Part C System of Payments: Family Cost Participation

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Section A: PART C SYSTEM OF PAYMENTS: FOCUS: FAMILY COST PARTICIPATION (FCP)

The IDEA Infant Toddler Coordinators Association (ITCA), as an organization providing leadership to promote the advancement of early intervention, Part C services on a national level, has responded to a variety of national interests and needs through member-sponsored surveys and product development. The issue of the use of family cost participation (FCP) for Part C services, within the context of the state's system of payments to support early intervention services, has evolved to become a pivotal public policy issue. To this end, ITCA requested a survey of the variations of FCP implementation on the national level emphasizing policy considerations, revenue enhancement, and specific state approaches.

The following components were identified by the ITCA to be included in this project:

1. The identification of current practices of respondent states in requiring parents to participate in the cost of the Part C services. (E.g., by directly paying for services received or authorizing access to their private insurance including potential costs to the family.)
2. A summary of the Part C services typically included in FCP.
3. A discussion of the varieties of state practices in FCP, including how these funds/revenue are collected and applied.
4. An understanding about the realities of such a system of family payments, including how much new revenue this effort has brought to individual states, implications from the program perspective, and any proposals for change that states are considering based upon their experiences.

The Request for Proposals directed the consultant to:

- Research policies and procedures relevant to the discussion of family cost participation;
- Evaluate the various components of family cost participation and the policy implications for State early intervention systems and the enrolled families.

The purpose of this Survey is to provide ITCA and Part C system planners, including many State Interagency Coordinating Councils, with information from other states that will allow them to have a thoughtful discussion of FCP as it may pertain to their Part C system. This Report provides the reader with the following:

- Summary of federal statutory and regulatory requirements related to family cost participation;
- Models currently in use by states;
- Policy implications that states must consider in developing a system of family cost participation; and
- Implementation considerations at the state and local level related to data gathering, revenue collection and cost/benefits.

As the successful bidder to this Request for Proposals (RFP), Solutions Consulting Group LLC brought to the project a recently completed survey of 11 states' FCP practices performed for the State of Missouri First Steps System. The survey utilized a web-based technology where the respondents could complete and submit the survey electronically. Several state administrators requested to complete the survey with a Solutions' Research Associate.

This summary report is based upon the survey responses from 34 individual states, 1 territory and the Department of Defense to total 36 respondents including the original 11 respondents in the Missouri sample. Participants in the original Missouri sampling were asked to update their survey responses, particularly given the fact that several of the states were undergoing revisions at the time of the initial survey (Spring 2003). Maine, Connecticut, Georgia, New Jersey, Virginia and Utah provided updated information to their original survey responses. The following is a full list of respondent states to the ITCA FCP Survey.

TABLE A: Respondents

Alaska	Iowa	*Pennsylvania
American Samoa	*Kentucky	Rhode Island
California	*Maine	South Carolina
Colorado	*Massachusetts	South Dakota
*Connecticut	Michigan	Tennessee
Department of Defense	Montana	Texas
Florida	New Hampshire	*Utah
*Georgia	*New Jersey	Vermont
Hawaii	New Mexico	*Virginia
*Idaho	North Carolina	West Virginia
Illinois	Ohio	Wisconsin
*Indiana	Oregon	Wyoming

*Indicates those states in the original Missouri sample.

The names and contact information for those states participating in the ITCA FCP Survey are attached as Appendix A.

Chart 1 illustrates the respondents with respect to geographic location, illustrating the participation in the ITCA FCP Survey. The participation of the Midwest and Southern states and Territories is not reflective of the total potential sample of states, whereas nearly all of the Northeast states responded. The category of "Other" includes the Department of Defense and the Bureau of Indian Affairs.

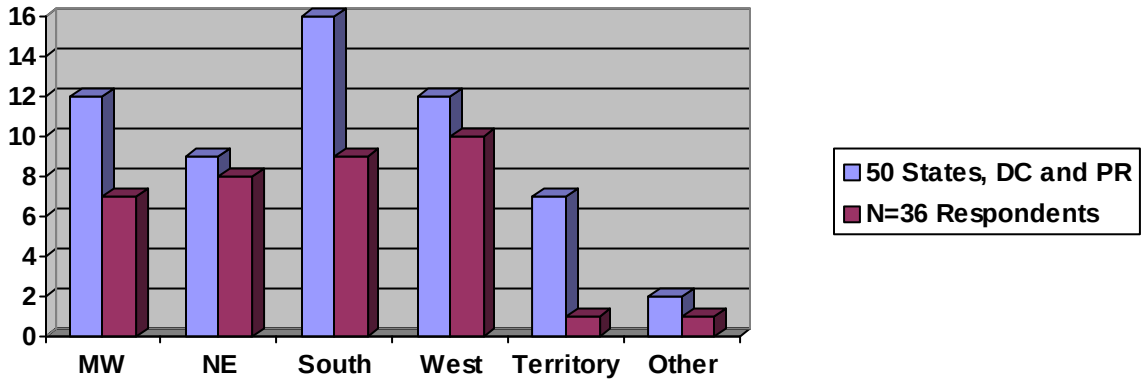


Chart 1: Respondent States by Geographic Location

When considering the variety of differences that individual states present, the respondent[1] analysis to this Survey that follows reflects the following representation against the national profile according to Lead Agency type (Charts 2 and 3) and eligibility groupings (Charts 4 and 5).

Chart 2: Respondents by Lead Agency Type

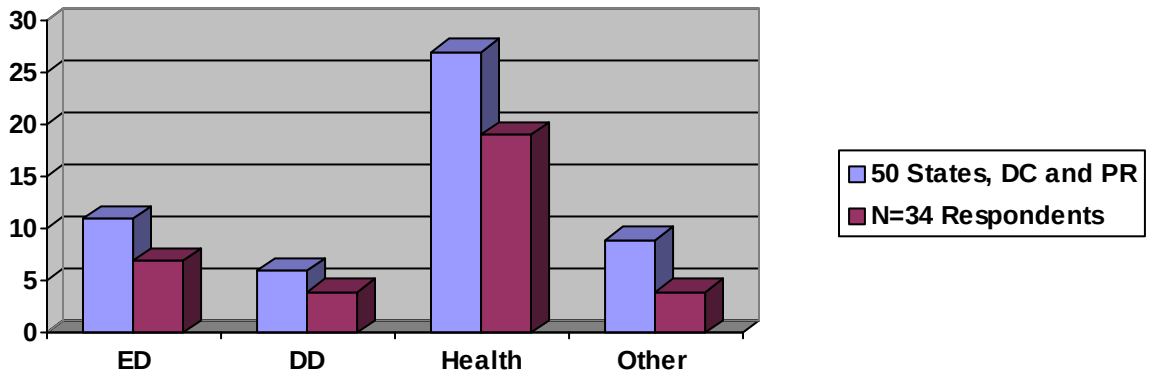


Chart 3: Respondents by Lead Agency
When examined by Lead Agency type, the respondents reflect the national portrait of states by Lead Agency:

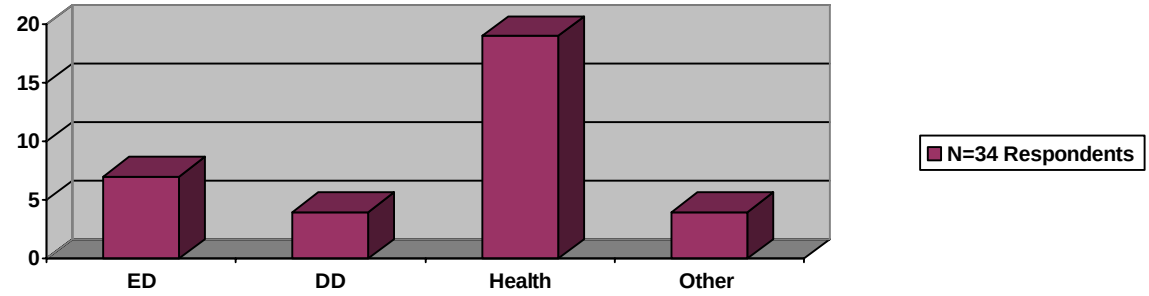
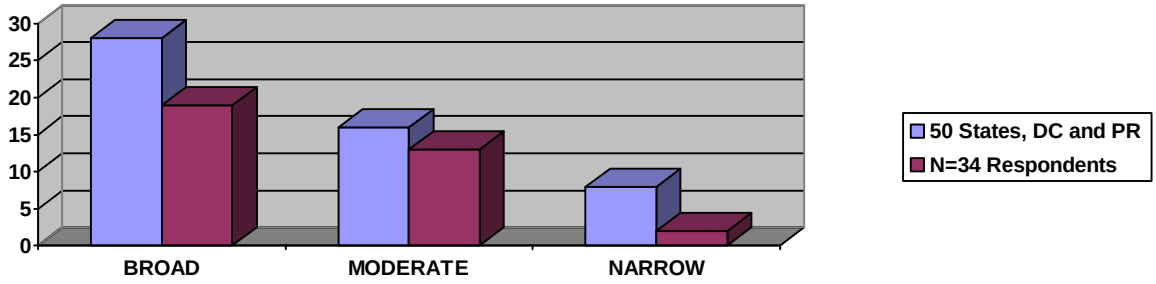


Chart 4: Respondents by Eligibility Groupings reflect the diversity of survey participants, indicating a slightly higher than average participation by states classified in the "broad" category.



[1] The Department of Defense and American Samoa are not included in these analyses.

Chart 5: Total Respondents by Eligibility Grouping

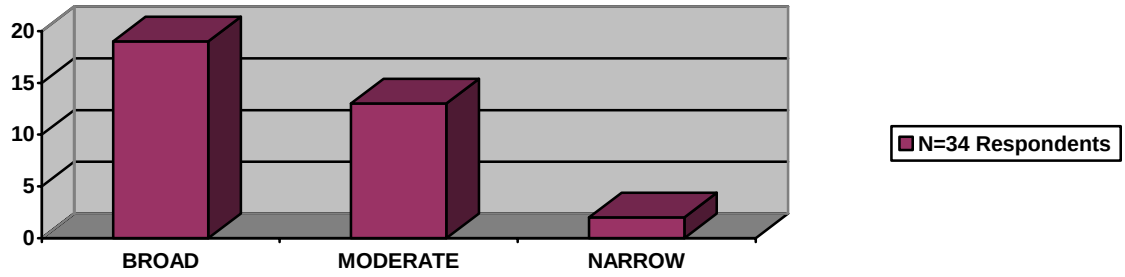
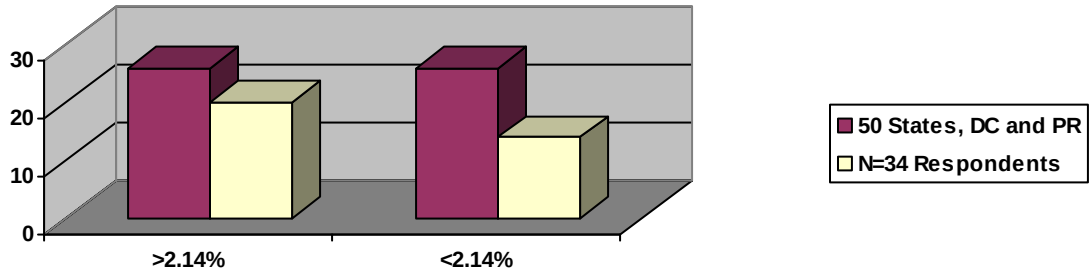


Chart 6: 2001 Child Enrollment, illustrates the respondents by percentage of total 2001 national average enrollment of 2.14%. More states with enrollment over 2.14% responded to the survey.



DESIGN, ORGANIZATION AND ADMINISTRATION OF THE SURVEY ACTIVITY

Data from the October 2002 Part C National Survey was reviewed to identify the status of states and Territories related to the reported use of family cost participation in any form for Part C services. Confirmed information was available for 34 states and one Territory, which indicated:

- Eleven (11) states have FCP in the form of BOTH insurance utilization and family fees.
- At least 14 states have some policy or practice, including legislation, regarding the use of family private insurance.
- Six (6) states have some level of FCP in the form of family fees.
- Four (4) states report no policies, procedures or practices for FCP including the use of insurance.

To summarize, at least 31 states (of the 34 respondents to the National Part C Survey) and Puerto Rico reported using some approach to FCP for some, if not all, Part C IFSP services. Twenty-seven states participated in BOTH the National Part C Survey and the ITCA FCP Survey.

A Briefing Paper was provided outlining the intended outcomes of the family cost participation (FCP) Survey and framing the concept of FCP as it is to be used for the purposes of this Survey. This Briefing Paper defined a variety of terms in order to ensure that participants were "on the same page" as they completed their survey. For the purposes of this Survey Report, the content of the Briefing Paper has been incorporated into this document.

The original survey instrument was developed specifically to capture information about the utilization of all forms of family cost participation including family fees or the access to private insurance, as well as the inter-relationship of fees and private insurance where these co-exist. The ITCA Board of Directors reviewed the original Missouri FCP survey and made thoughtful modifications to that document to reflect ITCA survey outcomes. The final survey is available as Appendix B.

States were invited to participate through the ITCA Board President and had approximately three (3) weeks to complete the survey. Most respondents completed their survey on the website, but there were some who requested and received a telephone interview from a Solutions' Research Associate. Two reminder notices were sent electronically to non-respondents, encouraging their participation, before the survey was closed on September 24, 2003. Individual telephone calls to these state administrators were also made prior to the closing date.

Of the respondent states, 15[2] or 42% reported that they do not have any form of family cost participation in their Part C system of payments. One state reported "not sure" to this question. Some follow-up was conducted with some of these states to identify if there were "informal" systems in place related to FCP. Informal systems were confirmed in more than half of the states, one of which responded "no" and another who had responded "not sure.[3]" One other state responding "no" to this question later reported that family cost is utilized "indirectly." Twenty (20) of the respondent states reported some form of FCP, with 6 reporting "insurance only," 2 reporting "fees only," and 12 reporting both insurance and fees.

