To the Graduate Council:

I am submitting herewith a dissertation written by Latha Keshav Bhushan entitled "Initial Individualized Family Service Plan Process: Parents' and Service Coordinators' Perceptions." I have examined the final copy of this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy, with a Major in Education.

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Initial Individualized Family Service Plan Process: Parents' and Service Coordinators' Perceptions

A Dissertation

Presented for the

Doctor of Philosophy

Degree

The University of Tennessee, Knoxville

Latha Keshav Bhushan

May 1996

DEDICATION

To my parents

Mrs. Lalitha Keshavamurthy

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Mr. Puttashamaiah Keshavamurthy

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ABSTRACT

Public Law 99-457 stipulated that an Individualized Family Service Plan (IFSP) be developed to serve infants and toddlers with disabilities and their families. This plan is developed through the process of interaction and through the activities that are carried out between families, professionals and service coordinators. This study was conducted to explore the initial IFSP process from parents' and service coordinators' perspectives within the Tennessee Early Intervention System (TEIS), a unique model in serving children and families.

Qualitative research techniques were used in this study. The overall research question is ***How do parents and service coordinators perceive the IFSP process?*** The participants in this study included five service coordinators from two district offices of TEIS and five parents (mothers) of infants and toddlers with developmental delay receiving services from TEIS. Four kinds of data were obtained from parents and service coordinators: 1) demographic data, 2) taped self-interviews, 3) open-ended interviews, and 4) artifacts (e.g., referral form, IFSP). The data were analyzed using qualitative methods.

Findings related to service coordinators' and parents' functions suggested that they complement one another, with the service coordinators encouraging parents to take an

active role in the IFSP process. The typical IFSP sequence within TEIS described by the service coordinators was consistent with a family-centered process of developing the IFSP. Both the parents' and service coordinators' responses suggested that there are several aspects of the child/family influencing the activities and interactions of the initial IFSP process. The service coordinators' responses indicated that they were unable to comply with the regulation of holding the initial IFSP meeting within 45 days for most families. Service coordinators' and parents' responses alike indicated that practices related to communication are crucial to a successful IFSP process. Suggestions provided by service coordinators and parents about the bureaucratic practice of appointing a surrogate parent for a foster child showed some agreement. Results indicated that adoption of the positive approaches identified by the service coordinators facilitated their developing a partnership with parents during the IFSP process. Exchange of information between service coordinators and parents appeared to help them to better serve the children/families, and the parents to make informed decisions about the services through out the initial IFSP process.

The findings of this study have implications for policy, practice, training, and future research.

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CHAPTER I

INTRODUCTION

In 1986, Congress passed Public Law 99-457 which supports early intervention services to infants and toddlers with disabilities and their families. This law provided revisions to Public Law 94-142 the Individuals with Disabilities Education Act. Title I or Part H, a section of Public Law 99-457, provides service to infants and toddlers with disabilities (birth to 3 years) and their families. According to this section of the law, each state choosing to participate is directed to develop and implement a statewide, comprehensive, coordinated, multi-disciplinary, interagency program of early intervention services (Federal Register, 1989). The law specifies 14 components that the statewide early intervention system must include. They are:

1. A state definition of the term "developmental delay";
2. A timetable to ensure services;
3. A multi-disciplinary evaluation of each eligible child;
4. An individualized family service plan (IFSP), including service coordination, for each eligible child and family;
5. A comprehensive child find system;
6 A public awareness system;

7. A central directory of services and other sources;
8. A comprehensive system of personnel development;
9. Designation of a single line of responsibility in the lead agency;
10. A policy on contracting with local service providers;
11. Procedures for timely reimbursement of funds;
12. Procedural safeguards;
13. Polices for personnel standards; and
14. A system for compiling data.

The IFSP, one of the essential elements in serving infants and toddlers with disabilities and their families has posed unique challenges to practitioners, parents, and researchers in the field of early intervention. Researchers have studied both the parents' and professionals' perspectives about the IFSP component (Able-Boone, Sandall,& Frederick, 1990; Summers, Dell'Oliver, Turnbull, Benson, Santelli, Campbell, & Siegal-Causey, 1990; DeGangi, Royeen, & Wietlisbach, 1992; Minke & Scott, 1993). However, no reports are available to date that have focussed on the parents' and service coordinators' perceptions about the initial IFSP process, specifically, when both the service coordinator and parent are engaged in the events of the IFSP planning process, on an ongoing basis. Thus, there is currently lack of research focussed on the time period between referral and completion of the initial IFSP. In

this present study the perceptions of parents and service coordinators about the initial IFSP development process during this time period is the focus.

Statement of the Problem

The present study explored the perceptions of both parents and service coordinators regarding the process of developing an initial IFSP within Tennessee Early Intervention System (TEIS). TEIS is a model established within the state of Tennessee to provide early intervention services to children with disabilities between the ages of birth and three and their families (Refer to p. 7 for the detailed description of the TEIS model). The emphasis in this study is on the 45 day time period within which an initial IFSP needs to be developed for the eligible child and his/her family, which the law stipulates. The study employed strategies commonly used in qualitative research methods, such as open-ended interviews, artifact collection and self-interviews to collect data.

Individualized Family Service Plan

The IFSP, one of the 14 components of the law, is at the heart of Part H program (Brown, 1991). The law makes IFSP's a requirement in providing early intervention

services to infants and toddlers with special needs and their families. This important required component of the law is referred to as the cornerstone of Part H provisions of the law (Summers, Oliver, Turnbull, Benson, Santelli, Campbell & Siegel-Causey (1990).

One of the basic elements in the process of developing an IFSP is the referral of the child and family for services. They may be referred to early intervention programs from a variety of sources (e.g., Neonatal Intensive Care Unit (NICU) or private physicians or other agencies (public or private) involved in serving children with disabilities and their families). It is typically at this point when families and agencies serving infants and toddlers with special needs and their families become aware of each other. The law stipulates timelines for agencies to act on referrals. From the time the service agency receives a referral, the law requires the agency to arrange for a meeting within 45 days to develop an initial IFSP for any child determined eligible for early intervention services (Federal Register, 1989).

The eligible children under Part H are those who are in the age range of zero to 36 months who are in need of early intervention services because they are experiencing developmental delays in one or more developmental domains (physical, cognitive, communicative, social or emotional, or adaptive development) as measured by appropriate diagnostic

instruments and procedures, or because they have a diagnosed physical or mental condition that has a high probability of resulting in developmental delay. The definition of the term "developmental delay" is determined by each individual state (The Tennessee state definition of "developmental delay" is included in Appendix-A). In addition, states may elect to serve infants and toddlers who are at risk of having substantial developmental delay if early intervention services are not provided (Federal Register, 1989).

Developing an IFSP for children who are eligible under Part H within the stipulated time involves the family and appropriate qualified personnel, including the service coordinator [formerly referred to as the case manager](Federal Register, 1989). Conducting service coordination activities for the child who is eligible for early intervention services and the child's family is the responsibility of the service coordinator.

Service coordination [formerly referred to as case management] refers to "activities carried out by a service coordinator to assist and enable a child eligible under this part and the child's family to receive the rights, procedural safeguards, and services that are authorized to be provided under the State's early intervention program" (Federal Register, 1989, p. 26311). The service coordinator is expected to coordinate all the services across agencies and serve as a central point in helping parents to obtain

the services and assistance they need for the optimal development of their child. The service coordination activities specified under the law include.

> ...coordinating the performance of evaluations and assessments; facilitating and participating in the development, review and evaluation of the IFSP; assisting families in identifying available service providers; coordinating and monitoring the delivery of available services; coordinating with medical and health providers; and facilitating the development of a transition plan to preschool services; and informing families of the advocacy services. (Federal Register, 1989, p. 26311).

The philosophical and conceptual basis of the Part H early intervention program is the family centered approach (McGonigel, Kaufman, Jonhnson, 1991). The significance of family in fostering optimal development of the child is addressed in the Part H provisions of the law. Central to providing family centered services is the IFSP element (Campbell, 1992). The IFSP designates the family as the service recipient, instead of the child alone (Krauss, 1990). McGonigel, Kaufmann, & Johnson (1991), view IFSP's in reference to children and their families as "a promise that their strengths will be recognized and built on, that their needs will be met in a way that is respectful of their beliefs and values, and that their hopes and aspirations

will be encouraged and enabled" (p. 46). Also, the provisions of the law state that IFSP's need to be developed jointly by the agency and the family. Thus, according to the spirit of the law, families are considered as joint partners in the education and development of their special needs child (Summers, et al, 1990). This study examined that partnership between parents and service coordinators as perceived by both, during the process of developing an initial IFSP.

Tennessee Early Intervention System (TEIS)

In accordance with Public Law 99-457 passed in 1986, Tennessee established the Tennessee Early Intervention System (TEIS, 1990) to provide services to children with disabilities between the ages of birth and three and their families. TEIS is a statewide, interagency, coordinated, multi-disciplinary, comprehensive network offering free services, including information, referral, and continuing support. TEIS operates within the nine districts of the state. Each district office serves as the Point of Entry (POE) for the referrals made by different sources.

The role of the POE staff is not to provide children who are referred to TEIS with early intervention programs on a day to day basis. Rather, the POE staff serve in the capacity of linking children and their families to other

community resources and services including the medical and health providers, parent groups, and early intervention programs.

Once the child or the child's family is referred to a TEIS district office, the eligibility for services under Part H is determined at this POE and interim service coordination activities are carried out by the service coordinators of TEIS. The service coordinator at TEIS handles referrals in two ways: 1) for those children and families who already have a service coordinator when they are referred to TEIS, the service coordinator at TEIS carries out service coordination activities that complement the activities of the other service coordinator, covering the duties under Part H; and (2) for those children and families who do not have a service coordinator, the service coordinator at TEIS carries out all needed service coordination activities.

Once the eligibility of the child for TEIS services is established a multi-disciplinary team is formed, including the TEIS service coordinator, professionals from other agencies and parents. The information, assessment results, and recommendations about the child and the family gathered by service coordinator and other members of the multi-disciplinary team during the initial IFSP process are reviewed at the first IFSP meeting and an IFSP document is developed.

Definition of Terms

Listed below are the definitions of the terms used in this study:

1. Individualized Family Service Plan(IFSP): An IFSP is an Individualized Family Service Plan written for providing early intervention services to a child eligible under P.L. 99-457 and the child's family. The plan must:
   (a) be developed jointly by the family and appropriate qualified personnel involved in the provision of early intervention services;
   (b) be based on the multi-disciplinary evaluation and assessment of the child, and the assessment of the child's family, and
   (c) include services necessary to enhance the development of the child and capacity of the family to meet the special needs of the child(Federal Register, 1989)
2. Point of Entry (POE): A single point of contact within each of the nine Tennessee developmental districts through which referrals are channeled, where Part H eligibility is determined at that POE [POE is described in detail in the section on Tennessee state model of providing early intervention services on p. 7](TEIS, 1989).

3. Service Coordinator (Case manager): Service coordinator is person who carries out service coordination (case management) activities to assist and enable a child eligible for early intervention services and the child's family to receive the rights, procedural safeguards, and services that are authorized to be provided under the state early intervention program [The term 'Service Coordinator' is now preferred over Case Manager and will be used wherever possible. References to 'Case Manager' in the review of literature will be consistent with the terminology used by cited authors](TEIS, 1990).
4. Interim Service Coordinator(Case Manager): The person who performs service coordination (Case Management) duties from the time the child and family are referred for Part H eligibility determination until the time an ongoing service coordinator is appointed. This may be a service coordinator already working with a child and family or someone from the POE staff (TEIS, 1989).
5. Parents: Parents refer to persons who are natural birth parents, guardians, person acting in place of a parent of a child, or a surrogate parent.

The Significance of the Study

This study is important, because it describes the perceptions of the service coordinators and parents about the initial IFSP development process. Particularly, the interactions between the parents and service coordinators and the events that occur from the time children and their families are referred to TEIS until the initial IFSP meeting are examined. These interactions and events might have a significant impact on the quality of collaboration and the way parents and service coordinators perceive the IFSP process, but, at this time we have little data on what occur during this time period. Therefore, this study will examine this critical period and its influences on the IFSP process. The basic assumption in developing an IFSP is that individualized programs based on specific child and family needs give rise to different child and family outcomes that have qualitatively different dimensions. Considering this basic assumption, it is more appropriate to conduct a qualitative inquiry than attempting to study this process with a quantitative method.

Further, the study fills the gap in the literature regarding the perceptions of service coordinators and parents who hold unique roles on the IFSP team. They are unique in the sense that they are the two members of the team involved in the development of an IFSP who remain

constant irrespective of the child and the family needs. In other words, the members (professionals) other than parents and service coordinator who are on the IFSP team may vary for each child and his/her family according to the needs of that particular child and family. The events that lead up to the development of an initial IFSP are investigated on an ongoing basis from both parents' and service coordinators'. Thus, the findings of this study should reveal the views of both parents and service coordinators involved in the initial IFSP development. This knowledge can inform policy makers, administrators, professionals in higher education and other practitioners in the field of early intervention in understanding the issues surrounding the initial development of an IFSP. This understanding is vital to bring about any modifications in the existing policies, practices, and training of professionals in order to serve children and their families in the most efficient, effective, and respectful manner.

Limitations

One of the limitations of this study is that the results are restricted to the TEIS model of delivery of early intervention services. Second, the pool of participants of the study are in no means a representative sample of that model, they are restricted to two out of the nine districts

of TEIS. Third, the sample size is small due to the research approach employed in this study. Fourth, the study has some constraints on the type of participants who can be part of the study. In other words, the participants must have the ability to read written material and use micro tape recorders. Since, both the self-interviews and open-ended interviews are taped, it is possible that the use of electronic devices may itself pose certain problems which are beyond the control of the researcher. One of the issues that may be considered as a limitation would be my language and cultural background (see Appendix - B for a description of the researcher's background). Because in qualitative research the researcher is the primary instrument (Lincoln & Guba, 1985), my background may have an influence on my interactions with the participants during data collection as well as during data analysis since the data comprises of words than numbers. However, this limitation may turn out to be an advantage because, I may not make assumptions about the participants as quickly as a person from the same culture would.

Research Questions

The overall guiding question in this research is how do parents and service coordinators perceive the IFSP process? The focus of the study will be the time frame of 45 days

between referral and IFSP development.

Listed below are seven sub-questions:

1. How do service coordinators and parents perceive their role/participation/involvement during this process?
2. What are the events that occur in an IFSP process as experienced by service coordinators and parents?
3. What are some issues that service coordinators and parents view as impeding this process?
4. What are some practices that service coordinators and parents have found to be helpful for them during this process?
5. What suggestions do service coordinators and parents have for improving this process?
6. What are service coordinators' and parents perceptions' regarding their joint participation through out the IFSP process?
7. How do service coordinators and parents exchange information during this process?

CHAPTER II

REVIEW OF RELATED LITERATURE

The purpose of Chapter II is to review literature related to parent/professional relationships in the field of special education. First, literature pertaining to the origins of parent/family involvement in the education of children with disabilities prior to P. L. 94-142 is covered. Second, literature related to the process of Individualized Education Program (IEP) development, a mandate for school aged children with disabilities according to P. L. 94-142, is reviewed. Particular attention is given to parents' and educators' perspectives on this process. Third, a detailed review of the Individualized Family Service Plan (IFSP) is presented. Literature pertaining to both the parents' and professionals' positions on the IFSP process is examined. Finally, the strategies adopted in establishing the trustworthiness and integrity of qualitative inquiry are discussed.

Historical Perspective on Parental Involvement

The emergence of the concept of parent involvement as a significant factor in the education of children with disabilities can be traced to the establishment of parent

organizations such as the National Association for Parents and Friends of Mentally Retarded Children in 1952. This association currently known as the National Association for Retarded Citizens (NARC) laid the groundwork for and provided support to Pennsylvania Association for Retarded Children (PARC) in their efforts to include mentally retarded children in the public education system. The 1972 decision in the landmark PARC v. Commonwealth of Pennsylvania case and other similar suits demonstrates the profound influence parents can have by staying involved in the education of their children with disabilities (Weintraub, Abeson, Ballard, & Lavor, 1976; Levine & Wexler, 1981).

The most significant and far reaching incentive to involve parents in the educational process of their children with special needs came from the P. L. 90-538 passed in 1968. This law authorized the establishment of the Handicapped Children's Early Education Program (HCEEP) for children under 5 years of age. This federal law made provisions for parental involvement in various activities, including parent training, which was established as an important component of these demonstration projects (Hocutt & Wiegerink, 1983). Another strong impetus to include parents in the education of their children with disabilities came from the strong parental involvement component of the federal compensatory education program for economically

disadvantaged children, known as Project Head Start (Haskins & Adams, 1983). This Head Start legislation gave parents the legal right to be involved in the education of their children who are below 5 years of age.

In 1975, P. L. 94-142 (The Individuals with Disabilities Act) was passed, which gave parents of school age children with disabilities the right to make decisions in the education of their children. This legislation established a policy where parents were considered as joint partners and active decision makers in the development of the Individual Education Programs (IEP) for school-aged children. Further, an amendment to this law was passed in 1986, known as P. L. 99-457 which differs significantly from the earlier policies. Under Title I of PL 99-457, which provides services to infants and toddlers from birth to three, the family is recognized as the service recipient instead of the child alone. This change, the culmination of years of research and advocacy supporting parent involvement in the education of children with disabilities, has caused a major departure in service delivery from other existing polices (Krauss, 1990). This law requires an IFSP to be developed for infants and toddlers with disabilities and their families instead of an IEP. In the following paragraphs literature pertaining to the IEP and IFSP processes and the parent-professional participation in these process will be reviewed.

The IEP: Parent and Professional Participation

In 1975, The Individuals with Disabilities Education Act (P. L. 94-142) was passed, establishing the right of all school aged children with disabilities to a free appropriate public education. This legislation has granted parents of these children the right and responsibility of being involved in their child's education. Further, it stipulates that an Individual Education Program (IEP) be written for each student with disabilities. The IEP document needs to be developed in a meeting attended by representatives of the local educational agency, the child's teacher(s), parents of the child and when appropriate the child (Federal Register, 1981). Kaye and Aserlind (1979) suggest that the IEP needs to be envisioned not merely as a product (document) but also as a process. They stated that "the process provides the vehicle for the development of the product; provides a series of activities; highlights the decision points; and encourages, facilitates, and stimulates interactions among participants" Kaye & Aserlind, 1979, p. 138). The IEP product which includes written statements is the direct result of these decisions and interactions that take place during the process between participants. These statements are to be written in accordance with the rules and regulations included in the policy. The product then serves as a guide in the on-going process and functions as an

evaluative tool (Kaye & Aserlind, 1979).

The implied nature of parent and staff interaction and the intent of the IEP meeting is apparent as specified in P. L. 94-142.

> The IEP meeting serves as a communication vehicle between parents and school personnel, and enables them as equal participants to jointly decide what the child's needs are, what services will be provided to meet those needs, and what the anticipated outcomes will be (Federal Register, 1981, p. 5462)

Terms such as "equal participation" and "jointly decide" suggest parents and staff to be actively involved in the creation of an IEP that is effective. However, the examination of recent literature invariably reflects parents' passive roles in the development of their child's IEP, as opposed to the active role attributed to them by the law (Goldstein, Strickland, Turnbull,& Curry, 1980; Meyers & Blacher, 1987). Baker and Brightman (1984) claim that "most parents are far from fulfilling their roles" (p. 297) and that they have not realized the degree of involvement implied in the provisions of the law (Baker & Brightman, 1984).

Parents' Perspective

For parents to participate and function adequately as active decision makers in the development of an IEP for

their child, it is important that they have the right kind of information. The law requires the schools to notify parents of children with special needs about their rights. Apparently the schools do not always observe the intent of the law. Barton, Barton, Rycek, and Bruelle (1984) investigated the participation of 822 parents of children with special needs by using a questionnaire. The results indicated that nearly 25% of parents reported that they were not notified or advised about their rights regarding their child's IEP. Moreover, schools were especially indifferent towards keeping parents informed about their rights to have a separate evaluation and their due process rights. Even when the information is provided to parents about their rights, the written materials used by the school districts is often difficult for parents to understand (Brantlinger, 1987; Roit & Pfohl, 1984).

Not only is the way parents are informed about their rights an issue, but also parents report that professionals tend to "intimidate and manipulate parents, ignore their rights, and violate due process procedures" (Gerber, Banbury, Miller, & Griffin, 1986, p. 158). Lusthaus, Lusthaus, and Gibbs (1981) conducted research involving parents of children with special needs (school age population). According to their findings, parents commonly perceive themselves in the role of giving and obtaining information more than anything else. Although parents seem

to be pleased with professionals making decisions, they like to reserve their right over any decisions made regarding medical services, school changes, and records (Lusthaus, et al, 1981).

Myers and Blacher (1987) conducted an investigation with the parents of children with disabilities (3-8 years) by interviewing 99 parents. The results of their study indicated that, on the whole, parents seem to be satisfied with their children's school programs. Most of the parents reported that they were involved in the creation of an IEP for their child (65%- very high; 20%-some; 4%- none). However, one of the drawbacks of this study is that the term "involvement" was not explicitly stated. Therefore, the authors were unable to explain what the highly involved parents did in the IEP process.

Lynch & Stein (1987) interviewed sixty-three Hispanic parents of children with special needs about their satisfaction and participation in their child's program. Eighty-nine percent of the parents were satisfied with their child's program as opposed to 29% who expressed displeasure. Half of the parents expressed that they were active participants in the IEP development.

Weber & Stoneman (1986) claim that poor, uneducated, nonwhite, and single parents rarely take part in IEP meetings. The common belief among such parents is that they do not have much to offer during these meetings. Among

those few who were present at one planning conference, most responded negatively when questioned whether their presence made any difference. Many parents who wanted to attend the meetings were unable to be present because the scheduling was done at the school's convenience rather than parents'. Their attendance was limited due to transportation problems and other work obligations.

Professional Perspective

In exploring the literature related to parental views about the IEP process, it is evident that parents' effective participation in their child's educational program is largely influenced by the attitudes of the professionals and the way professionals relate to them. The letter of the law suggests that parents and professionals are "equal partners" in the IEP process. However, educators are generally considered to be more knowledgeable by both parents and educators themselves.

Safer, Morrisey, Kaufman, and Lewis (1978) have described the common belief held by teachers regarding the shared responsibility of decision making with parents in their interview study.

> As one district director of special education noted, bringing others into the planning process to discuss and plan for classroom instruction makes many teachers feel that what they have been doing has not been

adequate. In addition, many of these teachers resented the fact that persons not responsible for classroom instruction would now have a role in planning for it. Some predicted that parents might insist on setting objectives inappropriate for a child ....Though not denying the value of input from parents or other professionals, teachers clearly believed they should have the ultimate say in determining an educational program. Teachers viewed P. L. 94-142 as potentially reducing their autonomy in determining educational programs and classroom activities by mandating the participation of other persons in the planning process(p.8).

One of the studies conducted by Hocutt and Wiegerink (1983) investigated how professionals translated the parent involvement mandate in Handicapped Children's Early Education Programs (HCEEP). According to their findings, professionals' responses suggested that parent involvement was viewed as being highest in more passive activities and lowest in active decision-making activities. These results indicate that professionals may not give high priority to the decision-making role of parents.

The results of the survey conducted by Yoshida, Fenton, Kaufman, and Maxwell (1978) with 1372 professionals who were members on the planning team corroborates the results of the

earlier study. Only 27% of professionals believed that parents' decisions concerning the IEP have to be taken as the last word. However, professionals placed a high premium on parental activities such as collecting information (57%) and presenting it (65%). Also, professionals viewed parental interpretation (29%) and summary of information (21%) to be of no great value.

Gilliam & Coleman (1981) examined the perceptions of the 130 participants at 27 IEP meetings by asking the participants to rank their roles according to their importance. The results of the survey conducted in two phases indicated that the status ranking given to the parents by the IEP committee participants prior to the IEP meeting was higher than their ranking after the meeting. Thus, the fact that professionals place less value on the parental input is quiet evident in the low ranking given to parents' after the IEP meeting. These rankings are consistent with their lack of influence and contribution to the IEP process. Gerber, Banbury, Miller, & Griffin (1986) examined the teachers' opinion regarding the significance of parent participation in the IEP process. They surveyed a total of 145 teachers in six states. Most professionals (71%) believed that parents need to permit professionals to arrive at a decision by foregoing their right to participate; 50% believed that parents' assistance did not facilitate the process; more than half (68%) acknowledged

that IEPs written prior to IEP meetings did not necessarily minimize parents' participation.

Shaefer (1983) investigated teachers' views about parent-teacher interactions. Teachers opted to furnish parents with information and solicited cooperation from parents in their efforts to teach. However, they did not show interest in receiving information from parents about how best they could interact with their child.

Individualized Family Service Plan

The Individualized Family Service Plan (IFSP) is at the center of P.L. 99-457 (Part H). This provision has been one of the most challenging components of the law. According to the legislation, the plan includes not only direct services to the child, but also to the family. Clearly, there is a significant change in emphasis from the basic philosophy of P.L. 94-142 which requires a plan that is child centered (IEP), to that of P. L. 99-457, which is family-centered (IFSP). The other terms used to refer to family-centered process are family-focussed intervention (Bailey, Simmeonsson, Winton, Huntington, Comfort, Isbell, O'Donnell, & Helm, 1986), and family-centered care (Shelton, Jeppson, & Johnson, 1987).

Krauss (1990) suggests that this major shift in the underlying philosophy of early intervention policy can be

viewed in two different ways: "radical change" or "Legislative incrementalism." The new policy, as a radical change, stresses the inclusion of the family as service recipient rather than the child alone. Seeing it as an incremental change, the provider focuses on the extension of the law which requires expansion of services to meet the needs not only of the child, but also of the family in relation to the child's development. Regardless of whether one views the change as being radical or incremental, the striking difference in the basic philosophy of developing an IFSP as opposed to an IEP is apparent (Fewell & Neisworth, 1991). The philosophy that underlies the IFSP plan is referred to as family-centered process (McGonigel, Kaufmann, & Johnson, 1991).

A framework for developing and implementing a family-centered IFSP process is provided by McGonigel, et al (1991). This framework embraces ten principles. One of the main principles is that "infants and toddlers are uniquely dependent on their families for their survival and nurturance and this dependence necessitates a family-centered approach to early intervention"(p.8). When dealing with these families, early interventionists must acknowledge and honor the racial, ethnic, cultural, and socio-economic differences among such families and their distinctive structures, roles, values, beliefs, and coping styles in providing services. In addition, they must accept and

respect each family's decision about their level and nature of involvement in early intervention. Finally service providers must render service that is flexible, accessible, and responsive to the perceived needs of each family, adopting a team approach. An effective IFSP process calls for collaboration, partnership, and mutual respect between families and professionals, although the family's control over the final decision and approval is recognized. Consequently, the IFSP process is conceived as being sensitive to the unique needs of each family and infant/toddler. As a process it involves essential routines, irrespective of the program model or eligibility criteria or the type of early intervention system or program. These routines are first contacts between a family and early intervention services; assessment planning; child assessment; identification of family concerns, priorities and resources; development of outcomes to meet child and family needs; IFSP implementation; and formal and informal evaluation of the IFSP and the IFSP process (McGonigel, Kaufmann, & Hurth, 1991). They involve a course of interactive events (Dunst, Trivette, Deal, 1988). The product of this entire interactive process is the written IFSP. According to the law, the IFSP as a product is developed collaboratively by a multidisciplinary team, including the parents or guardians.

The IFSP comprises of the following components:

1. A statement of the infant's or toddler's present levels of development (physical, cognitive, communication, social or emotional, and adaptive);
2. A statement of the family's resources, priorities, and concerns that relate to enhancing their capacity to meet the developmental needs of their infant or toddler with a disability;
3. A statement of the major outcomes expected to be achieved for the infant or toddler and family, and the criteria, procedures, and timelines to determine progress;
4. A statement of specific early intervention services necessary to meet the needs of the infant or toddlers and the family, and of the necessary frequency, intensity, and method of delivering services;
5. A statement of the natural environments in which early intervention services shall appropriately be provided
6. The projected dates for initiation of services and the anticipated duration of such services;
7. The name of the service coordinator, who is a member of the profession most immediately relevant to the infants's toddler's or family's needs, or who is otherwise qualified to carry out all applicable duties, who will be responsible for the implementation of the plan and for coordination with other persons and

agencies; and

8. The steps to be taken to support the transition of the toddler with a disability to services provided by public school districts.

McGonigel et al (1991) acknowledge the fact that the process of creating an IFSP is more vital than the product itself. Bailey et al (1990) further emphasize the significance of the process by stating that "the written product is possibly the least important aspect of family assessment, goal planning, and service provision. The interactions between families and professionals prior to goal planning are of critical importance in establishing a positive trusting and collaborative relationship with families. If this process does not occur, the goal document (IFSP) is likely to have little meaning (p.25)." Therefore, developing and implementing an effective IFSP is largely influenced by the nature of the relationship/collaborative partnership and interactions between families and professional (Campbell, Strickland, La Forme, 1992). This family-professional collaboration has been considered the cornerstone of the IFSP process (Lynch, Jackson, Mendoza, & English, 1991). The IFSP is viewed as a vehicle for relationship building, empowerment, interagency collaboration, and a guide to program implementation and evaluation (Espe-Sherwindt, 1991). This dynamic quality of

the IFSP component is at the center of providing family-centered intervention.

The IFSP as a crucial element in providing family-focused intervention has been explored in a nationwide study conducted by Mahoney, O'Sullivan, and Dennebaum (1990). In order to assess the extent to which early intervention programs had adopted family centered intervention, the authors asked 503 mothers to respond to a family-focused scale (Mahoney, O'Sullivan, and Dennebaum, 1990). The results of their study indicate that the mothers found the programs to have a family focus in their services wherever they had IFSPs in place. These results demonstrate the significance of the IFSP element in providing family-focused intervention.

One of these studies that examined parental perceptions of the IFSP was conducted by Able-Boone, Sandall, and Frederick (1990). In this ethnographic study, the authors interviewed 30 families to learn their views about the implementation of Part H. The results of this major study indicate that parents view their active involvement in the process as important and that they desire to become more informed decision makers in the IFSP process. Also, the parents suggested that the plan should be more flexible. In other words, it needs to be a working plan with goals written in the form of suggestions rather than definite goals such as "the mom will do that" or "dad will do that"

(p.108).

The focus of the Able-Boone study was only on the parental views regarding the implementation of the law. Summers, Dell'Oliver, Turnbull, Benson, Santelli, Campbell, & Siegel-Causey (1990) studied both families' and practitioners' opinions about the expected outcomes of early intervention for families employing the focus group approach. According to the findings of this research, the authors report that families emphasized the need for more information. Also, families prefer professionals to function in an informal, non-intrusive and unhurried manner while they gather information from families. With regard to identifying family strengths and needs, most of the respondents agreed that the responsibility lies with the family. One of the professionals remarked:

> What if the professional thinks what's needed is a balanced diet for the child, but the mother doesn't see it? You aren't going to get very far. We would try to educate the parents, but you can't do it if the parent doesn't see the need for it (p.90).

Although, this study includes the parents' and practitioners' preferences regarding the IFSP process, the authors maintain that "...a critical void in the field at this time is the lack of theoretically grounded, empirically-based, and family-friendly framework for conceptualizing expected family outcomes of early

intervention" (Summers, et al., 1990).

In another study, DeGangi, Royeen, and Wietlisbach (1992) conducted five focus group sessions involving professionals and four focus group sessions involving parents to examine the IFSP process. The authors listed the issues identified by both parents and professionals that are related to the IFSP process. Although similarities were observed between both parents and professionals in the way they view effective collaboration, the groups differed in the way they came up with solutions to the problems in the IFSP process. This difference appears to be the result of the differing roles parents and professionals take in the IFSP process.

A more recent study related to the development of the IFSP has been conducted by Minke & Scott (1993). In this naturalistic study, they investigated the role of parent and staff in the IFSP development process at three early intervention program sites. In their analysis they identified nine roles parents enact in the IFSP process: basic decisions, participating in goal setting and assessment, choosing their own level of participation, considering professional advice, voicing objections, advocating for their children, listening, and providing information. Although as the study reports, parents actively participate in the development of the IFSP, the staff's opposition to parental disagreement and their taking

over the decision-making role of the parents does not entirely support the family-focussed philosophy.

McBride, Brotherson, Joanning, Whiddon & Demmitt (1993) interviewed families and professionals. They reported four roles which professionals and parents described as being taken by the parents in developing an IFSP along with the professionals. First, they defer to professional expertise, which means less involvement in the decision making process. Second, they often adopt the role of an observer or informant during assessment and evaluation. Third, they exercise veto power, or having the "final say" which is apparent in one of the statements made by a mother: "staff let me set limits on what they will do with my child... I can say 'no' and they will listen"(p.19). Lastly, families share in decision making: one family said "we definitely felt like we were decision makers concerning long term goals for [child]"(p.20). Further, the roles taken up by the parents are not limited to any one listed above at any given time; rather families often adopt more than one. These different roles, which suggest different levels of involvement, seem to be more consistent with the family-focussed process.

The studies related to the IFSP process reviewed so far have focussed on the perceptions of the participants involved in the IFSP process. Campbell et al (1992) examined the possible influences of giving parents written

information and the option to participate in several types of training on the IFSP process. They studied 21 parents who had participated in at least one IFSP meeting. These parents were divided into two groups based on the parents' decision about whether or not to participate in formal training (i.e., workshops or discussion groups). The results of the study indicate that the IFSPs of children whose parents had attended the formal training contained significantly more present levels of development statements written in parental language than the other group. However, such significant differences were not observed in the outcome statements, although an increase was observed with the trained group. The results of this study indicate that formal training for parents had an influence on the way the IFSPs are developed. The study is limited in its scope in studying the IFSP process, as it examined only the use of parents' language on the IFSP document.

The focus of research carried out on a nationwide scale by Bailey, Winton, Rouse, & Turnbull (1990) was the IFSP product, specifically family goals. A total of 24 IFSPs were reviewed. A family goal in this study was defined as "any goal requiring action of some family member(s) or intended to benefit a family member(s) other than the child with a handicap"(p.17). The degree of family involvement observed in the statements of these family goals was categorized into three levels. Their analysis indicates

that more than half (53%) of the written family goals involved the family gaining basic knowledge or information. Secondly, thirty-four percent of the written goals indicated direct use or application of information by the family members. Finally, goals that called for generalized use or problem solving by the family member(s) totaled up to thirteen percent. This analysis demonstrates that the parents' level of involvement is still relegated to acquiring information the majority of the time. This does not fully promote the notion of family empowerment.

A similar study has been conducted by Espe-Sherwindt (1991) in which the IFSP's belonged to a group of parents who were mentally retarded. The analysis of six IFSPs revealed that the level of involvement of parents observed was in contrast to the results observed in the Bailey et al study. Of all the family goals written down for parents with mental retardation, not one focussed on the parents in the role of receiving basic information or knowledge. Nearly half (47%) of the goals called for parents using knowledge within a specific context, and the majority of the goals involved parents in problem solving or generalizing. In this case, a commitment to family empowerment was observed in the analysis of the family goals. Also, the authors pointed out the need for interventionists to work collaboratively with other agencies that are traditionally connected with providing services to adults (parents) with

mental retardation, such as vocational programs, supported living community services and case management in developing and implementing the IFSP component of the law.

Service Coordination/Case Management

Service Coordination seems essential when families of infants and toddlers with disabilities have several concerns and needs, which necessitate their accessing multiple services from different agencies of the system (e.g., health, education, and human services). In 1986, the need for service coordination in the field of early intervention was recognized by the enactment of P. L. 99-457. This law requires that early interventionists provide service coordination services to families of infants and toddlers with disabilities as part of the IFSP. The legislation stipulates that the written IFSP must include "the name of the service coordinator from the profession most immediately relevant to the child's or family's needs, who will be responsible for implementing the plan and coordinating with other agencies and persons" (Federal Register, 1989, p. 26322). Thus, the emergence of service coordination services is one of the most recent and significant developments in the context of early intervention.

Although the concept of service coordination is new in the field of early intervention, its historical roots can be

traced back to as early as 1920s in the field of social case work (Weil & Karl, 1985) as case management. Since then, case management practices have become widespread in various professions (e.g., nursing, mental health, child welfare) in diverse settings and target population groups (Rothman, 1991). Case management gained significance in the 1960s during the deinstitutionalization movement involving individuals with mental illness and developmental disabilities (Intagliata, 1982). In the 1970s, The United Cerebral Palsy National Collaborative Project, which fostered the practice of providing integrated and coordinated services for families of children with special needs, is an early example of using case management practice. In this project services planned by a team were carried out by the family and the primary service provider appointed by the team. The practices of the National Collaborative Project later were consistent with the principles legislated through the enactment of P.L. 99-457, which requires service coordination services to be provided (Smith, 1991). The premise on which the service coordination services are based in early intervention differs from the traditional assumption where the client is viewed as incompetent or unable to coordinate the required services. In early intervention, the family is assumed to be competent to collaborate with professionals in the service coordination process.

Service coordination has been defined in several different ways (Parker, Quinn, Viehl, McKineley, Polich, Detzner, Hartwell, Korn, 1992). Typically, in these definitions coordination of services in meeting the needs of the client remain as the central theme. The Individuals with Disabilities Education Act of 1986 refers to case management as "services provided to families of handicapped infants and toddlers to assist them in gaining access to early intervention.... and other services identified in the....Individualized Family Service Plan" (Individuals with Disabilities Education Act of 1986, p. 8). A use of the term "case management" has been an issue to many families and professionals, especially since it appeared in Part H of P. L. 99-457 (Dunst, 1991). The term "manage" is defined as "to have responsibility for," "to dominate or influence," and "to direct, govern or control in action or use" (Betz, 1991). These definitions do not reflect the family-centered philosophy which has gained acceptance in early intervention. In the focus group interview study conducted by Able-Boone et al (1990), parents expressed concerns related to the use of the term "case management". They suggested terms such as parent consultant and parent facilitator as an alternative to the term case manager. Betz (1991) recommended a change in the terminology from case managers to service coordinator or consultant. The change in the terminology appeared in the amendments to P.L.

99-457(IDEA). Since then case mangers are referred to as service coordinators. It is important that case managers consider families as competent to manage the service delivery system, provided they are given the right kind of information about the services that are available and the way in which they can be obtained (Dunst & Trivette, 1989). This assumption that families are competent, which is basic to family-centered philosophy, is evident in one of the case management models suggested by Dunst and Trivette (1989). Dunst & Trivette (1989) have proposed an enabling model of case management based on the definition of effective helping, which is defined as follows:

> The act of enabling individuals or groups(e.g., family) to better able to solve problems, meet needs, or achieve aspirations by promoting acquisition of competencies that support and strengthen functioning in a way that permits a greater sense of individual or group control over its development course(p.3).

This definition reveals the paradigm shift in the enabling model from traditional case management models. In the enabling model the clients (families) are "encouraged to function as independently as possible...and...assume an active, rather than passive role in the case management process" (Levine & Fleming, 1984, p.8). This shift in the philosophy enables case manager to "employ roles and functions that create opportunities for families to become

capable and competent using enabling experiences that support and strengthen family functioning"(Dunst & Trivette, 1989, p. 95). Thus the role of the case manager is most critical to the implementation of family-centered philosophy of the P. L. 99-457.

In the past, the parents of children with special needs have had to take up the role of coordinating services for their children by default (Allen & Hudd, 1987; Hazel, Barber, Roberts, Bahr, Helmsetter, & Guess, 1988). While, the recent legislation (Part H of IDEA) requires service coordination services to be provided to families of infants and toddlers with disabilities as part of the IFSP, the law does not designate the specific discipline of the professional who assumes the role of a service coordinator. The service coordinator could be a professional from any one of the disciplines listed in the regulations, or it could be a family if he/she acquires the necessary competencies to function in the role of service coordinator (Federal Register, 1989).

There are a plethora of labels given to the case manager's role, for example, mobilizer, problem solver, advocate, broker, planner, community organizer, boundary spanner, service monitor, record keeper, collaborator, counsellor, coordinator, and evaluator (Dunst, Trivette, & Deal, 1988; Weil & Karl, 1985). These labels suggest the complex and dynamic nature of the case management role.

Typically, the role of the case manager differs according to the evolving needs of the clients (families). Consequently, the role of a case manager in serving families with developmentally disabled children is shaped by the family's concerns, priorities and resources at a given time. Dunst, Trivette and Deal (1988) have illustrated the key roles case managers perform "linking people, mobilizing family resources and support, facilitating the development of new support structures, moderating exchanges among the members of a family's formal and informal network, and consulting with families about issues or concerns"(p. 152), thereby supporting and strengthening family functioning.

Smith (1991) explored the dual role of occupational and physical therapists who serve as case managers within the IFSP process. On the one hand, the therapists' role makes them responsible for specific goals in the IFSP, on the other hand the case managers' role involves coordinating the whole plan.

Bailey (1989) reported a review of research on case management in early intervention. He noted that not any of the research focused on case management with families of handicapped infants and argued that there is a critical need for such studies. In 1991, Fiene & Taylor did a report on case management in early intervention. They described the family centered case management services provided by social workers within a program (University of Tennessee

Developmental and Genetic Center) serving rural Appalachian families with developmentally disabled children under the age of 18 who are referred for genetic evaluation. The authors reported using three priority levels with these families, which established the kind of services required of the case manager (Level 1-3 = more - less amount of services). They described case management with a rural family (with the status of priority level 3) using a case study. They referred to the influence of aspects such as family structure, environmental influences, belief systems, continuity of care, planning for services, community coordination, counselling services and cost effectiveness in providing case management services. In reporting the case study, the authors made the point that the use of case management services is an appropriate way to assist families of children with disabilities. Although this case study is worthwhile, it is restricted to the field of social work. Not much attention has been given to case management and its relation to the IFSP process.

A more recent study pertaining to service coordination was conducted by Dinnebeil & Rule (1994). In this study, they employed structured interviews to explore the perceptions of the service coordinators and parents regarding the variables that influence their collaboration. They identified a number of variables which parents' perceived as productive and unproductive characteristics of

service coordinators. Similarly, variables which service coordinators' perceived as productive and unproductive characteristics of parents were identified. However, this study is limited to identifying characteristics of parents and service coordinators that help to build a collaborative relationship.

To date research related to service coordinators's perspective on the IFSP process is lacking. Further, none of the studies have focussed on service coordination as an ongoing process. Therefore in this present study an attempt is made to examine the perspective of service coordinators while they are actually engaged in the process of providing service coordination services with a particular family. It seems more appropriate to study service coordination within TEIS, since the primary function of TEIS is to provide service coordination services. One of the major objectives in this present study is to examine the service coordinator's (case manager's) perspective on the IFS process.

Strategies Adopted in Establishing the Trustworthiness and Integrity of the Inquiry

In the qualitative research method, the strategies used to establish the trustworthiness of the inquiry differ from those used in conventional quantitative methods. Although

in this mode of inquiry most researchers acknowledge that it is not feasible to lay out the procedures precisely at the beginning of the study, certain strategies are adopted to maintain the trustworthiness and integrity of the study. In this study, strategies will be selected by following the guidelines that have been established to ensure the credibility of the study (Lincoln & Guba, 1985). The guidelines are in two clusters: 1) reliability and 2) validity.

Reliability

In establishing reliability, one is essentially testing the extent to which the study can be replicated. In other words, if another researcher chooses to conduct a similar study using the same methods, he/she will obtain same results. In qualitative research the term reliability is commonly referred to by terms such as "dependability" and "confirmability" (Lincoln & Guba 1985).

Dependability is similar to the external reliability of a study. It refers to issues of whether individual researchers would uncover the same phenomenon or form similar constructs in settings that are comparable to the original settings (Goetze & LeCompte, 1984). Goetze and LeCompte (1984) claim that dependability can be attained by maintaining a audit trail. An audit trail is essentially the researcher's record of all the details influencing the

major decisions during the data collection and data analysis stages of inquiry. This detailed description serves as a guide for a researcher who is interested in replicating the study.

Confirmability is similar to the internal reliability of a study. This refers to the degree to which several researchers are able to agree in a given study (Goetze & LeCompte, 1984). To achieve confirmability in a study, the researcher has to incorporate strategies to maximize internal reliability. The five major strategies commonly used are 1) obtaining verbatim data; 2) mechanical recording; 3) peer examination; 4) multiple researchers; and 5) participant research assistant (Goetze & LeCompte, 1984). In this study, the first three strategies are utilized to achieve confirmability.

Validity

In establishing the validity of a study, researchers are concerned with the accuracy of the findings, usually the strength of qualitative studies. In qualitative research method, validity is referred to as "credibility" and "transferability" (Lincoln & Guba, 1985). Credibility is similar to internal validity which checks the extent to which scientific observations and measurements are authentic representations of some reality. Lincoln & Guba (1985) have outlined several strategies for establishing credibility of

a qualitative study. They are prolonged engagement, persistent observation, triangulation, peer debriefing, negative case analysis, member checking, and referential adequacy.

Three of the above strategies that were employed in the present study are - triangulation, prolonged engagement, and member checking. First, triangulation of data involves cross validation of data by obtaining data from multiple sources and by using multiple methods. Second, prolonged engagement, or spending substantial time in the field adds to the credibility of the data in qualitative research. Because the length of time in the field increases authentic responses, time is a significant element in gaining data that is trustworthy (Lincoln & Guba, 1985). Third, member checking a critical strategy in establishing credibility involves participants verification of the summarized or analyzed data.

The term transferability is analogous to external validity, which refers to the extent to which comparison across groups can be made - the generalizability of the study. In qualitative studies, transferability is enhanced when "thick" description of the contextual setting and the nature of the group of participants are provided. This precise thick description serves as a data base for other researchers in the field interested in conducting similar studies. Consequently, the extent of applicability in

qualitative studies is determined by similarity of settings which can be assessed only when thick descriptions are available.

