2016 ITCA Tipping Points

Part C Implementation:
State Challenges and Responses
For the eleventh consecutive year, the ITCA has surveyed its members regarding state responses to Part C implementation issues and challenges. The Association utilizes this information to track emerging issues and state responses related to eligibility, finance and decisions regarding continued participation in Part C. ITCA and its members also make this information available to the Administration, to the Congress, to our early learning partners and to state and local elected officials.

This survey was distributed to all Part C coordinators in May 2016. Forty-eight of the fifty-six states and jurisdictions (hereafter referred to as states) responded to the survey. Not every question was answered by every respondent. As with all ITCA surveys, the data are reported by frequency as well as by type of lead agency and state eligibility criteria status. In charts or tables that provide answers by these categories, the number of total respondents by those categories is included in parentheses. The charts in the report reflect the responses of those states who answered each specific question. ITCA draws no conclusions from the data analysis and does not verify the data but simply reports the data as provided by the states. All information is aggregated and the individual state responses are confidential.

**Executive Summary of State Responses**

The following questions were asked and the responses are summarized below. Where available, trend data from the last five years are included. For each question, additional information is provided in the body of the report.

**Q 1. Which statement describes the status of your state’s continuing Part C participation?**

Check all that apply.

Of the forty-five states that responded to this question:

- 41 states responded that there are no discussions related to dropping out of Part C;
- 1 state responded that they are having serious discussions related to continued participation in Part C;
- 1 state responded that in the last 18 months, we have been asked to prepare documents/plans about either 1) what our state early intervention system would be...
like without a federal Part C grant or 2) the benefits to our state of continuing participation in Part C as compared to the challenges; and

- 2 states provided other comments.

Q 2. If discussions about dropping out are taking place, what issue will cause the administration to decide to drop out? Check all that apply.

Of the seven states that responded to this question:

- 2 states indicated increased costs;
- 3 states indicated state budget availability;
- 1 state indicated program growth rate; and
- 1 state indicated increased costs of children with complex needs.

Q 3. Will your state be able to continue participation in Part C through June 30, 2017

Of the forty-five states that responded to this question, all 45 indicated that they would be able to continue participation through June 30, 2017.

Q 4. Please estimate the percentage of families refusing access to public insurance.

Twenty-three states could provide data for this question and reported an average declination rate of 3.7% (Range: 0% to 25%).

Q 5. Please estimate the percentage of families refusing access to private insurance.

Nineteen states could provide data for this question and reported an average declination rate of 21.46% (Range: 1% to 85%)
Q 6. As a result of state fiscal issues, what have you done in the last 12 months in order to continue participation in Part C? Check all that apply.

Of the twenty-two states that responded to this question:

- 1 state increased family fees;
- 1 state required families to use their private insurance or be placed on a fee schedule;
- 3 states reduced provider reimbursement;
- 2 states required prior approval for hours of service that exceed an identified amount;
- 2 states made changes in the state Medicaid plan to increase coverage for Part C services;
- 3 states added Autism coverage in the Medicaid state plan; and
- 10 states identified other actions.

Q 7. As a result of state fiscal issues, what will you do in the next 12 months in order to continue participation in Part C? Check all that apply.

Of the thirty states that responded to this question:

- 1 state will implement family fees;
- 3 states will require families to use their private insurance or be placed on a fee schedule;
- 2 states will reduce provider reimbursement;
- 1 state will require prior approval for hours of service that exceed an identified amount;
- 7 states will make changes in the state Medicaid plan to increase coverage for Part C services;
- 3 states will add Autism coverage in the Medicaid state plan;
- 3 states will develop legislation related to the use of private insurance; and
- 10 states identified other actions that will be considered.

Q 8. Which statement describes the status of eligibility in your state for the last three years? Check only one response.

Of the forty-one states that responded to this question:

- 37 states indicated they have made no changes in eligibility criteria and have no plans to make any changes;
- 1 state has made eligibility criteria more restrictive;
• 2 states have broadened eligibility criteria; and
• 1 state is planning to change eligibility in the 2016-2017 fiscal year.

Q 9. If you are changing eligibility criteria in the 2016-2017 year, please check the answer that describes what you are planning.

One state responded to this question and indicated that their eligibility will be narrowed

Q 10. What are you doing for children who no longer meet your eligibility criteria? Check all that apply.

Two states responded to this question and indicated they refer them to other community agencies.

Q 11. What is the average number of planned hours of direct service (excluding service coordination and evaluation/assessment) per child per month?

Of the twenty states that provided data to answer this question:

• The number of planned service hours per child per month ranged from 1.4 hours to 27.72 hours with a median of 6 hours.
Q 12. What is the average number of delivered hours of direct service (excluding service coordination and evaluation/assessment) per child per month?

Of the sixteen states that provided data to answer this question:

- The number of delivered service hours per child per month ranged from 1.4 hours to 12.58 hours with a median of 6 hours.

Q 13. What is the average length of time a child is in your Part C system?