Many of the current FCP systems started out informally and date back to the early implementation of Part C in the early 1990's. Seven (7) states indicate that their policies and practices are fairly new, having been designed and implemented since 2001.

Eleven (11) states or 69% of 16 states indicated that FCP had been discussed in the past with five of these same states indicating that they are currently considering FCP actively for implementation. New Hampshire had FCP for several years that was stopped in 1998 because it was hard to enforce with many agencies choosing not to bill the co-pay. Texas will institute FCP after January 1, 2004. FCP is an ongoing discussion in many states citing budget difficulties as the primary motivator, with at least 2 states pursuing other forms of revenue maximization (such as Medicaid) in the hopes of avoiding family cost participation. For many of these states, the topic is a continuing dialogue. Iowa, for example, is exploring and clarifying the use of public and private insurance largely from pressure from health care providers, local lead agencies and other parties responsible for the financial condition of Part C.

Of the states currently operating some form of FCP, 9 reported that changes were being considered or implemented. Again, state budgets were the typical driving force for these policy changes. ITCA hopes that the information gleaned from this survey will assist other states to refine their investigation of family cost participation, and to learn from others what works effectively as state economics, rising child enrollment, and competing priorities continue to be the reality for most states.

[2] Including the Department of Defense and American Samoa
[3] The responses reflected in this report reflect the original survey responses; no attempt has been made by the consultant to modify or change any individual state report.

Forty percent of states (of 20 total respondents) report that the impetus or primary force behind the decision to implement FCP resulted as a legislative order with 35% reporting that it was a state agency decision. Five states reported the decision as result of both legislative and state agency, with 2 states reporting that they implemented FCP in compliance with Federal Part C. One state reported a combination of forces: statute, revenue needs and an interest to bring family ownership to the IFSP process. For many states, FCP is a survival issue – raise more revenue, or consider pulling out of Part C.

The analysis is presented in a narrative fashion for the reader as well as in some comparative illustrations on selected variables. The consultants have also provided a discussion of the Federal regulations governing family cost participation, to further the reader's understanding of which practices are optional or required. To augment the information on respondent state practices, relevant communications from the Office of Special Education Programs (OSEP), U.S. Department of Education were also reviewed. As appropriate, the advice from these Federal communications is incorporated into the Survey Report discussion.

Section B: DEFINING FAMILY COST PARTICIPATION

Federal Part C requires states to have a "system of payments" for Part C that would include the consideration of FCP (e.g., a sliding fee scale). Therefore, FCP may be one component of each state's "system of payments."

For the purpose of this Survey, the term "family cost participation" (FCP) is used to describe any approach that a state may elect to institute that involves a family's personal resources in the payment for Part C services. This may be either by the use of private insurance, developing a family fee system, or both. 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 cost 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.

THE IMPACT OF FEDERAL PART B, IDEA LEGISLATION UPON FAMILY COST PARTICIPATION

The regulations guiding the implementation of Part B have historically included language that encouraged utilization of a variety of existing "partner" resources to finance IEP services. This is currently reflected in §300.301, FAPE – method and payments, which reads (in part):

> *"(a) Each State may use whatever States, local, Federal, and private sources of support are available in the State to meet the requirements of this part. For example, if it is necessary to place a child with a disability in a residential facility, a State could use joint agreements between agencies involved for sharing the cost of that placement.*
>
> *(b) Nothing in this part relieves an insurer or similar third party from an otherwise valid obligation to provide or to pay for services provided to a child with a disability."*

The Individuals with Disabilities Education Act (IDEA) (formerly the Education for All Handicapped Act or EHA) focusing primarily on 5-21 year olds includes language directing the state educational agencies to coordinate resources with existing other Federal, state and local (public and private) entities in the provision of special education and related services to eligible children. The amendments to IDEA completed in 1997 reinforced these requirements in § 1412 of the Statute. Sub-section (11) speaks to the state education agency's (SEA) responsibility for general supervision to include overall responsibility for all services rendered through the Individualized Education Program (IEP). Sub-section (12) addresses the SEA's responsibility to

ensure, through interagency agreements, the identification and assignment of financial responsibility of each agency for the provision of FAPE, and to provide supervision for these services even if they are not paid for with Part B funds.

34 CFR §300.142 discusses at length the obligations and opportunities of the Local Educational Agency (LEA) or SEA, including specifically addressing the resources available through each state's Medicaid (Title XIX) program and "other public insurers of children with disabilities" who precede their financial responsibility for services in the Individualized Education Plan. These relationships were clarified in the 1989 Omnibus Budget Reconciliation Act (OBRA '89) addressing Federal Medicaid requirements as payor of "first" resort.

The LEA or SEA must understand the relationship of the Federal regulations for Title XIX system, which require the utilization of third party payors, such as private insurance, before federal funds can be expended. This has a direct bearing upon the LEA or SEA's responsibility to ensure FAPE if Medicaid is accessed to support IEP services. While accessing Title XIX covered services are typically "at no cost" to the family, there are situations in which the child may be dually enrolled and have private insurance coverage. This means that, by virtue of Title XIX federal and state requirements, if Medicaid is accessed for a dually covered child, it may result in a "cost"[4] to the family if private insurance is accessed. This would be a violation of the Part B, IDEA requirements under Free Appropriate Public Education (FAPE) unless Part B assumed the family cost, which is permissible under P.L. 105-17. Sometimes state administrators outside of the state Medicaid agency are unaware of these regulations, and family resources are accessed often unbeknownst to the IDEA administrator. This can occur in both the Part B and Part C systems.

There are several other Federal resources which carry the same obligation to utilize other existing third party resources first. Access to the state's Title V, Children with Special Health Care Needs (CSHCN) system requires utilization of third party resources first. Title V agencies may also apply a family fee to covered services. Most states did not tap into public third party resources – particularly in the early years of EHA implementation – due in part to the potential for FAPE violations as a consequence of potential costs to the family.

FEDERAL PART C, IDEA LEGISLATION RELATED TO FAMILY COST PARTICIPATION (FCP)

In 1986, P.L. 99-457 was developed specifically authorizing Section 619 of IDEA, the Preschool Grants Program and Part C, Infants and Toddlers with Disabilities Program. Congress was adamant that they were not authorizing a new entitlement program for infants and toddlers. The Congressional intent was to ensure that all existing resources remain in place to support the service delivery system for very young children 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 for Part C is to: "Facilitate the coordination of payment for early intervention services from Federal, state, local, and private sources (including public and private insurance coverage)..."[5]

These major amendments to the Education for All Handicapped Act (EHA) were passed by Congress calling for, in part, national inclusion of the 3-5 population in each state's FAPE[6]

[4] Co-payments, deductibles, erosion or loss of the lifetime benefit cap, or loss or reduction of coverage
[5] Emphasis by the Author
[6] Free Appropriate Public Education

provisions through the state education agency. P.L. 99-457 also provided an opportunity to states to voluntarily participate in a new program to serve infants and toddlers with disabilities ages 0-2. Congress used this opportunity to reinforce the provisions as stated under §300.301 and established, in the Part C Statute, Subchapter III, §1440, Payor of Last Resort. This Section addresses both non-substitution and reduction of benefits, and currently[7] 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."*

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 the following sections:

§300.520, Policies related to payment for services
§303.521, Fees
§303.522, Identification and coordination of resources
§303.523, Interagency Agreements
§303.524, Resolution of Disputes
§303.525, Delivery of services in a timely manner
§303.526, Policy for contracting or otherwise arranging for services
§303.527, Payor of last resort
§303.528, Reimbursement procedures

Part C was envisioned by Congress with a primary role of facilitating access to resources, services and supports – not necessarily paying for them, as highlighted by the "Payor of Last Resort" language in both the Statute and regulations. Some 40-fund sources are often cited as resources for Part C (Table B) and are reflected in cluster groups in the Resource Hierarchy (Table C). There is a substantial discrepancy between the intent of this Federal legislation and the reality that many Lead Agencies, Part C Coordinators, State Interagency Coordinating Councils (SICCs) and other stakeholders at the state and local levels experience. Many states have tried to access additional resources, but have failed for a variety of reasons. This is reflected by 89% (N=32) of respondent states who report that Federal Part C funds is the most frequently used fund source to pay for services for eligible children and their families (Table D).

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

34 CFR §303.522, Identification and coordination of resources, requires that the Part C Lead Agency identify and coordinate "all available resources" within the state including those from "Federal, state, local, and private sources." This section goes on to list a variety of Federal resources including those previously mentioned as well as Head Start, Part B of IDEA, the Developmental Disabilities Assistance and Bill of Rights (P.L. 94-103) and Other Federal Programs. The pool of potential resources has grown exponentially for Part C through the implementation or expansion of many Federal programs designed to support very young children and their families. These include, but are not limited to Title XXI/the State Children's Health Insurance Program (SCHIP), Title XX/the Social Services Block Grant or SSBG, the Child Care and Development Block Grant (CCDBG) and Temporary Assistance to Needy Families or TANF, Impact Aid, and Tri-Care (military dependent health coverage) (Table B).

TABLE B. Potential Part C Resources

Federal Sources	**State Sources**
Part C	Medicaid EI System State Match
Part B – 619	State Part C appropriation
Part B General	Title V State Funds
Medicaid Administrative Agreement	State Maintenance of Effort (TANF) funds
Medicaid (XIX) - regular	Part B - Section 619 - State Funds
Medicaid (XIX) - EPSDT	Part B Special Education Funds
Medicaid - waiver program	Lottery Funds
Medicaid - managed care carve out	Healthy Families Initiative
Medicaid - managed care	Early Start
Medicaid –State Plan Option (Targeted Case Management)	Early Head Start
Medicaid/Title V Interagency Agreement	Head Start
S-CHIP (Title XXI)	HMO/PPO/IPA (private managed care)
Title V - MCH	
Title V - CSHCN	**Local Sources**
CHAMPUS/TRICARE	Family Fee - Sliding Fee
Impact Aid/DOE	Family Fee - Flat Fee
Indian Health Services	Family Co-Pay
WIC	Private Insurance
Early Start	Locally Raised Tax Revenue
Early Head Start	Provider Contributions
Title XX SSBG	Locally Raised Revenue Contributions
CCDBG/CCDF	HMO/PPO
Family Preservation	Municipality Match/Contributions
Dropout prevention	
Prevention of Juvenile Justice	
Title IV-A/TANF	
Title IV-B	
Title IV-E	

Federal regulations governing Part C define the provision of early intervention services 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; and…*

While Part B of IDEA requires education, special education and related services to be provided to eligible children "at no cost" to the family, Part C is very different. Some Part C services must be provided "at no cost" to the family, including evaluation, assessment, IFSP development, procedural safeguards and service coordination. The federal regulations specifically speak to these services as "not subject to fees" by families. 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[8]" including cost to the family, including a sliding fee scale.

Due to the interagency requirements of Part C, other resources and supports are available for individual families and bring with them their own rules and regulations. These may include 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 incorporated as a Lead Agency is developing their policies related to payments for services.

> *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*

[8] The 'system of payments" appears several times in Part C regulations. Sec. 303.12(a)(3)(14) is the only Section that includes the phrase "system of payments by families." All other Sections speak to the "system of payments" (e.g., Sections 313.20(b)(3) Policies, 303.23(d)(3) Service Coordination, 303.520(b)(3) Policies related to payment for services, and 303.521 Fees.

(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]

Early on, many states used their Part C federal funds to support the provision of services to eligible children. Part C funds, while not intended to supplant existing resources, often did just that. This was largely due to a variety of factors as reported by State Part C Coordinators:

1. The sometimes significant complexities of accessing other federal and state funds
2. Competition within the state for limited resources
3. Part C funds were often distributed through grants or contracts, and reimbursement did not need to be comparable with existing state Medicaid rates
4. Part C funds were easier for service providers to access

Additionally, states utilizing P.L. 89-313 “Follow the Child” Federal education funds for Part C services were required to provide these services as “FAPE” – free appropriate public education. While these funds no longer exist as such, some states have “at no cost” policies as a result.

Until recently, the historical resistance to family cost participation in Part C across the country, particularly related to the use of fees, has been a deterrent to FCP. This landscape has changed particularly over the last five years for two primary reasons. First, due to the national and individual state recessions, more states are now being forced to deal with the issues of family cost participation by their legislatures.

Secondly, many times the access to other resources (such as Title XIX/Medicaid or private insurance) is directly linked to some sort of cost participation on the family’s part. State Part C Lead Agencies are increasingly more cognizant of their overarching responsibility in financing Part C services, and recognize the interrelationship of fund sources as policies and procedures are established and/or revised. Such policies and procedures related to the “system of payments” must define how Part C services will be financed, and if – and if so, how -- family cost participation is reflected in these reimbursement or payment requirements.

TABLE C: RESOURCE HIERARCHY

Children and families typically come to Part C with other resources – either already available to them, or resources that the Part C system can assist them to locate and access. These multiple or existing eligibilities become the "payor of first resort[9]" for covered services.

A majority of Federal programs target persons living in poverty, or have some connection to family income through the Federal Poverty Level (FPL) which is developed and published annually by the Federal government. The second eligibility criteria is often a "special consideration" such as disability, age or family characteristic including immigrant or migrant families, single parent or adolescent parents, military dependents, Native Americans, persons dealing with substance dependency or abuse, family violence, child abuse, or mental illness, etc. This is an important point for Lead Agency decision-makers to understand as they investigate the potential for FCP in the Part C system. Each of these programs develop their own rules for participation that may include some level of cost to the family, or involve the use of other resources such as private insurance as "payor of first resort." Part C policies should align with these partner resources.

The criteria that are most frequently used for eligibility determination purposes are outlined in Chart 7, as follows.

