



nectac notes

The National Early Childhood Technical Assistance Center

Issue No. 22

January 2007

To Fee or Not To Fee: That Is The Question!

by Susan D. Mackey Andrews and Anne Taylor

Across the country, state planners and stakeholders continue to be challenged with ensuring a stable and adequate financing foundation for their Part C early intervention system. Increased enrollment (excluding children at risk) from 2001 to 2004 has been documented for all but nine states¹ and one Territory. Further, the challenges that states face related to implementing the “natural environment” requirements of Part C have placed additional demands at the state and local levels in terms of changes in practice, training and technical assistance needs. With this comes the potential for increased costs due to additional provider time and travel expenses. The difficulty of some states to “keep pace” with the latter demands has affected provider availability and resulted in reduced services for some children, and waiting lists for others. Clearly the financial issues for most states are a considerable challenge.

This landscape is further complicated by federal and state budget issues, including the potential for reductions in the federal contributions for key partner resources to most state Part C systems. Clearly, the effective and efficient access to and utilization of a variety of resources are not only required by the federal legislation, but are key to ensuring a viable Part C system. As these challenges to states continue to materialize, nearly all states report more pressure to access the personal resources of families enrolled in early intervention. The focus of this paper is the broad category of family cost participation (FCP), providing a general overview of what is permissible under current federal regulations under a “state system of payments” and how FCP can be structured within this requirement, including a discussion of public policy implications.

¹ FL, TX, MS, NC, KY, AK, CO, MN, UT, and DC

Continued...



UNC

FPG CHILD DEVELOPMENT INSTITUTE

Many states used their Part C federal funds to support the provision of services to eligible children in the early days of Part C implementation, rather than supporting systems development and infrastructure work. This created a perception of Part C as a “program” rather than a “system,” as intended by Congress, resulting in the loss of many of the financing opportunities that were in existence prior to 1991. Technical assistance requests from states often cite economic downturns at the state and federal level have resulted in budget cuts, reductions, and required priority changes in many programs and services in their state. This often is affecting Part C directly or indirectly through their funding partners. It is anticipated that budget reductions will have an equal effect upon federal resources allocated to support state initiatives contributing to Part C at the regional/local level.

The complex, interagency “quilt” of potential resources, as established in federal statute and regulations, offers a potentially rich variety of resources to assemble and ensure appropriate and needed services for each family with an eligible child. Yet few states have been able to master these resources into a manageable “system of payments” as appears in current federal Part C regulations (2004). Many states still struggle with developing a system of payments that includes an array of federal, state and local resources. Many states report that, without additional federal support (i.e. Medicaid, Title V, TANF, etc.) in leveraging resources to help implement Part C, accessing these resources is impossible at the state level. Possibly the most uncomfortable and difficult resource for states to incorporate has been that of family cost participation.

For our purposes in this paper, we will speak about FCP as the use of family resources, namely, private insurance and/or the direct

family payment of a fee structured specifically by the state Part C system. The first section of this paper defines the financing foundation for Part C, as established by Congress in 1986 and strengthened through a series of reauthorization activities since the original legislation. The second section discusses FCP from an implementation perspective. Why is this such a hot topic now, nearly 20 years after the passage of P.L. 99-457? The last section offers recommendations and policy considerations to planners and stakeholders as they study the development or revision of FCP for their own Part C system.

As we welcome families to Part C of the Individuals with Disabilities Education Act (IDEA), they invariably have three major questions to ask us:

1. Is my child eligible?
2. What does early intervention provide and what will it do for my child/our family?
3. How much will it cost?

Section I

Financing Foundation For IDEA Legislation Related To Family Cost Participation (FCP) -- Federal Part C

In 1986, P.L. 99-457 was enacted specifically authorizing Part C², Infants and Toddlers with Disabilities Program (for infants and toddlers, age birth-3). Congress was adamant that they were not formally authorizing a new entitlement program for infants and toddlers. Their intent was to ensure that all existing resources remained in place to support the service delivery system for infants and toddlers with developmental delays or disabilities and their families. In fact, in the Purpose Statement of the legislation, the second reason for providing federal funds to states

² Then, Part H of the Education for the Handicapped Act (EHA).

for Part C was to: “Facilitate the coordination of payment for early intervention services from Federal, state, local, and private sources (including public and private insurance coverage)...”³ This language has remained intact through the reauthorization of Part C of IDEA in 2004.

For most states, the passage of P.L. 99-457 did not introduce the concept of services to their most vulnerable young population; most states had some sort of service system in place prior to this point in time. These systems were largely rooted in the private, not-for-profit sector, which had been serving many populations with disabilities dating back to the early 1900’s. Four (4) states⁴ actually had special education “mandates” under Part B that included children under the age of three. However, eligibility for these services was typically quite restrictive. Services in both the public and private sectors were typically “free,” that is provided at no cost to families. They relied upon a blend of state and federal funds, used Medicaid and private insurance, and were highly dependent upon public and private charitable contributions such as United Way and foundation grants.

