

## Part III – Application Narrative

### **(a) Need for Project (20 Points)**

#### *Scope and Description of the Structure of the New York State Early Intervention Program*

The New York State Early Intervention Program (NYSEIP) under Part C of IDEA is one of the nation's largest early intervention service delivery systems for infants and toddlers with developmental needs and their families. December 1st child count data available from the U.S. Department of Education, Office of Special Education Programs (OSEP), indicate that New York State (NYS) currently provides Part C early intervention services to more children birth to three years of age than *any other state in the nation*. On December 1, 2002, there were 35,997 children with IFSPs in NYS (nearly 5% of *all* children ages birth to three years in the State) in comparison with 26,876 children in California, and 20,296 children in Texas – both states with significantly more children in this age group. New York State also provides early intervention services to more children than states that provide these services to at-risk children (such as Hawaii, Massachusetts, Indiana, and Florida)(see Appendix B). During the 2002-03 Program Year (July 1 – June 30), early intervention services were provided to more than 74,000 infants and toddlers and their families in NYS at some time during the year. The costs associated with the NYSEIP are also substantial, estimated at more than \$650 million across all sources of funding (State and local funds, Medicaid, and commercial insurance) for the 2001-02 Program Year (the most complete cost data currently available).

The NYSEIP is a statewide collaborative effort among the State, municipalities (fifty-seven counties and New York City), service providers, and families. The New York State Department of Health (NYSDOH) has been the Lead Agency for the Part C Early Intervention Program since the State joined the Federal program planning process in 1987. State legislation enacted in 1992, effective July 1, 1993, authorized a statewide early intervention service system consistent with all federal Part C requirements and designated the NYSDOH as the Lead Agency responsible for state-level administration and oversight of the State's comprehensive early intervention service delivery system.

The NYSDOH's many responsibilities in this capacity include: promulgating and maintaining regulations, policies, and procedures for the service delivery system; establishing standards for NYSEIP providers and approval and re-approval of these providers; rate-setting for early intervention service delivery; monitoring and supervision of all organizations and individuals involved in the delivery of NYSEIP services; provision of training and technical assistance to improve and enhance the quality of the service delivery system; and, collection and analyses of data with respect to the State's early intervention system.

NYS Public Health Law also delegates significant responsibilities to the State's fifty-seven counties and New York City (which has oversight for its five counties) for local administration of the program. Local responsibilities include: maintaining a child find system; developing Individualized Family Service Plans (IFSPs) for eligible children and their families; contracting with and reimbursing State-approved NYSEIP providers for the delivery of early intervention services; seeking reimbursement for early intervention services from third party payors and from the NYSDOH for the fifty percent State share of costs not covered by third party payors; and, collecting and reporting data on the

NYSEIP to the NYSDOH.

In the early years of the NYSEIP, the NYSDOH focused on establishing a statewide infrastructure for the early intervention service delivery system, including the development of reimbursement rates, program regulations, a statewide data system, administrative policies and procedures, and training and technical assistance. During the past five years, the NYSDOH has engaged in a number of efforts to enhance state-level oversight and improve the quality of the NYSEIP, including: development and maintenance of systems to monitor and enhance the quality of early intervention services; development of a series of evidence-based clinical practice guidelines on assessment and intervention practices for the NYSEIP; issuance of administrative guidance and maintenance of a regionally-based training delivery system; and, development of a request for proposals (RFP) to design and implement a new, state-of-the-art data management system for the NYSEIP (to be known as New York State Early Intervention System – NYEIS).

These efforts, and the increased costs associated with the NYSEIP, have resulted in a growing recognition of the critical need for a statewide, systematic approach to the collection and analyses of data necessary to evaluate the extent to which meaningful outcomes are being achieved for children and their families through participation in early intervention services. The imperative for enhanced Part C child and family outcome data for NYS is also motivated by internal and external forces with a vested interest in the quality and effectiveness of the State’s Part C early intervention system, including: at the national level, the U.S. Department of Education and Congress; the NYS Governor’s Office and NYS Legislature; families involved in the NYSEIP and their service providers; the State interagency coordinating council (NYS Early Intervention Coordinating Council (EICC)); and, payors of early intervention services (including the localities and State, Medicaid, and commercial insurers).

