An Examination of Medicaid and Part C Service Funding Mechanisms to Support Interventions for Young Children June 2003

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Suggested APA Citation

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# Table of Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>List of Tables</td>
<td>iii</td>
</tr>
<tr>
<td>List of Figures</td>
<td>iii</td>
</tr>
<tr>
<td>Executive Summary</td>
<td>I</td>
</tr>
<tr>
<td>Introduction</td>
<td>1</td>
</tr>
<tr>
<td>Medicaid</td>
<td>1</td>
</tr>
<tr>
<td>Part C Program</td>
<td>2</td>
</tr>
<tr>
<td>Research Design</td>
<td>5</td>
</tr>
<tr>
<td>Methodology</td>
<td>5</td>
</tr>
<tr>
<td>Research Questions</td>
<td>6</td>
</tr>
<tr>
<td>Data Analysis</td>
<td>6</td>
</tr>
<tr>
<td>Results</td>
<td>7</td>
</tr>
<tr>
<td>Administrative Data Analyses</td>
<td>8</td>
</tr>
<tr>
<td>Demographic Characteristics</td>
<td>8</td>
</tr>
<tr>
<td>Mental Health Diagnoses</td>
<td>10</td>
</tr>
<tr>
<td>Expenditures for Mental Health Services for Very Young Children</td>
<td>11</td>
</tr>
<tr>
<td>Mental Health Service Utilization</td>
<td>12</td>
</tr>
<tr>
<td>Exploratory Study of 20 Highest Users of Medicaid Funded Mental Health Services Among 0-3 Year Olds</td>
<td>14</td>
</tr>
<tr>
<td>The Stakeholder Perspective: An Examination of System Level Issues</td>
<td>16</td>
</tr>
<tr>
<td>Respondents</td>
<td>16</td>
</tr>
<tr>
<td>Pathways through Services</td>
<td>16</td>
</tr>
<tr>
<td>Identification of Children</td>
<td>16</td>
</tr>
<tr>
<td>Screening and Assessment Tools</td>
<td>17</td>
</tr>
<tr>
<td>Entry into Program</td>
<td>18</td>
</tr>
<tr>
<td>Exit from Program</td>
<td>18</td>
</tr>
<tr>
<td>Professionalization of Staff</td>
<td>19</td>
</tr>
<tr>
<td>Education</td>
<td>19</td>
</tr>
<tr>
<td>Training</td>
<td>19</td>
</tr>
<tr>
<td>Caseload Size</td>
<td>20</td>
</tr>
<tr>
<td>Family Engagement</td>
<td>21</td>
</tr>
<tr>
<td>Convenience</td>
<td>22</td>
</tr>
<tr>
<td>Cultural Competency</td>
<td>23</td>
</tr>
<tr>
<td>Substance Abusing Caregivers</td>
<td>24</td>
</tr>
<tr>
<td>Natural Environments</td>
<td>25</td>
</tr>
<tr>
<td>Interagency and Service Coordination and Communication</td>
<td>26</td>
</tr>
<tr>
<td>Barriers</td>
<td>28</td>
</tr>
<tr>
<td>Family Perceptions</td>
<td>28</td>
</tr>
<tr>
<td>Transportation</td>
<td>29</td>
</tr>
<tr>
<td>Gaps in Service Systems</td>
<td>29</td>
</tr>
<tr>
<td>Funding</td>
<td>29</td>
</tr>
<tr>
<td>Access to Funding</td>
<td>29</td>
</tr>
<tr>
<td>Lack of Funding</td>
<td>30</td>
</tr>
<tr>
<td>Dealing with Multiple Funding Streams</td>
<td>30</td>
</tr>
<tr>
<td>How Funding Influences Service Provision</td>
<td>32</td>
</tr>
<tr>
<td>Outcomes</td>
<td>32</td>
</tr>
<tr>
<td>Measuring Progress</td>
<td>32</td>
</tr>
<tr>
<td>Strengths of Service Programs</td>
<td>33</td>
</tr>
<tr>
<td>Policy Issues</td>
<td>34</td>
</tr>
<tr>
<td>The Clarification Process</td>
<td>34</td>
</tr>
<tr>
<td>How Policy Decisions are Made</td>
<td>35</td>
</tr>
<tr>
<td>Family Involvement in Policy Decisions</td>
<td>35</td>
</tr>
</tbody>
</table>
Table of Contents

Future Studies ........................................................................................................ 37
  • Community Awareness .................................................................................. 37
  • Outcomes and Accountability ...................................................................... 38
  • Evidence-Based Practices ......................................................................... 38
  • System Coordination .................................................................................. 38

Policy Recommendations .................................................................................. 39

Ongoing Research on the Integration of Part C and Medicaid Funded Services for Infants and Toddlers .......................................................... 42

References .......................................................................................................... 44

Appendix A: Infant and Toddler Mental Health Stakeholder Interview Protocol .......................................................... 46

Appendix B: Infant and Toddlers Early Intervention Focus Group Feedback Form .......................................................... 52

List of Tables

Table 1 Diagnostic Categories by Cost Expenditure (FY 2000) ............... 11
Table 2 Diagnostic Categories by Cost Expenditure (FY 2001) ............... 12
Table 3 Service Provider Type ....................................................................... 15

List of Figures

Figure 1 Age ..................................................................................................... 8
Figure 2 Gender ................................................................................................. 9
Figure 3 Gender by Age .................................................................................. 9
Figure 4 Race/ Ethnicity ................................................................................. 10
Figure 5 Speech/Language Therapy with MH Diagnosis ....................... 13
Figure 6 CMH: Day Treatment Service ......................................................... 13
Figure 7 CMH: Children’s Behavioral Health ............................................. 14
Figure 8 The Number of Claims for Top 20 Users ..................................... 15
Executive Summary

This study, developed and implemented by the Louis de la Parte Florida Mental Health Institute, examines the policy and funding issues that impact behavioral health services provided to children from birth until their third birthday and explores preliminary data for a subsequent analysis of system linkages between Medicaid and Part C funded services for children ages 0 to 36 months. This report details findings based on stakeholder interviews and an analysis of trends in the Medicaid claims data from FY2000 and FY2001. During this time period the percentage of children under age three who accessed Medicaid funded behavioral health services remained relatively constant with peaks in service occurring at age two.

In order to realize a commitment to support the mental health of the youngest children in the State of Florida, certain key programmatic indicators of quality mental health service provision have been implemented throughout various service systems, including DCF, DOH, and DOE. Strategies for quality service delivery have focused on the use of high ratios of mental health professional staff to children served; adequate educational/professional training of mental health staff; provision of comprehensive, individualized, and culturally competent services; and strong, established collaborative relationships with relevant community mental health providers. These efforts will help the early childhood mental health community in facilitating targeted and effective services for young children. However, additional supports are needed to achieve statewide implementation of coordinated services and supports. This task requires a commitment to training, program outcome monitoring, service coordination, and evaluation.

Given the tremendous challenges in behavioral and emotional functioning that are being identified in very young children and the subsequent co-occurrence of these challenges with mental health problems, a continuum of services and supports need to be offered over an extended period of time so that the critical window of opportunity during the early childhood years is maximized for its potential impact. Yet these issues transcend any one system. Service integration efforts should be undertaken which link multiple systems and supports to increase understanding of early emotional health and appropriate responses for healthy long-term growth and development.
An Examination of Medicaid and Part C Service Funding Mechanisms to Support Interventions for Young Children: June 2003

Introduction

Although there is an established base of knowledge regarding the conditions necessary to foster healthy development of young children, there is a concomitant awareness that increasing numbers of infants and toddlers are at-risk for serious emotional and behavioral problems (Carter, Little, Briggs-Gowan, & Kogan, 1999; Degangi, Breinbauer, Roosevelt, Porges, & Greenspan, 2000; Thomas, 1998; Zeanah, Boris, & Larrieu, 1997). Children under the age of three represent a high-risk group, especially among those who have been exposed to maltreatment, domestic violence, alcohol and drugs (both pre and post-natally), and unstable attachment relationships with substance-abusing or mentally ill caregivers (Albus & Dozier, 1999; Brooks, Zuckerman, Bamforth, Cole, & Kaplan-Sanoff, 1994; Knitzer, 2000; Reams, 1999). Additional factors with predictably negative consequences include poverty, placement in foster care homes with greater than three children, and placement with caregivers who have no prior experience attending to the needs of an infant or toddler (Reams, 1999).

A primary focus of infant/toddler initiatives is the creation of a system of prevention which promotes stable, nurturing and stimulating family interactions, child care experiences, and environmental conditions that foster well being. In order to serve the needs of young children, a variety of funding mechanisms foster access to differential services. Many agencies are involved in the delivery and funding of services to young children and their families, sometimes contributing to a fragmentation of interventions. Comprehensive mental health services are supported by combining numerous funding sources; however, a lack of cohesiveness can also contribute to duplication and/or omission of services to meet prevention and early intervention needs of young children and their families.

Medicaid

In order to develop a comprehensive behavioral health system for young children, the complexity of the funding resources needs to be better understood. Medicaid, authorized through the Social Security Act, Title XIX, is governed by the Agency for Health Care Administration (AHCA). Medicaid provides funding for many service programs across the State that help young children and their families. Specifically, covered
services include both in and out-patient hospital services for low income persons under the age of 21, pediatric or family nurse practitioner services, family planning services, laboratory and x-ray services, and early and periodic screening for young children. Screening services within Medicaid’s Early and Periodic Screening, Diagnostic and Treatment Program (EPSDT) includes a physical exam, hearing and vision testing, health and developmental history, laboratory tests, and immunizations. In addition, any treatment that is medically necessary to ameliorate a condition detected during screening is normally covered (Wishman, Kates, & Kaufmann, 2001).

Medicaid policy typically has mechanisms in place to fund many of the services for screening, diagnosis, and intervention which eligible children and families need. However, it is based on a medical model which is diagnosis-driven. This paradigm does not easily accommodate the needs of young children who require relationship-focused interventions that are integrated into the child's natural environment (Knitzer, 2001).

Part C Program

Conversely, the Individuals with Disabilities Education Act (IDEA) Part C: Special Education Grants for Infants and Families with Disabilities program is structured to provide services for young children that are family focused, multidisciplinary, and flexible. In Florida, the program is housed within the Bureau of Prevention and Early Intervention under Children’s Medical Services (CMS) in the Florida Department of Health. This program was initiated in 1986, originally under the Florida Department of Education. In 1997, CMS assumed administrative and programmatic oversight for statewide implementation of the Part C program. In 1994, children ages birth to three years became eligible for services under the Early Intervention Program. This program is financed through federal funds allocated to states to provide early intervention services to infants and toddlers who are developmentally delayed or at high risk for a developmental delay. This federal special education program focuses on early intervention, and comprehensive assessments are conducted for infants and toddlers ages 0 to 36 months to determine their eligibility for Part C funded services.

