RESEARCH AND TRAINING CENTER ON SERVICE COORDINATION

Delphi Study Report

March 27, 2001

PURPOSE

It is expected that effective service coordination would result in improved outcomes for children; however, data on outcomes are sparse. This study was designed to gain consensus among key stakeholder groups on the outcomes of high quality service coordination across a variety of state models, family diversity, and family location.

Focus groups were used to gather information from multiple stakeholders with different perspectives on service coordination within the early intervention system. These groups included families, service coordinators, service providers, childcare providers, program administrators, and physicians. Participants were asked to respond to the question, “If service coordination were of the highest quality for children, families, and systems, how would you know it?”

A Delphi consensus-building method was used to identify a hierarchy of outcomes, resulting in eight defining outcomes of high quality service coordination.

METHOD

Participants

There were two identified samples for this study; national and state. The national sample included families, Part C coordinators, and ICC chairs. 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 (N=20), one for families (N=17), and two for Part C coordinators (N=35).

The state sample included families, service coordinators, program administrators, childcare providers, and physicians in four focal states (North Carolina, Massachusetts, Indiana, and Connecticut). Three hundred and ninety-five participants representing six stakeholder groups attended 47 focus groups between April 2000 and February 2001. Participants included 80 family members, 86 program administrators, 144 service coordinators, 54 childcare professionals, 22 service providers (from Indiana only), and 9 physicians (from Connecticut and North Carolina only).

Eighty-nine percent (N=351) of the focus group participants were female and 11% (N=44) were male.

Table 1

Focus group participants (N=395)

State	Female participants (N)	Male participants (N)
Indiana	95	19
Massachusetts	85	7
Connecticut	71	10
North Carolina	100	8

Focus group participants were recruited from urban, suburban, and rural locations. Participants represented a variety of population densities with 35.5% (N=141) of the participants attending focus groups in rural areas, 36% (N=144) in suburban areas, and 28% (N=110) in urban areas.

The majority of focus group participants were Caucasian. In Indiana, 85% (N=98) of the participants were Caucasian, 14% (N=16) were African American, and less than 1% (N=1) were Latino. In Massachusetts, 94% (N=87) were Caucasian, 5% (N=5) were African American, and 1% (N=1) were Latino. In Connecticut, 87% (N=69) of the participants were Caucasian, 11% (N=9) were Latino, and less than 1% (N-1) were African American. North Carolina data is unavailable.

Table 2

Focus Group Participants

	Program administrator (N=86)	Service provider (Indiana) (N=22)	Service coordinator (N=144)	Childcare provider (N=54)	Family (N=80)	Physician (N=9)
Rural						
N=	32	8	58	17	26	0
%=	37	36	40	31	32	0
Suburban						
N=	30	6	49	26	28	5
%=	35	27	34	48	35	55
Urban						
N=	24	8	37	11	26	4
%=	28	36	26	20	32	44

Recruitment

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.

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.

In Connecticut, invitations to participate in focus groups were 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.

Research and Training Center 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 Division of Child and Family Studies' Medical Home Project. Invitations for childcare providers and physicians were mailed the first week of June 2000.

In Indiana, over 400 letters were sent to families using mailing lists provided by the Part C coordinator. Two articles were posted in regional childcare newsletters. The First Steps coordinators in Marion County and Monroe County also provided mailing lists and invited project staff to participate in board meetings. 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 whom 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. Physicians were initially contacted through a letter. A state First Steps consultant offered to schedule focus groups for service coordinators.

In Massachusetts, the Early Intervention Training Center (EITC) helped facilitate connections with stakeholders and recommend 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 was distributed at the annual statewide conference of the MEIC. Directors also received telephone calls to explain center activities and invite them to the focus groups.

For service coordinators, program directors in the northeast region received a telephone call to explain the center's activities and to solicit nominations of essential service coordinators to participate in focus groups. For the western region, the MEIC offices were helpful in soliciting participation for service coordinators in the central and western regions of the state. Service coordinators participating in any of the training activities of the EITC 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 a coordinator's 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 related to 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. For physicians, the Part C coordinator was consulted about statewide contacts. In under represented areas of the state in terms of focus group participation, program directors were asked for referrals of physicians who might be willing to participate.

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 2001. 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 (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, thus allowing 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 to explain the focus groups and 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 and suburban/small towns and rural areas were asked to submit 5 each. 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 socio-economic 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. 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.

Research design

The methodology for focus groups was developed using a combination of the Focused Conversation Method and the Workshop Method developed by the Institute of Cultural Affairs. The Focused Conversation Method is a simple 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: the objective level involves questions related to facts; the reflective level involves questions that evoke immediate personal reactions; the interpretive level involves questions that draw out meaning and values; and 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 thought process. This process consists of five steps: set the context, brainstorm, categorize, name categories, and evaluate the work. Data generated during focus groups included outcomes statements and indicators in response to the focus question. 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 the outcomes. A Delphi study approach draws on the collective wisdom and opinion 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, this study purposefully included a large number of respondents (all focus group participants) with diverse experience in regard to the implementation of service coordination.

