

## **RESEARCH AND TRAINING CENTER IN SERVICE COORDINATION**

### **PARENT ICC SURVEY**

#### **DATA REPORT**

**March 27, 2001**

#### **Purpose**

In December 2000, the Research and Training Center on Service Coordination at the University of Connecticut School of Medicine conducted a written survey of 319 parent leaders to examine issues related to service coordination under Part C of the Individuals with Disabilities Education Act. Data indicated that service coordination was an area of considerable concern to families. However, a significant number of the parents did not know about the service coordination model used in their state. In order to further examine issues regarding service coordination, a phone survey was conducted of parent representatives serving on Interagency Coordinating Councils (ICC) under statewide Part C programs.

#### **Method**

##### **Participants**

Participants in the survey were selected through recommendations from the respective Part C coordinator or state ICC staff liaison, or by contacting each of the state ICCs. Additional contacts were generated through the use of a database of participants in previous Research and Training Center activities.

##### **Survey Design**

The telephone survey was conducted in January and February 2001. The study focused on federal regulations related to service coordination, models of service coordination, the degree to which ICCs addressed service coordination issues, and outcomes of high quality service

coordination. The survey was comprised of a combination of 23 closed- and open-ended items related to:

- Demographic information (5 items)
- Federal regulations related to service coordination (8 items)
- Models of service coordination (5 items)
- ICC activity related to service coordination (4 items)
- Outcomes of high quality service coordination (1 item)

## **Results**

### **Demographics**

Of the fifty participants in the survey, most were Caucasian women (84%; N=42), 8% (N=4) were African Americans, 4% (N=2) were Asian Americans, and 4% (N=2) identified themselves as Latino or Hispanic. The majority (90%; N=45) had one child that had received early intervention services. Of this group, 65% (N=29) participated in early intervention within the past five years. The participants lived in the following locations: 26% (N=13) in suburban environments, 28% (N=14) in urban areas, 20% (N=10) in small towns, and 26% (N=13) in rural areas. Ninety percent (N=45) were women, ten percent (N=5) were men. Nearly 35% (N=17) had children who received early intervention services more than five years ago.

Slightly less than half of the participants (48%; N=24) were members of their respective councils for two years or less. Another 24% (N=12) were council members for 2 to 4 years, while 28% (N=14) had been members for more than 4 years. Sixty percent (N=30) were currently serving as parent representatives on the council. Forty-four percent (N=22) played multiple roles on their councils, including representative, committee chair, council chair, and vice-chair. Twenty percent (N=10) were chairs of their respective ICCs, while 10% (N=5) were either co-chairs or vice-chairs.

The largest percentage of parents interviewed had children with Down syndrome (30%; N=15). Sixteen percent (N=8) had children with developmental delays. The remaining parents had children with other diagnoses, including cerebral palsy, autism, language delay, deafness,

and mental retardation.

### **Federal Regulations**

Participants were asked how familiar they were with federal regulations related to service coordination, including the qualifications and expectations for service coordinators. They were also asked to assess the degree to which various stakeholder groups within their states were familiar with these same regulations.

Sixty percent (N=30) of the participants considered themselves to be familiar with federal regulations. Forty percent (N=20) said they were unfamiliar or unsure about their level of familiarity. When asked if they understood the role of the service coordinator according to federal regulations, 72% (N=36) said that they knew the role and 26% (N=13) said that they did not. Therefore, while most of the participants were generally familiar with the role of service coordinators within their state, many were not familiar with the definition and functions for service coordinators as laid out in federal regulations.

A minority of the participants were confident in their knowledge of the qualifications of service coordinators as defined by the federal regulations. Sixty-two percent (N=31) said that they were not knowledgeable about qualifications, while 38% (N=19) said that they were informed.

Survey participants were asked to assess the degree of familiarity of various stakeholder groups with the federal regulations related to service coordination. When asked about state level Part C administrators and their respective staff members, an overwhelming majority of participants (96%) were confident that state level staff were familiar with the regulations. Forty-eight percent (N=24) of the participants thought their states' service providers were familiar with the federal regulations, while 50% (N=25) said that service providers were not familiar with the federal regulations or they were unsure of their familiarity.

When asked about the degree to which service coordinators in their respective states were familiar with the federal regulations related to service coordination, 64% of the participants (N=32) thought they were familiar. Fourteen percent (14%; N=7) indicated that they thought the

service coordinators were unfamiliar with the federal regulations, while 22% (N=11) were unsure. Sixty-eight percent (68%; N=34) considered training personnel in their states to be familiar with the federal regulations related to service coordination. Only 6% (N=3) thought that training personnel were unfamiliar, while 26% were unsure. Sixty-four percent (N=32) of the participants considered their ICCs to be familiar with the federal regulations, while the remaining 18 participants (36%) indicated that their ICCs were unfamiliar or were uncertain of their level of familiarity.

