

Research and Training Center on Service Coordination

Annual Report

December 2002

**University of Connecticut
A.J. Pappanikou Center for Developmental Disabilities
263 Farmington Avenue, MC 6222
Farmington, Connecticut 06030**

Appendices

Appendix A: Conference call notes and meeting minutes

Appendix B: Part C survey with cover letter

Part C survey data report

Part C listserv results

Fiscal report

Supplemental Activity—service integration survey table of responses

Appendix C: Parent leader survey (English and Spanish)

Parent leader survey data report

Parent ICC telephone survey protocol

Parent ICC data report

Family guide

Appendix D: Curricula training survey data report

Curricula report

Service coordination policies and models report

Appendix E: Focus group protocol (outcomes)

Satisfaction questionnaire

Recruitment and invitation letters

Focus group protocol – facilitating guide (practices)

Appendix F: Delphi protocol (outcomes)

Delphi instrument and coverletters (outcomes)

Delphi data tables (outcomes)

Supplemental activity 2.14 data

Valued outcomes paper – theme list

Delphi protocol (practices)

Delphi instrument and coverletters (practices)

Appendix G: Parent survey

Parent survey protocol

Article

Appendix H: Family Interview Protocol

Service Coordinator Protocol

Family Interview Data Chart

Service Coordinator Data Chart

Comparison of Family and Service Coordinator Outcomes

Appendix I: Website, brochure

Newsletters

NASDSE brief

Appendix J: Outcomes

I. PROJECT SUMMARY

Service coordination is critical to the implementation of Part C of the Individuals with Disabilities Education Act (IDEA). Unfortunately, numerous studies and state evaluations have indicated that service coordination is the least satisfying area of service delivery for families and service providers. The Research and Training Center on Service Coordination (RTC) uses both quantitative and qualitative methods to conduct a series of descriptive and intervention (experimental) studies that will lead to the development of promising practices in the provision of effective service coordination. There are three strands of activities for the center: families, service providers, and system administration. Members from these groups participate in all center activities. These strands are interrelated into six objectives of the center; each designed as a separate component. The objectives are:

1. Describe the current models of service coordination across the nation.
2. Identify the outcomes of effective service coordination.
3. Describe the recommended practices for effective service coordination.
4. Measure effective and accessible service coordination through the use of new methodology and the use of existing tools.
5. Validate components and practices required for effective service coordination.
6. Disseminate information about center activities and products.

The center uses both national samples and specific sites within states to meet these objectives. Four target states (Connecticut, North Carolina, Indiana, Massachusetts) were

selected as primary sites for project activities. Additional states will be selected for specific activities at a later time. This will ensure the distribution of families, service coordinators, and administrators that differ according to:

- Geographic location throughout the United States.
- Place of family residence (i.e., urban, suburban, rural).
- Family socioeconomic background.
- Family structure.
- Family cultural background and ethnicity.
- Child disability and severity of developmental delay.
- State system.

The center is a partnership of four agencies, one in each of the four focal states:

University of Connecticut A.J. Pappanikou Center for Developmental Disabilities, University of North Carolina at Chapel Hill, Indiana University, and the Federation for Children with Special Needs in Massachusetts.

II. PROJECT STATUS

Personnel

At the University of Connecticut Health Center, Mary Beth Bruder is the principal investigator, Kathleen Whitbread is the project coordinator, Cynthia Mazzeella is the data manager, and Deborah Bubela and Rhonda Thompson are research assistants. Renee Roselle is a graduate assistant. Christine Jozef and Heather Nilson assist with website development and publications editing. At the University of North Carolina at Chapel Hill, Gloria Harbin is the co-principal investigator. Project investigators include Carl Dunst of The Orelena Hawks Puckett Institute and Michael Conn-Powers of Indiana University.

Consultants in three of the four focal states assisted in the planning and facilitation of focus groups. They included Janet Price of the Federation for Children with Special Needs in Massachusetts, Nancy Gordon in North Carolina, and Julie Das (year two only) in Indiana. In addition, Sue Mackey Andrews assisted with the study of financial aspects of service coordination. During year two, consultants in three of the four states conducted interviews with families and service coordinators. They were Kathy Klingerman in Indiana, Nancy Gordon in North Carolina, and Phoebe Teare and Janet Price in Massachusetts. Beginning in year three, Sara Miranda from the Federation for Children with Special Needs joined the project as the site coordinator for the Federation.

Since the start of the project in December 1999, there have been a number of staff changes. In July 2000, Kathleen Whitbread was hired as the full-time project coordinator, replacing Gabriela Freyre-Calish, who had been assigned to the project as a part-time (less than .5 FTE) coordinator from December 1999 through June 2000. In August 2000, Alissa Zolad

replaced Candace Reynolds as the full-time research assistant. Michael Conn-Powers began the first year of the project on a personal service contract; this was changed to a contract with Indiana University beginning in the second year of the project. At the start of the project, Glenn Gabbard was a co-principal investigator and was employed by the Federation of Children with Special Needs in Massachusetts. Mr. Gabbard joined the staff of the University of Connecticut Health Center/A.J. Pappanikou Center full time in August 2000. In August 2001, Mr. Gabbard reduced his time at the center to one day (.20 FTE) per week but remained on the Research and Training Center project as a co-principal investigator. In January 2002, Mr. Gabbard left the Health Center and the project.

Management

The center's team meets at least monthly via conference calls to discuss development and progress of project activities. Team members share documents through electronic mail (e-mail) and e-mail newsgroups. Agendas for conference calls reflect current project activities. For example, during the development of the Part C survey, the team included Sue Mackey Andrews and Maureen Greer from the Part C Association. During planning stages for focus groups, Part C coordinators from Connecticut, North Carolina, Indiana, and Massachusetts helped develop a recruitment strategy for each state. Other conference call agenda items have included recruitment for the parent leader survey, data entry and storage, timeline reviews, survey return rates, and updates on specific project activities. Scheduled conference calls, telephone calls, and e-mail contacts keep team members informed and actively involved in project activities.

Since the project began, six meetings have been held in Connecticut:

- During the first meeting (Dec 16 and 17, 1999) discussion focused on development and dissemination of surveys and methodology for the national focus groups. Gloria Harbin, Mary Beth Bruder, Glenn Gabbard, Carl Dunst, Candace Reynolds, Christine Jozef, and Gabriela Freyre-Calish attended the first meeting.
- The second meeting (April 12 and 13, 2000) addressed the refinement of focus group methodology following the national focus groups. Gloria Harbin, Mary Beth Bruder, Glenn Gabbard, Janet Price, Candace Reynolds, and Gabriela Freyre-Calish attended this meeting.
- A third meeting was held on September 21 and 22, 2000, and focused on a preliminary review of data, a discussion of Results Mapping, and an overview of activities for year 2. Participants included Gloria Harbin, Mary Beth Bruder, Glenn Gabbard, Janet Price, Kathleen Whitbread, Cindy Mazzarella, Nancy Gordon, Michael Conn-Powers, Alissa Zolad, Heather Nilson, Tamara Hechtner-Galvin, and Linda Stroud.
- A fourth meeting was held on January 29 and 30, 2001. The agenda included preparation for the annual National Early Childhood Technical Assistance System (NECTAS) Project Directors meeting and a review of the protocol for the next round of focus groups, which will result in recommended practices as related to outcomes of effective service coordination. Participants included Mary Beth Bruder, Michael Conn-Powers, Glenn Gabbard, Gloria Harbin, Celeste Jorge, Cindy Mazzarella, Heather Nilson, Kathleen Whitbread, and Alissa Zolad.

- The fifth meeting, held on August 1, 2001, focused on training in the protocol and scoring procedure for the family and service coordinator interviews. Participants included individuals who would be conducting interviews: Glenn Gabbard, Kathleen Whitbread, Cindy Mazarella, Alissa Zolad, Phoebe Teare, Kathy Klingerman, Jenn Root, Nancy Gordon, and Marisol Cruz St. Juste.
- The sixth meeting was held on March 18 and 19, 2002, and included a data review and a discussion of proposed training strategies for year 3 of the project. In attendance were Mary Beth Bruder, Michael Conn-Powers, Gloria Harbin, Ruth Ann Rasbold, Sara Miranda, Bonnie Keilty, Cindy Mazarella, Lynda Pletcher, Nancy Gordon, Deb Bubela, and Kathleen Whitbread.

In addition to project meetings, there have been three meetings of the Research and Training Center Advisory Board. The Advisory Board includes individuals with a broad range of professional and personal expertise, including family members who have been served by early intervention systems. Board members are knowledgeable experts with extensive experience in early intervention research, training, and service delivery. Advisory Board meetings have focused on a review of the center's work and recommendations regarding the proposed work plan.

The first Advisory Board meeting was held on July 10, 2000, in St. John, Virgin Islands. During the session, the Board reviewed the overall work scope for the project. Project investigators reported on the status of ongoing studies of Part C systems, parent leader perceptions of service coordination, and training approaches. Board members then participated in the focus group methodology used to generate outcome statements for high quality service

coordination. The Board offered feedback on the effectiveness of the methodology; they also offered perspectives on various aspects of the studies. Because timelines for completing data collection for the four studies extended beyond the date of the board meeting, the Board suggested ideas for analysis and dissemination to consider once the studies were complete.