Of the thirty states that provided data to answer this question:

- The average length of time a child was in the Part C system ranged from 11.68 months to 30 months with a median of 15 months.
Q 14. What is the average age of referral for a child in your Part C system?
Of the twenty-eight states that provided data, the range was 2.1 months to 24 months with a median of 17.8 months.

Q 15. Which statement describes the status of your state funding for Part C for 2016-2017?
Of the forty states that provided data for this question:
- 18 states had their state funding remain the same;
- 11 states had their state funding increased;
- 4 states had their state funding decreased; and
- 7 states indicated that their state budget was not finalized when this survey was completed.

Q 16. If you contract with agencies/organizations to serve as local lead agencies, did any of those agencies/organizations decline to continue because of fiscal constraints?
Of the forty-two states that responded to this question:
- 4 states indicated that they had agencies/organizations decline to continue because of fiscal constraints;
- 21 states indicated they did not have any agencies/organizations decline to continue because of fiscal constraints; and
- 17 states indicated this question did not apply to them.
Q 17. If your state uses contractors (agencies/individuals) to provide direct services, did any of those contractors decline to continue because of fiscal restraints?

Of the forty-three states that responded to this question:

- 11 states indicated that they had agencies/individuals decline to continue because of fiscal constraints;
- 21 states indicated they did not have any agencies/individuals decline to continue because of fiscal constraints;
- 7 states indicated this question did not apply to them; and
- 4 states provided additional comments.

Q 18. What is the status of provider reimbursement in your state over the last three years?

Of the forty states that responded to this question:

- 25 states indicated provider rates remained the same;
- 4 states decreased provider rates;
- 7 states increased provider reimbursement rates;
- 2 states will decrease provider rates in the next 12 months; and
- 2 states will increase provider rates in the next 12 months.

Q 19. Does your state have any of the following grants? Check all that apply.

Of the thirty-seven states that responded to this question:
• 15 states have RTT-Early Learning Grants
• 10 states have Preschool Development Grants; and
• 3 states have Preschool Enhancement Grants.

Q 20. Are the needs of infants and toddlers with disabilities being addressed in the implementation of these grants?
Twenty-three states responded to this question. States responses are reported in this chart:

<table>
<thead>
<tr>
<th></th>
<th>(1) Always</th>
<th>(2)</th>
<th>(3) Sometimes</th>
<th>(4)</th>
<th>(5) Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>RTT-Early Learning</td>
<td>2</td>
<td>5</td>
<td>3</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Preschool Development</td>
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<td>4</td>
<td>3</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Preschool Enhancement</td>
<td>1</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

Q 21. Is your Part C system involved with your state’s Home Visiting Initiatives?
Forty-one states responded to this question. Their responses to the degree of their involvement with seven system components are recorded in the following chart:

<table>
<thead>
<tr>
<th></th>
<th>(1) Always</th>
<th>(2)</th>
<th>(3) Sometimes</th>
<th>(4)</th>
<th>(5) Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>Common Personnel Training</td>
<td>4</td>
<td>1</td>
<td>8</td>
<td>2</td>
<td>15</td>
</tr>
<tr>
<td>Shared Policies</td>
<td>2</td>
<td>1</td>
<td>6</td>
<td>3</td>
<td>24</td>
</tr>
<tr>
<td>Joint Services</td>
<td>2</td>
<td>3</td>
<td>7</td>
<td>6</td>
<td>21</td>
</tr>
<tr>
<td>Joint Facilities</td>
<td>1</td>
<td>1</td>
<td>6</td>
<td>6</td>
<td>27</td>
</tr>
<tr>
<td>Monitoring</td>
<td>1</td>
<td>0</td>
<td>2</td>
<td>1</td>
<td>35</td>
</tr>
<tr>
<td>Shared Data</td>
<td>1</td>
<td>4</td>
<td>8</td>
<td>4</td>
<td>23</td>
</tr>
<tr>
<td>Combined Staff Meetings</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>25</td>
</tr>
</tbody>
</table>

Q 22. Has your state Part C system begun to address issues for infants with Neonatal Abstinence Syndrome (NAS)?
Of the forty-one states that responded to this question, 20 states indicated they have begun to address NAS.
Demographics of States Responding to the Survey

ITCA received responses from forty-eight states and jurisdictions. For the purpose of analysis, states self-identified their status for eligibility criteria and type of lead agency. While OSEP has discontinued categorizing states by eligibility criteria, ITCA members have requested that eligibility continue to be one of the components of analysis. The ITCA Data Committee, with membership approval, established the criteria for eligibility categories and states self-selected their eligibility status using the following criteria:

- **Category A**: At Risk, Any Delay, Atypical Development, one standard deviation in one domain, 20% delay in two or more domains, 22% in two or more domains, 25% delay in one or more domains;
- **Category B**: 25% in two or more domains, 30% delay in one or more domains, 1.3 standard deviations in two domains, 1.5 standard deviations in any domain, 33% delay in one domain; and
- **Category C**: 33% delay in two or more domains, 40% delay in one domain, 50% delay in one domain, 1.5 standard deviations in 2 or more domains, 1.75 standard deviations in one domain, 2 standard deviations in one domain, and 2 standard deviations in two or more domains.