*Status of Current Data Collection System*

Since the inception of the NYSEIP, the NYSDOH has supplied municipalities with a software application, known as “KIDS” (Kids Integrated Data System). KIDS is a distributed, DOS-based application designed to assist in local management activities; and, to collect and periodically transmit data to the State on child and family demographics and NYSEIP service delivery and payment system. Although this legacy system provides a substantial amount of data for local and NYSDOH management purposes, it has significant limitations. Current data collected through KIDS include basic demographic information on the children and families participating in the EIP; basis for eligibility; and, basic service delivery dimensions (such as the types of services authorized (e.g., special instruction, speech language pathology), service settings, length of stay, and exiting data). Only very limited data are currently available with respect to child outcomes, and there are no data collected statewide with respect to family outcomes, that can be attributed to early intervention services.

Data are collected and maintained by municipalities, with quarterly uploads of these data to the NYSDOH (which maintains a central repository of NYSEIP data for analyses for program management and reporting purposes). There is no user-interface for providers or families with the data system: all data are entered by county staff (posing resource, efficiency, and data quality issues). In summary, although NYSDOH has access to substantial data regarding the NYSEIP, no specific data are collected on

specific intervention methods or child and family outcomes being achieved through Part C services.

To address the data systems limitations, the NYSDOH will use a competitive bidding process to procure the services of a contractor to design a new, centralized early intervention information system (NYEIS). NYEIS will be built using state-of-the-art technology and will fully integrate databases for the NYSEIP into one, statewide information system for the NYSEIP. When implemented, NYEIS will provide access to real-time data on all aspects of the service delivery system. NYEIS will also be designed to include user interfaces for providers, as well as municipalities, to improve on the quality, accuracy, and timeliness of data available on the NYSEIP. A request for proposals for NYEIS development will be issued in August, 2004, and selection of a contractor for systems design and development will be made by early 2005. Design and development of the data system will take approximately eighteen months, with full, statewide implementation and use of NYEIS by municipalities and providers within three years.

The contract for systems design and development of NYEIS will be supported through Part C Formula Grants allocated to the NYSDOH as the State's Part C lead agency.

However, the NYSDOH relies on Part C Administrative Grants from OSEP to support the totality of State administration for this multi-million (approaching one billion) dollar service delivery system. The National IDEA Infant and Toddlers Coordinators Association estimates that NYS currently receives \$750.58 per child from OSEP for administration of its early intervention service delivery system, one of the lowest amounts per child across all states and territories (range = \$474.25 (Hawaii) to \$8,365.42 (Marianas)). including local administration, State staffing, the statewide comprehensive monitoring system, training and technical assistance, development and publication of clinical practice guidelines, child find and public awareness, and respite services.

Additional funds available through the IDEA General Supervision Enhancement Grant, Focus 2, are needed to develop a Part C Outcomes System for the NYSEIP.

A three-phase project is proposed to develop a Part C outcomes system for the NYSEIP. Given the scope of the NYSEIP, a Part C outcomes system for the NYSEIP will contribute not only to the State's, but to the nation's, collective knowledge of the value of early intervention services for young children with developmental needs and their families.

The proposed project builds upon the efforts of the OSEP-funded Early Childhood Outcomes Center and NYSDOH's success in developing six clinical practice guidelines for the NYSEIP on the assessment and intervention with young children in early intervention systems. The project will be synchronized with the NYSDOH planned efforts to secure a contract to design the new centralized early intervention data collection and management system (NYEIS). Results of the proposed project, if funded, will be used to ensure that NYEIS incorporates the necessary data elements to analyze and report on both OSEP-required child and family outcome indicators; and, on child and family outcome indicators uniquely tailored to the NYSEIP (and which could be used by other states).