P.L. 99-457 marked the efforts of Congress to encourage states to develop comprehensive, coordinated, community based and interagency systems of services for families with infants and toddlers under the age of three with a disability or developmental delay. Services to at-risk children were and continue to be optional for each state. Currently eight states/territories include at-risk in their eligibility definitions⁵.

Part C: Not A Traditional Entitlement

³ Emphasis by the authors.

⁴ IA, MD, MI, NE.

⁵ CA, GU, HI, IN, MA, NH, NM, WV.

Part B and Part C are often referred to as “entitlement” programs, meaning that each child found eligible is guaranteed to receive a certain array of needed services. Furthermore, it is commonly assumed that the individual child entitlement inherent in Part B of the IDEA is mirrored in Part C. This is not the case. The foundation of the entitlement under Part B is the Constitutional guarantee extended to all school-aged children for access to public education; perhaps our country’s only true civil right that is guaranteed irrespective of a variety of considerations including income. Each state defines when school age begins, which has been typically at kindergarten (or age five). There is no equivalent, universal guarantee of participation to children under the age of five for public education. Through P.L. 99-457, FAPE⁶ was supported for children at age three which marked a deviation from the traditional age population served through the public school systems throughout the country⁷. The guarantees that are included to families and children under Part C are inherently different from those in Part B.

Part B, addressing the special education needs of children ages 3-21, is limited to responding to the needs of eligible children within the context of public education. Services essential to ensure the participation of children within the regular public school setting and curriculum must be provided “at no cost” to the family, according to the IEP⁸. There are a myriad of other services, including those required by children that are not reflected on the child’s IEP and are beyond the scope of Part B. These services are not required to be funded through the IDEA. Part C is different from Part B in that

⁶ Free, Appropriate and Public Education

⁷ Weiner, R. & Koppelman, J (1987) *From Birth to Five: Serving the Youngest Handicapped Children*

⁸ Individualized Education Program

it focuses on establishing a system of care that is legislatively intended to incorporate the developmental, health and medical needs of eligible infants and toddlers into one comprehensive plan called the IFSP⁹. Thus, Part C is responsible for ensuring the provision of family-focused services that enhance and expand the family's ability to care for and enhance their child's development.

Eligibility also varies considerably throughout the country for Part C services, with 24 states identified by OSEP as having "broad", 13 with "moderate", and the remaining 15 with "narrow" eligibility criteria¹⁰. The criteria is based upon averaging descriptors (percent delay, age/month delay, standard deviation, and undefined variable related to if a state serves at-risk) in states' eligibility definitions. A variety of factors results in states identifying and serving very diverse percentages of children; factors which do not seem to include the diversity of eligibility criteria. For 2005, states reported serving as few as 1.34% of their 0-3 population, and as high as 5.90% (not including children at risk). The national baseline is 2.3%. Clearly how many children are being served, as well as how many could be served, are issues that directly influence the financing concerns and decisions that individual states are facing. Additional considerations include how many other resources are being accessed to support Part C services, what are the services, resources and supports being provided (type, frequency, intensity), and the average age of referral and enrollment in Part C.

⁹ Individualized Family Service Plan

¹⁰ Established by the Office of Special Education Programs (OSEP) for the IDEA Infant and Toddler Coordinators's Association 2006. Information Includes the District of Columbia and Puerto Rico

*Figure 1. 2005 Child Count Data
Summary by Eligibility Categories*

% Served - 2004 ¹¹	Broad Eligibility	Moderate Eligibility	Narrow Eligibility
>4%	4 states	3 states	N/A
3-3.99%	3 states	1 state	2 states
2-2.99%	8 states	6 states	4 states
<1.99%	9 states	3 states	9 states

Another key difference between Part B and Part C is that Part C is voluntary on the part of states, and at any point in time a state may elect not to participate, thus revoking the "entitlement" to families and children within that state. State participation in Part B, on the other hand, is mandatory. The national guarantee to FAPE is permanently authorized by Congress in federal statute, whereas Part C has not achieved this stature.

Thus, the frequent use of the term "entitlement" applied to Part C is a misnomer. Under Part C, different from Part B, families with eligible infants and toddlers are entitled to receive needed services according to the specific system that each state has defined to meet these federal requirements. These vary from state to state, and sometimes, even from locale to locale within a state. Different from mandates or traditional entitlements, Part C financing may include the use of family resources, including private or public insurance, co-payments, deductibles and/or sliding fee scales.

Part C was and continues to be envisioned by Congress with a primary role of facilitating access to resources, services and supports, not necessarily of paying for them. This priority is federally demonstrated through legislation in several ways. Perhaps the most significant way is that federal funds are assigned to states based upon their total 0-3 population and are not based upon other variables, such as the number of children

¹¹ WESTAT, 2004 Child Count for Part C, IDEA

served. Further, the priorities for allocation of federal resources are targeted towards several other federally required activities, not just service delivery.

