The Changing Environment of Early Intervention Services: Implications for Practice

Barbara Hanft

Key Words: family • history • legislation • pediatrics

A new plan for providing early intervention services for very young children and their families has been established with Part H of the Education of the Handicapped Act Amendments of 1986, Public Law 99-457. Each state is currently exploring how it can best develop one comprehensive system of care that combines health, education, social, and family services.

Health practitioners have traditionally provided early intervention services in medical settings such as hospitals and local health departments since the early 1900s. Educators, prompted by federal legislation, have provided early intervention services in the public schools primarily since 1975. Occupational therapy practitioners work in both medical and educational settings and must now meet the numerous challenges and opportunities in developing comprehensive, family-centered, community-based care for very young children with special needs. This paper traces the historical development of early intervention services and discusses the major practice issues associated with implementing Part H of the Education of the Handicapped Act Amendments of 1986.

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Early intervention encompasses a wide range of services provided for families with young children, from birth through 2 years of age, who are developmentally delayed or are at risk for developing delays. This population includes three groups: (a) those with obvious inherited or biological conditions such as Down syndrome or cerebral palsy, (b) those with medical problems such as seizures or low birth weight indicating risk of developmental delay, and (c) those who are subject to environmental risks such as neglect or parental drug abuse (Tjossem, 1976). Often developmental delay will be due to a combination of factors: An infant born with fetal alcohol syndrome will have an obvious medical condition and some developmental delay; the mother’s alcohol addiction may limit her ability to properly care for her baby, which places the infant at further risk for developmental delay.

Although infants and toddlers with developmental delay are a diverse population, there are similarities in the services they need. Young children, whether or not they are delayed, are totally dependent on their families for care and nurturing. Hence, the current emphasis in early intervention programs is on family services that enable parents and other caretakers to help their children grow and develop. These services can be delivered in the home, day-care site, or center-based program.

Many families of children with developmental delay need multiple, complex services that reach beyond the practice of any one discipline. The expertise of different professionals is usually required to provide a comprehensive assessment of the child’s development in physical, cognitive, psychosocial, language, and self-help domains. Families’ resources must be considered along with their need for services to help them care for their children. Finally, a therapeutic service plan must be designed and implemented in collaboration with the family.

Occupational and physical therapists, speech-language pathologists, audiologists, physicians, nurses, psychologists, and social workers have traditionally furnished health and social services to very young children with special needs. With the increasing recognition of the benefits of early intervention and the eventual need by some children for special education services, educators have also begun to work with very young children in public schools and early intervention settings (McCollum, 1987; Neisworth & Bagnato, 1987).

When health, social, and education services for very young children and their families are provided within an interagency system, the coordination of public and private programs for the benefit of the family becomes possible. Such a system coordinates the fiscal and programmatic responsibilities of all ser-
Early Intervention: A Historical Perspective

Since the early 1900s the health care system has provided services for very young children with delays in medical settings such as hospitals and local health departments. Currently, physicians, nurses, and social workers are the first contact for the majority of families with young children experiencing developmental delay.

The education system, on the other hand, generally did not provide early intervention services to preschool children until the Education for All Handicapped Children Act (Public Law 94-142) was enacted in 1975. At this time, the federal government encouraged schools to serve children under 6 years of age by making preschool incentive grants for specialized programs available to state educational agencies. By 1985, eight states provided special education and related services to children from birth through 2 years of age, and 31 states plus the District of Columbia served children from 3 through 5 years of age (U.S. Senate, 1986).

A historical review of early intervention services reveals two important points regarding the creation of a statewide system of care for infants with delay. First, there has been little overlap between health and education programs in the majority of states. State agencies implementing national programs with a health focus for children work with the U.S. Department of Health and Human Services. State and local education programs for children with disabilities come under the umbrella of the U.S. Department of Education. Thus cooperative agreements and lines of communication between health and education agencies at the local, state, and federal levels must be developed.

Second, both health and education early intervention services, at different points in time, grew out of programs for able-bodied children of different ages. Health programs have always targeted infants and toddlers whereas education programs have generally addressed the school-age child, beginning with 5- or 6-year-old. This has had an impact on how families secure services, their expectations for what kinds of services they will receive, and the nature of their involvement in programs.

