

RESEARCH AND TRAINING CENTER IN SERVICE COORDINATION

Outcome Interview Data Report

Purpose

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 area in which families and providers report the lowest levels of satisfaction. The current study was conducted in conjunction with a series of descriptive and intervention (experimental) studies aimed at identifying outcomes and practices of effective service coordination. A review of literature revealed that there are no efficient and effective measures of both service coordinator practices and outcomes. Therefore, the current study was designed to provide an innovative means of measuring service coordinator outcomes and practices.

Research Design

A qualitative research design was utilized to identify: (1) what outcomes families hoped to achieve for their child and family as a result of early intervention, (2) who helped to achieve those outcomes, and (3) what practices those individuals used to help. Semi-structured interviews with family members of a child participating in early intervention and a semi-structured telephone interview with each family's service coordinator were used as a means of generating data. The qualitative means of collecting input from family members and service coordinators provided a sound basis for examining essential outcomes and practices of service coordination. A combination of qualitative methods allows for verifying data and generates new ways of thinking which may reveal contradictions in the data (Brotherson, 1994). The use of multiple perspectives in this study is designed to help inform and assess the efficacy of early intervention service

coordination. Qualitative methods are advantageous in that they encompass interpersonal, social and cultural contexts more fully than quantitative methods (Solutes, 1990).

Site Selection

Four focal states were empirically selected for participation in this study. These states were Connecticut, Indiana, Massachusetts and North Carolina. Investigators serving at institutions within these states were collaborative partners in all aspects of the Research and Training Center (RTC) and serve on the advisory board. Family and service coordinator demographics within these states are representative of the national early intervention demographic data.

Participants

Participants for this study included 80 family members who had a child enrolled in an early intervention program in one of the RTC's four focal states and each family's early intervention service coordinator. Families were recruited according to specific guidelines to ensure that a representative cross-section was obtained. A recruitment grid listing each of the family and child demographic variables desired for participation in this study was sent to project staff in each of the focal states. As project staff identified potential participants they contacted staff members at the RTC in Connecticut to make sure there was equal distribution across the different recruitment variables and across states. 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

Staff at the RTC compiled a master list of family demographics that was centrally compared with the target demographics. See Table 1.

Table 1. Family Interview Recruitment Grid.

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		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

A total of 100 families were recruited for participation in this study; however, only data from 80 participants were included in the final analysis. Of the 80 families, 40.0 % lived in urban areas, 36.2% lived in suburban areas, and 23.8% of the families lived in rural areas. The majority of the families were white (42.5%), while additional ethnicity groups represented included Black (23.8%) Latino (12.5%), and other (21.2%). Approximately 42 percent of the families were from low-income households and 57 percent were from non low income households based on parent report. The children with disabilities were categorized according to three age groups: 0-1 year old (31.3%), 1-2 years old (31.3%), and 2-3 years old (37.4%). Children were also categorized

according to the complexity of their needs. Of the 80 families, 43.7% indicated their child's needs were mild, 31.3% were moderate and 25.0% identified their child's needs as complex.

In each of the four focal states some of the service coordinator participants served more than one family in the study, making the number of service coordinators smaller than the 80 family participants (N=65). Of the service coordinators participating in this study, 41.5% worked part time and 58.5% worked full time. The majority of service coordinators had 1.1-5 years of experience (44.6%), 26.1% had 5.1-10 years experience, 18.5% had less than one year experience and only 4.6% had more than 15 years experience.

Instruments

Interviews with family members and service coordinators were used to identify (1) outcomes that families hoped to achieve as a result of early intervention, (2) who helped to achieve those outcomes and (3) the practices that they used. Interviews were chosen as a means of data collection because of the rich detail that can be generated by allowing others to share their stories (Patton, 1990). During interviews, family members and service coordinators were asked questions that elicited their perceptions and experiences with early intervention, and specifically service coordination.