Comprehensive assessments are provided to determine eligibility for services. Part C initiatives serve infants and toddlers, 0 up to, but not including, 3 years of age and their families, regardless of the family’s income. Children must not be eligible for special education and related services and must either be diagnosed with a physical/mental condition that is likely to lead to a developmental delay or must already be experiencing a developmental delay in adaptive, cognitive,
communication, emotional, physical, or social development. Those children at risk for delay due to environmental factors are referred to other local providers. In Florida, eligibility for Part C services is based on the following criteria (Florida Department of Health, 2001):

Infants and toddlers who have been diagnosed with an established condition associated with developmental delay (metabolic/genetic disorder, neurological disorder, severe sensory impairment, or severe attachment disorders) and those who have a developmental delay (1.50 standard deviation or greater below the mean in at least one area of development/25% delay or greater in at least one area of development).

If eligibility requirements are met (as determined in the Part C comprehensive assessment), a coordinated effort is made to ensure families receive the services and care they need. The result of this service coordination is a Family Support Plan that is designed to the unique characteristics of each family setting. Depending on the needs of the child, services may include: assistive technology, audiology, health services, nursing services, family service coordination, family counseling, home visits, nutritional guidance, psychological services, physical and occupational therapy, family support groups, vision/mobility services, and transportation (Florida Department of Health, 2001). Other direct services can be funded through Part C dollars if the child is not eligible for service payment through Medicaid, State funds, or a family’s private insurance (Berson, Vargo, Dailey, Zheng, & Powell, 2002).

The Florida Early Intervention Program (EIP) employs Family Resource Specialists who must be parents/caregivers to a special needs child. These Specialists advocate for families, ensure that local service interventions are appropriate, and monitor for unmet needs. Overall goals of Part C initiatives often include support of child (within context of family) development, prevention/intervention regarding developmental delays, linkage to community resources, and school readiness (Florida Department of Health, 2001). Florida EIP funding is a mixture of state resources (Donations Trust Fund, General Revenue, and Tobacco funds), TANF (Temporary Assistance for Needy Families), and federal IDEA Part C and Part B funds (Florida Department of Health, 2001).

Given the structure of the early childhood service system, it is difficult to establish a seamless process of prevention and early intervention services. Whereas Part C services underscore the importance of fostering relationships and promoting attachment by providing services within the context of the family, current Medicaid funding systems typically target services to the individual. Additionally, the entitlement requirement of Part C poses a concern since it is a voluntary program with a finite Congressional appropriation to the State. The State must identify resources to fulfill the program requirements, and Medicaid financing is a critical component of this process. The system is
challenged by a fragmentation of services, restrictive eligibility criteria, lack of transportation, waitlists, and a limited number of certified providers who serve children with emotional and behavior problems (Berson, Vargo, Dailey, Zheng, & Powell, 2002; Powell, 2002).

The purpose of this research is to better understand the Medicaid funded service utilization of infants and toddlers who have been identified through the Part C Early Intervention Program. This study provides information to address policy issues specific to the behavioral health services available to young children and clarify the financing system which is in place to support services for young children with behavioral health challenges. Establishing a viable approach to funding the necessary early childhood prevention and intervention services and supports requires identification and understanding of the complex interplay between existing financing systems.
Research Design

This study was designed to: 1) assist in understanding the policy and funding issues that impact behavioral health services provided to children from birth until their third birthday; 2) identify emerging best practices guidelines for promoting behavioral health development of infants and toddlers; 3) identify providers who provide therapies, treatments, and relationship based interventions; 4) examine how the system currently links Medicaid and Part C funded services for children birth until age three; and 5) identify available reimbursement for infant/toddler behavioral health services and consultations, including criteria for Medicaid funded and Part C funded behavioral health services to infants and toddlers.

Methodology

Two research methods were used in this study: analysis of administrative data and stakeholder interviews. The quantitative component of this project focused on Medicaid-funded services offered to the birth to three population within Florida. Using Medicaid claims data from FY2000 and FY2001 the research team tracked trends in service utilization, diagnosis, and funding for behavioral health services to children ages 0 to 36 months. All children included in this analysis had a mental health diagnosis and/or received Medicaid-funded mental health services.

Stakeholder interviews with providers and coordinators of Medicaid, Part C, and other behavioral health services to children ages 0 up to 3 years were conducted to explore the interaction between the funding streams, examine the barriers to accessing needed services by specific financing mechanisms, and identify the gaps and overlays in services provided. The protocol used for the interviews was specifically developed for this study. The interview attempted to address agency, policy, and general systems issues. The questions were guided by principles that include child-focused and family-centered services approach; individualized and strength-based assessment and intervention; prevention and early intervention focus; and non-duplicative service delivery. Protocol format was semi-structured with a predominance of open-ended questions to allow for maximum flexibility and responsiveness to emerging issues for the stakeholders. Examples of questions that stakeholders were asked include: “What are the caseload sizes in your program?”; “What strategies do you use to make your services convenient and accessible to families?”; and “Do you have any areas of confusion about services provided to young children from the various service systems and funding streams?” (See Appendix A for a complete list of questions). Stakeholders were free to answer in their own words, and to some extent guide the direction of the interview (Ary, Jacobs, & Razavieh, 2002). Upon consent of respondents, all interviews were tape-recorded and transcribed.
Research Questions
This project focused on services provided to young children and explored available reimbursement for infant/toddler mental health services and consultations, including criteria for behavioral health services to children ages birth to three. The following research questions were addressed in the study:

- Based on authorization, what services for emotional, behavioral, and social delays of infants and toddlers are covered by each funding mechanism?
- How do the services and eligibility criteria differ?
- How many young children are receiving both Medicaid-funded and Part C services simultaneously?
- How are coordination and collaboration facilitated to avoid duplication of Medicaid funded interventions and Part C funded direct services?
- How do the Medicaid and Part C guidelines as well as stakeholders operationally define service duplication?

Data Analysis
Content analysis of the stakeholder interview responses was used to analyze the qualitative data collected for this study. Content analysis involves reviewing interview transcripts to select common themes and trends in the data. One may also note similarities and differences among stakeholders and their respective agencies. The primary goal of content analysis is to condense the amount of qualitative data into a list of variables that can be examined for correlations. The research team begins with text (qualitative data), makes formal hypotheses as to the nature of the text's content, performs systematic coding and analysis, and finally interprets the results in conjunction with quantitative data, thus allowing for the triangulation of data sources.
Results

This overview presents a descriptive analysis of the demographics of the groups included in the study and an examination of the mental health services provided. Using historical analysis of administrative records, Medicaid enrolled children birth to age three were identified, and their mental health claims were examined. The project team looked at trends in data related to demographics, delivery of mental health services, and types of services received. The findings in this report include a comparative summary of all relevant descriptive data and an analysis of the qualitative information gathered via telephone interviews.

Berson, Vargo, Powell, Dailey, Zheng, and Armstrong (2002) previously found that speech and language impairments, noted under communication disorders, were the most prevalent diagnosis across all age groups (0–5 years) in a sample of 29,158 users of Medicaid-funded mental health care services. Communication disorders comprised 25% of all assigned diagnoses and occurred in 39% of all 0–5 year olds. Developmental delays (21% of all diagnoses) and physical health problems (16% of all diagnoses) were also prominent. Conversely, emotional and behavioral disorders were significantly less diagnosed among young children, and were primarily reported as attention deficit disorders (11% of diagnoses), conduct disorders (4% of diagnoses), and adjustment reactions (7% of diagnoses). In addition, Berson et al. stated, “The broad range of diagnostic units and prevalence of atypical childhood diagnoses such as elimination disorders in infants and schizophrenia in very young children (0–3 year olds), denote the need for ongoing work in clarifying the validity and reliability of these constructs as well as the challenges of making informed and clinically relevant decisions in early childhood mental health.”
Administrative Data Analyses

Demographic Characteristics

The demographic data, presented in Figures 1–4, provide information on the age, gender, and race/ethnicity of young children who accessed Medicaid-funded mental health services during FY2000 and FY2001. Overall trends in service access based on age remained consistent over time with service utilization increasing as children age. A peak in service access occurred at age two.

In FY2000 there were 10,190 children between the ages of 0 to 36 months who received Medicaid-funded mental health services. This is equivalent to approximately 2% of the total population of children under 3 years old in Florida (N=563,068). A slight increase in the number of children served was noted in FY2001 with 11,420 recipients who were under age three; however, based on annual population growth rates for children in Florida, the overall percentage of children accessing services remained relatively constant. Across both periods of time the majority of children served were male and Caucasian.
Figure 2. Gender

Gender of Children

<table>
<thead>
<tr>
<th></th>
<th>FY2000</th>
<th>FY2001</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>6,116</td>
<td>6,889</td>
</tr>
<tr>
<td>Female</td>
<td>4,059</td>
<td>4,519</td>
</tr>
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Figure 3. Gender by Age

Age of Children

<table>
<thead>
<tr>
<th></th>
<th>FY2000</th>
<th>FY2001</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age 0</td>
<td>1,385</td>
<td>1,209</td>
</tr>
<tr>
<td>Age 1</td>
<td>1,605</td>
<td>1,163</td>
</tr>
<tr>
<td>Age 2</td>
<td>1,936</td>
<td>1,325</td>
</tr>
</tbody>
</table>
Mental Health Diagnoses

As we strive to better understand the prevalence of mental health problems among young children, the data, which capture the diagnoses assigned to young children receiving Medicaid funded mental health services, provide an initial overview of how needs have been labeled. The data include all primary and secondary diagnoses assigned to a child who received a mental health service, and as a result a single child may be counted under more than one diagnostic category. In order to organize the plethora of diagnostic units found in the Medicaid claims data into manageable and “user friendly” categories, several discrete diagnoses were condensed into more global descriptors which categorize young children’s mental health needs. These descriptors were based on DSM IV classifications and selected by eliciting clinical perspectives from four professionals with training and licensure in child clinical psychology and/or school psychology and experience in working with early childhood populations. Following a review of the relevant literature and discussion, unanimous consensus was reached on the linkages between DSM IV, ICD 9, and D-C: 0–3 terminology. Once the global categories were determined, diagnoses common among young children (as evidenced by existing prevalence data and current rates in the Medicaid claims data for children ages 0–3 years) were separated out of the broader categories to retain the specificity of these discrete areas of interest. These categories are presented in Tables 1 and 2.
In both FY2000 and FY2001, developmental delays, speech and language impairments (noted under communication disorders), and coordination disorders were by far the most prevalent diagnoses across all 0–3 year olds receiving Medicaid-funded mental health services. This represents a common trend in early childhood mental health practices. These early onset delays have generally been associated with co-occurring emotional and behavioral difficulties and tend to reflect an initial focus of assessment and intervention on developmental and relationship-based functioning among those children accessing services. Conversely, emotional and behavioral disorders are significantly less diagnosed among young children, primarily reported as attention deficit disorders, conduct disorders, and adjustment reactions. Differential diagnoses of emotional disturbance tends to become more frequent during the preschool years as difficulties in following directions or sustaining attention among distracting stimuli are exacerbated.

