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## ABSTRACT

This issue of the "Early Childhood Bulletin" consists of excerpts from recommendations prepared by the Education Task Force of the Consortium for Citizens with Disabilities (CCD), which were presented to the Senate and the House of Representatives as part of the reauthorization of Part H of the Individuals with Disabilities Act (IDEA). The CCD is a working coalition comprised of more than 65 national consumer, advocacy, provider, and professional organizations that advocate on behalf of more than 43 million Americans with disabilities. Items that are of particular relevance to families of children with disabilities and to parents serving on Interagency Coordinating Councils (ICCs) include: (1) procedural safeguards; (2) use of assistive technology; (3) case management issues; (4) minority and cultural issues; (5) the family as locus of control of services; (6) parent training and support; (7) ICC composition; and (8) schedule of sliding fees. (SG)

COALITION QUARTERLY  
EARLY CHILDHOOD BULLETIN  
SUMMER  
1991

RECOMMENDATIONS ON THE REAUTHORIZATION  
OF PART H OF THE INDIVIDUALS WITH  
DISABILITIES EDUCATION ACT

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# EARLY CHILDHOOD BULLETIN

*News by and for Parent Members of State Interagency Coordinating Councils*

Summer

Prepared by NEC\*TAS Parent Network Staff

1991

## Recommendations on the Reauthorization of Part H of the Individuals with Disabilities Education Act

Consortium for Citizens with Disabilities  
Education Task Force

### Excerpts

As part of the reauthorization of Part H of the Individuals with Disabilities Education Act (IDEA, formerly the Education of the Handicapped Act), both the Senate and the House of Representatives held hearings recently. The following excerpts are from testimony prepared by the Education Task Force of the Consortium for Citizens With Disabilities (CCD). These recommendations were developed following extensive discussion and analysis of the current implementation of Part H. The CCD is a working coalition comprised of more than 65 national consumer, advocacy, provider, and professional organizations which advocate on behalf of

more than 43 million Americans with disabilities. The National Parent Network on Disability is a CCD member.

Items of particular relevance to families and to parents serving on ICCs are included here. *Early Childhood Bulletin* readers will recognize many of the issues as ones ICC parents identified at the 1990 Partnerships for Progress Conference and reported in the Winter/Spring issue of this *Bulletin*. Interested readers may receive the complete document by contacting the Federation for Children with Special Needs, 95 Berkeley Street, Boston, MA 02116; telephone (617) 482-2915.

### Procedural Safeguards

The early intervention service system is an entitlement program. Infants and toddlers who meet the state's eligibility criteria, and their families, have a right, enforceable in law, to receive early intervention services and family support services in participating states.

While infants and toddlers with disabilities and their families are entitled to early intervention services, participation of families in the Part H system is voluntary and must remain so. Participating parents must be provided the information they need to make informed decisions about how their children (and they themselves) will receive services and supports, and states must fill in a number of gaps in the procedural safeguards system; CCD has several recommendations for further fortifying parental protections, as follows:

1. **Confidentiality of records:** Public and private agencies should not be permitted to exchange information freely without parental consent.
2. **Informed consent on IFSP [Individualized Family Service Plan]:** The IFSP should be fully

explained to and signed by the parents as evidence of their informed consent to the provision of services in the plan. Parental consent is "informed" when:

- The parent has had explained to him/her all information relevant to the activity(ies) for which consent is sought in the parent's native language or other mode of communication.
  - The parent understands and agrees to the carrying out of the activity(ies).
  - The parent understands and the IFSP specifies which records, including physical documents and recorded information, will be released and to whom.
  - The parent understands that the granting of consent is voluntary, and may be revoked at any time.
3. **Parental right to refusal of some services:** Parents may refuse a particular service recommended by the interdisciplinary team without jeopardizing their right to the remainder of services. The IFSP form should allow the parents to

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indicate refusal for some of the proposed services. The parents' refusal may be overridden only if such refusal constitutes child abuse or child neglect as determined by appropriate procedures.

