EARLY INTERVENTION

REPORT TO THE NC GENERAL ASSEMBLY

April 2002

ACKNOWLEDGEMENTS

A special thank you is extended to the individuals who worked long and hard to come up with consensus recommendations regarding the local systems design. These included:

Pat Adams,
Edgecombe-Nash Area
MH/DD/SAS Program

The Honorable Martha Alexander,
North Carolina General Assembly

Sam Bowman,
North Carolina Family
Support Network

Karen Chester,
North Carolina Interagency
Coordinating Council

Ann Crane,
Fayetteville Developmental
Evaluation Center

Kelly Davis,
Office of Education Services, Department
of Health and Human Services

Jann Harris,
Early Intervention Unit, Department of
Health and Human Services

The Honorable Kenneth Moore,
North Carolina General Assembly

Gene Perrotta,
Smoky Mountain Area
MH/DD/SAS Program

Azell Reeves,
North Carolina Interagency
Coordinating Council

Susan Robinson,
Division of Mental Health,
Developmental Disabilities, and
Substance Abuse Services

Kevin Ryan, MD,
Women's and Children's Health
Section, Division of Public Health

Kathryn Wilson,
Office of Education, Department of
Health and Human Services

Bob Wood,
Haywood County Health Department

EARLY INTERVENTION
REPORT TO THE
GENERAL ASSEMBLY

INDEX

A. EXECUTIVE SUMMARY

……..…..PAGES i - ii

B. INTRODUCTION

…….……P

AGE 1

C. LOCAL SYSTEMS DESIGN

……..PAGE 2

Values Directing Systems Design

…….PAGE 3

Outcome Measures That Should Be the Basis of Planning and

Executing Systems Design

……PAGE 4

Early Intervention Systems Issues and Needs Impacting System Design…….....PAGES 5 – 7

Proposed Early Intervention System Design

…….PAGE 8

Focal Points

…….PAGE 8

Responsibilities

…….PAGES 8 - 9

Timelines

……PAGE 10

D. WAITING LISTS FOR EARLY INTERVENTION…….…….PAGES 11-

12

E. MAXIMIZATION OF RECEIPTS

…….……PAGE 12

Health Choice

……..PAGE 12

Medicaid

…….PAGES 12 – 13

Insurance

……..……PAGE 13

APPENDICES

Appendix A – Senate Bill 1005, Sections 21.79 and 21.85 (a), (b), (c), and (d)

Appendix B – Public Hearing Script

Appendix C – DEC/Specialized Therapies Waiting List Reports

Appendix D – Summary of Findings: Assessment System Capacity & Practices Studies

EARLY INTERVENTION
SYSTEM DESIGN RECOMMENDATIONS

EXECUTIVE SUMMARY

Background

Early intervention is focused on children under three with or at risk for developmental disabilities, delays, or atypical development, and their families. Many children have special health care needs as well. Its purpose is to allow children to reach their maximum potential and provide the information and support related to this goal to families. It includes a variety of related services such as multi-disciplinary evaluations, speech, physical, and occupational therapy, special instruction, and service coordination.

Why

The 2001 Session of the General Assembly passed several Special Provisions related to early intervention. These included:

- Designation of the Division of Public Health of the Department of Health and Human Services as the state level lead agency responsible for planning, evaluating, and ensuring the availability of a statewide system of early intervention services.
- Directing the Division of Public Health to complete an evaluation of how early intervention services are organized and provided locally by the Health Departments, Area Mental Health Programs, and Developmental Evaluation Centers with the purpose of determining the feasibility of combining the administration of these services to assure efficiency and effectiveness of use of available resources, and requiring that a report be submitted to the General Assembly regarding the findings.

How

Input for the study was obtained through a variety of approaches including:

- Information and requests for recommendations regarding the early intervention system design were sent to over 1500 local public agencies, private service providers, and advocacy and professional organizations involved in early intervention.
- Four regional public hearings were held in Morganton, Greensboro, Fayetteville, and Greenville.
- An early intervention interagency system Design Team was formed to review the input and develop a proposal. The Design Team members included a director of an Area Mental Health Program, a Health Department, and a Developmental Evaluation Center, representatives of the involved state agencies such as the Division of Mental Health/ Developmental Disabilities/Substance Abuse Services and the Division of Public Health, staff and parents of children with disabilities from the North Carolina Interagency Coordinating Council, and local early intervention program managers. The Design Team developed the proposal through a consensus approach.

What

The proposal has two primary components:

A. Catchment Area Interagency Councils
   - ✓ Comprised of local representatives of all the different agencies involved in early intervention, private providers, and parents.

- ✓ Functions of the Councils include developing plans for how the catchment area wants to implement and evaluate:
  - ✦ child find and public awareness
  - ✦ assessment of local service system, identification of gaps and developing plans for services to address these gaps
  - ✦ evaluation of services and monitoring for compliance with state and federal early intervention regulations
  - ✦ staff development for personnel from all the participating agencies

B. Children's Developmental Services Agency

- ✓ Comprised of staff currently with the existing network of Developmental Evaluation Centers.
- ✓ Approximately 18 such agencies serving multi-county catchment areas to be determined based on population, consistency with other human services/early childhood programs.
- ✓ Functions include assuring the availability of all the required types of early intervention through direct provision or contract with other public and private agencies.

  NOTE: Through such contractual agreements, existing public agencies such as Health Departments and Area Mental Health Programs continue as service providers of some of the early intervention services as their own capacity, interests, and strategic planning allows.