Expenditures for Mental Health Services for Very Young Children

Mental health service expenditures for Medicaid enrolled 0–3 year olds were examined by diagnostic category and service type and are also presented in Tables 1 and 2. Cost estimates were generally associated with the number of users per category with the exception of children diagnosed with Oppositional Disorder, which was the classification with the highest cost per user per year (PUPY), for both FY2000 and FY2001. Overall, however, communication disorders accounted for the largest percentage of expenditures.

<table>
<thead>
<tr>
<th>Diagnostic Category</th>
<th>Users</th>
<th>Total Units</th>
<th>Total Cost</th>
<th>PUPY*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Other Develop Delays</td>
<td>4,751</td>
<td>201,515</td>
<td>$4,301,330.00</td>
<td>$905.35</td>
</tr>
<tr>
<td>Communication Disorders</td>
<td>3,582</td>
<td>103,795</td>
<td>$2,504,013.00</td>
<td>$699.05</td>
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<tr>
<td>Physical Health Problem</td>
<td>1,263</td>
<td>16,059</td>
<td>$1,505,471.00</td>
<td>$1,191.98</td>
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<tr>
<td>Coordination Disorder</td>
<td>801</td>
<td>48,864</td>
<td>$884,410.80</td>
<td>$1,104.13</td>
</tr>
<tr>
<td>Oppositional Disorder</td>
<td>159</td>
<td>7,712</td>
<td>$329,680.10</td>
<td>$2,073.46</td>
</tr>
<tr>
<td>Adjustment Reaction</td>
<td>258</td>
<td>8,244</td>
<td>$230,124.40</td>
<td>$891.96</td>
</tr>
<tr>
<td>Attention Deficit Disorders</td>
<td>374</td>
<td>2,939</td>
<td>$122,033.70</td>
<td>$326.29</td>
</tr>
<tr>
<td>Conduct Disorder</td>
<td>356</td>
<td>2,378</td>
<td>$85,379.27</td>
<td>$239.83</td>
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<tr>
<td>Autistic</td>
<td>86</td>
<td>2,661</td>
<td>$54,669.71</td>
<td>$635.69</td>
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<td>Sleep Disorder</td>
<td>120</td>
<td>4,009</td>
<td>$44,926.77</td>
<td>$374.39</td>
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<td>Affective Psychoses</td>
<td>58</td>
<td>1,210</td>
<td>$31,189.08</td>
<td>$537.74</td>
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<td>Anxiety States</td>
<td>117</td>
<td>1,382</td>
<td>$23,466.42</td>
<td>$200.57</td>
</tr>
<tr>
<td>Eating Disorder</td>
<td>199</td>
<td>350</td>
<td>$20,515.23</td>
<td>$103.09</td>
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</tbody>
</table>

* Per user per year
Mental Health Service Utilization

Among the services provided, speech/language therapy was the most common and most frequently delivered to children with communication disorders or developmental delays (Figure 5). Day treatment services have the largest cost per user per year and are primarily provided to children diagnosed with Oppositional Defiant Disorder or Attention Deficit Disorder, with service focus varying based on age of the child (Figure 6). Among emotional and behavioral disorders, CMH: Children’s Behavioral Health Services have the highest expenditure with services primarily provided to children diagnosed with adjustment reactions, emotional disorders, attention deficit disorders, and conduct disorders (Figure 7). The effectiveness and efficiency of service delivery are not captured in the findings and necessitate comparison of outcome indicators for interpretation.
Figure 5. 
Speech/Language Therapy with MH Diagnosis

Figure 6. 
CMH: Day Treatment Service
Exploratory Study of 20 Highest Users of Medicaid-Funded Mental Health Services Among 0–3 Year Olds

An analysis was undertaken of the Medicaid claims for the top twenty 0–36 month old children who had the highest expenditures for Medicaid claims in both FY2000 and FY2001. There were a total of 7,663 claims filed for these children, and on average each child received 383 service units over the two-year period, with a range from 73 claims to 822 claims per child. It should be noted that some children may have entered Medicaid late in first year due to date of birth or delay of diagnosis or left early in the second year due to a move out of State or other reasons. As a result, the findings may represent an underestimate of service utilization during the designated time frame.

Among the 20 top users of Medicaid-funded services who were between the ages of 0–36 months, 95% were diagnosed with a developmental delay. Thirteen out of the 20 children (65%) were diagnosed with a speech/language disorder. However, nearly 78% of the 7,663 claims were filed for treatment of developmental delays. Although
significantly less prevalent, communication disorders (14% of top users) and coordination disorders (3% of top users) were also treated conditions (Figure 8). The overall costs for services were directly proportional to the relative number of users for each diagnosis, with developmental delays requiring the greatest allocation of funds.

The 7,663 claims for these 20 children included treatment or services in nine different categories from five different types of service providers (Table 3). Occupational therapy (29% of top users), physical therapy (28%), speech/language therapy (18%), and hospital outpatient mental health services (16%) were the most common interventions.
The Stakeholder Perspective: An Examination of System Level Issues

The following section summarizes the qualitative data gathered from stakeholder interviews. Several themes emerged from stakeholder responses: Pathways through Services, Staff Professionalization, Caseload Size, Family Engagement, Interagency and Service Coordination and Communication, Barriers, Funding, Outcomes, Policy, and Future Studies.

Respondents

Stakeholders interviewed filled a variety of professional roles such as early intervention specialists, infant mental health therapists, executive directors of service agencies, early childhood coordinators, Part C administrators, service program managers, nurse liaisons, and researchers. Stakeholders had typically been in their current position from one to five years; however, several individuals that were interviewed had been working on behavioral health issues of this younger population for as many as twenty years.

Pathways through Services

- Identification of Children

  For many stakeholders, the primary referral sources are pediatricians and child care centers. The Part C community screening program has been designed to conduct outreach to physicians and child care programs and disseminate information about the screening program, and Part C staff will train child care center personnel to identify delays. Other referrals come from hospitals, insurance providers, and other public agencies, through Healthy Start, Healthy Families, Department of Children and Families (DCF), Children's Medical Services, other public entities that are responsible for the welfare or health of young children. One stakeholder mentioned that she had found screening efforts at the neonatal intensive care units to be a wonderful referral source.

  Stakeholders also reported getting referrals from parents and other family members who hear about Part C services from other caregivers or from public awareness events and activities. In Part C, under the federal regulations, anybody who suspects a child has a disability has 24 hours to refer that child, and parent permission is not required. The public awareness plan in place across Florida includes the development and dissemination of informational brochures. The local Part C programs also have to provide community plans with local policies for public awareness and information. These activities vary from putting brochures in doctors'
offices, speaking at health departments, attending community fairs, going to civic organizations, and conducting presentations. Part C staff are present at community health fairs, children's festivals, community baby shower events, and other activities that are marketed towards families or new parents. Part C staff will set up a booth where they display information and answer questions. Part C staff have also invested in media advertising, television commercials, and newspaper articles that profile their Early Intervention Programs (EIPs) and the service recipients.

Stakeholders varied in their opinions as to how well the identification process was working. Some were reasonably pleased with the process, while others felt that it was completely inadequate. Overall concerns included pediatricians needing more training in developmental issues because they often dismiss parents' concerns and children not being identified or identified too late because they didn't have a pediatrician that kept steady track of their development. Suggestions for improvements in the identification process included increasing outreach efforts, referring children for screenings earlier, and equipping parents with more information on typical/atypical development. Another stakeholder cynically referenced caseload issues by stating, “There is absolutely no desire to go and identify more kids for services so they can wait.” Yet another stakeholder felt that, “We are pretty good at identifying children who have those needs, but I am not sure that we are so good at really helping those children and families.”

**Screening and Assessment Tools**

Stakeholders most commonly reported using the Ages & Stages Questionnaire (ASQ), the Temperament & Behavior Scale (TABS), and the Children's Behavioral Checklist (CBCL) to assess social/emotional/behavioral issues of the child and family. The Family Assessment Device and the Parent and Child Relationship Inventory were also used.

There was a universal sentiment across stakeholders that everyone was struggling with finding best assessment tools and mechanisms to put them to good use. A duality of issues was present in conversations with stakeholders. First is the desire to determine what can be done in a way that best ascertains the critical issues that everybody wants to highlight. Second is the desire to determine what can be done without too much demand on limited resources and time. Many respondents agreed that the current assessments take an excessive amount of time from the perspective of both those who are doing them and also for the families and child involved. This process is then further complicated by the fact that there aren’t adequate tools to either provide a good screening or even a more global assessment for very young children. One provider commented, “I would like to do totally away with the protocol for Medicaid
comprehensive assessments, it is just ridiculous. To get all of your providers certified and to wait six months for that to happen, which is what we are waiting on, is ridiculous. And then in order for each kid to be certified they have to have a full assessment when it just doesn’t make any sense. I have no idea who came up with this but it is really the highest level of assessment you can provide in the mental health services arena and you do not have to come out of that assessment with a diagnosis and then have the high billable claims. It makes no sense. Now every kid in care is supposed to have one.”

While there is some emerging research and articles that are written about alternative techniques, such as transactional play-based models, these approaches are labor intensive and create a context very different from the medical model that is still in place in so many of these early intervention programs. The issue at hand is figuring out how big of a system change people want to achieve, and if it is going to be a gradual transition process, how to find resources or tools that can fit within the current system design in the meantime.

Entry into Program

Federal mandate states that Part C providers have 45 calendar days from the date of referral to have children screened. This was a challenge for many stakeholders because of the sheer volume of young children being identified. One stakeholder estimated that she received at least 200 new children per month. This same provider stated that Part C and Medicaid funds did not hurt the timing of this process; however, Medicaid HMO and private insurance did slow the screening and initiation of services down considerably. She stated, “I guess I am saying it depends on what funding stream we are going to try to access.”