![State Eligibility Diagram](image-url)
ITCA places lead agencies into three categories: Health, Education and Other (this includes Developmental Disabilities, Human Services, Early Learning Agencies and includes co-leads). States self-identify type of lead agency.

<table>
<thead>
<tr>
<th>Category</th>
<th>Survey Respondents</th>
<th>All States</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health (21)</td>
<td>6</td>
<td>21</td>
</tr>
<tr>
<td>Education (10)</td>
<td>5</td>
<td>10</td>
</tr>
<tr>
<td>Other (17)</td>
<td>8</td>
<td>17</td>
</tr>
</tbody>
</table>

**State Infrastructure**

Participants were asked to choose a category that most closely aligned with the Part C system infrastructure. Forty-eight states responded to this question.

- **Structure 1**: Twenty-five states (52%) responded that their infrastructure is primarily composed of programs/agencies that are responsible for all eligible children from referral through transition in an assigned regional or local catchment area. Services are provided by program staff or contractors hired by the program.
- **Structure 2**: Ten states (21%) responded that their infrastructure is primarily composed of programs/agencies that are responsible for referral to initial IFSP development including service coordination in an assigned regional or local catchment area. Services are provided through a statewide central reimbursement system that pays providers/practitioners.
- **Structure 3**: Seven states (15%) responded that their infrastructure is primarily composed of state lead agency employees: Based at regional/local areas; Provide services and are

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1 In charts or tables that provide answers by these categories, the number of total respondents by those categories is included in parentheses.
responsible for referral through transition; May also have some private EI service
providers/agencies as supplemental vendors.

- **Structure 4:** Two states (4%) responded that their infrastructure is primarily composed of
multiple state agencies and their regional/local counterparts that are responsible for
children based either on eligibility criteria or on a specific service.

- **Other:** Four states (8%) chose to identify an alternative structure. Those identified
structures included the following:
  
  - Contracted Regional points of entry house Service Coordination and manage from
    referral to transition. Independent or Agency Payees of direct services (non-contracted) Fee for Service;
  
  - Regional System Point of Entry Referral-Eligibility; Ongoing Targeted Service
    Coordination at eligibility; Early Intervention Programs with Targeted Evaluation
    Teams provide Initial & Annual evaluation and additional assessment; and Early
    Intervention Programs provide fee for service IFSP direct services;
  
  - State programs serve as point of entry in specified regions and develop IFSP and
    provide services for some children; parents are offered choice of state or community
    program; contracted programs are paid at a flat rate per month per IFSP; all service
    providers, including state programs bill third party independently.
  
  - State employees conduct service coordination. Program/agencies are responsible for
    some service coordination and all services.
Demographics of Part C Coordinators Responding to the Survey

In 2005, ITCA developed a profile of the Part C Coordinators. This profile looked at education, experience prior to becoming the coordinator, salary levels and additional responsibilities. Over the last several years, an increasing number of questions came to the ITCA office regarding the status of coordinators. This, combined with leadership turnover, resulted in a decision to add more extensive questions to develop a new profile of Part C Coordinators. Because of responses from 2 coordinators in a co-lead state, there were data from 49 coordinators included in this section.

- **How long have you been the Part C Coordinator?**

Forty-nine coordinators (from 48 states) responded to this question. Twenty-one of the forty-nine coordinators reported their state has a Part C Coordinator with two years or less of experience. The chart below compares data from 2005 to 2016 data.
Tenure as Part C Coordinator

- > 10 years: 12% (2016), 17% (2005)
- 6-10 years: 21% (2016), 23% (2005)
- 3-5 years: 17% (2016), 21% (2005)
- 1-2 years: 5% (2016), 17% (2005)
- < 1 year: 17% (2016), 23% (2005)

Tenure by Lead Agency

- Other (17):< 1 year 24%, 1-2 years 29%, 3-5 years 18%, 6-10 years 18%, 11-15 years 0%, >16 years 12%
- Education (10):< 1 year 0%, 1-2 years 60%, 3-5 years 30%, 6-10 years 0%, 11-15 years 10%, >16 years 0%
- Health (21):< 1 year 33%, 1-2 years 24%, 3-5 years 10%, 6-10 years 19%, 11-15 years 0%, >16 years 14%

Tenure by Eligibility

- Category C (13):< 1 year 15%, 1-2 years 23%, 3-5 years 15%, 6-10 years 38%, 11-15 years 0%, >16 years 0%
- Category B (18):< 1 year 11%, 1-2 years 28%, 3-5 years 22%, 6-10 years 22%, 11-15 years 0%, >16 years 17%
- Category A (17):< 1 year 41%, 1-2 years 12%, 3-5 years 29%, 6-10 years 6%, 11-15 years 0%, >16 years 12%
• **How many Part C Coordinators has your state had since 1985 when Part C was first enacted?**

Forty-nine coordinators responded to this question with a range of 2 – 9 coordinators with an average of 3.2 coordinators. In 2005 the average was 3 coordinators with a range of 1-5 coordinators. The average number of coordinators by lead agency are: Health (4.5), Education (4.2) and Other (3.9). The average number of coordinators by eligibility are: Category A (4.1), Category B (4.1) and Category C (4.6).

