

U.S. Department of Health and Human Services Assistant Secretary for Planning and Evaluation Office of Disability, Aging and Long-Term Care Policy

IDENTIFYING THE SERVICES, COSTS, AND REIMBURSEMENTS FOR YOUNG CHILDREN WITH DISABILITIES THROUGH DATA COLLECTED BY TENNESSEE PART H IDEA PROGRAM

April 1996

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INTRODUCTION

Approximately four and one half million children have a disability. For many children, their disabilities start early in their lives. One survey found a prevalence of 2.9% in children under six years of age for an activity-limiting chronic disability (Newacheck & McManus, 1988). Some of those who have survived because of advances in medical technology have done so at the cost of sustaining long term disabilities. As an example, some very low birth weight infants suffer from chronic lung disease, deafness, mental retardation or feeding problems. With our improved technical capabilities, the impression has been that the number of children with some degree of limitation is increasing (Newacheck et al., 1984).

Not infrequently these disabilities affect a child's health and development. Their health needs cause children with chronic disabilities to consume a large share of health care resources (Butler et al., 1985; Newacheck & McManus, 1988). Costs have been covered principally by private health insurance, but a substantial number receive Medicaid (Newacheck & McManus, 1988). The type of services required which often may vary include in- and out-patient services as well as allied health services (Jessop & Stein, 1994). The provision of these services has frequently required the participation of a number of programs such as the Regional Perinatal Programs, Supplemental Security Income (SSI), and Early and Periodic Screening Diagnosis and Treatment (EPSDT). Therefore even at a young age just the health care needs of children with disabilities require multiple coordinated services.

However, comprehensive care should address children's developmental needs. These developmental needs have been the impetus for early intervention programs. These programs improve the early development of children at risk or with a disability (Ramey & Ramey, 1992; Shonkoff & Hauser-Cram, 1987). Motivating both health and development interventions is the desire to minimize the impact of those disabilities on the child's development.

Because disabilities affect multiple aspects of a child's life, providing appropriate services at an early age is difficult. Given the child's health and educational needs, the services required are frequently beyond the scope any one agency can provide. To receive comprehensive services, families often have to receive support from more than one agency. As an example, a child with meningomyelocele may receive services financed through Medicaid, the Department of Mental Health and Mental Retardation and/or part H of the Individuals with Disabilities Education Act (IDEA). Typically families of children with disabilities must deal with multiple agencies in their attempts to obtain optimal services.

Frequently agencies dealing with families of children with disabilities have a difficult time defining the boundaries of the services they cover. For instance, many of the services can be viewed as functioning in both the educational and health domains. Therapists including physical, occupational and speech are professionally active in both

domains. Furthermore, chronic illnesses can impair cognitive functioning, and developmental disabilities can impact on the health status of a child. Given this situation, many times it is difficult for agencies to categorize their services. Since the way a service is categorized determines who pays for it, this is an important issue. Because both insurance and entitlement programs are under pressure in these times of cost containment, it is important to help them develop equitable criteria by which to determine how to share the service needs of children with disabilities. For this reason this project focused on the boundary between educational and health domains.

The project identifies the types of services that children under three years of age with significant delays or disabilities receive and what funding sources pay for them. To accomplish this, a currently existing source of data collection, the Part H programs of IDEA was used. Congress passed Part H of IDEA to address the coordination of services and the developmental needs of young children with disabilities. The programs are now fully implemented in all states except one. The programs are administered by the departments of Education (21 states), Health (17 states) and Human Services (8 states). In the remaining few states, they are under other assorted agencies including Mental Health and Interagency Councils (Sonnier, 1991). In many states Part H programs increasingly help families to obtain services.

The organizational mandates of the programs are to coordinate services and to help the families and care providers develop Individualized Family Service Plans (IFSP). this causes the programs to have a broad view of services crossing several agencies regardless of the lead agency. In fact, in funding the programs, it was anticipated that both publicly and privately financed health insurance programs would contribute to the financial support required in these programs (Sonnier, 1991). This includes both educational and health services, such as physical, occupational and speech and language therapies. In addition to developmental instruction, the programs coordinate and sometimes pay for speech, language and hearing therapy, physical and occupational therapy, diagnostic medical services, respite care, social and psychological services, and assistive technologies. By coordinating services, the Part H IDEA programs frequently determine who is responsible for what services. This places the programs in an excellent position to collect data on the types of services available to families of young children with disabilities.

In the State of Tennessee the Part H program is the Tennessee Early Intervention System. TEIS identifies most children under three years of age with evidence of significant developmental delay, or who have a condition putting them at high risk for developmental delays. TEIS provides service coordination as well as services identified. TEIS is also the payer of last resort. The information this process has generated provided unique access to most of the children in Tennessee under the age of three years with significant disabilities.

Existing studies have examined these programs from either an educational or a health perspective. The former survey intervention programs to determine the cost of the programs (Escobar, Barnett & Goetze, 1994). The health perspective surveys public

and private health insurers as to which services are included in their coverage (Fox et al., 1992). Escobar et al. (1994) found that the factors that had the greatest influence on cost were program duration, frequency of service, staff-child ratio, geographic location and volunteer resources. Unfortunately the study did not examine variations in the children such as diagnosis, variations in the types of service required or the sources of payment. Fox et al. found that some of the ancillary services were covered by health insurance companies but by only about half of the Medicaid programs and that, while they were covered by about three quarters of the private insurers, coverage was limited in many companies to the restoration of lost functions. The major limitation of this study was that it determined the companies stated benefits, and did not examine actual reimbursements.