Exit from Program

Part C discharge criteria require that the child meets his/her goals and objectives on his/her treatment plan and that the child no longer meets the criteria for having a diagnosis. However, most stakeholders reported that children often remain until age 36 months and then age out of the system. If a child receives normal evaluations, the family can still choose to remain enrolled in the program and receive service coordination services, but they would not always receive therapy services. One stakeholder reported that even if a child moves from a 25% delay to a higher level of functioning, the State does not encourage providers to close cases.

Stakeholders noted that parents are often so satisfied with services that they do not want to be discharged when the interventions are completed. As a result, part of the provider’s work involves helping the parents realize that they will be okay. One stakeholder explained that they do tell parents, “We are discharging you but if you get stuck and you don’t
know what to do, you can call us back.” Another stakeholder suggested that a grant-funded post-treatment support group for parents would be very helpful.

Very few parents were mentioned as being noncompliant. If parents did drop out of services it was normally because they were struggling to meet more basic needs such as food and shelter, or they were struggling with a substance abuse problem. One stakeholder estimated an 85-90% retention rate and a 73% show rate for appointments. She suggested that these figures were much higher than national standards. Another stakeholder attributed high retention rates to a procedure which required parents to sign a contract with the therapist prior to receiving services. The contract detailed what the therapist expected from the family and what they could expect from the therapist. Yet another provider commented, “It is more the other extreme, that they want more and more and more; if they get one speech therapy, they want four a week.”

Professionalization of Staff

• Education

There is a limited pool of licensed child mental health counselors within Florida. Many service programs find that while the college degree is common, the child mental health training and credentials are not. In addition, there is a high degree of staff turnover due to the misperception that the role of therapist/counselor is an easy job, lack of understanding about funding streams and the reimbursement process, a high volume of clients, and multiple demands on limited resources.

Service coordinators at many EIPs are required (via contract) to have a degree in a related field such as social work, nursing, or psychology, and to have at least a year of experience in working with families. EIPs that are co-located with hospital programs often have the most success at recruiting highly trained and experienced staff. One EIP reported that several intensive care nurses had come on board as service coordinators and others continued to express interest in the EIP. Providers reported that the more awareness that was created within the local network of service providers about the EIP, the less trouble the EIP had in filling positions.

• Training

In Medicaid, lack of providers with early childhood mental health expertise is a critical issue. EIPs reported that now that Medicaid funding is available for infant mental health services, many provider agencies are seeking training from the EIPs. EIPs are currently working in conjunction with the State’s Infant Mental Health (IMH) Task force and School Readiness Coalitions to bring in some of this
training to provider agencies. For example, trainings are occurring at childcare sites and home visitation programs. However, a major barrier is the commonplace assumption within the mental health field that one can simply apply a treatment model that works for older children to this younger age group. Likewise, many persist in thinking that children should not be treated for a specific disorder until they reach the age of five.

Despite the challenge of employing experienced staff and dealing with the misperceptions about infant mental health, those professionals who thrived have clinical experience working with young children and their families. One example of IMH staff initiative and infant mental health expertise is the crosswalk from DC:0-3 to ICD-9-CM, developed by Kathryn Shea in Sarasota, which allows for the billing of Medicaid in accordance with HIPPA requirements. The crosswalk has been approved by AHCA as a guideline for administrative/billing purposes. The crosswalk is also in the process of review by the diagnostic task force of Zero to Three in Washington. In addition, training and consultation are frequently provided by Dr. Joy Osofsky from LSU and Robert Harmon from DC:0-3.

**Caseload Size**

Overall, stakeholders reported that service agencies are “overwhelmed” and felt that providers were not allowed enough time to spend with families due to heavy caseloads. Providers struggled with finding the time and resources to educate parents. One provider attempted to deal with this obstacle by “working overtime, letting non-crisis kids slide for a week, and finding resources to give parents to read.” Turnover of state workers is a frequent result of large caseloads. He said that many workers are quitting, causing the remaining providers to manage caseloads that have doubled. Providers are forced to meet unrealistic goals, which in turn leads to burnout and increased turnover. “Caseloads are humongous,” commented one provider. “We need the ability to do justice with the clients with whom we work.”

During FY2002–2003, EIPs reported caseload sizes between 65 and 200 children per worker. Those at the upper end were expecting additional state funds this fiscal year that would drop the rates to 85–95 children per worker. One stakeholder shared that 75 children per worker was the State’s standard. Ideally, EIPs would like to see the caseloads drop to 50 children per worker. Put simply, high caseloads prevent high quality services. According to providers, there has been an approximate 50% increase in Part C eligible children statewide, but only an approximate 2% increase in funding. In addition, one program explained that only 15% of their overall funding goes to administrative costs, such as salaries, desks, phones, and clerical support. Administration and
service delivery staff often have to take on many clerical tasks due to the lack of clerical resources. Another EIP provider noted that the lack of funding for Part C influences caseload sizes, which in turn leads to a high staff turnover rate and lack of continuity of care for the children and families. Yet another stakeholder voiced frustration stating, “Unfortunately, what I see happening is that when the caseload comes down, the State places more and more requirements for the service coordinators to complete, so it almost nullifies the effect, and we still can’t get it all done.”

**Family Engagement**

EIPs coordinate some family support programs, which they cite as being critical to easing the denial parents have that their child needs developmental or behavioral interventions. However, more often than not, parents involved with Part C services are eager to take the help that providers are able to offer them. Sometimes parents have a difficult time initially and want to know why their child has not developed like other children. Many parents engage in self-blame for the child’s delays. EIP providers also deal with families that are under the belief that more is better and ask for or demand more services than can be provided under the present system. Stakeholders explained that not only are there insufficient funds, but there is also no evidence indicating that additional therapy is more beneficial. Another stakeholder explained that a clear advantage of Part C services is that they stand in contrast to other prevention efforts that have a negative spin to them. For example, Healthy Families is known by some families to be a child abuse prevention program and parents will turn down services because they are offended that they were targeted to receive the service or seen as being at risk.

In terms of parent involvement in the treatment planning process, the first thing EIP staff do is send the coordinator and family resource specialist (parent advocate) to the home in order to listen to the family’s story and what the family perceives their child’s needs to be. From that point, a family support plan (FSP) is developed. Another stakeholder shared that while the FSP process requires parent participation as an equal partner and the program tries to involve all parents as much as possible, the level of involvement varies.

Parent participation is also fostered throughout the screening process as parents remain present and receive an explanation of what is happening every step of the way. Parents are provided with materials on child development and parenting strategies. The initial stages of screening and plan development are designed as an educational experience for parents. In addition, parents must sign a consent form. One provider cautioned that although the Part C plan suggests that the parents have their choice of service coordinators, in reality the service coordinator is usually assigned.
Convenience

Home visitations have been very helpful in developing trust between staff and caregivers. Services remain convenient and accessible because providers bring the services to the families. Interpreters and transportation, though not always funded by the State, are provided to families if needed. Staff members maintain flexible hours and weekend appointments when necessary in order to make sure services are readily accessible and convenient for families. Ensuring the convenience of services is often a matter of location. Many providers make every effort to deliver services wherever their client feels most comfortable. Providers go to clients’ homes, schools, courtrooms, and/or places of employment. This approach of bringing services to the client rather than bringing the client to services is often referred to as a wraparound strategy (services are wrapped around the client). One provider stated, “Wherever the child and family are, that is where I go.” Another reiterated, “I go to wherever the major problem area is (e.g., childcare setting or school) to come to a solution.”

As previously alluded to, convenience of services is also a matter of timing. Families have busy lives, often struggling to meet basic needs. Providers find it necessary to maintain a very flexible work schedule in which they make themselves available for Saturday appointments if needed. One provider lamented that while she tried to work as many evenings and weekends as she could, she often “took flack” from coworkers for not being in the office during weekdays. “Standby” slots when no-shows occur were offered to some clients. In addition, providers tried not to schedule services during important family times such as the dinner hour.Providers also made sure to give clients a mobile phone and/or pager number. While having a contact number is the first step, providers stressed that it was crucial to make oneself available and able to return calls both quickly and during nontraditional office hours (evenings and weekends). Other providers tried to make it a habit to schedule appointments for future meetings during the current therapy session so that the caregiver would not have to schedule at a later date via phone or voicemail.

Families actively participate in determining the services their children receive through EIPs during the development of the Family Support Plan (FSP). Families are provided with information on what options are out there for them as far as providers to do the service and different options for service delivery models. The service coordinator is responsible for working with families to help them understand what their options are. One challenge some EIPs are currently facing is the family’s perception and understanding of what early intervention is. Providers explained that due to Part C originating from a medical model, families often initially think of the
early intervention as a mechanic coming in to fix their child or a magic bullet that will cure their child indefinitely. EIPs are currently working on ways to help families understand that EIP staff are simply the resource people who will provide them with information and support them in meeting the developmental needs of their child. In other words, EIP providers are still navigating through their transition from a medical to a developmental model. In addition, EIPs often encounter the challenge of parent’s “more is better” mentality. Caregivers are often convinced that the more services they can acquire for their child, the better.

EIPs are also mandated by the State to include parents in their Regional Policy Council (RPC) meetings—specifically, they are expected to strive for 51% of members to come from families with children who receive Part C services. Many EIPs reported difficulty in maintaining this percentage, with some dropping as low as one parent present per meeting. One EIP found that offering a stipend or reward for participation drastically improved their parent involvement; however, it has also been questioned whether or not the use of monetary rewards is appropriate. EIPs are allowed to reimburse parents for their travel expenses and any other kind of expenses related to participation, which seems to help to some extent. Some EIPs are considering offering gift certificates from local merchants or letting parents earn participation points to be redeemed for items such as toys and toiletry items. EIPs enjoy hearing feedback from families and whether they feel like Part C services are making a difference to their family.

**Cultural Competency**

A Part C administrator commented, “We are recruiting nationally for workers of varying ethnic backgrounds, but it has been hard to get and retain (culturally diverse) staff because the need is so high; we lose them quickly because they are a high commodity and can go anywhere else and make more money.” In some cases Spanish-speaking therapists were simply nonexistent. One stakeholder commented, “In our area we serve mostly Hispanic families, but there are no Spanish-speaking speech therapists, which is a real problem because speech is the number one reason we see little kids; that is the number one delay little kids have, but if they come from a home that speaks Spanish only, it doesn’t make a whole lot of sense to put them with a therapist that is English only, but it happens.”

