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ABSTRACT

Service coordination in early intervention for infants and toddlers with disabilities is the focus of this training guide and accompanying videotape. Section 1 describes service coordination as defined by Part H of the Individuals with Disabilities Education Act, the various models or approaches to service coordination, the history of early intervention service coordination, and positive and negative aspects of service coordination. Section 2 details the individualized family service plan (IFSP) process and the four phases of service coordination. The philosophy underlying the IFSP process is discussed and strategies for working with families and the early intervention team are provided. Procedural safeguards in the IFSP are also reviewed. Section 3 provides strategies for enhancing communication with families who have children with special needs. This part also addresses teamwork, interagency communication, strategies for working with conflict, and leadership styles and skills. A problem-solving technique and "real life" scenarios are presented in section 4. Each section in the guide includes group activities and individual activities based on the information provided and lists of additional resources. The videotape depicts four scenarios that illustrate some of the challenges faced in the provision of early intervention service coordination; a video guide summarizes the scenarios and offers questions for group discussion. (Each section contains references.) (CR)

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ED 406 815



# A Training and Resource Guide

## for Enhancing Skills in

## Early Intervention Service Coordination

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# ACKNOWLEDGMENTS

Service coordination in early intervention is a complex and multifaceted topic. The thoughts, ideas, reactions and efforts of many people helped us to more fully reflect the intricacies of service coordination and we hope make this guide more practical and useful to others. The content and training activities are based on a series of field tests and feedback from numerous groups representing the different audiences for which the material is intended. The participation of each group enriched our experience and the development process. We would like to acknowledge and thank those that have helped us and to represent the needs of parents, providers, faculty, and policy makers in the development of the guide.

Parents, their participation and feedback, have been central to our vision of effective service coordination. The Parent Advisory and Review Panel provided ongoing feedback from the beginning of the project with input into the project's design and in each development step along the way. We would also like to thank the families who allowed us to use their pictures to brighten the pages of the guide. The people in the photos do not correspond to those mentioned in the text.

A training guide is only as useful as the degree to which it reflects the daily experience of parents and providers and the degree to which it provides practices and information that are directly applicable to their work together. The Community Validation Team made up of providers in the State helped immeasurably to assure that content was closely tied to practical service realities. Further input was provided by the volunteer training sites. The Milwaukee Women's Center, the Langlade County Birth To Three Program, the Portage Project of Cooperative Educational Service Agency 5 and the Bridges for Families Program in Madison gave of their time and expertise. They provided us a window to the daily efforts of providers and

families and the very real needs they face. We hope this work honors the complexity and worth of the work they do day in and day out.

Much of the training content in the guide is based on two field test courses that were conducted in the first two years of the project. The courses were designed for both returning practitioners who wanted to enhance their skills and new students who were about to enter the early intervention field. Professor Ann Hains of the University of Wisconsin in Milwaukee was the first faculty member to work with us in offering the course. Her help in organizing the sequence of content and flexibility in adapting the course material to the needs of students set the tone for the entire course development process. Professor David Franks at the University of Wisconsin at Eau Claire helped to provide the inspiration and support to take the course to another level. Because of his pioneering and adventurous spirit we were able to develop a simultaneously taught course in Eau Claire and Madison using compressed video technology. Professors Mel Morganbesser and Marsha Seltzer provided the support necessary to make the effort possible in Madison. Steve Siehr of DoIt in Madison provided the technical support and guidance to navigate the complexities of distance technologies.

Lastly, it was critical for us that the content in the guide reflect emerging best practices in early intervention and the spirit and letter of Part H of the Individuals with Disabilities Education Act (IDEA) which has established service coordination as a mandated service for all eligible families. The State and National Advisory members provided invaluable insight and information from a broader perspective to inform our work.

We hope that all who have worked with us in the development of this guide see the impact of their efforts and feel part of the sense of pride that we all feel in its production and dissemination.

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# OVERVIEW

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## OVERVIEW OF THE GUIDE AND THE PATHWAYS: SERVICE COORDINATION PROJECT



## GUIDE OVERVIEW

### The Guide's Purpose: Reasons You Need This Guide

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Service coordination—as defined by the Infant/Toddler Section (Part H) of the Individuals with Disabilities Education Act (IDEA)—can be carried out by providers from a wide range of disciplines and experiences. Yet service coordination represents a relatively new role for practicing providers, students intending to work in the field of early intervention, and parents of infants and toddlers with special needs. This guide provides information, activities, and practical resources to help these individuals increase their skills and knowledge to meet the challenges of early intervention service coordination.

### The Guide's Suggested Uses: A Multifaceted Resource

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This guide is useful for parent and service provider inservice training and for interdisciplinary and discipline specific preservice courses. Pathways staff has used the content, activities, and materials for a variety of successful training adaptations. The guide's content and activities can be tailored for participants who have varying levels of knowledge and skills. We encourage trainers to structure activities to make the best of the abilities each participant brings to the training.

We have designed trainings to include parents in the content delivery. Parent participation is invaluable; they add their perspective and experience to discussion. Parents as presenters in the training sessions are highly rated in all evaluations of the Pathways trainings. We highly recommend recruiting parents as participants as well as presenters.



### Inservice Training

Trainers providing service coordination inservice for health, education, and social services personnel will find this guide to be an invaluable resource. The guide can be used in part or in its entirety, although we have designed the sections to be self-contained. It can serve as a basis for inservice training, self-study by individuals new to the field of early intervention service coordination, or for program staff development (e.g., problem solving using the stories in Section IV or distributing the guide's resources for staff and families). We encourage inservice trainers to apply the content and activities in ways that meet their needs and the needs of the participants.

### Preservice Training

Faculty from a variety of departments associated with early intervention will find the guide a useful

source for curricula development and student training. The content and activities are appropriate for interdisciplinary courses as well. The guide can assist faculty in their development or preparation of lectures, course modules, or semester-long courses. Guide content can be infused into existing courses related to infants and toddlers with special needs and their families.

## The Guide's Language: The Words We Chose

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We describe people in a positive way throughout this guide. How we talk reflects how we think and vice versa. Therefore, we used "people first" language, mentioning the person before a description of that person (e.g., an infant with Down syndrome). With respect to gender, we alternated between the use of he and she (except where a specific person is referred to in the text) to avoid the awkward he/she. We intend the term "parent" to be inclusive of caregivers (e.g., mother, father, foster parent, grandparent), just as the term "family" includes all members that the family defines as members.

In naming groups, we selected terms that are currently and generally acceptable. However, preferences for naming a cultural group is a personal choice by group members and people from the same culture may have different preferences. We acknowledge race and ethnicity and the language that surrounds these concepts are controversial and in flux. The words chosen today may not be acceptable tomorrow. Throughout the guide we emphasize that **EACH PERSON AND EACH FAMILY IS INDIVIDUAL**. Every attempt was made to communicate with the guide's reader in a way that is respectful of diversity.

## PROJECT OVERVIEW

### Pathways: Service Coordination Project

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A series of federally funded projects, Pathways assists states in meeting their need for qualified and appropriately trained personnel to carry out their role as service coordinators in early intervention. Pathways staff work collaboratively with parents, early intervention providers, community agencies and programs, state agency personnel, and higher education faculty.

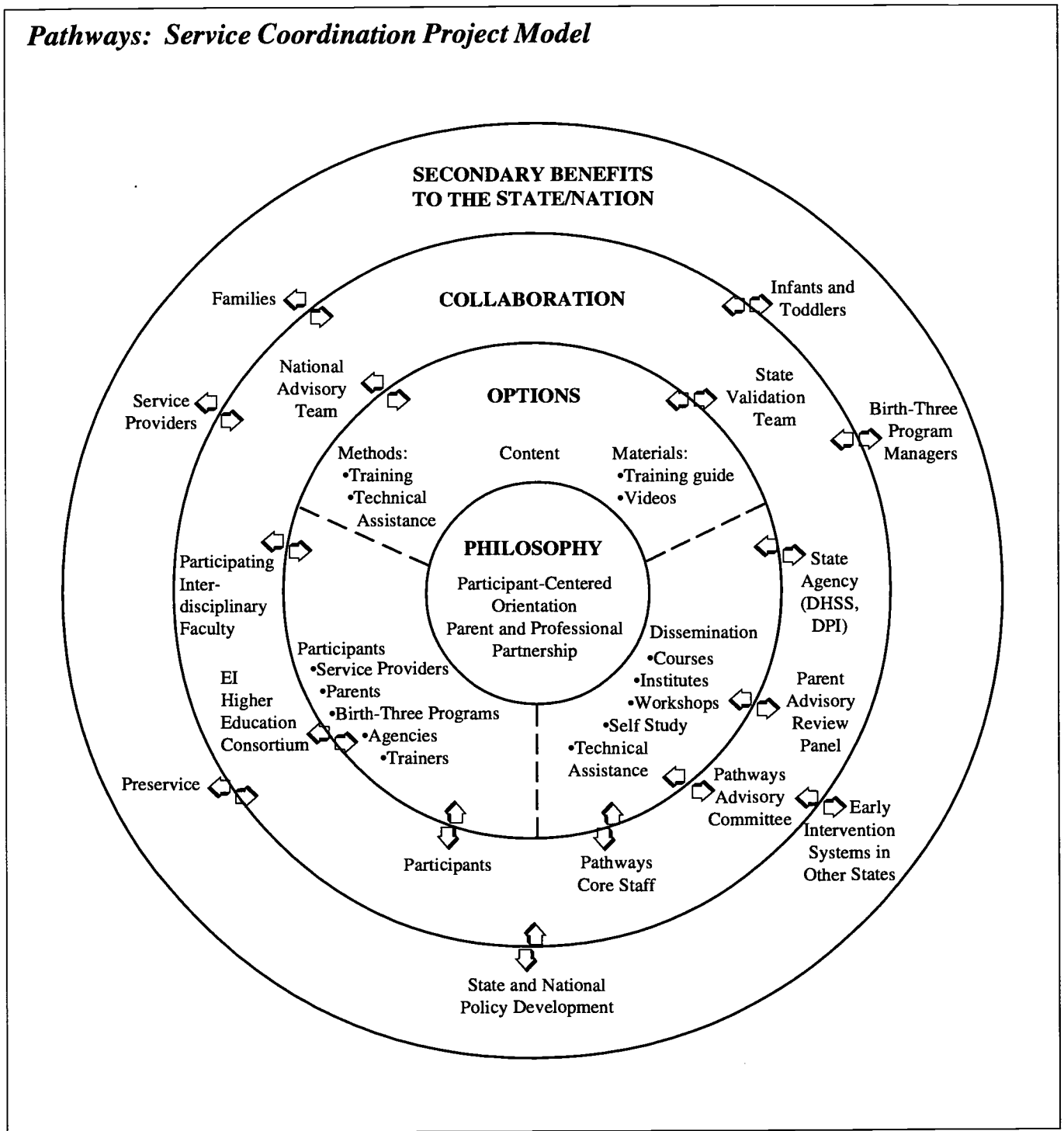
### Foundation Principles

As illustrated in Figure 1, Pathways is grounded in a participant-centered orientation and builds upon parent-professional partnerships. The *participant-centered orientation* is achieved by tailoring experiences to meet individual needs and by offering options so that participants exercise control and guidance over their learning. *Parent-professional partnership* is fostered through the employment of parents as staff and consultants, parent and professional teams in training and field experiences, and the inclusion of parents and professionals in all project activities. Parents are viewed as experts on the needs of their families and children. Their participation in the design, planning, and implementation of project activities helps insure that all materials and training practices fully recognize the critical, varied, and changing roles of parents.

*Collaboration* serves as the foundation of the Pathways training approach. There is a bi-directional flow of information and resources into and out of the project (see Figure 1). Information flows into the project from parents and service providers who are participants in training or technical assistance, state and national Advisory Group members, early intervention programs providing services to families, representatives from relevant state agencies, and university faculty. Information related to the service coordination content, activities, and materials is revised based on their input and flows out again to those involved in the input phase and to broader-based groups across the state and nation.

FIGURE 1

*Pathways: Service Coordination Project Model*



## Core Training Methods

Although there are numerous options for organizing and disseminating training content and activities, some techniques and methods are meant to be applied to each adaptation. These techniques and methods include the following:

- Model parent and professional partnerships in all training activities.
- Use self-assessment and individualized learning plans to assist participants in choosing and prioritizing the outcomes desired from their involvement in the training.
- Select field-based experiences to assist participants in meeting their course outcomes. Participants should keep a journal to track their activities and reflect on issues and questions arising from those experiences.
- Design flexible trainings to accommodate the various needs of the participants. Setting training agendas, in cooperation with participants, prior to each major topic area assists trainers in focusing on specific issues and questions from the participants.
- Apply a problem-solving approach based on family and service provider stories as a means for explaining theory and practices in service coordination.
- Thread adult learning principles (i.e., how adults prefer to learn and learn best; effective learning requires active participation, interaction and reflection) through all elements of training development and presentation.
- Employ training methods that promote the acquisition of new skills and knowledge. These include:
  - presentation of theory or description of skills or strategies (via lectures, the case method of instruction, panels, discussion),
  - modeling or demonstration of skills (demonstration, role play, video),
  - practice in simulated situations or use of family and professional stories,
  - structured and open-ended feedback (regular and consistent feedback; skill practice).

## Self-Assessment and Individual Learning Plan

One method of achieving the participant-centered orientation occurs as a result of a self-assessment by each participant of strengths, concerns, priorities, and resources. Based on the self-assessment, the participant develops an Individual Learning Plan with his desired outcomes for the course. A course facilitator acts as a "service coordinator" for the participant, providing information, support and access to material and human resources. The facilitator provides support at a level determined by the participant to meet his selected learning outcomes.

An example of the self-assessment used in the Pathways semester-long trainings is included in Appendix A. It consists of three components: "The Self-Assessment of Skills and Knowledge in Early Intervention Service Coordination," an "Individual Learning Plan," and "Reflections on the Individual Learning Plan and Future Directions." The third component of the self-assessment encourages participants to reflect on their accomplishments during the training and to set future outcomes. The intent is to encourage the participants to continue with the learning process. The Pathways self-assessment content and format can be modified to reflect the outcomes and targeted competencies for any particular training in service coordination.

## Core Training Content

What do service coordinators need to know and what skills do they need to meet the challenges they encounter? To answer this question, the following sources were tapped: (1) needs assessments and focus groups with a variety of stakeholders, including family members, service coordinators, program coordinators, higher education faculty, and local and state agency representatives; (2) state and national advisory committees (3) current literature, resources and practice in early intervention; (4) several field tests of the Pathways Project's curriculum with input from community sites; and (5) agenda setting with and feedback from each group of trainees.

A distillation of the information gathered from the sources described above shaped the curriculum that





has evolved over the years since the project was initiated. Two predominant categories of skills and knowledge emerged:

1. *Personal skills and knowledge*: values, attitudes, skills and knowledge related to families, disability, culture, communication, conflict management, grief, boundary setting, self care and stress reduction.
2. *Specific skills and knowledge related to service coordination*: the law; federal, state, and local early intervention system; the IFSP document and process; and management of the functions related to service coordination.

## Project Evaluation: Course Satisfaction, Effectiveness and Impact on Services

*Satisfaction* (degree to which participants found the trainings useful and enjoyable) was measured using both quantitative and qualitative measures. Satisfaction was consistently high across all trainings. On a 4 point scale (4=high, 1=low), most aspects of the trainings were ranked above 3.5. It should be noted that the second semester-long course was taught between two sites—at the University of Wisconsin-Madison and Eau Claire campuses—using interactive compressed video technology. This course had a lower overall rating of

satisfaction than other trainings. In specific evaluations designed to measure the use of the technology, it was clear that participants were less comfortable with this medium than with traditional class models.

*Course effectiveness* (changing participants' skills and knowledge) was measured for the semester-long courses only. These courses were taught in collaboration with the Universities of Wisconsin at Milwaukee, Madison and Eau Claire. (As mentioned previously, one of the courses was offered simultaneously via compressed video technology between the Madison and Eau Claire campuses). The self-assessment instrument was used as a pre- and post-test measure of the participants' perceived

change in their knowledge and skills related to service coordination. A matched pairs comparison of pre- and post-test scores revealed significant participant-perceived changes in their skills and knowledge in service coordination for both courses.

*Course impact* (effects on service coordination practice) was measured by offering participants in the semester-long courses the option of completing a follow-up questionnaire by mail or telephone interview three to four months following the last session. Participants completed a total of 32 questionnaires out of a possible 40 and expressed the following themes: personal knowledge related to service coordination increased; skills in working with families were enhanced; changes were made in the participants' early intervention program in areas such as organization of procedures to make them more family-friendly; and interagency collaboration and cooperation was developed or strengthened.

The *Pathways: Service Coordination Project* is an effective statewide training and technical assistance model that is consumer-driven, context-specific, and guided by collaborative efforts among parents and professionals. The *Pathways: Service Coordination Project* provides training opportunities for providers and parents interested in learning how to best negotiate the service delivery system. This guide shares the content and activities used by the project.



## SECTION I

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SECTION I

# EARLY INTERVENTION SERVICE COORDINATION: DEFINITIONS, MODELS, VIEWS, AND VISIONS

## OBJECTIVES

By completing this section, the reader will:

- understand service coordination as defined by the Infant/Toddler Section (Part H) of the Individuals with Disabilities Act (IDEA), a philosophy of family-centered care and current and emerging practice
- understand the various models or approaches to service coordination
- explore recent history regarding the beginning of early intervention service coordination
- consider possible positive and negative aspects of service coordination
- reflect on an analogy about service coordination as empowerment

## Service Coordination: Definitions

Service coordination is defined by federal and state rules and regulations as well as by philosophical perspectives and current and emerging practice. Let's start with how federal legislation defines service coordination.

According to Part H of IDEA, "service coordination (case management) services means the 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 service that are authorized to be provided under the State's early intervention program (34 CFR § 303.22)." Each child eligible under Part H and the child's family must be provided with a service coordinator who is responsible for coordinating all services across agency lines and serves as the single point of contact in helping parents to obtain the services and assistance they need. Service coordination is further defined by Part H as an active, ongoing process that involves:

- assisting parents of eligible children in gaining access to the early intervention services

and other services identified in the individualized family service plan (IFSP);

- coordinating the provision of early intervention services and other services (such as medical services for other than diagnostic and evaluation purposes) that the child needs or is being provided;
- facilitating the timely delivery of available services;
- continuously seeking the appropriate services and situations necessary to benefit the development of each child being served for the duration of the child's eligibility.

The service coordinator is responsible for the seven activities listed in Table 1. These activities define the primary functions of service coordination under the law.

TABLE 1.

### *The Seven Service Coordination Responsibilities*

- Coordinating the performance of evaluations and assessments;
- Facilitating and participating in the development, review, and evaluation of Individual Family Service Plans;
- Assisting families in identifying available service providers;
- Coordinating and monitoring the delivery of available services;
- Informing families of advocacy services;
- Coordinating with medical and health providers; and
- Facilitating the development of a transition plan to preschool services, if appropriate.

Whitehead (1996) offers a historical account of the evolution of service coordination and explains why several terms are used to describe the coordination of services. Definitions may vary by discipline or public agency purpose. Dunst (1991) explains that before the reauthorization of Part H of IDEA in 1991, when the title service coordinator officially replaced case manager, many states were using titles such as primary service provider, family resource coordinator, and care coordinator. Place (1994) pointed out that the change in terminology from case coordinator to service coordinator avoided the misleading label of families as "cases" to be "managed." As Johnson (1994) stated, "Whether we call it the service coordinator or case manager, there is a new set of skills and a much broader professional orientation than we have been accustomed to in the past" (p. 7). The term service coordinator encompasses the coordination of health care, human services, education, and other community supports and resources and is the preferred term in early intervention.

Here are several definitions of service coordination that differ from, or add to, the definition included in Part H of IDEA:

"Service Coordination (Case Management)—an active process for implementing the IFSP that promotes and supports a family's capacities and competencies to identify, obtain, coordinate, monitor, and evaluate resources and services to meet its needs" (Mc Gonigel, Kaufmann, and Johnson, 1991, p. 86).

"The service coordinator assists the family to integrate assessments by health, social/human services and education professionals and to coordinate and link needed services and funding sources. This process may reduce some duplication of evaluation and service, as well as help to determine gaps or service needs that no agency or system are meeting. Service coordination is designed to achieve continuity



of optimum, collaborative care by professionals from health, education, and human service systems" (Rosin, Wuerger, Schauls, Paisley, Sternat, Ditscheit, 1991, pp. 14-15).

"Case management is inherently a simple service—finding out what a family needs and helping them get it" (Morton, 1988, p. 13).

"Family-centered case management refers to services designed to help families locate, access, and coordinate a network of supports that will allow them to live a full life in the community" (Vohs, 1988, p. 41).

"Service coordinators (formerly called case managers) facilitate service delivery to families and represent the family in negotiations with public and private service providers" (Bowe, 1995, p. 24).

Duwa, Wells and Lalinde (1993) capture the shift in the role of the case manager to family-centered service coordinator in Table 2: Family-Centered Service Coordination. They see two major changes reflected in this shift: (1) families have the ability to find their own solutions, and (2) the service coordinator is free of preconceived ideas about what a family needs or should do. These notions at the core of family-centered service coordination are reflected in the vision of service coordination that unfolds in the Service Coordination: Views and a Vision section below.



**TABLE 2.**

<i>Family-Centered Service Coordination</i>			
Traditional Approach	Family Centered Approach	Strategies for Change Change	Expected Outcomes
Case Management is client-focused	Service coordination is family-focused and family-driven	View child in context of family and address needs of all family members	Needs of all family members are met, enhancing child outcomes
Several programmatic case managers	One family-identified service coordinator	Family chooses one primary service coordinator; family choice is respected	Coordinated, integrated, family-driven service coordination
Case management focus on child and family dysfunction	Service coordinator focus on child and family strengths and resources	Protocols and training specify process focused on strengths; tools are specified to help identify strengths	Family confidence increased; strengths are built upon increasing likelihood of success
Case manager offers only options their agency provides	Service coordinator provides options across agencies	Improve information sharing and cooperative agreements across agencies	Needs of whole family are met
Case manager views family in the context of the child's disability	Service coordinator views the child in the context of the family	Professionals are trained and skilled in meeting family concerns	Child outcomes are enhanced as family needs are met
Case manager provides family with information using professional jargon and shares only what they feel family can handle	Service coordinator provides unbiased, uncensored information in the family's language (both level and native)	Training is supplied so professionals skillfully provide information on family level	Family understands and has same information as professionals
Case managers make assumptions/decisions about what child needs	Service coordinator assists families in identifying their concerns, principles, and resources	Establish trusting relationship with family; identify most appropriate way to assist families in identifying their concerns, priorities, and resources	Family makes decisions resulting in increased control of their lives
Case manager must be trained professional	Service coordinator may be the patient(s), another family member, another family, or paraprofessional	Provide opportunity, ongoing skill building/training	Family choices are expanded

From Duwa, S., Wells, C., & Lalinde, P. (1993). *Creating family-centered programs and policies.* In D.M. Bryant and M.A. Graham (Eds), *Implementing Early Intervention from Research to Effective Practice.* New York: The Guilford Press. Reprinted with permission.

## Models or Approaches to Service Coordination

Federal and state laws guide the provision of service coordination in supporting families in negotiating the service delivery system. The federal law lists seven functions of service coordinators in their work with infants and toddlers who have special needs and their families (see Table 1 for a list of those functions). How caregivers and service coordinators work together in the service coordination process can vary from person to person, program to program, county to county, and state to state. There is no one approach to service coordination. Why might one or a combination of approaches be used rather than another? Some factors affecting how service coordination occurs include:

- Parents' or caregivers' desired level of involvement in service coordination
- State regulations and local program guidelines
- Statewide model of service coordination or local program decision
- State and program philosophy toward service coordination
- Program organizational and administrative structure
- Program logistics, such as geographic location, density of population, size and background of staff, number of resources, type of setting (urban vs. rural)
- Program history of case management, e.g., continuing existent systems, piggybacking early intervention onto existing systems
- Number of families provided service coordination by the service coordinator (i.e., caseload)
- Training and experience of the service coordinator

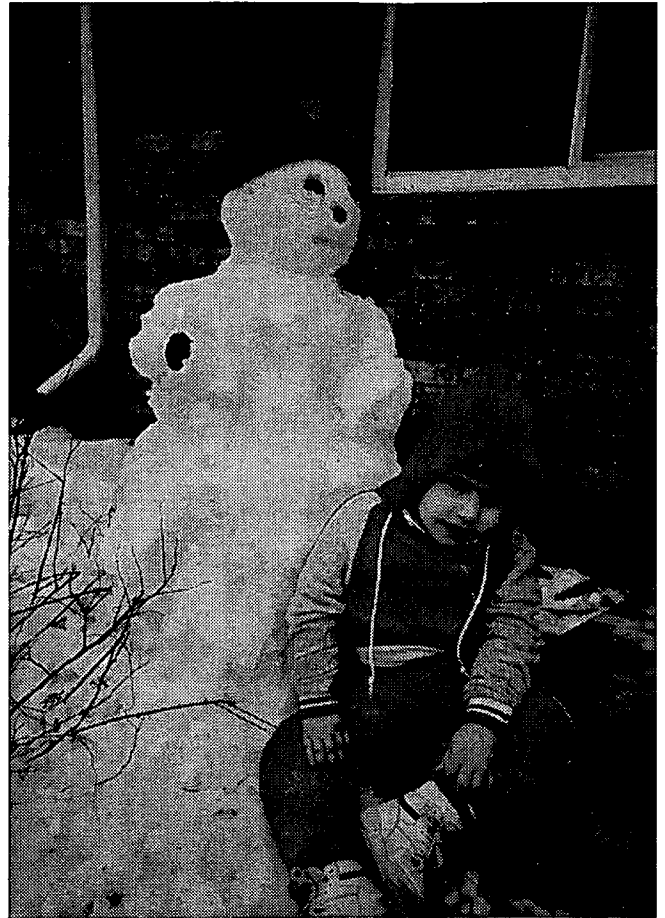


Table 3 lists some of the predominant models of service coordination being used in early intervention. For a more in-depth discussion of each of these models, see the chapter by Whitehead (1996).

TABLE 3.

### *Service Coordination Models*

Co-service Coordination

Interim Service Coordinator

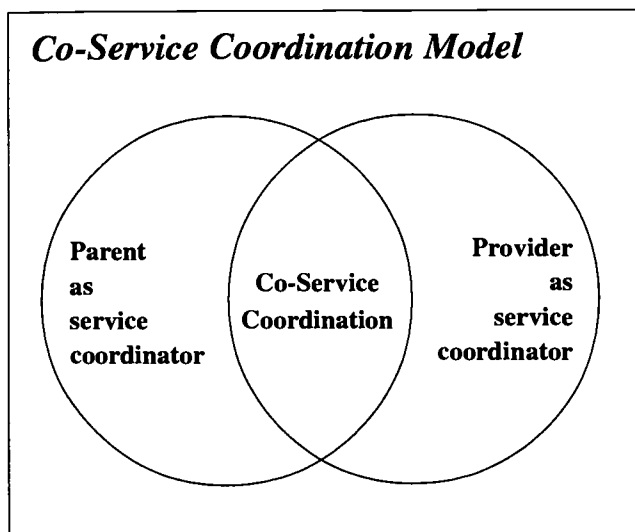
Position Dedicated as Service Coordinator only  
—Outside the program  
—Inside the program

Direct Service Provider as Service Coordinator

Parent as Own Service Coordinator

Combination of Models Within a Program

FIGURE 2.



A major impetus for the development of the *co-service coordination model* (Whitehead, Brown & Rosin, 1993) was to recognize that many, if not most, parents are involved in coordinating services for their family. The concept of co-service coordination (Figure 2) is based on the premise that many parents *choose* to be involved in service coordination responsibilities and could benefit from the system's acknowledgment and support of them in that role. Co-service coordination is defined as the parent and provider agreeing more formally to share in the responsibilities of the seven functions of service coordination described in Part H. The options for co-service coordination are discussed between the family and service coordinator and the outcome for co-service coordination is jointly agreed upon. For example, in seeking a new resource for the child or family, the service coordinator may agree to supply a list of appropriate telephone numbers and the parent may agree to make the contacts to obtain the information. The agreement is reviewed regularly since the nature of the co-service coordination relationship may vary, depending on what is happening in the family's life. What does "co" mean?

- "Co" does not mean equal, it means together, jointly, mutually.
- "Co" does imply mutual benefits to both the parent and provider.

The concept and practices of co-service coordination can be infused into all other models of service coordination. Parents have the option of taking on service coordination responsibilities. In some models of service coordination described below, parents and service coordinators may work together in a similar fashion without making this more formal agreement.

The *interim service coordinator model* is generally defined as an approach where a program or agency initially and temporarily assigns a person to coordinate services with a family. The length of involvement in the IFSP process may vary, but typically it extends from the point of referral through the development of the IFSP or up to the point of development of the IFSP so that the new service coordinator is familiar with its contents and the family. At that time, the responsibility for service coordination is transferred to another person on the early intervention team. This person might be selected in a number of ways: (1) he may be a primary service provider for whom it makes sense to add the service coordination responsibilities when working with the family; (2) families may choose who assumes the ongoing service coordination from the possible array of appropriate providers; (3) the program may have service coordinators whose sole responsibility is service coordination, i.e., dedicated service coordinators. No matter what the transition point between the interim service coordinator and the new service coordinator, it is useful that both meet together with the family.

Programs that follow the *dedicated service coordination model* have service coordinators whose sole responsibility is to carry out service coordination functions. They do not provide any additional early intervention service (e.g., special instruction, occupational or physical therapy, nursing, social work). In some instances, the program may hire the service coordinator and in other cases agencies outside the early intervention program may hire the service coordinator. For example, in Illinois, agencies outside the early intervention program hire the service coordinators. This system was designed to be responsive to parents' concerns about possible conflict of interest when the service coordinator may need to advocate for services from the early intervention program when resources are scarce or a service is unavailable.

The *direct service provider as service coordinator model* occurs when a therapist, teacher, nurse or other service provider most closely related to the child's needs acts both as the service coordinator and service provider. It may also happen when an early interventionist routinely takes on the role of service coordinator as a portion of their job responsibilities.

In the *parent as own service coordinator model*, parents agree to take on the functions of service coordination without the assistance of a "professional" service coordinator assigned by the program as part of the IFSP process. In a sense, the parents waive their right to having a service coordinator as specified in Part H. This model should not be considered as "an escape hatch" for programs and agencies not to provide service coordination. The program's service coordinator's name must be listed on the IFSP as well as the documentation of the parent's decision to take on the service coordinator's role.

Although the law allows states to decide whether they will reimburse parents for their service coordination efforts for their child and family, Pathways staff is unaware of any state that exercises this option. This does *not* mean that parents of children with special needs can not be hired to coordinate services for other families, if they meet the state's qualifications for service coordinators. Parents are being hired more and more frequently to positions as service coordinators because of their valuable life experience and skills gained in negotiating the service systems for themselves and their children.

A *combination model* describes a program using more than one approach in the provision of service coordination. Many programs blend approaches to best meet the program resources of their program and the preferences of the families. Smaller programs may not have as many personnel or options in the model of service coordination adopted. It may mean they can use only one approach or may not have the flexibility to switch models based on parent preference.

## Service Coordination: Views and a Vision

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Travel back in time ...back before October 8, 1986 when the federal legislation for early intervention was enacted. There was considerable discussion about whether or not service coordination should be a mandated service available for eligible children and their families. At the heart of the controversy was whether service coordination was the best or preferred way to assist families in accessing early intervention services and arranging any necessary financing. Service coordination was compared to a bandaid on a complex, cumbersome and often-times dysfunctional system. It was seen as a stop-gap measure forestalling the real need for simplifying the system. Many said that health, education and social service agencies should be reformed to make them accessible to families without adding yet another service provider (i.e., the early intervention service coordinator). Another aspect of the debate was that many parents do their own service coordination and may not want another person between them and the services they need for their child and family.

As in all debates there were at least two perspectives on the issue. The other perspective supported the mandate of service coordination. There was no question that many families raising young children with disabilities found it challenging to access the system of services and supports. It was argued that if service coordination was not mandated, the decision as to whether a family had a service coordinator would be at the program's discretion. There was concern that program personnel might choose whether or not to provide service coordination for reasons other than parent choice (e.g., limited financial resources). The controversy was resolved when service coordination became a core service in early intervention. Every child eligible for early intervention and the child's family is entitled to a service coordinator.

The intent of service coordination in early intervention is to assist families at their desired level to locate, access, and receive the services, resources, and supports they need for their child and themselves. Family-centered service coordination can





be a beneficial service to families, especially as they enter into the early intervention service delivery system. Sorting through the myriad services, knowing what questions to ask and of whom can be a daunting task. The service coordinator is there to support the family in deciding what outcomes

they desire for their child and what supports they need to achieve these outcomes. Some families' need for service coordination assistance may diminish as they learn more about negotiating the system. At any time, the level of service coordination support may vary depending on the resources (emotional, time, financial) available to the family.

## Possible Positive and Negative Aspects of Service Coordination

Even though service coordination was conceived as a helpful service, one should not lose sight of how it may have adverse effects on families. Dr. William Schwab (1994), a Wisconsin pediatrician and parent of a child with disabilities, offered some potential negative consequences which could result from service coordination:

- Service coordination acts as a filter between the family and the system. The family members may not learn directly whom to contact and how to find resources and services. Conversely, service systems might become less responsive to families because they do not work with them directly.

- Service coordination is insatiable: there is always more that can be done and the service coordinator may constantly feel overloaded.
- Service coordinators act as intermediaries between the family and the services and can make unintentional mistakes. When someone speaks for another, it is difficult to be as accurate as when the person relays the information directly.
- Service coordination is built on an assumption that it will bring consistency to families' lives by providing specific professionals who can support them in accessing the system. Several factors work against consistency in early intervention service coordination: positions are often entry level with high staff turnover; transitions to, from, and within agencies and programs; and numerous agencies and funding sources often compete for case management or service coordination responsibilities.

If these consequences are valid, why support early intervention service coordination? In reality, families of children with special needs often feel overwhelmed. Health, education, and social service systems are not easily negotiated. Knowledgeable service coordinators can assist families in maneuvering the labyrinth of the service delivery systems. They can offer families an array of information, recommend strategies to obtain resources and services, act as a dynamic resource, and be a single and consistent point of contact for families.

There are three major reasons to support the concept of service coordination. First, as mentioned above, the functions of service coordination described in Part H of IDEA (see Table 1) can be immensely beneficial to families. Second, service coordination is an opportunity for **SYSTEM ADVOCACY**. The service coordinator is in the position to discover where many families get bogged down or stuck in the system, and target these areas for change. The service coordinator can look for patterns in program and agency responses to families and encourage helpful responses while giving feedback about responses that are not helpful. The service coordinator can make personal

contacts and develop relationships with agency personnel that allow her to know how to best access the system.

These activities by service coordinators can work toward changing the system for families. Whitehead (1996) agrees that service coordinators have the potential to significantly influence change. She lists the following ways that service coordinators can work to make the system more accessible and "user friendly" to families of children with disabilities (see Appendix C for an overhead "Beyond the Law: Service Coordinator as Systems Change Agent"):

- organize parent support, advocacy, or networking groups;
- identify gaps or areas of duplication within the system;
- serve on interagency task forces to help integrate the service system's procedures and materials (e.g., consumer satisfaction surveys);
- reduce the number of forms families must complete and questions they must answer (e.g., by simplifying eligibility criteria or by using common referral and intake forms); and
- participate in training on partnerships between families and service providers, communication skills, health care financing, and other areas related to service coordination.

Whitehead (1996) adds that service coordinators can help make the system more accountable by educating parents. Parents who have learned service coordination skills can be powerful advocates for systems change. Parents and providers can often increase their effectiveness for achieving system's change by working together.

Third, service coordination is an opportunity for PARENT EMPOWERMENT whereby parents acquire the tools and strategies they need to navigate the system for their child and family. The notion of service coordination as a means to facilitate parent empowerment is illustrated in the following analogy.

## An Analogy About Service Coordination as Empowerment

*Through no fault of your own and without preplanning, you find yourself in the middle of a densely overgrown forest. After some confusion and disbelief you realize that you are lost and unprepared for what might happen as you try to get out. As you start to panic, a forest ranger steps from behind a huge burr oak. You feel relieved to see another human, especially someone who knows the forest. The forest ranger takes you by the hand and you stumble along behind her until you get to a parking lot and your car. You thank her.*

*Somehow the next week, at the same time, you find yourself back in the same spot, in that same forest, and are just as lost. You know that there is a way out of the forest because you got out last week. But how? Magically, the forest ranger appears again. The ranger tries a new approach this week. She asks you what might be helpful to you and what you need to know to get out of the forest yourself. As you trek along, the ranger shows you a few ranger tricks: how to clear and mark a trail, how to use a compass, how to locate the sun and stars for determining directions, how to identify edible berries and plants and dangerous ones. She provides you with a map of the forest and some landmarks, and gives you a list of important items to bring in your backpack. Before you know it you are in the parking lot and your car. You thank her.*

*A week passes and again you are in that forest. Your confidence is a little shaky but you recall some of the ranger's tricks. It takes some backtracking and it takes a little longer, but after a while you are in the parking lot feeling relieved and excited about making it on your own. The ranger is leaning on your car smiling. You ask her a few questions about your journey out of the forest. She listens to you about your adventures and provides several new ideas in response to your questions. You thank her... You know that next time you find yourself in a forest you will be able to find a pathway out.*

Service coordination can be like a walk in that forest. Service coordinators provide short-term support and guidance for families with young children with special needs who need time to figure out the system and make adjustments at home. The ultimate goal is to provide information and skills for independent navigation of the maze of human service options. Ideally, as service coordinators work to make the system accessible and build upon the family's competence, the need for service coordination will diminish.

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## DISCUSSION QUESTIONS

1. Reflecting on the definitions of service coordination provided in this section, what are the similarities and differences among the definitions? Develop your own definition of service coordination.
2. Several possible unintended negative consequences of service coordination were listed. How can knowledge of these potential consequences help to make service coordination more family-centered? What might be some other negative consequences?
3. List and discuss several positive consequences of service coordination.
4. Reflecting on the analogy in the section, how would you describe the concept of empowerment?
5. What kind of training and experience do service coordinators need to be effective change agents? What actions can be taken in the course of your routine work that can help move service systems?



## ACTIVITIES

### Group Activities

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#### **Activity 1: "Draw Your Own Vision"**

*Purpose:* To provide an opportunity for participants to develop their vision of family-centered, coordinated, comprehensive, culturally competent, individualized early intervention system. It is important for those involved in service coordination to have a vision to work toward as they take on the task of system advocacy.

*Directions:* Have participants work in small groups using chart paper and colored markers. Ask participants to draw a service system without restraints, obstacles and barriers that captures their vision. Have them share the critical components of their system with the group. Ask each participant to find something they can do next week that will move the system (at a personal, program, or larger system level) toward their vision.

#### **Activity 2: "Challenges Facing Service Coordination"**

*Purpose:* To provide a forum to discuss the challenges the group experiences in coordinating service.

*Directions:* Have participants break into six small groups. Assign each group a question from the "Challenges facing service coordination" handout (see Appendix D). Ask the group to identify a recorder, reporter and timekeeper. The group is asked to discuss their responses to this question for 15 minutes, allowing each person in the group an opportunity to participate. In a large group, the reporter is asked to summarize one to three main points from the responses, depending on time.

The activity could be modified by generating challenges participants face and using these as the basis for their small group discussion.

#### **Activity 3: Circle of Influence—Circle of Concern**

(Source: Covey, S.R. (1989). *Seven habits of highly effective people: Powerful lessons in personal change*. New York: Simon & Schuster.)

*Purpose:* We also have a sense that we can assert influence over some matters and not others. We frequently must make decisions about how we are going to address our concerns. Do we do something or not? Which "battles" do we want to and can take on? Which issues do we care passionately about, yet realize the issues are too big because of the larger political context or the resources we currently have available? Where can we make a difference?

One way to help sort out these issues is to understand which concerns you believe you can influence. The following activity provides an opportunity to identify personal concerns and map out those concerns you can realistically influence and those you cannot.

*Directions:* (1) Draw a circle on a piece of paper and call this your "Circle of Concern." In the circle, list all the things that concern you about being a service coordinator--from your family and/or service coordinator perspective. Consider issues related to day-to-day occurrences as well as larger policy issues. (2) On a second piece of paper draw a circle with another circle inside. Label the inner circle your "Circle of Influence" and the outer circle your "Circle of Concern." In your outer circle, place the items from your first "Circle of Concern" that you feel you have little or no influence over. In your inner circle, list the concerns you believe you can influence. (3) Review the items in your "Circle of Influence." Select one to three items that you would like to do something about. Write a commitment to

action that includes what you would like to do, when you will do it, and the identification of resources and supports you will need. Consider:

- In what issues do you want to invest your time and resources?
- How much time and resources do you have to put into your efforts?
- What outcomes do you anticipate for your efforts?
- What kinds of supports do you need?
- Are you prepared to accept the consequences of your actions- if you get what you want, and if you do not?

### *Group Discussion Questions*

In a small group or with a partner, share what you have put in your circles. Name what you feel you cannot influence, and what you feel you can. Discuss your reasons. Sharing ideas for coping can be very helpful.

### *Questions for Reflection*

In your group or with a partner, discuss the following questions. These questions can also be addressed individually.

- What happens to you when you feel you cannot influence circumstances around you? How do you cope? What helps? What makes matters worse?
- What kinds of support do you currently have to help you in taking on challenges? How could you develop further supports?

## **Individual Activities**

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### *Questions for Reflection*

See discussion questions above and reflect on three of these questions in a journal.

### *Field-Based Activities*

Survey three service coordinators and ask them to describe the major activities of their job.

Interview a family receiving early intervention and ask them to discuss four to five specific things they need or would like from a service coordinator.

Shadow a service coordinator for a day, log her activities, and associate these activities with the principal functions of service coordination.

### *Self-Study*

Write an analogy or create a metaphor related to service coordination reflecting how you think about empowerment.

Construct your own definition of service coordination based on the information in Section I. Explain why you included each critical component of your definition.

Describe how you might be involved in "systems change" in your life as a service coordinator. Provide an example from your own experience.

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## SECTION I: APPENDICES

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■ *Handouts (indicated by a ☒) are inserted in this section, as well as in a pocket in the back of this book.*

# APPENDIX A

## SELF ASSESSMENT OF SKILLS AND KNOWLEDGE IN EARLY INTERVENTION SERVICE COORDINATION

Developed by: Peggy Rosin, Linda Tuchman, Liz Hecht, George Jesien  
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at the Waisman Center, University of Wisconsin-Madison

Date: \_\_\_\_\_ Last 4 Digits of Social Security Number \_\_\_\_\_

### INSTRUCTIONS:

#### STEP 1: Self-Assessment of Knowledge and Skills:

Read each statement and circle the number on the corresponding scale which reflects your rating of your knowledge and skill. The 4-point rating scale corresponding to the knowledge column is interpreted as 1 = no knowledge to 4 = very knowledgeable. The 4-point scale corresponding to the skills column is interpreted as 1 = no skill to 4 = very skilled.

#### STEP 2: Prioritize the Importance of the Knowledge or Skill:

After you have rated your abilities in each of the content areas, prioritize how important that knowledge or skill is to your current work or life situation. The 4-point scale corresponding to the priority column is interpreted as 1 = unimportant to 4 = very important.

#### STEP 3: Choose and Prioritize Course Outcomes:

Based on self-assessment of your knowledge and skills and your priority ratings, you can organize your course outcomes. Remember that you can add any outcome which was not reflected in the SKSA statements. Look across the three content areas for statements that were rated as low ability and high need. These will most likely be targeted outcomes. The Individual Learning Plan provides a column for listing your course outcomes in order of priority.

Statement	Knowledge				Priority			
	(1 = No Knowledge 4 = Very Knowledgeable)				(1 = Unimportant 4 = Very Important)			
<b>Legal Issues</b>								
I understand how Service Coordination is defined by Part H of the Individual with Disabilities Act (IDEA) and State mandated rules (HSS 90).	1	2	3	4	1	2	3	4
I understand the seven functions of service coordination defined by HSS 90.	1	2	3	4	1	2	3	4
I know the rights and procedural safeguards for parents in early intervention.	1	2	3	4	1	2	3	4
I understand the timeliness in completing the Individual Family Service Plan (IFSP) process.	1	2	3	4	1	2	3	4
I understand the procedures in completing the IFSP.	1	2	3	4	1	2	3	4
I understand the issues and procedures of confidentiality.	1	2	3	4	1	2	3	4
I understand the differences between Part H and B of IDEA.	1	2	3	4	1	2	3	4

### ***Service Coordination***

I understand the role of the service coordinator in early intervention.	1	2	3	4	1	2	3	4
I know the services funded by Birth to Three, and recognize that families may need to access additional funding sources to meet their outcomes.	1	2	3	4	1	2	3	4
I know what federal, state, and local funding sources exist for families and their eligibility requirements.	1	2	3	4	1	2	3	4
I understand the structures supporting interagency collaboration, including referral, interagency agreements, memoranda of agreement, contracts, and consultation.	1	2	3	4	1	2	3	4
I understand how the principles of family-centered, culturally competent care relate to the service delivery system.	1	2	3	4	1	2	3	4

### ***Family and Systems Theory***

I understand the theories and models related to family systems and development.	1	2	3	4	1	2	3	4
I understand the social systems perspective and its application to early intervention.	1	2	3	4	1	2	3	4
I understand how multiple stressors may affect a family's use of early intervention services.	1	2	3	4	1	2	3	4

### ***Team Functioning***

I understand the importance of parents as team members.	1	2	3	4	1	2	3	4
I understand the levels of communication and cooperation in different team models (e.g., multidisciplinary, interdisciplinary, transdisciplinary, interagency).	1	2	3	4	1	2	3	4
I understand team dynamics.	1	2	3	4	1	2	3	4
I understand the various roles people play on teams.	1	2	3	4	1	2	3	4
I understand the models of service coordination and various benefits and costs of each model.	1	2	3	4	1	2	3	4
I understand the models of and issues of service delivery in home, medical, social, and educational settings.	1	2	3	4	1	2	3	4

### ***Personal Skills***

I provide a family-centered approach to early intervention that respectfully supports families.	1	2	3	4	1	2	3	4
I employ communication techniques for listening and responding.	1	2	3	4	1	2	3	4

I use strategies for preventing and managing conflict.	1	2	3	4	1	2	3	4
I apply problem-solving and negotiation methods.	1	2	3	4	1	2	3	4
I respond to diversity in a culturally competent manner.	1	2	3	4	1	2	3	4
I use strategies for taking care of myself.	1	2	3	4	1	2	3	4
I apply methods of organization to streamline tasks.	1	2	3	4	1	2	3	4
I practice time management techniques.	1	2	3	4	1	2	3	4
I actively promote the principles of family-centered, culturally competent, care.	1	2	3	4	1	2	3	4

### ***Service Coordination Skills***

I assist families in identifying strengths, resources, and needs in developing the Individual Family Service Plan.	1	2	3	4	1	2	3	4
I build respectful and beneficial relationships between families and professionals (on a one-to-one, team, agency, and inter-agency basis).	1	2	3	4	1	2	3	4
I offer families options for information, support, referral, and skill building.	1	2	3	4	1	2	3	4
I develop the Individual Family Service Plan with families and carry out tasks necessary to implement the plan.	1	2	3	4	1	2	3	4
I integrate identified child and family outcomes with resources and service options.	1	2	3	4	1	2	3	4
I evaluate services provided to families.	1	2	3	4	1	2	3	4
I ensure that parents are co-equals on the early intervention team.	1	2	3	4	1	2	3	4
I can appropriately identify and access federal, state and local funding sources to assist families in meeting their outcomes.	1	2	3	4	1	2	3	4
I apply strategies unique to specific geographical areas including inner city and rural.	1	2	3	4	1	2	3	4
I design processes and strategies supporting transitions for the child and family, and evaluate their effectiveness.	1	2	3	4	1	2	3	4
I use a systematic method for communicating and coordinating the activities of the providers on a family's team.	1	2	3	4	1	2	3	4
I facilitate and support child and family transitions.	1	2	3	4	1	2	3	4

## THE INDIVIDUAL LEARNING PLAN (ILP): INSTRUCTIONS

### ***STEP 1: OUTCOMES Column***

After you have completed the Open-Ended Questionnaire (OEQ) and/or Skills and Knowledge Self-Assessment (SKSA), organize the information on the Individual Learning Plan. This is your plan for the course. The ILP is a tool to assist you in organizing your goals, strategies, resources and timelines for reaching goals. The ILP is also a method of monitoring and evaluating your progress toward your course outcomes.

List the outcomes that you have written on the OEQ or determined from completing the SKSA on the ILP in the OUTCOMES column. Notice that the outcomes should be listed in the order of importance you have assigned them.

### ***STEP 2: STRATEGIES Column***

Next to each outcome, list what strategies you might use to achieve the goal. The strategies are the result of your creative brainstorming of means to accomplish the goal. Each strategy is specific to your goal and there may be a variety of ways to achieve the goal. It is important that your strategy be based on your strengths, resources and preferences.

### ***STEP 3: RESOURCES Column***

Think about and list what resources you have or think you might need to attain your outcome. There are many personal, professional or community resources that you may draw upon in completing the RESOURCES column. Remember that you can consider the course instructor as a resource and as someone to facilitate your getting the resources you need.

### ***STEP 4: TIMELINE Column***

You can use the TIMELINE column as a time manager. Each of your outcomes may differ in the amount of time and effort needed for their completion. If you have listed multiple outcomes, think about how you might coordinate and complete each in a timely fashion.

### ***STEP 5: EVALUATION Column***

You are reminded that the ILP is part of the Self-Assessment. The monitoring and evaluating of the ILP is strictly for self evaluation. It is recommended that you keep the ILP and refer to it frequently to monitor your progress toward your goals. At least at the midpoint and end of the course the rating scale should be applied to evaluate your outcomes. A number from 1 to 5 is assigned to determine your point on the continuum from no activity on a selected outcome to completion of the outcome (1 = No activity, 2 = Started, 3 = Half way there, 4 = Mostly accomplished, and 5 = Completed). A letter is assigned to designate whether the originally listed outcome continues as an outcome (a = No longer an outcome, b = Still an outcome).





# REFLECTIONS on INDIVIDUAL LEARNING PLAN and FUTURE DIRECTIONS

Name \_\_\_\_\_ Date \_\_\_\_\_

1. Review the list of outcomes you created on the individualized Learning Plan. To what extent did you accomplish your outcomes for this course?
2. What assisted you?
3. What obstacles did you encounter?
4. Were there unexpected results or outcomes?
5. What outcomes would you set for yourself for the next six months to a year? A follow-up contact will be made to discuss these outcomes. Specify what would be an appropriate timeline and strategy for this follow-up.

## ★ APPENDIX B

### THE SEVEN SERVICE COORDINATION RESPONSIBILITIES

1. Coordinating the performance of evaluations and assessments;
2. Facilitating and participating in the development, review, and evaluation of Individual Family Service Plans;
3. Assisting families in identifying available service providers;
4. Coordinating and monitoring the delivery of available services;
5. Informing families of advocacy services;
6. Coordinating with medical and health providers; and
7. Facilitating the development of a transition plan to preschool services, if appropriate.

## ★ APPENDIX C

### BEYOND THE LAW: SERVICE COORDINATOR AS SYSTEMS CHANGE AGENT

Ways that service coordinators can work to make the system more accessible and "user friendly" to families of children with disabilities:

- organize parent support, advocacy, or networking groups;
- identify gaps or areas of duplication within the system;
- serve on interagency task forces to help integrate the service system's procedures and materials (e.g., consumer satisfaction surveys);
- reduce the number of forms families must complete and questions they must answer (e.g., by simplifying eligibility criteria or by using common referral and intake forms); and
- participate in training on partnerships between families and service providers, communication skills, health care financing, and other areas related to service coordination.

(Whitehead, 1996)

## ★ APPENDIX D

### CHALLENGES FACING EARLY INTERVENTION SERVICE COORDINATION

- Is service coordination a long-term solution or a short-term band-aid?
- How will service coordinators provide quality service coordination to each family when they are responsible for many, many families?
- How will service coordinators operate on a proactive basis, rather than a respond-to-crisis basis?
- How will service coordinators keep updated on the frequent changes in health care program covered services or eligibility requirements?
- How will service coordinators share with parents the service coordination skills necessary to maneuver in the system?
- How will service coordinators acknowledge and respect parents who choose to do co-service coordination or parents who choose to do the service coordination on their own?

