Guidelines and
Recommended Practices for the
Individualized
Family
Service
Plan
Second Edition

Guidelines and Recommended Practices for the Individualized Family Service Plan

Second Edition April 1991

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Guidelines and Recommended Practices for the Individualized Family Service Plan

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Acknowledgments

Four years ago, when I was asked to serve, on behalf of the Association for the Care of Children's Health, as the Lead of the NEC*TAS Expert Team for the IFSP, I saw an exciting opportunity to expand our work in family-centered care. Although all members of the Team realized the critical importance of the IFSP to successful implementation of P.L. 99-457, no one fully realized the scope of the work we were proposing or the complexity of our task. The resulting document, Guidelines and Recommended Practices for the Individualized Family Service Plan, was published two years ago.

Many people participated in the development of that publication -- people representing federal and state agencies, various organizations, and early intervention programs; professionals from many disciplines; and parents caring for children with special needs.

Don Bailey, Carl Dunst, Shirley Kramer, and Ann Turnbull, all members of the IFSP Expert Team, made thoughtful and substantive contributions the publication and generously shared time and expertise. The work of the Task Force on the IFSP was critical to the early development of the document and again in reviewing a first draft. Carole Brown, then at OSEP, and Joicey Hurth and Roxane Kaufmann of NEC*TAS were active in planning the development of the document and in bringing together the diverse and talented Expert Team and Task Force.

Co-editors Mary McGonigel, Roxane Kaufmann, and I especially thank Corinne Garland, Nancy DiVenere, Linda Kjerland, and Terri Shelton, each a Task Force member, for the energy, enthusiasm, and expertise with which they responded to our many additional requests for help as we wrestled with the first edition.

We also thank Joyce Lindgren, Polly Edmunds, and Paula Goldberg of the PACER Center and George Jesien of the University of Wisconsin - Madison for their significant contributions to the review process. Ibby Jeppson, Josie Thomas, and Nancy Guadagno, ACCH staff members, also made important contributions to the content and format of the publication. Susan Hom, formerly of NEC*TAS at the Georgetown University Child Development Center, deserved a special acknowledgment for her important work on the Appendices.

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Since the book was published in 1989, it has been widely distributed throughout the country to professionals and families working to implement the IFSP component of Part H. The success of that first edition prompted NEC*TAS and ACCH to develop a second edition — revised and updated to reflect the final regulations related to the IFSP and our growing understanding of best practices for family-centered early intervention.

For the most part, the same people who were so instrumental in developing the first edition were responsible for this new edition. We do want to thank, however, David Jones, of the WINGS Project at the University of Wisconsin - Madison, for his substantial contributions to the new edition, both as a contributor and reviewer; Marcia Decker, of NEC*TAS, for her review of the second edition; and Bobbi Hitt, of ACCH, for her help in updating many of the Appendices.

It has been our privilege to work with NEC*TAS, especially Pat Trohanis, Joicey Hurth, and Joan Danaher, and to be part of their efforts to develop technical assistance for the IFSP component of Part H.

When we began this project in 1987, our hope was that it would result in a document that would help policy makers, planners, providers, and families implement the IFSP component in ways that are consistent with best practices as we understood them then. Writing in her former role as the chairperson of the Federal Interagency Coordinating Council, Madeline Will expressed this same hope -- her letter that appeared in the first edition of Guidelines and Recommended Practices for the Individualized Family Service Plan follows these acknowledgements.

My fervent hope today continues to be that each reader of these guidelines will help to shape the best practices of tomorrow for family-centered early intervention.

> Beverley H. Johnson April 1991

UNITED STATES DEPARTMENT OF EDUCATION



OFFICE OF THE ASSISTANT SECRETARY
FOR SPECIAL EDUCATION AND REHABILITATIVE SERVICES

We are presently in the midst of implementing the Part H Early Intervention Program for Handicapped Infants and Toddlers (Public Law 99-457, Education of the Handicapped Act Amendments of 1986). As we rapidly move forward to 1991, the end of the five-year phase-in period that Congress initiated in 1986 to develop comprehensive statewide systems of early intervention services, States must develop policies to put the fourteen required components of Part H into effect. The Individualized Family Service Plan (IFSP), one of these required components, represents the cornerstone of the entire system of early intervention services. The IFSP offers parents and professionals a mechanism to plan coordinated and individualized services to support the development of an infant with special needs in the context of the child's family.