• **What was the reason the last Part C Coordinator left the position? Check all that apply.**

Forty-nine coordinators responded to this question. "Retirement" was the most frequent response, followed by "moved to a position in another agency." Responses are included in the chart below. Other comments included:

- Lead agency change (2);
- Part C Coordinator retired in 2003, then two different folks held the position for short periods during our transition to a new state agency. Once established at new agency I took on role in 2007.
- Program moved from one Lead Agency office to another and new coordinator hired;
- Pursuing other interests;
- Removed from the position;
- She was running SpEd and EI for many years. She left to focus on SpEd and I was appointed interim coordinator; and
- Took a job with OSEP.
Reason for Departure

- Retirement: 12
- Promotion within the Agency: 7
- Moved to a position within...: 3
- Took a position in another...: 9
- Took a position with a National TA...: 2
- Illness: 2
- Moved: 1
- Unknown: 3
- Other: 8

Departure Reason by Lead Agency

- Retirement: 6
- Promotion within the Agency: 3
- Moved to a position within...: 3
- Took a position in another...: 5
- Took a position with a National TA...: 4
- Illness: 2
- Moved: 2
- Unknown: 3
- Other: 4

Legend:
- Blue: Health
- Red: Education
- Green: Other
- Did you have Part C experience prior to becoming the Part C Coordinator? Check all that apply.

Forty-nine coordinators responded to this question. Twenty-seven (55%) of them indicated they had worked for the lead agency in the Part C office prior to taking the coordinator position.
The coordinators were asked to describe their work experience if they did not have Part C experience. Responses were:

- I had Part C experience as a parent of a child with significant disabilities who helped to create and advocate for the system in my state.
- I served on the SICC for 7 years.
- I was a teacher and then an administrator for the LEA.
- I was the Lead Monitoring Specialist for Part C at the State Level.
- I worked at the state Medicaid agency for 11 years as a mental health policy analyst. I had familiarity with the Part C program.
- I worked with 3-5 at risk in a service coordination position.
- Program manager for early childhood and mental health for Children’s Integrated Services of which Part C is a part of.
- Our most recent coordinator had a Master’s degree in early childhood special education. After she left the state downgraded the position to a minimum of 3 years related experience and no degree requirement. Salary was decreased from $60,000 to just over $46,000. Education and salary adjustments are planned for all early intervention state positions, although funding for Part C has remained level to date, the department is aligning all positions within the state and our state is experiencing budget deficits year after year.
• **Is Part C your only responsibility?**

Forty-nine coordinators responded to this question. Thirty-four coordinators (69%) responded that Part C is their only responsibility. Part C as the only responsibility responses by Lead Agency: Health (67%), Education (40%) and Other (71%). Part C as the only responsibility responses by Eligibility Category: Category A (84%), Category B (71%) and Category C (50%).

Respondents were asked to identify additional programs for which they are responsible. Responses were:

- **Section Chief for Policy and Data.** I supervise both Part C and Part B data personnel.
- **All Medicaid programs for children with special health care needs;**
- **619 Coordinator;**
- **Home visiting programs and other abuse/ neglect prevention initiatives;**
- **Director, Bureau of Family Health & Nutrition - oversight for WIC, Office of Data Translation, Birth Defects, State Home Visiting Initiative and currently the programs under Children & Youth with Special Health Needs. State is in the process of hiring a Director of the Children & Youth with Special Health Needs which will provide direct oversight of Care Coordination, Pedi-Palliative Care, Newborn Hearing Screening, Catastrophic Illness.**
- **Early Childhood Special Education (Part B 619) State Special Education compliance monitoring, Various early childhood projects (early literacy, kindergarten assessment, P-3 alignment) State legislation for the Office of Student Services;**
- **Early Hearing Detection and Intervention Program;**

Home visiting, newborn screening, early childhood mental health, various grant projects;

HSCO Early Literacy DOE Initiative;

I also oversee Family Education and Support, a Title XX program.

I also oversee the Early Hearing Detection and Intervention Program.

I also serve as the Children & Family Services Administrator for the DD Division.

I am interim program manager for the Medicaid in Public Schools and Education-Based Medicaid Administrative Claiming programs.

I am the Director for Children and Youth with Special Health Care Needs. I oversee Part C, CYSHCN (Title V), Autism, and Screening.