The strategies described in the above paragraphs has been employed in the present study and are explained in Chapter Three.

Chapter Summary

In Chapter II, the literature was organized under four major headings: historical perspective, the IEP, the IFSP, and strategies adopted to maintain the trustworthiness of the study. Although all of the above studies reviewed so far have merit, both in the methods used in conducting the study and purpose, a gap in literature still exists specifically pertaining to the understanding of families' and service coordinators' perspectives on their collaboration during the initial periods of their relationship in the IFSP process. Therefore, in the present study, open-ended interviews, one of the primary approaches used in collecting data, is employed in examining individual perceptions of parents and service coordinators about the IFSP process. In addition, a self-interview approach will be used to capture the immediate thoughts and feelings of the participants on an ongoing basis to understand the collaboration effort in developing an initial IFSP.

CHAPTER III

METHODOLOGY

Introduction

This chapter describes the qualitative research techniques employed in this study, including the reliability and validity measures. Description of the participant selection, data collection, and data analysis methods are included.

Qualitative Research Techniques Employed in This Study

Readers need to trust the data they are presented. In this section four provisions intended to increase the trustworthiness of the data are presented. To achieve dependability (external reliability), the following materials were presented to the doctoral committee as audit trail information: 1)open-ended interview schedules, self-interview schedules, and demographic form as it was developed; 2)transcribed interview responses, data analysis products and synthesis products of the pilot study; and 3) a progress summary of the study. In addition, a description of the researcher's position (see Appendix B), description of the participants, and the context within which the data

was gathered are provided (see Chapter IV) to enhance dependability.

To achieve confirmability (internal reliability) in this study verbatim quotes, are included to give other researchers an opportunity to evaluate whether the investigator's findings and conclusions are grounded in data. Mechanical recording was used to obtain authentic data. The actual recorded self-interview and open-ended interview responses of the participants were transcribed to support the findings of this study.

Three strategies were used to establish credibility (internal validity). First, triangulation of data involves obtaining data from multiple sources, and using multiple methods. In this study, the phenomenon of the IFSP process was approached from two different perspectives (parents and service coordinators), using multiple sources for each perspective (multiple self-interviews and open-ended interviews) and different data collection methods (open-ended interviews, self-interviews and artifact collections). Therefore, the strategy of triangulation was met.

Second, prolonged engagement, a strategy which calls for frequent and lengthy contact with participants was employed. The researcher maintained regular contact with the service coordinators (SC) to obtain referrals during the data collection period. Also, the researcher made contact with parents and SCs who were participants on an ongoing

basis to collect the self-interviews. Thus, the amount of time spent with the participants before the open-ended interviews were conducted helped to build rapport with them, enabling the researcher to obtain more trustworthy data.

Third, member checking, a strategy which requires the researcher to present interpretation to the participants and knowledgeable others, was pursued. In February 1994, the researcher presented preliminary findings of the study at the Annual Collaborative Conference on Young Children with Special Needs and Their Families. This conference was attended by representatives from different disciplines (service providers, academicians, and parents of children with special needs), TEIS staff from the different district offices throughout the state (SCs, project coordinators and other staff), including those who participated in this study. During an interactive poster session, the researcher discussed the findings with the participants at the conference, particularly with a parent who participated in the pilot study, two SCs who were participants in the study, and other SCs and TEIS staff throughout the state. These attendees at the conference indicated agreement with the categories and analysis of the data. Thus, the presentation of the interactions at this conference served as a member check.

Transferability, which is covered in Chapter Four, requires thick descriptions of the participants from the two

different sites. SCs' descriptions involve details about their work experience and training. Descriptions of the parents include details regarding their marital status, relationship to the child, ethnic, occupational, and educational background. Descriptions of the children include aspects such as the child's age, sex, diagnosis, and family background.

Participants in the Study

Selection of participants was based on the purposeful sampling method used in conducting qualitative research (Patton, 1990). The basic reason for choosing this method was to select participants who could provide "rich information." SCs selected as participants had a minimum of nine months experience in their positions. It was assumed, the SCs prior experiences would enable the researcher to uncover significant issues related to the phenomenon under study.

Eight SCs at two district offices volunteered to participate. The researcher described the study to them, gave them a copy of the Service Coordinator Information and Consent Form (see Appendix C), and requested that they sign the Consent Form if willing to participate. At this time the researcher answered any questions and asked participating SCs to fill out the Service Coordinator

Demographic Form (see Appendix D). The Service Coordinator Self-Interview Information Sheet, Service Coordinator Self-Interview Guide (see Appendix E), and a tape recorder with blank tapes were then given to them. In addition, self-addressed envelopes were provided to mail self-interview tapes to the researcher.

The identification of SCs lead to the families who were selected from those whose children were "new referrals" at TEIS between February, 1994 and March, 1995. All the selected parents were "new referrals" who would be experiencing the initial stages of the IFSP process, the focal point of this study. One or both parents could participate in the study; however, only mothers did participate.

SCs at TEIS were asked by the researcher to inform parents of new referrals about the study during their first contact with the family. SCs then notified the researcher if families indicated a willingness to participate. Further, SCs obtained parents' permission for the researcher to accompany them during the first home visit. During the home visit, the researcher described the study and their role to the parents, and provided the parents with the Parent Information and Consent Form (see Appendix F). Parents who were willing to participate signed the Parent Consent Form. The researcher answered any questions from parents, and asked them to fill out the Parent Demographic

Form (see Appendix G). The Parent Self-Interview Information Sheet, Parent Self-Interview Guide (see Appendix H), and a tape recorder with blank tapes were given to the parents. In addition, self-addressed envelopes were provided to mail self-interview tapes.

Data Collection Procedure

Four kinds of data were obtained from participating parents and SCs. They were demographic data, self-interview reports, open-ended interview, and artifacts. Figure 1 illustrates the activities during the data collection process.

Demographic Data

Demographic data of parents and SCs were obtained by using the Parent Demographic Form and Service Coordinator Demographic Form. The information obtained through these forms allowed the researcher to describe the participants.

Self-interview Data

Self-interview is described as a form of verbal reporting or keeping a log of one's thoughts and feelings about an event by the participants in a study (Coleman, 1990). The participants in this study were asked to record their thoughts and feelings about the interactions and

RESEARCHER'S ACTIVITY	SERVICE COORDINATOR'S ACTIVITY	PARENT'S ACTIVITY
Identify SC's with minimum 6 months experience from TEIS district offices Request SCs to participate in the study, provide them with SCICF, and explain SC's activities on first contact with new referrals Receive signed consent forms from SC's who volunteer to participate Provide SC's with SCDF, SC's SIIG, tape recorder, audio tapes, self addressed envelopes, and a copy of the PICF Accompany the SC on their first home visit to the new referrals, and provide P's the PICF, PDF, P SIIG, tape recorder, audio tapes,and self addressed envelopes to mail the tapes and explain Collect recorded SI from P & SC on an ongoing basis Examine D at the TEIS office on an ongoing basis Conduct OI with P & SC separately soon after the first IFSP meeting	Sign SC consent form Complete the SCDF Inform P of new referrals about the study during their first contact Provide P the PICF to those parents who request it prior to them giving the researcher the permission to contact them Inform R about the new referrals Start recording the SI about the family(new referral) soon after P indicates willingness to participate Inform R on an ongoing basis as they complete the SI recording or to mail the tapes to the R OI with R after the IFSP meeting	Volunteer P to give their consent for the R to accompany the SC on their first home visit Sign P Consent Form Complete the PDF Start recording the SI using the P SIIG, including information about their first contact and first home visit with the SC and other professionals Inform R on an ongoing basis as they complete SI recording or to mail the recorded tapes to R OI with R after IFSP meeting

LEGEND: SC=Service Coordinator; SCICF=Service Coordinator Information & Consent Form; SCDF=Service Coordinator Demographic Form; SIIF= Self Interview Information & Guide; PICF= Parent Information & Consent Form; SI= Self Interview; P= Parent; D= Documents; R= Researcher; PDF= Parent Demographic Form; OI= Open-ended Interview

Figure 1. Data collection procedure

events that occurred prior to the IFSP meeting, using the Self-Interview Information Sheet and Self-Interview Guide. These self-interviews allowed the researcher to capture the reflections and feelings about the interactions and events while they were still fresh in the minds of both parents and SCs.

Parents

Parents were asked to conduct the self-interview each time they made a contact with a service provider from the time they were referred to TEIS until the first IFSP meeting was held. The service providers (including the TEIS staff) with whom they came in contact could have been any professional involved in providing services to the family in relation to their child with special needs. The type of contact the parents had with these service providers varied (e.g., home visit, office visit, telephone call, mail). The recorded tapes of the self-interview were collected by the researcher on an ongoing basis until the IFSP meeting was held.

Service Coordinators

SCs conducted self-interviews along similar lines. Each time they made a contact with a parent participating in this study (home visit, telephone call, mail) from the time the child with special needs and his/her family were

referred to TEIS until the IFSP meeting. The recorded tapes were collected by the researcher on an ongoing basis until the IFSP meeting was held for the family.

Open-ended Interview/Post-IFSP Meeting Interview Data

One of the basic approaches to collecting qualitative data is through open-ended interviews. The purpose of employing such an interview technique is to uncover people's thoughts, feelings, and intentions about an issue which cannot be observed directly. The technique helps researchers to understand "what is in and on someone else's mind and not to put things in someone's mind" (Patton, 1990). In other words, the perspective of the participants on a particular issue cannot be discovered if one imposes previously created categories through a structured questionnaire, where the participants have to fit the responses into those categories.

The open-ended interview technique was used to learn parents' and SCs' perceptions regarding the IFSP process. Open-ended interviews were conducted by the researcher with parents and SCs soon after the IFSP meeting was held. Parent open-ended interviews were conducted using Parent Open-ended Interview Schedule (Appendix I) and the SC open-ended interviews were conducted using the Service Coordinator Open-ended Interview Schedule (Appendix J). The interviews were conducted at a time and place convenient to

the participants and were audiotaped.

Artifact Collection

Artifacts are the "material manifestations of the beliefs and behaviors that constitute the culture" (Goetze & LeCompte, 1984). Artifacts are things that individuals make or use in a given culture or organization (in this case the TEIS). There are two different kinds of artifact collections: 1)physical trace collections; and 2)archival and demographic collections (Goetze & LeCompte, 1984). The artifacts that were collected as data in this study fall into the latter category. Artifact collection is regarded as a non-interactive method of data collection, restricting observer effects as they remain separate from the researcher (Goetze & LeCompte, 1985).

The artifact collection in this study consisted of the SCs' notes and the TEIS documents (including the IFSP) pertaining to the child/family (see Appendix K for sample copies of the forms listed below). The following written artifacts were collected:

1. Status Form or Minimal Data Form;
2. State of Tennessee Central Intake Form;
3. Plan of Action Form or Recommendation Form;
4. Family Needs Assessment Forms;
5. Individualized Family Service Plan; and
6. Service Coordinator's Progress Report.

The data obtained from these artifacts were used to triangulate with the evidence obtained through other sources such as self-interviews and open-ended interviews. This feature of triangulating data obtained through different sources has the power to increase the credibility of the study (Patton, 1990).

Data Analysis Procedure

The process of analyzing data in qualitative research is rather challenging. The analytic process is inductive as opposed to deductive, where data is analyzed either to refute or accept the set hypothesis. Inductive analysis involves managing, analyzing, and interpreting enormous amounts of data collected through different sources (Goetze & LeCompte, 1985). The aim of such an analysis is to identify and analyze significant patterns of meaning in the data which aid in building a conceptual framework. The framework facilitates interpreting and conveying what the data reveal.

The data gathered through the self-interview and open-ended interview stages of the study, in addition to the artifacts collected, were analyzed sequentially using the procedures that are derived from the qualitative methods described by Glaser and Strauss (1967) and Lincoln and Guba (1985). Further, a log of all the referrals received by

participating SCs during the data collection stage maintained by the researcher were analyzed.

The stages of data analysis and the corresponding researcher's activity are illustrated in Figure 2 and explained in detail in the following paragraphs.

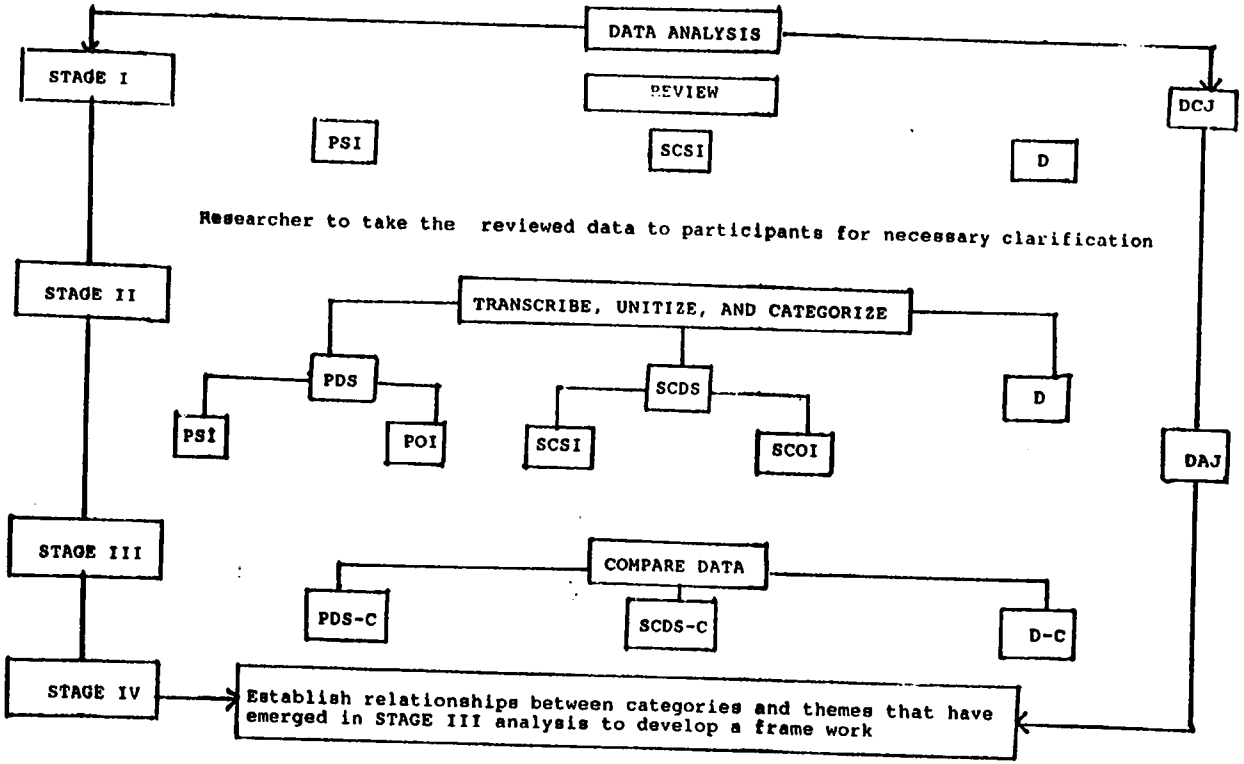
Stage I

The researcher reviewed the available self-interview recorded tapes and the documents/notes pertaining to each of the participants before conducting the open-ended interview. Clarification from the participants was obtained for the documents wherever necessary during the open-ended interviews. For example, abbreviations used by the SCs in the documents were clarified.

Stage II

Self-interview Data

The transcribed self-interviews of both parents and SCs were read separately to identify the units, also referred to as incidents (Lincoln & Guba, 1985). Each unit can either be a sentence or a paragraph within the data set "that will sooner or later, serve as the basis for defining categories" (Lincoln & Guba, 1985). These units of analysis of self-interview data sets of both the parents and SCs were coded into categories according to the constant comparison method (Glaser & Strauss, 1967).



LEGEND: DCJ=Data Collection Journal; DAJ= Data Analysis Journal; PSI=Parent Self-Interview; SCSI=Service Coordinator Self Interview; D=Documents; PDS=Parent Data Set; SCDS=Service Coordinator Data Set; POI= Parent Open-ended Interview; SCOI=Service Coordinator Open-ended Interview; PDS-C=Parent Data Set-Categories; SCDS-C= Service Coordinator Data Set-Categories

Figure 2. Data analysis procedure.

In this method a researcher follows two basic routines: 1) as one is coding a unit for a category, one has to compare it with earlier units that are coded in the same category; and 2) one has to stop coding to keep a log of one's ideas during the analysis. Lincoln and Guba (1985) suggest that the coding of a unit into a category during the initial stage be done on a "feels right" and "looks right" basis. Gradually as the analysis becomes more refined, one no longer codes units of data into categories on "looks right" or "feels right" basis. Rather, they are coded on the basis of the properties of each of the categories, which facilitates "integrating categories and their properties" (Glaser & Strauss, 1967). As revisions of the properties within categories and the emergence of new categories tend to subside, "categories become saturated" (Lincoln & Guba, 1985). Glaser and Strauss (1967) have elaborated on this point:

> This constant comparison of the incidents very soon starts to generate theoretical properties of the category. The analyst starts thinking in terms of the full range of types or continua of the category, its dimensions, the conditions under which it is pronounced or minimized, its major consequences, its relation to the categories, and its other properties (p.106).

Open-ended Interview Data

A similar analytical process was carried out with the transcribed open-ended interviews. Both the parents' and SCs' interview responses were transcribed, read, coded into units and categorized separately.

Documents

The data obtained through several documents for each child/family were categorized as well.

Stage III

Comparison of Data

The researcher compared the categories obtained from both the self-interview and open-ended interview responses of the parents (parent data set) with the categories that emerged from SCs' referral reports, self-interview, and open-ended interview responses (SCs' data set) and documents.

Stage IV

The relationship between the categories and themes that emerged during Stage III were determined. This analysis facilitated the development of a conceptual framework illustrating the phenomenon of the IFSP process from both parents' and SCs' perspective.

CHAPTER IV

RESULTS

Introduction

This chapter, describes the procedure of data collection. Second, a description of the participants is presented. Third, an overview and tabulation of the different data sources are provided. Lastly, the results are presented according to research questions.

Procedures

Preamble

In March 1993, I began my research on IFSP by reviewing the literature and simultaneously attending both the weekly staff meetings at TEIS, and the local interagency council meeting. This exercise helped me to get familiar with the IFSP process within TEIS. Research questions were formulated and an outline of my research was developed.

In the Fall of 1993, a pilot study was conducted with one of the SCs who had recently discontinued working at TEIS and one parent of an older child with disabilities who also happened to be an employee at TEIS. Open-ended interviews were conducted by the researcher with the SC and parent

using open-ended interview guides. Also, one SC recorded a sample self-interview to verify both the appropriateness of the self-interview guide and proposed information sheet, and the feasibility of conducting self-interviews. All the interviews were recorded, transcribed, analyzed and presented to the doctoral committee as part of the research proposal. These experiences helped the researcher, a novice to qualitative methods of research, become accustomed to qualitative research.

Data Collection Procedure

In February of 1994, approval from the Institutional Review Board (IRB) for research projects involving human subjects was obtained. A letter of invitation to participate in the study along with a copy of the research proposal was sent to four district project coordinators of TEIS. Out of the four districts two districts (Districts A & B) quickly responded positively. SCs from Districts A and B were chosen as participants. Approval to participate (signed consent form) in the study from all the eight possible SCs (100%) were received between February and April, 1994.

The criteria for a child/parent to participate was that the child/family had to be "new referrals" to TEIS. According to this criteria, the child/family would not have any early intervention services provided by any other agency

and that they were not referred to TEIS for only the payment of services. However, during the data collection process it was not common to find children/families who were not already receiving services.

Children/families who were considered as "not new referrals" were being evaluated or already evaluated, receiving therapy, receiving special instruction, or already receiving all the services except for the IFSP meeting to be held, or having completed the initial IFSP at the time of referral. One major group of children that were not considered as new referrals were those children who were referred to TEIS only for the purpose of payment. The following quotes (excerpts from SC referral reports) support this notion.

> M:in this case two children were referred (twins). During the home visit both the children were screened... the parents had pursued and gone to the program even before I initially had become involved. They just wanted some kind of confirmation that there was a problem with the children... I am not the service coordinator and I don't have an involvement because the children are already placed in a program that they wanted to be in. They will be receiving therapy.
>
> J:The next one... He has had an IFSP already before he came here. He had moved from another district... He has already had an IFSP when he came to Knoxville. He was transferred from another district. This was not a new referral.
>
> K:referred to TEIS on 5/19/94 by one of the agencies which provides early intervention services... IFSP in place and was receiving early intervention services. The reason the child was referred to TEIS was for therapy co-payment.
>
> M:this is another Agency S child which we did not pursue because of payment issue. All of the center referrals TennCare eligible. It may be that the Agency S was not receiving payment from TennCare. They asked TEIS to get involved because of payment. But we could not supplant what TennCare is involved with.
>
> M:This one has been... on the waiting list at Agency A. But the family moved and I went for intake and IFSP and the family--no shows--like three times. Now have got a message from Agency AK

which is Agency AM and this child is enrolled there in Town M. But the deal was that they were apparently traveling from Town M to Town B every day to get therapy and child care. And it ends up that they can stay in Town M... They wanted payment. That is the reason they would not follow through they wanted for us to pay for therapy occupational. Their insurance did not cover it, but at Agency AK at the Agency AM it is a MHMR type of--and they get therapy for free.

J:This was payment for transportation. Because--she does have access to TennCare transportation. She just doesn't like it. And wants us to pay for it and we can't. I got a message today saying they are not interested in our services.

Thus, due to the difficulty experienced in locating children/families who met the criteria a change was made to include those children/families who were receiving some services. Only children referred for payment of services to TEIS were excluded. The data collection lasted from February 1994 until March, 1995.

In spite of the changes in the criteria in collecting data, the researcher was able to get only five families to participate [out of the ninety-one referrals] during the entire data collection period [Refer to analysis of SCs' referral reports and the corresponding Table on Pg. 72-73 for details]. The issues reported by the SCs in getting families to participate were repetitive. The data collection was terminated after one year when the fifth child whose family had agreed to participate in October was determined as ineligible after the intake meeting in January. The researcher did still interview both the SC and parent in this case. No other referrals were immediately available. Since all other cases were complete, the initiation of another case would have prolonged the data

collection. The length of time between referral and IFSP ranged up to 8 months for the previous cases, therefore termination of the data collection was necessary.

Description of the Participants

Participants from two sites in Tennessee were included. These sites were two district areas in which the TEIS services are established. Information from the demographic information form is utilized to provide a description of the children, parents, and SCs from Districts A and B.

Children

Demographic data about the children is presented in Table 1. The age of the children at referral ranged from one month to 30 months. Out of the five children, one was a girl. One child was African-American and all others were Caucasian. Three had diagnosed conditions, one was eligible based on a speech and hearing evaluation, and the other was determined not eligible based on developmental evaluation.

All mothers indicated that their children were receiving services except the one whose child was not eligible. Two children along with their mothers lived with their extended families (maternal grandparents), two lived with both parents, and one lived with a foster family. Two children were first-born, two were second, and one was the

Table 1. Description of child and mother

CHILD							MOTHER				
No	Site	Name[a]	Sex	Diagnosis	Age[b]	Age[c]	Name[e]	Relation	Education	Occupation	Ethnicity
1.	A	Peter	M	Hearing loss	22	24	Pat	Mother	College	Home maker	Caucasian
2.	A	Sophie	F	Cerebral Palsy	30	32	Rene	Mother	College	Secretary	Caucasian
3.	A	Victor	M	Cerebral Palsy	5	13	Faye Beth	1st FM[f] 2nd FM[f]	Partial College High school	Home maker Home maker	African-American Caucasian
4.	B	Arnold	M	Profoundly Deaf	19	20	Nancy	Mother	Partial College	Home maker	Caucasian
5.	B	David	M	Premature	1	NE[d]	Sara	Mother	High school	Home maker	Caucasian

[a] Psuedonymn of the child.
[b] Age at the time of referral (in months).
[c] Age at the time IFSP was developed (in months).
[d] Not Eligible.
[e] Psuedonymn of the mother.
[f] Foster Mother

youngest foster child out of five foster children.

Parents

The demographic characteristics of the mothers are presented in Table 1. Four mothers (two foster mothers for one child) were from District A and two others were from District B. The sample included two single parents, two foster parents (married), and two sets of both parents. Two mothers had completed some years of high school, and the rest had obtained education ranging from a high school diploma to a college degree. The father's education in three cases included college degrees. The occupational status of the mothers was that one was a student, three were homemakers, and one mother was employed. Two single-parent families received public welfare assistance.

Service Coordinators

The demographic characteristics of the SCs are presented in Table 2. All were Caucasian females with varying educational backgrounds and experience. All had a master's degree. Two had an early childhood background, one had a social work background, one had a special education background and another psychology and counsellor education. Two SCs had approximately two years of experience as SCs and the other three had experience ranging from six months to one year. Four had previous experience with the IEP

Table 2. Description of service coordinators

No.	District Office	Name[a]	Education	Experience[b]	IEP[c]	IFSP[d]	Training[e]
1.	A	Kay	BS (Sociology) MS (social work)	15 years	none	35	3 hrs
2.	A	Jenny	BS (Child development) MS (Child development)	8 years	4	20	30 hrs
3.	A	Chris	BS (Child development) MS (Child development)	3 years & 6 months	4	12	3 hrs
4.	B	Liz	BS (German) MS (ECSE)[f]	4 years	10	35	6 hrs
5.	B	Tina	BS (Psychology) MS & Ed.S (Ed. Psychology & Counselling)	10 years	20	50	30 hrs

[a] Psuedonymn of the service coordinator

[b] Number of years of experience working with children with special needs

[c] Number of Individualized Educational Plan (IEP) participated

[d] Number of Individualized Family Service Plan (IFSP) participated

[e] Number of hours of specialized training received in the development of IFSP

[f] Early Chilhood Special Education

process. The number of IFSPs SCs had participated in ranged from 12 to 50. The number of hours they identified as having received training with the IFSP process varied widely.

Overview and Tabulation of Data Obtained from Different Sources

Data obtained are from four sources. They are: 1) SCs' referral report (potential participants) received during the data collection period; 2) parents' and SCs' recorded self-interviews; 3) parents' and SCs' recorded open-ended interviews; and 4) documents pertaining to the child/family.

Analysis of Service Coordinator's Referral Report

SCs agreed to inform the researcher about referrals. Their referral reports document referrals received from the time they agreed to participate until a particular child/family was identified as participants. However, many of these potential participants (referrals) could not be followed up due to various intervening factors. These factors are coded into seven major categories and presented in Table 3. The categories presented are not mutually exclusive. Descriptions of these are presented where relevant to research questions.

Table 3. Refferal log.

NAME OF SC	KAY	LIZ	CHRIS*	JENN	TINA	HANA	MARY	ELSA**	
DATE SC'S AGREED TO PARTICIPATE IN 1994	3/8	4/28	4/20	3/28	4/28	4/28	3/11	4/28	
DATE OF REFERRAL OF THE PARTCIPATING CHILD	5/23	6/15	12/13	6/13	9/20	-	-	-	TOTAL
NUMBER OF REFERRALS RECIEVED	18	1	1	11	22	13	25	0	91
NUMBER OF CHILDREN PARTICIPATING	1	1	1	1	1	0	0	0	5
RATIONALE FOR CHILD & FAMILY'S NON-PARTICIPATION									
Not Eligible	4	0	0	1	5	2	5		15
Not a New Referral	8	0	0	1	5	2	2		13
Not Able To Contact	3	0	0	3	1	3	4		10
Referred for Payment Only	1	0	0	1	0	0	7		8
Child Turned 3 years of Age	0	0	0	0	1	2	0		4
SC'S Apprehension	0	0	0	3	5	2	4		11
Family Refusing Services	1	0	0	1	4	2	3		10

*First referral for this SC was the participant in the study; ** No referrals from this SC because of the change in the duties at the office during the course of the study.

Analysis of the Service Coordinators' and Parents' Self-Interview Data

Self-interviews were recorded by both parents and SCs about events during the initial IFSP process, including the IFSP meeting. The number of self-interviews completed are tabulated in Table 4.

Table 4. Number of self-interviews completed by service coordinators and parents.

Case No.	Service coordinator	No. of Self-interviews recorded	Parent	No. of Self-interviews recorded
1	Kay	8	Pat	7
2	Liz	2	Nancy	5
3	Chris	2	Faye Beth	5 2
4	Jenny	2	Rene	-
5	Tina	2	Sara	1

Service Coordinators

SCs' recorded self-interviews totalled 16. All of them recorded the self-interviews. Three gave all of the self-interviews to the researcher prior to the open-ended interview meeting (conducted after the initial IFSP meeting). The other two gave them to the researcher at the time of the open-ended interview. SCs recorded some self-interviews after each contact with the parent or professionals, and other self-interviews after several contacts with the parents and/or professionals. Two SCs recorded self-interviews of all the contacts at one time

(self-interview of each contact).

Out of the the 16 self-interviews, 9 referred to telephone contacts and 7 referred to face to face contact. The telephone contacts with the professionals lasted from three to 20 minutes and the face to face contact ranged from 20 minutes to two hours. Three recorded self-interviews about the IFSP meeting.

Parents

Four parents recorded the self-interviews. One child had two foster parents prior to the IFSP meeting, and self-interview data from both foster parents were obtained. One parent who had agreed to complete her self-interviews expressed her inability to do so, and none were made. The total number of self-interviews recorded by the parents was 20. Out of the the 20, 9 referred to telephone contacts and 11 referred to face to face to contact. The telephone contacts with the professionals lasted from three to 20 minutes and the face to face contact ranged from 20 minutes to two hours. Three gave all of the self-interviews to the researcher prior to the open-ended interview meeting (conducted by the researcher with the parent after the initial IFSP meeting) excepting the self-interview on the IFSP meeting, which was given at the time of the open-ended interview. The other two gave the self-interviews at the time of the open-ended interview. Almost all the parents

recorded self-interviews after each contact with the professionals. Three of them recorded self-interviews about the IFSP meeting. One parent did not have an IFSP meeting as her child was determined ineligible. The other parent who did not record a self-interview about the IFSP meeting was the first foster parent who was no longer involved.

Analysis of the Open-ended Interviews

Open-ended interviews were conducted with all participants including the parent of the fifth child. The interviews with the parents were conducted at their homes, and with the SCs at the TEIS offices. The open-ended interviews for parents lasted from 20 minutes to 1 1/2 hours. For SCs they were between 1 1/2 hours to 2 1/2 hours.

Analysis of the Documents

Documents pertaining to each child/family that were filed at the TEIS office were analyzed. These are presented in Table 5 and described below.

Status Form or The Minimal Data Form

This form is the first document created for a particular child/family after they are referred. It includes the date of referral, the agency and/or the name of

Table. 5 Documents analyzed for each child and family.

No.	Title of the Document	Case 1 Peter	Case 2 Arnold	Case 3 Victor	Case 4 Sophie	Case 5 David
1.	Status Form	+	+	+	+	+
2.	Initial Plan of Action	+	-	-	+	+
3.	Central Intake Form	+	+	+	+	+
4.	Family Needs Form	-	+	-	+	-
5.	IFSP form	+	+	+	+	+
6.	Service Coordinator Progress Notes	+	+	+	+	+

the person who referred, basic information about the child/family, reason for request for TEIS services, diagnosis of the child's problem (if known), agencies serving the child, and the name of the person who is responsible for documenting all of the above information on the status form. The form includes a section relating to eligibility and action taken. Typically this section is completed after the initial home visit, during which time eligibility information is obtained.

Initial Plan of Action Form

The Initial Plan of Action Form is completed by the SC during her initial intake meeting with the parent, which may take place either at home or at a service agency. The original is filed along with the other documents for the child/family. A duplicate is given to the parents at the

end of the initial home visit. This form was completed for only three families. One family was moving out of state. Information typically discussed during the intake meeting was discussed by the SC with that parent over the phone, and a letter was written which seemed to serve the purpose of the form. Another family did not have a form completed because their child was in foster care and the parent did not have the legal rights to give permission for services. However, the activities and the interactions that occurred during a meeting with the foster parent were documented by the SC. The contents of the report were comparable to that which would be recorded on the form.

Central Intake Form

In the beginning of the IFSP process the "Central Intake Form" is used by the SC to gather information about the child/family. This form contains the child/family demographic, medical, insurance, and financial information. It was completed for all of the families. In one case, two forms were completed, because the child was moved to a second foster parent. The form included information relating to other agencies and professionals who were involved in providing services to the child/family.

Family Needs Forms

In an IFSP process, some families prefer to indicate their needs by completing questionnaires in addition to the discussion they have with SCs. Among the participating families, two had completed a family needs form. One family completed two different family needs questionnaires. They were "How can we best serve you?"(TEIS, 1994), and "Family Needs Survey" (Bailey & Simeonsson, 1988). In one family both parents completed two separate family needs forms.

Individualized Family Service Plan Form

The first IFSP document is developed for those eligible children/families during the initial IFSP meeting. The IFSP document was completed for four of the five cases. These four children met the Part B section of the State of Tennessee definition of "developmental delay" and were eligible for TEIS services.

Service Coordinators' Progress Notes

The progress notes are filed by the SCs along with the other documents pertaining to every referred child/family. They record their activities and interactions with parents and professionals from the time a child is referred. Typically, the details recorded on progress notes include the name of the person or agency to whom the call was made or received, purpose of the call, outcome of the call or any

other activity and the date on which the activity occurred. These were available for all participants.

Description of the Process of Developing the Categories

The recorded open-ended interview, and self-interview responses of both the SCs and parents were transcribed. Also, the referral report of the eight SCs who agreed to participate were transcribed. The seven documents for each child/family filed at the TEIS office were coded.

Analysis of the open-ended interviews of the SCs and parents involved unitizing and categorizing (Lincoln & Guba, 1985). The transcribed open-ended interviews of each of the SCs were stored on separate files. These transcribed interviews were read by the researcher separately in the order the open ended-interviews were conducted. Each line of the transcribed interviews was numbered as were the pages which were printed with a 2.5 inch margin. These printed transcriptions were coded into broad categories. That is, the transcribed interviews were unitized by research question by making notes in the margin, and by labelling the units of analysis by research question (e.g., research question 1 refers to SC 'roles' in the IFSP process). All the units of analysis pertaining to a SC's role in the open-ended interviews were coded into a broad category using the cover term roles. Thus, units of analysis pertaining to roles from individual SC open-ended interview responses were

grouped and merged into a large set called role (file). Similarly, the open-ended interviews were further coded into broad categories for the rest of the research questions by using the terms events, issues, practices, suggestions, and information.

The data under these broad categories were further coded by making notations and using abbreviations according to the constant comparison method (Glaser & Strauss, 1967). These coded data were sorted into sub-categories. The main features of the units under these sub-categories were used to describe them. A similar process was carried out with the data coded under each of the seven research questions.

This method was also employed to analyze the parent open-ended interview responses. They were separately transcribed, read, unitized, coded into broad categories, and sub-categories by the researcher.

The self-interviews of both the parents and SCs were transcribed and read separately. However, these self-interviews were not coded by research questions, but were coded as categories emerged from the data. Similarly, the referral reports of the SCs were categorized.

The total number of lines transcribed and unitized are presented in Table 6 by data source.

Table 6. Size of the Data

Data Source	Service Coordinator			Parent		
Number of lines	Total No. of lines	Unitized lines	% of unitized lines	Total No. of lines	Unitized lines	% of Unitized lines
Open-ended interview	5039	3477	62.3%	2270	1580	66.1%
Self-interview	1286	980	76.2%	361	310	86.5%
Service coordinator referral report	1491	966	64.8%			

Results

The results are organized by the research questions, and divided into Service coordinator (SC) and parent (P) sections. The excerpts from different data sources are used to support the categories described under each research question. These data sources are identified by the initial letter of the data source (open-ended interviews(O), self-interviews (S), documents (D), and SC's referral report (R) along with the initial letter of the pseudonyms given to parents and SCs.

Research Question 1: How do service coordinators' and parents' perceive their role/participation/involvement during the IFSP process?

Service Coordinators

The researcher identified the major functions performed by SC as they served children/families by examining open-ended interviews, self-interviews, and documents. These were communicating, meeting, verifying, coordinating, training surrogate parents, and empowering. These functions are described in the following paragraphs in the order in which they unfold typically in an IFSP process. However, it must be noted that some of the functions are not necessarily

carried out in the order in which presented and that they overlap throughout.

Ways of communicating

Communication seems to be the primary function SCs perform as children/families are referred to TEIS. According to all the SCs, they are engaged in communicating with families and professionals, and/or personnel representing different agencies soon after they are assigned to a child/family either through mail or telephone. One SC declared:

> J:Communicating, I mean that is probably the most important part of the role that I see.[We] send a parent packet as soon as I get the referral. Which has TEIS information and introducing myself... before they get the call, or I call them and say, "You will either be receiving this packet or I will send it, sort of depending on the severity of the case...sometimes too it will say on the referral form--contact the referral source before you contact the family... if it is a Agency G referral, child is in custody... any special situations to be careful... if we have got a child who is in foster care and it is a drug exposed child and the delays are from that, but the foster mother is not aware of that, so it was something that I was not to communicate that to the foster mother, because that wasn't our role.(SC-O)

The way in which SCs communicate varies from formal contact to informal exchange such as just listening to parents. Thus, SCs communicate in different ways such as contacting, deliberating, mediating, inquiring, and listening.

Contacting/corresponding involved SCs contacting parents and service providers by telephone or mail at the

outset and keeping them updated throughout the initial IFSP process. One SC "attempted [a] prior phone call when the mother was not at home... corresponded on 5/27... mailed Mrs. Pat a letter asking her to contact me since I was unable to reach her by phone" (SC-S). Four out of the five SCs mentioned that they typically mailed parents a letter introducing themselves along with other TEIS material. SCs also corresponded with other professionals such as physicians, therapists and other agencies for requesting services for the family, and the release of information pertaining to the child/family. The SC sent "...a correspondence ... [to] Town L City Schools telling them that Peter might need their services when he turns three" (K:SC-S), and to inform them about the IFSP meeting.

Four SCs mentioned updating as well as getting updated by both the parents and professionals about all related activities as part of contacting/corresponding. These activities included evaluation appointments, service availability, payment of services, information about important events such as training, meetings, and other services. According to one SC, "...she updated me on the status of Peter at agency D and I updated her with the services he is receiving and the plan for getting the services for him" (K:SC-S). However, another SC expressed that she was not updated with information about the major changes with the foster child, "people were not giving me

enough information... I felt like I was bugging them too... wanted to make sure that everybody knew what was going on with Victor--that was involved... It took her ten days to just give me the parents' names... she might have forgotten about me" (C:SC-S).

All the SCs reported deliberating with parents and professionals, which took the form of explaining, discussing, and addressing the needs of the child/family. SCs explained pertinent procedures to parents, such as the TEIS services, IFSP process/meeting, rights of their children, payment for services, and other services. One SC commented "... I sort of explained to her again what was going to happen at the IFSP meeting and who all was going to be present and what kind of things we were going to decide on, just to put down on paper the types of therapy and evaluations that she had and TEIS paying for the co-payments of the therapy that her insurance did not cover" (J:SC-S). SCs addressed the needs of the child/family, focussing on the child/family's immediate need, how they were going to obtain the services, and how they would do the payment "...[I] talked about how the physical therapist had suggested that due to Victor's condition that he have a side-layer-- which is some kind of apparatus that helps them to stand to be able to play and manipulate objects and they were talking about how they wanted to make sure that insurance would pay for it. And if not, could TEIS pay..."

(C:SC-S), SCs discussed the needs, resources, and priorities of a particular child/family "... I discussed this [payment of service for a family] with... the contract specialist in our office... we think that it might have to go through the Nashville contract line..." (J:SC-S). Two important settings in which SCs engaged in a discussion were the IFSP meeting and the intake meeting. Thus, SCs referred to about discussing matters with both parents and professionals.

Mediating calls for SCs to conduct the IFSP process in a consistent manner by facilitating the communication between parents and other professionals. As one SC puts it "I see my role more than anything as facilitating communication among other agencies and the family with the agencies" (SC-O). Assuming this role, three SCs explained that they were able to regulate different services the child/family needs. One SC stated "sometimes [I am a] mediator,... if a family has had a bad experience with a person or different agency then we try to work out that relationship so they can still get what they need" (T:SC-O). Two SCs maintained that facilitating the communication during the IFSP meeting in particular and the IFSP process in general is being important. Facilitating the discussion during the IFSP meetings involved encouraging parents to speak of their concerns regarding the program, their child's needs or transportation. One SC described it as, "facilitating that talking process so we can all pull it

together. And I don't try to put words in the mouth or anything like that, but at the same time, I do try to get the ball rolling so you are not just sitting there looking blankly at each other trying to figure out what to do" (C:SC-O).

SCs talked about inquiring about the various insurance plans at different agencies. Typically, these inquiries are done to secure services from an agency preferred by the family and which honors their insurance plan. The SC made a "call to Therapy Center to inquire about which TennCare plan they take. They do not take PHP so could not serve Peter" (K:SC-S). Also, the SC checked with the parents about the health status of the child, "I contacted the mom to check... I found out that Victor was at Agency E in ICU... So this was a trouble time for him ...getting in and out of the hospital" (C:SC-S), which seemed to affect both the planning of the evaluation and the IFSP meeting.

Two SC responses indicated that one of the essential attributes of serving families is listening like a friend.

> T:Sometimes people just need somebody to listen and I think that is often where support comes in. Families go through a lot of anger and stuff when they are particularly dealing with physicians or attorneys or whatever they might have to be dealing with like that. And sometimes they just need somebody they can fuss to....(SC-O)

Ways of Meeting

SCs discussed their involvement in meetings during the IFSP process. Meeting refers to SCs' face to face

encounters with parents and professionals. The SCs' involvement in these meetings seemed important as it was discussed by the SCs in both their self-interviews and open-ended interviews. In addition, the documents provided evidence of their involvement in these meetings. All the SCs mentioned being involved in two types of meetings: the intake meeting, and the IFSP meeting. The activities that occurred during the initial intake meeting were gathering and providing information from and for parents, and completing several forms.

> T:... the intake visit... We discussed the intake information and filled in the forms. Talked about TEIS and how we might be able to assist the family if David is eligible for our program...she was also interested in getting information about housing and child care when she is ready to start school. (SC-S)

The other meeting SCs discussed in detail was the IFSP meeting. During the IFSP meeting, SCs reported going through the present levels of development, which involved reviewing and discussing the reports provided by the doctors and therapists. Further, the child's levels of functioning were documented according to available reports. Also, they referred to parent reports about their child's development in the area of cognition, communication, and socio-emotional self-help and adaptive development, which were documented on the IFSP. SCs indicated in their responses that the other components of the IFSP document, such as the concerns, resources, and priorities, major outcomes, summary, and the

transition plan were completed. One mentioned that the IFSP document was presented to the parents during the meeting for review before signing.

> J:IFSP was held at Agency C... people present--Sam and Rene--the parents, Jenny, and Florence... lasted about one hour and fifteen minutes... we went over the present levels of development... resources included were agency C, insurance... TEIS, child care referral source. Concerns were to straighten out insurance in terms of were they going to pay the 80/20 ... improve overall development... handling follow through with Child Care and Referral Sources... outcome summary page... reviewed the services... anticipated date of transition... plan...family to a visit with County C Schools to see the three year old program... Both mother and father looked through it [IFSP document] and felt very comfortable with things that were written.(SC-S)

Ways of Verifying

One of the important duties of the SC is to see whether the child can be served based on his/her presenting needs. Therefore, it is her role to verify whether or not the child is qualified for intervention services. One SC stated, "Part of my role has to be to decide if the child is eligible for TEIS" (K:SC-O). The child's eligibility for TEIS services is established by conducting a screening test or ascertaining whether or not the child has a diagnosable condition, and/or referring the child for further evaluation. Also, based on the information obtained from the parents regarding other needs of the family, the SC verifies whether the child/family is eligible for other community services which require further referrals,

including financial assistance. For example:

> C:6/6/94--Victor is out from the hospital and he was diagnosed by Dr. Pinto (while in the hospital) as having CP.... Foster mom will call me back and let me know so we can do IFSP soon. (SC-D)

> T:I received a copy of the developmental evaluation report from Lynn and I sent the mother a copy and a letter stating that David is not eligible for our program at this time and that I will call back in about three months to check on how he is doing. (SC-S)

Ways of Coordinating

The title of the position "service coordinator" itself suggests the kind of duties they perform, that is, coordinating the activities of the IFSP team. All the SCs described coordinating as contacting a person or agency by phone about getting services, setting up services, expediting the needed services, providing necessary information to parents about services they are interested in, and arranging payment towards the services the family receives. One SC stated the situation well for herself and her fellow SCs,

> K:Coordinating involves calling up agencies, speeding up ... smoothening the process...with the agencies the family has been linked up with, asking about the possibility of serving the child for the parent, letting parents know that they need to call the agency back for more information....(SC-O)

As a member of the IFSP team, the SC coordinates the activities, or, streamlines all the services that the family needs. Bringing the members of the team together to develop the IFSP document jointly is another duty. This meeting is

arranged at a place and time that is convenient to all the members of the team. As one SC puts it "... for the most part the team is pretty identifiable. So my role is to pull that group together and find a nice time that we could all meet and then hold the meeting, wherever, is convenient for most of the members" (C:SC-O). One SC felt she was in a better position to coordinate the services that the child/family require than a professional who provides services on a daily basis or a few days during the week. SCs mentioned different ways of coordinating services for children/families such as referring, arranging, and completing documents.