Procedures

The focus group methodology was piloted at the annual NECTAS / Project Directors meeting in January 2000. 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. In addition, the formula for the labeling of the categories was modified to the verb ending in “ed” instead of “ing” to encourage the group to focus on outcomes rather than process. A satisfaction questionnaire was designed for participants to evaluate the content of the focus group questions, the facilitation, and to find out from them any suggestions for future focus groups and how to keep them informed about the progress of the project.

In Connecticut, 13 focus groups were scheduled between April and October 2000 across different geographical areas throughout the state. Between June and November 2000 across various geographic areas in each state, 14 focus groups were scheduled in Indiana, 11 in Massachusetts, and 11 in North Carolina.

Family focus groups in Indiana and North Carolina were rescheduled several times due to lack of attendance, with the final family focus group occurring in February 2001, two months later than planned. Physicians’ focus groups did not occur in Indiana and 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. Focus groups were lead by two trained facilitators at locations convenient to participants.

Data Collection

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.

A total of 250 outcome statements were generated during the focus groups. In response to the question "If service coordination were of the highest quality for children, families, and systems, how would you know it?" participants were asked to record as many ideas as possible on a sheet of paper. They were then asked to write their three clearest ideas on large index cards and to share these ideas with a small group of three to five people. These ideas were placed on a large wall chart and the larger group organized these cards into clusters. The group named each cluster with a three- to four-word title that expressed all the ideas in the cluster. For example, Connecticut family focus group participants generated the following list of ideas (outcome indicators) in response to the focus question:

- Families have practical information.
- Families advocate for themselves.
- Families have choices.
- Family participation is increased.

In the final step of the process, participants grouped these indicators into a cluster and named the cluster "empowered families." This title is the outcome statement used in the Delphi survey.

Survey design

Following the completion of focus groups, the outcomes generated by each stakeholder group and each state were used to design surveys. Outcomes were listed alphabetically in a column on the left side of the page 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 they deemed necessary to improve the meaning of the outcome.

All outcome lists for each stakeholder group were coded by state, enabling center staff to group outcomes across stakeholders within states. 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 survey within five working days. Stakeholder Delphi surveys were distributed between December 2000 and March 2001. See Appendix B for stakeholder group and state returns.

Table 3

Stakeholder group	Round 1	Round 2
Service providers (N=22)	02-05-01	
Service coordinators (N=144)	01-29-01	03-02-01
Physicians (N=9)	01-02-01	02-01-01
Family members (N=79)	02-05-01	03-07-01
Program administrators (N=87)	12-04-00	02-01-01
Childcare providers (N=54)	12-05-00	02-02-01

State Delphi surveys were distributed to Connecticut, Massachusetts, and North Carolina on January 23, 2001, and to Indiana on March 7, 2001.

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."

The second round of the stakeholder survey was distributed to five stakeholder groups between January 1 and March 7, 2001 (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. The data reduction procedure for round two was implemented as follows:

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 spreadsheet.
4. The top 6 outcomes for stakeholder groups and top 6 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 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 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.

Results

Forty-seven focus groups were held in Connecticut, Massachusetts, Indiana, and North Carolina. Three hundred ninety-five participants in six stakeholder groups produced 250 outcomes. Of the 250 outcomes, 15 were from physicians (N=9), 42 from childcare providers (N=54), 64 from program administrators (N=87), 19 from service providers (N=22), 54 from service coordinators (N=144), and 56 from family members (N=80).

These 250 outcomes comprised the first round of the Delphi study. Surveys were sent to participants who were asked to rate the desirability of each outcome as it relates to service coordination. Through consensus, the first round of a Delphi study reduced the initial list of 250 outcomes to 75. This included 6 outcomes from physicians, 11 from childcare providers, 22 from program administrators, 4 from service providers, 14 from service coordinators, and 18 from families. These 75 outcomes were then used to create the second round of the Delphi study, which was redistributed for rating by study participants.

This process was repeated with each state's list of outcomes. Outcomes were ranked, and each outcome was assigned a score. The top ten outcomes across all states and stakeholder groups were retained. The retained 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.

11. Finally, outcomes 1, 6, and 9 were combined to form the following statement: Children and families receive appropriate supports and services that meet their individual needs. This resulted in a final list of eight outcomes;

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.

These eight defining outcomes of high quality service coordination will be used in subsequent focus groups for the development of recommended practices. See Appendices outcome rankings by state and stakeholder group.

Discussion and Implications

This Delphi study resulted in 8 outcomes of service coordination deemed most important by key stakeholders. The final list of outcomes included 5 that were directly related to children, 2 that were related to families, and 1 that was related to the team process. While the outcomes described by this Delphi process were consistent with the intent of the federal IDEA law, research has shown that there is not always a clearly identifiable relationship between ideal service coordination outcomes and the practices employed by service coordinators. Recent studies conducted by the Research and Training Center have confirmed a lack of coordinated efforts between and within states leading to inequitable service delivery. In the absence of a commonly held set of outcomes and related practices, it comes as no surprise that there is a perceived and actual disparity between what people expect from service coordination and what they receive.