The second meeting of the Board was conducted on June 29 and 30, 2001, in St. John, Virgin Islands. Board membership was expanded to include a representative of the national Part C Association; additional participants included consultants to the project. On Friday, June 29, each of the project investigators presented various aspects of their work. An overview of the project work for year 1 was outlined and detailed highlights of the completed studies of Part C administrators, training curricula, and parent leaders were presented. Outcomes of the study of child and family outcomes, conducted by Carl Dunst, were also reviewed. The Board then reviewed and commented on the outcomes work conducted in the four focal states as well as progress made toward meeting goals and objectives for year 2. Objectives include the production of written guides developed from the studies of Part C statewide policies, the study of parent leader perceptions, and information taken from the survey of training curricula in various states. The group reviewed dissemination strategies, ranging from the project website to newsletters and pending articles. They provided detailed responses to the research methodologies employed by the project and offered perspectives on continuing to reach a broad, diverse constituency. On Saturday, June 30, the Board was asked to review proposed training strategies for year 3 of the project and to offer opinions about optimal approaches for identifying target audiences for training and ongoing systems change in the four focal states.

A third Advisory Board meeting was held on October 24 - 26, 2002 in St. John, Virgin Islands. On Friday, October 25, the group met to review accomplishments of years 1 and 2 and

to discuss objectives for year 3 including the Delphi practices study and current available Delphi data. Project staff reviewed reasons Results Mapping and Outcome Engineering were not utilized as data collection methods for family/service coordinator interviews. The final family and service coordinator interview protocols were reviewed. Mary Beth discussed issues with data analysis, including recruitment of underrepresented families for interviews, and the decision to transcribe all family and service coordinator interviews to ensure reliability. The group discussed proposed dissemination activities followed by a discussion of results of the site visit in Washington, DC. Mary Beth reviewed a draft of the Site Review Report, which was provided by the review panel for the purpose of the Advisory Board Meeting. The document itself could not be shared, but general points and recommendations were shared with Advisory Board members.

On Saturday, October 26, Board members and project staff broke into small groups to discuss the project's future agenda including validation studies and training protocols. See Appendix A for a copy of conference call notes and meeting minutes.

Objective 1.0 – To describe the current status of Part C service coordination models

Activity 1.1 - Design surveys

Two surveys were designed. The Part C coordinator survey provided a national description of service coordination. The center worked collaboratively with the Part C Association as well as consultant Sue Mackey Andrews to design the survey. A meeting was held with members of the Part C Association at the NECTAS conference (January 2000) to increase awareness of the center and its first set of activities, including the Part C survey. The officers of the Part C Association who represent the center's focal states, as well as coordinator

Ron Benham, consultant Sue Mackey Andrews, and the principal investigators, discussed the design and timing of the Part C survey. Coordinators from three of the focal states (Greer, Munn, and Benham) piloted the survey in draft form and made recommendations regarding survey design. The survey was sent to the Part C coordinator in each of the 57 states and territories. In addition to the survey, each state was asked to provide information on training curricula for service coordinators. See Appendix B for a copy of the Part C survey with cover letter and curricula survey.

Data from the parent leader survey provided a description of families' perceptions of their state's model of service coordination. The parent leader survey included a combination of 51 items distributed over nine pages, combining both open- and closed-ended questions. Twenty-nine items were closed-ended, including 22 Likert-scale questions with 7 multiple-choice items. Participants were asked to write short responses to 22 open-ended questions, which gave participants the opportunity to amplify or clarify their responses to closed-ended items.

Items were grouped in seven categories: (1) system entry, (2) evaluation and development of the IFSP, (3) service provision, (4) transition, (5) training, and (6) collaboration. The final cluster of questions (7) focused on general commentary regarding the quality of service coordination and its relationship to identified family and child outcomes. Participants were also asked to complete a brief demographic questionnaire.

A draft version of the family survey was piloted in Pennsylvania to obtain recommendations from a representative sampling of parent leaders in that state. Reviewers were asked to respond to the overall scope of the survey, the clarity of the language used, and the degree to which the survey was "family friendly." Responses from the pilot reviewers were

integrated into a final version of the survey, which was sent to parent leaders in each state and territory.

A “parent leader” was defined as an individual who:

- Had a child with a disability who had received Part C services.
- Was knowledgeable about the experiences of other families with Part C services and supports.
- Understood the state system of service coordination and how it affects the families that it is designed to serve.

And/Or

- Had served in a formal or informal leadership capacity on the local, state, and/or national level.

The National Interagency Coordinating Council (ICC) Parent Leadership Support Project, housed at the Federation for Children with Special Needs, initiated contact with parent leaders from across the country using its database of ICC parent leaders and participants in its leadership institutes and related activities. Because the population of parents engaged in Part C leadership activities is in constant flux, staff expanded the pool of initial contacts by contacting:

- ICC chairs for each state.
- Key parent leaders from each state and territory, including parent staff liaisons.
- The Federal Interagency Coordinating Council (FICC), including the Family Empowerment Committee.

- Key parent training and information centers with active programs related to Part C services and supports.
- Family Voices regional coordinators.
- Parent leaders who have attended the national OSEP Part C and 619 meetings.
- Statewide Parent-to-Parent coordinators.
- State Part C personnel engaged in working with families.

Solicitation of participants included postings on listservs that targeted parents who were engaged in the policy arena, including the ICC Parent Leadership listserv, the Family Voices listserv, Our-Kids listserv, and the FICC listserv. These recruitment strategies expanded the database of parent leaders to over 1100 individuals representing each of the states and jurisdictions. Since nominations were received at different times, four rounds of surveys were mailed out within a three-month period. Project staff provided telephone follow-up for states with limited return rates. The parent leader survey was presented to Spanish-speaking families in Spanish. See Appendix C for a copy of the English and Spanish parent leader surveys plus a copy of the survey data report.

In January 2001 a telephone survey was conducted as a follow-up to the parent leader survey to gather additional information from families across the country. The decision to undertake the follow-up survey was made after data from the original parent leader survey indicated that respondents did not have critical and basic information about service coordination models in their states. The survey, completed in February 2001, targeted parent

leaders in 50 states who were serving on ICC boards. Participants were selected through recommendations of state ICCs, Part C coordinators, or ICC staff liaisons.

The survey contained 23 closed- and open-ended questions in the following six areas:

1. Demographics.
2. Awareness of federal regulations related to service coordination.
3. Perceived awareness of other stakeholders' knowledge of federal regulations related to service coordination.
4. Descriptions of statewide models of service coordination and perceptions of how well these models served families.
5. Perceived awareness of ICCs within the respondents' states and the degree to which they address service coordination issues.
6. Perceived outcomes of service coordination.

See Appendix C for a copy of the protocol for the Parent ICC telephone survey plus the survey data report.

Activity 1.2 - Type/Print surveys

The final Part C and parent leader surveys were typed and printed in March 2000, incorporating information gathered from the pilot surveys.

Activity 1.3 - Mail surveys

The Part C survey was distributed as an e-mail attachment the week of April 17, 2000, to the Part C coordinators. The Part C Association and consultant Sue Mackey Andrews recommended e-mail as the preferred method of distribution. The survey was mailed or faxed to coordinators unreachable by e-mail.

The parent leader survey was distributed in four rounds. Along with the survey, each recipient received a cover letter from the principal investigators and a self-addressed stamped envelope to facilitate return of the completed survey.

- Round one was mailed on May 16, 2000, to 347 families across 25 states.
- Round two was mailed on May 23, 2000, to 229 families across 25 states.
- Round three was mailed on June 2, 2000, to 123 families across 13 states.
- Round four was mailed on June 27, 2000, to 107 families across 14 states.

Activity 1.4 - Follow-up calls for surveys and curricula

Follow-up for the Part C survey was conducted through telephone calls and e-mail. An e-mail message was distributed to the Part C Association listserv on May 17, 2000, thanking the first 16 states for returning their surveys and informing the remainder of the states that they would be receiving a telephone call to discuss methods of facilitating the return of their surveys. Subsequently, follow-up telephone calls were made to each state and territory that had not submitted a survey.

Following the first round of e-mail messages and follow-up telephone calls, four additional states submitted completed surveys. A second e-mail message was posted to the Part C Association listserv thanking the 20 states for returning their surveys promptly. After persistent follow-up, eight additional states returned completed surveys. A third e-mail was sent to the Part C Association listserv on May 30, 2000, extending thanks to the 28 states and territories that returned completed surveys.

Between May 30 and October 30, 2000, telephone contact and e-mail reminders from center staff and the principal investigators continued, resulting in a total return of 55 Part C surveys by the end of October. All 50 states and five of the seven territories completed and returned surveys. An average of three to four contacts was made to each state and territory before receiving a completed survey.

Two of the four focal states (Massachusetts, Indiana) completed pilot surveys and were mailed additional questions from the final version of the survey for completion. Two focal states (North Carolina and Connecticut) completed the final version of the survey.

Following the four rounds of parent leader survey mailings, reminder letters were mailed to all families who received a survey. The first reminder letter was mailed in early July 2000. A second reminder letter, which included a copy of the survey, was mailed in early October 2000. Additional strategies used to encourage returns included reminders to key stakeholders via personal telephone calls, e-mails, and via the ICC parent listserv, sponsored by NECTAS and the National ICC Parent Leadership Project. A total of 319 surveys were received, for a return rate of 40%. Fifty parent leaders, representing each of the U.S. states, participated in the follow-up telephone survey.

Activity 1.5 - Enter survey responses

Survey responses were entered into SPSS as they were received. Fifty-five Part C surveys and 319 parent leader surveys were received and entered by December 30, 2000. Fifty telephone surveys were conducted. Curricula data were collected from 53 states and territories. Data were entered into a computerized database (SPSS for quantitative data, MS Word for qualitative input and coding).

Activity 1.6 - Data analysis: surveys

Analysis of the Part C survey data and parent leader survey data was completed in November 2000. Analysis of the follow-up parent leader telephone survey was completed in February 2001.