4. **Inclusion in natural environments:** The natural environment for an infant is the family; the natural group environments for infants and toddlers in today's society are day care centers, preschools, and other group settings with age-mates. CCD feels strongly that infants and toddlers with dis-

abilities should be included in these natural environments consistent with Title III, Public Accommodations, of P.L. 101-336, the Americans With Disabilities Act (ADA). We recommend that language be inserted in Part H to recognize the importance of including infants and toddlers with disabilities in these natural environments. We will work with the Subcommittee to identify statutory language that will operationalize these values.

### **Inclusion of Assistive Technology Services and Devices Under the Definition of Early Intervention Services**

CCD recognizes the critical importance of assistive technology in liberating many infants and toddlers with disabilities and their families from barriers encountered in all aspects of daily living, and in significantly enhancing learning and development. We have been made aware of many instances in which the provision of assistive technology has dramatically altered prospects for a child's future—where access to technology has resulted in labels being dropped, in the provision of opportunities in integrated environments, in increased confidence and ability of the child, and in changed perceptions

of the child by the family and others.

Assistive technology is currently included in the regulations to the Part H. program. CCD believes that adding it to the statute will clarify that these important supports are included as part of early intervention services for those infants and toddlers and their families who can benefit, and thus ensure their provision when appropriate. We therefore recommend that assistive technology services and devices be added to the definition of early intervention services under Section 672(2).

### **Issues Relating to Case Management**

CCD recommends that the term "case management" be replaced by "service coordination," and that family members be able to act in this capacity when they so choose.

1. **Change in terminology from Case Management to Service Coordination**  
Families consistently tell us that they do not want to be referred to as "cases" nor do they want their lives "managed." CCD recommends that the term 'case management,' at the point of its initial insertion in the Act read "case management (hereafter referred to as 'service coordination'), and that succeeding references utilize the terminology "service coordination" in lieu of "case management," in order to clarify the original intent of the law — that the family is the locus of control of services. The term "service coordination" is compatible with the current Part H regulatory definition of "case management." Because of concern over potential jeopardy to Medicaid financing for "integrated case management," we further suggest inclusion of report language to clarify that the Committee intends for the Secretary of HHS to continue to fund service coordination activities for Part H under Medicaid's state plan option for targeted case management.

2. **Family members as service coordinators**  
CCD recognizes that a second issue with respect to services to the family is the current regulation which precludes family members from serving as the case manager (service coordinator) for their child. Some families may wish to share the service coordination responsibility with a professional. Statutory changes are recommended to allow families who wish to serve as service coordinators to demonstrate necessary competencies in order to assume that responsibility for their family member, and to be paid commensurate with other qualified personnel. This can be accomplished by expanding the definition of the term "qualified personnel" to include "family members trained in the delivery of service coordination" (case management).

The IFSP section should also be amended to include the possibility for a family member serving as service coordinator, with accompanying report language addressing the need for family training as a prerequisite for this role. Each state must indicate in their state plan how training will be accomplished, such as through use of the Parent Training and Information Center[s].

## Minority and Cultural Issues

CCD believes that the statutory language in Part H should emphasize that early intervention professionals be sensitive and responsive to the needs of children and families from diverse cultural and language backgrounds. Families will have different cultural histories, values, and beliefs that must be recognized and acknowledged. Families may differ in their views of medical care, the meaning of a disability, and in childrearing practices. They may also differ in their willingness to seek help, in their communication style, in the amount and type of their

participation, in their goals and in the involvement of family members. Professionals need to be sensitive to such cultural differences, and demonstrate a willingness to adapt to and respect the diverse needs of families and children from different racial and cultural groups. CCD recommends that language be added to the Act to reflect such sensitivity, including use of evaluations that are culturally unbiased, and addressing training needs in the service of a multicultural population in the comprehensive system of personnel development.

## Clarification of the Family as Locus of Control of Services

Current "best practice" in family support suggests that family support is much more than a "program" — it is an attitude. The legislative history and intent of the Part H program supports this approach by recognizing that primary care giving for infants and toddlers belongs to families — not to systems, agencies and professionals. The legislation builds on the presumption that families have strengths, are competent, and know a lot about what they need. Unfortunately, language in the statute has been interpreted by some professionals in such a way as to allow them to approach families from a

deficit/dysfunctional perspective, rather than a competency perspective, and does not clearly indicate that the family is responsible for directing the services and supports which they feel would be of greatest benefit.