Chart 7: Resource Access/Eligibility Criteria	
Child Age	**Special Considerations** such as child with disability, specific disabilities, teen parents, migrant families, low birth weight, etc.
Family Finances (Federal Poverty Level, Cost Participation, etc.)	**Service** (covered or provided)

As such, the resource or funding hierarchy is established based upon the existing individual regulations, policies and procedures of individual resources, support and services that may partner to support Part C systems.

The design and application of Part C family cost participation is determined by the individual state. FCP may apply to some or all of the Part C services, with a variety of cost approaches to be considered. Federal regulations[10] under Part C require that the state define "inability" to pay and ensure that services will be provided irrespective of the family's inability to pay. This flexibility permits the state to "fit" their policies and procedures according to their demographics. This flexibility also allows the state to make revisions in their policies, as their economics and demographics change, over time.

[9] "Payor of first resort" is used here to mean ensure the provision of, including through the payment or direct delivery of a covered service.
[10] 34 CFR §303.520(3)(ii)

APPROACHES TO FAMILY COST PARTICIPATION (FCP)

FCP was divided into three distinct components for the purpose of this Survey: the use of a family's private insurance, family fees or a combination of the insurance and fees. It was important to clarify with respondent states the terms "direct" and "indirect" as they completed their surveys. For the purposes of this activity, "direct" means that the policy related to use of insurance or family financial contribution is established by the Part C system. FCP may include both the use of insurance and/or the application of a family cost to some or all of their Part C services including evaluation for eligibility determination and assessment for service planning. This was the primary focus on this Survey activity for ITCA.

"Indirect" cost means the existing regulations, policies or procedures established by partner resources[11] that require family co-pays or the access of existing third party resources prior to the application of public dollars for services. Both direct and indirect application of family resources exist within the Part C financing interagency fabric. This places a responsibility upon the state Lead Agency to understand the total impact of resource utilization for individual families served through their Part C system.

We confirmed that there are many informal structures related to family cost participation throughout the country as we talked with Part C Coordinators. Some states have "permissive" policies related to the access and utilization of insurance that are more locally determined and managed. These result in varying practices throughout a state that the Part C state office is not able to necessarily describe or quantify.

How Is Your State Paying for Most IFSP Services?

Survey respondents reported the following resources as utilized for their Part C IFSP services:

Table D: Funds Which Support Part C IFSP Services	**# of States**	**Percent**
Federal Part C funds	32	88.9%
Medicaid/Title XIX	28	77.8%
State Part C funds	26	72.2%
Private Insurance	22	61.1%
CSHCN/Title V	12	33.3%
Family Fees/Co-payments/Sliding Fee	10	27.8%
Other[12]	10	27.8%
Temporary Assistance to Needy Families (TANF)	7	19.4%
State General Fund not designated specifically for Part C	6	16.7%
State Children's Health Insurance Program (SCHIP)	6	16.7%
Local Municipality or County Funds	6	16.7%
Child Care Development Block Grant (CCDG)	4	11.1%

[11] Including but not limited to Title XIX/Medicaid, Title V/Children with Special Health Care Needs (CSHCN), or the state Children's Health Insurance Program (SCHIP)

[12] "Other" sources of support include United Way and other locally raised dollars (N=2), Part B funds (N=4) (local and state), County MRDD funds, TriCare (N=2), DD Council, Smart Start, Early Head Start, State School Ready Funds, Title 2 Federal Funds, CFP Overseas and Part 80 Domestic.

States were asked to quantify their fund sources in this Survey. Ten of the 36 respondents were able to provide itemized resource listings. Six states were able to report revenue from insurance and 3 could report revenue from family fees. Fund source information was sometimes "estimated," with as many as 8 fund sources cited by one state that currently supports Part C services. There appears to be no correlation between the number of fund sources and states that have family cost participation activated in their Part C system.

FAMILY COST PARTICIPATION: A DISCUSSION

The evolution of disability services in general dates back more than 35 years, well before the EHA in 1975. Some of the historical not-for-profit agencies[13] providing services were started by parents of children with disabilities, with the original intent to create or improve services for other families. Services rarely had any family cost responsibility and were funded through a collection of private grants and local contributions of time and money.

The evolution of FAPE in the provision of services to children with disabilities under IDEA is discussed earlier in this summary. The concept of family participation in the cost of services dates back to the original Part C legislation and has not changed. What has changed, however, is the individual state sophistication about interagency financing opportunities, and appreciation of the inter-relationships among the variety of resources, supports and services available for children and families.

Family cost participation is an emotionally charged, sometimes highly political discussion in most states. Each state contemplating any form of FCP will benefit from implementing strategies designed to inform key stakeholders before crafting the final plan, and certainly – before implementing any change in practice. Work that Solutions Consulting Group LLC has done in approximately 15 states focusing on Part C financing has illustrated the importance of providing the opportunity to listen to a variety of perspectives, fears and concerns. It is important to provide a foundation, based in regulation, with information to family members, providers and community partners about what the opportunities are for the state, as well as the desired outcomes. Sometimes the simple publication of "facts" helps to allay fears of the unknown, and put the discussion into a perspective that permits a more objective examination.

When fully and accurately informed, most families indicate[14] that family fees are acceptable in Part C under a given set of conditions:

1. The approach to determining "inability" to pay must be consistent for everyone;
2. The policy and procedures should be sensitive to the changing situations of families and open for revision at any time;
3. Collection of fees should be consistently and uniformly applied; and
4. The services that families make a direct contribution for should be a service that they value and choose to participate in.

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 reduce eligibility. Families often willingly participate in the development of a formal Part C FCP system in order to ensure that there is no reduction in eligibility for services. In states where fees and the use of insurance have been a historical practice, many families

[13] E.g., United Cerebral Palsy Centers, Easter Seals, ARCs (Association for Retarded Citizens)

[14] Mackey-Andrews in 1998, ISSUES AND METHODOLOGIES IN FAMILY COST PARTICIPATION Sliding Fee Scales/Co-Payments, Private Insurance, state Legislative Mandates with Anne Lucas and Barbara Popper at the *NEC*TAS EASTERN REGIONAL FINANCE MEETING, Santa Fe, New Mexico*

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. Other families have reported that the idea of "free services[15]" can be unsettling to them. Does this imply that there is a lesser value or quality to the service by either the public system or family when it is "given" to them "free?"

Perhaps the greatest resistance to FCP comes from providers. The evolution of the EHA into the IDEA continued to emphasize FAPE; this concept has carried over to Part C. The opinions of local program administrators and providers range substantially. Families are sometimes perceived as already being overwhelmed and burdened by the extended care needs of their child with a disability. Some providers and local administrators want to ensure that these families don't have to deal with any more stress or complications. Others believe that cost participation helps to ensure the family's commitment and participation in the services, and will improve overall attendance. These opinions are typically voiced without regard to family income.

Other providers frequently express the opinion that Part C should follow the pathway of Part B – FAPE. Why should there be, within the same Federal legislation, two different systems for children with developmental delays or disabilities and their families? One provider succinctly said: "Free for all, or fees for all.[16]"

Certainly, Congress has clearly communicated the message of "personal responsibility" through its work on a variety of public policy issues – not the least of which was welfare reform. State administrators and legislators are now applying this same philosophy to Part C public policies and practices in most states.

Most state Part C systems rely upon the individual provider to access third party resources including public and private insurance payments and family fees. This may mean that the provider must establish a bookkeeping system to manage the assignment and receipt of fees. It also may mean that the provider needs to collect the fees. Providers typically report that collecting the fees from family is burdensome and the revenue received is not sufficient even to meet the cost of their record keeping, multiple documentation requirements and payment delays.

Provider resistance to any form of FCP is also related to the anticipated additional burden that this will place on them, depending upon the individual state system for reimbursements. FCP may result in more documentation, record keeping and reporting for the provider as well as potential delays in payments. There may be different billing forms, codes, documentation requirements and rates that are required, complicating the reimbursement for providers. The more individual sources of funding that the individual provider has to comply with may equate to a substantial cost for them in terms of both time and income.

In order to ensure "payor of last resort," some states have requirements that providers submit documentation of payment denials or partial payments from insurance before funds such as Medicaid or Part C funds can be distributed. This can result in lengthy delays in reimbursement for providers. Adding family cost to the list raises the timeframe and provider cost proportionately.

[15] As compared with "services at no cost to the family" term
[16] West Virginia Birth to Three Systems Evaluation, Public Informing Sessions Summary (unpublished), 2000

Rarely are the fees which are assigned to families close to the reimbursement rate that is paid to providers. Fee schedules typically reflect a contribution by the family towards the service. Family contributions may be computed as a percentage of the total cost based upon the family's income, or a flat co-payment amount – either of which may be then assigned per service or per month. The Family Poverty Level (FPL) is most often utilized as a common base from which to establish fee assignments, currently ranging in respondent states from 150% FPL to 500% FPL.

These impressions were recently echoed by a study of 38 participants in the Commonwealth of Virginia, focusing on the cost of accessing Part C services to include insurance, co-pays and fees[17]. This study illustrates the significant financial, emotional and psychological burden that finance issues related to accessing early intervention services could place upon families when policies are not carefully integrated.

Having an individual provider collect fees from the family (which is the most common approach) may be very debilitating to the provider. Most direct service providers don't see the other end of the billing system, where grants or a fee for service reimbursement from the funding source are structured to compensate the agency for delivering the service. Providers often describe collecting the fee from the family as demeaning as well as difficult for them to perform, given their role as "coach" or helper to the family related to their child's needs. In one instance, personnel at a relatively small agency reported that some of the staff paid the fee themselves rather than "bother" the family for it.

There is typically no payment when services are not delivered although one state is currently "fielding" the concept of a cancellation fee if there was not sufficient prior notice to the provider.

Section C: USE OF PRIVATE INSURANCE

Congress used P.L. 99-457 as an opportunity to reinforce the provisions as stated under §300.301 and established, in the Part C Statute, Subchapter III, §1440, Payor of Last Resort. This Section addresses both non-substitution and reduction of benefits, and currently[18] 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.*

Part C regulations require that states address the "inability to pay" requirement of the federal regulations by developing method(s) for determining each family's "ability to pay." This requirement implicitly includes the utilization of private insurance for Part C services in order to address the issues of co-pays and deductibles, which Part C systems may "cover" for families if they can't demonstrate ability to pay. Historically, private insurance coverage indemnified the

[17] *Families' Perceptions of the Ability to Pay for Early Intervention Services*, Shannon/Grinde/Cox, Journal of Early Intervention, 2003, 25:3

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

enrollee from cost other than what cost is defined in the insurance company's own policy or contract requirements. In individual policies, this may include premiums, co-pays, deductibles, caps or maximum rate payments that can be structured in a variety of ways. With the advent of managed care however, some policies do permit the provider to charge the enrollee the difference between the established insurance rate of reimbursement and what the provider charged. Overall, if the state provides services to Part C children "at no cost," private insurers would not readily see themselves participating in reimbursement for any Part C service because, statewide, there is no cost or liability to anyone participating in Part C including their enrollee[19].

Involving private or public insurance to support Part C services is possible in several ways:

- Accessing the family's private insurance coverage for covered Part C services
- Determining who will pay the co-payment for the family's share/cost of accessing their private insurance for Part C services. This cost is typically a co-pay or deductible that the family incurs when services are billed against their private insurance coverage.
- Paying insurance premiums for Part C enrolled children (this could apply to Title XXI/State Children's Health Insurance Program (S-CHIP) also) in order to access insurance reimbursement for covered Part C services.

Of the respondent states, Rhode Island, Pennsylvania, Idaho, Florida, South Carolina and Hawaii (30%) report that they utilize private insurance as their only form of FCP. Utilization of private insurance is most commonly cited as one of the "informal" policies that some states have which are implemented at the local level, according to their discretion.

Fourteen states reported that the family must give permission or consent. Eight states (AK, FL, GA, ID, IL, MA, SC and VA) report policies and procedures that require the use of a family's private insurance for Part C covered services. At least five states utilize insurance to support the costs of assessment and evaluation services. Idaho was the first state requiring utilization of private insurance, dating back to the initial implementation of Part C. Illinois included this policy in their Part C State Plan in 2001, which was approved by OSEP. There is an extensive array of regulations, policies, procedures and documentation available on their website related to the use of insurance and assignment of family cost participation (http://www.state.il.us/agency/dhs/eisnp.html).

Reasonably, families are concerned that utilization of their private insurance for any purpose will ultimately have an effect on their overall access to health and medical services for their child. They worry about lifetime benefit caps and about increased premiums. For many, their child has multiple needs beyond their IFSP or IEP and families rely upon their insurance to meet these needs for a period of time much longer than their participation in Part C. For still others, the decisions made related to family cost participation can have significant implications upon the entire family – including siblings, family unemployment or forced under/unemployment, reduction or compromises in their standard of living, and/or the sheer time and effort that it takes to coordinate charges and manage payments.

There are positive sides to the use of third party resources to be considered. Depending upon a state's eligibility criteria, not all children enrolled in Part C will necessarily be eligible for Section 619, Early Childhood Services under Part B of IDEA. Some families feel it is important to

[19] Chester County Intermediate Unit v. Pennsylvania Blue Shield, 896 F.2d 808 (3d Cir. 1990)

establish utilization of private insurance for needed services for these children in order to ensure the continuation of services at age three.

Billing and Collections

The organization of a state's reimbursement system, as stated earlier, plays a pronounced role in the utilization of private insurance benefits. If the state operates a system whereby the provider is directly responsible for invoicing, the additional documentation and delays in payment may be barriers to full utilization of any fund source. Part C Coordinators report that providers generally prefer to bill Part C funds even if the reimbursement is lower because the time and effort in recovery of funds is less.

