
- Significant language gains including the development of useful speech by age 5.
- Improved social behavior and decreased autistic behaviors, making social interaction more successful.
- As a result of one or two years of early, intensive intervention programming in the majority of studied programs, approximately 50% of the autistic children were able to be integrated into regular general education classrooms.

[See research cited in Commissioners' Report.]

These research findings should cause Minnesota's decision-makers to reexamine the State's allocation of public resources now dedicated to the provision of services for individuals with autism. Investing public funds in early intervention programming for autistic children will maximize the results for the children, and should minimize the long-term investment required of the public. The research indicates that two years of early, intensive intervention programming can reduce and even eliminate otherwise predictable special education services for many children diagnosed with Autism Spectrum Disorders.

> **Recommendation:** *Invest in accessible early intervention strategies designed to maximize the outcomes for young children. While these strategies may vary from community to community throughout the State, all public investments should be designed to capitalize on the research findings that reveal the most effective methods to optimize results for young children.*

Intensive Intervention Is Required To Assure The Best Outcomes For Autistic Children.

While intervention must commence as early as diagnostically possible to result in the most improvement for children with autism, the intervention must also be sufficiently intense in order to bring about the gains cited in the academic literature. A treatment program's intensity is measured by the amount of time a child spends in systematic instruction, whether in the home, school or community. **The research reveals that early intervention programs for children with autism are effective when they provide an average of 27 hours of programming per week for a period of two years.** According to the Twin Cities Autism Society, most Minnesota families receive only an average of 4-6 hours of early special education services per week for their young children diagnosed with an Autism Spectrum Disorder. The low intensity of programming available in Minnesota is insufficient to achieve the necessary outcomes for autistic children.

The Task Force debated the following issues related to the task of making a recommendation concerning the proper intensity of services: (1) the potential financial ramifications that would flow from a recommendation of increased intensity for Minnesota's early childhood special education program; (2) the individual nature of the needs of each child with autism; (3) the legal requirement that all Individual Education Plans be determined by the team charged with serving the needs of the individual child; (4) the ability of parents to educate themselves about the autism research findings related to intensity and to advocate in support of the research-based levels without professional support; and (5) the concern that any recommended minimum level of service could lead to expensive litigation for the State and for families. Following months of debate, the majority of the Task Force included the following recommendation in its report to the Commissioners:

> **Recommendation:** *Based upon current research and promising practice service recommendations for children under eight years of age with an Autism Spectrum Disorder, service recommendations will be based upon team determination of individual needs. The range of intervention is a minimum of 20 hours per week, unless determined unnecessary, and up to 40 hours per week. Services must be provided and paid for through interagency shared responsibility among private insurance, state and county human services, school districts, health departments and families. Progress must be monitored by the team on a routine and frequent basis and adjustments made as necessary based on objective data.*

The affected state agencies deleted this recommendation from the Commissioners' Report. This Supplemental Report includes the recommendation for the consideration of policy-makers seeking to improve the outcomes for children with autism.

Early, Intensive Intervention Results In Long-term Savings In Treatment And Social Costs.

The Task Force was statutorily required to make recommendations for service improvement for children with autism within existing funding levels. In order to comply with that charge, it is necessary to calculate what the State currently spends on individuals with Autism Spectrum Disorders. It is also necessary to determine the extent to which those funds will be stretched in the future due to impending increases of the disability within Minnesota's population of children.

Current Funding Levels: Who Pays What.

According to the Commissioners' Report, the State spends money on individuals with Autism Spectrum Disorders through both the DCFL budget and the DHS budget. The DCFL budget includes the costs of special education provided to individuals ages 0-22. The DHS budget supports children with autism by providing social services to eligible individuals through the Medical Assistance program.

Public Costs.

As reported in the Commissioners' Report, during the 1996-97 school year local school districts spent $5,446,108 for personnel responsible for providing special education services to 1,283 students with Autism Spectrum Disorders.[4] Using rough mathematical calculations, it is reasonable to conclude that Minnesota's average special education system cost is approximately $4,245 per student with autism per year.