A protocol was developed by project staff specifically for this study in May 2001. The RTC staff revised the protocol in July 2001 and conducted a pilot study with five families in the four focal states, which resulted in further refinement of the protocol. Project investigators approved the final protocol on July 17, 2001 and obtained IRB approval from the University of Connecticut Health Center. The protocol consisted of semi-structured questions and probes aimed at eliciting rich and pertinent conversations with family members and service coordinators about families' experiences and the outcomes they hoped to achieve as a result of

participating in an early intervention program. The family interview protocol was designed to gain input from families based on their experiences with early intervention and service coordination to: (1) identify outcomes of effective service coordination, (2) identify who helped to address those outcomes as perceived by families and (3) identify and measure practices that lead to effective service coordination outcomes. The protocol also included questions pertaining to the importance of each identified outcome, how service coordination helped with the outcomes, and how long it took to achieve the outcomes. 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 data recording forms.

The protocol used for service coordinator interviews was designed to elicit conversation pertaining to service coordinators’ perceptions of what outcomes were important to families, how the service coordinator helped the family reach those outcomes and what they did to help. Additional questions pertained to service coordinator’s years of experience, training and supervision.

Procedures

In-person interviews with 80 family members and telephone interviews with each family’s early intervention service coordinator were conducted as a means of identifying (1) outcomes families wanted to achieve for their child and family as a result of participating in early intervention, (2) the people who helped to achieve those outcomes and (3) the practices used to help achieve those outcomes.

Train Staff

Staff were trained on data collection procedures and how to use the protocol for the family and service coordinator interviews on August 1, 2001. This training session was held at the RTC in Connecticut. Participants included all individuals who would potentially be conducting interviews. Once trained, staff at the RTC in Connecticut mailed packets of the interview protocols, including an introductory letter, the interview forms and self-addressed return envelopes to each location. Each site was provided with a checklist to ensure proper return of all interview materials.

Recruitment Procedures

Families were primarily recruited through service providers and service agencies. Project staff from all sites contacted providers in their state to request their help in informing families of the opportunity to participate in the present RTC study. Staff gave an overview of the RTC to providers and explained what the interview process would entail. Staff also informed providers of the specific guidelines that were being followed during the recruitment process.

Providers identified families that were interested in participating in the project and matched them with the requested demographic variables that were needed. Families were given the option to call RTC staff directly or give permission to share their information and have staff contact them directly. With family consent, project staff contacted the identified families and further informed them about the project and the approximate time commitment for conducting an interview. Service coordinators were recruited for participation by virtue of the fact that they provided service coordination for one or more of the families participating in the study.

Interview Procedures

Interviews were scheduled and conducted beginning August 6, 2001, and were completed by March 2002. Project staff in the four focal states (Massachusetts, North Carolina, Indiana, Connecticut) contacted families and informed them about the project and the approximate length of time necessary to complete the interview. All interviews with family members were conducted in a location the family identified as being convenient. At the time of the interview, families were asked to give written informed consent to conduct the interview, as well as consent to obtain a copy of their child's most recent Individualized Family Service Plan (IFSP) and permission to contact and interview their service coordinator through the early intervention program. Participants were given a copy of the interview guide prior to conducting the interview. Families were introduced to the concept of service coordination and asked "tell me about your family", which led to a discussion about 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. In addition to documenting key points on a data recording form, each interview was audio-taped to provide accuracy during data analysis. Member checks were completed at the end of each interview to ensure the researchers captured the true intent of what families communicated.

Upon completion of the family interviews and with written informed consent, project staff called each family's early intervention service coordinator to request a copy of the child's most recent IFSP and to request a time to conduct a telephone interview with the service coordinator. A written informed consent form was faxed to the service coordinator to sign and send back to the RTC in Connecticut. Telephone interviews were scheduled at times convenient for the service coordinators. Each interview was audio-taped in addition to the researcher

documenting critical information regarding outcomes and practices of service coordination on a data recording form. Staff in each of the four focal states mailed materials back to the RTC as interviews were completed, including audio-tapes, data recording forms, and IFSPs.