Part C survey. Descriptive statistics (means, standard deviations, frequencies, and percentages) were used to describe the data of the Part C survey from the 50 states and the District of Columbia. In addition, conceptually similar items were categorized in order to better understand and describe broader types of values and service coordination approaches.

Findings included:

- Thirty-nine Part C coordinators reported a lack of uniformity in how service coordination was provided in their state.
- A regional approach to service coordination was used in 36 states.
- Caseloads for service coordinators ranged from 9 to 70 with a mean of 38.

- Seventeen states were in the process of changing their model of service coordination.

A full data report for the Part C survey may be found in Appendix B.

Supplemental activity. One of the findings of the Part C survey was that few states have models of service coordination that cross agency lines such as Temporary Assistance for Needy Families (TANF), Women, Infants, and Children (WIC), or Title V. To learn more about this aspect of service coordination, a question was posted on the Part C Association listserv in October 2001 to request information from Part C coordinators on state approaches to service integration. The question posted was:

The Research and Training Center in Service Coordination is trying to identify things that work in Part C service coordination/integration. Can anyone provide examples of exemplary models of service integration for children and families across programs and agencies (TANF, WIC, Title V) in the context of Part C? We are looking for both local and state examples and we intend to interview key stakeholders in these models.

Nine states responded to the survey question. One response was a request for more information about the RTC project. The remaining eight responses described programs or initiatives in the planning stages or existing programs that were working to improve service integration. The following quote is representative of the responses received:

I believe we have some great first steps toward integration both at the local and state level. We are working very hard to integrate all of the programs that touch children with special needs, emphasizing Part C, Title V, a high risk infant follow-up program, and a program which tracks and links infants at risk to appropriate programs and services.

None of the states recommended a program that they felt was exemplary. See Appendix B for a table of all responses.

Parent leader survey. Descriptive statistics (means, standard deviation, frequencies, and percentages) were used to formulate the results of the closed-ended items. Two independent raters categorized qualitative responses by generating a set of themes, which were tested and refined through recursive review to ensure category independence. Initial coding was conducted and when inter-rater reliability reached 80% or higher, final coding was begun. The project coordinator monitored the validity of the results and assessed reliability. Findings included:

- Twenty-six percent (26%) of the families didn't learn who their service coordinator was until after the IFSP meeting.
- Thirty-six percent (36%) of the parents felt that service coordination was very helpful in providing the services and supports their family needed.

- Thirty-eight percent (38%) of parents believed that service coordination was extremely effective in developing IFSPs that were responsive to the needs of children and families.

A full data report for the parent leader survey is in Appendix C.

Parent ICC survey. Frequencies were calculated to report the results of the closed-ended items. Qualitative data were reviewed for recurring themes. Findings included:

- Sixty percent (60%) of the ICC parent representatives considered themselves familiar with the federal regulations related to service coordination.
- Sixty-four percent (64%) of the respondents said that their ICCs were familiar with the federal regulations for service coordination.
- Forty-eight percent (48%) of the respondents stated that they were not sure if their state had a specific model for service coordination.

The parent ICC survey report is found in Appendix C.

Activity 1.7 - Data analysis: content analysis of curricula; data analysis of fiscal policies

Each state was asked to provide information on their curricula for training service coordinators. Data were collected through telephone interviews, e-mail questionnaires, and content analysis of training materials. Each Part C coordinator was asked to identify the person responsible for training in their state, and that individual was asked to respond to the following four questions:

1. Does your state have separate standards (requirements) for service coordinators as compared to other service providers?
2. What type of training does your state use to train service coordinators?
3. How do you know if the service coordinators have acquired the information from training (is there follow-up)?
4. Do you have any training materials you might send us?

Curricula information was received from 55 states and territories. Data revealed that:

- The average length of service coordination training in 37 states was between two and three days.
- Twenty states mandated service coordination training.
- Nearly half of the states (47%) were in the process of revising or developing service coordination training curricula.

The full curricula training survey data report may be found in Appendix D.

An analysis of fiscal policies was completed in March 2001 by Sue Mackey Andrews, which combined information from the Research and Training Center Part C survey and parent leader survey along with data from a separate national survey sponsored by the IDEA Infants and Toddler Coordinators Association. These studies had been closely coordinated to avoid duplication. These data were used to develop a report on service coordination policies and models, which may be found in Appendix C.

Activity 1.8 - Write up family guide

A family guide, summarizing the results of the parent surveys, has been written and appears in Appendix C. This guide includes a set of recommendations for improving service coordination based on the results of parent surveys.

Activity 1.9 - Write up curricula guide

A curricula report has been written which includes a summary of data collected on service coordination training as well as recommendations for designing and delivering service coordination training. The report is included in Appendix D.

Activity 1.10 - Write up finance guide

Sue Mackey Andrews and Gloria Harbin completed a fiscal report, which contains a summary of the types of funding sources used to finance service coordination in all fifty states and the District of Columbia. The report includes recommendations for families, service coordinators, and program administrators. Please see Appendix B for a copy of this report.

A report on service coordination typologies has been completed and is included in Appendix D. It was anticipated that these typologies would be used for comparison purposes by states (and our center) to identify states with similar typologies. Specifically, it was hoped that data from the Part C survey would enable comparison between survey results and state models of service coordination. However, data from the Part C survey revealed over 20 typologies, making it unlikely that comparison between states would be helpful. The

typologies paper was routed to selected Part C coordinators and administrators, including Ron Benham, Maureen Greer, Duncan Munn, and Linda Goodman for feedback. Generally, it was felt that while the information was helpful in describing the current status of service coordination throughout the U.S., the concept that all states would fit into clear and identifiable typologies has not proved true.

Objective 2.0 – To describe outcomes of effective service coordination, including those associated with family, service provider, and system administration, across a diversity of state models, families, and family locations.

Activity 2.1 - Identify samples

There were two identified samples for this study: national and state. The national sample included families, Part C coordinators, and ICC chairs. The state sample includes families, service coordinators, program administrators, childcare providers, and physicians in four focal states (North Carolina, Massachusetts, Indiana, and Connecticut).

Activity 2.2 - Develop protocol

The Research and Training Center team met in Connecticut on April 12 and 13, 2000, to design the questions and methodology for focus groups. A combination of the Focused Conversation and the Workshop Methods developed by the Institute of Cultural Affairs (ICA) was used. The Focused Conversation Method is a process that enables a conversation to flow from surface level facts to more in-depth personal beliefs about a topic. A facilitator leads the conversation through a series of questions at four levels:

1. The Objective Level involves questions related to facts.
2. The Reflective Level involves questions that evoke immediate personal reactions.
3. The Interpretive Level involves questions that draw out meaning and values.
4. The Decisional Level involves questions that enable the group to make a decision about the topic discussed.

The Workshop Method is based on a natural decision-making process. This process consists of five steps:

1. Set the context
2. Brainstorm
3. Categorize
4. Name categories
5. Evaluate the work

Following the national focus groups, the focus question was adapted to prioritize outcomes of effective service coordination associated with children, families, and the early intervention system. A satisfaction questionnaire asked participants to evaluate the content of the focus group questions and facilitation, to make suggestions for future focus groups, and to identify their preferred method of being updated on the progress of the project. See Appendix E for a copy of the protocol and satisfaction questionnaire.

Activity 2.3 - Recruit samples

A national sample of Part C coordinators and ICC chairs was recruited through letters and follow-up telephone calls. The letter was mailed to all Part C coordinators and ICC chairs identified by NECTAS. The national families' sample was recruited through a letter from the Parent Leadership Project at the Federation of Children for Special Needs in Boston. See Appendix E for a copy of the national recruitment letter.

Recruitment of samples for the focal states' focus groups was coordinated with each state's Part C coordinator. A diverse group of participants was recruited from urban, rural, and suburban settings in each of the focal states. An introductory letter was sent to all prospective participants by a member of the Research and Training Center team and endorsed by the state's Part C coordinator. See Appendix E for a copy of the target states' recruitment letter.

In Connecticut, an invitation to participate in focus groups was mailed to all 39 program administrators. Follow-up calls were made to explain center activities and to invite program administrators to participate. In collaboration with the Part C coordinator, 468 invitations were mailed to families and 118 to recent (1998-1999) graduates of service coordination training. Parent support groups were contacted to generate interest in the project and solicit participation. Program administrators assisted in the identification of service coordinators/service providers; 385 invitations were mailed to individual providers across the state. Staff attended regional Birth-to-Three meetings to explain center activities and recruit focus group participants. Invitations were distributed at those meetings. A flyer was designed for childcare providers and a letter for physicians. A mailing list of all childcare providers was created in collaboration with the Department of Social Service Childcare Inclusion Training Project. The mailing list for physicians was created in collaboration with the Medical Home Project. Invitations for

childcare providers and physicians were mailed the first week in June 2000. See Appendix E for a copy of the letters and invitations for all groups.

In Indiana, over 400 letters were sent to families with labels provided by the Part C coordinator. Two articles were posted in regional childcare newsletters. The First Steps coordinators in Marion County and Monroe County invited project staff to participate in board meetings and provided mailing lists. An article was printed in the Marion County First Steps family newsletter. The system point-of-entry intake coordinator provided a list of 12 contacts, all of which agreed to participate in a focus group.

Eight hundred letters were mailed to service providers/administrators. For childcare providers, an announcement was included in newsletters for three regions. Childcare trainers provided contacts at two community colleges that work with childcare providers working on their CDA/AA. Initial contact with physicians was done through a letter. A state First Steps consultant offered to schedule focus groups for service coordinators. See Appendix E for a copy of the recruitment letters.