States have a choice whether they will participate in Part C and currently all eligible states and territories do participate. To manage resources, states have been faced with difficult decisions. Some states have restricted eligibility for services; a majority of states have moved to some sort of shared payment responsibility, or family cost participation, with families enrolled in the system.

Additionally, as highlighted by language in both the statute and regulations, Congress used the opportunity under P.L. 99-457 to reinforce the provisions as stated under §300.301 and established, in the Part C Statute, Subchapter III, §1440, Payor of Last Resort requirements¹². This Section addresses both non-substitution and reduction of benefits, and currently¹³ reads:

“(a) Nonsubstitution

Funds provided under section 1443 of this title may not be used to satisfy a financial commitment for services that would have been paid for from another public or private source, including any medical program administered by the Secretary of Defense, but for the enactment of this subchapter, except that whenever considered necessary to prevent a delay in the receipt of

appropriate early intervention services by an infant, toddler, or family in a timely fashion, funds provided under section 1443 of this title may be used to pay the provider of services pending reimbursement from the agency that has ultimate responsibility for the payment.

(b) Reduction of other benefits

Nothing in this subchapter shall be construed to permit the State to reduce medical or other assistance available or to alter eligibility under title V of the Social Security Act (42 U.S.C. 701 et seq.)(relating to Maternal and Child Health) or title XIX of the Social Security Act (42 U.S.C. 1396 et seq.) (relating to Medicaid for infants or toddlers with disabilities) within the State.”

While Part B of the IDEA requires education, special education and related services to be provided to eligible children ages 3-21 “at no cost”¹⁴ to the family, Part C is very different. While some Part C services must be provided “at no cost” for the child and family, including evaluation, assessment, IFSP development, procedural safeguards and service coordination, no such parallel entitlement from Part B (e.g., “at no cost”) exists from the federal statutory or regulatory level for Part C services contained in the IFSP. In Part C, eligible children and their families are entitled to receive needed early intervention services according to the state policies and procedures established which may include “a system of payments” including a sliding fee scale; FAPE or Free, Appropriate and Public Education services at no cost to the family for infants and toddlers and their families only exists in those “birth mandate” states discussed earlier.

¹² The requirements for “payor” of last resort were further expanded in the Part C federal regulations in Policies and Procedures Related to Financial Matters including §300.520-524 inclusive, encompassing a broad array of policies related to timely delivery of services and timely payment, family cost participation, procedural safeguards and resolution of disputes, etc.

¹³ The inclusion of the Department of Defense was added in 1988; all other language existed since the original passage of the EHA in 1975.

¹⁴ Under the guidelines of Free, Appropriate and Public Education or FAPE

One issue frequently raised during a state's discussion related to FCP for Part C services is the comparison with Part B, where services are "free" under the Free, Appropriate and Public Education (FAPE) requirements. This unfortunately is an inaccurate comparison. Part B services are limited to what is needed to supporting the child to participate and be successful in the typical or regular education environment – the classroom and the curriculum. Based upon this foundation of "regular education," the IEP team identifies what special education and related services the child needs to participate in regular education. There are many services that children continue to need, often the same service(s) they received in Part C, once they become eligible for special education. However these services are not needed for the purposes of the child to participation in the regular education program. Families often use their own resources to maintain these important supports, which may be resources available to them based upon their child's eligibility for other federal or state resources such as Title V, SSI Disability, Children with Special Health Care Needs or a state's Medicaid Waiver program. Part C systems across the country assist families to access these resources and supports, and utilize these resources in the implementation of the IFSP.

Federal Regulations Defining The System Of Payments

Federal regulations governing Part C define early intervention services (excerpt) as follows:

Sec. 303.12 Early intervention services.

(a) *General. As used in this part, early intervention services means services that--*

...

(3) *Are provided—*

...

(iv) *At no cost, unless, subject to Sec. 303.520(b)(3), Federal or State law*

provides for a system of payments by families, including a schedule of sliding fees;

Thus, federal regulations speak more broadly than simply fees. They address the requirement of each state to develop a system of payments which may include sliding fees. This system of payments refers to the range of funding resources that exist at the federal, state and local level.

Defining a "System of Payments" under Part C of IDEA

Under the interagency requirements of Part C, other resources and supports bring with them their own rules and regulations. These include delineation related to: eligibility, the types of services provided, the payment arrangements (including parent participation in payment), provider requirements, etc. The implication of the language in §303.12(3)(iv) is that these existing federal or state "partner" resource regulations apply to Part C if they "fit" within the state's Part C-developed policies and procedures meeting the requirements of §303.520. Minimally, these "partner" regulations or requirements should be considered as the lead agency is developing their policies related to payments for services. The state may choose to adopt policies and procedures that exceed the federal requirements, but may not be more restrictive than the Part C regulations.