Through the DHS budget, the State spent at least $4,361,801 in calendar year 1997 on services for no more than 977 individuals[5] with Autism Spectrum Disorders of all ages. [See Appendix A.[6]] As a very gross average, DHS programming costs $4,464 per autistic individual receiving services. As shown in

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[4] The state reimbursed local school districts a total of $3,901,217 in calculated state aid. The remaining $1,544,891 is a cost borne by local school districts, generally out of their general education revenues.

[5] DHS data indicates that the State served 230 individuals through Developmental Disability funding. In addition, DHS served 747 individuals through the Mental Health Services funding.

[6] Appendix A includes DHS data detailing the State's costs spent on individuals with Autism Spectrum Disorders in calendar year 1997. The figures utilized in the Supplemental Report include the costs paid through the Department's Developmental Disability funding streams for individuals carrying a primary diagnosis of autism or Pervasive Developmental Disorder and also includes the costs paid through the Department's Mental Health Services funding streams for individuals bearing the same diagnoses. All underlying data is included in Appendix A.

the following chart, the cost of these social services varies greatly by age of the autistic individual.

Average DHS Costs for Services Provided to Individuals with Autism

	Age 0-8	9-20	21 and over	Total all ages
Costs	$1,496,932	$1,977,340	$929,982	$4,361,801
Individuals served	353	417	207	977
Average Cost per Individual	$4,341	$4,742	$4,493	$4,464

While 770 children (ages 0-20) received services through the DHS funding streams, the autism incidence rates indicate that there are approximately 3,960 other autistic children (ages 0-20) who are autistic and who receive no DHS-funded services.

Combining both the special education and social services costs and extending those costs over a normal lifespan, it appears that Minnesota may spend as much as $420,795 (on average) on an individual with autism throughout his or her lifetime.

Public Costs – A Lifetime Summary

$ 63,675 – cost for 15 years of special education ($4,245 times 15 years)
357,120 – DHS cost per year for 80 years ($4464/year times 80 years)
420,795

Private Costs.

The State does not bear the largest share of the costs of meeting the needs of children with autism. Families do. Families reported to the Task Force that they spend an average of $6,000-$13,000 annually on the needs of their children associated with their Autism Spectrum Disorders. If there are 4,667 children (ages 0-22) with Autism Spectrum Disorders in the State, we can estimate that autism costs families up to $44,336,500 in Minnesota each year.

Private health insurers and health maintenance organizations were unable to document their costs associated with medical and therapy services provided for individuals with autism. Families report that many health care coverage providers have avoided sharing in the cost of treatment programs for children with autism through the following methods:

- Classifying autism as a mental disorder and then either excluding or limiting coverage under the mental/psychological limits within the plan.
- Excluding coverage when the treatment is provided in the home, such as with Intensive Behavior Therapy programs.
- Excluding coverage under clauses that prohibit "expenses for recreational or educational therapy, vocational training, developmental delay, or non-medical self-care training."

Given the biological/neurological basis for the disability of autism, the health care industry's reticence to provide coverage for autism on a comparable basis to the coverage provided for other biological conditions is a cause for concern. The industry's practice of excluding coverage for interventions proven effective for autistic children adds to the financial burdens borne by the families of those children. These concerns led to the recommendation that all health care plans issued in Minnesota be required to include coverage for these services needed to treat the medical condition of Autism Spectrum Disorders. [See Commissioners' Report.]

Incidence Rates: The Problem is Growing.

According to the 1998 data of the National Institute of Child Health and Human Development, the national incidence rate for children born with Autism Spectrum Disorders is measured as 1 in every 200 births. This rate is growing at an alarming pace. Researchers are unable to determine the cause of the rising incidence of autism, but are documenting the increase in populations throughout the world.