When

Fiscal Year 2002-03

- ➢ Development of detailed implementation plan
- ➢ Review and reform of existing programmatic and fiscal policies and regulations
- ➢ Training and capacity development of Catchment Area Interagency Councils

Fiscal Year 2003-04

- ➢ Councils activated and develop catchment area plans
- ➢ Additional service providers identified where necessary

July 2004

- ➢ New system fully operational

Advantages

- ➢ Simplified service system with easier access for families (two of the most consistently made comments during public input process – currently one agency does the evaluation, two others provide ongoing early intervention services and this can result in a disjointed approach)
- ➢ Requires no additional resources to implement consistent level of services in all communities statewide
- ➢ Makes most effective use of available resources by keeping administrative costs low
- ➢ Ensure accountability for service delivery and consistency of services statewide
- ➢ Allows for local direction and control of planning and evaluating early intervention services

For Further Information, contact:

Karen Chester, (919) 662-4543 or Karen.Chester@ncmail.net

Duncan Munn, (919) 715-7500 or Duncan.Munn@ncmail.net

Kevin Ryan, MD, (919) 733-7937 or Kevin.Ryan@ncmail.net

A. INTRODUCTION

The 2001 session of the North Carolina General Assembly passed a number of Special Provisions related to early intervention services for children under three years of age with or at risk for developmental delays, disabilities, or atypical development and their families. These provisions were contained in Sections 21.85 (a) – (d) and 121.79 Session Laws 2001-424. The complete Provisions are contained in Appendix A of this report.

The Provisions call for a statewide assessment of some key aspects of the early intervention system; waiting lists for evaluation and follow-up services, use of Medicaid and third party receipts as funding sources for early intervention services, and an evaluation of ways to combine local services currently provided through the Area Program Mental Health, Developmental Disabilities, and Substance Abuse Services, Health Departments, Developmental Evaluation Centers, and regional therapists in order to improve service delivery efficiency.

In addition to the direction provided by these referenced Special Provisions, a number of other factors underscore the timeliness of this systems evaluation. The most relevant of these is an increased rate of referrals to early intervention. The annual December headcount of children served shows an increase of 19% in 2001 over the December 2000 headcount. These additional demands on service delivery capacity come at a time when state early intervention funds will be, at best, unchanged from previous fiscal years.

Also, the 2001 session of the General Assembly assigned to the Division of Public Health state level lead agency responsibilities for the early intervention system. Issues of consistency, accountability, and authority indicate the need to complete a corresponding, thorough review of the local systems. Finally, a state self-assessment carried out by an interagency team of local and state level representatives of the different involved agents, parents, and other stakeholders was completed in response to monitoring by the Office of Special Education Programs of the US Department of Education. One of its findings also called for this local systems review and finalization of responsibilities.

The Division of Public Health was designated as the state agency with responsibility for completing this report. In addition to the Division of Public Health, the North Carolina Interagency Coordinating Council, the Intervention Services Unit of the Department, the Division of Mental Health, Developmental Disabilities, and Substance Abuse Services, and the Office of Education Services were also involved in preparing the report.

B. LOCAL SYSTEMS DESIGN

Background:
Section 121.85 (c) of Senate Bill 1005 stipulates that attention be given to evaluate ways of combining the different early intervention services provided by the Developmental Evaluation Centers, the Area Mental Health Programs, and the Health Departments to improve the efficiency of service delivery.

- ✓ To ensure a broad range of input from public and private providers and families on this issue, these steps were taken:

  1. A letter discussing the charge of the Special Provision and soliciting recommendations was sent to 1,520 agencies, organizations, and individuals including all involved public agencies at local, regional, and state levels, and to advocacy and professional organizations.

  2. Four public hearings – in Greenville, Morganton, Greensboro, and Fayetteville – were held. A total of 76 persons attended the hearings. Thirty-four additional individuals responded directly to the above-mentioned letter. Appendix B includes the agenda for the hearings. Recommendations from both sources are reflected in the "Values", "Measures", and "Issues" sections that follow.

- ✓ To review the input and formulate the recommendations, an Early Intervention Interagency Design Team was formed. Agencies and organizations represented included:

  - **PARENTS OF CHILDREN WITH SPECIAL NEEDS**
  - **DIVISION OF MENTAL HEALTH/DEVELOPMENTAL DISABILITIES/SUBSTANCE ABUSE SERVICES** – Child and Family Services Section
  - **OFFICE OF EDUCATION SERVICES**
  - **NC GENERAL ASSEMBLY**
  - **NORTH CAROLINA INTERAGENCY COORDINATING COUNCIL**
  - **AREA MENTAL HEALTH/DEVELOPMENTAL DISABILITIES/SUBSTANCE ABUSE SERVICES PROGRAMS** –Area Director, and Early Childhood Services Coordinator
  - **LOCAL HEALTH DEPARTMENTS** – Director
  - **DEPARTMENT OF HEALTH AND HUMAN SERVICES SECRETARY'S OFFICE** – Intervention Unit
  - **DEVELOPMENTAL EVALUATION CENTER** – Director
  - **DIVISION OF PUBLIC HEALTH –** Women's and Children's Health Section

The following report represents a consensus of the Design Team. The report was then reviewed and approved at the Department level with the appropriate Assistant Secretaries and management staff from both the Divisions of Public Health and Mental Health, Developmental Disabilities, and Substance Abuse Services.

Values Directing System Design

Any systems design should be predicated on core values that relate to best practices in early intervention.

- ✓ Planning and implementing services should be a decentralized process, and occur primarily at the local and sub-regional level with appropriate authority and resources
- ✓ Planning for early intervention services and evaluating these services should be closely integrated with systems planning and evaluation efforts for all children
- ✓ Birth to five years of age is the most appropriate chronological framework for early intervention service planning, not birth to three. It should be closely coordinated with the Department of Public Instruction given their special education and related service responsibilities for ages three to five.
- ✓ Easy access to services for families
- ✓ Simple, streamlined systems work best in managing and providing early intervention services
- ✓ There should be equity and consistency in the availability of early intervention in all parts of the state
- ✓ Assessment and intervention should be an integrated process
- ✓ Flexibility is critical to ensure responsiveness to the wide range of child and family needs particularly those that are different in different parts of the state
- ✓ Early intervention policies must be implemented consistently in all parts of the state
- ✓ Capacity for comprehensive, accurate, accessible, and consistent data about children served and services provided must be assured
- ✓ Each child and family should have access to assessment and intervention services provided by a team of professionals from all the different disciplines relevant to their individual needs
- ✓ Any systems design should maximize opportunities for family involvement in planning, providing, and evaluating services in all parts of the state
- ✓ Services must be culturally responsive and reflect the ethnic and cultural diversity of children and families receiving services

Outcome Measures That Should Be the Basis of Planning & Evaluating Systems Design

The systems design should not focus solely on process, but be designed to achieve specific outcomes or measures.