Part C of IDEA, is the first federal legislation that mandated Part C funds be payor of last resort before any other federal, state or local funds. As state planners implement the Part C "system of payments," they will need to consider the various conditions and requirements of individual fund sources in their overall policy development for early intervention services. Partner fund requirements, such as "payor of first resort," family cost participation, service definitions, restrictions, etc., should

be incorporated into each state's system of payments as it is developed. No state Part C system should expect its partner resources to "fit" their Part C system in total. The Part C quilt of financing resources requires flexibility in the assignment of resources to meet the needs of each child and family.

Several federal and state partner resources have requirements for family cost participation. State Part C systems must understand these requirements and determine if they will incorporate these considerations into their Part C family cost participation policies and procedures. Many state Title V Children with Special Health Care Needs (CSHCN) systems have implemented family "cost" conditions that include a) required use of private insurance and/or b) family fees. Part C systems utilizing Title V funds to support early intervention services need to have a discussion about whether the Title V CSHCN payments are factored in when determining costs to families.

Failing to consider the implications of other funding requirements may place the state's Part C system at risk for violating the federal requirement to ensure the provision of services, as articulated in the regulatory section entitled "Policies and Procedures Related to Financial Matters." The first section deals with policies related to payment for services; other sections set forth a variety of requirements including procedural safeguards and resolution of disputes, timely delivery and payment for services, contracting, use of interagency agreements, and payor of last resort.

Sec. 303.520 Policies related to payment for services.

(a) General. Each lead agency is responsible for establishing State policies related to how services to children eligible under this part and their families will be paid for under the

State's early intervention program. The policies must--

(1) Meet the requirements in paragraph (b) of this section; and

(2) Be reflected in the interagency agreements required in Sec. 303.523.

(b) Specific funding policies. A State's policies must--

(1) Specify which functions and services will be provided at no cost to all parents;

(2) Specify which functions or services, if any, will be subject to a system of payments, and include--

(i) Information about the payment system and schedule of sliding fees that will be used; and

(ii) The basis and amount of payments; and

(3) Include an assurance that--

(i) Fees will not be charged for the services that a child is otherwise entitled to receive at no cost to parents; and

(ii) The inability of the parents of an eligible child to pay for services will not result in the denial of services to the child or the child's family; and

(4) Set out any fees that will be charged for early intervention services and the basis for those fees.

(c) Procedures to ensure the timely provision of services. No later than the beginning of the fifth year of a State's participation under this part, the State shall implement a mechanism to ensure that no services that a child is entitled to receive are delayed or denied because of disputes between agencies regarding financial or other responsibilities.

(d) Proceeds from public or private insurance.

(1) Proceeds from public or private insurance are not treated as program income for purposes of 34 CFR 80.25.

(2) If a public agency spends reimbursements from Federal funds (e.g., Medicaid) for services under this part, those funds are not considered

State or local funds for purposes of the provisions contained in Sec. 303.124. (Authority: 20 U.S.C. 1432(4)(B), 1435(a)(10)) [58 FR 40959, July 30, 1993, as amended at 64 FR 12536, Mar. 12, 1999]

The Title V CSHCN program is one example of “partner” resources that Part C may access to support a required service(s) on the IFSP. If these partner resources do have a payment or fee structure, Part C systems need to consider if these fees will be considered in the determination of Part C cost to the family. Families served under Part C encounter a variety of “costs” in accessing services for their children that may not be direct, such as the purchase of gasoline to transport their children to services, or time spent away from home or work, etc. Part C systems need to examine “cost” that is incurred through the use of partner resources in determining Part C “cost,” since the collection of these costs could result in a family’s “inability to pay” under Part C regulations. This is particularly true if the service has been identified as needed by the multidisciplinary team and is on the IFSP.

Until recently, the resistance to family cost participation in Part C across the country, particularly related to the use of fees, has been strong, deep and fairly universal. This landscape, though, has changed – particularly over the last five years – for two primary reasons. First, due to national and individual state recessions, more Part C systems are now being directed to deal with the issues of family cost participation by their lead agencies and/or legislatures. Secondly, access to other partner resources often requires some cost participation on the part of the family. This may be in the form of required use of private insurance, a sliding fee scale, and/or some sort of enrollment premium and/or co-payment

schedule. State policies and procedures must clearly describe the ways that Part C services will be financed, and if (and, if so, how) family cost participation required by partner resources will be reflected in these Part C “system of payments” including provider reimbursement or payment requirements. Thus, FCP and/or shared payment responsibility has been implemented in a majority of states.

FCP policies also should not discourage families from enrolling children in Part C who have chronic illnesses or long term needs that will require ongoing care and possibly hospitalization. FCP policies that fail to recognize the other needs and demands that families face daily may place families in a position of forgoing important services, or considered potentially neglectful, if they choose not to participate in Part C due to the financial impact that they may experience. Depending upon the state’s collection of resources, it may be important to consider establishing protections against undue cost, loss of coverage, etc., by having a “ceiling” that limits the use of private insurance and perhaps would exempt early intervention services from the lifetime benefit cost.

