2019 TIPPING POINTS
ANNUAL SURVEY:
STATE CHALLENGES

IDEA INFANT AND TODDLER COORDINATORS ASSOCIATION
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Overview

For the fourteenth 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 aggregate information available to the Administration, to Congress, to our early childhood and disability partners, and to state and local elected officials.

This survey was distributed to all Part C coordinators in May 2019. Forty-seven 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. 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 individual state responses are confidential.

Executive Summary

The following questions were asked and the responses are summarized below. Questions were categorized by theme. For each question, additional information is provided in the body of the report including any trend analysis that is available.

Continued Participation

1. Which statement describes the status of your State's continuing Part C participation?

Of the forty-three states responded to this question:

- Thirty-eight states indicated that there were no discussions related to dropping out of Part C.
• Three states indicated 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;
• One state indicated it was having discussions about possibly dropping out of Part C; and
• One additional state indicated it was having serious discussions related to continued participation.

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

Of the six states that responded to this question:
• Two states cited increased costs of the system;
• Four states cited state budget availability;
• Five states cited program growth rate;
• One state cited reduction in federal Part C funds; and
• One state cited reduction/changes in other federal funds such as Medicaid.

3. Please check the statement that applies to the 2019-2020 fiscal year.

Of the forty-three states that responded to this question:
• Forty-two states indicated they will be able to continue to participate in Part C through June 30, 2020; and
• One state indicated that it is possible that my state will not be able to continue participation through June 30, 2020 due to lack of funding.

4. Which statement describes the status of your state funding for Part C for 2019-2020?

Of the forty-one states that responded to this question:
• Twenty states indicated their funding was increased;
• Fifteen states indicated their funding was frozen; and
• Six states indicated that the state budget was not finalized yet.
5. As a result of state fiscal issues, what changes have you made in the last 12 months, in order to continue participation in Part C? Check all that apply.

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

- Three states made changes in the state Medicaid plan to increase coverage for Part C services;
- Three states added autism coverage in the Medicaid state plan;
- One state reduced provider reimbursement;
- One state required prior approval for hours of service that exceed an identified amount; and
- Fifteen states provided comments.

6. 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 twenty-seven states that responded to this question:

- Ten states will make changes in the state Medicaid plan to increase coverage for Part C services;
- Three states will develop legislation related to the use of private insurance;
- Two states will narrow eligibility;
- Two states will require prior approval for hours of service that exceed an identified amount;
- One state will require families to use their insurance or be placed on a fee schedule;
- One state will reduce provider reimbursement;
- One state will add autism coverage in the Medicaid state plan; and
- Nineteen states provided comments

**Eligibility**

7. Which statement describes the status of eligibility in your state for the last three years?

Of the forty states that responded to this question:

- Thirty-two states indicated they had not changed eligibility criteria in the last three years;
• Two states indicated they had broadened their eligibility; and
• Seven states provided comments.

8. **If you changed your eligibility criteria, what are you doing for children who no longer meet your eligibility criteria?**

Of the four states that responded to this question:
• Two states indicated the children are referred to other community agencies; and
• Two states indicated there was no state policy or procedure.

9. **If you are changing your eligibility criteria in the 2019-2020 year, please check the answer that describes what you are planning.**

Of the two states that responded to this question, both states indicated that eligibility would be broadened.

**Child Services**

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

Of the forty-two states that responded to this question, only 21 states were able to provide data. The median number of planned hours of direct service per child per month was 4.5 hours with a range of 1.5 hours to 18 hours.

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

Of the forty-two states that responded to this question, only 15 states were able to provide data. The median number of delivered hours of direct service per child per month was 4 hours with a range of 2 hours to 16 hours.

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

Of the forty-three states that responded to this question, 29 states were able to provide data. The median length of time a child is in the Part C system is 14.8 months with a range of 6 months to 19 months.
13. What is the average age of referral for a child in your Part C system?
Of the forty-two states that responded to this question, 30 states were able to provide data. The median age of referral for a child in the Part C system is 18 months with a range of 2 months to 27 months.