In respondent states such as IL, IN, KY and WV, their central finance/billing system permits an efficient and cost effective approach to accessing private insurance. These systems pay providers for services rendered, at common statewide rates for Part C, and have the capacity to "chase" the private insurance company and other resources (including family fees) for reimbursement. Indiana and Kentucky have recently completed the final stages of implementing this systems change where their central finance system will bill insurance directly. The economies of scale make this approach highly successful in addressing the barriers that confront most states in the access to these private funds.

New Jersey is in the process of implementing central financing for their Part C system, as well as redefining their family cost participation system for implementation in 2004. Informal practices of accessing insurance are quite prevalent and are largely determined at the local level. Three states have taken steps in the last four years to formalize their previously informal policies and procedures, in order to ensure statewide equity and standardization for all system participants including families. Five states continue to assign the decision to bill insurance to the local level at this point in time. One other state reported that they only access private insurance when the service provider is a contracted entity, and then only with family consent.

State Policy Regarding Family Co-Pays and Deductibles

The Lead Agency may – in order to access private insurance – use Part C Federal funds to pay the co-payments on behalf of the family. This language does not appear in Part C regulations, but is delineated in Part B regulations and the application of this regulation for Part C has been supported by OSEP. Section 300.142(g)(2) does permit the use of Part B funds to pay the cost the parents otherwise would have to pay to use the parent's insurance (e.g., the deductible or co-pay amounts). This is individual to the state, however, and highly dependent upon the system that they have established in general to pay for the provision of Part C services. Due to the potential conflict with the indemnity provisions of private insurance, it is questionable if these practices have the knowledge or support of the state insurance commission or the insurance companies practicing in individual states.

States that are accessing private insurance for Part C services all report that they have approved policies in their State Plans that address the issue of family cost related to the utilization of private insurance.

Information collected in this Survey concerning insurance co-pays concluded that policies were present in 14 states to permit Lead Agency payment of co-pays and deductibles when private insurance is accessed. Rhode Island was the only state to report the amount ($7,000) that they had expended on co-payments for families. Fourteen states reported policies related to the use of insurance and protect the family from potential cost by offering to cover the co-payment or

deductibles if applicable; five of these 14 states mandate the use of private insurance for Part C covered services.

Pennsylvania reported that providers might elect not to collect the co-pay at the local level. New Jersey has no policy one way or the other, and Georgia reported that it is not officially stated but they know that some providers do not collect the co-pays. It is not known in these states if the local agencies apply this practice generally to all families, or to selected families.

Insurance Revenue Status Report

The revenue benefits of private insurance remain to be quantified for most states, with the exception of Massachusetts and Connecticut. Massachusetts reports that the revenue from insurance accounts for approximately 40% of the total Part C budget or $32.3 million/year in 2003. For Connecticut, a total of $3.6 million for 2002 was reported and is cited as the third highest revenue source currently for this state.

Table E illustrates the estimated percentage of private insurance use by families enrolled in Part C compared to eligibility classification and Part C total enrollment.[20]

[20] Classification as determined by the Office of Special Education Programs, U.S. Department of Education. Child Count data as of December 1, 2001

TABLE E. Private Insurance Access as Compared to Part C Enrollment (2001 Child Count Data) In Alphabetical Order

STATE[21]	% Private Insurance Utilization in Part C[22]	What % of your State's Part C total budget is generated from private insurance?	Eligibility Criteria Classification	# of Children Enrolled in Part C 2001	% of Children Enrolled in Part C of Total 0-3 Population
Alaska	NA	2%	Narrow	824	2.21
Connecticut	63%	10%	Moderate	3,879	2.97
Florida	NA	NA	Broad	14,442	2.57
Georgia	21%	NA	Moderate	3,512	0.98
Hawaii	NA	NA	Broad	3,961	8.53
Idaho	30%	NA	Moderate	1,257	2.15
Illinois	45% (est)	10%	Moderate	10,021	1.93
Indiana	NA	NA	Broad	9,165	3.62
Kentucky	52% (est)	NA	Moderate	3,810	2.39
Maine	10% (est)	NA	Broad	947	2.28
Massachusetts	60% (est)	40%	Broad	12,906	5.47
New Jersey	NA	NA	Moderate	6,412	1.92
New Mexico	NA	1%	Broad	1,834	2.34
North Carolina	21%	1%	Broad	5,655	1.73
Pennsylvania	4% (est)	NA	Broad	10,191	2.38
Rhode Island	41% (est)	1%	Moderate	1,088	2.88
South Carolina	NA	NA	Moderate	2,093	1.31
Utah	NA	NA	Moderate	2,494	1.93
Virginia	45% (est)	NA	Broad	4,743	1.71
Wisconsin	NA	NA	Broad	5,212	2.56

Two (2) states reported that the percentage of their state's total Part C budget generated from insurance revenue was 10% with four other states reporting that these funds accounted for 1-2% of their overall Part C budget.

[21] Respondent states with insurance legislation are: CT, IN, MA and VA
[22] NA means Not Available

Insurance Legislation

Five respondents (CT, IL, IN, MA, VA) have state-specific insurance legislation that, while the language varies by individual state, essentially requires coverage of Part C services for eligible children. Massachusetts was the first state to enact insurance legislation in 1990, followed by New York. Connecticut, Indiana and Virginia have the most recent legislation addressing Part C utilization of private insurance, with modifications to this legislation for both CT and IN in 2003. With the exception of MA and VA, state insurance legislation does not apply to ERISA or self-insured plans. Massachusetts mandates that both indemnity and managed care plans participate, and VA also includes provisions that apply to the insurance program for state employees under a separate act. The various state regulations may be accessed on the Web through http://nectac.org/topics/finance/statelegis.asp.

North Carolina reports that a similar bill was introduced in 2003 but did not pass; it will be reintroduced in the next legislative session.

Insurance legislation in VA and CT is reported to exempt payments made by private insurance for Part C services from the lifetime benefit cap for each child. Payments for Part C services from private insurance were reported to be primarily in the form of individual service reimbursement. A few states report annual maximum amounts per child ranging from $3,500 to $5,000. Insurance payments typically apply to all services with the exception of special instruction. Massachusetts appears to be the only state collecting insurance reimbursement for the full array of Part C services including special instruction, with their original legislation dating back to 1990.

CT, VA and MA, as respondent states with insurance legislation, illustrate a significant participation by private insurance in the financing of Part C services (Table E) as compared with other respondent states.

Public Supports/Resource Application Requirements

There will be many families with children eligible for Part C services who are also eligible for other “partner” resources or supports. The Office of Special Education Services (OSEP), in a letter to Frymoyer and Berger at the PA Legislative Budget and Finance Committee dated November 22, 1996, stated that families couldn’t be required to apply for Medicaid coverage. This may be suggested to them, but the state cannot refuse to provide Part C services to the family if they will not or don’t make application for this coverage.

Six states (out of 20 total respondents) reported that they do require families to make application for enrollment to “partner” resources or supports; with the majority of states reporting that they “strongly encourage” families to make application and facilitate this through service coordination. Indiana has a combined enrollment form that facilitates referral to other programs that the family or child may be eligible for.

Some states have policies that link when a family refuses to apply for public programs, such as Medicaid (Title XIX), Children with Special Health Care Needs (CSHCN or Title V) or their State’s S-CHIP program, to their overall FCP policies. This situation may exist if the Part C system is relatively certain that the family is eligible and that the needed services are covered under the other federal program.

Part C Services Reported Covered by Insurance

The variety of Part C resources and supports available all have one thing in common: few, if any, resources have the same eligibility criteria, covered service(s) listing, provider qualifications/requirements, etc., as does Part C. As states include individual resources into the Part C financing "quilt," they must be mindful of both the resource "rules" as well as the Part C requirements. Utilization of private insurance brings some specific rules for Part C consideration.

- **Federal Medicaid regulations require that the payments made to providers be accepted as "payment in full," which prevents the assignment of any family co-payment.** Many private insurers also require that their payments are accepted "in full" for services rendered. Typically, the state (or central finance system on behalf of the Part C system) or local provider would bill private insurance using their usual and customary rate (UCR). This reimbursement may be influenced by the difference between the insurance reimbursement rate and the billed rate. These providers may, as we have seen from selected state examples, choose to collect the family co-payment or not.

- **"Caps" on the number of services that are established by Medicaid as a public insurer, or by private insurance, cannot restrict or direct the frequency of services for children and their families in Part C.** When these public or private resources are exhausted, Part C funds would be used to cover the remainder of the services that the IFSP identifies are needed by the child and/or family. The Office of Special Education Programs (OSEP) in a letter to Senator Robert C. Byrd (WV) dated April 16, 2001 formally articulated this policy[23].

- Private insurance is typically accessed at the local Part C provider level (either agency or individual). Exceptions to this include Idaho, which bills from the state level, and the central finance office functions in Indiana which initiated insurance billing in April 1, 2003. Kentucky reports that they use a combination of provider and central finance office invoicing for insurance receipts. NJ reports that families often bill for the insurance reimbursement. **It is essential that policies clearly articulate the family's responsibility to the Part C system for not only the billing, but also how the Part C system is reimbursed for delivered services when covered under private insurance.**

Table F illustrates the types of Part C services reported by respondent states as typically covered by private insurance.

Policies and Practices Related To Earned Income/Revenue

Survey questions were asked focusing on the status of FCP revenue collected at the local level. Specifically, were these revenue reported to the Lead Agency and was there any relationship between revenue and the future allocation or distribution of Part C funds to the provider? Of the 18 states responding to this question, 50% of the respondents reported that there were policies and procedures requiring the routine reporting and consideration of this revenue in terms of the overall allocation of resources to the local level.

[23] 20. U.S.C. §1436, 34 CFR, §§303.340(b) and 303.344

Kentucky and Connecticut report that there is reciprocity between the amounts paid through insurance and Part C funds distributed from the Lead Agency. Insurance revenue is subtracted from other Part C allocations. Massachusetts' insurance regulations directly address the earned revenue with routine provider reporting to the state Lead Agency. Further, MA pays the local provider for any family co-pay, where applicable, upon submission of an invoice by the provider.

In all remaining instances, the generated revenue is reported to go back into services at either the state or local level. As reported by 16 of the 18 respondents to this question, there is no adjustment to the funds that the local agency receives from the state. At the local level, this revenue is reportedly added to the provider's general operating budgets to support personnel salaries and benefits, expand or enhance early intervention services through provider training, etc. Two states noted that these funds help to offset the provider costs for services, including transportation costs, the costs of collection, etc. One state reported that they permit the local provider to use 10% of their earned revenue in any way that they wish.

One respondent reported that the perception of the revenue earned by providers from insurance is akin to a gratuity or "tip" for services rendered. Some states justify the additional revenue earned by providers as payment for their effort, time and cost incurred in third party billing. One respondent noted that the rates do not cover the provider costs for transportation so that the earned income is helpful to offset these additional costs.

As New Jersey moves from a grants/contracts system in 2004, all third party receipts will go to the central level through the implementation of a fee for service system and central financing. Likewise, Indiana's implementation of family cost participation effective April 1, 2003 initiated through their Central Reimbursement Office or CRO will ensure that all earned revenue returns to Part C at the state level.

TABLE F. Part C Services Typically Funded by Private Insurance (N=17 respondents)

Part C Service	FL	ID	PA	RI	SC	AK	CT	GA	IL	KY	ME	MA	NJ	NM	NC	VA
Assistive Technology (9)	✓				✓	✓	✓		✓				✓	✓	✓	✓
Physical Therapy (14)	✓	✓		✓	✓	✓	✓	✓	✓	✓	✓	✓	✓		✓	✓
Audiological Services (11)	✓	✓	✓			✓	✓	✓	✓	✓			✓	✓	✓	
Service Coordination (1)												✓				
Evaluation/Assessment (5)	✓	✓			✓							✓			✓	
Social Work (3)									✓			✓				✓
Health Services (9)	✓		✓		✓				✓			✓	✓	✓	✓	✓
Special Instruction (1)												✓				
Medical/Diagnostic Services (12)	✓	✓	✓		✓	✓	✓	✓		✓			✓	✓	✓	✓
Speech/Language Therapy (12)	✓	✓		✓	✓	✓	✓			✓	✓	✓	✓		✓	✓
Nursing (6)	✓					✓						✓		✓	✓	✓
Transportation (1)														✓		
Nutrition (1)									✓							
Vision Services (6)					✓			✓	✓				✓	✓	✓	
Occupational Therapy (13)	✓	✓		✓	✓	✓	✓	✓		✓	✓	✓	✓		✓	✓
TOTAL	9	6	3	3	8	7	6	5	7	5	3	9	8	7	10	8

Section D: USE OF FAMILY FEES INCLUDING A SLIDING FEE SCALE

Federal regulations delineate the conditions under which fees may be charged to families, as follows, and identify those services that must be provided at no cost to the family. The "at no cost" for the family does not mean that Part C funds pay the full cost. The Part C system includes the resources under a variety of existing public resources, supports and services where there are shared regulatory requirements for the same population and for similar services.

> *Sec. 303.521 Fees.*
>
> *(a) General. A State may establish, consistent with Sec. 303.12(a)(3)(iv), a system of payments for early intervention services, including a schedule of sliding fees.*
>
> *(b) Functions not subject to fees. The following are required functions that must be carried out at public expense by a State, and for which no fees may be charged to parents:*
>
> *(1) Implementing the child find requirements in Sec. 303.321.*
>
> *(2) Evaluation and assessment, as included in Sec. 303.322, and including the functions related to evaluation and assessment in Sec. 303.12.*
>
> *(3) Service coordination, as included in Secs. 303.22 and 303.344(g).*
>
> *(4) Administrative and coordinative activities related to—*
>
> *(i) The development, review, and evaluation of IFSPs in Secs. 303.340 through 303.346; and*
>
> *(ii) Implementation of the procedural safeguards in subpart E of this part and the other components of the statewide system of early intervention services in subparts D and F of this part.*
>
> *(c) States with mandates to serve children from birth. If a State has in effect a State law requiring the provision of a free appropriate public education to children with disabilities from birth, the State may not charge parents for any services (e.g., physical or occupational therapy) required under that law that are provided to children eligible under this part and their families.*
>
> *(Approved by the Office of Management and Budget under control number 1820-0550)*
> *(Authority: 20 U.S.C. 1432(4))*

Part C family fees can take many different forms.