The complexity of these policy issues is largely influenced by the state’s demographics, the type and number of publicly sponsored supports and services, the state’s political and economic context and the Part C delivery system itself.

Section II *Implementation of Family Cost Participation*

The term “family cost participation” (FCP) is a broad term used to describe any approach that a state may elect to institute either by the use of private insurance, developing a family fee system, or both, that results in some degree of cost to a family participating in the Part C system. FCP may

mean indirect or direct cost, either formally or informally, to the family through the use of their private insurance coverage, or the assignment of some sort of financial cost¹⁵ to the family to receive Part C IFSP services. These policies may be developed at either the local or state level; this varies from state to state.

As of December 2004, information collected from 36 states by the IDEA Infant and Toddler Coordinators' Association indicated that 11 states had implemented FCP utilizing insurance and family fees, 14 states had policies and some practice regarding the use of family insurance and 6 states utilized just family fees. Consequently, 31 of these 36 respondents had some form of FCP in place for Part C services.

Family Perception

In discussions with families representing six states, SOLUTIONS learned that three major considerations are important to them when considering Part C FCP.¹⁶ Overall, most families were supportive of FCP as long as three conditions are in place:

1. Families want the state policies and procedures to be implemented uniformly and consistently.
 - a. Everyone participates in the same process.
 - b. Provisions exist for the equitable and fair inclusion of "extenuating circumstances" (e.g., more than one child with a disability, high medical/prescription medication expenses, specialized child care costs, elder care, etc.)
2. Fees are charged and collected for services that the family values and that are important to them.

3. A procedure is in place to protect families whose situations change whereby a new assessment of "inability to pay" would be conducted and the family's changing status recognized.

Training and technical assistance for local programs, service providers, administrators and service coordinators are key to ensuring that all of these conditions are addressed successfully.

Families are also concerned that the Part C services be available to as many children and families as possible. When budgets are tight, one of the most common approaches that states contemplate is to be more restrictive in their state's eligibility requirements. Families often willingly participate in the development of a Part C FCP system in order to ensure that there is no reduction in eligibility for services. In states where the combination of fees and the use of insurance have been a historical practice, many families report that they feel more "in control" of the services in their child's IFSP and often have an easier time expressing concerns or problems with the delivery of services.

Still other families have said that the idea of "free services"¹⁷ can be unsettling to them. What does this mean? Welfare? Is there somehow assigned a lesser value or quality to the service by either the public system or family when it is "given" to them "free?" In several states, families have informed us¹⁸ that they feel more in control of the services that they are receiving if they are contributing in some way and, consequently, believe they are better "heard" when evaluating the provision of these services.

¹⁵ E.g., Sliding Fee Scale, Co-payment, Participation Fee, Cost Share

¹⁶ SOLUTIONS Consulting Group, LLC six (6) state data collection

¹⁷ As compared with "services at no cost to the family"

¹⁸ Data collected by SOLUTIONS Consulting Group, LLC from six (6) states

In Indiana and Georgia, Part C FCP includes an educational component for and with the family to help them understand the variety of supports and resources available to them, eligibility and enrollment criteria, etc. Accessing important supports and resources early not only assists families at that moment, but may put in place a system of support for the lifespan of that child, and ensure that families are more knowledgeable and better prepared to advocate for themselves and their children beyond their Part C system participation.

Provider Perception

Several states¹⁹ report that providers were a major impetus for instituting family fees. The majority of these providers reported that they felt having family cost involved in the payment for services helped to ensure the family's participation, or investment in their IFSP. In some states, the family fee is collected by the provider, which is in addition to the reimbursement paid by other resources including public and private insurance; it becomes a "bonus" for the provider and one that they have the ability to defer on an individual family basis or collective basis if desired. This is typically in contrast to what families expect or want from their cost participation efforts.

Typically, however, determining which families have the ability to pay a fee and what that fee should be is not something that most providers of any specialty area want to be responsible for deciding. Prior to the implementation of Part C, the financing of early intervention services was not something generally discussed with families and providers alike. The concept of "free" early intervention services were available in many states prior to the passage of Part C.

This concept was reinforced by some of the Part C federal regulatory language which, when quickly read, seems to support a continued system of "free" services. Careful reading of the statute and regulations reveals language to the contrary and, as many states are learning, "shared responsibility" or FCP is one of several funding streams that could be employed to support the continuation of Part C in their state.

Overwhelmingly, providers do not want to be the ones responsible for collecting family fees. In some states, providers must routinely report these revenues in a "cost settlement" activity against grant or other payments. Issues related to invoicing families for their payment, accounting for funds received and figuring out what to do when the invoices aren't paid are voiced most frequently by providers as a major barrier to FCP. Some have commented that these responsibilities have changed their role from the more traditional "helper" role.