The relationship between the health and educational domains has been further complicated by health reform. Current studies and impressions suggest that there are both positive and negative effects of managed care on children with special needs (Cartland & Yudkowsky, 1992; Fox et al., 1993; Newacheck et al., 1994). The state of Tennessee was one of the first states to implement significant comprehensive health reform on its own moving towards a managed care system. The full implementation of a total reform of Medicaid to a managed care system occurred in the second year studied in this project. This allowed us the unique opportunity to collect information from a fully functional statewide Part H IDEA program functioning in an environment that has undergone health reform to a managed care system.

Even prior to the changes in the systems described above, it was not always clear if or how the participation of different agencies was coordinated. Many times decisions appeared to be very individualized depending on the family, the programs, the child's diagnosis, and the type of services requested. With the need to control expenses, there is added pressure on each of the agencies to try to limit their expenses and only to provide those services for which they are clearly obligated. TEIS has had the experience of trying to address these issues for the past two years. Reviewing their experience through the process of examining their data collected rigorously on a statewide basis provided some insight into what factors affect the decision about who should pay for what services..

Therefore, the goal of this project was to better identify what services are provided to young children with disabilities and what factors affect how they are financed. This was accomplished by the following: (1) identifying the services received by children with chronic disabilities who are age 36 months and under; (2) identifying who paid for those services; and (3) identifying how factors such as referral sources, diagnosis, types of service, health insurance coverage, socioeconomic status (SES) and geographical region related to the decisions about what services the children receive and who pays for them.

METHODS

Description of the Agency

After passage of Part H of PI-99-457, the governor of Tennessee appointed the Tennessee State Department of Education as the lead agency to implement a statewide program of early intervention services for infants and toddlers with disabilities, birth to under 36 months of age, and their families in accordance with Part H of PL99-457 now known as PI-1 02-119. After three years of planning TEIS was implemented.

In 1989 the state contracted with nine district offices, and in each district, the state chose to contract with a university or nonprofit agency for the needs assessment and pilot phase. The state developed a separate contract with one additional university for technical assistance. In all but one district the state contracted with an institution of higher learning. This arrangement worked so well that it was continued in the full implementation phase. Pilot implementation occurred in 1990, with partial implementation in 1991 and full implementation in 1992.

The mission of TEIS is to advocate for families of young children (birth to under 36 months) with established disabilities or in circumstances likely to cause developmental delay and empower the families. It also promotes comprehensive, coordinated systems of early intervention including the full spectrum of service delivery options. It accomplishes this by (a) increasing public awareness among Tennessee citizenry regarding early intervention, (b) offering basic services to families by providing resource information and therapeutic referrals, (c) supporting families in the ongoing process of finding and accessing early intervention services (service coordination), (d) fostering coordination and communication among service providers on the behalf of families, (e) assisting families in the process of planning for and accomplishing transitions between service settings, (f) operating a statewide network of nine district level "points of entry" and a statewide toll-free telephone number, and (g) filling gaps in services to meet Individualized Family Service Plan (IFSP) requirements.

Organization and Operation of TEIS

The program is organized into nine district offices. Each district office is staffed with a primary principal investigator or two co-principal investigators. The training of the PI's is varied and represents the disciplines of early childhood education, clinical psychology, occupational therapy, speech/language therapy, pediatrics and early childhood development. The PI's are generally faculty from the contracting institutions of higher learning.

In addition, each office has a staff of service coordinators who also represent various professional disciplines including early childhood education and special education, nursing and social work. Several of the service coordinators are also parents

of children with special needs. Each service coordinator makes family visits, helps obtain evaluations, helps families to determine eligibility for various programs, helps identify appropriate services, organizes IFSP meetings, develops IFSP's, and helps monitor services. Most of the regional offices also have a contract coordinator and an individual responsible for screening and "child find".

The regional offices work closely with a Part H technical assistance office and with the lead agency staff. The technical assistance office designs, coordinates the collection of, and analyzes the information gathered and maintained by the district offices. Each district office and the state office collects information related to payment of services provided to the eligible population.

The district offices receive referrals from multiple sources including parents, physicians, therapists or day care workers. Service coordinators contact the families, and if the families are interested, appointments are made to obtain information about the child and family for intake purposes. They clarify what is required to determine if the child is eligible. Some children are eligible because they have a condition such as Down Syndrome which is known to make the child at high risk for developmental impairments. Obtaining a statement from a clinician that the child has the condition automatically makes the child eligible without any further evaluation. This is referred to as "paper eligibility". If such a condition does not exist, they child is still eligible if they are delayed 25% or greater in two developmental domains or 40% in one domain. (The domains are gross motor, fine motor, communication, cognitive, social/emotional and adaptive.) The service coordinator will arrange for an evaluation paid for by TEIS, if needed, to determine if a child is eligible. If a child is not eligible but is felt to be at risk, the service coordinator can choose to continue to monitor that child's progress by periodic screens.