**What percentage of your salary is supported by resources other than Part C?**

Forty-nine coordinators responded to this question. Thirty coordinators indicated that 100% of their salary is paid for by Part C. Nine coordinators indicated that 100% of their salary is paid for by other funds.
• What is the highest education degree you have achieved?

Forty-eight coordinators responded to this question. Twenty-six coordinators (54%) indicated they had a Master's degree. Ten coordinators (21%) Four coordinators (8%) had doctoral degrees. Eight (16%) coordinators indicated that they had other types of degrees including:

- Associates Degree. Working on my B.S. right now;
- Candidate for a Ph.D. degree;
- Halfway through 2nd Masters;
- High School Diploma with some college;
- J.D. (2)
- Prior coordinator had a masters; new hire no requirement beyond high school; and
- Specialist (School Psychology).
• Please indicate your salary range.

Forty-nine coordinators responded to this question. The most frequently cited salary range was $81 – $90,000 and represented thirteen coordinators (27%). In 2005, the most frequently cited salary range was $51-46,000 representing 31% of the respondents.
Tipping Points Survey Questions

Q1. Which statement describes the status of your state’s continuing Part C participation?
Check all that apply.

Of the forty-five states that responded to this question, forty-one states (91%) responded that there are no discussions related to dropping out of Part C; one state (2%) responded they are having serious discussions related to continued participation; one state (2%) responded that in the last 18 months, they have been asked to prepare documents/plans about either 1) what their state early intervention system would be like without a federal Part C grant or 2) the benefits to their state of continuing participation in Part C as compared to the challenges; and two states (5%) provided comments.
Other comments included:

- The Lead Agency has been undergoing reorganization. Recommendations from external evaluators have not yet been provided. It is possible these conversations may begin this year.
- There have been some discussions about dropping Part C in the next legislative session (2017-19).

Analyzing the responses to this question by Lead Agency and Eligibility resulted in the following:
Q2. If discussions are taking place, what issue will cause the administration to decide to drop out? Check all that apply.

Seven states responded to this question. Two states (29%) cited increased costs of the system. Three states (43%) cited state budget availability. One state (14%) cited program growth rate, and one state (14%) cited increased costs of children with complex needs.

Analyzing the responses to this question by Lead Agency and Eligibility resulted in the following:
Q3. Will your state be able to continue participation in Part C through June 30, 2016?
Of the forty-five states that responded to this question, all 45 states (100%) indicated that they would be able to continue participation through June 30, 2017.

Q4. Please estimate the percentage of families refusing access to public insurance.
Twenty-three states provided data in response to this question and reported an average declination rate of 3.7% (Range: 0% to 25%). This is a slight increase from 3.4% in 2015.

Q5. Please estimate the percentage of families refusing access to private insurance.
Nineteen states provided data in response to this question and reported an average declination rate of 21.46% (Range: 1% to 85%). This is an increase from the 2015 average declination rate of 12.3%.

Q6. As a result of state fiscal issues, what have you done in the last twelve months in order to continue participation in Part C? Check all that apply.
Twenty-two states responded to this question. The strategy cited by three states (14%) was adding autism coverage in their state Medicaid plan. One state (4.5%) increased family fees. One state (4.5%) required families to use their private insurance or be placed on a fee schedule. Three states (14%) reduced provider reimbursement and two states (9%) required prior approval for hours of service that exceed an identified amount. Two states (9%) made changes in the state Medicaid plan to increase coverage for Part C services and ten states (45%) identified other actions.
Analyzing the responses to this question by Lead Agency and Eligibility resulted in the following:

<table>
<thead>
<tr>
<th></th>
<th>Health (11)</th>
<th>Education (2)</th>
<th>Other (9)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Increased Family Fees</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Required Use of Insurance or Pay Fee</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Required Prior Approval for Excess Services</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Reduced Provider Reimbursement</td>
<td>1</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Made changes in State Medicaid Plan</td>
<td>1</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Added Autism Coverage in Medicaid Plan</td>
<td>2</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Other</td>
<td>4</td>
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<table>
<thead>
<tr>
<th></th>
<th>Category A (8)</th>
<th>Category B (8)</th>
<th>Category C (8)</th>
</tr>
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<tbody>
<tr>
<td>Increased Family Fees</td>
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</tr>
<tr>
<td>Required Use of Insurance or Pay Fee</td>
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<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Required Prior Approval for Excess Services</td>
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<tr>
<td>Reduced Provider Reimbursement</td>
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<tr>
<td>Made changes in State Medicaid Plan</td>
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<td>2</td>
</tr>
<tr>
<td>Added Autism coverage in Medicaid Plan</td>
<td>1</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Other</td>
<td>4</td>
<td>4</td>
<td>2</td>
</tr>
</tbody>
</table>

**Additional Comments:**

1. Educated providers and service coordinators on benefits of accessing private insurance.
2. Finalized policy/procedure for public/private insurance use. Clarified eligibility practices to ensure correctness.
3. Flat funded using previous year budget and not the state statute amount despite increase in children served.
4. Last year’s executive budget included proposals to address insurance proposals, none were enacted. We are planning to submit a state plan amendment on ASD coverage.
5. Legislation and system redesign.
6. Legislature increased two new tracking categories.
7. Reduced provider reimbursement is on the fiscal agenda. The state has submitted information to CMS regarding a state autism plan.
8. Restructured contracts and funding formulas.
9. Worked to improve knowledge of local system leaders on fiscal management.
10. Working on moving from bundled to fee for service billing with Medicaid.
Q7. As a result of state fiscal issues, what will you do in the next 12 months in order to continue participation in Part C? Check all that apply.