Further, the structures of most state Part C systems are not typical programs but rather a system that overlays a number of programs, making it often difficult to determine just where and by whom fees should be collected. When the use of private insurance is included under a state's FCP policies, providers often report²⁰ that the challenges and paperwork required to bill private insurance is very labor intensive. The claims filing process and resubmissions for denied claims are typically different forms and documentation than what is required by Part C. Delays in reimbursement are common complaints, as well, when utilizing private or public insurance.

¹⁹ Part C System of Payments: Family Cost Participation, ITCA, October 2004. Some states did not want to be personally identified.

²⁰ Data collected from ten (10) states by SOLUTIONS Consulting Group, LLC

Section III

Recommendations And Considerations For Planners And Stakeholders

To assist in working through the many decisions that need to be made when considering developing or making changes to a family cost participation structure for infants and toddlers with disabilities and their families, we have identified some key considerations to be addressed as decisions are made. Depending on the structure of your state's financing system, some of these decisions have major implications, whereas others are much more limited in their scope. States should conduct a comprehensive demographic study to determine if there are variables, such as the incidence of poverty, which will likely exempt a large portion of the population from the assignment of fees or utilization of private insurance.

The following are some of the issues that a state should consider when discussing FCP. These considerations will vary depending upon the organization of the state's early intervention system, its demographics, the degree of "local control" that is present, and how funds are collected, tracked and managed.

1. **Family considerations** – As mentioned elsewhere in this paper, Congress envisioned Part C to take a primary role of facilitating access to resources, services and supports, with Part C funds to be used as payor of last resort. Since other fund sources must be accessed to satisfy a financial commitment for services that would have been paid for from another public or private source, states must consider the effect that use of all other fund sources may have on a family's cost including fees and co-payments that may be required by any fund source that is accessed.
2. **Political considerations** – Decisions in states are frequently made outside of the

Part C lead agency. Due to federal and/or state budget issues, state legislatures may increase pressure to access the personal resources of families enrolled in early intervention. States may need to demonstrate or "show something" to illustrate the contributions that family cost participation is making to the system as a whole.

3. **Accessing family information considerations** – Finally and perhaps most importantly, are the complex issues that impact the needs of the families. State decision makers need to carefully consider the multiple factors that impact a family's decision to participate in the Part C system. Often states require information to document a family's "inability to pay" for services. States struggle to collect sufficient documentation to establish a measure of the family's income and sufficient evidence of extenuating circumstances. In addition to collecting the information, storing the information has been problematic in some states where the consensus was that family financial information should not be part of the EI record, which would possibly mean access to this sensitive information to others beyond the FCP determination process.

The procedures a state develops must be flexible, equitable and reliable measures of an inability to pay. Without careful consideration of these factors, states face further issues related to implementation and enforcement when implementing a FCP system.

Considerations For Public Policy

Due to the interagency nature of Part C funding, decisions regarding family cost participation – including the use of family fees – may be made externally to the Part C

lead agency. That is, a funding source may often have their own requirements related to the use of private insurance, family co-payments or fees, etc., that should be considered by the Part C system when defining “cost” to Part C services. As states increasingly implement FCP, they learn that the policies related to family cost participation are indeed complex when developing good public policy.

Some states question the efficiency of cost participation for Part C families. There may be states spending as much to collect the fees as the fees generate. Effective “economies of scale” may be compromised by costs to the state, or incurred by local providers, required in “chasing” small payments. Each state needs to have a broad discussion of these issues and ensure that they have taken them into consideration as public policies are crafted.

Access to the majority of federal and state resources and supports for families and children are income-based; that is, children from low-income families are usually eligible for a wider variety of public supports. These supports may complement one another, or may duplicate – in which case, regulations are typically in place that define “who goes first.” For families in Part C in other income categories, the blending of private insurance together with public supports available based upon their child’s disability proves to be equally challenging for state planners when considering “cost.” Invariably, existing regulations include private insurance coverage first on the list of which source is tapped first.

Consequently, it is critical for state planners and decision-makers to understand the range of supports available to individual families, the individual operating rules and regulations, and how resources and supports interact with one another. Further, states’ Part C policy makers must develop an

understanding and agreement as to what constitutes “cost” under Part C, and develop policies and procedures that, ideally, incorporate their partner funding sources as well as federal and state Part C funds.

Considerations For Constructing Family Cost Participation Systems For Part C

States have developed their FCP in a variety of ways and usually employ a blend of the approaches below:

- co-payments, similar to private insurance, constitute a standard fee that is required from the consumer for each service utilized. This may vary depending upon the nature of the service rendered.
- sliding fee scales generally utilize the Federal Poverty Level (FPL) as guidance to implement a fee schedule. Depending upon the family’s income (differently defined) and family size, the family’s cost would vary. Some states include extenuating circumstances as one way to reduce the family liability as well.
- enrollment or annual fee is one standard cost per year for all participants above a certain FPL. This fee may also be based upon family income and would be higher for some than for others.
- fees by individual service are one approach to assign fees that determines family cost for each IFSP service that they are receiving. Some states exempt those services where private insurance is being accessed; others do not.
- fees assigned against the whole cadre of services in the IFSP are another approach to fee application, where the specific number or frequency of services is not a factor. Families are assigned a “not to exceed” cost based upon income and family size.