Applying the current 1/200 ratio to Minnesota's population data, one would expect to find at least 4,667 individuals with Autism Spectrum Disorders aged 0-22 in Minnesota. Interestingly, the data collected by DCFL indicates that there are only 1,283 children aged 0-22 who carry a documented diagnosis of autism receiving services in Minnesota's public schools. At this count, DCFL programmatically classifies autism as one of the State's "low incidence" disabilities. In the Commissioners' Report, DCFL acknowledges that its data underrepresents the population of children with Autism Spectrum Disorders in

Minnesota and attributes that undercounting to various issues including the difficulty of diagnosing autism in very young children.[7]

The Commissioner's report correctly notes that **the incidence rate for autism has increased by a factor of 20% for the past six years.** Minnesota's public schools are educating more and more autistic children every year, and this trend is expected to continue. As the incidence of autism rises, the public costs attributable to the State's provision of services to individuals with Autism Spectrum Disorders will continue to grow.

This fact should have implications for policy development, resource allocation and special education programming for DCFL. For these reasons, this Supplemental Report makes the following recommendations:

> **Recommendation:** *The State should collect more accurate data on the rising incidence of Autism Spectrum Disorders in Minnesota.*
>
> **Recommendation:** *If justified by more-accurate data, DCFL should categorize students with Autism Spectrum Disorders independently from any other disability to allow a more complete analysis of the needs and resource use attributed to this population of students.*

Investing Early Reduces Long-Term Costs.

A review of the cost and rising incidence data, coupled with the findings of the research detailing the positive outcomes for autistic children provided programs of early, intensive intervention, leads to one common-sense conclusion: investing early in children with autism will save the State money in the long-term. While the current data collected in Minnesota did not allow the Autism Task Force to calculate the extent of savings that should flow from increased investments in early, intensive intervention programming, that analysis has been undertaken utilizing cost figures of the Commonwealth of Pennsylvania. According to the research authors of *Financial Cost and Benefits of Intensive Early Intervention for Young Children with Autism – Pennsylvania*

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[7] One of the main reasons for the undercount is the use of the "diagnosis" of "Early Childhood Special Education" (ECSE) for young children. Minnesota law requires public school districts to provide special education services to children from the age of 3 through the age of 22. The law does not require that young children carry a categorically specific diagnosis of autism to quality for special education services in early childhood. This lack of a required diagnosis, coupled with an institutionalized philosophy that families should be "spared" the emotional strain of identifying their child as autistic, combine to support the wide-spread practice of qualifying most 3-5 year olds for special education services under the label of ECSE only. Many of the children categorized in the DCFL data as ECSE children are actually children with Autism Spectrum Disorders who are not counted in the DCFL autism data.

Model Achieving Cost Savings,[8] **competently-delivered early, intensive intervention programming[9] could result in cost-benefit savings per child served of $61,768-$68,606 to age 22 and from $668,678-$823,920 to age 45.**

The extent of the savings that Minnesota would realize by investing in early, intensive interventions for children with autism should be consistent with the Pennsylvania projections. Perhaps just as important are the "soft" savings that should be realized. Children who succeed in decreasing their autistic behaviors and increasing their academic and social success as the result of early, intensive intervention programming will be less likely to be dependent on public assistance or other social service supports in adulthood and will be more likely to function self-sufficiently in their communities.

Conclusion

While Minnesota's data is insufficient to support a precise calculation of cost benefit savings, numbers are not necessary to support what we already know:

- Every child that makes significant academic and social gains as a result of early, intensive intervention programming will need less, or no, special education services throughout their K-12 career.
- Each child that masters the skills necessary to succeed academically and in their communities is one less adult who requires public support for independent living throughout a normal lifespan.

These facts justify a thorough discussion about the advisability of investing in early, intensive intervention programs to optimize the outcomes for autistic individuals living in Minnesota.

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[8] John W. Jacobson, Ph.D., James A. Mulick, Ph.D. and Gina Green, Ph.D., *Financial Cost and Benefits of Intensive Early Intervention for Young Children with Autism – Pennsylvania Model Achieving Cost Savings*, a 10/96 briefing paper. Copies of the entire report can be obtained from the Twin Cities Autism Society.