(Whitehead, 1996)



## SECTION II

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# THE PATHWAYS FRAMEWORK FOR ENHANCING SERVICE COORDINATION SKILLS AND KNOWLEDGE

SECTION II



## INTRODUCTION

Service coordination in early intervention presents a new and challenging role for many family members and service providers. Some challenges include:

- Working in partnership with families and other team members to reach desired outcomes for infants and toddlers with special needs and their families.
- Understanding Part H of the Individuals with Disabilities Education Act (IDEA) and state rules related to the individualized family service plan (IFSP) process and the delivery of services.
- Working on teams and across agencies made up of people from different backgrounds and perspectives.
- Negotiating complex health, educational, and social service systems to access service for children and families.
- Finding creative ways to meet family and child service and resource needs.
- Creating positive changes in systems and practices to be responsive to all families.

To meet these challenges, service coordinators need knowledge and skills related to the laws, the IFSP process, services, resources, and personal skills involving communication, conflict management, decision making, problem solving, and stress reduction. The first and best tool a service coordinator brings to the job is her knowledge, skills, and experiences. It is impossible to separate the interpersonal aspects of service coordination from the knowledge and skills involved in managing the various roles and responsibilities of a service coordinator. However, this section emphasizes specific and essential information that applies directly to early intervention service coordination, while Section III emphasizes the "people skills" that underlie the service coordinator's role. Developing competence as a service coordinator necessitates an ongoing commitment to cultivating a blend of personal skills and skills specific to early intervention service coordination.



## Fundamentals of Service Coordination

This section begins by listing a few preliminary definitions, briefly discussing of the importance of understanding federal and state regulations and offering a few philosophical principles for coordinating the IFSP process.

### Defining the IFSP Process

The IFSP process, as defined in this guide, encompasses the complete process a child and family may go through during their involvement in early intervention. The bench marks are noted on Table 1 and include: (1) screening, (2) intake, (3) evaluation, (4) assessment, (5) development, implementation, review and evaluation of the IFSP, (6) early intervention services and other resources and supports, and (7) transitions into, during, and out of early intervention. This is the process through which the service coordinator and family work in partnership to meet the concerns and priorities a family has for their child and themselves.

**TABLE 1.**

***The IFSP Process***

SCREENING	INTAKE/ EVALUATION	ASSESSMENT	IFSP	EARLY INTERVENTION	T R A N S I T I O N  P L A N
<ul style="list-style-type: none"> <li>• Community resources</li> <li>• Determine need for evaluation</li> </ul>	<ul style="list-style-type: none"> <li>• Early intervention team</li> <li>• Eligibility</li> <li>• Developmental status                             <ul style="list-style-type: none"> <li>-cognition</li> <li>-physical (vision/hearing)</li> <li>-communication</li> <li>-social and emotional</li> <li>-adaptive</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Child's unique needs</li> <li>• Family's strengths and needs related to the child's development (family-directed assessment)</li> <li>• Definition of services needed</li> <li>• Ongoing process</li> </ul>	<ul style="list-style-type: none"> <li>• Development</li> <li>• Implementation</li> <li>• Review</li> <li>• Evaluation</li> </ul>	<ul style="list-style-type: none"> <li>• Early intervention services</li> <li>• Other community resources</li> </ul>	

## Defining the Pathways Framework

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Carrying out the many tasks and responsibilities in service coordination utilizes numerous skills. Although these tasks and responsibilities overlap throughout the IFSP process, they may be divided into four groups of activities or phases, including:

1. **CHOOSING THE PATHWAY:** *Getting started* in the IFSP process.
2. **THE JOURNEY:** Providing *follow along* to families in implementing and monitoring of the IFSP.
3. **DETOURS ALONG THE WAY:** Facing *unexpected, immediate needs or crises*
4. **CHANGING PATHWAYS:** Facilitating *transitions*

These phases are not necessarily sequential. For example, a family may experience a number of transitions during the IFSP process and some families may never experience crisis. This framework, however conceptualizes the process for training purposes and assists in targeting specific skills and knowledge. The first phase contains the bulk of the content, since "getting started" in the IFSP process necessitates drawing upon a lot of the knowledge, skills, and strategies the service coordinator uses throughout the process. Table 2 defines the four phases and highlights the service coordination responsibilities of each phase.

Some of the challenges an individual may face during the four phases of the IFSP process include:

- Challenges for family members: too much, too little, unclear or inaccurate information; duplication of efforts; too many and complex forms; cultural or value differences between family and system and/or service coordinator; jargon; timing of information; learning about existing community resources; and enhancing creative problem solving abilities to get needs met.
- Challenges for service coordinators: time and resource management; paperwork, record keeping and forms; timing of information to fami-

lies; meeting prescribed timelines; keeping up with changing resources and service providers; knowing the multiple systems in which a family may participate; understanding multiple funding sources and program eligibility; undertaking strategies for working with outside agencies and funding sources; balancing the philosophy of family-centered care with the reality of available resources; successfully applying personal and interpersonal skills with families, other team members and agency personnel; and creative problem solving.

- Challenges for early intervention programs: organizing staff and resources; managing the IFSP process; keeping track of resources and availability of services; dealing with limited financial resources; working with outside agencies and developing interagency agreements.

Throughout the guide, strategies to meet these challenges and others will be offered. Section IV uses the Pathways framework to illustrate select challenges that may occur within a phase and provides strategies for managing the activities and accompanying emotions.

## Knowing the Law

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Service coordinators must attain a clear understanding of federal and state laws regulating the provision of early intervention services. These rules and regulations mandate the form and function of the early intervention system nationally and shape and direct statewide systems of early intervention. The federal regulations specify that qualified service coordinators must be persons who have demonstrated knowledge and understanding about (1) Part H of the Individuals with Disabilities Education Act (IDEA) and its regulations, and (2) the nature and scope of services available under the state's early intervention program, the system of payments for services in the state, and other pertinent information (Federal Register (1993) 34 CFR Part 303 § 303.22).

Knowledge and understanding of the rules and regulations governing Part H can be obtained by securing a copy of the July 30, 1993 Federal Register

**TABLE 2.**

***Four Phases of Service Coordination***

PHASE	DEFINITION	RESPONSIBILITIES
Getting Started	First contact with family through the development of the IFSP	<p>Coordinating the performance of evaluations and assessments</p> <p>Facilitating and participating in the development of the IFSP</p> <p>Assisting families in identifying available service providers</p> <p>Coordinating the delivery of available services</p> <p>Informing families of the availability of advocacy services</p>
Follow Along	IFSP development through transition from early intervention	<p>Facilitating and participating in the review and evaluation of the IFSP</p> <p>Coordinating and monitoring the delivery of available services</p> <p>Coordinating with medical and health providers</p>
Unexpected, Immediate Needs/Crisis	May occur during any point in the IFSP process	<p>Assisting families in identifying available service providers</p> <p>Coordinating and monitoring the delivery of available services</p> <p>Informing families of the availability of advocacy services</p>
Transitions	Includes transitions into, during or from early intervention	Facilitating the development of a transition plan

and reading, rereading, and discussing its contents and interpretation with colleagues. Appendix A contains excerpts from the federal rules and regulations and includes the definition of service coordination, a listing of general and specific responsibilities, and the qualifications for being a service coordinator, and gives direction to how service coordinators are employed and assigned.

Service coordinators should know whether or not their state has passed legislation that regulates how early intervention is implemented. Wisconsin, for example, passed such legislation and the Department of Health & Social Services (Wisconsin's Lead Agency) published Chapter HSS 90-Wisconsin Administrative Code: Early Intervention Services for Children from Birth to Three with Developmental Needs (1993). Appendix B includes extracted information from HSS 90 related to 13 sections of the Wisconsin Administrative Code with the rules and regulations Wisconsin uses to interpret and implement the federal law. Appendix C includes those sections of Wisconsin Administrative Code that focus on the definition of service coordination and the roles, responsibilities, and qualifications of service coordinators. Although there are similarities between the federal law and Wisconsin's rules and regulations, it is important to know how each state has structured and defined early intervention.

## Understanding the Philosophy Underlying the IFSP Process

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The individualized family service plan (IFSP) is the cornerstone of family centered early intervention services for infants and toddlers with special needs and their families (McGonigel, Kaufmann, & Johnson, 1991). The IFSP, required by Part H of the Individuals with Disabilities Education Act (IDEA), describes not only a document but a planning process. The law specifies the content of the IFSP and sets out some requirements for participation and implementation. The purpose of this planning process, involving the family and service providers, is to identify the family's desired outcomes for its child, and the resources, priorities, and preferences necessary for reaching those outcomes.

This process surrounding the development, implementation and monitoring of the IFSP provides a major focus for service coordinators. Service coordinators act as the facilitators of this process and are responsible for ensuring that the steps for accomplishing the plan are accomplished and recorded. See Section IV of this guide for opportunities to apply service coordination knowledge to situations that may occur during the IFSP process. Clearly, the way the service coordinator reacts in the first meeting with the family will set the stage for the entire IFSP process. This process should foster a partnership between the family and service providers throughout the family's participation in the early intervention system. One needs to think beyond the paperwork and take an expanded view of the IFSP process. The IFSP process can be viewed as a:

### ■ *Promise to families*

The IFSP is a promise to children and families — a promise that their strengths will be 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." (McGonigel & Johnson, 1991, p. 1)

The service coordinator has the responsibility for coordinating, monitoring, and evaluating all the activities leading to the fulfillment of the IFSP's promise.

### ■ *Means for building trusting relationships*

The relationship between the parent and the service coordinator has a strong influence on how successful early intervention will be in meeting the outcomes for the child and family. Through the IFSP process, the family and service coordinator can develop a partnership based on mutual trust and respect. This can be accomplished through communication about concerns, priorities, and resources and working together in an open and respectful manner. When parents are asked to rank what they consider the most important characteristics a service coordinator brings to the relationship, respect and communication skills consistently top the list.



### ■ *Vehicle for empowerment*

Empowerment implies that: (1) parents are competent or capable of becoming competent; (2) opportunities should be created for parents to exert their competence; and (3) needs should be met in a way that promotes the parents' sense of control over their lives and their children's. The process of developing the IFSP should afford an opportunity for mutual problem solving; parents should feel more capable and in control as they progress through early intervention. The IFSP process also can empower families as service coordinators acknowledge, work through and build on a family's strengths.

Parents are the ultimate decision-makers in a collaborative process that includes all team members. A central role of the service coordinator is to ensure that service providers give families accurate, understandable information and encourage parents to serve as active team members in making decisions about their child's IFSP. Parents may desire different levels of involvement at different times based on their emotional, physical, and financial resources. The service coordinator should establish a relationship with families that strikes a delicate balance between being too open-ended and being too restrictive in offering parents options and information.

Empowerment implies that the service coordinator acknowledges and builds on the capabilities of the family in meeting the exceptional needs of their child. The service coordinator needs the skill and finesse to present information and transfer skills at the right time and in the way that works for the family. This is especially important because families often will not have a service coordinator or case manager after early intervention.

### ■ *Mechanism for interagency collaboration*

Frequently, one agency is unable to meet all the needs of infants and toddlers with special needs and their families, especially children with complex medical conditions or multiple developmental delays. It is necessary to draw upon formal and informal resources and services from various agencies to address child and family outcomes. The service coordinator must take the responsibility for

pulling together the interagency personnel needed at various points in the IFSP process (e.g., evaluation, assessment, provision of service and review and evaluation of the IFSP). The IFSP documents what services, resources, and supports each agency provides. The service coordinator, through his knowledge of the system, links the family with the appropriate services, resources, and supports across agencies.

### ■ *Document that records the ongoing relationship*

The IFSP document is a record of the conversations between the team members and the decisions they made. The IFSP document should be fluid and responsive to the changes that are ongoing in the life of the child and family. More will be said about the IFSP document later in this section.

### ■ *Guide to program implementation and evaluation*

The IFSP specifies the desired outcomes for the child and family. Periodic review of the IFSP provides opportunities to measure progress toward these outcomes. It is helpful to use specific, clear outcomes and refer repeatedly to the outcomes. With child and family outcomes, it is helpful to use phrases such as "in order to" or "so that" to clarify the outcome's relevance to early intervention. For example, "Mother would like to learn to read in order to keep track of appointments and classes for herself and child." "I would like Tommy to talk so that he can communicate what he wants and needs."

In addition to measuring parents' satisfaction with the early intervention program, review of IFSP outcomes allows for evaluation of the success of the program. Programs can use these two data sources can be used by programs to guide changes needed in the services and supports for children and families.



## CHOOSING THE PATHWAY—GETTING STARTED IN THE IFSP PROCESS

Getting started in the IFSP process sets the stage for all that follows in early intervention: the relationships with family and other team members, the determination of eligibility for early intervention, the sorting out of the concerns and priorities of the team and the clarification of outcomes and strategies (services, resources, and supports) to achieve the desired outcomes through the development of the IFSP. Getting started with families is the point where the service coordinator brings to bear all her talents.

### Strategies for Working with Families

Section I of this guide provided an expanded view of service coordination as a combination of parent empowerment and systems advocacy. Although empowerment may sound like a 1990s buzz word, operationalizing this concept is paramount to service coordination. In coordinating services with families, empowerment can be actualized through the options provided, mutual problem solving, and the transference of skills and knowledge related to service coordination and the system. Some service coordinators find that the 45-day time frame for completing the IFSP may work against rapport and relationship building. A few helpful strategies for working within this time frame include: viewing the evaluation and assessment as beginning with the first contacts with the family; spending several sessions preparing the parent for the IFSP meeting; inviting the parents to bring a friend or advocate to meetings. Appendix D provides strategies for working in partnership with families while organizing evaluations, assessments, and IFSP meetings.

In setting the stage for partnership in the IFSP process, the service coordinator asks himself three basic questions:

1. What do parents need to know to get started (e.g., information on the IFSP process, program information related to early interven-

### *Apply Partnership Principles Throughout the IFSP Process*

- Ask parents about their desired level of involvement in all steps of the IFSP process.
- Revisit the parents' level of involvement throughout the process, since families' level of availability may fluctuate with their personal resources.
- Ask family members about their preferred method of involvement and communication. It may be different from caretaker to caretaker, even within a family.
- Check out best times and locations for interactions and services (e.g., use of checklists, open-ended questionnaire, conversation, or a combination of methods).
- Get a picture of the family's daily activities, resources, supports, concerns, and priorities. Be mindful of potential changes that affect the child, family, and the IFSP.
- Offer a continuum of choices for involvement. It is not an all-or none commitment. It's important that the choices for involvement are meaningful to the parent.
- Use a problem-solving format so that parents are always part of the process of defining issues, alternative solutions, plans for action, and evaluating the outcomes.
- Commit program resources for families to be supported in participating in advisory and other program activities.
- Involve willing parents in coming up with creative ways to gain parent participation and involvement in the program.

tion and the specific program, knowing the players and knowing their rights)?

2. What does the service coordinator need to know to get started (e.g., information about the child and family related to their concerns, priorities, and resources; methods for obtaining and sharing the information; knowledge about services, resources and supports, parents' rights, and philosophy, laws, and resources)?
3. How do we best share what we know (e.g., verbal methods—conversation, interview, questions; written methods—records, forms, pamphlets, folders; other methods—modeling, demonstrating, videos)?

DeGangi, Royeen, & Wietlisbach (1993) examined issues relevant to the IFSP process through separate focus groups set up for parents and providers. The results offer service coordinators advice as they shape their strategies for working with families. A summary of the important issues follow:

#### ■ *Providers Focus Groups:*

- Good communication and listening skills are central to effective collaboration.
- Parents' concerns should be elicited and information shared at the family's pace and level of understanding.
- Important qualities of professionals in effective collaboration included flexibility, open-mindedness, respectfulness, and the ability to maintain a nonjudgemental view toward families.
- Key qualities of parents as effective collaborators included flexibility and willingness to share concerns.
- Barriers in the IFSP process were poor communication and limited resources.
- Solutions to alleviate barriers to the IFSP process included more training, more professionals who can serve as service coordinators, and more time and money to implement the IFSP process.



#### ■ *Parent Focus Groups:*

- The sharing of information was viewed as the most important aspect of effective collaboration.
- Professionals should be knowledgeable, competent, empathetic, caring, patient, and good listeners.
- Qualities of parents essential for collaboration included taking responsibility, sharing information, and being willing to participate.
- The major barriers included incompetent professionals, differing expectations, professional jargon, limited services, and parents' feelings of guilt or rejection of the child.
- Strategies to overcome these obstacles necessitated that parents be promoted as service coordinators and receive training related to the IFSP process and the educational system.

These findings are consistent with Summers, et al., (1990) who found that families preferred service providers who use a conversational style with nonintrusive questions, have keen listening skills and a willingness to spend time developing rapport.

## Confidentiality and Procedural Safeguards

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From the beginning of the IFSP process, the service coordinator needs to share information across providers and agencies while respecting the privacy of the family. Each family in early intervention is entitled to know that the information they provide will be kept confidential and passed on to others only with their permission and in a respectful way.

The service coordinator is also responsible for seeing that parents are informed about the procedural safeguards that protect their rights throughout the early intervention process. Part H of the Individuals with Disabilities Education Act (IDEA) specifies a series of rights and safeguards to ensure parent participation in early intervention. As an introduction to early intervention, parents receive a set of procedural safeguards. It is critical that parents be given and understand their rights. The context and manner in which this information is shared should set the stage for future positive interactions.

*"Procedural safeguards are not meant to be used only to resolve adversarial situations. They are a basis for mutual knowledge about the IFSP process and parents' involvement in that process. Legislation makes it clear that parents and service providers are intended to work together throughout the IFSP process. It specifies the following: when parents must receive written notice, when parents must give consent, how parents should be involved in evaluation, programming and placement, their right for review of records, and parent's rights to due process"* (Rosin, 1996, p. 71).

In Table 3: Understanding Procedural Safeguards: Examples of Explanations and Implications for Families, Hurth and Goff (1996) summarize the rights and safeguards from 34 CFR 303.1-.670 in Part H of IDEA. While in Figure 1: Explaining Part H Procedural Safeguards to Families: A Step by Step Model, Hurth and Goff (1996) suggest a model for explaining procedural safeguards in the context of the IFSP process.

## Strategies for Working with the Early Intervention Team

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The early intervention team is at the heart of the IFSP process and acts as the decision-making body throughout the process. The service coordinator, frequently identifies the team and facilitates and coordinates team activities. The early intervention team consists of the parents, the service coordinator and others. These "other" team members are selected based on the concerns being addressed and the purpose of the team meeting. For example, if the purpose of the meeting is to determine eligibility or to review the IFSP, then there are regulations about who must minimally be involved on the team.

Service coordinators need to know all the options for services and the potential service providers who may make up an early intervention team with the family. In small communities, the roster may be short, but in larger communities the number of players can be hard to keep track of. The service coordinator must also know the role or function of potential team members. This will help to ensure that the right team is pulled together to address the family's concerns. The service coordinator might ask himself, What role does each team member play? For example, what does a pediatric neurologist do? Do you need to enlist the services of a nutritionist on the team based on family concerns?

After the team is identified based on the child's suspected areas of need, it is the service coordinator's responsibility to pull this team together. Scheduling the team members and meeting family preferences for time and location is a goal. The service coordinator will find that applying team facilitation skills during meetings will make them more successful. Appendix E offers tips for planning and running effective meetings by listing what is helpful to do before, during, and after the meeting to develop and keep to the agenda for the meeting. It is helpful for record keeping to document for each meeting: (1) the meeting's purpose, (2) who attended the meeting and their roles, (3) what was discussed, (4) any decisions made, (5) next steps, (6) who is responsible for any follow-up with timelines. Some meetings, such as the IFSP

## ***Understanding Procedural Safeguards: Examples of Explanations and Implications for Families***

*Rights and safeguards under 34 CFR ~303.400-.460, Regulations for the Early Intervention Program for Infants and Toddlers With Disabilities, Part H of IDEA (U.S. Department of Education, 1993)*

### **Written prior notice (§.403)**

The early intervention program must give you advance written information about any evaluations, services, or other actions affecting your child. Parents know their children best. The information you share with us will make sure that the evaluations and services are right for you. The "paper work" assures that you get all the details *before* any activity.

### **Use of parent's native language or preferred mode of communication (§§.401 and.403)**

It is your right to thoroughly understand all activities and written records about your child. If you prefer another language or way of communicating (explain relevant option, such as braille, sign language, etc.), we will get an interpreter (use your mode of communicating), if at all possible. The early intervention program wants you to understand so that you can be an informed team member and decision maker.

### **Written consent (§.404)**

The early intervention program needs your permission to take any actions that affect your child. You will be asked to give your consent in writing before we evaluate or provide services. Be sure you completely understand the suggested activities. By being involved, you can help the early intervention program plan services that match your family's preferences and needs. The early intervention program needs to explain what happens if you give your consent and if you do not give your consent.

### **Confidentiality and release of information (§.401-.404)**

The early intervention program values the information you and other service and health care providers have learned about your child. We will ask others for this information, but we need your written permission to do so. Just as the early intervention program needs your permission to get your child's records from other providers, the records that the early intervention program will develop will not be shared with anyone unless you give your permission.

### **Examine records (§.402)**

The early intervention record is your family's record. You can see anything in the early intervention program's records about your child and family. If you do not understand the way records are written, the information in the child's record will be explained to you in a way you understand. You are a team member and we want you to have the same information as other team members.

### **Accept or decline services without jeopardy (§.405)**

With the other members of your child's early intervention team, you will consider which services can best help you accomplish the outcomes that you want for your child and family. You will be asked to give your consent for those services that you want. You do not have to agree to all services recommended. You can say no to some services and still get the services that you do want. If you decide to try other services at a later date, you can give your consent then.

### **Procedures for resolving complaints (§.420)**

If you and the early intervention team do not agree on plans or services, or if you have other complaints about your experience with the program, there are procedures set up for resolving your concerns quickly. There are many informal ways of sharing your concerns with your team and the early intervention program. Your feedback will help the early intervention program improve. However, if informal steps do not work to satisfy your concern, there are administrative steps to assure that a knowledgeable and impartial person, from outside the program, hears your complaint and helps you resolve it. The early intervention program recognizes your right to make decisions about your child and will take your concerns seriously. If you have questions, call \_\_\_\_\_.

**Bold type:** Section headings from regulations.

**Narrative:** Sample of language that might be used by an early intervention system to explain implications of regulations to families.

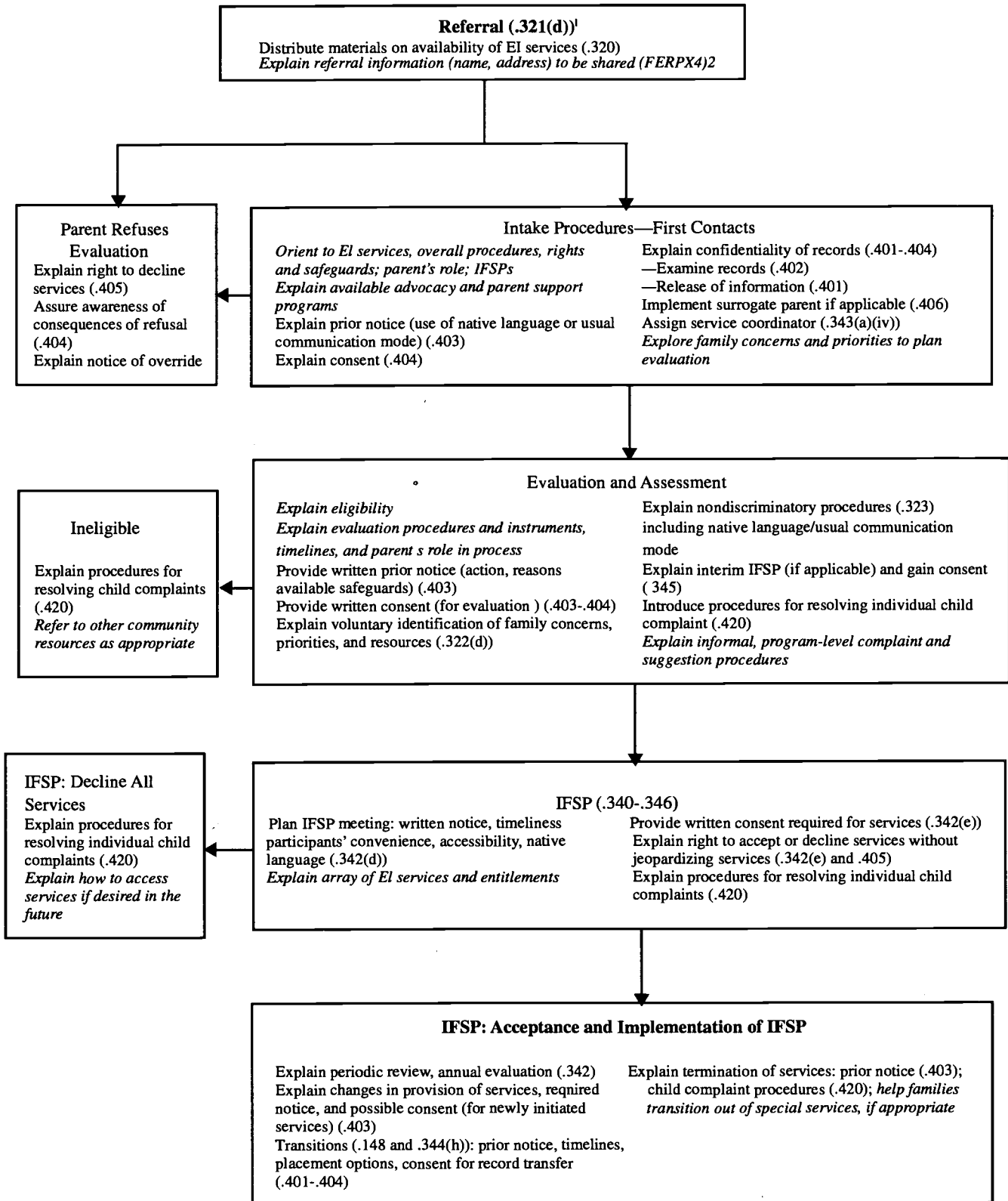
Reprinted with permission of the National Early Childhood Technical Assistance System (NEC\*TAS) from *Assuring the Family's Role on the Early Intervention Team: Explaining Rights and Safeguards (1996) (p. 4)* by J.L. Hurth and RE. Goff.



**FIGURE 1.**

***Explaining Part H Procedural Safeguards to Families: A Step-by-Step Model***

*Text in italics indicates practices that are recommended but are not required by legislation.*



<sup>1</sup>Numbers in parentheses reference 34 CFR Part 303, Regulations for the Early Intervention Program for Infants and Toddlers With Disabilities (Part H) under the Individuals With Disabilities Education Act (IDEA) (U.S. Department of Education, 1993)

<sup>2</sup> Family Educational Rights and Privacy Act (FERPA) of 1974, as amended, enacted as Sec. 438 of the General Education Provisions Act (codified as amended at 20 U.S.C. 1232g; regulations at 34 CFR, Part 99).

Reprinted with permission of the National Early Childhood Technical Assistance System (NEC\*TAS) from *Assuring the Family's Role on the Early Intervention Team: Explaining Rights and Safeguards (1996) (p. 6) by J.L. Hurth and RE. Goff.*

meeting, have specific documentation and paperwork associated with them but often times you may meet with family members and/or other team members. It is important that these meetings are documented as well.

Keeping a log for phone and other contacts related to the families you work with will help you in your follow along and communication among agencies and team members.

A role frequently allocated to the service coordinator is that of meeting facilitator. Numerous strategies can be applied to assist the service coordinator in organizing and facilitating a successful meeting. Appendices F, G and H list "Ways to move a meeting along," "Techniques for encouraging participation," and "Techniques to try when the team gets stuck." These strategies may contribute to working with any team.

## Eligibility

When a child is referred for early intervention, the question arises, "Is this child eligible for services?" Evaluation is the process used by the early intervention team to answer this question. The service coordinator needs to understand the federal and state mandates for who needs to be part of the early intervention team and how to elicit family concerns and priorities in determining team membership. The team conducting the evaluation consists of the child's parent(s) and interdisciplinary personnel qualified in the area(s) of concern. Frequently, team members will represent more than one agency. The team examines all relevant data, including medical records, developmental records, and records of previous intervention. The team looks at five areas of development: (1) cognition, (2) physical, including motor, vision and hearing, (3) communication, (4) social and emotional, and (5) adaptive or self-help.

The federal law defines three categories by which a child may become eligible for early intervention services: (1) exhibiting a developmental delay as defined by each state, (2) having a diagnosed condition that is likely to result in a developmental delay, or (3) being "at-risk" for developmental delay. It is up to each state to define what is meant by

developmental delay. The use of the at-risk category is discretionary (e.g., Wisconsin does not provide services to infants and toddlers who are at risk). Informed clinical opinion at the individual and team level is an integral part of the eligibility determination. Part H regulations safeguard against the use of test scores as the sole measure of eligibility. It is essential that service coordinators understand how their state defines developmental delay and who is eligible for services.

## Assessment

If the team determines that the child is eligible for services, an assessment follows. Assessment, according to Part H, means the initial and ongoing procedures used by family members and qualified personnel to determine an eligible child's unique strengths and needs and the nature and extent of early intervention services required by the child and the child's family to meet those needs.

In addition to the assessment of the child, Part H also incorporates a "family-directed assessment" into the IFSP process. The term "assessment" is misleading as it relates to families. It is not the family that needs to be assessed, but how the outcomes on the IFSP fit the family's context and concerns. There should be no negative consequences to a family who opts to forego this family-directed assessment; it is strictly voluntary. The family-directed assessment refers to the ongoing process by which the family and service providers work together in partnership to identify and understand the family's concerns, resources and priorities. The family's beliefs and values and relevant cultural factors are taken into account. The goal is to provide services and support and to build the family's capacity to meet the child's developmental needs.

Conversations, interviews, checklists, questionnaires, and eco-maps are some of the methods used for gathering family information (see Appendix I for some sample methods). The service coordinator should make it clear to families that providing information to the early intervention team is voluntary. Service coordinators are cautioned to make certain that collected information is directly tied to identifying the family's resources, priorities, and concerns as it relates to enhancing the development



***Paisley, Irwin, and Tuchman (1994) summarize the process of identifying family concerns, priorities and resources as follows:***

1. provides family members with an opportunity to explore the ways they influence their child's development;
2. ensures that the IFSP will "fit" the family;
3. gives families options for ways to identify and address their concerns;
4. is confidential;
5. includes only what family members intend to share;
6. acknowledges the family's concerns; and
7. provides a record of the family's experiences.

of their child. Otherwise, the queries may seem prying and intrusive to families. It is important to make clear how this information will be used and that it be shared only with the parents' permission.

## Services, Resources, and Supports

Early intervention services for an eligible child and his family are based on the parents' desired outcomes for their child and on the child's developmental needs. IFSP outcomes are collaboratively developed with the entire early intervention team providing input and guidance. Services are provided with the parents' written consent. Parents and service providers together review the desired outcomes and then develop strategies for working toward those outcomes. Early intervention services (Part H) that may be provided as part of these strategies include:

- assistive technology
- audiology
- communication
- family education and counseling
- health care services, to enable the child to benefit from other early intervention services
- medical services, for diagnostic or evaluative purposes only
- nursing
- nutrition
- occupational therapy
- physical therapy
- psychological services
- social work
- special instruction
- transportation needed to enable the child and family to receive early intervention services
- vision

The location of these services can vary. Services may be provided in the home, a classroom, clinic, or in a community child care setting. It should be noted that services are to be provided to the maximum extent appropriate to the needs of the child in natural environments, including home or community settings in which children without disabilities participate.

A service, as defined by Part H, may be one means of addressing the desired outcomes for the child and family. However, to reach some IFSP outcomes, it may be necessary to creatively link early intervention services (listed above) with other community resources. Examples of other major resource categories for families include economic, child care, recreation, and life necessities. Resources offered to families in reaching an outcome



can come in the form of emotional or informational support. This broad-based conceptualization of resources discourages the early intervention system, program, and provider from matching child and family to existing services and fitting the IFSP to an existing menu of services. Instead, a resource-oriented approach takes into account a full range of formal and informal resources and methods for meeting individual child and family needs and helps link families to their communities.

Service coordinators often report financial resources as a constraining factor reported by service coordinators for not exploring broad-based community resources. They are concerned that what is written on the IFSP must be paid for by Part H dollars if there are not other (e.g., private insurance, Medical Assistance Program) means to cover the service, resource, or support. This is true only if the service is an early intervention service. The IFSP can be clearly written to state what is and what is not an early intervention service. This important distinction specifies who is responsible for the payment of services. Service coordinators can write IFSP strategies for obtaining a service outside early intervention in a way that also makes clear the program's responsibility (e.g., the service coordinator will assist the family in finding a child care facility with an accessible playground; the service coordinator will provide parents with information on warm water pools; the service coordinator will provide the family with resources for sibling support groups).

The service coordinator is encouraged to:

- recognize that children and families live in communities that have a much broader context than the early intervention system
- think beyond early intervention services for resources and supports for children and families
- use formal and informal supports (parent to parent, community, advocacy groups, Central Directory, Internet)
- explore creative ways to finance needed services, resources, and supports by looking across agency boundaries to community organizations, and work toward ways to blend resources across funding streams

## Strategies for Coordinating Services, Resources and Supports

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The options you provide to families to address the child and family outcomes on the IFSP depends on your knowledge of the myriad services, resources, and supports available in the community and at the state and federal level to address the child and family outcomes on the IFSP. Service coordinators learn quickly that they will be called upon to know a broad range of services, resources, and supports extending well beyond the 14 early intervention services. Learning what is available in a community can itself be a daunting job, especially in a major metropolitan area. No one person can possibly be aware of all that is available. Rather, the goal is to acquire knowledge about frequently requested resources and how to access information when other less frequently requested resources are needed. These strategies will serve the service coordinator well during each of the four phases of service coordination (i.e., follow along; unexpected, immediate needs/crisis, and transition).

### ■ *Developing relationships with key resource people*

Service coordinators spend a great deal of time communicating with families, other team members, and agency personnel from health, education, social and community services. One strategy for working more effectively and efficiently is to foster relationships with key people in various agencies. Knowing who to call for what information can save an incredible amount of time and energy. Some people have their finger on the pulse of different services, resources, and supports and occasional contacts with these people can provide information about changes or new policies, procedures, and directions. For example, one contact may know about insurance and key financial resources, while another may know about child care providers in the community. Developing a system (perhaps one that parallels the resource map described in the next section) that has key people's names, telephone numbers, and any helpful anecdotal information will eliminate the need to retrieve the same information again and again. Think about a personal system (e.g., a rolodex, notebook, files) for organizing information that will work best in your agency.

## ■ *Developing a resource map for service coordination*

Knowledge of resources and strategies for organizing and accessing resources appears to consistently be a priority for early intervention programs. With well organized resources, the early intervention program can both serve families better and save staff time and energy in locating needed resources. During the Pathways: Service Coordination Inservice Project, two of the early intervention programs serving as training sites for the project independently prioritized the organization of program resources as a top need. The program's goals for resource organization were to build on the cumulative knowledge of the staff who access resources for families and to develop strategies that make the system dynamic, current, and community specific. Additionally, newly hired service coordinators for the program would benefit by having access to a system that would familiarize them with existing resources.

Together the Pathways staff and program personnel developed an organizational framework for resources that was current and program specific (See Appendix J). This resource map listed the major headings and subcategories of resources that were called upon in meeting the needs of children and their families in a particular community. Other considerations in the organization of the resources within these categories were:

- How would the information about resources be organized (e.g., use of computer technology or other methods such as file cabinets, drawers or folders, notebooks, rolodex)?
- How would the content be organized within a category (e.g., alphabetize by resource or by disability, develop a strategy for cross-referencing information using the index, contents or section notes)?
- How would staff access the system (e.g., computer, file drawer in program or staff office; if a home-based program, is there a method for having access from the vehicle)?
- How would staff update and communicate about resources to make the system dynamic (communication is the key and each person

needs to agree to update the system as they locate and use new and existing, successful contacts)? Updates could be structured into staff meetings, e-mail, memos or entered directly into the system.

## ■ *Accessing the Central Directory*

The central directory—a part of each state's early intervention system—provides another source of information related to early intervention services. This directory is generally accessed by an 800 # and is often computerized. In Wisconsin, Lutheran Hospital in La Crosse in conjunction with the Maternal Child and Health (MCH) Hotline coordinates First Step, the Birth to Three central directory. First Step consolidates and coordinates information and referral databases on Wisconsin MCH services, including: Health Check, Healthy Start, WIC, and a broad variety of MCH services and programs. An 800 number (1-800-642-STEP) gives parents and providers access to information about services, resources, and supports seven days a week from 7:00 a.m. to 11:00 p.m.

## ■ *Accessing the Internet and World Wide Web*

A rapidly expanding source of information is the Internet and World Wide Web. Numerous "bulletin boards" allow people to chat about topics ranging from augmented communication to the latest techniques for teaching reading to children with Down syndrome. An increasing number of people have access to computers and the Internet at home, but there are other ways to access the Internet, including friends, relatives, libraries, local school districts, and university facilities.

Currently, a variety of efforts are under way to develop information for parents who have children with disabilities. One example is the "Family Village," a project funded by the Kennedy Foundation and administered through the Waisman Center at the University of Wisconsin-Madison. The Family Village Project includes a web site on the Internet featuring information about organizations, educational topics, health care, consumer products, and much more.

The Pathways: Service Coordination Outreach Project is developing a home page on early intervention service coordination. This home page will

provide access to resources and information on service coordination and related topics. Access to Pathways staff via electronic mail will also be possible. Appendix K offers a list of addresses on the Web that will provide the service coordinator with a range of information on different topics (e.g., assistive technology, education, toys, etc.).

### ■ *Understanding eligibility criteria for programs*

Many of the services and resources for children and families that are accessed outside of the early intervention services have specific eligibility criteria. These criteria may include the child's chronological age, type or degree of disability, geographic location or residence, and level of family income. For example, it is helpful to know who is eligible for what and how to access programs outside of early intervention, such as, Medical Assistance Program, Family Support, Head Start, and Healthy Start. In addition to knowing the eligibility criteria for key programs, the service coordinator will want to know: (1) how to make a referral to each of these resources, (2) if there is a waiting list for services (3) if the application is complicated, (4) which applications parents might need support in filling out, (5) which programs will be easy to access and welcoming to the families served, and (6) if possible, a contact person the service coordinator knows and recommends as knowledgeable and helpful. As one father said, "You can find 100 people who tell you 'No'; the trick is to find the one person who says, 'Yes'."

## Financing Services, Resources, and Supports

Although it may be impossible to acquire expertise on all of the intricacies of financing, it is imperative that service coordinators know the key financial resources for children and families and have a variety of strategies for assisting families in obtaining the accurate information they need. The IFSP can be used to specify how child and family needs will be financed. The IFSP can facilitate creative funding strategies by looking across agencies and funding streams to finance family and child needs.



The service coordinator must also develop strategies for those times when funding sources indicate that their agency or company is not responsible for payment for a service or when requests for financial assistance are rejected. It is important not to take "no" as an answer but to question the interpretation that resulted in the rejection of the request. Persistence, patience, and a properly worded rebuttal can lead to a different interpretation of a policy that will favor the family. If the answer continues to be "no," it is a good idea to explore other avenues of funding. Appendix L includes a listing of some key financial resources that families frequently access for services.

Clifford and Bernier (1993) list 44 funding sources that support early intervention services, including public health insurance at the federal, state, and local level and private health insurance sources. On the average, states use 21 sources to finance the early intervention system. The top 10 sources of funds listed by Clifford and Bernier's (1993) reviews of the literature and surveys are: (1) Part H, (2) state mental retardation/developmental disabilities programs, (3) Chapter I/ Handicapped Children, (4) Federal Medicaid programs, (5) state Medicaid match, (6) state public and mental health programs, (7) federal Maternal and Child Health (MCH) Block Grant, (8) state MCH match, (9) WIC Supplement Food Program, and two sources tied for (10) Special Education and Early Periodic Screening, Diagnosis, and Treatment (EPSDT). Private health insurance has played a more limited role in the financing of early intervention services. The service coordinator will need to be aware of the Medical Assistance Program, which many fami-





lies in early intervention find useful. The following provides some detail on this federal program.

## The Medical Assistance Program

Medical Assistance covers the cost of medically necessary services, including general health care, hospitalizations, and many early intervention services. Families may access this program through a variety of means.

- Eligibility for Aid to Families With Dependent Children (AFDC)
- Eligibility for SSI because of the child's level of disability. Eligibility also depends on the family's income. This program provides a cash benefit.
- Eligibility through the TEFRA MA Waiver Program. This waiver program allows for payment of medical services in the community for children who might otherwise be cared for in an institution/hospital. In Wisconsin this waiver program is called the Katie Beckett Program.
- Eligibility through Healthy Start, which expands the income levels for eligibility for Medical Assistance for pregnant women and children up to the age of six. In some states, this program is known as EPSDT.

It is important to keep track of the changes occurring at the state and federal levels related to all of the key resources and programs for children and families. Numerous changes in our laws and policies occur as politicians and their constituency struggle to reform health, education, and social service policies.

## Content of the IFSP: the Document

The IFSP—the written product itself—is possibly the least important aspect of the entire IFSP process. Far more important are the interaction, collaboration, and partnerships between families and professionals that are necessary to develop and implement the IFSP. (McGonigel & Johnson, 1991, p. 1)

Although the interactive and interpersonal components of the IFSP process are of primary importance, the service coordinator cannot afford to neglect the written portion of the IFSP. It represents the formal contract the early intervention program makes with the family. It not only reflects and records the process the early intervention team has gone through to identify goals, strategies, and services, it becomes the legal basis for the provision of services. The IFSP is the document of reference for any questions about the appropriateness of the services or the frequency, location, or intensity of these services. What is written on the IFSP forms the legal basis for appeals and for formal decisions by a hearing officer if the actions are challenged.

It is the responsibility of the service coordinator to insure that the IFSP is appropriately developed, includes all the required components, and that all modifications to the IFSP are appropriately noted and signed. The following components must be included in the document:

- information about the child's developmental status, including statements about the child's present level of ability that are based on "professionally acceptable objective criteria";
- the basis for the determination of the child's eligibility for early intervention services;
- summaries of the evaluation and initial assessment of the child and reports of any ongoing assessment;
- a summary of the family's strengths, resources, concerns, and priorities related to enhancing the child's development (with the parents' permission);

- a statement of the expected outcomes for the child and family, as identified by the IFSP team, and the criteria, procedures, and timelines to be used in determining progress toward those outcomes (or need for modification of outcomes);
- the early intervention services needed to reach the outcomes. This includes the frequency, intensity, and service delivery model to be used; the setting in which the service will be provided; payment arrangements; the projected dates for initiation of services and their expected duration; and, if appropriate, medical or other services the child needs, but which will not be provided by the early intervention program, and the steps that will be taken to secure those services;
- the name of the service coordinator;
- steps taken to support the family through transitions; and
- provisions for ongoing review, evaluation, and, when needed, revision of the plan.

Keeping the IFSP up to date and ensuring that all required components are included takes time, organization, and careful record keeping. The first step is to develop a format for the IFSP that is easy to use, family friendly and helps to guide the process. Some states have developed an "official" IFSP format to be used by all programs. Other states have provided the basic framework but have left the specific format up to the individual programs. Wisconsin follows the latter model (see sample IFSPs in Appendix M).

A consideration in developing the IFSP format is its use and meaning to the family. Since the IFSP belongs to the family, hopefully it will be attractive and readable. It is a document that explains the services the child is receiving and how and why these services were identified. The IFSP should therefore be written in language understandable to the family and the plan should reflect the concerns and priorities of the family.

## Timelines in the IFSP Process

The IFSP document is meant to reflect a fluid process, responsive to the changing needs of a child and family. Service coordinators must have a method to track the changing needs and time elements related to the IFSP process for each family they work with. There are four points on the timeline in determining eligibility for early intervention services and the need for developing, reviewing, and revising the IFSP.

The primary referral source has *two working days* to refer the child for an evaluation from the time he concludes there is cause to believe the child has a developmental delay or a condition with a high probability of resulting in a developmental delay.

From the day the responsible agency receives the referral, it has *45 days* to complete the evaluation and initial assessment and hold an IFSP meeting to develop a service plan. The initial and annual IFSP meetings should include the following participants: parent or parents of the child; other family members as requested by the parents; an advocate or person outside the family, if the parent requests; the service coordinator; a person or persons directly involved in conducting the evaluations and assessments; and, as appropriate, persons who will be providing services to the child or family. If any of these participants (other than family members) are unable to attend the meeting, arrangements must be made for their involvement through other means (e.g., a teleconference call, availability of pertinent records, attendance by a knowledgeable authorized representative). Exceptional circumstances (e.g., if a child is ill) may delay the evaluation and assessment, and therefore the development of the IFSP. Part H does not clearly define or restrict the term "exceptional" but states that the lead agency should develop procedures for the public agency to use in documenting the circumstances. An interim IFSP is developed in collaboration with the parents under these circumstances.

After the initial IFSP has been developed, it must be reviewed *every six months*, or *sooner* if warranted or if the parents request a review. The purposes of such a review are to determine progress



toward desired outcomes and to revise the outcomes or services as needed.

*At least annually*, the service coordinator must convene a meeting to evaluate and revise the IFSP as needed. This meeting, unlike the six month review, must include a person directly involved in conducting the evaluation or assessment.

A challenge for service coordinators is to have an effective system of tracking the IFSP process to ensure that the child and family are receiving the services in a timely fashion as required by law. The service coordinator must garner all his skills to coordinate teams and agencies to be responsive to these timelines. Meeting the required timelines is a challenge; however, an even greater challenge may be to meet with families frequently enough to develop a partnership in the process.

## THE JOURNEY—PROVIDING FOLLOW ALONG TO FAMILIES

The activities of follow along draw upon many of the resource management and communication skills essential in all phases of the IFSP process. During this phase it is important for service coordinators to have methods to: (1) monitor, evaluate, and document the IFSP process and its associated timelines; (2) collect, update, and distribute information on services, resources, and supports; (3) link, connect, and communicate with families, other team members, and agency personnel; and (4) share with families the skills and knowledge involved in coordinating services for their child and family.

### Strategies for Coordinating Early Intervention Services

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As a service coordinator, it is no surprise that the majority of your efforts will be focused on the coordination of services. The success of your early intervention coordination begins with your organizational and facilitation strategies and proceeds to the way you coordinate with families, other team members, and agency personnel. The following section offers a few thoughts about the essential skills for service coordination.

### Strategies for Organizing the Job

Organizational skills have an important impact on how you use your time and manage your paperwork and record keeping. You should develop time management strategies in a way that works for you. However, when working with families and other team members, you need to respect their approach to time and may need to accommodate and adapt. The following considerations might be helpful in analyzing how you use your work time. Think about whether there are changes you would like to make in how you manage time:

1. Use a "To Do" list to help keep track of what needs to be done. These lists can be used to track what you need to accomplish related

to each of the families you work with and also for your overall activities during the day. Make sure to periodically revise these "To Do" lists.

2. Think about the source of the activities on your "To Do" list. Are the tasks supervisor or agency-imposed and uncontrollable or are they colleague or self-imposed and controllable? How can you balance the two sources? Remember there is a tendency for all of us to have too many items on our "To Do" list.
3. If you are concerned about how you manage time, keep a time log for a few weeks until you have a representative sample of your typical work week. Attach the time log to a clip board, your desk, or a folder and update it a couple of times during an hour or hourly depending on your day. If you wait until the end of the day, you will be dealing with impressions. After you have collected the information, analyze the time log by asking yourself—
  - What am I doing that doesn't have to be done?
  - What am I doing that could be done by someone else?
  - What am I doing that could be done more efficiently?
  - What am I doing that wastes the time of others?
  - What did I do during my prime times when my energy is at its highest?
  - What is my "down" or least efficient time?
  - Have I gotten any breaks or support time?
4. Appraise how you set priorities based on the urgency or importance of the task. People set priorities differently. For example, one person may set as first priority

those tasks that are both important, urgent, and job-related, while another may see their first priority as quieter, non-urgent activities that have to do with health, family, long-range plans, or personal or staff development. Having a balance of all these activities may be a goal for many of us.

5. Consider keeping a daily or weekly plan. Within that plan, set deadlines for tasks, group related activities, plan time blocks, exploit your prime time, schedule quiet time, and establish routine and habit. Take satisfaction in checking off completed tasks and reprioritize uncompleted tasks.

You will need to develop your own methods for managing the paperwork. Here are a few strategies:

1. Develop and use forms for any paper tasks you do over and over again. Look across the program for paperwork that is used repeatedly and develop forms for these tasks as well.
2. Keep handy resources that are used repeatedly, such as program brochures or description of your program, services, procedures, program options, and procedural safeguards. Other frequently used informational handouts might include: one-page listings of area health, education, and social services telephone numbers and addresses and one-page descriptions of funding sources. Some programs have put together a packet of information for each family in their program. The packet can then be individualized based on the family's concerns and priorities.

Some programs have found it beneficial to put together a transition packet for families. This has been consistently identified by parents as a stressful and confusing time. This packet or booklet can also contain service coordinator timelines and activities during transitions (see Appendix N for some items to include in a transition booklet).
3. Develop categories for paperwork based on what you generally do on the job. These categories can serve as the headings for divid-



- ers in your filing system and for the file folders that contain your paperwork. Some categories to consider are: intake, developmental history, emergency information, referral, permission or consent forms, invitations to meetings with an RSVP format, standard letters to physicians, school districts, insurance companies or other agencies, progress notes, billing and keeping track of units, travel, evaluation and assessment, IFSP, and follow-up questionnaires for families.
4. Develop a process for needed paperwork. Depending on the size of your program, this may be best accomplished with co-workers who have similar responsibilities. Make explicit why the paperwork needs to be done, how it should be completed, when it needs to be done, and to whom it goes. It works well to have one set of all forms in one location (e.g., three-ring binder, file drawer) along with an explanation of the process.
  5. If you have a computer available, use it to personalize letters, agendas, memos, forms, or reports that have minor changes from a standard format.
  6. Post pertinent information in a central location (e.g., bulletin board) or use a routing slip to share the information. Make sure the routing slip specifies how long each person can keep the information.
  7. Create your own file system that will expedite retrieval of information. Organize by subject, chronological, alphabetical, or color code files. Other file systems that can be useful are: a desk file sorter where information is separated into files and prioritized later; color-coded files to indicate priority (e.g., red is high priority and green is low priority); and a tickler or follow-up file. This can be built into your calendar to help you to remember tasks in the future.
  8. Keep track of current phone and fax numbers and addresses. Though it can be a challenge, it will save time and hassle in the long run. Keep a directory or rolodex of parents, providers, agencies, and other resources.
  9. Use a calendar and put your timelines for yourself and families in as dates are set. For example, at the IFSP meeting, indicate the six month review and the yearly reevaluation.
  10. Put all those interesting papers that come across your desk into different files (e.g., to be read, to be filed).
  11. **THROW OUT/RECYCLE** all unneeded paper. When you read it over the first time, make a decision to keep or throw. Be brutal!
  12. Encourage your program to publish a newsletter to keep families apprised of upcoming events and information. This removes the necessity of repeating the information and also ensures that all parents in the program receive the same information. If your program includes a large number of families who speak English as a second language or who do not speak English, you might arrange for translating the newsletter into other languages. Many communities have resources for these services. Developing a relationship with these groups or individuals can also assist you in developing a pool of people who may act as interpreters.

## Strategies for Record Keeping

The service coordinator is responsible for keeping a variety of records. A record central to early intervention is the IFSP. The section Content of the IFSP: The Document details keeping this important record. In addition to the recording of early intervention plans and services on the IFSP, service coordinators also keep what are often called case notes. These notes record the contacts service coordinators make with the family, with service providers, or with outside agencies. When the service coordinator works in a system where "case management" services are billable, these case notes document the activities that are the basis for the billing. In Wisconsin, where service coordination activities on behalf of children are covered under Wisconsin's Medical Assistance Program (billable under targeted case management), these case notes

need to include specific information about the service coordination activities. Most service coordinators find it helpful to keep this information for all children they serve.

The Wisconsin Medical Assistance Provider Handbook provides information on eligibility, covered services, and the procedures to be followed for record keeping and billing. Part U deals specifically with case management services and required documentation. It also defines those activities that are recognized as billable under this service. These activities include: assessment, case plan development, ongoing monitoring or service coordination (face to face and phone contact with the recipient, the family, or providers), case staffing and formal case consultation, record keeping necessary for case planning, coordination or monitoring (i.e., case management). A Wisconsin Medicaid Update 95-10, March 24, 1995, summarized the minimum requirements for documentation under this program. They included:

- name of recipient
- who made contact
- what was the content of the contact
- why was the contact made
- how much time was spent
- when was the contact made (date of contact?)
- where was the contact made

The update provides an example that *included the minimum requirements for case notes*:

*Met with Ms. Smith on 12/20/94 for an hour in her home. We reviewed her case plan. The plan includes the goal of health care needs stabilization using supportive home care assistants. She is dissatisfied with one of her workers from the XXX agency. Apparently the worker is not turning up on time. I will contact the agency today.*

The update then gave an example that did not meet the minimum requirements:

*Visit with Ms. Smith. There was a problem with her supportive home care.*

In this example, not only was information on time and location missing, but the specific activity the

service coordinator performed or would perform was not identified.