If a child is eligible, the service coordinator will help the families to determine their needs. This will usually include an assessment of the child for programming purposes to determine what interventions are appropriate. From the information available about each of the children including that generated by his or her assessments, a plan is developed with the family and service providers. This is called the IFSP, and it consists of specific outcomes and the services required to achieve those outcomes. The plan is developed at a meeting including the providers who evaluated or are likely to provide service to the children and their families, the service coordinator and the parents. In some cases, this service coordination is provided by someone other than the TEIS service coordinator. For instance, if the child is enrolled in a Department of Mental Health and Mental Retardation program, one of their staff may assume the case coordinating role instead of a TEIS service coordinator. (In these cases, the same information about the IFSP is generated and sent to the TEIS program but the service coordinator from TEIS may not have to attend the IFSP meetings.)

Collecting and Analyzing the Data

Sample 5 1

The original intent of this proposal was to collect data on all children who received services in the 1993-94 and 1994-95 fiscal years in all nine of the districts. This was found to be about 1800 subjects. It became clear that these were more, subjects than was feasible to review within the limitation of the grant's resources. In order to preserve the intent of the project while lowering the number of subjects to a quantity feasible to complete the chart reviews, data were collected from each odd-numbered TEIS client chart which had recorded the performance of a TEIS Intake during the time periods January 1 through June 30, 1993, and January 1 through June 30, 1994. In addition, we chose not to collect data from District 9 (the Memphis area) because of the selection bias of that region's procedures which at the time of the study almost exclusively enrolled only children who were in community based early intervention programs sponsored by the Department of Mental Health and Mental Retardation. Data were entered into FileMaker Pro 2.1 database files directly from the charts by one individual (LC) from 2/20/95 to 12/22/95. Services data not available in the charts by July 1, 1995, were not entered.

Data Collected

The data collection system was developed to collect the data outlined in our proposal reflecting the practicality of what data were available in each district. The <u>demographic variables</u> were obtained from the Individualized Family Service Plan (IFSP), the Progress Notes, Central Intake Form or TEIS Staff. The demographic data are presented in Table One.

| TABLE ONE. Demographic Information | | | | | |
|------------------------------------|--------------------------------|--|--|--|--|
| Age at Intake Sex of Parent(s) | | | | | |
| Current Age | Occupation of Parent(s) | | | | |
| Race | Funding Eligibility | | | | |
| County of Birth | Government Program Eligibility | | | | |
| State of Birth | Agency of Coordinator | | | | |
| Age of Parent(s) | TEIS District | | | | |

The Evaluations And Cost are presented in Table Two. All costs for evaluations listed below were flat rate estimates for each evaluation service. In the few cases where the cost estimate provided by TEIS was an hourly rate, the cost of two hours of that evaluation service was used as the flat rate, with the exception of psychology, where the cost of 3.25 hours was used. For all payers except TennCare cost was an estimate based on the TEIS payment rate from the given district for the appropriate year. If this information was unavailable, the 1994 TEIS established maximum payment rate was used. Where TennCare was the payer, cost was estimated using an average of MCO payment rates from the following TennCare MCO's: Access MEDPlus, Blue Cross/Blue Shield, HealthNet, Omni Care, Preferred Health Partnership, Prudential Community Care, TLC Family Healthplan, Total Health Plus and VHP Community Care.

| TABLE TWO |
|--|
| Audiology |
| Ophthalmology |
| Speech/Language Pathology |
| Early Interventionist |
| Social Work |
| Physical Therapy |
| Occupational Therapy |
| Nutrition |
| Nursing |
| Primary Care Physician |
| Pediatrician |
| Developmental Pediatrician |
| Other Medical Specialty |
| Psychologyflat rate is equal to 3.25 hours |
| Cost of Professional Team EvaluationThe sum of the cost of each team member's evaluation |
| Total Cost of All Evaluations for Each Record |
| Number of Specialist Physicians Involved in CaseObtained from Intake or medical records |
| found in the chart. |
| Participants in Team EvaluationObtained from the team evaluation report in the chart |
| Payers for Evaluation ServicesThe information identifying the payers for each evaluation |
| service was obtained from progress notes, IFSP's, TEIS district staff, or deduced from funding |
| source eligibility and government program eligibility |

The <u>variables related to services and goals</u> are presented in Table Three. The data was obtained from IFSP, Service Provider Reports, TEIS Service Coordinators or Their Progress Notes.

| TABLE THREE |
|--|
| Date of the Initial IFSP Meeting |
| Professionals Involved in the Development of the IFSP |
| Services Received By the Client and/or Family |
| Setting of Each Service |
| First-Listed and Second-Listed Payers for Each Service Listed |
| Number of Service Hours (or Days of EIP) Per Month for Each Service |
| Total Number of Hours/Units for Each Service |
| Duration in Months for Each ServiceMonths of service prior to June 30, 1995 are not counted |
| in the total, because data collection from cases still active during the research period began |
| July 1, 1995. |
| Goals Specified on IFSP, e.g., Fine Motor, Expressive Language, Respite Care |
| Degree of progress Toward IFSP-Specified Goal |
| Date of Comment Related to IFSP-Specified Goal Progress |
| Degree of Progress Toward Desired Outcome When No IFSP Goals Were Specified |
| Date of Comment Related to above Progress |

The <u>cost by service</u> for each record is presented in Table Four. Cost was per hour of service with the following exceptions: transportation cost was per mile; special instruction cost was per 1/2 day of an Early Intervention Program when the service setting equaled Home and Early Intervention Program(EIP) or EIP alone; assistive technology cost was per item, e.g., hearing aids with ear molds. For all payers except TennCare, cost was an estimate. based on the TEIS payment rate from the given

district for the appropriate year. If this information was unavailable, the 1994 TEIS established maximum payment rate was used. Where TennCare was the payer, cost was estimated using an average of MCO payment rates from the TennCare MCOs listed in the section on Evaluations and Costs.