[9] The study examined the cost benefit questions in the context of a specific type of intervention: applied behavior analysis. This Supplemental Report utilizes this data not to endorse one treatment option over others but as an example of the potential for cost savings that can be achieved through investment in quality, early, intensive intervention programming in general.

The following members of the Autism Task Force respectfully submit this Supplemental Report to the Minnesota Legislature:

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Costs for DD Clients Diagnosed with Autism--Calendar Year 1997

Data from the MMISII Screening and Paid Claims files as they existed on 9/4/1998 and 10/2/1998 (for Non-HC Therapies)

	Age Group	0-3	4-8	9-20	21 and over	Total
	# Undup. Recips.	6	81	121	22	230
	With SILS	0	0	0	0	0
	With FSG	0	3	9	0	15
DD Waiver	Case Management	$0.00	$13,808.84	$69,289.47	$16,814.45	$99,912.76
	DT&H	$0.00	$0.00	$11,292.28	$106,169.27	$117,461.55
	Homemaker	$0.00	$579.20	$9,463.00	$0.00	$10,042.20
	In-Home Support	$0.00	$89,740.77	$593,792.19	$1,549.52	$685,082.48
	Modifications	$0.00	$2,220.21	$13,592.42	$639.28	$16,451.91
	Respite	$0.00	$26,916.45	$34,735.09	$7,104.92	$68,756.46
	Crisis Respite	$0.00	$1,585.60	$24,895.66	$2,160.00	$28,641.26
	Supported Employment	$0.00	$0.00	$0.00	$0.00	$0.00
	Adult SLS	$0.00	$7,409.86	$75,239.94	$485,120.49	$567,770.29
	Child SLS	$0.00	$22,092.68	$378,551.04	$0.00	$400,643.72
	Specialist Services	$0.00	$30,060.17	$12,189.62	$0.00	$42,249.79
	Caregiver Training	$0.00	$229.00	$49.00	$0.00	$278.00
	Personal Support	$0.00	$4,499.62	$971.04	$0.00	$5,470.66
	Assistive Technology	$0.00	$447.95	$1,037.91	$0.00	$1,485.86
	Housing Access	$0.00	$0.00	$0.00	$0.00	$0.00
	$ Total	$0.00	$198,004.75	$1,200,203.00	$617,302.44	$2,015,510.19
	# Undup Recips	0	13	49	12	74
	Avg. Cost/Recip.	$0.00	$15,231.13	$24,493.94	$51,441.87	$27,236.62
DD ICF/MR	$ Total	$0.00	$0.00	$40,624.65	$140,557.90	$181,182.55
	# Undup Recips	0	0	4	3	7
	Avg. Cost/Recip.	$0.00	$0.00	$10,156.16	$46,852.63	$25,883.22
DD RTC	$ Total	$0.00	$0.00	$0.00	$46,488.42	$46,488.42
	# Undup Recips	0	0	0	4	4
	Avg. Cost/Recip.	$0.00	$0.00	$0.00	$11,622.11	$11,622.11
DTH Non-Waiver	$ Total	$0.00	$0.00	$0.00	$37,177.55	$37,177.55
	# Undup.Recips	0	0	0	4	4
	Avg. Cost/Recip.	$0.00	$0.00	$0.00	$9,294.39	$9,294.39
Home Care						
Personal Care	$ Total	$25,000.73	$562,434.95	$561,695.47	$13,405.33	$1,137,535.75
	# Undup.Recips	3	44	50	1	95
	Avg. Cost/Recip.	$8,333.58	$12,782.61	$11,233.91	$13,405.33	$11,974.06
Other	$ Total	$0.00	$1,790.43	$50.28	$0.00	$1,840.71
	# Undup.Recips	$0.00	1	1	0	2
	Avg. Cost/Recip.	$0.00	$1,790.43	$50.28	$0.00	$920.36
Home Care Therapies and Assessments						
Occupational Therapy	$ Total	$0.00	$555.83	$13,385.15	$0.00	$13,940.98
	# Undup.Recips	0	1	4	0	5
	Avg. Cost/Recip.	$0.00	$555.83	$3,346.29	$0.00	$2,788.20
Physical Therapy	$ Total	$0.00	$396.08	$99.02	$0.00	$495.10
	# Undup.Recips	0	1	1	0	2
	Avg. Cost/Recip.	$0.00	$396.08	$99.02	$0.00	$247.55
Speech Therapy	$ Total	$0.00	$201.08	$4,170.18	$0.00	$4,371.26
	# Undup.Recips	0	2	2	0	4
	Avg. Cost/Recip.	$0.00	$100.54	$2,085.09	$0.00	$1,092.82
Assessment	$ Total	$613.08	$6,437.34	$4,802.46	$306.54	$11,546.34
	# Undup.Recips	3	44	36	2	82
	Avg. Cost/Recip.	$204.36	$146.30	$133.40	$153.27	$140.81