Many programs have established a standard format for service coordination notes that helps to facilitate the organization of the case notes and ensures that the notes meet the requirements of the funding agency. One county found a particular format helpful. Information on the recipient appeared at the top of the page. Space was provided on the left hand margin for noting the date, the type of contact from the defined case management services in Part U of the handbook, and the time spent. The first few lines of the narrative contained a brief summary of the activity. More descriptive information followed, with a clearly identified line at the end of the case note for follow-up activities. The same page could include a number of contacts and activities (see Appendix O for a sample case note form from the Portage Project).

Sometimes the activities of a service coordinator will include a change in a service specified on the IFSP. In this instance, the case notes might reference the activity (e.g., a change was made in the location of speech services) and refer to the IFSP rather than writing up a full explanation in the case notes.

A comment needs to be made about the confidentiality of case notes. Case notes become part of the early intervention record. They may be requested by a family and if there is a court case, may be subpoenaed. Service coordinators should limit case notes to observations or facts. Impressions, unrelated personal information, comments from third parties should probably be left out of case notes. Personal notes that will not be shared with anyone else can not be subpoenaed. However, many service coordinators find they would rather keep these impressions or concerns in their memory and not write them down because of the concerns of confidentiality.

When families share with a service coordinator concerns that they do not share with the rest of the team, the service coordinator needs to decide how she is going to handle this information. If the information affects the child's development and would be helpful for other team members to know, the service coordinator may want to encourage the



parents to share this information or ask if she may. Often, families take a risk in revealing personal and confidential aspects of their lives. The service coordinator wants to build on this trust and keep this information confidential. The case notes might simply indicate that the family discussed a family situation, or that the service coordinator agreed to locate some resources outside of early intervention for the family. The case notes do not need to describe in detail the situation, the feelings expressed, and the service coordinator's responses.

Service coordinators should talk to the employing agency and with supervisors to establish what are required components to be included in case notes, what formats are being used, and how confidential information is handled.

## Advocating for Services

Part H of IDEA specifies an activity of the service coordinator as informing families of the availability of advocacy services. Advocacy is defined by Edelman, Elsayed, & McGonigel (1992) as influencing systems and decision makers on behalf of individual children and families; participating in efforts to strengthen and improve services for all children. Table 4: Advocacy is... Advocacy is not... from Des Jardins (1993), lists what activities might

be considered advocacy and what falls outside the definition. Our vision of service coordination takes advocacy a step further and views the service coordinator as advocating with and for families to make sure that the necessary services, resources, and supports are available and accessible.

Advocacy supports for families may come from within the early intervention program. There are numerous other sources of support for parents, however, that result from parent-to-parent matching, parent support groups, and state and community services. Several advocacy organizations in Wisconsin include: the Center for Public Representation, the Parent Education Project, Families Forward, and the Wisconsin Coalition for Advocacy (see Appendix P for a listing of state and national advocacy organizations).

## Strategies for Working Across Agencies

Interagency coordination and communication relies on many of the strategies already discussed, with the exception of interagency agreements. The service coordinator should be aware of any and all formal and informal contracts or agreements. These agreements will specify critical information about



TABLE 4.

*Advocacy Is... Advocacy Is Not...*

*Advocacy Is...*

1. Helping parents help themselves
2. Building confidence so parents are able to help themselves
3. Supporting efforts toward independence
4. Providing necessary tools for appropriate decisions and appropriate action
5. Informing parents of their rights
  
6. Helping parents get their rights
  
7. Analyzing a problem and pinpointing areas of responsibility
8. Stating options available to resolve a problem
9. Providing technical assistance and training
10. Providing assistance in locating appropriate services
11. Referring to appropriate agencies
  
12. Lobbying for necessary legislation
13. Agitating to get legislation implemented
  
14. Organizing for change
15. Initiating new services
  
16. Investigating grievances
17. Following up on complaints
18. Going to court when other avenues have failed to get results
19. Bringing parents and groups together for mutual support and action
20. Advocating and/or interceding on behalf of parents only when they are unable to help themselves
21. A partnership with parents, with mutual sharing of information, tasks, and action
22. Helping parents go through appropriate channels whenever possible to get services

*Advocacy Is Not...*

1. Taking over parents' lives (or problems) and making all decisions for them
2. Squelching efforts of self-help
  
3. Reinforcing feelings of helplessness and dependence
4. Keeping parents in the dark while doing everything for them
5. Keeping parents uninformed about their rights, making them rely on the advocate for everything
6. Discouraging parents from becoming activists
  
7. Making excuses for unavailability or inadequacy of services
8. Making decisions for parents
9. Controlling parents
10. Persuading parents to accept "make-do" services
11. Closing the door to parents because "there's nothing I can do to help"
12. Keeping "hands off" of politics
13. Accepting the status quo when legislation is not implemented
14. Seeking individual solutions to group problems
15. Accepting unavailability and inadequacy of services
16. Denying existence of problems reported
17. Dropping a complaint after initial contact
18. Filing a lawsuit as the first approach to a problem
19. Working only with individuals when others share a mutual problem
20. Interceding on behalf of parents who can help themselves
  
21. A parent/child relationship
  
22. Ignoring appropriate channels when trying to get services

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Des Jardins, C. (1993). *Advocacy is... Advocacy is Not...* In C. Des Jardins (ed). How to Organize an Effective Parent/Advocacy Group and Move Bureaucracies. Chicago, IL.: Family Resource Center on Disabilities.

how the two agencies collaborate in working with families. The service coordinator can ask the early intervention program coordinator whether such agreements are in place and gain some insight into the history related to the agencies' collaboration.

A few additional strategies for working across agencies might include: (1) getting to know about other agencies (e.g., read an agency's mission statement, informational brochures, and progress reports; set up meetings to introduce yourself and your early interagency program); (2) getting to know agency personnel (e.g., visiting other programs, collaborating on a project of mutual beneficial to the two agencies, belonging to other programs' advisory committees and inviting other agency personnel to be part of your program's advisory groups, invite other agency staff to do an inservice for your program staff and reciprocating by doing an inservice at the other program, holding joint social gatherings for staff or families from both programs); and (3) attending local interagency coordinating councils, if they exist. See Tables 5 and 6 for strategies promoted by Jesien (1996).

## Monitoring the IFSP Process

State and federal regulations describe a function of the service coordinator as "facilitating and participating" in the development, review, and evaluation of the IFSP. This means that the service coordinator is not solely responsible but collaborates with all team members in this process. The major tasks associated with the monitoring function are included in the organizational skills described above. Appropriate follow along with each family includes: keeping in contact with the family to see if new concerns or issues have arisen; tracking timelines and organizing the team to convene at appropriate times; being available to support families when immediate and unexpected events occur; sharing new information, with parent's permission, that is necessary for the provision of the early intervention services; and providing families with information and resources related to questions or concerns. The purpose of the service coordinator at this time is to be a conduit through which information and resources flow to all team members and to impart support and information to family members to address their questions and concerns.

TABLE 5.

### *Personal Behaviors and Attitudes that Facilitate Collaboration*

The heart of collaboration consists of individuals working together. Regardless of the larger context, each of us can either foster or hinder collaboration in our day-to-day contacts with other people. These are some suggestions to consider in working with families and other service providers:

- Be willing to listen to and understand the needs, goals, and procedures of others.
- Respect the operating procedures of other individuals and organizations.
- Keep the goal in mind.
- Be flexible enough to accept numerous paths to the goal.
- Be willing to let go of some decision-making power.
- Be the first to offer to share a resource, assist in an activity, or try a different way.
- Let someone else take the lead in carrying out an activity.
- Give others the credit for having accomplished an objective or achieved a success.
- Reach out to a counterpart in another agency. Invite him to participate in an upcoming activity or planning effort.

Adapted from Jesien, G. S. (1996). *Interagency Collaboration: What, Why, and With Whom*. In P. Rosin, A.D. Whitehead, L.I. Tuchman, G.S. Jesien, A.L. Begun, & L. Irwin, *Partnerships in family-centered care: A guide to collaborative early intervention*. Baltimore, MD: Paul H. Brookes Publishing Co.; reprinted by permission

TABLE 6.

### ***Guidelines for Collaboration***

#### ***Establish a shared goal or vision—***

Motivation will be based on this vision, so this may be the most important principle of collaboration.

#### ***Involve all key players in the development of the activity—***

Be sure to include those who could contribute or who could potentially pose barriers, as well as representatives of all those who may be affected.

#### ***Be realistic—***

Cooperation may be a first step to developing a trusting relationship before true collaboration can take place. Take a developmental approach; use today's successes to build closer working relationships.

#### ***Agree to disagree on steps in the process—***

Perfect agreement on everything is neither possible nor necessary. Collaboration involves give and take on many of the specifics. Each party needs to be willing to give in, at times, to the needs of others.

#### ***Make realistic commitments—***

"Under-promise and over-produce" is a good strategy, especially when participants have experienced previous failures or frustrations. One small success is often preferable to a dozen stalled attempts at major change.

#### ***Keep the goals and vision clear—***

This is especially important when the effort gets bogged down in administrative details or obstructive regulations. Keeping the larger vision in the forefront can help sweep away minor problems, freeing energy for the important but difficult issues.

#### ***Build ownership at all levels—***

Although time consuming, developing and maintaining good communication with all parties involved will maintain a broad base of support.

#### ***Publicize success—***

Successes can build momentum for larger systematic changes in programs and agencies. Disseminating information about successful changes can encourage other organizations to undertake similar processes or to join in community-wide efforts.

Adapted from Jesien, G. S. (1996). *Interagency Collaboration: What, Why, and With Whom*. In P. Rosin, A.D. Whitehead, L.I. Tuchman, G.S. Jesien, A. L. Begun, & L. Irwin, Partnerships in family-centered care: A guide to collaborative early intervention, Baltimore, MD: Brookes Publishing Co.; reprinted by permission.

## DETOURS ALONG THE WAY: UNEXPECTED, IMMEDIATE NEEDS OR CRISES

One of life's lessons is to expect the unexpected. For families with young children, the odds increase that the unexpected will happen. If the family has a child with special developmental or health needs, the ante rises and with it the potential for the unexpected. The unexpected, immediate need may relate to any aspect of the family's life. Service coordinators work with families who have young children with special needs and crises may be common in their jobs. Crisis, by its very nature, is impossible to be prepared for, but service coordinators can have strategies for reacting when faced with crisis.

### Strategies for Dealing with Unexpected, Immediate Needs or Crises

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An unexpected, immediate need can take a service coordinator off the intended path during a meeting, home visit, or telephone call. Some of these unexpected, immediate needs may take us off course but be relatively minor in nature. The unexpected, immediate need may take the form of a child who isn't feeling well, a neighbor dropping in during a home visit, a sick animal vomiting on papers brought for a parent signature, or a long-awaited doctor's appointment scheduled at the time of your visit. Having an agenda for meeting with a family is critical to its success. Equally important is the ability to set the agenda aside when more urgent or unexpected issues arise for the family.

Some unexpected, immediate needs can be perceived as a crisis. When faced with a crisis, each service coordinator might think through the following questions.

#### *What is the nature of the crisis?*

A crisis can stem from a variety of sources. Some potential sources include:

- Health (illness of child or family member; mental health issues)
- Financial (job, money, insurance, housing)
- Death (family member, friend)
- Relationship (marital discord, divorce, dissatisfaction with providers)
- Accidents (injury) Issues with alcohol and other drugs (AODA) Abuse or neglect

Understanding the nature of the crisis will assist the service coordinator in knowing what resources might assist the family, what referrals might be appropriate, and whether other team members might be called upon in the situation.

#### *Is the family asking for my support in this crisis?*

The service coordinator may see a family struggling with a situation and yet not be asked for assistance by the family. The service coordinator needs to sort out whether the family wants this assistance or not. Asking for help is not easy for many people. To determine whether there is need to involve in the situation, the service coordinator may comment on what has been observed and ask whether there is any way to be helpful. Opening up the topic to discussion and naming the apparent difficulty may enable the family member to ask for assistance. On the other hand, the family may not want or need your help. The service coordinator needs to respect the family's decision.

Sometimes, family members may want the service coordinator to just listen or be a sounding board while they figure out the best course of action. At other times, the family may want your help. Depending on the nature of the crisis, the service coordinator may call upon the same skills used when acting as a "trouble shooter" to assist the family in thinking through options and possible solutions when a proposed course of action is not working, when conflicts arise, or when priorities for the child and family have shifted since the IFSP was implemented. The service coordinator often uses conflict managing skills in these situations to help the family: (1) identify and clarify the issue, problem, or challenge; (2) collect and sort through the information and feelings related to the issue; (3) develop a plan of action for resolving the issue; (4) implement the new plan; and (5) review and evaluate the plan as it is being implemented to ensure that the chosen path is working. This process does



not have to be time intensive and may incorporate these decision-making steps:

- Acknowledge the person's problem by reflecting what you hear him say. This avoids the pitfall of you taking on the problem.
- Instead of offering advice or trying to solve the problem for the person, you might ask him how he thinks the problem might be solved.
- You can use a decision-making process with the person, asking relevant questions to stimulate him to identify the nature of the crisis. "So what do you see as the problem?", you might ask. If the person is struggling, you can ask, "If the problem was solved, what would you like the outcome to look like?" After the person has identified the problem, move to the second part by restating, "You have identified the problem as ..., what do you see as some possible solutions?" Here the person generates solutions; the next step is initiated by asking, "Which of these solutions or combination of solutions best meets the criteria for a successful outcome?" You might next point out that the person has come up with a solution.
- Determine if there are barriers to carrying out their plan. After possible barriers and potential solutions and strategies are discussed, a course of action is decided upon.
- The service coordinator may ask if and how she might be of use in carrying out the plan. Here the service coordinator's knowledge of services, resources, and supports can be invaluable. Ask the family if there are activities they want you to pursue and discuss a time to check back to see if the plan has been successful. If the plan is working, fine; if it isn't working, the service coordinator and family return to the process and try to determine where the process is breaking down.

*Can I address the crisis with the family or am I in over my head?* As the family relates the nature of the crisis, the service coordinator needs to determine whether he feels competent to address the family's crisis or whether there are more appropriate people to act as a resource to the family. It is important for the service coordinator to make a referral to draw upon his knowledge of community resources to assist the family.

*Do I need support and where do I get it?* Dealing with crisis is stressful even if the service coordinator has strategies to apply in the situation. The service coordinator may experience less burn out if she knows her sources of support and how to best use them. The service coordinator can get support from within the early intervention program. Early intervention programs often have guidelines and procedures related to handling certain types of crises. This takes some pressure off the individual service coordinator to figure out how she should proceed in some situations. Program support can occur through training and the provision of information on potential crisis situations that might face service coordinators.

Service coordinators might look for support from key people within the early intervention program, which ideally, has mentor and peer support systems. In a mentor relationship, the service coordinator is paired with a staff person who has greater experience, while in a peer support relationship, both people may have equal experience. This support person can assist the service coordinator in difficult situations by listening as she reflects on her options. The support person may provide ideas based on his experience.

Depending on the nature of the crisis and the supports available in the community, the service coordinator draws upon all of his resources to find appropriate sources of support for the family. Support for the service coordinator from outside the program could take the form of a friend, spouse, significant other, or family member who is willing to listen.

Section III of the guide offers many ideas and strategies for service coordinators and families confronted with unexpected, immediate needs or crisis. Those personal skills, in conjunction with the resources you may have to offer, will be critical when in this phase of the IFSP process.

## CHANGING PATHWAYS: FACILITATING TRANSITIONS

Transition can occur at any point in the IFSP process: at the beginning of early intervention, within early intervention, and at the end of early intervention at age three. Transitions are typically times of stress and service coordinators must call upon many of the skills discussed in the previous three phases. In the transition phase, the following service coordination skills are emphasized: preparation, planning, resource management, facilitation, and the provision of emotional support.

### Transitions Mean Change

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By their very nature and definition, transitions can be difficult periods. They are times of reorganization and perhaps uncertainty. They are times of adjustment. Transitions often mean developing new relationships, learning new skills, and finding new ways of behaving. Some transitions are easy. We can be excited about new changes, view the move as positive, and look forward to the new opportunities. Sometimes the transition is more challenging. We mourn the loss of what we are leaving, we are uncertain about the future, and we need support in making the move. We may even experience both excitement and uncertainty at the same time.

Preparing for transitions is important. It gives us time to collect information, explore our choices, develop new skills if we need to, and prepare ourselves emotionally for the loss of the old and the challenge of the new. Anticipating how you will feel and what new skills you might need can give you time to learn and prepare. Collecting information and finding out all you can about the new situation will often make it easier to make the move.

Federal regulations for early intervention under Part H of the Individuals with Disabilities Education Act (IDEA) require that a plan for transitions be included in the IFSP:

#### 303.344 Content of the IFSP

(h) Transition from Part H services.

(1) The IFSP must include the steps to be taken to support the transition of the child to –

(i) Preschool services under Part B of the ACT, in accordance with 303.148, to the extent that those services are considered appropriate; or

(ii) Other services that maybe available if appropriate.

(2) The steps required in paragraph (h)(1) of this section include–

(i) Discussions with, and training of parents regarding future placements and other matters related to the child's transition;

(ii) Procedures to prepare the child for changes in service delivery, including steps to help the child adjust to, and function in, a new setting; and

(iii) With parents consent, the transmission of information about the child to the local educational agency, to ensure continuity of services, including evaluation and assessment information required in 303.322 and copies of the IFSPs that have been developed and implemented in accordance with 303.340 through 303.346.

Typically the service coordinator is responsible for coordinating the transition plan and for ensuring that all the timelines and requirements specified in the federal regulations are met.

Transition can be broken down into a number of steps that help a family through the process. These steps are reminiscent of other decision-making processes that service coordinators and families use throughout the IFSP process. Ask the family to:

- reflect upon the change or transition.
- identify the available options.
- collect more information on each option.
- look at the impact of each option.
- decide on the best option.
- plan the actual transition (timing, logistics etc.)
- let go of the old and embrace the new.

## Planning Is The Key

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Service coordinators can facilitate the transition process by planning ahead and by helping prepare families for the changes that will occur. The planning occurs on two levels. On the systems level, it involves developing agreements with the “sending” agencies and /or “receiving” agencies. Clarifying what services they offer, what their process is and how they either make or take referrals. Getting to know the agencies and programs and developing a relationship with the staff is crucial if smooth transitions are to occur.

On the individual family level, the service coordinator is responsible for ensuring that the transition process goes smoothly for the family. Service coordinators can facilitate this process by following the steps outlined below:

- Anticipate transitions so that families have lots of time for the process of change.
- Identify the options, the choices families might have in making the transition.
- Help families learn about the new situation so that they and their children will be more familiar and comfortable with the new program.
- Arrange for visit to the new program so families and children can meet staff and see the actual location.
- If possible, work out agreements so that the child can spend a few hours or days “visiting” the program before they actually start. This is helpful for all children, but is particularly important for children who do not easily adjust to new situations. For a child with special care needs, it often helps staff at the new program.

## Transitions From Hospital To Community And Early Intervention

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Many questions and issues arise in the referral and transition from hospitals to home, community, and early intervention. Federal requirements in Part H of IDEA require professionals who have identified a child potentially eligible for early intervention to be referred to the program within two working days. This can create real challenges for professionals working in hospitals and neonatal intensive care units (NICU). Some of the questions that arise include: What if the child’s health is not yet stable? What if the child will be spending several weeks or months in the hospital? Should the referral go to the public health nurse first? What is the role of the hospital physician and the community doctor in this referral process? What if the parents are grieving the birth of this child and the professional is not sure if they are “ready” to hear about early intervention?

There are no straightforward or easy answers to these questions. Early intervention programs and hospital staff and community nurses and doctors need to work out agreements on how referrals will be made, when they are appropriate, and how families will be helped to make the transition from the hospital to the community and to early intervention when appropriate. Many early intervention program staff have joint meetings with community NICUs so they can learn more about the services each provides and work cooperatively to support families. Some hospitals refer children to the early intervention program weeks or months before the child is discharged. That allows families to obtain information and support from the early intervention program even though the child is not yet receiving services. Other hospitals include the service coordinator in the discharge planning process. The discharge plan in this instance also serves as a transition document facilitating the family's transition, not only to the community, but also to the early intervention program.

## Transition Out of Early Intervention

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Children and families may experience many transitions during the time they are in the early intervention program and all children will experience a transition as they leave the program at age three. Recognizing that parents should be aware of and knowledgeable about their transition options, Part H of IDEA requires that a written plan be developed for any transition. HSS 90, the administrative rules for the early intervention program in Wisconsin, details the following requirements for transition plans:

- Discuss with parents a prospective transition in advance and give them information about the new setting and other matters related to the child's transition, including the role of the family;
- Implement procedures to prepare the child for changes in the service delivery setting, including adjustment to and functioning in the new setting;
- With parental consent, forward information about the child to the local education agency or other service agency to ensure continuity of services;
- Convene, with approval of the family, a conference involving the county administrative agency, the family and the local educational agency responsible for early childhood special education program or other service agencies at least 90 days before the child reaches age three;
- Update the written transition plan to reflect decisions made at the conference under subd.4. and the roles of the sending and receiving agencies; and
- Review the child's program options for the period from the child's third birthday through the remainder of the school year.

As you can see from these rules, the transition plan at age three must meet some specific criteria and timelines, particularly if the child may be eligible for early childhood special education services through the public schools.

## Procedural Safeguards

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Throughout any transition, it is important to be aware of confidentiality issues and to consider what rights and responsibilities parents have in the transition process. First and foremost, the Family Education and Privacy Act (FEPA) ensures that no identifying information can be shared with another agency without a parents's written consent. Early Intervention records are equally protected.

There are many issues for early intervention programs and schools to work out so that transition will go smoothly for children and families. Some of the issues include: How often will local education agency (LEA) staff be available to meet with families from the early intervention program to inform them about the services available through the LEA? How can early intervention staff share with LEA personnel what they know about children to assist in a smooth transition? Are early intervention staff included on the school's multidisciplinary evaluation team (M Team)? Are the early intervention evaluations of the child's development used by the schools when they determine eligibility or programming? What happens as children leave a 12-month program and move to a system where most services are provided from September through June? What if a child turns three in May, or July, or September? There are provisions in IDEA that allow schools to take some children before age three and allow early intervention programs to serve some children who turn three during the summer. Many LEA/early intervention transition agreements discuss options for children around their third birthday.

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## DISCUSSION QUESTIONS

1. Why should every service coordinator understand Part H rules and state regulations for early intervention? How does one transfer this knowledge to family members?
2. How can a service coordinator's practice reflect partnership when often times caseloads are high and timelines are short? What strategies have worked for you personally?
3. Knowledge about services, resources, and supports are an essential service coordination responsibility. How do you keep up-to-date on local, state, and federal resources? What methods do you have for sharing what is known about resources with the team members you work with?
4. Many of the functions of service coordination are served by utilizing effective and efficient organizational methods. Discuss the strategies you use to keep on track.
5. Discuss your role related to advocacy. Do you see yourself as an advocate for the child and family? What happens if the needs of the child and family may potentially be in conflict with the practices and procedures of your program?

# ACTIVITIES

## Group Activities

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### *Activity 1: "Exploring the models of service coordination"*

*Purpose:* This small group activity helps participants to explore the advantages and disadvantages of three service coordination models through the use of a family story. The models explored include:

1. Dedicated service coordinator—inside the program,
2. Dedicated service coordinator—outside the program, and
3. Service provider as service coordinator.

One of two stories ("Proceed with Caution" or "At Risk for Medical Debt") can be used in this activity. We acknowledge that each story represents only one family and have attempted to make the scenario familiar without being stereotypic.

This activity also provides an opportunity for sharing your own expertise related to service coordination.

#### *Directions:*

1. Assign small groups (30 minutes)
2. Ask groups to choose a reporter
3. Read one of the two stories ("Proceed with Caution" or "At Risk for Medical Debt")
4. Discuss the advantages and disadvantages of three models of service coordination based on the information in the story
5. Return to larger group for sharing. Each group will be asked to report on the advantages and disadvantages of one of the models.

### ✪ *PROCEED WITH CAUTION*

Beverly is a single parent with two children—Jeffery who is 14 months and Amanda who is three years old. Beverly has been separated from Ed for four months now. Police were called twice for domestic trouble between the parents before the separation. Beverly chose not to press any charges. Ed still lives in town and calls or tries to visit periodically. Beverly has contemplated a restraining order. She has expressed concern about her and the children's safety both at home and in the neighborhood, where gang activity occurs.

Jeffery was referred to early intervention by the public health nurse (who was following him due to failure to thrive) for significant developmental delays primarily in social and motor skills. He does not make eye contact or engage others. He is extremely irritable and cries much of the time and does not sleep through the night. His lack of weight gain continues to be Beverly's primary concern. One incidence was reported of a broken arm that was not completely explained. Child protective services have been following the family and some staff have voiced concerns that the broken arm may have occurred during a fight between Beverly and Ed.

Beverly is a very caring mother. She is gentle and attentive with her children and appropriate with discipline. She finds it very difficult to pull everything together and do what needs to be done to access the resources she needs. She either postpones making calls or filling in forms or just forgets to keep appointments when other concerns come up. Beverly has expressed considerable frustration with the number of people and agencies involved with her family and the duplication of paperwork.

She gets along well with her early intervention service coordinator, and has asked the coordinator to help simplify communication between agencies. She is now on Aid For Dependent Children (AFDC), but has not availed herself of Women Infants and Children (WIC) and other possible benefits, such as Supplemental Security Income (SSI).

Early intervention staff are becoming concerned about going into the home and need some guidance about what to do if the father shows up while they are there. They have also expressed frustration in coordinating home visits with early intervention staff, the occupational therapist and the public health nurse on issues related to feeding and nutrition.

One week ago, the landlord threatened to evict Beverly and the two children because they have fallen two months behind in rent payments.

### ★ *AT RISK FOR MEDICAL DEBT*

Joan and Arlan Tauber have three children—Molly is nine, Jan is six, and Craig is 12 months old. Craig, the youngest, was born nine weeks prematurely (adjusted age approximately 10 months) and has special health care and developmental needs. He has chronic lung disease and spent the first three months of his life in a Neonatal Intensive Care Unit (NICU). As a result of these conditions, he has had three hospitalizations due to pneumonia and related complications in the first six months he was home from the NICU. In addition, he has difficulty eating and thus getting adequate nutrition. His muscle tone fluctuates and at 12 months he is beginning to sit up with assistance. For the past two months, his health has been relatively stable and he has been at home on oxygen, receiving services from the county's early intervention program and periodic visits from a respiratory therapist. However, he just returned to the pediatric intensive care unit with pneumonia.

Joan and Arlan are very concerned about how they will keep up with all the expenses of supporting Craig at home and also paying off past and current hospitalization bills. So far most past medical expenses were covered through their family's health insurance. However, Arlan has heard rumors that the small business where he works is concerned about the high cost of Craig's insurance. He fears he will either lose his job or his health insurance. Joan has given up her teaching job to care for Craig, either at home or in the hospital.

Joan has generally been coping, but every now and then has expressed that she is somewhat overwhelmed, especially during hospitalizations and when she doesn't sleep well. Craig hasn't slept through the night since birth. Recently she mentioned that she and Arlan could use an evening out. Joan feels isolated from the community and her teaching friends who have come by less and less often.

Craig has four physician specialists and a local physician. Through the county's early intervention program, Craig and his family are receiving service coordination from a new, full time service coordinator with a social services background. Craig now receives special education and occupational therapy services at home. Craig has also been to a feeding clinic to ascertain why he is having eating difficulties. Right before this recent hospitalization, Joan and Arlan had asked for more intensive/frequent motor services because of their concerns about his motor development.

Now that Craig is in the hospital again, his family feels considerable stress. Joan has called her early intervention service coordinator to let her know Craig is in the hospital again and to express her concerns about "holding it all together," especially making ends meet due to all the expenses involved in Craig's care.

## ***Activity 2: "The Great Debate: An Exploration of Approaches to Service Coordination"***

**Purpose:** Participants explore the strengths and potential weaknesses of three approaches to service coordination.

**Directions:** Prepare either a handout or overhead listing and definition of the three approaches to service coordination to be discussed:

### ***APPROACHES TO SERVICE COORDINATION***

**Approach # 1:** The service coordinator is also a direct service provider (e.g., speech and language pathologist, physical therapist, teacher, occupational therapist). There may be other providers in the community who are also service coordinators.

**Approach #2:** The service coordinator is a parent who is hired by the program to coordinate services for/with other families.

**Approach #3:** The service coordinator is a staff member who primarily does service coordination (e.g., social worker, program coordinator). This person may be the only early intervention service coordinator in a community.

- **Group Assignments:** Participants join a small group that has been assigned one of the three approaches.
- **Group Task:** As a group, the task is to discuss the pros and cons of the particular approach. In the discussion, consider:
  - When your approach would or would not be appropriate;
  - How you would decide whether or not to use your approach; and
  - How you would review your choice.

Prepare an overhead for a group spokesperson to present to the whole group.

- **Discussion and Critique of Approaches:** Group discussion will follow presentations by the group spokesperson

## ***Activity 3: Eco-Map: An Option***

**Purpose:** The Eco-Map is a family portrait that pictures how a family interacts with the world. It assists the family and service provider in visualizing the oftentimes complex connections within their social context (e.g., immediate family, extended family, informal supports and friends, professionals and organizations, and societal influences). The Eco-Map describes how the family experiences its resource networks and support systems, the costs and benefits of interactions with people and services, and sources of stress and of relief. This can be a valuable tool for assisting in developing IFSP outcomes and strategies.

**Directions:** The Eco-Map is completed during a conversation with the family. To draw an Eco-Map, use several large sheets of paper (such as newsprint), writing utensils, and a table or floor space large enough for everyone to gather around the drawing. The amount of time needed will vary; allow at least an hour.

Step 1. Identify the family. Family members define who are members of their household. Start with a large circle in the center of the page. Inside it, make a smaller circle for each member of the household. Inside of each small circle, write the name of the person it represents, along with any important information about that person's role or position in the family.

Step 2. Look at how the family is related to the rest of the world. Start by identifying the most significant other people in the family's life. Begin adding circles around the central household circle. Label each as it is drawn. The circle closest to the family circle might be extended family; the next concentric circle might be friends or informal networks; the next circle could be professionals and organizations; and the final circle might be societal influences. The circles should be tailored to the family's reality.

Questions may help people get started:

- How about the extended family? Who is there? Where should we put them?
- Think of how your time and energies are spent. Who brings in new experiences, information, resources, etc.?

Step 3. Describe your family's relationships with these other circles. Draw special lines of connection between the central family circle and each of the other surrounding circles. Different kinds of lines represent various kinds of relationships between the family and the other circles:

*A SOLID LINE* shows a strong interaction. This other circle has a lot of impact, influence or meaning for the family.

*A DOTTED LINE* indicates a weaker impact or involvement, but one strong enough to be included in the picture.

*ARROW HEADS* drawn on the line show the direction of flow of energies and resources.

*HASH MARKS* mean that the interactions are distressing, conflicted or stressful for the family.

#### ***Activity 4: Thinking About Interagency Collaboration***

*Purpose:* Practice in working through a process of collaboration using a role play that focuses on a county-wide issue.

*Directions:* Ask the participants to choose one of the issues and address the questions that follow:

1. The cost of early intervention services are such that there is a shortfall in the counties' budget. You have come together for a meeting to look at ways to make services more efficient or cost effective.
2. You work together in the same county and you have just been informed that there are resources available to increase your outreach to families who have been under served in the county. You need to narrow the focus for a proposal to obtain funds from the state for a plan to better meet the needs of these families.



Questions to address:

1. How do you define the goal?
2. How do you reach consensus on the goal?
3. What kind of information do you need?
4. How do you determine your alternatives or options for your plan of action?
5. What should be part of your plan of action?
6. How do you evaluate whether your plan works?

Choose a role to play at the meeting:

**Sarah** works for the Department of Health. You have been working with families for 20 years as a public health nurse and you believe there is a lot of redundancy in what the early intervention staff does and what you do from your office. You would like to see more recognition of your roles with families.

**Mildred** is from Education. You are a relatively new administrator from the Department of Education (DOE) and have been hired to act as liaison between the DOE and the state's Part H office. You recently were told that the governor's proposed budget targets your position as of July 1. There are many substantial cuts in budgets at your agency and restructuring of the department as a whole.

**Juanita** works for Social Services. You work in the County Social Service Agency that administers many programs for families including Child Protective Services, AFDC, WIC.

**Jane** is a Parent. You have a child with special health care needs who has received a variety of services since your daughter, Paige, was born three months prematurely. You have been invited to come to the meeting but you have not really gotten much information about your role.

**Vivian** is an early intervention service coordinator and program director for the county. You feel as though you know the direction the group should take because you have been part of the early intervention process since before the state decided to serve infants and toddlers. You will facilitate the meeting today.

### **Activity 5: The Human Knot**

**Purpose:** This activity can be used to highlight how people work together toward a goal and can be applied to their roles on a team.

**Directions:** Ask participants to stand in circle and take the hand of someone who is not standing directly next to them. Then again take someone else's hand not standing directly next to them. Then tell the group that the task is to untangle themselves without letting go of anyone's hand. Process the activity and connect their experiences during the activity to team processes such as communication, problem-solving, decision-making, and leadership. Ask participants to reflect on the role/s they assumed on the team.

### ***Activity 6: Getting Started in the IFSP Process***

***Purpose:*** To provide a forum for the participants to discuss their own challenges in service coordination and benefit from hearing about strategies to meet these challenges from other participants.

***Directions:*** Each person at the table should take three minutes to jot down three to five challenges they have experienced in "getting started in the IFSP process" when coordinating services.

As a group, discuss for ten minutes the challenges you wrote down and come to consensus about which one you would most like strategies to address.

Each group shares the challenge selected as the facilitator lists them on an overhead.

From that list, each table should agree on one challenge to address and write it on an index card.

Pass the index card to the next table. The group takes five minutes to brainstorm strategies for addressing the challenge.

Share strategies with the group as facilitator lists them.

### ***Activity 7: Resource Fair***

***Purpose:*** Participants have an opportunity to bring and present service coordination resources they have found invaluable in their practice.

***Directions:*** Inform participants prior to the resource fair about the date and purpose of the activity. Ask all participants to bring their resources and to put the name of each resource on an index card along with information on how to obtain the resource and a brief annotation. Allow sufficient time for participants to peruse the materials and for participants to highlight one especially useful resource. At the end of the session, collect the index cards and prepare a handout listing the resource information. Distribute the handout to participants.

### ***Activity 8: Transferring Skills & Learning Styles: A Chopsticks Game***

***Purpose:*** Participants explore both their own learning style and how they transfer information to others.

***Directions:*** Divide the group into pairs. Each pair receives two sets of chopsticks and in a bag a variety of gadgets, dodas, and edibles to pick up with the chopsticks. A note is included that gives further instructions, such as "Close your eyes during the activity" or "Use your nonpreferred hand." For five minutes, one in the dyad uses the chopsticks while the other coaches the chopstick user. After five minutes, switch roles. When both participants in the pair have had an opportunity to use the chopsticks and be a coach, process the activity (e.g., What did your coach do that was helpful? What did the coach do that didn't help you? How did you feel about the directions you got from your coach? What did you learn about your own learning and coaching style? How might this apply to our work with families?)

## **Activity 9: What's Wrong with This Picture**

**Purpose:** Participants explore ways of giving information to parents in a clear and sensitive manner.

**Directions:** The participants watch a role play. They freeze the action and offer suggestions to make the interaction more in alignment with developing a partnership and good communication skills. They freeze the action simply by yelling out "freeze."

**Setting:** An initial meeting to ask a parent about her concerns, priorities, and resources.

Peggy is the service coordinator. She exhibits problems in communication: too much, too fast, not checking in for clarification, taking control, not negotiating tasks, asking yes/no questions, making assumptions. Liz is the parent and exhibits problems in communication: not offering, not asking for clarification or to repeat, silence.

### **The Role Play**

Peggy: Well Ms. Hecht — hi, I'm glad to finally meet you. As you know I am the service coordinator from the Gateway early intervention program. We are a program that ...(give long explanation of program). Any questions?

Liz: No

Peggy: During your daughter's recent visit to the Doctor's office, you expressed a concern about your child's development. The nurse completed a Denver and found that you were correct that your child has delays in motor and speech and made the call to our program for a more complete evaluation to determine eligibility for early intervention. Is that correct?

Liz: Uhuh...

Peggy: Well let's get some information about your daughter, okay? Let's see, she was born at term, following an uncomplicated pregnancy and was released from the hospital at three days, right? She has been healthy, with the exception of a few bouts of ear infections and URIs, and is followed by her pediatrician, Dr. Flanders.

Liz: Yes...

Peggy: Your daughter is now 14 months old and is having some delays in her motor and speech skills.

Liz: I think so...her older sister, Tammy, was doing much more at Betsy's age. She was walking and saying words.

Peggy: It is hard not to compare children, isn't it? But children do unfold at their own speed..but we will take a look at her skills, especially in light of her low scores on the Denver. And we have a whole team of professionals at Gateway that are experts in working with children and will be able to give you more information about Betsy's abilities. So what are some good times for you and I'll go ahead and set up an evaluation to determine whether Betsy's delays are significant enough to make her eligible for E.I., okay?

Liz: Yes, I do want to know if there is something I should be doing to help her.

Peggy: After the evaluation, we will be able to give you some suggestions.

# Individual Activities

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## *Field-Based Activities:*

1. Visit a parent support group.
2. Shadow someone from an agency with whom families in your early intervention program frequently interact.
3. Interview someone in a social service, health, education, or other community agency that you want to know more about.
4. Identify someone in your program who might serve as a mentor for you. If the person agrees, meet to discuss what your relationship might look like, when, where, and how frequently you will meet and what will happen during these meetings.
5. Attend a meeting on medical assistance programs if you are unfamiliar with the scope of the program and procedures for assisting families eligible to participate.

## *Self-Study Activities:*

1. Read that portion of the federal or state regulations you don't understand or are unfamiliar with. Record the main points you have learned in your journal.
2. Write an agenda for an upcoming meeting and facilitate the meeting using suggestions from this section. Record your reactions to the meeting.
3. Create or modify a system to organize one aspect of your life (e.g., appointments, follow-up with families on the IFSP, resources, etc.) Share it with others for feedback. Then promise to use the system for the next month and determine if it saves time.

## RESOURCES

### *Readings:*

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Clifford, R. M., Bernier, K. Y. (1993). Systems of financing early intervention. In D. M. Bryant & M. A. Graham (Eds.), Implementing early intervention: From research to effective practice, 313-335. New York: Guilford Press.

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Kelker, K. A. (1987). Making the system work: An advocacy workshop for parents. Portland, OR: Portland State University, Regional Research Institute for Human Services.

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McGonigel, M. J., Kaufmann, R. K. and Johnson, B. H. (Eds.). (1991). Guidelines and recommended practices for the individualized family service plan (2nd ed.). Bethesda, MD: Association for the Care of Children's Health.



Rosin, P., Whitehead, A., Tuchman, L., Jesien, G., Begun, A., & Irwin, L. (1996). Partnerships in family-centered care: A guide to collaborative early intervention. Baltimore, MD: Paul H. Brookes Publishing Co.

Rosin, P., Whitehead, A., Tuchman, L., Jesien, G., & Begun, A. (1993). Partnerships in early intervention: A training guide on family centered care, team building and service coordination. Madison, WI: Waisman Center, University of Wisconsin.

### **Videos:**

#### **1. Family & The IFSP Process: Training in Family-Centered Approaches (1993)**

Time: 90 minutes

This videotape and facilitator's guide offer an interactive approach to training about the Individualized Family Service Plan (IFSP). The videotape identifies 11 key landmarks in the IFSP process; describes what happens at each landmark; and models family-centered approaches in vignettes about five landmarks. Black and white scenes show things can go wrong. Colored scenes model some family-centered practices. The guide includes activities to promote discussion and skill building.

Available from:

Kennedy Krieger Community Resources, Publications  
2911 E. Biddle Street  
Baltimore, MD 21213  
410-550-9700  
Cost: \$150.00 + shipping

#### **2. Individualized Family Service Plan (IFSP) (1990)**

Time: 25 minutes

Across the country, service providers in education, health, mental health and social services are wrestling with what the "family first" approach means in developing the Individualized Family Service Plan (IFSP). In this video, providers discuss and illustrate new approaches and practices as they work cooperatively with families to identify and access resources to help families identify and reach their goals. Additionally, families talk about their experiences and expectations with the IFSP process.

Available from:

University of Nebraska Medical Center  
Meyer Rehabilitation Institute  
Media Resource Center  
600 South 42nd Street  
Omaha, NE 68198-5450  
402-559-7467  
Cost: \$25.00

#### **3. Parents & Professionals: Partners in Co-Service Coordination (1993)**

Time: 20 minutes

This video and accompanying guide present a model of service coordination for families who have infants or toddlers with special needs. The model is Co-Service Coordination, where parents and professionals work together as partners to find, access, arrange, and monitor services the families need. In three vignettes, parents and professionals illustrate the complicated issues surrounding effective co-service coordination and the mutual benefits of this model. The video also includes Part H service

coordination responsibilities. The guide provides an explanation of the model, discussion questions related to the video, and suggested activities.

Available from:

The Early Intervention Program  
Waisman Center—Room 231  
1500 Highland Ave.  
Madison, WI 53705-2280  
608-263-5022  
Cost: \$39.00 + shipping and handling

#### 4. *Sharing Sensitive Information with Families (1988)*

Time: 30 minutes

This videotape aims to make professionals aware that delivering sensitive information is not just a one-time, brief encounter with parents. Parents of children with special needs express their need for an empathic informer who provides support, information, resources, and follow-up when sharing difficult news. Developed for health care professionals, educators, and parents the video demonstrates ways professionals can inform parents about a medical condition or a disability.

Available from:

Child Health And Development Educational Media (CHADEM)- #911  
5632 Van Nuys Boulevard, Suite 286  
Van Nuys, CA 91401  
818-994-0933  
Cost: \$60.00 + shipping and handling

#### 5. *And You Thought They Were Just Playing: Transdisciplinary Play-Based Assessment (1995)*

Time: 65 minutes

This video complements the popular books by Toni W. Linder, *Transdisciplinary Play-Based Assessment* and *Transdisciplinary Play-Based Intervention*. Viewers will see portions of play sessions and learn first hand how transdisciplinary, play-based assessment can be used to assess young children's skills. The video also shows activities that link assessment information with intervention.

Available from:

Brookes Publishing Co.  
Cost: \$175

#### 6. *Preparing Paraprofessional Early Interventionist: Infant Parent Interaction Activities (1994)*

Time: 37 min

This video and accompanying training guide serve as excellent resources to prepare paraprofessionals who are part of early intervention teams. They focus knowledge and skill building to support paraprofessionals in extending professional early interventionists roles and to assist with implementing IFSPs. The video and guide can be used in the following ways: (a) to support individual paraprofessionals on the job, (b) to assist supervisors with defining jobs, hiring and monitoring paraprofessional personnel, and (c) for inservice and preservice training. The materials are applicable in any early intervention setting and recognize that responsibilities will vary with settings.

Available from:

Communication/Therapy Skill Builders  
Cost: \$79

## SECTION II: APPENDICES

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■ *Handouts (indicated by a ⊕ ) are inserted in this section, as well as in a pocket in the back of this book.*

## APPENDIX A

# FEDERAL RULES AND REGULATIONS RELATED TO SERVICE COORDINATION

The Federal Register (1993):

### 303.22 Service coordination (case management)

#### (a.) General.

(1) As used in this part, except in 303.12(d)(11), service coordination means the 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 service that are authorized to be provided under the State's early intervention program.

(2) Each child eligible under this part and the child's family must be provided with one service coordinator who is responsible for—

- (i) Coordinating all services across agency lines; and
- (ii) Serving as the single point of contact in helping parents to obtain the services and assistance they need.

(3) Service coordination is an active, ongoing process that involves -

- (i) Assisting parents of eligible children in gaining access to the early intervention services and other services identified in the individualized family service plan.
- (ii) Coordinating the provision of early intervention services and other services (such as medical services for other than diagnostic and evaluation purposes) that the child needs or is being provided.
- (iii) Facilitating the timely delivery of available services; and
- (iv) Continuously seeking the appropriate services and situations necessary to benefit the development of each child being served for the duration of the child's eligibility.

#### (b) Specific service coordination activities. Service coordination activities include—

- (1) Coordinating the performance of evaluation and assessments
- (2) Facilitating and participating in the development, review, and evaluation of individualized family service plans;
- (3) Assisting families in identifying available service providers;
- (4) Coordinating and monitoring the delivery of available services;
- (5) Informing families of the availability of advocacy services.
- (6) Coordinating with medical and health providers; and

(7) Facilitating the development of a transition plan to preschool services, if appropriate.

**(c) Employment and assignment of service coordinators.**

(1) Service coordinators may be employed or assigned in any way that is permitted under State law, so long as it is consistent with the requirements of this part.

(2) A State's policies and procedures for implementing the statewide system of early intervention services must be designed and implemented to ensure that service coordinators are able to effectively carry out on an interagency basis the functions and services listed under paragraphs (a) and (b) of this section.

**(d) Qualifications of service coordinators.**

Service coordinators must be persons who, consistent with 303.344(g), have demonstrated knowledge and understanding about -

(1) Infants and toddlers who are eligible under this part;

(2) Part H of the Act and the regulations in this part; and

(3) The nature and scope of services available under the State's early intervention program, the system of payments for services in the State, and other pertinent information.

(Authority: 20 U.S.C. 1472(2))

**Note 1:** If States have existing service coordination systems, the States may use or adapt those systems, so long as they are consistent with the requirements of this part.

**Note 2:** The legislative history of the 1991 amendments to the Act indicates that the use of the term "service coordination" was not intended to affect the authority to seek reimbursement for service provided under Medicaid or any other legislation that makes reference to "case management" services. See H.R.REP.NO.198.102d Cong., 1st Sess. 12 (1991); S. REP. NO. 84, 102d Cong., 1st Sess. 20 (1991).

**(g) Service coordinator.**

(1) The IFSP must include the name of the service coordinator from the profession most immediately relevant to the child's or family's needs (or who is otherwise qualified to carry out all applicable responsibilities under this part), who will be responsible for the implementation of the IFSP and coordination with other agencies and persons.

(2) In meeting the requirements in paragraph (g)(1) of this section, the public agency may -

(i) Assign the same service coordinator who was appointed at the time that the child was initially referred for evaluation to be responsible for implementing a child's and family's IFSP; or

(ii) Appoint a new service coordinator.

(3) As used in paragraph (g)(1) of this section, the term "profession" includes "service coordination."



**APPENDIX B**  
**CHAPTER HSS 90**  
**WISCONSIN ADMINISTRATIVE CODE**

***EARLY INTERVENTION SERVICES  
FOR CHILDREN FROM BIRTH TO AGE 3  
WITH DEVELOPMENTAL NEEDS***

HSS 90.01 Authority & Purpose	HSS 90.08	Evaluation
HSS 90.02 Applicability	HSS 90.09	Assessment
HSS 90.03 Definitions	HSS 90.10	Development of
HSS 90.04 Eligibility		Service Plan
HSS 90.05 Department Responsibilities	HSS 90.11	Service Provision
HSS 90.06 County Administrative Agency Designation & Responsibilities	HSS 90.12	Procedural Safeguards for Parents
HSS 90.07 Identification & Referral	HSS 90.13	Surrogate Parent

Prepared by Peggy Rosin of the Wisconsin Family-Centered Inservice Project based on the Birth to Three Emergency and Proposed Permanent Rules distributed by the State of Wisconsin Department of Health and Social Services, Division of Community Services, on December 23, 1992. It includes the amendments to the Department's rules for operation of the Birth to Three Program under §51.44, Stats., for children with disabilities. In particular, the changes provide for full implementation beginning January 1, 1993 of the statewide system of early intervention services.

## **HSS 90.01**

### **AUTHORITY AND PURPOSE**

#### Authority

- Promulgated under authority §51.44 (5)(a), Stats., as created by 1991 Wisconsin Act 39, and §227.24(1) Stats., the Department of Health and Social Services repealed, renumbered, amended, repealed, recreated and created rules interpreting §51.44, Stats., as created by 1991 Wisconsin Act 39 and amended by 1991 Wisconsin Act 269.

#### Purpose

- Implement statewide program of services for eligible children age birth to three.

## **HSS 90.02**

### **APPLICABILITY**

#### Applies to

- DHSS (lead agency)
- county agencies administering EI program
- other county agencies providing services
- all providers of EI who are under contract or have an agreement with agencies who provide services

## **HSS 90.03**

### **DEFINITIONS**

(See HSS 90.03 directly for definitions)

## **HSS 90.04**

### **ELIGIBILITY**

#### Developmental Delay

- determination is based upon your EI team's clinical opinion supported by-
- developmental history and other pertinent information
- observations in daily settings
- determination of at least 25% delay or a score of 1.3 or more standard deviations below the mean in one or more areas of development as measured by norm-referenced instruments
- formal results closely approach but do not equal the above criteria but some aspect of child's development is atypical

Diagnosed Condition Likely to Result in Developmental Delay

## **HSS 90.05**

### **DEPARTMENT RESPONSIBILITIES**

#### Develop & Support Statewide Comprehensive System

- technical assistance
- interagency agreement with DPI and others
  - child find
  - transition to school
- public awareness
- central directory of services
- personnel development

#### Supervise and Monitor Local Birth to Three Programs

- collect information from counties
- access to county files and staff
  - make independent on-site investigation
- ensure deficiencies are corrected

### Procedures for Receiving and Resolving Complaints

- written and signed statement of complaint
- appoint a complaint investigator
- gather facts, conduct interviews and possibly an on-site investigation
- consider merits of complaint
- recommend resolution of the complaint (written decision within sixty days unless the time is extended due to exceptional circumstances)

### ***HSS 90.06***

#### ***COUNTY ADMINISTRATIVE AGENCY DESIGNATION & RESPONSIBILITIES***

##### Designation by County Board

##### Responsibilities of County Administrative Agency are to:

- ensure parents and service providers are involved in planning, development and operation of the early intervention service system
- establish a comprehensive child find system
- designate a service coordinator for each child referred
- ensure parents are informed verbally and in writing about purpose of program and the process, and procedural safeguards
- collaborate with parents in IFSP process
- obtain written consent from parents before evaluation, assessment and provision of service in IFSP
- provide appropriate early intervention services, including core services at no cost
- enter into interagency agreements
- maintain confidentiality
- appoint an impartial decision maker to resolve complaints
- determine need for and appoint surrogate parent
- maintain EI record (IFSP, core services, parental consent documents) separately from other records unless parental agrees to maintaining other records with the EI records
- provide Department information regarding funds and programs

### ***HSS 90.07***

#### ***IDENTIFICATION & REFERRAL***

##### Establish Child Find System

##### Informed Referral Network

- formal system of coordination and communication
- parents, agencies receiving funds directly or through a subcontract under relevant federal programs, health care providers, day care providers, schools and other qualified personnel

##### Screening and Referral for Evaluation

- conduct or arrange for formal or informal screening to determine referral for evaluation or refer directly for evaluation
- referrals are made with parents permission
- referral for evaluation is made no more than 2 working days after the child is identified
- parents are informed of the reason, procedures and results of screening

### ***HSS 90.08***

#### ***EVALUATION***

##### Designate Service Coordinator

##### Determine Eligibility/Determine Developmental Delay

##### Conduct Early Intervention (EI) Team Evaluation

- parent/s, service coordinator, and at least two qualified personnel in area of suspected needs

### Qualified Personnel

- audiologist, nutritionist, occupational therapist, physical therapist, physician, psychologist, rehabilitation counselors, registered nurses, school psychologists, social workers, special educators, speech and language pathologists, and other persons qualified by professional training and experience to perform evaluations

### EI Team Procedure

- service coordinator ensures parent involvement
- examines all relevant data and records
- determines child's abilities in these areas of development
  - cognitive
  - physical including vision and hearing
  - communication
  - social and emotional
  - adaptive

### Test Instruments

- primary language
- not racially or culturally discriminating
- validated for specific purpose and age group
- administered by trained personnel
  - assess specific areas of development, not simply a general IQ
  - if tests are administered to children with sensory motor problems, results must reflect what test purports to measure

No single procedure as sole criteria for eligibility

With parent's consent, members of EI team can consult with persons outside team to determine EI services

At the conclusion of the evaluation, all members of EI team meet to discuss findings and evaluations

EI team report written including:

- levels of functioning in areas of development
- determination of eligibility
- service coordinator provides parents with the EI team report

If EI team finds child not eligible,

- offer re-screen within 6 months
- information re: community services
- statement with parental consent

If an eligible child relocates to a new county, the child remains eligible for services on the IFSP until a new IFSP is developed

## ***HSS 90.09***

### ***ASSESSMENT***

#### Assessment of Child

- initial assessment to determine child's unique developmental needs
- all tests and procedures comply with HSS 90.08
- report prepared including strengths and needs and list of potential services
- parent/s receive copy of report
- ongoing assessments are carried on by either the EI or IFSP team
- discussion with non-participating parent and documentation by service coordinator as to rationale for non-participation and steps taken to share findings and recommendations
- parents role in child assessment

#### Family-Directed Assessment

- must have family's consent
- directed by family

- focuses on family's description of their strengths, resources, concerns and priorities related to enhancing development of the child
- family offered choice of methods
- information is based on personal interviews

## ***HSS 90.10***

### ***DEVELOPMENT OF SERVICE PLAN***

#### **Time Limit**

- 45 days after receiving referral, the county administrative agency shall complete evaluation, assessment and service coordinator convenes IFSP meeting

#### **Interim IFSP**

- completed if there is a delay in the evaluation and assessment due to exceptional circumstances
- services can be provided before completing the evaluation and assessment if clear and obvious need

#### **IFSP Team**

- consists of parent, other family members requested by parent, service coordinator, an advocate if requested by parent, at least one qualified personnel who took part in evaluation and assessment, at least one professional with expertise in assessment of typical and atypical development and program planning, and appropriate service providers

#### **IFSP Meeting**

- plan based on evaluation and assessment
- meeting scheduled for parents convenience

#### **IFSP Content**

- may have different sections completed at various times throughout the process
- parents have current copy of the plan and the contents are fully explained and kept current
- 8 components are mandated:
  - child's development status
  - basis for eligibility
  - summaries of the evaluation and assessments
  - summary of family's strengths, resources, concerns and priorities (with permission)
  - statement of outcomes expected
  - identification of services [frequency, intensity and length of time; group or individual basis; location; how provided; and payment arrangements, if any; if appropriate other services not required by Birth to Three program; projected dates for initiation of the services and duration of services]
  - name of service coordinator
  - transition plan

IFSP and IEP can be consolidated

#### **Review and Evaluation of IFSP**

- periodic review (6 months or more frequently)
- annual meeting

## ***HSS 90.11***

### ***SERVICE PROVISION***

#### **Role of the Service Coordinator**

- coordinate delivery of all services across agency lines
- serve as the single point of contact for family

#### **Functions of the Service Coordinator**

- coordinate evaluation and assessment
- facilitate and participate in the development, review and evaluation of the IFSP



- assist families in identifying available service providers
- facilitate access to services and coordinate and monitor the timely provision of services
- inform parents of the availability of advocacy services
- coordinate with medical and other health providers
- facilitate the development of the transition plan

#### Qualifications of the Service Coordinator

- at least one year supervised experience working with families with special needs
- demonstrate knowledge about Part H and the federal implementing regulations, 34 CFR pt.303, and HSS 90; the nature and scope of EI services and how they are financed
- may be a person from the list of qualified personnel in HSS 90.08, person with qualifications above, or a parent facilitator

#### Early Intervention Services—General Conditions and General Role of Providers

- general conditions for EI services

Appropriate early intervention services for an eligible child and the child's family, provided to the maximum extent appropriate to the needs of the child in natural environments, including the home and community setting in which children without disabilities participate, shall be based on the developmental needs of the child and shall be provided with the written consent of the parent. Services shall be provided in collaboration with the parent, by qualified personnel, and in compliance with applicable state standards and Part H requirements.