In Massachusetts, the Early Intervention Training Center helped facilitate connections with stakeholders and recommended effective recruitment and marketing strategies. The Massachusetts Part C coordinator was an active consultant in recruitment efforts. The Massachusetts Early Intervention Consortium (MEIC) was instrumental in orchestrating participation and providing physical space for focus groups. The National ICC Parent Leadership Project assisted in recruitment through its newsletter and connections with local leaders.

For program directors, a personalized letter was faxed to each of the 65 early intervention programs throughout the state. Center activities were described and a flyer distributed at the annual statewide conference of the MEIC. Directors also received telephone calls explaining center activities and inviting them to the focus groups.

For service providers, program directors in the northeast region received a telephone call to explain the center's activities and to solicit nominations of essential service providers to participate in focus groups. For the western region, the MEIC offices were helpful in soliciting participation for service providers in the central and western regions of the state. Service providers participating in any of the training activities of the early intervention training center were asked to participate in focus groups. As an incentive to participate in the focus groups, the EITC agreed to award competency credits for certification for their participation. A request of nominations for participation was distributed at the statewide ICC meeting.

For families, a call was placed to each of the early intervention directors in the northeast region of the state to explain center activities and solicit nominations of family members who might participate in the focus groups. For the western region, the MEIC offices were helpful in encouraging participation by family members in the central and western regions of the state. The statewide parent liaison for the Department of Health provided names and contact information for parents who participated in the statewide parent leadership project as well as key parent leaders. Representatives from parent advisory councils were consulted to solicit participation and generate interest in the project and its activities.

The Massachusetts Family Network, a statewide organization providing training and technical assistance to families regarding childcare, helped locate childcare providers. Early intervention directors were helpful in identifying networks of providers who were invited to

participate. The Regional Childcare Resource and Referral offices were consulted in different areas of the state. The Part C coordinator was consulted about statewide contacts for physicians. See Appendix E for a copy of the letters and invitations for the groups.

In North Carolina, due to the occurrence of focus groups for another project, the Part C coordinator and the coordinator for Child Service Coordination decided not to begin focus groups for this project until June 2000. They were concerned that it would be confusing to conduct focus groups with different purposes, while using the same stakeholder groups. The counties targeted for participation were identified in collaboration with the Part C coordinator and the coordinator for Child Service Coordination. These state policymakers identified counties for each level of population density (i.e., rural, suburban/small town, urban).

Two criteria were used for each level of population density: 1) counties that were judged more successful in service coordination, and 2) scattering locations across the entire state. Since program administrators were contacted directly, their focus groups were first. This allowed time for service coordinators to be recruited by program administrators and for families to be recruited by the Family Support Network.

For program administrators, the Part C coordinator and coordinator of Child Services Coordination identified program administrators in each of the selected counties and contacted them regarding the focus groups and to request participation in the study.

For service coordinators, program administrators in early intervention and the Child Service Coordination Program in the targeted counties were asked to submit a specific number of service coordinators. Urban areas were asked to submit 8-10 service coordinators; suburban/small towns were asked to submit five; and rural areas were asked to submit five.

Program administrators then distributed focus group invitations to selected service coordinators.

For families, the local Family Support Network in Charlotte, Greenville, and Henderson recruited families from different social, cultural, and socioeconomic groups and ensured that there was diversity regarding the types and disabilities of the children. The Family Support Network distributed a letter of invitation to selected families. Each Family Support Network was asked to nominate and invite 20 families.

For childcare providers, three organizations that work with childcare providers were each asked to nominate eight community childcare providers. The three organizations are:

- Partnerships for Inclusion, a statewide technical assistance program to facilitate the inclusion of children with disabilities in community programs.
- A program in which public health nurses go into childcare settings.
- A childcare organization that provides technical assistance to childcare centers across the state.

Every effort was made to recruit both center-based and home-based childcare providers. For physicians, the director of Maternal and Child Health in North Carolina contacted the chair of the Pediatric Society to obtain the support and participation of the society. See Appendix E for detailed information about North Carolina focus group recruitment and facilitation.

Activity 2.4 - Plan focus groups

In Connecticut 13 focus groups were scheduled between April and October 2000 across different geographical areas throughout the state. In Indiana 14 focus groups were scheduled between June and November 2000 across different geographical areas throughout the state. In Massachusetts 11 focus groups were scheduled between June and November 2000 across different geographical areas throughout the state. In North Carolina 11 focus groups were scheduled between June and November 2000 across different geographical areas throughout the state. See Appendix E for a schedule of focus groups in the four target states.

Activity 2.5 - Implement focus groups

At the national level, focus groups were held at the NECTAS Part C meeting at the end of January 2000. There were four focus groups, one for ICC chairs, one for families, and two for Part C coordinators.

In Connecticut the following focus groups were held:

- Two program administrator
- One regional manager
- Three service coordinator
- Two childcare provider
- Three family
- Two physician (one group contained a participant who was not a physician and data from that group will not be included)

In Indiana the following focus groups were held:

- Three program administrator
- Three service provider
- Three service coordinator
- Three childcare provider
- Five family (two focus groups contained less than the requisite number of participants and will not be included)

In North Carolina the following focus groups were held:

- Three program administrator
- Three service coordinator
- Five family (two focus groups contained families whose children were over 3 years of age and will not be included)
- One physician
- One childcare provider

In Massachusetts the following focus groups were held:

- Three program administrator
- Three service coordinator
- One childcare provider
- Three family

Family focus groups in Indiana and North Carolina were rescheduled several times due to lack of attendance, and the final family focus group occurred in February, two months later than planned. Physicians' focus groups did not occur in Indiana or Massachusetts due to the difficulty of recruiting participants. The total number of childcare focus groups per state was reduced from three to one due to difficulty soliciting participation.

Activity 2.6 - Collect and analyze data

Consumer satisfaction data were collected from national and state focus groups. The survey scale ranged from strongly disagree (1) to strongly agree (5) with six satisfaction statements (three specific to content and three specific to facilitation). Data collected from the national focus groups revealed that participants were highly satisfied with the content of the sessions as well as the facilitation. Data collected from the four focal states were similar to national data.

Nearly 400 participants in 47 focus groups generated an initial set of 250 outcomes of high quality service coordination. A Delphi method was selected as the best means of prioritizing these outcomes. A Delphi study approach draws on the collective wisdom of knowledgeable "experts" who are highly conversant about the topic or issue for which consensus is desired. The technique involves a series of "rounds" of data collection in which panel members are polled separately, with each person's opinion having equal weight in the process of reaching consensus.

The approach used in this study differed from typical Delphi applications in one important way. Whereas the method generally involves a small number of expert respondents,

we purposely included a large number of respondents (all focus group participants) with diverse experiences with regard to the implementation of service coordination. The survey targeted the following six stakeholder groups: families, service coordinators, service providers (in Indiana only), program administrators, childcare providers, and physicians. Outcomes generated in focus groups were transcribed into alphabetized lists. Two staff members of the center independently reviewed each data set to eliminate redundancies and to ensure that all outcomes were stated as single item outcomes (e.g., “happy and healthy families” became “happy families” and “healthy families”). Differences were resolved by a group review of the outcomes, which was overseen by the project coordinator.

Activities 2.7 and 2.8 - Develop and distribute Delphi measures within state

All outcome lists for each stakeholder group were coded by state, enabling center staff to group outcomes across stakeholders within states. Each focus group participant received a survey formulated from the list of outcomes unique to their state (e.g., all participants in all stakeholder groups in Massachusetts).

Outcomes were listed alphabetically with directions appearing across the top instructing respondents to rate the outcomes according to a five-point scale ranging from “not at all desirable” to “extremely desirable.” Participants were invited to make any wording changes deemed necessary to improve the meaning of the outcome.

Outcome lists were mailed to focus group participants with a cover letter describing the Delphi process, a stamped self-addressed envelope, and instructions to return the list in five working days. State Delphi surveys were distributed to Connecticut, Massachusetts, and North

Carolina on January 23 and to Indiana on March 7, 2001. Cover letters and Delphi instruments appear in Appendix F.

Activities 2.9 and 2.10 - Develop and distribute Delphi measures across target states

Following completion of all focus groups in a stakeholder category in all four focal states, participants were given the list of outcomes generated by their stakeholder group. As in the state Delphi surveys, outcomes were listed alphabetically with directions appearing across the top of the page instructing respondents to rate the outcomes according to a five-point scale ranging from “not at all desirable” to “extremely desirable.” Participants were invited to make any wording changes deemed necessary to improve the meaning of the outcome. Outcome lists were mailed to focus group participants with a cover letter describing the Delphi process, a stamped self-addressed envelope, and instructions to return the list in five working days. A paragraph was included in the cover letter reminding participants that the state and stakeholder surveys were being mailed concurrently but were two separate surveys.

The second round of the stakeholder surveys was distributed to five stakeholder groups between January 1 and March 7, 2001 (Indiana service providers did not receive a second round, as results from the first round resulted in only four outcomes). Participants received the final list of outcomes resulting from round one that was unique to their stakeholder group.

Activity 2.11 - Analyze measures within, across states by stakeholders

The data reduction process was implemented as follows:

Round one:

1. Frequency distributions were generated for survey returns.
2. Two people identified outcomes that 55% of the respondents chose as “extremely desirable.”
3. The project coordinator reviewed discrepancies.
4. Retained outcomes were alphabetized, redundancies eliminated, and outcomes formatted into a Delphi survey for round two. The round two survey contained a Likert scale of three choices: “not at all desirable,” “somewhat desirable,” and “extremely desirable.”