Part H of Public Law 99-457 has given us a significant opportunity to rethink and reconcile what we know about child development with our beliefs about the best ways to provide early intervention services to infants and toddlers with handicaps and their families. Knowing that infants can thrive best in nurturing environments, it is insufficient to be solely child-centered in our approach to early intervention. Our target for service delivery must therefore be the *family*, to enhance the capacity of the family to meet the special needs of the child.

Recognizing the challenge that the IFSP presents, the Office of Special Education and Rehabilitative Services (OSERS) has sponsored several activities to develop viable models for carrying out IFSP's. These activities are particularly timely and important because the IFSP, as an essential component of the Part H early intervention program, must be in place soon -- by the fourth year of a State's participation, all children served under P.L. 99-457 must have an IFSP. We have had continuing support from the Federal Interagency Coordinating Council in implementing these activities. In particular, the Bureau of Maternal and Child Health and Resources Development has collaborated extensively throughout this effort to develop best practices for the IFSP.

A call to the field for best practices in IFSP development was initiated in the fall of 1987, and submissions were analyzed by the Carolina Institute for Research on Infant Personnel Preparation. Based upon the preliminary analysis of the call to the field, an interagency group representing the Office of Special Education Programs, (OSEP), the Bureau of Maternal and Child Health and Resources Development (MCH), and the Early Intervention Consortium funded by the Administration on Developmental Disabilities (ADD) recommended that work to develop best practices be continued. This interagency group became the IFSP Task Force and was expanded to include representatives from the National Institute on Disability and Rehabilitation Research (NIDRR), the National Institute of Mental Health (NIMH), the Administration for Children, Youth and Families (ACYF), parents of children with special needs, and a multidisciplinary group of professionals with expertise in early intervention.

Meeting in May, 1988 the IFSP Task Force began the process that resulted in recommended best practices for IFSP development in the following specific areas: philosophy and conceptual framework, building positive relationships between professionals and families, identifying child and family strengths and needs, developing outcomes, and implementation. This document was written by the subgroup leaders of the Task Force, the NEC*TAS Expert Team, and is based upon the findings of the Task Force and feedback from State representatives.

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We are pleased to share with you the product of these activities to develop best practices for the IFSP -- Guidelines and Recommended Practices for the Individualized Family Service Plan. We share this with you in the knowledge that the process matters as much as the product -- and that you in your role as parent, professional, or policy planner are critically important in the development of best practices for the IFSP. Read, reflect, and discuss with others the principles in this document. We look forward to continued refinement of these concepts as comprehensive early intervention services become a reality for all children with special needs and their families in this country.

Madeleine Will Assistant Secretary

Madeline Will

Chair, Federal Interagency Coordinating Council

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Representatives from ten states attended a technical assistance event in conjunction with the IFSP Task Force meeting. Their comments and suggestions were incorporated in the document.

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An Overview

By Mary J. McGonigel and Beverley H. Johnson

Introduction

Public Law 99-457, the Education of the Handicapped Act Amendments of 1986, Part H, directed states "to develop and implement a statewide, comprehensive, coordinated, multidisciplinary, interagency program of early intervention services for handicapped infants and toddlers and their families" {20 USC 671(b)}. As state policy makers, practitioners, and families work together to develop this comprehensive system, they have a unique opportunity to reshape and redirect early intervention services to infants and toddlers with special needs and their families — to form a "community of caring" (DiVenere, 1988).

Since the first edition of this monograph, the 101st Congress again reauthorized the Education of the Handicapped Act (EHA). This legislation, Public Law 101-476, changed the name of EHA to Individuals with Disabilities Education Act (IDEA) and changed all terminology to people first language. The term "handicap" is replaced with "disability." Therefore, "handicapped infants and toddlers" in Part H became "infants and toddlers with disabilities."