--**Co-payments** are a flat amount that is assessed to families based upon income and, sometimes, the type or intensity of services in their IFSP. This amount may be "capped" meaning that there is a total amount (usually based annually) that the family would pay after which no co-payments would be required.

--**Sliding fees or cost share** are typically based upon family income and may be assigned to individual services, or to the whole IFSP.

--**Contribution or donations** are "voluntary givings" from the family that may be defined by them, or there may be some sort of payment "assessed" that guides the family or the public Part C system as to what would be an appropriate contribution.

If states utilize both private insurance and family fees, it would be important to incorporate the insurance co-payments into the overall family fee consideration and assignment.

Fees are typically assessed for most, if not all IFSP services. Federal Medicaid regulations prohibit families from being charged for covered Part C services. One implication of this is that families with children enrolled in Medicaid, or those with private insurance, could be assessed a

fee for any IFSP service that is NOT a covered service. For one state, this distinction has been important.

Georgia has a broad waiver program under Medicaid that determines eligibility based upon medical need and counts only the child's income for eligibility determination purposes. There are several children enrolled in both Part C and in this waiver program where the family income may be in excess of $250,000 annually. These families also are likely to have private insurance coverage. Earlier family cost participation policy in this State exempted families with children covered by Medicaid. Georgia's policies and procedures were revised several years ago to determine FCP with all enrolled families, for all Part C services, and to coordinate this contribution carefully with the access to public and private insurance. If a Part C service is not a covered Medicaid or private insurance services, the family may be assigned cost participation even though other Part C service(s) are publicly funded.

Reciprocity Between Family Fees and the Use of Private Insurance

Of the twelve respondent states[24] using both fees and insurance, ten states reported that they have policies and procedures related to the integration of fees and use of private insurance. In several states, these policies permit family choice between using their private insurance and participating in the fee structure for Part C. Families can often select, by service, whether they want to use their insurance or participate in the fee system.

As earlier discussed, where the insurance co-pays would result in the family's inability to pay, Part C systems can assume this liability on behalf of families. Depending upon the reimbursement structure of the state, the Lead Agency may either forego collecting the co-pay from the family, or by paying the co-pay to the provider on behalf of the family. The current practice in most states where insurance is being utilized is that collection of the co-pay is a local decision that providers make individually. Three states have taken steps in the last four years to formalize their previously informal policies and procedures, in order to ensure statewide equity and standardization for all system participants including families.

CURRENT FAMILY FEE STATUS

As stated earlier, the discussion of family cost participation is drawing significant attention throughout the country – the respondent states to this survey reflect this dialogue.

Georgia's fee structure continues to undergo refinements on an annual basis, with a comprehensive review conducted routinely that identifies relevant policy issues for consideration in their overall FCP policies and procedures. This state has been operating FCP including insurance and fees since 1991. Georgia has developed a wide variety of policies, procedures and forms for local health district utilization based upon their experience including revisions in their utilization of insurance.

Connecticut recently passed legislation that speaks to FCP as "using insurance AND/OR a sliding fee" and will implement, July 1, 2003, a system where there is a family fee as well as use of insurance. They are currently working out the structural and administrative details, but speak to the fee as applied to the IFSP generally rather than a specific service. Their website provides a wealth of information including regulations, publications, procedures manual and summary of family fees (http://www.birth23.org).

[24] AK, CT, GA, IL, IN, KY, ME, MA, NJ, NM, NC, VA

Massachusetts is also working to develop family fees that will apply to all families including those covered under Medicaid. For those families at 200-400% FPL, it is anticipated that an annual fee of $25 will be charged to each family. For those families over 400% Federal Poverty Level (FPL), the annual fee will be $50.00. The state expects to earn slightly more than $500,000 from this new fee program. They are operating a web-based system including claims verification complete with business rules.

Both CT and MA will use a central form of collection at the state level for this new revenue.

Idaho and Pennsylvania reported no fees at this time, although Idaho did comment that legislative activity could direct this answer differently. New Jersey will move to a different approach for "cost sharing" which will be applied to all families. Previously, cost sharing was not applied to families receiving 12 or fewer hours of services per month. New Jersey has changed their policies to eliminate the service criteria and apply "cost sharing" to all families irrespective of how much service they are receiving. This policy change also coordinates with their planned implementation of a central financing system for Part C in 2004. This policy change is currently in public hearing and due for final revisions and promulgation for a January 1, 2004 implementation.

Kentucky plans to implement changes to their historical fee structure targeting families with incomes over 500% of the Federal Poverty Level. Indiana implemented a new family fee structure on April 1, 2003 using the term "co-payment" whereby all families exceeding 350% Federal Poverty Level (FPL) would have a co-pay assessment. This assessment ranges from $5.00 per session with a maximum fee of $180.00/month. Indiana will also collect and credit a family's private insurance to their co-payment, resulting in refunds to families when insurance receipts offset their family share. Indiana's website (http://www.state.in.us/fssa/first_step/) provides extensive discussion including policy and procedures, as well as documentation formats developed specifically for this initiative.

Table G illustrates the services as reported by states, which are commonly included under a family fee structure. Massachusetts reported that respite care was also included under their fee structure, and Hawaii reported that hearing aides were the only service in their fee schedule.

Table G: Part C Services Included In Family Fees Policies(N=10 Respondents)

Part C Service	Total	%	AK	CT	GA	IL	NJ	NM	NC	VA	UT	WI
Assistive Technology (6)	8	22%	✓	✓	✓	✓	✓			✓	✓	✓
Physical Therapy (8)	10	28%	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Audiological Services (6)	8	22%	✓	✓		✓			✓		✓	✓
Service Coordination (1)	1	3%		✓	✓		✓					
Evaluation/Assessment (2)	2	6%	✓	✓								
Social Work (5)	6	17%		✓	✓	✓			✓		✓	✓
Health Services (5)	6	17%		✓	✓	✓			✓		✓	✓
Special Instruction (7)	9	25%		✓	✓	✓	✓	✓	✓	✓	✓	✓
Medical/Diagnostic Services (3)	3	8%	✓	✓								✓
Speech/Language Therapy (8)	10	28%	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Nursing (6)	8	22%	✓	✓	✓	✓	✓		✓		✓	✓
Transportation (5)	7	19%		✓	✓	✓	✓		✓		✓	✓
Nutrition (5)	7	19%		✓	✓	✓	✓		✓		✓	✓
Vision Services (4)	6	17%		✓	✓	✓	✓		✓			✓
Occupational Therapy (8)	10	28%	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
TOTAL			8	15	12	12	10	4	11	5	11	13

Family Fee Collection and Revenue Information

States report that family fee collections are typically performed on a monthly basis. Information related to earned revenue is slim due to the local collection practices and changes to most of the respondent state's fee structures. Georgia estimates 40% participation in fees, where CT anticipates 50% of families will be eligible under their new fee structure estimated to earn $1 million annually.

Kentucky estimates that 48% of their total Part C enrollment is assessed a fee, resulting in $80,000 annual revenue. Connecticut documented revenue earned from fees last year at $2,000. In July 1, 2003, they implemented family fees for all families with an adjusted gross income over $55,000. They estimate the number of families billed increasing from 6 per year to probably over 4,000, and will be utilizing a central billing agency solely for this function.

Utah reported that 1997 receipts in family contributions/donations totaled $35,000 with receipts for 2003 anticipated to be $200,000. Again, this state reports they are moving in the direction of a central finance office to manage family fee collections.

Respondent states did not address the issue of cost of collecting these fees, the majority of which is currently performed at the local level. Findings from the Early Intervention Research Institute (EIRI) titled "*Utah Parent Participation Impact Study*[25]" revealed that the actual collections were lower than the anticipated potential revenue, and the amounts collected were "still insufficient to offset the costs reported by programs to maintain the parent fee program as it is currently designed."

Two states were able to provide actual annual revenue reports from family fees and 4 states provided annual estimates; one state provided both. Three additional states will be able to provide this information over the coming year. TABLE H, below, illustrates current state data.

STATE	Family Fee Utilization in Part C	What % of your State's Part C total budget is generated from family fees?	Actual Revenue	Estimated Revenue	Eligibility Criteria Classification	# Of Children Enrolled in Part C 2001	% Of Children Enrolled in Part C of Total 0-3 Population
AK	1%		$4,920		Narrow	824	2.21
CT	50%	3%		$1,000,000	Moderate	3,879	2.97
IL	31%	3%		$2,500,000	Moderate	10,021	1.93
KY	48%			$80,000	Moderate	3,810	2.39
NM	2%	1%			Broad	1,834	2.34
NC	5%			$63,408	Broad	5,655	1.73
WI (fees only)	20%	1%	$251,589	$350,000	Broad	5,212	2.56

[25] Linda D. Goetze, Ph.D., James F. Akers, Ph.D., Daniel R. Judd, M.P.A., Early Intervention Research Institute, November 20, 1998

One state, which didn't report as using fees, did later state that fees were targeted only to one group (families with children with autism) when the IFSP service frequency exceeded a state established "ceiling."

Section E: FCP POLICIES AND PROCEDURES

Federal regulations articulate the responsibility of the state Lead Agency to have policies and procedures related to the provision of services when they are NOT at no cost to the family (excluding the required "at no cost" services):

> *Sec. 303.20 Policies.*
> *(a) As used in this part, policies means State statutes, regulations, Governor's orders, directives by the lead agency, or other written documents that represent the State's position concerning any matter covered under this part.*
> *(b) State policies include--*
> *...3) A statement that, consistent with Sec. 303.520(b), provides that services under this part will be provided at no cost to parents, except where a system of payments is provided for under Federal or State law.*

In reviewing these policies and procedures, most states have developed comprehensive policies, procedures and documentation to assist providers at the local level to administer the FCP as defined in state Part C State Plan. Of 18 states responding, 16 reported that they are actively implementing FCP statewide. Two of these states reported continued challenges to statewide implementation due to varying local implementation issues. Eleven of the respondent states indicated that there is FCP training available for local providers; this training is required by 4 states. Training is an important component of any FCP system in that, not only is this often a significant practice shift for most providers in early intervention, it can also be an intricate process requiring a high degree of skill.

State Authority

It is not clear if the Part C Federal regulations related to a "system of payments" refer simply to Part C, or if this regulation subsumes the existing Federal and state regulations for other funding sources (e.g., Medicaid/Title XIX, MCH/CSHCN/Title V). In this interagency system, where other funding sources are required payors of "first resort", it would be logical that these existing regulations apply under the generic "system of payments" requirement for all states and Territories.

TABLE I: State Authority Base for FCP Summary

State Regulations	State Procedures	State Policy	Local Procedures	Local Policies	Policy Guidelines
3 States	3 States	6 States	1 State	1 State	1 State

State policies and practices would also need to reference, for example, the opportunity that MCH/CSHCN/Title V has to charge family fees. Title V is one resource opportunity that varies in its local implementation; each individual Lead Agency would need to study the current state policy and its implications upon Part C.

Three states report having an agreement with the Title XIX/Medicaid agency to "forgive" third party insurance utilization for children also enrolled in the Part C system; one state reports a similar agreement with the state Title V agency. This agreement means that, for dually enrolled children (either Medicaid and/or Title V and Part C), the family's private insurance is not accessed for covered Part C services by one or both of the other resources.

The Impact of Public Policies Upon Families

State policies and procedures regarding the level of detail and documentation in information gathering also vary. Some states report "taking the family's report" as sufficient for documenting income and extenuating circumstances, while still others require copies of the family's income tax returns. These approaches have both cost and practical implications in terms of when and how copies can be made, where to store sensitive income information as well as confidentiality concerns, etc.

In the article entitled "*Families' Perceptions of the Ability to Pay for Early Intervention Services*" (earlier cited) one family reported having to go before the financial committee, feeling that her financial life was on public display and leaving her open to criticism. Many states are working hard to make sure that the presentation of FCP, including the options available to families, includes the procedural safeguard options that families have should they disagree.

One of the fears or speculations that is often brought up is that FCP will discourage families from participating in the state's Part C system. The "*Utah Parent Participation Impact Study"* verified that the "negative predictions that were made about family attrition, stress, and changing relationships between service providers and families are not supported by the survey data. Many families do not mind the fees and are willing to pay a positive amount for their early intervention services." In this study, the researchers learned that some families were willing to pay a higher fee for the early intervention services that they were receiving than was recommended as their contribution.

Additionally, state planners must consider the relationship of the fee to be charged against issues such as participation in the service (e.g., how to handle missed appointments)? Could the fee collected ever exceed the cost of the service or the approved state rate for an individual service? Could the fee collected ever exceed the total cost of the IFSP? If the adjudication of family cost is performed AFTER the service is provided, there can be months before the full reimbursement to the provider is complete and potential family cost identified.

Another consideration in planning is the fact that individual child eligibilities for "partner' resources such as Medicaid may frequently change, adding more time to the adjudication process in some situations.

Extenuating Circumstances

The policy implications of any type of FCP for families are significant. Part C services are a small piece of the family's overall life and responsibility. Planners and stakeholders need to be sure that the obligations required for Part C participation are proportionate to the rest of the family's obligations – which may include other children, elder care responsibilities, basic family economics, etc.

Part of the determination of "inability to pay" for several states includes the consideration of "extenuating circumstances" which typically consists of costs related to the child's disability, or to the disability of others in the family. This may include special diets or foods, medications,

nursing services, the cost of unemployment or specialized child care in order to work, caring for another family member who is elderly or disabled, etc. Some states provide these considerations for families with more than one child in Part C, or who may have more than one child with a disability in the family that includes a child over age three. GA, IN and ME are examples where this consideration is included in the determination of "inability to pay."