Thirty states responded to this question. One state (3%) will implement family fees. Three states (10%) indicated that they will require families to use their private insurance or be placed on a fee schedule. Two states (6%) will reduce provider reimbursement. One state (3%) will require prior approval for hours of service that exceed an identified amount. Seven states (23%) indicated they will make changes in the state Medicaid plan to increase coverage for Part C services and three states (10%) will add Autism coverage in the Medicaid state plan. Three states (10%) will develop legislation related to the use of private insurance. Ten states (33%) identified the following other actions that will be considered:

1. Work to increase commercial insurance reimbursement and review the assessment and plans of the increasing number of children identified by programs as being on the autism spectrum.
2. Attempt to negotiate new fees with Medicaid as part of state Medicaid Reform.
3. Continue efforts to control # children who aren’t eligible. Clarify direct service provision practices to match policy/procedures to minimize over-billing.
4. Continue to educate on private insurance and implementation of RBI and FGRBI.
5. Continue to improve fiscal oversight at the local and state level.
6. Evaluate current Medicaid and Tri-Care reimbursement and as needed, make changes to increase the reimbursement amount.
7. Examine impact of using private insurance on other current finance structures. Examine potential implementation of family fees. Maximize eligibility matching for Medicaid and CHIP.
8. Request authority from state budget writers to use additional Part C appropriations.
9. We are currently looking at changes in our state Medicaid plan to cover part C services. Our local county programs have continued to contribute more dollars to cover cost related to delivering part C services.
10. We implemented our changes July 1, 2016 and will monitor effects this next year but we also have strong data to go ask for a large sum from our legislature for state appropriations. If we do not get the state appropriation, we may look at narrowing eligibility.
Analyzing the responses to this question by Lead Agency and Eligibility resulted in the following:

<table>
<thead>
<tr>
<th>Action in Next Twelve Months</th>
<th>Health (18)</th>
<th>Education (1)</th>
<th>Other (11)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Implement family fees</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Require use of insurance or be placed on a fee schedule</td>
<td>3</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Reduce provider reimbursement</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Require Prior Approval for Excess Services</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Make changes to State Medicaid Plan</td>
<td>4</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>Add Autism coverage to State Plan</td>
<td>3</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Develop Insurance Legislation</td>
<td>2</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Other</td>
<td>3</td>
<td>1</td>
<td>6</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Category</th>
<th>Category A (9)</th>
<th>Category B (11)</th>
<th>Category C (10)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Implement family fees</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Require use of insurance or be placed on a fee schedule</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Reduce provider reimbursement</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Require Prior Approval for Excess Services</td>
<td>0</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Make changes to State Medicaid Plan</td>
<td>4</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Add Autism coverage to State Plan</td>
<td>9</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Develop Insurance Legislation</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Other</td>
<td>3</td>
<td>4</td>
<td>3</td>
</tr>
</tbody>
</table>
Q8. Which statement describes the status of eligibility in your state for the last three years?

Of the forty-one states that responded to this question, thirty-seven states (90%) indicated they have made no changes in eligibility criteria and have no plans to make any changes; one state (2%) have made eligibility criteria more restrictive; two states (4%) have expanded eligibility criteria. One state (2%) is planning to change eligibility in the 2016-2017 fiscal year. Five states (11%) provided additional comments.

Additional Comments:

1. *In the pst 3 years we have clarified our eligibility requirments to ensure consistency, which resulted in less children found eligible in some local areas of state.Reviewing eligibility but may or may not change.*

2. *We are reviewing eligibility and if we decide changes are needed, it would be in the 2017-2018 year.*

3. *We have discussed changing eligibility criteria*

Q9. If you are changing eligibility criteria in the 2016-2017 year, please check the answer that describes what you are planning.

One state responded to this question and indicated that their eligibility will be narrower.

Q10. What are you doing for children who no longer meet your eligibility criteria? Check all that apply.

Two states responded to this question and indicated they refer them to other community agencies.
Q 11. What is the average number of planned hours of direct service (excluding service coordination and evaluation/assessment) per child per month?

Of the twenty states that provided data to answer this question, the number of planned service hours per child per month ranged from 1.4 hours to 27.72 hours with a median of 6 hours.