In 1986, when Part H was first enacted, perhaps no provision generated more discussion than the requirement for an Individualized Family Service Plan (IFSP). The IFSP is just one component of a statewide system of comprehensive early intervention. The purpose of the IFSP is for families and professionals to work together as a team to identify and mobilize formal and informal resources to help families' reach their chosen goals. The IFSP is a promise to children and families — a promise that

their strengths will be recognized and built on, that their beliefs and values will be respected, that their choices will be honored, and that their hopes and aspirations will be encouraged and enabled.

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. The Parents as Partners Project (1988) at Alta Mira Specialized Family Services, Inc., in Albuquerque, New Mexico, beautifully illustrated this point in their document for other parents, *Preparing for the Individualized Family Service Plan*:

As you begin this early intervention program you will be asked to form a partnership with the professionals who will be working with your child and family. As with all good relationships, it takes time to build the trust, respect, and sharing that is the foundation of a successful partnership. To this end the Individualized Family Service Plan (IFSP) is not just paperwork or evaluations that must be done so that your child can be enrolled in a program. The IFSP is a partnership that will last the entire time your child and family are with the early intervention program. (p. 1)

The IFSP requires new approaches and practices on the part of the many agencies, institutions, and professional disciplines that provide early intervention services to children with special needs and their families. If the IFSP is to fulfill its promise of meeting the broad-based needs of these children and their families, the same coordination that is

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Timetable for Implementation of the IFSP Component

The IFSP provision must be implemented no later than the beginning of the fourth year of the State's participation under Part H. {20 USC 1475}

modeled by the Interagency Coordinating Councils at the state level must become a reality at the local level.

As a field, "early intervention is still in the process of defining itself" (Healy, Keesee, & Smith, 1989, p. 121). Some professionals who provide services to young children with special needs think of themselves first as early intervention practitioners, while other professionals providing very similar services think of themselves as specialists in their particular disciplines. In this document, the term "early intervention professional" is used to mean any professional who provides early intervention services to children and families. This designation is not meant to exclude any professional or any discipline; in whatever way they identify themselves, all those serving infants and toddlers with special needs have an important contribution to make to the IFSP process.

Professionals must be willing to go beyond the narrow boundaries of their disciplines or agencies and to reach out to others who are also planning or providing services to these children and their families. Public Law 99-457 provided a timely reminder that the field of early intervention is multidisciplinary — made up of professionals from education, health, mental health, and social services who are concerned with comprehensive developmental services to infants and young children with special needs and their families.

The IFSP component of the law challenges professionals and families to work together in new ways. At the state planning level, Part H grantees and other state agencies are searching for innovative approaches to interagency coordination. At the local level, families and service providers are developing community responses to the IFSP. All are continu-

ing to search for best practices for Individualized Family Service Plans.

As this body of information grows, policy makers and practitioners are taking a new approach to working with infants and toddlers and their families. In like manner, families are creating new opportunities to develop partnerships with professionals. Past practices and approaches are being examined and refined in light of newly emerging family-centered philosophies, models, and program practices. These approaches can then be directed toward enabling and empowering families to enhance the development of their children with special needs and toward preventing families and children from becoming isolated from friends and community.

Evolution of the Monograph

To help state planners, families, and practitioners develop IFSP policies and procedures that are consistent with emerging best practices, the Office of Special Education and Rehabilitative Services (OSERS) of the U.S. Department of Education initiated several activities that resulted in the development of the first edition of this monograph.

Call to the Field for Exemplary Practices

As a first step, the Office of Special Education and Rehabilitative Services, working collaboratively with the Maternal and Child Health Bureau and the Administration on Developmental Disabilities, issued a call to the field in October 1987, to identify exemplary IFSP practices and formats. Notices were sent to state departments of health and special education; universities and University Affiliated Programs; Parent Training and Information Centers and other parent organizations; and early intervention programs and practitioners asking for submissions of materials related to best practices for the IFSP process, including philosophical statements, assessment tools, IFSP formats, and sample IFSPs.