Referring seemed to be a key function of the SCs. All the SCs reported referring parents/children to those professionals and agencies selected by the parents for evaluation, intervention, preschool services, and for more information parents need. Evaluation services covered general physical, gross motor, fine motor, self-help, and speech and hearing development. One SC said, "I made a referral to Lynn for developmental evaluation to determine eligibility" (T:SC-S). Intervention services included therapy, child care, and special instruction. Only children who were two years and above were referred for preschool services. Referring children to such three year old programs typically involved mailing a referral report to the school system. Children not eligible for TEIS services, but

who were close to their third birthday were also referred to public schools " ... I did the REAL for the parent interview to find out about the child's language, she was not delayed... not eligible for TEIS... child was turning 3 years soon. I made a referral to the school system" (M:SC-R). One obtained parental permission, referred the sibling of the child for evaluation and also informed the parents after the referral was made "I called Agency X to refer Verline who is Peter's older sister for counseling regarding behavior problems..." (K:SC-S). One referred parents to other organizations for information (e.g., parent organization).

According to all the SCs, one of the major activities of coordination was arranging/scheduling. SCs arranged for evaluations, payment for services, and transition. They were engaged arranging for evaluations by making appointments at times suitable to both parents and professionals. One SC stated "I phoned the mother and arranged an appointment for 11-9-94 at 10:00 a.m. for Lynn to come to the home and do the developmental evaluation" (T:SC-S). Also, they were involved with arranging for the payment of services the child receives by submitting the necessary documents. "I completed the purchase of service form which is for TEIS to pay for the co-payment for physical therapy and occupational therapy" (J:SC-S). One SC was engaged in arranging for transitioning the child from

early intervention services to a preschool program, sending the child's report to the school system.

Three out of the five SCs indicated that parents, professionals and SCs were engaged in scheduling. Scheduling was related to the intake and IFSP meetings. They usually scheduled the intake meeting with the parents, and they received from and made calls to parents as well as other professionals for scheduling throughout the IFSP process. One SC claimed, "... I did try to call her several times before and tentatively scheduled the IFSP meeting" (J:SC-S). One SC's response suggested that she sent a written notice to parents and professionals confirming with them when the IFSP meeting was scheduled.

Completing documents is an essential routine performed by all the SCs. They reported completing several forms during the process, including the Status Form, Release of Information Form, Central Intake Form, Plan of Action Form, Request for Service Form, and Purchase of Service Form. One SC stated that she "... got the releases of information, completed intake form, and the releases to send for information--to send for evaluation records from other agencies" (J:SC-S). Prior to the initial IFSP meeting, one of the necessary documents that SCs submit for families who get financial support from TEIS is the Purchase of Service Form, "...[I] gave Pat travel forms for POS (Payment for Services) travel reimbursement for 6 months" (K:SC-D).

Finally, the IFSP form is developed during the initial IFSP meeting by the SCs, "... and we completed the IFSP form..." (L:SC-S).

Training surrogate parents

Although only one SC was involved in training and appointing surrogate parents, it seemed like a crucial activity in serving children in foster care. The child in this study, who had been originally abandoned by the biological mother, was in the care of two foster families, and needed two surrogate parents appointed by the time the initial IFSP was developed. The SC described the situation which prompted her to conduct a surrogate parent training as, "...the child is presently in foster care, birth mom is out of state (whereabouts unknown) and therefore surrogate parent needs to be in place... we were able to schedule a training for surrogate parent" (C:SC-D). According to the SC, appointing a surrogate parent who has undergone the surrogate parent training is an essential component of the IFSP process for children who are in foster care, because "... that is when... official services began surrogate parent appointed that is Faye his foster mom..." (C:SC-S). The appointed surrogate parent has the authority to sign papers and make decisions for the child. However, during the initial IFSP process the first foster parent, also a surrogate parent, had to relinquish her rights due to a

bureaucratic inconsistency in the foster care system. Therefore, the SC "...needed to appoint a new surrogate parent and...[had to] chose from the pool of people who had been trained... to be the surrogate parent... would not have to wait again for training" (SC-S).

Ways of Empowering

Parents of children with special needs have rights which they can exercise as they secure appropriate services. Three SCs discussed empowering parents. SCs see themselves in the role of empowering the parents to obtain the required services to which their child is entitled by providing the right support to the family in their efforts to obtain appropriate services, financial support, and telling them about their rights. According to SCs, parents differed in their level of awareness of their rights and exercising their rights. One SC declared:

> J:my biggest role is being an advocate for families, to make sure that they get what they deserve and to empower them. To let them know that they have the ability to do all of these things... to insure that she knew her rights as a parent... She can fight for it... That is what that family needed, really was boosting and saying, "You are doing a great job... And direct the family to fight the system a little bit and that will happen, and it will work sometimes. (SC-O)

In the process of empowering parents, SCs were engaged in helping parents make decisions, accept that they do not have to be experts to care for their children, understand that they are capable of caring for their children, realize

plausible expectations, identify the needs of the child/parents, locate the services that they need for their child/family, and obtain services. The following comments of two SCs demonstrate the complexity of the process of empowerment.

> J:Helping the family make a decision...the mother who is mildly retarded but is able to care for her child and to help her realize that she has the ability to make sure that all this stuff gets done. She can fight for it. It is okay for her to do that... helping them realize realistic expectations too ...to help the father to realize it was okay for him not to know everything about child development and he did not have a degree in it" (SC-O).

> K:I think that my role is...to help identify the needs of the child... helping to give some idea of--yes, it looks like your child, you know, might be behind in this area or no, you know, what I have done with him. He seems to be doing fine, but we can get other evaluations if we decide we need them...to help the parents find the services that the child needs...if they need help with accessing those services--to help with that. Some do and some don't, you know, some would rather do it themselves and are very capable and others really don't know where to begin and are overwhelmed and want some help with it" (SC-O).

Parents

Parents' perception of the IFSP process differed from SCs. After examining the parent open-ended interview responses(P-O), self-interview responses(P-S), and documents(P-D) four major actions emerged: communicating, decision-making, advocating, and transporting. Unlike SCs, parents do not use the word role, instead they use action words in describing their role in obtaining services for

their child/family.

Communicating

Communicating with professionals was a basic part of parents effort to obtain services. They adopted different ways of communicating with professionals: asking, informing, listening, and discussing. The extent to which all of them adopted these different ways of communicating seemed to differ.

Four out of the five parents responded that they began asking from the time they sensed their child had a problem. Parents asked professionals about their child's problem. As one parent described, "...everyone I see like... I ask them if they know what's wrong because they have the reports, no one knows nobody. I have asked Becky [speech therapist],... the doctors at Agency E,... no one knows, nobody knows so [it] leaves you in the dark hole. You don't exactly know what to say; what to ask; where he is going to go; You don't even know what the problem is other than that there is one" (P:P-O).

During the process of finding out the nature of the child's problem, parents begin to ask about the details of the child's diagnostic reports and proceed to look into available services to meet child/family needs. Two families asked about the different programs from which their child/family could receive services by completing family

needs questionnaires. Parents asked about child care, therapy, housing, utilities, and job training services by checking the appropriate statements within the family needs questionnaire. For example: "Information about services that are presently available for my child,... services my child might receive in the future..." (N:P-D). Often parents are concerned about the financial implications of obtaining services and ask about such matters. Three parents mentioned inquiring about it with professionals. One parent stated, "...we were interested in is if there were any financing resources that were available to us..." (R:P-O).

Three parents asked about information to meet the family needs. One parent asked for more information by checking the following statement on the family needs questionnaire.

> N: Our family would like to know if we qualify for help with: housing, child care, utilities(phone, electric).(P-D)

In one exceptional situation, a current foster parent was asking the former foster parent about the health condition of the foster child. She reported, "I called her several times and asked questions. She sent a little book with information on his eating, his sleeping habits, you know, when he had been sick. All of his doctors' names. You know, how much he ate and stuff like that. Just so that we would know his daily schedule" (B:P-O).

Parents' responses suggested that another way of communicating was informing professionals. All parents were engaged in informing professionals about medical information, family background, and the behavior of the child in different settings. One parent indicated that she provided professionals, "...copies of his medical records... I think I had to fill out a small family history... gave them some background on him... telling them everything that he has already learned...just the type of person he is and how he is able to learn. I think that helps them design a program especially for him, because he just picks up on things so fast"(L:P-O). Parents inform professionals about the family insurance plan for receiving services from agencies.

The number of professionals parents informed varied according to the needs of the child/family. The first foster parent informed at least seven different professionals (pediatrician, physical therapist, occupational therapist, child care staff, eye specialist, service coordinator, hospital staff). In addition she informed the second foster parent. In the case of David, who was determined as ineligible for TEIS services after the intake meeting, the parent mentioned informing about four different professionals.

It is evident in the responses of three parents that they were actively listening to professionals as they were

communicating with them. As active listeners parents paid attention to the details that professionals point out. For example:

> R: they were telling us to read it in context as we knew applied to Sophie,...her pediatrician... he was telling us then,... it was something that she would outgrow.(P-O)

> F:...explained to me that before TennCare will provide this service that the doctor will have to re-screen Victor.(P-S)

Discussing with professionals seemed to be another way parents communicated during the IFSP process. According to parent responses, discussing involved more depth and deliberation in their meetings with professionals. Particularly, parents talked about their involvement in the discussions with SCs and other professionals during the IFSP meetings. They discussed with professionals the child's therapy, behavior, overall development, progress, goals, transitioning, future needs, and their role in the action steps that were stated on the IFSP document. The following statement supports the above notion.

> N:We discussed all his goals...for the next six months, and what things that we needed to accomplish or get done before then,... We also discussed his weight, ... We are discussing having a nutritionist come over there and see his daily diet. See if there is any thing that could be changed or that might be affecting him, because he is real active and he sweats all the time, but, you know, he is still there. So they were going to see if somebody would come check that out... So that was about the only things that we discussed other...it wasn't that long. (P-O)

Decision making

The act of parents' decision making refers to those moves parents make in obtaining services for their child/family once they have the necessary information. Parents make decisions with regard to the kind of services the child/family needs, and the kind of financial commitment they are able to make in receiving services for their child/family. Sometimes, a parent decides to overrule authority. She stated,"...he [pediatrician] did not believe in taking him [David] back to Agency AC, because he felt like it would be just another exam for David. And I said well I don't think that would hurt him, he was born there and they are very good there and he said no, he did not believe in it. But I took him [to Agency AC] anyway" (P-O).

The foster parent indicated her decision about having a foster child.

> F:...our foster son [older foster child not involved in the study]... was moved to a new program and that program does not allow Agency M foster children and welfare foster children to reside in the same home. So we had to make a decision to have Victor removed. It was hard because..., so we made the decision to have him moved. (P-S)

The activities that refer to the parent function of decision making are planning and authorizing. In carrying out these activities it appears that they are involved in making decisions that are both implicit and explicit. Although parents do not always explicitly mention their decision making role, their actions indicate their

decisions. In the following statement one parent described her decision making role with regard to her child's needs.

> R:you have to make the judgement call of what your child really needs and then somewhere down the line someone says--even the doctor may admit, you know, they did not really need this, maybe only this and this....doing the evaluation at six...one of the reasons I felt like six months from now was realizing that her skill demand will be greater in six months than it is now. That may indicate that she would need the occupational therapy, because of things that she will need to do will be a little more tedious and will take more skill. (R:P-O)

As part of the decision making process, parents' planning to obtain current and future services that would help their child was evident in their responses. Thus, parents presented with multiple options in terms of services and payment for services needed to evaluate the services their child needs. Parents seemed to evaluate the information regarding all the services while making decisions either implicitly or explicitly. One parent indicated that she evaluated the quality and convenience of the services that her child was going to receive. Parents also evaluate the services available for their child in terms of the financial commitments they have to make and their personal philosophies regarding the kind of services their child needs. One parent explicitly stated:

> R:type of services we were looking for... family or center-based... and so we got those [information] and we are still evaluating those ourselves... child care information and referral... That is something we ourselves are going to evaluate...looking for services that we could check into that did not have an income limit, because I knew we would probably not be eligible

for ones that have limits. And TEIS was one of those. (P-O)

One parent described her involvement in planning for the child, particularly taking into consideration the future of the child. She said "Even though her disability seems to be minor--it is still something that is going to be with her for the rest of her life and just... whatever we could do to help with that development process and help in transitioning from toddler stage and the pre-school stage and on up"(R:P-O). Another parent described her plans for her child as, "Of course have him continue the speech. To set up the Agency B--physical therapy there..." (P:P-O). On similar lines, another parent explained more specifically being involved in planning the timing for the child's therapy. She said, "We basically worked our schedule, our request from them is to make our appointments--the latest in the day and I think they have... evening... Sam and I try to rotate it" (R:P-O). One parent explained planning to give a try to one of the therapy sessions before she made any commitment to take the child regularly. In her words she stated, "I do plan to go to the first one and see what all this includes... And then if this is something that I feel will be beneficial then, you know, go ahead and schedule for her to return in November,... plan type of home program" (R:P-O). They often talked about "setting goals." with the help of professionals particularly during their meetings regarding the kind of services to get for their child and

the way they have to go about getting it. Therefore, the role of a planner seems be influenced by the level of involvement of the parents in the informational role described in the previous paragraphs.

However, two parents expressed that they were not involved in all of the activities and decisions that occurred while planning services. These were on occasions when professionals did not take into consideration the suggestions of the parent. For example:

> R:the therapist, like I said, recommended that we do the--come in for an hour every two months and do the reevaluation in six. And I don't want to just, you know, totally ignore that. I am not happy that they would not fully take my recommendation... I was just a bit annoyed by that because I felt like I had made my recommendation clear and I felt like I also made it clear to her how I felt about it and why I felt that way. I don't think I just said, "No, we are not going to do this." I mean I told her what I thought. My reasoning for making that decision.(P-O)

On another occasion, one parent indicated that the professionals were engaged in discussion among themselves while the parent was present during the IFSP meeting. She did not see her involvement to be of any great significance. The parent described the situation as:

> P:They talked mostly among themselves,...Becky answered most of the questions ... I mean at first Kay asked the questions to me and then Becky would answer them I guess... because she read it from the report... then the only time really that they directed anything to me to was ask me about the sheet you fill about your concerns things you might want in the future I don't even remember to what the sheet was... but it was really vague like I said... I don't even know why I had to be there really... they talked between themselves she could have read the report over the phone no one

> really had to be there (laughs) you know technically why it just seemed like you it was a formality more than anything I suppose that's the impression I got. (P:P-O)

Parents authorizing involves giving their consent to SCs and other professionals involved in serving their child/family to release/receive information, to conduct assessments or request services. All parents indicated their willingness to receive services from the agencies identified on the IFSP document by signing it. In other words, parents' authorization reflects their decision with regard to the kinds of services they are interested in obtaining. One parent maintained, "... We signed release forms from other organizations that have been involved...In order for Jenny, or TEIS to get the records they need to do their assessments and evaluations..." (R:SC-O). Further, parents give their consent to refer for further services to those agencies initially recorded on the Plan of Action Form. Also, parents indicated signing papers that help them to receive payment towards the services the child is going to receive. Thus, professionals obtaining parent's permission before any action is taken seemed to make them feel that they were involved in decision making. One parent described her involvement as, "... I am pretty involved in everything that is going on. So, everything goes by me first. If I approve or disapprove,... but they run everything by me first. If I have an idea or something, I

will ask them and they will find out about it" (N:P-O).

Advocating

Some parents functioning as their child's advocate was evident. As advocates, two parents described their support by using words such as "argue," "yell," "will fight," "hard nosed," "raising voice," or "look at what is best for her [child]... will hurt her,... will help her at this point in her life," or "being cautious," "defensive." One parent clearly stated as follows:

> N:If there are any problems I am the one that is the first to yell, so, I will argue about anything. If I know something is not right I will argue about it... so...I know there are things out there and if I have to fight for them--I will fight for them because he can't do it on his own right now... if I have to be hard nosed about it for the next twenty years, I guess I will, but he is going to have the best... I know he has rights... and if I feel something is not right I will raise my voice about it and I will ask. (P-O)

One parent of a child with speech/hearing problems indicated that she functioned as an interpreter as she tried to be her child's advocate.

> N:I don't think I am exactly the key person. I am just kind of like his interpreter maybe... there are different things that he does at home... that most people might not understand, so, not just necessarily with them but the whole general public or whatever. I have to tell them he is deaf and he can't hear, you know, he will sign things and people will be inquisitive and want to know what he is saying. So I am kind of having to explain... I will fight... because he can't do it on his own right now. That is where I become his interpreter. (P-O)

Another, parent seemed to function as an advocate to another

family who had a child with special needs. She shared information about TEIS services with the family and further referred the child for TEIS services. The following is an excerpt that supports this notion.

> S: How do I see my role? Well, I tell people about it... because I believe in it. I think if they can help the people .. that is great...because I think if a child can get a head start they deserve it. Like I have a girlfriend--she just had a baby and it was born with holes in its lungs at the hospital... I told Tina about her, and she said,'we will sure check into that...." (P-O)

Transporting

Parents transport their children for services such as assessments, doctor appointments, therapies, intervention and emergency services. They typically used the word "we took him/her" or "I take him" while discussing about their role of transporting children for services. One parent described her involvement as, "...the involvement I see is that... I have to take him [child] for services" (P:P-O). Another parent indicated that she had to take the child to the hospital. She said, "we had to take him to Agency E Emergency Room. He was in respiratory distress. He had been outside and a woman across the yard was smoking is what set it off. And they put him in ICU and kept him in ICU" (B:P-S). The following is a quote from one parent who described sharing the role of taking her child for services with her partner. She described it as, "we rotate taking her--that way we don't leave our jobs as much and

considering we have to drive, you know, the drive in... that would knock off possibly a half hour of time we could be on our jobs" (R:P-O).

On the whole, parents' responses indicated that they viewed their involvement more positively and had a sense of being involved. This is an excerpt of one parent who felt positive. She described her feeling by stating, "I feel like the parent can take a positive role and I like that part of it because I like a lot of input into what is going on and I like to know where I can go to get that information and stuff to act on" (R:P-O). Parents experienced a sense of inclusion as professionals made efforts to hear parents' opinions in all the different matters. Also, professionals making efforts to keep parents updated about all the activities they have taken up seemed to strengthen their sense of inclusion. One parent claimed, "I have had no negative things with them [TEIS]. Everything has been positive" (S:P-O). However, the foster parent felt staggered in her involvement in receiving services for her child/family because of having to meet the regulations. Another parent felt that she did not see much of her involvement in receiving services for her child/family.

Research Question 2: What are the events that occur in an IFSP process as experienced by service coordinators and parents?

Service Coordinators

All SC responses were consistent with respect to the events of the initial IFSP process. However, the detail in which each of them described these events varied to some extent. The responses (open-ended, self-interview, referral report) of the SCs and documents included descriptions of events which seemed to occur in a progressive manner. Therefore these events are described according to four major phases of the initial IFSP process. They are: 1) referral; 2) intake meeting or first home-visit; 3) service coordination; and 4) initial IFSP meeting.

Phase I - Referral

According to the SCs, at the outset, one of the typical events that occurs in an initial IFSP process is receiving a referral at TEIS. The referral could come from different sources, such as the parent or an agency. One SC reported that she received a "referral...from the parent... [about a] child... has a congenital heart defect and Histoplasmosis" (H:SC-R). Another SC reported receiving a referral from an agency, "... referral came from... our local hospital. This

baby was very premature--twenty-six and three-quarter gestation. Under 1200 grams"(T:SC-R). These referrals are generally obtained by phone or mail. The activities that ensue once the referral is received are: 1) logging of the case (referral); 2) distribution of the case; 3) preliminary routines (or handling the case); and 4) establishing contact with the parents.

SCs indicated that logging of the case by a staff member occurs soon after TEIS receives the referral. Information is taken from the referring individual and recorded on a referral sheet, also known as the Status Form, which is submitted to the project coordinator. The following statement is illustrative of a usual referral.

> J:Typically we get a referral from either a mother or most typically from another service agency... Either by mail, often it is by mail. But mostly it is a telephone call from another agency that has made a referral on a child who either has a known diagnosed syndrome or suspected delay and we get the referral, well, actually someone takes the call and writes it down on a referral sheet.(SC-O)

The referral information consists of a brief background about the child, the child's condition and the family needs.

Each SC is mainly responsible for serving children/families from a certain county or counties. Thus, the cases are distributed to the concerned SCs at each district office according to the county from which the child comes. One SC stated:

> J:...the referral has to come in and be delegated to someone...the project coordinator...determines which county it is in and gives it to [service] coordinators

by county or rotation of case load.(SC-O)

Routines of SCs that occur before the intake meeting are referred to as "preliminary routines." These preliminary routines include 1) making note of the diagnosis of the child, and information of interest to the family prior to contacting them; 2) in exceptional cases, confirming with the referral agency the release of information obtained from the family; 3) checking with the referral source regarding payment issues; 4) getting prepared for the number of releases needed; and 5) noting any special conditions of the family (e.g., foster parents) and following these up. The following excerpt shows one SC's effort to describe the activities related to the referral:

> J:the SC look at the referral,... See what kinds of things I might need to have on hand before contacting the parent. We have a comment section on the status form...if it says--family needs information on condition,...I will try to pull something from my files so I will be knowledgeable...You don't always check with the referral source but in some instances you do and what I do is eyeball the referral and see and make sure they have actually obtained a release and the family knows about us... to check...if it was an appropriate referral--to see if it was indeed something that we could pay for. For instance, someone wanting co-payment on a TennCare provided therapy which we cannot do because TEIS is payor last resort so that referral was sort of a not referral, so to speak... sometimes too it will say on the referral form--contact the referral source before you contact the family..., if the child is in custody or...any special situations to be careful about,... if we have got a child who is in foster care and it is a drug exposed child and the delays are from that, but the foster mother is not aware of that, so it was something that I was not to communicate that to the foster mother, because that wasn't our role.(SC-O)[emphasis added]

On receiving the referral, the SCs contact families within two working days. One SC noted that she must contact the family, "... within 48 hours. We should make contact from time of the referral to contacting the family and the referral source" (J:SC-O). The way in which SCs contact families seemed to vary in relation to the nature of the case, that is, either by making a telephone contact or mailing information. One SC described the way she handles the referrals she is assigned, "We contact... the family [by] sending a parent packet as soon as I get the referral or I call them and say, You will either be receiving this packet or I will send it, sort of depending on the severity of the case" (J:SC-O). Generally, SCs wait to hear from the family after sending parents the TEIS information packets. They then arrange for a home visit. If they do not hear from parents after sending the information packet, they make contact by phone. Typically, for families who do not have a phone or find it difficult to understand the services of TEIS, SCs make arrangements to meet them along with a referring service provider. Two SCs described contacting in this manner:

> J:Often too, if it is a family with no phone, you get the referral from another agency and I try to go on a home visit with [accompany] them when they are going and that works out well.(SC-O)

> T:A referral I just recently got, the parents are low functioning and I made a phone contact but they don't quite understand, so I am making arrangements to go with the agency G worker... so find a different route

to help them understand who you are....(SC-O)

SCs discussed sending more information to families without phones to be read prior to their home visit. This is information they would typically exchange with parents over the phone.

> L:... in the case of this family where they did not have a phone--what I did was with my letter of introduction I sent a brochure on TEIS and also the parent booklet... and a Family Need's Survey and asked them to read through that so we could talk about it when I come on the intake visit. If I can get them by phone... then usually we do that at the intake meeting.(SC-O)

SCs claimed making several attempts to establish the first contact with some of the families (this aspect is described in detail under research question three). SC time-logs indicated the amount of time spent during the first telephone contact with parents, which usually ranged from 5 to 20 minutes. One SC recounted her time for the first contact with the family in her self-interview. She reported that, "... [she] telephoned [David] his mother... and ...This first contact on the telephone lasted from 5-10 minutes" (T:SC-S).

Phase II - Intake Meeting/First Home Visit

Once the SCs are able to contact the families, they try to move on to the next phase by scheduling an intake meeting. As described earlier, the first contact of the SC with the family may also serve as the intake meeting. This

situation arises when SCs visit the families along with the professional from the referral agency or when families do not have a phone. The intake meetings are scheduled conveniently for the family. SCs usually go to the home to conduct the meeting, but if it is convenient for the family to meet at the service agency, then such is arranged. As it was done in the case of Arnold, the SC went to an agency, and "[the parent] brought Arnold to Agency G...Nancy [parent] and I sat down... filled out intake form and an initial plan of action"(L:SC-S). According to the SCs, this meeting is usually the first time parents and the SC meet. The meeting generally lasts from one to two hours. One SC reported that, she "... completed the intake and gathered information...it probably lasted about 2 hours(SC-S)."

SCs described several activities related to the intake meeting. They are: 1) beginning conversations between parents and SCs; 2) determining the child's eligibility; 3) providing the family the option to identify the family needs; 4) informing the family about the IFSP process; 5) obtaining release of information from the parents for identified agencies and for doctors; and 6) recording all the recommendations and the necessary information on the "Plan of Action Form," and leaving a copy for the family.

Beginning conversations between parents and SCs involves SCs explaining TEIS services, reviewing the rights of the parents, and gathering information about the

child/family after brief introductions.

> J:Well, at intake...families get a lot of different information... on what TEIS is... at first,... I tell them who I am, what I do, what we can do for them--are you interested and they have a right to refuse period... That is their right is to say, no. Then from there we do just [give] any kind of literature they need... and/or tapes even that I have used, video tapes on what TEIS does, on parent groups...the reading of the Parent's Rights... review those... directory that we have...highlight whatever is applicable to them in their county ... that is real helpful to them... encourage them to look through it and call me and all of that. And bring brochures on other programs--that kind of stuff. (SC-O)

> T: Intake information--the demographic information... we usually expand it.. the...pregnancy... birth... medical history the child has had... type of problem the child is having,... so these are some of the things that we can do to pull it together some of the information... you get a lot of environmental information that has to do with the family. The structure... and how they work as a family or don't work as a family very well...(SC-O)

Based on the information of the child, SCs proceed further with the major activity of <u>determining the child's eligibility</u> during their home visit. SCs note that children fall into three major groups when their eligibility is determined: a) children who meet the eligibility, b) children who do not meet eligibility criteria, and c) those who did not qualify for TEIS services, but who were experiencing delays in certain areas.

The responses of the SCs suggested that a child is "determined as eligible" only if his condition meets the Tennessee definition of "developmental delay." There are four ways in which the child is determined as eligible.

First, if the child has a diagnosed condition, then the child is considered as eligible. One SC explanation was, "...the children that don't need assessment are the ones that have already been diagnosed... have been eligible due to a diagnosable condition. Which is part B of the law, and this is something that they are born with--Spina Bifida, Cerebral Palsy, any kind of syndrome. Even Fetal Alcohol Syndrome--they are automatically eligible for services" (C:SC-O). Second, if the child is referred by a physician, then that serves as a screening for eligibility. In addition, a screening test may be used by the SC. "If it is like from a physician or another agency that... we sort of consider that the screening. They would not have referred them on to us if they did not feel there was a significant need for it" (L:SC-O). Third, if the child has already had an evaluation, then that child could be considered eligible. As another SC stated, "...[If] it is also decided at that first visit whether he... is eligible for TEIS... and you might already know that the child needs physical therapy. Sometimes they will come to us already having had an evaluation and being referred" (K:SC-O). Lastly, if the child is referred by a parent or extended family member, then a screening test is administered. For children who have undergone a screening test administered by SCs, the scores are calculated in the presence of the parents. Based on the results of the test, they determine provisional

eligibility and inform parents accordingly. However, SCs indicated that the child's eligibility is not solely based on the screening results. An additional evaluation from another professional is still required.

> C:If a child does not have a diagnosable condition but is suspected of having global developmental delays then we would need to do a screening to see if the child qualifies. The way that a child qualifies is if they are 20% in two areas or 40% in one area--developmental area. So, the screening tool will give us that result. We do not... we qualify them on the front end there, but they have to have additional, and additional evaluation to make sure they truly do have a problem that would warrant them being eligible. We cannot determine sole eligibility is what I am saying. We have to go through two steps to determine eligibility in the child. We have to do a screening and if the screening yields a problem--say in motor development--then we would recommend a motor development evaluation. And based on the motor development evaluation and our own screening then we can make the child eligible. So it takes two different tools to make them eligible. (P-O)

According to SCs, there are some "children who do not qualify" for TEIS services. But these children, even though they do not qualify, are still considered as open cases at TEIS, because they are followed up after three months. One SC described the common practice of dealing with such children at TEIS as, "...if the child is not eligible then we just follow up with the family in a two to three month period... The case is not closed--it is not active though because it is not an eligible child" (C:SC-O). Among these ineligible children are those who do not qualify after a screening is done by the SC. There are other children who do not get TEIS services and are referred to as a "closed

case." "This is a child who is closed, we did not do anything with child she was already receiving services she already had an IFSP. The only reason we were involved was for POS. Which we could not do because she was covered under TennCare" (M:SC-R).

SCs claimed that there are some families who may think that there is nothing wrong with the child, "you might go in... and the family says, you know, 'We don't have any concerns. We think he is doing fine and you can test him if you want to. I don't know why we were referred,' And that will happen often" (L:SC-O). According to another SC statement, "There are some children referred by other agencies... to check on them... and some people will just refer these just for follow up for us to just make sure everything is okay. And those kids will be ineligible" (L:SC-O). Parents of these children are offered help during the intake meeting and the children are followed up after three months. Therefore, services to children do not end when they are determined as ineligible.

> L:There have been some occasions where I have done an intake and it has been obvious that the child will not qualify under Part H and that time I try to explain... that it doesn't appear that their child qualifies for TEIS and ask if there is anything that we can make referrals to--like if they have concerns about health or something that we might make a referral to--the Agency D Pediatric Clinic or the Health Department, something like... we usually don't just say, "It is too bad he doesn't qualify. We are out of here." You try and, or if they have concerns about behavior then I can ask them if they want me to send them information on that, you know. (SC-O)

According to one SC, there are some children who do not exhibit enough delays to meet the TEIS eligibility criteria, but may exhibit substantial delays which may warrant them to be referred to an appropriate professional for further evaluation in a particular area. However, even to get an evaluation sometimes doctors have to give written authorization. This policy was called by a SC as the "gate keeper's approach."

> J:...if a child has a motor development problem and we need him in to see a physical therapist--the agency has to have a prescription from a doctor before the child can receive even a physical therapy evaluation... you try to get medical records from the doctor indicating that the child--yes, indeed, does need physical therapy, or whatever they might need. Usually you have to have a prescription for any therapy a child might receive, for any evaluation a child might need. It is kind of like a gatekeeper approach. The doctor has to okay it and say, "Yes, indeed he does need this."... yes, doctors can be instrumental. (SC-O)

SCs suggested that recommendations are made by them to get assessments done for some children who may need further evaluation. There are several ways in which the children can be evaluated: a) through an agency if the family qualifies; b) through a program the child plans to attend; and c) through a contract from TEIS with a professional. Thus, a decision as to where to get further assessment is made based on the child's condition, and the program the child plans to attend or on the family's eligibility for certain programs (state, federal or private) or the availability of professional services. One SC statement

pointed out the way assessments are done for children who plan to attend center-based programs or need assessments from another agency.

> L:... if we do need assessments done then we make arrangements for that. Either...like if they are going into a program like Agency G--Agency G will do the assessment when the child starts there.(SC-O)

Contracting for assessment through TEIS is done for those who may need home-based programming or if they are unable to get it done any other way.

> L:If they don't qualify for Agency D and the family want the speech and language evaluated then we can contract with a speech pathologist to do that in the home. So we can usually ...we can get the assessments and evaluations done in a variety of ways.(SC-O)

For those children coming from families who qualify for certain programs based on their income, the assessments are generally conducted by those specific programs.

> L:If they feel they need speech and language evaluation--if they qualify for Agency D then we would make a referral to Agency D for speech and language evaluation through them. (SC-O)

During the intake meeting not only do SCs find out the needs of the child, but also find out the needs of the family by providing the family the option to identify the family needs. They learn about the family needs through verbal discussions. In addition, SCs indicated that they present the parents with the option to complete a questionnaire. Both the parents may choose to complete separate questionnaires.

> L:We have three different family, sort of family

surveys, and either the family will fill out one or they might not fill out any, but we ask them if they would fill out, so that gives us a little information on what they feel their needs are... There is a lot of factors that go into deciding what is best for a family. Like if the child is severely disabled then they might need in-home therapy... You have to consider... the family's insurance plan. Any time payment comes into play... we have to extinguish all possible options before we [TEIS] can actually pay for something.(SC-O)

Once the child qualifies, the SCs provide information regarding the IFSP process during the intake meeting or later. In addition to describing the IFSP process that is in the TEIS information booklet, SCs indicated that they read and/or explain to parents the information sheet on IFSP. Further, they explained that they give a brief background to parents, such as what an IFSP meeting is like, who will be involved, what they would be doing; and an appropriate time frame within which they plan to schedule the IFSP meeting.

J:... if they are clearly eligible then I explain that this [IFSP] is the process...we also have--TEIS Parent Pamphlet Booklet that discusses it in layman's terms--this is what happens first. We get a referral and we do an intake. We might need to do a screening, we do this and then it is time to write it all down on paper and I kind of use that as a guide... and there is a meeting where we formulate this plan and this is the process to get it all through and of course, it doesn't stop at the plan itself. The process is ongoing at least until the child is three. And then hopefully transition into another program or is fine and can go on.(SC-O)

K:We will talk at that point,... I will kind of explain that ... The next step that we do soon is to have what is called an Individualized Family Service Plan Meeting... that is where you and I and any other people that are involved with your child that you want to

include, we will sit down and talk about what... he needs, what you are concerned about for him, and how we are going to go about getting what he needs--his services, or programs, or whatever you feel like he needs, but that will be scheduled probably, but we try to schedule those within a month, but, you know, that is something that we would talk about later, and setup a time for later, but just kind of go over and say....(SC-O)

SCs indicated that obtaining release of information permissions from the parents for all the concerned agencies and professionals during the intake meeting was crucial because, SCs can make necessary contacts with the concerned individuals or agencies only after receiving these releases. Thus obtaining signed releases help them to arrange for the services for the child/family in a timely manner. Otherwise, the services can get held up.

L:... if we feel that medical records would be important to have for our information then we get them to sign releases so that we can send out for the medical records. And we ask permission to make referrals to programs if they have indicated that they want or are considering the child going into program or specific therapy then we ask them for permission to go ahead and make the referrals or requests for services at that time.(SC-O)

SCs' responses indicated that recording all the recommendations and necessary information on the Plan of Action Form as the concluding routine of the intake meeting. On this form they enter the results of the screening test (only for those children for whom a screening test is administered) and other recommendations. This form is done in duplicate so a copy can be given to the parents.

K:So toward the end...there is a [Plan of Action] form

> that I fill out, that I leave with the parents. This sheet... it says--your child meets the eligibility criteria for TEIS and based on the information gathered during the initial visit the results and recommendations are as follows... If I have done a screening on the child I put... the results of the screen, but I think all the service coordinators do it, I use it to say what is going to happen, you know. What the parent is going to do, and what I am going to do at that point... for this one [Peter] I am looking at..., the mom was going to contact ... a certain person... [at] Agency B to make an appointment. And I was going to setup the IFSP meeting... the next thing that is going to happen is that you are going to call child care and you are going to call Agency B and I am going,... setup the IFSP, but usually it is not that immediate. In this case the child was already getting some services so we could go ahead and do that. (SC-O)

However, in the case of the foster child, the SC mentioned that the plan of action was "initiated" but was not completed because some of the procedures in serving foster children had to be followed. However, examination of the documents indicated that the SC had done a report on this child/family which was comparable to a plan of action.

> C:...due to the fact that Victor did not have a surrogate parent I was not able to find services for him until I appointed a surrogate parent so I was only able to take intake information... a plan of action was started or initiated... it was not written down during the intake....(SC-S)

SCs indicated that they received referrals of children who were close to their third birthday. They had intake meetings with the families of these children as well and either conducted the screening and/or recommended further evaluations for them. Children determined as eligible were transitioned into preschool programs of local education agencies. Children who were not eligible for TEIS services

were also referred to school systems, however transition planning was not part of the process. The following statements support this notion.

> T:I got the referral... I went into this home and when I looked at this little boy I thought ADHD...and we transitioned him to the Pre-school program... and he is doing beautifully. We just basically had enough time to get this going and get him transitioned so we had about a month or six weeks for the home-based services. We got the things going. He turned three in December. (SC-R)

> M:referred...by a doctor...did the REAL for the parent interview to find out about the child's language, she was not delayed... not eligible for TEIS. Also since the child was turning 3 years soon I made a referral to the school system. (SC-R)

SC self-interview responses indicated that the intake meetings lasted more than an hour. Two of the intake meetings were at the service agency and three others were at the child's home. Four were scheduled during the day and only one, in the child's home, was in the evening (both the parents were employed outside the home during the day).

Phase III - Routines of Service Coordination

SCs refer to the phase that follows the intake meeting as service coordination. The experiences of this phase are best described in the words of one SC as, "... most of your service coordination begins after that home visit--after you establish the ground rules in terms of what the family has, what they need, and where they want to go. That is where your work really begins (C:SC-O)." The activities of this

phase include 1) writing reports; 2) establishing services; and 3) setting up a time for the IFSP meeting.

Immediately after the intake meeting SCs, write a report about their meeting with the family. One SC mentioned, "... after that home visit... You go back to the office. You write reports"(C: SC-O). Even if the child is determined as not eligible for TEIS services, SCs write reports. According to one SC, "even though he is not eligible this is kind of goes to show that you are supposed to sort of coordinate--[for children who] are eligible but I am still doing a report on this case even though he is not eligible"(J:SC-R).

SCs establishing services for children/families is claimed to be a "lengthy process" during this phase. According to them, their initial home visit gives the infrastructure for their work, based on which, efforts to establish services for the family are made. The infrastructure includes the family needs, resources and priorities. Typically, establishing services for the families involves SCs performing certain tasks. They are: a) helping parents to the extent they prefer in establishing services for further evaluation or therapy, intervention services and/or transportation for the child; b) accessing records; and c) determining payment of services. Accomplishing all these tasks necessitates that they network with other professionals and agencies through calls,

letters, and review of records.

> C:...based on what their issues are... we try to find something that is convenient for the family in terms of transportation, or availability...You try to access medical records, and you try to get the ball rolling in terms of trying to find out where the best place is for the child to go... I mean, there is lots of agencies that serve children ... But lots of times it gets narrowed down because of these issues like insurance, transportation, some people don't have cars and can't get to there. Or there is medical issues with the children in terms of being medically fragile. They can't be transported. There are a lot of issues that go into play ... Once we have established where the child is going--going through all those steps. This can be a lengthy process,... in terms of,... phone calling, networking and trying to find out the best places can take several weeks to finally iron out. Once you do that then usually the IFSP is held....(SC-O)

SCs described being engaged in <u>setting up a time</u> for the IFSP meeting. The IFSP meeting is "set up" by the SC taking into consideration the 45 day time limit, the family's situation, the evaluation process, and the schedules of other professionals. One SC described her efforts, "... it might be after the evaluation depending where we stand on time, that I would try to set up a time with the parents to have the IFSP meeting and we are trying real hard to meet the 45 days, but more often than not, that is not happening" (K:SC-O). The planning process involves SCs making calls back and forth between parents and other professionals to find a suitable time, particularly for the family. One SC related this routine as, "Well, there again we pick a time that is best for the family. We usually have

it at the family's home... So we find out what is a good time for the family and then contact the other people that need to be there and ask them if they can be there at that time" (L:SC-O). Following the telephone calls, SCs send written notices in advance to all the members of the IFSP team, including the parents.

> J:You give at least two weeks written notice to all participants which is a little difficult sometimes. I will call by phone and do a written notice, but it has to be in writing so the parents...so nobody will be caught off guard. So everyone has ample time to adjust their schedules, but I think as courtesy it is important to make phone calls too. And say, "I am sending you a letter about this, this is the time we have talked about." And sometimes to call around and schedule with everyone and then you send a letter. It just depends if you already know the people are available at that time.(SC-O)

Phase IV - IFSP Meeting

The last phase is the IFSP meeting for children/families determined as eligible. This event involves parent/s, SCs, and professionals. One SC characterized this meeting as, "... IFSP meeting [we] sit down with the parent and possible providers and the people that did the assessment if they were available and do the IFSP at that time" (L:SC-O). SCs mentioned that it occurs at a location convenient for the parents, often the home or agency serving the child. Generally, the meeting lasts from one to three hours, "The meeting will typically last one and a half hours, but they have lasted as long as three hours or

a short one would be an hour. I don't think I have had one that lasted a shorter time than that" (K:SC-O). Members of the IFSP team who are present are probably meeting for the first time.

After introductions, SCs reported that they explain the IFSP process, "Okay, the meeting... first we kind of... explain the process..." (K:SC-O). Then all the members of the team including the parents discuss the child's present levels of development. Each member contributes his/her views. One SC reported this aspect of the process as, "...we will talk about the present levels of development. Being how the child is doing right now in different areas...What does the parent see? What do other people that are working with the child see? What is he doing now? And we will go through... each of those areas and address each area" (K:SC-O). This conversation is followed by a discussion of parent needs, resources, and priorities. One SC explained,

> K:...the Family Needs Assessment ... part of that we have already talked about when I was in the home the first time, or by telephone contact,... and so some of that we have already talked about and we will summarize that... we want to talk about and hear the parents' concerns and priorities and as well as things that they think are helpful to them. And also this is focused on the parents, but we also want to hear concerns or priorities that other people see for the child. (SC-O)

SCs expressed that, based on the family's concerns, resources, and priorities, future services are planned, and the necessary steps to be taken are recorded; that is the

"technical" aspects such as the type, frequency, duration, location, payment of the service; and individuals responsible for the action steps also identified and recorded on the document. One SC delineation of the process of planning the action steps for the child/family during the meeting is presented below:

> K:We would talk about the services that can help to address those needs and concerns... anything new that they are concerned about or anything they want to add... what steps need to be taken to get those services.... then... put it down into steps--okay this means that,...he will continue to, like in the case of [Peter]... he will continue to receive speech and language services through the home-based program... another one might be that the mom will follow-up with Agency B to see about getting PT services because that hasn't been set up yet, but a referral is already made. We might just take it down the various steps, and the bottom of that page just lists services and it that is kind of the technical part of it, you know, where you say when a service began, when it is going to end, how many times a week, was it individual or group, and what kind of a setting it was in--a center-based or in the home, or whatever.(SC-O)

During this meeting, SCs stated that they discussed transitioning the child to the school system with parents of children who are 2 years and above. However, one SC indicated that she would mention about transitioning the child at three years irrespective of the child's age so that parents are aware that their child will receive intervention services only until the child is three years. Finally, the parents sign the completed document.

> K:...in the transition plan we may talk about if the child is two or older and if he is not I will usually just say, "Well we will talk about this more later."

> But to let the parents know, even it is a baby, that at three years old our services will stop but there still will be services, you know. The reason we stop at three is that the public school picks up. There will be other services available and a plan for getting those. Then the IFSP kind of ends when we sign, we all sign the front sheet, give the parents a brochure about the rights... the rights..., but let me put it this way--I give them one on my very first visit, the family, ...sometimes at the beginning, sometimes at the end of the [IFSP] meeting I will give them another one if they have lost that unless they are sure they have it. Just kind of talk about the different kinds of rights.(SC-O)

However in one extreme case, the activities of the different phases progressed differently, because the family was referred to TEIS after the IFSP meeting was already scheduled by the agency. According to this SC, "So... The intake was done on 9-20. This was after that IFSP had already been scheduled at the center. They called me" (T:SC-O). Therefore, the SC set up the intake meeting with the family just before the IFSP meeting took place. Also, the IFSP document remained incomplete after several attempts to schedule the meeting with the family. The SC aptly referred to such a meeting as the "wandering IFSP meeting".

> T:This was like a wandering IFSP meeting. We did the first part at the... the child is still currently active--I am trying to reach the parents--the phone has been disconnected... Well, it was very hard to pin this mother down to getting anything done and I thought should we just start over. Or finish what we have started. And since we already had that input from the people at the Center--I thought well, we can just go ahead and we had basically talked about it and then just get the rest of it written up and signed and so forth. We went ahead and did that and I have tried... we talked about getting her into a integrated day care setting consultation for her. The mother wanted to do that and she stopped working and she did not want it any more. She just wanted to be home. (SC-O)

Further, this SC expressed difficulty in scheduling to meet with the mother from the month of September to February in the following lines.

> T:So right now I am still trying to find her again to see. And I have made a few home visits where we would have a visit scheduled and in five minutes she says, "I have to leave." And doesn't give any explanation. You know, she has to go somewhere. You can't make people stay and do something they don't want to do. 9-23 it was partially completed and I wrote that Mother had friend with her and informed us in the middle of the meeting that she had to leave immediately and go with her friend to doctor in... The forms were mostly completed. Mother agreed to finish 9-26-94 at 9:00 in home. I phoned her that morning--9-26 she cancelled. Scheduled for 10-4 at 11:00--she phoned asked that we delay the appointment until 12:00. And we finished the IFSP on 10-4. Then she had to leave--did not explain why. She will look for a pre-school program and call when she finds one that suits her. Then 11-15--disconnect message. 11-29 I went by and no one was home. There was a new phone number. Reconnected--I arranged an appointment for 12-5 - a home visit. She called and asked if I could come tomorrow at 11:00. And I did make that home visit and she said that she is not working now so she does not need child care for now. And wants to keep the child at home. And she said maybe after Christmas. I tried to call her in January and I have tried in February--no answer, no answer, no answer. And so I got a disconnect. So I am going to drop by and if she is not at home I will leave a note on the door and ask her to call me. We are down to doing basically a transition for her and I think that is probably all she will accept.(SC-O)

Thus, from phase one to four changes occurred as a result of the activities for individual children/families. A comparison of the initial document (Status Form or the Minimal Data Form) completed at the beginning of the initial IFSP process; that is at the time of referral, and the IFSP document completed at the end of the initial IFSP process, revealed changes with the number of agencies serving the

family. The following table shows the number of agencies serving each individual family at two different times of the initial IFSP process.