Who Is Responsible To Collect The Information?

In 17 states, these services are performed by Service Coordinators (Intake and/or ongoing) who must both explain the process, including the options and consequences of available choices, and then complete the documentation needed to support the information collected so as to determine family fees or the use of private insurance. They are also responsible for managing the implementation of the IFSP with the family including assisting them to access all available resources. Individual service providers or agencies perform these functions in 4 states. Clerical staff is cited as a back up for these personnel by one state, with another state indicating that the "(local) agency" is responsible. The reality of implementing FCP and its impact upon service coordination (irrespective of the system design which may include intake/interim, blended, independent or dedicated models) must be taken into consideration, as this is likely one of the most significant components of the Part C system to be affected.

Service Coordinators have a wide range of responsibilities[26], not the least of which is to understand and be able to implement the system of payments with families. Service coordination (intake or ongoing) caseloads must be considered when implementing any form of FCP, as the requirements for documentation, interviewing and implementation appear to be largely the purview of the Service Coordinators in the majority of the states surveyed. Depending upon the complexity and frequency of FCP obligations, and the demographics of the state, this could reduce the number of families that an individual service coordinator could reasonably and effectively be responsible for. These functions also imply special considerations related to personnel preparation for Service Coordinators, not just in the system of payments – but also in related functions such as interviewing, negotiating and documentation.

With the exception of IN, the determination of "inability" to pay is made by the Intake/ongoing Service Coordinator or a local agency Administrator based upon the policies and procedures set forth by the state. In 9 states, this same person also makes the fee assignment or negotiates insurance utilization including co-payment status. The majority of these states have tables [27]that illustrate the family cost by using the Federal Poverty Level (FPL) scale and adjusting it for cost participation.

Indiana, implementing their FCP effective April 1, 2003, reported that the assignment of cost is made through the use a software program, utilizing income and other information obtained by the Intake or ongoing Service Coordinator. In another state, the central finance office will make this determination using information obtained locally.

What Information Is Collected?

States vary substantially when it comes to what kind of information is collected, and how the information is collected, in order to determine "inability to pay" and make a fee assignment. Almost 70% of the respondents report standard forms or a format that is to be used with families, however the methods for documenting income vary substantially. Two states require

[26] 34 CFR §303.23

[27] GA's cost assignment table is a good example of how the FPL chart can be "customized" for FCP purposes.

copies of the family income tax returns; two states require weekly/bi weekly pay stubs. Georgia requires visual verification of tax returns, pay stubs or W2 forms but does not require copies. All remaining states report reliance upon the "family's word" using the "honor system." Connecticut is currently investigating if they would have the ability to tap state income tax records to verify family income rather than relying upon self-report or having to collect tax returns or other income documentation.

What Happens When A Family Refuses To Provide The Necessary Information for FCP?

The survey asked states: "What happens if a family refuses to complete or provide the required documentation?" Five states surveyed reported that, if a family declined to provide documentation to determine if private insurance would cover the IFSP services, Part C services would be made available to them only at full pay. Two states would place the family at the maximum family share amount, which may be less than the reimbursement rate and not at full pay. One state makes this documentation a Part C enrollment requirement.

Three states reported that services would be provided at public expense; in two of these states, the family would have to sign a form indicating that they declined to provide requested the information.

No state reported any problems with family participating in providing the required documentation, however.

IMPLEMENTATION AND ENFORCEMENT ISSUES:

The Question of Enforcement

Establishing a FCP system versus actual implementation of the FCP system are two different discussions for many states in Part C. In the Part C National Survey, some participating states report that they have FCP policies and procedures "on the books," but that these are not actively enforced. In a few instances, policies were developed in order to ensure that the states have established "family cost" in order to facilitate the collection of private insurance. There is little or no enforcement of these policies particularly related to the application of family fees or rigorous collection of insurance benefits.

Still other states report that they developed FCP policies that would address a directive from the lead agency, Governor or State Legislature – but that the assignment of cost was set so high that it rarely was applied. Thus, the national data indicating more than 31 states with some sort of FCP may be misleading since some of the states do not formally implement these policies and procedures, or the policies and procedures are implemented locally and not consistently statewide.

The trend of state narrative comments, and changes reported since the 2002 National Survey data collection, indicates that the issue of enforcement and statewide consistency is getting more formal attention as more states implement FCP policies and procedures.

What Happens If Family Payments Aren't Made?

In a letter to Thaler (PA) dated July 12, 1996, OSEP advises that Part C services can be withheld where parents have not adhered to the system of authorized payments. Ten states reported that they had policies defining the actions to be taken when a family does not pay the fee that has been assigned to them, once their ability to pay has been documented. One state has policies and procedures included in their new fee schedule, proposed for implementation January 2004.

Seven states reported that they notify the family that the affected service will be terminated, and that they do take action that incorporates informing the family of their procedural safeguards. Three months is the typical period of time that a state Part C system would go without receiving a family payment before terminating a service.

The family is billed the full charge for the service in VA. CT reported that they would establish a collections process as they implement their new fee structure. This option was cited by other states as something they are considering as well. On two states, the child is exited from Part C for failure to meet the FCP requirements. Two other states simply record the failure to comply in the child's chart and continue to provide the service in question.

Even if the specific service subject to cost participation is withheld due to payment or accessibility issues, the Individualized Family Service Plan still remains in place with any other services to be provided as well as the provision of service coordination for the eligible child and family. The failure to pay the determined fee does not mean that the child is no longer eligible or enrolled in Part C. At least three states report having talked with OSEP to confirm this understanding. If a family does not agree with the assignment of FCP, the IFSP must be implemented with the agreed upon services while the disagreement is being sorted out.

States have incorporated a series of procedural safeguards in their family cost participation policies. Several respondent states reported that this is still a challenge and are working on policies and procedures to address a variety of compliance issues. Only one state reported any formal complaints related to family cost participation, with two other states reporting "informal" complaints: all of which were resolved.

BENEFITS AND CONCERNS RELATED TO FAMILY COST PARTICIPATION

Respondent states were asked to discuss the benefits and concerns from their perspective related to family cost participation for Part C. Their comments are organized topically according to three areas of consideration: family, system, and fiscal and appear in Tables J, K and L. The comments are reported as state representatives wrote them and illustrate many of the "environmental" concerns that are raised when the topic of family cost participation is introduced in any state.

TABLE J. Family Benefits and Concerns Expressed by Respondent States

FAMILY ORIENTED BENEFITS	FAMILY ORIENTED CONCERNS
• Want to arrive at individualized service recommendations • Like to think families are a little more of a partner in decisions re: IFSP treatment • Families have more ownership of services compared to idea of "hand-out" • Will result in a better use of services by families • Providers feel service will be more valued and more used. Those families not interested will withdraw and that would be okay as providers feel disrespected • Maybe additional revenue, maybe great family participation if there's a sliding fee • Family commitment and buy-in • It is a priority of the legislature to have families participate in the cost of their services • Family incentive to use private insurance • Like to think families are a little more of a partner in decisions regarding IFSP treatment • Want to get beyond the "more than 2 hours per week at public expense" rule – this is going away • Greater access to services for more children • Meaningfulness	• ICC is concerned about decline in participation, families exiting services, therefore no services. Believe that this is already starting. Will track and report. • Also, families may opt out; referral sources not refer with fees in place • Are families able to access (all needed) services? • Going after families for $ when they are most vulnerable • Might unintentionally cause out-of-pocket expenses • Will result in cost to families • Unequal use of family fees – a provider agency in one county may use a sliding fee scale while the provider in the next county chooses not to • Parents may drop out because of fees • Children who need the services won't receive them • With new changes, concerned families withdraw because they don't want to pay • Parents may not access the services if they are told there may be a fee • Focus groups consisting of families and providers do not support asking families to fund Part C services • Challenge to CBO • Verification of income – families need a system and this may be difficult and make providers unhappy • Going after families for money when they are most vulnerable. Families pay different amounts. • Some families believe there should be no cost assessed to services • Too costly to collect • Could deter families from accessing EI • Administrative paperwork and costs may keep families out of services • Children in need of early intervention may not be served

TABLE K. System Benefits and Concerns Expressed by Respondent States

SYSTEM BENEFITS	SYSTEM CONCERNS
• Family incentive to use private insurance • Has allowed continuation of the Part C system • Increased funding from legislature tied to requirement to implement sliding fees • Parent fees may have positive impact on quality of early intervention service delivery • All funds go back to enhancing the local program • Consistent system throughout the state • The fee system is uniform, consistent and statewide • Increasing share of cost for services and utilizing other funding sources, e.g., Title V, private insurance • May be additional revenue, great family participation if there's a sliding fee • Receipts to support cost of services • Up to now, incentive to families to allow insurance billing • Will apply to all, the benefit will be the revenue – it is needed • Providers feel the service will be more valued and more used. Those not interested will withdraw and that would be okay, as providers feel disrespected. • Able to ensure service delivery • Possibly less cost to the state	• Concerned that this will be an administrative nightmare. All types of exclusions are likely to appear. • That it exists at all. Providers are concerned about administration and oversight costs • Verification of income: families have been self-reporting, need a system, may be difficult and providers unhappy • The work load required related to family requests to re-calculate, re-evaluate cost assignment/inability to pay • All types of exclusions. Administrative nightmare. • Processing requests for decreases or waivers from FCP due to family financial circumstances (waiver is only good for 3 months, so it must be resubmitted quarterly and requires tracking.) • Central billing system that provides us with child information oftentimes provides incorrect information, so we bill family share inappropriately (e.g. child already discharged from Part C, deceased, over age 3, address incorrect, etc.) • Possible cost to the system for implementation and maintaining a system (depending on the type of system selected) • Still reviewing impact of costs of program now that has switched to fee-for-service for providers. Currently reviewing private insurance payments. • Equity • (State) is very decentralized and there would have to develop a centralized system, or at least provide more guidance to counties on how to implement FCP

TABLE L. Financial Benefits and Concerns Expressed by Respondent States

FINANCIAL BENEFITS	FINANCIAL CONCERNS
• Primarily, there are several hundred thousand dollars in additional revenue • Legislature thinks this is a revenue source • Results in a small amount of revenue • The proposed changes create one more funding source for EI • Demonstrated to Legislature that program doing everything they can while asking for increased funding (goodwill) • The fee system is uniform, consistent and statewide • Additional source of payment • Billing insurance preserves Part C dollars for other services • Source of revenue for Part C • Projecting increased revenue from families and from private insurance.	• Revenue earned will be less than costs to implement (computer, staff, service coordination) • Major concern: how much it costs to collect compared to actual fee collection. Is it worth it? • Revenue may not exceed cost to implement • Implementation of new fee policy causing stress among providers who were not given additional funding • No way to collect data on revenue generated • Families are paying different amounts • Too costly to collect; could deter families from accessing EI • Parents may drop out because of fees and children who really need the service may not get it • Parents may not access • The cost of administering it (FCP) for the amount of resources returned • Very low family participation rate (<1%) • Inability to bill insurance for services that are not “rehabilitation” • It may cost more to collect the family resource than the actual revenue generated • Cost prohibitive • Administrative paperwork and costs may keep families out of services • Decrease in enrollment and more costly services later on for families who don’t participate

Section F. STATE TECHNICAL ASSISTANCE

As the survey responses have illustrated, the process of FCP is complicated. The discussion and outcome in each state will be different, depending upon their culture, history of disability services, demographics, political will and external pressure. While we cannot take one state's policies and procedures related to most Part C components and "carte blanche" apply them to another state, we can learn much from one another. When developing Part C components and using other state resources, there is always "tweaking" and, sometimes, substantial modifications that need to be made. FCP is no different.

This Section attempts to guide the reader through a series of "steps" or discoveries designed to individualize the investigation, discussion and development of FCP for individual states.

APPLICATION AND UTILIZATION OF STATE DEMOGRAPHICS

Step One

It will benefit lead agency decision-makers to review the child and family demographics in their state to determine the profile of families enrolled or eligible in Part C. States can identify a variety of resources available to assist to support the provision of Part C services by using demographics including income, poverty, family household information, birth and health statistics, etc. Using this information, each Lead Agency or State Interagency Coordinating Council (SICC) should be able to make a determination which – if any – specific approach(es) to FCP would make the most sense from a demographic standpoint; and, which will also be more likely to produce a fiscal benefit based upon the state's own figures.

Current research confirms that there is a direct correlation between poverty and the prevalence of disability, meaning that the more poor a state is, the more children eligible for IDEA it can anticipate. This is true even considering some of the states with "narrow" eligibility definitions for Part C services. A review and understanding of the state's demographics related to children will be useful to verify if additional third party resources are available to support Part C services and what – if any – financial impact upon families there would be. Because income is the more widely used eligibility tool, a state with a higher incidence of poverty will likely have more federal resources available to partner to support Part C services.

Conversely, these data may assist to determine if the implementation of FCP with family fees would have any reasonable fiscal benefit to the Part C system. Table M[28] displays some common data and illustrates the diversity among respondent states. These data may help to explain why some states appear to be more successful in diverse resource access including FCP than others. While the median family income in 2000 was $50,000 nationally, it ranged from $34,700 (West Virginia) to $66,800 (New Jersey). The national average for children without health insurance in 2000 was 26%, ranging from a low of 5% (South Carolina) to a high of 22% (Texas) within the respondent states.