Many of the Pensacola programs exist in a much less culturally diverse area; however, they have found it most important to build on the natural strengths of the family unit. Some of the Pensacola area providers stressed that while they have translated materials in Spanish, the ethnic group they most commonly deal with are Asian
populations that need entirely different translations, which are not yet available. Other areas of the State reported similar problems even finding a translator to communicate with Vietnamese, Pakistani, Russian, and Ukrainian families. In addition, there are often cultural differences in developmental issues, child rearing, and parenting practices. Providers try to support the family's set of beliefs and attempt to keep the lines of communication open.

Substance Abusing Caregivers

Some EIPs do assess for problems that a caregiver may be having such as substance abuse; however, if a serious problem is noted, the caregiver receives a referral to an outside agency (beyond the EIPs provider network). In other communities where residential substance abuse programs are not yet available, it is common practice for young children to go directly into the foster care system should their mother be identified and need treatment.

EIPs do not have a formal screening process for caregiver substance abuse either; however, staff explained that identification of caregiver problems is more a function of the relationship building with the family that occurs both during and after the creation of the Family Support Plan. One stakeholder explained, "If we get a mother who has mental illness herself and because of her mental illness she is not taking her medicine, and it is affecting the child, we have to go in and try to work with that parent first to get that parent hooked into her mental health issues and get her back on track before we can even begin to work with building on the strengths of the child and family."

In general, there are not a lot of residential substance abuse treatment programs for families. Parents are normally removed from the geographic area in order to participate in such programs; however, EIP staff noted that they will make a special effort to maintain communication with biological parents where appropriate to involve them in the family support plan process, to give them feedback on how the child is doing, and if they are returned to the home with the child, to provide services to that parent to help them understand where their child is in the Early Intervention process and bring them back into the program.

One EIP director described an incident she encountered during an initial visit to a family's home, which illuminates reasons as to why caregiver issues must sometimes be dealt with before those of the child:

Through the intake we found that the mom was in an abusive relationship, where she was under the supervision of the Department of Children & Families, but found herself pregnant in an unwanted pregnancy with the partner she was not supposed to be having contact with in front of her children. This mom was so overwhelmed with being afraid of this guy, that we were really
worried about her safety. So to worry about her 2-year old talking or not talking was higher up the ladder than where she was at and I think if I had not been there the staff person who was doing it probably would have said 'well, we don't take care of that, let's move on to talk about your child.' But as a matter of fact we pulled out the phone book and gave her phone numbers and addresses for pregnancy clinics. The new staff person that I mentioned kept saying, 'do we need to get her to sign this?' We get so focused on teaching staff how to deal with the immediate handicap with the kids, but all that extraneous family stuff, we just don't get it, even when it is thrown in our face sometimes. If we had caseloads of 20 or 50, we could really have a relationship with the family, build some charts, get to a deeper level of what all is going on. We need to train staff to do that and to ask those questions and to recognize that part of the picture.

Natural Environments

There is much interest in meeting requirements to provide services in natural environments. Currently the service systems operate on medical or professional models that can be disempowering to families and do not enhance their capacity to help their children. Part C talks with families about services in natural environments, but if the private insurance carrier or Medicaid will only pay for services in a clinical setting, the family ends up receiving mixed messages. Travel is something that is very rarely funded by any other third-party payment for therapists or services to go to the natural environments. Much of the problem throughout the State is that no one seems to have a clear and definitive understanding of what natural environments mean. However, most families tend to be in favor of the initiative once they have experienced home or community-based services.

This year has been challenging for EIPs as they attempt to transition to 100% of their services provided in these natural environments. Because EIPs are in a transition year, expenses are doubled in some instances. Most payers do not have a reimbursement rate for travel or the downtime providers experience as they attempt to get from here to there. Another related issue is no-show appointments. Providers are not reimbursed for their time if they do not see the family. While no-shows can be reclaimed in a clinical setting by taking walk-in appointments, it is impossible to make up for the lost time when a provider has traveled an hour out of their way to find an empty house.
Interagency and Service Coordination and Communication

Stakeholders perhaps had the most to say about communication or the lack thereof between colleagues, provider agencies, and different systems. The majority of stakeholders agreed that interagency communication and collaboration directly benefits both the children and families to which they provide services. Stakeholders mentioned the need to share information, within limits of confidentiality, with each other to ensure appropriateness of services and nonduplicative services. For example, stakeholders coordinated wraparound or home services with previous therapists, they shared client history information in order to understand current needs and past progress, they collaborated with DCF regarding case history and failed placements, and they worked closely with physicians to ensure appropriate dosage of medications. One stakeholder stressed, “I make a lot of phone calls”.

Multidisciplinary treatment planning meetings were mentioned by several providers. These meetings are beneficial because they bring everyone who plays a different role in the child’s life to one table where issues and barriers can be discussed in a group format. For example, with the EIP, all providers are invited to the IFSP meetings. If they cannot attend, EIP staff acquires their input via phone calls or written reports. The EIP is also attempting to do more of the IFSP meetings in the homes at times when the therapists are already there for an appointment.

While effective coordination and continuity in the organization and provision of services to young children and their families was acknowledged to vary from community to community, most stakeholders reported a big disconnect between systems. There are procedures & structures in place; however, adequate communication and coordination are not occurring because the key players are overwhelmed with their individual work and caseloads. In other words, stakeholders feel that they don’t have time to converse with each other and that meeting a child and family’s immediate needs had to come before cross system communication efforts. One stakeholder mentioned that another dimension of the systems chasm is that some of the top administration in the State agencies do not necessarily have the knowledge base required to understand service and child level issues.

Stakeholders also described a frequent mismatch between goals set by DCF for the child and family and the treatment objectives set by a Part C agency. It was not uncommon for agencies to get very short notice that a child they were working with was being returned to their biological home. This does not allow provider agencies enough time for an adequate termination process with the child with whom they have built a relationship. In addition, stakeholders complained that DCF would often send them children with very little background information. Ideally, providers would like the opportunity to consult family members and
review medical records. This gap was reported to disrupt a provider agency's ability to develop appropriate interventions. Specific to the Part C Regional Policy Council (RPC), providers noted that all of the various service systems need to be at the table; however, DCF is often not represented. This was noted as problematic because Part C serves many children who are in the child welfare system.

In general, when providers help families transition from Part C to Part B services, navigating and making sense out of the changes in DOH and DOE regulations remains a difficult task for all involved. Stakeholders struggle with trying to eliminate duplication of evaluations; however, most families that make the transition from Part C to Part B have to go through the full evaluation process again with the school district. EIPs have tried to work with school districts in getting their approval to conduct this evaluation piece for them, but this change has not yet been agreed upon by both systems. Parents often complain to EIP staff about having to go through the entire evaluation process again with the school system. There is a tremendous amount of confusion regarding the different services that are provided under Part C and Part B. Providers report that parents suffer a lot of confusion and frustration from Part C to Part B because they function very differently. EIP providers often hear from families that Part C staff are much more "touchy feely" than the educationally-based staff with Part B. It appears to often set up adversarial roles between families and the school system. However, families who are getting therapy services under Medicaid seem very appreciative at being able to continue those services when they move into Part B because there is a substantial difference between the consultative therapy model under Part C and what children may need medically, depending on their physical needs, etc. for therapy services after they go into Pre-K.

Differences in eligibility criteria among programs and differing focus/purpose of programs providing mental health services presents a discontinuity in messages sent to families. For example, the purpose of Head Start is school readiness, the purpose of Healthy Families is abuse/neglect prevention, and the purpose of Part C is remediate delays/disabilities. This creates a disconnect for families and many fall through the cracks. For example, Head Start has different disability definitions than Part C/Part B. Children who have an Individualized Education Plan (IEP) in Head Start and transition to school are not always eligible for Part B services. Medicaid eligibility criteria can also create access problems. The Medicaid criteria for income level change with age so that a young child in one family may be eligible for Medicaid while older siblings are not. Also, if family income rises, the family loses eligibility. This is a barrier to continuity of care and is especially problematic for young children receiving mental health services.
While a communal information system would certainly be helpful in aiding interagency communication, stakeholders noted that confidentiality issues were the major barrier. Currently, in order to get comprehensive descriptive data pertaining to a child, one has to go to a number of different data systems. This is an on-going concern. Information systems cannot talk to each other. Inadequate reporting mechanisms and differing definitions used by different systems (e.g. Head Start & Part C have different definitions of developmental delay) further complicate this situation and make coordination difficult. In addition, different systems/agencies have different levels of reporting. For example, programs may report State level data or their data may be specific to zip code, county, or DCF district.

Stakeholders also reported a lack of resources in order to simply be able to use information systems. Many provider agencies are non-profit organizations and do not possess the money for many computers. In addition, many staff who have been in the field for a good while are still getting used to the idea of using computers on a daily basis and need training to feel comfortable with this technology at even the most basic level. One EIP noted their frustration in finally acquiring several laptops to facilitate the Family Support Plan development only to have them stolen; however, it was generally believed that laptops were critical to being able to provide services and planning in natural environments.

Yet another problem stakeholders faced were the parents who refused to give authorization for a provider to access their insurance. According to one stakeholder, “Then what they do is go around behind us and get services under their insurance to supplement what we are paying for. Stuff like that happens.”

**Barriers**

- **Family Perceptions**

  The two barriers stakeholders identified within this category were denial of a problem and the idea of the more services the better. According to one stakeholder, “we have some families at the very beginning that will say, ‘no, I don’t want services’ and then they will call up a month later and say, ‘I need you.’ They go through a little denial period there.” Stakeholders all noticed that caregivers were overwhelmed and dealing with feelings of guilt because “getting to a more nurturing level besides feeding them and clothing them and having a roof over their head is a big challenge.” Alternately, some parents approach the system insisting that more therapy sessions are better than providers educating the caregivers themselves to do informal play therapy on a regular basis.
• **Transportation**

Even if funding for services is in place, there is still the more basic need of ensuring children and families can get to services. Many families live in more rural areas, making it a much longer trip to reach the provider and agency. Stakeholders reported that as a result, many needs go unmet or not adequately attended to. Stakeholders reported a specific concern for gathering information that would help develop policy and mental health service provision in the sparsely populated counties of both north and south Florida.

Another problem cited was that some facilities are not located on bus routes so that cheaper methods of transportation were ruled out. Many of the service providers across all systems are finding resources to reimburse families for their travel through the Department of Transportation in Tallahassee; however, some agencies are still providing transportation “in-kind”. Even if families are reimbursed at the State rate of 29 cents per mile, the reimbursement process and delay in repayment still remain an inconvenience for the families who make use of this option.