<table>
<thead>
<tr>
<th></th>
<th>Health (9)</th>
<th>Education (4)</th>
<th>Other (7)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average hours of planned service</td>
<td>4.9</td>
<td>11.7</td>
<td>8.7</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Category A (8)</th>
<th>Category B (8)</th>
<th>Category C (4)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average hours of planned service</td>
<td>6.4</td>
<td>7</td>
<td>12.5</td>
</tr>
</tbody>
</table>

Q12. What is the average number of delivered hours of direct service (excluding service coordination and evaluation/assessment) per child per month?

Of the seventeen states that provided data to answer this question, the number of delivered service hours per child per month ranged from 1.4 hours to 12.58 hours with a median of 6 hours.

<table>
<thead>
<tr>
<th></th>
<th>Health (7)</th>
<th>Education (4)</th>
<th>Other (6)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average hours of delivered service</td>
<td>5.7 hours</td>
<td>6.9 hours</td>
<td>7.9 hours</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Category A (7)</th>
<th>Category B (6)</th>
<th>Category C (4)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average hours of delivered service</td>
<td>5.4 hours</td>
<td>7.6 hours</td>
<td>8.1 hours</td>
</tr>
</tbody>
</table>

Analyzing the responses to the questions regarding planned and delivered services by type of lead agency and eligibility category resulted in the following:

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\[2 \text{ The numbers in parentheses reflect planned/delivered services} \]
Q13. **What is the average length of time a child is in your Part C system?**

The data from thirty states documents that the average length of time a child was in the Part C system ranged from 11.68 months to 30 months with a median of 15 months.

<table>
<thead>
<tr>
<th>Category</th>
<th>Health (13)</th>
<th>Education (6)</th>
<th>Other (11)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average length of time</td>
<td>14.5 months</td>
<td>18.5 months</td>
<td>16.9 months</td>
</tr>
<tr>
<td>Category A (13)</td>
<td>14.4 months</td>
<td>19.5 months</td>
<td>14.3 months</td>
</tr>
</tbody>
</table>

Q14. **What is the average age of referral for a child in your Part C system?**

Twenty-eight states provided data in response to this question. The range of responses was 2.1 months to 24 months with a median of 17.8 months.

<table>
<thead>
<tr>
<th>Category</th>
<th>Health (15)</th>
<th>Education (6)</th>
<th>Other (7)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average age at referral</td>
<td>17.9 months</td>
<td>18 months</td>
<td>16 months</td>
</tr>
<tr>
<td>Category A (10)</td>
<td>15.1 months</td>
<td>18.7 months</td>
<td>18.9 months</td>
</tr>
</tbody>
</table>

Q15. **Which statement describes the status of your state funding for Part C for 2015-2016.**

Forty states responded to this question. Eighteen states (45%) had their state funding frozen. Eleven states (27%) had their funding increased. Four states (10%) had their funding reduced and seven states (18%) did not have a finalized state budget at the time they responded to the survey.
Analyzing the responses to this question by lead agency and eligibility resulted in the following:

Q 16. If you contract with agencies/organizations to serve as local lead agencies, did any of those agencies/organizations decline to continue because of fiscal constraints?

Forty-two states responded to this question. Four states (10%) indicated that they had agencies/organizations decline to continue because of fiscal constraints. Twenty-one states (50%) indicated they did not have any agencies/organizations decline to continue because of fiscal constraints and seventeen states (40%) indicated this question did not apply to them.
Q 17. If your state uses contractors (agencies/individuals) to provide direct services, did any of those contractors decline to continue because of fiscal restraints?

Forty-three states responded to this question. Twenty-one states (49%) indicated they did not have any contractors (agencies/individuals) decline to continue because of fiscal constraints. Eleven states (26%) indicated that they had agencies/individuals decline to continue because of fiscal constraints and seven states (16%) indicated this question did not apply to them. Four states provided additional comments.

**Additional Comments:**

1. *A small number of providers have left the program, but this has been balanced by new providers joining the program.*

2. *Some declined to continue due to new data/billing system.*
3. They declined, funding may have been a factor.

4. We do not contract with direct service providers. They are under Provider Agreements but we did lose some due to the uncertainty of the program during the budget impasse.

Q 18. What is the status of provider reimbursement in your state over the last three years?

Forty states responded to this question. Twenty-five states (62%) indicated provider rates remained the same. Four states (10%) decreased provider rates. Seven states (18%) reported they increased provider reimbursement rates. Two states (5%) indicated they would decrease provider rates in the next twelve months and two states (5%) indicated they will increase provider rates in the next 12 months.

Additional comments:

1. An increase in provider rates was proposed in last year’s budget but was not included in the enacted budget.

2. Per child funding has decreased.

3. The rates have remained the same for the past 8 years.

4. We may decrease provider rates for ST, OT and PT in the next 12 months pending the outcome of a lawsuit.

5. We estimate that local programs are level funding their staff and contractors or providers are doing more for same amount of reimbursement.
Q 19. Does your state have any of the following grants? Please check all that apply.
Thirty-seven states responded to this question. Fifteen states (41%) indicated they have Race to the Top - Early Learning Grants. Ten states (27%) reported they have Preschool Development Grants. Three states (8%) indicated they have Preschool Enhancement Grants.
Q20. Are the needs of infants and toddlers with disabilities being addressed in the implementation of the grants?
Twenty-three states responded to this question. The following chart indicates the number of states that indicated the needs of infants and toddlers with disabilities were being addressed by the grants.