[28] Sources: Kids Count 2003, Annie E. Casey Foundation

TABLE M: A SAMPLING OF RESPONDENT STATE DEMOGRAPHICS

	MEDIAN Income of Families with Children 2000	Children in Extreme Poverty (<50% FPL) 2000	Children <Age 6 in Paid Child Care While Parent(s) Work 2000	Children without Health Insurance 2000	Percent Low Birth Weight Babies 2000	Infant Mortality (Deaths per 1,000 live births) 2000	Teen Birth Rate (Births per 1,000 females ages 15-17) 2000	Percent of Families with Children headed by a Single Parent
NATIONAL	**$50,000**	**7%**	**26%**	**26%**	**7.6%**	**6.9%**	**27**	**28%**
Alaska	$54,600	4%	29%	15%	5.6%	6.8%	24	30%
California	$50,000	6%	20%	16%	5.8%	5.4%	27	26%
Colorado	$59,100	6%	20%	14%	8.4%	6.2%	30	26%
Connecticut	$66,100	4%	25%	7%	7.4%	6.6%	17	2%
Florida	$43,600	8%	28%	16%	8.0%	7.0%	29	30%
Georgia	$44,800	8%	28%	12%	8.6%	8.5%	36	30%
Hawaii	$52,300	5%	23%	9%	7.5%	8.1%	23	29%
Idaho	$44,800	7%	27%	16%	6.7%	7.5%	21	23%
Illinois	$56,400	8%	24%	11%	7.9%	8.5%	28	28%
Indiana	$52,000	5%	28%	11%	7.4%	7.8%	26	24%
Iowa	$52,400	3%	36%	6%	6.1%	6.5%	18	24%
Kentucky	$43,300	6%	27%	10%	8.2%	7.2%	29	27%
Maine	$47,800	7%	36%	7%	6.0%	4.9%	50	27%
Massachusetts	$60,400	6%	21%	8%	7.1%	4.6%	15	27%
Michigan	$58,100	6%	28%	8%	7.9%	8.2%	22	28%
Montana	$38,000	9%	35%	17%	6.2%	6.1%	19	30%
New Hampshire	$60,300	2%	32%	7%	6.3%	5.7%	10	25%
New Jersey	$66,800	4%	26%	10%	7.7%	6.3%	17	23%

	MEDIAN Income of Families with Children 2000	Children in Extreme Poverty (<50% FPL) 2000	Children <Age 6 in Paid Child Care While Parent(s) Work 2000	Children without Health Insurance 2000	Percent Low Birth Weight Babies 2000	Infant Mortality (Deaths per 1,000 live births) 2000	Teen Birth Rate (Births per 1,000 females ages 15-17) 2000	Percent of Families with Children headed by a Single Parent
New Mexico	$35,100	11%	22%	21%	8.0%	6.6%	39	34%
North Carolina	$44,700	6%	29%	11%	8.8%	8.6%	34	29%
Ohio	$50,900	7%	25%	9%	7.9%	7.6%	24	30%
Oregon	$47,600	6%	32%	12%	5.6%	5.6%	23	28%
Pennsylvania	$53,600	6%	26%	7%	7.7%	7.1%	20	25%
Rhode Island	$56,000	6%	21%	5%	7.2%	6.3%	21	29%
South Carolina	$43,400	8%	30%	13%	9.7%	8.7%	35	29%
South Dakota	$50,700	4%	37%	9%	6.2%	5.5%	19	24%
Tennessee	$42,300	8%	32%	7%	9.2%	9.1%	34	29%
Texas	$42,700	8%	25%	22%	7.4%	5.7%	42	27%
Utah	$53,000	3%	22%	11%	6.6%	5.2%	21	17%
Vermont	$46,900	4%	28%	7%	6.1%	6.0%	10	28%
Virginia	$59,300	4%	34%	11%	7.9%	6.9%	21	27%
West Virginia	$34,700	10%	21%	10%	8.3%	7.6%	23	28%
Wisconsin	$56,600	5%	37%	6%	6.5%	6.6%	19	26%
Wyoming	$46,500	4%	35%	13%	8.3%	6.7%	19	26%

SOURCE: KIDS COUNT 2003

State data including child enrollment in Medicaid helps to round out the state portrait, targeting resources that "match" the state demographics and which are likely to be the more prevalent other program and resource options of Part C eligible children and/or their families. Other Part C specific data that is helpful includes:

TABLE N: STATE ENROLLMENT INFORMATION
FAMILY INCOME INFORMATION:
Median Income
Per Capita Income
Enrolled Family Poverty Level (FPL) – average, ranges

PUBLIC SYSTEM ENROLLMENT:
Part C State Medicaid Enrollment (by specific programs within Title XIX as applicable)
Part C State Title V Enrollment (CSHCN)
Part C State Childrens Health Insurance Program (SCHIP) Enrollment

PRIVATE SYSTEM ENROLLMENT:
Number and Percentage (#/%) Enrolled Families with private insurance coverage

PART C ENROLLMENT INFORMATION:
Number and Percentage (#/%) Total Enrollment: Aggregate
Number and Percentage (#/%) December 1 ChildCount
Age Breakdown (<12 months, 13-24 months, 25-36 months)
Average Age of Referral
Number and Percentage (#/%) by Referral Sources

SPECIAL CONSIDERATIONS:
Military Families/Dependents
Number and Percentage (#/%) of Children in Foster Care
Native Americans
Children in Foster Care/Child Protective Services Custody

SERVICE DATA:
Service, by type, Utilization
Current Resources/Funds
(By type, amount and for which service(s) and specific population requirements)

Some states report as many as 80% of their enrolled Part C children also eligible and enrolled in Title XIX/Medicaid. Clearly the balance between public program eligibilities and FCP is a serious data and public policy issue.

These data will help to identify the availability of public and private resources, and provide the opportunity for state planners to assess the linkages between existing resources based upon the currently enrolled Part C population, and to target investigation areas for the next level of discovery and discussion.

Step Two
Individual state Part C eligibility criteria are a strong influence to determining if family cost participation (either fees and/or access to private insurance) is a reasonable and cost efficient direction for the Lead Agency to pursue. By comparing the individual state demographics to the

Part C eligibility criteria, the state is able to determine the percentage of eligible children and families for public systems of support (e.g., Title XIX), private insurance, and their financial ability to participate in family fees. Not all state Part C systems currently collect this information and will need to consider how it can reasonably and reliably be collected, including the use of sampling techniques. Because this information can also assist a Lead Agency to identify and access other resources, these might be data elements worth considering for on-going collection and recording.

Step Three

The regulatory relationship between Part C and Title XIX/Medicaid, Title V and other resources as payor(s) of first resort is very important for state planners to take into account. Special populations, such as Native Americans and military dependents, influence the availability and use of the Indian Health Services and Tri-Care respectively. Further, state planners should understand how many children are "dually" covered or enrolled in Title XIX/Medicaid and/or Title V/CSHCN and private insurance. If there are a meaningful percentage of children in this category, state planners need to investigate if either Title XIX or V is actively billing private insurance for covered Part C services, and if Title V imposes a fee for covered services. Discussions in some states have resulted in formal and informal practices which exempt either Federal program from pursuing third party recovery for this population of children, reflecting opportunities that are included in existing Federal regulations.

Step Four

Many states participating in the ITCA FCP Survey report that they benefited from making this discussion a highly visible and participatory one. This approach engaged a diversity of key stakeholders at all levels, including family members, and permitted the Lead Agency to disseminate actual and factual information about the discussion at hand and to solicit meaningful input. Before these sessions are conducted, it would be incumbent upon a state to have certain levels of data and public policy questions prepared to guide participants through a meaningful dialogue.

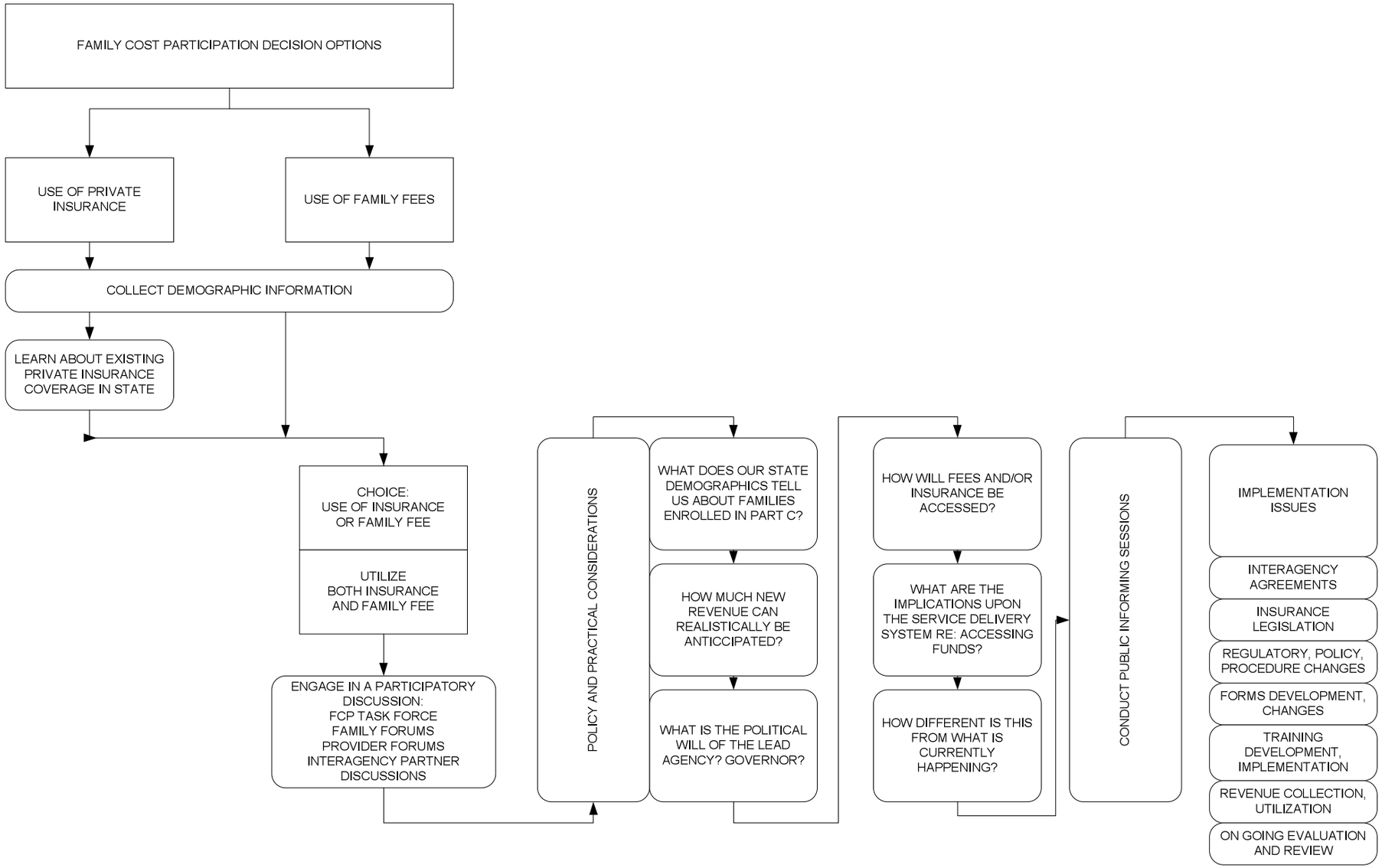
The flow charts provided on the following three pages attempt to layout the various issues and considerations in a sequential manner for state consideration. It is hoped that this level of detail will stimulate state discussions in a productive and helpful manner. Chart 8 illustrates the global policy issues as states study the concept of FCP. Chart 9 focuses on the use of private insurance considerations; Chart 10 addresses family fees.

Section G. IN CLOSING

Participants in the ITCA FCP Survey indicated that the topic of family cost participation continues to be of interest and importance, particularly as each state individually addresses its economic and budgetary challenges. We learned through some state survey responses that FCP issues need constant review and benefit from improvement. And, we have seen where many states are moving from informal practices to formal, statewide policies and procedures designed to ensure statewide equity and accessibility.

More states report that they will be able to quantify the revenue earned through third party resource access. This information will help key decision makers and stakeholders to better understand the impact upon the service delivery system, families and providers as they proceed to implement the Federal Part C regulations related to the use of Part C funds as "payor of last resort."