- ✓ The number of children and families served, age at referral
- ✓ The time between referral, assessment, Individualized Family Service Plan (IFSP) development, and initiation of services
- ✓ The number of qualified early intervention providers (agencies and individuals, public and private)
- ✓ Family satisfaction with service system entry, types and levels of early intervention services provided, transitions
- ✓ Parent participation in planning, implementing, evaluating, and training professionals at the state and local level
- ✓ Volume and appropriateness of paperwork
- ✓ The appropriateness of services provided in relation to the identified needs of the children and families served
- ✓ Quality of services as measured through recognized program evaluation instruments
- ✓ Compliance rates with federal and state regulations
- ✓ Staff retention rates
- ✓ Percentage of Individualized Family Service Plans that document family services and support meeting identified family needs
- ✓ Diversity of different funding sources for early intervention with consistent application of fiscal policies
- ✓ Percent of services provided in natural child care environments of high quality
- ✓ Profile of children served by three eligibility categories - developmental delay, atypical development, and high risk – reflects recognized incidence patterns
- ✓ Diversity of personnel in terms of culture and ethnicity
- ✓ Awareness of community professionals of early intervention services and how to access them
- ✓ Number of counties with integrated early childhood service planning efforts
- ✓ Number of agreements with institutions of higher education that reflect staff development, training, and research in the field of early intervention
- ✓ Consistent availability of core services in all parts of the state
- ✓ Availability of parent education that improves accessibility and quality of services

Outcome Measures That Should Be the Basis of Planning & Evaluating Systems Design

- ✓ Consistent application of program and fiscal policies across agencies and providers wherever appropriate

Early Intervention Systems Issues & Needs Impacting System Design

System design planning should be specific to existing early intervention service system realities and needs that must be addressed.

A. Compliance/Timeliness of Services

- ✓ Coordinated quality improvement and control across the different agencies
- ✓ More expeditious referral procedures and supports, strategies and approaches needed; single toll-free number, one designated office for initial home visit, setting up child record, etc.

B. Significant Number and Quality of Personnel

- ✓ Staff turnover rates in some of the early intervention agencies
- ✓ Shortage of management, support, and clinical staff in local early intervention agencies, particularly specialized therapies and nutrition
- ✓ Increasing ethnic and cultural diversity of consumer and provider base
- ✓ System-wide application of the Infant-Toddler Program Personnel or B-K Certification process
- ✓ Preservation and enhancement of clinical expertise in all the different disciplines relevant to assessment and intervention
- ✓ Availability of technical assistance and clinical supervision inconsistent across participating provider agencies and organizations

C. Quality of Services

- ✓ Implementing natural environments: training, policy, fiscal supports
- ✓ Lack of family support services in many catchment areas; also, not integrated well into local early intervention service system
- ✓ Still insufficient parent involvement in key areas of Infant-Toddler Program implementation such as Community Review, Consortia, evaluation planning
- ✓ Substantial inadequacies in some types of early intervention services: infant mental health, audiology, family counseling
- ✓ Capacity for a broad range of intervention models: direct therapies, consultation, etc.
- ✓ More focus on outcomes in addition to process in evaluating services

D. Funding

- ✓ Increasing infant-toddler referrals in the context of personnel and fiscal shortages
- ✓ Not all early intervention agencies can fully utilize their Medicaid receipts

- ✓ Inconsistency in capacities of Local Interagency Coordinating Councils
- ✓ Staff support for Local Interagency Coordinating Councils
- ✓ Lack of any requirements on Insurance System regarding coverage of early intervention-related services
- ✓ Inconsistent Medicaid reimbursement policies, and other service delivery program policies and procedures
- ✓ Lack of an interagency unit cost reimbursement system specific to and appropriate for the services relevant to early intervention

E. Serving all Eligible Children

- ✓ Growing number of preschool referrals for transition and other evaluations
- ✓ Insufficient service delivery capacity, particularly in partner agencies: Area Programs and Health Departments
- ✓ Increased capacity for county based "satellite" services

F. Policies

- ✓ Policy communication and interpretation between State/Local and Local/Local early intervention agencies
- ✓ Conflicting priorities in participating agencies, impacting staff time and responsibilities
- ✓ Better, more consistent approaches to reimbursing Early Intervention providers for services provided; both policies and "mechanics"
- ✓ Transition problems: lack of integrated approaches across Infant-Toddler and Preschool Programs, inability to focus much on the needs of preschoolers
- ✓ Paperwork levels continue to increase
- ✓ Better use of available technologies (local teleconferencing, electronic child records, etc.)

G. Organizational Structure

- ✓ Fragmentation in management structure of local early intervention service
- ✓ Difficulties in coordinating consistent approaches/services/training across multiple counties and agencies
- ✓ Need for a unified birth to three early intervention local system that has responsibility for all the full range of early intervention services and is closely coordinated with special education and related services for preschoolers

Early Intervention Systems Issues & Needs Impacting System Design

- ✓ State level fragmentation of early intervention management and services within and across Divisions
- ✓ More consistent, statewide coordination and collaboration with Governor Morehead School and Early Intervention for the Hearing Impaired and the Infant-Toddler Program
- ✓ Raleigh Early Intervention Branch infrastructure support for local early intervention systems: fiscal, personnel, technical assistance
- ✓ Complexity of system, lack of one entity with actual responsibility for all aspects of Infant-Toddler Program, particularly for families to turn to if they have issues with services
- ✓ No consistent source of information for families about early intervention services – "one stop shopping"
- ✓ Any systems design implementation should be carried out at a deliberate pace, with specific steps and goals

Proposed Early Intervention System Design

I. FOCAL POINTS

A) Children's Developmental Services Council

- ✓ An interagency, regional group with membership comprised of representation from the local interagency councils in the catchment area which reflects all public agencies involved in early intervention and private sector providers as well

- ✓ Responsible for developing the Children's Developmental Services Catchment Area Plan for the designated catchment area

- ✓ Possibly integrated into an existing structure representing the different local interagency groups required by Smart Start, Mental Health Systems of Care, Juvenile Justice, etc.

- ✓ If part of another interagency structure, specific focus on early intervention assured through specific operational procedures and designated staff responsibilities

  NOTE: The purpose here is to avoid having multiple interagency planning councils.