Table 7. Comparison of the Status Form and the IFSP Form

Name of the child	No. of agencies/ professionals serving at the time of referral	No. of agencies/professionals identified at the initial IFSP meeting
Peter	2	5
Sophie	3	5
Victor	3	7
Arnold	1	5
David	1	Initial IFSP meeting was not held for the family because the child was not eligible

Parents

The parents' description of the events that they experienced are grouped into two broad categories: 1) telephone conversations; and 2) meetings. Parents' descriptions mirrored those of SCs.

Telephone Conversations

All parents mentioned occasions when they had telephone conversations with professionals, including SCs, therapists, nurses, and librarians. Parents discussed their first telephone conversations with SCs. Three parents indicated that they called TEIS to make the referral. One parent's statement represents this event, "...I don't know who I

ended up calling first, ...I came into contact with was Liz [SC]... from Town A..."(N:P-O).

Parents had telephone conversations with SCs and other professionals in order to set up appointments. These appointments were in reference to the SCs' home visits and IFSP meeting; and professionals conducting evaluation and setting up home-based services. One parent said, "Jenny called and wanted to set up an opportunity to come out and meet and everything..." (R:P-O). Parents also mentioned having telephone conversations with professionals about many things. One parent's description of telephone conversations with professionals on three different occasions for three different purposes illustrates the complexity of the process. They are: 1) referral, 2) insurance, and 3)confirmaton of services at the agency for the child:

> F:... Victor's pediatrician office... we spoke by telephone... The conversation involved a referral for Victor to see a physical therapist... explained to me that before TennCare will provide this service that the doctor will have to re-screen Victor... I just received a call from Victor's pediatrician about his physical therapy. There seem to be a problem. Victor's medical insurance has expired so now we have to go through the process of getting him some more medical insurance, and that means more frustration... Hopefully we can get this solved because this little boy really needs the help.... I received a call from George at Agency B to notify us that Victor has indeed been okayed for his physical therapy and occupational therapy that will take place twice a week.(P-S)

Discussion also occurred about completing necessary forms for therapy. The parent reported, "George [physical therapist]... called me... [he] needed doctor's approval to

set up appointment... but [for that he needed some] papers... [which] I had to fill out..."(P:P-S). Parents received/made calls to professionals for more information about the needs of the child/family. The following quote from a parent indicated that she was involved in search for more information.

> N:the library up in Town C. The Library for the Deaf, I think it is... I called and talked to a lady there and she went out of her way... She said, "If I see anything like that I will just go ahead and send it to you." So, I mean, everybody is kind of looking out for me, I guess.(P-O)

One parent indicated receiving calls from the SC to check/follow-up with the parents about the child (David who was ineligible for TEIS after the intake meeting).

> S:she [SC] calls me about every two months just to check on him to see if there has been any change. And now she knows about his heart murmur so she will probably call sooner than that. To see how that is.(P-O)

According to parents, these telephone conversations ranged from about three to twenty minutes. One parent reported about her conversation with a therapist. She stated, "... physical therapist... he called me... around 3 p.m. the conversation lasted may be about 20 minutes..."(P:P-S). Parent responses suggested that they made/received calls to/from professionals typically between 9:30 and 3.00.

Meetings

During the IFSP process, all parents mentioned several face-to-face encounters with professionals. Parents used the word contact for both telephone contacts and meetings. All the parents reported about their meetings with the doctors before and after their involvement with TEIS.

> N:we took him to the Ear, Nose and Throat doctor here in town, and you know, he confirmed that there was something that needed to be checked further. So they sent him to Town D and they did an ABR on him and he did not respond to anything. That was back in September. It hasn't been a year yet, so....(P-O)

Two mentioned meetings particularly after the child was involved with TEIS. One parent reported, "just recently... my son and daughter went to Agency D pediatrician... to different doctors, nutritionist, the audiologist..." (P:P-O).

In addition to their visits with the doctors, parents discussed their meetings with some of the other professionals at home or an agency for evaluation, therapy, intake, and IFSP meeting. According to parents, typically these meetings, lasting between thirty minutes and two hours, were arranged at a place and time that was most convenient for them. One parent stated, "what we [have] done is we went on... we met [IFSP meeting] when Sophie was having her therapy session" (R:SC-O). In the following paragraphs parent meeting with different professionals during the IFSP process is elaborated.

Parents talked about their first encounter with the SCs. One parent said, "Jenny... came out and visited, she kind of done like assessment of needs so forth. We talked about different things we were looking for from them [TEIS]. What type of resources... one of the things we were interested in learning was child care closer to our jobs... she provided information... Jenny has been resourceful..." (R:P-O). Another parent described her meetings at home with a parent trainer. She said, "... she comes out here on Thursdays... brings her stuff and she goes out of her way,... to do things with him. I know the parent trainer is not... you probably think is specifically for me, but as well as me she is doing it with Arnold" (N:P-O). Parents discussed their meetings with professionals during their child's evaluation session. According to one parent, "...the nurse came over and she tested him and there was nothing they could do to help me because he was fine. He did not have any disabilities per say. Just a little bit slower" (S:P-S). The foster parent reported her visit to the therapist's office in a different tone. She said,

> F:Victor's occupational therapy evaluation at the Agency B... Victor and I attended. At the end of the therapy session the therapist assured me that Victor does need this type of care. We will be submitting a letter to the TennCare source so they can provide the necessary treatment for him. It has been a slow thing with getting Victor the necessary physical therapy that he needs. But it looks like we are finally going to be able to do that. Victor will be receiving his physical therapy evaluation in a week--and after that information has been compiled to set up the necessary times for me to bring him on a regular basis.(P-S)

Four parents referred to "IFSP meetings" (the fifth parent did not have an IFSP meeting, because her child was determined ineligible for TEIS service).

> B:we had that [IFSP] meeting at the Agency U... We were discussing Victor's progress... kind of therapy he was getting... his future needs... kind of equipment he would need and... where we could get the funding for them if his Access Med Plus would not pay... that he was not having to be held all day at the day care now...(P-O)

Parents referred to one of the activities at the meetings as doing "paper work" or "filling out forms." One parent mentioned being involved in completing documents, "She came out to the house... and we went over all the paperwork, filled it out..."(N:P-O). The other activity was discussing with professionals topics such as the child's progress, therapies, equipment, goals and how they are going to be accomplished, child's behavior in general, transitioning, funding, and future needs. One parent said, "...we had the IFSP meeting... we discussed all his goals and everything for the next six months, and what things that we needed to accomplish or get done before then, and that is basically it" (P-O).

Another event, which was casually mentioned buy one parent was with regard to her surrogate [parent] training.

> F:I was under the assumption that Victor would receive his physical therapy after I received my surrogate training and was able to sign off on the papers.(P-S)

Research Question 3: What are some issues that service coordinators and parents view as impeding the process?

Service Coordinators

SCs voiced some of the issues related to the initial IFSP process in their open-ended interview responses, self-interview responses, documents, and referral report. These issues pertained to 1) requirements of the law; 2) the IFSP form; 3)parents/families; 4) professionals; and 5)payment of service.

Issues Associated in Meeting the Requirements of the Law

One of the legal requirements in the IFSP process SCs refer to is arranging an initial IFSP meeting within 45 days, and they expressed a number of issues/concerns about that. According to them, the time is insufficient to contact the family and to develop a meaningful IFSP. One SC explained, " [in] some cases... it could easily be a month from referral before we get to talk. Then you can't possibly have an IFSP meeting within two weeks, but if you do it is just not meaningful,... it is just to meet the requirements" (K:SC-O). Some of the reasons SCs provided to explain the delay in having an IFSP meeting within 45 days are establishing contact, determining eligibility, ill children, appointing surrogate parents for foster children,

and approaches (professionals).

> C:Okay. So there is a lot of things that can happen to clog up the wheel. And if the family does not have a phone, or if hospitalized, or...it totally stops everything for a period of time. So there is a lot of factors that enter in but I think this 45 days is unrealistic. (SC-O)

The inability of SCs to establish contact with parents is a barrier to developing an initial IFSP within 45 days. All the SCs agreed that there are several intervening factors that affect holding the meeting within that time frame: 1)telephone, 2) families migrating, and 3)scheduling.

The use of the telephone seemed to be significant in making initial contacts with the families as soon as TEIS receives a referral. There are problems related to the dependence on the telephone in establishing contact with the family, because some do not have a telephone or their services has been disconnected. One SC described the family's situation poignantly, "I am trying to reach the parents--the phone has been disconnected. A lot of people lost their phones in January and February... Some people say they spent too much on Christmas... But it just a real hard time with the winter and the heating bills and all that go out the ceiling and people... a lot of phones have been disconnected, so in those cases you have to go out and hope you can catch them at home" (T:SC-R).

SCs recalled that they may still have difficulty reaching families even if they do have a telephone, either

because they did not answer the phone or did not respond to the phone messages. One SC made several entries in her progress notes stating that she was unable to reach the parents. For example: "5/23/94--pc no answer" (K:SC-D). One SC described her frustration in trying to contact the family in several different ways,

> J:As far as the most frustrating ones, are those that I can't get in touch with. I can't find them. I have gone to their house. I have knocked on their door. I have sent letters and I can't find them. Then they call and, "Why haven't you called?" And I am like, "Gee, I have, I have, that is all I have been doing.(SC-O)

At other times SCs were unable to establish contact with the families because they moved. SCs stated that families move for several reasons: family domestic violence, insurance coverage, or other reasons. One SC stated, that "... the family moved... I went for intake...--no shows--like three times. Now [I] have got a message from Agency AK ... this child is enrolled there in Town M. But the deal was that they were apparently traveling from Town M to Town B every day to get therapy and child care. And it ends up that they can stay in Town M..." (J:SC-R).

In one case, the mother had to move into a shelter due to domestic violence and the child stopped attending the program. The SC was unable to locate the family. The SC illustrated the situation by stating that, "it took a long time (nearly 2 months) to contact the family from the time the child was referred to TEIS... the child dropped out of the agency where the child was receiving services, because

the mother went into a family shelter due to domestic problems... tried to contact the mother over the phone and by writing a letter, but was unable to establish contact with the mother" (K:SC-R).

To circumvent this problem of establishing contact with the parents by phone, SCs tried to contact families by writing letters. Even then they had difficulty because some did not respond to the letters or they did not respond in time to meet at appointed times. According to one SC, "... This family does not have a phone, I sent a... parent packet,... a letter with dates and I sent a need for directions. Received a letter back,... after the date that she had circled. The next time I sent a letter asking for more dates and that I needed directions, it came it was supposed to be 12 o' clock on a specific date. I got that letter at 3 o' clock the same day... what I plan to do is just make a visit... now [that I] have directions" (M:SC-R). Another SC experienced a similar problem, she recounted her unsuccessful attempts to get in touch with the family, "I started calling, sending letters,... it took me 2 months to get in touch with the family, and... it took me 3 months [to make a home visit] to see this child... [The delay was due to] lack of communication with the parent and the difficulty in getting in touch with her" (J:SC-R).

At times when SCs were unable to get in touch with the families after several contacts, they approached the problem

by getting back to the referral source for help. Then, either they got caught up with leaving and returning telephone messages to/from professionals or the message to the appropriate individual got lost in the chain of communication from one individual to the other. The following statement supports the above notion.

> J:I have not been able to get a response from the family... I called... no answer in June and in July. The number had been disconnected or was actually no longer in service. Mailed a TEIS information packet ... sent the TEIS information packet again on the 14th... called... number was still disconnected... I called Doctor office because I still had not heard from the family and explained that I had mailed the information and had not heard from them. Then... again... left the message with his office. Then on the 8th of September I left a message with his secretary and on the 22nd I mailed a letter to him. To say that I had not heard back from it... it could be... I don't know if it is the communication from the nurse or secretary or not to him or what....(SC-R)

SCs reported that at times, even after scheduling a time to meet, families would postpone or cancel the meeting at the last minute, or they were not available at the scheduled time, and they did not respond to notes left on the door.

> T:...I am trying to reach the parents, the phone has been disconnected..., it was very hard to pin this mother down to getting anything done... So right now I am still trying to find her again..., I have made a few home visits where we would have a visit scheduled and in five minutes she says, "I have to leave." And doesn't give any explanation... I phoned her that morning she cancelled. Scheduled for 10/4 at 11:00--she phoned asked that we delay the appointment... Then 11/15--disconnect message, 11/29 I went by and no one was home. There was a new phone number. Reconnected--I arranged an appointment for 12/5-- a home visit. She called and asked if I could come tomorrow at 11:00...

> I tried to call her... no answer, no answer, no answer. And so I got a disconnect. So I am going to drop by and if she is not at home I will leave a note on the door and ask her to call me.... (SC-R)

SCs suggested that determination of eligibility may take more time than the 45 days in the law. When children do not have a diagnosed condition to meet the eligibility, or when they do not show delays required by the state definition, then they need to be further evaluated. This often delays having the IFSP meeting within 45 days. Some of the reasons provided by the SCs for the delays are: 1) time needed for additional evaluation; 2) uncertainty with the screening results of premature children; 3) difficulty in determining eligibility for children who present unusual behaviors; 4) inability to meet the criteria of "developmental delay" set by the state definition and other agencies; 5)incompatibility of policies and practices in determining eligibility of children with special needs; and 6) uncertainty about the child's eligibility which hinders planning the IFSP meeting.

When children do not show sufficient delay to meet the criteria, SCs must then recommend further evaluations, involving more time, such as setting up appointments for evaluation, making sure agencies will accept the family's insurance or working out alternative means of payment. One SC stated "... it could be...if I am not showing a complete delay,... and if I feel like I need to refer an evaluation

to determine eligibility, I'd say that happens about 25% of the time-ish... well, you are still supposed to have the 45 day time limit from referral to IFSP, but if you don't know if the child is eligible or not you don't know if you need to have an IFSP, so that is kind of tricky" (J:SC-O). If TEIS is involved in the payment for evaluation, then a contract for payment has to be approved before any evaluation can be carried out. Three have expressed this concern.

> C:Sometimes 45 days is not enough time...you haven't even got the evaluation to determine eligibility within 45 days. I know that sounds absolutely ludicrous but it is true. If we have to pay for the child's evaluation to determine eligibility--the paperwork process in just payment can take weeks. And they can't do a service unless the contract is in place and the payment is secured.(SC-O)

Another SC explained the complexity of determining eligibility within 45 days with some families. She explained factors that act as barriers, such as bad weather, transportation problems, the application process in public agencies, and children's health. In the following quote the SC elaborates.

> T:I still am thinking about the time frame... They [families] do an application--if they don't have one. They go through a pediatric clinic..., to be evaluated for speech language--that can take two or three or more months to get them through that... And then suppose you've got the application process and they have to wait a month for peds clinic, then they have to wait another month for speech eval. and or genetics or whatever the case might be... one of the families... was scheduled for peds--we had an ice storm--they were trying to use the public transportation--the TennCare transportation and they did not run that day... were rescheduled for this month--this month the children

have the chickenpox. And they could not come. So there are all kinds of things that can delay the process.(SC-R)

During the process of determining eligibility, SCs feel uncertain about the accuracy of their screening with premature infants. One SC explained in the case of one child, "... [During the] home visit the child was only 2 or 3 months old and was premature, very tiny baby, did the intake and the PEACH [screening test]. I don't know how accurate it could be... The fact that at this point of time since the child is so young we don't know how involved the child is as far as his special needs are concerned" (M:SC-R). Another SC described newborn who was premature.

H:... came from--our local hospital. This baby was very premature--twenty-six and three-quarter gestation. Under 1200 grams... The baby is just home and is three months premature. So at three months prematurity--she is three months old... We could not establish any delay because it should not be doing anything much. Just like a newborn. (SC-R)

In one case, where the child presented some autistic type of behavior, it was difficult to establish eligibility. However, the older sibling who presented similar behavior seemed to help in establishing the diagnosis and, in turn, eligibility for services. In such cases the time taken to establish eligibility seemed unusually long.

J:... We were not able to make her eligible until the end of August... now it turns out that she has had an eval at Agency E they did a complete psychological. I think they have found high level of autism. We don't know what that is. So that is something that has not been determined definitively yet they have suspected

> autism--because they did find that in the brother. The older brother who came in for testing while the visit went on... They did the same thing with him and found out he has high level of autism--so they think he might be too--it took us that long and she got into Agency E. Because otherwise they never would have pinpointed it out, I don't think. But she really is well, and you would never think it. She really presents almost as gifted, but it is perseverance--over and over again.(SC-R)

SCs' responses indicated that there are bureaucratic incompatibilities with regard to agency philosophy, policy, practices, and funding which have a dramatic influence on the initial IFSP process. Agencies obtain funding from sources with different eligibility guidelines. The following example is illustrative. The SC described this situation as. " ... Consequently there is no service for those other children [a center closed because of no funding and the eligibility criteria was different from TEIS] in the... area now... The ones that are delayed but not enough for Part H are not getting anything" (T:SC-R). Similarly, when children do not have sufficient delays to be qualified for TEIS services, no intervention services can be offered. The same SC gave another example. She stated,

> T:[the child was] referred... by one of the pediatric groups in the area... conducted a screening test. The scores on the test indicated some delay in gross motor area, but not a 40% delay in one area which is the eligibility criteria of TEIS. Therefore the child was not eligible for TEIS services. The mother was concerned, the SC referred her for a physical therapy evaluation... still the evaluation is pending.(SC-R)

In some cases the children may be eligible for services according to the eligibility determined in one area of

development, but they may not be eligible to receive TEIS services in other areas of development. One SC described this point.

> M:When I did the screening, this was the child where it was not sure whether she would be eligible for TEIS... the child was recommended for special instruction. She was not eligible for special instruction, because she showed on cognitive and self-help skills either at her age level or beyond, so therefore the only eligibility I have is from Agency A and they said that she meets the criteria because she has 40% delay in her gross motor skills... this was such a lengthy process. (SC-R)

A SC indicated another loophole in determining eligibility for children with heart defects. According to the SC, these children seemed to have delays in development which are not substantial enough to make them eligible, yet would profit from some services. Even though these children are not eligible, some SCs do coordinate services for them.

> H:She has a congenital heart defect and Histoplasmosis. And I don't know if she is going to qualify or not. And I did not... she is currently being evaluated to see if she will qualify. Her delays are minimal. She might come up 25 in two areas--I just don't know... We are working on it. (SC-R)

The SC referred to children who do not meet the eligibility criteria as those "falling through the cracks." In one case, the child was experiencing behavior problems. According to the SC,

> J:[child] was diagnosed with Oppositional Defiance Behavior Disorder... He doesn't have developmental delay just behavior problem... It is a behavior disorder...Agency AN... He was not delayed enough--So I referred him again back to the original referral source to see if they could pick him back up. Part of the problem is they can't... I am a little bit unclear

> on what this is, but I did on the 22nd contact Agency AN. Talked to the director. She said... he is too severe for the Children's House & Protection Program. He has fallen through the cracks, however we can't make him eligible because he does not have a diagnosis nor does he have a developmental delay, it is a behavior thing. And this is kid's program I really know of. What is unfortunate about this is that he has to be potty trained in order to go to this one program... The thing is behavioral. That is the deal... but I am still doing a report on this case even though he is not eligible. Trying to make sure he does not totally fall through the cracks. (SC-R)

Ill children can hold up the IFSP process. Some children who were referred have often been hospitalized, shuttling between home and the hospital because of their health condition. One SC said, "She [child] was just in the hospital and we did it [IFSP meeting] when she came out. She was in the hospital more than she was home the time she was with us" (M:SC-R). This situation makes holding the IFSP within 45 days challenging. One SC pointed out in the case of Victor, "I think that probably the 45 day time limit is probably the hardest thing to me, because just in my case Victor is a classic example. He was hospitalized over two times during that time ... if hospitalized, or... it totally stops everything for a period of time" (C:SC-O).

Thus, when children become sick, they pose challenges to carrying out the activities in an IFSP process. SCs reported having no responses to their queries from families of such children or involved professionals. SCs indicated that they had more contacts with these families, referring agencies, physicians, and other professionals. For example:

M:this is the child... I have made very many contacts and have been unfortunately not been able to get in touch, got in touch with parents but they wanted TEIS to be involved, 8 contacts with referral source with Agency H. The child was still in the hospital when I contacted the parents so what I did was I sent them a parent packet and information about TEIS to look over the material. Now I would call them back, I got back in touch with Diane because she was going to make a home visit and I asked her to talk personally, talk about TEIS and how we could be involved. Diane said that the parent was not at home at the time of visit, so she has not been in contact with the family and again tried so since then I have contacted three times and not been in touch with Diane. (SC-R)

Appointment of surrogate parents for foster children with disabilities pose unique problems. These children are in custody of individuals/agencies other than their biological parents, therefore, a surrogate parent must be appointed. SC responses indicated that due to the rigorous policies that govern these children/families, serving them has been very challenging and present barriers to holding the IFSP within 45 days. The different policies and practices of the various agencies involved with these children can further clog up the process.

C:there is a lot of red tape that you have to go through when they are foster children in terms of appointing a surrogate parent and all this. And so that held up the process so much that I was not able to do the IFSP until--he was referred in December--and I was not able to do the IFSP until the beginning of August and that is ...everything is documented, but there were a lot of problems with me getting things going for him. And he got services before then, but the actual IFSP was not able to be held until August. So you can see that is 8 months and they are telling us that we have to do it in a 6 week period. And that would be great but I don't know of many people that can actually meet that. (SC-O)

In order for SCs to conduct screening tests with foster children, they need to have a signature from the parent of the child, if the rights are not severed. According to one SC, this practice can hold up the process.

> M:This child is now in foster care... I have made lots of contacts with Agency M worker... due to the fact that the child parental rights have not been severed in order to do any screening, I need to get the parent has to sign that. Allen at Agency M was sent all the information and the all the letters, paper and she is supposed to get in touch with the parent and she has not been able to do that... (SC-R)

One SC explained that the communication between herself, agencies serving the foster child, and parents about significant changes in the child's life was limited, further delaying the IFSP process. According to the SC, such lack of communication may be because too many individuals were involved. She said, "this is just really a wild case and I think that there might be too many people involved or whatever,... maybe I did not communicate that well to the people at Agency U or to Faye the foster parent--that it was of utmost importance to keep me informed on major life changes..." (SC-O). The SC expressed that she felt dodged by other agencies. She was uncertain of the time it takes for agencies to get the necessary information about the child in order for them to further proceed. According to this SC, when some agencies did not provide the necessary information in a timely manner, she made repeated inquiries to those agencies. She expressed uneasiness about this communication pattern. The SC elaborated on this issue

in the following statement.

> C:...the IFSP was still not done and I was just really frustrated... nobody even thought to call me to tell me anything about a major change in Victor's life..., I had to kind of find out about it in a round about way... Director at Agency U--I tried to get her to give me information and she did not know anything... it took about a week for her to get back [to tell me that]... Victor is with a new family... I told her the importance of how I need to have IFSP..., particularly since the foster parent had changed, ...I had appointed Faye... as the surrogate parent and if she was not involved any more with the child--then I needed to appoint a new surrogate parent... I felt like I was getting the run around and being put off... She [director] would not disclose the name of the foster mom... I felt like I was bugging them too... she finally called me back to give me the parents' names. It took her ten days to just give me the parents' names... she might have forgotten about me. (SC-S)

Sometimes, professionals who represent different fields of expertise have <u>different approaches</u>, influencing the initial IFSP process. One SC maintained that a delay in contacting a family was because the social worker from another agency told her to contact her first before she contacted the family. She described the situation as, "... baby was very premature... I contacted the family on 10-10 and it was that late because the social worker at the hospital wanted me to make sure to talk to her first" (H:SC-R). Similarly in another case, one SC specified that one of the agencies involved in serving the child influenced on her actions in establishing the contact with the family. She said that "[it] was a Agency M referral and I called Agency M to locate the family and they kept saying wait, wait. They were sending him through the Team Evaluation Center at

Town E, which took about two or three trips and we had a couple of rescheduling and I really wanted to go ahead and work with him but Agency M kept saying wait, don't do anything yet" (T:SC-R).

At times agencies have different agendas than that of the child/family, hindering timely services. One of the necessities of serving children/families is the documentation of services. At times SCs do not have access to documents needed to provide efficient and effective services. This holds up the initial IFSP process. One SC reported, "I was trying to get the records--after they closed from... that is the agency that got these programs. And it took a very, very long time to get the scores on the development (T:SC-R)."

Another concern pointed out by one SC is when different agencies are involved in serving these children/families, agencies need to understand the role of TEIS, avoiding duplication of services.

> T:It came from... the MHMR Program that was here and he was going to that center in... and the center closed in October.... Should have been referred long before but had not been. That is one of the things that we tried to work on was to get people to understand that we do things in addition to what they might be doing (SC-R).

In general, one of the SCs maintained that the majority of the cases she is involved in do not have the initial IFSPs within the stipulated time. Even when they are able to meet the time limit, she claimed that the quality of some

of the IFSPs suffer.

> K:...have heard from other service coordinators that they are having the quality of the Individualized Family Service Plan meeting and the plan itself is lacking. They are trying to push it to just meet that deadline instead of having a full comprehensive array of services investigated and looked into. (SC-O)

Issues Associated with the IFSP Form

The IFSP form creates problems for SCs. It has several parts which are viewed as "confusing," "redundant," "not clear," and "cumbersome." One SC has pointed out the problem with the format of one section.

> L:like on the signature page--the front piece where everybody signs--the parent has to sign three separate places, which always seems a little ridiculous... there is the Review Modification page has this big space and it is for change of address, but a lot of us have been using that to write in what changes are made to the, when we do a modification, what changes are made there--noted on the outcome page and also put it on that page because that is the signature page for the review.(SC-O)

Another SC expressed her thoughts about the form as follows:

> C:I was intimidated by it at first because all of the laws that were surrounding it in terms of--on the back pages they say do this--then do this. It made me really nervous that somebody was going to be watching over me, making sure I dotted all my i's and crossed all my t's. (SC-O)

The feelings expressed by the SCs about the act of completing the form during the meetings that it is "awkward," "strange," and "hard," which seemed to be less than positive.

> K:Well, it is kind of hard to,... we are sometimes governed by the paperwork more than the process,... that can happen. When we have a meeting we have to

> fill out this form and so sometimes I think that the form can get in the way of the process of just talking about it and deciding this is what we need to do. (SC-O)

Issues Related to Parents/Families

One of the major issues for SCs is that parents do not follow through with services. One SC perceives it as, "... the biggest problem, I guess that I see and it is pretty often is parents not following through (K:SC-O)." SCs recognized that there were circumstances that make following through for parents very difficult. They perceive that in the beginning the families are overwhelmed by the disability of the child. Second, SCs note that the different responsibilities within the family makes following through a challenge. Third, they noted that parents' with limited psychological or intellectual capacity have difficulty following through.

> K:there are some parents...overwhelmed because they have a handicapped child. They may have other children too. They are also working or have other family responsibilities that might have a hard time following through. Or there maybe parents who themselves have psychological or mental or emotional or other kinds of problems that are going to make it hard for them to follow through on what the child needs....(SC-O)

Finally, parents' absence when SCs make home visits poses a problem related to follow through with families.

> L:...and sometimes it is a case that families may not follow through with things too, which complicates it. You may get a service lined up but if they are not there when the person comes then that is a problem too(SC-O).

SCs expressed feelings of frustration when families do not follow through.

> C:... I have dealt with some people who have...are very limited in terms of their understanding... It is like, "Don't you understand what I am asking you to do?"... I get frustrated... that they don't follow through. (SC-O)

SCs noted that certain family conditions impact the IFSP process to a great extent such as involvement in domestic violence, child abuse, psychological problems, and the penal institution/judicial system. SCs used terms such as "hard," "difficult," "strange," "scary," "complicated," "lengthy," as they described serving children/families under these family conditions/situations. The following is an excerpt from one SC describing the situation of a family experiencing domestic violence.

> T:This was one that was also kind of hard to get things going for. Because domestic violence problems. The parents were separated and she was living with her parents. She and her three children at this time so the parents are back together now and....(SC-R)

In another case, the SC was perplexed with the complicated situation of a family where the mother was mentally ill, the child had a behavior problem, and the father was in prison.

> J:... The mother is Schizophrenic and his father is in prison. He doesn't have developmental delay just behavior problem... It is a behavior disorder... Agency M has been called probably for a minimum of seven times for protective custody, for neglect, but they won't get involved for some reason... however we can't make him eligible because he does not have a diagnosis nor does he have a developmental delay, it is a behavior thing... What is unfortunate about this is that he has to be potty trained in order to go to this one program. The mother doesn't have the ability to potty train...

> Because his mother can't take care of him, she is very mentally ill....(SC-R)

Involvement of the judicial system was apparent with one family because of suspected child abuse with one referred child. One SC provided details about the issues particular to this family.

> H:Diagnosis is fluid on the brain--Hydrocephalus... I am unclear as to whether it is from birth--Agency M is involved because there is some question,... Yeah and they [family] were very worried about us coming out, but we sent our parent contact out. They understand that we are not Agency M and it is okay... They are under a lot of stress because there is a court order on the father and stuff like that. To stay away from the children... I guess the mother reported it. She saw him [father] hit the baby and shake the baby... he may of been doing this for a long time... They have been worried for a long time,... the daddy took care of the children... the mother was trying to go to school. And now they are looking back and what they are trying to determine is if this was more than congenital but this is something that has happened over time because of abusing the baby. (SC-R)

Issue Related to Professionals

SCs often related the lack of professionals to provide services and the differing views of professionals as an issue. SCs indicated that families had difficulty in finding professionals for assessment services, in-depth medical evaluations, and therapies. The gravity of the problem related to lack of professionals in rural areas was elaborated by one SC. She said, "It is very hard to get everything together in this area being so rural and with not enough service providers... within the time frame. Often it is impossible... Sometimes it is just hard to find people to

provide the services that are necessary without families having to travel long distances. Transportation is always a big, big problem" (T:SC-O).

One SC reported that a family had to travel to another town to get medical evaluations. She stated, "Well, there is difficulty of getting, you know, if you want or need more thorough medical evaluations--then they usually have to go to Town C or Town B for it. That can be a real problem for a family--transportation to services like that" (L: SC-O). Further, the SC declared that it was a problem for families to receive therapy for their children. According to her, "...getting specialized therapy like speech or PT are real hard to get lined up. Because there aren't the therapists available... pediatric physical therapists and occupational therapists--there aren't any in this area. Either the family has to go to them or we...if we have a pediatric physical therapist that comes up from Town E periodically and consults,...it has to be done on a consultative basis than having weekly therapy" (L:SC-O).

To overcome the problem of professionals not available in the area, TEIS contracts with professionals to conduct evaluations. Yet, families may have difficulty receiving the needed services in the most convenient manner. One SC explained the complicated nature of the problem, "...if we contract for an assessment..., we still have to find a person to... go when it is convenient with the family...

there is usually a time lag on that" (L:SC-O). Even if the families are referred to other agencies for evaluation, delays still occur. One SC described the process as, "For getting speech and language evaluations done, if we go through Agency D that usually takes a while, because their speech person is only here a couple days a week. And the family has to go there and they have to be scheduled through the office there. It is not as convenient for the family to do it that way. And sometimes that holds things up too" (L:SC-O).

As noted above, SCs indicated that there was a need for professionals to meet the needs of the child. However, the lack of professionals to meet family needs was an issue as well.

> T:Some families who are experiencing domestic violence, alcohol and drug abuse, sexual abuse, all kinds of things and it is real important, I think, to... find some resources, support groups, we need some so badly in this area for these types of things... there is not much. (SC-O)

Another problem relates to getting professionals to attned the IFSP meeting itself. According to one SC, "I would say probably the most problems would be getting all the professionals... the physicians and other professionals on the team may not be able to attend the IFSP meeting and therefore becomes problematic" (K:SC-O). Even when all the professionals on the team are able to come, one SC said the problem was for them to remain throughout the meeting. She

maintained, "the meeting takes time and sometimes that is a problem, you know, getting professionals there for the time that is needed to do the IFSP" (L:SC-O).

SCs explained that when professional (SCs and service providers) views were different from that of the parents with regard to needs and philosophy then it remains as an issue. When families do not see the need for any services, but involved professionals do, but want to honor the family's decision, the problem gets prolonged.

> J:Doctor said he was suffering from lead poisoning... mother she said he was doing fine... I sent a TEIS information packet and told her I would check back in a couple of months... she had gotten the packet but she was not interested... I have sent many letters to the parents. She has already said she does not want services. He is the one, the doctor keeps calling me back. But he needs to initiate the follow up testing.... (SC-O)

At other times, the services which the SC believes are best for the child/family may not correspond with the family's ideas of what is needed. Although, SCs agree that services should be provided to families based on the family's decisions, irrespective of their beliefs, they view such as problematic.

> L:they [parents] might want something or do something that we might not think was appropriate,... then it should not be a problem for us,... it maybe hard for us to accept and I guess it is problematic in that sense, but we are not there to judge their decisions and if they don't see it as a problem then we should not make it one (SC-O).

When family decisions do not agree with what the SC thinks is best for the family, it can be very uncomfortable for the

SC. According to one such situations are upsetting.

> L:...one family...they want to move to Town F and they got all the services they need in Town G and if they move to Town F there will be a lot of problems. There isn't a doctor in Town F we can find that will take TennCare and their children are both medically fragile and are going to Agency K all the time so they have to have a TennCare physician to authorize all this stuff. And so it is upsetting to me that they want to move to what might be a less ideal situation but, I can't say, "No, don't do it." You know it is their decision and so all I can do is--I have already made a referral to the school system down there and, you know, when they move I will do the best I can to get services lined up down there.(SC-O)

Even after parents decide to receive services for the child, they may not allow SCs to assist to the extent that they feel the child needs help. One SC expressed her feelings in such situations as "it breaks your heart."

> T:That particular mother has not let us do anything of significance to help the child yet... you know some of them kind of break your heart because you know they need something and they just won't let you help them do it. (SC-O)

In one case, an SC narrated a situation where there was a discrepancy in the diagnosis of the child. The child was evaluated by two different agencies and received a different diagnosis from them, which upset the mother.

> M:This case is "a really really really strange case". The child was diagnosed with cerebral palsy... then [the] child was evaluated at Agency Q... and it was decided by Agency Q that the child did not have cerebral palsy and that he was an "idiopathic toe walker". Mother is now deciding not to put him in any therapy, he is not going to be in any program. They [family] moved out of County D and she [mother] is pursuing legal representation. She feels that he has been misdiagnosed with cerebral palsy, he is going through all this therapy, they have been going through a lot of stressful times, and to find out that he

> really doesn't have cerebral palsy. The family has decided to pursue some legal action... the case [is] a very complicated one. (SC-R)

Issues Related to Payment of Service

SCs said that when the parent's philosophy with regard to the type and amount of services needed differs from that of a funding agency then it becomes an issue. One SC described an IFSP meeting in which there were philosophical differences regarding the type of services the parents needed for the child and those the funding agency was ready to finance. The SC described the situation of the family as experiencing "turmoil."

> J:it was the oral versus total communication battle going on in this meeting and it was ridiculous. The mother chose--she wanted total communication... and there is a big rift between those schools of thought... And she was just freaking out... She left there crying, Agency D said that they weren't going to approve this other agency... but the next day Agency D approved services for that program,... it is a shame that that family had to go through all of that turmoil that should have been handled at a different level...It shouldn't have to happen in an IFSP meeting--those battles. Agencies, professionals, philosophies, those things should not be addressed and I have been in a IFSP meeting that lasted close to five hours over that issue.(SC-O)

In another case, the SC expressed the situation to be "aggravating." According to the SC the family believed that they had the right to get a certain amount of services for which the payment had to be made by an agency. In such situations, the SC indicated lack of clarity as to whose judgement should prevail, whether it is the person providing services, parents or the funding agency.

> J:family was demanding that we pay for everything--24 hour nursing care. Thinking that they had a right to everything ...that is not so. When they have the resources and the means to pay for every single cent of it--not the 24 hour nursing care, anybody would be broke for that. The mother was a nurse and could take care of a lot of things... This was just a situation that I feel that we were taken advantage of. I truly believe it was due to another agency telling the mother that, "They are just not doing their job. They have to pay for this." And I am like, "AH....." That is aggravating when there is an interagency, not only in agreements and collaboration but there isn't any support, I mean, you sort of need to support each other. (SC-O)

The process of obtaining payment through TEIS or through other agencies seems to be a problem.

> M:this is another Agency S child which we did not pursue because of payment issue. All of the center referrals TennCare eligible. It may be that the Agency S was not receiving payment from TennCare. They asked TEIS to get involved because of payment. But we could not supplant what TennCare is involved with. (SC-R)

Agencies involved in serving children with special needs and/or low income families with children are funded by different programs (e.g., MHMR, CSS). These programs offer free services to a specific population. Therefore, when the family's insurance does not cover the available services, some parents seek such programs, even moving from one location to another.

> M:... the family moved... Now have got a message from Agency AM this child is enrolled there in Town M. But the deal was that they were apparently traveling from Town M to Town B every day to get therapy and child care. And it ends up that they can stay in Town M... They wanted payment... at the Agency AM it is a MHMR type of--and they get therapy for free. (SC-R)

At times parents prefer to receive payment from one agency over another, leading to a possible conflict.

According to one SC, a parent wanted, "...payment for transportation... [however] she does have access to TennCare transportation. She just doesn't like it. And wants us to pay for it and we can't" (J:SC-R). Also, the different criteria set by agencies, hospitals, and physicians in accepting insurance payment presents as major problem to families. Some children have insurance, but have different coverage, and others do not have any coverage. These situations make it difficult for families to locate appropriate services. One SC described a family's turmoil in trying to get insurance coverage for their child's services. She explained that,

> J:They [parents] moved out of the district... Here I did a intake--they moved about a month ago--back to Town C. TennCare was the biggest problem with that. Was trying to find TennCare Provider and I think that is why they moved back to Town C, because they could see a physician that would accept TennCare. I tried four different pediatricians' offices in County E and all of them said unless the child was straight out of the neonatal ICU they could not take at all. Even if he was very sick, had to go to the emergency room to just get antibiotics. The mother and father were both upset. They decided to move back... They weren't taking any other TennCare patients... at Agency E. So it was just fear--I think..." (SC-R).

According to one SC, the process of obtaining payment for services is a lengthy process and causes confusion to families. At times SCs efforts to obtain payment through TEIS may go waste.

> M:...there was some confusion since the family did not have insurance. We wanted to get an evaluation for physical therapy and they were in between getting TennCare and not having TennCare. This was a very lengthy process, once I wrote the purchase of service,

> the parents were accepted by TennCare so TEIS could not pay for the evaluation. Getting the evaluation through was a very lengthy process, going through the family physician, finding a place for the child to get his evaluation that was scheduled at Agency B and the parent's couldn't make it for physical therapy. (SC-R)

Parents

Parents related some of the problems they experienced during the IFSP process and their feelings as a result of these problems. The problems parents pointed out were related to the child's diagnosis, the IFSP meeting, service providers, and insurance. In addition, parents' feelings towards these issues are categorized as well.

Issues Concerning the Child's Diagnosis

Parents were faced with the difficulty of understanding the child's presenting problem. Two parents described their experiences of understanding the child's problem even before they got involved with TEIS, and one parent was having difficulty in understanding the child's problem even after she got involved with TEIS. Although, the majority of them were describing earlier experiences, they could not talk about other current issues without bringing up the issue of their child's diagnosis.

Three parents mentioned not understanding their child's problem. They indicated that they were unaware of the problem when their child was younger because they were under

the impression that the child behaved like age mates. According to one parent, "I thought he was hearing when he was younger. I guess basically all infants react the same way. He was babbling and cooing... But my mom was the first one that recognized that he wasn't responding when she would call his name..." (N:P-O).

Also, parents reported that they were unable to understand the test results in relation to the delays they observed. As one parent stated,

> P:... all the tests come back normal... all they can come up with is his chronic ear infections... the other delays, motor skills other than the walking,... his fine motor skills his grasping things feeding himself I don't know whether... it is any good... he can't feed himself; he can't pick up things; he can't follow commands; other things that a two year old will be able to do he cannot do; and... I think there is something else there besides ears. I think they are a big part of it. (P-O)

Parents expressed <u>difficulty understanding terms</u> used by the doctors. One parent said that, "...not understanding what he [orthopedic doctor] was saying made it even more complicated...; not understanding the term I did not know what questions to ask; ...came away with really a lot of confusion and felt overwhelmed" (R:P-O). Generally, they posed their questions to all professionals who were directly involved in serving their children. The interview responses suggested that parents have some dissatisfaction with the responses given by different professionals. For example:

> P:everyone I see... I ask them if they know what's wrong because they have the reports no one knows nobody. I have asked Becky of course I have asked the

> doctors at Agency E, I have asked they just recently went to a hearing... my son and daughter went to Agency D pediatrician where they take them to the different doctors nutritionist, the audiologist ... I asked them no one knows nobody knows... you don't even know what the problem is other than that there is one. (P:P-O)

Issues Related to the IFSP Meeting

Out of the four parents who attended IFSP meetings, two parents' expectations regarding the meeting seemed incongruent with what really occurred. These parents do not seem to value the time professionals spend doing the paper work during the meeting. Two parents believed that during the meeting professionals were engaged in rewriting reports.

> P:They sat and went over the reports that were already written up and rewrote and then supposedly made plans for the future which I had already heard... they could have sat and done it themselves... I could pretty much guess what was written like I said Becky read right off the reports in her chart and Kay wrote it down... I would assume [that it was about] what level he was at; what they had done so far; what doctors had diagnosed or said she was writing down, but I was never shown the papers, I didn't actually see what was written... I don't know or remember. I mean by this time they had lost me. (P-O)

One parent suggested that the discussion was mere repetition. She perceived the discussion by professionals as something they had already rehearsed several times. "... [the] IFSP meeting was the same old thing to me I didn't really see the point in it. It was like repeating the same thing over again. Nothing was really new"(P:P-O). The parent did not see any benefit for her or her child in being part of the IFSP meeting. This parent believed that the

purpose of the meeting could be served just by the professionals, as she viewed her participation as being physically present not actively involved. She continued, "... [I] didn't really see any purpose in it I don't know how to explain it" (P:P-O). The meeting seemed uninteresting to her, apparently she was waiting for it to end as soon as possible. In her words, "It was pretty boring... I just sort of tuned it out. They talked to their-self and I really did not talk... I was ready for it to be over. So I guess I was just signing just to go" (P:P-O).

Although, the majority of this section was devoted to one parent's perception, it seemed important to show that some parents may not value the IFSP meetings when professionals report the present levels of development or the way professionals involve them in the meetings.

Issues Related to Therapy and Time

Disparity in the parents' and service providers' views about the purpose and the amount of time the child requires therapy was another area of concern. Out of the five parents who participated, two mentioned this. One parent indicated that she was dissatisfied with the limited frequency and duration of therapy of the home based therapy services. Further, the therapist was irregular in maintaining the appointments.

> P:...the speech therapy I having problem with that... she only comes once a week... it doesn't seem to be enough She doesn't spend a whole lot of time with him and... she has cancelled two or three appointments [within one month],... I am disappointed with that, because I don't even think once a week is enough and plus when she cancels it makes it even worse. (P-O)

Further, the same parent was not satisfied, because the severity of her child's problem and the intensity of the services that her child was provided were not consistent with her views. According to her, "...at this rate I say he won't be any better, unless it is from ... what he learns at home. It sure won't be from her [speech therapist] because she isn't with him enough... especially as severely as he is. He doesn't even talk at all. I don't see how that time can make any improvement" (P:P-O). She also could not see the significance of the kind of exercises the therapist had her child do. She said,"... she does the little exercises with him for a few minutes... with his feeding... It is the same way anyone would do it,... speaking which is really my concern,... she will do little exercises with him to make sounds... But that only last maybe fifteen minutes. Well fifteen minutes once a week--there is no way that is going to impact the child" (P:P-O). In essence, this parent viewed her child as being neglected due to the therapist's infrequent service. In her words, she said " ...he is not even getting his once a week in, you see it is like he is being slighted..." (P:P-O).

Another parent, receiving center-based services for the

child felt that the recommended number of therapy sessions was more than necessary. According to this parent, it was waste of time and money. She resented the fact that the occupational therapist was not spending enough time with the child before making major decisions concerning services. She disliked professionals making decisions for them.

Two parents seemed to have problems communicating to the therapist their views about the appropriate amount of therapy. One parent admitted that she was hesitant to voice her opinion to the therapist about the amount of therapy she felt her child needed. She feared that it might interfere with her child obtaining services. She explained, "I have a hard time with that. Like I said she is nice and I don't want to cause any problems I assume she will be the one seeing my child so, I don't want any friction there. So no, I haven't said anything to her" (P:P-O). Another parent reported that the service provider was unwilling to take a suggestion they made ignored parental suggestions. She expressed, "I am not happy that they would not fully take my recommendation... I was just a bit annoyed by that, because I felt like I had made my recommendation clear and I felt like I also made it clear to her how I felt about it and why I felt that way. I don't think I just said, "No, we are not going to do this." I mean I told her what I thought--my reasoning for making that decision" (R:P-O).

One parent response also suggested that frequent

changes among professionals providing therapy services was a problem. She explained, "... we have changed, initially there was one person did her physical therapy evaluation... we had one therapist that we hadn't met before until the first day of her session... and then just this last session... And now we have,... we are on our third one" (R:P-O).

Since many agencies are involved in serving children with disabilities and their families, there is lack of clarity for parents regarding the role these professionals play on the IFSP team. She said, "I don't understand, Are the two connected [TEIS and Agency E]? [Does] TEIS have some ruling over all this I don't understand" (P:P-O). Parents raised concerns in terms of the limited number of contacts with the professionals.