Several states have developed FCP recognizing when families utilize their private insurance, offering “protection” under the “inability to pay” requirements for some families where the co-payment or deductible would be beyond their “ability to pay.” In these instances, the Part C system may be responsible for the family’s co-payment or deductible liability. This however is not universal.

Additional considerations include the difference between planned and delivered services, the total cost of the IFSP, the inclusion of other fund resources and their family payment requirements, etc. Every state will be a little different depending upon their local customs and history, their funding “mix,” and their demographics.

Who Collects The Fee?

A major consideration for most states is where and how fees will be collected, maintained and reported. If fees are determined and collected at the local level, some sort of cost settlement with the provider should be implemented so that these new revenues truly off-set the overall payment for services. The effort and documentation required for a \$5.00 collection is the same as is required for a \$100 collection. These realities need to be factored in as policies and procedures are crafted and implemented.

Program Income

How will fees be used? Families want to be sure that their contributions are reinvested in Part C services. EDGAR²¹, which governs Part C of the IDEA, requires that income be reinvested into the program which generated it. The revenue earned from family fees should be invested into the Part C system, off-setting expenses and contributing to the

overall costs. Family fees should be recorded, and their contribution to the overall Part C budget documented and publicly credited.

In summary, the degree of uniformity and consistency that states use to define and implement policies and procedures related to FCP are very important to all Part C stakeholders. Equity, parity and appropriate protections are very important to families, providers, state administrators and state legislators – equally.

Related And Difficult Issues That Need To Be Considered

The FCP policies are in place, everyone is trained and informed, the documentation is ready ... all of the rules for FCP have been determined ... we are ready to “roll.” Or, are we?

Part C speaks to protecting the family and child from loss of service where there is an “inability to pay” determined by the system. This is very different from the policies and procedures that states need to discuss, develop and implement when family “refuse” to pay. Defining failure or refusal to pay, determining when and how a redetermination of ability to pay would be made, and thinking thoughtfully about “how long” the failure to pay would be permitted to occur until something happened – and, what would that “something” be are all significant public policy issues.

Several states have procedures whereby, if family payments are not received in a timely manner, the process of “inability to pay” determination is automatically performed. This is often a task completed by the family with the Service Coordinator although this is not necessarily the rule. No services can be reduced or terminated without implementing the family’s full procedural safeguards. This includes the obligation of the system to provide, in writing, a notice of action

²¹ Education Department Guidelines and Regulations (34 CFR 80.25)

proposed and use the intervening period to work with the family to figure out what the problem and solution are. During this period of time, services specified in the IFSP continue to be provided and it is only after all of the procedural safeguards steps have been completed that services could actually be terminated.

Because most Part C systems assign and collect the fee after the service has been provided, adjudication of fees – including recognition of the failure to pay – can sometimes be months later. This can often be well past the child's exit from Part C. Some states have written agreements or contracts with families that establish the fee understanding including conditions under which the family fee would be reassessed, etc.

In Summary

As the variety of economic and political forces continue to grow, State Part C administrators are increasingly forced to respond to the challenges of increased enrollment, increased costs, and the potential for decreased revenue from a different perspective. Family cost participation is now openly discussed. This scenario was established in 1996 when TANF²² was passed, establishing a national theme of “personal responsibility.” Other measures to manage costs (e.g., reduction in eligibility, service guidelines” reimbursement reductions) are equally open for public discussion. Continuing financial challenges sometimes provoke the dialogue

²² Temporary Assistance for Needy Families (TANF) is a block grant created by the Personal Responsibility and Work Opportunity Reconciliation Act of 1996, as part of a federal effort to “end welfare as we know it.” The TANF block grant replaced the Aid to Families with Dependent Children (AFDC) program, which had provided cash welfare to poor families with children since 1935.

in a state about whether they can remain as participants in the Part C federal system.

In some instances, the implementation of FCP has been reported by states to be more cosmetic; that is, establishing something developed in response to a legislative demand to demonstrate that parents are paying their share of the responsibility but is not implemented. FCP is reflected in policy but may not be a viable fund source. Establishing the threshold at a very high Federal Poverty Level (usually over 350% of poverty) is one example of creative public policy making that meets the challenge but not the intent. Another example would be implementing the determination of individual family fees, but failing actually to collect them.

Limiting or reducing eligibility is a typical discussion that states engage in as enrollment rises and costs escalate. This discussion is probably more painful to states than the discussion about FCP – no one wants to see children and families excluded from Part C, particularly those who may benefit most immediately. In some states, families have rallied against the reduction of eligibility by supporting FCP as long as certain criteria and conditions are assured.

Recently, at least five (5) states²³ have reported that they have been required to implement FCP from the state legislative level; in at least three of these states, the Legislature made specific statements as to how the fees would be assigned (e.g., degree of Federal Poverty Level).