The wide variety of responses to this call highlighted a need to gather and explore best practices for the IFSP. An Expert Team and Task Force was formed for this purpose.

The Expert Team and Task Force

The National Early Childhood Technical Assistance System (NEC*TAS) at the University of North Carolina at Chapel Hill appointed the Expert Team to develop a document to help state and local policy makers, personnel preparation programs, early intervention professionals, and families as they plan, implement, and evaluate IFSP procedures. The Expert Team was composed of both parents and professionals.

The Expert Team worked in conjunction with a Task Force composed of representatives from all of the federal departments and offices involved in services to young children with special needs and their families, state planners, university personnel preparation faculty, and parents and service providers from across the country. The Task Force members represented racial, ethnic, and geographic diversity. Among the disciplines and perspectives represented were advocacy, child development, law, medicine, nursing, occupational therapy, physical therapy, psychology, social work, special education, and speech and language pathology. A list of Expert Team and Task Force members is provided in the Foreword, along with more information about the process used to develop the first edition of this monograph.

This first edition of this document represented an emerging consensus about current best practices for providing family-centered, comprehensive early intervention services. Because states and programs differ in the ways they have served, or will serve, infants and toddlers with special needs and their families, the monograph did not attempt to provide a blueprint for implementation. Rather, it suggested a philosophy and conceptual framework for the IFSP and recommended practices and procedures consistent with state-of-the-art, family-centered early intervention.

More than 7,000 copies of Guidelines and Recommended Practices for the Individualized Family Service Plan were distributed to lead agencies, Part H planners, Interagency Coordinating Councils (ICC), personnel preparation programs, early intervention programs and providers, and parent and family organizations. The principles articulated in the monograph have been used in many states as a foundation for their IFSP work — in Part H and ICC mission statements, in state and local IFSP task forces, in university training programs, in family advocacy efforts, and in local early intervention programs.

The Second Edition

Guidelines and Recommended Practices for the Individualized Family Service Plan was published before the Department of Education released the final regulations for Public Law 99-457 and before most states had begun significant work on IFSP policies and procedures. When it was time to reprint the book, NEC*TAS and ACCH decided to collaborate on a new edition that would include the final IFSP regulations and an update on IFSP best practices.

This new edition does not attempt to provide a comprehensive report on how states are implementing the IFSP component of Part H. Such information is available from NEC*TAS and from the Carolina Policy Studies Program, both at the Frank Porter Graham Child Development Center, University of North Carolina at Chapel Hill. It does, however, include new resources and new examples of creative IFSP approaches being developed in states and programs across the country.

Overview of the Monograph

Chapter Two, "Philosophy and Conceptual Framework," suggests principles and concepts that are critical to developing a family-centered philosophy and conceptual framework for the IFSP. Among the issues addressed are definitions of "family," the importance of culturally competent services, principles for enabling and supporting families, and a collaborative team approach to the IFSP. The necessary components of the IFSP, as outlined in Part H, are listed, and the regulations related to the IFSP are summarized.

Chapter Three, "The IFSP Sequence," describes a family-centered process for IFSP development. This process typically begins with the first contacts between a family and early intervention services and continues throughout assessment, outcome develop-

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ment, implementation, and evaluation. A diagram of an interactive, nonlinear process for the IFSP is provided. Because children and families enter early intervention for different reasons and through a variety of routes, four vignettes illustrating this diversity are provided. The experiences of the children and families highlighted in these vignettes are used as examples throughout the document to clarify the IFSP process.

Chapter Four, "Building Positive Relationships Between Professionals and Families," addresses the interactions between families and professionals that shape the character of early intervention. The composition of the IFSP team is outlined, and the family's role as final decision maker is discussed. The impact of the values and beliefs that both staff and families bring to the team process is acknowledged. Additionally, the importance of collaboration and negotiation is stressed.

Chapter Five, "Identifying Children's Strengths and Needs," discusses current best practices for identifying a child's strengths, needs, and resources as part of a family-centered IFSP process. Principles and guidelines for nonintrusive assessment approaches are presented and professional and family roles are discussed.