The NYSEIP Part C outcomes system will also rely, to a certain degree, on the NYSEIP comprehensive monitoring system. The NYSEIP monitoring system is a data driven system that involves the collection of data using child record reviews and review of

municipal and provider policies and procedures. Currently, the monitoring system focuses on regulatory compliance. We plan to expand our monitoring system to also include a clinical and quality improvement component. The proposed project will assist us in identifying those child and family outcomes, outcome indicators, and measures that can best be implemented through a centralized data system (NYEIS); and, those that may be more effectively implemented through collection of data through our statewide monitoring system.

**(b) Project Design (25 Points)**

The April, 2004 report, “Considerations Related to Developing a System for Measuring Outcomes for Young Children and Their Families”, issued by the Early Childhood Outcomes Center (the ECO Center) funded by the U.S. Office of Special Education Programs (OSEP), provides an excellent framework to assist states in the process of developing outcome systems for their Part C early intervention systems. The ECO Center report identifies preliminary decisions made by OSEP with respect to key the national Part C outcomes system to be developed by the ECO Center, including:

- The ECO Center’s approach to develop a national Part C outcomes system will proceed along two tracks: a “fast-track” to identify a small set of outcomes to be reported by all states to meet immediate need for information by the federal government for the Government Performance Results Act and Program Assessment Rating Tool; and, “slower track” to support the development of a more comprehensive set of outcomes to meet the needs of states and localities (some or all of which will be optional to states).
- OSEP is proposing that a common set of outcomes be used for all children, but has also decided that a common assessment (i.e., measurement) will not be required.

Because terms such as “outcomes” and “indicators” can have different meanings, the ECO Center has also proposed the following set of common definitions, which are being adopted by NYSDOH for use in this proposed project. In addition to these definitions, the NYSDOH will apply the principles for Part C outcomes systems articulated by the ECO Center to guide the NYSEIP outcomes system development project (see Appendix C).

Although this application focuses on Part C outcomes, and is not being jointly submitted by the NYSDOH and the NYS State Education Department, our two agencies collaborate closely on implementation of the early intervention and preschool special education systems under IDEA. Both agencies are committed to, sharing data and information (to the extent permissible by State and federal law and regulations) to assess child developmental and functional gains achieved through early intervention and preschool special education; and, the impact of early intervention services on the need for special education and related services as children enter preschool and continue with their education as children and youth (see Appendix F, Letters of Support).

NYS is the only state in the nation that has used an *evidence-based approach* to develop clinical practice guidelines on recommended assessment and intervention with children in the NYSEIP (see Appendix D for a brief description of the initiative). These guidelines provide evidence-based consensus recommendations on assessment and intervention practices for *the vast majority of serious developmental problems* seen in children from birth to three years of age in the New York State early intervention service

delivery systems. Of the children in the NYSEIP *with a diagnosed condition* with a high probability of developmental delay, 47% have a specific condition addressed by one or more of the guidelines (e.g., autism, Down syndrome, etc); and an additional 38% have related conditions (dyspraxia (24%) and extreme prematurity (14%)). Of the children *with developmental delays only*, 89% have a delay involving communication and/or motor development. NYSDOH's experience in guideline development uniquely positions us to develop an outcomes system that will: provide information to improve the quality of NYSEIP services; use measurement techniques to collect outcomes data that reflect high standards of validity; and, make research-based decisions about the NYSEIP Part C outcomes system with input from experts and key stakeholders.