B) Children's Developmental Services Agency

- ✓ The Developmental Evaluation Centers will become the public Children's Developmental Services Agencies with designated catchment areas, and significantly different mission and responsibilities.

- ✓ Staff of these agencies will include existing personnel from Developmental Evaluation Centers and from Area Mental Health/Developmental Disabilities/Substance Abuse Service Programs and Health Departments who do not wish to continue as early intervention provider agencies and consequently cut positions. Early intervention staff from other service providers such as Division TEACCH, Governor Morehead School and the Schools for the Hearing Impaired would also be "connected to" the Developmental Services Agency through such approaches as co-location and joint participation on IFSP teams.

- ✓ County catchment areas to be determined; consistency with existing and future Smart Start catchment areas, Mental Health Local Management Entities, etc., will be a goal

- ✓ Attached to Early Intervention Branch of the Women's and Children's Health Section of the Division of Public Health

II. RESPONSIBILITIES

A) Children's Developmental Services Council

- ✓ Developing a Catchment Area Plan for and monitoring implementation of the key systems and service delivery responsibilities required under Part C of the Individuals with Disabilities Education Act (IDEA) through focusing on:

  - ➢ Child find/public awareness

- Coordination and integration with other early childhood special education and related human service planning such as that carried out by the Mental Health Local Management Entities (LMEs), Smart Start, and the Local Education Authorities (LEAs)

- Assurance of the availability of early intervention required services through assessment of service delivery capacity, identification of needs, and development/revision of a catchment plan to address gaps/inadequacies

- Interagency professional development

- Compliance monitoring/qualitative evaluation of service

B) Children's Developmental Services Agency

✓ Implementation of the Catchment Area Plan through:

- Assuring availability of all required evaluation and intervention services required by state and federal regulations for all children referred by:

  - providing these services directly as necessary
  - identifying and contracting with other public and private agencies and organizations as needed

NOTE: These are the required services under Part C of IDEA and the North Carolina Infant-Toddler Program. They include screening and early identification, multidisciplinary assessment, child service coordination, specialized instruction, speech, physical, and occupational therapy, assistive technology, respite care, vision and audiology services, parent counseling, family counseling and therapy, nutrition, transportation, nursing, medical and health services necessary to access these services. Additionally, these agencies will provide assessments for children referred to the preschool program. Other related services for children under three and non-special education services for preschoolers may be provided as resources permit.

- Systems responsibilities that must be consistent across all parts of the state

  - child and service data collection
  - mediation and due process

- Provide staff support to Children's Developmental Services Council

- Assure family support services required by early interventions regulations

NOTE: Early intervention providers could be any public or private agency that agrees to use revised Infant-Toddler Program policies and procedures and not impose additional policies or procedures. Current public agencies such as Health Departments and Area MH/DD/SAS Programs would be encouraged to continue as providers of specific early intervention services consistent with their own strategic planning and areas of expertise.

C) Early Intervention System Design Oversight Work Group

✓ The Department shall establish an oversight group comprised of representation of all involved Divisions and the North Carolina Interagency Coordinating Council, Smart Start, Juvenile Justice, Department of Public Instruction, and other stakeholder organizations to monitor and evaluate the reorganization process.

NOTE: An integral component of this early intervention system design process must be a thorough review and revision of all state fiscal and program policies impacting early intervention. The focus of such a review is to include:

- Reduction of unnecessary paperwork and service delivery procedures
- Consistency of policies across the involved agencies
- Equal access to available Medicaid and other third party revenues by the different DHHS Divisions and the private provider community involved in early intervention

TIMELINES:	
April – June 2002	▪ Discuss proposed design with all stakeholders ▪ Review all existing federal and state policies and guidelines of all involved agencies, including Medicaid, to identify duplications, conflicts, and barriers in an effort to streamline early intervention service delivery ▪ Develop a complete implementation plan using experiences of current Local Interagency Coordinating Council pilots and other data ▪ Develop communication plan ▪ Develop evaluation plan
July 1, 2002 to June 30, 2003	▪ Establish state supports necessary to implement the plan; policy changes, etc. ▪ Identify staff supports and necessary existing resources for implementing the plan ▪ Change program and fiscal policies as necessary ▪ Area MH/DD/SAS Programs and Health Departments would continue their current service delivery responsibilities unless they requested to cease doing so ▪ Training and technical assistance to current and new provider agencies
December 2003	▪ All catchment areas will have completed planning process related to all facets of the proposed early intervention system
June 30, 2004	▪ Complete statewide implementation
July 1, 2005	▪ Complete year one evaluation report

C. WAITING LISTS FOR EARLY INTERVENTION

Background:
Sections 121.85(a) and (b) of SB 1005 focus on evaluation and follow-up early intervention services and the waiting lists that exist for such services.

- ✓ The Early Intervention Branch of the Women's and Children's Section of the Division of Public Health has completed a detailed review of the data regarding the numbers of children waiting for such services as of November 1, 2001. Appendix C contains this information. The first question the service system review looked at was the reason for these numbers and whether or not existing personnel are being used most efficiently while reflecting best practices. As part of an earlier phase of the reorganization of early intervention process an interdisciplinary team of nationally recognized experts was brought in to evaluate practices at the Developmental Evaluation Centers. This evaluation was completed in July of 2000. Findings reflected the fact that the numbers of children served and the quality of services provided was commensurate with the numbers and types of available staff and that the Developmental Evaluation Center system represented a nationally unique resource. Appendix C contains a summary of this review. The Early Intervention Branch carried out a six month productivity review of clinical staff at each of the Developmental Evaluation Centers. As a result of this review, some locations were provided technical assistance on organizing and scheduling clinical services but no significant patterns of underutilization were identified.

- ✓ A number of specific approaches have been identified to contribute to long-term capacity building. These include:

  1. A greater use of paraprofessionals to assist in providing ongoing services. The Division plans to pilot such approaches in the upcoming fiscal year.

  2. Integration of the assessment and intervention (therapy provision) responsibilities as delineated in the reorganization recommendations included in this report will allow even better coordination and focus of staff currently in different agencies.

  3. Greater use of third party receipts through more extensive insurance coverage of early intervention services and availability of consistent Medicaid covered early intervention related service categories will significantly enhance the level of resources available for evaluation and specialized therapies.