### **Models of Service Coordination**

The participants were asked if their state had a specific model for conducting service coordination. Thirty-eight percent (N=19) reported that they did have a model, 14% (N=7) responded that they did not, and almost half (48%; N=24) said that they were unsure if their state had a model. When asked to describe how service coordination was implemented in their states, all of the participants were able to describe a process in which eligibility was determined, followed by an assessment and the development of a service delivery plan. In response to a follow-up question about the state model, 26% (N=13) indicated that their state was in the process of making changes, while 58% (N=29) said that their states were not. Eight of the parents (16%) said that they were unsure if their state was making changes.

Participants were asked two questions related to the quality of service coordination: “Who does the system of service coordination work for?” and “Who does the system of service coordination not work for?” Seventy-eight percent (N=39) of the parents identified families as the primary recipient of quality service coordination. Six percent (N=3) didn’t know who was best served and 4% (N=2) said there was too much variability in their state systems to adequately answer the question.

When asked to identify for whom the system of service coordination did not work, the 50 participants generated a list of 55 distinct responses. Families with distinguishing characteristics were mentioned most frequently (44% of the time). Families who were not resourceful in locating services or who were not assertive or confident were identified 11% of the time, and families with

children with complex medical needs were mentioned 9% of the time. Other factors related to a negative experience with service coordination included a lack of interest or motivation in services (8%; N=4), children who had transitioned into school-aged services (8%; N=4), and location of the family home, especially those in rural, urban, or other areas considered “unsafe” by service providers (8%; N=4).

### **ICC Activity Related to Service Coordination**

Participants were asked if their ICCs discussed service coordination. Sixty-two percent (N=31) stated that their ICC discussed service coordination as a general topic. Sixty-two percent (N=31) reported that they discussed financing or funding of service coordination, particularly as part of the larger discussions that their ICCs conducted related to budget. Thirty-four percent (N=17) said that financing of service coordination was not discussed. Four percent (N=2) said that they did not know if finance was a topic of discussion.

Training related to service coordination was discussed by ICCs in 66% (N=33) of the states; twenty-eight percent (N=14) noted that they did not discuss training. Six percent (N=3) responded that they did not know if their ICC discussed training.

In 44% (N=22) of the states, the ICCs discussed the qualifications of service coordinators; in 50% (N=25) of the states, they did not. Six percent (N=3) did not know if this was a topic of discussion.

### **Outcomes of High Quality Service Coordination**

Participants in the survey were asked: “If service coordination were of the highest quality for children, families, and systems, how would you know it?” The most common response, mentioned by 68% of participants (N=34) was that the best indicator of high quality service coordination would be that children and families were getting the services and supports they needed and that families were satisfied with the services. Another outcome of high quality service coordination, mentioned by 38% of the participants (N=19), would be families who were aware of the services that they needed and who were empowered to seek out these services.

Seven participants (14%) noted that an easier transition to Part B related services was an important outcome.

## **Summary**

Data from this nationwide survey revealed that service coordination is a topic that is discussed at more than half of the ICCs across the country. More than half of the ICC parent representatives interviewed considered themselves familiar with the federal regulations related to service coordination. A larger number said that they were familiar with the role of the service coordinator within their state.

Though nearly all of the participants considered the state Part C administrators and staff to be familiar with the federal regulations related to service coordination, parent representatives who were interviewed were less confident of the knowledge of the ICC about these same issues. Sixty-four percent said that their ICCs were familiar with the federal context for service coordination, while more than half said that their ICC discussed service coordination in general. It is important to note that, in the perception of the ICC parent representatives who were interviewed, nearly half of the service providers in their states were viewed as unfamiliar with federal policy definitions and guidelines related to service coordination.

It is disturbing to learn that a relatively high percentage of ICC parents were unsure or unaware of the federal policies related to role definition, qualifications, and training. Over one quarter of those interviewed were not aware of the role of the service coordinator according to federal regulations, while over half of the participants were unfamiliar with the required baseline qualifications established by the government. Equally troubling is the fact that less than one quarter of the participants did not know how well their respective systems of service coordination were serving families, while an additional, but smaller number noted that they were certain that families were not being served well at all.

These data indicate a need for increased involvement of parents in the discussions on service coordination that are occurring on councils nationwide. Given the fact that service coordination is not discussed at almost half of the ICCs across the country (with less attention

given to qualifications, training, and financing) there is a related need for more in-depth discussions of specific areas of policy development.

Our original survey of 319 parent leaders (December 2000) revealed a high degree of variability in approaches to service coordination nationwide and the current survey of 50 ICC parent leaders confirmed that finding. Both surveys revealed that families view service coordination as a critical element in assuring that families receive appropriate, beneficial services and supports.