• **Gaps in Service Systems**

Stakeholders emphasized that many children fall through the cracks of early intervention systems due to restrictive eligibility criteria. For example, a child with behavior problems who begins Part C services near his third birthday, and receives in-home early intervention services, will not get these services when he transitions to Part B services. Many children referred for behavior problems don’t even meet Part C eligibility criteria and have to be referred to a local Early Head Start program. Stakeholders also commented on the tendency of many community mental health centers not to serve young children who don’t have Medicaid and to lack expertise for serving young children who are Medicaid eligible.

**Funding**

• **Access to Funding**

Many funding suggestions related to hiring more workers so that caseload sizes could be reduced and service coordinators and therapists would be less likely to quit. Another common suggestion was increasing providers’ salary in order to offer a financial incentive to match the strain of their workload. Other suggestions were that more resources be put into child protective investigations and staff training. “Good training is expensive,” commented one stakeholder. This stakeholder tried to use her membership in professional organizations to get free training for her agency. She also mentioned that it was helpful when agencies collaborated on training events and shared in the expense.
Despite these concerns, stakeholders were very pleased that Medicaid started to reimburse for family therapy in 2001. Stakeholders were also grateful for the opportunity to apply for Medicaid-funded bus passes in order to provide incentives for caregivers who comply with treatment. In addition, they would like to see Medicaid reimburse for provider's travel and phone expenses. Stakeholders stressed that they increase their propensity for success to the extent that they can treat the family as a whole rather than the child in isolation from the larger family and environmental context. Stakeholders emphasized the critical nature of integrated funding for behavioral health services to young children.

• Lack of Funding

Stakeholders who had been in the field of early intervention for several years were disappointed that funding levels seem to have diminished over time. While more children have been identified, the resources have not been increased to support services for them. One stakeholder commented that, “the number of children/families being served has grown over 50% since 1994, but funding has increased only 2%.” Another stakeholder admitted that her program was struggling fiscally just to bring the children back in to conduct an annual evaluation. This stakeholder explained, “When you keep getting more and more kids being referred and you have to hit the 45-day timeline and you don’t have any money to hire more clinic staff, doing annual re-evaluations gets pushed down on the priority list. Consequently, I don’t have good data on outcomes, just like a typical nightmare.” Stakeholders also voiced complaints that the Medicaid reimbursement rate is “grossly inadequate” and fosters a community of providers who do not want to treat Medicaid children.

• Dealing with Multiple Funding Streams

Medicaid may only contract with one provider for a service (e.g., speech therapy); however, that provider may or may not have any experience with young children or may be located a long distance from the family. In this case, EIP programs will use their Part C dollars so that families can access the appropriate services. Providers may also encourage these types of families to apply for Medipass as opposed to remaining with an HMO. EIPs often encounter providers who are qualified to do behavioral intervention, but do not have the necessary credentials to bill Medicaid. Since Part C has a shortage of funds and functions as the payer of last resort, there is pressure to refer families to providers who are eligible to bill Medicaid (i.e., licensed providers). The problem is that licensed providers often do not have expertise in mental health and
behavioral health issues, and are not qualified to treat these problems effectively. People who do have the experience/training/expertise to provide effective treatment may not be licensed, and thus cannot bill Medicaid and receive referrals under Part C. Consequently, when a Part C child has behavior problems, they may get an early interventionist who knows little about behavior simply because the provider can bill Medicaid. Put simply, referral is predetermined by funding stream. Stakeholders urged for the loosening of restrictions on which providers are eligible to bill Medicaid.

Stakeholders reported that some insurance companies will restrict funding to services only provided in certain types of settings, like therapy services, and only offered on a one-to-one basis in a clinical setting rather than consultative therapy services or services in natural environments. It is this “hoop-jumping” and knowing how to deal with different systems that ultimately weighs on service coordinators’ time and patience. Service coordinators must understand whom they have billed for what and what is the policy and procedure for all of the different funding sources. Also, while many of the private insurance companies require a diagnosis, many of the Part C children either have a diagnosis of developmental delay because of an underlying cause that has not yet been identified or because the parent chooses not to put a label on their child. It is sometimes the case that service coordinators cannot access funds because the payer does not consider developmental delay as an appropriate diagnosis for services such as speech therapy, which many children with delays require.

In terms of how long it takes from the time a caregiver requests services for their child and when agencies receive authorization to provide services, it can vary significantly depending on what the source of the funding is. One stakeholder noted a recent situation in which the process had dragged on for months. In general, the approval process takes approximately 4 to 6 weeks, although with private insurance groups, it may take 2 to 3 months.

Overall, stakeholders viewed the multiple funding sources as a requirement for agency survival. It allows Part C money to go farther and allows some flexibility within the service program. According to one stakeholder, “If we were strictly a Medicaid funding program, we would have to turn away families, so being able to have those two funding sources coming in has added flexibility.” Another stakeholder explained, “I think if you learn how to navigate them all successfully, it broadens your financial base so that little changes that happen here and there of these different sources don’t throw your entire program into crisis. It is like having a diversified investment portfolio; if one stock goes belly-up, you don’t go broke. It certainly makes
adjustments to the sweeping changes the insurance industry makes easier to deal with." However, the disadvantage to this is that it multiplies reporting, documentation, and paperwork requirements. Another disadvantage is that the various funding entities have become savvy about each other. For example, private insurance companies actually tell clients to access Part C first. Stakeholders wished that they had some FTE time to allot a staff person to apply for grants, so that there would be fewer restrictions on funding.

• How Funding Influences Service Provision

Medicaid HMOs won't cover services delivered at a shelter placement because they consider a shelter to be the child's home. A global delay, (which is what many of the Part C children are identified as having) does not qualify for Medicaid reimbursement, so service coordinators must use Part C money. Typically, these funding sources do not pay for travel, so less in-home services are provided. According to one stakeholder, "You are not going to have a physical therapist who can get $50/hour go to the home when it takes 30 minutes to get there and 30 minutes to come back. The funding totally drives the services."

However, many stakeholders did not feel that Part C funding negatively influenced service delivery. For example, one stakeholder explained, "The philosophy of Part C is intervening, so that our eligibility category is fairly general and broad and even if the child does not meet the exact percent of delay described in the policies, clinical judgment is an option. So by looking at it as an intervention, you don’t have to wait until a child gets so far behind that he is eligible for the service. You are able to bring them in early so I really don’t think that it does limit our ability to deliver needed services."

Yet, Part C providers acknowledged severe time delays with Medicaid and private insurance authorization and explained that they often use Part C funds to pay for services until the authorization takes place.

Outcomes

• Measuring Progress

Stakeholders were asked how they determined whether their services were having a positive effect on children and their family's lives. The following are methods currently in place for measuring such progress:

• Monitor/document outcomes with Ages & Stages.
• Monitor success of post-shelter placement.
• Facilitate smooth transition to Part B.
• Keep track of number of children screened, referred, and connected to services.
• Engage in On-going quality improvement: parent, provider, stakeholder satisfaction surveys.
• Do annual evaluations. IFSP has outcomes set by families, and these are tracked, but results don’t go into data system.
• Administer a variety of instruments every six months to find out developmentally and emotionally how the child is progressing..
• Review the Family Support Plan and find out what goals have been met, what the family is still working on, and what strengths the family demonstrates.

Many stakeholders commented that while they had outcome data, they did not have the funding to hire anyone to analyze it. According to one stakeholder, “It is just a wealth of information we have not been able to pull together.” Another stakeholder commented, “We don’t have a research base here at the agency, and I think it has been needed for so many years — it is almost a deficit.”

**Strengths of Service Programs**

Stakeholders were asked to identify aspects of their service programs that they believed were most effective in meeting the behavioral health needs of young children and their families. Providing a responsive, nurturing, stimulating environment for children and using a comprehensive approach were identified as being most helpful. Part C service coordinators were repeatedly mentioned as a family’s greatest asset throughout the service delivery process. According to one stakeholder, “We hear that many times they don’t know what they would have done without that person that helped them kind of pull everything together and find out where to go and then that really helps them as they leave our system in that they have learned how to kind of find things on their own and they feel empowered.”

A few stakeholders mentioned that involving families in their child’s service provision offered them hope. One stakeholder explained, “It is this intangible thing called hope. Let’s say you have cancer, knowing that you are getting radiation treatment gives you hope, or if you have AIDS, AZT gives you hope. Getting treatment gives you hope that your child will get better whether they really do or not and this should not be underestimated.” Other stakeholders cited the identification process as a strength. One stakeholder commented, “If those things were not in place we would have a lot of children starting into the school system and not making it through Kindergarten. Part C and Medicaid are the key to getting these kids a head start.”
The family-centered approach and empowering families were two very common themes during the stakeholder interviews in reference to program strengths. According to one provider, “I think being a source of support to the family and working really hard to be a very good listener and to encourage them, not to overwhelm them. We are starting to have families say, ‘I gained out of participating in the system with a better understanding of how I can help my child. I learned how my behavior influences my child instead of ‘you fixed, or didn’t fix, my child’.” The overall sentiment across stakeholders was that empowering parents was the best thing that could be done for a child, especially in the long run.

In conclusion, all stakeholders interviewed did feel that services funded through Part C and Medicaid did help young children and their families. One provider noted that a lot of private insurance companies will not pay for preventative services and that these funds help families who would otherwise not have been able to afford it. Services were acknowledged to identify children in a timely fashion and get interventions in place early in the child’s life when it can make the most significant difference. Services were also credited for emotionally supporting families and helping them to understand their child’s developmental issues. Providers have often heard from families that their children would not have achieved so much or been able to do what they are doing now were it not for such services. According to one provider, “We get that so many, many times, so I feel like it definitely has helped and it definitely has made a difference.”

Policy Issues
As in any field that spans several service systems, confusion about policies will from time to time develop. In order to optimize the delivery of services and related outcomes, providers and administrators must have people to turn to for clarification on policies and procedures.

• The Clarification Process

When stakeholders had questions about Part C funding, many went to the Part C director for their county or the technical assistance liaison at the State level. One stakeholder explained, “We are a federal program, we receive funding and we have to abide by the requirements under the IDEA, so ultimately we go to the Office of Special Education in Washington. We have a contact person there for the State of Florida and we seek out information and clarification regarding the federal regulations, if it is regarding our program.” Another stakeholder lamented that the EIP staff were not helpful, stating, “They won’t discuss issues, just quote regulations even though they’re not following them.”
For Medicaid issues, it seemed that many stakeholders had expertise within their agency or could consult a local Medicaid Liaison. If they did need to consult staff at the State level, some were very satisfied with the responses they received. For example, one stakeholder described the clarification she received as “Very, very, very helpful. We get excellent support. We get excellent cooperation from other State agencies.” However, others remained frustrated. One early intervention administrator commented that she had posed some very specific questions to the State Medicaid office and had not gotten any answers. “I feel like the left hand doesn’t know what the right hand is doing in government.”