14. Is your state addressing the developmental needs of infants with the following conditions?
Of the forty-two states that responded to this question:

<table>
<thead>
<tr>
<th>Condition</th>
<th>Extensive efforts</th>
<th>Some efforts</th>
<th>Beginning to address</th>
<th>Not at this time</th>
</tr>
</thead>
<tbody>
<tr>
<td>Perinatal Substance Use (42)</td>
<td>15</td>
<td>15</td>
<td>9</td>
<td>3</td>
</tr>
<tr>
<td>ZIK A Virus (43)</td>
<td>6</td>
<td>12</td>
<td>5</td>
<td>20</td>
</tr>
<tr>
<td>Lead Poisoning (42)</td>
<td>12</td>
<td>18</td>
<td>4</td>
<td>8</td>
</tr>
<tr>
<td>Fetal Alcohol Syndrome Disorder (43)</td>
<td>12</td>
<td>24</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Other Adverse Conditions (30)</td>
<td>8</td>
<td>9</td>
<td>4</td>
<td>9</td>
</tr>
</tbody>
</table>

15. What specific activities are you implementing to address the needs of infants prenatally exposed to substance use/neonatal abstinence syndrome (NAS)?
Thirty-one states identified activities that they were conducting. Details will be provided in the body of the report.

Provider Issues

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 in the last three years?
Of the forty-one states that responded to this question:
- Two states responded yes;
- Fifteen states responded no;
- Twenty-three responded that this did not apply to them; and
- One state provided a comment.
17. If your state uses contractors (agencies/individuals) to provide direct services, did any of those contractors decline to continue because of fiscal constraints in the last three years?

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

- Fifteen states answered yes;
- Nineteen states answered no;
- Five states indicated that this did not apply to them; and
- Three states provided comments.

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

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

- Twenty-six states indicated that rates have remained the same;
- Eight states increased rates;
- Two states decreased rates; and
- Five states will increase rates over the next 12 months.

19. Is your state experiencing shortages in qualified providers?

Of the forty-two states that responded to this question, 41 are experiencing a shortage in qualified providers.

20. Which type of providers are you experiencing shortages in?

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

- Thirty-seven states: Speech Therapists;
- Thirty-four states: Physical Therapists;
- Twenty-eight states: Occupational Therapists;
- Seventeen states: Special Educators;
- Fifteen states: Psychologists;
- Thirteen states: Orientation and Mobility Specialists;
- Twelve states: Audiologists;
- Twelve states: Vision Specialists;
- Eight states: Social Workers;
- Seven states: Nurses;
- Six states: Registered Dieticians; and
21. What are you doing to address the shortages?
Forty states responded to this question and their comments are included in the body of the report on page 43.

Home Visiting
22. Is your Part C system involved with your state's Home Visiting initiatives?
Of the forty-two states that responded to this question:

<table>
<thead>
<tr>
<th></th>
<th>Always (1)</th>
<th></th>
<th>Sometimes (3)</th>
<th></th>
<th>Never (5)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Common Personnel Training (42)</td>
<td>2</td>
<td>8</td>
<td>21</td>
<td>3</td>
<td>12</td>
</tr>
<tr>
<td>Shared Policies (42)</td>
<td>1</td>
<td>3</td>
<td>14</td>
<td>12</td>
<td>21</td>
</tr>
<tr>
<td>Joint Services (41)</td>
<td>2</td>
<td>4</td>
<td>15</td>
<td>36</td>
<td>13</td>
</tr>
<tr>
<td>Joint Facilities (41)</td>
<td>1</td>
<td>3</td>
<td>7</td>
<td>9</td>
<td>22</td>
</tr>
<tr>
<td>Monitoring (39)</td>
<td>0</td>
<td>2</td>
<td>2</td>
<td>3</td>
<td>32</td>
</tr>
<tr>
<td>Shared Data (42)</td>
<td>1</td>
<td>4</td>
<td>13</td>
<td>11</td>
<td>13</td>
</tr>
<tr>
<td>Combined Staff Meetings (42)</td>
<td>1</td>
<td>3</td>
<td>5</td>
<td>5</td>
<td>28</td>
</tr>
</tbody>
</table>

23. Have you collaborated with your MIECHV program to discuss how the joint guidance document could be implemented in your state?
Of the forty-three states that responded to this question:

- Sixteen states responded yes;
- Fifteen states responded no; and
- Twelve states responded not yet but planned.
State Demographics
ITCA received responses from forty-seven states and jurisdictions (hereafter referred to as states). For the purpose of analysis, states self-identified their type of lead agency, their eligibility criteria and state infrastructure.

