

DATA REPORT: PARENT LEADER SURVEY

Purpose

The purpose of the survey was to explore families' perceptions of their statewide systems of service coordination. Early intervention service coordination represents a complex set of activities and relationships, which begin at the time a family enters into the system and continue through the family's transition from Part C services to preschool services. Service coordination functions as a cornerstone for assuring the design and implementation of high quality, family centered, culturally competent, coordinated, comprehensive, multi-disciplinary, interagency early intervention services.

The survey was designed to probe how early intervention service coordination works in relation to the phases of involvement which families experience, including:

- System entry
- Evaluation and development of the IFSP
- Service provision
- Transition
- Training
- Collaboration

In addition, families were asked to reflect on the strengths and problems of service coordination in their state as well as their vision of the "best system of service coordination."

Method

Participants

Fifteen “parent leaders” from each of the 50 states and the District of Columbia were identified to receive a survey. A “parent leader” was defined as someone who:

- Had a child with disabilities who received Part C services.
- Could provide information on other families’ experiences with Part C services and supports.
- Was perceived by other parents or state system staff as having an understanding of the statewide system of service coordination and how it affected the lives of the families who received early intervention.

In order to identify the sample of families, we consulted with a number of different stakeholder groups from across the country. These included: Part C coordinators; ICC chairs; Family Voices regional and state coordinators; PTI directors; FICC members; University Affiliated Programs; and selected outreach and demonstration projects. In addition, we contacted individual parents who had participated in national conferences or leadership activities sponsored by the National Early Childhood Technical Assistance System (NECTAS) or the National ICC Parent Leadership Support Project. The latter provided access to key parents in local communities who served in some leadership capacity on local or state interagency councils or family leadership training and technical assistance initiatives. Representatives from these stakeholder groups and individuals were asked to nominate parent leaders whom they believed to be likely participants for the survey. Nominated participants were in turn requested to suggest other parent leaders as well. Altogether, over 800 surveys, or 15 per state and 10 per 5 territories, were distributed. The survey was translated into Spanish in order to facilitate participation by Spanish-speaking parent leaders.

Three hundred nineteen parent leaders responded to the survey (note: not all respondents answered every question on the survey), representing each of the 50 states and the District of Columbia with a response rate of approximately 40% of the initial 800. Twenty-three percent of the families (N=73) had children who were between birth and three years old. The majority of the families (84%) had between one and three children. Approximately a third of the families (32%) reported having children currently receiving Part C services. Less than half of the participants (40%) were professionally involved with the Part C system in some way. The educational level of the parents represented in the survey deserves some note. A majority of the mothers (62%) responding to the study reported having undergraduate and/or graduate level degrees; the number is slightly less for fathers (49%).

Survey Design

The family survey included a combination of 51 items distributed over 9 pages, combining both open- and closed-ended questions. Twenty-nine (29) items were closed-ended, including 22 Likert-scale questions (each with four prompts) and 7 multiple-choice items. (Note: some survey questions resulted in more than one answer from respondents.) Participants were asked to write short responses to 22 open-ended questions, which gave participants the opportunity to amplify or clarify the responses related to particular closed-ended items. These data are available in a separate report.

Items were grouped into 7 categories: (1) system entry; (2) evaluation and development of the IFSP; (3) service provision; (4) transition; (5) training; (6) collaboration; and (7) the quality of service coordination and its relationship to identified family and child outcomes. Participants were also asked to complete a brief, anonymous demographic questionnaire.

The survey was distributed in four distinct rounds between April and June 2000. In addition to the survey, each recipient received a cover letter from the 3 principal investigators of the Research and Training Center and a self-addressed stamped envelope to facilitate return of the completed survey. A combination of strategies was used to follow up the initial mailing. In addition to reminders to key stakeholders via personal telephone calls and/or e-mails, reminders to complete the survey were sent out via the ICC Parent listserv, sponsored by NECTAS and the National ICC Parent Leadership Project. A follow-up reminder mailing to all participants in all four rounds was sent in mid-June. Because returns remained low, a second complete mailing was sent out in September 2000 to all individuals who initially received the survey.

Results

System Entry

Over two thirds of the respondents (85%) reported that it was easy or extremely easy to access service coordination in their states. Only a small number (15%) reported that it was difficult or impossible to access service coordination. Approximately one third (34%) of the respondents learned who their service coordinator was when they first entered the early intervention system, yet over a quarter (26%) did not learn who their service coordinator was until after the first IFSP meeting or after the IFSP was signed. Approximately 12% of the families felt it was never clear who their service coordinator was as described in Table 1.