  4. The Division of Public Health and the North Carolina Partnership for Children have collaborated closely in the development of the Smart Start Performance-Based Incentive System measures. One of these includes serving additional children in early intervention. This will help further focus Smart Start resources on such evaluations, intervention services, and specialized therapies, and encourage more joint planning at the local level.

  5. Additional approaches to making specialized therapy services available to families need to be implemented. One model that has been used with other types of early intervention services such as respite and transportation is a voucher or reimbursement approach. Here the family secures the service from a provider of their choosing from a list of potential providers compiled by the agency. They are given vouchers to use with the provider, or they pay for the services themselves and are reimbursed by the agency. The amount of the voucher or reimbursement varies based on the income level of the family. This model has a number of significant attributes: it provides more choices for the family while

avoiding the more extensive administrative time required for hiring and supervision of personnel.

6. The transdisciplinary model funded by the General Assembly through a Special Provision being implemented in the Eastern part of the state provides significant promise in that it increases flexibility in how existing specialized therapy personnel can be utilized as well as help to ensure that the perspectives of all disciplines needed by the child are appropriately involved in the intervention plan.

- ✓ Negative factors related to ongoing systems capacity for keeping waiting times as brief as possible include:

  1. The growing number of referrals (midyear data for Fiscal Year 01-02 shows a 17% increase over the comparable time period Fiscal Year 00-01)

  2. Federal early intervention regulations that stipulate that assessments and intervention be carried out in "natural environments" such as the child's home or child care center (this makes good programmatic sense but does require that clinical staff spend time traveling to such settings).

- ✓ Other factors:

  1. The Division of Public Health sponsored an interagency review of its referral policies and procedures in the fall of 2001 to ensure that these provided the proper framework for promoting expeditious responses. Revisions made in these policies reflected additional clarity of expectations.

  2. The reorganization related proposals delineated in this report will allow even more streamlining of the referral and entry process for early intervention and will free up clinical staff time for the provision of direct child and family services.

- ✓ The current Infant-Toddler Program data set does not allow monitoring of the time period between referral – evaluation – eligibility determination and Individualized Family Service Plan development. Data will be reviewed and disseminated on a quarterly basis. It does not allow measurement of the time between Individualized Family Service Plan and initiation of services nor the identification of services needed but not available. The proposed Integrated Birth to Five database does capture all of these areas. Statewide implementation of this database is encouraged as quickly as possible to allow better targeting of available resources.

D. MAXIMIZATION OF RECEIPTS

Background:
Section 21.79 of Senate Bill 1005 directs the Divisions of Public Health and Mental Health/Developmental Disabilities/Substance Abuse Services to ensure maximum utilization of receipts from Health Choice, Medicaid, and other third party payors.

- ✓ HEALTH CHOICE
  To the extent possible, under state and federal legislation, Health Choice policies are consistent with Early Intervention policies in terms of covered services. The only early intervention services not covered by Health Choice are those specifically prohibited by state statutes. A remaining systems issue is that the number of children participating in both

Health Choice and early intervention is relatively small. To address this, a variety of public awareness activities are underway to ensure health care providers are aware of early intervention services and how to refer families to them:

1. Video and print information specifically targeted for physicians has been developed by the Division of Public Health in collaboration with the North Carolina Interagency Coordinating Council. Local interagency council members are delivering these materials to physicians in their communities.

2. Recently revised Health Choice Outreach materials also give referrals about how to refer families to early intervention.

✓ MEDICAID

North Carolina is frequently cited as an example of best practices in terms of communication and coordinating of effort between the Medicaid and early intervention agencies. However, there are a few remaining service areas where Medicaid coverage of early intervention is not the maximum allowed by federal Medicaid or early intervention regulations. Examples of this include:

1. When Health Departments provide child service coordination for children participating in early intervention, their reimbursement is not based on a per unit of delivered service amount as is the case with other Department of Health and Human Services agencies.

2. Some of the new service categories such as Community Based Services are not available to other Department of Health and Human Services public service provider agencies such as the Developmental Evaluation Centers and the early intervention services through the Schools for the Hearing-Impaired and the Governor Morehead School. The latter two components do not have an agreement with the Division of Medical Assistance to be a provider of other early intervention related services such as evaluation, child service coordination, and specialized therapies.

✓ INSURANCE

Currently insurance receipts are not a significant revenue source for early intervention in North Carolina as very few insurance plans cover early intervention services. This is a problem for families as well. Since it is allowable for fees to be charged to families when a family insurance policy does not cover early intervention related services, the family is often unable to participate because of the cost implications for them. In recognition of this problem, a number of states have recently revised their insurance legislation to include some degree of inclusion of early intervention services. Some of these states include Massachusetts, Virginia, Indiana, and Connecticut. This has increased access to early intervention as well as provided much needed non-state dollars for early intervention. In Fiscal Year 00-01, four others developed proposals to amend their legislation. Massachusetts, a state with roughly the same population as North Carolina, generated almost seven million dollars per year in insurance payments for early intervention. A similar effort in North Carolina is strongly recommended. In February, staff from the Division of Public Health and the North Carolina Interagency Coordinating Council met with Department of Insurance personnel to exchange information about different approaches to strengthening provisions for early intervention in state statutes. These efforts should be expanded with the goal of having some type of bill ready for consideration in the next long session of the North Carolina General Assembly.

GENERAL ASSEMBLY OF NORTH CAROLINA SESSION 2001

MAXIMIZATION OF RECEIPTS FOR EARLY INTERVENTION PROGRAMS

SECTION 21.79. The Department of Health and Human Services, Division of Public Health, area mental health, developmental disabilities, and substance abuse services programs, and local health departments shall maximize receipts for the evaluation and services provided by the Developmental Evaluation Centers and through Early Intervention programs. The Division shall maximize receipts from Health Choice, Medicaid, and other third-party payers. All receipts collected shall remain within the Division and shall be used to offset appropriations for operations of the Developmental Evaluation Centers and Early Intervention services.