Because of the long history of programs and practitioners with child assessment and the wealth of material and training available in this area, this chapter does not attempt to break new ground in child assessment. Rather, it outlines principles and practices consistent with family-centered assessment approaches. A NEC*TAS-convened Expert Team on screening and assessment of infants and toddlers produced a document in this area, Screening and Assessment: Guidelines for Identifying Young Disabled and Developmentally Vulnerable Children and Their Families (Meisels & Provence, 1989).

Chapter Six, "Identifying Family Concerns, Priorities, and Resources," addresses family-centered approaches to helping families identify those family concerns, priorities, and resources that they determine are "related to enhancing the development" of their infant or toddler with special needs {1477(d)(2)}. The strictly voluntary and individualized aspects of this IFSP activity are stressed. Consistent with emerging best practice, the chapter

emphasizes family self-identification of priorities and choices and of the resources available and necessary to bring about those choices.

Chapter Seven, "Outcomes, Strategies, Activities, and Services," provides guidelines for developing IFSP outcomes, selecting the strategies and activities that will be used to bring about those outcomes, and negotiating the early intervention services that support the outcomes. "Outcomes" is defined and distinguished from "goals and objectives." Family and staff responsibilities are discussed, and procedures that enable and support families are outlined.

Chapter Eight, "Implementing the Individualized Family Service Plan," outlines key concepts and procedures for implementing and evaluating the IFSP in local programs and communities. The case management, or service coordination, provision in the IFSP is discussed; recommended practices are suggested; and a process for protection of family rights is outlined. This monograph does not attempt to address fully all issues of importance to service coordination and IFSP implementation, because to do so was not the mission of this Expert Team and Task Force.

Chapter Nine, "Future Directions for the IFSP," updates and summarizes the implications of the Individualized Family Service Plan component for state planners and policy makers, for personnel preparation programs, for service providers, and for families. The continuing need for family/professional collaboration and interagency and interdisciplinary coordination and cooperation is stressed.

Key terms used in this document are defined in the Glossary. Also defined are any terms that might be considered professional jargon. It may be helpful for readers to peruse the Glossary before reading the body of the monograph.

The Appendices include additional materials to assist with the IFSP process. Sample IFSPs, updated to be consistent with the regulations, are provided for the four families described in the vignettes and followed throughout the document. Also provided are family-centered principles, guidelines, and checklists; sample forms and procedures; copies of instruments for identifying family concerns, priori-

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ties, and resources; and sample family satisfaction measures.

Use of the Monograph

This document contains suggested guidelines and recommendations for those who are responsible for implementing family-centered IFSP policies and procedures. As the work of many parents and professionals from diverse states, disciplines, and backgrounds, it represents a growing consensus on a family-centered process for the IFSP. This document also reflects the consensus of the Expert Team and Task Force members. Though individual members may differ in their beliefs, emphases, and priorities, the entire group supports the philosophy and principles included in the monograph.

Although such diversity ensures that a variety of concerns and viewpoints are represented in this book, no one document can provide all the answers. Each state is now developing IFSP policies and guidelines for its local programs. Local programs and families are using those state guidelines and regulations to develop policies and procedures for implementing the IFSP requirement in a way that

supports, rather than supplants, the caregiving role of families.

In the almost two years since the first edition of this book was published, the family-centered principles advanced by the original Expert Team and Task Force have become the standard of practice in many states. Many of the finer points of family-centered practice that some found revolutionary when the first edition was published have since become commonly accepted IFSP practice.

The coming years will undoubtedly continue to yield much discussion and further field-testing of IFSP principles and best practices. Early intervention program staff can use this monograph and other materials to examine all aspects of their program practice and to refine their work with families in light of the continued evolution of best practices for the IFSP. At the policy level, families can use the document to collaborate on the development of responsive early intervention systems, programs, and services. At the service delivery level, families can use the document to ensure the development of Individualized Family Service Plans that match family concerns, priorities, resources, and choices.