Lead Agency
Of the states that responded to the survey, 19 identified themselves as a health lead agency, 10 were education lead agencies and 18 were from agencies categorized as “Other” which includes early childhood, developmental disabilities, human services and states that have co-lead agencies meaning there is shared responsibility between state agencies.

Eligibility
OSEP has discontinued categorizing states by eligibility criteria, however ITCA members have requested that eligibility continue to be one of the data elements collected from states. The ITCA Data Committee, with membership approval, established the criteria for eligibility categories and states self-select 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.

Sixteen states that responded to this survey selected Category A as most closely aligning with their eligibility criteria. Twenty states selected Category B and eleven states selected Category C.

<table>
<thead>
<tr>
<th>State Eligibility</th>
<th>Category A (16)</th>
<th>Category B (20)</th>
<th>Category C (11)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health (19)¹</td>
<td>5</td>
<td>10</td>
<td>4</td>
</tr>
<tr>
<td>Education (10)</td>
<td>4</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>Other (18)</td>
<td>7</td>
<td>6</td>
<td>5</td>
</tr>
</tbody>
</table>

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

- **Structure 1:** Twenty-nine states (61.7%) 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.

¹ In charts or tables that provide answers by these categories, the number of total respondents by those categories is included in parentheses
• **Structure 2:** Five states (10.6%) 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:** Eight states (17%) responded that their infrastructure is primarily composed of state lead agency employees: Based at regional/local areas; Provide services and are responsible for referral through transition; May also have some private EI service providers/agencies as supplemental vendors.

Five states responded they had a different structure:

• Agencies are responsible for referral to initial and ongoing IFSP development including service coordination in an assigned catchment area. Early intervention services are provided through recognized provider types who seek reimbursement through public or private insurance.

• Regional Points of Entry entities (public/private) house Service Coordination and process the work from referral through transition. EI Services are reimbursed to private/independent direct service providers/groups/agencies.

• The lead agency employs staff who determine initial eligibility. Ongoing SC and other service providers are contractors of the lead agency.

• Providers, under contracts/sub-contracts from the State Education Agency, provide most EI services for all eligible children from referral through transition in an assigned regional catchment area. Services are provided by staff of the responsible contracted entity. Some EI services are provided by non-contracted entities and billed through fee-for-service billing to the family's insurance.

• Lead Agency and local agency staff are responsible for Service Coordination. Local agency staff provide early intervention services.
Demographics of the Part C Coordinator

Because of the continuing turnover in state Part C leadership, the ITCA is committed to tracking the status of Part C Coordinators and attempting to better understand the needs of cohort of leaders at the state level. Understanding the demographics of the individuals who serve in this important role is the responsibility of ITCA and provides an opportunity to identify trends and to analyze stresses and challenges to better meet the needs of our members.

1. How long have you been the Part C Coordinator?

Forty-seven states responded to this question. Nineteen of the forty-seven coordinators (40.4%) reported their state has a Part C Coordinator with two years or less of experience. Thirty-two states (68.1%) have coordinators with 5 years of experience or less. The charts that follow compare data from the baseline of 2005 to current data for 2019, by type of lead agency and a trend analysis of the changes over the last several years.
**Tenure as Part C Coordinator**

<table>
<thead>
<tr>
<th>Tenure</th>
<th>2005</th>
<th>2019</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 1 year</td>
<td>17%</td>
<td>19%</td>
</tr>
<tr>
<td>1-2 years</td>
<td>5%</td>
<td>21%</td>
</tr>
<tr>
<td>3-5 years</td>
<td>17%</td>
<td>28%</td>
</tr>
<tr>
<td>6-10 years</td>
<td>17%</td>
<td>40%</td>
</tr>
<tr>
<td>&gt; 10 years</td>
<td>17%</td>
<td>15%</td>
</tr>
</tbody>
</table>