Community Support for Minnesotans with Disabilities
pwkey25
Printed on 10/16/1998

Costs for DD Clients Diagnosed with Autism—Calendar Year 1997

Data from the MMISII Screening and Paid Claims files as they existed on 9/4/1998 and 10/2/1998 (for Non-HC Therapies)

	Age Group	0-3	4-8	9-20	21 and over	Total
Non Home Care Therapies and Assessments	**(therapies, assessments and evaluations combined)**					
Occupational Therapy	**$ Total**	$0.00	$45,175.49	$9,718.80	$6,268.83	$61,163.12
	# Undup. Recips	0	32	8	5	45
	Avg. Cost/Recip.	$0.00	$1,411.73	$1,214.85	$1,253.77	$1,359.18
Physical Therapy	**$ Total**	$0.00	$1,767.34	$813.60	$0.00	$2,580.94
	# Undup. Recips	0	9	2	0	11
	Avg. Cost/Recip.	$0.00	$196.37	$406.80	$0.00	$234.63
Speech Therapy	**$ Total**	$0.00	$55,510.43	$14,052.12	$2,485.40	$72,027.95
	# Undup. Recips	0	30	8	1	39
	Avg. Cost/Recip.	$0.00	$1,850.35	$1,756.52	$2,485.40	$1,846.87

Community Support for Minnesotans with Disabilities
pwkey25
Printed on 10/16/1998

DRAFT 9/26/98

MENTAL HEALTH SERVICES FOR RECIPIENTS WITH A PRIMARY DIAGNOSIS OF AUTISM (CY 95/96/97)

1995

AGE*	0 to 3	4 to 8	9 to 20	21 and Older	TOTALS
SERVICE	AMOUNT-(CLIENTS)				
Diagnostic Assessment	1,324.10 (6)	8,246.48 (49)	4,149.99 (37)	4,471.23 (41)	18,191.80
Psychological Testing	197.40 (2)	3,217.81 (23)	1,019.90 (6)	2,560.47 (16)	6,995.58
Explanation of Findings	302.78 (6)	3,596.05 (35)	721.24 (8)	782.48 (11)	5,402.55
Individual Psychotherapy	85.98 (3)	1,387.63 (15)	3,922.06 (25)	3,139.14 (15)	8,534.81
Family Psychotherapy	644.00 (8)	2,318.50 (21)	683.78 (12)	313.74 (7)	3,960.02
Group Psychotherapy	0 (0)	594.00 (3)	198.00 (1)	2,164.20 (10)	2,956.20
Medication Management	20.00 (1)	544.00 (12)	2,522.83 (47)	5,289.20 (59)	8,376.03
Day Treatment	10,346.70 (4)	247,162.65 (36)	2,899.35 (1)	0 (0)	260,408.70
Skills Training	0 (0)	0 (0)	0 (0)	0 (0)	.00
Case Management	0 (0)	2,976.25 (2)	3,033.75 (6)	522.50 (2)	6,532.50
TOTALS	12,920.96 (10)	270,043.37 (105)	19,150.90 (89)	19,242.96 (106)	321,358.19 (310)