> R:occupational therapist,... She met her one time--did her evaluation--and that is it. So I mean, how can you make that kind of decision about someone's life and future in one hour... I am a little skeptical of someone that is going to tell me that this what is best for my child--when I spend numerous hours with my child and they spend one, but yet they are going to tell me this is what my child needs.(P-O)

Issues Related to Insurance

Parents were concerned about delays caused by insurance. Completing necessary documentation and difficultly in locating professionals who honor the family's insurance plan both presented problems, resulting in confusion regarding the timing of the evaluation and therapy

for their children. One parent reported, "...his last hearing evaluation--it was due in July so he is behind in that. He is supposed to have one every three months... You know, [by the] time he gets his next one it might be six months. So we don't know if he is going to be responding to any sounds yet or not. So, I think that they have to do that first before we can get a speech therapist, I am not sure" (P-O). Another parent expressed similar concerns. She stated, "...about his physical therapy. There seem to be a problem. Victor's medical insurance has expired so now we have to go through the process of getting him some more medical insurance, and that means more frustration because we thought this problem was going to be taken care of in a few weeks--now it looks like it is going to go on longer... This little boy really needs the help" (F:P-S).

As families move from one state to another, services get held up. One parent reported, "...he still hasn't got his TennCare through the State yet, so that is a big concern right there, because we can't do any of the other stuff until that comes through... Finding a doctor, getting hearing evaluations, and speech therapy" (N:P-O). Also, when children have multiple problems, it is difficult to identify the specialist best suited to treat the child who also accepts the insurance plan. Often, this process of matching the family's insurance plans with the concerned professional is a major issue for parents.

> N:Well, he can't have his hearing evaluations done, I mean those are expensive, I can't pay for them out of my pocket. And CHAMPUS will cover up until my husband gets out of military next month, so, but we would have to go through, you know, call the CHAMPUS and have them change his, because he was going to Agency Y up there, that was his main provider, or whatever was on the insurance form so they would have to change that all around, and by the time that gets done he will be out, so, that puts...said something about Agency D or I am not sure who that is, but I think that goes hand in hand. (P-O)

According to the parents, abiding by the regulations of necessary documentation often delayed services. According to a foster parent, "... It has been a slow thing with getting Victor the necessary physical therapy that he needs."

> F:Victor's final evaluation for his physical therapy. It seems like that we will finally get the services that Victor need. Once Agency B submits all the necessary papers to the Access Med to cover Victor's care. (P-S)

Parent's feelings related to these issues

Parents experience various feelings during the IFSP process, including expressions of being "bored," "unhappy," "skeptical," "confused," "annoyed," "disappointed," "overwhelmed," and "frustrated." One parent felt bored in the meetings, she said, "...they had lost me,...it was pretty boring,... nothing new, ... I tuned it out. They [professionals] talked to their self,... I just sort of sat there,...I was ready for it to be over" (P:P-O). Another parent felt confused and overwhelmed. She felt that way

because,"... [she was] not understanding the term [the doctor used], did not know what questions to ask;... so really came away with really a lot of confusion and felt overwhelmed" (R:P-O). Disappointment was the word one parent used to express her feelings towards the speech therapist. She stated, "speech therapy I [am] having problem with... it doesn't seem to be enough... and she has cancelled... appointments,... I am disappointed with that" (P:P-O).

According to one parent, she had mixed feelings when her child's therapists changed very frequently. She described having, "Mixed [feelings] because... one person did her physical therapy evaluation... we had one therapist that we hadn't met before until the first day of her session... and now we have... Elsa, and not that she is not as good it is just... I find it confusing... it has been hard to set a consistency with it because of the changes" (R:P-O). The same parent in another situation reported that she was not happy, and that she felt annoyed and skeptical, especially when professionals did not acknowledge her suggestions for her child's therapy.

> R:I am not happy that they [OT] would not fully take my recommendation... I was just a bit annoyed by that, ...occupational therapist,... She met her one time... how can you make that kind of decision about someone's life and future in one hour... I am a little skeptical of some [one] that is going to tell me that this what is best for my child--when I spend numerous hours with my child and they spend one, but yet they are going to tell me this is what my child needs.... We have insurance, I mean, so they know they are going to [get]

that... when I am telling someone that this is what I want from them, yet they keep pushing something else at me, that just really makes me feel like it is a money racket. And that annoys me.(P-O)

Research Question 4: What are some practices that service coordinators and parents have found to be helpful for them during the IFSP process?

Service Coordinators

SC responses indicated certain sound practices that are helpful while working with both parents and service providers. First, SCs discussed certain skills which enabled them to perform their duties more effectively. Second, they pointed out techniques used in other professions which help them in conducting the service coordination activities. Third, they highlighted specific qualities of SCs which enable them to carry out the IFSP process in an effective way. Lastly, they mentioned acquiring knowledge related to providing services as an essential component.

Skills

SCs pointed out three skills that are necessary for them to carry out the activities of the IFSP process in a effective manner: communication, organization, and

professional skills.

All SCs acknowledged communication skills as a critical skill. One SC highlighted stating, "Probably the most important skill to have is dealing with communication... (C:SC-O)." They pointed out communication was important not only for communicating with parents, but also for communicating with service providers who represent different agencies. One SC described, "... you not only talk to the family and represent them but you also talk to the agency that is going to be serving the family and try to work out what is best and so there is a lot of communication" (C:SC-O).

SCs specified that communication skills include both the ability to listen and self-expression. They considered both of these essential for carrying out the activities efficiently. SCs stressed the importance of listening skills, particularly while communicating with parents. One SC stated, "listening skills is very, very important and [also] being able to communicate in an effective way with people" (T:SC-O). Another SC mentioned that it would be worthwhile to practice listening. According to her, providing necessary coaching to enhance listening skills was of value. She stated, "... training on listening, I think, for me, if I was going to set up training for service coordinators, I would probably put in listening skills" (L:SC-O).

SCs described the way one has to listen to parents. They used terms such as, "having big ears," "listening to their [parents'] story," "being insightful and intuitive," as ways in which one needs to listen to parents. One SC differentiated ways of listening by stating, "listening skills is very, very important. Sometimes you have to listen for what people are meaning as opposed to what they are saying" (T:SC-O).

Talking with parents in a manner that is befitting and beneficial to parents seemed to be of equal importance to four SCs. One SC considered it be a major skill, noting that, "Ninety-nine percent of my job is talking. I need to, constantly [be] trying to evaluate how I am doing in terms of expressing myself (C:SC-O)." The different styles SCs adopted while speaking with parents include asking them questions, making suggestions, presenting to parents different options, and keeping the language simple.

> L:if you are not sure about what they want--ask them ....And if they are not sure, maybe make some suggestions or, you know, say--this is an option why not think about this, or these are all your options think about this and what you are most comfortable with, and it is a process of building their trust with us. (SC-O)

One SC indicated her way of keeping the language simple was, "to communicate in an effective way with people. To break things down into language that they understand" (T:SC-O). Thus, while using different styles of expression, the SCs suggest they have to make sure that they are not in any way

intimidating the parents or making it complicated for them to understand. Rather, they need to keep it simple and be clear, allowing parents to form a trusting relationship with them. One SC explained,

> C:... communication is...just knowing... how to express yourself in a nonthreatening simple, but not patronizing way. It is just knowing how to put people at ease--in terms of what you say to them... with coordination you have to be talking to a lot of different people.(SC-O)

The ability to be <u>organized</u> is central and challenging for SCs to serve different families in a harmonious fashion. This skill involves in the words of four SCs the ability to "remember things at once," "follow through," "staying focussed," "wrap things up," "loose ends to tie up." One SC stressed the importance of this skill in her description.

> C:So it is challenging for me to try to be sure that I get the things done that I am suppose to get done and get back to the parents, follow-up, and get back to the parents and so I guess organization is the big one... you have to be organized... You got to juggle. You got to be able to do a lot of different things for a lot of different people... and it does take organization skills. You do have a lot of things going on at the same time(SC-O).

One SC mentioned the importance of carrying out her responsibilities proficiently. She described <u>professional skills</u> as necessary for being a SC. Although, only one SC's response is included under this category, this information is presented as a category because of the comprehensive nature of the response. Also, this comprehensive response

reflects professionalism of service coordination which is still an emerging profession in the field of early intervention. Professional skills include the way in which SCs discuss children/families with other professionals, make commitments with the families and other service providers and keep them, represent their colleagues and their organization, use the level of responsibility given to them as a SC, follow through, handle decisions, and handle telephone calls. The following is a detailed description provided by one SC.

> C:... how you present yourself professionally--to me are the most important... returning phone calls on time,... just some basic little professional skills that... just how you conduct yourself in front of others--that you never talk about a family and disclose any identifying information. Because that is confidential between you and the family, unless you have a release. If you have a release it is just to get business done and not to give subjective comments about, "I wish Sally would cut her hair," or say horrible things like that... To return phone calls in a timely manner... Don't promise things that you can't follow through on. It is better to err on the side of caution than not to say, "I know the family will come to your agency, I can promise you that," because you can't promise anything. Things happen and it would be better to not say something like that and let them be happy that they did--than to expect it and you say, "I am sorry they are not coming." It is kind of this follow through business,... even if you are having issues--hard issues--back at the office, dealing with dynamics, group dynamics, never present that outside of the office because it is nobody else's business. It is kind of like your family--you wouldn't air your dirty laundry to just any old stranger--it is the same thing for your office. You need to always present a united front... then to go to the project coordinator and to express the concern and let them deal with it in terms of how they handle it. But don't be the crusader who goes to fight these battles by yourself. We need to be united in our decisions to handle issue involving outside agencies. If it is a billing thing and they

> are overcharging us or something like that--the thing to do is to make the project coordinator aware of it and let them handle it rather than little old service coordinator saying, "I think you are overcharging." You know, it is really too many chiefs and not enough Indians. You know, you need to have one person to do that. And that needs to be your boss rather than yourself. Just things like that, I mean, basic professional little standards and expectations of being a professional--which can in turn affect any job, I mean, these are rules that should govern any job you have. (SC-O)

Techniques

SCs referred to some techniques as being helpful in an IFSP process. They acknowledged that some of the techniques they use while working with families and agencies are comparable to ones used by sales persons, waitresses, social workers, counsellors, and a public relations person.

The SC as a sales person must be able to encourage service providers to provide service through negotiations. The SC described it as:

> J:[service coordinator] willing to call and say, "Will you do this? Okay, thanks. Do you do this?" I mean it is this kind of stuff. Then trying to encourage people to do something that is a little bit of...so I guess it is sort of a sales technique, "If you do this then I will do this." Sort of. (SC-O)

Another SC compared the approach employed in doing service coordination work for different families to the ones used in a waitressing job. According to this SC, a waitress synchronizes various activities to fulfill the specific requirements of each of her customers. Similarly, a SC has to align her activities in a way that allows her to

meet the different needs of numerous families at a given time. According to the SC, each family is at a different stage in the process, ranging from families who have just entered the system to families who are already served by the system.

> C:...I am a very simple-minded person and I like to think about this job as being almost like a waitressing job. You got some people that just need menus--they are just starting out. You have some people that need their check--they are just wrapping up--they have already eaten. They have already been served. You got some people that still haven't decided what they want yet. And you got to go back and check on them and make sure. Then you got some people who are starving and they have already ordered. You know, you have to meet all of these needs at the same time. All of these people are at the restaurant at the same time. You got to juggle. You got to be able to do a lot of different things for a lot of different people. You have to keep on. And you have to act like... it is not act, but you have to present it as if their child is the most important thing. Because their child is the most important thing to them. So they don't care about little Johnny down the street--they care about their little boy. And you have to care about their little boy. And not bring in the kitchen sink--in terms of what you are dealing with--in terms of, "I got another child that needs that same service." You know, who cares. They just want you to focus in on their little boy and help him. (SC-O)

According to one SC, in order to link the child/family with several agencies for different kinds of services, the SC may have to function like a <u>public relations</u> person. She said, "You got to do that in a way that gets the services for the child, but doesn't alienate the other agencies, you know... I guess it is--public relations..." (K:SC-O).

One SC discussed about the techniques she had learned as a <u>counsellor</u> as being helpful in being a SC and also

those used by a social worker.

> T:I have some families who are experiencing domestic violence, alcohol, and drug abuse, sexual abuse, all kinds of things and it is real important, I think to be able to pick upon some of these things and help them talking it out... I guess all the counselling that I have have come in very important, most important thing is being nonjudgmental and to realize that you have to help people within their value system and you have to respect that... and a social worker [such as] collaborating with other agencies, pulling together resources that are available, sometimes we create resources where there don't seem to be any....(SC-O)

Qualities

The SCs' responses suggested that there are individuals with a certain disposition more suited to function as SCs than others. One SC stated, "I think to a certain extent there is a natural personality that does better as a SC. I mean some people are good teachers or doctors and some people are good SCs... I suppose some of it could be learned, but some of it is just who you are as a person and whether or not you can be a good SC" (L:SC-O). The ones who are more suitable are the ones who have qualities such as being "nonjudgmental," "nonpatronizing," "non authoritarian," "sense of humor." Another SC enumerated some of the other characteristics that she viewed as being important. She said, "I think, characteristics of [the] people that are "open," "communicative," "flexible," "interactive," "sympathetic," "sometimes empathetic, if it is a situation that I have experienced as well"... "task oriented," you can't get too off on a tangent or you would

be there all night..." (J:SC-O).

Two SCs stated that their experiences as parents helped them to relate better to other parents.

> L: I think for me it really helps that I have children, because, you know, my kids have grown up and so I know what they were like when they were one year and what they were like when they were three years old and I know problems or when they won't sleep and you are going crazy and all this...this kind of stuff and so I think being a parent is a big plus. For me, that helps me relate to the parents as another parent(SC-O).

Knowledge

The knowledge that the SCs indicated as being important involved the law, child development, counselling, and resources available to families. One SC said, "... I have a background in counselling, so that is one of my strengths with families" (T:P-O). According to them, knowledge regarding child development is something acquired through formal education, whereas the knowledge of the community resources is acquired through experience. One SC pointed out the knowledge acquired through experience as "in terms of knowledge of resources and all that kind of stuff in your area... to... know who does what--where, how much it is, and that takes living it and doing it and being trained. Just training yourself by the more contacts you make in the community, finding out who provides what service" (J:SC-O). SC responses suggested that the knowledge acquired on the job is a process by itself. It involves discovering available services, reaching out to various agencies and

professionals, and informing oneself about their distinctive features. One refers to this process of learning about the resources as going on a "scavenger hunt." Another stresses the fact that it is not imperative for them to be knowledgeable about all the aspects and resources. However, it is critical for them to be aware of whom to get in touch with to learn about a particular resource.

> L:None of us know everything, but we know who to talk to, to find out what we need to know. So I think that is important too. You don't have to know everything, I mean, it is okay to say to a family, "Well, I don't know about that but I will check into it." (SC-O)

One SC refers to the knowledge obtained by being on the job as "product knowledge." She pointed out significance of this kind of knowledge in relation to how and when SCs could acquire that kind of knowledge.

> C:I dont think that we necessarily need to be hiring people who know all the services out in the sixteen different counties. Because that kind of knowledge is kind of like product knowledge, it just comes with learning the job. (P-O)

Parents

Parents used lay terms in describing some of the practices that were helpful in obtaining services for their child/family. The practices parents indicated as helpful were noticing, asking, explaining, researching, and praying. These practices emerged from their open-ended interview

responses.

Three parents recalled noticing/recognizing the child's problem which helped them seek services for their child. Although, this practice is not observed among parents during the initial IFSP process, it seemed to act as a precursor to those practices adopted by them during the initial IFSP process. They took notice of their child's problem in different situations and tried to talk to concerned professionals about it. One parent reported, "... by her [Sophie] second birthday we were noticing that she was not turning her foot not actually in--she was turning it over as she walked... it was noticeable on the wear of her shoes... And we would notice that when she would run with her friends at the sitters--that she was falling a lot. And noticing it in the yard, you know, when we would be outside..., When she went for her two year checkup, we had talked to her pediatrician about it" (R:P-O). Another parent described her efforts to recognize her child's problem and added that an extended family member was involved in recognizing the problem. She stated,

> N:...I thought he was hearing when he was younger. I guess basically all infants react the same way. He was babbling and cooing. I swear up and down he said, "Daddy", twice and it sounded like he said some other words,... My mom was the one that picked up on it... but she was the first one that recognized that he wasn't responding when she would call his name, or when she would come up behind him he wasn't paying any attention to her. So we took him to the Ear, Nose and Throat doctor here in town, and you know, he confirmed that there was something that needed to be checked further.(P-O)

Three parents indicated that asking questions allowed them to seek answers that were helpful in understanding the child's problem/development. One parent explained, "Me and the nurse were talking and I told her I would like some papers on development and what he should be doing at his age and ...[it] really helped... the pamphlets on the developmental that showed me more what to work with him on" (P-O). In the case of the foster child, the second foster mother asked for more information about the child from the previous foster mother in order to help to understand the child's problem. She said "I called her several times to ask questions on, he was getting sick and I called her asked her. I would tell her what was going on and she told me I should probably get him on to the hospital because that was signs that he was getting ready to get into trouble... [it] just helped me as far as getting to know Victor" (B:P-O).

Two parents reported their ability to explain their child's problem as being helpful in making professionals and other individuals understand the child's problem. One parent explained her conversation with the doctor, "I took her back and I told him... I was pretty insistent on going further. I told him, I said, you know... she was telling me, "Mommy I can't fall." Now she was having a fear of falling and to me that was her way of telling me that something was not right" (R:P-O). Another mother was engaged in interpreting her child's ability to those

individuals who had wrong notions about her child's ability. She stated,

> N:So, that is what I try to explain to people, I tell them he is deaf and they are like, "Oh, I am sorry." I say, "Don't feel sorry for him, you know, he is smart and he learns fast. Don't feel sorry for him... That is where I become his interpreter. (P-O)

One parent explained that she started to do some research in her efforts to understand her child's problem, which helped her in obtaining services for her child. She said,"... what I started doing was doing some research on her disability or her diagnosis. Where it would help me understand what was going on? What was the expectation? How we... What we could do about it. If there was anything... to make it better" (R:P-O). The researching strategies adopted by this parent were posing questions to the concerned professionals, identifying the terms that relate to the child's diagnosis, and reading. She described her practice as, "I just referred my questions to the therapist... what I had asked them to do was send his letter of diagnosis... And that would give me some of the spelling and everything and I could look back over it and know exactly what to look for... the orthopedic doctor... I asked him... and he was trying to clarify some questions" (R:P-O). She indicated that she was engaged in reading for more information.

> R:...not understanding the term I did not know what questions to ask;... that is why I wanted to start reading on that... now I had read too,... in the

> medical encyclopedia--where I had been reading about it? ...I did read in the book ...about Cerebral Palsy was the development of the muscle structure in children isn't usually stable till they are about three. So that helped me understand a little bit more of why they wanted to delay... I had done some reading and it kept like it was referring to Cerebral Palsy. (P-O)

One parent acknowledged praying to God was helpful for her. In her words she described:

> N:I prayed to God, I said, "If this is not to be then they will correct it or find out what is wrong." I said, "If it is then you got to help me deal with it." I guess he answered that prayer because, you know, everything has just come so easy. I never had one problem getting hold of anybody, or somebody telling me, "Well, I don't deal with this, but so and so does. (P-O)

Although, only two parents referred to the practice of researching and praying it seemed helpful for these two parents in dealing with the problems.

Research Question 5: What suggestions do service coordinators and parents have for improving this process?

Service Coordinator

SCs' suggestions were mainly observed in their open-ended interview responses. These suggestions were concerning the IFSP and approaches to better serve children/families.

IFSP

SC suggestions were related to the legal requirements of the IFSP. These requirements are the 45 day time frame, completing the IFSP document during the meeting, the format of the document, and the requirement of two professionals at the meeting.

SCs indicated that the requirement pertaining to the 45 day time frame needed reconsideration. One SC rationalized the need for flexible policy by stating, "The 45 days is a good idea but it is just really not practical in many cases. So there needs to be some flexibility with that because it's sometimes not helpful to have it too early in the process before the evaluations on the child and you don't know what kind of services the child will need" (K:SC-O). Another SC pointed out that the 45 day policy may hold good in an urban area, but may be problematic in rural areas. She explained the need to be flexible with the policy of 45 days in rural areas in the following excerpt.

> T:... [There is] room for improvement [in] ...the time frame, I feel bad that we don't meet it because it is the law--we are supposed to have a lot done in 45 days and that is very, very hard. I think in an urban area where you don't have to go so far, and you may have more providers that is more sensible than it is out here... (SC-O)

One SC proposed that the 45-day time limit be extended to 60 days. She said, "I mean that is the purpose of the law and the spirit of it is to make sure you do it in a timely manner, so... sometimes it does work out, more like

60 days would be reasonable..." (J:SC-O).

According to one SC, one way to plan the IFSP meeting within the time limit is to "eyeball" and mark on the calendar the 45-day limit for each case from the time SCs receive the referral. She said, "... I mean if you realize on the onset when you get the referral--"How many days do I have?" ...circle on calendars, or whatever, how much time they have got, try to eyeball it and see what I need to do..." (J:SC-O). Another suggested that the initial IFSP meeting be held once all the services are in place for the child/family rather than having one just to meet the 45-day deadline. Because in some cases, when an initial IFSP meeting is held before some of the services are set up for the child/family, then a review IFSP meeting has to be reconvened within a short time period. She maintained that efforts to reconvene such a meeting were ineffectual. One SC recommendation to this problem was,

> C: ... this is purely my philosophy, but why should we be so tied down to rules and regulations that we actually see the forest for the trees in terms of helping the family. I would rather take the longer time... to pull it [the services] altogether than to just push papers, rush to have a meeting that really doesn't decide anything. Just for formality... It can be the final accumulation of all the services and... we will write this all down and then we will re-evaluate in six months." That is personally how I like to do it because to me it brings everything together in a nice neat little package... That is just a personal feeling I have about the IFSP process... I would rather wait and get all the work done and then hold the IFSP and then that way your chances of having to reconvene the group in a matter of weeks is very near to nothing... That is why personally I think it would be better to wait and make sure that you have ironed out all of the

issues before you have the meeting. (SC-O)

SCs claimed that to complete the IFSP document as well as take part in the discussion was an unmanageable act. SCs seemed to be uncomfortable completing the form during the meeting. They hoped that the form will be altered in a way which would help them to complete it and conduct the meeting smoothly. One SC expressed, "... it feels kind of strange to be sitting there while you are meeting and trying to fill in the form while it is going on... We had an IFSP training on Friday and they said they are going to be some changes made which may simplify things too--so that will probably be good" (L:SC-O). They suggested that it would be more convenient to lead the meeting if someone else completed the form. The same SC expressed, "It would be nice to have someone that could fill in the blanks while you are sort of conducting the meeting or you know, leading the discussion" (L:SC-O). Also, some suggested that meticulous documentation during the IFSP meeting was not necessary. "...if they are real meticulous, they may have an excellent document, but that is a two and a half hour meeting and that is not necessary in my opinion" (J:SC-O). According to SCs, completing the present levels of development in the IFSP document seemed to be a time consuming process. She said, "...like going through the present levels of development, ...it takes time" (L:SC-O). Another's desire was to have an option to fill the current levels of development before the

meeting, especially when the information was straight forward. For example:

> K:Test result,... written reports... [you] go ahead and put that on current level of functioning and then add other comments,... we have been told that everything should be written at the meeting. Which I think is another unrealistic expectation... It makes sense to me to do that... if it is something clear ... because it saves time. (SC-O)

Another important suggestion was not to bring in issues of agencies, philosophies, and policies at the IFSP meeting. They suggested that professionals should solve those kinds of issues before the IFSP meeting and not to bring it up in front of parents during the meeting, but to be supportive.

> J:...in an IFSP meeting--those battles. Agencies, professionals, philosophies, those things should not be addressed... when there is an interagency,... you sort of need to support each other and say, "Well, I am sure her intentions were thus and so." Instead of saying, "Well, obviously I am the best person around."... "Well, you know, nobody knows your baby like I do." That is not the way. (SC-O)

Another SC recommendation included that IFSP meetings be organized at the end of a therapy session or any other service, as that arrangement seemed to be a convenient setting and time for both the professionals and parents most of the time. She stated, "... find a nice time that we could all meet and then hold the meeting, wherever, is convenient for most of the members. Usually in the parents' home, or in the therapy session. Like I have done IFSP's where I have tacked on to the end of the child's therapy session, because the mom is already there and the therapist is there... Those are the nicest ones because you are right

there and the child is right there too and you just see how he is doing" (J:SC-O). SCs claimed that at times professionals are unable to attend the planned IFSP meeting. In such situations, they suggested that it would be better to explain to parents what would actually have occurred during that meeting rather than to cancel because of the absence. She explained, "...if one person cancels then your 45 day limit is out, because you cannot have that IFSP without that person not present... Actually what I do was go over with the family... well, this is what we would of done today" (J:SC-O).

The recommendations of one SC to other SCs was to have knowledge of the resources in the community before attending an IFSP meeting. She stated, "... you should have some of your leg work done in terms of knowledge of resources and all that kind of stuff in your area before you get to the meeting so you will know who does what--where, how much it is,... by contacts you make in the community, finding out who provides what service..." (J:SC-O).

SCs anticipated some modification in the <u>format</u> of the form in order to avoid redundancy. One anticipated change was related to reducing the number times parents must sign the form. She stated, "Well,... the front piece where everybody signs--the parent has to sign three separate places, which always seems a little ridiculous, ...down the line it will just be one place where the parent has to sign

...then there is the Review Modification page... So they will probably be changing that one a little bit too. So that will simplify things" (L:SC-O). They proposed that the review modification page and the outcome page be linked so repeated information on these pages can be eliminated.

> K:... you update it when there are major changes... There is a separate page that you fill out for change review that the parent and the service coordinator sign, but on that page it doesn't have a place for the change review, it just has a place to sign saying we reviewed it and modified it this date. Then you have to go back on the actual original IFSP--make the changes, and initial everywhere it has changed and that can be, that can get real messy, because you have marked through and you have made changes and it...maybe you have to add things,... it just seems to me like it would make more sense to have a place to write the changes, you know, separate from going back to the original form and marking through and changing. There should be a better way to do that.(SC-O)

Lastly, one SC suggested that a change be made in the requirements of the law, whereby two professionals other than themselves and the parent need to be present during the IFSP meeting. They suggested that just any two professionals does not serve the purpose, but it should be specified that two involved professionals be present. One SC explained:

> K:...sometimes there aren't and it is early in the process usually, there is not another professional who is going to be there and or there is not another professional who is involved with the child so it is hard to meet that requirement. People will,... take another person who is not involved with the child just to meet that legal requirement. Which to me doesn't make any sense because they don't know the child, ...they are not really going to contribute, but some people in our agency and other agencies this is happening where they will just... call and ask us to go because they don't have another professional to go,

> just to meet the requirements. And, so, I think... There needs to be some flexibility there,... it needs to be people that are involved with the child or family not just a professional who comes along to meet these requirements. (SC-O)

Approaches

SCs suggested certain approaches that would help to improve the process of serving children/families. They suggested approaches that they "figured out," or "works well," or they thought are "better," or "the best," while serving children/families. These approaches relate to contacting/scheduling and communicating with families, and communicating with agencies.

SCs discussed contacting parents. They maintained that as professionals they should avoid making a "cold call" to families. They need to keep the families informed about themselves and TEIS by mailing information before placing their first call to parents. One SC reported, " ...avoid a cold call type approach where somebody might be taken offgaurd... they have information right in front of them about TEIS--rather than just getting this call from a stranger. It is kind of threatening... it is like selling something over the phone... so it makes it more legitimate in terms of, 'Hey, we are an organization that cares about your family" (C:SC-O). As SCs contact the parents, they maintained that it is important to learn about the baby's good time in the day and schedule an appointment around the baby's good time. One SC said, "you just figure out... if

you have ever made a visit around nap time then you don't do it ever again... it is a bad time of day... Try to schedule an evaluation around the child's good time... try to fit in to their schedule" (J:SC-O).

One SC suggested that she tries to confirm her scheduled appointments with the families by giving them a choice of a confirmation call the day before or on the day of the appointment. For families with no telephone the SC confirms through mail and/or accompanies another professional who is making a home visit. These alternative ways of confirming appointments with families seemed to reduce "no shows" in the process of serving families. She stated:

> J:... I try to call to confirm before I leave my office to go on the home visit. Or even the day before because I have had that with a couple of families and I got there and they say, "Well, you did not call me yesterday like Agency G does." And I thought, "Well, we are not Agency G." But you understand that a lot of these families that... many agencies involved [They] get... confused and ... when I schedule the home visit... I will say, "Would you like for me to call you the day before, or I will call you that day." I let them know when they will hear from me and sometimes it is done by mail because often they don't have a telephone, or something, so you try to sort of coordinate it. Often too, if it is a family with no phone, you get the referral from another agency and I try to go on a home visit with them when they are going and that works out well. (SC-O)

SCs discussed their <u>communication with parents</u>. They suggested that it is important to recognize whether the family has the ability to understand the information being

presented, noticing the way parents ask questions or look at SCs (during face to face contact) or by being intuitive. Further, SCs suggested that one should be able to reword or rephrase information in simple terms for parents who are unable to read or understand written materials. Also, they stressed the importance of listening very carefully to such parents. One SC described her experience of dealing with such parents as she provided her suggestions.

> C:A lot of times when you go... you can tell by the questions that they ask you whether or not they really are in tune to what is going on. It is like if they ask insightful questions about the program, "Oh, I was thinking about referring my child to such and such. What do you think about that?" Then you know that this family is on the ball and they know what. And there are other families that are just kind of sitting there blankly at you. And you are thinking, "Do you understand what I am saying?" So you just have to stop... There is a lot of times when you just stop and listen to what they have to say. And then based on what they say--then you give them information. *I*t just depends... I go by feel, my intuition. If they look blankly at me like they don't understand what I am talking about then I rephrase it and say it in a simpler way. I tend to talk a lot, obviously and so, by me just keep on talking eventually they get the hang of what I am trying to say. It is like I reword it several different times before I ever get off the subject. (laughs) And, you know, it seems to work. I mean, but I just kind of do it by feel. (SC-O)

SCs encouraged talking to families because some families may not be able to read written information. Also, SCs believed that parents paid attention to conversations as opposed to written information, because some parents are unable to understand the written information. According to one SC, "... people pay more attention... to your voice on

the phone than they do to a letter. And in quite a few cases families don't read very well and don't understand what is written into the letter--that much. So it is better if you can talk on the phone" (L:SC-O).

On the other hand, when some parents have limitations in understanding over the phone as to how TEIS could assist them, SCs recommended that one should approach such families by accompanying the professionals who are already involved with the family during their home visit. According to the SC, approaching families through a known source seemed to help to establish trust. One SC said, "...the parents are low functioning... they don't quite understand,... to go [on a home visit] with the CHAD worker... you find a different route to help them [parents] understand who you are and that you are not there to irritate them or cause them problems" (T:SC-O). Also, giving parents more time to understand what is said is valuable. One SC maintained, "...you have to give them some time to get used to the idea. And to understand that you are not there for any reason other than to help that family" (L:SC-O).

One SC suggested that the present levels of development of the child should be so documented that it reflects what parents understand and express about their child. The following quote describes her efforts in writing the present levels of development:

> J:... if I am writing the plan to report where the child is and get the parent to put their input...

> reflecting exactly what is going on with the child.... you don't want to say, "This is what your child is doing right, okay," sign, instead you say, "This is what I am hearing you say, this is what this report says. Is this accurate?" Then you write down--this is where the child is presently... (SC-O).

SCs stressed the importance of teaching parents to fight for their rights from the beginning by making them understand ways in which they can get the services. They suggested that parents should be made aware of the loopholes in the service system so that it becomes easier for them to take the initiative rather than wait for the system to take care of them. One SC explained the above notion in her statement as,

> J:...try to not to make the family dependent on you,... the critical component is... if you get the child at birth and at that point if you teach them that you are going to do it for them every time they are going to want the system to do all of these things for them--if you teach them--you have to fight for your child--then they will fight for their child and they will be more effective. And you don't want a really unhappy disgruntled family just because you communicated something--like society owes you this. That's a huge disservice to do to families. Instead you can say these are some of the things, yes, there are kinks in the system, but this is probably the best way to go about them. (SC-O)

Further, the SC recommended making families aware of the change in the way services will be offered once the child is three years old. She explained that, "...if we tell families that they deserve the cadillac of services then that is unreasonable--that is not going to happen once they move from early intervention to the school system... So

it is being realistic and creating realistic expectations" (J:SC-O).

Typically, when services in the rural areas are limited, most professionals are aware of all available services. SCs indicated that one should take advantage of the awareness, keeping releases ready for signatures. One SC explained a better way of handling the releases in such situations in the following excerpt:

> C:... once you get into this job and you know what is available in your county in terms of services. You can write the names of those agencies down on releases so that you could possibly make a referral for the family to that agency... I serve County A. I know that Agency T serves children for OT, PT, and speech. If I have got a child who needs all of her therapies--more than likely I am going to recommend Agency T because Agency T is a rural area and there is not a lot available out there... So you try to take as many releases... it is better to have releases for everybody you can think of than to not. Because you never know, you may be calling those people for something.... (C:SC-O)

One SC discussed establishing clear <u>communication with professionals</u> to better serve children/families. She pointed out that there are several sensitive issues that may arise while dealing with foster children. In such situations she recommended that those issues be communicated by professionals directly responsible for the welfare of foster children. She stated,

> J:If the child is in foster care... if it is something touchy like that I would ask the Agency G worker, which I did in that case, to communicate with this foster mother who expressed concerns to me about the child's behavior. That I felt were probably a result of her

no, and until one of those people complains or a bunch of those people complain and say, 'This TennCare is not quite working out like you thought it would.' Then when it gets to legislators and senators and people--that is when things change" (J:SC-O).

One SC suggested an approach that would make services for children/families in rural areas more family centered. According to her, this approach involved having a parent representative contact from TEIS in each community and encourage other parents to communicate with the parent representative rather than to a professional. She explained the positive side of this approach by stating,

> L:Well, I think one of the pluses that we have in this area... are parent contact down in Town G. We have been trying to develop a system of parent... they are parents of children with disabilities and ideally what we would like to have is one parent contact in each of the fourteen counties. Because... people will call her [parent representative] because they get her name from a friend or when Julie first started working for us,... they were people that she knew and so they were comfortable contacting her where they might not be comfortable calling an 800 number.... (SC-O)

This parent to parent contact seemed to personalize the IFSP process. Also, the SC indicated that it was a good way of linking the families with the practicum students and other providers in the area. She said, "Okay. We have five parent contacts... they are a wonderful resource because... Julie down in Town G has started a parent group... we had music therapy students... go down and work with the families as a group. She is there as a resource and also... if one

> exposure to this particular drug... all of those behavioral things--are often closely linked. And I felt that the mother, foster mother, would be more patient with these children... (SC-O)

Another suggestion related to the policy of agencies (already involved in serving families) is to have them obtain consent from parents to release information prior to their referral to TEIS. She suggested that, "Release from the parents [should be obtained] so they should... inform them in signing that. That doesn't always happen and we had a case of a large agency in another county making a bulk of referrals and no releases were obtained and families were getting very upset that their children's names had been released. So we stopped calling and called the referral source...and said, "we need this piece of the puzzle in place before we are involved. So that started happening and now it is protocol with that agency" (SC-O). Further, clarifying with agencies whether or not they have obtained release from parents seemed to be a better approach. One SC stated, "... You don't always check with the referral source but in some instances you do and what I do is eyeball the referral and see and make sure they have actually obtained a release and the family knows about us" (J:SC-O).

The same SC suggested that one of the ways to solve the problem related to TennCare was for parents and service providers to discuss the issue with the concerned policy makers. She said, "as long as parents are happy and service providers are happy then is the system ever going to change,

of the families is having a problem then she can call us and say they need help with this and so where the family might hesitate calling us or it is a long distance phone call, so it is easier for them to call Julie and Julie to call us" (L:SC-O). Also, she thought it was one of the ways to improve the child find system in a community.

> L:Like I said as far as child find it works really nice because, especially in rural communities, there is a lot of distrust of people that are not local and so they are much more willing to approach a person from their county that they know and that is a parent and not "a professional" and say, "I understand you can get me some help for my child." Then like I said trying to call the 800 number and talking with a stranger that you don't know. So that is one of the big pluses as far as child find. (SC-O)

Parents

The way parents expressed their suggestions for improving the IFSP process were different from the way SCs did. The parent suggestions are more implicit than explicit. Therefore, the researcher assumed that parents were expressing their suggestion in the form of their wishes and hopes, as to how they would like or would have liked for their child to receive services. Parent suggestions emerged from their open-ended interview responses. These suggestions are in relation to better services and parent involvement.

Suggestions for Services

All parents had suggestions for improving services for their child/family. These suggestions were related to: a) obtaining early diagnosis of the child's problem; b) awareness of TEIS services for children with special needs at birth; c) increased therapy services; d) professionals keeping their appointments; e) availability of programs in different areas; f) day care for foster children with special needs; and g) more funding for TEIS services.

Three parents indicated the need to obtain early diagnosis of their child's problem, because they could do more to help their child early, which would be "better" for the child. One parent expressed, "...if we could [have] diagnosed him even earlier than what he was when he was nine months--that would probably been better for him, ...That was kind of young to have diagnosed him, but if we had known it from the get-go, we could of done probably a lot more" (N:P-O). Also, parents expressed that it was important to alert people of TEIS services as early as when children are born so that parents/children could "benefit" from it. One parent explained the significance of having an awareness of services,

> R:I wish we had been able to find out about it sooner,... the diagnosis was made late... I think it is a really great program and I am proud they have it. I think folks that would really benefit from it. Any parents,... of children who are right out of the hospital and stuff. That would be a really good resource, immediately... It is a transitional life thing that helps transition on into other areas that

> you can work on like that and helps you go from the feeling like you are just... totally helpless [to] feeling like there is something that you can do, this is where you can go to do. This is what you can get, this is where you can get information. (P-O)

One parent wish was to have facilities to increase therapy sessions for her child. She expressed, "... like I said... I wish it [therapy sessions] is more often... it just seems to me like once a week is not enough. There needs to be more...(R:P-O)." Also, parents said professionals keeping their appointments as they provide services to children/families as something she would prefer. For example: "[All] I could ask them to do, really [is], other than the speech therapist showing up for her appointments" (P:P-O).

According to one parent, she was very pleased with the services she obtained currently for her child. Therefore, she wished that such programs were available in the area where the family had lived previously as it would have benefitted the child more. According to her, "I just wished they had this program up there so he would even be further ahead than he is right now, so... that is the only thing" (N:P-O).

Another foster parent felt that it was better to have day care services available for her foster child. Because, the day care may be the only stable environment for such children when compared to the family environment. She stated, "As far as the Agency U--is wonderful for Victor.

Because that is his one stable thing in his life right now" (B:P-O). One parent viewed the opportunity to have two separate family needs forms to be completed by the parents separately as an "ideal thing." This may be taken as a valid suggestion to maintain such services for families.

> R:the ideal thing--Jenny had given us two separate forms that Sam and I could each fill out our own... because there may of been things that Sam had thought of that I hadn't as far as long-term. And vice versa. You know, so that was very helpful everything. (SC-O)

Suggestions for other Parents

Three parent responses included suggestions for other parents who have children with special needs. They are: a) an opportunity to contact other parents experiencing problems in obtaining services; b) to be more involved, c) to ask questions, and d)to take help from organizations such as TEIS. These suggestions are presented with the accompanying quotes from parent responses.

One parent's suggestion was to have the opportunity to make contact with parents experiencing similar problems. One parent expressed her willingness to work in that capacity. She said, "... like an advocate... if anybody had any problems or whatever, you know, call me and ask me how I got around--like loopholes, I guess. There is always ways to get around things... just like with social security, I heard that takes anywhere from six to nine months to get that... I would let them know there is people you can contact [or] different agencies" (N:P-O). The same parent

recommended that parents should get more involved with their children and to take the initiative. According to her, "... as a parent I think it is everybody's responsibility to be involved in what is going on with their children, because if not, you see what has happened with some of [the children in] society... I just wish that anybody else that has to go through the same thing,... you can't sit back and just wait for things to happen. That is the way I figure it and if you get out there, because I know there is all kinds of help for him" (N:P-O). Another parent indicated that parents need to find out details about available services. Also, parents indicated that they would encourage other parents to take the help of organizations such as TEIS. She declared, "I would definitely recommend to any parent, parents, that has a child that is less than two years of age to take advantage of it" (R:P-O). One parent encouraged other parents to ask questions to receive services.

> N:Don't be afraid to pick up the phone and call somebody or ask questions. I mean, no question is a dumb question. If you don't know--then you don't know, so you ask. If that person doesn't know, somebody has got to know. So you just keep on going on down the line so eventually you will find your answer. (P-O)

Lastly, one parent wished that it would become eventually easy for other parents to know where to get the necessary help that are already there. She stated, "I think that anybody that has to go through the same thing...I just wish and pray that it is just as easy for them to get the help that is needed. I mean, it is out there and people just

have to know that" (N:P-O).

Research Question 6: What are service coordinators' and parents' perceptions regarding their joint participation through out the IFSP process?

Service Coordinator

SCs' responses indicated that they strive toward building a partnership with parents. They emphasized that the very basis for working jointly as partners is to establish a relationship with each family. The responses suggested that the important aspects that need to be considered in their partnership with parents are, positive initial contacts, communication, attitudes, and backing-up and backing-off from parents' decisions and actions. Some of the elements observed in the following paragraphs are comparable to the ones described by Volster-Hunter, (in Dunst, Trivette, & Deal, 1994) about parent-professional partnerships. Therefore, the researcher has discussed SCs responses by using the term partnership as she recognized its manifestation in their responses.

Positive Initial Contacts

The process of SCs forming a partnership with parents seems to begin with the very first contact SCs make with

parents following the referral at TEIS. It is important to note that SCs refer interchangeably to their sending the information packet to the parents and their first telephone contact as their initial/first contact. Typically, SCs send parents information by mail about the organization and themselves before the first phone contact. According to the SCs, sending information avoids catching the parents offguard. Two SCs refer to calling parents without prior notice as the "cold call approach." One SC explained, "the initial contact is the letter... information about TEIS ...If we haven't heard from the family in three or four days of us sending out that parent packet then we contact the family and say, "Did you receive the information, I am Chris from TEIS. This avoids a cold call type approach where somebody might be taken off guard" (C:SC-O). According to them, calling parents for the first time without prior notice may have an effect on their partnership. Further, she described,

> C:Well they have information right in front of them about TEIS--rather than just getting this call from a stranger saying, "Hi, I am Chris from TEIS and I would like to come out to your house." It is kind of threatening because they don't necessarily know what in the world you are talking about. It is like somebody selling something over the phone... Sending out a packet of information to precede the phone call... makes it more legitimate in terms of, "Hey we are an organization that cares about your family and your child and we would like to help. The information that you received is what we are all about. Can I answer any questions at this time? I would like to come out and talk more about the program to you" and it just makes it go smoother, I believe. (SC-O)

Another SC indicated that she reviews the referral sheet to see where the referral came from to verify that the parents know about TEIS. She explained her action as, "What I do is eyeball the referral and see and make sure... the family knows about us. So I won't make a 'cold call' on them and just bombard them with this new agency or something" (J:SC-O). According to SCs the first contact with the parents seems to be a crucial point in the relationship building process with parents. It is an occasion for them to share with parents the purpose of their contact, the organization they represent, and their professional background. One SC brings out the significance of the first contact with parents.

> T:first contact is real important. So that they can realize who we are and what we are there for... I think it either kind of lets you in the door or it does not in many cases. If they have a first bad impression then you have to do a lot of extra work sometimes to get through that barrier. And some of the families who have lots of problems--Agency involvement... are reluctant already--so sometimes we have to work through a lot of barriers that are already put up. (SC-O)

According to one SC, it is important to communicate to some parents that SCs are concerned about education of the child, not other more sensitive and personal family matters. She explained, "Sometimes they need to know that you are concerned with education. And in some cases they need to know that some of the other issues of their lives are not important for our program. That this child is entitled, by law, to whatever it needs" (T:SC-O).

Communication

The way SCs communicated and acquainted themselves with parents influences the formation of a trusting relationship. All SCs indicated that in addition to the way they communicated during meeting, the way they communicated with parents both in the beginning and on an ongoing basis as being important.

SCs encouraged parents from the beginning to stand up for their rights and decisions. One SC explained, "I think we try from the very start to communicate to them that they are the ones that are calling the shots. It is their child and whatever happens should be what they want. And that is always the way we approach it" (L:SC-O). Further, one SC emphasized teaching parents to fight for their child's rights in receiving services and also the best way to access those services as an effective approach in promoting a partnership with parents.

> J:In some cases,... if you teach them--you have to fight for your child--then they will fight for their child and they will be more effective... you can say these are some of the things, yes, there are kinks in the system, but this is probably the best way to go about them--based from my experience and all of that, so, it is kind of a gamble. (SC-O)

At "the front end," SCs keep parents informed of all the options that are available and the steps they needed to obtain the best services. Further, they make parents aware that previously involved professionals should give parents appropriate information related to the reports and parents'

options.