- Core and EI services listed on IFSP are provided at no cost to the child's family
- state funds allocated for B-3 program may not be used to satisfy a financial commitment for services paid by another source. B-3 funds may only be used for EI services that the eligible child needs but is not currently entitled to under other funding sources
- General role of EI service provider
  - follow requirements of HSS 90 and to the extent appropriate:
- ensure that service is effective
- educate parents, other service providers and community agencies in how to provide that type of service
- participate in EI team's assessment and development of IFSP and assist child in achieving IFSP outcomes
  - attend 5 hours of EI training per year
  - is not liable if child does not achieve growth projected on IFSP
  - bill third parties for EI services with parent's consent

#### Early Intervention Core Services

- identification and referral
- screening
- evaluation
- assessment of eligible child
- development of the IFSP
- service coordination
- protection by means of procedural safeguards

#### Other Early Intervention Services

- assistive technology
- audiology
- communication
- family education and counseling
- health care
- medical
- nursing
- nutrition
- occupational therapy
- physical therapy
- psychological

- social work
- special instruction
- transportation
- vision

#### Service Delivery

- natural environment or document why not
- method of delivery—most appropriate to meet needs of child and family

#### Qualified Personnel

- meet Wisconsin requirements for practice of their own profession or discipline

### ***HSS 90.12***

#### ***PROCEDURAL SAFEGUARDS FOR PARENTS***

Refer directly to HSS 90.12 for specifics regarding procedural safeguards related to:

- Notice
- Consent
- Confidentiality
- Opportunity to Examine Records
- Procedures for Resolution of Parent Complaints

### ***HSS 90.13***

#### ***SURROGATE PARENT***

Appointment of surrogate parent if:

- cannot identify a parent of the child
- after reasonable efforts, cannot discover parents whereabouts
- child is a ward of the state, county, or a child welfare agency, or was placed in legal custody of the state, county, or child welfare agency

Appointment is for an indefinite period if:

- surrogate parent resigns
- appointment terminated
- child no longer eligible for EI services

Qualifications of surrogate parent:

- at least 18 years of age
- not employee of service providing agency
- have no interests that conflict with the child
- same ethnic background or sensitive to factors of ethnicity relevant for EI services
- knowledge and skills to provide adequate representation for the child
- familiar with available EI services
- committed to being acquainted with child and needed services
- not a surrogate for more than 4 children at one time

Functions

- evaluation, assessment, IFSP development, implementation and evaluation, service provision, other procedural safeguards

## APPENDIX C

### WISCONSIN STATE REGULATIONS RELATED TO SERVICE COORDINATION

#### 322-10 Wisconsin Administrative Code

##### HSS 90

(33) "**Service coordinator**" means the person designated by a county administrative agency and responsible to that agency for coordinating the evaluation of a child, the assessment of the child and family and the development of an individualized family service plan, and for assisting and enabling the eligible child and the child's family to receive early intervention and other services and procedural safeguards under this chapter. a "service coordinator" is called a "case manager" for purposes of reimbursement for service under chs. HSS 101 to 108.

#### 322-14 Wisconsin Administrative Code

(c) A service coordinator is designated for every child referred for evaluation. The service coordinator need not be an employee of the county administrative agency but shall be accountable to the county administrative agency;

#### 322-25 Department of Health & Social Services

##### HSS 90.11 Service provision. (1) COORDINATION.

(a) **Role of the service coordinator.** The service coordinator shall coordinate the delivery of all services across agency lines and serve as the single point of contact in helping a family obtain the services the child and family need as described in the IFSP.

(b) **Functions of the service coordinator.** Service coordination activities include:

1. Coordinating the performance of evaluation and assessments as described in ss. HSS 90.08 and 90.09;
2. Facilitating and participating in development, review and evaluation of the IFSP;
3. Assisting parents in identifying available service providers;
4. Facilitating access to services and coordinating and monitoring the timely provision of services;
5. Informing parents of the availability of advocacy services;
6. Coordinating with medical and other health care providers; and
7. Facilitating the development of transition plans under s. HSS 90.10 (5)(h).

(c) **Qualifications of the service coordinator.**

1. A service coordinator shall have at least one year of supervised experience working with families with special needs, and have demonstrated knowledge and understanding about:
  - a. Children in the age group birth to 3 who are eligible for the program.
  - b. Part H and the federal implementing regulations, 34 CFR Pt. 303, and this chapter; and
  - c. The nature and scope of services available under the birth to 3 program and how these are financed.
2. The service coordinator may be a person from the list of qualified personnel in s. HSS 90.08 (3)(b), another person with experience and training indicated under subd. 1 or a parent facilitator.

## ★ APPENDIX D

# BUILDING PARENT-PROFESSIONAL PARTNERSHIPS

### *Before evaluation and assessment*

- Obtain parents' consent in writing prior to initial evaluation and assessment.
- Explain the process and procedural safeguards.
- Ask whether an interpreter is needed if the family's first language is not English.
- Offer suggestions to the family about how they might prepare for assessment.
- Determine a location for evaluation and assessment. If the evaluation and assessment will be center-based, discuss things to bring (e.g., toys, clothes, snacks).
- Discuss time options (i.e., options that are best for child and family).
- Discuss possible roles for the family and determine how they want to participate.
- Ask parents to think about goals, desired outcomes, and dreams. (The McGill Action Planning System [Forest & Lusthaus, 1990] is an example of a process that can assist parents in preparing for the evaluation and assessment.)
- Ask parents to fill out preassessment surveys in their areas of concern.
- Ask parents if they want others (e.g., advocates, friends, relatives) involved in the evaluation and assessment process or during meetings.
- Ask parents if there are other settings in which their child should be observed.
- Ask parents to describe their child's preferences regarding materials (e.g., toys, snacks).
- Ask parents how they think their child's best behaviors might be elicited (e.g., structuring the environment, presenting toys, assigning motor and visual tasks).
- Elicit parents' concerns and preferences.
- Discuss who will be involved in evaluation and assessment and why.
- Ask parents if siblings will attend evaluation and assessment meetings and whether they would like child care to be arranged.
- If parents ask questions to which the professional does not have answers, explain how the evaluation and assessment might answer the questions or that answers may otherwise be available from other sources. Be aware, however, to acknowledge that answers sometimes are not known.
- Encourage parents to ask specific questions about their child's development.
- Explain to parents that discussions can occur in a variety of settings and that information can be gathered using a variety of methods.

### *During evaluation and assessment*

- Respect parents' preferences concerning times, locations, and desired levels of participation.
- Discuss the evaluation and assessment protocol and how it addresses the parent's concerns.
- Explain tests, instruments, and methods as they are presented.
- Ask parents if the child's behavior is typical.
- Before administering a standardized test, explain the parent's roles to maintain standardization.
- Encourage parents to ask questions.
- Ask parents if the child's behavior indicates that a change in tasks or a break is needed.
- If jargon and acronyms are used, explain their meaning.
- Use person-first language (e.g., refer to a child with Down syndrome rather than a Down syndrome child).

### *After evaluation and assessment*

- Invite and encourage parents to speak first, ask questions, and make comments.
- Ask parents whether they feel that the evaluation and assessment process was valid. If they do not think that it was valid, find out why. Ask what was not observed or elicited.

- Provide immediate feedback regarding the evaluation and assessment to the maximum extent possible.
- Focus on a family's resources rather than deficits.
- Address parents' concerns clearly, even if all their questions were not answered.
- Ask parents how they would like to receive feedback and organize staffing (e.g., one person talks and others offer support or answer questions). Find out the level of detail (e.g., test scores, standard scores, age equivalencies) that the parents would like.
- Use visual and/or graphic tools, not just words, to present information.
- Do not use jargon without explaining it.
- Write reports using person-first language.
- Have a circle of support rather than traditional staffing (Mount & Zwernik, 1988).
- Ask parents about next steps. Ask if and when they would like to meet with either the team as a whole or specific team members to follow up on issues that have not been resolved.
- Ask parents if they have additional questions. Find out if there were things discussed that were not clear or that do not accurately reflect their child as they see him or her.
- Discuss with parents when they will receive written reports.
- Provide the parents with one or two concrete suggestions regarding their concerns.

From Rosin, P. (1996). The individualized family service plan. In Rosin, P., Whitehead, A. D., Tuchman, L. I., Jesien, G. S., Begun, A. L., & Irwin, L. (1996). *Partnerships in family-centered care: A guide to collaborative early intervention*. Baltimore, MD: Paul H. Brookes Publishing Co.; reprinted by permission.



## ★ APPENDIX E

# TIPS FOR PLANNING AND RUNNING A MEETING

### Preplanning

1. Plan the meeting carefully.

#### What?

- do you want to accomplish at this meeting or series of meetings? Why?
- roles and responsibilities will individuals have?
- materials need to be prepared (e.g., agenda, minutes of prior meetings, reports)?
- decision-making process will be used?

#### Who?

- should be there?
- should be represented?
- will facilitate the meeting?
- will have power and authority to make decisions?
- will present?
- will take notes?
- will prepare materials?
- will notify participants?
- will reserve meeting space?

#### When?

- will the meeting be held?
- will the agenda go out?
- will participants be notified?

#### Where?

- will the meeting be held?

#### How?

- will records be kept?
- will decisions be made?

2. Notify participants of the meeting.
3. Prepare and send out an agenda in advance (if appropriate).
4. Arrive early to set up the meeting room.

### Running the meeting: The beginning

1. Start on time.
2. Have participants introduce themselves, consider including a warm up activity.
3. Pass out materials.
4. Review, revise and order the agenda.
5. Discuss time limits and set if appropriate.
6. Review activities of previous meeting(s).

### Running the meeting: The middle

1. Focus discussion on agenda item(s).
2. Move the group towards action/decisions.
3. Allow participants to be heard.
4. Respond to stresses as they occur.
5. Monitor the time and take a break, if needed.

### Running the meeting: The end

1. Establish future actions (who, what, when).
2. Review groups decisions and actions. Prepare a "to do" list.
3. Set the date and place for the next meeting.
4. End on time, bringing closure to activity.
5. Clean up the room.

### Follow Up

1. Prepare minutes if appropriate.
2. Follow up on "to do" list.
3. Begin to plan for the next meeting.

From Tuchman, L.I. (1996). Team dynamics and communication. In P. Rosin, A.D. Whitehead, L.I. Tuchman, G.S. Jesien, A.L. Begun, & L. Irwin, Partnerships in family-centered care: A guide to collaborative early intervention, Baltimore, MD: Brookes Publishing Co.; reprinted by permission.

## ★ APPENDIX F

### WAYS TO MOVE A MEETING ALONG

#### ***BEFORE A MEETING***

- Do a team self assessment
- Develop a team plan to address self-assessment
- Have in place a decision-making process

#### ***STARTING A MEETING***

- If the team meets on an ongoing basis, make sure to set ground rules about starting times (e.g., within five minutes, plan to start without those present unless there are extenuating circumstances)
- If your team needs time to evaluate personal or work issues, consider building it into the agenda
- If the team has new members, make sure to introduce them and take time to share information about roles on the team. You might share a personal interest.

#### ***DURING A MEETING***

- State the obvious. If the team's discussion has become too general, ask how the discussion relates to the specific issue and visa versa.
- If important issues arise that are not related to the issue at hand, acknowledge it. Make a notation and plan to address it at another time.
- If the team appears confused, acknowledge it. Summarize what you are hearing and try to get clarification. Write down the points, since it may be difficult to keep them all in mind.
- If someone talks too much or not enough, use facilitation techniques.

#### ***AFTER A MEETING***

- Evaluate the meeting from all team members' perspectives
- Follow-up on any team issues

## ★ APPENDIX G

### TECHNIQUES FOR ENCOURAGING PARTICIPATION IN MEETINGS

*Consider what you say, what you do, how you structure the meeting and the physical set up of the room*

#### **Verbal Techniques:**

- Ask open-ended questions
- Phrase requests to encourage more responses
- Acknowledge and positively respond to contributions made
- Ask for more specifics or examples
- Redirect questions or comments to parents
- Encourage nonvocal parents
- Ask for and encourage different points of view
- Paraphrase for clarity and understanding
- Refer to contributions parents have made
- As a facilitator avoid stating your opinion or interjecting your ideas first
- Summarize and check for confirmation on your interpretation

#### **Nonverbal Techniques:**

- Attentiveness
- Voice and facial expressions
- Silence
- Movement and position in the room

*Share information (before, during and after meetings)*

*Make sure roles are clear*

*Use a common vocabulary*

## ★ APPENDIX H

# TECHNIQUES TO TRY WHEN THE TEAM GETS STUCK CREATIVE PROBLEM SOLVING

Use a series of phases that include divergent thinking to generate new ideas and possibilities and convergent thinking in which the "ideas" are selected, synthesized, and refined. Attempt to reach a balance between these creative and critical phases.

Break assumptions—What if this didn't happen? What if this did happen?

Take a new perspective—"Experience the other side"

Use forced relationships—How is this issue like a waterfall?

Think of unusual combinations/associations

Generate lots of ideas—go for quantity not quality

Think about what helps you to be creative

Ask "what if..."

Reverse the process—Look at the outcome you want and work backwards to the purpose, goals, or objectives.

Force yourself to think of as many alternatives as possible

Take on different roles

Use all your senses

Define your goal in different ways

Break the problem into subproblems—"salami technique"

Hitchhike on others ideas—build onto others' ideas

Use idea-spurring questions and words (substitute, combine, rearrange, modify, adapt, eliminate, etc.)

Try using a matrix with the problem, criteria, evaluation, etc.

Use mind mapping—a method of graphically depicting the issue

Brainstorming—set ground rules, i.e., allow no negative reactions or evaluative comments, defer judgement, welcome free wheeling, emphasize quantity, set a short time limit (3 to 5 minutes), assign a recorder

Round robin—everyone in the group gets an opportunity to add to the discussion but may pass. The round continues until everyone passes.

Clustering of ideas after brainstorming. Ask the group to put together those ideas that are related. Mark those that are related with a colored marker, then label those ideas you have grouped with an appropriate title.

Prioritizing—after the group has generated a list of goals or ideas. Pair a letter with each goal/idea. Ask the group which of them has the highest priority. Give everyone three cards and have them list the letter associated with their top three priorities. Collect and tally the priorities. Take the top three to five priorities and discuss them again. Reach consensus on the top three.

Open space agenda setting—define the issue and question to be addressed. The group then responds to the question by writing down any related ideas on large pieces of paper. Everyone can see what has been written and can respond or build on others' ideas. This occurs in silence. Then cluster ideas into groups and label the group. The group then discusses each topic that is contained within a group and prioritizes the topics using a decision-making process.

## ★ APPENDIX I

# TOOLS FOR DETERMINING PARENTS' CONCERNS, PRIORITIES AND RESOURCES

### *Verbal Interactions*

- Interviews—following a predetermined format or style (e.g., Family Assessment Interview Guide [Turnbull & Turnbull, 1986])
- Conversations—having face-to-face informal contacts or making telephone calls
- Brainstorming—generating many ideas about a topic
- Stories and anecdotes—sharing meaningful occurrences
- Parent-to-parent contact—learn from others' experience

### *Written Instruments*

Checklists—informal menus of services (e.g., program developing its own checklist or adapting an existing one)

Scales—priority ratings of needs for a family (e.g., the Family Needs Scale [Dunst, Cooper, Weeldreyer, Snyder, & Chase, 1988])

Surveys—(e.g., the Family Needs Survey [Bailey & Simeonsson, 1990] and the Parent Needs Survey [Seligman & Benjamin Darling, 1989])

Questionnaires—lists of questions to be answered by the family (e.g., How Can We Help? [Child Development Resources, 1988])

### *Graphic Instruments*

Videotapes, artwork, and photo albums

Guided team strategies (e.g., McGill Action Planning System [Forest & Lusthaus, 1989], personal futures planning [McGonigel et al., 1991]).

From Rosin, P. (1996). The individualized family service plan. In Rosin, P., Whitehead, A. D., Tuchman, L. I., Jesien, G. S., Begun, A. L., & Irwin, L. (1996). Partnerships in family-centered care: A guide to collaborative early intervention. Baltimore, MD: Paul H. Brookes Publishing Co.; reprinted by permission.

## APPENDIX J

### A RESOURCE MAP AND TAXONOMY FOR PARENTS AND SERVICE COORDINATORS

*An organizational framework for information and materials that is current and specific to a program.*

#### CONTENT:

1. conceptual map
2. list of major headings and subcategories
3. index-alphabetical and subject
4. how to organize information
5. how to use-communication
6. bibliography-resources by disability

#### IDEAS FOR ORGANIZING RESOURCE FILE:

Put section dividers in a notebook and keep materials in it and available to all staff.

Put section headings as dividers in a file drawer and add new material, ideas, experiences over time.

Use a Rolodex to organize resources and contacts.

Use computer program to organize information and retrieval.

Include a note in file about recent experience with a resource and problem-solving strategies.

#### STRATEGIES FOR USING THE FILE:

The goal is to build on the cumulative knowledge of the people in a program who are accessing and manipulating resources for families and to develop a strategy that works for the people using the file to add information and experiences that are current for that community. This helps familiarize a new service coordinator with local resources.

Communication is the key. The file should be easily accessible to everyone using it. Each person agrees to update, as they make new/successful contacts, with a written note. Provide a structure for sharing information at weekly/monthly staff meetings, E-mail or memos. Develop a strategy for cross-referencing information using the index, contents or section notes.



# MAP

BASIC NEEDS

HEALTH CARE

FINANCIAL RESOURCES

EARLY INTERVENTION

## FAMILY

TRANSPORTATION

ASSISTIVE TECHNOLOGY

PARENT RESOURCES & SUPPORT

COMMUNITY  
RESOURCES

EDUCATION

TRANSITIONS

## BASIC NEEDS

housing	emotional
respite	spiritual
24-hr emergency	counseling
food (WIC, food stamps)	
furniture	literacy/GED
Social Services-AODA, CPS	
utilities	child care

## HEALTH CARE

well baby	nutrition
medical specialties	
Public Health Nurse	
pediatricians	
specialty clinics	
MCH-lead screening program	
home health care agencies	
diagnostic services	
Health Check (EPSDT)	
personal care providers	
emergency service	
Healthy Start	

## FINANCIAL RESOURCES

private insurance	Health Check
EPSDT	MA Waiver Programs
fund raising	SSI
CIP,COP	AFDC
Family Support Program	

## EARLY INTERVENTION/ CORE THERAPIES

communication	audiology
OT	PT
psychological	social work
special instruction	vision
IFSP	assessment/evaluation

## TRANSPORTATION

car seat

## ASSISTIVE TECHNOLOGY/ SERVICES

home safety	
communication	
mobility	accessibility
customized adaptations	vendors
carpenter/architect	home modifications

## PARENT RESOURCES/SUPPORT

advocacy	educational materials
parent to parent	training opportunities
newsletters	legal issues
financial planning	bibliography
residential care	national organizations
Foster care	(UCP, ARC)
legal rights for foster parents	
disability information	
parenting classes	

## COMMUNITY RESOURCES

recreation	childcare
camps	playgrounds
activities	

## TRANSITION

NICU	schools
surgery	materials

## RESOURCES/ STAFF DEVELOPMENT

national	state
training	skill building

## EDUCATION

transition	IDEA
IEP	

## APPENDIX K

### SELECTED WEB SITES

#### ***The Family Village Web Site***

<http://www.familyvillage.wisc.edu/>

This site contains a virtual community of information for families who have children with disabilities and services providers.

#### ***Pathways Service Coordination Project***

<http://www.waisman.wisc.edu/earlyint/pathways>

This site will provide up-to-date information on the activities of the Pathways: Service Coordination Project related to training and technical assistance in early intervention service coordination. In addition, the site will provide resources and links relevant to service coordination.

#### ***The Waisman Center***

<http://www.waisman.wisc.edu/>

This site highlights the research being performed at this combination Mental Retardation Research Center (MRRC) and University Affiliated Program (UAP) and provides links to many other disability-related sites.

#### ***The ARC Home Page***

<http://TheArc.org/welcome.html>

Sponsored by the National ARC, this site offers useful information, including fact sheets and position statements on a variety of subject.

#### ***National Institute on Life Planning for Persons with Disabilities***

<http://www.sonic.net:80/nlpl/>

This site includes information on life planning, government benefits, and community services.

#### ***Dr. John M. Grohol's Mental Health Page***

<http://www.coil.com/~grohol/>

This site is a one-stop index for psychology, support, and mental health issues, resources, and people on the Internet.

#### ***OMIM Home Page—Online Mendelian Inheritance in Man***

<http://www3.ncbi.nlm.nih.gov/omim/>

This site contains scientific articles on hundreds of genetic disorders along with bibliographies. It has a searchable index.

#### ***Oncolink — Cancer Resources Home Page***

<http://cancer.med.upenn.edu/>

This site contains comprehensive information on services and supports for cancer patients and their families.

#### ***EdLaw***

<http://www.access.digex.net/~edlawinc/>

This site features a variety of information concerning special education law.

#### ***Thomas —Legislative Information on the Internet***

<http://thomas.loc.gov/>

Maintained by the US Congressional library, this site contains a multitude of information on current Congressional activities and the legislative process.

#### ***NEC\*TAS***

<http://www.nectas.unc.edu/>

This site is the Home Page for the National Early Childhood Technical Assistance Project.

#### ***Inclusion Press***

<http://www.inclusion.com/>

A small independent press, Inclusion Press produces readable, accessible, user-friendly books and resources about full inclusion in school, work, and community.

# APPENDIX L KEY FINANCIAL RESOURCES

## WISCONSIN MEDICAL ASSISTANCE PROGRAMS 1995

*Income guidelines shown are effective April 1, 1995*

PROGRAM	ELIGIBILITY	SERVICES	INCOME/ASSET*	BACKDATE	DEDUCTIBLE	APPLICATION SITE
HEALTHY START PRESUMPTIVE ELIGIBILITY	Pregnant women	Temporary Medical Assistance card for ambulatory, prenatal care only	Income 155% FPL, or \$1956, no asset test	No	No	County Public Health Agency and other designated sites
HEALTHY START	Pregnant women and children under 6	Medical Assistance card	Income 155% FPL, or \$1956, no asset test	Yes	Yes	County Dept. of Social Services
HEALTHY START NEWBORN	Birth to end of 12 mos.; born to MA recipient	Medical Assistance card	No income or asset test	Yes	NA	County Dept. of Social Services
HEALTHY START OBRA KIDS	Children over 6-19, but born after 9/30/83	Medical Assistance card	Income 100% FPL, or \$1262, no asset test	Yes	Must now use MEDICALLY NEEDY guidelines	County Dept. of Social Services
MEDICALLY NEEDY	Disabled, blind, 65 and over	Medical Assistance card	Income-varies Assets-varies	Yes	Yes	County Dept. of Social Services
	Pregnant women, under 18 or in school, 18 and dependent	Medical Assistance card	Income at \$822, Assets \$3600	Yes	Yes	
MEDICAL ASSISTANCE THROUGH AFDC	Low income families with deprived kids due to unemployment, incapacity, absent parent	Medical Assistance card to family	Income (Area 1) \$772 Income (Area 2) \$749, Assets \$1000	Yes	No	County Dept. of Social Services

SSI	Disabled, blind, 65 and over	Medical Assistance card, cash	Income-varies Assets-varies	Yes	No	Social Security Administration
KATIE BECKETT	Disabled children under age 19, living at home, level of care	Medical Assistance Card	Income for child only at \$1374/mo, Asset of child \$2000	Yes	No	Katie Beckett Program P.O. Box 7851 Madison, WI 53707
INSTITUTIONS	Disabled, 65 and over, in institutions	Medical Assistance Card	Income-varies Assets-varies	Yes	No	County Dept. of Social Services
COMMUNITY WAIVER PROGRAMS CIP-1A, CIP-1B, CIP-II, COP-W	Disabled, 65 and over, requiring special services and a level of care	Medical Assistance card, payment of special services	Income at \$1374, Assets \$2000 for one person or MEDICALLY NEEDY guidelines	Yes	Yes	County Dept. of Social Services
ADOPTION ASSISTANCE	Pre-adopted children with special needs	Medical Assistance card	No income or asset test	No	No	Adoption Agency
FOSTER CHILDREN	Children in foster care	Medical Assistance card	Income/assets for child only as family of one	Yes	Yes	County Dept. of Social Services

**MEDICAL ASSISTANCE IS: MEDICAID, M.A., TITLE 19, T.19, WMAP and HEALTHY START**

**MEDICAL ASSISTANCE IS NOT: MEDICARE**

\* Federal guidelines for one month/family of four after allowable deductions

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FPL= Federal Poverty Limit

Last Updated: 3/95

## APPENDIX M

### SAMPLE IFSP FORMATS

*These excerpts of IFSP formats are courtesy of:*

- *New York State Early Intervention Program*
- *Northern Pines in Wisconsin*
- *Project Dakota*
- *Minnesota*
- *New Jersey*



## NEW YORK STATE EARLY INTERVENTION PROGRAM INDIVIDUALIZED FAMILY SERVICE PLAN

Referral to EIO/date \_\_\_\_\_  
 6 month review/ date \_\_\_\_\_

Interim IFSP/date \_\_\_\_\_  
 Annual (12 month)/ date \_\_\_\_\_

Initial IFSP/date \_\_\_\_\_  
 Transition meeting/date \_\_\_\_\_

**Child's name:** \_\_\_\_\_ **Sex:** \_\_\_\_\_ **Date of birth:** \_\_\_\_\_

**Parent/Guardian/Family Member**

Name \_\_\_\_\_ City \_\_\_\_\_  
 Address \_\_\_\_\_  
 State \_\_\_\_\_ Zip \_\_\_\_\_ County \_\_\_\_\_  
 Telephone: Day \_\_\_\_\_ Evening \_\_\_\_\_  
 Primary Language: \_\_\_\_\_

**Parent/Guardian/Family Member**

Name \_\_\_\_\_ City \_\_\_\_\_  
 Address \_\_\_\_\_  
 State \_\_\_\_\_ Zip \_\_\_\_\_ County \_\_\_\_\_  
 Telephone: Day \_\_\_\_\_ Evening \_\_\_\_\_  
 Primary Language: \_\_\_\_\_  
 Address: \_\_\_\_\_ Telephone: \_\_\_\_\_

Physician or Health Care Provider: \_\_\_\_\_ Telephone: \_\_\_\_\_  
 Child's present concerns and/or diagnosis: \_\_\_\_\_  
 Insurance carrier: \_\_\_\_\_ Policy # \_\_\_\_\_  
 Medicaid #: \_\_\_\_\_ Social Security #: \_\_\_\_\_  
 Emergency contact: \_\_\_\_\_ Resident School District: \_\_\_\_\_  
 Relationship: \_\_\_\_\_ Telephone: \_\_\_\_\_  
**Initial Service Coordinator:** \_\_\_\_\_ Telephone: \_\_\_\_\_  
**Ongoing Service Coordinator:** \_\_\_\_\_ Telephone: \_\_\_\_\_

**Informed Consent by Parents:**

Initial and date: \_\_\_\_\_  
 I have received a copy of "Your Family Rights" book. \_\_\_\_\_ I have been informed/understand my rights under this program.  
 I give permission to carry out service coordination services. \_\_\_\_\_ I give permission to the service coordinator to share information with the evaluators.  
**Check one or more:**  
 I have had the opportunity to participate in the development of this IFSP.  
 I want to meet again before I decide to sign this IFSP.  
 I give permission to the Early Intervention Official to carry out only the following services in this plan: Please list. \_\_\_\_\_

I give permission to carry out this IFSP. \_\_\_\_\_  
 I do not accept this Individual Family Service Plan. \_\_\_\_\_  
 Parent signature \_\_\_\_\_ Date \_\_\_\_\_  
 Early Intervention Official or Designee signature \_\_\_\_\_ Date \_\_\_\_\_



Child's name: \_\_\_\_\_

Date: \_\_\_\_\_

**FAMILY RESOURCES, CONCERNS AND PRIORITIES**

Parents can invite extended family members and friends to give information for this page.

- This page was worked on with the family by the service coordinator.
- This page was also used by the evaluators when planning the child's evaluation.
- And, the IFSP team used this page when discussing IFSP outcomes.

1. Can you please tell me about your child?
  
2. On most days, what goes well and what is difficult?
  
3. How are you doing?
  
4. What would be helpful for you and your family now?
  
5. Is there anything else you would like to talk about?

Yes, I give permission to share information on this page, as is, with IFSP team members.

Parent signature \_\_\_\_\_

Date \_\_\_\_\_

**I WANT TO KNOW MORE ABOUT:**

- Meeting with other families to share information, to learn about a child like mine
- Finding or working with doctors or other specialists
- How different services work or how they could work better for my family
- Planning for the future; what to expect
- People who can help me at home or care for my child so I/we can have a break; respite or child care
- Housing, clothing, jobs, food, telephone
- Information on the child's disability, what it means
- Ideas for brothers, sisters, friends, extended family
- Money for extra costs of the child's special needs
- Equipment; supplies; assistive technology devices
- Other kinds of help that might be available
- Ways to have fun as a family
- Other:

**I WANT HELP FOR MY CHILD'S:**

- Getting around
- Talking and listening
- Thinking, learning, playing with toys
- Feeding, eating, nutrition
- Having fun with other children; getting along
- Behaviors and feelings
- Toileting; getting dressed; bedtime
- Helping my child calm down, quiet down
- Pain or discomfort  Special health care needs
- Seeing or hearing
- Other:

**TRANSPORTATION NEEDS:** (What the parent can do, what the parent and child needs, safety and other concerns)

Child's name: \_\_\_\_\_

Date of birth: \_\_\_\_\_

## EVALUATION SUGGESTIONS, METHODS AND RESULTS

- For the evaluation summary, attach "How the Child is Doing"  
 For the evaluation report, attach full evaluation report

Yes, report recommends supplemental evaluation(s) be part of the IFSP

EVALUATION METHODS AND RESULTS			
Family Suggestions	Name/discipline/agency	Date(s)	Method/tool/measures
When is a good time for you and your child?			
Where should it take place?			
With whom: You and other family or friends?			
How: What would make the evaluation comfortable for you?			
TESTING OR CLINICAL OPINION:			
How do family, evaluators and other team members think the child did during the evaluation?			
DEVELOPMENT:		CODE:	TESTING OR CLINICAL OPINION:
Cognitive: _____			
Physical: _____			
Communication: _____			
Social/emotional: _____			
Adaptive: _____			
Diagnosed condition: _____			

Child's name: \_\_\_\_\_

Date: \_\_\_\_\_

## HOW THE CHILD IS DOING — EVALUATION SUMMARY

A. What the child can do now • interests • motivators • new skills • things to celebrate • what's working well:

B. Concerns • worries • frustrations • what's not working well • things to work on next:

C. Make sure all areas of development are included above:

- Doing things for him/herself — Adaptive • Thinking and learning — Cognitive
- Moving, seeing, vision, health — Physical
- Feelings, coping, getting along with others — Social/Emotional
- Understanding, communicating with others — Communication

D. The family and team can now use "How The Child is Doing" and "Family Resources, Concerns and Priorities" to write the IFSP outcomes.

Child's name: \_\_\_\_\_ Date: \_\_\_\_\_

<b>DESIRED CHANGE/OUTCOME #</b> _____		
<b>What is happening now: (including child and/or family resources and concerns)</b>		
<b>Ideas and activities (Things we will do to make this happen):</b>	<b>People (Who will teach, learn, do):</b>	<b>Places/Natural Environments (See section six for ideas)</b>
<b>How we will know we have been successful: (Criteria, procedures, timeline)</b>		
<b>Review date:</b>	<b>By whom/how:</b>	<b>Family and staff comments and degree of progress:</b>
<input type="checkbox"/> This review includes update of family resources, concerns, priorities <input type="checkbox"/> We will need to continue <input type="checkbox"/> We have revised: <input type="checkbox"/> Completed (Reached our outcome)		

Child's name: \_\_\_\_\_

Date: \_\_\_\_\_

**EARLY INTERVENTION SETTINGS AND SERVICES**

(Note: Letters in parentheses are KIDS codes)

**SETTINGS TO CHOOSE FROM:**

- Home (E)
- Relative's home (E)
- Neighborhood places (E)  
with children such as:  
 park or play area
- getting out and about
- \_\_\_\_\_
- Family day care (B)
- Day care center (A)  
or nursery school
- EI center (C)  Office (H)
- Hospital inpatient (F)
- Hospital outpatient (G)
- Residential Facility (D)
- Other (O) \_\_\_\_\_

**METHODS TO CHOOSE FROM:**

- Visit by staff to home or other community setting (A), extended time (H)
- Visit with staff at EI center/facility (Z)
- Children's group – basic (B), enhanced (C)
- Children's group – basic with 1:1 (D), enhanced with 1:1 (G)
- Parent and child group (E)
- Support group (F) for:  parents  brothers/sisters  
 day care staff  foster parents  other caregivers

Service	Name/Agency	Method	Where (Setting)	How long: units/visits (frequency/duration)	Start/End Date

**Programs or services other than Early Intervention:**

Will this IFSP help the child play and learn with typical children? If not, why?

How will EI staff work with and help child care staff if the child goes to child care?





# PLANNING TRANSITION TO PRESCHOOL SPECIAL EDUCATION

Child's name: \_\_\_\_\_ Date of birth: \_\_\_\_\_ Date: \_\_\_\_\_  
 Family: \_\_\_\_\_ Service Coordinator: \_\_\_\_\_ Telephone: \_\_\_\_\_  
 Transition from: \_\_\_\_\_ Transition to: \_\_\_\_\_

<b>Parent Initials</b>	<b>Planning the Transition</b>	<b>Action Taken</b>	<b>Date Completed</b>	<b>Results</b>
	Explain to the parent their rights and responsibilities under Section 4410 of the Education Law (Preschool Special Education System).			
	Explain to the parent the steps in transition and their choices to remain in the Early Intervention Program services or transition (according to the child's date of birth).			
	With parent permission, inform the Committee on Preschool Education (CPSE) 120 days before the child is eligible to transition.			
	The parent and service coordinator choose which information and records should be sent to the Committee on Preschool Special Education. The parent's permission should be in writing.			
	Plan the transition conference of the family, Early Intervention Official, service coordinator, and the representative from Committee on Preschool Special Education 90 days before the child is eligible to transition. All meetings should be at a time and place that works well for the family and others.			
	At the transition conference the choices and plan will be decided. The plan will include steps which will help the child, family, and staff be comfortable and prepared for the new services, setting(s), and team members.			
	The service coordinator helps the family learn more about the services, where they are, and how they might use them.			
	With parent permission, the plan for transition becomes part of the IFSP.			
Other steps or notes for transition:				

## PLANNING TRANSITION TO OTHER SERVICES AT AGE THREE

Child's name: \_\_\_\_\_ Date of birth: \_\_\_\_\_ Date: \_\_\_\_\_  
 Family: \_\_\_\_\_ Service Coordinator: \_\_\_\_\_ Telephone: \_\_\_\_\_  
 Transition from: \_\_\_\_\_ Transition to: \_\_\_\_\_

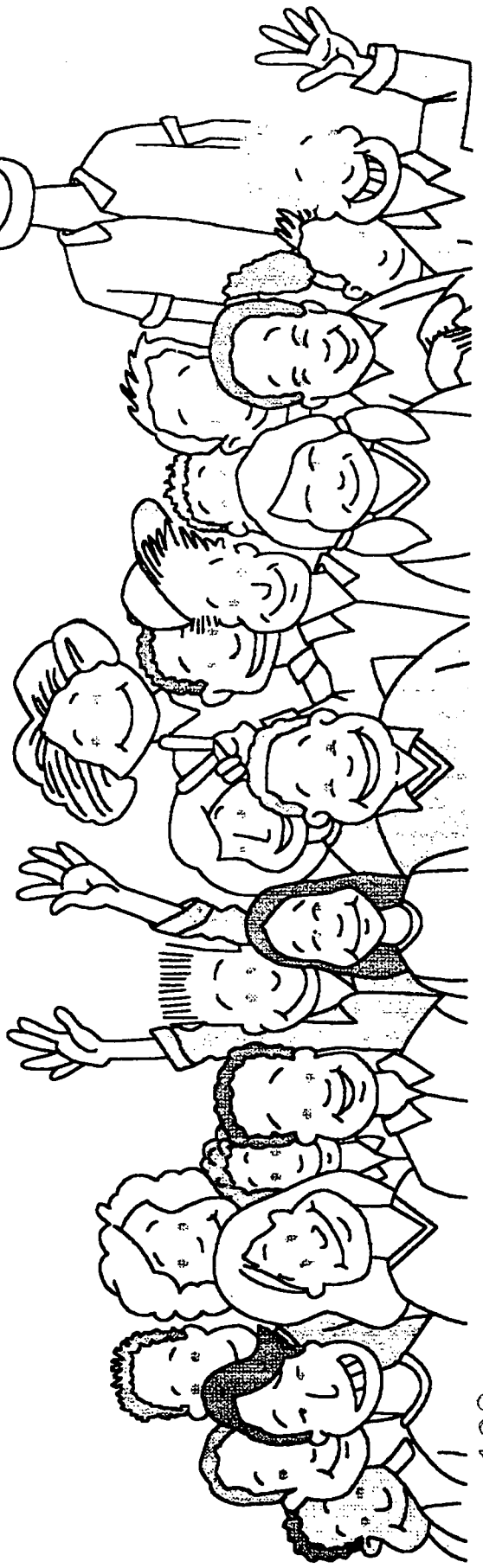
Parent Initials	Planning the Transition	Action Taken Person Responsible	Date Completed	Results
	Explain and talk about with the family the different options and programs that may be useful when the child leaves the early intervention program. Some places may be Head Start, child care, etc.			
	Plan how the team will help the child get comfortable with any new settings so the child can function well there.			
	With the permission of the parent, plan how new program staff or individuals can prepare for a smooth transition for the child and the family.			
	With the permission of the parent, copy and send information such as evaluation and assessment or the IFSP to the next program or individual who will serve the family.			

Other steps or notes for transition:

NORTHERN PINES COMMUNITY PROGRAMS  
EARLY INTERVENTION PROGRAM

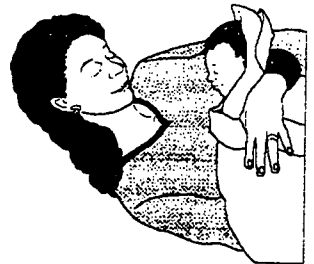
# GROWING TOGETHER WITH ME

MY INDIVIDUALIZED FAMILY  
SERVICE PLAN (IFSP)

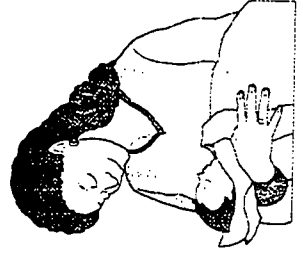


# ALL ABOUT ME

IDEAS: PREGNANCY AND BIRTH  
GROWTH AND DEVELOPMENT  
HEALTH  
LIKES AND DISLIKES  
STRENGTHS



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Name \_\_\_\_\_

# \_\_\_\_\_

Northern Pines Community Program



# ME AND MY TEAM



NAME \_\_\_\_\_ BIRTHDATE \_\_\_\_\_

PARENTS/GUARDIAN \_\_\_\_\_

ADDRESS \_\_\_\_\_ PHONE \_\_\_\_\_

COUNTY \_\_\_\_\_ SCHOOL DISTRICT \_\_\_\_\_



MY TEAM

NAME \_\_\_\_\_ RELATIONSHIP \_\_\_\_\_ AGENCY \_\_\_\_\_ PHONE \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

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# SEE ME GROW

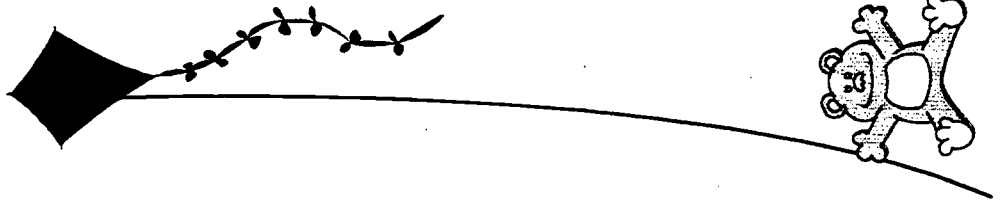
DATE \_\_\_\_\_

MEDICAL:

SENSORY:

GROSS MOTOR:

FINE MOTOR:



135

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# SEE ME GROW

DATE \_\_\_\_\_

SOCIAL:

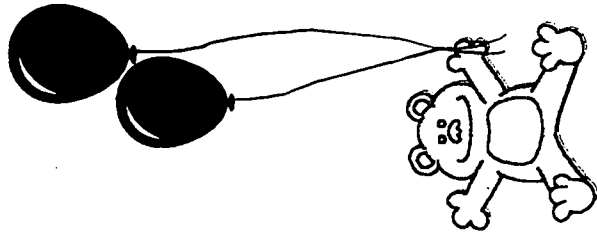
INDEPENDENCE:

PLAY AND LEARNING:

COMMUNICATION:

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EVALUATION TOOL





# MY DREAMS AND PLANS



DATE

STEPS TO TAKE

STRATEGIES

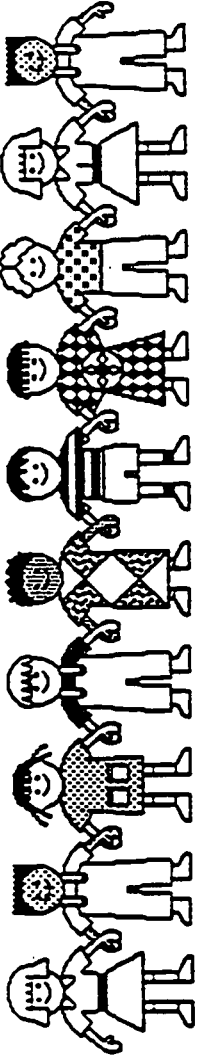
REVIEW

DATE	STEPS TO TAKE	STRATEGIES	REVIEW
		141	142

ID# \_\_\_\_\_ Child's name: \_\_\_\_\_

Age \_\_\_\_\_ Date: \_\_\_\_\_

"All About Me"



I. Things I do: X and things I'd like to do: ✓

- Go to parks, playground \_\_\_\_\_ Go to church/synagogue \_\_\_\_\_
- Play with children in \_\_\_\_\_ Go to parent/child groups \_\_\_\_\_
- my neighborhood \_\_\_\_\_ Other: \_\_\_\_\_
- Go to library/story hour \_\_\_\_\_
- Play with cousins \_\_\_\_\_
- Go swimming \_\_\_\_\_
- Go to tumbling/dance \_\_\_\_\_
- Go to child care/babysitting \_\_\_\_\_
- Family outings/trips \_\_\_\_\_
- Go for walks, stroller rides \_\_\_\_\_
- Eating out \_\_\_\_\_
- Shopping \_\_\_\_\_

II. People I am with: (include names and ages of children)

In my home:

At preschool or child care:

With neighbors, relatives:

Other places:

III. When playing with other children I:

V. Here is what would help me get out and about more easily:

IV. My family's wishes for me having friends to play with:

My family's concerns for me having friends to play with:

Child's name:

Date:

**EVALUATION OF TEAM EFFORT TO DEVELOP AND PROVIDE SERVICES AND SUPPORT**

This tool can be used at any time throughout or after IFSP development by IFSP team members as team evaluation or self-evaluation.

What worked well?

How could the team be more responsive, effective or supportive?

What needs to be improved?

How will the team work together from now on?

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**MEETING PLAN** After reviewing Family Considerations, the family and facilitator determine what to discuss at the IFSP team meeting. (List the topics, questions and information to share; decide what sequence to follow, and estimate time needed.)

People to consider for team members who will be helpful or supportive to the child and family outcomes/issues/tasks.

**Family/Community:**

- \* parents
- other family members, relatives, friends
- community, civic, disability or parent group representatives
- respite care providers
- child care providers
- advocates
- legal representatives
- ministers, other support personnel
- other:

**Health Care : (continued)**

- public health nurse
- community health service provider
- habilitation providers (private therapy)
- MCSHN staff
- mental health providers
- personal care attendants
- other:

**Education:**

- \* School District representative
- \* Early Childhood Special Education teacher/staff
- school nurse
- Early Childhood Family Education teacher/staff
- Head Start teacher/staff
- Community Education staff
- early childhood program staff (eg. nursery school, child care)
- kindergarten-regular/special educators, related service providers
- occupational therapist
- physical therapist
- speech therapist
- other:

**Social Services:**

- developmental disabilities case worker
- income maintenance/economic assistance worker
- mental health professional
- child welfare worker
- social worker
- other private providers

**Health Care:**

- primary physician
- other physicians
- private home health care provider
- primary nurse
- other hospital staff

\* must attend to meet Educational requirements  
note: If there is an overriding medical condition, a health professional must attend

**SCHEDULING IFSP MEETINGS**

*Settings and times convenient to family.*

**GENERAL NOTES**

Child's Name \_\_\_\_\_

IFSP Date \_\_\_\_\_

### Family Information

<b>Concerns</b> (needs, issues, and/or challenges we face)	<b>Resources</b> (friends/other people/places who can support and/or assist us)

**Statement of Natural Settings:** (our everyday routines/activities; places we like to go/would like to go; people and children we like to be with/would like to be with)

--

**Priorities**  
(what is important to us and how it fits within the routines of our family)

--

Child's Name \_\_\_\_\_

IFSP Date \_\_\_\_\_

**Child Information**

<b>Abilities, Interests, Motivators, New Skills, Things to Celebrate</b>	<b>Challenges, Worries, Frustrations Things to Work on</b>

**The following areas of development are included above: (age levels are optional)**

\_\_\_\_\_ social/emotional behavior    \_\_\_\_\_ fine motor/manipulation    \_\_\_\_\_ cognitive    \_\_\_\_\_ gross motor  
\_\_\_\_\_ adaptive/self-help    \_\_\_\_\_ receptive communication    \_\_\_\_\_ expressive communication

**Summary of \_\_\_\_\_'s general health: (include vision and hearing)**

--

Child's Name \_\_\_\_\_

IFSP Date \_\_\_\_\_

**Outcomes**

Outcome # \_\_\_\_ (what we hope will happen)

<b>Activities/Strategies</b> (things we will do to achieve this outcome)	<b>Family Members, Service Providers, Others</b> (who will teach/learn/do)	<b>Places, Times, Routines</b>

We will be satisfied we are finished when: (criteria, procedures, timelines)

projected review date(s):

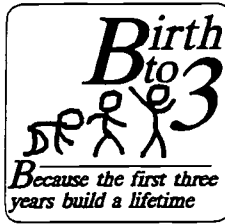
## APPENDIX N COMPONENTS OF A TRANSITION GUIDE

- Timeline of activities
- Discussion of parent rights and roles
- Overview of special education
- The individualized education plan (IEP) process
- Glossary of terms and acronyms
- Community resources
- Letter of welcome from receiving agency
- Suggestions for preparing child

Pathways:Service Coordination Inservice Project. Waisman Center, University of Wisconsin, Madison WI.

## APPENDIX O SAMPLE CASE NOTES

*(Page 133)*



Birth to Three Program
626 East Slifer Street
Portage, WI 53901
(608) 742-8811, ext: 268
1-800-862-3725

HOME VISIT SUMMARY

Family: \_\_\_\_\_ Date: \_\_\_\_\_

Summary and caregiver/child interactions:

Five horizontal lines for writing summary and caregiver/child interactions.

Parent issues and concerns: \_\_\_\_\_

Two horizontal lines for writing parent issues and concerns.

Data collected: \_\_\_\_\_

Two horizontal lines for writing data collected.

The following events or calls will be completed and person responsible:

- 1. \_\_\_\_\_
2. \_\_\_\_\_

Affirmations and suggestions:

Three horizontal lines for writing affirmations and suggestions.

Parent/Caregiver \_\_\_\_\_

Home Visitor \_\_\_\_\_





## APPENDIX P

### STATEWIDE INFORMATION AND ADVOCACY GROUPS

Statewide organizations formed to advance the interest of persons who have disabilities of a specific nature can be extremely valuable not only in providing information on services and in financing of health care, but also in offering a source of support for individuals and families. Some, but not all, of the organizations in Wisconsin are listed below. Also, many of these organizations have national chapters, or branches in other states.

ABC for Health Project  
Center for Public Representation  
121 South Pinckney Street  
Madison, WI 53703  
1-800-369-0388

Access to Independence  
22 North Second Street  
Madison, WI 53704  
608-251-7575  
608-251-7485 (TTY)

Alliance for the Mentally Ill of Wisconsin  
1245 East Washington Avenue, Suite 76A  
Madison, WI 53703  
608-257-5888

American Cancer Society  
Wisconsin Division, Inc.  
P.O. Box 44388  
Madison, WI 53744-4388  
608-833-4555  
1-800-227-2345

American Diabetes Association  
Wisconsin Affiliate  
2949 North Mayfair Road, Suite 306  
Milwaukee, WI 53222  
414-778-5500

*and*  
American Diabetes Association  
Western Regional Office  
6320 Monona Drive  
Madison, WI 53716  
608-222-3181

American Heart Association of Wisconsin  
795 North Van Buren Street  
Milwaukee, WI 53202  
414-271-9999  
1-800-242-9236

American Liver Foundation of Wisconsin  
741 North Milwaukee Street, Suite 400  
Milwaukee, WI 53202  
414-271-6877

Arthritis Foundation—Wisconsin Chapter  
8556 West National Avenue  
West Allis, WI 53227  
414-321-3933  
1-800-242-9945

Association for Retarded Citizens in Wisconsin  
121 South Hancock Street  
Madison, WI 53703  
608-251-9272

Autism Society of Wisconsin  
Judith Griffin, President  
519 North Union Street  
Appleton, WI 54911  
414-731-1448 (call after 5:00 p.m.)