Data Analysis

During data analysis it is critical that standards of rigor are adhered to by all project personnel (McWilliam, 2000). A reliability check was conducted on a randomly selected sample of 20% of tapes from the initial 100 interviews. The trained researcher denoted outcomes, who helped to achieve those outcomes, and practices from the transcribed interview. A comparison of data sets extracted from the interviewer and those of the project researcher was performed demonstrating 81.6% correspondence between interviewer and researcher. Project staff elected to transcribe all 100 interviews and record data from the interviews as a reliability assurance and means of recording data for future measures. Reliability checks have been completed on 100% of the initial family and service coordinator interviews. Of the 100 families who were recruited and interviewed, six (6) of the family interviews tapes did not yield enough data for analysis and fourteen (14) family interview tapes were not audible, yielding a total participation of 80 families and their respective early intervention service coordinator.

Statements pertaining to outcomes families hoped to achieve as a result of early intervention, persons responsible for addressing those outcomes, and the practices they used were extracted from the transcriptions and organized in to a master database of outcomes, practices and persons who helped for both the family and service coordinator interviews. Outcomes and practices from the family and service coordinator interviews were independently themed into categories to yield outcome codes. A five step process of data reduction (Li, Marquart & Zercher, 2000) and sorting was utilized to yield eight interview outcome codes.

Similarly family and service coordinator interview practices were sorted and reduced into 12 interview practice codes through a five step process. Once theming of all family and service coordinator interview data was completed, the individual outcome statements were coded according to the interview outcome codes, as well as the Delphi outcome codes and by the system-family-child codes. Likewise, the practices were coded by the interview practice codes, the Delphi practice codes and the system-family-child codes.

Interview Outcome Reduction and Theming

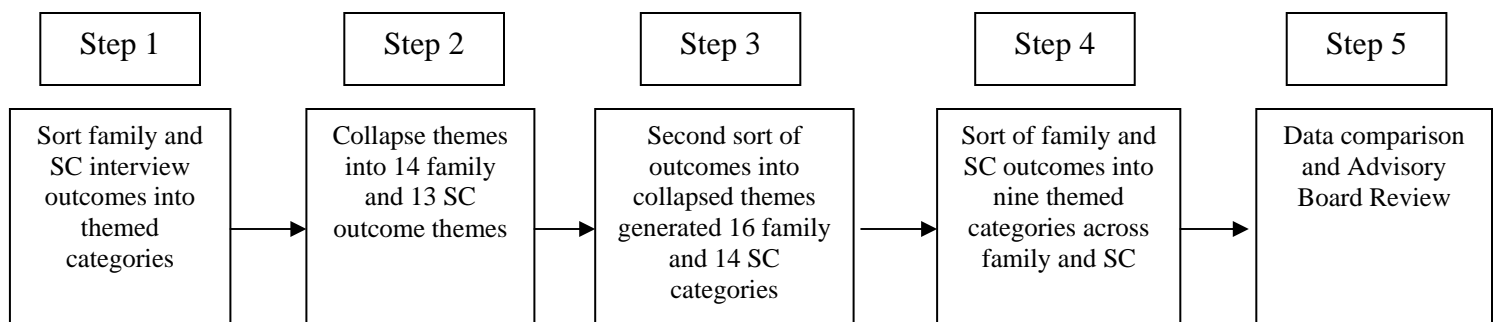
The individual outcomes generated from interviews with family members and outcome responses from service coordinators were analyzed by theming the individual outcomes and creating coded statements that encompassed the meaning of like outcomes. Theming of both the family and service coordinator outcome statements was conducted in five distinct steps to ensure that no potential outcome category was overlooked.