Both the separate development of services and their evolution from programs for able-bodied children of different ages are vital to understanding the changes in early intervention practice highlighted by Part H of the EHA.

Health programs. The federal government first focused on issues affecting the well-being of children of all ages when it established the Children's Bureau in 1912, largely in response to concerns about the problems of child labor. The bureau's initial investigation of infant mortality was the first of its kind in any nation and identified family income, housing, and sanitation as crucial factors in determining whether infants and mothers lived or died (Davis & Schoen, 1978).

Julia Lathrop, the first chief of the Children's Bureau, presented a plan for the “Public Protection of Maternity and Infancy” in her annual report to Congress in 1917 (Eliot, 1972). She detailed the need for nationwide early intervention services, including centers for well baby care and public health nurses to instruct and serve mothers. Eventually, the Children's Bureau helped influence Congress in 1921 to enact the Maternity and Infancy Act, also known as the Sheppard-Towner Act.

This was the first federal law to provide grants-in-aid to the states for health services (previously, federal aid to states had been allocated only for agriculture, vocational training, and road construction). The states' maternal and child health services promoted birth registration, fostered cooperation between public health authorities and health providers, and established infant welfare and maternity centers (Bailey, 1983).

The Great Depression in the 1930s influenced Congress to enact the Social Security Act in 1935 (Bailey, 1983). Title V of this act established two state grant programs, one for Maternal and Child Health (MCH) services and the other for Crippled Children's Services (CCS). This was the first time that the federal government created a health program specifically for children with disabilities (Bailey, 1983). Neither MCH nor CCS, however, was designed to provide services to children with mental disabilities. The state MCH programs generally focused on preventive health care services such as prenatal clinics, maternity nursing services, and immunization and school health programs. The CCS programs initially treated children in need of orthopedic services or plastic surgery. Services were later expanded to treat children with rheumatic heart conditions and congenital heart disease (Davis & Schoen, 1978). Today, the Children's Bureau is part of the U.S. Department of Health and
Human Services, as are the CCS and MCH programs. Recent federal legislation changed the designation of Crippled Children's Services to Children with Special Health Needs.

Education programs. Education historically has been viewed as the responsibility of the states. Public programs for educating children without disabilities have been available since the early 1800s (Oryshke-wych, 1979). States began educating children with disabilities with the establishment of schools for children with specific disabilities. In 1823, Kentucky established a state school for the deaf. Similarly, one of the earliest federal programs for educating young adults with disabilities was established in 1864 when President Lincoln signed a bill creating Gallaudet College, an institution of higher education for the deaf (Weintraub & Ballard, 1982).

State and local policy for educating children with disabilities expanded during the period from 1850 to 1910. In 1869, Boston established the first public day school for the deaf. In Providence, Rhode Island, classes for children with mental retardation were established just before 1890; at about the same time, Chicago started classes for children with physical disabilities and visual impairments. New Jersey was the first state to adopt a special education law in 1911.

The federal government first attended to the problems of educating school-age children with disabilities in 1966 when Congress created a grant program for the states to educate children with disabilities. Additionally, a federal Bureau of Education for the Handicapped (BEH) was created within the Office of Education in the Department of Health, Education and Welfare (now called the Office of Special Education Programs and located in the Department of Education). Education services for preschool children were initially authorized under the Handicapped Children's Early Education Assistance Act of 1968. However, all services were discretionary.

In 1970, Congress enacted Public Law 91-230, the Education of the Handicapped Act (EHA), authorizing funding for regional resource centers for deaf and blind children, experimental early childhood education programs, and personnel training. In the early 1970s, judicial decisions ensured that children with disabilities will have access to public education. Federal mandates enacted in 1974 included parental rights and requirements that children with disabilities be taught in the "least restrictive environment" with peers who were not disabled.

A national deadline (in 1980) requiring states to educate children with disabilities was finally provided in 1975 when Part B of EHA commonly known as Public Law 94-142, was enacted. However, children under 5 years of age were not included in this guarantee for services unless education was available for able-bodied students between the ages of 3 and 5. Public Law 94-142 guarantees each child a free, appropriate education, including special education. Related services, such as occupational therapy, are required only if documented on the student's individualized education program (IEP) and must be designed to help him or her benefit from special education.