| TABLE FOUR |
|--|
| Cost Per Unit |
| Total Cost of Each Service |
| Total Cost (Charges) of Services for Each Record |

The <u>variables related to the subjects' developmental delays</u> are presented in Table Five. They were obtained from IFSP or Service Provider Reports in the Chart.

| TABLE FIVE |
|--|
| Areas of Developmental Deficits, e.g., Fine Motor, Expressive Language |
| Functional Age Equivalent (AE) in Months |
| Chronological Age (CA) in Months |
| 100 - (AE/CA)100 Yields Percent of Developmental DelayComputer calculated. |

In a case where a language delay was recorded only in terms of level of delay, e.g., mild, moderate, severe, etc., an estimated value was entered for AE in the formula above. A value was entered which allowed the formula to yield the average of the given range of percent delay that corresponds to the level of delay. This range of percent delay comes from a chart developed by the Vanderbilt University Child Development Center. The chart, entitled "Criteria for Percentage of Language Delay," can be found in the appendix.

Analyses

The analysis plan is designed to answer 7 main questions:

- 1. In a six-month period, what services do children with disabilities receive? How many of those services do they receive?
- 2. Are some combinations of services more common than others?
- 3. What are the costs of providing services to the average child? How does this vary by type of service?
- 4. Do some combinations of services produce better progress toward treatment goals?

- 5. Who bears the cost of treatment? Do families depend on more than one source?
- 6. Do individuals with different means of paying for those services differ in the types and amounts of services they receive?
- 7. How have reimbursement patterns been influenced by the introduction of managed care?

RESULTS

A total of 550 charts were reviewed. Fifty-five charts in the Greater Nashville Region were reviewed prior to the realization that it would not be possible to review all the children. Only those cases that coincided with the specified timeframe and odd-number designation were included. The numbers of cases for the eight districts are presented in Table Six. These were reduced to four regions (East, Middle, Greater Nashville, and West) for purposes of analysis. One hundred-ninety-eight were from the 1993-94 year and 297 from 1994-95

| TABLE SIX | | | | | | | |
|---------------------|-----------|---------|--|--|--|--|--|
| District/Region | Frequency | Percent | | | | | |
| East | 108 | 21.8 | | | | | |
| First Tennessee | 53 | 10.7 | | | | | |
| East Tennessee | 55 | 11.1 | | | | | |
| Middle | 149 | 29.9 | | | | | |
| Southeast Tennessee | 59 | 11.9 | | | | | |
| Upper Cumberland | 49 | 9.9 | | | | | |
| South Central | 40 | 8.1 | | | | | |
| Greater Nashville | 174 | 35.2 | | | | | |
| West | 65 | 13.1 | | | | | |
| Northwest Tennessee | 26 | 5.3 | | | | | |
| Southwest Tennessee | 39 | 7.9 | | | | | |

| TABLE SEVEN | | | | | | |
|---------------------------|-----------|---------|--|--|--|--|
| Diagnosis | Frequency | Percent | | | | |
| Congenital Defects | 99 | 19.9 | | | | |
| Down Syndrome | 16 | 3.2 | | | | |
| Cerebral Palsy | 24 | 4.8 | | | | |
| VATERS Syndrome | 2 | 0.4 | | | | |
| Spina Bifida | 7 | 1.4 | | | | |
| Cleft Lip or Palate | 5 | 1.0 | | | | |
| Congenital Heart | 9 | 1.8 | | | | |
| Congenital Other | 36 | 7.3 | | | | |
| Developmental Delays | 205 | 41.4 | | | | |
| Speech, Language, or | 131 | 26.5 | | | | |
| Feeding | | | | | | |
| Autism | 4 | 0.8 | | | | |
| Developmental Delays | 62 | 12.5 | | | | |
| Pervasive Delays | 8 | 1.6 | | | | |
| Prematurity (Premie) | 97 | 19.7 | | | | |
| 7 weeks or less premature | 32 | 6.5 | | | | |
| 8 to 12 weeks premature | 37 | 7.5 | | | | |
| 13 or more weeks | 28 | 5.7 | | | | |
| premature | | | | | | |
| Other/Missing | 94 | 19.0 | | | | |

The number of children with each of the diagnoses are presented in Table Seven. These were reduced to the most common diagnostic categories (Congenital Defects, Developmental Delay, Prematurity, and Other/Missing)'for purposes of subsequent analyses.

The demographic information is present in Table Eight and Table Nine.