Round two:

1. Frequency distributions were generated for survey returns.
2. Two people identified outcomes that 75% of the respondents chose as “extremely desirable.”
3. All outcomes and their percentages (for stakeholders and states) were entered into an Excel database.
4. The top six outcomes for stakeholder groups and top six outcomes for states were prepared for review.
5. Comparison charts listing the type of Delphi (state or stakeholder), the number distributed, percentage returned, number of outcomes over 62% (for states only), and the number of outcomes over 75% (for stakeholders) were prepared.

6. Two independent coders reviewed lists to eliminate redundant items and combine similar items. Eighty percent (80%) accuracy between raters was achieved.
7. Each list (combined state outcomes and combined stakeholder) was reviewed to determine the distribution of participants.
8. The combined state list was determined to contain the best representation of stakeholders/states.

The Delphi process resulted in 10 outcomes of high quality service coordination. These outcomes were:

1. Children receive appropriate services.
2. Children reach their full potential.
3. Children are healthy.
4. Children's development is enhanced.
5. Children have successful transitions.
6. Each individual family and child's needs are met.
7. Families are involved in decision-making.
8. Families are informed about resources and services.
9. Family and child supports are provided.
10. People work together as a team.

This list of ten outcomes was further reduced to eight outcomes. Several outcomes were combined so that the resulting statement would reflect all of the concepts in the original clusters. Specifically, the original outcome 1, "Children receive appropriate services and

supports,” was combined with the original outcome 6, “Each individual family and child’s needs are met,” and the original outcome 9, “Family and child supports are provided,” to make the combined outcome statement “Children and families receive appropriate supports and services that meet their individual needs.” The final list of outcomes of high quality service coordination was:

1. Children and families receive appropriate supports and services that meet their individual needs.
2. Children reach their full potential.
3. Children are healthy.
4. Children’s development is enhanced.
5. Children have successful transitions.
6. Families are involved in decision-making.
7. Families are informed about resources and services.
8. People work together as a team.

See Appendix F for the Delphi protocol and data tables.

Activities 2.12 and 2.13 - Distribute Delphi measures to additional stakeholder groups in eight states; analyze measures across states

The Delphi measures were not distributed as described in the original proposal. Focus groups were not completed until February 2001, and in order to prevent the delay of the second round of focus groups, the decision was made to proceed without Delphi data from the additional eight states. However, to acquire data from additional stakeholders, a

parent/practitioner survey was distributed to family members and service providers across 50 states and the District of Columbia. This activity was added to the original proposal in order to collect additional data regarding outcomes of effective service coordination. The intent of the survey was to determine if desirable outcomes of service coordination could be distinguished from outcomes of natural environments and/or the early intervention system. The survey, developed by Carl Dunst, used 69 outcomes derived from the focus group process described in Activity 2.1 through Activity 2.6. The outcomes were arranged in three identical, alphabetized lists under the headings of “Service Coordination,” “Early Intervention,” and “Natural Environments.” Respondents were asked to choose the 10 most desired outcomes in these three categories. Space was provided to add outcomes not appearing on the list.

The survey was distributed to 5,100 family members and service providers across 50 states and the District of Columbia. A table of random numbers was used to select 255 program directors from a national database of Part C providers. Five randomly selected providers from each state/territory were contacted and asked to participate in the study by distributing surveys to 10 families and 10 providers associated with their respective program. Participants included 879 early intervention program practitioners and directors (59%) and parents of children with disabilities (41%) in 48 of the 50 states.

Activity 2.14 Data analysis

Survey participants judged from among 69 outcome indicators those that they considered to be the most valued benefits of each IDEA Part C service. Results indicated that families and providers differed in the identification and prioritization of outcomes. Differences

were detected in how outcomes were ranked between the categories of service coordination, natural environments, and the early intervention system. Certain categories of outcomes were more likely to be judged as the desired benefits of a specific Part C service, and only two outcome categories (family satisfaction and improved family quality of life) were considered valued outcomes for all three services. This study was completed in May 2001. See Appendix G for surveys, article submitted for publication, and protocols.

Objective 3.0 - To describe recommended practices in service coordination for families, service coordinators and providers, and system administrators.

Activity 3.1 - Identify samples

There were two identified samples for this study: national and state. The national sample included families and Part C coordinators. The state sample included families, service coordinators, service providers (Indiana only), and program administrators in four focal states (North Carolina, Massachusetts, Indiana, and Connecticut).

Activity 3.2 Develop protocol

The Research and Training Center team met in Connecticut on January 29 and 30, 2001, to plan the methodology for the second round of focus groups to identify recommended practices needed to achieve positive service coordination outcomes for children and families. A draft protocol was developed by Glenn Gabbard, refined by the team, and piloted with families and Part C coordinators at the National Project Directors meeting on February 25, 2001. Following the national focus groups, the protocol was revised based upon the responses

of participants. The decision was made to reduce the length of the focus groups from three hours to two hours based upon the effort required by participants to complete the activities. The final protocol involved a two-hour process that included both large and small group activities.

Focus groups of 5 to 15 participants were planned in the four focal states (Indiana, Massachusetts, Connecticut, and North Carolina) in urban, suburban, and rural settings with the following stakeholder groups:

- Program administrators (3 groups)
- Family members/parents of children birth-five (3 groups)
- Service providers/service coordinators (3 groups)
- Service providers (3 groups - Indiana only)

See Appendix E for a copy of the protocol.

Activity 3.3 - Recruit samples

A national sample of Part C coordinators was recruited through letters and follow-up telephone calls. The national families' sample was recruited through telephone contact by center staff. Recruitment of samples for focus groups was conducted by center staff in each focal state and preceded as the first round of focus groups. A diverse group of participants was recruited from urban, rural, and suburban settings in each of the focal states. A member of the Research and Training Center team sent an introductory letter to all prospective participants.

In Connecticut an invitation to participate in focus groups was mailed to all 39 program administrators. Follow-up calls were made to encourage participation and answer questions about the project. Parent support groups were contacted to generate interest in the project and solicit participation. Information about the project was distributed at seminars and meetings of parents of children in early intervention programs. Program administrators assisted in the identification of service coordinators/service providers by distributing 1500 flyers to individual providers across the state.

In Indiana letters were sent to six service providers and service coordinators. Each was also contacted by telephone. Parent support groups were contacted to assist with identifying families. Childcare was provided on site during focus groups to allow families with children to participate. In addition, notices were posted in a newsletter to families and providers. A mass mailing was sent to over 200 providers in urban areas.

In North Carolina center staff met with the director of the Health Department to explain the project and gain assistance in locating families that might participate. Health Department staff made the initial contacts to explain the project to families or professionals via 50 telephone calls and 25 visits. Ten fact sheets were sent out describing the project and activities, and Research and Training Center staff followed up with telephone calls to schedule focus groups with interested participants. This process was repeated with the Family, Infant and Preschool program, the Development Evaluation Center, the North Carolina School for the Deaf, Head Start program, Smart Start program, and private physical therapy and occupational therapy groups.

A cover letter and flyer was sent to invite those administrators, service coordinators, and families who were invited to the first round of focus groups (those who attended and those who did not). Center staff followed-up with telephone calls to encourage participation. Flyers were distributed with full information about location, time, and other details. Directions were faxed or e-mailed to confirmed participants.

In Massachusetts providers were recruited through contact with each of the early intervention programs located across the state. Particular emphasis was given to those participants from year 1 focus groups and those who attended trainings related to service coordination conducted by the Early Intervention Training Center housed at the Federation for Children with Special Needs. Individuals who either attended training in service coordination or participated in a focus group were sent personal invitations. Personal phone calls were made to reinforce written invitations. Additional information about the focus groups was disseminated through the conference of the MEIC.

Program directors were recruited through contact with each of the early intervention programs located across the state and through regular presentations at the state ICC meetings, which are held quarterly. A large number of providers attended this meeting and have been kept abreast of key developments in the Research and Training Center's work on service coordination. In addition, participants from the first year of focus groups received written invitations and personal phone calls.

Family members who participated in the first year's focus groups received written invitations as well as personal phone calls inviting them to attend this year's groups. An article appeared in a statewide publication disseminated by the Parent Leadership Project (funded by

the Part C lead agency, the Department of Public Health) noting the participation of one parent leader in last year's groups.

Activity 3.4 - Plan focus groups

Focus groups for three stakeholder groups were scheduled in Connecticut, Massachusetts, Indiana, and North Carolina. Additionally, Indiana scheduled focus groups with service providers. Three focus groups were planned for each stakeholder group in each focal state between April 2001 and August 2001.

In Connecticut nine focus groups were planned across different geographical areas throughout the state. In Indiana 12 focus groups were planned across different geographical areas throughout the state. In Massachusetts nine focus groups were planned across different geographical areas throughout the state. In North Carolina nine focus groups were planned across different geographical areas throughout the state.

Activity 3.5 - Implement focus groups

Families, service coordinators, service providers, and administrator groups were convened in each of the four focal states. Participants were asked to identify practices that supported the outcomes developed through the Delphi technique in Objective 2. There were 275 participants: 97 in Indiana, 53 in Massachusetts, 58 in North Carolina, and 97 in Connecticut. Stakeholders included 73 family members, 93 service coordinators, 86 program administrators, and 23 service providers (in Indiana only).

Focus groups were conducted over a period of approximately two hours and were managed by a trained facilitator. All facilitators operated from a 16-page facilitation guide (see

Appendix E) to ensure that group activities were practiced uniformly. Focus groups were structured into three activities:

1. Introduction to service coordination.
2. Discussion of the tool kit available to service coordinators.
3. Discussion of practices that would lead to quality service coordination.