During step one, four research assistant were asked to sort the outcome statements and reduce them into meaningful themes. Two independent research assistants sorted the family interview outcomes into themed categories and two different independent research assistants sorted outcomes identified by service coordinators into themed categories. The themes were tested and refined through recursive review to ensure category independence. Coding to consensus and reliability checks were completed for 100% of the interview data for families and service coordinators. Reliability was also completed for 100% of data entry for both family and service coordinator data.

Step two was conducted by one of the project investigators and the project coordinator who reviewed the list of categories created in step one and collapsed similar themes to generate a list of 14 family and 13 service coordinator interview outcome themes. Step three was conducted

to ensure that these themes were inclusive of all outcome statements generated during both the family and service coordinator interviews. During step three, the project investigator, the project coordinator and three project staff members re-sorted the family and service coordinator outcomes. The sorting conducted in step three yielded additional outcome categories for a total of 16 family outcome categories and 14 service coordinator outcome categories. The fourth step included running frequencies and percentages for each of the categories and rank-ordering them to compare the family and service coordinator outcomes. The investigator and project coordinator collapsed outcome categories with less than 5% frequency into other categories that reflected similar content for a final listing of 9 themed categories that were the same for both family outcomes and service coordinator outcomes. Finally, during step five a data comparison of all outcome data sources from the RTC was conducted and reviewed by the project advisory board. Board members reviewed the data comparison and came to consensus on the wording of 8 final outcome statements. See Figure 1 for Outcome Methodology.

Figure 1. Interview Outcome Methodology



Outcome Coding

Outcome statements from families and service coordinators have been put into tables, respectfully, and coded according to the final eight interview outcome codes, the Delphi outcome codes and by a system-family-child framework. The final interview outcomes are as follows:

1. Families are knowledgeable of their child's unique needs
2. Families have the tools, knowledge and supports to access resources
3. Families acquire and/or maintain a quality of life that enhances their well-being
4. Families make informed decisions about services and opportunities in the community for their children
5. Children are safe and healthy
6. Children's development is enhanced
7. Children and families receive quality early intervention services that are individualized, coordinated and effective
8. Children will have successful transition

The seven Delphi outcome codes include:

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

The responses were also coded based on child-family-system framework outlined in the original grant proposal:

1. System
2. Family

3. Child
4. System/Family
5. System/Child
6. Child/Family
7. Child/Family/System

Project staff independently coded the family interview outcome data separate from the service coordinator interview data. Outcome statements were coded to consensus with the project coordinator and data manager conducting reliability checks on 100% of the coded outcomes. Family interview data were compared to service coordinator interview data according to the interview codes and the Delphi codes to determine the level of agreement between families and service coordinators on key issues related to service coordination outcomes. Descriptive statistics were run for each comparison. In addition to the coding of outcome statements, project staff accounted for the individuals who families and service coordinators identified as helping to meet each outcome. These data were extracted from the interviews and put into a table. Descriptive statistics were run on the “who helped” data in order to compare family responses with those of service coordinators.

Results

Interviews with family members and conversations with service coordinators in early intervention have helped to identify essential outcomes of service coordination and the practices that support those outcomes. Eighty family members with a child enrolled in early intervention in RTC focal states (Connecticut, Indiana, Massachusetts, and North Carolina) and their early intervention service coordinators engaged in meaningful conversation to reveal what outcomes families hoped to achieve as a result of early intervention, who helped them to achieve those

outcomes, and what those individuals did to help. The focus of the analysis for this report was the data on outcomes identified by families and service coordinators during in-depth interviews. The integration and comparison of families' and service coordinators' accounts help to clarify how service coordination is experienced.