**Tenure by Lead Agency**

- **Other (18)**
  - < 1 year: 33%
  - 1-2 years: 39%
  - 3-5 years: 11%
  - 6-10 years: 11%
  - > 10 years: 6%

- **Education (10)**
  - < 1 year: 30%
  - 1-2 years: 10%
  - 3-5 years: 40%
  - 6-10 years: 10%

- **Health (19)**
  - < 1 year: 16%
  - 1-2 years: 16%
  - 3-5 years: 26%
  - 6-10 years: 11%
  - > 10 years: 5%

**Tenure of Part C Coordinators**

<table>
<thead>
<tr>
<th>Year</th>
<th>5 years or less</th>
<th>6 years or more</th>
</tr>
</thead>
<tbody>
<tr>
<td>2005</td>
<td>39%</td>
<td>61%</td>
</tr>
<tr>
<td>2013</td>
<td>41%</td>
<td>59%</td>
</tr>
<tr>
<td>2014</td>
<td>40%</td>
<td>60%</td>
</tr>
<tr>
<td>2015</td>
<td>39%</td>
<td>61%</td>
</tr>
<tr>
<td>2016</td>
<td>33%</td>
<td>67%</td>
</tr>
<tr>
<td>2017</td>
<td>25%</td>
<td>75%</td>
</tr>
<tr>
<td>2018</td>
<td>30%</td>
<td>70%</td>
</tr>
<tr>
<td>2019</td>
<td>32%</td>
<td>68%</td>
</tr>
</tbody>
</table>
2. Did you have Part C experience prior to becoming the Part C Coordinator? Check all that apply.

Forty-seven states responded to this question. Twenty-three of the forty-seven coordinators (48.9%) had worked for the lead agency in the Part C office. Nine of the twenty-three (39.1%) had also worked at a local agency/provider.

Those who responded that they had no background in Part C were asked about their previous experience:

- I worked at the state Medicaid agency.
- I had child welfare experience for 17 years working with children and families.
- My former career was as an educator in both public and private schools.

Three respondents also indicated that they had children with disabilities.
3. Is Part C your only responsibility?

Forty-six states responded to this question. Thirty respondents (63.8%) indicated that Part C was their only responsibility. Respondents were asked to identify additional programs for which they are responsible. Responses to I am responsible for were:

- Family Education and Support Program for children and young adults ages 3 to 21. This program is limited in enrollment and is funded through Title XX dollars;
- Monitoring activities related to other federally funded programs;
- Other state and federal Medicaid programs designed to support children with disabilities that are living in the community;
- Responsible for the Head Start Collaboration Office;
- Supervising all B-5 Special Education staff and 619 programs;
- Part B - 619 Coordinator and Family Support Services (MIECHV and state funded home visiting, family center funding, Children's Trust Fund);
- Section Chief for Policy and Data. This includes supervising three education specialists who manage the EI/SE data Birth - 21. I am also a Birth-Kindergarten liaison and provide programmatic early intervention and preschool special education support and technical assistance to five counties and the MD School for the Deaf.
- Home visiting (state and federally funded), Early Childhood Mental Health, Strengthening Families, Help Me Grow, Childcare Health Consultation;
- Two Medicaid waiver programs for individuals who experience Developmental Disabilities. Training for the entire Senior and Disabilities Division;
- As the CDS State Director, I'm also responsible for Part B Section 619;
- Oversee Medicaid's home and community-based services for children with special health care needs;
- Head Start Collaboration Office EHDl Program;
- Integrating Part C with other Medicaid programs and integrating Part C data system with Medicaid data systems;
• Contract administration for broader lead agency services and technical assistance for broader services offered by the lead agency;
• Early Hearing Detection & Intervention (EHDI) and Early Periodic Screening, Detection, & Treatment (EPSDT); and
• Children with Special Healthcare Needs Program.