Groups were then focused on determining answers to the following core question:

“What do service coordinators need to do in order to reach the best outcomes for children and families?” Various approaches to generating responses were used including discussions of:

1. What quality service coordination would look like.
2. The tools available for ideal service coordination.
3. The attitudes desired for ideal service coordinators.
4. The skills desired for ideal service coordinators.
5. The tools required for ideal service coordination.

The group’s individual ideas were posted for general discussion to synthesize the ideas most representative of the group. These core ideas became the output of the focus group, which lead to the practice statements used in the subsequent Delphi processes.

Completed Focus Groups				
Group	MA	IN	NC	CT
Program Administrators (Suburban)	5/08/01	4/18/01	6/12/01	6/21/01
Program Administrators (Urban)	4/4/01	6/05/01	6/6/01	5/17/01
Program Administrators (Rural)	5/14/01	5/7/01	6/5/01	6/19/01
Service Providers (Suburban)		4/30/01		
Service Providers (Urban)		6/08/01		
Service Providers (Rural)		5/9/01		
Service Coordinators (Suburban)	4/12/01	6/01/01	6/20/01	5/31/01
Service Coordinators (Urban)	5/10/01	6/01/01	5/22/01	4/4/01
Service Coordinators (Rural)	5/1/01	5/1/01	5/31/01	5/7/01
Families (Suburban)	5/23/01	5/25/01	5/15/01	5/9/01
Families (Urban)	5/30/01	7/24/01	5/17/01	5/9/01
Families (Rural)	5/16/01	4/5/01	4/6/01	8/07/01

Activity 3.6 - Collate and analyze data

Over 2000 practice statements were generated in the focus groups described in Activity 3.5. Project staff sorted the practice statements by stakeholder group. Two independent raters created categories based on common themes for the practices. These themes/categories were finalized by consensus of two independent raters. There were 18 themes for practices generated by family members, 19 themes for practices generated by service coordinators, 13 themes for practices generated by service providers, and 20 themes generated by program administrators. A list of samples of themes appears in the following table. A full list of themes is found in Appendix F.

Following the development of themes, two additional reviewers coded statements. Items that reviewers disagreed on were consensus coded for 100% agreement. A practice statement was generated for each category that encompassed all the ideas in the group. The project coordinator and principal investigator reviewed the final practice statements for accuracy. These statements comprised the four Delphi survey instruments, one for each stakeholder group (program administrator—76 practice statements, service coordinator—67 practice statements, service provider—30 practice statements (Indiana only), and family—55 practice statements). Please see Appendix F for copies of Delphi surveys.

Practice Themes	
Program Administrators:	Families:
1. Evaluation of services	1. Ongoing monitoring and assessment
2. Developmentally appropriate tools	2. Family and provider work together
3. Preparing families for transition	3. Preparing for transition
4. Coordinating/scheduling transition	4. Coordinating transition
5. Training	5. Mandatory reporting
Service Providers (Indiana Only):	Service Coordinators:
1. Ongoing monitoring and assessment	1. Communicate with team
2. Administrative tasks	2. Family centered
3. Health care needs of child/family	3. Locate/provide services
4. Family centered	4. Communicate with family
5. Knowledge of school system	5. Educate and inform families

Activities 3.7 and 3.8 - Develop and distribute Delphi measures within state

The focus group process produced a high number of statements (over 2,000). Many participants from the previous Delphi study on outcomes stated that the time involved in completing three rounds of surveys was excessive, particularly for surveys with high numbers of statements. For this reason, the Delphi survey for the practices study required focus group participants to complete only one survey. This survey, distributed in November 2001 to all

participants of focus groups on practices, included both practice and outcome statements from both sets of focus groups. There was an overall return rate of 65%. Individual stakeholder return rates, as shown in the following table, were as follows: service coordinators—40%, program administrators—44%, family members—38%, and service providers—56% (Indiana only).

Delphi Return Rate: Round 1 for Recommended Practices		
Stakeholder Group	Number Distributed	Number Returned
Service Coordinators	93	37
Program Administrators	86	38
Families	73	28
Service Providers	23	13
Total	275	179

The eight outcomes of high quality service coordination identified in Objective 2.0 were listed across the top of each survey. The practice statements generated by each stakeholder group were listed in a column down the left side of the survey. Respondents were asked to review each practice statement and circle the outcomes they would expect to occur from each practice. Respondents were instructed to circle no more than three outcomes per practice. Data

from returned surveys were entered into SPSS and frequencies were generated. Practices that were rated in 26% or more of the responses as being likely to result in a particular outcome were retained. These practices comprised the surveys in the next phase of the project: the national Delphi survey.

National Delphi Survey. In the next phase of the study, the recommended practices underwent additional validation using a large-scale survey, which was distributed to practitioners, administrators, and family members across all 50 states and the District of Columbia. Eight surveys were developed. Each survey contained one of the eight outcomes of high quality service coordination, which appeared at the top of the survey. The list of the recommended practices associated with that outcome (derived from data in the previous Delphi survey) was listed down the left-hand side of the survey. Participants were asked to rate their level of agreement that each practice would lead to the outcome listed at the top of the survey. A four-point Likert scale was used that included the following statements: “strongly agree,” “agree,” “disagree,” and “strongly disagree.” Surveys were distributed to over 5,000 participants from four stakeholder groups in 50 states plus the District of Columbia and Puerto Rico. A message was posted to Part C coordinators on the Part C listserv asking Part C coordinators in each state to distribute surveys to service coordinators, service providers, and program administrators. Only one Part C coordinator declined to distribute surveys. In states that had dedicated service coordinators, the Part C coordinators were asked to distribute the surveys separately to service coordinators and providers. In the remaining states, service coordinators who were also providers were asked to complete the service coordinator survey. Part C coordinators were also asked to fill out a survey themselves. In addition, 112 Parent Training

and Information Centers (PTIs) were contacted to request assistance in distributing surveys to parents. The Federation for Children with Special Needs contacted each PTI by e-mail or letter to request participation and followed up by telephoning the PTI representatives.

Each of the eight surveys contained between 14 and 53 items. The RTC team determined that it would not be practical to ask each respondent to fill out all eight surveys (one for each of the eight outcomes). In order to keep survey items to a manageable number and to increase the survey return rate, it was decided that participants would be asked to fill out only two surveys each. Surveys were paired for distribution so that no participant would have more than a total of 67 items to complete between the two surveys. The surveys were anonymous, but they were coded for stakeholder group and state. A demographic question on the service coordinator and service provider surveys asked how long the respondent had been a service coordinator. The following table details the distribution procedure:

Delphi—national/practices					
	Family	Part C coordinator	Program administrator	Service coordinator	Service provider
Number of Participants	112 PTIs distributed packets of two surveys to 12 families each	53 coordinators received 2 surveys	8 administrators per state received 2 surveys	8 coordinators per state received 2 surveys	8 providers per 15 states received 2 surveys
How many surveys for each of the eight outcomes	336 of each outcome	14 of each outcome	106 of each outcome	106 of each outcome	30 of each outcome
Total surveys distributed	2688 total surveys distributed to families	106 total surveys distributed to Part C coordinators	848 total surveys distributed to program administrators	848 total surveys distributed to service coordinators	240 total surveys distributed to service providers
Color of surveys	Pink	Blue	Yellow	Green	White

Data for the national Delphi on recommended practices of service coordination have been collected and analyzed. The RTC team sent two e-mail reminders and follow-up phone call reminders at approximately 2-week intervals beginning in late August. A total of 1318 Delphi surveys from 35 of the 53 states/territories were received for a return rate of 27.9%. The analysis identified practices of exemplary service coordination. Practices were defined as exemplary when 95% or more of the respondents “agreed” or “strongly agreed” that a given practice would lead to outcomes of high quality service coordination.

Objective 4.0 To develop a model that validates service coordination outcomes and practices through the use of measurement tools.

The interview protocol developed for this study was a departure from the previously selected methodology, Results Mapping, which recently underwent significant revision by its originator, Barry Kibel, Ph.D. The revised methodology, called Outcome Engineering, was designed to replace Results Mapping. Results Mapping was no longer being recommended by Kibel. Given this new information, project staff conducted a review and comparison of Results Mapping and other measures (Outcome Engineering, Goal Attainment Scaling) to determine the methodology most appropriate for this objective.

Below is an outline of the factors considered in the methodology evaluation process.

Goals of this objective:

- To provide rigorous, comprehensive information about the outcomes of service coordination (knowledge generation).
- To provide a sound, yet practical approach to measurement.

Intent/Purpose:

- To use a valid, reliable measure of the complex and multi-dimensional outcomes of service coordination.
- To use a measure that could be employed by local programs to determine service coordination outcomes (program accountability).
- To use a method that not only measures the outcomes, but also documents the practices and amount of effort needed to achieve positive outcomes for children and families with diverse abilities, needs, and circumstances.
- To gather both qualitative and quantitative data.

Results mapping provided a comprehensive measure of outcomes, producing both qualitative stories and quantitative scores. However, it was rejected as an optimal methodology based on the following justification:

Justification for Rejection of Results Mapping	
INTENT/PURPOSE	PROBLEMS ENCOUNTERED
To use a valid and reliable measure.	Reliability was difficult to achieve among researchers who reflected different experiences and perspectives of early intervention in determining qualitative scores, making its reliable use among diverse local program personnel doubtful.
To be used in local programs.	Data reduction (development of accurate narratives from transcripts) and scoring narratives were reported to be exceedingly time consuming, rendering this method an unlikely choice by local programs.
To document practices and amount of effort needed to achieve outcomes.	Would need to interview multiple providers and parents to obtain accurate information.
To gather qualitative and quantitative data.	With qualitative data, it would be difficult to separate service coordination from other activities. Quantitative scores haven't been standardized, making it difficult to obtain comparisons of scores.