1996

AGE*	0 to 3	4 to 8	9 to 20	21 and Older	TOTALS
SERVICE	AMOUNT-(CLIENTS)				
Diagnostic Assessment	2,818.90 (9)	7,710.88 (45)	4,498.15 (40)	3,673.06 (30)	18,700.99
Psychological Testing	8.70 (1)	3,378.67 (17)	2,167.11 (11)	1,628.06 (15)	7,182.54
Explanation of Findings	71. 25 (2)	1,852.80 (31)	936.56 (15)	1,332.36 (15)	4,192.97
Individual Psychotherapy	658.00 (0)	1,146.39 (13)	5,547.64 (29)	2,657.97 (16)	10,010.00
Family Psychotherapy	729.00 (5)	2,532.00 (14)	2,440.00 (15)	28.00 (1)	5,729.00
Group Psychotherapy	0 (0)	0 (0)	641.25 (3)	3,438.00 (9)	4,079.25
Medication Management	24.00 (1)	372.00 (8)	2,964.60 (55)	6,016.29(66)	9,376.89
Day Treatment	35,308.56(15)	268,373.07(44)	16,922.36 (3)	0 (0)	320,603.98
Skills Training	0 (0)	3,206.50 (1)	5,420.11 (3)	0 (0)	8,626.61
Case Management	0 (0)	4,196.25 (3)	2,999.50 (9)	332.50 (2)	7,527.25
TOTALS	39,618.41 (21)	292,768.56 (108)	44,537.27 (120)	19, 106.24 (105)	396,030.48 (354)

1997**

AGE*	0 to 3	4 to 8	9 to 20	21 and Older	TOTALS
SERVICE	AMOUNT-(CLIENTS)				
Diagnostic Assessment	1,028.80 (10)	6,513.40 (47)	3,747.38 (35)	3,114.18 (29)	14,403.76
Psychological Testing	1,002.22 (7)	2,796.64 (19)	1,888.25 (9)	484.16 (3)	6,171.27
Explanation of Findings	78.37 (2)	1,072.21 (30)	869.20 (11)	819.30 (10)	2,839.0
Individual Psychotherapy	52.64 (1)	1,246.61 (15)	5,599.91 (32)	3,365.45 (20)	10,264.6
Family Psychotherapy	2,759.72 (8)	5,855.27 (25)	5,324.00 (18)	21.00 (1)	13,959.9
Group Psychotherapy	0 (0)	0 (0)	0 (0)	1,431.00 (1)	1,431.0
Medication Management	0 (0)	1,072.00 (14)	3,122.68(62)	5,214.26 (68)	9,408.9
Day Treatment	32,218.74 (12)	392,713.69 (63)	11,047.85 (2)	0 (0)	435,980.2
Skills Training	0 (0)	14,294.65 (4)	7,965.96 (3)	0 (0)	22,260.6
Case Management	0 (0)	7,537.50 (5)	2,511.75 (4)	0 (0)	10,049.2
TOTALS	37,140.49 (23)	433,101.97 (126)	42,076.98 (127)	14,449.35 (103)	526,768.79 (379)

* Age groupings based on age of recipient as of 12/31 of that year.

** 1997 Claims Data not complete.

DRAFT9/26/98

MENTAL HEALTH SERVICES FOR RECIPIENTS WITH A PRIMARY DIAGNOSIS OF PERVASIVE DEVELOPMENTAL DISORDER (CY 95/96/97)

1995

AGE*	0 to 3	4 to 8	9 to 20	21 and Older	TOTALS
SERVICE	AMOUNT-(CLIENTS)				
Diagnostic Assessment	1,223.10 (6)	7,168.99 (56)	6,608.69 (55)	1,898.10 (13)	16,908.88
Psychological Testing	394.80 (2)	4,420.38 (18)	3,133.25 (21)	444.15 (3)	8,392.58
Explanation of Findings	459.51 (5)	2,739.42 (32)	1,605.77 (22)	541.44 (6)	5,346.14
Individual Psychotherapy	139.03 (2)	9,111.01 (32)	16,645.42 (63)	5,200.82 (14)	31,096.28
Family Psychotherapy	1,121.50 (5)	3,397.10 (19)	8,312.72 (32)	138.60 (3)	12,969.92
Group Psychotherapy	33.75 (1)	168.75 (2)	234.00 (1)	508.50 (3)	945.00
Medication Management	80.00 (1)	1,832.20 (21)	4,171.61 (48)	2,308.97 (24)	8,392.78
Day Treatment	21,716.70 (6)	184,768.87 (29)	21,404.50 (12)	1,819.20 (2)	229,709.27
Skills Training	0 (0)	0 (0)	5,752. 43 (5)	0 (0)	5,752.43
Case Management	0 (0)	5,239.75 (6)	12,302.50 (19)	2,426.00 (3)	19,968.25
TOTALS	25,168.39 (17)	218,846.47 (121)	80,170.89 (151)	15,285.78 (42)	339,471.53(331)