Requested by: Senators Martin of Guilford, Dannelly, Metcalf, Purcell, Wellons, Plyler, Odom, Lee; Representatives Earle, Nye, Baddour, Esposito, Easterling, Oldham, Redwine, Thompson
(page 144, Senate Bill 1005, S1005-PCCS3926-E-1)

EVALUATION OF EARLY INTERVENTION SYSTEM

SECTION 21.85.(a) The Department of Health and Human Services, Division of Public Health, shall determine the reasons why children are waiting for evaluation services provided by the Developmental Evaluation Centers. The Division shall develop an action plan to reduce the waiting period for evaluation services.

SECTION 21.85.(b) The Department of Health and Human Services, Division of Public Health, shall determine the reasons why children and their families are waiting for services that follow the evaluation process. The Division shall identify the specific services that children are waiting for and develop a plan to address the waiting period.

SECTION 21.85.(c) The Department of Health and Human Services, Division of Public Health, shall assess ways in which to create efficiencies among the therapies that are provided within the Early Intervention Program, Children With Special Health Services program, and other programs. The Division shall also evaluate ways to combine early intervention services provided by the Developmental Evaluation Centers, regional therapists, local health departments, and area mental health, developmental disabilities, and substance abuse authorities to gain efficiencies.

SECTION 21.85.(d) Not later than December 1, 2001, the Department of Health and Human Services shall report to the Senate Appropriations Committee on Health and Human Services, the House of Representatives Appropriations Subcommittee on Health and Human Services, and the Fiscal Research Division on the assessment and plans of action for all of the above. The Department shall present a final report on the implementation of this section not later than April 1, 2002.

Requested by: Senators Martin of Guilford, Dannelly, Metcalf, Purcell, Wellons, Plyler, Odom, Lee; Representatives Earle, Nye, Baddour, Esposito, Easterling, Oldham, Redwine, Thompson
(Page 147, Senate Bill 1005, S1005-PCCS3926-E-1)

PUBLIC HEARING SCRIPT

A. BACKGROUND

2001 Session of the General Assembly called for a number of specific recommendations to be presented to them in the spring of 2002. These recommendations are to focus on key aspects of the early intervention system. Specifically they are:

- how best to integrate the efforts and early intervention services of the Health Departments, Area MH/DD/SA Programs, and the Developmental Evaluation Centers at the local level;
- how to respond to the growing number of referrals for evaluations specialized therapies and other early intervention services while reducing the amount of time the children are waiting for these services; and
- how to ensure we realize the maximum benefit of all types of third party receipts as a funding source for early intervention.

B. PURPOSE OF HEARING

The purpose of this hearing is to provide an opportunity for parents, staff from any of the early intervention agencies, professional and advocacy organizations, or other interested individuals to share their ideas and concerns regarding the above items.

C. HEARING FORMAT

We'll use our time to hear your ideas. We don't have the time, nor is it our purpose to present specific recommendations about "reorganization", or to debate the "pros & cons" of the ideas shared. We want to be sure we capture your ideas fully and completely.

D. HOW PUBLIC HEARING INPUT WILL BE UTILIZED

Today's input will be shared (*without editing*) with the management staff of the Early Intervention Branch of the Division of Public Health and the other early intervention agencies. It will be some of the data they will use as they develop the recommendations regarding early intervention.

E. SPECIFIC QUESTIONS TO ASK

- What do you see as the good points about how we currently organize and provide early intervention services at the community level?
- What, in your experience, are some of the things that are not working so well?
- If you were in charge of designing a community based early intervention system and if it could truly reflect how you felt about best practices, what would be the key features?

DEC Waiting List Information
January through September, 2001
Children from Birth through Age 5 years, for Evaluation Services

	January		February		March		April		May		June		July		August		September	
	Under 3	3 -- 5	Under 3	3 -- 5	Under 3	3 -- 5	Under 3	3 -- 5	Under 3	3 -- 5	Under 3	3 -- 5	Under 3	3 -- 5	Under 3	3 -- 5	Under 3	3 -- 5
ASHEVILLE	18	11	24	11	58	29	27	20	35	15	25	15	32	15	30	13	30	25
BOONE	14	18	19	25	20	23	23	21	18	13	14	33	10	19	12	14	17	15
CHARLOTTE	45	21	59	12	35	34	40	19	67	28	74	25	118	21	121	17	90	38
CONCORD	11	24	2	10	8	23	4	26	5	13	4	10	6	8	4	9	3	7
CULLOWHEE	9	5	14	9	26	6	20	9	23	4	26	4	15	3	18	4	15	13
DURHAM	58	43	62	35	85	39	76	33	66	33	52	45	49	28	51	38	56	27
ELIZABETH CITY	8	23	12	29	17	24	31	29	18	29	42	49	35	50	29	46	21	50
FAYETTEVILLE	42	47	35	42	45	59	73	58	76	53	80	77	54	58	41	47	29	35
GREENSBORO	47	80	54	109	51	121	56	119	68	125	62	127	63	93	49	81	53	62
GREENVILLE	121	85	116	92	91	84	98	77	82	78	96	86	89	57	83	55	82	56
MORGANTON	35	49	39	51	48	51	46	46	38	52	42	52	31	30	24	24	19	34
NEW BERN	3	49	10	34	5	84	10	30	49	58	53	60	49	75	43	25	55	77
RALEIGH	71	45	61	59	71	57	78	58	74	50	69	68	53	43	70	60	52	62
ROCKY MOUNT	28	40	32	30	29	33	54	26	28	26	26	24	34	22	21	29	22	30
SANDHILLS	27	11	28	24	40	28	38	27	28	20	32	24	74	47	78	42	75	48
SHELBY	3	4	3	4	6	4	8	7	12	20	10	12	2	4	10	15	5	8
WILMINGTON	43	49	33	60	35	51	71	51	71	52	39	40	32	36	34	43	42	27
WINSTON-SALEM	79	29	90	35	101	28	87	32	79	34	95	13	89	20	42	60	61	44
Totals (By Age Group):	**662**	**633**	**693**	**671**	**771**	**778**	**840**	**688**	**837**	**703**	**841**	**764**	**835**	**629**	**760**	**622**	**727**	**658**
Grand Total on Waiting List (by month)	**1295**		**1364**		**1549**		**1528**		**1540**		**1605**		**1464**		**1382**		**1385**	
	774	**Average Monthly Waiting List – Statewide, children under three years of age, January through September, 2001**																
	683	**Average Monthly Waiting List – Statewide, children three through five years of age, January through September 2001.**																