| | TABLE EIGHT. Demographic Information | | | | | | | | | |
|----------------------|--------------------------------------|-------------|-----------------|--------------|-------------|-----------------|--------------|--|--|--|
| | Female (%) | Male (%) | Afr-Amer (%) | Asian (%) | Cauc (%) | Hispanic (%) | Mixed (%) | | | |
| REGION | | | | | | | | | | |
| East | 45 | 55 | 11 | 0 | 89 | 0 | 0 | | | |
| Middle | 35 | 67 | 10 | 1 | 87 | 0 | 2 | | | |
| Greater | 43 | 57 | 31 | 1 | 65 | 1 | 1 | | | |
| Nashville | | | | | | | | | | |
| West | 31 | 71 | 31 | 0 | 68 | 2 | 0 | | | |
| p value | 0.1 | 12 | 0.001 | | | | | | | |
| CHILD'S DIAGN | IOSIS | | | | | | | | | |
| Congenital defects | 41 | 59 | 14 | 2 | 83 | 0 | 1 | | | |
| Developmental delays | 31 | 69 | 21 | 0 | 77 | 1 | 1 | | | |
| Premie | 45 | 55 | 24 | 1 | 73 | 0 | 2 | | | |
| Other/missing | 44 | 56 | 24 | 0 | 75 | 1 | 0 | | | |
| p value | p value 0.03 0.39 | | | | | | | | | |
| ALL | 38 | 62 | 21 | 1 | 77 | 1 | 1 | | | |

| | TABLE NINE. Age At Intake | | | | | | | | | |
|----------------------|---------------------------|-----------------|------------------|------------------|------------------|------------------|--|--|--|--|
| | <6 mos (%) | 6-12 mos (%) | 12-18 mos (%) | 18-24 mos (%) | 24-30 mos (%) | 30-36 mos (%) | | | | |
| CHILD'S DIAGNOSIS | | | | | | | | | | |
| Congenital defects | 26 | 21 | 12 | 14 | 17 | 9 | | | | |
| Developmental delays | 6 | 11 | 12 | 17 | 29 | 25 | | | | |
| Premie | 28 | 24 | 16 | 9 | 13 | 9 | | | | |
| Other/missing | 17 | 14 | 14 | 12 | 20 | 23 | | | | |
| p value | | | 0.: | 21 | | | | | | |
| REGION | | | | | | | | | | |
| East | 19 | 20 | 13 | 10 | 22 | 16 | | | | |
| Middle | 20 | 15 | 14 | 12 | 26 | 14 | | | | |
| Greater Nashville | 13 | 13 | 13 | 16 | 21 | 25 | | | | |
| West | 14 | 22 | 14 | 18 | 15 | 17 | | | | |
| p value | | | 0.0 | 001 | | | | | | |
| ALL | 16 | 16 | 13 | 14 | 22 | 19 | | | | |

The information about the education level of the parents and their occupations was too incomplete to be meaningful.

The remaining results are presented in reference to the questions presented in the proposal:

1. In a six-month period, what services do children with disabilities receive? How many of those services do they receive?

The percentage of children receiving each of the evaluations or therapeutic services are presented in Table Ten and Table Eleven.

| TABLE TEN. Percent Receiving Each Type of Evaluations | | | | | | | | |
|---|---------------------|-------------------|-----------|-----------|-------------------|------------------|------------------|--|
| | Sp & Lang (%) | Psychology (%) | PT (%) | OT (%) | Pediatrics (%) | Audiology (%) | Education (%) | |
| REGION | | | | | | | | |
| East | 36 | 7 | 23 | 29 | 5 | 19 | 44 | |
| Middle | 43 | 2 | 29 | 9 | 10 | 26 | 47 | |
| Greater Nashville | 51 | 6 | 14 | 8 | 25 | 42 | 13 | |
| West | 49 | 0 | 38 | 32 | 9 | 11 | 80 | |
| p value* | 0.07 | 0.04 | 0.001 | 0.001 | 0.001 | 0.001 | 0.001 | |
| CHILD'S DIAGN | IOSIS | | | | | | | |
| Congenital defects | 40 | 4 | 42 | 25 | 20 | 20 | 37 | |
| Developmental delays | 65 | 6 | 15 | 13 | 12 | 38 | 40 | |
| Premie | 24 | 2 | 30 | 18 | 9 | 24 | 41 | |
| Other/missing | 28 | 3 | 17 | 12 | 18 | 20 | 33 | |
| p value** | 0.001 | 0.44 | 0.001 | 0.03 | 0.07 | 0.001 | 0.59 | |
| ALL | 45 | 4 | 24 | 16 | 14 | 28 | 39 | |

The sum of the rows is greater than one because children received more than one evaluation (as discussed below)

^{*} p value pertains to a test of the hypothesis that there are no differences by region ** p value pertains to a test of the hypothesis that there are no differences by diagnosis

| | TABLE ELEVEN. Percent Receiving Services by Type | | | | | | | | |
|----------------------|--|-----------|-----------|---------------|----------------|------------------|----------------|------------------|--|
| | Sp & Lang (%) | OT (%) | PT (%) | Vision (%) | Nursing (%) | Transport (%) | Home EI (%) | Center EI (%) | |
| REGION | | | | | | | | | |
| East | 42 | 27 | 34 | 6 | 6 | 7 | 23 | 3 | |
| Middle | 32 | 9 | 32 | 1 | 5 | 11 | 22 | 3 | |
| Greater Nashville | 33 | 10 | 13 | 3 | 5 | 9 | 5 | 3 | |
| West | 28 | 25 | 26 | 0 | 5 | 14 | 35 | 8 | |
| p value* | 0.24 | 0.001 | 0.001 | 0.04 | 0.93 | 0.50 | 0.001 | 0.30 | |
| CHILD'S DIAGN | IOSIS | | | | | | | | |
| Congenital defects | 29 | 30 | 44 | 3 | 5 | 13 | 25 | 6 | |
| Developmental delays | 49 | 10 | 18 | 1 | 3 | 10 | 17 | 3 | |
| Premie | 20 | 16 | 31 | 5 | 11 | 7 | 18 | 4 | |
| Other/missing | 21 | 11 | 15 | 3 | 4 | 7 | 13 | 2 | |
| p value** | 0.001 | 0.001 | 0.001 | 0.33 | 0.02 | 0.45 | 0.13 | 0.45 | |
| ALL | 34 | 15 | 25 | 3 | 5 | 10 | 18 | 4 | |