## **Methodology**

The NYSDOH is proposing a three-phase project to develop a Part C outcomes system for the NYSEIP that will meet Federal, State, and local information needs on the child and family outcomes attributable to Part C early intervention services. Parents of children involved with the NYSEIP and who participated in the guideline development process will be actively recruited to participate in all phases of the project. A project website will be used to solicit input from a wide variety of key constituents, including parents of children in the NYSEIP who have participated in NYSEIP-sponsored "Partners in Policymaking" training sessions (more than 700 parents to date statewide – see Appendix F, Letters of Support) and parents on the State Early Intervention Coordinating Council and local early intervention coordinating councils (LEICCs). Each phase of the project is described in detail below.

### **Phase I – Development of Child /Family Outcomes, Outcome Indicators, and Measurements**

Phase I builds on our experiences and success in developing six peer-reviewed, evidence-based clinical practice guidelines on assessment and young children in early intervention systems. NYS Clinical Practice Guidelines on the Assessment and Intervention with Young Children with Autism/Pervasive Developmental Disorders, and Clinical Practice Guidelines on the Assessment and Intervention with Young Children with Communication disorders were published in 1999. Four additional guidelines, addressing assessment and intervention with young children with Down syndrome, motor disorders, vision impairment, and hearing loss are in publication and will be released in the Fall/Winter, 2004. We credit this success to the use of following approach in guidelines development: (1) we identified and applied a well-established, research-based methodology to develop the guidelines; (2) we contracted with methodologists and consultants who were experts in the area of guideline development, child development, and early intervention; (3) we convened consensus panels comprised of parents, researchers, and expert clinicians were convened to develop the guidelines; and, (4) we ensured key constituents, including members of the State Interagency Coordinating Council (the Early Intervention Coordinating Council), had opportunities throughout the process to provide input on the process and content of the guidelines.

A similar approach is proposed to develop child and family outcomes, outcome indicators, and measurements for the NYSEIP Part C outcomes system. A sole source contract will be established with Concepts System, Inc. (CSI), (see Appendix E, Letter of

Commitment to Contract, CSI president) to use concept mapping and pattern mapping methodology (CMPM) (Trochim, 1989a; 1989b; Trochim, Dupont and Campbell, 1993; Kane and McMahon, Trochim, 2002; Milstein, et.al. 2003) to work with NYSDOH leaders, project staff, national consultants, an expert group comprised of professionals and parents who participated in the guidelines development process, and representatives of key constituents (i.e., *the NYSDOH Part C Outcomes Project Team*), to develop proposed child and family outcomes, outcome indicators, and measures for a NYSEIP Part C outcomes system. The firm will also evaluate the success of the project (see Phase III) as part of their contractual agreement. Concept Systems, Inc., (CSI) is woman-owned small business located in Ithaca, New York, that consults with a wide variety of public and not-for-profit organizations in using CMPM for program evaluation and systems planning. Concept mapping and pattern mapping methodology is a coherent, systematic, rigorous, defensible, and useable methodology that combines group processes, internet data collection methods, and rigorous analysis to guide and implement the planning process; and, to evaluate the results of the planning process by comparing outcomes of the planning process with data collected in the field.

CSI is the owner and sole licensor of The Concept System software suite and the only organization with CSGlobal web-based participation, which enables participation in a project anytime and/or anywhere to increase the reach and access to decision-making levels for participants. Concept Systems, Inc, will supply the Concept System software suite, manage a CSGlobal NYSEIP Part C Outcomes project website, and provide expert assistance to the NYSDOH Part C Outcomes Project Team in preparation, planning, and execution of all aspects of Phases I and III. The Concept Systems software was developed specifically for application of concept mapping, and can be used with groups in live sessions and/or as a web-based application that can be used to involve key constituents in the development process. The NYSDOH intends to use a combination of both of these strategies for this project.