Public Law 99-457: Early Intervention

Congress enacted the Education of the Handicapped Act Amendments of 1986, Public Law 99-457, because of an urgent and substantial need for early intervention services to minimize the cost of future education and institutionalization to society (U.S. Congress, 1986). Public Law 99-457 added an eighth subpart to the EHA by establishing Part H, a discretionary early intervention program to award grants to the states to develop and expand comprehensive services for infants and toddlers and their families. Part B of EHA was also expanded to provide special education and related services to preschool children with disabilities aged 3 through 5 years.

Recognizing that early intervention services in many states were provided in separate health and education programs, Public Law 99-457 encourages states to develop one interagency system, addressing four major needs: (a) to enhance the infant's development and minimize delay; (b) to be cost-effective by reducing future educational costs; (c) to establish community-based programs, reducing the likelihood of institutionalization; and (d) to support families in their quest to meet their children's special needs [20 U.S.C. §1471 (a) (1987 Supp.)].

In the provisions of Part H, there are three major implementation issues of interest to practitioners: interacting with families, working in an interdisciplinary team, and providing services in an interagency system.

Family focus. Part H emphasizes the essential role of the families in facilitating the growth and development of their children with special needs. The law contains numerous provisions designed to facilitate family involvement in services, from assessment and design of the therapeutic plan to membership on each State Interagency Coordinating Council.

Early intervention services include family training and counseling and must be designed to meet the developmental needs of the infant or toddler in one or more of the following areas: physical, cognitive, language and speech, psychosocial, and self-help. Children are eligible for services if they are delayed in at least one of these five areas or if they have a diagnosed physical or mental condition which probably will result in developmental delay. States have the option of providing services to children environmen-
tally at risk for becoming "substantially delayed" if early intervention services are not provided [20 U.S.C. §1472 (1) (B)]. Each state is also given the authority to define developmentally delayed.

The plan for intervention services must be documented on an individualized family service plan (IFSP) developed by a multidisciplinary team, including the parent or guardian. Each child receives an annual evaluation, and the family is provided with a review of the IFSP at 6-month intervals.

Interdisciplinary services. Occupational therapy is included in the definition of early intervention as one of the ten primary developmental services. This means occupational therapy can be provided independent of the infant's or family's need for other psychological, health, or education services. Occupational therapy is not considered a related service supporting special education, as defined in traditional school programs under Public Law 94-142. The complete list of early intervention services includes family training, family counseling, home visits, special instruction, speech-language pathology and audiology, occupational therapy, physical therapy, psychological services, case management services, medical services only for diagnostic or evaluation purposes, early identification, screening services, assessment services, and health services necessary to enable the infant or toddler to benefit from the other early intervention services [20 U.S.C. §1472 (2) (E)].

Another Part H provision requires that early intervention services be provided by qualified personnel, including occupational therapists, who are "appropriately and adequately prepared and trained." For each area in which personnel are providing early intervention services, the state must establish and maintain standards consistent with state licensure or certification. If standards are not based on "the highest requirements in the state applicable to a specific profession or discipline," then the state must document its plan to retrain or hire personnel to meet appropriate professional requirements [20 U.S.C. §1476 (b) (13)]. This means that state licensure requirements for occupational therapists must be followed by early intervention programs. Moreover, state agencies can require specialized training for those working with children from birth to 2 years of age, if they desire.

Interagency system. Critical provisions of Part H require interagency responsibility for programs [20 U.S.C. §1476, 1479, and 1482]. State departments of education, human resources, health, developmental disabilities, and mental health must all collaborate to provide comprehensive programs to infants and their families.

Federal funds under Part H can be used for planning, developing, and implementing statewide systems for providing early intervention services. All services must be provided at no cost, unless state or federal law allows fees. Any such fees must be on a sliding scale. Funds may also be used for the general expansion and improvement of services already available. However, federal funds are the "payer of last resort" for direct program services [20 U.S.C. §1481 (a)]. This means that federal funds may not be used when there are other public, private, federal, state, or local monies available. It becomes critically important, therefore, to achieve efficient and effective interagency participation throughout each state.