Specialized Therapies Waiting List Report 9-Nov-01

County	PT: UnMet	PT: UnderMet	OT: UnMet	OT: UnderMet	SLP: UnMet	SLP: UnderMet	SI: UnMet	Not on IFSP
Alamance	0	2	0	1	0	6	0	0
Alexander	0	0	0	0	0	0	0	0
Alleghany	0	0	0	0	0	6	0	0
Anson	5	0	1	0	8	0	9	9
Ashe	0	2	0	4	0	2	0	2
Avery	0	0	0	0	1	0	0	0
Beaufort	1	1	0	0	0	0	3	0
Bertie	3	3	2	2	9	0	8	0
Bladen	3	1	2	1	13	4	0	1
Brunswick	3	0	1	0	0	0	0	0
Buncombe	3	0	0	0	0	0	18	0
Burke	0	0	0	0	0	0	0	0
Cabarrus	0	0	0	0	1	0	0	0
Caldwell	0	0	0	0	0	0	0	0
Camden	1	0	0	0	1	0	0	0
Carteret	1	2	1	2	6	4	7	19
Caswell	0	2	0	1	0	6	0	0
Catawba	0	0	0	0	1	0	0	0
Chatham	0	0	0	3	0	3	0	1
Cherokee	0	3	1	3	1	1	1	2
Chowan	1	0	0	0	3	0	0	0
Clay	1	1	1	1	0	0	0	0
Cleveland	0	0	0	0	0	0	0	0
Columbus	0	0	0	0	2	0	0	0
Craven	6	4	2	4	10	0	8	0
Cumberland	4	0	2	0	20	0	18	18
Currituck	0	0	0	0	3	0	1	0
Dare	1	0	0	0	0	0	1	0
Davidson	0	9	7	0	0	0	0	0
Davie	1	0	1	0	1	0	0	0
Duplin	0	0	0	0	1	0	0	4
Durham	6	20	17	20	22	20	8	20
Edgecombe	0	0	0	0	0	0	0	5
Forsyth	1	0	2	0	6	1	0	0
Franklin	Reflected in Vance County numbers: VGFW reported globally, not by county.							
Gaston	0	0	0	0	0	0	0	0
Gates	1	0	0	0	1	1	3	0
Graham	1	1	1	1	2	0	0	0
Granville	Reflected in Vance County numbers: VGFW reported globally, not by county.							
Greene	0	0	0	0	2	0	4	0
Guilford	20	33	13	38	10	42	15	0
Halifax	0	0	0	3	5	1	0	5
Harnett	3	0	0	0	0	0	6	9
Haywood	2	4	5	14	0	0	3	4
Henderson	0	0	0	0	0	0	6	1
Hertford	1	0	0	0	0	2	3	0
Hoke	2	0	0	0	3	0	6	6
Hyde	1	0	1	1	3	0	0	0
Iredell	0	0	1	0	2	0	21	21

Appendix C

County	PT: UnMet	PT: UnderMet	OT: UnMet	OT: UnderMet	SLP: UnMet	SLP: UnderMet	SI: UnMet	Not on IFSP
Jackson	2	3	2	1	1	1	4	0
Johnston	3	16	14	28	16	38	12	8
Jones	2	0	2	0	0	2	0	0
Lee	2	0	0	0	7	0	9	9
Lenoir	6	0	3	0	5	0	0	9
Lincoln	0	0	0	0	0	0	0	0
Macon	2	1	1	2	2	2	2	4
Madison	0	0	0	0	0	0	3	0
Martin	0	0	0	0	3	3	3	0
McDowell	0	0	0	0	0	0	0	0
Mecklenburg	14	0	13	0	21	0	0	0
Mitchell	0	0	0	2	2	2	2	0
Montgomery	0	0	0	0	0	0	0	0
Moore	1	0	5	0	5	0	5	5
Nash	0	1	0	0	0	0	0	4
New Hanover	0	1	0	0	1	1	0	0
Northampton	0	0	0	0	0	0	5	0
Onslow	1	0	1	0	15	0	8	20
Orange	3	11	4	10	15	12	0	0
Pamlico	1	0	1	0	0	1	0	0
Pasquotank	3	0	1	0	5	0	0	0
Pender	0	0	0	0	0	0	0	0
Perquimans	0	0	0	0	1	0	0	0
Person	0	0	0	0	0	0	0	0
Pitt	11	5	13	5	5	5	0	0
Polk	0	0	0	0	0	0	0	0
Randolph	4	14	3	3	2	2	21	0
Richmond	1	0	3	0	4	0	12	12
Robeson	3	0	3	0	18	0	0	9
Rockingham	0	0	0	0	0	0	0	0
Rowan	1	0	1	0	0	0	0	0
Rutherford	0	0	0	0	0	0	0	0
Sampson	3	0	0	0	30	0	0	3
Scotland	2	0	1	0	5	0	7	7
Stanly	0	0	0	0	0	0	0	0
Stokes	5	0	2	0	0	0	0	0
Surry	0	2	4	0	1	6	0	0
Swain	1	3	3	2	1	0	1	3
Transylvania	0	0	0	0	0	0	8	0
Tyrrell	0	0	1	0	3	0	2	2
Union	1	0	1	0	2	0	0	0
Vance	1	2	1	2	0	1	15	12
Wake	5	54	35	52	22	70	48	20
Warren	Reflected in Vance County numbers: VGFW reported globally, not by county.							
Washington	1	0	0	0	4	0	3	3
Watauga	0	0	0	0	2	1	0	0
Wayne	0	0	0	0	6	2	6	0
Wilkes	0	6	0	6	0	4	0	2
Wilson	0	0	0	0	0	0	4	4
Yadkin	1	4	3	1	7	1	0	2
Yancey	0	0	0	0	0	0	3	1
Totals:	**152**	**211**	**182**	**213**	**348**	**253**	**332**	**266**

Early Intervention Birth to Five Child and Family Assessment Capacity and Practices Study

FOCUS:
To identify practical approaches to:
- Respond more quickly to the increasing number of referral for assessments of both infants-toddlers and preschoolers.
- Increase the quality, comprehensiveness, and functionality of assessments provided.