> J:I think from the onset. Telling them everyone that is involved tells them "To make sure that so and so tells you about all of your options. Make sure that Dr. So and So sends you his reports." Asking them, "Do you know everything that they do? Do you know this?..., or let me tell you a little bit about thus and so." Making sure that I represent all options. In my collaborative style that is hopefully something that they observe and... Some times it is easier to use a program that you know is right down the street but you still have to present all of your options and stuff. And the family chooses based on what they want. (SC-O)

According to another SC, presenting options to parents which are available to families without bias seemed to have an influence over their partnership. She stated, "to find out where the best place is for the child to go... we have to explore all the options, because we have to present all the options to the family. It would be very incorrect for us to just suggest one place over and over again. I mean, there are lots of agencies that serve children and we have to be able to present that whole option to them" (C:SC-O). Further, SCs added that the way SCs present themselves and the information to parents have value for building a trusting partnership with parents. According to her, "If you can present yourself as helping and trying to get the answers, and seeking the answers out, and trying to help these families--then you are going to do just fine" (C:SC-O).

SCs suggested that listening to parents, asking appropriate questions and making relevant suggestions were vital for parents to feel comfortable in their partnership.

One SC stated, "Well, basically listening to what they are saying and if you are not sure about what they want--ask them. And if they are not sure, maybe make some suggestions or, you know, say--this is an option why not think about this, or these are all your options think about this and what you are most comfortable with, and it is a process of building their trust with us" (L:SC-O).

According to SCs for collaboration with parents to be effective, the communication has to be ongoing. The ongoing communication with families allowed SCs to have an update of all the services the child/family was obtaining and to keep families informed about their efforts. SCs said that putting the parents in touch with individuals who have needed information and providing appropriate information on an ongoing basis has an impact on their joint participation. Keeping parents informed of all the concerned individuals about new developments and all the activities in a timely manner also seemed to facilitate the process. This involved communication about the status of the child's health, child's evaluation and about the services for the child/family between SCs, parents and professionals. One SC said, "usually the parents know and they will participate actively and... they will follow through on contacting the agencies to get the service and calling me back" (J:SC-O). Another SC described the on going communication between her and the family as, "I think keeping them informed kind of

too of what I am doing, if I am doing something, which I am usually doing something while they are doing something" (K:SC-O).

There are different kinds of records that serve as reference to both parents and SCs. One such record used in the beginning of their collaborative work is the Initial Plan of Action Form. Keeping it as a reference while SCs and families work together seemed to help them to work on those aspects each have agreed upon and put enough information on the form that it helps to refer to it.

> K:This little written list kind of helps and I do know that some of them do keep that and refer to it. And there will be phone numbers on it and that kind of thing. And then if I am making contact that I will try to call them back and let them know what is happening, what I have found out, or if we are trying to pay for transportation, you know, to let them know that has been turned in and it maybe a month before you hear from it, but what is kind of going on in our end. (SC-O)

SCs described their communication with parents during <u>meetings</u>. They communicated with the parents during the meeting in a way that parents were encouraged to take on an active role. One SC said,

> L:When we go into meeting with other professionals we try to encourage the parents to feel that they are the ones that are in control and, I don't want to say sit on, but in some cases, sit on the other professionals so that the parents can control what is going on... We try to do is be on the parents side and so it is the parents telling everybody else--this is what you have to do, and hopefully by the time you get to the IFSP meeting the family... we have helped the family get clear in their minds what they want and what they are entitled to and their comfortable enough with us that they know we are on their side. So that they are

> comfortable enough to say in this meeting--this is what I want or no, I don't like that. (SC-O)

Further, SCs mentioned that at times parents communicated with them during the IFSP meetings through gestures. Typically, parents nodded their heads to indicate agreement or glanced at SCs to show interest. One SC attempted to illustrate her communication with parents during the meeting. She distinguished her communication with families who are more expressive from those who are less expressive during the IFSP meeting. For example:

> C:The IFSP--they will be looking at me while I am talking and they will nod or, [say] "Yes, you are right," or, "No, I think this." It is like we have got our relationship going on and we are showing it to everybody else in terms of what the needs of the child are, so. It just kind of happens naturally for me. You know, I believe...we can always work more at that. The goal is to always make sure that we are really listening to the parents and do what they are wanting. (SC-O)

On the other hand, she described her communication with families who were less expressive as, "there are other families that are just kind of sitting there [looking] blankly at you. And you are thinking, "Do you understand what I am saying?" So you just have to stop... there is a lot of times when you just stop and listen to what they have to say. And then based on what they say--then you give them information. It just depends" (C:SC-O). In another case, the SC described her approach to communicate with families who are less expressive by stating, "if they are a soft spoken individual you can say, "Now, Pat, I think you were

saying a couple of days ago that you were concerned about such and so." It is like you are giving them the words to be able to say, 'Yeah, yeah, that is a concern.' It just depends on the family" (C:SC-O).

One SC said that soliciting parents input during meeting and confirming by restating what the parents say as another way in which she communicated. She said "get the parent to put their input...making sure that I am reflecting exactly what is going on with the child... you don't want to say, "This is what your child is doing right, okay," instead you say, "This is what I am hearing you say,... Is this accurate?" (J:SC-O).

Attitude

All SCs emphasized that developing or having an attitude that promotes their partnership with parents was critical. One SC elaborated about her attitude towards families with children who have special needs and her beliefs about herself in relation to those families. She said, "everybody is a challenge because you are dealing with a different population. And it is a challenge to me, but I am no better than they are and they are no better than I am, we are all, you know, out here to do what is best for these children. So I just kind of have that attitude, so nobody really feels threatened by me or anything like that. It is not like I am checking up on them or anything..." (C:SC-O).

Further, SCs said looking at each child/family issue and addressing it with a proper perspective as necessary during their joint participation. She said, "I put myself in their shoes and I think--what if my little boy or what if my little girl, Golly, I would sure hope somebody would reach out to me and help me, you know, and so, I think just having that perspective of being kind of sensitive" (C:SC-O).

SCs said that developing an understanding in the beginning of their relationship seemed to be important. SCs used words such as "getting a rapport," "being sensitive," "insightful," "intuitive," "giving them time," "including," "allowing them to express themselves," in describing their attitude towards families. One SC explained,

> K:I think that by making sure that you are including them... You have to give them that arena in which to express themselves, but some don't express themselves as openly as others--so you have to be able to be sensitive to that and try to still get that information out--so I just kind of...I tell you, I don't really think about it that much. What I do is I just develop a rapport with the family on the front end and it just kind of happens.... (SC-O)

Another SC said, "having big ears and really trying to get at exactly being insightful and intuitive in terms of what the parents are actually trying to say" (C:SC-O). SCs believed that parents whose earlier experiences in obtaining services for their child/family are unpleasant may be hesitant to get involved with TEIS. Therefore, SCs explained that as they embark upon a family partnership they must deal skillfully with each family by giving them time,

offering to serve the family in different ways.

> T:Most cases this does not happen, but pretty frequently it does. If they have had some bad experiences somewhere they are reluctant to have anyone else messing around in their lives, so ... Usually. They are usually angry and they will tell you. And sometimes they are kind of just withdrawn and really don't want anymore involvement. In those cases you may make an appointment and go out and they won't be there....You keep going back. (Laughs) We don't drop children. We keep on offering our services. Offering to call back in two or three months, or whatever. I am working with one such case now. Where the family they just feel really bogged down and they are not ready to do an intake. And we have had a few phone contacts. And so I have told this mother--we can help you without coming to your home. If you would like our services and so we have put that one on hold until the baby goes back for further evaluation. Then we will follow it up after that. So you have to give them some time to get use to the idea. And to understand that you are not there for any reason other than to help that family. (SC-O)

SCs making sure that the parents understand that delays in obtaining services are due to the formalities in the system helps.

> C:these families have an understanding...most of them have an understanding that everything takes a process, especially if their children are trying to apply for SSI, Social Security, or disability, or Children's Special Services, or whatever. Everything takes a long time. And, so, they are not... I think we are more nervous about doing it fast. They are more understanding and don't...and are not saying to us don't worry about it--we understand, you know. And we are the ones that are nervous about it. It is because of this time limit we got. (SC-O)

SCs reported their impressions, particularly with the families who participated in the study. The SCs' impressions about their interaction with the families in general during their initial intake meeting were receptive,

supportive, and friendly. Their impressions about the mothers were good, intelligent, receptive, enthusiastic, knowledgeable, and articulate. Only one commented about a mother as being overwhelmed.

One SC maintained her impressions about the mother and her extended family as, "the family was very friendly and appeared to be very supportive of Sara and David... It was a very nice visit. A nice home... Sara will be a good mother... a good social worker... Sara seemed to be quite intelligent and rather articulate. She seems to understand her son's needs" (SC-S).

Another SC reported her attitude towards the foster mother by stating, "she has been appointed the surrogate parent and she is a very enthusiastic, a women who wants only what is best for Victor so I am already looking forward to working more closely with her and trying to do what is best for him" (SC-S). The following is an excerpt from one of the SCs indicating her opinion about the mother she was working with.

> L:a very concerned and capable mother who was very appropriately lining up services for her son. In the way of getting things in line so that he could get certain services as soon as possible when they resettled here... She brought Arnold to Agency G... Arrangements were made for Arnold to start at Agency G on July 5th. The mom seemed very pleased that services could be arranged so quickly and that Arnold would be able to attend a center-based school day program... so she was very pleased at the opportunity for him to receive services all day--five days a week... at this point Arnold is beginning to receive services and his mother seems to be following through and making arrangements for other services he needs and I am

pleased that some services seem to be falling into place for him. (SC-S)

Another expressed her feelings about the case as a whole after contacting the family, "... the contact was very effective and that I got a real feel for the family, the family's needs and kind of what my role was going to be and figured that it would be a successful case" (J:SC-S).

Lastly, one SC reported that the "mother was receptive to TEIS referral services and she seemed aware and knowledgeable of Peter's evaluations and needs at this point... Pat had forgotten that we were coming today so she was a little unprepared for the visit and embarrassed because the house was messy... She is a bit overwhelmed by the volume of appointments she has to keep for Peter as well as other demands in her life" (K:SC-S).

Backing-up and backing-off

SCs acknowledged that it is critical for them to find a balance between backing-up and backing-off from families in their decisions and actions. Because each family's resources, priorities, and concerns differ and change over time, the SCs have to be sensitive as to how much they have to back-up and/or back-off from family's decisions and actions. One SC explained, "Now there are some other things like OT evaluation that mom never, or dad, parents never followed through on and finally were able to say, "Well, we

just want to wait until she is 3 and the school can do it," which is just going to be a matter of just a few months. And so I had to back-off on that even though the physical therapist is over here saying, "If it was my child I would get them anywhere they had to go. I would take them" (K:SC-O).

The activities in which the SCs need to find a balance occur while they are locating appropriate services in the beginning of the process or while they are following up with services. They offer to carry out certain activities entirely or partially depending on what the parents prefer.

> J:Really I give it to them on the front end. I ask them what they would rather me do. And some will say, "I would much rather you do it than me." And some will say, "Oh, let me do it. I want to do it." So I give every family the option. I guess just by talking about that and you know, "I am here for a resource for you if you need help, but you can call and arrange this yourself and then you know your schedule and but if you need help with it you can call me and that kind of thing... leaving too not just trying to take everything and say, "Well, I am going to refer your child to Agency D, but, you know, is this the program that you are interested in, or you can call Greta at this number and talk to her about it and see if it is something that you are interested in." I don't know that is kind of the whole process... I think, and most parents want to be very active in that role anyway. (SC-O)

Further, the SC explained that they needed to balance their actions in a way that they would not make the family dependent.

> J:In some cases, but the main thing is to try to not to make the family dependent on you,... but the critical component is--this is only three years of their child's life--Birth to Three--if you get the child at birth and at that point if you teach them that you are going to

> do it for them every time they are going to want the system to do all of these things for them--if you teach them--you have to fight for your child--then they will fight for their child and they will be more effective. (SC-O)

Another SC referred to her finding a balance in her actions while dealing with families by stating, "we don't want to hold their hands too much," because that would not prepare parents to deal effectively in future.

> C:... we don't want to hold their hands too much as to where--once the child is three they are thrown to a pack of wolves, so to speak, but we want to help them along because we realize that this is a very stressful time in their lives and they are having to deal with a lot of issues. And so, we are there to help them. And there are some families that I feel more comfortable calling and making the referral to the doctor or making the referral to the therapist. And then there are other families that I say, "Why don't you call this number right here and ask information and if that suits you--then you go for it." And I let them alone. I let them do it. (SC-O)

The same SC seemed to prefer to take up the responsibility to do the follow up work for some families. She stated,

> C:For the most part, I offer whether or not to follow through with the stuff of let them follow through. And usually I follow through. It is just my style to do it, because I feel better. I feel better if I make the phone call--then I write it in my notes and I know I have talked to them--rather than having to call them back and having to say, and almost bug them like a mother, "Did you do that? Did you call the doctor?" I don't ever want to seem patronizing to the family and so if I take the responsibility--then it is my responsibility and I have relieved them of one less thing to do. It is my job and they don't have...I mean, you know, it is my job to do this. So it does not bother me doing it. (SC-O)

SCs mentioned that there are situations where they have to reserve their views about the parent's decision. The

practice of holding their views back is believed to be an effective approach that promotes collaboration.

> K:In my mind it is still not enough, you know, I mean, but it's moved the family along a little bit. It is what they could accept at the time. Maybe they can accept a little more the next time... I feel like we made some progress, it did not go as far as I would like it to go, or as far as other people would like to see them go. We have moved along that way so that mom is working with the physical therapist and she is doing these activities... they are very receptive to the school working with this child when she turns three so that, you know, just feel like they moved forward anyway, you know, and that the child is not getting as much as I would like to see her get but she is certainly better than getting nothing. (SC-O)

SCs indicated backing-up families by way of assuring parents of their support. For example: "total communication using sign language or oral-habilitation... those two schools are real philosophically driven and... family wants total communication I am not going to refer them to Agency J because they are going to be told "Don't do this." And it is the family's choice. I can tell them "These are the places you can go that will help you work with sign language and some things like this for your child. This is what you have identified to me" (J:SC-O). In another case, the SC described her efforts in backing-up the family by assuring parents of their support as they move into a different town.

> J:the family has moved into this district. But I am doing a lot of work on this case already, prior to their moving to the Town B... So with that one I got a call from someone saying--call family immediately their freaking out, called them--they were. And just more than anything just talked to them and spent... in some cases you spend a lot of time on the phone assuring

them that you are there--that you will do your part in enabling them to move forward with their child. (SC-O)

Parents

Parents' perceptions about their joint participation with professionals correspond with the views expressed by the SCs. For the most part, parents discussed their participation in relation to professionals in general, and on occasions specified their participation with SCs. Parent responses indicated their attitude towards SCs/professionals and the nature of their partnership with SC/professionals as being discussive, extraordinary, instantive, and informative.

Attitude

The parents' attitudes towards professionals seemed to be influenced by the way professionals interacted with them as joint participants. They used phrases such as "professionals being there," "getting answers," "willing to help," "supportive," and "intuitive." Three parents viewed professionals as being responsive as they participated in the IFSP process. Parents valued professionals who were responsive to the needs of their child/family. One parent said, "But... I don't know--they have been real responsive and everything. So it has been... probably the most supportive of any one we have worked with so far, you know,

being real responsive and kind of just being there when we need them... And that has been really good..." (R:P-O).

Parents respected professionals for being available and willing to be contacted any time of the day. According to one parent, "N:...if I call them they are there. If not, they return my phone call, so...I mean they are willing to help. It does not matter if I call them at twelve at night and they would be concerned, but, yeah, they are always there"(P-O). Another parent was pleased when it was easy to access professionals. "Jenny has been very resourceful and available, I mean, she has called. She called me yesterday,..." (R:P-O). Parents appreciated professionals providing them with different service options and seemed to be satisfied when professionals were able to answer some of their questions. One parent expressed her appreciation by stating, "I think that having those resources has been invaluable to us. Because we have been able to get a lot of answers that we did not know where to go with those, and so it has been like a light,..." (R:P-O).

Thus, parents appreciated the supportive character of the professionals. Also, professionals following up with the necessary services for the family in a consistent manner was of great significance to parents. Further, professionals showing interest in their children's welfare, their willingness to help and responding in an appropriate manner to the questions posed by the parents had an impact

on their partnership. One parent stated,

> S:I mean I could tell from the very beginning that, you know, if he had had any trouble, any problems that they would of helped me no matter what. You know, I mean, money wise, emotionally wise, or physically wise--that they would of really worked with him. And I could just tell that. (P-O)

One parent's attitude towards her interactions with professionals was that it was unproductive. She said, "everything they sat and went over the reports that were already written up and rewrote him... plans for the future which I had already heard you know they have told me a thousand times it was nothing different just the same thing there was no point in it... they could have sat and done it themselves I know it is terrible to say but that is the truth..." (P:P-O).

Discussive

Parents' responses indicated that they were establishing a partnership with professionals during the initial IFSP process. One of the indicators was that parents incorporated the word "we" in their statements while describing their interactions with the professionals and SCs. Four parents used the word "discussion" along with the word "we" in describing their interaction with professionals during the meetings. Four parents indicated discussing with professionals regarding the child's health concerns, child's development, evaluations, therapy, the goals set for the

child, the steps taken to achieve those goals, their roles, transitioning, financial resources, child care, the family's insurance plan honored by the specialists in the community, adaptive equipment, and future needs of the child. One parent explicitly stated, "We were all discussing things during the meeting because before when Jenny would tell us what she was going to be working on, you know, would ask for our input and everything. You know, she just asked us about our concerns and our priorities and things. I mean a lot of it we weren't just discussing the whole time, we were talking" (R:P-O). Another parent's response indicated that she was discussing the future needs, equipment, insurance coverage for the child, and child's behavior. She said,

> B:We were discussing what would be his future needs as far as his having the Cerebral Palsy--what kind of equipment he would need... he would need a side layer--which would make him lie on his side and use the arm that was not dominate. The Access Med Plus agreed to pay for that... We discussed also about trying to find a eye doctor appointment--which was giving us a little trouble at that point. Finding someone that would take his insurance and take a child that young to see--to refer him to Dr. Ford. We discussed him seeing Dr. Oliver for the bronchial dilation... We were discussing the fact that he did not cry in the car as much now. Where he use to just scream continuously in the car. (P-O)

One parent mentioned discussing the role of all the members of the team. She described, "In the IFSP meeting these were things that we discussed... You know, then we discussed about what role we would all play in getting all those met... family and TEIS will insure that insurance

covers therapies..., family will follow through with Knox area child care information and referral. And TEIS will check to insure progress. That is something we ourselves are doing to evaluate" (R:P-O). The following is an excerpt from the parent's open-ended interview which indicated that she was engaged in discussing with professionals the goals for the child, and concerns related to the child's health.

> N:We discussed all his goals... for the next six months, and what things that we needed to accomplish or get done before then,.... We also discussed his weight, we are getting concerned with that because he is not two years old yet and he weighs 43 pounds. We are discussing having a nutritionist come over there and see his daily diet. See if there is any thing that could be changed or that might be affecting him, because he is real active and he sweats all the time,... They said something about having a genetics counseling done with him because thyroid problems run in my mom's side of the family. So we don't know if that is affecting him or not, so that was another thing that we questioned. Just to check about getting done... The other one was just to get him to wear his hearing aids a lot longer and getting the hearing evaluation and speech therapy. Those were all kind of different kinds of goals... (P-O)

Another parent indicated that she had the opportunity to prioritize her needs as they discussed her child's overall development, child care, therapy, transitioning, and financial resources.

> R:when we had our meeting--we all discussed different...the assessment of what we wanted and I think we pretty much narrowed it down to 3 or 4 items. And basically probably our number one priority was Sophie's overall development. And one of the others was transitioning. And what resources were available after she got older. And of course the financial resource. And of course the child care availability--being closer to our jobs and stuff. And, so those were things that we pretty much covered there. Discussed

about what the therapist's recommendations were as far as Sophie's treatment. (P-O)

Extraordinary

Three parents often expressed that their interaction with professionals as being extraordinary. One parent regarded finding out the requested information as exclusive. She said, "if we had questions--Jenny has been extra great about doing that, I feel like, making that extra effort to find those answers for us... And I really appreciate that. That really means a lot. But, like I said, probably the most supportive part"(R:P-O). Another parent valued a professional coming from a distant county just for her child. Her response was, "Diane she has went out of her... everybody has went out of their way, you know. She came out here from Town B for a two hour visit and we both sit down and filled out all the paperwork and she played with Arnold"(N:SC-O). She added that professionals were taking extra interest in learning sign language for her child. She said, "They are all learning their sign language at home. They are studying up on it... so they are all going out of their way to learn faster than he is learning so they can keep up with him" (N:P-O). Further the parent appreciated the SC making a program transition smooth for the child/family from one program to the other, especially while they were moving from one state to the other. She said, "The SC that's... She has went out of her way, you know, to

find out things for me, first when I got here that I thought was the main priority... She went out of her way to find out a lot of information for me that I asked about... and setting up a time to get his hearing checked out or whatever. She has went out of her way to check and make sure that that can be done" (N:P-O). One parent expressed her confidence in obtaining support from professionals from the beginning by stating,

> S:I had any problems they would of been right there on them.... They were great and supportive... So I have had no negative things with them. Everything has been positive. (P-O)

Instantive

Four parents seemed to value the pace that services were provided. Parents acknowledged professionals offered information in a timely manner. One parent expressed, "One of the things that we were interested in of course was learning to find child care closer to our jobs. And so she provided us with information on that, pretty much immediately... so we got that probably about a few day right afterwards" (R:P-O). Also, parents noted that their association with the SCs helped them to navigate the bureaucratic system with less time, which typically gets prolonged. One SC compared her previous experience with dealing with agencies and her current experience in relation to the amount time invested in obtaining services. She said, "Services have come pretty easy. It hasn't been

difficult to get services. That's been nice, instead of a lot of red tape you know lot of times it takes a long time you have to go through a bunch of stuff before you finally get there" (P:P-O). Parents maintained that professionals taking immediate action on their decisions seemed to facilitate their activities. According to one parent, "From the evening... [SC] came by... Jenny had called and followed up the following day and we were able to set up a TEIS meeting for the family with a counselor at the Agency C and with Jenny. I think it was less than two weeks. Which I was surprised. I think we were all surprised at how quick, and several other things that we discussed... How soon it was set up. How soon things were going, you know, going along and stuff" (R:P-O).

However, one parent was displeased with the bureaucratic practices that were hindering her child from obtaining services in a timely manner. She reported,

> F:It has been a slow thing with getting Victor the necessary physical therapy that he needs. But it looks like we are finally going to be able to do that. Victor will be receiving his physical therapy evaluation in a week--and after that information has been compiled to setup the necessary times for me to bring him on a regular basis... I was under the assumption that Victor would receive his physical therapy after I received my surrogate training and was able to sign off on the papers. With all this new Tenn Source crap it makes it kind of hard now for people to obtain services easy for their children who are in need. Hopefully this will be the last stumbling block and Victor can start receiving the much needed physical therapy that he needs for his CP. There seem to be a problem. Victor's medical insurance has expired so now we have to go through the process of getting him some more medical insurance, and that means more frustration

> because we thought this problem was going to be taken care of in a few weeks--now it looks like it is going to go on longer. Hopefully we can get this solved because this little boy really needs the help.(P-S)

Informative

Parents acknowledged professionals provided helpful information on certain topics, such as child development, therapy, evaluation, housing, child care, service organizations and financial support. Parents expressed satisfaction with the choices that were offered for their children in relation to programs and were gratified with all the available resources and information. The following is a response from one parent who indicated that the SCs furnished them with requested information.

> R:we had talked about in our meeting last week...I was teasing Sam about having some more development, knowing some more things about fathering and that type of thing and so she sent us some things--that came in the mail today--things about child development and that type of thing. (P-O)

Another parent reported that the SC provided her information about organization that were of interest to the parent. She said, "She named some organizations that we could go to in the future if we needed them" (B:P-O). One parent stated that she received information from the SC in relation to both the needs of the child and family. She said, "The service coordinator that's... She went out of her way to find out a lot of information for me that I asked about. One was the child care and the other was housing, and

getting him speech therapy" (N:P-O). According to another parent, obtaining information from the SC made her feel positive and relieved her of some of the stress.

> R:And one of the things that we were interested in of course was learning to find child care closer to our jobs. And so she provided us with information on that, Jenny... gave a lot of information about those things and I would be very interested in having a day care... it has been like a light, ...as far as being able to get information that we needed and check on resources and stuff to see what was available to us... probably the greatest positive point... it is positive that there is some help that you can get there without worry how you are going to pay for it... it is less stressful about what it is going to cost. And so that is refreshing. (P-O)

Research Question 7: How do service coordinators and parents exchange information during the process?

Service Coordinators

SCs exchanged information through three different modes with parents: mail, telephone, and face to face encounters, using written materials and verbal exchanges.

Written Materials

All SCs shared several types of written information with the parents. SCs said that they gave as well as received written information to/from parents. The first and foremost information that SCs give parents is background information about their role and the organization they

represent. Also, they informed parents about the agency or individual who made the referral. One SC statement illustrated the points made above, "we send our introductory letter which just introduces ourself and tells what program we are from. Who referred the family to us"(C:SC-O). Typically, SCs send this written information by mail soon after the referral.

SCs exchanged information about TEIS with parents by sharing a "booklet" or "brochure." The booklet included details about how TEIS as an organization works and about the IFSP process. SCs indicated that they provided this booklet to parents either before or during the intake meeting. One SC described the use of the booklet in sharing information with parents, "We also give some information about TEIS, general information. One little booklet that we always give is a booklet written to the parents that goes through the whole TEIS process. It talks about first step is the initial meeting, the intake and your child might be evaluated, and so on. And it is included in there the IFSP and what that is, and that is part of the process" (K:SC-O). Typically, the SCs mail the "booklet" to parents soon after they received the referral at TEIS. However, one SC indicated that they have to be able to judge in some cases whether or not families will benefit from the written information prior to the intake meeting. She explained, "Sometimes we will mail the brochures ahead so they can be

looking at them. I just sent one out this morning to a family. We have already made an appointment for the intake but I want them to have this information so they can sit down and look at it and know a little bit more about us before we get there. This is often very helpful, on the other hand to families who don't read very much and understand what they read it can be very confusing. So you have to be a little bit selective sometimes" (T:SC-O).

SCs furnished the parents with the details of the parental rights. Typically, brochures about parental rights were mailed along with the introductory letter and TEIS information. One SC mentioned providing another copy of the parental rights at the time of the meeting, if the parents needed one.

> K:[I] give the parents a brochure about [their] rights... at that point, after the IFSP meeting. But let me put it this way--I give them one [brochure] on my very first visit [to] the family, but at this time we have talked [about it]... Sometimes at the beginning, sometimes at the end of the [IFSP] meeting I will give them another one if they have lost that unless they are sure they have it. Just kind of talk about the different kinds of rights. (SC-O)

SCs stated that they gave parents additional information about the IFSP process apart from the information included in the TEIS booklet. They referred to this written information as the "IFSP Sheet." One SC mentioned, "there [is] also a sheet on what is the IFSP that is for the parents that we kind of... we were putting that in the initial packet... it just explains what the IFSP is" (K:SC-

O).

Finally, the SCs maintained that they gave parents information about the different services that are available by referring to the "directory of services." They indicated that the directory included information about various services available in the different counties of a particular district. One SC recounted, "We give the directory of services... It has all of the services in the 16 counties that we serve--What is available out there" (SC-O).

SC's talked about giving families written information when families solicited more information on specific topics. Two SCs gave parents information about the developmental stages of children and one SC discussed about offering more information to help grandparents to be more accepting of the child's problems. Typically, these exchanges were after the intake meeting. One SC mentioned that, "... grandparents or extended family will have difficulty accepting the child's disability or accepting the child having a disability--so... we give them information about how to deal with" (T:SC-O).

SCs not only give written information to parents, but also receive written information from them. Typically, this involves medical reports of the child that SCs collect from the concerned professional by obtaining a written consent from parents for releases. One SC stated, "We get... if we feel that medical records would be important to have for our information then we get them [parents] to sign releases so

that we can send out for the medical records" (L:SC-O). SCs also get the completed family needs questionnaire from those parents who choose to complete it. Typically, they requested parents give this information at the intake or following the intake meeting.

Verbal exchanges

Verbal exchanges refer to SCs' conversations with the parents during their telephone contacts and meetings. SCs' responses indicated that during their telephone contacts and meetings they shared information in several ways such as explaining, talking, suggesting, asking, answering, discussing, and reading.

The telephone contacts with parents are typically after SCs receive the referral and after their home visit/intake meeting. SCs said in the beginning it is important to find out if the parents are aware of TEIS. One SC stressed the importance of the telephone contact in exchanging information, "That few minutes on the telephone gives me a lot of information and lets them know something about me before we go out. I think that is very important. I like that better than the letters. Because it is a personal contact... a lot of times we get things in the mail and we may or may not look at it and we toss it. And it is hard to toss somebody on a telephone... but that way they get more information through the phone I think" (T:SC-O).

SCs ask parents about the needs of the child/family, and kinds of services the child is already receiving. Based on this information, they ascertain the details they need from the parents. One SC said, "I discussed with the mother the referral and what TEIS is. She told me that Peter has begun speech therapy through Agency E. This is through the home-based program with Becky as therapist...full evaluation. Agency E is providing hearing aid. Peter also needs PT and OT. We discussed how TEIS might be of benefit to them and arranged a home visit" (K:SC-S).

In one particular case, the SC mentioned that while calling the parents she obtained information on the Minimal Data Form (Refer to Appendix K for a sample copy), and obtained permission from parents to refer children to other services which the parent had requested over the phone. She reported,

> L:The mother had called from Town A... She was planning to move to Town H the end of June. I called her back at home in Town A and spoke with her there, and filled out the Minimal Data Form at that time. Arnold is profoundly deaf. Hearing aides in both ears. And he was learning sign language and attending Toddler Center at the University of Town A. I got the address in Town H to send TEIS materials to where Nancy would be moving... I said there was a program in Town H that is five days a week that--would you be interested in a center-based, and she said, "Oh, yeah that is what she would really like. (SC-O)

SCs said that during telephone conversations, parents request different kinds of information from them: 1) other parents who have children with similar disabilities; 2) the school system; and 3) TEIS services. One SC described,

> J:The first contact was by telephone... Some of the things that we talked about were her needs in terms of interest in making contact with another parents needs on her child's condition--specific to her diagnosis. More information on the school system. She explained evaluations that had already happened at Agency C and we just discussed what TEIS does and things that we could help with. I explained to her the process from referral to transition including the IFSP... (SC-S)

Another opportunity to have a verbal exchange with parents is during the intake meeting. During this time, the SCs learn what the parents know about TEIS, go over the written information such as the TEIS booklet, IFSP sheet, parents rights, and directory of services. The following examples show the way SCs shared information during the meeting.

One SC indicated the way she shared written information with some parents who had difficulty understanding. She referred to the way she shared information as "talking it out."

> T:Sometimes the information is over their heads and they need that to be broken down into words that they can understand. And sometimes they just need to go over it. Talking it out helps them to understand and they can accept better, so these are some of the things that we can do to pull together some of the information that is family oriented, friendly type of information and give that to the parent or discuss it with them. (SC-O)

One SC said that she explained to parents information about the services offered by different agencies. "I also explained to her about Agency H which is the home-based services for Hearing Impaired children and their families" (L:SC-O). One said that she was answering parents'

questions as she was exchanging information with them. "Then try to answer their questions about TEIS" (C:SC-O). It was observed in their responses that they read out information to parents to assure that they were aware of their rights. "... it is a little pamphlet that we read out to them and make sure they understand what their rights are as parents" (C:SC-O).

SCs get parents to talk about the information in relation to the Central Intake Form, which is completed as parents tell the SCs. The following quote from one SC supports this notion. She said, "You just ask the parents the questions that would yield you the answers to the form" (C:SC-O). One SC described the way she asked questions to get information concerning the different professionals from whom the child has received/receiving services.

> C:Say you are talking to the mom and you say, "Has anybody seen Johnny? Has any doctor seen Johnny besides his pediatrician?" "Oh, yes, he saw a neurosurgeon and he saw an ophthalmologist and an orthopedic surgeon. Then what you do is you start writing those names down and you start trying to get-- you get their names on a form so that you can get as much information from those doctors as possible. (SC-O)

Further, SCs acquired medical information related to the child/family at large. This information is sometimes used to establish the child's eligibility for TEIS services. One SC described the kinds of details they obtain related to this area. She said, "we also get medical information. I will start with the pregnancy and birth histories, and then

any medical conditions that the child has had and what medical treatment is the child getting now. We also get the names of the doctors the child sees. What kind of specialists he has seen... We have to get the information that we need for eligibility. Which may mean get some medical reports..." (K:SC-O).

Also, the Central Intake Form allowed SCs to obtain information from parents about other agencies/professionals from whom the family is already receiving services. One SC stated, "Is the child receiving any kind of special services or in any kind of program" (K:SC-O). SCs obtained information related to financial status. This information is needed to assess the eligibility of the child/family for certain programs. According to one SC, "we get information about insurance and other funding sources that might help find services for the child like--Children Special Services, and we look into that, SSI, WIC" (K:SC-O).

Parents

Parents' descriptions of exchanging information with professionals closely corresponded with those of the SCs. Parents mentioned exchanging information through the three different modes, mail, telephone, and meetings with written materials and through verbal exchanges. One parent described videos as another form of information which she preferred over books particularly while referring to

specific information.

Written materials

Parents indicated exchanging different types of written information with professionals. These different types of written materials included books, lists, directories, brochures, pamphlets, letters, questionnaires and medical reports. Parents discussed receiving written information not only from SCs, but also from other professionals. Some of the written information parents received from SCs and professionals were ones they specifically solicited and others were offered to them.

The information parents solicited were related to child's diagnosis, child development, child care, and housing. In the beginning, one parent requested information from professionals to learn more about the child's diagnosis. She said, "...they loaned us a book about cerebral palsy and everything. It was real informative... the book covered all areas, ...mildest to the extreme. And so, of course, they were telling us to read it in context as we knew applied to Sophie, instead of being concerned about... I did read in the book that they loaned us from the Agency C about cerebral palsy was the development of the muscle structure in children isn't usually stable till they are about three. So that helped me understand a little bit more of why they wanted to delay" (R:P-O). Another parent

requested more information on housing during her telephone conversation as she was moving from another state. She reported, "She sent something about housing--like low income housing and things like that" (N:P-O).

Two parents requested more information on child care from the SC during the first home visit. As a result of this request, the SCs followed up with the concerned professional who forwarded to them information about child care. She stated, "... [we needed] child care closer to our jobs. And so she provided us with information on that, pretty much immediately. She referred, or talked to someone else, and they [child care agency] sent us information about that..." (R:P-O). The parent was very pleased to receive that information as it cleared some of the concerns she had about child care. She expressed, "... but the information we have is great, I mean it is real informative. We have got a lot of answers. Matter of fact, it answered one of the concerns that I always have with any child care is the adult--child ratio. Jenny had followed up... gave a lot of information about... day care" (R:P-O). Another parent reported receiving information about child care by mail after a telephone request. She said "My main concern at first when I got here was finding a day care for him... she just sent a list of all kinds of things that were available, programs that were available to him..." (N:P-O).

Two parents requested information on child development.

One mother requested it at the time her child was evaluated by a nurse, that is after the intake meeting. She said, "I received a whole big pamphlet on child development and what they should be doing at what age. And I mean she sent me that through the mail... it is up to about three years old--from birth on up. [For] ...any information I needed I could just call her and she would answer my questions for me, you know, she was always there. What really helped was the developmental--the pamphlets on the developmental--because that showed me more what to work with him on" (S:P-O). In the case of another child, the father requested information during the IFSP meeting to learn more about two-year-old children. The parent recalled receiving information on that from the SC soon after the IFSP meeting. She said "TEIS will send information on children's developmental stages, and we received those today" (R:P-O).

One parent mentioned receiving information about TEIS from one of the coordinator at the school the child was attending. "Okay, the first thing was I was in Town A... they gave me... It was one of the coordinators for that little school up there... Yes. It was just a little book that had all fifty states and it showed that this was who to call and they set you up with whoever else. And I called them [TEIS]..." (N:P-O). In another case, the parent mentioned receiving TEIS information from a professional at the agency the child was receiving therapy. She recalled,

"Florence had give us a list of resources that we could use to contact if we chose... and TEIS was one of those.. so I went ahead and called [TEIS]..." (R:P-O).

All parents acknowledged receiving written information from TEIS. Two parents acknowledged that they had not been able to look through the information. One parent recalled receiving a information packet from TEIS. She said, "We had received some books and frankly I hadn't gotten around to reading them. They looked like they would be very interesting. She provided us a packet with like different little books and stuff in it. One of the things--it was real neat--Sophie and I were looking at it, there were a couple of brochures in there about selecting day care" (R:P-O).

Four parents mentioned being aware of the information on parental rights. One parent stated, "I have been given rights but I have not read them all yet" (N:P-O). In the case of the foster child, the second foster mother mentioned receiving the rights at the IFSP meeting, "She gave me his rights, gave me information on what rights he had" (B:P-O).

One parent discussed her actions after receiving information from one of the professionals involved in providing home based services. The types of information she mentioned receiving were, "... I got a book full of like--videos, books, and magazines that I could check out if I wanted to [from Diane]. I have already sent off for I think

25 tapes we are going to watch..." (N:P-O).

Parents discussed giving SCs mainly two types of written information. One was medical information which parents gave SCs. Either, they gave copies of medical records or they provided their consent for them to receive records. One parent said, "I give them copies of his medical records" (N:P-O). In another case parent said, "We signed release forms from other organizations that have been involved. Like the doctor's office, the pediatrician's office, the Agency C, I think that is all. In order for Jenny, or TEIS to get the records they need to do their assessments and evaluations... Appropriate release forms for her to get the information she needs" (R:P-O). Two parents had completed the family needs questionnaire. One parent expressed, "I think it is great. I think it is... number one it gives you some things that you can look at that you may not of thought of" (R:P-O). In examining the questionnaires parents had completed, it was observed that families indicated their interest in becoming more informed about the different programs from which their child/family could receive services. These services included child care, therapy, housing, utilities, and job training.

Verbal exchanges

Verbal exchanges occurred either during meetings or in telephone conversations with professionals and SCs. All

parents reported having verbal exchanges with professionals other than the SCs. The professionals they referred to were the therapists, a nurse, a home-based service provider, and a librarian.

Four parents reported that they provided information about the background of the child/family to the SC to determine eligibility for various services, including TEIS services during the initial meeting. In the case of David (child determined as ineligible for TEIS), the parent referred to the details she provided to the professionals (SC and nurse) during the intake and evaluation meeting,

> S:I just gave when he was born and how much he weighed. They just wanted to know his developmental--what he could do, what he couldn't do. And they wanted to know if I needed help with anything with him. They asked all kinds of questions. It was all about you and what you might need and what the baby might need. So they asked some pretty good questions. When they called back and asked me how we were doing and how he was doing on developing and all that. I have to say they have been right on it. (P-O)

Another parent indicated giving the SCs information about family. She stated, "Verbally we have given her information concerning ourselves and background information about ourselves" (R:P-O). Another parent recalled professionals asking her during the meeting about parent trainers. She mentioned, "...I think that when I was at the school they had mentioned something about, you know, parent trainers and asked if I had had one of those before. I said, "Up in Town A I had a parent trainer" (N:P-O).

Also, parents mentioned the information SCs and other professionals discussed with them during the meetings. One parent reported that the professionals directed her to read specific information in a book related to the child's medical condition and how it would affect the child in the future. According to her, "...they were telling us to read it in context as we knew applied to Sophie... the therapist reassured us that the damage that was done was not progressive--it was an initial thing and it wouldn't get worse" (R:P-O). Another parent noted that she got information regarding the payment for transportation during a meeting. She said, "TEIS brings up that they can provide me--is paying for mileage for me to take him to physical therapy...they told me [they will] pay me back the mileage for taking him to his physical therapy at Agency B" (P:P-O).

Parent responses suggested that SCs discussed the IFSP process within TEIS with parents on two occasions, during the initial telephone contact and the intake meeting. One parent mentioned the way one SC described it, "Jenny had talked to us about it when she came out to visit. And told us this [IFSP] is something that was a process that they did... in order to assess the family's needs and the child's needs. Concerning TEIS and how they could help and stuff... I think it is great. I think it is... number one it gives you some things that you can look at that you may not of thought of" (R:P-O).

The discussion with the therapist the parent referred to was a telephone conversation. According to her, "... from the Agency B, he [therapist] called me to discuss Peter getting physical therapy there at Agency B..." (P:P-S). Another parent brought attention to the discussion she had with the home based service provider. She stated that, "she [service provider] explained several different things that they do through the program. She let me know that there was like a library of things that I could check out. Like video tapes or sign language books, magazines or finding any other kind of information that she could provide..." (N:P-O). In her self interview response, the parent reflected on her conversations with the professionals. She expressed,

> N:...this meeting--I just was really impressed with the types of programs that Tennessee has to offer. There is an abundance of information and types of literature, video tapes, and all kinds of people willing to help, or different kinds of people that can do evaluations, speech therapist, just lots and lots of things. Basically just the resources in Tennessee are far more superior than what was available to us in Town A. I found out that Tennessee has a library in Town C where I am able to check out video tapes on sign language and teach them to my son as well as other family members that are wanting to learn to communicate with Arnold and as I was told...there is only two places like that in the United States and that is Tennessee and New Jersey, so, just, I mean, the resources and schooling and everything they have in Tennessee is just far more superior than I could ever imagine. (P-S)

Further, the parent reported acting on the information she got from the service provider. She said that she contacted the librarian by phone. During the telephone conversation with a librarian the parent indicated asking

for more information that would benefit her child, "I said, 'Well, my son is only 20 months old and if there is anything that you could recommend that would be beneficial for him, you know, feel free to say something.' She said, 'If I see anything like that I will just go ahead and send it to you.' So, I mean, everybody is kind of looking out for me, I guess" (N:P-O).

Three parents mentioned about providing information about the child's behavior. According to one parent, "... I told her as far as his playing more at home--he was trying to vocalize and making different sounds. He was getting more interactive with people. His sleeping habits--he was starting to sleep a little better" (N:P-O). Another parent recalled, "She [SC] named some organizations [at the IFSP meeting] that we could go to in the future if we needed them" (B:P-O).

Videos

Only one parent mentioned receiving information on video. The information was pertaining to sign language. According to the parent the information on video was more helpful than having the same information in a book form, particularly to share with the extended family.

> N:... what I like--is the video tapes, because you can learn. You see it being done instead of looking at it in a book, because in a book it doesn't have any motion so you don't know if you are doing it right or not, so...that is what I like... (P-S)

CHAPTER V

DISCUSSION, IMPLICATIONS, AND REFLECTIONS

This research was designed to foster understanding of the perceptions of SCs and parents about the initial IFSP process within TEIS. In this chapter, a discussion of the findings are presented. The discussion is followed by sections on the implications of the results and a section on the reflections of the study.

Discussion

The perceptions of both the parents and professionals about IFSPs has been documented in the literature (Able-Boone et al., 1990; Summers et al., 1990; DeGangi et al., 1992; McBride et al., 1993; Minke et al., 1993). However, the present study allowed the researcher to capture the perceptions of both SCs and parents in the immediate time frame of the initial IFSP process. The descriptions provided by both SCs and parents offer the opportunity to make comparisons of their broad perceptions of the process. The study also provided SCs' perceptions of the IFSP process in general by including descriptions of 91 referrals of children/families who have been served by TEIS, but were not in the study. The findings include the typical sequence of

events of the initial IFSP process as well as the SC attempts to respond to varying needs of these children/families and parent perspectives of the process. The varying needs of these children/families resulted in an IFSP process which took different forms as they changed during the process.

Research Question 1: How do service coordinators' and parents' perceive their role/participation/involvement during the IFSP process?

The findings indicated the parents' actions during the initial IFSP process were communicating, decision-making, advocating, and transporting. Findings related to the first three actions are comparable to the ones reported by Minke et al. (1993). These researchers described parent roles during the IFSP process as listening, advocating, participating in goal setting, and involvement in basic decisions.

Findings indicated that parents' decision making action is called for every step of the way, and these decisions seemed to have a bearing on the plans made during the process in general and the initial IFSP meeting in particular. Parents needed to make informed decisions throughout the process, because they were presented with many options related to the services such as timing,

payment, location, type of intervention services (home-based, center-based), and evaluations. Minke et al. (1993) reported similar findings by referring to parents' decisions about obtaining services as "basic decisions." One of the activities related to decision-making is parents authorizing services for their children/families. Parents play a powerful and pivotal role in receiving services for their children/families. Authorizing services is consistent with the findings of McBride et al. (1993), who described parents' authorizer role as "veto power."

Results also indicated that SCs in the IFSP process perform multiple functions: communicating, empowering, coordinating, meeting, verifying, and training surrogate parents. The first three functions of the SC were consistent with some of the assertions made about case management by Bailey (1989). The terms Bailey used to describe these roles were advocate, service coordinator, and broker which coincides with the findings of this study. The ways in which SCs perform functions such as listening, informing, mediating, empowering, providing information were in agreement with those illustrated within the framework of case management proposed by Dunst, Trivette, & Deal (1995).

The other functions described by the SCs such as meeting, verifying, and training have received less attention in social work literature as compared to the other

functions. The terms reported in this study that refer to these functions, are given by the SCs themselves, which suggested that these functions may be more commonly performed by SCs in the field of early intervention in general and by SCs in model programs such as TEIS in particular. Also, it may be important to examine further whether SCs in the field of early intervention are prepared to perform these functions such as verifying, conducting meetings, and training surrogate parents.

SCs' and parents' perceptions were very similar with regard to ways of communicating, which included inquiring, listening, deliberating/discussing, corresponding/informing, except that SCs added mediating as another way of communication. Further, these different ways of communicating seemed to promote the parents' informed decision making function. Also, SCs' function of empowering complemented the parents' action of advocating. Only one parent indicated that she was not actively involved in the process.