Table 1

Time of Introduction of Family and Service Coordinator

When do families typically find out who their service coordinator is?	Percent Responding
When they enter the early intervention system	34.4
Initial evaluation	17.0
First IFSP meeting	24.0
After the IFSP is signed	2.5
Sometimes it is never clear	12.6
Other	9.5

Over a third of respondents (39%) thought that it was easy, or extremely easy, to choose their service coordinator. However, the majority (61%) thought that it was difficult or impossible for them to participate in the selection of their service coordinator. In cases where one service coordinator handled issues related to system entry and a different person coordinated services according to the IFSP, most parents (90%) thought that this split in role was successful. Only 21 parents (7%) reported that a single service coordinator worked with families for the duration of their enrollment in early intervention.

States differed in who was permitted to act as a service coordinator. The majority of respondents (89%) reported that professionals providing Part C services were service coordinators. A third (33%) indicated that professionals working for an agency that does not provide Part C services could fill this role. Approximately 1/3 (29%) indicated that parents of a child receiving Part C services could act as a service coordinator, albeit on an unpaid basis (66%). In cases where parents provided service coordination services, half (47%) were not

authorized to work with children and families other than their own. This information is in Table 2.

Table 2

Roles of Service Coordinators

Who can be service coordinators in your state?	Percent Responding Yes	Percent Responding No
Professionals that provide Part C services	88.9	11.1
Professionals working for an agency that does not provide Part C services	32.8	67.2
Paraprofessionals that provide Part C services	37.3	62.7
Paraprofessionals working for an agency that does not provide Part C services	16.7	83.3
Parents of a child receiving Part C services and supports	28.9	71.1
<i>If responded "Yes" to above question:</i>		
Are they limited to their own child?	47.3	52.7
Are they paid for their work?	34.3	65.7

Evaluation and IFSP

Most respondents (79%) felt that service coordination helped children get evaluated within 45 days of entering the system. About 1 in 5 (18%) indicated that service coordination sometimes ensured a timely evaluation, while 3% (N=10) said service coordination never helped children get evaluated within 45 days. In the development of the IFSP, thirty-eight percent of respondents (N=120) commented that service coordination is extremely effective in developing an IFSP that is responsive to the needs of the child and family. Forty-eight percent (N=147) claimed that it is somewhat effective in responding to child and family needs. Only 14% found

service coordination ineffective to some degree in ensuring an IFSP that meets the needs of children and families.

One role of a service coordinator is to provide linkage between families and available resources. Thirty-four percent (N=106) of parent leaders expressed strong confidence in service coordinators' awareness of community and family resources, while a third (33%) stated that service coordinators are fairly knowledgeable in this area. Finally, a third of respondents (33%) expressed reservations about the knowledge level of service coordinators.

When asked how effective service coordination was in helping families find services and supports, approximately 30% of the parent leaders (N=101) believed their state's service coordination was extremely effective, while nearly 50% (N=147) felt it was somewhat effective. Eighteen percent (N=56) noted that service coordination was somewhat ineffective in helping families find services, while 3% (N=10) find it completely ineffective.

Parents were asked how well service coordination linked families to advocacy services. Less than 25% (N=75) responded that service coordination was extremely effective in this area, while nearly 40% (N=123) claimed it was somewhat effective. Conversely, over a quarter (N=80) noted that it was somewhat ineffective in locating these services, another 12.5 % (N=39) felt service coordination was completely ineffective in fostering these linkages.

The parents were asked to rank the level of helpfulness of 8 different stakeholder groups in identifying the services and supports that best meet the needs of families within their respective states as listed on Table 3. The groups that were ranked as most helpful were service coordinators (N=92) early intervention staff (N=61) and other families (N=63) Ranked as significantly less helpful were immediate family members (N=23) parent training organizations (N=17), advocacy groups (N=5) physicians (N=8); and social service agencies (N=4) (see Table 3).