1996

AGE*	0 to 3	4 to 8	9 to 20	21 and Older	TOTALS
SERVICE	AMOUNT-(CLIENTS)				
Diagnostic Assessment	1,534.80 (11)	6,090.29 (48)	5,681.26 (48)	2,248.93 (22)	15,555.28
Psychological Testing	737.35 (5)	4,388.96 (21)	5,478.97 (21)	1,385.39 (9)	11,990.67
Explanation of Findings	14.25 (1)	1,791.82 (26)	1,794.41 (18)	391.85 (6)	3,992.33
Individual Psychotherapy	231.15 (3)	7,718.25 (31)	19,387.78 (47)	7,007.50 (25)	34,344.68
Family Psychotherapy	545.32 (4)	4,966.55 (25)	8,097.84 (29)	172.20 (3)	13,781.91
Group Psychotherapy	0 (0)	249.75 (2)	549.70 (7)	1,074.60 (3)	1,874.05
Medication Management	40.00 (1)	1,965.60 (23)	4,428.00 (61)	4,526.32 (41)	10,959.92
Day Treatment	8,931.65 (4)	170,152.05 (25)	18,358.45 (10)	8,480.54 (4)	205,922.69
Skills Training	0 (0)	2,171.34 (4)	7,128.94 (4)	0 (0)	9,300.28
Case Management	0 (0)	5,115.00 (5)	17,487.50 (24)	3,015.00 (5)	25,617.50
TOTALS	12,034.52 (20)	204,609.61 (120)	88,392.85 (157)	28,302.33 (77)	333,339.31(374)

1997**

AGE*	0 to 3	4 to 8	9 to 20	21 and Older	TOTALS
SERVICE	AMOUNT-(CLIENTS)				
Diagnostic Assessment	97.20 (3)	7,453.44 (57)	5,215.93 (50)	1,822.41 (19)	14,588.98
Psychological Testing	648.90 (4)	2,621.50 (21)	5,219.64 (24)	928.31 (5)	9,418.35
Explanation of Findings	64.13 (2)	1,011.69 (15)	1,232.50 (17)	776.32 (9)	3,084.64
Individual Psychotherapy	0 (0)	6,118.08 (19)	15,161.20 (56)	8,744.73 (27)	30,024.01
Family Psychotherapy	1,802.50 (2)	5,007.07 (23)	6,180.00 (33)	0 (0)	12,989.57
Group Psychotherapy	0 (0)	270.00 (2)	1,200.37 (3)	2,295.00 (2)	3,765.37
Medication Management	24.00 (2)	1,788.00 (22)	6,117.24 (74)	4,706.22 (51)	12,635.46
Day Treatment	4,974.86 (1)	85,708.52 (15)	14,098.80 (6)	9,845.46 (4)	114,627.64
Skills Training	2,270.02 (2)	5,232.44 (2)	6,505.01 (6)	0 (0)	14,007.47
Case Management	1,102.50 (1)	2,610.00 (5)	24,719.25 (22)	6,596.00 (6)	35,027.75
TOTALS	10,984.11 (9)	117,820.74 (108)	85,649.94 (169)	35,714.45 (82)	250,169.24(368)

* Age groupings based on age of recipient as of 12/31 of that year.

** 1997 Claims Data is not complete.