Trochim et. al. (2004) describe concept mapping as an approach to planning and evaluation that integrates qualitative group processes with multivariate statistics, to assist a group in describing its ideas on any topic of concern and represent group consensus visually using a map. The typical process involves requiring participants to brainstorm and/or rate a large set of statements on the topic of interest (for example, in our case, child and family outcomes), individually sort items for similarity, rate statements on one or more dimensions (e.g., how likely the outcome is to be affected through intervention), and interpret maps that result from data analyses (Trochim et. al., 2003). Statements on topics of interest can also be gleaned through existing documents for rating by participants and development of concept maps. We anticipate that for this project, the statements for rating will be derived both using brainstorming techniques and through use of the six evidence-based clinical practice guidelines.

A CSI expert facilitator will guide and manage the concept mapping process for the NYSEIP outcomes systems development project. CSI will work extensively with Department leaders, project staff, and national consultants to prepare and decide upon how the concept mapping methodology will be used with an expert group and key constituents for this process. The content, interpretation, and use of the resulting concept map(s) will be determined by the Department leaders, project staff, national consultants, and expert group.

We intend to establish an expert group, selected from among the 20 parents and 62 professionals who participated on guideline consensus panels, to complete the initial work on the development of child and family outcomes, outcome indicators, and proposed measures. The expert group will also be asked to identify parameters of interventions that should be collected through the outcomes system to fully understand the impact of intervention services on child and family outcomes. The group will include representatives from each guideline panel, will be multidisciplinary in its composition, and will include no fewer than four parents. This group will work with a facilitator, NYSDOH leaders and project staff, and national consultants to develop a proposed set of child and family outcomes, outcome indicators, and measures.

The CSGlobal project website will be used to obtain input on the proposed child and family outcomes, outcome indicators, and measures from key constituents (municipalities, EIP providers, and *families/parents of children in the EIP*), particularly on the dimensions of relevance, importance, and feasibility. There are various options related to the nature and timing of the involvement of key constituents in the concept mapping process. For example, the web-based application could be used with both key constituents and the expert group in the generation and rating of child and family outcomes, outcome indicators, and measures. The results from each of these groups could then be compared and used with the expert group to complete its work to finalize proposed child and family outcomes, outcome indicators, and measures for field testing. Alternatively, statements could be generated by the expert group and then rated by key constituents. The results of these ratings could then be compared and used to develop the final set of proposed outcomes, outcome indicators, and measures for field testing (Phase II). The exact approach for use of the CIGlobal project website will be decided upon by NYSDOH leaders and project staff, in consultation with CSI, national consultants, and two representatives of the expert group.

Three meetings will be convened with the expert group, and one meeting with selected representatives of key constituents (families, providers, and municipalities) to complete Phase I. In addition to the CSI facilitator, NYSDOH leaders and project staff will participate in meetings of the expert group and key constituents. National consultants will participate in the first and last meetings of the expert group, to offer consultation and provide a national perspective on child and family outcomes, outcome indicators, and outcome measurements for the NYSEIP outcomes system.

#### *Phase II – Field Test of Child and Family Outcomes, Outcome Indicators, and Measurements*

For Phase II of this project, a contract will be procured with an organization with extensive expertise and experience in research methods to develop and field-test methods to collect and analyze data using the results of Phase I of this project (e.g., proposed child and family outcomes; measurements; and, outcome indicators). Three NYS counties, and a subset of providers selected in conjunction with each of the municipalities, will be recruited to participate in Phase II. National consultants from the ECO Center will also be accessed to provide consultation to the NYSDOH leaders, project staff and the contractor on the design and implementation of the field test.

The key purposes of the field test will be to assess the feasibility of the measurements identified in Phase I to assess child and family outcomes; and, to address the measurement questions, analytic issues, and logistical issues with respect to

implementation of a NYSEIP outcomes system. The contractor will be responsible for development of a data collection protocol, collection of the data (either through a record review process or collaboration with each site to collect data on a sample of children and families currently in the NYSEIP), data entry and data analyses. The contractor will be required to prepare a final report on the field test, including data analyses and recommendations on key implementation questions, including: feasibility and limitations of proposed measures; periodicity of data collection; training needs of municipalities and providers to implement measurement strategies; sampling methodologies; data collection methods for ongoing use in the NYSEIP outcomes system; and, statistical analyses to derive Part C outcome indicators. The contractor will be expected to work with CSI, the NYSDOH Part C Outcomes Project Team and national consultants in the Phase III/project evaluation finalize recommendations for design and ongoing implementation of the NYSEIP Part C outcomes system.