*or*  
Autism Society of Wisconsin  
Patty Meerschaert  
4317 South Packard Street  
Cudahy, WI 53110  
414-481-5094 (home)  
414-272-4500 (work)

*or*  
Autism Society of Wisconsin  
Fran Bicknell  
6622 Green Briar Road  
Middleton, WI 53562  
608-836-8190

Bureau of Community Mental Health  
Division of Community Services  
1 West Wilson Street, Room 433  
P.O. Box 7851  
Madison, WI 53707-7851  
608-267-7792

Children's Trust Fund  
110 East Main Street, Room 318  
Madison, WI 53703  
608-266-6871

Cleft Lip and Palate Hotline  
2408 East Newton Avenue  
Milwaukee, WI 53211  
414-962-1053

Council on Exceptional Education  
Department of Public Instruction  
Division of Handicapped Children and  
Pupil Services  
125 South Webster Street  
P.O. Box 7841  
Madison, WI 53707  
608-266-1781

Easter Seal Society of Wisconsin  
101 Nob Hill Road  
Madison, WI 53713  
608-277-8288

Governor's Committee for People with Disabilities  
1 West Wilson Street, Room 558  
P.O. Box 7850  
Madison, WI 53707-7850  
608-266-5378  
608-267-2082 (TTY)

Great Lakes Hemophilia Foundation  
8739 Watertown Plank Road  
P.O. Box 13127  
Wauwatosa, WI 53213-0127  
414-257-0200

Leukemia Society of America  
Wisconsin Chapter  
1126 South 70th, Suite N107B  
Milwaukee, WI 53214  
414-256-4020

March of Dimes Birth Defects Foundation  
Wisconsin Division  
320 Holtzman Road  
Madison, WI 53713  
608-274-2590

Mother United for Moral Support (MUMS)  
150 Custer Court  
Green Bay, WI 54301  
414-336-5333

Muscular Dystrophy Assoc. Regional Office  
2949 North Mayfair Road, Suite 104  
Wauwatosa, WI 53222  
414-476-9700

National Kidney Foundation of Wisconsin  
280 Regency Court  
Waukesha, WI 53186  
414-821-0705  
1-800-543-6393

National Multiple Sclerosis Society  
Wisconsin Chapter  
W223 N608 Saratoga Drive  
Waukesha, WI 53186  
414-547-8999  
1-800-242-3358

National Society to Prevent Blindness  
Wisconsin Chapter, Inc.  
759 North Milwaukee Street  
Milwaukee, WI 53202  
414-765-0505

National Spinal Cord Injury Association  
P.O. Box 2685  
Madison, WI 53701  
608-222-8302

Parent Education Project of Wisconsin, Inc.  
2192 S 60th Street West Allis, WI 53205  
414-328-5520  
414-328-5527 (TTY)

Parent Projects  
Wisconsin Personnel Development Project  
227 Waisman Center  
1500 Highland Avenue  
Madison, WI 53705  
608-263-5022

Parenting Premies  
P.O. Box 530  
Stevens Point, WI 54481  
715-824-2596

United Cerebral Palsy of  
South Central Wisconsin  
1-800-924-2596  
*Look in your phone book for the United Cerebral  
Palsy branch in your area.*

United Way of Wisconsin  
*Look in your phone book for listing of the local  
United Way Office.*

Wee-life Parents  
216A South Main Street  
P.O. Box 193  
Lodi, WI 53555  
608-592-4255

Wisconsin Association for Adults and  
Children with Learning Disabilities  
5218 Century Avenue  
Middleton, WI 53562  
608-238-8588

Wisconsin Association of Alcohol and Other  
Drug Abuse, Inc.  
310 East Broadway Street  
Madison, WI 53716  
608-223-3355

Wisconsin Association of the Deaf  
P.O. Box 11  
Madison, WI 53701-0011  
608-266-8081  
608-266-8083 (TTY)

Wisconsin Association of Family and  
Children's Agencies  
315 Wisconsin Avenue  
Madison, WI 53703  
608-257-5939

Wisconsin Brain Trauma Association  
735 North Water  
Milwaukee, WI 53202  
608-271-7463

Wisconsin Coalition for Advocacy  
16 North Carroll Street, Suite 400  
Madison, WI 53703  
608-267-0214

Wisconsin Community Action Programs  
2059 Atwood Avenue  
Madison, WI 53703  
608-244-4422

Wisconsin Council of Human Concerns  
16 North Carroll Street  
Madison, WI 53703  
608-258-4380

Wisconsin Council of the Blind  
354 West Main Street  
Madison, WI 53703  
608-255-1166

Wisconsin Council on Developmental Disabilities  
722 Williamson Street  
Madison, WI 53703  
608-266-7826

Wisconsin Early Childhood Association  
1245 East Washington Avenue  
Madison, WI 53704  
608-257-0909

Wisconsin Epilepsy Association  
6400 Gisholt Drive  
Madison, WI 53713  
608-221-1210

Wisconsin First Step  
c/o Lutheran Hospital-La Crosse  
1910 South Avenue  
La Crosse, WI 54601-9980  
1-800-642-STEP (Voice/TTY)

Wisconsin Nutrition Project  
607 East Washington Avenue  
Madison, WI 53703  
608-251-4153

Reprinted with permission from: Griffiths, B., & Peterson,  
R. A., Jr. (1993). Statewide information and advocacy  
groups. In Families Forward: Health care resource guide for  
children with special health care needs (pp. 171-175).  
Madison, WI: Center for Public Representation, Inc.

# NATIONAL INFORMATION AND ADVOCACY RESOURCES

## **GENERAL**

NPND: National Parent Network on Disabilities  
1727 King Street, Suite 305  
Alexandria, VA 22314  
703-684-6763 (V/TTY)

## **HEALTH CARE**

Association for the Care of Children's Health  
7910 Woodmont Avenue, Suite 300  
Bethesda, MD 20814  
1-800-808-2224, ext. 306  
301-654-6549, ext. 306

## **INDEPENDENT LIVING**

Independent Living Research Utilization  
Program  
2323 S Shepherd, Suite 1000  
Houston, TX 77019  
713-520-0232  
713-520-5136 (TTY)

## **LEGAL RESOURCES**

American Bar Association Center on Children  
and the Law  
740 15th Street NW, 9th floor  
Washington, DC 20005-1009  
202-662-1720

## **WISH ORGANIZATIONS**

TASH: The Association for Persons with Severe  
Handicaps  
29 W Susquehanna Avenue, Suite 210  
Baltimore, MD 21204  
1-800-828-8274  
410-828-8274  
410-828-1306 (TTY)

## **ASSISTIVE TECHNOLOGY**

Activating Children Through Technology  
27 Horrabin Hall  
Western Illinois University  
Macomb, IL 61455  
309-298-1634

## **CHILD CARE/LEGAL RESOURCES**

Child Care Law Center  
22 Second Street, 5th floor  
San Francisco, CA 94105415-495-5498

## **PARENT TRAINING & INFORMATION CENTERS**

For more information, contact the National  
Parent Network on Disabilities (NPND) 1727  
King Street, Suite 305, Alexandria, VA, 22314;  
703-684-6763 (V/TTY)

## **COLORADO**

PEAK Parent Center  
6055 Lehman Drive, Suite 101  
Colorado Springs, CO 80918  
800-284-0251

## **ILLINOIS**

Designs for Change  
6 N Michigan Avenue, Suite 1600  
Chicago, IL 60602  
312-857-9292  
312-857-1013 (TTY)

## **MINNESOTA**

PACER Center  
4826 Chicago Avenue S  
Minneapolis, MN 55417-1098  
800-537-2237  
612-827-2966 (V/TTY)

## **MISSISSIPPI**

Parent Partners  
3111 N State Street  
Jackson, MS 39216  
800-337-4852  
601-366-5707

## **NEW JERSEY**

SPAN: Statewide Parent Advocacy Network  
516 North Avenue E  
Westfield, NJ 07090-1446  
800-654-7726  
908-654-7726 (V/TTY)

## ***NEW MEXICO***

### **EPICS**

PO Box 788  
Bernalillo, NM 87004  
800-765-7320  
505-867-3396

## ***NEW MEXICO***

Parents Reaching Out to Help  
1000A Main Street NE  
Los Lunas, NM 87031  
800-524-5176 (V/TTY)  
505-865-3700 (V/TTY)

## ***PUERTO RICO***

Asociacion de Padres por Bienestar de Ninos  
Impedidos de Puerto Rico  
PO Box 21301  
Rio Piedras, PR 00928-1301

## ***WISCONSIN***

Parent Education Project of Wisconsin  
2192 S 60th Street  
West Allis, WI 53219  
800-231-8382  
414-328-5520  
414-328-5527 (TTY)

## ***PARENT TO PARENT PROGRAMS***

The Beach Center on Families and Disability at  
the University of Kansas, 3111 Haworth Hall,  
Lawrence, KS 66045; 913-864 7600 (V/TTY),  
compiled this listing of P-P programs.

## ***ILLINOIS***

Parent to Parent-S Cook Greater  
Interagency Council  
Governor's State University  
University Park, IL 60466-0975  
708-534-4369

## ***IOWA***

Parent Educator Connection  
1382 4th Avenue NE  
Sioux Center, IA 51250  
800-572-5073  
712-772-4374

## ***MISSISSIPPI***

Mississippi Gulf Coast Exceptional Parents  
PO Box 271  
Hurley, MS 39555  
601-588-2260

## ***NEW HAMPSHIRE***

Parent to Parent of New Hampshire  
PO Box 622  
Hanover, NH 03755  
800-698-5465  
603-488-6393

## ***NEW JERSEY***

Support Parentss  
Arc Bergen Passaic Cty  
223 Moore Street  
Hackensack, NJ 07601  
201-343-0322

## ***NEW JERSEY***

The Arc Developmental Day Care  
The Arc Early Intervention Program  
The Arc Special Needs Adaptive Preschool  
PO Box 123  
Morris Plains, NJ 07950  
201-765-9661

## ***NEW MEXICO***

Parents for Behaviorally Different Children  
1720 Louisiana NE, Suite 204  
Albuquerque, NM 87110  
800-273-7232  
505-265-0430

## ***WISCONSIN***

Wee-Life Parents  
PO Box 193  
Lodi, WI 53555  
608-592-4648

## ***WISCONSIN***

Parent to Parent Support  
The Arc of Racine  
818 6th Street  
Racine, WI 53403  
414-634-6303

Adapted from Exceptional Parent (1996, January)

## ★ GUIDELINES FOR COLLABORATION

**Establish a shared goal or vision.** Motivation will be based on this vision, so this may be the most important principle of collaboration.

**Involve all key players in the development of the activity.** Be sure to include those who could contribute or who could potentially pose barriers, as well as representatives of all those who may be affected.

**Be realistic.** Cooperation may be a first step to developing a trusting relationship before true collaboration can take place. Take a developmental approach; use today's successes to build closer working relationships.

**Agree to disagree on steps in the process.** Perfect agreement on everything is neither possible nor necessary. Collaboration involves give and take on many of the specifics. Each party needs to be willing to give in, at times, to the needs of others.

**Make realistic commitments.** "Under-promise and over-produce" is a good strategy, especially when participants have experienced previous failures or frustrations. One small success is often preferable to a dozen stalled attempts at major change.

**Keep the goals and vision clear.** This is especially important when the effort gets bogged down in administrative details or obstructive regulations. Keeping the larger vision in the forefront can help sweep away minor problems, freeing energy for the important but difficult issues.

**Build ownership at all levels.** Although time consuming, developing and maintaining good communication with all parties involved will maintain a broad base of support.

**Publicize success.** Successes can build momentum for larger systematic changes in programs and agencies. Disseminating information about successful changes can encourage other organizations to undertake similar processes or to join in community-wide efforts.

(Jesien, 1996)



## ★ PERSONAL BEHAVIORS AND ATTITUDES THAT FACILITATE COLLABORATION

The heart of collaboration consists of individuals working together. Regardless of the larger context, each of us can either foster or hinder collaboration in our day-to-day contacts with other people. These are some suggestions to consider in working with families and other service providers:

Be willing to listen to and understand the needs, goals, and procedures of others.

Respect the operating procedures of other individuals and organizations.

Keep the goal in mind.

Be flexible enough to accept numerous paths to the goal.

Be willing to let go of some decision-making power.

Be the first to offer to share a resource, assist in an activity, or try a different way.

Let someone else take the lead in carrying out an activity.

Give others the credit for having accomplished an objective or achieved a success.

Reach out to a counterpart in another agency. Invite him to participate in an upcoming activity or planning effort.

(Jesien, 1996)



## SECTION III

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# PERSONAL AND INTERPERSONAL SKILLS FOR SERVICE COORDINATION

## INTRODUCTION

The focus on personal and interpersonal skills in this guide acknowledges that successful service coordination relies on effectively dealing with people, close up and at a distance. We work with families, children, co-workers, and other professionals. We interact with many public and private agencies, organizations, and institutions. Our actions range from individual caring to policy making. Service coordination requires that we are able to: (1) communicate, (2) work on teams (3) deal with diversity, change, grief and loss, (4) provide leadership, and (5) take care of ourselves in the process. The expectations are great, and seldom do we come into this job fully formed and ready to perform in all of these areas. However, if we bring our curiosity, an openness to new information and new experiences, and a willingness to try new roles and directions, we can learn the skills we lack and teach others the ones we already know.

Effective personal skills are a collection of things we do and say to the people we work and play with that help things to go better. These skills enable us to find ways of being together that are caring and respectful; they help us improve our understanding and communication. We acquire these skills as we grow up in a family and in a larger culture; we seldom learn them in an academic setting. They operate at an interpersonal level that enhances the technical and professional work people do. They are an addition to, not a replacement for, other skills. They come from a knowledge base that stretches through time and culture and may require some unlearning or new learning as we work in the human service field.

This section of the guide can be used by individuals or small discussion groups and will offer better results if readers take time to actually do the exercises instead of just reading about them. In-depth information on a particular subject can be obtained by following up on the references listed at the end of each section.

## COMMUNICATION: THE BASICS

We spend much of our life talking to (and sometimes at) each other. Through language we try to make ourselves understood. We attempt to understand what others are saying, what they need or want. We may struggle with language or dialect differences that complicate what is being said. In conversations, we may hear only what we want to hear or expect to hear, or listen just long enough to find an opening for us to speak. Sometimes we succeed in communicating and sometimes not, but mostly we take the process for granted.

Our earliest developmental experiences are highly influenced by language and the subtle nuances of interaction between infant and caregiver. Even before toddlers can speak, a lot of communication is happening. Tone of voice or facial expressions tell a parent what is going on with a child even without words. As we get older, we carry on many conversations at the same time, both verbal and non-verbal. Body language has long been acknowledged by social scientists as a source of information beyond the spoken word and one that can cue the listener to unspoken messages.

These communication processes come into play when working with families who have children with special needs. The language and tone used by professionals to describe a delay or disability can communicate respect or can diminish and devalue the child or the caregiver. The manner in which a condition or diagnosis is explained is as important as the spoken words. Faces that belie tragedy and hopelessness may cancel out words of encouragement offered by a well intended professional or friend. Taking time to reflect upon how we communicate can give us information about what works well and what does not. Communication seems so simple, like putting a seed in soil and giving it water. In time, if carefully tended, the seed becomes a plant and blossoms and bears fruit. "Gardening" in relationships needs to be as carefully tended as that plant. It is a lot harder to go back and "pull weeds" from a relationship that has been neglected than it is to keep an eye on it as we go along. So let's begin at the beginning, by planting that first seed.

*One-to-one* communication is the cornerstone of all human relationships, and if done well it creates a symphony of care and understanding. If not done well, it can result in the discord of misunderstandings, hurt feelings, and angry frustrated people with unmet needs and unaccomplished tasks. It takes conscious effort and frequent practice to acquire communication skills that work well with many people in varying situations. It is not a skill or aptitude that some people are born with and others are not. Service coordinators can and need to be expert communicators in this piece of the family-centered process. These skills are equally valuable to a parent trying to communicate with the service coordinator or other early intervention professional.

What are these communication components and how can we work at improving them? *Listening skills* top the list. Listening is not as simple as it seems and is an area where most of us can easily make improvements. Listening to someone means really paying attention, not just going through the motions, but truly hearing the speaker and what is being said. We do this in a variety of ways and it looks different for each person, but we all recognize when it is happening to us (and also when it is not!). As the listener, we need to check in with ourselves to see if we really have the time, attention, and energy to give to someone else. We can admit that we are not available at the moment to listen well if other things temporarily distract us. An example might be when you are on a home visit and a child is crying—a hard time for anyone to pay attention to anything but the needs of the child. It is far more respectful to say that you are unable to really listen to a problem right now than going through the motions and pretending to listen.

Having someone listen to us with care, concern, and without judgement is a powerful and empowering experience. It frees us up to solve our own problems, make clearer decisions, set aside our grief and move on to other things that need doing. Being listened to can help to resolve conflicts and end stand-offs, can mend broken relationships and heal long standing hurts. Being listened to is a gift that we can give to each other and that each of us deserves, whether parent or professional, adult or child.

The reason for focusing on listening seems clear enough, but what does it look like in our daily lives? Listening well to the other person means not interrupting with suggestions, our own good ideas or stories, or solutions to problems. We just listen, giving full attention. We recognize the capable human who is speaking, we set aside judgements of approval or disapproval, and trust that they are doing the very best they can under the circumstances. If they could do better, they would, and we reflect that level of respect with our body language, with our eyes, with our verbal responses.

An important point here is the difference between casual conversation and meaningful communication about something that is worrisome, sad, or thrilling. The required level of listening is not the same. In casual conversation, the amount of attention is not as intense, because the purpose is different. There is a deeper emotional base when someone is communicating something strongly felt that is not there in a casual encounter. Understanding this difference is especially important in service coordination because a casual exchange may unexpectedly turn into a significant conversation. It can catch you off guard.

When working as a service coordinator it is best to have your attention available at all times just in case the emotional climate shifts. For example, when you first meet a family (or service coordinator, depending on your position), you probably have casual conversations. You chat about the weather, the traffic, or if you'd like a cup of tea. Not too hard so far. As your time together increases and the small talk diminishes you begin to move deeper into the conversation. What's really going on here? What are the concerns and what does this family or person need? Now it is time to increase your focus and notice what is being said as well as what is NOT being said. What are the emotions behind the words, what do periods of silence tell you? What are the interpersonal dynamics between parents or parent and child? The listening becomes important and your listening skills are invaluable. Observe all the subtle sights and sounds of the interaction and not just what is said (See Appendix A and B for Characteristics of Good Listening and Roadblocks to Listening).

Having cleared your mental slate to listen with full attention, what is next? The second aspect of the fine art of communication between two people is that of *asking thoughtful, open-ended questions* that give the listener more information and provide the speaker an opportunity to further explain what is going on. This is a time to invite the speaker to elaborate further on the situation, in her own terms by asking for additional information. The difference between "What happened next?" and "What color were his eyes?" might illustrate this. One question can be answered by a story, and one can be answered by the word "brown."

Open-ended questions show that we are paying attention, and can clarify things we might not understand. They let us reflect what we think is going on and give the listener a chance to set us straight if we are making assumptions that might not be true. Question asking deepens our involvement in the conversation and demands more of us in a relationship. Questions can also indicate that we have indeed listened and that we are trying to understand the conversation. A service coordinator might say: "Tell me, how has it been for you to move in with your parents and adjust to a new baby at the same time?" or "What has happened with your son since the last time we met?" These kind of questions invite the parent to share what has been going on for them and indicates a sincere interest in the answer. These questions also ask for information in a natural way. They do not lead the speaker with answers that are expected or pre approved.

Another way of saying that we are not ready or willing to hear about problems is to ask questions that head off that kind of discussion. By asking "How are you feeling now that you have made the adjustment to the diagnosis?" implies that we assume the adjustment is over with and we can go on to discuss other things. It can close the door on a conversation that might allow us to offer support or information that is badly needed. Asking the right questions at the right time and being available to listen to the answers is an art and one that improves with experience.

## *Enhancing Communication*

"Tell me what you think or feel about it."

"I'd like more information about that."

"I'd be interested to hear what you have to say about..."

"What are you thinking about this?"

"Let's discuss it."

"I don't understand what you mean, could you put it another way?"

"What does that mean?"

"How do you feel about...?"

"This seems important to you."

"Tell me the whole story."

### *These kinds of responses say:*

*I respect you as a person.*

*I might learn something from you.*

*I really want to hear more.*

*Your ideas are worth listening to.*

*I care for your opinion.*

*I want a working relationship.*

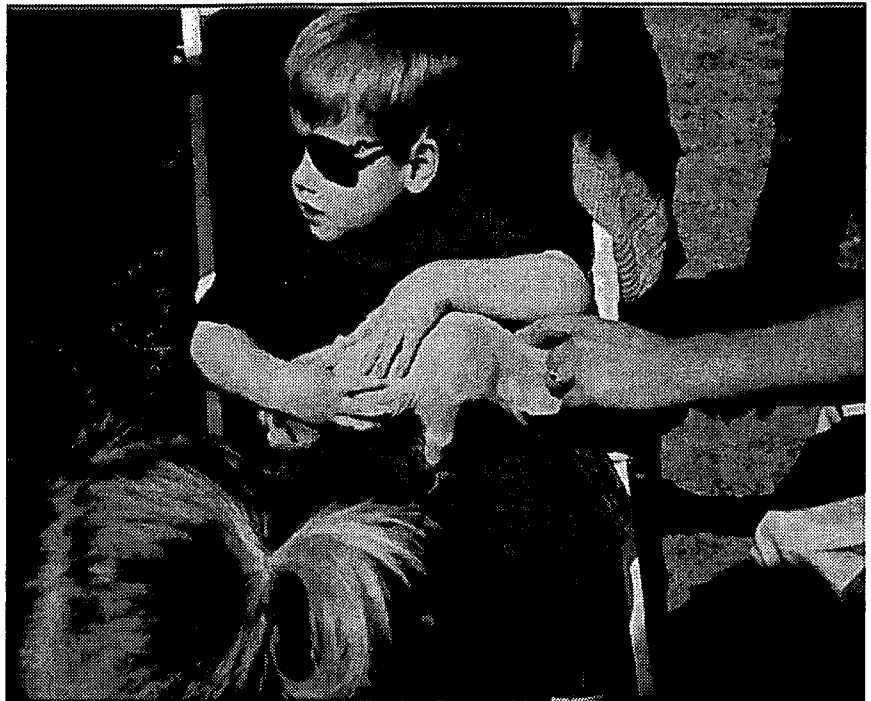
*I want the best program for my child.*

Adapted from Washington PAVE, Tacoma, WA



A third aspect of effective communication concerns the *sharing of feelings*. It is a challenge and a skill to quietly listen to someone as he expresses himself and acknowledge the fear, excitement, anger, joy, or dread that lies within the message. Acknowledging feelings is part of the listener's responsibility. Why is this so important? After all, how we feel about something is our own business, isn't it? Our feelings are very much part of who we are and what we do, but for many of us it seems to be difficult to express them easily. We often spend a lot of energy trying to hide, suppress, or deny them. Feelings are uniquely human qualities that we sometimes do not know what to do with. But feelings of any kind that are suppressed or denied can block our understanding and perception. Tears of frustration or pain or tears that express our emotions in other ways provide a healing tool and clear our vision. They free us to turn our attention to what's next in our lives. Feelings unexpressed pile up like garbage and become too difficult to sort through, avoid, or escape. Whether parent or service coordinator, we need to dump that load off as soon as possible in a place where it will not get in the way of us or anyone else. We need to give ourselves permission to cry, laugh, shake, yell, or pound a pillow, so we can clear the air and gain energy to start fresh with new challenges.

Acknowledging a speaker's feelings and reflecting them back to someone is a sincere kindness, not an invasion of privacy. Being able to share the joy brings pleasure; sharing the burden takes away some of the weight and we move forward more easily. When we work in or with families, there are many opportunities to notice people's feelings. And once again, we do so without judgement. Feelings aren't bad or good, they simply are. Feelings of anger—"I hate this situation!"; feelings of frustration—"I feel like such a failure"; feelings of anxiety—"I feel scared and confused"; or feelings of ecstasy—"I am thrilled he's finally talking, walking or standing"; are all part of the experience. It isn't our job to make them go away or transform



them into something else. We are there to listen. Simply notice what they are and then let go. This skill will endear you to people for life. Instead of saying "don't cry," invite them to "go ahead, let it out, cry until there are no more tears left." When the storm is over you can move on with greater confidence and enthusiasm.

This simple listening task may be difficult for some service providers. It is especially hard if we have not dealt with our own feelings of grief, anger, frustration, or loss. None of us have dealt with all the old feelings that occasionally make a surprise appearance, but we can be aware of them when they do show up. It may sound scary to give permission to express feelings and support to people, yet it is important that we do. Listening and sharing feelings encourages growth in new and surprising ways, and it requires a lot of trust. Trust that each of us will be able to listen to the other's feelings and not be overwhelmed by them. Trust that even if we get in over our heads we can bring in reinforcements to help us figure out the next step. It is not every job that can offer such opportunity! And we do not need a master's degree in counseling or a Ph.D. in psychology to make this work. All of us can be effective listeners.



## ■ *Moving On To Problem Solving*

When emotions are expressed and acknowledged, the speaker can move on in the communication process. Exploring options and solving problems becomes easier, more comfortable, and less likely to be met with road blocks. It is time to look at the possibilities that are available and brainstorm solutions if there is some kind of problem or an action that needs to be taken. You may find you do not have adequate information to make a decision at this time, so the next step is to get more. If you have the data you need, then examine the choices, consider the consequences or benefits of each, and make a plan to move forward. Do not rush through this process. Families need time to consider what makes sense, what will work best for them, and what resources they have available. It is not the job of the service coordinator to offer a set menu of choices, but rather to help determine what is really needed and how it can best be accomplished.

If a plan of action has been agreed upon, take time to be sure that everyone understands what needs to be done and who is going to take responsibility for what part of the plan. For the plan to work well, all the parties involved in the process need to agree. Having a written document that states what has been agreed to and includes a timeline for completion or check-in, makes communication at a later time simpler and more accurate. It is important when doing follow-up that participants are not blamed or shamed if they have been unable to complete the agreed upon task. If a parent has not made the phone call she said she would or a co-worker has not convened the meeting that he promised, it is more productive to ask what blocks the way and what kind of help will ensure that things move forward. It may be time to revisit the plan and prioritize. Perhaps a new configuration of responsibilities is advisable, keeping in mind that the job of service coordinator is one of empowerment, a sharing of skills, not caretaking or overseeing peoples lives.

## Some Other Facets of Communication

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Person first language is one of the ways we show respect for individuals and recognize their value above and beyond their diagnosis, individual difference, or disability. "Person first" means that we notice the person before the diagnosis, we speak about a specific child, who happens to have a disability, rather than a disabled child. Yet many professionals fail to recognize the significance of this and to *change their own language accordingly*. Failing to use person first language can distance professionals and allow them to objectify the children and families they work with. A few examples of person first language demonstrate this point. We as professionals change our language and our thinking, from noticing a wheelchair-bound client to seeing Paul, who happens to use a wheelchair. While speaking with a family, address the needs of their child who has a disability instead of their mentally retarded child. In an IFSP meeting, name the child before the condition. At first it may feel awkward or cumbersome to speak to the child first and the diagnosis second, but it is essential that we do so. This change in language shifts our thinking and our perspective, and acknowledges the value of the person above any limitation or difference he may have. It also gives us comfortable ground upon which to proceed with conversations, programs, treatments, and recommendations.

*Professionals use jargon* as a communication short cut. It is a common practice in specialty areas ranging from plumbing to nuclear science. The use of jargon, however, creates unintentional barriers in partnerships between families and professionals. Parents can easily become lost in conversations with professionals when struggling with jargon and acronyms. Jargon is like a foreign language and many people are baffled by its use and embarrassed when they are unable to decipher what is being said. Using jargon can separate people when what you want to do is bring them together. We need to be aware of our jargon and minimize it when working with families or professionals from other fields. Defining jargon so that families and providers from other agencies can become familiar with it and learn how to use it comfortably and appropriately is also

helpful. Like any acquisition of a new language, time and practice are required to become familiar with terms and definitions. Each of us, parent or professional, gradually learns this new language and how to best use it to express our concerns and communicate our needs. Our fluency and ability to understand jargon may vary at any given time and it is important to be alert to its use as we build and nurture relationships.

The *use of a positive versus negative* perspective in our language is another consideration when communicating with families. Issues defined in a negative manner state what is lacking or wrong, rather than recognizing what works well, what are assets and strengths. In a Western paradigm, control, independence, and dominance are often valued. If something is wrong or broken or just different, the goal has been to fix, correct, or standardize. We have learned this in our schools, our families, our places of work, worship, and recreation. It is not anyone's fault but it is everyone's responsibility to change it. Working with families and young children provides an opportunity to act differently; to emphasize the strengths of the individual. Find the things that are going well in spite of difficult odds and use those as building blocks for growth. "Find the good and praise it" is common advice in child rearing but it is an equally successful approach in working with adults and families. That isn't to say that real difficulties are denied or ignored. They need to be acknowledged too. However the strengths and capabilities also need full recognition. This means a shift in our thinking and language when talking to and about parents and children. It is the difference between saying "I work with handicapped kids in early intervention," and saying "I work with young children who are funny and smart and cute, and who need some extra supports to develop their full potential." Notice and name the good things, the things that are going well, before talking about limitations and difficulties.

*Literacy and learning styles* should be considered when communicating with families. Many brochures that explain a program, a syndrome or a service are freely passed out to families. We write newsletters and send home consent forms and letters of invitation or encouragement, yet the literacy rate in the United States is surprisingly low. Ac-

ording to research done by Jonathan Kozol (1985) in his book *Illiterate America*, "Twenty-five million American adults cannot read the poison warnings on a can of pesticide, letters from their children's teachers or the front page of a daily paper. An additional 35 million read only at a level which is less than equal to the full survival needs of our society." (p.4) This is one third of the entire adult population. As we communicate with families, we want to be sure that our outreach does not exclude people because of limitations in reading skills or learning styles. The use of videotapes or other verbal communication to relay information about programs and services is becoming common practice in many programs. A variety of informational tools allow people to learn in a manner that works best for them. Yet programs often report a lack of parent participation; literacy levels and learning styles may be something to consider in trying to remedy that situation.

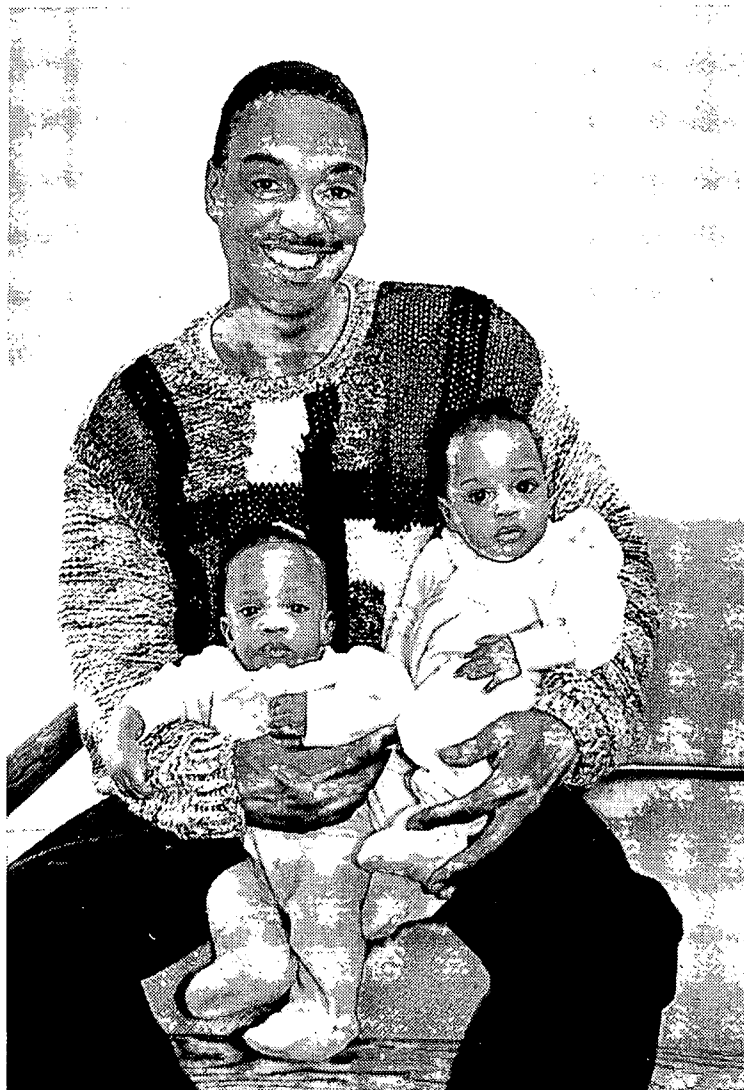
Communicating with families where *English is a second language* is a frequent challenge in service coordination when we do not speak their native language. Families in early intervention programs come from many parts of the world. Resources for translation are a necessary link to reaching and serving these families. This may mean that programs hire staff fluent in both English and the languages of the families served by the program, or use written material or videos that have been translated into other languages. Having a translator or a staff person from that family's culture present for meetings enhances the effectiveness of interaction and parent participation and reduces inaccuracies and misunderstandings.

*Sharing difficult information* is uncomfortable for just about everyone. The only thing worse may be receiving it. Yet in the role of service coordinator, it is highly probable that you will find yourself in these situations one or more times. How can you communicate clearly, honestly, and with sensitivity, without soft-pedaling or watering down information?

One of the biggest problems with being "the bearer of the bad news" is that we confuse our own hurts and fears with those of the people with whom we share this information. We project how we would

feel, or perhaps did feel at some time in the past when someone brought unwelcome news. We confuse ourselves with the message and worry that we will be blamed or in some way held responsible for a diagnosis or a developmental setback. Sometimes the receiver has that same confusion and may temporarily blame the messenger for the message. It makes the task doubly hard. We would like to protect people we have come to care about from further pain. That is not within our power. *We do not deliver bad news, we provide information.* How that message is received and what is done with it is beyond our control. We can, however, help. We can anticipate what might happen. We can certainly be prepared to be supportive, to listen to the sorrow, fear, or anger that may come with new or unexpected information about the illness or injury of a small child. We can allow parents time to process and to ask questions.

On the other hand, we are not expected to be robots that go unfeelingly about our business without regard for the experience of another. Sometimes service coordinators are upset by events that occur to a family they have become involved with. The very best way to be effective in our own role is to find a friend or a professional who can listen to us without judging and let us acknowledge our own feelings of hurt, fear, or loss as we do this work. When we have had our own needs met it is much easier and more comfortable to be a gentle companion as well as a professional bearer of information that may be hard to receive. If you do not feel comfortable giving difficult information by yourself, you do not have to. Ask a co-worker to meet with you and the family. Not only are you taking care of yourself by enlisting help from an ally, but you are modeling how parents might use support when things are challenging. Be aware of supports available to families and be prepared to offer these. Parent-to-parent, diversity specific organizations, or the identification of other families who may have gone through a similar experience, can provide encouragement and comfort to families (See Appendix C for Considerations for Delivering Sensitive Information).



## Summary

We have touched on several important aspects of communication as it influences service coordination and early intervention—listening, reflecting, asking questions that clarify things for the speaker as well as the listener, problem solving, and taking responsibility for ourselves and our work. Encouragement to look within, to continually examine our thoughts and feelings is a valuable undercurrent that will surface again in the sections on conflict and self care. Doing the activities and exercises at the end of this section, practicing communication skills with co-workers, friends, and associates, as well as with the families, will further improve our effectiveness as we go about this rewarding work.



## ACTIVITIES

### Working in Pairs

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#### **Activity 1: "Practice Listening Skills"**

*Purpose:* To improve the ability to listen carefully to each other, to respond in a caring way to what is being said, and to ask relevant questions and summarize for the speaker. To enhance the ability and increase the confidence of the service coordinator in communicating with families in early intervention.

*Directions:* Divide into pairs and identify a speaker and a listener in each pair. Ask the speaker to talk about something exciting they have done or experienced recently. The listener should restate, reframe, and summarize what the speaker says without adding anything of their own experience. Give the first speaker two or three minutes, call time and reverse roles so the speaker becomes the listener in the pair. Process the activity by asking what was easy or hard about it and what worked and what did not. Did you feel really listened to by your partner? What might they do to listen better?

Repeat the activity, having participants share an experience that was challenging or painful for them as they grew up. Process the activity again, asking how the second topic changed the activity. Discuss how this sharing relates to working with families in service coordination.

#### **Activity 2: "Mirrors"**

*Purpose:* To become aware of body language and non-verbal communication in a playful way.

*Directions:* Have participants work in pairs. Identify one person as the leader and the other as the follower. Standing up facing each other, the lead person begins to move his body, arms, hands, legs, feet, etc. in slow motion. His partner should be a mirror, reflecting what the lead person is doing. Partners should work for about two minutes, then reverse roles. Process questions: How did it feel to be the lead person and to have someone in complete harmony with you? What was difficult or easy about it? How might this activity relate to working with families in service coordination?

### Group Activities

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#### **Activity 3: "Interview-Getting Acquainted"**

*Purpose:* To create familiarity and safety in a new group of people and to practice interview skills, asking open-ended questions.

*Directions:* Ask participants to pair up with someone they do not know. Tell them at the end of the interview they will be asked to introduce the person they are paired with to the larger group. In an interview format, share something about yourself that others might be interested in knowing and something you value highly in your life. Also share what brought you to this group. Bring the full group back together and have the partners introduce each other.

#### **⊕ Activity 4: "Where Do You Stand"**

*Purpose:* Exploring and respecting values.

Please read each statement carefully and decide whether you agree or disagree with it, then mark your response in the left margin by putting an (A) for agree, or (D) for disagree in the space provided. You will have an opportunity to discuss your choices later. There are no right or wrong answers, just your answers.

- \_\_\_ 1. Families who don't keep appointments that are scheduled with therapists should be give warning and then dropped from the schedule.

- \_\_\_ 2. The service coordinator or therapist should not be expected to go into a neighborhood or area that is considered 'unsafe'.
- \_\_\_ 3. If parents do not speak English, the service coordinator should be trained to understand their culture and learn their language.
- \_\_\_ 4. Parents are the best teachers of young children and should be interested and willing to learn how to do therapies at home.
- \_\_\_ 5. When working with families from a different culture, agencies should make every possible effort to hire a service coordinator and other staff from that culture.
- \_\_\_ 6. Most families need outside help and support in coming to terms with a disability diagnosis for their child.
- \_\_\_ 7. National Health Insurance is the best way to be sure that all families that need services receive them.
- \_\_\_ 8. Families who are suspected of drug or child abuse should be reported to Child Protective Services immediately.
- \_\_\_ 9. Children who have severe and multiple disabilities deserve to have specialized school facilities and not be expected to attend public school.
- \_\_\_ 10. Families who use a faith healer or homeopathic remedies are not taking their children's health care issues seriously.
- \_\_\_ 11. Bussing preschool children long distances for services is a form of child abuse and should not be tolerated by early intervention programs.
- \_\_\_ 12. More and more children are born with severe disabilities every year and prenatal care should be legally mandated as a means of prevention.

*Directions:* After everyone has completed their choices, ask which point they would like to explore further. Select four or five questions to work on. Read the first one and ask participants to stand on the left side of the room if they agree with the statement and to the right if they disagree. Discuss in small groups why you chose this answer and then summarize your discussion for the other group. Listening to different opinions and ideas is important. Be sure to maintain group safety during discussions and listen to everyone's ideas and thoughts. Some people may change their "stand" after hearing ideas of another group. Repeat the process three or four more times. Discuss how you react when people disagree with your opinions. How does it feel? How do you respond to families who hold values different than yours?

### **Activity 5: "Values Activity"**

*Purpose:* To help participants identify the relationship between their own beliefs and values and their interactions with others.

*Directions:* This activity requires a facilitator who is comfortable supporting people in disclosing personal information about their beliefs and values and talking about emotionally charged information. It may be helpful to begin the activity by talking about creating a safe environment for discussion. Ask participants to identify a saying or a rule they grew up with. It helps if the facilitator gives an example to start the discussion (e.g., "If you don't have anything good to say about someone, don't say anything". or "We don't need other people to help us solve our problems"). Also ask the participants to identify one aspect of their work with families that they find challenging. The facilitator can give another example (e.g., "I find it challenging when....I ask questions to learn more about a family, and don't get much information from my question." or "...people don't seem interested in doing anything about their problems"). Record individual responses on a flip chart or in another way so that the group can see them. After information is shared go back and look for relationships between challenges in practices and beliefs participants reported. Discuss how these sayings reflect values we grew up with, which we may or may not still adhere to, but may influence how we relate to and possibly judge others. Often patterns emerge showing that behaviors participants find most challenging relate to deeply seeded values (e.g., Family rule: "You should try to solve your own problems." Challenge: "I find it challenging when women see themselves as and act like victims.")

Examination of these connections opens the door for further discussion of: Why is it important to know your own values? How do they influence your day to day work with families? What do you do when your values differ than those of the families you work with? How do you keep your judgements out of the picture? What do you do when you can't?

## Individual Activities

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### *Questions for Reflection*

1. Who are the people closest to you who you communicate with easily and comfortably? What is it about those relationships that create safety and respect and how can you translate this into your work with families? Identify at least three specific things you are currently doing or can do within the next six months to enhance these relationships and practice communication skills.
2. Who are the people you have the most difficulty relating to in your personal or professional life? What is it about these relationships that makes you uncomfortable or frustrated and what could you do to change and improve it?
3. What is your own preferred learning style and how do you feel when information is given to you in some other form? Do you receive information best by listening to it (auditory), by reading about it, by watching someone else do it (visual), or by actually trying it out yourself (kinesthetic)? How do you cope or make adjustments? How might you make adjustments for families that you work with?

### *Field-Based Activity*

#### *"Parent Interview"*

*Purpose:* To practice listening skills in a work setting.

*Directions:* Ask several parents if you can have about 30 minutes to do a personal interview. Ask each parent to tell you something from their family history or experience that has shaped who they are today. Listen, reflect, ask clarifying questions, summarize and thank them at the end of the interview. When you have completed three or four interviews, ask a friend or co-worker to listen to you for 30 minutes while you talk about how the interviews went. How did it feel to be the listener? Did you find out anything surprising about the person or the process?

### *Self-Study Activities*

#### *"Self Assessment of Communication Skills"*

In a journal format, do a self assessment of your communication skills, where you feel your strengths in this process are, and where it becomes difficult or uncomfortable for you. If you need to, think of a few specific situations to help you focus the self-assessment. Identify one thing that you can do in the next two weeks to improve your skills. Be specific about what you hope to accomplish and how you will measure your progress. List three things that might get in the way, how you will be sure that they don't and who your allies are in this process.

#### *"Noticing Jargon"*

Make a list of the jargon you use as an early intervention professional. Ask co-workers to add to the list. Include definitions next to all terms and acronyms. Have this list available for parents who participate in your program or for professionals who work with you and may come from disciplines outside of early intervention.



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## ★ APPENDIX A CHARACTERISTICS OF GOOD LISTENING

- Give the other an opportunity to talk.
- Establish an environment where the other person feels comfortable speaking.
- Demonstrate interest by asking appropriate questions.
- Lead the other to talk.
- Show interest through your body language.
- Attend to the content, not just the delivery of the message.
- Listen to the complete message.
- Deal effectively with emotionally charge language.
- Listen for the main idea.
- Deal effectively with others' listening roadblocks.
- Identify areas of common experience and agreement.
- Practice listening.

(Adapted from Wolfe, Petty & Mc Nellis 1990)

## ★ APPENDIX B ROADBLOCKS TO LISTENING

- Comparing: what the speaker says to him or herself or to others.
- Rehearsing: what you will say in response to the speaker.
- Mind reading: what the speaker is really feeling or thinking.
- Judging: the merits of what the speaker says or how it is said.
- Identifying: what the speaker says with your own experience.
- Advising: the speaker and providing solutions without being asked.
- Diverting: the speaker by changing the subject, distracting him or her from the topic.
- Being right: in your position or idea, leaving no room for listening to the other's perspective.
- Placating: the speaker by agreeing with him or her without being involved in what is said.

(Adapted from Wolfe, Petty, & McNellis, 1990)

## ★ APPENDIX C

### CONSIDERATIONS FOR DELIVERING SENSITIVE INFORMATION

(Adapted from The Parent Center, Albuquerque Public Schools, from a talk by Joan Guntzelman)

1. Provide a comfortable environment.
2. Tell the parents together if possible. When one parent has to tell the other misunderstanding and confusion can be the result.
3. Be aware of the readiness level of the parent to receive the information.
4. More information may be communicated through non-verbal cues than by what is said.
5. Try to have some sense of what the diagnosis means to the parents.
6. Try to keep the information simple and basic.
7. Try to communicate a sense of being calm and composed. Try not to communicate feelings hastily. Allow time for questions from the parent.
8. When delivering bad news, it is best not to give the heaviest information at the first visit. The rapport established during the intake (initial) interview will be helpful.
9. It is not necessary to argue with denial. Denial may be part of the process in the parent adjusting to a disability.
10. Try to be honest and straight without being brutal.
11. Avoid jargon, whenever possible.
12. Be accepting of parents' reactions.
13. Be aware of one's own need for power and control in the conference or situation.
14. Depending upon the degree of difficulty expected, allow sufficient time for information to be communicated.
15. Be open to new information from parents, who are often the best gatherers of information about their child.
16. Be aware that parents may not process all the information given them.
17. Speak to possibilities, not the negative things that may happen.

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## TEAMWORK

Having touched on a few of the issues and strategies in one-to-one communication, we turn our attention to the larger context of teamwork. Most people involved in early intervention spend a large portion of their professional time as a team member, and perhaps even as a facilitator. Anyone who lives in a family also participates on a team, which may include parents, children, and extended relations. There are rewards and delights in these team processes as well as challenges. It is important to acknowledge both aspects and to appreciate what this special dynamic offers us.

Team membership implies that participants are on the same side of the issue or game. It means that we work together for the same goal or purpose and that the success of the team will benefit all the players. We may not always feel that way, but that is the underlying assumption. Communication between team members can set the tone for cooperation and a sense of support, or it can be a bumpy road of personalities in conflict over turf or funding, side conversations and sabotage. Understanding group process and team building techniques can be useful tools in setting the course and charting the waters of teamwork.

Increasing the number of people involved in discussion, decision making, problem solving, or planning, increases the complexity and richness of the team process. When working in pairs, the communication bounces back and forth between the players with some predictability. When one pauses, the other has an opportunity to speak, to share thoughts, ideas, or reflections. There are two personal histories, perspectives, and agendas. Add one more person, add two or three, and what was a simple "broth" becomes a "stew." It has a richness and a deeper flavor, but there also is an increased possibility that differences will arise. Do the combined flavors produce a savory meal or one dominated by an overpowering ingredient?

Most people find teamwork challenging and sometimes frustrating, but also rewarding and interesting. As in any relationship, what you love best about it can also be the part that drives you crazy. Teamwork allows you to share responsibility, to tap into



the creative stream of many minds and experiences, and to avail yourself of resources not otherwise known or available. It also provides fertile ground for seeds of conflict, blame, competition, and hostility. Better understanding about how people work in teams can enhance the positive experiences of teamwork and minimize the "hot spots."

A team should address a number of practical questions, including:

- Who is in the position of leadership?
- Who facilitates the group?
- Who sets the agenda?
- What are the "ground rules," spoken or implicit, that you operate under?
- Who is responsible for record keeping, for distributing minutes and for watching the group process to be sure that everyone is heard and that the goals of the group are met?

Teams that work well do not happen by accident or luck. They usually have help from some or all of the people involved. Due to the complexity and extensiveness of the team building process, we only touch on a few key elements in the guide and invite readers to pursue additional information in outside resources such as: *Successful Team Building* by Thomas Quick (1992) and *Partnerships in Family-Centered Care: A Guide to Collaborative Early Intervention* by P. Rosin, A. Whitehead, L. Tuchman, G. Jesien, A. Begun, & L. Irwin (1996).

## Why is Teamwork so Important?

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In early intervention, the family is at the heart of the team. Their needs and wishes guide and direct what goes on, when it goes on, and where it goes on. Meetings are scheduled around the availability of family members, and their skills and resources are considered a major part of the collective pool of information and wisdom available to everyone on the team. When working with families under stress, we often need the cooperation and resources of a team. Ideally, people in the family's community could make up the team, but seldom are sufficient resources available at an informal level. The alternative model is a professional team that focuses on the child's developmental or health issues. It could also have members who specialize in housing, family finance, social work, teaching, public health, transportation, or employment. The more varied the group, the more critical it is that they function together as a team and identify common goals to work toward. When the team's vision gets lost in disagreements, team members need to remember what brought them together and what they want to change or accomplish.

Here are some points to consider when a service coordinator convenes a team or is a member of one:

*First, it takes a while for people to become familiar with each other, to develop trust and feel comfortable in a new group. All members bring their experiences and values with them, and may also bring doubts about their own competencies. We may wonder if we have something to contribute to the group. Will we be welcome? It can be helpful to start the meetings with some kind of group sharing, such a warm-up or check-in exercise. Early intervention teams are constantly changing and being reconfigured based on the child's needs and staff turnover. New team members need time to get acquainted, to become familiar with the current situation, and to figure out how they fit in and what contribution they can make.*

*Second, if the group will be meeting over an extended period of time, some commonly agreed-upon guidelines can be very helpful. These might include such simple (but often neglected) rules as not interrupting when someone else speaks and*

being sure that everyone's ideas are represented in a brainstorming process or in a decision made by the group. Allowing a few minutes for the discussion of ground rules at the beginning of a group can prove invaluable as the intensity of group process increases. There is, then, a structure created by the group to fall back on. This activity helps the group to feel safe to proceed, to work, plan and even disagree in a way that is useful and caring.

*Third, teams have their own dynamics and can change from meeting to meeting. Teams are like family units in many ways. Occasionally, issues of disagreement and conflict arise that may produce intense feelings in participants. Family or other team members may feel that they are not being listened to regarding decisions or planning. They may withdraw or confront others on the team. Misunderstandings or misinterpretations of information may anger or upset people. When things heat up, it's harder to keep in mind the ultimate goal or common purpose that brought everyone together. The goal, however, has not gone away and it may even become stronger or clearer as a result of successfully dealing with conflict. Or the group may break apart under the stress. It is very important at these times to *pay attention*. It is appropriate to acknowledge what is going on and name it from your own perspective. How is it affecting you? You do not have to be the person in charge of facilitation or the convener of the meeting to speak up. Does it feel frustrating? It is okay to say that. Does it feel like the group is losing sight of its purpose? Name it. And keep practicing those "listen with full attention" skills that provide the basis for the one-on-one relationships. They work great in groups as well. If the feelings of the group go unacknowledged, chances are they will fester and erupt at some future time. Cleaning out the wound so you can let it heal and people can continue to work together is the ultimate goal. It is worth the trouble and time it takes.*

Perhaps the most difficult thing for groups that go through periods of conflict or disagreement is its unexpectedness. It is not uncommon for these situations to surprise everyone, and that is why it is so important to slow down and just talk about what seems to be going on. You can get back to your original work more quickly if you pay attention to the nurturing process, instead of muddling along



with all the excess baggage of misunderstanding or miscommunication.

Groups that survive disagreements often form a special bond that continues long after their work concludes. It enhances their ability to deal with other challenging events that may come along. They have acquired skills and relationships for dealing with conflict in the future. It is a rewarding and satisfying time, not unlike the experiences of parents who see their child through some crisis of growth or development and find a deeper attachment or sense of pride on the other side. Being a service coordinator can be stressful and isolating, even for a seasoned professional; the support and encouragement of a team that works well together is invaluable and is a contradiction to feelings of isolation and powerlessness.

## Facilitating a Meeting

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There are many techniques that can be utilized to facilitate team activity, and each person who leads a group will have her own style and set of tools to use in the process. The most important skill or technique, involves listening to each person, without judging or trying to change his mind. This has more power to alter the course of events than any argument you can make. So save your breath and listen! Especially listen to what the family tells you about themselves and about their child. Be sure everyone on the team has a chance to share her information and her thinking. The richness of team process comes from all the participants. Invite those who are less forthcoming to contribute their ideas if they have not already done so.

A *written agenda* distributed to team members ahead of the meeting keeps people focused and gets the work done in a timely fashion. For people who cannot attend the entire meeting, they can at least be present for the pieces of the agenda that most relate to their work. Taking time to write or review a statement of purpose or expected outcome for a meeting can keep things on track. Team members will appreciate punctuality about starting, ending, and sticking to the agreed-upon agenda; it will make it easier for them to participate. Asking pre-

senters to arrive with concise and comprehensive handouts is another way to improve communication and maximize the use of everyone's time. Section II lists additional strategies for working with the early intervention team, that may be useful to review periodically.

## Celebrations

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Another aspect of teamwork is the evaluation and celebration of accomplishments. It is a significant effort for many professionals and family members to coordinate schedules and show up at the same place and the same time on a regular basis to work collaboratively with a family on behalf of its child. Everyone deserves recognition and appreciation for what is accomplished and for what has been attempted, whether it succeeds or not. It is important to allot time for assessing and celebrating even small successes.