^{*} p value pertains to a test of the hypothesis that there are no differences by region

The sum of the rows is greater than one because children received more than one evaluation (as discussed below)

| | TABLE TWELVE. Average Number of Hours/Miles of Services | | | | | | | |
|--|---|-----------------------|-----------------------|---------------------------|----------------------------|------------------------------|----------------------------|---------------------------------|
| Units/Hr or Mile | Sp & Lang (Mean Hours) | OT (Mean Hours) | PT (Mean Hours) | Vision (Mean Hours) | Nursing (Mean Hours) | Transport (Mean Hours) | Home El (Mean Hours) | Center El (Mean Hours) |
| REGION | | | | | | | | |
| East | 45 | 51 | 65 | 13 | 565 | 1157 | 40 | 102 |
| Middle | 34 | 24 | 41 | 14 | 1229 | 3096 | 52 | 156 |
| Greater Nashville | 52 | 29 | 43 | 41 | 384 | 414 | 33 | 113 |
| West | 23 | 33 | 28 | NA | NA | 1064 | 35 | 87 |
| p value | 0.04 | 0.07 | 0.02 | 0.73 | 0.53 | 0.003 | 0.19 | 0.07 |
| CHILD'S DIAGN | CHILD'S DIAGNOSIS | | | | | | | |
| Congenital defects | 42 | 41 | 43 | 60 | 1765 | 805 | 44 | 149 |
| Developmental delays | 37 | 39 | 59 | 8 | 158 | 951 | 39 | 121 |
| Premie | 66 | 37 | 46 | 13 | 57 | 695 | 55 | 99 |
| Other/missing | 41 | 26 | 41 | NA | 1032 | 249 | 31 | 92 |
| p value** | 0.07 | 0.79 | 0.42 | 0.07 | 0.05 | 0.81 | 0.29 | 0.24 |
| ALL | 41 | 38 | 48 | 30 | 741 | 774 | 43 | 121 |
| NOTE: Mean calculated using only individuals who received that particular service. | | | | | | | | |

This is organized by region and diagnosis, and is the percentage of children receiving the evaluation or service. Of 17 possible therapeutic services, only the eight presented occurred with greater than 2% frequency. Those services occurring less frequently included psychology, pediatrics, nutrition, social work, developmental pediatrics, or medical specialists. Table Twelve presents the extent of services provided. These figures represent the average number of hours or miles each child received based on those children who received any of that particular service.

^{**} p value pertains to a test of the hypothesis that there are no differences by diagnosis

2. Are some combinations of services more common than others?

The percentage of children receiving zero to five services are presented in Table Thirteen divided by regions and diagnosis. Those receiving no services, received evaluations only.

| TABLE THIRTEEN. Number of Types of Services Received | | | | | | |
|--|-------------------|-----------|----------|----------|----------|----------|
| | 0 | 1 Service | 2 | 3 | 4 | 5 |
| | Services | (%) | Services | Services | Services | Services |
| | (%) | | (%) | (%) | (%) | (%) |
| REGION | | | | | | |
| East | 33 | 28 | 15 | 14 | 8 | 2 |
| Middle | 33 | 40 | 20 | 5 | 2 | 1 |
| Greater | 53 | 34 | 6 | 4 | 3 | 1 |
| Nashville | | | | | | |
| West | 42 | 15 | 22 | 18 | 3 | 0 |
| p value | 0.001 | | | | | |
| CHILD'S DIAGN | CHILD'S DIAGNOSIS | | | | | |
| Congenital | 31 | 24 | 24 | 12 | 6 | 2 |
| defects | | | | | | |
| Developmental | 34 | 43 | 13 | 7 | 2 | 0 |
| delays | | | | | | |
| Premie | 42 | 32 | 11 | 8 | 5 | 1 |
| Other/missing | 66 | 15 | 7 | 7 | 4 | 0 |
| p value | | | 0.0 | 001 | | |

It was not possible to determine when services began so that we could not determine sequences.

3. What are the costs of providing services to the average child? How does this vary by type of service?

The cost divided by region and diagnosis are presented in Table Fourteen.

| TABLE FOURTEEN. Average Cost of Each Service for Each Child Receiving That Service | | | | | | | | |
|--|-----------------------------------|-------------------------|-------------------------|-----------------------------|------------------------------|--------------------------------|---------------------------------|-----------------------------------|
| | Sp & Lang (Mean Dollars) | OT (Mean Dollars) | PT (Mean Dollars) | Vision (Mean Dollars) | Nursing (Mean Dollars) | Transport (Mean Dollars) | Home El (Mean Dollars) | Center El (Mean Dollars) |
| REGION | | | | | | | | |
| East | 3601 | 2247 | 3305 | 484 | 33713 | 278 | 1432 | 3498 |
| Middle | 1709 | 1583 | 2620 | 490 | 55313 | 681 | 1789 | 4425 |
| Greater Nashville | 2665 | 3055 | 3385 | 1496 | 14649 | 99 | 1263 | 3160 |
| West | 1078 | 2053 | 1792 | NA | NA | 255 | 1232 | 2539 |
| p value | 0.001 | 0.60 | 0.40 | 0.73 | 0.65 | 0.006 | 0.35 | 0.13 |
| CHILD'S DIAGN | CHILD'S DIAGNOSIS | | | | | | | |
| Congenital defects | 2574 | 2837 | 2489 | 2207 | 88800 | 193 | 1543 | 4284 |
| Developmental delays | 2116 | 1823 | 3362 | 282 | 7863 | 219 | 1341 | 3524 |
| Premie | 3937 | 1944 | 2861 | 484 | 2631 | 167 | 2023 | 2805 |
| Other/missing | 2454 | 1259 | 3013 | 0 | 39216 | 60 | 1107 | 2952 |
| p value** | 0.06 | 0.39 | 0.67 | 0.06 | 0.08 | 0.81 | 0.20 | 0.30 |
| ALL | 2435 | 2217 | 2871 | 1092 | 36147 | 182 | 1500 | 3536 |