The scope of this initiative would encompass all of the infant-toddler and preschool agencies providing assessments: DECs, Area MH/DD/SAS Programs, Satellite Schools for Children with Hearing Impairments, Governor Morehead School, LEAs, and Regional TEACCH Centers.

FORMAT:
Phase I - Survey
- Questionnaire to all Consortia, LICC, and other collaborators (pre- and in-service training providers, NICU, research organizations, Family Support Network)
- Respondents would be asked to complete questionnaire as an interagency team.
- Questionnaire would focus on:
  - 9 local practices that are felt to be particularly effective
  - 9 gaps and unmet needs in capacity for assuring quality assessments for both infants-toddlers and preschoolers
  - 9 other recommendations for improving assessment practices
- Complete review of practices in other sites.
- Analyze and incorporate findings from previous system reviews: ICC Legislative Study, Part C Family Centeredness Study, DEC Models Report, ICC Parent Surveys, Community Review Process results, etc.

Timeframe: Survey out April 25
Results summarized May 25

Phase II – Focus Groups
- Complete 4-6, dispersed across the state with representatives in each from all the involved agencies and substantial participation by families.

Timeframe: May 5 through May 20

Phase III – Site Visitations
- National experts would carry out visits to 4-6 communities to review practices.

Timeframe: June 1-13

Phase IV – Development of Recommendations and Action Plan
- Participants would include the Steering Committee (See recommended composition.) and a group of national experts.
- They would review the information from the surveys, site visits, other resource documents, and the focus groups.
- The national experts and the Study Coordinator would then develop recommendations.

- The national experts, along with the Steering Committee, would develop a specific action plan to implement the recommendations and an evaluation process to assess state progress towards the action plan.
- Elements of the action plan would include, but not be limited to:
  - 9 changes identified in existing practices to improve responsiveness and quality
  - 9 concomitant pre- and in-service training
  - 9 identification of other, already existing fiscal resources that could be added to the funding base for al agencies carrying out assessments
  - 9 determination of levels of need for new fiscal resources

Timeframe: June 14-15

Steering Committee Composition:
- ✓ DEC Directors (3)
- ✓ Area Program Early Intervention Director (1)
- ✓ LEA Preschool Director (1)
- ✓ Governor Morehead Preschool Representative
- ✓ Satellite Preschool for the Hearing Impaired Representative
- ✓ Division of Early Intervention and Education Infant-Toddler Program Manager
- ✓ Division for Exceptional Children Preschool Consultant
- ✓ Parent/ICC Representative (3)
- ✓ Division TEACCH Representative
- ✓ Representative of Early Childhood Community: NCAEYC, NC Partnership for Children

Possible National Experts:
Susan Moore – University of Colorado
Judy Niemeyer - UNC Greensboro
Mark Wolerly – UNC Chapel Hill
Emily Fenichel – Zero to Three
Others to be designated

Project Coordinator:
Mary Boat, PhD
Department of Human Services
Western Carolina University
828-227-3280
mboat@wcu.edu

Summary of Findings (July 2000):
Early Intervention Child and Family Birth to Five Assessment System Capacity and Practices Study

I. Strengths
- A. DECs, unavailable in many states are an excellent resource for assuring that all children referred to early intervention receive appropriate evaluations and appropriate levels and types of early intervention services.
- B. They provide very comprehensive, interdisciplinary services.
- C. They are a very productive service in regard to the levels and types of services provided given personnel available.
- D. Their impact in the community goes far beyond child assessment and evaluation. They provide a focal point for related activities such as child find, community needs assessment, professional development, family support services, and quality assurance.

II. Priority Areas for Ongoing Improvement
- A. More assessments should be carried out in natural environments such as homes, NICUs, child care centers, etc.
- B. Enhancing cultural competence is needed given the state's rapidly changing demographics.
- C. Increase the role of families in planning and providing assessments.
- D. Statewide standards for the types of services to be available through each DEC (i.e., audiology) should be established and implemented.
- E. The Consortium is the foundation of North Carolina's interagency approach to early intervention and should be maintained. Guidance and training should be provided on approaches to expediting procedures for children who will always be eligible such as those with Down Syndrome or sensory impairments.
- F. Provide technical assistance and other support to enable all DECs to be a resource for evaluation and intervention approaches for children with low incidence disabilities, vision and hearing impairments, autism, and child mental health.
- G. Develop active partnership with Neonatal Intensive Care Units (NICUs) to expedite evaluation and assessments for children served here.
- H. Develop common interagency forms such as applications and consent forms that can be used by all public and private provides to minimize duplicative experiences by both families and professionals.
- I. Identify other potentially available existing resources and new resources needed to ensure that infants, toddlers, and preschoolers can be evaluated within federal timeframes in all communities and to increase capacity to assess additional children related to the 0-5 service delivery goals.
- J. Integrate assessment and ongoing early intervention services at the community level.

III. Action Plan
- A. Broaden membership of ICC Cultural Diversity Committee to include DEC representation and plan and implement enhanced cultural competence training through this group.
- B. Include funds for additional interpreter services in expansion budget request.
- C. Establish an interservice, interagency Work Group to develop specific strategies and professional development activities.
- D. Broaden membership of DEC Clinical Committee to develop recommendations. (Initial possibilities include audiology, nutrition, pediatrics, and professionals with expertise in infant mental health issues.)

E. Develop through the Infant-Toddler Initiatives Committee, supplemental guidance.
F. Maintain Project LINK in the East and develop an additional replication site in a DEC in one other region.
G. Identify other funds for therapy time so some of the existing DEC staff and other agency personnel can serve as mentors.
H. Use planned 8/30-31, 2000 Statewide Conference and follow-up agency Directors' Planning Session to identify best practices and areas where procedures need to be revised.
I. Identify additional resources to contract with NICUs for components of the entry-level evaluation.
J. Utilize existing interagency group established by the Family, Infant, and Preschool Program to develop specific forms.
K. Include funds for both age groups in the expansion budget request.

Implementation Note: There are examples of exemplary practices in each of these areas throughout the DEC and broader early intervention system. Part of the solution will be to disseminate information from DECs and other early intervention providers throughout the Infant-Toddler and Preschool Programs.