To ensure that a comprehensive program of care is provided to all eligible children and their families, the law requires that each state must do the following:

- Adopt a definition of developmentally delayed
- Develop a timetable to provide services within 5 years
- Provide for timely multidisciplinary evaluations and family needs assessment
- Use individualized family service plans (IFSP), including case management
- Establish a comprehensive child find and referral system
- Conduct a public awareness program
- Compile a central directory of services, experts, and resources
- Develop a comprehensive system of personnel development
- Establish a lead agency to administer, supervise, and monitor the program and develop interagency agreements
- Establish a contracting process or make other arrangements with service providers
- Develop a payment system
- Develop procedural safeguards
- Establish and maintain personnel standards
- Develop a data collection process

Since Part H programs are discretionary, there is no national deadline for providing early intervention services. However, each state must set up its own identification, evaluation, and intervention programs according to a 5-year timetable. Since all states and territories applied for federal funds in 1987, they all must meet the 14 requirements described above by 1991 in order to continue receiving federal dollars. This includes demonstrating that a statewide system of appropriate early intervention services is being provided to infants and toddlers with disabilities.

Implementation Issues
The success of Public Law 99-457 will rest on the willingness and capabilities of the education, social service, and health care communities to work together and develop new systems of services and
methods of collaboration. As states develop and expand their early intervention programs, there are numerous issues and concerns regarding interdisciplinary cooperation, collaboration with families, and interagency services that must be addressed by service providers and administrators. Table 1 outlines the major implementation questions posed in these three areas for occupational therapists and other providers. Specific issues identified in Table 1 and related to occupational therapy practice are discussed as follows.

Interdisciplinary cooperation. Numerous professional groups are currently working to define the competencies their members need to have to serve developmentally delayed infants and toddlers and their families. At a minimum, each professional must understand typical and atypical infant development as well as how to interact effectively with families. Each profession also must consider how to define its contribution in early intervention. With regards to occupational therapy the following definition has been suggested for describing early intervention services under Part H for both the child and family:

"Occupational therapy" means services provided by a licensed or certified occupational therapist to address the functional needs of a child related to performance of self-help skills, adaptive behavior and play, and sensory, motor, and postural development. These services are designed to help families and other caregivers improve the child's functioning in home, school, and community settings, and include—

1. identification, referral, assessment, intervention and consultation;
2. adaptation of the environment, and selection, design and fabrication of assistive and orthotic devices to facilitate development and promote the acquisition of functional skills; and
3. prevention or minimization of the impact of initial or future impairment, delay in development, or loss of functional ability. (AOTA, 1988)

The occupational therapist's perspective on service provision will influence his or her formulation of goals and therapeutic activities for each child and family (AOTA, in press). This perspective helps define the outcome of occupational therapy services. Therapeutic intervention can be recommended to prevent further delay, remediate an underlying neurodevelopmental problem, or compensate for a delayed or nonexistent function. It is crucial that the family's, as well as other team members', needs for and conceptualization of occupational therapy services be solicited by the therapist.

Table 2 presents five perspectives for providing occupational therapy for Jason, a 5-month-old boy with Down syndrome. Jason needs early intervention services to address his low muscle tone and delayed motor skills, feeding problems, congenital heart anomalies, and decreased alertness. Family resources include a motivated single mother with extended family support nearby and two older siblings who are very interested in playing with their brother. Jason's

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Table 1
Implementing Public Law 99-457: Practice Issues Affecting Early Intervention Professionals