Finally, the contractor will be asked to analyze and provide recommendations on the extent to which other existing data sets may be useful in measuring Part C child and family outcomes; and, possible methods for linkages with other data sets. The NYSDOH is particularly interested in linkages with data available from State and national data systems.

#### *Phase III – Project Evaluation and Final Recommendations*

In Phase III, CSI will work with the contractor for Phase II and NYSDOH Part C Outcomes Project Team to evaluate the project. Phase III will result in a set of final recommendations to the NYSDOH on implementation of a statewide outcomes system and will be the basis of the project evaluation, and is described in detail under *(d) Project Evaluation*.

#### **(c) Management Plan (10 Points)**

The budget for this project includes a full-time Project Manager who will report to the Project Director and who will be responsible for ensuring that the objectives of the proposed project are on-time and within budget. A person loading chart identifying responsibilities of the Project Director and Project Manager can be found on pages 19-20. Recruitment for this position will begin immediately upon receipt of grant notification.

A sole source contract will be established with Concept Systems Inc. (CSI) for Phases I and III of this project should the grant be funded. The contract with CSI will include a detailed project plan for Phases I and III of this effort. The NYSDOH will be required to comply with competitive bidding rules to establish a contract for Phase II of this project. As part of this procurement process, the prospective will be required to provide a detailed work plan, including timelines and milestones for accomplishing project tasks. Phase II of this project will be dependent on the timely and successful completion of Phase I, and this will be articulated in the bidding process and contract with the successful contractor.

#### **(d) Project Evaluation (20 Points)**

Concept Systems, Inc (CSI) will be responsible for evaluating the success of the NYSEIP outcomes system project. CSI will also provide guidance on the Phase II field

test, to ensure that the content and structure for field-testing data aggregation is useful and consistent with the project at large. CSI will be asked to examine the quality of the field test and provide an objective opinion about the recommendations developed by the contractor in Phase II with respect to the measurement, analytic, logistic, and infrastructure design aspects of the NYSEIP outcomes system. CSI will work with the NYSDOH Part C Outcomes Project Team and the contractor selected for Phase II field testing, using concept mapping and concept matching methodology for this evaluation effort.

The project evaluation will focus on the following questions: (1) How successful was concept mapping methodology in helping NYSDOH leaders, project staff, the expert group, and key constituents to reach on child and family outcomes, outcome indicators, and measurements the NYSEIP outcomes system? (2) Were the Part C outcomes, outcome indicators, and measures identified Phase I successfully operationalized and field-tested? (3) Were the concept map(s) from Phase II used successfully to develop and implement data collection protocols? and, (4) Do the data resulting from Phase II confirm the expectations of the project team and/or assist the team in refining child and family outcomes, outcome indicators, and outcome measures for statewide implementation?

CSI will prepare, plan, and convene a meeting with the full project team (NYSDOH leaders, project staff, expert group, key constituents, and contractors/contractor staff for Phases I and II of the project) to review the results of the evaluation and refine recommendations on child and family outcomes, outcome indicators, measures, and data collection methods. The project evaluation will yield a recommended data collection protocol and recommendations to the NYSDOH for incorporation and implementation of an outcomes system within the new NYSEIP data system under development (NYEIS) and the statewide monitoring system. CSI will prepare a final report to the NYSDOH detailing the results of the project evaluation.