4. Do some combinations of services produce better progress toward treatment goals?

Direct analysis of this question was limited because the majority of the charts (55%) did not report on progress toward goals. The distribution as to who had notes about progress towards goals, and the data about progress on those children where goals were written is presented in Table Fifteen.

| TABLE FIFTEEN | | | | | |
|--------------------|------------------------------|--|--|--|--|
| | Progress Status Recorded (%) | Made Progress When Status was Reported (%) | | | |
| REGION | | | | | |
| East | 35 | 21 | | | |
| Middle | 47 | 42 | | | |
| Greater Nashville | 45 | 32 | | | |
| West | 55 | 53 | | | |
| p value | 0.07 | 0.02 | | | |
| CHILD'S DIAGNOSIS | | | | | |
| Congenital defects | 59 | 41 | | | |
| Development delays | 52 | 34 | | | |
| Premie | 35 | 41 | | | |
| Other/missing | 23 | 32 | | | |
| p value | 0.01 | 0.68 | | | |
| ALL | 45 | 37 | | | |

5. Who bears the cost of treatment? Do families depend on more than one source?

The percentage of children with each of 5 sources of funding are provided in Table Sixteen. Many children had services funded by more than one source. The columns in Table Sixteen represent the most common combinations.

| TABLE SIXTEEN. Payment Sources | | | | | | | |
|--------------------------------|------------------------------|------------------------------|---------------|--------------------------|------------|--|--|
| | | Child's Diagnosis | | | | | |
| | Congenital Defects (%) | Development Delays (%) | Premie (%) | Other/ Missing (%) | ALL (%) | | |
| TEIS only | 6 | 22 | 14 | 13 | 16 | | |
| TEIS+ PRIV | 22 | 23 | 14 | 16 | 20 | | |
| TEIS+ | 35 | 27 | 25 | 34 | 29 | | |
| MDCAID only | 7 | 8 | 16 | 16 | 10 | | |
| MDCAID + | 14 | 8 | 9 | 13 | 10 | | |
| PRIV only or + | 4 | 1 | 4 | 0 | 2 | | |
| MHMR, CSS + | 13 | 11 | 19 | 9 | 13 | | |
| ALL | 100 | 100 | 100 | 100 | 100 | | |
| p value | 0.18 | | | | | | |
| | Region | | | | | | |
| | East (%) | Middle (%) | GN (%) | West (%) | ALL (%) | | |
| TEIS only | 11 | 22 | 13 | 10 | 16 | | |
| TEIS+ PRIV | 10 | 25 | 25 | 13 | 20 | | |
| TEIS+ | 34 | 26 | 21 | 46 | 29 | | |
| MDCAID only | 24 | 8 | 3 | 3 | 10 | | |
| MDCAID + | 11 | 5 | 14 | 15 | 10 | | |
| PRIV only or + | | 3 | 5 | | 2 | | |
| MHMR, CSS + | 9 | 10 | 20 | 13 | 13 | | |
| ALL | 100 | 100 | 100 | 100 | 100 | | |
| p value | 0.001 | | | | | | |

TEIS only

TEIS + PRIV: TEIS and private insurance

TEIS+: TEIS and something other than private insurance

MDCAID only: Medicaid

MDCAID +: Medicaid and something other than TEIS

PRIV only or +: private insurance and not TEIS and not Medicaid (in some cases includes other)

MHMR, CSS +: Dept. Mental Health and Mental Retardation) and/or CSS (Children's Special Services) and other state sources other than TEIS

Because we could not determine when services started, we were unable to determine changes overtime.

6. Do individuals with different means of paying for those services differ in the types and amounts of services they receive?

The percent of services provided by the different funding sources is presented in Table Seventeen.