Existing instruments, such as Goal Attainment Scaling, measured a single dimension of service coordination and did not produce a combination of quantitative and qualitative data. Outcome engineering was found to have the same limitations as Results Mapping and was reported to be more cumbersome to implement. Based on this information, the project team

made the decision to develop a protocol that would be specifically designed for the goals of this project.

Activities 4.1 and 4.4 - Identify and recruit families

The families participating in this phase of the project were different from the families who participated in the focus groups. The decision was made to recruit more families than needed for the study with the expectation that some families would drop out of the study or decline to participate following initial recruitment. In addition, the RTC team recruited a large number of families from traditionally underrepresented ethnic groups due to the fact that the majority of focus group participants were Caucasian. Families were recruited according to specific guidelines to ensure that a representative cross-section was attained. Efforts were made to achieve a balance across each state based on demographics including:

Ethnicity:

- Black
- Latino
- White
- Asian/Middle Eastern/Other

Child's level of need:

- Mild = Two (2) standard deviations below the mean or average of the testing instrument used.

- Moderate = Three (3) standard deviations below the mean or average of the testing instrument used.
- Complex = Four (4) standard deviations below the mean or average of the testing instrument used.

Family location:

- Rural
- Suburban
- Urban

Socioeconomic status:

- Low income
- Not low income

Below is the grid used to guide recruitment in each state:

Recruitment Grid				
Ethnicity	State			
	CT	NC	IN	MA
Black	9	9	9	9
Latino	9	9	9	9
White	9	9	9	9
Asian/Middle Eastern/Other	9	9	9	9

As project staff in each state identified a candidate family, recruiters contacted the Center in Connecticut where the family's demographics were centrally compared with the target demographics and final acceptance or rejection was made to include the family for participation. Due to the specific sampling procedure, recruitment proved challenging and continued several months past the targeted date of September. Other factors affected recruitment, including difficulty communicating with the person hired to conduct interviews in Massachusetts.

The staff problems resulted in the decision to hire a second person in November to finish recruitment and interviews in Massachusetts. There was a brief lapse in the interview schedule in Indiana in November when the person completing the interviews had a baby. In addition, the individual who had been trained to conduct interviews in Spanish in Connecticut left the A.J. Papanikou Center sooner than expected to have twins, causing a delay in recruitment and implementation of Spanish-speaking families. All family interviews were completed by April 2002. The following is a table showing the recruitment grid for the study:

Family Selection Criteria										
Ethnicity	Child Age	Less than 1 year			1 – 2 years			2 – 3 years		
	Needs*	Com	Mod	Mild	Com	Mod	Mild	Com	Mod	Mild
Black	Urban		CT IN IN	CT IN		NC IN	NC CT	CT	CT MA	CT NC
	Rural			IN	IN	NC NC	NC NC			
	Suburban		IN IN	MA				CT		NC NC
Latino	Urban	MA					CT	MA	CT MA	MA CT CT
	Rural			NC						
	Suburban	NC	CT IN	NC			IN	CT		CT CT
White	Urban	MA	MA	IN IN	MA	MA	CT	MA	MA CT	IN MA
	Rural	IN		IN	CT	IN	IN NC	IN CT	IN	NC NC
	Suburban	MA MA	CT IN IN	CT NC	IN NC	IN	CT MA	MA	CT	IN
Asian/ Middle Eastern/ Other	Urban			IN			NC MA	MA	NC MA	CT CT MA
	Rural			NC	NC					MA
	Suburban			NC MA	NC	NC	MA NC		MA	MA

* Needs=complex, moderate, mild

As part of the interview process, a telephone interview was conducted with each family's service coordinator. Families were asked to sign a consent form allowing project staff to contact their service coordinators to request their participation in the study. Project staff then contacted each service coordinator to explain the project more fully and conduct an interview by telephone.

Activity 4.2 - Develop protocol

As previously described, a protocol was developed by project staff specifically for this study following the discovery that the methodology originally chosen, Results Mapping, was no longer recommended by its author, Barry Kibel, Ph.D., for measuring outcomes. In May 2001, the project team developed an interview protocol that underwent revision in June 2001 and early July 2001. The protocol was piloted with five families in the four focal states, resulting in further refinement. The team approved the final protocol on July 17, 2001. See Appendix G for Family Interview Protocol. The interview process was designed to gain input from 100 families based on their experiences with early intervention and service coordination to:

1. Identify outcomes of effective service coordination.
2. Measure the outcomes of effective service coordination as perceived by families.
3. Identify and measure practices that lead to effective service coordination outcomes.

Families were introduced to the concept of service coordination and asked to explain something about their family, their child, their experience with early intervention, and the status of services being provided. The interviewer, during the course of listening to the family's

story, identified outcomes that were described by the family during the interview. At the conclusion of the story, the interviewer asked specific questions about each identified outcome including:

- The importance of the outcome.
- Who assisted the family in achieving the outcome.
- How service coordination helped achieve the outcome.
- What specific tasks the service coordinators performed to achieve the outcome.
- How long it took to achieve the outcome.

Finally, the family was asked: “If service coordination is working well, how would you know it?” Interviews were audio taped and responses were recorded on a data sheet (see Appendix G for sample data sheets).

In addition to interviewing families, project staff interviewed each family’s service coordinator. A protocol was developed which included questions regarding the service coordinators training, supervision, and work activities. In addition, the following questions were included:

1. Please take a moment to think about the _____ family. If you were to ask this family what outcomes are important to them, what do you think they would say?
2. For each of the outcomes that the service coordinator identifies, respond with: “You said that _____ was an important outcome for the family.”
 - How close is the family to reaching that outcome?

- Who on the team helped reach that outcome?
- How did service coordination help the family reach that outcome?
- Did anything else happen that helped the family reach that outcome?
- How long did it take to accomplish that outcome?
- If service coordination were working its absolute best for this family, how would you know it?

Activity 4.3 - Train staff in interview protocol and data collection procedures

Staff were trained in the protocol and data collection procedure for the family and service coordinator interviews on August 1, 2001. This training session was held at the University of Connecticut. Participants included all individuals who would potentially be conducting interviews, including Kathleen Whitbread, Jenn Root, Marisol Cruz St. Juste, Cindy Mazzarella, Alissa Zolad, Phoebe Teare, Glenn Gabbard, Kathy Klingerman, and Nancy Gordon.

Activities 4.5 and 4.6 - Schedule and implement visits

Visits were scheduled and implemented beginning August 6, 2001, and were completed by March 2002. Project staff in the four focal states (Massachusetts, North Carolina, Indiana, Connecticut) conducted 25 family interviews and 25 service coordinator interviews for a total of 100 family interviews and 100 service coordinator interviews across a diverse population of families. The most recent Individual Family Service Plan (IFSP) was requested to complete the data set for each family.

Activity 4.7 - Data analysis of family and service coordinator interviews

Traditionally underrepresented groups continue to be accounted for in the demographic characteristics of the remaining sample. Families living in urban areas account for 41.6% of the sample, and those with low income represent 46.1% of the sample. With respect to ethnicity, 61.8% of the sample families/children are non-Caucasian. Sample demographics are represented in the following table.

A reliability check was conducted on a randomly selected sample of 15.7% of tapes. The trained analyst denoted outcomes (“What would you like to see for your child/family?”), who helped, and practices (“What was done to help?”) from the transcribed interview. A comparison of interviewer and analyst data was performed demonstrating 81.6% correspondence between interviewer and analyst. Project staff have selected to transcribe all interviews and record data from the interviews as a reliability assurance and means of recording data for future measures.

Eighty-six (86) family interview tapes have been transcribed. Fourteen (14) family interview tapes were either not available or not clearly audible and were not included in the study as reliability via tape review was not possible.

A trained research assistant has reviewed transcriptions of 70 family interviews thus far. Outcomes, practices and people who assisted the family/child were identified in family interviews and were recorded in a Word Document chart format. Fifty-five (55) service coordinator interviews were reviewed and corresponding data was identified and charted. See family and service coordinator interview data charts in Appendix H.

Sample Demographics

Characteristic	Frequency	CT	IN	MA	NC	Percent
Location:						
Urban	37	9	8	15	5	41.6
Suburban	33	8	9	6	10	37.1
Rural	19	2	8	1	8	21.3
Ethnicity:						
Black	21	5	7	1	8	23.5
White	34	6	15	9	4	38.5
Latino	16	7	2	4	3	18.0
Other	18	1	1	8	8	20.2
Income:						
Low	41	8	6	14	13	46.1
Not Low	48	11	19	8	10	53.9
Child's Age:						
0-1	28	4	13	5	6	31.5
1-2	30	5	7	5	13	33.7
2-3	31	10	5	12	4	34.8
Needs:						
Mild	42	8	10	9	15	47.2
Moderate	27	7	10	6	4	30.3
Complex	20	4	5	7	4	22.5

Data from family and service coordinator interviews are currently being analyzed. Outcomes are being categorized based on previous Delphi studies and by the system-family-child framework outlined in the original grant proposal.

Family interview data are being compared to service coordinator interview data to determine the level of agreement between families and service coordinators on key issues related to service coordination outcomes and practices. Thus far, thorough analysis has been performed for 55 family interviews and corresponding service coordinator interviews using qualitative methodology, representing 64% of available data.

Responses from parents and services coordinators were identified for the questions:

- 1) “What would you like to see for your child/family? ”, asked of families and
- 2) “If you were to ask this family what outcomes are important to them, what do you think they would say?” asked of the corresponding service coordinator.