Several stakeholders mentioned that they had consulted the Florida Strategic Plan (FSP). However, one stakeholder admitted there was much work yet to do subsequent to this document: “We have all agreed that that was very well written, a very nice document as a starting point. But moving from the FSP to implementation in a local community, and it is so big, it is like, where do we start here?” While frequent discussion has occurred on the plan and implementation of it, general consensus was that implementation efforts still needed to be strengthened.

• How Policy Decisions are Made
Stakeholders were asked to describe how policies concerning services provided to young children were created. Many believed that they were direct products of requirements of federal regulations and State funding sources. One stakeholder stated, “I tell them what I think, but they (State level) are free to ignore it, and usually do.” Another explained, “We rely very heavily on stakeholder input. We have a State coordinating counsel, called the Florida Interagency Coordinating Council for Infants and Toddlers. It is in federal regulations. We have to have the State coordinating council. It is made up of representation outlined in the federal regulations, and these representatives are appointed by the Governor, and this group advises and assists us in the implementation of this program.”

Normally planning meetings attempted to include stakeholders, families, providers, and community constituents across the state in order to solicit recommendations regarding policy change, as well as how to go about implementing new policies, such as the move toward services in natural environments.

• Family Involvement in Policy Decisions
Stakeholders felt that more family input and more local collaboration across agencies that provide funding & services to young children was necessary. One stakeholder explained, “Everyone is so overwhelmed with their little portion of this that we have too many people looking at the trees and nobody is really looking at the forest.”
People respond when their awareness is raised, people want to do this. People want to make a difference for children and families, people want there to be better outcomes for children and families, it is the how do you do it, how do you get it paid for, issues that people don’t know about.”

Across stakeholders, several ways to involve families in policy decisions were identified:

1. **Parent Resource Organization**
   This is a statewide parent organization funded through Part C that has a membership of approximately 20 caregivers who live across the State of Florida. They have been in existence since Part C began in the early 1990’s and assist with policy making, policy development, implementation, evaluation, and also provide support within local communities.

2. **Regional Policy Council**
   This Council is a local interagency coordinating body to help make decisions and recommendations regarding how services are delivered within the local area, and it is a requirement that 51% of that local group be families. Parents are part of councils, but members may have different levels of understanding of the system, which makes the work of the councils difficult. Many times the parent representative on the Regional Policy Council is most often a Family Resource Coordinator, or in other words, a Part C employee.

3. **Family Resource Specialists**
   Every EIP resource center must have 1.5 FTE family resource specialists within their local service area that works with families as they come into the system and helps them throughout their stay within the program related to local community resources, community support groups, and anything that they might need within that local level.

4. **Parent Consultant**
   This is a State funded position within the State office that coordinates and works with all of the parent groups throughout the State.

5. **Incentives for Participation**
   Stakeholders mentioned that they knew of some active parents who are trying to recruit other caregivers to be involved at the policy-making level. Many Part C programs will pay for parents’ expenses to attend meetings. For example, they will reimburse child care and mileage. One program offered a Wal-Mart gift card as a token incentive for
participation. At some point, this issue of incentives for participation become very controversial. One program countered this concern by holding a drawing amongst all parents present, thus only one individual could win the gift card or reward. The Part C/EIP staff throughout the State have also convened parents in a focus group to get their input on improvement of services, strengths of the program, getting parents more involved in policy changes, and fostering improved communication between staff and parents (Appendix B; For an in-depth discussion see Vargo, Berson, & Whitlock, 2003). Suggestions from families who access the services are used to improve service delivery and engage families in the development and implementation of policies.

**Future Studies**

Respondents were asked what they would like to see highlighted in future studies regarding mental health services for very young children and the funding sources that support them. Suggestions focused on community awareness, outcomes and accountability, identification of evidence-based practices, and system coordination.

- **Community Awareness**
  
  Stakeholders were anxious to have additional tools to educate both the general public and the medical/behavioral health community about the target group of very young children and their unique developmental challenges and behavioral health needs. One stakeholder wanted to provide education and guidance to physicians in identifying & referring young children with developmental delays & mental health issues. “Do Medicaid physicians even know that there are Medicaid community mental health services for kids under five? I don’t think so. It is like the mental health world is separated out from the disability world.” Another stakeholder wanted to simply identify and inventory all of the community mental health centers in her area that could provide services to young children.

  Competency training was suggested for behavioral health professionals who work with children under three. There was concern that the typical medical model emphasizes cognitive or awareness therapy with the target person; however, individual reflective counseling would not be the best intervention for a 2-year old. Parenting and caretaking must be addressed. According to one stakeholder, “There are a lot of mental health professionals who say, I don’t know how to do play therapy, as if there is some magical teddy bear or Barbie doll that you can bring out and change a child’s behavior and that is not what infant and toddler mental health really is about. People don’t know that.” It was suggested that work with young children heavily emphasize involvement of their families.
• **Outcomes and Accountability**
  Stakeholders were interested in Part C accountability. Some suggested studies in which individual children were tracked through the system in order to determine if there are inconsistencies or arbitrary decision-making about services. One stakeholder wished for the following regarding outcome data: “I would love to learn that kids are getting better and kids were getting served and they were getting served within 45 days of referral and that they were getting the intensive intervention that they need.” Another stakeholder commented, “I think one of the faults in mental health in general is that we haven’t been able to show outcomes, we have not been able to say, this service works. If you can’t prove that what you are doing is working, then you should not get any funding and we have got to show that we are making an impact.”

• **Evidence-Based Practices**
  Many stakeholders were anxious to know what services and interventions are most effective with this young population. In reference to evidence-based practices, one stakeholder commented, “I would like more about interventions that really work. I think there needs to be more careful study on interventions and outcomes. There is very little that I have seen to support it in the literature. People want it, people will provide it, people are demanding it.”
  There was also considerable interest concerning screening measures. One stakeholder explained, “It would be very helpful for me to see what is out there, to see what has been done and what kind of empirical data they might have on some of these measures they have used.” Once guidelines for interventions are established, stakeholders would like to see them disseminated on a wider basis.

• **System Coordination**
  Seamless transitions between programs were a desire of several stakeholders. Avoiding duplicate screenings of children was also mentioned as a goal. One stakeholder felt that the initial excitement behind the emergence of infant mental health had dissipated and that many providers still did not understand what they could do. This stakeholder commented, “A smaller work group would be very helpful to say, how is this going to be integrated into what we are doing already and specifically in terms of what does it really mean to have a behavioral health problem as an infant or toddler?”
Policy Recommendations

In order to realize a commitment to support the mental health of the youngest children in the State of Florida, certain key programmatic indicators of quality mental health service provision have been implemented throughout various service systems. However, additional repetitive supports are needed to achieve statewide implementation of coordinated services. This task requires an emphasis on training, program outcome monitoring, service coordination, and evaluation.

An expanding research base in the area of early childhood mental health must address the need to track outcome indicators, which can assess the efficiency and effectiveness of service delivery. This includes monitoring the association between early mental health issues, early intervention, subsequent school readiness and preparation for cognitive tasks. Since the young child's medical and emotional needs are linked with the quality and continuity of family relationships as well as biological characteristics (i.e., low birth weight, drug exposure, chronic illness), a comprehensive and coordinated mechanism for service delivery is vital to healthy development. In contrast, when supports and interventions are not designed to assist caregivers in addressing their own issues while providing for their young child, sleep disorders, regulatory disorders, attachment disorders and affective disorders can result (Zero to Three, National Center for Clinical Infant Programs, 1994).

Based on the findings of this study, it is apparent that mental health professionals are paying increased attention to the emotional needs of young children; however, they may lack the knowledge, skills, and infrastructure to sufficiently assess and serve children in this age span. The field of early childhood mental health is still relatively new, and there is a paucity of well-trained people who understand relationship-based prevention and intervention practices. Specific training on social-emotional development, supports, and services for young children and their families may provide an important foundation for promoting well-being of children throughout their growth and development. The use of reference points (i.e., comparisons to a peer group, cultural context) and triangulation of information are vital for assessing the functioning of young children. The context of behavior in terms of relational, family, community, and cultural dynamics provides critical information for providing prevention and intervention services.

Issues associated with the diagnosis of disorders among young children were noted in the findings. The difficulty in applying the diagnostic process is in recognizing specific symptoms and the degree of severity they represent. The lack of a common language about early childhood mental health exacerbates the imperfection of a descriptive diagnostic classification and highlights the importance of training and experience to establish expertise in young children’s issues. Without
intensive exposure to infants, toddlers, and preschoolers some clinicians may lack a baseline for comparison of behaviors to a continuum of typical patterns of development. A major issue which further confounds the reliability and validity of the diagnoses is incongruence between DSM IV, ICD-9 and DC: 0–3 classification systems. Assessment, which is guided by a process of systematic observation, can lead to diagnostic information that is useful for communication with caregivers and child professionals, as well as documentation of the etiology, manifestation and course of the child’s difficulties. It is also recognized that a diagnosis is only one step in a comprehensive evaluation designed to formulate a treatment plan. Developing a universal language that can be recognized and understood by all would yield increased clarity and enhance collaboration across the professional disciplines which must work together to address early childhood emotional health.

Decisions for diagnosing and service delivery may be guided not only by clinical judgment, but also by available funding. Further examination of efficacy of services can assist in establishing a rationale for securing resources, which address prevention and service delivery in a family context. The willingness to address and further investigate options for meeting the needs of young children reflects the collective commitment to build capacity for child-focused, family centered service systems.

Given the tremendous challenges in behaviors and emotional functioning which are being identified in very young children as well as observations of symptoms which often simultaneously or subsequently co-occur with mental health needs, a continuum of services and supports need to be offered over an extended period of time so that the critical window of opportunity during the early childhood years is maximized for its potential impact. Yet these issues transcend any one system. Service integration efforts should be undertaken which link multiple systems and supports to increase understanding of early emotional health and appropriate responses for long term healthy growth and development (Berson, Vargo, Powell, Dailey, Zheng, & Armstrong, 2002).