On the whole, examination of the functions of both SCs and parents suggested that they complement one another, encouraging parents to take an active role in an IFSP process. One may suspect that SCs are inclined to help parents to navigate the social system, a notion similar to Wheeley's (1981a, 1981b) "human development liaison specialist." According to Wheeley, the liaison specialist's

client is not the individual child or family, "The client... is the troubled social system"(p.324). In spite of SCs attempting to perform functions that are more consistent with the enablement model, the established social system of services may force them to function as a liaison specialist.

Overall, these results, show evidence that SCs encourage parents to take an active role in the IFSP process. However, at times the existing social services may not be conducive enough to match their efforts.

Research Question 2: What are the events that occur in an IFSP process as experienced by service coordinators and parents?

The typical IFSP process within TEIS described by the SCs appeared to fit broadly into the IFSP sequence illustrated within a family-centered approach by McGonigel et al (1991). Further, the findings from both SC and parent responses support the notion that the activities within an IFSP process are individualized for each child/family and that they are fluid and interactive in nature as described by McGonigel.

The four phases of the initial IFSP process within the TEIS model of service delivery described by SCs are comparable to the service coordination activities of the first half of the four-tier model of the family-centered

service coordination described by Cormany (1993). Although, the parents' description of events do not exactly match the detailed description of the four phases provided by the SCs, the events were comparable to the extent that they had telephone contacts and meetings with SCs and professionals in relation to their child's evaluation, therapy, and intervention services, and family needs. Most parents valued both the meetings and telephone contacts with the professionals. However, one parent did not seem to value the IFSP meeting which points to possible incongruency in the perceptions of the parent and SC.

Thus, results indicated that the on-going events and interactions between parents and SCs during the four phases of the initial IFSP process are significant in themselves, and that they appeared to have an impact on the development of the initial IFSP document. Particularly, SCs indicated that some events were more significant than other events during the initial IFSP process. One such event is the first contact with the family which appeared to 'set the stage.' Further, determining eligibility for TEIS services on the 'front end' appeared to be vital. Thus, qualifying the child during the intake meeting with the family seemed to allow SCs to carry out other activities of the initial IFSP process.

Findings from both the parent and SC data sets suggested that there are several aspects of the child/family

influencing the activities and interactions of the initial IFSP process, such as the age at which the child is referred for services and the type of: a)eligibility determined for the child; b)needs exhibited by the child; c) needs indicated by the family; d)services obtained by the child/family at the time of referral; and e)payment the family plans to make for the services. Furthermore, individual children/families variation with respect to these aspects may be represented along a continuum. To illustrate, Figure 3 provides a graphical representation of the different aspects related to Victor and Sophie and their families (participants in the study). They are compared in relation to different aspects by showing variation along the continuum during the process which necessitated different activities and interactions. Further, details as to how Victor and Sophie and their families vary with regard to different aspects are described.

Research Question 3: What are some issues that service coordinators and parents view as impeding the process?

Findings indicated issues related to requirements of the law, eligibility criteria, payment of service, communication with the families and professionals, differing views of parents and professionals, and SCs' apprehensions as issues.

Time of referral

At birth..... Nearing 3rd birthday
Victor Sophie

Victor was referred at 3 months of age, whereas, Sophie was referred to TEIS when she was nearing her 3rd birthday which meant that they had to plan on transitioning the child for preschool services during their initial IFSP meeting.

Eligibility

Paper eligible .....not eligible
Victor, Sophie

Both Victor and Sophie were diagnosed as having cerebral palsy at the time they were referred to TEIS. Therefore, they did not have to be evaluated further to determine their eligibility.

Child needs

Few.....Intense
Sophie Victor

Victor exhibited more needs as compared to Sophie. Victor needed physical therapy, occupational therapy, day care, special equipment, doctor's appointment for the examination of the eye and respiratory tract. Sophie's needs were related to physical therapy and day care only.

Family needs

No family needs.....Intense family needs
Victor, Sophie

Victor was in foster care, needed a surrogate parent to be appointed. Sophie's family needed information on child development and child care.

Service in place

No services.....Most services
Victor Sophie

Victor was in day care at the time of referral but needed physical and occupational therapy evaluation services, doctor's appointments. On the other hand Sophie was already receiving physical therapy.

Payment by family

No payment..... All the payment
Victor Sophie(Partial)

Payment for the service Victor obtained was covered by Access Med plus and Sophie's family made partial payment towards Sophie's physical therapy.

Figure 3. Comparison of children/families on different aspects

One major issue pointed out by the SCs which has not received much attention in the literature relates to the policy of holding the initial IFSP meeting within 45 days from the time of referral. Findings from the SCs' responses suggested that, due to several intervening factors, they were unable to hold initial IFSP meetings within 45 days for many families. These intervening factors were establishing contact with the family, determining eligibility of the child for services, and processing of the documentation related to the payment of services for families. Also, the findings suggested that foster children with disabilities posed unique problems in meeting the 45 day time frame to develop an initial IFSP. Further, when children were sick and hospitalized, IFSP meetings were delayed. Results indicated that realizing the policy of having two professionals present during the initial meeting was problematic more so in District B, which is more rural, than in District A. Therefore, to have the 45 day time frame as a policy to be adopted across the nation without consideration of the issues specific to the geographical location (rural and urban) and other complications raises some concerns.

Another policy issue relates to the different eligibility criteria established by various agencies. These differing criteria make the families experience uncertainty regarding the services for which their children are

eligible. Children who are not "paper eligible" or who do not demonstrate significant delays need to have an "informed clinical opinion" to be eligible for TEIS services. SCs expressed concern with regard to the lack of clarity as to who has the authority to give the informed clinical opinion. Thus, determining eligibility for children for early intervention services seemed to be elusive, particularly for children who are premature, have language delay or behavioral problems, present autistic characteristics or have heart defects.

Findings from both the SCs' and parents' responses suggested that the policies related to children in foster care who have special needs may hinder meeting the needs of these children/families effectively. Particularly, the foster child who was exposed to drugs in utero was in double jeopardy since he was placed in one foster family and changed (since this study was concluded the child has been placed in a third foster home) to another to meet the regulations. This unstable foster care environment may pose challenges to these children to thrive. This finding appeared to coincide with the foster care crisis reported by Poulsen (1994). Furthermore, the legal issues surrounding children with special needs who were in foster care often seemed to delay the IFSP process.

One SC referred to the way families were provided with

services in an early intervention system as offering a "cadillac of services." In other words, the SC indicated that families have choices with regard to services and payment options in the early intervention system which they would not have once the child moves from early intervention to the school system. Another SC, operating on the same premise, remarked that transitioning children and their families from early intervention to preschool services was like throwing the families to "a pack of wolves." These views expressed by the SCs suggested that parents were going to be hurled into a system at the time their children were three years of age where they cannot find the same quality of services as they were accustomed to in the IFSP process. This finding supports the contention for the continued use of the IFSP through out the preschool years (DEC, 1995).

SCs' apprehensions were indicative of issues that are very sensitive and pose challenges in serving some of the families. These issues were distance, children's illness and hospitalization, and concern for meeting the needs of those families who experienced domestic violence, child abuse, parent's psychological problems, and parents involved in penal institutions.

Parental concerns focused on their child's diagnosis which needed to be conveyed to them by the concerned professionals with more clarity and sensitivity. Further, when there was a discord regarding policies related to

payment of services between agencies, families seemed to experience confusion and delay in the services.

A parent issue which corresponded with a SCs' issue was the discrepancy in the way professionals and parents view the need for services. Parents in this study who made partial payments for therapy viewed the amount of therapy recommended by the professionals differently (recommending more therapy by professionals was viewed as a money-making scheme) than those parents whose children were provided therapy and payment through a public agency (the amount of therapy recommended was viewed as being insufficient). Thus, there seemed to be a conflict when there was a mismatch between the amount of services requested by parents for their children and the amount of available services when payment is covered by agencies as opposed to parents. The comments from both parents and SCs revealed ambiguity as to whose judgement should prevail.

Both SCs' and parents' concerns pertaining payment of services were identical. The issue was matching the insurance plans of the family with the plans that were honored by available physicians or service agencies. Typically, this process seemed to delay the evaluations for the child and/or further intervention services. One parent remarked that some of the intervention plans may not be appropriate without the timely evaluations.

The other common issues identified by both SCs and

parents were related to the IFSP. SCs indicated that conducting the meeting and completing the document (particularly the present levels of development) during the IFSP meeting as cumbersome. This issue coincided with the views of parents that they did not value professionals writing reports during the meetings.

Research Question 4: What are some practices that service coordinators and parents have found to be helpful for them during the IFSP process?

SCs and parents agreed that practices related to communication are crucial to a successful IFSP process. These practices refer to parents asking and explaining to professionals and SCs listening and talking to parents in a way that is beneficial to families. This finding is similar to the findings observed by DeGangi et al. (1992). Also, analysis revealed organizational skill of the SCs being central in carrying out the activities during an IFSP process because of the numerous cases and the multiple needs these cases presented at a given time. Professionalism was also an essential element for SCs to work collaboratively with parents as well as other professionals. The principles identified by the SC regarding professionalism seemed to point to the ethics of the profession of service coordination. Also, SCs with qualities such as being more

flexible, interactive, empathetic, nonpatronizing, nonauthoritarian, and nonjudgmental were considered better coordinators than others. SCs suggested that the techniques that were helpful in carrying out service coordination activities were those that were used by a sales person, a waitress, counsellor, social worker and a person in public relations. SCs acknowledged that the knowledge they acquired through formal education, as well as the knowledge they acquired while they were on their job, was helpful in practicing service coordination.

On the whole, SCs discussed specific skills, SC qualities, knowledge, and certain techniques as helpful in carrying out the activities in an IFSP process. The parents discussed asking, explaining, researching and praying as being helpful during the process.

Research Question 5: What suggestions do service coordinators and parents have for improving this process?

SCs had several suggestions for improving the IFSP process: 1) examine the format of IFSP form for redundancy and content to utilize the time during the IFSP meeting more efficiently; 2) hold the IFSP meeting once the services are in place for the child/family (as it may be more meaningful and efficient rather planning a meeting to meet the 45 day deadline); 3) avoid discussing issues particularly related

to other professional agencies during the IFSP meetings; and 4) make policies more flexible with regard to appointing surrogate parents.

Findings related to parents' suggestions, call for early diagnosis, more awareness about TEIS services, increased/decreased therapy sessions and time for their children, avoidance of bureaucratic practices, and an opportunity for foster children to have a more stable environment. Both, parent and SC suggestions appeared to show some agreement in relation to the bureaucratic practice of appointing a surrogate parent. Further, SCs suggestions to have the option to complete the current levels of development prior to the meeting for some families may be agreeable to some parents (like the one parent who participated in this study) who express discomfort about SC/professionals rewriting reports/completing documents during the meeting.

Research Question 6: What are service coordinators' and parents' perceptions regarding their joint participation throughout the IFSP process?

SCs' responses indicated that elements such as positive initial contacts, communication, attitudes, back-up, back-off, were necessary for developing a partnership with parents. Positive initial contacts were important for

building a collaborative relationship. It is important for the SCs to gain parents' trust, and for the parents to learn about the background of the SCs and the purpose of their contact to feel comfortable. The findings suggested that the collaborative relationship begins to take shape further during the first telephone contact. Another important occasion for parents and SCs to work collaboratively seemed to have its roots in their first face to face encounter, typically the initial intake meeting. According to SCs, their attitude towards parents and their efforts to develop a rapport with parents were essential elements in building a partnership with parents during this meeting. Further, exchanging information with parents with sensitivity, making provisional plans and arrangements for obtaining services, and identifying the responsibilities of both SCs and parents to carry out the plan were helpful elements in building partnership with parents. These elements of the intake meeting are comparable to the components of the building relationship phase for effective problem solving and negotiation described by Brandt(1993).

Further, findings suggested SCs responded in a manner which indicated to parents that their families' concerns were a high priority, helping to building a partnership. SCs elaborated that, as they attempted to develop a collaborative relationship with parents, they tried to empower them. SCs needed to balance the act of backing-up

and backing-off from families' decisions during the IFSP process for the relationship to be collaborative. This notion is comparable to Minke et al. (1995). The observations made by these researchers were in relation to staff attitudes towards collaboration, where professionals tried balancing dependence and independence in their relationships with families.

Findings about parents' perceptions of professional collaboration during the IFSP process were positive. They described their attitude towards professionals and the nature of their interaction with them as discussive, exclusive, instantive, and informative. The parent responses revealed that they used the word "we" while referring to their interactions with professionals, which suggested that they had a sense of partnership with others on the IFSP team as opposed to feeling disregarded or disconnected. Minke et. al. (1993) observed similar findings.

Although parents had the final authority in all the decisions taken during the IFSP process, their inclination to discuss matters with professionals seemed to facilitate their collaboration. The usage of the term "discuss" by most of the parents suggested that they may have been more inclined to balance professionals' suggestions with their own ideas while making decisions. Thus, parent responses demonstrated that they neither completely conceded to all

the suggestions offered by the professionals nor totally disregarded professional suggestions, facilitating their collaborative efforts.

Most of the parents expressed a sense of satisfaction with their relationship with the SCs and some of the other professionals who were involved in serving their family, because they felt that they showed interest, expressed willingness to help, answered questions sensitively, and responded in a timely manner. Their approach of "going an extra mile" to meet the needs of the family rather than doing it merely to fulfill their duties added to building a positive relationship with parents.

Findings which appeared to deter parents from developing a positive relationship with professionals appeared when parents were unable to understand their child's problem. Most of the parents' responses point to the fact that the communication regarding the diagnosis of their child's problem with their physicians was not clear. Lack of clarity suggested that there was a need for professionals who are directly serving families who had children with special needs to interact sensitively. These professionals may be physicians or nurse practitioners who come in contact with such families early.

One parent indicated that reiteration of some of the information by professionals made the IFSP process less interesting. This concern pointed out by the parent

suggested that professionals needed to interact with parents during the meetings in a way that would stimulate interest in parents to take an active role.

The findings suggested that the collaboration between parents and SCs is influenced by the attitudes held by both toward each other. Some of the SCs' attitudes about parents were that: 1)parents had varied emotional states; 2)parents priorities change; 3)parents had other family issues operating simultaneously; and 4)parents had varying levels of understanding. On the other hand, parents' attitudes towards SCs and professionals were as follows: 1) SCs/professionals had the best interest of the child/family in mind; 2)SCs/professionals operate with limitations of policies; 3)SCs/professionals were supportive; 4)SCs/professionals were accessible and available; and 5) SCs/professionals made extra efforts to meet the needs of the child/family.

Overall, findings related to the development of the collaborative relationship during the initial IFSP process appeared to be a reflection of the kinds of interactions occurring throughout this timeframe. Findings suggested that adoption of more of the positive approaches by the SCs, as listed below, facilitate developing a partnership with families for SCs.

In Figure 4, positive approaches, such as prior notification, updating, maintaining regular contact all

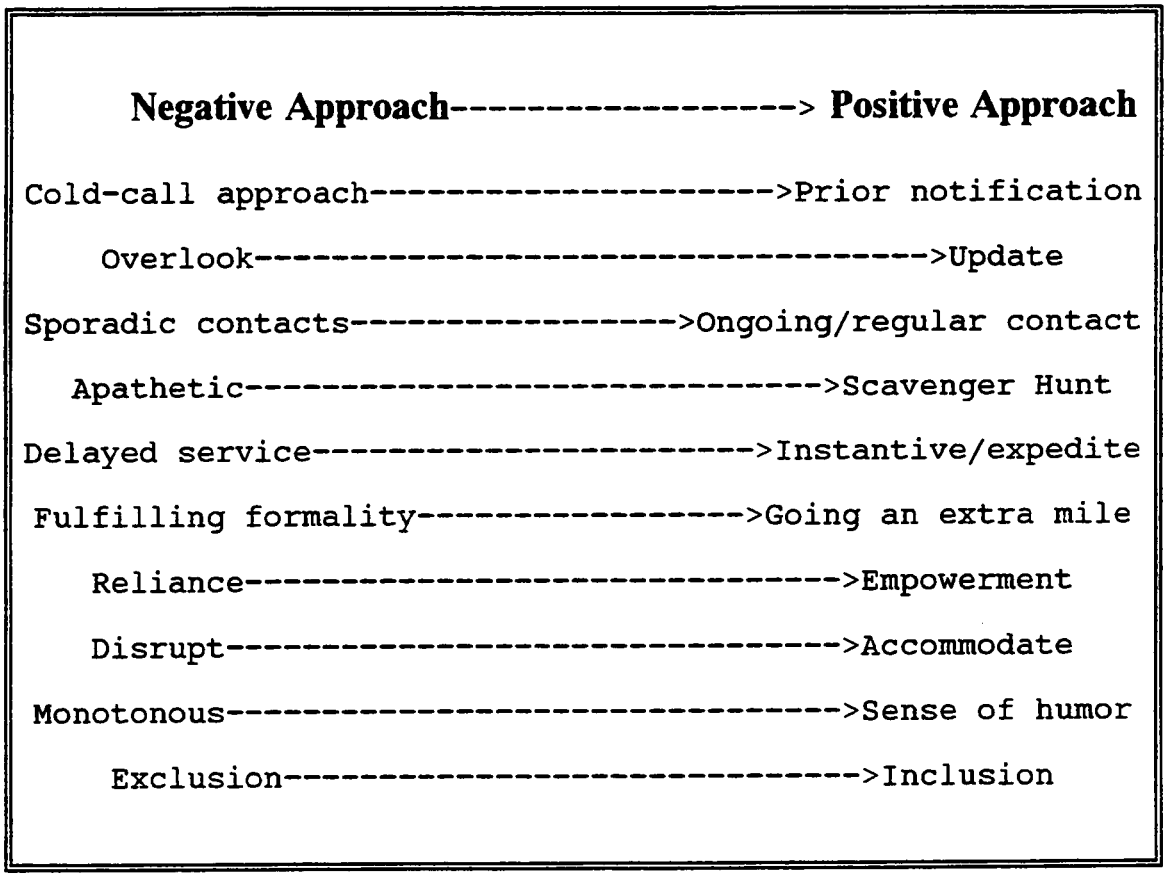


Figure 4. Approaches to Service Coordination

refer to SCs' ways of communicating with families, which promote their partnership. Positive approaches, such as SCs going on a "scavenger hunt," expediting services, and going an extra mile, are ways in which SCs render services to families which facilitate the partnership. Positive approaches that refer to empowerment, accommodation, inclusion and sense of humor point to the behavior of the SCs toward parents which fosters a sense of partnership.

Research Question 7: How do service coordinators and parents exchange information during the process?

Findings indicated that the mutual sharing of information between parents and SCs facilitated parents making informed decisions about the services they needed for their child/family. As the word "exchange" suggests, SCs were not only involved in eliciting information from parents, but were also engaged in providing information to parents. Just as the information SCs received from parents appeared to help them to better serve the children/families, the information SCs provided helped the parents make informed decisions about services. SCs appeared at different times to have shared several types of information with parents, both solicited and unsolicited. This information was shared through the telephone, mail, and face to face encounters. Thus, sharing information seemed to be

a beneficial aspect for all during the IFSP process. This finding is consistent with the observations made by DeGangi et al.(1992) and Summers et al. (1990).

Results indicated that the exchange of information between SCs, parents, and other professionals formed the very foundation on which the IFSP process took shape. The Status Form, one of the first documents created for children/families at the time of referral, contains information crucial for SCs to take timely action for the child/family. The referral date on the form started the clock ticking for SCs to contact the family within two working days and to arrange for the initial IFSP meeting within 45 days. Information of the child's date of birth on the form allowed SCs to decide whether or not the child was ready to be transitioned to the school system, and plan accordingly. The information relating to the number of agencies serving the family at the time of referral helped SCs coordinate services in an efficient manner. It helped them determine the number of releases to have the parents sign if they needed to obtain or provide information from or to other agencies. Also, the information seemed to help SCs avoid duplicating services for the family. Thus, the Status Form served as an important document in learning about the amount of time that had elapsed from referral to the development of the initial IFSP.

The Central Intake Form allowed SCs to elicit

information about the child/family during the intake meeting. The comprehensive information obtained on this document from a family served as a basis from which both the SCs and parents could collaboratively plan until the initial IFSP meeting.

The analysis of the information pertaining to the family needs showed that some of the needs identified by the parents in the beginning of the process were addressed before the initial IFSP meeting, and some remained to be addressed during the initial IFSP meeting. This indicated that the interactions and activities from the time of referral until the initial IFSP meetings were helpful in meeting the needs of the child/family.

Thus, findings suggested that, in an IFSP process, exchange of information occurred between parents and SCs, and other professionals as well from both SCs' and parents' perspective. Both the exchange of written material as well as verbal exchanges were to be high according to both parents' and SCs' responses. One parent talked extensively about the usefulness of video tapes as a source of information as opposed to printed material. This statement suggested that there is certain information which parents prefer to learn through a video presentation as opposed to reading it. Moreover, SCs indicated that they had to read and explain some of the printed information to parents who were unable to read. These findings suggested that SCs

interacted with parents who functioned at different reading levels.

There is a great deal of attention given to studying the IFSP as a document in literature (Bailey et al. 1990; Espe-Sherwindt, 1991), and studying the appropriateness of family needs questionnaires (Sexton, Snyder, Rheams, Barron-Sharp, & Perez, 1991) in an IFSP process. But little is known about some of the other documents that are useful in an IFSP process. In this study, the analysis of the different forms completed for each child/family revealed that information on these forms facilitated the IFSP process and as a result the development of the IFSP itself.

IFSP: A Volatile Process

The findings help to extend the conceptualization of the IFSP process from a fluid and interactive one (McGonigel, 1991), to one which is fluid, interactive, and volatile in nature. The nature of the process is volatile from the swing in the intensity of the different elements: attitudes of parents and SCs; aspects influencing the process; attributes of SCs and the parents; and the approaches employed by the SC. The nature of the initial IFSP process in general and the IFSP document in particular echos the nature of these different elements for each child/family and its interactions which are illustrated in the form of an equation, IFSP PROCESS = ATTITUDES X ASPECTS

X ATTRIBUTES X APPROACHES.

The following case described by one of the SC illustrates the volatile nature of the IFSP process.

> M: The child was diagnosed with cerebral palsy... IFSP meeting took place... parents were interested in Agency F for speech therapy at that time... We wanted to get an evaluation for physical therapy and they were in between getting TennCare and not having TennCare... Getting the evaluation through was a very lengthy process, going through the family physician, finding a place for the child to get his evaluation that was scheduled at Agency B and the parent's couldn't make it for physical therapy... the child was evaluated at Agency Q and parents had decided to take him to Agency Q and it was decided by Agency Q that the child did not have cerebral palsy and that he was an "idiopathic toe walker". Mother is now deciding not to put him in any therapy, he is not going to be in any program. They have moved out of County D and she is pursuing legal representation. She feels that he has been misdiagnosed with cerebral palsy and he is going through all this therapy they have been going through a lot of stressful times and to find out that he really doesn't have cerebral palsy. The family has decided to pursue some legal action and that has been the end of the case...(SC-R).

In the above case, SC discussed the parent showing her willingness initially to obtain services for her child, but, after the parent learned that the child did not have cerebral palsy, the parent's attitude changed because of the change in one of the aspects relating to the diagnosis. This meant that the parent was wilful (attribute) to the extent that she refused services and planned on pursuing legal action because of the stress she had to undergo due to misdiagnosis. Because of these changes, the SC had to take the approach of backing-off from family's decision.

Thus the volatile nature of the IFSP process for this

particular child/family refers to the change in the parent's decision from receiving early intervention services to the decision to refuse intervention services and pursue legal action.

Implications

The findings have implications that could influence policy and practice pertaining to IFSP process. Also, the results have implications for training of SCs and for future research.

The findings challenge the meaningfulness and feasibility of the existing policy related to the 45 day time frame for developing initial IFSPs for children/families. One of the implications for policy is that for children who are paper eligible the 45 day time frame may be feasible, but it may be advantageous to extend this time frame for children: 1) for whom eligibility has to be established only after further evaluation; 2) who need an informed clinical opinion; 3) who are in foster care; and 4) who are attending programs in different geographical settings (e.g., rural areas).

Findings suggested that children may tend to "fall through the cracks" because of differing eligibility criteria of multiple agencies. These children may be the ones who are less likely to be picked up by the system

providing services. This issue encourages practitioners to conceptualize early intervention in terms of prevention. This would allow agencies to incorporate a more inclusive eligibility criteria. As a result, agencies might accommodate children presenting different kinds of needs, rather than children having to meet the eligibility requirements of the agencies.

Findings indicated that the requirement to have two professionals present at the initial IFSP meeting is problematic. Flexibility in this policy is needed, particularly for children who have a diagnosed medical condition with only a physician involved. Research supports that physicians are less likely to attend IFSP meetings because of lack of time (Peter, 1992).

Findings indicated that SCs/professionals come across parents whose literacy levels and preferences for information exchange vary. Therefore it may be important for SCs/professionals to: 1) verify the readability level of all the written information before it is given to parents; 2) make information available to parents in different formats (e.g., printed material with illustrations, audiotapes, video tapes); and 3) be trained with basic concepts and practices of adult education/literacy so that they can incorporate them into their professional practice.

Results indicate that SCs need to play multiple functions for which they need several skills and techniques

as they try to meet diverse needs of children as well as families. SCs who are typically trained to perform functions specific to a single discipline may not have the necessary training to perform multiple functions. Therefore, there seems to be a need for professionals in early intervention to have additional training at the preservice or inservice level in areas that would complement the knowledge of their specific discipline. This would enable them to be better prepared to play diverse roles as SCs on the IFSP team.

The findings of the study also have implications for future research. First, gaining multiple perspectives about the events and interactions of an IFSP process for a child/family from all the members of the IFSP team would help to understand the IFSP process holistically. Second, conducting case study research about the IFSP process with specific populations such as migrant, foster, and homeless children/families would help broaden our understanding of the issues specific to that population whose living conditions are transient. Third, it would be interesting to compare the views of SCs who primarily function as SCs with those SCs who perform service coordination duties in addition to their primary function of providing intervention services.

Reflections

Reflections on using qualitative research methods to study the initial IFSP process relates to both data collection and analysis procedures. Data collection involved more time than anticipated because of the way the study was designed. It lasted from February 1994 to March 1995. During this time period, although SCs reported receiving 91 referrals, it took more time in getting families to participate. Because, SCs were asked to inform the researcher about the referrals received at TEIS, SCs used their discretion in inviting families to participate. This screening process prolonged the time needed to obtain referrals and also had an influence over the kinds of families who participated. Thus, SCs functioned as gatekeepers (Bogdan & Taylor, 1975), which delayed getting families to participate in the study in addition to other intervening factors (Table 4 in Chapter Four refers to these intervening factors). One of the major categories which supports this notion is the "service coordinator's apprehensions" uncovered from the data obtained from the SCs' report of all the referrals received during the study period. This category captures the rationale behind SCs acting as gatekeepers in choosing families for this study. The reasons provided by the SCs in their referral reports for not informing the researcher about some of the referrals

was that some families were living in far off counties and a few families were dealing with sensitive issues such as domestic violence, abuse, complex foster care situation (Discussed in detail in Chapter Four).

One way to circumvent the problem of SCs functioning as "gatekeepers" in future research could be that the researcher pursue all referrals that the participating SC is assigned until she is able to locate families who meets the criteria (e.g., Families referred to TEIS for payment purposes only do not meet the criteria). In other words, the researcher could pursue all the referrals by accompanying the SC during their home visit and choose to pursue only families that meet the set criteria, instead of the researcher providing a set of criteria to SCs to screen families.

Using the self-interview method to learn participants' views about the initial IFSP on an ongoing basis proved to be beneficial. For example, the recorded self-interviews obtained from the first foster parent illuminated some of the problems faced by her and her frustration in obtaining timely services for the child during the initial IFSP process. By the time the IFSP meeting was held for the child for whom she was the foster parent, she had relinquished her rights as a foster parent.

The open-ended nature of the study helped to obtain participant views about the initial IFSP process which they

thought to be of most importance (e.g., one of the major issues that emerged from the SC data set was conducting the meeting within the 45 day time-frame). Also, the qualitative nature of the study helped the researcher to obtain the finer details of the problems in conducting the IFSP meeting within 45 day time frame. Further, parents' and SCs' perceptions (linking SCs with the respective families) helped to compare the views in context as events were occurring.

Data analysis was time-consuming because of the volume of the data. The total number of lines transcribed was 11,457 (open-ended interviews [8,309], self-interviews [1657], and referral reports [1,491]). In addition, documents related to each child/family were analyzed (refer to Appendix K).

The other procedures used to select the participants prior to the data collection were problematic in how the results were affected. In this study, the first criterion underlying the decision to approach four district offices out of the nine district offices paralleled Patton's(1990) convenience sampling. The four district offices that were closer as compared to the other five were chosen. This approach is not encouraged in qualitative research because it may be that the most accessible sites are unique in various aspects from less accessible sites (Bogdon & Taylor, 1975). But at the same time it is not prohibited because

the intent is not to generalize beyond the local context. However, in this research there was no reason to believe that the districts not involved in this study conducted the IFSP process differently. Throughout the state all districts follow statewide policies and procedures in the service coordination process.

Geographically, District A was more urban than District B. These two district offices located in two different geographical locations enabled the researcher to look for the core elements of the initial IFSP process across variable sites. This strategy of building a sample which represented the geographical variation of the research sites is analogous to Patton's (1990) maximum variation sampling. According to Patton (1990) adopting this strategy allows the researcher to capture the differences due to the variation and also to examine the central themes of the process within that variation. For example, one of the differences pointed out by the SC serving in the rural counties was *"...in rural places everybody knows everybody anyway--so in one of the counties, particularly I work closely with family resource center. And the people there know a lot of the families. And have gained their trust."* Also, the difference in serving more rural areas lies in the limited service options that are available to children and their families. One SC stated *"...it is very hard to get everything together in this area being so rural, and with not enough service providers it is hard to get everything together within the time frame. Often it is impossible."* Another difference specific to

rural areas maintained by the SC is *"...to realize that you have to help people within their value system and you have to respect that... particularly I think rural people. And I am a rural person, you know, and native to the area, and I find that an advantage in understanding people."*

Utilizing a sampling method such as criterion sampling (Lincoln & Guba, 1990) in qualitative methods proved to be beneficial in conducting this study. SCs who were chosen in this study were not the ones who had just started doing service coordination, but they had to have at least six months of experience as SCs. The results indicated that this was a good decision because SCs do things differently as they become more experienced. SCs' responses support this notion. *"Now I love IFSP's.... But I used to be scared to death to do an IFSP.... I am not scared anymore", "I don't have a problem with that [IFSP] anymore. I used to because I thought it was too lengthy and too many pages..."*

A decision to exclude children referred to TEIS only for payment of services was another strategy adopted during data collection. In other words, this strategy involved sampling children/families who met a certain criteria (referred to TEIS for services other than payment) to be considered as participants in this study which is similar to criterion sampling (Patton, 1990). This strategy enabled the researcher to examine the IFSP process in depth for those children/families who were referred to TEIS for services instead of payment alone.

The process of data collection added to the credibility of the study as it pertains to SCs because the researcher was able to have "prolonged engagement" (Lincoln & Guba, 1990) with SCs (February 1994-March, 1995) by keeping in constant contact with them by phone or on few occasions accompanying SCs during their initial intake meeting with families or during the weekly staff meetings at District A. The data collection procedure helped the researcher to understand the initial IFSP process more in depth because analysis of 91 referrals revealed that initial IFSP process involves unanticipated events, actions, and attitudes. For example, unanticipated event during the IFSP process refers to one of the parents having to move to a "shelter" due to domestic violence. The SC was unable to get in touch with the parent and therefore could not provide timely intervention services to the child/family. An example of the unanticipated action was parent who discontinued obtaining intervention services for her child because there was discrepancy in the diagnosis of the child. Further, the parent decided to take legal action as the family had to undergo stress because of the misdiagnosis. An example of unanticipated attitude was a case described by the SC where there was discrepancy in what the family and the professional from the funding agency believed as the best service for the child. If a methodology other than a qualitative methodology had been used, the researcher doubts

these subtleties would have been documented.

Limitations of the study

All the SCs who participated in this study were Caucasians, except one foster parent (African American). The participants were those who lived in a particular geographic area of the country. The results may not be applicable to parents from other cultures or geographic areas. The SCs acted as gatekeepers (Bogdan & Taylor, 1975) while choosing families for this study. This gatekeeper approach seemed to restrict the kind of families who could participate. Typically, parents who were easily agreeable to participate, and those who were more expressive and easily accessible seemed to be the ones that took part in this study. Another limitation in this study lies in the volunteer nature of the participants. The participants in this study are only those who volunteered to participate.

Using self-interview as a method of data collection was a problem in the research design because of family difficulties and and transcription. Although, in the design of the study it was mentioned that self-interviews would be collected at the end of every week, it was not feasible because the participants were unable to keep up with the schedule, even though all the participants had agreed to do so at the outset. Entries from the researcher's data collection journal indicated that one particular family had

to be excluded from the study because of this design. During the first home visit along with the SC, the researcher learned that it was not convenient for the parents to follow the instructions provided for them on the self-interview guides, because they were unable to read. Secondly, the mother was speech and hearing impaired and therefore unable to record the self-interviews on a tape recorder. Also, the volume of data made it difficult for the researcher to transcribe, and take back the self-interviews to those parents and SCs who turned in some of their self-interviews prior to the open-ended interview session. However, the researcher, reviewed those self-interview tapes that were returned to her prior to the open-ended interview sessions with the parents and SCs.

Another disadvantage of the methodology was the reliance on the electronic gadgets such as audiotapes for data. This proved to be a risky approach when one of the SC's self-interview recording was inaudible.

In general, utilizing different methods to collect data appeared to have enabled the researcher to capture cognitive, affective, and factual details of an initial IFSP process. The open-ended interview responses of the participants seemed to include more of the cognitive aspects of the initial IFSP process. SC responses indicated that they try to understand the needs of the family. This process was described by a SC as *"trying to get at exactly being*

insightful and intuitive in terms of what the parents are actually trying to say", "...at the outset parents are informed about the IFSP meeting...." The self-interview responses of the participants seemed like they constituted more of the participants' attitudes, and emotions that were ongoing. One of the SCs described feelings towards the families as *"...first contact you get a feel that it would be a successful case."* Documents, on the other hand, were reflective of the facts of the initial IFSP process. Findings showed documentation being one of the routines of the initial IFSP process.

Thus, the strategies adopted in collecting data, such as consolidating data from different sources (parents and SCs), different methods (open-ended interviews, self-interviews, and documents), and on an ongoing basis seemed to have enabled the researcher to uncover those aspects in this research that were factual as well as aspects that are more implicit in an initial IFSP process.

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APPENDICES

APPENDIX A

DEFINITION OF DEVELOPMENTAL DELAY FOR THE STATE OF TENNESSEE

The term "infant and toddler with disabilities" means a child from birth through age two who is eligible for early intervention services because he or she:

A. Is experiencing developmental delays as measured and verified by appropriate diagnostic procedures, administered by qualified examiners using appropriate diagnostic instruments, indicating that the child is functioning at least 25% below his or her chronological age in two or more of the following developmental areas:

1. Cognitive development,
2. Physical development, including fine motor, gross motor and sensory development,
3. Speech and language development,
4. Psychosocial development,
5. Self-help skills;

OR

Is functioning at least 40% below his or her chronological age in one of the areas listed above;

OR

B. Has a diagnosed physical or mental condition that has a high probability of resulting in developmental delay, i.e., known, obvious, or diagnostic conditions such as sensory losses and severe physical impairments. Examples are:

1. Hearing loss which can be verified or estimated to be significant as indicated through an audiological evaluation,
2. Visual loss which meets the definition of legally blind or is such that the infant is unable to respond effectively to visual stimuli as a result of some other factor involved in visual functioning; for example, brainstem disorder or dysfunction of visual cortex,
3. Neurologic, muscular or orthopedic impairment which prevents the development of other skills; for example, congenital dislocation. of hip, spina bifida, cerebral palsy, rheumatoid arthritis, autism, epilepsy,
4. Organic conditions or syndromes which have been significant consequences; for example, tuberous sclerosis, hydrocephalus, muscular dystrophy, fetal alcohol syndrome,
5. Chromosomal, metabolic, or endocrine abnormalities; for example, Down syndrome, Klinefelter Syndrome, Turner Syndrome, hypothyroidism.

Eligibility for services shall be determined by a multidisciplinary team based on a review of these assessments.

APPENDIX B

Researcher's perspective

In qualitative research the researcher is the primary instrument and the data collected by the researcher comprises more of words than numbers (Lincoln & Guba, 1985). The researcher's perspective has a major influence on both data collection and data analysis. Therefore, it is imperative that the researcher provide a description of their background in relation to the study as they enter the research situation. This information enables to establish the credibility of the study.

My academic training includes a Bachelor's degree in psychology, a Bachelor's degree in special education, and a Master's degree in clinical psychology. My professional experience spans around 7 years during which time I worked as an elementary school teacher, a special educator at the center for children with disabilities, a clinical psychologist in an urban setting, and as a coordinator for a UNICEF (United Nations Children's Education Fund) project involved in delivering services to children who are disabled and deprived in the rural areas of India.

As a professional in the field of early childhood special education I bring into this research a broad world view. This broad world view is with regard to the governmental, medical, technological, cultural, and educational positions in relation to children with special

needs and their families in a developing country, such as India and a developed country, such as the United States. In the past five years of my doctoral program, I have acquired knowledge concerning all these different aspects in relation to children with special needs and their families in the United States, which differs from that of what I have acquired and observed for several years in India. The resources and the way individuals with disabilities are perceived by the parents, society and the government at large also differ. In addition, the geographical setting, family system, and the cultural practices allow children with disabilities to grow and develop in settings (developed and developing countries) that vary. Therefore, these differing perspectives allows the researcher to appreciate the unique kinds of resources and support that are available to children with special needs and their families in both these countries and the issues that exist at the governmental, societal, educational, medical, familial, and financial level. Thus, a broad world view held by the researcher places her in a unique position to interact openly with the participants of the study. Because, the participants by and large may have experienced what is present in the United States and therefore their views regarding children with special needs and their families may be limited to their experience.

One very striking aspect that is exceptional to United States as compared to India is the rights children and

parents have to obtain different services and the degree to which parents have a voice in the education of their children. The rights of these children and their parents necessitates appropriate documentation of the services by the professionals in order to protect the rights and confidentiality of the children and their parents. Further, the legal liabilities that professionals have to face are relatively high in cases where the rights of these children and their parents are violated. Thus, the laws pertaining to the rights of the children and their parents seemed to place professionals often to function and serve children and their families with a more defensive stance.

My interactions with the participants of the study has been that of a doctoral student conducting research. As a researcher my role has been in the capacity of being an interviewer or a person willing to listen to the participants story. During my home visits with the SCs I have taken the opportunity to interact and play with the child while both the parents and SCs are occupied with themselves.

My conjecture regarding the perspectives of both SCs and parents regarding the IFSP process is that it varies and that it is context specific. Therefore these perspectives can be learnt best if they are captured on an ongoing basis in an open-ended fashion with each individual rather than posing questions where the responses can be pre-conceived by the researcher.

APPENDIX C

SERVICE COORDINATOR INFORMATION

Dear participant:

I am a doctoral student in the College of Education working on a research project leading to my doctoral dissertation. I invite you to take part in a study of how parents and service coordinators perceive the process of developing an Individualized Family Service Plan (IFSP) from the time infants and toddlers and their families are referred to the Tennessee Early Intervention System (TEIS). Your participation in this study as a service coordinator will greatly enhance our understanding about the IFSP process, as service coordinators experience it. Service coordinators are the ones who serve as a central point in helping parents to obtain the services and assistance for the optimal development of their child from the time the child is determined as eligible for services at TEIS. Therefore, this understanding is very important in bringing about appropriate changes in service coordination activities which could facilitate serving families with children with special needs more efficiently and effectively.

If you agree to take part in this research project you will be requested to: 1) inform the researcher of the new referrals at TEIS after the parents indicate their willingness to participate in the study; 2) to distribute the information sheet to parents (new referrals) during your first meeting; 3) complete a demographic form; 4) conduct self-interviews which involves recording your thoughts and feelings on tape after each time you make a contact with the family (see attached - Service Coordinator Self-interview Information Sheet & Service Coordinator Self-interview Guide); 5) participate in an open-ended interview with the researcher after the first IFSP meeting of the particular family, which may last minimum for an hour; and 6) have access to other notes you make about that particular family.

The recorded tapes will be transcribed into written form. Only the researcher will know your name. All of the tapes and transcripts will be labelled with a code name so that your identity will not be known. Your identity and confidentiality will be maintained in accordance with the federal regulations and the University of Tennessee Research with Human Subjects Guidelines.

You will need to sign a consent form, which is attached, stating that you understand the conditions of the study. Your participation in this study is completely voluntary. You have the right to withdraw from participating in this study even after you have agreed to participate. You may choose not to answer some of the questions without penalty. Your choice to participate or not to participate in this study will not in any way affect your position as a service coordinator at TEIS.

Neither the TEIS staff nor the parents will have access to your tapes or transcripts. Your responses will be confidential.

The recorded tapes, written material, transcriptions and sealed envelope containing your signed consent will be kept in a locked filing cabinet at UT College of Education. After three years of the completion of the study the audiotapes will be erased and other materials will be destroyed.

Please feel free to ask me or my professor any questions you may have about the research project at any time. You may contact at the following address:

Ms. Latha Bhushan
RM 112, Claxton Addition
Department of Special
Services Education,
College of Education,
The University of Tennessee,
Knoxville, TN-37996
Phone: (615) 974-2321(w)

Dr. Susan M. Benner
RM 328, Claxton Addition
Department of Special
Services Education,
College of Education,
The University of Tennessee,
Knoxville, TN 37996
Phone: (615) 974-6228

SERVICE COORDINATOR INFORMED CONSENT

I understand that one of the purposes of the study is to learn about the way service coordinators perceive the IFSP process.

I understand that the self-interviews and open-ended interviews will be audiotaped. I understand that all my responses are confidential. Code names will be used on all data, such as researcher notes and transcripts of the audiotaped discussions. Parents and TEIS staff will not have access to my responses.

I understand that my participation in the study is completely voluntary, and that it will not affect my position as a service coordinator at TEIS by my choice to participate or not to participate in this study. I may withdraw from participation or refuse to answer specific questions at any time without penalty.

I understand that the researcher does not expect any risks to me as a participant in the study. The benefits to me are in thinking about the research questions and in helping the researcher better understand the way service coordinators perceive the IFSP process, and adding to the research base.

I understand that I am granting the researcher the permission to have access to the notes I make pertaining to the child and family participating in the study that exist at the TEIS office.

I understand that I am free to contact the researcher and her professor at any time if I have any further questions about the project or my participation in it.

Name

Signature

Date

APPENDIX D

SERVICE COORDINATOR DEMOGRAPHIC FORM

Your name
Address
Telephone number

Please respond to the following questions by marking the most appropriate answer or writing your response

1. **What is your educational background?**
   Bachelor's Degree Field of study
   Master's Degree Field of study
   Doctorate Degree Field of study
   Any other (Please specify)

2. **What is your experience in working with children with disabilities?**

Title	Location	Dates

3. **Have you been involved in the development of individualized Education Plans (IEP)?** Yes No

   If Yes, in approximately how many IEP conferences have you been involved?

   Approximately with how many Individualized Family Service Plan (IFSP) meetings have you been involved?

4. **Have you received any training related to Individualized Family Service Plan (IFSP) development?**

   Yes No

   Workshop Inservice Other

   If yes, please specify the number of hours and the type of training.

5. **Are you a parent of a child with disabilities?**
   Yes No

6. **What is your ethnic background?**

APPENDIX E

SERVICE COORDINATOR SELF-INTERVIEW INFORMATION SHEET

* **Who will conduct the self-interview?**

  Service coordinator.

* **How to conduct self-interview?**

  a) Use the tape recorder provided by the researcher (please check the tapes and batteries before use).
  b) Responding to the questions in the Service Coordinator Self-Interview Guide.

* **When to conduct the self-interview?**

  After each time you contact a child and the family in the study to whom you are providing services.

* **Where to conduct the self-interview?**

  In a place where there are no disturbances, preferably soon after the contact or on the same day (e.g., while driving back after meeting the family or in the office).

* **How long does it take to conduct a self-interview?**

  The interview should take no more than 15 minutes.

* **When will the recorded tapes be collected?**

  The recorded tapes will be collected on a weekly basis (at the end of every week) until the IFSP meeting is held for the family.

* **How will the recorded tapes be collected?**
  Two choices: a) The tape will be picked by the researcher (at the time and place convenient to the service coordinator), OR b) The service coordinator will mail the tape to the researcher by enclosing it in the stamped, self addressed envelope provided by the researcher.

  SUGGESTION .....please store the recorded tape where you do not anticipate any damage to it.

SERVICE COORDINATOR SELF-INTERVIEW GUIDE

Record the events by responding to the questions listed below:

1. Your Name

2. What is the **name of the child and the parent** with whom you had a meeting or contact?

3. What **date** did you contact the parent?

4. What is the **type of contact** with the parent?
a) telephone, b)home visit, c) office visit, d) through the mail, e)others, please specify.

5. What is the **time of day** at which the parent was contacted?

6. **How long** was the contact? (approximate **duration**)

7. **Who was present** during the contact? (member/members of the family, friends, neighbors, service providers, or others)

8. **What occurred** during the contact? (e.g., activities/topics) Please explain.

9. **What are your impressions and feelings** about the contact? Please elaborate. (e.g., Was the purpose of the meeting served? Were your questions answered? Was the visit successful or overwhelming? any other)

10. **What was the day and time** at which the self-interview was recorded?