| TABLE SEVENTEEN | | | | | |
|-----------------------|---------------|------------------|------------|-------------|-------------|
| | MDCAID (%) | PRIV INS. (%) | CSS (%) | MHMR (%) | TEIS (%) |
| SPEECH & LANG | | | | | |
| Received the | 39 | 15 | 8 | 54 | 51 |
| service | | | | | |
| Funded the | 36 | 28 | 16 | 40 | 70 |
| service | | | | | |
| OT | | | | | |
| Received the | 32 | 19 | 12 | 47 | 62 |
| service | | | | | |
| Funded the | 53 | 33 | 13 | 46 | 59 |
| service | | | | | |
| PT | | 1 | 1 | 1 | 1 |
| Received the | 27 | 16 | 12 | 45 | 60 |
| service | | | | | |
| Funded the | 53 | 31 | 13 | 48 | 65 |
| service | | | | | |
| VISION | | 00 | 10 | 1 45 | 0.4 |
| Received the | 36 | 22 | 12 | 45 | 61 |
| service Funded the | 57 | 21 | 29 | 71 | 71 |
| service | 37 | 21 | 29 | / 1 | / |
| NURSING | | | | | |
| Received the | 34 | 23 | 12 | 47 | 63 |
| service | 54 | 25 | 12 | 77 | 05 |
| Funded the | 73 | 15 | 19 | 46 | 42 |
| service | . • | | | | |
| HOME EI | | | | | |
| Received the | 34 | 24 | 13 | 42 | 61 |
| service | | | | | |
| Funded the | 44 | 17 | 10 | 57 | 63 |
| service | | | | | |
| CENTER EI | | | | | |
| Received the | 37 | 23 | 13 | 45 | 62 |
| service | | | | | |
| Funded the | 44 | 11 | 11 | 72 | 61 |
| service | | | | | |

7. How have reimbursement patterns been influenced by the introduction of managed care?

We addressed this by comparing the first year of analysis under Medicaid with the second year under TennCare. The differences between the two fiscal years (before and after TennCare) are presented in Table Eighteen.

| TABLE EIGHTEEN | | | | | |
|----------------------|------|------|-----|--|--|
| | 1993 | 1994 | ALL | | |
| | (%) | (%) | (%) | | |
| TEIS only | 17 | 15 | 16 | | |
| TEIS+ priv | 14 | 25 | 20 | | |
| TEIS+ | 38 | 23 | 29 | | |
| mdcaid only | 7 | 12 | 10 | | |
| mdcaid + | 10 | 11 | 10 | | |
| priv only | 1 | 3 | 2 | | |
| mhmr and/or css only | 14 | 12 | 13 | | |
| p value | | 0.03 | | | |
| ALL | 100 | 100 | 100 | | |

DISCUSSION

In terms of ethnic/racial distribution, the sample overall reflected the distribution of minority individuals living in Tennessee. This consisted almost exclusively of African-American children and they were clustered to a greater extent in the West and urban area of Nashville. They were over represented in the diagnoses of developmental delay and prematurity, both of which are also influenced by economic disadvantage status.

The remainder of the discussion section will be organized based on the seven proposed questions. In determining the services that children with disabilities receive, it is also useful to determine what evaluations the children received. The most common evaluation was speech and language followed by education. This is not surprising since speech and language delays were the most common diagnosis followed by developmental delays in other domains as the next most common. The prominence of speech and language problems is also reflected in the services received where again speech and language therapy was the most common service. Surprisingly PT services were the second most common with early intervention including home and center based only third. A major intent of the program has been to provide early interventions services. From our data, it suggests that the most commonly identified disability or delay in children birth to three years of age is in speech and language, and that the services for these children are specific speech and language interventions without other early intervention components. Based on the data presented in Table Eleven, these children most commonly receive just the one service. We were not able to identify sequences of services because the charts were not clear as to exactly when each service began.

The greatest allocation by TEIS was for speech and language services since this was the most common service while the most expensive service was nursing. Nursing was expensive because the children who required the service, required an extensive number of hours for each child, but the overall cost to the program was low because the number of children were very few. Center based earlier intervention services were more expensive than home based early intervention services, because they were also more intensive, Children with congenital defects required a greater number and more intense services because they frequently had multiple problems that required intervention from a number of disciplines. While this was true for some of the children who had been premature, there were a large number of premature infants who had mild impairments or were at risk.

Because a large number of charts did not have any comments about the <u>progress</u> the children made <u>towards the goals</u> as outlined in their IFSP (over half of lhe cases had no indications), any analysis has to be interpreted with caution. Notation about progress was most frequently made for infants with congenital defects and least frequently made for those with prematurity. While the rate of indication of progress was lowest for those with prematurity, this was still at 40% rate of those reporting.

In terms of <u>who bears the cost of treatment</u>, the families mostly used more than one source. TEIS was the most used source. A common combined pattern was TEIS, Medicaid and Other sources. We were not able to examine individual cases overtime, but between the two years of the analysis, there was a shift to more private insurance payers away from TEIS and CSS resources.

It is difficult to answer the question about <u>individuals with different means of paying for those services differing in the types and amounts of services they receive because the results are confounded by the diagnosis of the child. Those with congenital anomalies received more services and required OT, PT and Nursing that are more likely to be reimbursed by the health care system (Medicaid and Private Insurance).</u>

The reimbursement patterns did not change with regard to Medicaid between the first year (preTennCare) and the second year (conversion to TennCare). This slightly increased under TennCare. This may reflect no change in reimbursements or may be due to the fact that TenriCare was in its beginning phase and Managed Care Organizations initially maintained the Medicaid policies.

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APPENDIX

| Criteria for Percentage of Language Delay | | | | |
|---|---------------------------------------|--|--|--|
| Mild delay | 10% below age level | | | |
| Mild-Moderate delay | 11% to 19% below age level (mean=15%) | | | |
| Moderate delay | 20% to 30% below age level (mean=25%) | | | |
| Moderate-Severe delay | 31% to 44% below age level (mean=38%) | | | |
| Severe delay | 45% to 55% below age level (mean=50%) | | | |
| Severe-Profound delay | 56% to 69% below age level (mean=63%) | | | |
| Profound delay | 70% or more | | | |

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