4. What is the highest educational degree that you have achieved?
Forty-six states responded to this question. Twenty-four respondents (52.2%) have a master’s degree; twelve respondents (26%) have a bachelor’s degree; six respondents (13%) have a Doctoral degree; and four respondents (9%) indicated other. Those that indicated other include:
  • J.D. - An attorney;
  • Specialist degree;
  • An associate degree; and
  • High School diploma.
5. Please indicate your salary range.

Forty-six states responded to this question. Eleven respondents (23.9%) indicated that their annual salary ranged between $61,000 – 70,000. This was the most frequent response. In 2005, the most frequently cited salary range was $51-60,000 representing 31% of the respondents. In 2019, there were no respondents with a salary range between $31 – 40,000 but there were also no respondents with a salary range above $126,000.
6. Identify the factors that are the most stressful in your position as the Part C Coordinator.

Check all that apply.

Forty-seven states responded to this question. The top three factors identified that produce the most stress were:

- Lack of providers to meet service needs (74.5%);
- Insufficient funding for services (57.4%); and
- Lack of staffing at the lead agency level (46.8%).

While in 2017, the most stressful factor reported was insufficient funding for services, for the two most recent years, the most stressful factor is the lack of providers to meet service needs.

Other factors reported include:

- While there is agreement that there should be sufficient funding, budgets decisions for the Part C program are made at the agency level without consultation of the program office;
- State processes that hinder the ability to be responsive and/or contribute to the amount of time it takes to get anything done. No accountability by state employees;
- Staffing turnover at the state and local levels;
- Professional development/ensuring all staff providing early intervention services understand current evidence-based practices; staff, especially leadership turnover;
• Politics;
• Part C (along with other early childhood programs) has become a political lightening rod, with occasional pressure from outside of the agency;
• New early childhood lead agency without sufficient infrastructure (HR, fiscal, IT);
• Many competing priorities (e.g., committees, workgroups, initiatives, projects, personnel needs/attention, etc.). Also, while it is not fully a lack of staff at the lead agency level, personnel related circumstances (e.g., unexpected extended leaves and key position vacancy) is another factor;
• Lead Agency and Division misunderstandings of the federal requirements of Part C, constant battles to protect the ability to operate per regulations;
• Lack of early childhood support by state leaders Being in the same division as Child Welfare;
• I'm new, so I'm still learning structure - takes time;
• Have a lot of other responsibilities; and
• Difficult to complete all the federal requirements, meet agency expectations and have time to plan for new initiatives and training.
7. What type of supports would new coordinators need to be more effective in the first two years? Check all that apply.

Forty-seven states responded to this question. Thirty-seven respondents (78.7%) identified *New Coordinator Toolkit* as an important support. Peer mentoring was identified by thirty-three respondents (70.2%) and Customized technical assistance was identified by 30 respondents (63.8%).

![Types of Supports for New Coordinators](chart1)

![Types of Supports by Lead Agency](chart2)
Comments included:

- Learning from the stories of other states;
- All items listed are equally important and will depend on the Part C Coordinator’s experience and knowledge. It would be ideal for the toolkit to have all items listed and the Part C Coordinator can choose it as an option since everyone's comfort level and learning style will vary;
- Written documents are available, but it would be helpful to have documents that are written in plain English (less legal jargon) and are step-by-step guides. I know that the legal piece is important, but the terminology is difficult to follow especially at first.
- Support in conducting a system assessment (if one was not recently conducted for the state) to identify strengths, weaknesses, opportunities for improvement, and threats to; and
- Written guidance on revising policy and procedure.
Tipping Points Questions

Continued Participation

1. Which statement describes the status of your State's continuing Part C participation?

Forty-three states responded to this question. Thirty-eight states (88.4%) indicated that there were no discussions related to dropping out of Part C. Three states (6.9%) indicated 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; One state (2.3%) indicated it was having discussions about possibly dropping out of Part C; and one states (2.3%) indicated it was having serious discussions related to continued participation.