## How Decisions Are Made

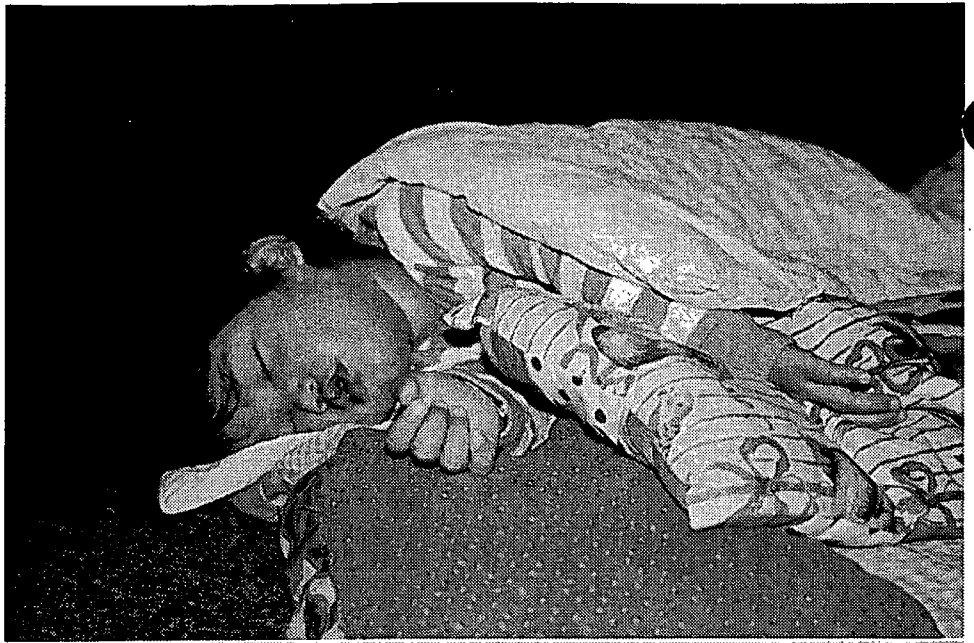
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A group needs to establish early on how decisions will be made and by whom. For example, it is better to decide how decisions will be made at the beginning of the IFSP process, rather than half way through it. Make a commitment to use a process before disagreements arise. It is much harder to make difficult decisions under stress than when people are just beginning a collaborative effort.

Consensus provides one way to make decisions consistent with the philosophy and practice of early intervention. Many people consider a consensus process cumbersome and time consuming. Sometimes it is. It means that you keep working and keep talking until everyone at the table agrees on the next step or the plan of action or at least feels comfortable enough about the process to move on without blocking consensus. It is quite a different approach from "majority rule" that requires agreement by just over half of the people present. It is quite different from dictatorship or having the most skilled professional decide. It means spending time listening to everyone's ideas and then melding them into a program that the entire group feels comfort-

able with. Consensus does not mean that everyone has to agree 100 percent. People who disagree can "stand aside" and express a minority opinion without holding up the process or being outvoted. Consensus is something that people and groups can grow into, and can learn from even when it doesn't work perfectly. It is worth exploring with an early intervention team or within an agency team that makes policy decisions. It helps to eliminate the grumbling and passive participation that can drag an effort down. Once again, remember that the family plays a key role in the process of building consensus. Family members are the ones who ultimately will be affected by the decisions. All the best engineering and creative solutions will fall flat if caregivers are not actively involved in all of the decisions being made about their child and family.

Having touched on a few elements of team communication, it is worth noting that this is not an inclusive picture of the many aspects of teamwork. The easy times —when everyone agrees, the solutions are obvious, and there are adequate resources of personnel, time, and money—don't require much explaining. A good foundation in team communication can keep a team moving along smoothly or help move it on when the going gets rough. Creating teams that model the importance and the power of families by including them on a team is a part of the work of service coordination.



## Interagency Communication

Interagency communication brings with it all of the quirks and challenges of one-to-one and team communication, plus an additional layer of administrative complexity. Interagency collaboration also provides the opportunity for greater diversity as well as another set of guidelines and skills for service coordination. One definition of collaboration, put forth by Mattessich and Monsey (1992) in their book *Collaboration: What Makes it Work*, states that it is "a mutually beneficial and well-defined relationship entered into by two or more organizations to achieve common goals" (p. 7). It expands to include "a jointly developed structure and shared responsibility; mutual authority and accountability for success; and sharing of resources and rewards." Interagency collaboration is teamwork on a grander scale.

Availability of resources and the increasing complexity of community problems has created a shift in the human service paradigm in the 1990s. The federal government has made interagency collaboration a requirement and scarce resources have made it a necessity. But this does not magically make cooperative efforts happen. The law does not provide people with the negotiation and problem solving skills that are required to make collaboration effective. And agencies are made up of people,



the same ones who were there before collaboration was mandated. Just as individuals have their own agendas, their own ways of doing things, their own style and purpose, so do agencies and organizations. Collaboration facilitates the sharing of resources and minimizes the duplication of services, but it requires trained and talented individuals with strong communication skills to make a joint effort successful. Any person who has been a part of, or worked with a "blended family" where two parents come together in a relationship, each with children from a previous relationship, has a grasp on some of the issues of collaboration. Yes, you can share resources; yes, you can have mutual goals and shared responsibility, mutual authority and accountability for success; but not without a lot of hard work (See Table 4 and 5 in Section II for Personal and Group Strategies for Enhancing Collaboration).

Interagency cooperation depends on agreements that are clearly stated and mutually agreed upon. This requires negotiation and exploration of skills and resources. It may be mutual, but that doesn't make it equal in all ways. A high level of trust is important for it to work well, and honest, direct communication is essential. All of these qualities must be valued by the participants, and there must be the ever present willingness to work together for the collective good of families.

Specific situations where interagency cooperation draws upon the experience and skills of a service coordinator include transition times when children and families move from one major provider of services to another. An example might be the transition from an early intervention program to a public school. The meetings that precede the transition set the stage for the next program and model parent involvement from IFSP to the Individual Educational Program (IEP). Schools generally have fewer structures to welcome family involvement and to see it as a resource in planning for students. Service coordinators may need to be models and facilitators for their counterparts in school settings. This can be a difficult and scary time for families, leaving a familiar environment where they have played a central role in planning and moving into a less familiar one where their role is not as clearly built into the process. Make sure that all parties continue to feel they are on the same side of the

fence and are working for the best interest of the child. Interagency or interdisciplinary teams bring problem-solving skills and differing perspectives to the transition process. This collaboration is necessary for comprehensive planning and successful outcomes.

Negotiation skills begin with careful listening, reflecting, summarizing, and asking clarifying questions. Recognize that this is not just an academic exercise and that many personal feelings may be present and need to be acknowledged. These include feelings of the family about "letting go" of their cherished pre-schooler, to fear on the part of school administrators that they may not have accessible classrooms or teachers trained to work appropriately with a particular child. Finding common ground and working from a place where everyone can agree is an important first step toward a successful transition.

Another transition requiring interagency cooperation and communication occurs when an infant is being discharged from the Neonatal Intensive Care Unit (NICU) and moves from the security and support of a hospital environment into the larger world of family and community. Medical information needs to be shared and confidentiality must be respected. Negotiating this process requires patience and persistence to meet the Part H requirements and at the same time attend to the personal needs of family members and professionals in the community. For more information on transitions see Sections II and IV.

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## Summary

Teamwork is invaluable in the field of early intervention, just as it is in the family unit. We do not live, or function in isolation -- we need each other. There will be many opportunities to practice and to experience teamwork in every aspect of early intervention. Assessments and evaluations, implementation of the IFSP, and transition invariably require the input from a team to make it work well. Working with families and young children is built into the nature of our work and our lives. We need to explore, enjoy, and cherish the collaborative experiences that it provides.

## DISCUSSION QUESTIONS

1. What are the qualities that enhance and motivate team cooperation and how can you build these into in your team experience?
2. Discuss the differences between a professional team meeting and a meeting convened with a family to plan for the needs of their child? In what ways are they similar?
3. Spend some time discussing how to involve the geographic community in your team process and what the advantages and disadvantages of that might be. What resources exist in the community that could assist families in your program —parks and recreation, theater, gardening, crafts people?
4. How do decisions get made on your team? What happens that makes you feel part of the decision making process? What can you generalize from this to think about supporting parents as active decision makers on the team?

## ACTIVITIES

### Group Activities

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#### ***Activity 1: "Paper Bag" Dramatics for Team Building***

***Purpose:*** To get team members working together on a project, feeling more comfortable with each other's styles and skills in a non-threatening, playful way.

***Directions:*** Assemble assorted toys, tools, hats, etc. in a brown grocery bag. Have as many bags as you have teams. Keep the team size to four or five people to maximize interaction. Give each team a bag (the contents can be different in each one) and ask them to tell a story, make a commercial for their program, or make a statement before Congress using the props from their bag. Give them 15 or 20 minutes to work on their "skit" and then present to the larger group. Process by asking how each group worked together as a team, how leadership was shared and individual skills utilized.

#### ***Activity 2: "Group Juggle"***

***Purpose:*** To get a team or large group better acquainted and to use the activity as a teaching point.

***Directions:*** Ask the group of 10 to 15 participants to form a circle. Start to "juggle" one item, such as a soft ball, by calling out someone's name, making sure you have their attention, and then throwing the item to that person. Continue until everyone has passed the item to someone across from them, creating a "juggling pattern." You should only have the item one time, to catch it—then throw it on to someone else. When you have completed this a couple of times successfully, being sure to call out names, add another item to the circle and continue gradually doing this until you have four or five items in the air at one time. Then "throw in a towel" and stop the action. Everyone should be pretty well warmed up and more familiar with each other. Ask participants to think about and share how this experience might reflect work in service coordination.

## Individual Activities

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### *Questions for Reflection*

1. What has been your best team experience and what were your personal contributions to the successful work of the team?
2. What was your worst team experience and what did you learn about yourself as you went through it? What would you have liked to do at the time but didn't?
3. If you were going to assemble a team of people to work on an issue in early intervention, to make some significant program or policy change, who would you choose and what are the reasons for your choice? Who will you have on your team to represent alternative opinions and ideas that may differ significantly from yours?

### *Field-Based Activities*

1. Sit in on a team process where you have no vested interest in the outcome or results. Notice how the team operates and what you feel comfortable or not comfortable with in the process. What would you change about this team to make it work more effectively? What are the different roles people play? How are decisions made? Who is in leadership and what is their style?
2. Develop a team warm-up activity and teach it to a group you work with. Ask participants what they liked about this activity.

### *Self-Study Activity*

1. Using your journal process, remember a time in your childhood, perhaps at school or summer camp, when teams were being formed. Where were you in that process? Did you have a position of leadership? Were you a first or last choice on the team? What were your feelings and how might some of those feelings influence your current work as a team leader or team member?

## RESOURCES

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## ENCOUNTERING CONFLICT OR CRISIS

Conflict is about change, and change happens all the time. We live in a culture fraught with negative, violent reactions to conflict. It reverberates across the six o'clock news and makes headlines in the printed media. We find conflict in our families, our friendships, and our work places. It destroys nations and depletes resources. We, as a species, have not been very good about dealing with our differences. Children learn the dynamics of conflict on the playground and in the classroom, as well as at home. In response to this, many people in our society are examining alternatives to the "might makes right" philosophy that we may have learned growing up. Some schools are teaching mediation skills to children in kindergarten, in the hopes of heading off acts of violence and dissent that may later threaten the stability of educational institutions and the safety of classrooms. We cannot buy our way out of this current environment, we cannot run away from it, and we cannot ignore it any longer. We need to begin dealing with it now.

There is another side to conflict that also needs to be considered. Conflict can be a source of renewal and of growth. It can be life enhancing. We can learn new ways of perceiving the nature of conflict and we can develop new skills that will help us settle our differences in gentle and respectful ways. We can welcome conflict instead of avoiding or perpetuating it.

In early intervention, our conflicts seldom show up in violent acts, but rather in differences of opinion, protection of territory, competition for funding. These are problems we need to acknowledge and change.

We may experience conflict internally as we struggle to make a moral decision or sort out personal choices, or externally as we are affected by the lives and choices of others. Situations of inner turmoil are difficult in their own way, but as long as we have control and only ourselves to consult, we hold all the necessary cards to make decisions. Interpersonal conflict begins when two or more people have a disagreement over a decision, an action, or a role. As with other communication

experiences, the more people who are involved, the greater the difficulty in untangling the problem. Similarly, the longer a disagreement or misunderstanding is unattended or ignored, the harder it will be to deal with. In group settings when differences arise and strong feelings are expressed, they tend not to disappear on their own. People involved in disagreements may need some help. Many of us have had bad experiences in group conflict and may tend to shy away from such confrontation. It is important to realize that the same seed of conflict that makes us uncomfortable also has the potential for new life. "Nature doesn't see conflict as negative. Nature uses conflict as a primary motivation for change" (p. 31), according to Thomas Crum (1987), author of The Magic of Conflict. Dealing with conflict forces us to take a look at old and dear values that may have outlived their usefulness. It gives us opportunity to practice our listening skills, to try on someone else's perspective, to listen to our own feelings and respect those of others as we seek common ground and mutually agreed-upon solutions. It is helpful for service coordinators to have a basic appreciation for the way conflict works and to recognize differences in personal values that may be encountered. It is helpful for family members to realize that they have power in planning for their children who have special needs and that their voices and ideas are important. Even when parents may not agree with proposals, therapies, practices, and services offered by the early intervention system, they can make choices and speak out. Parents need and deserve the help and support of the service coordinator and others to express their choices.

Understanding some techniques for settling disputes and negotiating for what is needed is a learnable, teachable skill. It can serve us well in many arenas, personally and professionally. For service coordinators, there are numerous opportunities to experience negotiation and to resolve differences. How we respond to difficult situations is our choice. Moving beyond the idea that conflict is about winning and losing, will open up new vistas and reduce the fear that often tags along with it. When we change our perspective and feel comfortable dealing with conflict, we can more easily stay in touch with ourselves and our integrity and open ourselves to potential change and growth.



## Personal Strategies for Working with Conflict

The first rule when encountering conflict is "*don't get stuck in it.*" Conflict traditionally sounds the battle cry. If you don't stand up for yourself, who will? If you don't make demands, how can you hope to get simple basic services? If you don't raise your voice, how will anyone hear you or take you seriously? Wheels begin to spin and you find yourself falling deeper and deeper into a hole. Whether you are a parent making a request or a service coordinator having to explain why you cannot meet a request, all parties must listen closely to what is being said and try to understand the issues. (See Techniques to Try When Teams Get Stuck in Section II Appendix.)

The second point to remember is to *listen to the issue and gather information*. There is a story about two people who lived together and usually got along. But one day they both arrived in the kitchen and at the same time reached for the last orange in the fruit basket. Each insisted that she NEEDED that orange, and both needed ALL of it. There was no simple solution like cutting it in half. Both people demanded the whole orange. Just at that time a friend stopped by and heard the uproar. After calming down both people, she asked each one why she needed the orange. One needed two tablespoons of peel to make a cake and for her, that meant the whole orange. The other needed a glass of juice to sooth a sore throat, and for her, that meant the whole orange. In this case, it was possible that both of them could get what they needed—but first they had to listen to each other.

We do our best to accomplish the steps of noticing our own feelings and listening carefully to others, but it is not always enough to head off a difference of opinion that threatens to delay or derail a project.

The third point is to *summarize and reflect* what is being said by all parties involved, and consider all options. That seems pretty straightforward and certainly would have worked for the two people and the orange. Stating our own position and then listening to the position of another is basic to any mediation or resolution of difference. Taking time

### ***The most important things to remember in dealing with conflict in a preventative way are:***

1. Pay attention and know your own feelings and how to take care of them.
2. Listen carefully to the issue before jumping to conclusions and trying to make decisions based on inaccurate or inadequate information.
3. Reflect that you understand the others' point of view by summarizing their thoughts and feelings.
4. Ask for help when you need it.

to brainstorm all the possible solutions can net some very interesting "fish," some of which might be just the "catch" that is needed.

A fourth strategy is to **GET HELP!** If you find yourself mired in a complicated situation where there are hurt feelings, poor listening and problem solving, and lots of fractured conversations, you do not have to figure it out by yourself. Invite a neutral party to participate. Bringing in someone else changes the dynamics. If that person is not invested in a particular outcome, she may think more clearly and may identify more easily what is going on. If you are a parent attending a team meeting, you have the option to invite a friend or neighbor to come with you for support. As a service coordinator, you might want to have co-worker or other professional accompany you. There are many ways to make this work once you let go of the idea that it is not okay to have someone accompany you in times of difficulty or to ask someone else to intervene.

Teamwork is an ongoing process, almost like a living entity. It grows and changes and is subject to the pitfalls and limitations of its parts. Sometimes discussions are held between individuals outside of group meetings and, as a result, everyone does not have the same information when you reconvene. Take time to talk about this. Also remember the importance of letting every person on the team speak about their feelings and perceptions concerning the issue being addressed by the group. During this time, simply listen and reflect. (You use this same technique in a one on-one conversation.) It provides a forum to discover what has been misunderstood, assumed to be true, or is just lacking in information. Following this airing of feelings, the group needs a chance to go around again and suggest possible solutions to the problem or situation. From this process can come the best combination of ideas available and it will help the whole group to feel investment in the outcome and success of the decision.

#### *What if it still does not work...?*

There is no single strategy that will magically settle every dispute or resolve every difference. You will have to do some trial and error, vary your strategies until something begins to click. And sometimes your best efforts still may not move things forward. Conflict may indicate that everyone on the team does not feel comfortable with the direction of the team. Stop and reflect. Maybe the team is not going in the right direction. If there continues to be a problem and you cannot reach agreement, you may want to take a break, gather more information, and give ideas a chance to settle. Then try again. Everyone on your team, in your group or family, is doing their best to meet their needs and you will not always see eye to eye. Give yourself credit for trying. Take a bow for listening well. Appreciate your skill in asking questions and reflecting feelings. Do not let the opinions and behaviors of others determine your own self worth. Be willing to forgive yourself when you have not been the perfect team player and try again at the next opportunity. Sometimes your best strategy may be to start over with new players. As a parent, you may want to request a change in a therapist or service coordinator if you are unable to resolve differences. As a service coordinator, you may find it impossible to work effectively with a particular family. Give yourself permission to let go, to try

again with new information and new players. Some situations may extend beyond the skills and resources that any one of us may have at a particular time. That does not mean we are in the wrong job or that we should give up on parenting. It does mean that we need to take a break and take another look at what we want to accomplish and what it is possible to accomplish.

## Summary

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Dealing with disagreements, conflicts, and misunderstandings is a small portion of the work we do in early intervention. We need to remember that it can and does happen, sometimes when we least expect it, but we do not need to marshal our forces to deal with it. We are not preparing for armed conflict, we are "getting to yes" in a way that meets the most basic needs of all parties concerned. Strong communication and listening skills are the best tools available to us in difficult situations. As in other areas of personal development, we need to find opportunities to practice using these skills effectively when the emotional stakes are low. Negotiating what movie to see, what toy to purchase, how you want to spend your weekend with another person, are all things that give us a chance to negotiate and to find the common ground that leaves both people satisfied. Doing this successfully gives us confidence to try these same techniques when the pressure of time, emotions, and resources may be much higher. Attending workshops, reading additional literature, and having discussions with co-workers or friends may further enhance your ability to slow down and use your communication skills when conflicts show up at your job or in your personal life.



## DISCUSSION QUESTIONS

1. Spend some time thinking about the sources of conflict or disagreement in your service coordination or parent role. List the potential problems and then identify your possible emotional reactions (e.g. fear, anger, frustration) and how to address them. List the tangible components of the problems (ie resources, time management, transportation). Discuss a plan that might allow you to address all aspects of the problem.
2. Think about how your team or family goes about solving difficult problems or disagreements. What is the process they use to decide an issue? Are they able to use consensus methods? Discuss the advantages and disadvantages of the model you use.
3. Identify and discuss how conflict was handled in your family or school setting and what was effective or not effective about it. What part of that process do you still use when in a conflict situation? What part would you like to change?

## ACTIVITIES

### Group Activities

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#### ***Activity 1: "Ground Rules"***

*Purpose:* To create a safe climate to discuss difficult issues.

*Directions:* Ask participants to sit in a circle and close their eyes and relax. (If people do not feel safe closing their eyes they can just look down at the floor or their hands). Ask them to take several slow deep breaths and to relax their body. Ask people to think of something that they have never told anyone (or very few people). *Be sure to tell them that they will NOT be asked to share this with the group!* What would it feel like to tell this group and what would have to happen for it to feel safe enough to tell this group? What rules would have to be in place or agreed to by everyone? Give participants a few minutes to sort this out with their eyes closed, then ask them to take a deep breath, open their eyes, and return to the group. Ask people to share what it felt like to imagine telling this group their "secret." Ask the group to develop a set of rules that would make it feel safe. Put this list on a flip chart and post them in the room. These rules should include, but not be limited to; confidentiality; no name calling; no judging; right to pass; okay to express feelings. Use these ground rules to guide the group as they work together.

#### ***Activity 2: "Whose Problem is This?"***

*Purpose:* To practice problem solving in a safe space when you are not under pressure and to find common ground in personal issues.

*Directions:* Have each group member write down a challenging problem they may be facing, or have faced in the past but may not have resolved satisfactorily. Do not put names on the problems. Put the written situations in a "hat" and then pass the hat, asking everyone to take out someone else's problem. Spend some time discussing, role playing, or problem solving using basic listening, reflecting, and communication skills.

## Individual Activities

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### *Questions for Reflection*

1. What are the things about conflict you find uncomfortable or threatening? Look back on your experiences to see where these feelings may originate. How would you like to change the way you deal with conflict? Write down three things you would like to do differently and practice them in the next month. Note in your journal any changes you observe.
2. Think about a team experience you have had where conflict was resolved fairly and successfully. What worked in this process? Identify specific things that were said or done to help make the outcome successful.

### *Field-Based Activities*

1. Offer to go with a parent to a team meeting, just as an observer and ally, not as an active participant. Be supportive of the parent before and after the meeting regardless of the outcome. Ask him how he is feeling about the meeting and what, if anything, he wished he could change. Make notes in your journal about the experience.
2. Lead a team meeting in which you agree to help the group come to consensus about an item on the agenda such as where you will hold your staff retreat or what equipment purchase staff needs the most. Notice how long this decision takes using consensus. Be sure everyone has an opportunity to be heard and their information considered. Reflect on how this might work with families.

### *Self-Study Activity*

Watch the video called Pow Wow Highway, starring A. Martinez, Gary Farmer, and Amanda Wyss and directed by Jonathon Wacks (1988, 91 minutes). Rent it from the video store and observe the conflicts that arise during the story. Think about how some of these conflicts could have been resolved in a "win-win" fashion. Some of the conflicts have deep historical and cultural roots. How might these be addressed? Identify one conflict situation and map out a process to work it through in a different way than the video. Where might you find resistance and how could you overcome it? What cultural norms about conflict does the video perpetuate? Spend some time reflecting and taking notes on this.

## RESOURCE

Crum, T. (1988). The magic of conflict, turning a life of work into a work of art. New York, NY: Touchstone.

## TAKING CARE OF YOURSELF

Whether you are a parent, caregiver, or professional working in early intervention, issues of self care are part of the picture. We live in a fast paced environment. High expectations and a lack of personal or community supports to nurture ourselves can result in a great deal of stress.

Avoiding "burnout" is equally important to parents and professionals. It doesn't just happen when people are doing difficult jobs, with long hours and sometimes low pay. Burnout also can impact parents who manage the personal care for a child with unusually complex and urgent needs, often without adequate help and information. Realizing that we are responsible for ourselves and our own care is a necessary part of service coordination, whether providing it or receiving it. It is absolutely essential that we realize no one is going to really take care of us as well as we can. There may be a spouse, a partner, a friend, or a co-worker who can notice and comment on our lack of energy and who will tolerate our short temper out of kindness and concern. It is useful when we can do that for each other. Nevertheless, it still falls to each of us, to notice what is going on, how we are feeling, and to commit to making changes that will provide ongoing healing and refreshment. Most of us do not have employers or family members that encourage us to take a "mental health" day every month, or a quarterly retreat to rest and restore ourselves. It is our responsibility to do this for ourselves. As professionals, we work in a society that expects us to do more with less and do it better, faster, and more creatively than we did last year or the year before. We work with families who have many stresses and with children who have complex needs. As parents, it feels like we are expected to do more care, know more about treatments, take time to lobby for basic needs, attend leadership training, advocacy meetings, school team meetings and show up on the job with the regularity of everyone else. The tasks seem endless. Let us admit how hard this is to ourselves and to each other. The load really feels too heavy at times for each of us. So what can we do about it? Solutions will look different for each person. It is okay to pull back and



reflect about sources of stress and overload. How long we need, what we do and where we go to refresh and restore are choices we get to make. Our next task is to ask for help in following through to be sure we take the planned action for rest or recovery. This section will address in more detail some of the issues that pertain to taking care of ourselves as service coordinators and as parents.

### Stress Reduction

Reducing stress, managing stress, avoiding stress, dealing with stress—these are common phrases in most of our lives. We live in a world filled with delight, beauty, and surprise. It is also filled with difficulties, with challenges, with sadness. In a controlled environment where no risk is required and no demands are made, there is little stress, and few surprises. But we don't live in a controlled, safe, risk-free world. Our environment keeps changing and sometimes we need time to make adjustments to these changes. We cannot be protected from difficulties and so we must find ways to adapt, to survive, to find joy and pleasure in life as it unfolds each day.

Stress can wear us down, and it can also make us strong. How we respond to it depends on the coping tools, the choices we make, and the support system we have. Many families feel overwhelmed with care giving responsibilities for children while trying to manage employment demands, economic

limitations, housing scarcity; the list is long. These families need to develop techniques and resources that include healthy coping strategies. What works for some people may be of no use to others in dealing with stress, and so we each must decide what works best for us. Professionals in the human service field have developed a body of knowledge that makes figuring out what to do for our stress just a little easier. A variety of coping strategies have been shown to be successful in reducing tensions and minimize stress. Listening to families and service coordinators talk about how they contend with stress further confirms that these tools are tested and useful to a variety of people in many different circumstances.

## Some Tried and True Methods to Help Relieve Stress

■ Nature has an incredible capacity to heal itself, and it seems to have a great capacity to heal human beings as well. Being outside, in a natural environment, can be soothing and can promote feelings of well being and contentment. Find a park, a garden, an open field, or a back yard and relax. Spend some time there just noticing the temperature, the light, the color or texture, the direction of the breeze and let go of the worry or stress for the time being. Feel the pulse of the planet and notice your part in it. Breathe deeply and slowly. Let go for just this brief time. Then ease back into the situation and see if it isn't improved just by being away for awhile.

■ Water—bath water, dish water, rain water, beach water—bring comforting sounds and sights to many people. A long soak in warm bubble bath is one of the most acceptable and effective means of soothing away distress. It ranks among the top five ways for stress reduction reported at training and workshops across the country. A variation might be to take off your shoes and go wading in the lake, at the edge of the ocean, or even a public fountain and let the water wash away stress and worry. Some people even claim that putting their hands in warm soapy dish water and seeing a specific task accomplished is both relaxing and productive. Making use of a community swimming pool or health club whirlpool can be soothing and energizing at the same time. Water has many healing forms.

■ Music, in all its infinite variations, can lift our spirits and gladden our hearts. Some people have skills to play an instrument as small as a harmonica or as large as a piano, and find it absorbing as well as relaxing. For those who have neither access nor inclination to play music but may prefer to listen, there is an abundance of music that can be a comfort in times of stress and a safe way to unwind when things get too hectic at home. There are even specific tapes for stress reduction and relaxation. In addition to being an effective stress reduction tool for adults, music can be equally calming for small children. Everyone can benefit from this kind of activity.

■ Moving our bodies—in dancing, walking, swimming, jogging, or any other way—can be another effective tool to alleviate stress. Taking oneself or a friend for a walk can be more than just time away, it can mean renewal. Having a regular exercise program helps your body to release the natural healing chemicals that serve as anti-depressants as well as increasing your sense of well being. The program might be as basic as walking or a class in aerobics, or yoga, or just a period of time set aside regularly to get some kind of physical workout. Making an investment in yourself is basic to being effective in working with others.

■ Telling stories, especially our own stories, to a willing listener can give perspective to a problem and may even provide us with solutions. Verbalizing our troubles has a way of diminishing them. And for some people, taking time to write down things in a journal that are bothersome or painful is yet another way of telling a story and transforming a difficulty.

■ Meditation, sitting in silence, looking inward, or asking for help from a higher power is a comfort for many people when other supports are unavailable or inadequate. As a regular practice, this can even be useful as a stress prevention strategy.

■ Focus on a child. Many parents report that they find renewal in taking a break with their children. Spending time with an art project, a favorite T.V. program, or a bedtime story, or perhaps a walk around the block, out of the house and away from family demands, can be refreshing. Taking time to be totally away from children for awhile is the other



side of that coin. Parents can set up respite with family members or professionals, or use day care providers to supervise children while they take some time off.

■ Journal writing can be nurturing and quieting, and can also track progress and allow us to notice how much our situations and our children change and grow.

These are some of the ways of reducing stress that have been mentioned by service coordinators and parents at professional and recreational gatherings and come highly recommended as being effective. It is not meant to be a complete listing of the many options available to help us cope with difficulties, but rather a starting point. Take time to notice what works for you. Ask families and co-workers what has been useful for them.

## Some Not so Effective but Commonly Used Approaches to Stress Reduction

There are many coping strategies that dull the pain of stress, but are not effective in reducing it. Alcohol and other drugs are a frequently used method of turning off the noise of fear, pain and confusion, without really healing or strengthening us. Substance abuse takes a heavy toll on families and professionals under stress. Early intervention professionals need to understand what is happening and what they can do about it for themselves and for the families they serve. Other activities that can be addictive include gambling, overeating, shopping and overspending, playing video and computer games, and watching television. None of these things are harmful in and of themselves. But when they are used consistently and frequently to avoid dealing with personal difficulties and to keep from facing issues or problems, they can become harmful. They keep us from feeling and thinking. Sometimes, for a short period, these activities help people cope. However, when they become a life style and people depend on them to get through the day or the next crisis, they are no longer just a harmless way of spending time, energy, or money. They become the end in itself and it is important to understand this and talk about it.

Because early intervention services take professionals into family settings, on a casual and personal basis, they are in a position to notice coping patterns that may be problematic and can make referrals to counseling services or 12 step support groups when that seems appropriate. A service coordinator can express a concern and ask the parent if help is needed or wanted. Being familiar with local Alcohol and Other Drug (AOD) resources is one more tool to have in your resource bag and this information is readily available at mental health centers and community resource information directories or even the phone book. If you notice problems within a family that seem to recur or persist, it is worth mentioning and can move people in the direction of getting the help they need. Having a staff inservice to share this kind of information can be helpful both personally and professionally.

## Setting Boundaries

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Noticing and enforcing our limits is one way we have of setting and respecting personal boundaries. This is equally true for family members and professionals. Setting boundaries may be more difficult, when the urgency of parenting responsibilities requires so much attention and energy.

Participation in early intervention programs requires personal disclosure and this can feel intrusive to families. They are asked to provide a volume of personal information as part of their service plan. They may be asked what the family income is, what kind of insurance they have, how personal relationships among family members are going, and what other resources are available. Additionally, homes and life styles may be examined by an assortment of professionals, as parents repeatedly tell all they know about their child and her skills and development. Very private information is given in a one-way process. Although service coordinators may disclose personal information in their relationships with a family, they are not required to divulge income, insurance, or other financial information; in fact, they would be considered unprofessional if they did. Yet families are asked to do it routinely. We need to be aware of this and be as respectful as possible when asking

questions and seeking information from families. Providing some personal information in a sharing discussion may serve to build trust and increase communication between family and service coordinator. Each situation will have to be considered individually. The primary caution here is to be sure that the service coordinator respects family boundaries and does not use the family as a resource to share his personal concerns, thereby reversing the roles of support. Boundary setting for parents can be difficult. Trying to set limits may tag them as uncooperative or inflexible and some may choose not to participate in programs because they do not want to deal with this potentially intrusive process. We need to give people opportunities to set their own limits, and respect their efforts to set boundaries.

Service coordinators also need to set boundaries for themselves. It may take practice and some getting used to, but ultimately things will go better if we support each other and respect boundaries that are set as part of self care and self-preservation. Deciding whether or not it is permissible to give out home phone numbers of therapists or service coordinators so that questions can be fielded at home as well as at the office, is an issue that affects personal boundaries. Developing an agency wide policy to deal with this issue is one solution, or it may be left up to the discretion of each individual to decide on a case-by-case basis. For some families, it is reassuring and helpful to contact the professionals who support them outside of traditional office hours. For others, it may create an unwise and unhealthy dependency. Think through these kinds of policy decisions and consider them in light of personal needs for privacy and self care. Being in partnership with a family in the service coordination process does not mean enmeshment in each other's lives. It does not mean a fifty-fifty split of responsibility or tasks. It is a carefully defined and constantly changing dance of cooperation and caring.

Much has been researched and written about how grief and loss affect families who have children with disabilities. Sociologists have identified stages or phases that caregivers sometimes go through in making adjustment to expectations for their child. Evidence supports this process as cyclical. It may begin in the hospital at the birth of a child or with the initial diagnosis or developmental evaluation that identifies and labels a child as delayed or disabled. What this means for service coordinators is that they should have a basic understanding of the grief process, what it is and how it works. Grieving may be a lifelong, though intermittent, experience for families that have children with permanently disabling conditions. And dealing with our own grief or with that of others ranks as one of the more challenging parts of the service coordinator's job. If all of us had extensive training in how to work with people who are experiencing grief and loss, it would be much easier. But most of our education did not include that training. Sometimes we try to avoid the parent in tears. We try to cheer them up, distract them with questions, even delay giving information that might possibly be upsetting. Those tactics do not really serve families well.

Over the past several years, some things have been learned about the human process of dealing with grief and loss that can help us be more effective in our role as service coordinator:

1. The first thing to remember is that no matter how well intended we are or how hard we try, we cannot possibly know exactly how someone else is feeling. Saying "I know just what you are going through" is seldom a comfort to a grieving parent. On the other hand, saying "I respect how you feel and you have every reason to feel that way" can be invaluable and help us honor those feelings.
2. Secondly, do not judge someone else's process of healing. It serves no purpose to label a parent as "in denial of the disability" or "refusing to admit the severity of a diagnosis." It may take some parents a long time to make the necessary adjustments in their



lives and their plans that the birth of a child with a disability can require. We cannot and do not know what this means for them. Our task is to accept where they are and be patient as they sort things out. This means listening, using those basic skills of paying attention without judgement, reflecting back what they are telling us, and being comfortable with whatever feelings come up for them—anger, confusion, or deep sadness. We need to stay with the process and not let our feelings of concern or a desire to fix things get into the interaction.

3. When we do not know what to say or how to offer comfort, it is fine just to be there, be calm and be present. Sharing grief diminishes it. Sometimes grief can feel isolating and a caring, sensitive service coordinator can lessen those feelings and alter that experience by being there.

There may be times of tragedy when all of the people who are working with a child feel grief and loss. There is nothing wrong with sharing our tears with parents or family members when we have become a part of the extended care circle that is invested in a child's success. But it isn't the place for us to work on our grief issues on a regular basis. That needs to be done in another arena.

Doing grief work with families is especially difficult if we are afraid or uncomfortable with feelings of sadness and hopelessness that may need to be expressed. It is important to remember that all feelings are transitory and just as feelings of exuberance or joy cannot be held on to indefinitely, neither can our feelings of sadness. They may return with less intensity or frequency, but for most people they come and go. It is acceptable to offer the help of family counselors who deal extensively with grief and loss when we do not feel confident to fill this role ourselves. And we also have to trust the resiliency of families and believe that they can figure out a way to cope with difficult news if they have support and encouragement. If parents are functioning in other areas of their lives, such as buying groceries, going to work, doing laundry, eating and sleeping, then it is a good bet that, with help and support, they will rise to the challenges of caring for their child. Service coordinators, thera-

pists, and early interventionists do not have to be the only ones to give support. Connecting parents with others who have similar experiences can be a great gift. Some will be eager to share with other parents and welcome support and information, others will find it uncomfortable and prefer to avoid other parents. Each family will be a little different. There is no template that will work in every situation, except our compassion and concern, one person to another.

None of us are expected to be the perfect listener in every situation, and some situations may be too close to us. Sometimes we need to let go for awhile, to take care of ourselves, so we can return to take care of and work with others. This reflects boundary setting and respect for ourselves as well as for the family in need of support. There are many resources available to help families through painful times and it becomes part of our responsibility to know where they are and how to make use of them when our skills are stretched to the limit and we are unable to meet an obvious need.

## Personal Safety

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Personal safety on the job is a growing concern for some service coordinators. It is a recurrent theme in training and workshops for human service professionals who do community outreach. Some families that receive service coordination for their child with special needs have economic difficulties that may force them to live in places with a transient population, inadequate community resources, and poor public transportation. It is a challenge to be sure that the needs of these families are met just as completely as for those who live in middle income suburbia. In urban areas, people worry about going into unfamiliar neighborhoods where there may be gangs or drug dealers. Families needing services may not have a phone so the service coordinator can call to see if the family needs help or to find out if someone will be home before he makes a home visit. Rural areas, where families are isolated from neighbors and community may also pose a threat to personal safety if there is a history of family violence or if bad weather occurs and your transportation is unreliable.

Part of agency planning involves taking precautions and anticipating alternatives to providing services so staff can feel safe. The early intervention team needs to work on evaluating what constitutes a threat or a risk to service coordinators doing home visits or community outreach. Everyone needs to think clearly about what makes sense and what ensures safety. It may be the use of car phones, or working in pairs instead of individually. It could require safety and self defense training for all staff, or finding a safe space outside the family's home that can be used for meetings and therapies. Other useful steps might include a call to local law enforcement agencies to check their activity in a particular area, an inservice from them on safety, or a call to let them know you will be working in the area. Doing home visits during daylight hours may be inconvenient for some families, but it may be a sensible solution for a particular situation. These circumstances present a perfect opportunity for some group problem solving, where everyone has an investment in the outcome.

*What* we choose to do as a team needs to be framed in terms of *why* we are doing it. We need to be able to explain changes to our advisory boards, our funders, and to the families with whom we work. It is not acceptable to refuse services to someone because they live in an area you consider unsafe or unsavory. But it is totally acceptable to set up services in such a way that staff needs for safety are met. It is difficult to do a good job if we are worried about getting back and forth safely or we are concerned about how to protect ourselves.

It is equally important that we include the families' input in determining how to safely serve them. They have a vested interest in our success, and most of them cope with the environmental stress of their living situations. Part of our jobs may be to help them create or even move into a safer location, but that is a choice they need to make, we do not make it for them. Our best strategy is to obtain their assistance. They may know when there is little threat from street activity, where phones are available if not in their living unit, where the law enforcement supports are located and how they can be reached. They probably know of safe public places that could serve as meeting locations for planning or for doing therapies if their home is not an option.

Yet another aspect of personal safety has to do with who we hire and how we orient them. Economic differences between families and staff in early intervention programs can cause difficulties and misunderstandings. This is something to consider and plan for as new staff are hired and trained to work in neighborhoods that have an economic base of poverty and the often accompanying problems of crime or violence. Service coordinators need to understand their biases, value differences and personal limits when serving a broad spectrum in the community. We also need to recruit, hire, and train people from specific communities as part of outreach and intervention staff. Currently, most early intervention programs that serve low income and culturally diverse families have a staff that are largely middle-class European-American. Staff does not reflect the population being served and often those that are the most knowledgeable about how to work effectively within a particular community are people from that community. Finding people from different ethnic groups or other diverse populations, that can be hired as consultants or trained as service coordinators will enhance the effectiveness of early intervention work and minimize some of the differences that exist between professionals and families when staff do not reflect the culture of the community.

## Summary

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The heart of service coordination work begins within each of us. How well we listen to ourselves and take care of ourselves is directly proportional to how well we can do that for others. Time spent in this area is not only valuable but important to our effectiveness both on and off the job. It is everyone's responsibility to attend to personal needs, along with the more finite and tangible aspects of our work. Persisting with these efforts also requires vigilance, commitment, and a high level of awareness. The beauty of it is that when we wander off the path, get too immersed in technicalities, or forget to notice personal care issues, something usually happens to remind us. And it is seldom too late to go back and mend fences or pick up pieces and put them back together again. Staying on the path is self reinforcing in a way that helps us to feel better and be more capable about doing the work of parenting or service coordination.

## QUESTIONS FOR REFLECTION

1. In what ways are your personal or family experiences reflected in your job? In what ways are those experiences helpful and in what ways do they get in the way?
2. What ways have you found to set limits in your life? What are the areas you find especially challenging and what changes would you like to make in the next six months? (Be as specific as you can, listing situations, people, preferred outcomes).
3. If you could create the ideal support network for yourself and the people you work with, what would it look like? What piece of that could you actualize this month? This year? What kind of assistance or encouragement would you need to make that happen? Who can give it to you?

## ACTIVITIES

*Choose at least two—*

1. Become familiar with Alcohol and Other Drug self help and treatment resources in your community. Attend an AA, Alanon, or other anonymous meetings so you can knowledgeably speak to families about these resources.
2. Take the afternoon off, by yourself, to evaluate your own self-care process. Write down a list of five things that help you relieve stress and practice one of them.
3. Ask a friend to exchange time listening well without judging or interrupting. Use a timer and take 30 minutes each to share one thing that is going well for you and one place that you are having difficulty. Notice at the end of that time how you are feeling and what has changed. Agree beforehand that anything you or your partner say will be kept confidential and that you will not give each other advice or try to fix things.
4. Present a program on self-care to your staff or a group that you belong to using information from this text or other resources you have identified.
5. Make a self-care treasure box that contains the items you need to nurture yourself when things feel overwhelming. This might include bubble bath, phone numbers of a friend you can call, recipes for your favorite "comfort food" (potato soup or banana cream pie anyone?) and keep the ingredients on hand—in the freezer or pantry shelf; perhaps a particularly meaningful poem or book, or a box of crayons and some paper. Use something from this box at least once a week.

## DISCUSSION QUESTION

1. How have you and your agency addressed the issues of personal safety and self care? Are there concerns you have not yet discussed or resolved? What is the next step in that process?

## RESOURCES

### Videos:

#### *Lost Dreams and Growth —Parents' Concerns*

Available from: Resource Networks, Inc.  
1618 Orrington Avenue #210  
Evanston, IL 60210  
708-864-4522  
Cost: \$95.00 + shipping and handling

#### *Assisting Parents Through the Mourning Process*

Available from: Child Health and Developmental Educational Media (CHADEM)- #7  
5632 Van Nuys Boulevard, Suite 286  
Van Nuys, CA 91410  
818-994-0933  
Cost: \$30.00 + shipping and handling

#### *Sharing Sensitive Information with Families*

Available from: Child Health and Developmental Educational Media (CHADEM)- #7  
5632 Van Nuys Boulevard, Suite 286  
Van Nuys, CA 91410  
818-994-0933  
Cost: \$60.00 + shipping and handling

## ★ APPENDIX D

### SUPPORTING THE SERVICE COORDINATOR STRATEGIES FOR REDUCING STRESS

#### *What Can an Individual Do?*

- Recognize and acknowledge that the work you do—as a parent or a service provider —can be fun...can be rewarding...and can be very hard!
- Recognize what you can and can't influence. Strive to understand the difference and establish priorities for yourself based on this knowledge.
- Know the policies and climate in which you are working. Understand such things as:
  - How decisions get made;
  - What the Budget is;
  - What rules are attached to various funding sources;
  - Who makes budgetary decisions;
  - What supports are available; and
  - What are the prevailing values and attitudes within the program/community.
- Have a good understanding of your job description/roles and responsibilities.
- Be organized and understand the priorities for your time.
  - Become familiar with time management strategies, if you aren't already.
  - Use technology available to you in order to create more time for people.
  - Have an efficient filing/organizing system for processing paperwork and sharing resources.

- Identify an ally who will listen and support you without judging you, especially when you are hurt, angry and/or frustrated. For providers and families this may or may not be within your place of work.
- Be willing to ask for help. Acknowledge when you are dealing with situations you feel unprepared to handle alone.
- When you recognize you need a break, find your own way to take space to regroup. Some people take a walk, close their door, don't take phone calls for an hour, sit quietly, or listen to music.
- If you feel sunk and have few resources to face the moment, do something that is a complete distraction. This is a short term "band aid" and should not be used as a long term solution. Difficult situations need to be faced directly at some point.
- Maintain your vision and mission. Recognize setbacks, learn from mistakes, and build new ways of addressing stressful situations.
- If you are dealing with a situation that you feel unable to influence, be sure you have other areas in your life where you feel successful and optimistic about your efforts.
- Have a professional/personal development plan. Identify what you want to learn more about and who or what can help you achieve your goals.

### ***What Can a Program Do?***

- Build time into your staff's day/week/month to process the situations they have been dealing with. This can be done within a team (e.g., routine team meetings), with an ally, or with a small group (e.g., brown bag lunch). Be sure to honor the confidentiality of families.
- Have a process for dealing with crises—an unexpected event that can have a deep emotional impact—such as the death of a child, violence within a family, or injury/harm to a team member. This could include access to services of someone who can help with emotional crises (e.g., psychologist, social worker). This person may or may not be within a program or agency.
- Strive to create safety in your environment. Directly deal with personal safety issues. Agencies are encouraged to have guidelines for acting in real or perceived "unsafe" situations (e.g., when is it O.K. to pull out? how to get help? —911, cellular phones, how can you arrange schedules to travel in teams?, regular checks with law enforcement about their activities in a particular area and notice to them of yours).
- Know your legal responsibilities and boundaries (e.g., reporting child abuse and neglect, the complete range of early intervention services available under the law, roles and responsibilities of service coordination, procedural safeguards for families).
- Support staff attendance to workshops, classes, conferences, and meetings to get to know and network with people who have similar interests.
- ***BE FLEXIBLE!***
- ***MAINTAIN A SENSE OF HUMOR!***
- ***HAVE FUN!***
- ***FIND THE POSITIVES!***
- ***CELEBRATE ACCOMPLISHMENTS!***
- ***LAUGH!***

Developed by Pathways: Service Coordination Inservice Project, 1994. Waisman Center, Early Intervention Program. Madison, WI.



## LEADERSHIP AND CHANGE AGENT SKILLS

Leadership is not necessarily something that we consider as part of the job of service coordinator or parent. Problem solver, nurturer, organizer, chauffeur, guide, cook, teacher, therapist—the list is quite long. But the word leader does not come to mind when someone asks what we do in our jobs or our families. And yet leadership is a subtle thread that weaves its way throughout our lives, and we may find times or situations when we are called upon or volunteer for that leadership role. Many people believe that they are powerless to influence the events around them, that they cannot affect or change what is happening. It is useful to consider change in small and incremental steps. Each action we take has an influence on someone or something, and like the ripples in a pool, this influence moves out and has an impact on larger and larger circles.

Let's look first at the impact or influence you have with the families you come in contact with. You can influence how they see themselves, how they feel about their ability to support and nurture their child, and what skills and information they will gain while in the early intervention program. What they learn during the time they spend working with you and receiving early intervention services they will bring to other situations with friends, family, the public schools, and the larger community. Your influence for change with them will ripple far beyond the boundaries of your relationship.

The same is true for your contact with other service providers and the community. Your actions affect how the team functions and how you are perceived by the larger community. You influence how conflicts and different perspectives are handled. Your attitudes and actions can encourage cooperation and consensus building. The way you bring in other team members and listen to their opinions and perspectives can model and encourage respect for each person's abilities. You play a



role in establishing the environment, in building and supporting relationships where there is an openness to listening, learning, and working together. All of your actions impact on the learning and behavior of others. The changes you support or initiate may influence the behavior of these people. Again the ripples move far beyond what you can observe.

Just as the interactions you have with individuals create the possibilities for change on a one-to-one basis, your interactions in the community have an impact on that system as well. As you work with families, you will probably begin to identify the need for expanded community services and resources. You make an impact or change in the community in many ways: by taking the time to share your perceptions with others on interagency planning groups; identifying resources through directories or newsletters; and inviting community involvement. Another way service coordinators act to shape and lead the community is by providing education and information about early intervention to community citizens and policy makers. This might involve developing a news article for the local paper, appearing at the county fair or other community events, presenting an education session to the county board of supervisors, or testifying at a public hearing.



As service coordinators, we accumulate information about families and communities that may be seen by few other practitioners and this is valuable when designing systems change. As parents of children with disabilities, we can speak to certain issues better than anyone else, and in doing so, we have the power to alter the future. Yet most of us shy away from both the title and the responsibility of leader. Without the leadership of parents speaking out against injustice and inequity, the human service system might look for the most expedient low cost solution without considering the needs and desires of the consumers they are there to serve. We need to be involved. Claiming our place as leaders, recognizing ourselves as leaders, and supporting each other as leaders, is very much a part of early intervention programming.

## Styles of Leadership

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Perhaps one of the things that keeps us from perceiving ourselves and each other as leaders is that there are many different leadership styles. Some kinds of leadership are easily apparent but others may not be. We do not always notice that change is happening due to someone's special effort or their protest against an issue, and that by doing so they are leading. Leadership can mean standing up for something, and it can also mean sitting down for something. It can be voiced or it can be silent. It can be doing it yourself or empowering others. It can happen in board rooms and over the kitchen table. There are no hard and fast rules on leadership. We may be leading the parade on some issues and blocking traffic on others, but sooner or later, we usually find ourselves in that enviable and sometimes dreaded position called leader.

Charismatic leaders are familiar to most of us. The person who can speak eloquently to a crowd with confidence and enthusiasm, telling jokes or stories to make a point. These people have political savvy that may escape many of us and we tend to look at them with awe. They thrive in corporate and political offices, but are also among us less conspicuously. They serve on school boards, teach in classrooms, facilitate workshops, and campaign actively for and against all kinds of issues and causes. They claim their role as leader and have a following of support that keeps them going. Fed-

eral and state legislation in early intervention would never have happened without their voices, their thinking, their leadership.

But there are other kinds of leaders that we may not recognize quite so readily. The quiet dissent of the families who refused to let their children with disabilities be institutionalized and decided instead to take them home for care was a bold stroke of leadership. The few became the many, and along the way things began to change. Standing in front of a classroom of nursing or physical therapy students and telling a family story about what it means to be a parent of a child with exceptional needs is taking leadership by altering the perception of future professionals and the care they will offer to families. Talking with a group of parents about re-designing services, asking a day care center to build a ramp, or even baking cookies to feed the planning group contributes to leadership. Sitting quietly in the back of the hall during a community meeting, being a presence when others stay home is also being a leader.

Leadership in its broadest sense includes facilitation, guiding, giving direction, influencing, and shaping. Consider the job you do as parent or service coordinator. Are you the facilitator of IFSP meetings? Do you bring resources together across agencies? Do you help families to articulate their vision or help with team problem solving? If you answer "yes" to any of these questions, then you are already taking on the work of leadership.

## Intentional versus Spontaneous Leadership

Intentional leaders tend to approach their target or goal in a formalized way. They carefully design a program or plan that meets their objectives, they map out the potential pitfalls and difficulties and how these can be overcome, they figure out who is likely to become involved and they develop a timeline of events and activities to take them toward that goal. A good example of this process is the legislative efforts that have occurred around IDEA (Individuals with Disabilities Education Act). Several families decided that their children would not be denied full access to the educational system and they organized not just for their own

children, but for all children with disabilities. Not just for themselves but for all parents. It was a long slow process but the momentum it gathered, the vision it held forth, captured the spirits of many people, and after years of work it was successful. These families took on leadership in a systematic and persistent way.

On the other hand, some leadership comes to us spontaneously. We are having coffee with friends and someone says "I'm furious that the county wants to eliminate transportation funding for early intervention programs." Others at the table murmur their agreement and someone picks up the phone, calls the T.V. station, makes a list of people affected and sets up a community meeting to get organized. It can and does happen that fast. And things change. Either way, whether the issue is well mapped out or suddenly comes upon us, something is different because of our leadership. We may even find ourselves the "assigned leader," the person who is handed the job of representing families or positions, because of our experience or our skills. We may not have sought out such a leadership role, and it may come to us anyway. Perhaps our supervisor asks us to take the lead on an issue, or the parent group we attend insists we are the right person for a particular job. It is an opportunity to use our leadership skills, and we have the choice of accepting or declining. It is worth taking some time to consider and evaluate our own situation. Is this the time and place for us to take a leadership role? Do we have the energy, the passion, and the support to do the required task? Would we be happier, or more willing to be the ally of a leader than actually taking on this responsibility ourselves? We have choices about leadership, as we do with other parts of our lives.