APPENDIX F

PARENT INFORMATION AND CONSENT FORM

Dear Parent,

I am a doctoral student in the College of Education working on a research project leading to my doctoral dissertation. I invite you to take part in this study of how parents and service coordinators perceive the process of developing an Individualized Family Service Plan from the time infants and toddlers and their families are referred to the Tennessee Early Intervention System (TEIS). Your participation as a parent in this study will greatly enhance our understanding about the IFSP process, as parents experience it. This understanding is very important, as this would facilitate in developing appropriate programs which can serve families with children with special needs more efficiently and effectively.

If you agree to take part in this research project, you will be requested to 1) complete a demographic form; 2) conduct self-interviews which involves recording your thoughts and feelings on tape (see attached Parent Self-interview Information Sheet & Parent Self-interview Guide); 3) participate in an open-ended interview with the researcher after the IFSP meeting; and 4) grant permission to the researcher to have access to the files and records that exist at the TEIS office pertaining to your child and your family.

The recorded tapes will be transcribed into a written form. Only the researcher will know your name. All of the tapes and transcripts will be labelled with a code name in order to protect your identity. Your and your family's identity and confidentiality will be maintained in accordance with the federal regulations and the University of Tennessee Research with Human Subjects Guidelines.

The materials will be kept in a locked filing cabinet at UT College of Education. Three years after the study is completed, the audiotapes will be erased and other materials will be destroyed.

You will need to sign a consent form, which is attached, stating that you understand the conditions of the study. Your participation in this study is completely voluntary. You have the right to withdraw from participating in this study even after you have agreed to participate. You may choose not to answer some of the questions without penalty. Your choice to participate or not to participate in this study will not in any way affect your or your child's program at TEIS. The members of the TEIS staff will not have access to your tapes or your transcripts.

Please feel free to ask any questions you may have about the research project at any time. You may contact me or my professor at the following address:

Ms. Latha Bhushan
RM 112, Claxton Addition
Department of Special Services
Services Education,
College of Education
The University of Tennessee,
Knoxville, TN-37996
Phone (615)-974-6228 (w)

Dr. Susan M. Benner
RM 328, Claxton Addition
Department of Special Education
College of Education
The University of Tennessee,
Knoxville, TN-37996
Phone (615)-974-2321(w)

PARENT INFORMED CONSENT

I understand that the purpose of the study is to learn the way parents perceive the IFSP process.

I understand that the self-interviews and open-ended interviews will be audiotaped. I understand that all my responses are confidential. Code names will be used on all data, such as researcher notes and transcripts of the audiotaped discussions.

I understand that my participation in the study is completely voluntary, and that it will not affect any of the services provided by the University of Tennessee to my child and family or by TEIS. The TEIS staff will not have access to my interview tapes or transcripts. I may withdraw from participation or refuse to answer specific questions at any time without penalty. I understand that the researcher does not expect any risks to me as a participant in the study. The benefits to me are in thinking about the research questions and in helping the researcher better understand the way parents perceive the IFSP process, and adding to the research base.

I understand that I am granting the researcher the permission to have access to the files and records pertaining to my child and family that exist at the TEIS office.

I understand that I am free to contact the researcher or her professor at any time if I have any further questions about the project or my participation in it.

Name Signature
Date
Relationship to the child

APPENDIX G

PARENT DEMOGRAPHIC FORM

Part A:

a. Your name

b. Address at which you can be reached

c. Telephone number where you can be reached

Part B: Information about your child receiving services at Tennessee Early Intervention System (TEIS)

a. Date of birth : (month) (day) (year)

b. Sex ( )male ( )female

c. Order of birth of the child

d. Indicate the number of siblings of your child if any

Name	Sex	Birth date of siblings

e. Reason for obtaining services for your child from TEIS

f. Age of your child at the time of referral to TEIS

g. Other kinds of services your child is receiving at present (for example: occupational therapy or speech therapy).

Part C: Information about your family

a. Indicate the one that best describes your family.
Dual parent
single parent
extended family in the home

b. Your relationship to the child receiving services.
natural parent adoptive parent
step parent foster parent
other(please specify)

Part D: Information about Education

	Yours	Your Partner's
Graduate/professional		
College/University		
Partial College		
High School		

Part E: Information about Occupation
Yours
Your Partner's

Part F: Information about ethnic background/race
Yours
Your Partner's

APPENDIX H

PARENT SELF-INTERVIEW INFORMATION SHEET

* **Who will conduct the self-interview?**

  Parent/parents or primary caregiver of infants and toddlers with special needs.

* **How to conduct the self-interview?**

  a) Use the tape recorder provided by the researcher (please check the tapes and batteries before use).
  b) Recording your responses to the questions in the Parent Self-Interview Guide.

* **When to conduct the self-interview?**

  After each time a service provider (e.g., service coordinator or therapist or physician or medicaid personnel) contacts you to provide services to your child and your family from the time your child has been referred to Tennessee Early Intervention System (TEIS).

* **Where to conduct the self-interview?**

  In a place where there are no disturbances, preferably soon after the contact or on the same day (e.g., while the child is taking a nap or while driving in your car).

* **How long does it take to conduct a self-interview?**

  The interview should take no more than 15 minutes.

* **When will the recorded tapes be collected?**

  The recorded tapes will be collected on a weekly basis (at the end of every week) until the IFSP meeting is held.

* **How will the recorded tapes be collected?**
  Two choices: a) The tapes will be picked by the researcher (at the time and place convenient to the parents), OR b) Parents will mail the tape to the researcher by enclosing it in the stamped, self addressed envelope provided by the researcher.

  SUGGESTION .....Please store the tape where you do not anticipate any damage to it.

PARENT SELF-INTERVIEW GUIDE

Record the events by responding to the questions listed below:

1. Your Name
2. What is the **name of the service provider** with whom you had a meeting or contact? Whom does she/he work for? What does she/he do?
3. What **date** did you contact the service provider?
4. What was the **type of contact** with the service provider?
   a) telephone, b)home visit, c) office visit, d) through the mail, e)others, please specify.
5. What was the **time of day** at which the service provider was contacted?
6. **How long** was the contact? (Approximate **duration**)
7. **Who was present** during the contact? (member/members of your family, friends, neighbors or others)
8. **What occurred** during the contact? (e.g.,activities/topics) Please explain.
9. **What are your impressions and feelings** about the contact? Please explain.
   (For example: Was the purpose of the meeting served? Was your questions answered? Was the visit helpful or overwhelming or frustrating? any other)
10. **What was the day and time** at which the self-interview was recorded?

APPENDIX I

PARENT INTERVIEW SCHEDULE

1. Tell me what was the experience like from the time your child was referred for services until the first IFSP document was developed.

   Probe:

   How did you learn that an IFSP could be developed for your child and your family?

   How did you see your involvement in the development of an IFSP for your child and your family?

   What kinds of information did you give to the service coordinator?

   What kinds of information did you receive from service coordinator?

2. What are some aspects you liked most (positive) about this process you have experienced?

3. What are some aspects that were of the concern to you about this process?

4. Have you felt uncomfortable or uneasy as you interacted with service coordinators?

5. What are some ways in which service coordinators could assist you in enhancing your and your family's involvement in this process?

   Probe:What do you think that service coordinators should do differently?

APPENDIX J

SERVICE COORDINATOR INTERVIEW SCHEDULE

1. Tell me what is a typical IFSP process like at TEIS from the time the child is referred for services until the original IFSP document is developed in the meeting.

   Probe:

   How are parents informed about the IFSP process?

   How are IFSP meetings planned?

   What kinds of information do you share with families before and during the IFSP meeting?

   What kinds of information do you receive from families?

   What are some problems associated with meeting the requirements of IFSP component of the law?

   How do you encourage the parents to take on a collaborative role in this process?

2. What is your role in this process?

3. Tell me what was the IFSP process like with the (particular) family you have been working.

4. Tell me about one of the most successful initial IFSP meetings you have had with a family.

5. Tell me about one of the least successful initial IFSP meetings you have had with a family.

6. What has been your experience as you interact with families?

7. What are some skills and practices you have found to be effective as you interact with these families in developing an IFSP?

8. What are some problems you have faced as you interact with families during this process?

APPENDIX K

STATUS FORM

DISTRICT CODE_____ CHILD CODE_____ SER COOR._____

CALL TAKEN BY:_____ REFERRAL DATE:_____

REF. BY:_____ AGENCY:_____ PHONE:_____

ADDRESS:_____

CHILD'S NAME_____MI_____LAST NAME_____

SEX:___ AGE:_____ DOB:_____

NAME OF PARENT/GUARDIAN:_____

ADDRESS:_____CITY:_____

ZIP:_____ COUNTY:_____ PHONE: (H/W)_____

REASON FOR REQUEST:_____

_____

_____

DIAGNOSIS:_____

AGENCIES SERVING FAMILY: 1)_____

2)_____3)_____

4)_____5)_____

DOES CHILD HAVE IFSP: _____YES _____NO

HAS CHILD BEEN EVALUATED: _____YES _____NO

TENNCARE HMO _____ #_____

OTHER COMMENTS:_____

_____

_____

_____

MINIMAL DATA FORM

CALL TAKEN BY: _____ TODAY'S DATE: _____

CALLER'S NAME: _____ PHONE: _____ RELATIONSHIP TO CHILD: _____

CHILD'S NAME: _____ SEX: _____ AGE: _____ DOB: _____

NAME OF PARENTS/GUARDIANS: _____

ADDRESS: _____

CITY: _____ ZIP: _____ COUNTY: _____

PHONE: (home) _____ (work) _____ (IF NO PHONE, NUMBER WHERE PARENT/GUARDIAN CAN BE REACHED)

LOCATION OF PHONE: _____ PHONE NUMBER: _____

BEST TIME TO REACH PARENT/GUARDIAN: _____

REASON(S) FOR REQUEST (LIST SPECIFIC CONCERNS): _____

PARENT WILL CONTACT POE	DATE OF CONTACT:
POE WILL CONTACT PARENT	DATE OF CONTACT:

HAS CHILD BEEN SCREENED? YES NO DON'T KNOW

(If YES, provide CHILD FIND information)

CHILD FIND SOURCE: _____ CONTACT PERSON: _____

ADDRESS _____ PHONE: _____ DATE ADMINISTERED: _____

HAS THIS CHILD/FAMILY PREVIOUSLY RECEIVED OR IS HE/THEY CURRENTLY RECEIVING SERVICES? YES NO DON'T KNOW

(If YES, provide SERVICE information)

PROVIDER NAME	ADDRESS	PHONE	SERVICES RECEIVED	DATE OF SERVICES

ACTION TAKEN	EXPLANATION
INELIGIBLE DUE TO AGE - REFERRED	
REFERRED FOR SCREENING	
REFERRED FOR EVALUATION	
FOLLOW-UP TO FAMILY	
FOLLOW-UP TO REFERRING AGENCY	
PARENT CHOSE NOT TO ACCEPT SERVICES	

REFERRED TO: _____ CONTACT PERSON: _____

PHONE: _____ DATE REFERRED: _____ DATE OF FOLLOW-UP: _____

	PARENT WILL CONTACT APPROPRIATE SERVICE PROVIDER(S)		
	AUTHORIZATION FOR RELEASE OF INFORMATION FORM SENT TO LEGAL GUARDIAN	DATE SENT	DATE RETURNED
	AUTHORIZATION FOR RELEASE OF INFORMATION SIGNED IN PERSON	DATE	OBTAINED BY:

Tennessee's Early Intervention System

Date_____

Dear_____:

Your child meets the eligibility criteria for inclusion in the Tennessee's Early Intervention System. Based on the information gathered during the initial visit and/or obtained from the developmental evaluation, the results/recommendations are as follows:

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____
7. _____
8. _____

We will be glad to assist you in whatever manner you deem appropriate. Please feel free to contact the staff of Tennessee's Early Intervention System at any time.

Sincerely,

_____
TEIS Staff Member

Initial Plan of Action

Tennessee's Early Intervention System

Child's Name: _____
Date of Birth: _____
Child's SS#: _____
Child's TennCare# & MCO: _____
Parent's Name(s): _____
_____
Parent(s) SS#: _____
_____
Address: _____
_____
Phone: _____

Date: _____
To: _____
From: _____

On _____, I met with _____.
the parents of _____. During this meeting we discussed the role of TEIS and _____
_____
_____

At this time, the family wants me to help them to: _____
_____
_____
_____
_____
_____
_____
_____

This is our initial plan of action. Please let me know if I can be of further assistance.

I give my permission to release _____*the information above* _____*intake information*
to the following offices for one year:

_____ Social Security Office
_____ Lifeline Phone Service
_____ Family Support Services
_____ Department of Human Services
_____ TennCare: _____
_____ Children's Special Services
_____ Health Department
_____ Early Intervention Program: _____
_____ Head Start
_____ Physician, Dr. _____
_____ Other: _____

_____ _____
Parent or Guardian Signature **Date**

_____ _____
Witness **Date**

State of Tennessee
Central Intake Form

CHILD'S NAME: _____ State and County of Residence at Birth. _____

Date of Birth: _____ Birth Certificate #: _____

Sex: _____ Race: _____ Referral Source: _____

Address: _____

_____ Social Security #: _____
City State Zip Code

FATHER'S NAME: _____ Social Security #: _____

Address: _____ Employer/Company: _____

_____ Work Shift: _____ Monthly Income: _____
City State Zip Code

Phone: _____ Address: _____

Marital Status: ( ) Single ( ) Married
( ) Divorced ( ) Widowed

_____
City State Zip Code

Phone: _____

MOTHER'S NAME: _____ Social Security #: _____

Address: _____ Employer/Company: _____

_____ Work Shift: _____ Monthly Income: _____
City State Zip Code

Phone: _____ Address: _____

Marital Status: ( ) Single ( ) Married
( ) Divorced ( ) Widowed

_____
City State Zip Code

Phone: _____

Child in State Custody? If yes, Department: _____

Does Child Have a Legal Guardian? If yes, Name _____

Address: _____ Phone: _____

Employer: _____

Please list all members of the household:

Name	Birthdate	Sex	Relationship to Child	School/Occupation

Language Spoken in Home: _____

Evaluation/Assessment Inform on (please attach results):

Instrument:	Date Performed:	Performed By:

Eligibility Determination:

Diagnosed Condition: _____

MEDICAL HISTORY: (include dates or age where applicable)

Measles: _____ Rubella: _____ Mumps: _____ Chicken Pox: _____

Frequent sore throat: _____ Ear ache: w/drainage: _____ w/o: _____

Scarlet Fever _____ Bronchitis: _____ Pneumonia: _____ Asthma: _____

Urinary Infections: _____ Rheumatic Fever: _____ Heart Disease: _____

Diabetes: _____ Epilepsy: _____ Tuberculosis: _____ Injury: _____

Seizures: _____ Seizure Medication (s): _____ Surgery: _____

_____ Other: _____

Please attach a copy of immunization record, additional medical history, and brief family medical history (See key for completing intake form for additional information).

Length of pregnancy: _____ Birth weight: _____ Length of hospital stay: _____

Concerns/complications during pregnancy and/or birth (please explain): _____

Medicare #: _____ Medicaid #: _____

SSI #: _____ CSS#: _____ Model 2000: _____

Foodstamps: _____ Champus: _____ WIC: _____ AFDC: _____

Other: _____

Insurance Company	Policy #	Group #	Address:

Primary Physician/Medical Home		Specialty	Address	Phone
Other Physicians Consulted				

Service Providers (services which are currently being provided for the child):

Agency/Individual	Contact Person	Phone	Service Being Provided	Address

Transportation Requirements (please specify): _____

Child Care Services:

Agency/Individual: _____ Phone Number: _____

Address: _____

Signature/Title of Person Completing this Form: _____ Recorder

Information Provided By: _____ Relationship to Participant: _____

Information Gathered By: _____ Date: _____

CENTRAL INTAKE FORM

Child's Name: _____ Date of Birth: _____

Place of Birth: _____ Sex: M F Race: Caucasian Black Hispanic Asian Other: _____
(City) (State)

Birth Certificate #: _____ Social Security #: _____

Address: _____ Language spoken in the home:

_____ TN _____ English Spanish Other: _____
(City) (Zip Code)

Father's Name: _____ Social Security #: _____

Address: _____ Employer: _____

_____ Work Shift: _____ Monthly income: _____
(City) (State) (Zip Code)

Home Phone: _____ Work Address: _____

Work Phone: _____ _____
(City) (State) (Zip Code)

Marital Status: Single Married Divorced Widowed

Mother's Name: _____ Social Security #: _____

Address: _____ Employer: _____

_____ Work Shift: _____ Monthly Income: _____
(City) (State) (Zip Code)

Home Phone: _____ Work Address: _____

Work Phone: _____ _____
(City) (State) (Zip Code)

Marital Status: Single Married Divorced Widowed

Child in State Custody? yes no If yes, Dept. & Caseworker: _____

Legal Guardian? yes no Name of Legal Guardian: _____

Address: _____ Guardian Employer: _____

Guardian Phone: _____

_____
(City) (State) (Zip Code)

Members of the household:

Name	Birthdate	Sex	Relationship to Child	School/Occupation

Pregnancy History

Length of Pregnancy: _____ Birth Weight: _____ Length of Hospital Stay: _____

Please check (√) all that apply:

_____ Anemia	_____ Medication	_____ Normal Delivery
_____ Early Labor	_____ Emotional Stress	_____ Toxemia
_____ Accident or Injury	_____ Bleeding	_____ Infections
_____ High Blood Pressure	_____ Rh Incompatibility	_____ Diabetes
_____ Alcohol/Drug Use	_____ Nutritional Problems	_____ Caesarian Delivery
	_____ Hospitalization	_____ Breech Delivery

Describe the items checked above. Also please explain any concerns or complications during pregnancy or birth. _____

_____

_____

_____

_____

_____

Medical History of Child

Condition	Date or Age	Condition	Date or Age	Condition	Date or Age
Measles		Frequent Sore Throat		Heart Disease	
Rubella		Ear Infection with Drainage		Diabetes	
Mumps		Ear Infection w/out Drainage		Epilepsy	
Chicken Pox		Bronchitis		Seizures	
Scarlet Fever		Pneumonia		Injury	
Rheumatic Fever		Asthma		Hospitalization/Surgery	
Urinary Infections		Tuberculosis		Other	

Medication History

Please list prescribed medications and frequently used over-the-counter medications for this child during the past 6 months.

Date	Medication/Dosage	Reason Prescribed	Physician

Physician Information

Child's Physicians	Name	Specialty	Address	Phone
Primary Physician				
Other Physicians Consulted				

Any other information concerning the child's medical history: _____

_____

_____

_____

Service Providers

(Please list services which are currently being provided for the child):

Agency/Individual Contact Person Phone Service Provided Address

_____

_____

_____

_____

_____

_____

_____

Child Care Service

Agency/Individual: _____

Phone: _____

Address: _____

_____

Transportation

Please explain what is needed: _____

_____

_____

Eligibility Determination Plan

_____ Eligible by Diagnosis: Diagnosed Condition _____

_____ Referred for Eligibility Evaluation to: _____

_____ Seeking Informed Clinical Opinion from: _____

_____ Other: _____

Evaluation/Assessment Information

Type of Evaluation	Date Performed	Performed By:	Report Rec by TEIS
			Yes, attached No
			Yes, attached No

Resources Available to Family

Resource	At Intake	Number	Resource	At Intake	Number
TennCare: Blue Cross/ Blue Shield	Y N		SSI	Y N	
TennCare: HealthNet	Y N		Model 200	Y N	
TennCare: MedAccess Plus	Y N		Champus	Y N	
TennCare: Advantage Care	Y N		WIC	Y N	
Medicare	Y N		Foodstamps	Y N	
CSS	Y N		AFDC	Y N	

Insurance Company	Policy Holder Name	Policy #	Group #	Address

Other concerns or comments: _____

_____

Signature/Title of Person Completing this Form: _____ *Please remember to date this form. Thank you.*

Date: _____

Information Provided By: _____ Relationship to Child: _____

For Office Use

Child's Name: _____ Child's SS Number: _____

Screened: _____ Prior to referral _____ By TEIS Child Find _____ Rescreened _____ Not screened

Receiving services at Referral? _____yes _____no

Family Needs Survey

(Revised, 1990)

Child's Name:_____ Person Completing Survey:_____

Date Completed:___/___/____ Relationship to Child: _____

Dear Parent:

Many families of young children have needs for information or support. If you wish, our staff are very willing to discuss these needs with you and work with you to identify resources that might be helpful.

Listed below are some needs commonly expressed by families. It would be helpful to us if you would check in the columns on the right any topics you would like to discuss. At the end there is a place for you to describe other topics not included in the list.

If you choose to complete this form, the information you provide will be kept confidential. If you would prefer not to complete the survey at this time, you may keep it for your records.

TOPICS	Would you like to discuss this topic with a staff person from our program? No	Not Sure	Yes
Information			
1. How children grow and develop			
2. How to play or talk with my child			
3. How to teach my child			
4. How to handle my child's behavior			
5. Information about any condition or disability my child might have			
6. Information about services that are presently available for my child			
7. Information about the services my child might receive in the future			
8. More time to talk to my child's teacher or therapist			
Family & Social Support			
1. Talking with someone in my family about concerns			
2. Having friends to talk to			
3. Finding more time for myself			
4. Helping my spouse accept any condition our child might have			
5. Helping our family discuss problems and reach solutions			
6. Helping our family support each other during difficult times			
7. Deciding who will do household chores, child care, and other family tasks			
8. Deciding on and doing family recreational activities			
9. Meeting with a counselor (psychologist, social worker, psychiatrist)			
Financial			
1. Paying for expenses such as food, housing, medical care, clothing, or transportation			
2. Getting any special equipment my child needs			
3. Paying for therapy, day care, or other services my child needs			
4. Counseling or help in getting a job			
5. Paying for babysitting or respite care			
6. Paying for toys that my child needs			

Topics	Yes	Not Sure	No
Explaining to Others			
1. Explaining my child's condition to my parents or my spouse's parents			
2. Explaining my child's condition to his or her siblings			
3. Knowing how to respond when friends, neighbors, or strangers ask questions about my child			
4. Explaining my child's condition to other children			
5. Finding reading material about other families who have a child like mine			
Child Care			
1. Locating babysitters or respite care providers who are willing and able to care for my child			
2. Locating a day care program or preschool for my child			
3. Getting appropriate care for my child in a church or synagogue during religious services			
Professional Support			
1. Meeting with a minister, priest, or rabbi			
2. Meeting with a counselor (psychologist, social worker, psychiatrist)			
3. More time to talk to my child's teacher or therapist			
Community Services			
1. Meeting and talking with other parents who have a child like mine			
2. Locating a doctor who understands me and my child's needs			
3. Locating a dentist who will see my child			

Please list other topics or provide any other information that you feel would be helpful to discuss.

Is there a particular person with whom you would prefer to meet? _____

Thank you for your time.

We hope this form will be helpful to you in identifying the services that you feel are important.

The Family Needs Survey was developed by Don Dailey, Ph.D. and Rund Simeonsson, Ph.D.
For additional information, write the authors at the Frank Porter Graham Child Development Center, CB#8180
University of North Carolina, Chapel Hill, NC 27599

How Can We Best Serve You?

Dear Parent:

Many families of young children have needs for information or support. Listed below are some needs commonly expressed by families. Please check any items you would like help with. At the end there is a place for you to describe other topics not included in the list.

If you choose to complete this form, the information you provide will be kept confidential.

Child's Name: _____ Date: _____

Our family would like to know if we qualify for help with:

	Check (√)
adult education/GED classes	_____
child care	_____
clothing	_____
food bank	_____
food stamps	_____
job training	_____
housing	_____
special equipment	_____
transportation	_____
utilities (phone, electric)	_____
WIC (nutritional supplements)	_____
other:_____	_____

Our family would like more information about how we can help our child with:

her/his growth & development	_____
her/his behavior	_____
her/his disability or delay	_____
other:_____	_____

Our family would like help in locating:

child care	_____
a preschool program	_____
respite care	_____
special equipment	_____
other:_____	_____

(Please continue on the back.)

Our family would like help in locating the following special services:

	Check (√)
audiologist	_____
a comprehensive assessment	_____
contact with another parent or support group	_____
CPR training	_____
a dentist	_____
a doctor	_____
early intervention teacher	_____
home nursing services	_____
individual or family counseling	_____
occupational therapist	_____
physical therapist	_____
special equipment or supplies	_____
speech pathologist	_____
vision specialist	_____
other:_____	_____

Our family would like help in planning for our child's future education by:

locating the best setting for him/her	_____
working to transition him/her into school when the appropriate age is reached	_____
other:_____	_____

Please list other topics or provide any other information that you feel would be helpful to discuss.

_____

_____

Thank you for your time.

INDIVIDUALIZED FAMILY SERVICE PLAN

Child's Name _____

IFSP Meeting Date: _____

IFSP Type: _____ **Initial** _____ **Annual**

Planned Review Dates:

_____ **Six Month Review**

_____ **Annual**

When Transition Plan is initiated, enter date: _____

When Review/Change Form is completed & attached, enter date for each form:

_____ _____ _____ _____

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IDENTIFYING INFORMATION

Child's Name: _____

Parent's Name(s): _____

Address: _____
Street

_____ _____ _____
City State Zip

_____ _____
Phone County

Child's Birthdate: _____ Child's Present Age: _____
m/d/y yr/mth

	Part H/89-313	DMR	CSS
Eligibility	Meets Part A of Definition _____ Meets Part B of Definition _____ Informed Clinical Opinion___	DMR _____	CSS _____
Referral Date	_____ m/d/y	_____ m/d/y	_____ m/d/y
Referral Source	_____	_____	_____

DOCUMENTATION

IFSP Team Member- Signature	Agency/ Title	Date	Contributed but not present/method	Fully Agree	Area(s) of Concerns/ Comments
	/Incoming Service Coordinator				
	Parent				
	Parent				

Informed Parental Consent

I have participated in the development of this IFSP and understand its contents. I agree to its implementation to the degree noted above.

_____ _____ _____ _____
Parent Date Parent Date

Part H/89-313 Only

I have been informed of & understand my rights as a parent in Tennessee under Part H of P.L. 99-457. I have received a copy of Rights of Infants and Toddlers with Disabilities.

_____ _____ _____ _____
Parent Date Parent Date

Designated Service Coordinator/Agency and Rationale _____

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Instructions
COVER PAGE
Enter:
--child's name (first, middle, last)--(2 spaces provided for agency filing purposes)
--IFSP meeting date
--IFSP type-check whether this is an initial or annual IFSP
--planned review dates--approximate dates for the six month review and for the next annual IFSP
Transition Plan--when a transition plan is developed, enter date the transition plan was initiated.
Review/Change Form--as IFSP reviews are conducted or changes/additions made to identifying information, complete a Review/Change Form (p.6), attach it to IFSP document, and enter date each form was completed.

Instructions
PAGE ONE: IDENTIFYING INFORMATION and DOCUMENTATION
(Purpose: To have an accurate recording of all those involved in the IFSP process so each can be reached for additional help and information. Also for administrative purposes for state/federal laws.)
Identifying Information
Provide requested information regarding child's name, address, birthdate, age. Enter parent's name(s). *Parent means a parent, a guardian, a person acting as a parent of a child, or a surrogate parent who has been appointed in accordance with 303.406. This does not include the State if the child is a ward of the State.* (from P.L.99-457-Part H Regulations) Persons acting as a parent include grandparents or stepparents with whom the child lives as well as persons who are legally responsible for the child's welfare. For a child in state custody, the biological parents, unless their right to make decisions about the child have been severed by the court, must be included in decisions about early intervention services for the child. If the parental rights have been severed, a surrogate parent must be appointed to ensure the child's rights are protected. Employees of state agencies (i.e.-DHS caseworkers) or foster parents (unless they are appointed as a surrogate parent) may not replace parents in the IFSP process.
Eligibility, Referral Date and Referral Source
Enter a check next to the eligibility guideline(s) the child meets (some children may meet more than one eligibility, check all applicable). Enter referral date(s) and source(s) (state specific agency, professional, person making referral).
Documentation--(TO BE COMPLETED AT END OF IFSP MEETING)
All members of the IFSP team should:
1. Sign (if a team member contributed, but was not present at the IFSP meeting, see #4).
2. Enter capacity in which member is serving as IFSP team member. Members who are representing an agency or other organization should enter the agency name and their title.
3. Enter date.
4. If team member contributed, but was not present at IFSP meeting, print name in IFSP Team Member-Signature column and describe the method by which the member contributed (conference call, written input, telephone call, etc.).
5. If the team member fully agrees with the IFSP, enter a check under "Fully Agree". If the team member disagrees with part of the IFSP, use the space indicated to document area(s) of concern (see below regarding parent(s) consent). Attach additional pages if more space is needed for comments.

Informed Parental Consent--(TO BE COMPLETED AT END OF IFSP MEETING)
The contents of the IFSP must be fully explained to the parents and informed written consent from the parents must be obtained prior to the provision of services described in the IFSP. If the parents do not provide consent with respect to a particular service, that service may not be provided. The services to which parental consent is obtained must be provided. (from P.L.99-457-Part H Regulations) Parents should sign and date in this "Informed Parental Consent" section and sign, date and enter their comments in the Documentation section as described in #5 above.
Rights Statement--(TO BE COMPLETED AT END OF IFSP MEETING)
Parents of infants/toddlers served with Part H or 89-313 funds must be informed of their rights in Tennessee under Part H of P.L. 99-457 and be given a copy of the brochure, Rights of Infants and Toddlers with Disabilities. The parent's signature here indicates that these procedural safeguards have been followed.
Designated Service Coordinator and Rationale--(TO BE COMPLETED AT END OF IFSP MEETING)
Enter name of designated service coordinator/agency and reason team selected this person.

PRESENT LEVELS OF DEVELOPMENT
(Strengths and Needs)

Child's Name _____

Health Within Normal Limits By _____ Date_____ Chron. Age _____ (Corr. Age)____	**Communication Development (Speech/Language)** Within Normal Limits By _____ Date_____ Chron. Age _____ (Corr. Age)____
Physical Development-Fine Motor Within Normal Limits By _____ Date_____ Chron. Age _____ (Corr. Age)____	**Cognitive Development** Within Normal Limits By _____ Date_____ Chron. Age _____ (Corr. Age)____
Physical Development-Gross Motor Within Normal Limits By _____ Date_____ Chron. Age _____ (Corr. Age)____	**Social/Emotional Development** Within Normal Limits By _____ Date_____ Chron. Age _____ (Corr. Age)____
Vision Within Normal Limits By _____ Date_____ Chron. Age _____ (Corr. Age)____	**Adaptive Development** Within Normal Limits By _____ Date_____ Chron. Age _____ (Corr. Age)____
Hearing Within Normal Limits By _____ Date_____ Chron. Age _____ (Corr. Age)____	**Other** By _____ Date_____ Chron. Age _____ (Corr. Age)____

Instructions
PAGE TWO: PRESENT LEVELS OF DEVELOPMENT (Strengths and Needs)
(Purpose: To get a current picture of the child from which a meaningful plan of action can be developed.)

A child's IFSP must include a statement of the child's present levels of physical development (including fine motor and gross motor skills, vision, hearing, and health status), cognitive development, communication development, social/emotional development, and adaptive (including feeding, dressing, toileting, etc.) development.

Record the name of the person who conducted the formal or informal screening, evaluation, or assessment which provided the information for the statement of development. Enter the date of the procedure and the child's chronological age at the time of the screening, evaluation or assessment. (If the child was more than two weeks premature and is age two years or under, enter corrected age.) "Within normal limits" may be circled to indicate this information, if the procedure so indicated. A narrative statement must also be provided.

Record the strengths and needs of the child in the developmental areas, based on information from the screening/evaluation/assessment procedures. These may be entered in narrative or list form. This information, along with the information regarding the family's resources, concerns, and priorities will be used in determining major outcomes. The "other" space may be used for any additional information, including the family's assessment of the child's present levels of functioning (especially if the family has chosen not to have a Summary of the Family Resources, Concerns, and Priorities discussed at the IFSP meeting).

Child's Name _____

SUMMARY OF FAMILY RESOURCES, CONCERNS, AND PRIORITIES RELATED TO ENHANCING THE DEVELOPMENT OF THE CHILD

Family did ☐ /did not ☐ agree to a voluntary family-directed assessment.
Family did ☐ /did not ☐ agree to the inclusion of the voluntary family-directed assessment in the IFSP.

Date of Voluntary Family-Directed Assessment _____

Participants _____ _____ _____ _____

Resources	Concerns	Priorities

Instructions

PAGE THREE: SUMMARY OF FAMILY RESOURCES, CONCERNS, AND PRIORITIES RELATED TO ENHANCING THE DEVELOPMENT OF THE CHILD

(Purpose: To be sure that the family's voice is heard, if the family so chooses, and documented in addition to those of the professionals on Page Two. This helps to assure a family focus.)

Information given in this summary is to reflect the resources, concerns, and priorities of the family as identified by the family. This information could come from two sources:

1) Prior to the IFSP meeting the family should have had an opportunity to voluntarily participate in a family-directed assessment of its resources, concerns, and priorities. The written assessment, as entered into the child's record, should be the result of a process of a developing partnership between the family and professional--a process which might include discussions, interviews, or a family needs assessment . If the family chose to participate in an assessment and if the family chose to have the assessment included in the IFSP meeting, this summary page can draw upon all the information discussed in the family assessment. Families also might choose to have only part(s) of the information discussed at the IFSP meeting.
2) If the family did not agree to a family assessment prior to the IFSP meeting, the resources, concerns, and priorities of the family members present at the IFSP meeting can be discussed and documented if the family so chooses.

Indicate, by checking either *did* or *did not* in the statements at the top of the page, the family's decisions concerning participation in a voluntary family-directed assessment and the inclusion of the assessment information in the IFSP meeting.

Enter the date of the family-directed assessment and the names of all who participated in the assessment, including family members and professionals. This may be the date when information from several sessions is summarized in written form.

Enter, either in narrative or list form, a summary of:

1) the resources of or available to the family, including formal/informal support systems, educational resources, personal resources of family members (for example, the mother does not work outside the home and is very motivated to take her child and has the time readily available to take her child to needed appointments, or the family is aware of their financial situation and is willing to accept financial help if it can be secured);
2) the concerns of the family, including concerns the family has regarding the child's situation (for example, the family is concerned that their child is not talking or communicating as they expected) and concerns the family has regarding their ability to cope with the child's situation (for example, the family has a very low income and is very concerned about its ability to pay for services their child needs);
3) the priorities of the family--following discussion of the concerns and resources of the family, prioritize those for which the family would like to develop a plan of action at this IFSP meeting (these will become part of the major outcomes on Page(s) Four).

OUTCOME/ACTION STEPS/SERVICES

Child's Name _____

Major Outcome #_____ Timeline (Target Date) _____ Review Date _____

_____ Modify Date _____ *Review Status _____

Action Steps	Person(s) Responsible

Services Related to Outcome	Required or Non-required	Provider	Starting Date	Expected Duration	METHOD			Payor	Review Date	Modify Date	*Review Status
					Environment	Frequency	Intensity				

* Review Status Key (1) on going (2) completed (3) delayed (4) unavailable (for non-required services only) (5) modified

PAGE FOUR: OUTCOME/ACTION STEPS/SERVICES--Instructions
(Purpose: To develop outcomes (goals and objectives) from prioritized concerns of the family and methods to reach those goals.)

Major Outcome

Based upon information discussed prior to and during the IFSP meeting and documented on Page 2 (Present Levels of Development--Strengths and Needs) and on Page 3 (Summary of Family Resources, Concerns, and Priorities), with the family identify major outcomes--changes the family and the other members of the team would like to see for the child and/or family. The major outcomes may range from broad, long-term goals to short-range objectives. Major outcomes should be written in commonly understood language which is family-friendly. Outcomes should be written with criteria included which could be used to determine whether the goal/objective was met. A separate page is to be used for each major outcome.

Enter

-major outcome--for example: Johnny will eat at least 5 different ground table foods at family meals
-timeline--the date by which the team hopes this outcome will be reached
-review date--when this outcome is reviewed, enter the date on which the review occurs (Page 5--Review/Change Form should also be completed on this date)
-review status--using the key at bottom of page, enter number indicating status of this outcome at review
-modify date--*If modifications are made to the major outcome and/or services (changes, additions, deletions) enter the date modified. If space allows on the original IFSP, enter modifications to major outcome(s) and/or services below the original outcome or service and have parent initial and date the modification. If space does not allow, attach and enter the modifications on an additional Page Four. Parent should sign and date.

Action Steps

List the steps, activities, strategies needed to achieve outcome, for example: 1) will accept placement of spoon and textured food in his mouth, 2) will accept 3 different textures in his mouth without gagging, 3) determine appropriate positioning for feeding, 4) adapt Johnny's high chair for feeding at dinner table.

Enter the name of person(s) responsible for each step, activity, or strategy.

Services Related to Outcome

Enter:

-services needed to achieve outcome. Include services required by Part H and also additional services not required by Part H. Non-required services might include those provided through informal supports and/or community resources/services. Also list services (not required by Part H only) needed but unavailable at this time
-required or non-required--enter an "R" if the service is required by Part H or an "N" if the service is not required by Part H--see listing of required services on Page 5 (Outcome/Service Summary Page)
-provider name--the agency or person recommended to provide the service
-date initiated--date on which service is scheduled to begin
-expected duration--approximate length of time (weeks/months) service is expected to last
-environment in which the service is to be provided--*to the maximum extent appropriate to the needs of the child, early intervention services must be provided in natural environments, including the home and community settings in which children without disabilities participate...natural environments means settings that are natural or normal for the child's age peers who have no disability.* (from P.L.99-457-Part H Regulations) Identify natural environment(s) by entering a * in front of the stated environment
-frequency--the number of sessions scheduled each week or month, whichever is most appropriate
-intensity--record the length of time a service is provided during each session and whether it is provided on a group or individual basis
-payor--by whom or how the provider will be compensated. Part H funds should be used only as a "last resort", after all other resources have been accessed

"Review Date", "Modify Date", and "Review Status" columns are to be filled in when reviews are held and/or modifications to the outcome and/or services are agreed upon (and documented with a Review/Change Form--page 6).

Enter:

-review date-- date on which review took place
-modify date--*see instructions under Major Outcome
-status at review--refer to Status Key and enter appropriate number

Key: C-Child
F-Family
C/F-Child and Family

OUTCOME/SERVICE SUMMARY PAGE

Child's Name_______________

MAJOR OUTCOME	Services to be Provided (required by Part H): Assistive Technology	Audiology	Family Training/ Counseling/Home Visits	Health	Medical (for diagnostic purposes only)	Nursing	Nutrition	Occupational Therapy	Physical Therapy	Psychological	Service Coordination	Social Work	Special Instruction	Speech/Language	Transportation	Vision	Non-required Services									
# ___																										
# ___																										
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REMINDER: UPON COMPLETION OF THIS PAGE AT THE IFSP MEETING, TURN BACK TO PAGE ONE TO ENTER DOCUMENTATION INFORMATION

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PAGE FIVE: OUTCOME/SERVICE SUMMARY PAGE

(Purpose: To have available at a glance all the services being provided or to be provided. This page is most helpful in keeping one informed of what is going on for the child and family.)

On the left hand column of this page, list the outcomes (by number and description) from Page(s) Four. Across the row, identify those services to be provided to the child by entering a "C", those services to be provided to the family by entering an "F", and those services which will be provided to child and family by entering "C/F".

Services which are required to be provided by Part H when needed are listed. List other non-required services which have been identified as beneficial to the child and/or family in the spaces provided.

If more than ten outcomes have been identified, add additional copies of this page to enter information.

REMINDER: UPON COMPLETION OF THIS PAGE AT THE IFSP MEETING, TURN BACK TO PAGE ONE TO ENTER DOCUMENTATION INFORMATION.

REVIEW/CHANGE FORM

Child's Name _____

Child Status _____ Inactive _____ Date inactive status began

Reason

_____ deceased
_____ no longer eligible
_____ not in Tennessee
_____ transition (Part B/Other)
_____ parent declined further service
_____ whereabouts unknown
_____ other (specify) _____

Date Form Completed _____

Reason Form is Used
Change in Child Status _____
Change in Identifying Information _____
IFSP Review _____

Enter any changes or additions to identifying information listed on Page 1 of IFSP.

IFSP REVIEW

Review Date _____

Review Type
_____ six month
_____ parent request
_____ provider request

Review Status
_____ continue IFSP
_____ modify IFSP

I have participated in the review of this IFSP.

_____ _____
Parent **Date**

I approve the review status indicated and consent to the modifications of outcome(s) and/or service(s) as noted in the IFSP.

_____ _____
Parent **Date**

_____ _____
Service Coordinator **Date**

Other IFSP Team Members Contributing to Review

Name	Title/Agency	Date	Method

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PAGE SIX: REVIEW/CHANGE FORM

(Purpose: To keep track of changes in information regarding the child and family and of reviews/changes made to the IFSP.)

This is a "multi-purpose" page. It is to be used to enter:

1) changes/additions to identifying information entered on Page One
2) information if there is a change in the Child Status
3) information regarding an IFSP Review

Enter date this form was completed in appropriate space on this page and on Cover Page. A separate form should be completed each time one is needed.

Enter a check to indicate reason form is used.

Child Status

If child's status becomes inactive, enter a check and the date inactive status began. Also indicate the reason for status change.

Changes/Additions

Use this space to enter any changes to identifying information recorded on Page One (address, phone, parent). Enter a slash through any outdated information on Page One when new information is entered on Page Six.

IFSP Review

Enter:

- review date
- review type
- review status--as determined during review

Signatures of parent and service coordinator are required. Space is provided for signatures and dates. The parent is to sign in two spaces. One indicates the parent's participation in the review and one is an informed consent statement indicating the parent's understanding of and consent to noted modifications. As noted in the instructions for Informed Parental Consent on Page One, modifications can be implemented only to the extent to which the parent consents. As modifications are entered on Page Four, the parent should initial and date those to which the parent consents.

Other IFSP Team Members Contributing to Review

Enter:

- name
- title and agency representing
- date contributed
- method contribution was made (for example: phone call, conference call, written review)

TRANSITION PLAN

Anticipated Date of Transition _____

Child's Name _____

Date Transition Planning Initiated _____

Date of Birth _____
m/d/y

Current Program _____ _____
Name Type

Program type(s) to be transitioned to _____

For children/families transitioning to Part B Services:
Date of notification of appropriate local educational agency (LEA) _____
Date of planning conference _____

Planned Transitioning Procedures	Implementor	Timeframe	Date Completed

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Transition Plan (cont.)

Child's Name _____

Transition Page # _____

Planned Transitioning Procedures	Implementor	Timeframe	Date Completed

Instructions

PAGES SEVEN AND EIGHT: TRANSITION PLAN

(Purpose: To serve as a record of transition plan development and implementation for programs and services for the child and/or family.)

Transition planning for a child already receiving early intervention services through an IFSP shall begin no later than the child's second birthday (referral to the local education agency [LEA] must also be made at this time for those children who are expected to enroll in public schools). For children who are referred and determined to be eligible for early intervention services after the age of two, a written transition plan is to be included in the initial IFSP.

Enter:

- anticipated date of transition
- date transition planning initiated (also enter date on Cover Page of IFSP)
- child's name and date of birth
- name and type of current program*
- type of program(s)* child and/or family to be transitioned to (all must be new to child and/or family)

*program types might include:

-Part B services	-Headstart	-primary health care
-home-based early intervention	-diagnostic/advisory clinics	-surgical care
-center-based early intervention	-home health care	-WIC program
-integrated pre-school	-hospitalization	-parent education
-regular pre-school	-mental health services	-parent support

As the transition plan is developed with the family, enter:

- planned transitioning procedures--the following should be considered for inclusion as appropriate:
  - -discuss with parents all available community program options
  - -meet with family and school personnel from the LEA regarding the LEA's resposibility for the provision of services at age three
  - -review and discuss procedural safeguards and parental rights and responsibilities related to transition (both Part H and Part B)
  - -make appointments to vist program site
  - -observe and meet with program personnel
  - -help family identify advantages/disadvantages of program choices
  - -identify, schedule and conduct evaluations/assessments/procedures to determine eligibility for programs
  - -identify and implement steps to help families access eligible and available services
  - -notify new program/school system
  - -transmit, with parental consent, to the LEA records and information necessary to ensure continuity of service
  - -transmit, with parental consent, to other programs and/or services records and information necessary to ensure continuity of service
  - -hold transition conference with new program
  - -identify strategies to help child and/or family adjust to new program and to facilitate communication and problem solving between families and service providers
- implementor--the person responsible for implementing procedure
- timeframe--include date to begin procedure and approximate length of time expected until completed
- date completed--enter date procedure was completed

For children/families transitioning to Part B services, also enter date of required notification of appropriate local educational agency and date of required planning conference. The planning conference may serve as the IEP/IFSP meeting for the local educational agency.

In the spaces provided, and continuing on Page Eight (Transition Plan, cont.), enter appropriate information.

IFSP CONFERENCE NOTES

Child's Name_____

Date _____

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VITA

Latha Keshav Bhushan was born in Bangalore, India, on May 11, 1959. In June 1979, she graduated from National College, Bangalore, receiving a Bachelors Degree in Psychology. In June 1981, she graduated with a Master of Arts Degree in Clinical Psychology from Jnana Bharathi, Bangalore University, Bangalore, India. In June of 1985, she received a Bachelor of Education Degree in Special Education from Shreemati Natibhai Damodhar Thackersay University, Bombay, India, and continued to work at the same University as a special educator. In 1987 she joined as a coordinator for a project serving the rural disabled and deprived children in southern India. In 1990 she entered The University of Tennessee at Knoxville, accepting a research asistantship in the Bureau of Educational Research.