#### **(e) Project Personnel (15 Points)**

##### *Key Project Personnel*

The Project Director for this project is a Developmental Psychologist with 15 years of experience within the NYSDOH Early Intervention Program. She has served in leadership positions in the NYSEIP since 1989, and of particular relevance to this project, was responsible for the development of the six clinical practice guidelines produced by the NYSDOH for the NYSEIP. She currently serves as Co-Part C Coordinator and Director of Clinical and Policy Services and is funded full-time on the NYSDOH Part C formula grant. Dr. Noyes' in-kind contribution to the project will be a minimum of 15%.

A Project Manager will also be recruited and hired for this project and will report to the Project Director. NYSDOH and HRI recruitment and contracting practices promote the employment and advancement of individuals with disabilities.

A Person Loading Chart, which was developed based on a 210 day work year and estimates the amount of time to be allocated by the Project Director and Project Manager to project activities, can be found on pages 19-20 of this application.

In addition, the Acting Director of the Early Intervention Program and Part C Coordinator will have an integral role in this project. She supervises the Project Director

and has responsibility for overall management and direction of the NYSEIP. Other NYSDOH leaders who will be involved in providing guidance for this project include the Director of the Division of Family Health (a pediatrician); and the Director for the Center for Community Health. Vitae for these individuals can be found in Appendix G.

*Qualifications of Project Consultants or Subcontractors*

The NYSDOH has secured and budgeted for consultation services from the OSEP-funded ECO Center. Dr. Michael Guralnick, Director, Center on Human Development and Disability, University of Washington, who served as a consultant to the NYSDOH on the clinical practice guidelines project has agreed to consult with the NYSDOH on this effort (see Appendix F, letters of support). Concept Systems, Inc., will manage Phases I and III of the project and will provide guidance on Phase III. CSI has extensive experience with both Federal, State, and not-for-profit organizations in program evaluation and systems planning projects, including the Centers for Disease Control; the National Cancer Institute's Division of Cancer Control Planning initiatives; American Cancer Society; and, many State Departments, including State of Hawaii Department of Public Health and the New York State Department of Labor Workforce Develop Plan for Adults with Disabilities (see Appendix E for Letter of Commitment, Project List, description of the methodology, and vitae for key personnel). The NYSDOH has also secured a commitment from Dr. Judith Gravel and Dr. Raymond Romanczyk to assist in the NYSDOH Part C Outcomes Project Team in this effort (Appendix F – Letters of Support and Appendix G - Vitae).

With respect to Phase II, New York State has three university-affiliated programs and a myriad of universities and consulting firms that may be potential bidders in this effort. Appendix H includes a comprehensive list of all of the parents and professionals who participated in the development of the NYSEIP clinical practice guidelines, and from among whom the expert group for Phase I of this project will be selected.

NYSDOH and HRI recruitment and contracting practices promote the employment and advancement of individuals with disabilities.

**(f) Project Resources (10 Points)**

The NYSDOH/Health Research Institute has a substantial infrastructure to support this project, including facilities, supplies, and other resources that will be needed for implementation. The project budget in Part II of this application describes use of funds to support recruitment of staff and basic office equipment, meeting expenses, travel expenses, expenses associated with national consultants, and procurements for contracts necessary to implement the project. NYSDOH will provide in-kind support for the Project Director (15%) and travel reimbursement for key constituents to participate in meetings required for Phase I and III.

The NYSDOH will support the ongoing implementation of the NYSEIP outcomes system through its Part C Administrative Grants. In particular, the outcomes system will be implemented as part of the design and development of NYEIS - the planned, new statewide data system for the NYSEIP; and, the NYSEIP comprehensive monitoring system. The NYEIS procurement involves a multi-million dollar commitment of Part C funds for design and development. Part C funds will be used to support updating, maintenance, and operation of NYEIS. Part C funds are also used to support a multi-

million dollar monitoring system for the NYSEIP. Finally, the NYSEIP training delivery system will be used as a vehicle to provide training and technical assistance to municipalities, providers, and families with respect to measurement and data collection needed for the NYSEIP outcomes system.