Interview Outcome Reduction

Family and service coordinator outcomes were themed into outcome categories through a five step theming process. A comparison of the outcome data points from the family and service coordinator interviews, Delphi study and national outcome survey was conducted. The project advisory board reviewed the comparison and came to consensus on the wording of the final 8 outcomes broken down into four family outcomes, two child outcomes, and two system outcomes:

Family

Families make informed decisions about services and opportunities in the community for their children with a disability

Families acquire and/or maintain a quality of life that enhances their well-being

Families are self-sufficient

Families are knowledgeable of their child's disability

Child

Children's development is enhanced

Children are safe and healthy

System

Children will have successful transitions

Children and families receive early intervention services that are individualized, coordinated and effective

Outcome Coding Comparison

Interview data for families and for service coordinators were coded to consensus by project staff according to the interview outcome codes, the Delphi outcome codes and system-family-child codes. Comparison of family and service coordinator interview outcomes, coded by the Delphi outcome codes, are represented in Table 1:

Table 1. Comparison of Interview Outcome Statements Coded by Delphi Outcomes

Total Percent of Interview Responses by Delphi Outcome Code: Families vs. Service Coordinators							
Interview	Families Informed	Families Involved	Services	Health	Transition	Devel.	Teaming
Family	3.1	1.8	37.5	8.3	4.5	43.8	.9
Service Coordinator	7	0	33.4	5.3	4.4	48.7	1.2

Both groups identified the outcome of “child’s health and development is enhanced” with the greatest frequency (families 43.8%, service coordinators 48.7%), followed by receiving “appropriate supports and services” (families 37.5%, service coordinators 33.4 %). The least frequent response offered by families related to “people work together as a team” (.9%). Service coordinators failed to report outcomes of “families being involved in decision-making”.

Interview outcome data were also coded and compared according to the interview outcome codes. The results are reported in Table 2.

Table 2. Comparison of Interview Outcomes States Coded by Interview Outcome Codes

Total Percent of Outcome Statements by Interview Outcome Codes: Families vs. Service Coordinators								
Interview	Knowledge	Quality of Life	Sufficient	Decisions	Safe and Healthy	Dev.	Services	Transition
Family	9.9	13.8	6.8	11.1	10.4	37.2	4.9	6.5
Service Coordinator	6.2	7.9	9.7	8.5	6.7	45.2	10.3	5.6

Family members as well as service coordinators identified “children’s developing being enhanced” most frequently (36.2% and 45.2% respectively). The second highest outcome responses for families were around “quality of life” (13.8%) followed by “families will make informed decisions” (11.1%). Service coordinators identified “families receive quality services” as the second most frequent outcome (10.3%), followed by “families are self-sufficient” (9.7%).

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). Family members identified a total of 964

family members and professionals that helped make the outcome happen. Service coordinators identified 988 different individuals that helped. Table 3 reports percent of total family and service coordinator responses relating to identification of people who helped the child/family reach identified outcomes.

Table 3. Comparison of Family and Service Coordinator Report of “Who Helped”

Total Percent of Interview Responses According to Who Assisted The Family					
Interview	Parent/Family	Service Coordination	Service Provider	Doctor	Other
Family	32.4	20.9	28.6	7.2	10.9
Service Coordinator	25	33.6	30	3.7	7.7

Both families and service coordinators identified themselves as playing the primary roles in assisting children/families. Families acknowledged their own involvement in 32.4% of the outcomes they sited as important and service coordinators in 20.9% of their outcomes. Service coordinators, on the other hand, identified themselves as assisting in 33.6% of family outcomes and families in 25%. Family members rated service providers second to themselves (28.6%). Service coordinators also ranked service providers as assisting in outcomes second to themselves (30%).

Summary

Listening to the accounts of family members and their early intervention service coordinators has been a critical component of the research activities carried out by the Research and Training Center in Service Coordination. Family members have helped to identify essential

outcomes of service coordination. As noted by Patton (1990), there is much to learn from listening to those directly impacted by social phenomena. Service coordinators also helped identify what is important to families and how we can best help them meet outcomes they hoped to achieve for their child and family as a result of early intervention. The outcomes identified through talking with family members and service coordinator can assist the field of early intervention in providing quality services to families.

References

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