## Fear and Leadership

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It seems worth mentioning that most positions of leadership have two sides. The obvious one is the glory, the fame, and the credit we may experience. The less apparent one, but the one that may keep many more of us from stepping forward, is the fear. Not everyone will agree with what we want to change, and leadership is definitely about change. Not all people will want to support our efforts and some will even choose to sabotage and undermine what we wish to accomplish. This is the challenge

and the difficulty of putting ourselves in leadership positions. Most of us want people to like us, to appreciate us, and to accept us. But changing a system that is complex and well established takes heroic measures. If we believe in the value of this work and the importance of children and families, then we can move beyond or act outside of our fear. Parents and service coordinators are often the unsung and unnoticed heroes that help to put a new face on a traditional way of doing things.

Knowing that there will be difficult times and people with whom we have differences allows us to prepare for that eventuality. Part of any plan includes what to do if the first three attempts at something do not succeed. Careful thinking about possible road blocks and how to go over, under, around, or through them will make them less ominous and threatening when they do appear. Building in time to nurture the leader, be it yourself or someone else, is part of succeeding with a plan.

## Support for Leadership

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Leadership does not occur in a vacuum. Any action we wish to accomplish requires the support of others to succeed. You may consciously take on a project because you believe in it and know in your heart it is the right thing to do, or you may find yourself suddenly propelled into the frontline because you can no longer keep silent about something. Whichever happens, people look to you for direction. If you are driven to make a change because something is very important to you, there is the likelihood that it is important to others as well. These are the people who are your allies, who will support you as you move forward. You need to know who they are and how to best make use of what they have to offer. Being in the spotlight, in front of the cameras, at the head of the crowd is hard work. You need support and encouragement to stay there. Invite others to help you and ask them to invite more people. The broader the base of your support, the more likely it is that you will succeed. If an issue needs to be addressed or policy changed within your agency, you can take it on. Find co-workers and parents who agree with you and make a plan. Believe that something can be done and empower yourself and your supporters to take ac-

tion, to make a difference. Administrators will probably be more willing to listen to a proposed change if it is well thought out and supported by staff than they will to the discontented grumblings of one or two people. There is power in numbers and it begins with the number one. The leader.

## Vision and Leadership

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In every instance of successful leadership, a vision keeps the work alive. The goal, the purpose, the possibility of what can be is the nucleus of any change effort. We live within the limitations of a social and political system that holds forth ideals of equality and justice for all. After more than 200 years of striving toward that end, we still fall short. But the vision has continued to lead us forward. The civil rights movement of the 1960s did not succeed in creating equality in economic, environmental, or political rights for African Americans, but it did shake things up. It did change some things for the better. And we live into the future guided by the vision and hope of true justice, real equality.

Working in the field of early intervention, we have a vision of what can be possible for children with disabilities and their families and we can dedicate ourselves to fulfilling that vision. We get to chip away at the marble block of what is, to revel in thinking about the beautiful sculpture that will exist in some future time. A future that finds all children receiving the medical care and the educational programming that assists them to reach their full potential. A future that finds communities creating support systems and services designed for easy accessibility to all families. A future that has no need for service coordination because we have done our jobs so well that families can function and get what they need without the advocacy, mediation, and overseeing of service coordination.

## Service Coordinator Leadership as Empowering Families

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One of the guiding principles of the service coordination vision is that of empowering parents to

do for themselves what we may currently be doing for them. As leaders we need to share our leadership with them. We have a responsibility to support them as they advocate for themselves because the world needs to hear from them directly, not always from us as we try to represent them. We need to assist them in navigating the system, so they can succeed when we are no longer available. We need to listen to their dreams and take them seriously because they hold the candle that lights our way into the future. As leaders, we need to encourage them to be faithful to themselves and their dreams, to trust the change process, to pay attention and to inspire others with their knowledge and their wisdom. We need to help them find the confidence to move on patiently and persistently, to become the change agents that are so desperately needed. We need to be sure they find each other, and build the bases of support they need to succeed. We need to trust that they can figure out what needs to be done and just who can do it. And then we need to get out of the way.

## Summary

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Leadership is a common and yet complex piece of service coordination. We need to recognize that all of us have leadership skills that take many forms. What works best for some people will not work well for others. Each of us has something to offer in the way of leadership and we can look for opportunities to see ourselves that way and to act accordingly. In the Tao of Leadership: Leadership Strategies for a New Age (1988), John Heider puts forth powerful images and new ways to think about leadership. One of the many images he shares is of the "soft and strong" leader. "Water is fluid, soft, and yielding. But water will wear away rock, which is rigid and cannot yield. As a rule, whatever is fluid, soft, and yielding will overcome whatever is rigid and hard. The wise leader knows that yielding overcomes resistances, and gentleness melts rigid defenses. The leader does not fight the force of the group's energy, but flows and yields and absorbs and lets go. If the leader were not like water, the leader would break. The ability to be soft makes the leader a leader" (p. 155).

# ACTIVITIES

## Group Activities

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### *Circles of Influence Activity—Circle of Concern (See Section I, Activity 3)*

#### *Identifying Leadership Skills*

This exercise will help a large group identify the many aspects of leadership and look individually at their own leadership skills.

Ask the large group to identify all of the qualities that they associate with effective leadership. List these on a flip chart or overhead.

Hand out the Identifying Leadership Skills form (next page) and ask participants to consider the qualities on the flip chart that apply to them. They should fill in at least 10 qualities that they have. Next they should consider in what areas of their life they make use of these skills and check these. Finally, they should identify skills they wish to improve on and areas they wish to take greater leadership and share these with one other person in the group.



## Individual Activities

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### *Questions for Reflection*

1. On which projects, causes, or issues would you like to take a leadership position, but have not yet done so? What is getting in the way of taking on a piece of that leadership? What would have to change in your life if you took that on? How would you feel if you did something? Who would support you? Who would oppose you?
2. As a parent or service coordinator, what would you most like to change about the Early Intervention system? If you could do one thing this week to move in that direction, what would you do? Do you know someone who would like to make similar changes? What would it feel like to work with this person? What would be fun about such a task? What would be difficult?

### *Field-Based Activities*

1. Sit in on a legislative hearing at the local or state level and journal your experience. What do you notice that is working with this process and what is not? What would you change about it. Write a letter to your legislator telling him what you think should be done.
2. Interview someone you know and admire in a leadership position. Ask her how she arrived at that position, what she likes about it, what has been challenging. Ask if there is something you can do to help her (consider the time and energy you have available and be prepared to practice your limit setting).

### *Self-Study Activities*

1. Create your own metaphor for leadership using pictures, drawings, poetry, photos, music (anything you want) and share it with your friends or co workers or publish it in your group's newsletter. Go ahead, take the risk. That's leadership.
2. Attend a leadership training or take a class in leadership skills.
3. Invite your friends join a support group, to work on any issue that is of interest to you and to them. (A parents support group, a service coordinators support group etc.) Take on the role of leader, organizer, facilitator. Practice your skills.

## REFERENCES

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Rees, F. (1991). How to lead work teams: Facilitator skills. San Diego, CA: Pfeifer & Co.





## SECTION IV

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# PUTTING IT ALL TOGETHER: INTEGRATING THE SKILLS AND KNOWLEDGE USED IN SERVICE COORDINATION

## INTRODUCTION

In previous sections, we explored the knowledge and skills essential to service coordination. In this section, you will have an opportunity to practice this knowledge and skills and apply them to familiar situations encountered by service coordinators every day. Enhancing family and provider partnerships will be emphasized. You will utilize a problem solving technique adapted from McWilliam and Bailey (1993) in which scenarios serve as a catalyst for discussion by depicting the "real-life" experiences of families and service coordinators. Each story is followed by discussion questions or points for reflection.

## Four Phases of Service Coordination

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There are specific responsibilities under Part H of the Individuals with Disabilities Education Act (IDEA) that define the activities of a service coordinator throughout the IFSP process. Section II of this guide incorporates these responsibilities into a framework that includes four phases of activities involved in service coordination (see Section II, Table 2). These phases reflect the type of interaction that might occur between a service coordinator and family and some potential shared responsibilities for service coordination. The first phase, *Choosing the Right Pathway: Getting Started* in the IFSP Process, includes the initial contact through the development of the IFSP. The *Journey: Providing Follow Along to Families* covers the implementation and evaluation of the IFSP process. *Detours Along the Way: Unexpected, Immediate Needs or Crises* occurs when the family or service coordinator experiences an urgent and immediate need for support and problem solving. The fourth and final phase, *Changing Pathways: Facilitating Transitions*, represents the activities and sharing of information across the interface between early intervention and a system of community supports and services for children and families.

This section uses these four phases as its foundation and includes a discussion of each phase, some activities and situations concerning the family and the service coordinator, and is followed by a short scenario depicting an aspect of that phase for you

to explore further. Each discussion concludes with a listing of additional resources for families and service coordinators. Although these lists are not meant to be comprehensive, the resources will get you started.

## The Use of Scenarios

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The scenarios in this section draw from the personal experiences of both families and service coordinators and illustrate the many issues involved in service coordination in early intervention. These accounts highlight many of the challenges that confront parents and service providers as they navigate multiple systems to locate, access, and finance services and resources for children with disabilities. Analysis of these scenarios provides:

- an opportunity to practice problem-solving and decision making;
- a basis for dialogue about real situations that may be unfamiliar or uncomfortable;
- an opportunity to critically examine and practice interpersonal skills;
- a way to ground theoretical learning into practice; and
- a forum to explore personal values and beliefs.

An opportunity to focus on one particular family situation allows us, through discussion, to pool resources and expertise to develop creative plans to address a particular situation.

## The Problem-Solving Process

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After reading each scenario, a decision-making framework (McWilliam & Bailey, 1993) is used to generate a plan of action based on the information presented. Here are the steps in the problem-solving process:

- **Identify the issue.** Identify the issue or a number of issues and agree to focus on one issue at a time. Consider the issue from the different perspectives of the people involved. Talk about whose problem it is and whether everyone perceives the same problem. While discussing the scenario, practice communication skills, such as reflective listening, by asking questions that clarify the issue. For example, "So you think the most important issue is domestic violence even though the parents have not clearly stated that. Is that right?"
- **Identify positive aspects of the situation.** Discuss the strengths that each of the players brings to the situation. For example, "It sounds like she really respects your work." What is going well?
- **Identify and discuss factors contributing to the issue.** Is there a history to the issue you want to discuss? Are there cultural beliefs or biases that contribute to peoples' perception of the issue?
- **Identify available options.** Consider a variety of alternatives for dealing with the situation. Brainstorm. Be as creative as possible. Keep the vision or outcome in mind. Ensure a range of choices even when the first solution seems like the "best" choice.
- **Choose a plan of action.** Select one alternative and develop a course of action. Be specific about resources, tasks, and who will do them. Discuss timelines for action and alternatives if the plan does not proceed as expected. "Will it work for you to try this out for two weeks and then talk again?"

Use this problem-solving process as an opportunity to try out some of the personal skills discussed in Section III, e.g., asking open-ended questions that help clarify the goal for an IFSP or good listening that leads to the resolution of a team issue. It can be helpful to generate some ground rules for discussion with your group. Here are some to keep in mind: avoid premature solutions; allow all opinions to come to the table; maintain a nonjudgemental stance; acknowledge emotional as well as factual statements.

This process can also be used by service coordinators in many other situations. Using the problem-solving framework with a program can be particularly effective. It provides an opportunity for staff with varied experiences to share their knowledge and skills with each other. This cumulative sharing can help staff share information they have learned about community resources and services while building the skills of new staff members unfamiliar with a particular community. The decision making process can facilitate the IFSP process when the family and team are identifying outcomes and strategies that will be utilized to meet these outcomes. It is also useful when working individually with families and in identifying and solving problems affecting teams, programs, or even agencies. Explore and practice using this problem-solving process whenever you want to clarify an issue and break it down into manageable parts.

## CHOOSING THE RIGHT PATHWAY: GETTING STARTED IN THE IFSP PROCESS

Often the first contact with a family is by phone after either a family member or a concerned professional has made a referral to an early intervention program. Next, a series of activities result in the development of an IFSP if a child is eligible for early intervention. Although many of these activities and their timelines are defined by law, the nuances of beginning a relationship with a family, sorting out the layers of concern that a family has, and finding the needed services and supports can be challenging. This section will provide a spring board for exploration of some of those challenges.

Getting started includes the initial contact with a family where intake information is obtained and an initial screening of a child may be performed. The service coordinator collects and reviews medical records and any other developmental reports. A formal evaluation is scheduled with the family at a mutually convenient time and the child is evaluated for eligibility in the program. If the child is ineligible, the service coordinator discusses other supports and services and may follow the child on a recheck schedule. When a child is found to be eligible for early intervention, an IFSP is written with the family. This plan reflects the outcomes the family is working toward for their child and themselves and draws upon formal and informal supports and services. The assessment process continues throughout a family's participation in early intervention, sometimes with formal IFSP reviews and often with less formal discussions between the family and its service coordinator (see Section II for more detail).

The development of a partnership with a family begins with the initial contact and subsequent activities in the getting started phase. Often the way you give information and ask questions sets the tone for a family's perception of their participation. The experience of many families has been



with systems that do not respect or value their input. Often the professional "expert" is unable to listen to the experience of the family, which may result in a plan for intervention that does not fit the family's needs. Other families may feel dehumanized by the bureaucratic nature of many systems to the point where they see no meaningful outcome from their participation.

The core of early intervention philosophy is family participation. The service coordinator must give a clear message to the family that what they want for their child will truly guide the development and implementation of the intervention plan. The challenge for a service coordinator and the team is to integrate the many pieces of information from a family into a goal or outcome and then break that outcome down into activities and strategies. Even more challenging can be reaching an understanding of what a goal really means to the family, for example, if the outcome is "I want Betsy to walk," what does "walking" mean to that family? Does the parent mean Betsy will stride confidently across the room unassisted; or does it mean Betsy will take several steps with maximum support? It is important to clarify the language that we use as different disciplines and families work collaboratively on a plan for intervention.



## Roles and Responsibilities

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Although each child and family in early intervention is entitled to a service coordinator under the law, service coordination is almost always a shared responsibility between families and their service coordinator. This responsibility changes over time as a family's comfort and knowledge of the system of supports and services evolves. Many economic, cultural, and human resource factors contribute to a family's level of participation in service coordination. The complexity of a child's disabilities and medical stability are important factors and can consume all of a family's energies. A child with disabilities affects the ability of family members to work (lack of daycare for children with disabilities, loss of job insurance when costs result in small employer dropping employee) and on the family's ability to survive and thrive.

Few families begin in early intervention with the myriad personal skills needed to meet the needs of a child. Families wear many hats, from advocate to therapist to parent to interventionist, and learn the language that goes with each one in a very short period of time. The confidence and ability to make these adjustments varies depending on circumstances at any particular time. Many factors affect how a family decides to participate in service coordination and how much they decide to do, but it is always up to the family. As the partnership between family and service coordinator evolves, the shared role of service coordination also changes.

Some families are ready to participate from the very beginning and others may have no perception of their role. The ability to participate in a partnership as well as the partnership itself are both developmental processes. Vincent (1994) describes this developmental process for families as moving from being concerned first with meeting their basic needs to being ready and able to take advantage of information. This then results in the confidence to begin to ask questions and make decisions concerning a child's care and future plans. Such a process produces families that are able to participate as partners with the professionals involved in their children's lives. A vitally important role for early intervention service coordinators is to support families in this growth toward partner-

ship in early intervention and beyond. Many of the communication skills that are helpful to this process are discussed in Section III.

## What Else is Going On?

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Getting started involves the obvious, although not easy, steps of screening, evaluation, assessment, and IFSP development as previously discussed. At the same time, both the family and service coordinator face issues that affect their ability to participate and form partnerships.

Some factors that may affect a family's ability to understand information and participate in decision making during this phase include:

- the native language and literacy level of a family
- the complexity of a child's disability and the amount of time the child's care takes, e.g., is the parent up multiple times during the night?
- the amount of new information a family is dealing with (the language of disability, medicine, and intervention)
- the number of professionals in a child's life and how you fit in (how many "goals" can a family reasonably work on; and can early intervention collaborate with other agencies to work toward these goals, e.g., feeding and nutrition problems)
- the emotional impact of having a child with disabilities on the immediate and extended family
- the family's access to their natural system of supports since having a child with disabilities, e.g., can they go to church or synagogue? Are they still able to see friends?
- the invasion of privacy and requirement of personal disclosure
- the ability of care givers to continue working, e.g., is childcare available?

- the family's cultural attitude towards disability
- the family's expectations of early intervention staff
- previous experiences with "government" agencies
- the impact of a child with disabilities on the financial well being of the family

Some of the issues a service coordinator faces during this phase that may affect her ability to establish relationships with families include:

- a high work load due to increasing referrals or changes in staff
- an inability to reconcile value differences with a family
- lack of time to become familiar with a new cultural group
- language and literacy issues
- concern about personal safety in a particular setting
- the need for interagency collaboration where multiple people are involved with one family
- lack of professional staff either with experience or availability due to program setting
- limited educational or advocacy resources for families
- a limited menu of options to meet diverse family needs
- funding constraints
- lack of training

All of these present challenges to effective service coordination and are experienced to a greater or lesser extent by all programs. You will have an

opportunity to explore some of these in the upcoming scenario.

## Scenario for Getting Started

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*Julia Graves is a teen mother of a nine month-old daughter who lives with both of her parents in their suburban home. Julia's mother takes care of her daughter Amanda during the day while she attends high school. Today, Julia has her first meeting with Alyssia Adams, the service coordinator from the Gateway Early Intervention Program. Prior to this meeting, Julia and Alyssia spoke briefly by phone. Julia is not sure what to expect from Alyssia's visit, even though she called the program herself at the urging of the school social worker. She really wanted to know more about what was going on with Amanda, but also felt frustrated because no one seemed to be listening to what she had to say. She wondered if this time would be different or more of the same. We join Julia and Alyssia in the midst of their first meeting at the home of Julia's parents.*

Julia: I try to do all the right things. I try to get to all my appointments, take care of my baby and get to school. I can't say exactly what, but I'm really concerned something is wrong with my baby. The message I get from my mom is that I don't do enough. She feels like I leave her with Amanda all the time. She says if I spent more time with Amanda, she'd be fine. The doctor doesn't think anything is wrong either. Each visit I try to tell her I'm worried about something, she tells me to wait and see. She reminds me I'm a young mom who hasn't had a lot of experience with babies. Every time I hear that I could die. I've spent hours baby sitting ever since I was 12. I practically raised our neighbors' little girl. I don't know why I'm telling you all of this. You probably don't believe me either.

Alyssia: Well, it sounds like you have some concerns, you're not sure what they are, and you feel like nobody is listening to you. I'd like to help you try to get clearer on what you're concerned about. Can you tell me more about Amanda?



Julia: What do you want me to tell you?

Alyssia: What she likes to do. How she lets you know when she needs something. How she eats and sleeps. You know... does she cry a lot? Does she let you comfort her?

Julia: How's that going to help? I've been through all of this already.

Alyssia: Give it a try. Maybe together we can put our finger on your concerns, and then possibly bring in other people who could also help. As I said on the phone and earlier today, this is a program that might be able to help you and Amanda. If Amanda is eligible for the program, we can work together to figure out what she needs.

Julia: What do you mean by eligible?

Alyssia: If Amanda shows a 25% delay in one or more areas of development or has a diagnosed condition likely to result in a disability, she is eligible for the program.

Julia: You mean we have to pin that down to get help?

Alyssia: Yes, and that's one reason I want you to tell me more about Amanda.

Julia: You asked me a lot of questions before. I'm not so sure going through all of this again will end up getting me help with Amanda, but I'll give it a try.

*Just as Julia starts to talk about Amanda, her mother comes into the room. Julia continues, but her whole demeanor changes. The flow changes and she has trouble getting out her thoughts. Those she does get out are contradicted by her mother at least twice.*

*Alyssia senses the change and is starting to feel frustrated because she was feeling like she and Julia were beginning to make progress in their conversation. She felt the seeds for a partnership were planted.*

## ACTIVITIES

### *Activity 1.*

Use the problem-solving approach outlined in the introduction to consider the next steps to take in this scenario (see Appendix A for an outline of the problem-solving framework).

### *Discussion Questions or Points for Reflection*

How would the discussion have been different if Alyssia had observed Amanda with Julia and reflected together on what they saw?

In the phone call to set up the meeting are there questions Alyssia could have asked that would give Julia options on where to meet? What are those options?

Is there other information Alyssia could obtain so Julia does not "have to go through it all again"?

Which listening skills did Alyssia use to keep the conversation moving forward in a positive direction?

Think of a "family friendly" way to discuss eligibility criterion that most teenagers would be comfortable with.

### *Activity 2.*

Use the scenario Choosing the Right Pathway, presented in Pathways for Early Intervention Service Coordination video to begin a discussion using the problem-solving framework.

## ADDITIONAL INFORMATION AND RESOURCES

Getting started is a time for the service coordinator to ask family members if they would like more information about community resources.

- Many families, for example, have found access to other families with older children with similar disabilities to be extremely helpful for some of the day-to-day coping strategies. Helping families find each other or existing local parent forums facilitates this kind of networking.
- Getting started is a time when families may struggle with financial concerns related to medical bills, loss of income due to loss of a job, reduced work hours or an inability to find childcare for their child with disabilities. Often there are local or state level resources that can address some of the financial concerns.
- Provide information about educational opportunities for families to learn more about the "systems" they will need to negotiate. Often these are available through Part H personnel preparation activities or Parent Training Information Programs (PTI).

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## THE JOURNEY: PROVIDING FOLLOW ALONG TO FAMILIES

In the follow along phase, the service coordinator often has less frequent contact with a family while other early interventionists may see a family more consistently. Typically the initial flurry of activity around entry into a program has ended and the service coordinator now needs to begin the process of monitoring and coordinating services that were put in place during the getting started phase. This is a good time to have periodic check-ins with the family and team in order to reassess goals, answer questions and incorporate new information. The service



coordinator or family member may facilitate these meetings. As families begin to look to the future for their child, they often are ready for more information about how disabilities may reshape their expectations for their child, family, and society. The family may take on more service coordination as they become more familiar with the various service delivery systems. Other families who are doing a lot of the service coordination for their child will need regular opportunities to update the service coordinator and those providing intervention. This is a time to explore and support the enhancement of the family's skills and knowledge.

## What Else is Going On?

The follow along phase can be a time for greater introspection about the long-term impact of a child's disabilities on the child and family as families begin to assimilate all the information they have received. A child's condition may become more stable, and a family may receive a diagnosis and begin to implement a plan of care and intervention. These are times when the urgency to act may be minimal and a discussion can take place about issues that have not been dealt with yet, or information that has not been shared. Some of the considerations at this time include:

- the family's struggle to develop a future vision for their child
- cyclic grief
- burnout of caregivers, particularly when a child's condition is very involved either medically or behaviorally
- the long-term financial impact of a child's disabilities
- the family's ability to cope and access formal and informal support systems
- the caregivers' management of stress

This might be a time when the service coordinator draws on skills that involve coordinating the communication between people on a child's team and facilitating meetings with those people outside of a particular early intervention program. For example: a mother may be ready to go back to work once her child's medical condition has stabilized and is now looking for child care. Finding child care and coordinating the support of the child in that setting may require collaboration between the child's early intervention team and the daycare provider. The service coordinator may find the role of facilitator challenging and may want more information about teams and the role of a facilitator on those teams. Similarly, skills in interagency collaboration may be needed. Balancing these sometimes less immediate activities with the more demanding ones related to referral timelines can be

difficult. A personal system of task management can be very helpful as a reminder when these types of ongoing check-ins are needed (Section II).

The service coordination approach used by a program affects the communications process with the family. When the service coordinator works within a program and has regular contact with a family, she can keep up with concerns or new developments in a timely way. When the service coordinator works outside the program providing intervention and has little contact with the team working with the family, it becomes more important to have frequent, planned contact with the family and team. This presents challenges, given the number of people to coordinate, particularly for families where both parents are working or where there is no access to a phone or transportation. Some of the time management strategies discussed in Section II can be helpful in developing a record keeping system that reminds you when a follow along phone call or visit is due. Let's see how some of these issues come into play in the following scenario.

## Scenario for Follow Along

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*Maria Jackson is a full time service coordinator for the Pathways Early Intervention Program. She is just initiating a phone call to James Hill, the father of a child in the program. She is calling for several reasons. First, contacting James has been on her list of calls to make for a while; and second, Lindsay Green, the early childhood teacher who makes weekly visits, asked her to call James. Lindsay told Maria that she was beginning to feel that she spent more than half of her home visits talking with James. She wasn't getting around to the special instruction interventions on James Junior's IFSP. She doesn't mind talking with James, but thought he could use some additional support. He seemed to have so much to talk about every week. Lindsay also didn't want Maria to think she was taking her job away from her.*

Maria: Hi James. This is Maria Jackson from the Pathways Early Intervention Program. I'm sorry it's taken me so long to get back to you. I just wanted to call to see how things are going. When we last met we didn't schedule another check in. We left it that I would call if I didn't hear from you in a couple of months. Also, I saw Lindsay Green yesterday and she thought it would be a good idea if I gave you a call. How are things going with James Junior?

James: Things are fine. Everything is moving along. We have our scheduled appointments at the clinic with the therapist and Lindsay comes to our home just about every week. Things are fine.....(slight pause).....listen to what James Jr. did last week! He pulled himself up to standing on the edge of the sofa. I couldn't believe it! It was great! (another pause, but no additional comments follow).

Maria: That's good news! I'm glad to hear he is making progress. It sounds like you're thrilled! What else is he up to? Is there anything else you'd like to tell me about James Jr.?

James: He has a new toy stuffed lion that he loves to cuddle with.





Maria: I bet he's really cute all cuddled up with the lion.

James: Yes, he is (pause, no additional information is forthcoming).

Maria: Is there anything I can help you with today?

James: Not that I can think of. I usually talk to Lindsay when things come up. I see her practically every week. She's very helpful. When little things do come up we talk about it.

Maria: Perhaps you'd be interested in knowing about support groups or workshops for parents?

James: I'll check with Lindsay about that too.

Maria: That's good you have someone to talk to. I'm glad Lindsay is helpful. You know you can

always contact me too; that's my role as your service coordinator.

James: Thanks, I can't think of anything (another quiet pause).

Maria: If something comes up, please feel free to call me any time. I'm usually in and out of the office meeting with families and other service providers throughout the week. If I'm not in my office, you can leave me a voice message. I check those regularly so I can get back to you right away.

James: I appreciate that. I'll keep you in mind. Like I said before, things are moving along for James Jr. and Lindsay sees us all the time.

Maria: Ok, bye. It's good to hear things are going well for you. Remember, give a call if I can help you with anything.

James: Ok, bye.



## ACTIVITIES

### *Activity 1*

Use the problem-solving approach outlined in the introduction to consider the next steps to take in this scenario (see Appendix A for an outline of the problem-solving framework). What do you hope will be the outcome from the next step you identified?

### *Discussion Questions or Points for Reflection*

Do you think James understands Maria's role as the family's service coordinator?

How might the conversation have been different if Maria offered information for James's feedback?

What might she have talked about, e.g., an educational event, a family gathering, a new resource, a community activity? Who is carrying the burden of the conversation in this scenario and what could you do to shift it?

Think about the issue of intimacy when a family is asked a question like, "Is there anything else you would like to tell me about James Jr.?" What might Maria say to help this conversation feel two-way?

What can Maria and Lindsay do to increase their communication about the family?

Who has James informally identified as the service coordinator and what options are there to respect this choice?

### *Activity 2*

Use the scenario, *The Journey*, presented in the Pathways for Early Intervention Service Coordination video, to begin a discussion using the problem-solving framework.

## ADDITIONAL INFORMATION AND RESOURCES

All families are unique and it is therefore helpful to offer each family a variety of options for obtaining information—

- Conversation, written information, videotapes, and workshops are some of the most common means of distributing information.
- Every state has a central resource directory for Part H. In Wisconsin, this is First Step.
- Sometimes developmental disability councils have loan libraries and offer training opportunities. Videotapes about many aspects of early intervention can be purchased or loaned to programs.
- Many of the disability organizations have fact sheets and resource information about specific disabilities. For example, the National Information Center for Children and Youth with Disabilities (NICHY) has information in both English and Spanish on a wide range of disability and family issues and MUMS (Mothers United for Moral Support) specializes in information concerning rare and low incident conditions and in connecting parents with other parents.

- The Internet is rapidly becoming a source of information, albeit unorganized, as many counties, states, universities, and disability groups set up information sharing for dissemination.
- There are a number of national magazines, for example *Exceptional Parent*, that are good sources of information on current issues for children and families, new equipment, the latest in assistive technology, or vacation and travel.

## ORGANIZATIONS

Beach Center on Families and Disability  
The University of Kansas  
3111 Haworth Hall  
Lawrence, Kansas 66045-7516

Mothers United For Moral Support (MUMS)  
150 Custer Court  
Green Bay, WI 54301  
(414)336-5333

Parents As Leaders  
Parent Projects  
Waisman Center-Room 227  
University of Wisconsin  
1500 Highland Ave.  
Madison, WI 53705-2280

National Information Center for Youth with  
Disabilities (NICHY)  
P.O. Box 1492  
Washington, DC 20013-1492  
1-800-999-5599

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### Video

Special Kids, Special Dads: Fathers of Children with Disabilities (1989). (Available from: The Association for the Care of Children's Health, Bethesda, MD)

## DETOURS ALONG THE WAY: UNEXPECTED, IMMEDIATE NEEDS OR CRISES

Situations that arise unexpectedly and need an immediate response or action require the same skills we have talked about already. There are elements of responding to the unexpected, however, that make it harder to see the best pathway. The unexpected can take many forms for service coordinators. It can be life threatening situations for a child, such as emergency surgery, or for the service coordinator, such as gunfire in the neighborhood you are visiting; situations that feel out of control, such as sudden and deep seated anger by a team member; it can be situations that bring to the forefront unfaced issues such as the emotional backlash by extended family towards the early interventionist; or a situation where you have no experience or reference point to begin to respond, such as marital stress in a home you are visiting.

Families raising children with disabilities experience many events that are unexpected, such as: (1) a routine visit to the doctor may result in an unanticipated diagnosis; (2) a family may lose health insurance; (3) a childcare provider may be unwilling to continue care for the child with disabilities; (4) a family member may have to cut back on work hours; or (5) a caregiver may be unable to provide care due to illness or injury. All of these unexpected events happen more often than we would like. The service coordinator may be able to offer support and resources in some cases and not in others. This is a time when service coordinators are faced with setting clear boundaries for themselves that help guide their involvement during these high stress times.

Good communication, especially listening, can be a helpful skill for service coordinators during crisis. A family is often clear about what will help in a given situation. By listening, the service coordinator can identify actions to take, such as identifying resources or expertise outside of the program, linking families to those resources, and coordinating their delivery. At other times, the service coordinator may need to just listen, ask questions, offer support and help clarify the issues. The service

coordinator can create an opportunity to focus on an issue helping the family break it down into manageable proportions. This may be an opportunity to use the problem-solving format with families.

Service coordination involves a dynamic relationship where the amount of coordination is shared by the family and service coordinator. Although the goal for service coordination is to enable a family to gradually increase participation in service coordination as they choose to, sometimes a family that has been doing a lot of the service coordination for their child may ask the service coordinator to take on more of those responsibilities while they focus on their own needs during times of stress. This is also a time to remind families how their service coordinator can be helpful.

Support during times of crisis involves both knowing how to help as well as being able to ask for help. The following suggestions may be relevant for families and service coordinators as they move through challenging situations: (See Section III, Appendix D)

- Recognize and acknowledge that the work you do can be very hard!
- Know your legal responsibilities and boundaries.
- Talk with others who have dealt with similar situations.
- Identify an ally who will listen and support you without judging you.
- Seek guidance or advice from someone you respect who has had a lot of experience.
- Build time into your day/week/month to process stressful situations.
- When you need a break, find a way to take one, even if it is only a few minutes.
- Remind yourself why you do the work you do.
- Have a vision for your child and family.

- Know the policies and agency culture you are working with and how they address crisis.
- Determine how much energy and resources you have to influence change over the crisis.
- Be organized and understand the priorities for your time.
- Attend workshops, classes, conferences, and meetings to get to know and network with people who have similar interests.
- Eat chocolate!

Think about how some of these strategies could come into play in the following scenario.

## Scenario for Responding to the Unexpected

Anita: I'm sorry this happened, Lisa. I can tell you're really upset. I know you wanted Mark to come with you to the IFSP review meeting. The meeting is three weeks away. We have some time to figure out what would be helpful. You see what happens at your end and I'll think about ways I might be able to help you.

Lisa: Yes, but I'm really worried. I don't see any way that Mark will change his mind and come to the meeting. I don't want to go by myself. I only wish he'd talk to me.

Anita: Let's see what happens. We'll talk again in two days when I make my regular visit.

Lisa: OK. See you then.

*This is the end of a telephone conversation between Lisa Bonfiglio, the mother of 1-1/2-year-old Tony, and Anita Levy, the Bonfiglio's service coordinator and occupational therapist and special instruction provider with the Pathways Early Intervention Program. Anita called to confirm a date for Tony's six month IFSP review meeting. She expected a routine call and walked into a marital disagreement. Anita was very uncomfortable and*

*didn't know what to do or what was expected of her. As soon as Lisa heard Anita's voice on the phone, she burst out crying and tried to tell Anita what had happened. Bit by bit, Lisa explained to Anita that she and her husband Mark had just had a huge fight. He left the house angry. Lisa related that Mark blew up while she was trying to tell him about the upcoming IFSP review meeting. He refused to go and said no program was going to make what was wrong with Tony go away.*

*Tony is Mark's first and only son. He and Lisa have been married for two and a half years. Lisa has a seven-year-old daughter, Madeline, from a previous marriage. Mark has worked hard to build a relationship with Madeline, but has always been aware that she is not his own daughter. He was so excited to become the parent of a son. He had great dreams about who his son would be in his life and pictured sharing many of his favorite activities. Mark had known for quite some time that Tony had some problems and seemed very positive about the help he was getting from the early intervention program. However, four weeks ago, Tony was diagnosed with a mild form of cerebral palsy. Mark didn't say much about the diagnosis. Lisa talked about being relieved to know that his problems had a name.*

*Anita's perception was that Lisa and Mark were taking the information in stride. They didn't seem overly concerned or want to talk about it. Besides, she thought it was pretty good that the diagnosis was only mild cerebral palsy. She was unprepared for the information Lisa unloaded on the phone. A number of times during the call, Anita wanted to end the conversation. She was unhappy that she had been unsuccessful in getting Mark to talk to her and that Mark's parents wouldn't have anything to do with Tony any more. She especially didn't want to hear that Mark threw one of Tony's toys across the room before he left the house. All of this added to Anita's discomfort. She felt Lisa's desperation and was overwhelmed by her expectation that she get Mark to the meeting. She was immediately relieved to be off the phone, but panicked at the thought that the situation wouldn't go away with the end of the phone call. She already had several pressing matters on her agenda. This was the week she planned to meet two newly referred families.*

## ACTIVITIES

### *Activity 1*

Use the problem-solving approach outlined in the introduction to consider the next steps to take in this scenario (see Appendix A for an outline of the problem-solving framework).

### *Discussion Questions or Points for Reflection*

Do you think the family's involvement with early intervention is increasing their stress at this time? What can Anita do to change the situation?

Where or to whom might Anita go to get support and clarification about her role in this situation?

How can Anita deal with her own emotional issues brought out by Mark and Lisa's situation?

Where else can Lisa look for the support she needs from Mark and how can Anita be of help to her?

### *Activity 2*

Use the scenario *Detours Along the Way*, presented in *Pathways in Early Intervention Service Coordination* video, to begin a discussion using the problem-solving framework.

## ADDITIONAL RESOURCES AND INFORMATION

Service coordinators should have strategies in place to respond to emotionally charged and unexpected situations.

- Outside experts can be invited to talk with program staff about how to respond to specific types of difficult situations. For example, invite local police officers to talk about strategies for personal safety, such as mobile phones, team visits, or information about what to do when illegal activities occur while on a home visit. Plan inservice training on pertinent topics, such as grieving, alcohol and drug abuse, or working with families with developmental disabilities. Often the resources for this type of information are available within the community.
- Parent-to-parent support continues to be one of the best ways for families to find new resources and strategies to deal with stressful situations. Many states have made some effort to connect parents with each other. Every state is required to have a central resource directory under Part H and this may serve as a starting point to obtain more information for connecting with parents.
- Family support programs and respite centers may also provide both resources and contact with other families.
- The Internet continues to be a growing source of contact between families.



- In some states, respite for short periods of time (one to two weeks) is also available from the institutional care system.

## ORGANIZATIONS

MUMS Newsletter. Mothers United For Moral Support.  
150 Custer Court  
Green Bay, WI 54301  
(414)336-5333

Wisconsin First Step (Central Directory)  
1(800) 642-STEP

Family Support Program  
Developmental Disabilities Office  
Division of Community Services  
1 W. Wilson St.  
Madison WI. 53707  
(608) 266-7469



## READINGS AND RESOURCES

Mitchell, L. (1994). Parent to parent support: Literature review. Institute of Life Span Studies, University of Kansas, Lawrence, KS: Beach Center on Families and Disability.

Griffiths, B., & Peterson, R. (1993). Families Forward: Health care resource guide for children with special health care needs. Madison, WI: Center for Public Representation.

Krahn, G., Thom, V., Hale, J., Williams, K. (1995). Running on Empty: A look at burnout in early intervention professionals. Infants and Young Children, 7(4), 1-11.

For a list of Parent to Parent Organizations in each state see Exceptional Parent Magazine, January 1996, Resource Directory.



## CHANGING PATHWAYS: FACILITATING TRANSITIONS

Transitions in early intervention are just the beginning of many transitions a child and family will go through. Some are relatively easy, such as the introduction of a new respite provider into a home. Others require a major planning effort with multiple systems, such as the transition from hospital to home for a child or the transition from early intervention to a public school program. Some narrowly view transition as a paperwork process. At its best, transition is a process that begins well in advance of the event. It involves information and support to families that enable them to make informed decisions for their child and helps them begin to negotiate the new system effectively. The service coordinator is often an interface between these systems. In this capacity, he can utilize a variety of planning strategies to help families.

Some of the unintended negative consequences of service coordination (see Section I) become clear during transition. Because the service coordinator has been the go between for many of the professional and interagency relationships, families may not have developed the knowledge and confidence to maintain those relationships and begin new ones. Conversely, other systems may have lost the capacity and skills to responsive to families precisely because they do not have to. They can work with the service coordinator. Service coordinators often express concern for families as they move into different programs that provide less supportive or comprehensive services. Some families fall back on the early intervention system for information and advocacy when they find barriers to their participation or a lack of knowledge about the new system and how to participate in it. It is essential that the service coordinator include the family as a full participant in these interactions and planning efforts. This will be the family's future responsibility. The greatest help is to provide modeling and an opportunity for skill building as soon as a family enters early intervention, with the goal of increased independence and capability after leaving early intervention. Transition planning is a key time to encourage and support family involvement.

Transition out of early intervention can be a stressful time for families and children. It may be the first time some families have put their child in another person's care. Others may be looking at multiple transitions during one day for children traveling between child care and school. Concerns for the child will need to be communicated and coordinated with more people. Families will need a host of ideas and skills for working with these new situations. Early intervention, with its family-centered approach to serving the needs of children with disabilities, provides an accepting, supportive culture for family participation. Parents may find themselves struggling to find a forum for participation in new programs. Some of the information or discussions that a family may find helpful during this phase are:

- What is the new program like?
- Will my child be eligible?
- What do all the terms and acronyms mean?
- What are my legal rights and responsibilities in the new system?
- What are the policies and procedures for placement in the program?
- Who can I find to trust?
- How can I get our schedules to fit with all these changes?
- Will she be all right without me?
- Will he be safe?
- How will she get there?
- Will she like it?
- How will the other children treat him?
- Who will help her?

There are many options for beginning to address some of these questions, such as the problem-solving framework used with the scenarios in this section. Visiting several potential programs that meet

the family's goals for their child can be helpful. Sometimes a visual image of a setting can allay concerns. Information on educational events a family member can attend, such as a workshop on writing an IEP, assistive technology, or parents rights and responsibilities in exceptional education can be helpful. In Wisconsin, these types of learning opportunities are available through the Department of Education, the Parent Education Project, WisTech, the Parent Projects (Waisman Center, Madison, WI), and local school districts.

Transition planning can begin as soon as a family is settled into the routine of early intervention. This is a good time to begin discussions with families about the options for a child after he turns three and to provide information about those options, such as an early childhood program in the public schools, Head Start, or a local daycare setting. As the transition approaches, a more specific transition plan can be written with the family that outlines the steps a family wants to take towards another placement, including a time line that meets legal requirements. Many service coordinators and early intervention programs develop transition guides that both the service coordinator and family use together. It often includes the timelines for addressing a family's concerns. In thinking about transition consider:

- planning in advance
- exploring all options
- preparing the family and child for separation
- helping the family learn about the new setting
- creating open lines of communication, formal and informal
- identifying supports needed for the child
- accessing educational and advocacy opportunities that increase parents' knowledge about the new system
- identifying helpful people and programs to support the child and family after transition, both within and outside of the new program

- identifying other families that can act as supports within the new setting

A transition plan for a child moving into early childhood in the public schools might include the following:

- a time line of activities
- a discussion of parent rights and roles
- an overview of special education
- the IEP process
- a glossary of terms and acronyms
- a listing of other community resources
- a letter of welcome from the receiving agency
- suggestions for preparing the child

Transition is also a time that is challenging for service coordinators. After working with a child for several years, service coordinators have many of the same concerns as parents. The following activities for programs and individual service coordinators can help this process:

- develop transition procedures your program will use
- identify allies and build relationships with people in other programs
- bring people together
- develop interagency agreements
- develop time lines that clarify steps and activities
- formalize transfer of information from all relevant professionals
- outline the process
- get organized



## A Scenario for Facilitating Transitions

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Amy and Sam Chen have two children. Their oldest child Sandy is in kindergarten in their neighborhood school. Their youngest, David, receives services from the Stepping Stones early intervention program. David has complicated needs around feeding and his care can be very intensive at times. He will be three in four months and plans for his transition to the public schools for early childhood are in process. Amy and Sam recently attended their first meeting with staff from the school district and their early intervention service coordinator, Janice O'Brian. We join Amy and Sam as they discuss what happened at the meeting.

Early intervention programs may find it helpful to enter into interagency agreements that clarify roles and streamline the testing and paperwork procedures around transition (Hadden, Fowler, Fink, & Wischnowski, 1995). For example, in Wisconsin the Department of Public Instruction (Part B) and the Wisconsin Department of Health and Social Services (Part H) developed an interagency agreement at the state level that encourages county level agencies and local school districts to develop local agreements around transition. Although not all local agencies choose to do this, the state has created a policy that encourages collaboration through formal agreements. Informal agreements and a memorandum of understanding can also be useful (see Appendix B for a summary of useful transition information).

In the final scenario you have an opportunity to discuss some of the transition suggestions given above as you apply the problem-solving process.

Amy: Was that a tough meeting! I'm so glad we've started this now. The people all seemed nice enough, but I'm so confused. Maybe by the time David turns three I'll figure out what is going on. They talked about so many things that I didn't understand. I know Janice gave us written information a couple of weeks ago and even talked to me about the purpose of today's meeting. Still, I couldn't keep track of everything. Who were all those people? They probably thought I was really out of it; I was so quiet. Besides, why do we need to go through such a big thing to get David into school? We all know he has problems and that he has gotten services since he was three months old.

Sam: Yes, I know what you mean. I was hoping for more information about when he would be in school so you can start looking for that job you want to get when he goes to school. All we heard was that the program runs mornings and afternoons four days a week. We don't know whether he'll go in the morning or afternoon or which days.

Amy: At least Janice said she'd help us find child care or a preschool program to extend his day if we need more child care. Even so, I just can't imagine someone else caring for David all day. You know as well as anybody, I spend half of my days just keeping him fed and comfortable.

Sam: Yes, it is hard to think of someone else giving David the care you do. Are you sure you want

to go back to work? I know we talked about this a lot, and that we could use the money, but....

Amy: That's a whole different conversation for another time! Not now.

Sam: O.K., another time. The other thing I didn't like hearing is that David and Sandy may or may not be in the same school. That would be terrible. It's hard enough thinking of David going off to school, especially on a bus. I'd like it a lot better if both kids were in the same school. You know how much David lights up when Sandy's around, and how Sandy looks out for him.

Amy: Yes, I thought about that too. It never occurred to me they wouldn't be in the same school. There's so much I don't get. I didn't know this transition would be so complicated. Why does it feel so hard?

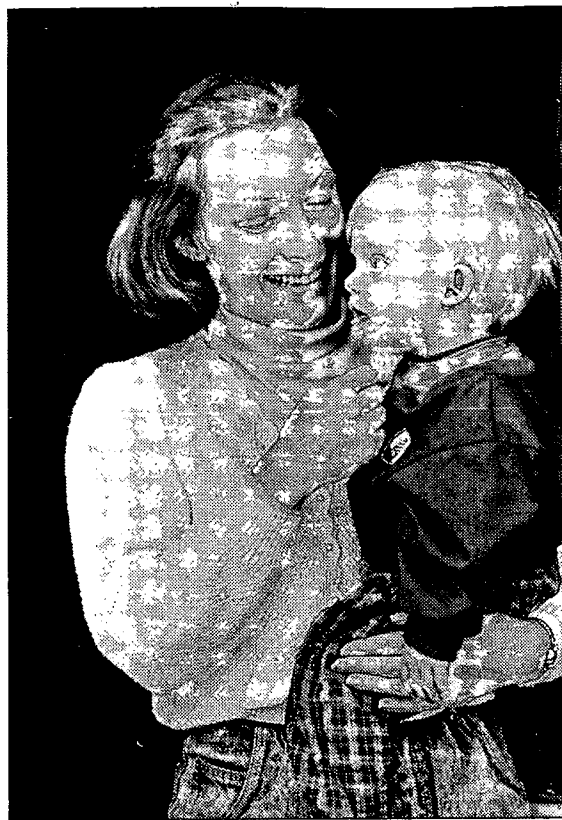
Sam: So what are we going to do?

Amy: I don't know. Maybe we need time and more information. It sounds like we don't have to decide anything for a while, but we both know how quickly three or four months can pass. I didn't get a chance to talk with Janice after the meeting. Maybe she can help us sort things out and give us more information before the next meeting with school people.

Sam: I know school is the place for David to get help and I want to make sure we get things worked out right for him. Starting with Janice sounds like as good a place as any. Are you going to call her?

Amy: Sure. I'm home tomorrow with David, as usual.

Janice also left the meeting feeling uncomfortable. She couldn't figure out why Sam and Amy were so quiet. They are usually much more talkative. She thought she had prepared them for the meeting. She gave them the program's transition booklet and talked with Amy about what was going to happen. She asked her if she had any questions and did not get any. Maybe they did not read the materials or could not make sense of them. Why didn't they ask. Janice also wondered if there was something specific that happened to make the meeting so stress-



ful for them. She hadn't talked to Amy or Sam since the meeting and decided she'd better call. Maybe she can find out what happened and do something before the next meeting. Janice barely had a chance to write "Call Amy and Mark" on her "To Do List" when Amy called her.

Janice: I'm so glad you called me. I've been thinking about you. I had a feeling something happened at the transition meeting, but I don't know what. What's going on?

Amy relates her concerns about what the transition may mean for her family. Janice listens and responds as follows:

Janice: I'm sorry this has been so hard for you. Perhaps I can talk to someone at the school to get more information and share your concerns. Do you and Mark want to be part of that discussion? Maybe that will help us get back on track for the next meeting. Maybe we can talk some more before that.

Amy: Do you think any of this will help?

Janice: It's always helpful to get more information to understand what we're working with.



## ACTIVITIES

### *Activity 1*

This conversation gives us an idea about the impact transitions can have on a family. Use the problem-solving approach outlined in the introduction to consider the next steps to take in this scenario (see Appendix A for an outline of the problem-solving framework).

### *Discussion Questions or Points for Reflection*

How might transition information be presented to families in a way that reduces the confusion and bureaucracy of the process?

Think of some ways you might explain the roles of the school and staff involved in transition in a person friendly way.

Where can you direct Amy and Sam to get more information about early childhood special education?

How might you help Sam and Amy find other parents to talk to who have been through transition or are currently dealing with similar issues?

What other options are available to Sam and Amy? Develop a plan for evaluating these options.

Families have very legitimate concerns about changing service systems and its impact on their child. Generate a list of benefits to the child and family of transition.

### *Activity 2*

Use the scenario, Changing Pathways, presented in Pathways in Early Intervention Service Coordination video, to begin a discussion using the problem-solving framework.

## ORGANIZATIONS

The Parent Education Project of Wisconsin (PEP)  
2192 S. 60th St.  
West Allis, WI 53219  
1-800-231-8382

WISTECH  
Assistive Technology Information Network  
2917 International La.  
P.O. Box 7852  
Madison, WI 53707  
608-243-5676

Parent Projects  
Waisman Center-Room 231  
University of Wisconsin  
1500 Highland Ave.  
Madison, WI 53705-2280

## READINGS AND RESOURCES

Catlett, C., & Winton, P. (1995). Resource Guide: Selected early intervention training materials. University of North Carolina, Chapel Hill: Frank Porter Graham Child Development Center.

Rosenkoetter, S., Hains, A., & Fowler, S. (1994). Bridging early services for children with special needs and their families. Baltimore, MD: Paul H. Brooks Publishing Co.

The National Information Center for Youth with Disabilities. A parent's guide: Accessing programs for infants, toddlers, and preschoolers with disabilities. Washington, DC: Author.

Step ahead at age 3: A guide for families in Wisconsin (1995). (Available from Wisconsin's Birth to Three Program (608)266-8276 or Bridging Early Services Transition Project Outreach (316)241-7754)

Lusk, L. (1996). Assistive technology and the IEP [Manual]. (Available from WISTECH, Assistive Technology Information Network, 2917 International La., P.O. Box 7852, Madison, WI 53707).

### **Video:**

Partners in the process. Identifying children with exceptional education needs: A video and workbook for family members. ( Available from Appleton Area School District, Twin Willows Early childhood Center, 3335 N. Lynndale Dr., Appleton, WI 54915).  
1-414-832-6214.

## REFERENCES

Hadden, S., Fowler, S., Fink, D., & Wischnowski, M. (1995). Writing an interagency agreement on transition: A practical guide. University of Illinois at Urbana-Champaign: Family and Child Transitions into Least Restrictive Environments.

McWilliam, P. J., & Bailey D. (1993). Working together with children and families: Case studies in early intervention. Baltimore, MD: Paul H. Brooks Publishing Co.

Vincent, L. (1994). Keynote address to Midwest Consortium for Faculty Development, June 17-20, 1994, Minneapolis, MN.



## SECTION IV: APPENDICES

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■ *Handouts (indicated by a ☺) are inserted in this section, as well as in a pocket in the back of this book.*

## ★ APPENDIX A

# THE PROBLEM-SOLVING FRAMEWORK

### *Identify the Issue*

- Is it one issue or a number of issues?
- Does everyone involved see the same issue?

### *Identify Positive Aspects of the Issue*

- What strengths are there in the family in the provider, in the team?
- Acknowledge and build on these strengths in your discussion and planning.

### *Identify Factors That Might Have Led to This Issue*

- Collect more information to better understand the issue.
- What occurred in the past or present that might keep you from achieving a desirable outcome?

### *Identify Available Options*

- Don't look for solutions too quickly.
- Tap the creativity in the group to generate possible options.
- Look at all the alternatives. Sometimes other options become fall back strategies if the first option does not work.
- This is a good practice in early intervention planning where families need to be aware of choices and options.

### *Decide on a Course of Action*

- What will you do?
- Who will do what by when?
- What are your next steps?

## ★ APPENDIX B TRANSITION ISSUES AND STRATEGIES

### ***FAMILIES CONCERNS ABOUT TRANSITIONS***

#### ***Information***

What is the new system like?

What do all the terms and acronyms mean?

What are my legal rights and responsibilities under the new system?

What are the policies and procedures for placement in the new program?

Will my child be eligible?

#### ***Emotional***

Can I trust them?

How can I get our schedule to fit with all these changes?

Will she be all right without me?

Will she be safe?

How will she get there?

Will she like it?

How will other children treat him?

Who will help her?