<table>
<thead>
<tr>
<th>General Practice Issues</th>
<th>Implications for Occupational Therapy</th>
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<tr>
<td><strong>INTERDISCIPLINARY ROLES AND FUNCTIONS</strong></td>
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<td>What is the nature and scope of early intervention services? What generalized knowledge must all early intervention professionals possess?</td>
<td>• What is the occupational therapist's role in relation to other professionals? • What is the certified occupational therapy assistant's role in early intervention? • Where and how do occupational therapists receive specialized training in early intervention? • Are there specialized early intervention roles in occupational therapy, i.e., in the neonatal intensive care unit or in case management?</td>
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<tr>
<td><strong>COLLABORATION WITH FAMILIES</strong></td>
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<td>How do early intervention professionals provide family-centered services as compared with child-centered therapy? How are effective interactions between families and early intervention personnel best achieved?</td>
<td>• How do you involve the family in the child's occupational therapy assessment and intervention? • How do you provide family-centered assessment and involve parents in goal setting? • How can you best provide occupational therapy for families with diverse ethnic, cultural, and racial backgrounds? • How does occupational therapy enhance the child's development and support the family as primary caregivers?</td>
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<tr>
<td><strong>INTERAGENCY SYSTEM</strong></td>
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<td>How can comprehensive early intervention services best be delivered in each state? How do payment and due process requirements affect service delivery? How do various professionals work in a system where all services may not come from a single agency?</td>
<td>• Which service delivery models (monitoring, direct service, and consultation) will most effectively meet the needs of different families? • How do you provide occupational therapy when direct services may not be available? • What responsibility does the occupational therapist have for follow-up and consultation with other service providers?</td>
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Table 2  
Occupational Therapy Intervention for a 5-Month-Old Boy

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<tr>
<th>Practice Perspective</th>
<th>Examples of Occupational Therapy Goals and Activities</th>
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| Prevention: (check the negative effect of developmental problems on future abilities) | • Develop awareness of body parts through sensory input to prevent spatial orientation problems  
• Increase attention and eye contact to enhance interaction with others |
| Habilitation: (promote developmental acquisition of future skills) | • Develop child’s head control through movement, neuromuscular facilitation, and positioning  
• Enhance basic oral-motor functions of breathing, sucking, and swallowing in preparation for speech |
| Remediation: (attempt to diminish dysfunction) | • Decrease drooling through neuromuscular facilitation to mouth  
• Enhance interaction through alerting techniques before play |
| Compensation: (substitute different skills for delayed ones) | • Encourage mother and father to carry child in baby carrier (“snugli”) until child can move on his or her own  
• Position child so pacifier remains in mouth |
| Maturation: (utilize child’s own developmental schedule) | • Provide appropriate toys to enhance visual attention in crib and play areas  
• Offer finger foods during meals as child develops pincer grasp |

strengths include his emerging head control and positive response, although brief, to family members.

Each of the five perspectives provides the basis for equally important occupational therapy intervention for Jason at different points in his development. The therapist must be sensitive and know when to use each perspective or combine them to achieve specific results. Most important, the therapist must know how to collaborate with other team members to provide services that will enhance the parents’ roles as primary care givers. Communication and negotiation skills are essential since the occupational therapist is not likely to be the only service provider involved with the family.

Collaboration with families. Providing family-centered, rather than child-centered, therapy requires professionals to reconsider for whom services are primarily designed. Typically, professionals trained in the medical model treat a patient’s problems and prescribe intervention based on clinical judgments and accepted protocols. Professionals trained in the educational model teach academic and readiness skills, selected from a standard curriculum, according to students’ individual behavior and learning styles.

Although occupational therapists traditionally have followed the medical model, providing child-centered therapy, they have considered working with parents an important part of pediatric care (Poncher & Richmond, 1947; Brungate, 1949; Tyler & Chandler 1978). Recently, the need to develop collaborative and supportive relationships with families and other care givers as a primary aspect of occupational therapy intervention has been acknowledged (Day, 1982; Friedman, 1982; Anderson & Hinojosa, 1984; Burke, Clark, Hamilton-Dodd, & Kawamoto, 1987; AOTA, in press). The nature of this relationship depends on the experience of the occupational therapist, the role of other professionals, the availability of services, and the desires and resources of parents.

Family-centered care, then, recognizes the individual resources and needs of three partners—the child, the family, and the service provider(s)—in an interactive system. For example, providing speech-language therapy to Sharon, a 2-year-old girl with delays primarily in motor and language development, may meet the girl’s need to develop communication skills. Her parents may also need support and counseling to help them care for their child who is not communicating in the expected manner. Occupational therapy to improve Sharon’s oral-motor skills could be provided through direct service to her and through consultation to the parents, other therapists, and social worker.