Chart 8: DECISION MAKING TREE: UTILIZATION OF PRIVATE INSURANCE AND/OR FAMILY FEES FOR PART C SERVICES



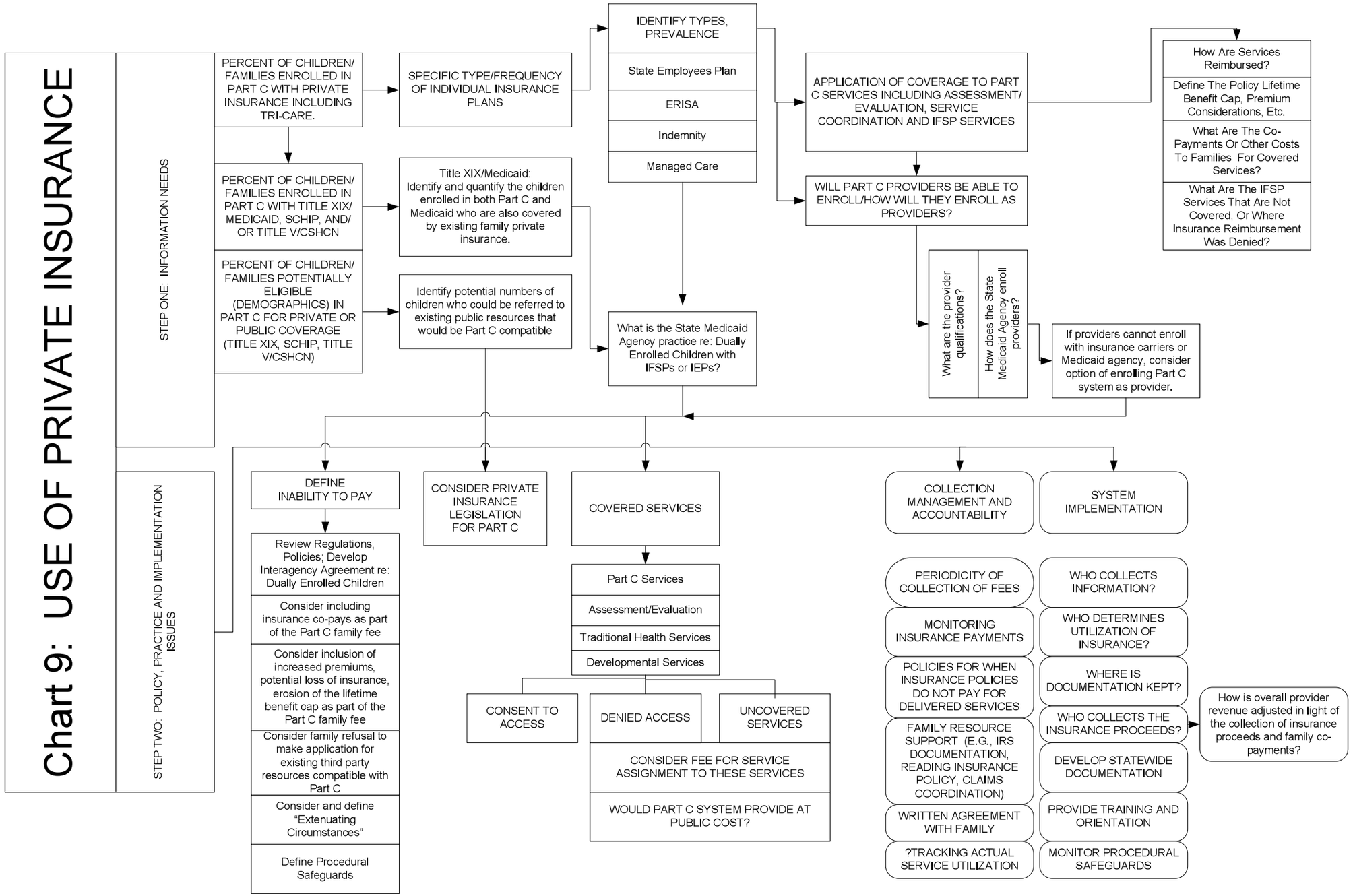


Chart 9: USE OF PRIVATE INSURANCE
STEP ONE: INFORMATION NEEDS
STEP TWO: POLICY, PRACTICE AND IMPLEMENTATION ISSUES
PERCENT OF CHILDREN/ FAMILIES ENROLLED IN PART C WITH PRIVATE INSURANCE INCLUDING TRI-CARE.
SPECIFIC TYPE/FREQUENCY OF INDIVIDUAL INSURANCE PLANS
IDENTIFY TYPES, PREVALENCE
State Employees Plan
ERISA
Indemnity
Managed Care
PERCENT OF CHILDREN/ FAMILIES ENROLLED IN PART C WITH TITLE XIX/ MEDICAID, SCHIP, AND/ OR TITLE V/CSHCN
Title XIX/Medicaid: Identify and quantify the children enrolled in both Part C and Medicaid who are also covered by existing family private insurance.
PERCENT OF CHILDREN/ FAMILIES POTENTIALLY ELIGIBLE (DEMOGRAPHICS) IN PART C FOR PRIVATE OR PUBLIC COVERAGE (TITLE XIX, SCHIP, TITLE V/CSHCN)
Identify potential numbers of children who could be referred to existing public resources that would be Part C compatible
What is the State Medicaid Agency practice re: Dually Enrolled Children with IFSPs or IEPs?
APPLICATION OF COVERAGE TO PART C SERVICES INCLUDING ASSESSMENT/ EVALUATION, SERVICE COORDINATION AND IFSP SERVICES
How Are Services Reimbursed?
Define The Policy Lifetime Benefit Cap, Premium Considerations, Etc.
What Are The Co-Payments Or Other Costs To Families For Covered Services?
What Are The IFSP Services That Are Not Covered, Or Where Insurance Reimbursement Was Denied?
WILL PART C PROVIDERS BE ABLE TO ENROLL/HOW WILL THEY ENROLL AS PROVIDERS?
What are the provider qualifications?
How does the State Medicaid Agency enroll providers?
If providers cannot enroll with insurance carriers or Medicaid agency, consider option of enrolling Part C system as provider.
DEFINE INABILITY TO PAY
Review Regulations, Policies; Develop Interagency Agreement re: Dually Enrolled Children
Consider including insurance co-pays as part of the Part C family fee
Consider inclusion of increased premiums, potential loss of insurance, erosion of the lifetime benefit cap as part of the Part C family fee
Consider family refusal to make application for existing third party resources compatible with Part C
Consider and define "Extenuating Circumstances"
Define Procedural Safeguards
CONSIDER PRIVATE INSURANCE LEGISLATION FOR PART C
COVERED SERVICES
Part C Services
Assessment/Evaluation
Traditional Health Services
Developmental Services
CONSENT TO ACCESS
DENIED ACCESS
UNCOVERED SERVICES
CONSIDER FEE FOR SERVICE ASSIGNMENT TO THESE SERVICES
WOULD PART C SYSTEM PROVIDE AT PUBLIC COST?
COLLECTION MANAGEMENT AND ACCOUNTABILITY
SYSTEM IMPLEMENTATION
PERIODICITY OF COLLECTION OF FEES
WHO COLLECTS INFORMATION?
MONITORING INSURANCE PAYMENTS
WHO DETERMINES UTILIZATION OF INSURANCE?
POLICIES FOR WHEN INSURANCE POLICIES DO NOT PAY FOR DELIVERED SERVICES
WHERE IS DOCUMENTATION KEPT?
FAMILY RESOURCE SUPPORT (E.G., IRS DOCUMENTATION, READING INSURANCE POLICY, CLAIMS COORDINATION)
WHO COLLECTS THE INSURANCE PROCEEDS?
DEVELOP STATEWIDE DOCUMENTATION
WRITTEN AGREEMENT WITH FAMILY
PROVIDE TRAINING AND ORIENTATION
?TRACKING ACTUAL SERVICE UTILIZATION
MONITOR PROCEDURAL SAFEGUARDS
How is overall provider revenue adjusted in light of the collection of insurance proceeds and family co-payments?

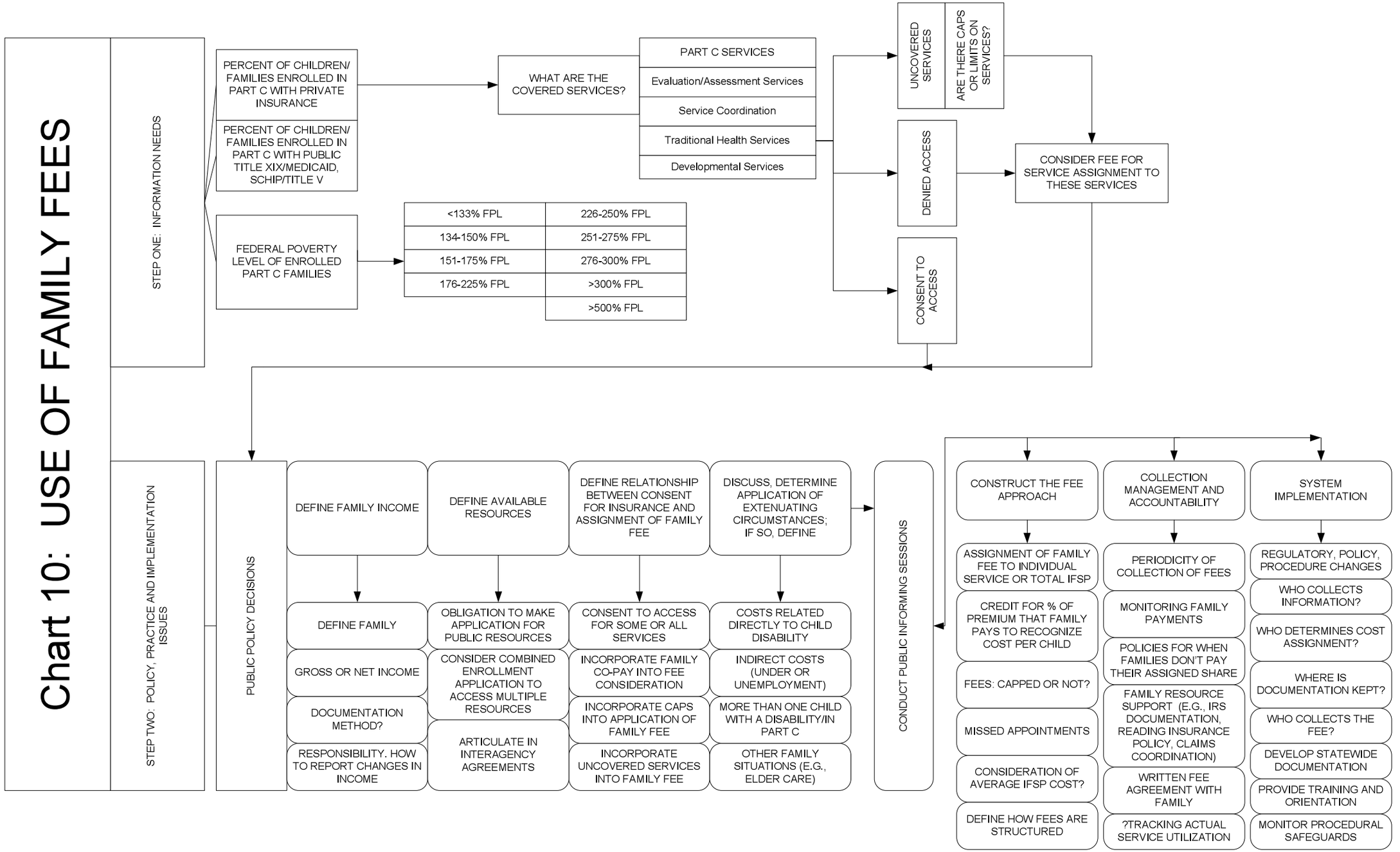


Chart 10: USE OF FAMILY FEES
STEP ONE: INFORMATION NEEDS
PERCENT OF CHILDREN/ FAMILIES ENROLLED IN PART C WITH PRIVATE INSURANCE
PERCENT OF CHILDREN/ FAMILIES ENROLLED IN PART C WITH PUBLIC TITLE XIX/MEDICAID, SCHIP/TITLE V
FEDERAL POVERTY LEVEL OF ENROLLED PART C FAMILIES
<133% FPL
134-150% FPL
151-175% FPL
176-225% FPL
226-250% FPL
251-275% FPL
276-300% FPL
>300% FPL
>500% FPL
WHAT ARE THE COVERED SERVICES?
PART C SERVICES
Evaluation/Assessment Services
Service Coordination
Traditional Health Services
Developmental Services
UNCOVERED SERVICES
ARE THERE CAPS OR LIMITS ON SERVICES?
DENIED ACCESS
CONSENT TO ACCESS
CONSIDER FEE FOR SERVICE ASSIGNMENT TO THESE SERVICES
STEP TWO: POLICY, PRACTICE AND IMPLEMENTATION ISSUES
PUBLIC POLICY DECISIONS
DEFINE FAMILY INCOME
DEFINE AVAILABLE RESOURCES
DEFINE RELATIONSHIP BETWEEN CONSENT FOR INSURANCE AND ASSIGNMENT OF FAMILY FEE
DISCUSS, DETERMINE APPLICATION OF EXTENUATING CIRCUMSTANCES; IF SO, DEFINE
DEFINE FAMILY
GROSS OR NET INCOME
DOCUMENTATION METHOD?
RESPONSIBILITY. HOW TO REPORT CHANGES IN INCOME
OBLIGATION TO MAKE APPLICATION FOR PUBLIC RESOURCES
CONSIDER COMBINED ENROLLMENT APPLICATION TO ACCESS MULTIPLE RESOURCES
ARTICULATE IN INTERAGENCY AGREEMENTS
CONSENT TO ACCESS FOR SOME OR ALL SERVICES
INCORPORATE FAMILY CO-PAY INTO FEE CONSIDERATION
INCORPORATE CAPS INTO APPLICATION OF FAMILY FEE
INCORPORATE UNCOVERED SERVICES INTO FAMILY FEE
COSTS RELATED DIRECTLY TO CHILD DISABILITY
INDIRECT COSTS (UNDER OR UNEMPLOYMENT)
MORE THAN ONE CHILD WITH A DISABILITY/IN PART C
OTHER FAMILY SITUATIONS (E.G., ELDER CARE)
CONDUCT PUBLIC INFORMING SESSIONS
CONSTRUCT THE FEE APPROACH
ASSIGNMENT OF FAMILY FEE TO INDIVIDUAL SERVICE OR TOTAL IFSP
CREDIT FOR % OF PREMIUM THAT FAMILY PAYS TO RECOGNIZE COST PER CHILD
FEES: CAPPED OR NOT?
MISSED APPOINTMENTS
CONSIDERATION OF AVERAGE IFSP COST?
DEFINE HOW FEES ARE STRUCTURED
COLLECTION MANAGEMENT AND ACCOUNTABILITY
PERIODICITY OF COLLECTION OF FEES
MONITORING FAMILY PAYMENTS
POLICIES FOR WHEN FAMILIES DON'T PAY THEIR ASSIGNED SHARE
FAMILY RESOURCE SUPPORT (E.G., IRS DOCUMENTATION, READING INSURANCE POLICY, CLAIMS COORDINATION)
WRITTEN FEE AGREEMENT WITH FAMILY
?TRACKING ACTUAL SERVICE UTILIZATION
SYSTEM IMPLEMENTATION
REGULATORY, POLICY, PROCEDURE CHANGES
WHO COLLECTS INFORMATION?
WHO DETERMINES COST ASSIGNMENT?
WHERE IS DOCUMENTATION KEPT?
WHO COLLECTS THE FEE?
DEVELOP STATEWIDE DOCUMENTATION
PROVIDE TRAINING AND ORIENTATION
MONITOR PROCEDURAL SAFEGUARDS

APPENDIX A
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