### ***WHAT HELPS FAMILIES DURING TRANSITION***

Plan in advance

Explore all options

Prepare self and child for separation

Learn about the new setting, make a personal contact

Create open lines of communication, formal and informal

Identify supports needed for child

Access educational opportunities

Identify helpful people and programs both within and outside school to support the child and family after transition

Identify other families

### ***WHAT HELPS PROGRAMS***

Develop a transition plan

Identify allies and build a relationship with new system

Bring people together

Develop interagency agreements

Develop time lines that clarify steps and activities

Formalize transfer of information from all relevant professionals

Outline the process

Get organized

# HANDOUTS & OVERHEADS

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*The Seven Service Coordination Responsibilities*  
*Beyond the Law: Service Coordination as Systems Change Agent*  
*Challenges Facing Early Intervention Service Coordination*  
*Proceed with Caution*  
*At Risk for Medical Debt*  
*Building Parent-Professional Partnerships*  
*Tips for Planning and Running a Meeting*  
*Ways to Move a Meeting Along*  
*Techniques for Encouraging Participation in Meetings*  
*Techniques to Try when Teams Get Stuck*  
*Tools for Determining Parents' Concerns, Priorities and Resources*  
*Guidelines for Collaboration*  
*Personal Behaviors and Attitudes that Facilitate Collaboration*  
*Where do You Stand*  
*Characteristics of Good Listening*  
*Roadblocks to Listening*  
*Considerations for Delivering Sensitive Information*  
*Supporting the Service Coordinator*  
*Identifying Leadership Skills*  
*Scenario for Getting Started*  
*Scenario for Follow Along*  
*Scenario for Responding to the Unexpected*  
*Scenario for Facilitating Transitions*  
*The Problem-Solving Framework*  
*Families Concerns about Transitions*  
*What Helps Families During Transitions*  
*What Helps Programs During Transitions*

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# THE SEVEN SERVICE COORDINATION RESPONSIBILITIES

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1. Coordinating the performance of evaluations and assessments;
2. Facilitating and participating in the development, review, and evaluation of Individual Family Service Plans;
3. Assisting families in identifying available service providers;
4. Coordinating and monitoring the delivery of available services;
5. Informing families of advocacy services;
6. Coordinating with medical and health providers; and
7. Facilitating the development of a transition plan to preschool services, if appropriate.



# BEYOND THE LAW: SERVICE COORDINATOR AS SYSTEMS CHANGE AGENT

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Ways that service coordinators can work to make the system more accessible and "user friendly" to families of children with disabilities:

- organize parent support, advocacy, or networking groups;
- identify gaps or areas of duplication within the system;
- serve on interagency task forces to help integrate the service system's procedures and materials (e.g., consumer satisfaction surveys);
- reduce the number of forms families must complete and questions they must answer (e.g., by simplifying eligibility criteria or by using common referral and intake forms); and
- participate in training on partnerships between families and service providers, communication skills, health care financing, and other areas related to service coordination.

*(Whitehead, 1996)*

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# CHALLENGES FACING EARLY INTERVENTION SERVICE COORDINATION

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- Is service coordination a long-term solution or a short-term band-aid?
- How will service coordinators provide quality service coordination to each family when they are responsible for many, many families?
- How will service coordinators operate on a proactive basis, rather than a respond-to-crisis basis?
- How will service coordinators keep updated on the frequent changes in health care program covered services or eligibility requirements?
- How will service coordinators share with parents the service coordination skills necessary to maneuver in the system?
- How will service coordinators acknowledge and respect parents who choose to do co-service coordination or parents who choose to do the service coordination on their own?

*(Whitehead, 1996)*

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# PROCEED WITH CAUTION

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Beverly is a single parent with two children—Jeffery who is 14 months and Amanda who is three years old. Beverly has been separated from Ed for four months now. Police were called twice for domestic trouble between the parents before the separation. Beverly chose not to press any charges. Ed still lives in town and calls or tries to visit periodically. Beverly has contemplated a restraining order. She has expressed concern about her and the children's safety both at home and in the neighborhood, where gang activity occurs.

Jeffery was referred to early intervention by the public health nurse (who was following him due to failure to thrive) for significant developmental delays primarily in social and motor skills. He does not make eye contact or engage others. He is extremely irritable and cries much of the time and does not sleep through the night. His lack of weight gain continues to be Beverly's primary concern. One incidence was reported of a broken arm that was not completely explained. Child protective services have been following the family and some staff have voiced concerns that the broken arm may have occurred during a fight between Beverly and Ed.

Beverly is a very caring mother. She is gentle and attentive with her children and

appropriate with discipline. She finds it very difficult to pull everything together and do what needs to be done to access the resources she needs. She either postpones making calls or filling in forms or just forgets to keep appointments when other concerns come up. Beverly has expressed considerable frustration with the number of people and agencies involved with her family and the duplication of paperwork. She gets along well with her early intervention service coordinator, and has asked the coordinator to help simplify communication between agencies. She is now on Aid For Dependent Children (AFDC), but has not availed herself of Women Infants and Children (WIC) and other possible benefits, such as Supplemental Security Income (SSI).

Early intervention staff are becoming concerned about going into the home and need some guidance about what to do if the father shows up while they are there. They have also expressed frustration in coordinating home visits with early intervention staff, the occupational therapist and the public health nurse on issues related to feeding and nutrition.

One week ago, the landlord threatened to evict Beverly and the two children because they have fallen two months behind in rent payments.

## AT RISK FOR MEDICAL DEBT

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Joan and Arlan Tauber have three children—Molly is nine, Jan is six, and Craig is 12 months old. Craig, the youngest, was born nine weeks prematurely (adjusted age approximately 10 months) and has special health care and developmental needs. He has chronic lung disease and spent the first three months of his life in a Neonatal Intensive Care Unit (NICU). As a result of these conditions, he has had three hospitalizations due to pneumonia and related complications in the first six months he was home from the NICU. In addition, he has difficulty eating and thus getting adequate nutrition. His muscle tone fluctuates and at 12 months he is beginning to sit up with assistance. For the past two months, his health has been relatively stable and he has been at home on oxygen, receiving services from the county's early intervention program and periodic visits from a respiratory therapist. However, he just returned to the pediatric intensive care unit with pneumonia.

Joan and Arlan are very concerned about how they will keep up with all the expenses of supporting Craig at home and also paying off past and current hospitalization bills. So far most past medical expenses were covered through their family's health insurance. However, Arlan has heard rumors that the small business where he works is concerned about the high cost of Craig's insurance. He fears he will either lose his job or his health insurance. Joan has given up her teaching job to care for Craig, either at home or in the hospital.

Joan has generally been coping, but every now and then has expressed that she is somewhat overwhelmed, especially during hospitalizations and when she doesn't sleep well. Craig hasn't slept through the night since birth. Recently she mentioned that she and Arlan could use an evening out. Joan feels isolated from the community and her teaching friends who have come by less and less often.

Craig has four physician specialists and a local physician. Through the county's early intervention program, Craig and his family are receiving service coordination from a new, full time service coordinator with a social services background. Craig now receives special education and occupational therapy services at home. Craig has also been to a feeding clinic to ascertain why he is having eating difficulties. Right before this recent hospitalization, Joan and Arlan had asked for more intensive/frequent motor services because of their concerns about his motor development.

Now that Craig is in the hospital again, his family feels considerable stress. Joan has called her early intervention service coordinator to let her know Craig is in the hospital again and to express her concerns about "holding it all together," especially making ends meet due to all the expenses involved in Craig's care.

# BUILDING PARENT-PROFESSIONAL PARTNERSHIPS

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## *Before evaluation and assessment*

- Obtain parents' consent in writing prior to initial evaluation and assessment.
- Explain the process and procedural safeguards.
- Ask whether an interpreter is needed if the family's first language is not English.
- Offer suggestions to the family about how they might prepare for assessment.
- Determine a location for evaluation and assessment. If the evaluation and assessment will be center-based, discuss things to bring (e.g., toys, clothes, snacks).
- Discuss time options (i.e., options that are best for child and family).
- Discuss possible roles for the family and determine how they want to participate.
- Ask parents to think about goals, desired outcomes, and dreams. (The McGill Action Planning System [Forest & Lusthaus, 1990] is an example of a process that can assist parents in preparing for the evaluation and assessment.)
- Ask parents to fill out preassessment surveys in their areas of concern.
- Ask parents if they want others (e.g., advocates, friends, relatives) involved in the evaluation and assessment process or during meetings.
- Ask parents if there are other settings in which their child should be observed.
- Ask parents to describe their child's preferences regarding materials (e.g., toys, snacks).
- Ask parents how they think their child's best behaviors might be elicited ( e.g., structuring the environment, presenting toys, assigning motor and visual tasks).
- Elicit parents' concerns and preferences.
- Discuss who will be involved in evaluation and assessment and why.
- Ask parents if siblings will attend evaluation and assessment meetings and whether they would like child care to be arranged.
- If parents ask questions to which the professional does not have answers, explain how the evaluation and assessment might answer the questions or that answers may otherwise be available from other sources. Be aware, however, to acknowledge that answers sometimes are not known.
- Encourage parents to ask specific questions about their child's development.
- Explain to parents that discussions can occur in a variety of settings and that information can be gathered using a variety of methods.

## *During evaluation and assessment*

- Respect parents' preferences concerning times, locations, and desired levels of participation.
- Discuss the evaluation and assessment protocol and how it addresses the parent's concerns.

*over—*

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- Explain tests, instruments, and methods as they are presented.
- Ask parents if the child's behavior is typical.
- Before administering a standardized test, explain the parent's roles to maintain standardization.
- Encourage parents to ask questions.
- Ask parents if the child's behavior indicates that a change in tasks or a break is needed.
- If jargon and acronyms are used, explain their meaning.
- Use person-first language (e.g., refer to a child with Down syndrome rather than a Down syndrome child).

### ***After evaluation and assessment***

- Invite and encourage parents to speak first, ask questions, and make comments.
- Ask parents whether they feel that the evaluation and assessment process was valid. If they do not think that it was valid, find out why. Ask what was not observed or elicited.
- Provide immediate feedback regarding the evaluation and assessment to the maximum extent possible.
- Focus on a family's resources rather than deficits.
- Address parents' concerns clearly, even if all their questions were not answered.
- Ask parents how they would like to receive feedback and organize staffing (e.g., one person talks and others offer support or answer questions). Find out the level of detail (e.g., test scores, standard scores, age equivalencies) that the parents would like.
- Use visual and/or graphic tools, not just words, to present information.
- Do not use jargon without explaining it.
- Write reports using person-first language.
- Have a circle of support rather than traditional staffing.
- Ask parents about next steps. Ask if and when they would like to meet with either the team as a whole or specific team members to follow up on issues that have not been resolved.
- Ask parents if they have additional questions. Find out if there were things discussed that were not clear or that do not accurately reflect their child as they see him or her.
- Discuss with parents when they will receive written reports.
- Provide the parents with one or two concrete suggestions regarding their concerns.

*From Rosin, P. (1996). The individualized family service plan. In Rosin, P., Whitehead, A. D., Tuchman, L. I., Jesien, G. S., Begun, A. L., & Irwin, L. (1996). Partnerships in family-centered care: A guide to collaborative early intervention. Baltimore, MD: Paul H. Brookes Publishing Co.; reprinted by permission.*

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# TIPS FOR PLANNING AND RUNNING A MEETING

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## *Preplanning*

1. Plan the meeting carefully.

### **What?**

- do you want to accomplish at this meeting or series of meetings? Why?
- roles and responsibilities will individuals have?
- materials need to be prepared (e.g., agenda, minutes of prior meetings, reports)?
- decision-making process will be used?

### **Who?**

- should be there?
- should be represented?
- will facilitate the meeting?
- will have power and authority to make decisions?
- will present?
- will take notes?
- will prepare materials?
- will notify participants?
- will reserve meeting space?

### **When?**

- will the meeting be held?
- will the agenda go out?
- will participants be notified?

### **Where?**

- will the meeting be held?

### **How?**

- will records be kept?
  - will decisions be made?
2. Notify participants of the meeting.
  3. Prepare and send out an agenda in advance (if appropriate).
  4. Arrive early to set up the meeting room.

## *Running the meeting: The beginning*

1. Start on time.
2. Have participants introduce themselves, consider including a warm up activity.
3. Pass out materials.
4. Review, revise and order the agenda.
5. Discuss time limits and set if appropriate.
6. Review activities of previous meeting(s).

## *Running the meeting: The middle*

1. Focus discussion on agenda item(s).
2. Move the group towards action/decisions.
3. Allow participants to be heard.
4. Respond to stresses as they occur.
5. Monitor the time and take a break, if needed.

## *Running the meeting: The end*

1. Establish future actions (who, what, when).
2. Review groups decisions and actions. Prepare a "to do" list.
3. Set the date and place for the next meeting.
4. End on time, bringing closure to activity.
5. Clean up the room.

## *Follow Up*

1. Prepare minutes if appropriate.
2. Follow up on "to do" list.
3. Begin to plan for the next meeting.

*From Tuchman, L.J. (1996). Team dynamics and communication. In P. Rosin, A.D. Whitehead, L.J. Tuchman, G.S. Jesien, A.L. Begun, & L. Irwin, Partnerships in family-centered care: A guide to collaborative early intervention, Baltimore, MD: Brookes Publishing Co.; reprinted by permission.*

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# WAYS TO MOVE A MEETING ALONG

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## ***BEFORE A MEETING***

- Do a team self assessment
- Develop a team plan to address self-assessment
- Have in place a decision-making process

## ***STARTING A MEETING***

- If the team meets on an ongoing basis, make sure to set ground rules about starting times (e.g., within five minutes, plan to start without those present unless there are extenuating circumstances)
- If your team needs time to evaluate personal or work issues, consider building it into the agenda
- If the team has new members, make sure to introduce them and take time to share information about roles on the team. You might share a personal interest.

## ***DURING A MEETING***

- State the obvious. If the team's discussion has become too general, ask how the discussion relates to the specific issue and visa versa.
- If important issues arise that are not related to the issue at hand, acknowledge it. Make a notation and plan to address it at another time.
- If the team appears confused, acknowledge it. Summarize what you are hearing and try to get clarification. Write down the points, since it may be difficult to keep them all in mind.
- If someone talks too much or not enough, use facilitation techniques.

## ***AFTER A MEETING***

- Evaluate the meeting from all team members' perspectives
- Follow-up on any team issues

# TECHNIQUES FOR ENCOURAGING PARTICIPATION IN MEETINGS

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*Consider what you say, what you do, how you structure the meeting and the physical set up of the room.*

## **Verbal Techniques:**

- Ask open-ended questions
- Phrase requests to encourage more responses
- Acknowledge and positively respond to contributions made
- Ask for more specifics or examples
- Redirect questions or comments to parents
- Encourage nonvocal parents
- Ask for and encourage different points of view
- Paraphrase for clarity and understanding
- Refer to contributions parents have made
- As a facilitator avoid stating your opinion or interjecting your ideas first
- Summarize and check for confirmation on your interpretation

## **Nonverbal Techniques:**

- Attentiveness
- Voice and facial expressions
- Silence
- Movement and position in the room

*Share information (before, during and after meetings)*

*Make sure roles are clear*

*Use a common vocabulary*

# TECHNIQUES TO TRY WHEN THE TEAM GETS STUCK

## CREATIVE PROBLEM SOLVING

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Use a series of phases that include divergent thinking to generate new ideas and possibilities and convergent thinking in which the "ideas" are selected, synthesized, and refined. Attempt to reach a balance between these creative and critical phases.

Break assumptions—What if this didn't happen? What if this did happen?

Take a new perspective—"Experience the other side"

Use forced relationships—How is this issue like a waterfall?

Think of unusual combinations/associations

Generate lots of ideas—go for quantity not quality

Think about what helps you to be creative

Ask "what if..."

Reverse the process—Look at the outcome you want and work backwards to the purpose, goals, or objectives.

Force yourself to think of as many alternatives as possible

Take on different roles

Use all your senses

Define your goal in different ways

Break the problem into subproblems—"salami technique"

Hitchhike on others ideas—build onto others' ideas

Use idea-spurring questions and words (substitute, combine, rearrange, modify, adapt, eliminate, etc.)

Try using a matrix with the problem, criteria, evaluation, etc.

Use mind mapping—a method of graphically depicting the issue

Brainstorming—set ground rules, i.e., allow no negative reactions or evaluative comments, defer judgement, welcome free wheeling, emphasize quantity, set a short time limit (3 to 5 minutes), assign a recorder

Round robin—everyone in the group gets an opportunity to add to the discussion but may pass. The round continues until everyone passes.

Clustering of ideas after brainstorming. Ask the group to put together those ideas that are related. Mark those that are related with a colored marker, then label those ideas you have grouped with an appropriate title.

Prioritizing—after the group has generated a list of goals or ideas. Pair a letter with each goal/idea. Ask the group which of them has the highest priority. Give everyone three cards and have them list the letter associated with their top three priorities. Collect and tally the priorities. Take the top three to five priorities and discuss them again. Reach consensus on the top three.

Open space agenda setting—define the issue and question to be addressed. The group then responds to the question by writing down any related ideas on large pieces of paper. Everyone can see what has been written and can respond or build on others' ideas. This occurs in silence. Then cluster ideas into groups and label the group. The group then discusses each topic that is contained within a group and prioritizes the topics using a decision-making process.

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# TOOLS FOR DETERMINING PARENTS' CONCERNS, PRIORITIES AND RESOURCES

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## *Verbal Interactions*

- Interviews—following a predetermined format or style (e.g., Family Assessment Interview Guide [Turnbull & Turnbull, 1986])
- Conversations—having face-to-face informal contacts or making telephone calls
- Brainstorming—generating many ideas about a topic
- Stories and anecdotes—sharing meaningful occurrences
- Parent-to-parent contact—learn from others' experience

## *Written Instruments*

Checklists—informal menus of services (e.g., program developing its own checklist or adapting an existing one)

Scales—priority ratings of needs for a family (e.g., the Family Needs Scale [Dunst, Cooper, Weeldreyer, Snyder, & Chase, 1988])

Surveys—(e.g., the Family Needs Survey [Bailey & Simeonsson, 1990] and the Parent Needs Survey [Seligman & Benjamin Darling, 1989])

Questionnaires—lists of questions to be answered by the family (e.g., How Can We Help? [Child Development Resources, 1988])

## *Graphic Instruments*

Videotapes, artwork, and photo albums

Guided team strategies (e.g., McGill Action Planning System [Forest & Lusthaus, 1989], personal futures planning [McGonigel et al., 1991]).

*From Rosin, P. (1996). The individualized family service plan. In Rosin, P., Whitehead, A. D., Tuchman, L. I., Jesien, G. S., Begun, A. L., & Irwin, L. (1996). Partnerships in family-centered care: A guide to collaborative early intervention. Baltimore, MD: Paul H. Brookes Publishing Co.; reprinted by permission.*

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# GUIDELINES FOR COLLABORATION

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***Establish a shared goal or vision.*** Motivation will be based on this vision, so this may be the most important principle of collaboration.

***Involve all key players in the development of the activity.*** Be sure to include those who could contribute or who could potentially pose barriers, as well as representatives of all those who may be affected.

***Be realistic.*** Cooperation may be a first step to developing a trusting relationship before true collaboration can take place. Take a developmental approach; use today's successes to build closer working relationships.

***Agree to disagree on steps in the process.*** Perfect agreement on everything is neither possible nor necessary. Collaboration involves give and take on many of the specifics. Each party needs to be willing to give in, at times, to the needs of others.

***Make realistic commitments.*** "Under-promise and over-produce" is a good strategy, especially when participants have experienced previous failures or frustrations. One small success is often preferable to a dozen stalled attempts at major change.

***Keep the goals and vision clear.*** This is especially important when the effort gets bogged down in administrative details or obstructive regulations. Keeping the larger vision in the forefront can help sweep away minor problems, freeing energy for the important but difficult issues.

***Build ownership at all levels.*** Although time consuming, developing and maintaining good communication with all parties involved will maintain a broad base of support.

***Publicize success.*** Successes can build momentum for larger systematic changes in programs and agencies. Disseminating information about successful changes can encourage other organizations to undertake similar processes or to join in community-wide efforts.

*(Jesien, 1996)*

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# PERSONAL BEHAVIORS AND ATTITUDES THAT FACILITATE COLLABORATION

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The heart of collaboration consists of individuals working together. Regardless of the larger context, each of us can either foster or hinder collaboration in our day-to-day contacts with other people. These are some suggestions to consider in working with families and other service providers:

Be willing to listen to and understand the needs, goals, and procedures of others.

Respect the operating procedures of other individuals and organizations.

Keep the goal in mind.

Be flexible enough to accept numerous paths to the goal.

Be willing to let go of some decision-making power.

Be the first to offer to share a resource, assist in an activity, or try a different way.

Let someone else take the lead in carrying out an activity.

Give others the credit for having accomplished an objective or achieved a success.

Reach out to a counterpart in another agency. Invite him to participate in an upcoming activity or planning effort.

*(Jesien, 1996)*

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# WHERE DO YOU STAND

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Please read each statement carefully and decide whether you agree or disagree with it, then mark your response in the left margin by putting an (A) for agree, or (D) for disagree in the space provided. You will have an opportunity to discuss your choices later. There are no right or wrong answers, just your answers.

1. Families who don't keep appointments that are scheduled with therapists should be give warning and then dropped from the schedule.
2. The service coordinator or therapist should not be expected to go into a neighborhood or area that is considered "unsafe."
3. If parents do not speak English, the service coordinator should be trained to understand their culture and learn their language.
4. Parents are the best teachers of young children and should be interested and willing to learn how to do therapies at home.
5. When working with families from a different culture, agencies should make every possible effort to hire a service coordinator and other staff from that culture.
6. Most families need outside help and support in coming to terms with a disability diagnosis for their child.
7. National Health Insurance is the best way to be sure that all families that need services receive them.
8. Families who are suspected of drug or child abuse should be reported to Child Protective Services immediately.
9. Children who have severe and multiple disabilities deserve to have specialized school facilities and not be expected to attend public school.
10. Families who use a faith healer or homeopathic remedies are not taking their children's health care issues seriously.
11. Bussing preschool children long distances for services is a form of child abuse and should not be tolerated by early intervention programs.
12. More and more children are born with severe disabilities every year and prenatal care should be legally mandated as a means of prevention.

# CHARACTERISTICS OF GOOD LISTENING

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- Give the other an opportunity to talk.
- Establish an environment where the other person feels comfortable speaking.
- Demonstrate interest by asking appropriate questions.
- Lead the other to talk.
- Show interest through your body language.
- Attend to the content, not just the delivery of the message.
- Listen to the complete message.
- Deal effectively with emotionally charge language.
- Listen for the main idea.
- Deal effectively with others' listening roadblocks.
- Identify areas of common experience and agreement.
- Practice listening.

*(Adapted from Wolfe, Petty & Mc Nellis 1990)*

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# ROADBLOCKS TO LISTENING

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- **Comparing:** what the speaker says to him or herself or to others.
- **Rehearsing:** what you will say in response to the speaker.
- **Mind reading:** what the speaker is really feeling or thinking.
- **Judging:** the merits of what the speaker says or how it is said.
- **Identifying:** what the speaker says with your own experience.
- **Advising:** the speaker and providing solutions without being asked.
- **Diverting:** the speaker by changing the subject, distracting him or her from the topic.
- **Being right:** in your position or idea, leaving no room for listening to the other's perspective.
- **Placating:** the speaker by agreeing with him or her without being involved in what is said.

*(Adapted from Wolfe, Petty, & McNellis, 1990)*

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# CONSIDERATIONS FOR DELIVERING SENSITIVE INFORMATION

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1. Provide a comfortable environment.
2. Tell the parents together if possible. When one parent has to tell the other misunderstanding and confusion can be the result.
3. Be aware of the readiness level of the parent to receive the information.
4. More information may be communicated through non-verbal cues than by what is said.
5. Try to have some sense of what the diagnosis means to the parents.
6. Try to keep the information simple and basic.
7. Try to communicate a sense of being calm and composed. Try not to communicate feelings hastily. Allow time for questions from the parent.
8. When delivering bad news, it is best not to give the heaviest information at the first visit. The rapport established during the intake (initial) interview will be helpful.
9. It is not necessary to argue with denial. Denial may be part of the process in the parent adjusting to a disability.
10. Try to be honest and straight without being brutal.
11. Avoid jargon, whenever possible.
12. Be accepting of parents' reactions.
13. Be aware of one's own need for power and control in the conference or situation.
14. Depending upon the degree of difficulty expected, allow sufficient time for information to be communicated.
15. Be open to new information from parents, who are often the best gatherers of information about their child.
16. Be aware that parents may not process all the information given them.
17. Speak to possibilities, not the negative things that may happen.

*(Adapted from The Parent Center, Albuquerque Public Schools, from a talk by Joan Guntzelman)*

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# SUPPORTING THE SERVICE COORDINATOR

## STRATEGIES FOR REDUCING STRESS

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### *What Can an Individual Do?*

- Recognize and acknowledge that the work you do—as a parent or a service provider —can be fun...can be rewarding...and can be very hard!
- Recognize what you can and can't influence. Strive to understand the difference and establish priorities for yourself based on this knowledge.
- Know the policies and climate in which you are working. Understand such things as:
  - How decisions get made;
  - What the Budget is;
  - What rules are attached to various funding sources;
  - Who makes budgetary decisions;
  - What supports are available; and
  - What are the prevailing values and attitudes within the program/ community.
- Have a good understanding of your job description/roles and responsibilities.
- Be organized and understand the priorities for your time.
  - Become familiar with time management strategies, if you aren't already.
  - Use technology available to you in order to create more time for people.
  - Have an efficient filing/organizing system for processing paperwork and sharing resources.
- Identify an ally who will listen and support you without judging you, especially when you are hurt, angry and/or frustrated. For providers and families this may or may not be within your place of work.
- Be willing to ask for help. Acknowledge when you are dealing with situations you feel unprepared to handle alone.
- When you recognize you need a break, find your own way to take space to regroup. Some people take a walk, close their door, don't take phone calls for an hour, sit quietly, or listen to music.
- If you feel sunk and have few resources to face the moment, do something that is a complete distraction. This is a short term "band aid" and should not be used as a long term solution. Difficult situations need to be faced directly at some point.

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- Maintain your vision and mission. Recognize setbacks, learn from mistakes, and build new ways of addressing stressful situations.
- If you are dealing with a situation that you feel unable to influence, be sure you have other areas in your life where you feel successful and optimistic about your efforts.
- Have a professional/personal development plan. Identify what you want to learn more about and who or what can help you achieve your goals.

### ***What Can a Program Do?***

- Build time into your staff's day/week/month to process the situations they have been dealing with. This can be done within a team (e.g., routine team meetings), with an ally, or with a small group (e.g., brown bag lunch). Be sure to honor the confidentiality of families.
- Have a process for dealing with crises—an unexpected event that can have a deep emotional impact—such as the death of a child, violence within a family, or injury/harm to a team member. This could include access to services of someone who can help with emotional crises (e.g., psychologist, social worker). This person may or may not be within a program or agency.
- Strive to create safety in your environment. Directly deal with personal safety issues. Agencies are encouraged to have guidelines for acting in real or perceived "unsafe" situations (e.g., when is it O.K. to pull out? how to get help? —911, cellular phones, how can you arrange schedules to travel in teams?, regular checks with law enforcement about their activities in a particular area and notice to them of yours).
- Know your legal responsibilities and boundaries (e.g., reporting child abuse and neglect, the complete range of early intervention services available under the law, roles and responsibilities of service coordination, procedural safeguards for families).
- Support staff attendance to workshops, classes, conferences, and meetings to get to know and network with people who have similar interests.
- ***BE FLEXIBLE!***
- ***MAINTAIN A SENSE OF HUMOR!***
- ***HAVE FUN!***
- ***FIND THE POSITIVES!***
- ***CELEBRATE ACCOMPLISHMENTS!***
- ***LAUGH!***

*Developed by Pathways: Service Coordination Inservice Project, 1994. Waisman Center, Early Intervention Program. Madison, WI.*

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# SCENARIO FOR GETTING STARTED

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*Julia Graves is a teen mother of a nine month-old daughter who lives with both of her parents in their suburban home. Julia's mother takes care of her daughter Amanda during the day while she attends high school. Today, Julia has her first meeting with Alyssia Adams, the service coordinator from the Gateway Early Intervention Program. Prior to this meeting, Julia and Alyssia spoke briefly by phone. Julia is not sure what to expect from Alyssia's visit, even though she called the program herself at the urging of the school social worker. She really wanted to know more about what was going on with Amanda, but also felt frustrated because no one seemed to be listening to what she had to say. She wondered if this time would be different or more of the same. We join Julia and Alyssia in the midst of their first meeting at the home of Julia's parents.*

Julia: I try to do all the right things. I try to get to all my appointments, take care of my baby and get to school. I can't say exactly what, but I'm really concerned something is wrong with my baby. The message I get from my mom is that I don't do enough. She feels like I leave her with Amanda all the time. She says if I spent more time with Amanda, she'd be fine. The doctor doesn't think anything is wrong either. Each visit I try to tell her I'm worried about something, she tells me to wait and see. She reminds me I'm a young mom who hasn't had a lot of experience with babies. Every time I hear that I could die. I've spent hours baby sitting ever since I was 12. I practically raised our neighbors' little girl. I don't know why I'm telling you all of this. You probably don't believe me either.

Alyssia: Well, it sounds like you have some concerns, you're not sure what they are, and you feel like nobody is listening to you. I'd like to help you try to get clearer on what you're concerned about. Can you tell me more about Amanda?

Julia: What do you want me to tell you?

Alyssia: What she likes to do. How she lets you know when she needs something. How she eats and sleeps. You know... does she cry a lot? Does she let you comfort her?

Julia: How's that going to help? I've been through all of this already.

Alyssia: Give it a try. Maybe together we can put our finger on your concerns, and then possibly bring in other people who could also help. As I said on the phone and earlier today, this is a program that might be able to help you and Amanda. If Amanda is eligible for the program, we can work together to figure out what she needs.

Julia: What do you mean by eligible?

Alyssia: If Amanda shows a 25% delay in one or more areas of development or has a diagnosed condition likely to result in a disability, she is eligible for the program.

Julia: You mean we have to pin that down to get help?

Alyssia: Yes, and that's one reason I want you to tell me more about Amanda.

Julia: You asked me a lot of questions before. I'm not so sure going through all of this again will end up getting me help with Amanda, but I'll give it a try.

*Just as Julia starts to talk about Amanda, her mother comes into the room. Julia continues, but her whole demeanor changes. The flow changes and she has trouble getting out her thoughts. Those she does get out are contradicted by her mother at least twice.*

*Alyssia senses the change and is starting to feel frustrated because she was feeling like she and Julia were beginning to make progress in their conversation. She felt the seeds for a partnership were planted.*

# SCENARIO FOR FOLLOW ALONG

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*Maria Jackson is a full time service coordinator for the Pathways Early Intervention Program. She is just initiating a phone call to James Hill, the father of a child in the program. She is calling for several reasons. First, contacting James has been on her list of calls to make for a while; and second, Lindsay Green, the early childhood teacher who makes weekly visits, asked her to call James. Lindsay told Maria that she was beginning to feel that she spent more than half of her home visits talking with James. She wasn't getting around to the special instruction interventions on James Junior's IFSP. She doesn't mind talking with James, but thought he could use some additional support. He seemed to have so much to talk about every week. Lindsay also didn't want Maria to think she was taking her job away from her.*

**Maria:** Hi James. This is Maria Jackson from the Pathways Early Intervention Program. I'm sorry it's taken me so long to get back to you. I just wanted to call to see how things are going. When we last met we didn't schedule another check in. We left it that I would call if I didn't hear from you in a couple of months. Also, I saw Lindsay Green yesterday and she thought it would be a good idea if I gave you a call. How are things going with James Junior?

**James:** Things are fine. Everything is moving along. We have our scheduled appointments at the clinic with the therapist and Lindsay comes to our home just about every week. Things are fine.....(slight pause)....listen to what James Jr. did last week! He pulled himself up to standing on the edge of the sofa. I couldn't believe it! It was great! (another pause, but no additional comments follow).

**Maria:** That's good news! I'm glad to hear he is making progress. It sounds like you're thrilled! What else is he up to? Is there anything else you'd like to tell me about James Jr.?

**James:** He has a new toy stuffed lion that he loves to cuddle with.

**Maria:** I bet he's really cute all cuddled up with the lion.

**James:** Yes, he is (pause, no additional information is forthcoming).

**Maria:** Is there anything I can help you with today?

**James:** Not that I can think of. I usually talk to Lindsay when things come up. I see her practically every week. She's very helpful. When little things do come up we talk about it.

**Maria:** Perhaps you'd be interested in knowing about support groups or workshops for parents?

**James:** I'll check with Lindsay about that too.

**Maria:** That's good you have someone to talk to. I'm glad Lindsay is helpful. You know you can always contact me too; that's my role as your service coordinator.

**James:** Thanks, I can't think of anything (another quiet pause).

**Maria:** If something comes up, please feel free to call me any time. I'm usually in and out of the office meeting with families and other service providers throughout the week. If I'm not in my office, you can leave me a voice message. I check those regularly so I can get back to you right away.

**James:** I appreciate that. I'll keep you in mind. Like I said before, things are moving along for James Jr. and Lindsay sees us all the time.

**Maria:** Ok, bye. It's good to hear things are going well for you. Remember, give a call if I can help you with anything.

**James:** Ok, bye.

# SCENARIO FOR RESPONDING TO THE UNEXPECTED

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Anita: I'm sorry this happened, Lisa. I can tell you're really upset. I know you wanted Mark to come with you to the IFSP review meeting. The meeting is three weeks away. We have some time to figure out what would be helpful. You see what happens at your end and I'll think about ways I might be able to help you.

Lisa: Yes, but I'm really worried. I don't see any way that Mark will change his mind and come to the meeting. I don't want to go by myself. I only wish he'd talk to me.

Anita: Let's see what happens. We'll talk again in two days when I make my regular visit.

Lisa: OK. See you then

*This is the end of a telephone conversation between Lisa Bonfiglio, the mother of 1-1/2-year-old Tony, and Anita Levy, the Bonfiglio's service coordinator and occupational therapist and special instruction provider with the Pathways Early Intervention Program. Anita called to confirm a date for Tony's six month IFSP review meeting. She expected a routine call and walked into a marital disagreement. Anita was very uncomfortable and didn't know what to do or what was expected of her. As soon as Lisa heard Anita's voice on the phone, she burst out crying and tried to tell Anita what had happened. Bit by bit, Lisa explained to Anita that she and her husband Mark had just had a huge fight. He left the house angry. Lisa related that Mark blew up while she was trying to tell him about the upcoming IFSP review meeting. He refused to go and said no program was going to make what was wrong with Tony go away.*

*Tony is Mark's first and only son. He and Lisa have been married for two and a half years. Lisa has a seven-year-old daughter, Madeline, from a previous marriage. Mark has worked hard to build a relationship with Madeline, but has always been aware that she is not his own daughter. He was so excited to become the parent of a son. He had great dreams about who his son would be in his life and pictured sharing many of his favorite activities. Mark had known for quite some time that Tony had some problems and seemed very positive about the help he was getting from the early intervention program. However, four weeks ago, Tony was diagnosed with a mild form of cerebral palsy. Mark didn't say much about the diagnosis. Lisa talked about being relieved to know that his problems had a name.*

*Anita's perception was that Lisa and Mark were taking the information in stride. They didn't seem overly concerned or want to talk about it. Besides, she thought it was pretty good that the diagnosis was only mild cerebral palsy. She was unprepared for the information Lisa unloaded on the phone. A number of times during the call, Anita wanted to end the conversation. She was unhappy that she had been unsuccessful in getting Mark to talk to her and that Mark's parents wouldn't have anything to do with Tony any more. She especially didn't want to hear that Mark threw one of Tony's toys across the room before he left the house. All of this added to Anita's discomfort. She felt Lisa's desperation and was overwhelmed by her expectation that she get Mark to the meeting. She was immediately relieved to be off the phone, but panicked at the thought that the situation wouldn't go away with the end of the phone call. She already had several pressing matters on her agenda. This was the week she planned to meet two newly referred families.*

# SCENARIO FOR FACILITATING TRANSITIONS

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Amy and Sam Chen have two children. Their oldest child Sandy is in kindergarten in their neighborhood school. Their youngest, David, receives services from the Stepping Stones early intervention program. David has complicated needs around feeding and his care can be very intensive at times. He will be three in four months and plans for his transition to the public schools for early childhood are in process. Amy and Sam recently attended their first meeting with staff from the school district and their early intervention service coordinator, Janice O'Brian. We join Amy and Sam as they discuss what happened at the meeting.

Amy: Was that a tough meeting! I'm so glad we've started this now. The people all seemed nice enough, but I'm so confused. Maybe by the time David turns three I'll figure out what is going on. They talked about so many things that I didn't understand. I know Janice gave us written information a couple of weeks ago and even talked to me about the purpose of today's meeting. Still, I couldn't keep track of everything. Who were all those people? They probably thought I was really out of it; I was so quiet. Besides, why do we need to go through such a big thing to get David into school? We all know he has problems and that he has gotten services since he was three months old.

Sam: Yes, I know what you mean. I was hoping for more information about when he would be in school so you can start looking for that job you want to get when he goes to school. All we heard was that the program runs mornings and afternoons four days a week. We don't know whether he'll go in the morning or afternoon or which days.

Amy: At least Janice said she'd help us find child care or a preschool program to extend his day if we need more child care. Even so, I just can't imagine someone else caring for David all day. You know as well as anybody, I spend half of my days just keeping him fed and comfortable.

Sam: Yes, it is hard to think of someone else giving David the care you do. Are you sure you want to go back to work? I know we talked about this a lot, and that we could use the money, but....

Amy: That's a whole different conversation for another time! Not now.

Sam: O.K., another time. The other thing I didn't like hearing is that David and Sandy may or may not be in the same school. That would be terrible. It's hard enough thinking of David going off to school, especially on a bus. I'd like it a lot better if both kids were in the same school. You know how much David lights up when Sandy's around, and how Sandy looks out for him.

Amy: Yes, I thought about that too. It never occurred to me they wouldn't be in the same school. There's so much I don't get. I didn't know this transition would be so complicated. Why does it feel so hard?

Sam: So what are we going to do?

Amy: I don't know. Maybe we need time and more information. It sounds like we don't have to decide anything for a while, but we both know how quickly three or four months can

*over—*

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pass. I didn't get a chance to talk with Janice after the meeting. Maybe she can help us sort things out and give us more information before the next meeting with school people.

**Sam:** I know school is the place for David to get help and I want to make sure we get things worked out right for him. Starting with Janice sounds like as good a place as any. Are you going to call her?

**Amy:** Sure. I'm home tomorrow with David, as usual.

Janice also left the meeting feeling uncomfortable. She couldn't figure out why Sam and Amy were so quiet. They are usually much more talkative. She thought she had prepared them for the meeting. She gave them the program's transition booklet and talked with Amy about what was going to happen. She asked her if she had any questions and did not get any. Maybe they did not read the materials or could not make sense of them. Why didn't they ask. Janice also wondered if there was something specific that happened to make the meeting so stressful for them. She hadn't talked to Amy or Sam since the meeting and decided

she'd better call. Maybe she can find out what happened and do something before the next meeting. Janice barely had a chance to write "Call Amy and Mark" on her "To Do List" when Amy called her.

**Janice:** I'm so glad you called me. I've been thinking about you. I had a feeling something happened at the transition meeting, but I don't know what. What's going on?

Amy relates her concerns about what the transition may mean for her family. Janice listens and responds as follows:

**Janice:** I'm sorry this has been so hard for you. Perhaps I can talk to someone at the school to get more information and share your concerns. Do you and Mark want to be part of that discussion? Maybe that will help us get back on track for the next meeting. Maybe we can talk some more before that.

**Amy:** Do you think any of this will help?

**Janice:** It's always helpful to get more information to understand what we're working with.

# THE PROBLEM-SOLVING FRAMEWORK

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## *Identify the Issue*

- Is it one issue or a number of issues?
- Does everyone involved see the same issue?

## *Identify Positive Aspects of the Issue*

- What strengths are there in the family in the provider, in the team?
- Acknowledge and build on these strengths in your discussion and planning.

## *Identify Factors That Might Have Led to This Issue*

- Collect more information to better understand the issue.
- What occurred in the past or present that might keep you from achieving a desirable outcome?

## *Identify Available Options*

- Don't look for solutions too quickly.
- Tap the creativity in the group to generate possible options.
- Look at all the alternatives. Sometimes other options became fall back strategies if the first option does not work.
- This is a good practice in early intervention planning where families need to be aware of choices and options.

## *Decide on a Course of Action*

- What will you do?
- Who will do what by when?
- What are your next steps?

# FAMILIES CONCERNS ABOUT TRANSITIONS

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## *Information*

- What is the new system like?
- What do all the terms and acronyms mean?
- What are my legal rights and responsibilities under the new system?
- What are the policies and procedures for placement in the new program?
- Will my child be eligible?

## *Emotional*

- Can I trust them?
- How can I get our schedule to fit with all these changes?
- Will she be all right without me?
- Will she be safe?
- How will she get there?
- Will she like it?
- How will other children treat him?
- Who will help her?

# WHAT HELPS FAMILIES DURING TRANSITION

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- Plan in advance
- Explore all options
- Prepare self and child for separation
- Learn about the new setting, make a personal contact
- Create open lines of communication, formal and informal
- Identify supports needed for child
- Access educational opportunities
- Identify helpful people and programs both within and outside school to support the child and family after transition
- Identify other families

# WHAT HELPS PROGRAMS DURING TRANSITION

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- Develop a transition plan
- Identify allies and build a relationship with new system
- Bring people together
- Develop interagency agreements
- Develop time lines that clarify steps and activities
- Formalize transfer of information from all relevant professionals
- Outline the process
- Get organized

# Pathways in Early Intervention Service Coordination

## A VIDEO GUIDE

Peggy Rosin  
Editor and Project Coordinator

February, 1996



Waisman Center  
Early Intervention Program  
George Jesien, Director  
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Waisman Center  
Early Intervention Program

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Pathways:  
Service Coordination Project

**Pathways in Early Intervention Service Coordination  
A VIDEO GUIDE**

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## INTRODUCTION

Service coordination is a new and challenging role for many family members and service providers in early intervention. Some challenges include:

- Working in partnership with families and other team members to reach desired outcomes for infants and toddlers with special needs and their families.
- Understanding federal legislation and state rules related to the individualized family service plan (IFSP) process and the delivery of services.
- Working on teams and across agencies made up of people from different backgrounds and perspectives.
- Negotiating complex health, educational, and social service systems to access services for children and families.
- Finding creative ways to meet family and child service and resource needs.
- Creating positive changes in systems and practices to be responsive to all families.

To meet these challenges, service coordinators need knowledge and skills related to the laws, the IFSP process, services, resources, and personal skills involving communication, conflict management, decision making, problem solving, and stress reduction. These personal skills are at the heart of the partnerships developed between family or other team members, agency personnel and community members.

Carrying out the many tasks and responsibilities in service coordination takes different skills. These tasks may be divided into four clusters of activities, including:

- **CHOOSING THE PATHWAY:** getting started in the IFSP process
- **THE JOURNEY:** providing follow along to families in implementing and monitoring of the IFSP
- **DETOURS ALONG THE WAY:** facing unexpected, immediate needs or crises
- **CHANGING PATHWAYS:** facilitating transitions

## ABOUT THIS VIDEOTAPE & GUIDE

This videotape illustrates some personal challenges faced in the provision of early intervention service coordination. It presents four scenarios that coincide with the four clusters of service coordination activities. Each scenario targets one of the clusters of activities and highlights important skills. In the brief vignette, one or more unresolved dilemmas are depicted. To acknowledge that there are NO ready solutions to these dilemmas a problem solving format is used. Viewers are asked to generate solutions, respond to questions and solve problems that are viable from their perspective and community context.

Following each scenario, stop the videotape and answer the questions appearing on-screen:

- What do you see as the most pressing issue for the service coordinator?
- What would you do in this particular situation?
- What might be your next steps?
- What other information do you need?
- Who should be responsible for the next steps?
- How will you know if your plan was successful?

After group discussion or individual reflection, restart the videotape. As the tape progresses, additional questions will be offered for the viewer's consideration. If any of these questions were not addressed, the viewer can stop the videotape again for further discussion or reflection. The videotape does not need to be shown in its entirety.

For the viewer's convenience, this guide includes a recap of each scenario with its accompanying questions from the videotape. Viewers can also refer to the talking points and additional discussion questions in the following sections of the guide. The discussion questions and talking points highlight issues in each scenario and are offered to enrich reflections and discussions.

This guide can not provide detailed information about the complex issues raised on the videotape. Please refer to a companion product, *Pathways: A Training and Resource Guide for Enhancing Skills in Early Intervention Service Coordination*, for more comprehensive coverage of these issues. This product can be obtained using the ordering information in the front of this pamphlet. It is further suggested that if viewing the video in a group, the group sets "ground rules" before discussion to ensure people believe their concerns have been heard and feel comfortable with the process.

## SCENARIO I:

### Choosing the Right Pathway— Getting Started in the IFSP Process



#### Recap of the Scenario:

Beth and Bradley are divorced, well educated and work outside the home. They both have high expectations for their only child, Benjamin. Last month, just before his second birthday, he was diagnosed with a Pervasive Developmental Disorder (PDD) at a nearby university clinic. Beth and Bradley also have high expectations of the system. Bradley is interested in some services but doesn't want Benjamin to be constantly programmed. He doesn't see Benjamin's problem as being particularly significant, while Beth is thinking about organizing a 40 hour a week program. Sarah, the service coordinator, has recently received a master's degree in social work. At a recent staff meeting, she heard about the limited program resources for this year.

#### Talking Points:

- Family members do not always have the same perspective on an issue or on the steps to be taken to meet the needs of their child or themselves. Beth and Bradley seem to be in different places related to Benjamin. These differences could stem from a variety of sources such as a reaction to Benjamin's recent diagnosis, feelings about Benjamin's developmental issues or what outcomes they want from early intervention services. To be successful in the IFSP process it is essential to get at the concerns and issues of all family members and to have strategies to move forward in the IFSP process if the concerns and desired outcomes are different.

- In talking with families about options for their child and themselves there can be numerous informal supports, resources and services to consider in addition to the mandated early intervention services. How could you talk with families about what these supports might be for them? Might informal supports be an important way to provide support for Benjamin's needs? What would they look like?
- As service coordinators, you may not know the answers to many questions that are asked by parents or other team members. Sarah may be feeling some tension because she does not know about the different programs and approaches for working with children with PDD. What Sarah needs to remember is that she is part of a team and others on her team can help her to obtain the requested information for the family. In this situation, a service coordinator's responsibility is to seek out information or link parents with knowledgeable others. Another consideration in responding to families' requests for information is to present the information in as neutral a manner as possible. It is up to the family to make the decision based on the information provided.

#### Questions on Videotape:

- What methods could Sarah use to determine the concerns of Benjamin's parents?
- Since their concerns and desired outcomes for Benjamin differed, how do you think Sarah could help them identify the common ground between Beth and Bradley?
- What strategies could Sarah use, given that she lacked adequate information to address Bradley's inquiry about other programs?

#### Additional Questions for your Consideration:

- How could Sarah present intervention information that Beth seeks for Benjamin when such a vast array of options are available?
- How might informal community supports and resources assist in addressing both parents' concerns?
- How might Sarah's knowledge that program resources are limited affect her discussions about services, resources, and supports? Should this knowledge affect the information she supplies to Beth and Bradley?

## SCENARIO II:

### The Journey

#### Follow Along—Implementing and Monitoring the IFSP



#### Recap of the Scenario:

Claire is a service coordinator and a speech-language pathologist. She has a 50% position with the Gateway Birth to Three Program. Claire has two preschool children and sometimes feels guilty about the time she spends away from her children. She is currently contemplating a separation from her husband.

Claire experiences stress as she juggles the needs of all the families she serves and as she tries to complete some overdue follow-up. Tammy, the program director, comes to Claire's desk and informs Claire about the record number of referrals this month. In order to meet the 45-day time line to develop an IFSP, Tammy wants Claire to increase her workload by completing intake with referred families and adding several evaluations.

#### Talking Points:

- Service coordination follow-along during the implementation of the IFSP takes an incredible amount of organization and priority setting. Service coordinators need to develop personally effective methods of organization and take care of themselves when dealing with competing priorities and job-related stress.

- Service coordinators need to clearly understand their functions and responsibilities but also need to know what personal and professional boundaries they are comfortable with and why.
- Programs that acknowledge the challenges of providing early intervention services by building in program supports may have less staff burnout and turnover. Support may come from colleagues or supervisors by setting up a mentoring system and strategies to provide emotional and informational support.

#### Questions on the Videotape:

- What possible negative effects may stress have had on Claire while doing her job as a service coordinator?
- How might Claire take care of herself while dealing with competing priorities? How do you do it?
- What tips could you give Claire on how to organize and prioritize the numerous and varied tasks of her job?

#### Additional Questions for your Consideration:

- What types of program support might be helpful to Claire in her situation? What is helpful to you?
- How might Claire negotiate with Tammy, her program coordinator, when she needs to shift her priorities? How do you negotiate a situation like this?



### SCENARIO III: Detours Along the Way—Unexpected Immediate Needs



#### Recap of the Scenario:

Hugh and Anna, self-described New Agers, believe in alternative health measures and are leery of the "system." They live in a rural area and have a low income. Anna works within the home and provides home schooling to their three older children. Hugh works on a neighboring organic farm and does some construction work. The newest family member, Alexis, was born at home and has an undiagnosed condition that has resulted in both delays and health problems. Alexis has been in and out of the hospital. Each time she returns from the hospital, her parents believe she has a "new problem."

Alexis is nine months old and has been losing weight. It has been recommended that she return to the hospital for tests. Anna is distraught, as Martha, the service coordinator arrives. Anna doesn't know what to do because she feels these hospital stays have too many negative affects on Alexis. The public health nurse has just left the house and has threatened to turn the family's situation over to Child Protective Services because she believes that the family is not meeting Alexis' medical needs and is putting Alexis in a life-threatening situation by not admitting her into the hospital.

Martha has been a service coordinator for a number of years. She has a 15-year-old child with cognitive disabilities and remembers some of the hard decisions she needed to make about her son's health and development. Martha had arranged to come to the house today to check on how services with the early interventionist are going and to talk about some of the current health issues and the possibility of a consultant visit by the occupational therapist to observe Alexis' feeding.

#### Talking Points:

- Having an agenda for any meeting with a family is critical to the success of that meeting. Equally important in service coordination is the ability to set the agenda aside when more urgent or unexpected issues arise for the family.
- Fundamental to service coordination is the ability to ask family members questions in a way that leads them to pinpoint their concerns or issues, to generate options or alternatives that address the concern, to determine the plan that meets their needs and to know if the selected direction is successful. Ongoing use of this service coordination skill can lead to a transfer of the skill to the family members and enhance their feelings of competence in solving their own problems.
- Coordination of services across health, educational and social service agencies will be a major service coordination function. It is beneficial in any collaboration to agree either formally or informally on a vision or philosophy of service provision, roles, and the process and procedures for working together, including communication and conflict management.

#### Questions on the Videotape:

##### *Please consider...*

- How your own experiences and values come into play when working with families, other team members or personnel from other agencies?
- How the Public Health Nurse should proceed if she feels the family's decision could jeopardize Alexis' health or development?
- How Martha might approach the PHN if she does not agree with her concern about neglect?
- What the differences are in decision-making if a situation warrants swift action on your part?

#### Additional Questions for your Consideration:

- How do you handle changes in the planned agenda if you arrive at a family's house and other issues take priority?
- What kind of coordination and communication should Martha have with personnel outside of early intervention to help ensure that families are not receiving competing or erroneous information?

## SCENARIO IV:

### Changing Pathways—Facilitating Transitions



#### Recap of the Scenario:

Theresa, a single parent, has a child Roberto, who has cerebral palsy and will be three years of age in June. This is a preplanning meeting for Roberto's probable transition into an early childhood program. The meeting includes Theresa, Mary, the service coordinator from the early intervention program, and Diane, an early childhood teacher from the local school district. Theresa works full-time and has medical insurance through her employer. Roberto receives SSI and Katie Beckett.

#### Talking Points:

- Transition can be a stressful time for all involved. In addition to following the federal and state procedures around transition, it needs to be a well planned time. Discussions about transition with families need to occur early and often, not just at prescribed times. Many programs find it beneficial to put together a transition booklet that provides families with the procedures and timelines involved in all possible transitions during early intervention.
- Negotiation and decision making across agencies is a challenge. Having written agreements across agencies can help to make the procedures consistent and responsibilities for the sending and receiving agencies clear.
- Transitions can be an opportunity to see whether existing procedures are working for families or whether there are gaps or glitches

in services. Service coordinators are in the position to see where and when families get stuck and to work toward making the system (programs, agencies, procedures) more responsive to families.

#### Questions on the Videotape:

- What are the feelings that need to be acknowledged in the scenario?
- What do you need to know about the rights of the child and parents in the transition to the public schools?
- How can Mary help the family identify and access therapy services for Roberto and pay for those services?
- What strategies might Mary, Diane and Theresa use to change policies or practices that are not working for children and families?

#### Additional Questions for your Consideration:

- What agreements, if any, does your program have with other agencies?
- What are the consequences for Roberto and his family in the various arrangements for services and supports that may be decided upon to meet his needs?
- What creative uses of informal and community resources and supports might be useful in situations like this?



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