## **Appendix C – Early Childhood Outcomes Center – Definitions and Principles**

### **Definitions**

- **Outcome:** A statement of a measurable condition(s) desired for the population of children with disabilities or their families (e.g. “children show physical and motor competence”).
- **Indicator:** A measure or metric that serves to quantify whether the outcome has been obtained (e.g., an assessment of motor skills).
- **Measure or measurement:** The method or tool used to collect the data for the indicator (e.g., a survey or specific assessment).
- **Evidence statement:** A statement that incorporates a statistic and provides evidence as to whether or not an outcome has been achieved (e.g., the percentage of children showing gains in motor skills).
- **Outcomes system:** A process for regular collection, analysis, reporting, and use of indicator data. The ECO Center, April 2004, “Considerations Related to Developing a System for Measuring Outcomes for Young Children with Disabilities and Their Families”, pg 3 and pg 6.

### **Principles**

- The outcomes system will provide information to improve programs for young children with disabilities and their families.
- The outcomes system will do no harm to young children with disabilities, their families, and the programs that serve them.
- What is measured by outcomes systems will be aligned with the goals for Part C and 619.
- The outcomes system must reflect a state and federal partnership that meets the needs of both partners insofar as possible.
- Universal design principles will be followed to the maximum extent possible in the design of the outcome system.
- Measurement techniques employed to collect outcomes data will reflect high standards of validity and reliability.
- Major decisions about the outcome system will reflect (1) best practice as determined by research and (2) input from key stakeholders.
- To the maximum extent possible, the outcome system will not add undue burden to families, providers, or local or state administrators.

## Appendix D – NYSEIP Clinical Practice Guidelines Initiative

### **Brief Description of the Clinical Practice Guideline Effort**

In 1996, the New York State Department of Health's Early Intervention Program (NYSDOH-EIP) began a multi-year project to develop evidence-based clinical practice guidelines focused on identification, assessment, and intervention for young children with developmental problems likely to require early intervention services. The overall goal of the clinical practice guidelines project was to improve the quality and consistency of care for young children with developmental problems, by providing families, service providers and public officials with recommendations about best practices based on scientific evidence and expert clinical opinion. Specific objectives of the guidelines were to: *improve knowledge* about care for young children with developmental problems by providing families, professionals and government officials with accurate background information and evidence-based recommendations on assessment and intervention; *enhance communication* among all those involved with early intervention services (parents, professionals and EIP administrators) when deciding upon assessment and intervention approaches, and in monitoring the child's progress; *improve developmental functional outcomes* for young children with developmental conditions and their families; and, *facilitate program evaluation and quality improvement efforts* by defining appropriate outcomes measures and quality criteria for early intervention services; and, *promote research* by identifying gaps in current knowledge about the care of young children with developmental disabilities.

The NYSDOH-EIP convened multidisciplinary panels of clinicians and parents, assisted by a research and methodology staff, to develop separate clinical practice guidelines for infants and young children with the following developmental conditions: autism/pervasive developmental disorders (PDD) communication disorders, Down syndrome, hearing impairment, motor disorders and vision impairment. The attached table provides an overview of the composition of each consensus panel, with respect to the number of parents on each panel and number of representatives from professional disciplines involved in the delivery of early intervention services.

All six clinical practice guidelines have now been completed. The guidelines on autism/PDD and on communication disorders were published in 1999, and have been widely disseminated to public early intervention officials, service providers, parents and others associated with the State's EIP (NYSDOH, 1999a; NYSDOH, 1999b). Training on the use of these guidelines for professionals and parents has been ongoing. The remaining four clinical practice guidelines are currently in press and will be issued in the Winter, 2004. The Department has planned for ongoing training opportunities for parents and professionals on the use of all six guidelines in decisions regarding assessment, intervention, and monitoring of children's progress, through its statewide regionally-based training system.