<table>
<thead>
<tr>
<th></th>
<th>No Discussions</th>
<th>Some Discussions</th>
<th>Serious Discussions</th>
<th>Prepared Documents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health (18)</td>
<td>17</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Education (9)</td>
<td>8</td>
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</tr>
<tr>
<td>Other (16)</td>
<td>13</td>
<td>1</td>
<td>0</td>
<td>2</td>
</tr>
</tbody>
</table>
2. If discussions are taking place, what issue will cause the administration to decide to drop out? Check all that apply

Six states responded to this question. Five states (83.3%) cited program growth rate. Four states(66.6%) cited state budget availability. Two states (33.3%) cited increased costs of the system. One state (16.6%) cited reduction in federal Part C funds; and one state (16.6%) cited reduction/changes in other federal funds such as Medicaid.
24. Please check the statement that applies to the 2019-2020 fiscal year.

Forty-three states that responded to this question. Forty-two states (97.6%) indicated they will be able to continue to participate in Part C through June 30, 2020; and one state indicated that it is possible that it will not be able to continue participation through June 30, 2020 due to lack of funding.

25. Which statement describes the status of your state funding for Part C for 2019-2020?

Forty-one states responded to this question. Twenty states (48.7%) indicated their funding was increased. Fifteen states (36.5%) indicated their funding was frozen; and six states (14.6%) indicated that the state budget was not finalized yet.
26. As a result of state fiscal issues, what changes have you made in the last 12 months, in order to continue participation in Part C? Check all that apply.

Twenty-three states responded to this question. Three states (13%) made changes in the state Medicaid plan to increase coverage for Part C services. Three states (13%) added autism coverage in the Medicaid state plan. One state (4.3%) reduced provider reimbursement. One state (4.3%) required prior approval for hours of service that exceed an identified amount; and fifteen states (65.2%) provided the following comments:

- Currently conducting a statewide needs assessment;
- Requested additional state funds;
- Provided data to justify increased $ needed for increased #s;
- Provided data and justification for costs of the program to the Business Office and State leadership;
- Private insurance legislation is back on the discussion table, but no formal action has been started or picked up again legislatively;
- Moved salaries for five (5) positions from Part C Grant to Title V;
- Legislative request to add additional service coordinators with funding was approved;
- Increased accessing third party funding;
- Had to request a supplemental budget allocation for 2018-19 and 2019-20 due to increase in number of children being served;
- Developed legislation to increase state support for Part C;
- Decreased PD opportunities, reduced staff size, eliminated contracts to support work of lead agency;
- Currently working with Medicaid to increase funding for EI services;
- Created ICC Fiscal Committee and working very closely with them to educate Governor's off and Medicaid on current fiscal challenges and proposed solutions;
- Convened internal stakeholder workgroup to review/revise fiscal policies; and
- Added child count targets to contracts - more children served, more available funds + fewer children served, fewer available funds.
27. 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.

Twenty-seven states responded to this question. Ten states (37%) will make changes in the state Medicaid plan to increase coverage for Part C services. Three states (11.1%) will develop legislation related to the use of private insurance. Two states (7.4%) will narrow eligibility and two additional states (7.4%) will require prior approval for hours of service that exceed an identified amount. One state (3.7%) will require families to use their insurance or be placed on a fee schedule. One state (3.7%) will reduce provider reimbursement and one state (3.7%) will add autism coverage in the Medicaid state plan. Nineteen states (70.3%) provided the following comments:

- To be determined based on the needs assessment findings;
- Resubmit request to move three (3) direct service positions from Part C grant to State General funds. This will allow us to submit Medicaid and TriCare claims for services delivered by these positions. Also, will begin work to support changing Medicaid reimbursement from Rehab to EPSDT;
- Request increased budget amount to address increases in number of children served;
- Re-establish travel reimbursement rates;
• Received an increase in state funding;
• Received $2.1 m additional allocation for the fiscal year from the legislature;
• Narrowing eligibility requires approval from the legislature;
• Monitoring indicated regional agencies were not following eligibility criteria which already was narrow. Increased monitoring and a specific established condition list are now being implemented to ensure eligibility criterion is being applied state-wide effectively;
• Meet with insurers and MDs about existing CI legislation;
• Implement evidence-based practices for children with autism that are less costly and allow providers to maintain their current caseload capacity;
• Implement "testing out" of Part C- yearly eligibility determination for continued services;
• Establish Medicaid reimbursement for telehealth, develop a legislatively mandated plan to maximize funding including evaluating the Medicaid rate for special instruction and seeking additional federal funds;
• Convened internal stakeholder workgroup to review/revise fiscal policies;
• Continue to decrease PD opportunities, further reduced staff size, eliminate more contracts that support work of lead agency;
• Completed RFP process and solicited contractors with a new scope of work, that ensures they abide by regulations and fiscal requirements, this is more detailed and ensures accountability to using funds appropriately; and
• All the above are under consideration (not sure if any will be implemented).
Eligibility