The responses were reviewed and categorized under five main outcomes previously identified through the Delphi process:

1. Families are informed about resources and services.
2. Families are involved in decision-making.
3. Children and families receive appropriate supports and services.
4. Children’s health and development is enhanced.
5. Children have successful transitions.

The responses are also being categorized based on Child-Family-System framework outlined in the original grant proposal.

Consensus coding by two independent raters was utilized to assure reliability of categorization. The percent of total responses as categorized into outcomes for 55 families and their respective service coordinators are represented in the table below.

Total Percent of Interview Responses by Outcome					
Interview	Families Informed	Families Involved	Appropriate Services	Health/ Development	Successful Transitions
Family	5.5	4.6	37.9	46.6	5.5
Service Coordinator	8.0	2.4	32.1	54.2	3.3

Both groups identified the outcome of “child’s health and development” with the greatest frequency (families 46.6%, service coordinators 54.2%), followed by receiving “appropriate supports and services” (families 37.9%, service coordinators 32.1 %). The least frequent response offered by families related to “families being involved” (4.6%). Service coordinators also anticipated “families being involved in decision-making” with the least frequency (2.4%).

Family and service coordinator responses were compared to determine percent of agreement. The percent agreement between family and service coordinators ranged from 11.1 - 100.0, with a mean of 54.5 and standard deviation of 16.82.

Both families and service coordinators were asked to identify individuals who helped the family meet the outcomes that were important to them. Families and service coordinators acknowledged many individuals and groups as contributing to children’s development, including parents/family members, service coordinators, service providers (therapists, teachers, nurses, and other personnel from Birth-to-Three agencies), doctors, and other individuals (daycare, funding sources, child/programs other than Birth-to-Three). Parents identified 720 people who assisted them, while service coordinators identified a total of 504 people who assisted the family. Please see the table below for percent of total family and service coordinator responses relating to identification of people who helped the child/family reach identified outcomes.

Total Percent of Interview Responses According to Who Assisted The Family					
Interview	Parent/Family	Service Coordination	Service Provider	Doctor	Other
Family	32.0	25.0	24.7	7.1	11.2
Service Coordinator	25.1	39.5	22.8	4.8	7.8

Both families and service coordinators identified themselves as playing the primary roles in assisting children/families respectively. Families acknowledged their own involvement in 32.0% of the outcomes they sited as important and service coordinators in 25.0% of their outcomes. Service coordinators identified themselves as assisting in 39.5% of family outcomes and families in 25.1%. Service providers ranked third highest in frequency of assisting in outcomes for both family and service coordinator responses. Percent of agreement between families and service coordinators ranged from 9.1 – 76.9. The mean percent of agreement between family and service coordinator responses was 48.2 with a standard deviation of 14.4. The data tables for these responses are in Appendix H.

Activity 4.8 – Analyze IFSP (Individual Family Service Plan) Data.

As of December 31, 2002, demographic information from 80 IFSPs has been collected. Outcomes and practices from 80 IFSPs have been identified, along with individual(s) who assisted the family in pursuing the outcomes. Data have been entered in an Access program that can calculate frequency, trend, and comparative analyses. Thirty-four (53.9%) of the IFSPs reviewed presented challenges for analysis due to missing data or confusing documentation. Data analysis will continue in the manner described until the 89 available cases are completely analyzed.

Activity 4.9- National Parent Survey of Service Coordination and Early Intervention.

In October, the RTC team distributed 5000 parent surveys to agencies and providers of services to children from birth to three years who have a disability and their families. Each agency was mailed a packet that included a cover letter explaining the study and requesting their assistance in distributing the survey to an average of five families. A self-addressed stamped postcard asking agencies to indicate whether they were willing to participate in the study and a request to return the postcard within two weeks also was included in the packet. Participating families were asked to return the completed survey and signed consent form in the self-addressed stamped envelope provided. The RTC team has received 267 of the 5000 surveys distributed through agencies in 44 states. The survey data currently are being coded and entered into SPSS. Investigation is underway to identify agencies and/or service providers capable of distributing the survey to eligible families in the remaining states with low numbers of agency contacts.

Objective 5.0 – To develop training models to ensure the acquisition and maintenance of recommended practices in effective service coordination for families, service coordinators and providers, and system administrators.

Activity 5.1 - Develop curricula on outcomes and practices of service coordination

The curricula content for this objective will revolve around recommended practices to produce effective outcomes for service coordination. Training will be based on data from the

national Delphi study of service coordination practices as well as data from the family and service coordinator interviews described in Objective 4.0 that is currently being analyzed.

The RTC team met in March 2002 to review the training objective and proposed activities. There will be three training audiences: families, service coordinators/providers, and system administrators. Learning Communities will be established in each of the four focal states. In addition to learning communities, other training models were discussed including web-based instruction, self-study, guided group study, workshops with follow-up, and distance education. RTC staff are in the process of researching each of these training methods in order to develop a comprehensive training plan that reaches a diversity of learners in all stakeholder groups.

Objective 6.0 - To disseminate information about the center's research and training outcomes and products nationally across a wide range of stakeholders using a variety of formats.

Activity 6.1 - Establish website

A project website was established in September 2000 and is available at www.uconned.org/rtc/rtchome. The website provides information about the project, including project description, methodology, key contacts and project personnel, literature and resource references, and project data reports.

The website is updated regularly and is an important component in the project's dissemination plan. There have been over 1,500 hits to the Research and Training Center project page since March 2001. See Appendix I for a copy of the website.

Activities 6.2 and 6.3 - Develop and disseminate materials, products, policy papers

A quarterly newsletter describing the project, including activities completed to date, is distributed electronically and by post to over 3,000 people, including:

- Part C coordinators
- ICC chairs
- Focus group participants
- State Part C monitors
- State curricula contacts

Newsletters were distributed to over 2,500 people in September 2000, December 2000, March 2001, May 2001, August 2001, December 2001, March 2002, June 2002, September 2002, and December 2002. See Appendix H for copies of the newsletters and the Research and Training Center brochure.

Data reports, detailing the results of project studies conducted to date, were distributed as PDF downloadable documents on the Research and Training Center website. Copies of reports were made available at a poster session at the annual Project Directors meeting in January 2001, along with brochures and handouts describing center activities. Results from project studies were presented at the Division for Early Childhood of the Council for Exceptional Children (DEC) conference in Boston in December 2001 and the Conference on Research Innovations in Early Intervention (CRIEI) in February 2002. Updated findings from

the project were presented at the annual meeting of University Centers of Excellence in Developmental Disabilities Education, Research, and Service (UCE) in October 2002, the Division for Early Childhood of the Council for Exceptional Children (DEC) annual meeting in December 2002, and the Office of Special Education Programs (OSEP) Project Directors' Meeting in October 2002. In addition, the Research and Training Center received approximately four requests per month for information about the center's work as well as requests for center products. Thirty-three percent (33%) of these requests were from early intervention service providers, 17% were from family members, 17% were from university students, and 12% were from early intervention program administrators. The remaining 21% were from other categories (ICC members, higher education faculty, and Part C Coordinators).

Project FORUM of the National Association of State Directors of Special Education (NASDSE) published a synthesis brief of the Research and Training Center report entitled, "Service Coordination Policies and Models." The purpose of a FORUM synthesis brief is to capture the essence or key points from an important document for policymakers and others who do not wish to read a longer technical document. The brief was disseminated the week of September 19, 2001, by mail, e-mail, and posting of the document on a downloadable website. A copy of this brief appears in Appendix I.

In June 2002, the project director shared findings from the Research and Training Center project in a presentation on service coordination at the Pennsylvania Statewide Service Coordination Institute.

The following article was published in association with this project:

- *Dunst, C. (2002) Valued Outcomes of Service Coordination, Early Intervention and Natural Environments, Council for Exceptional Children, 68;3, 361-375.*

Manuscripts in progress include:

- *Implementing Federal Policy: Approaches to Service Coordination*
- *Key Elements of Effective Service Coordination: Consideration for Systems and Direct Services*
- *Policies that Guide Service Coordination*

Findings of the various Research and Training Center's studies were incorporated in the Early Intervention Specialist Credentialing/Certification Course at the University of Connecticut in the Fall 2002 semester. In addition, The AJ Papanikou Center for Development Disabilities hosted an Open House and the RTC team created a poster presentation describing the project. The RTC brochure, handout from the OSEP presentation, and current newsletter were available for the guests.

Appendix A

Conference call notes and meeting minutes

Appendix B

Part C survey with cover letter

Part C survey data report

Part C listserv results

Fiscal report

Supplemental Activity—service integration survey table of responses

Appendix C

Parent leader survey (English and Spanish)

Parent leader survey data report

Parent ICC telephone survey protocol

Parent ICC data report

Family guide

Appendix D

Curricula survey data report

Curricula report

Service coordination policies and models report

Appendix E

Focus group protocol (outcomes)

Satisfaction questionnaire

Recruitment and invitation letters

Focus group protocol – facilitating guide (practices)

Appendix F

Delphi protocol (outcomes)

Delphi instrument and coverletters (outcomes)

Delphi data tables (outcomes)

Supplemental activity 2.14 data

Valued outcomes paper

Delphi protocol (practices)

Delphi instrument and cover letters (practices)

Appendix G

Parent survey

Parent survey protocol

Article

Appendix H

Family interview protocol

Service coordinator protocol

Family interview data chart

Service coordinator data chart

Comparison of family and service coordinator outcomes

Appendix I

Website

Brochure

Newsletters

NASDSE brief