Accordingly, CCD believes that the role of the family in this family-centered legislation should be more accurately reflected in statutory language. We will provide a list of specific references for inclusion as "clarifying" amendments to accomplish this goal.

## Parent Training and Support

CCD has identified a clear need to increase parental ability to participate knowledgeably in the determination of scope and intensity of service needed by their infants and toddlers. Under Part D of the IDEA, parent information and training activities are carried out through federally funded Parent Training and Information Centers (PTI) and the national Technical Assistance for Parent Programs (TAPP). Currently, each of the fifty states has a Parent Training Center. Although the language of the statute does not differentiate between the needs of parents of infants and toddlers and parents of

older children, in practice the Centers emphasize training and information for Part B parents.

CCD recommends that Congress modify the current emphasis and increase funding for the Parent Training and Information Centers (PTI) under Part D so that parents of children of all ages can equally benefit from the information and training support they provide. Further, we recommend that each funded Parent Training and Information Center receive an additional \$50,000 per year to serve parents of infants and toddlers, thus increasing the authorization levels for the PTI by \$3 million.

## I.C.C. Composition

CCD recognizes that one of the underlying principles in Part H is the inclusion of infants and toddlers with disabilities and their families in the mainstream of community life. Nevertheless, the usual practice in most communities and states is to exclude representatives of generic community resources from policy and program planning. This traditional practice often results in these generic resources being perceived as a part of the problem. By including individuals representing these resources in the planning process, we have the opportunity to let them become part of the solution. This value-based policy

takes on further statutory importance as a result of the specific listing of day care centers and private preschools as entities required to be in compliance with the public accommodation mandate of Title III of the Americans with Disabilities Act.

Therefore, CCD recommends that statutory language regarding the I.C.C. specify that its composition include at least one provider of generic day care or pre-school services, and that at least two of the other members be from "outside" the disability community. In addition, in view of the increasing role that third party private insurance is

expected to play in the financing of Part H services, we recommend that the statute be amended to mandate that one of the Governor's appointments to the I.C.C. must be the state insurance commissioner. This person's presence on the I.C.C. will greatly enhance his/her understanding of the program and facilitate improved communication for families, providers and policy makers with insur-

ance companies.

CCD further recommends that the Director of the Parent Training and Information Center in each state be included on the I.C.C. In addition, because of the importance of parental participation on this Committee, CCD recommends that as a state expands the I.C.C. composition to incorporate these recommendations the overall percentage of parents be maintained.

### Schedule of Sliding Fees

The Findings in P.L. 99-457 relative to the establishment of the Part H program strongly state the benefits to society, to taxpayers, and to state and federal government, as well as to the child and family, of the provision of family-centered early intervention and family support services in order to reduce educational costs to society, to minimize the likelihood of institutionalization, to maximize potential for independent living, and to enhance the capacity of families so that they will not seek out of home placement.

Current law allows the use of a sliding fee schedule in the implementation of the Part H program. CCD is concerned that such a fee schedule becomes a significant barrier for some families, particularly low-income and minority families, to access the supports and services necessary to achieve the intended benefits of the program. We realize the critical importance of accessing Medicaid to fund some of the early intervention services authorized under Part H. We further recognize that ability to

pay technically cannot be a reason to deny services. However, we question whether the reality of implementation of a schedule of sliding fees is in fact [a question] of services delayed or denied. In addition, we are particularly concerned about the sliding fee schedule in light of the President's budget request, which emphasizes that the Department of Education intends to actively promote such a system. For many non-Medicaid services, the costs of administering a program of sliding fees essentially "washes out" any financial benefits gained from such a program.

CCD strongly recommends that the Subcommittee carefully examine this sliding fee system as it relates to the part H program in order to better understand its practical effect on infants and toddlers with disabilities and their families. CCD is strongly opposed to the addition of any provisions which would mandate, or in any way penalize or otherwise bias a state's decision regarding whether to implement a schedule of sliding fees.

OSEP/NEC\*TAS  
ICC Parent Meeting  
September 11 - 13, 1991  
Hyatt Regency  
Crystal City  
Arlington, Virginia

For more information,  
ICC parents can contact their ICC Chair,  
Part H Coordinator or  
Mimi Holt at the NEC\*TAS Coordinating Office,  
(919) 962-7317.

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