Table 3

Rank Order of Supports to Families in Identifying Supports and Services

Who is most helpful to families in identifying the services and supports that best meet their needs?								
	Percent Responding							
	(1) Most Helpful	(2)	(3)	(4)	(5)	(6)	(7)	(8) Least Helpful
Service coordinator	33.6	20.8	16.1	11.3	6.2	5.5	4.0	2.6
Early intervention program staff	22.3	32.8	17.2	9.5	8.4	6.2	2.9	0.7
Other families	23.2	14.7	17.6	14.0	11.0	10.3	4.8	4.4
Physicians	2.9	5.9	8.8	13.2	14.3	9.9	15.4	29.7
Advocacy groups	1.9	10.0	12.6	15.2	14.5	14.1	22.7	8.9
Social service agencies	1.5	1.9	6.4	12.8	11.3	22.2	21.4	22.6
Family members	8.5	4.4	9.6	10.7	17.0	15.6	14.4	19.6
Parent training organizations	6.3	10.7	13.3	15.6	18.1	14.4	12.6	8.9

In relation to IFSP development, the majority of parents (80%) stated that service coordination is fairly helpful to very helpful in the process, while roughly 20% (N=65) believe it is somewhat helpful to not helpful at all.

Service Provision

Parents were asked to rate the degree to which service coordination was helpful in providing the services and supports that families need, once the IFSP was developed. Thirty-six percent (N=116) of the parents indicated that service coordination is very helpful while 36% (N=114) said that it was fairly helpful. Twenty four percent (N=77) of the parent leaders found service coordination somewhat helpful, while almost 4% (N=11) did not find it helpful at all. Over half (N=182) of the respondents reported that families, in general, have enough contact with their service coordinator, while forty-one percent (N=129) of those responding noted that the amount of time families spent with their service coordinator was insufficient.

Parents were asked to rate the effectiveness of their service coordinators as team members with other Part C service providers. Less than a third (N=92) indicated that service coordinators were extremely effective team members while 53% (N=164) of the respondents noted that coordinators were somewhat effective. Fewer respondents (4%, N=11) stated that service coordinators were ineffective in teaming.

In many states, service coordinators play multiple roles, often coordinating services and providing them at the same time. Parents were asked to rate service coordinators' effectiveness in performing this dual role. Over 70% (N=190) of the respondents indicated that coordinators were somewhat to extremely effective while nearly over a quarter (26%) reported that coordinators in their states were somewhat to completely ineffective.

Transition

The transition to pre-school services is a delicate time for any family accustomed to early intervention services and supports. Service coordination can function as a link between two distinct service delivery systems, and the coordinator can often function as a mediator between

these two systems and the family. Over a quarter of respondents (N=83) felt that service coordination was extremely effective in ensuring that needed services and supports were in place when a child turned three. Forty-three percent (N=129) believed that transitions were somewhat effective, while 22% (N=66) felt that transitions were somewhat ineffective. Six percent (N=19) stated that the service coordination system is completely ineffective in facilitating a smooth transition to school services.

Because families can acquire advocacy and service coordination skills from their experience with Part C related systems and supports, we asked our respondents to comment on the degree to which service coordination helps families learn the skills and knowledge necessary to coordinate services after the transition from early intervention. Only 13% (N=40) noted that the system is extremely effective in accomplishing this, while over 46% (N=137) were less favorable, rating service coordination as somewhat or completely ineffective.

Training

We asked parent leaders a series of questions about training. Nearly one in five respondents (18%) indicated that no service coordination training was provided in their state. When training was offered, it was most frequently (56%) provided by the lead agency. Nearly a quarter of respondents (N=64) noted that training was provided by a state agency other than the lead agency, while another 25% (N=65) indicated that the training was delegated to a university, college, or community college. Twenty percent (N=55) of those surveyed noted that training was subcontracted to a parent training organization. Fifteen percent (N=40) stated that training was subcontracted to a private consultant, 10% (N=28) to an OSEP funded demonstration project, while 16% (N=43) stated that some group other than those mentioned above was responsible for training as described in Table 4.

Table 4

Primary Agent for Training in Service Coordination

Does your state provide <u>in-service training</u> in service coordination?	Percent Responding Yes	Percent Responding No
No special training provided	17.9	82.1
Training provided by lead agency staff	55.6	44.4
Provided by another state agency	23.9	76.1
Subcontracted to a university, college or community college	24.3	75.7
Subcontracted to a private consultant	14.9	85.1
Subcontracted to OSEP – funded demonstration or outreach project	10.4	89.6
Subcontracted to a parent training organization	20.5	79.5
Other	16.0	84.0

Most parents (63%) were not formally trained in service coordination. More informal training opportunities are available through a family's service coordinator (25%) or through a parent program (30%). Some 21% of the parents (N=65) noted that they learned service coordination skills from reading written materials on the topic provided by the lead agency, the service coordinator, or a local parent program. Given the significance of family-centered training in general, it is somewhat of a surprise that only 12% of parents (N=38) received instruction in the same training group as the professionals.