State Part C stakeholders are wise to raise the issue of FCP themselves and utilize their broad-based, participatory process to gain ideas and recommendations that result in effective and responsible public policy. By

²³ Part C System of Payments: Family Cost Participation,” ITCA, October 2004

this, we mean that the outcome will meet several important criteria. These include:

- 1) the majority of Part C stakeholders understand the reason for implementing FCP;
- 2) the system reflects the entire state in terms of the process for implementation, management and reporting requirements;
- 3) the appropriate procedural safeguards are developed and in place to protect individual families from being denied services based upon their “inability” to pay; and,
- 4) a variety of training and technical assistance approaches are developed and in place to ensure that the FCP system reflects a reasonable and meaningful process that is consistently and uniformly implemented statewide (by all providers, for all families).

FCP can be an important strategy for collaboration between families, state, and local providers for supporting meaningful and effective public policy, and demonstrating to families that their contribution is making a difference. Each collaborator is provided the opportunity to achieve success and satisfaction as a result of the effort.

As this information is synthesized, each state will be better able to create reasonable and effective public policies and procedures related to financing Part C services. Well researched and thoughtful policies and procedures, integrated resources and supports, and family cost participation guidelines that are respectful to family situations are more likely to support the delivery of quality early intervention services. Partnering with families helps to ensure the continuation of Part C within individual states and works to avoid unnecessary eligibility restrictions or program policies and procedures.

There is no national consensus about family cost participation in Part C. More states are implementing some form of cost participation. Family cost participation should not create barriers to Part C enrollment or produce a negative impact upon a family’s financial stability or health care coverage. Family cost participation should be organized so that it facilitates appropriate access to all available fund sources and establishes a flexible continuum of care.

Many Part C system stakeholders report that early intervention is a very different “atmosphere” from other disability service systems. The early intervention experience can assist families to understand the variety of resources available to them and to their child that may be needed in the future.

References

- Early Intervention Programs for Infants and Toddlers with Disabilities Rule, 34 C.F.R. § 303 (1999).
- Mackey Andrews, S. D. (2003). *Part C system of payments: Family cost participation*. IDEA Infant & Toddler Coordinators Association. Available from ideaitca@aol.com.
- Individuals with Disabilities Education Improvement Act of 2004, 20 U.S.C. § 1400-1487 (2004).

Citation

Please cite as:

Mackey Andrews, S. D. & Taylor, A.
(2007). *To fee or not to fee: That is the question!* (NECTAC Notes No.22).
Chapel Hill: The University of North Carolina, FPG Child Development Institute, National Early Childhood Technical Assistance Center.

Credits

This paper is based upon two sources. The first is a presentation made at the February 2005 Office of Special Education Programs National Early Childhood Conference in Washington, DC. The panel presentation included the facilitator, Susan Mackey Andrews, with Part C coordinators and representatives including Ron Benham (MA), Terry Harrison (NJ) and Kate Numerick (MO). The presentation materials are available at:

<http://www.nectac.org/~meetings/national2005/Resources/Round1/sessions1.htm#tofeeornot>

The second source for this paper is a document entitled "Part C System of Payments: Family Cost Participation" from SOLUTIONS Consulting Group, LLC published by the IDEA Infant & Toddler Coordinators Association in October 2003. This document is available by contacting ideaitca@aol.com.

Our recognition and thanks to reviewers for this paper are extended to:

Ron Benham, Massachusetts Part C
Coordinator

Maureen Greer, Emerald Consulting
Karleen Goldhammer, SOLUTIONS
Consulting Group, LLC

Barbara Popper, Federation for Children
with Special Needs

Judy Swett, PACER Center

nectac notes is produced and distributed by National Early Childhood Technical Assistance Center (NECTAC), pursuant to contract ED-01-CO-0112 with the Office of Special Education Programs, U.S. Department of Education (ED). Contractors undertaking projects under government sponsorship are encouraged to express their judgment in professional and technical matters. Opinions expressed do not necessarily represent the Department of Education's position or policy.

This document appears at:

<http://www.nectac.org/~pdfs/pubs/nnotes22.pdf>

Additional copies of this document are available from NECTAC at cost. A list of currently available NECTAC publications can be viewed at our site on the World Wide Web or requested from us. NECTAC is committed to making the information it disseminates fully accessible to all individuals. To acquire this publication in an alternate format, please contact the Publications Coordinator in Chapel Hill.

NECTAC is a program of the FPG Child Development Institute at The University of North Carolina at Chapel Hill. The address is:

Campus Box 8040, UNC-CH
Chapel Hill, NC 27599-8040
919-962-2001 phone
919-843-3269 TDD
919-966-7463 fax
nectac@unc.edu
www.nectac.org



Principal Investigator: Pascal Trohanis
Contracting Officer's Representative at OSEP:
Peggy Cvach
Contract Specialist at U.S. ED: Delia Johnson