In conclusion, the following items highlight areas to be considered in ongoing work on policy development and implementation:

- Inadequacies of funding for early intervention therapies remain a concern since financial incentives appear to be in conflict with emerging standards of quality care. By reexamining private insurance coverage and studying Medicaid rates for therapeutic interventions in natural environments, a sufficient base of resources may be created. This includes consideration of changes in provider qualifications for Medicaid reimbursement. In order to serve the growing numbers of identified young children with behavior issues, broadening provider lists to include psychologists, unlicensed early interventionists, developmental specialists, and behavioral specialists should be explored.
• AHCA should consider a communication system or list serve that would disseminate information on changes in policy and services to children 0 to 3 years to relevant stakeholders. This communication system could enhance the coordination of various social service systems, provide opportunities for common planning, and co-facilitate the continuum of supports and services needed to address the mental health needs of young children. This process may also serve as a mechanism to foster specialized staff training and further technical assistance in mental health services and developmental issues of children ages 0 to 3 years.

• Outcome studies are needed to establish the efficacy of services provided and establish a foundation of best practices in the field.
Ongoing Research on the Integration of Part C and Medicaid-Funded Services for Infants and Toddlers

In order to expand on the policy implications identified in our baseline study of Medicaid-funded behavioral health services for young children in Florida (Berson et al., 2002) and the findings of this year’s report, further research is needed to clarify the complex interplay between existing financing systems. As a result of ongoing collaboration between the Department of Health and FMHI, a process to allow access to Part C data has been finalized, and FMHI will engage in a continuation study for 2003–2004 which involves an in-depth quantitative analysis of the early intervention and mental health service data.

In 2003–2004 the project team will examine the influence of two principle service sectors on access to and continuity of care which emanates from divergent financing and policy systems. Using historical analysis of administrative records, Medicaid eligible children birth to 36 months of age will be identified and their behavioral health claims activity will be examined. These children will be linked with claims in the Part C service data to identify an inventory of existing services and identified needs (i.e., diagnoses). Trends in the coordination of funded services will be noted.

The following research questions will be explored:

- Based on authorization, what services for emotional, behavioral, and social delays of infants and toddlers are covered by each funding mechanism?
- How many young children are receiving both Medicaid-funded and Part C services simultaneously?
- What proportion of children are first identified through Part C Early Intervention and then linked with Medicaid funded behavioral health services?
- How are coordination and collaboration facilitated to avoid duplication of Medicaid funded interventions and Part C funded direct services?
- Do Medicaid eligible children who are identified through the Part C Early Intervention Program have different service needs or longer duration of service access than young children who do not access Part C funded assessments/interventions?
This study will focus on Medicaid-enrolled children ages 0 to 36 months of age who have been identified as part of the Early Intervention database. All infants and toddlers, birth to age three, within the State of Florida who show up in the Medicaid claims data and/or the Part C data, who have a mental health diagnosis or are receiving behavioral health services (including prevention), will be included.

The analysis will include a description of the frequency of services accessed for various subpopulations of young children. Young children identified through Part C will be compared with children who access Medicaid services outside of the early intervention program. The role of Part C in facilitating early access to needed services will be explored. Moreover, service duration and changes in diagnostic status will be examined to determine trends based on changes in developmental functioning and services available. In addition to basic frequency distributions, analyses will be conducted using logistic regression and event history to explore categories of service outcomes. The project team will be exploring if coordinated linkages between the service delivery systems, as evidenced by early service intervention, contributes to subsequent improvements in child well being.
References


Appendix A:

Infant and Toddler Mental Health Stakeholder Interview Protocol

Name of interviewer(s) ______________________________

Date/time of interview ______________________________

Name of stakeholder ______________________________

Name of Agency ______________________________

Introduction
The purpose of this interview is to explore the types of prevention and early intervention services provided to very young children across the various systems of child welfare, health, and education through the means of prevention and early intervention. Specifically, we need to gather information about the benefits and challenges of providing and coordinating specialized services (e.g. Medicaid, Part C, and Part B) to best serve this population. We are interested in learning more about the conditions and resources supportive to coordination of services and funding streams, any conditions that have hindered these processes, and the role of AHCA, DCF, the Department of Education, the Department of Health, and direct service agencies. We are interested in learning about “best practices” your agency has developed while serving this population. Your experience is very valuable to us and we believe that the information you will share with us can be very useful for improving programs and helping young children and their families. Your participation in this study is voluntary, and you will not be identified by name. Although we may publish reports as a result of this study, we will never include personally identifiable information.

Agency

1. What is your current position?

2. How long have you been in your current position?

3. How long have you been with your current agency?

4. How long have you been involved with the administration/provision of interventions for young children?
5. What has been your role in services to infants and toddlers?
   a. ___ Service Provider Agency Administration
   b. ___ DOE Administration
   c. ___ DOH Administration
   d. ___ AHCA Administration
   e. ___ DCF Administration
   f. ___ Other______________________

6. What are the objectives of your program?

7. What services does your program provide to children 0–5 with emotional / social / behavior problems and their families?

8. Who do you serve (target population)?

9. What are the eligibility requirements for your services for children 0–5 and their families?

10. What are the funding/reimbursement sources for your services to young children and their families?

11. What percent of funding comes from each source?

12. What are the advantages of being able to draw from multiple funding sources for comprehensive services to this population?

13. What are the disadvantages of being able to draw from multiple funding sources for comprehensive services to this population?

14. Do the funding sources your agency has access to require that a child have a diagnosis?
   □ Yes
   □ No
   a. If so, how does this requirement affect the type of services offered and/or the way services are provided?

15. Please describe any ways in which regulations governing funding streams limit the type/amount of services your agency is able to provide.

16. Please describe how long it takes from the time a caregiver requests services for their child and when your agency receives authorization to provide services. Feel free to elaborate on any consequences of this time span, if applicable.
17. Are there young children who need services whom you are unable to serve?
   □ Yes
   □ No
   a. If yes, why?
   b. If yes, do you refer them elsewhere? Where?

18. What are your referral sources?

19. Does your program do Medicaid-billed psychosocial assessments on children 0–5?
   □ Yes
   □ No
   a. If yes, what instruments do you use?

20. What are the qualifications/education/training of your staff?

21. Do you have any difficulty finding staff qualified to serve young children?
   □ Yes
   □ No
   a. Please describe.

22. What are caseload sizes in your program?

23. What strategies do you use to make your services convenient and accessible to families?

24. In what ways do you adapt your services to the cultural needs of the families you serve?

25. Describe how families participate in determining the services they and their children receive.

26. What are the barriers to providing services to the children and families you serve related to: Social-economic factors, family perceptions/stigma, denial, language, identification, wait lists, program/eligibility restrictions, transportation, hours, location, knowledge of services, funding mechanisms/restrictions.

27. What do you see as the most effective aspect of your services?

28. How does your program determine/measure progress and success with the children/families you serve?

29. How long do participants remain in the program?
30. What are your discharge criteria?

31. What percentage of the children/families served by your agency complete treatment?

32. Are the children/families you serve typically also receiving services from other agencies/programs?
   □ Yes  
   □ No
   a. If yes, what services, from which agencies/programs?
   b. How are these services funded?

33. How are these services coordinated to avoid duplication?

34. How does your program deal with issues of parental substance abuse, mental health & family violence? (screen for? treat? refer out?)
   a. How do Medicaid/Part C/Part B service plans provide direction and support for making smooth transitions across settings, providers, and levels of service?

**Policy**

35. Do you have any areas of confusion about services provided to young children from the various service systems and funding streams?
   □ Yes  
   □ No
   a. If you do have areas of confusion, please describe them.

36. When you have had questions or concerns such services and/or funding streams, whom have you gone to for clarification?
   a. How helpful were their responses?

37. How are policy decisions made for services provided to young children and their families?
   a. Is everyone involved who should be in policy decisions?
      □ Yes  
      □ No
   b. If no, please explain.
   c. Are parents of young children receiving services involved in policy decisions?
      □ Yes  
      □ No
d. Have you felt you have had sufficient input into policy decisions?
   □ Yes
   □ No

38. Have the appropriate procedures and organizational structures been established to facilitate adequate communication and coordination between the various departments and agencies providing services to young children and their families?
   □ Yes
   □ No

39. Have the following been adequate?
   a. Information Systems
      □ Yes
      □ No
   b. Fiscal Policies
      □ Yes
      □ No
   c. Reporting Mechanisms
      □ Yes
      □ No
   d. Policy Oversight
      □ Yes
      □ No
   e. Personnel Oversight
      □ Yes
      □ No

**Systems**

40. Are you aware of young children/families in need of services for social/emotional/behavioral problems who cannot get them?
    □ Yes
    □ No
    a. Please explain.

41. In general, what are the mechanisms across the various systems to identify children at risk or in need of a behavioral intervention/prevention services?
    a. How adequate are these mechanisms?
42. In general, how do professionals decide to whom the referral should be made?

43. What changes in Medicaid would facilitate the delivery of services to young children with social-emotional-behavior problems?

44. What is being done for young children who stay with their mothers while the mothers are in substance abuse residential care?

45. Do you think Medicaid/Part C/Part B services have helped children and their families?
   □ Yes
   □ No
   a. If so, how?

46. Is there effective coordination and continuity in the organization and provision of services to young children and their families?
   □ Yes
   □ No

47. Is there a single point of coordination and accountability for assuring that service plans are implemented, that monitoring activities are conducted, and that information is shared with the service team so that smart and timely changes are made in strategies, supports, and services across settings and providers?
   □ Yes
   □ No

48. What issues would you be interested in learning more about through an exploratory study of services provided to young children and their families?

49. Is there anything else you wish to comment on?

Thank you very much for your time.
Appendix B:

Infant and Toddlers Early Intervention Focus Group Feedback Form

Infants & Toddlers Early Intervention Program
Florida Department of Health

1. How can family involvement be increased or improved throughout the early intervention process (for example evaluation, assessment, Family Support Plan and delivery of services)? (What barriers do you currently see in families being actively involved in the process? What suggestions do you have for overcoming the identified barriers?)

2. How can the state and families in the early intervention system work together better and help each other? (What barriers do you currently see in involving families and caregivers in the early intervention system both at the local and state level? What suggestions do you have for overcoming the identified barriers?)

3. From your perspective, what are the most important supports and services that service coordinators should be providing? (What barriers do you currently see to these service coordination supports and services being provided? What suggestions do you have for overcoming the identified barriers?)

4. What can be done at the state and local levels to help ensure that supports and services are provided in natural environments? (What barriers do you currently see to providing services in natural environments? How can information best be provided to all participants in the early intervention system (i.e., CMS, EIP, providers, families) regarding the shift to providing services in natural environments?)

Please return this form by February 21, 2003 to the following address:

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