Over 30% (N=93) of the parents who responded to the survey indicated that they have never served as a trainer during an in-service training program, while nearly 40% (N=110) have

conducted training for other families. Thirty-six percent (N=102) of the respondents noted that they have participated as co-trainers for professionals.

In regard to preservice training, 12% (N=33) of the parents participated most of the time or always. The rest of the parents sometimes (42%; N=117) or never (46%; N=126) participated in preservice training. Once providers begin providing services, families assist in slightly larger numbers in training activities, though 33% (N=92) indicated that this “never” occurs, while nearly 50% (N=134) said that families participate in training activities “some of the time.”

Collaboration

Given the importance of authentic collaboration to effective practice in service coordination, families were asked to comment on the nature of the collaborative process, the mediation process employed when disagreements occur between families and coordinators, and parents’ perceptions about the frequency with which families change their coordinators. Slightly more than half of the parents (N=156) reported that family-professional collaboration was somewhat effective with another 30% (N=91) rating it as extremely effective. Nearly 20% (N=57) stated that the quality of the collaborative processes was somewhat to completely ineffective. When conflict occurred between families and providers, a majority of respondents noted that service coordination was effective in mediating these disagreements. Over 50% (N=137) rated service coordination somewhat effective, while 18% (N=48) declared it as extremely effective. Nearly a third (31%, N=83) rated it as somewhat to completely ineffective.

When asked how frequently families request a different service coordinator, over 87% of parents (N=239) stated that this occurred infrequently or never. Only 12% (N=34) responded that this occurred frequently. When asked how effective their state’s service coordination was in helping families reach their desired outcomes, over half of the respondents (N=155) declared that

their state system was somewhat effective, while nearly 30% (N=87) felt their systems was very effective. Nineteen percent (N=56) believed their system was somewhat ineffective or not at all effective.

Summary

Parent leaders view service coordination as an important function in each phase of involvement in the early intervention system. Service coordination is:

- An important catalyst for organizing and implementing effective, family-centered supports for young children with disabilities and their families.
- A critical factor in sustaining flexibility in family involvement in IFSP planning and implementation.
- A facilitating facet of service delivery which can function as training for parents in acquisition of skills and knowledge necessary to coordinate future services and supports beyond the early intervention system.
- A significant factor in making transitions easier, extending from entry into the system to transition to Part B related services.

The data indicated variability of function and utility of service coordination across the country. The varied (and often multiple) roles, which service coordinators may play within any given system, complement the national approaches to early intervention. However, service coordinators have multiple responsibilities, which may limit their potential for playing key roles within the lives of the families they serve. Coordinators are not always clearly understood or valued by families, possibly because of limitations of time, fragmented expectations from multiple constituents, and variable approaches to training.

The multiple expectations that parent leaders have for service coordination may be an indicator of a lack of clarity in defining the actual role and importance, which this function has. Though they value the system of service coordination, parent leaders often have as many concerns about what and how much they can expect from it.

Service coordination has multiple definitions for families, with expectations ranging from the organizational and logistical to more esoteric, interpersonal skills aimed at identifying community supports and facilitating involvement of families within those communities. When expectations are of such a varied and complex nature, the importance of clear policy guidelines that define the parameters that guide the delivery of high quality service coordination is vital. As important are high quality training programs that match the policy parameters that are laid out on the state and local levels. Collaboration with parents on the conceptualization, development, and implementation of this training is critical to its success in responding to family needs.

This survey has underscored the multiple roles that parents have assumed in key leadership positions across the country. Parents are not only leading initiatives in policy development on the local, state, and federal levels through membership on interagency councils, they are also engaged in training and family support initiatives aimed at parents of young children within their communities. However, even among such a broad-based pool of respondents, there was significant variability in the definition, expectation, and expected outcomes for service coordination. Beyond this variability, a further cause for study is the relatively high number of respondents who did not have important and basic information about the service delivery system that was needed to complete the survey. This is an obvious call for more accelerated and in-depth involvement of families in all aspects of service delivery and policy development. It is only with this kind of involvement that the potential for high quality service coordination can begin to be realized.