<table>
<thead>
<tr>
<th></th>
<th>Always (1)</th>
<th>(2)</th>
<th>Sometimes (3)</th>
<th>(4)</th>
<th>Not at All (5)</th>
</tr>
</thead>
<tbody>
<tr>
<td>RTT-Early Learning</td>
<td>2</td>
<td>5</td>
<td>3</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Preschool Development</td>
<td>1</td>
<td>4</td>
<td>3</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Preschool Enhancement</td>
<td>1</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

**Additional Comments:**
1. *Three Innovation Zones through RTT identified EI in their plan.*
2. *A significant part of RTT-EL has support development of our Early Childhood Integrated Data System.*

Q21. Is your Part C system involved with your state’s Home Visiting initiatives?
Forty-one states responded to this question. The following chart documents the degree of their involvement with seven system components:

<table>
<thead>
<tr>
<th></th>
<th>Always (1)</th>
<th>(2)</th>
<th>Sometimes (3)</th>
<th>(4)</th>
<th>Never (5)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Common Personnel Training</td>
<td>4</td>
<td>1</td>
<td>8</td>
<td>2</td>
<td>15</td>
</tr>
<tr>
<td>Shared Policies</td>
<td>2</td>
<td>1</td>
<td>6</td>
<td>3</td>
<td>24</td>
</tr>
</tbody>
</table>
Q22. Has your state Part C system begun to address issues for infants with Neonatal Abstinence Syndrome (NAS)?

Forty-one states answered this question. Twenty states (49%) indicated they had begun to address this population.

<table>
<thead>
<tr>
<th></th>
<th>Always (1)</th>
<th>(2)</th>
<th>Sometimes (3)</th>
<th>(4)</th>
<th>Never (5)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Joint Services</td>
<td>2</td>
<td>3</td>
<td>7</td>
<td>6</td>
<td>21</td>
</tr>
<tr>
<td>Joint Facilities</td>
<td>1</td>
<td>1</td>
<td>6</td>
<td>6</td>
<td>27</td>
</tr>
<tr>
<td>Monitoring</td>
<td>1</td>
<td>0</td>
<td>2</td>
<td>1</td>
<td>35</td>
</tr>
<tr>
<td>Shared Data</td>
<td>1</td>
<td>4</td>
<td>8</td>
<td>4</td>
<td>23</td>
</tr>
<tr>
<td>Combined Staff Meetings</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>25</td>
</tr>
</tbody>
</table>

![Part C and NAS](image1)

![Part C Involved with NAS](image2)
Additional Comments:

1. Automatic eligibility.
2. Children showing drug withdrawal are eligible for services due to a condition that puts them at high-probability for delay.
3. Currently addressing this issue.
4. I participate on a team focused on maternal substance use and have added detail to our guidance manual about NAS.
5. Identified as a condition with high probability of developmental delay (i.e., eligible under biological risk).
6. Infants are eligible for Part C under established condition with NAS.
7. It has only been in past couple of years that physicians have had agreement on consistent criteria and processes for diagnosing NAS. The Part C system is experiencing a continued increase in referrals/eligible children, believed to be impacted by substance abuse including children diagnosed with NAS. Discussions are occurring about the most effective follow up plans for these babies...including maximizing other existing resources such nursing and social work home visitation services.
8. It is an eligibility category under established condition for a period of time then need to become eligible under another category.
9. Meeting with other agencies and making Part C eligibility known to them.
10. Neonatal withdrawal symptoms from maternal use of drugs of addiction is an automatic qualifier for Part C services.
11. Task force has been established to address the needs of the NAS population as well as pilot program between EIPs and birthing hospitals to enhance early engagement and enrollment in EI.
12. The governor’s Children’s Cabinet has a pilot program that involves two district offices. We have a memorandum of agreement with the Department of Health to supply information regarding children born with NAS. We participate on the Department of Health’s wellness council that address issues for children diagnosed with NAS.
13. There is beginning to be discussion about this issue in the context of the MCH block grant initiatives related to infant mortality/morbidity.
14. Currently addressing this issue.
15. This is listed as criteria for eligibility.
16. Training Initiatives/Part C Referrals.

17. Vaguely covered in our existing policies, but seeing the need to increase clarity to serve under Part C.

18. We are exploring.

19. We have indicated that this is an environmental/biological risk factor and our state is not an at-risk state so NAS is not a condition that makes a child automatically eligible. Children are referred to other community agencies/partners for either continued developmental monitoring, home visitation services, or group services.