Each child and family also have their own personal and community resources. These need to be identified as the base upon which to provide services. In the example mentioned above, Sharon may have a strong desire to communicate and may be willing to try again and again to get her message across. The parents have friends and family who are willing to provide respite and assistance with suggested therapeutic activities. The service needs of this family would be very different from those of a single, adolescent mother who is living alone and has no support system to help with parenting her child with developmental delay. How families cope with the stresses of...
daily life, as well as the additional stress of parenting a child with a disability, influences the overall functioning of the family and therapeutic outcomes. (Beckman-Bell, 1981; Turnbull, Summers, & Brothers, 1983).

The service providers, as the third partners in this system, contribute resources in many different forms, from therapeutic programming for the child to support and instruction for the parents. Each professional, as a collaborator, must design services together with the family and other service providers to facilitate the child’s growth and development. The extent of the families’ involvement should depend on their desires and capabilities.

This last point, that families can choose services as well as how involved they want to become in implementing them, is essential to the success of any therapeutic program. It rests on the view that each family has its own set of values, needs, and resources related to the care of its child. There is not one best way to interact with all families since each has different service needs and support systems. Identifying the needs and resources of each family and the degree to which the family wants to become involved in early intervention services is the center piece of effective collaboration.

Interagency Services. Public Law 99-457 was approved by education committees in Congress and will be administered by the U.S. Department of Education. A cooperative agreement with the U.S. Department of Health and Human Services has been written because the health care system must be primarily involved in the identification of children as well as in the provision of services. The actual implementation of early intervention services within each state will require the coordination of funds from the state department of education, Title V programs for Maternal and Child Health and Children with Special Health Needs, Medicaid, and other public and private agencies.

For early intervention providers, one of the basic issues will be who will fund the services, particularly those that can be viewed as both education and health related, such as occupational therapy or audiology. Public Law 99-457 specifies that Part H funds may not be used to fund services that would have otherwise been paid for by other public or private sources, such as the public school system. In addition, states may not reduce medical assistance or alter eligibility for Title V services and Medicaid.

A second issue regards eligibility for services and the definition of developmental delay each state chooses to adopt. Public Law 99-457 gives each state the authority to define who qualifies as developmentally delayed for early intervention services. By setting either restrictive or broad criteria, states will have some influence over expenditures for services. Federal funding for Part H actually supplies only a very small proportion of the actual program cost in each state.

A third issue is the flexibility of the program in meeting the individual needs of young children whose developmental needs vary markedly and of their families whose service needs differ according to their own financial and psychosocial resources. In addition to identifying when to use specific service perspectives, occupational therapists must also address how best to provide their services.

Models of direct service, consultation, and monitoring (supervising others carrying out occupational therapy recommendations) have been discussed in relationship to school-based practice for older children (AOTA, 1986). Applying these models to early intervention practice requires expanding the occupational therapist’s traditional role as direct-service provider to one of consultant and case manager. The occupational therapist may be one of several service providers from different agencies contributing knowledge of the child’s and family’s needs for services. Part H mandates that one case manager “from the profession most immediately relevant to the infant’s and toddler’s or family’s needs” will be responsible for implementing the IFSP and coordinating services [20 U.S.C. §1477 (d) (6)]. Although the role of case manager may be new for occupational therapists, many of its functions as service provider, advocate, and referral source are not.

Conclusion

Early intervention practitioners, including occupational therapists, must redefine their services to meet the numerous challenges inherent in the changing political, financial, and social environment prompted by Part H of Public Law 99-457. These challenges center on developing comprehensive, family-centered and community-based care for young children with developmental delays and for their families. Previously, early intervention services were provided to children with disabilities at birth by health programs and later, at school-age, by the public schools. Occupational therapists, who work in both medical and educational settings, must focus their efforts on contributing to the development of comprehensive early intervention services that integrate health, education, and family services in one system throughout each state. Cooperative agreements between agencies to develop a continuum of services will place additional emphasis on consultation and monitoring as primary service models. Providing consistent follow-up and interacting with family members and professionals from different agencies will become paramount to effective consultation in an interagency system.
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