Providing the field with a common set of outcomes is the first step toward ensuring that families and children receive consistent, high quality service coordination and that a benchmark exists for measuring families' progress toward realizing those outcomes. Subsequent studies by the Research and Training Center will focus on achieving consensus on the specific practices that will lead to the achievement of the outcomes identified by the current study.

Appendix A

Ten outcomes following round 2 of the Delphi survey

Outcome	Appeared in top 5 outcomes of state(s)	Appeared in top 6 outcomes of stakeholder group(s)
Children receive appropriate services and supports	Indiana	Families Service coordinators Physicians Program administrators Service providers
Children reach their full potential	Connecticut North Carolina Massachusetts	Families
Children are healthy	North Carolina	(None)
Children's development is enhanced	North Carolina Connecticut	Families
Children have successful transitions	Connecticut Indiana	(None)
Each individual family and child's needs are met	Massachusetts North Carolina	Families Childcare
Families are involved in decision-making	North Carolina Massachusetts	Program administrators
Families are informed about resources and services	Indiana	Program administrators
Family and child supports are provided	Connecticut Massachusetts	Families Service providers
People work together as a team	Indiana	(None)

Appendix B

Stakeholder group and state returns
March 23, 2001

Stakeholder Group	N=	% Returned	# Outcomes rated extremely desirable by 75% or more respondents	# Outcomes rated extremely desirable by 65% or more respondents
Service Coordinators	144	48.6	8	10
Program Administrator	87	47.1	10	16
Families	80	21.2	6	13
Childcare Providers	54	29.6	2	6
Service Providers	22	63.6	0	2
Physicians	9	66.6	1	2

State	N=	% Returned	# Outcomes above 65%	# Outcomes above 55%
Connecticut	81	41.9	3	11
Indiana	115	44.3	2	9
Massachusetts	92	47.8	4	9
North Carolina	104	46.1	10	22

Appendix C

Highest rated outcomes by stakeholder group
March 23, 2001

Stakeholder Group	Outcome	% of respondents selecting "extremely desirable"
Service Coordinators	Families have an understanding of child	91.4
	High quality services are delivered	91.4
	The system is effective	88.2
Program Administrators	Families are supported as decision makers	92.7
	Families are informed	90.2
	Families are linked to available services	90.2
Families	Kids get the best therapy	94.1
	Child's needs are met	94.1
	Aided the development of children	88.2
Childcare Providers	Children's needs are prioritized	87.5
	Children's successes are promoted	87.5
	Abundant funding is provided	81.3
Service Providers	Administrative functions are completed	78.6
	Paperwork is completed in a timely and efficient manner	78.6
	Administrative functions are carried out	71.4
Physicians	(Child) is supported by adequate resources	83.3
	Provided best services	83.3
	Achieved a better existence (for child and family)	66.7

Appendix D

Top three rated outcomes by state

State	Outcome	Percent
Connecticut	Child potential is maximized	73.5
	Children are supported	67.6
	Children are transitioned to the next step	67.6
Indiana	Children receive appropriate services	74.0
	Informed families of services	66.0
	Worked as a team	62.7
Massachusetts	Met child's needs	69.8
	Developed optimal potential of child	67.4
	Met individual family needs	65.1
	Provided excellent family support	65.1
North Carolina	Child's needs are met	77.1
	Children reach their optimal potential	77.1
	Child's development is enhanced	72.9
	Children are healthy	72.9
	Families are involved in decision making	72.9

Appendix E

Top rated outcomes by stakeholder group

Stakeholder Group	Outcome	Percent
Service Coordinators	Families have an understanding of child	91.4
	High quality services are delivered	91.4
	The system is effective	88.2
	Effective communication exists	87.1
	Families capabilities are increased	87.0
	Child is supported	86.8
Program Administrators	Families are supported as decision makers	92.7
	Families are informed	90.2
	Families are linked to available services	90.2
	Families know their rights	90.2
	Coordinated services are provided	87.8
	Families move toward independence	87.8
Families	Enables kids to get the best therapy	94.1
	Met child's needs	94.1
	Aided the development of children	88.2
	Children are treated with equality	88.2
	Helped child reach best potential	88.2
	Provided excellent family support	88.2
Childcare Providers	Children's needs are prioritized	87.5
	Children's successes are promoted	87.5
	Abundant funding is provided	81.3
	Affordable care is provided	81.3
	Trust is promoted between providers and families	81.3
	Providers know who to call for help	75.0
Service Providers	Administrative functions are completed	78.6
	Paperwork is completed in a timely and efficient manner	78.6
	Administrative functions are carried out	71.4
Physicians	(Child) is supported by adequate resources	83.3
	Provided best services	83.3
	Achieved a better existence (for child and family)	66.7