28. Which statement describes the status of eligibility in your state for the last three years?

Forty-one states responded to this question. Thirty-nine states (95.1%) indicated they had not changed eligibility criteria in the last three years. Two states (4.8%) indicated they had broadened their eligibility. Several states provided the following comments:

- While eligibility is technically the same, changes we are making 7/1/19 in how diagnoses of lead exposure and NAS are treated will likely have the practical effect of broadening eligibility;
- We have not changed eligibility criteria but have had brief discussions on this;
- We are exploring changing eligibility to make it more restrictive;
- We are considering adding established eligibility for babies with substance exposure;
- Conversations about expanding eligibility criteria are occurring, but not in the next year or two;
- Considering changing eligibility in next few years; and
- Attempts to change eligibility were unsuccessful due to family and provider outcry.
29. If you changed your eligibility criteria, what are you doing for children who no longer meet your eligibility criteria?

Four states responded to this question. Two states (25%) indicated they the children are referred to other community agencies and two states (25%) indicated there was no state policy or procedure.

30. If you are changing your eligibility criteria in the 2019-2020 year, please check the answer that describes what you are planning.

Two states responded to this question and both states indicated that eligibility would be broadened.

**Child Services**

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

Forty-two states responded to this question, but only 21 states (50%) were able to provide data. The median number of planned hours of direct service per child per month was 4.5 hours with a range of 1.5 hours to 18 hours.
32. What is the average number of delivered hours (excluding service coordination and evaluation/assessment) per child per month?

Forty-two states responded to this question. Only 15 states (35.7%) were able to provide data. The median number of delivered hours of direct service per child per month was 4 hours with a range of 2 hours to 16 hours.
33. **What is the average length of time a child is in your Part C system?**

Forty-three states responded to this question, 29 states (67.4%) were able to provide data. The median length of time a child is in the Part C system is 14.8 months with a range of 6 months to 19 months.

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

Forty-two states responded to this question, 30 states (71.4%) were able to provide data. The median age of referral for a child in the Part C system is 18 months with a range of 2 months to 27 months.
35. Is your state addressing the developmental needs of infants with the following conditions?

Forty-two states responded to this question.

<table>
<thead>
<tr>
<th>Condition</th>
<th>Health (12/13)</th>
<th>Education (5/5)</th>
<th>Other (12/12)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Perinatal Substance Use (42)</td>
<td>15</td>
<td>15</td>
<td>9</td>
</tr>
<tr>
<td>ZIKA Virus (43)</td>
<td>6</td>
<td>12</td>
<td>5</td>
</tr>
<tr>
<td>Lead Poisoning (42)</td>
<td>12</td>
<td>18</td>
<td>4</td>
</tr>
<tr>
<td>Fetal Alcohol Syndrome Disorder (43)</td>
<td>12</td>
<td>24</td>
<td>4</td>
</tr>
<tr>
<td>Other Adverse Conditions (30)</td>
<td>8</td>
<td>9</td>
<td>4</td>
</tr>
</tbody>
</table>

Length of Stay and Age at Referral by Lead Agency:

![Bar chart showing Length of Stay and Average Age at Referral by Lead Agency]

<table>
<thead>
<tr>
<th>Length of Stay</th>
<th>Average Age at Referral</th>
</tr>
</thead>
<tbody>
<tr>
<td>15.5</td>
<td>16</td>
</tr>
<tr>
<td>11.5</td>
<td>18</td>
</tr>
<tr>
<td>17.5</td>
<td>16</td>
</tr>
</tbody>
</table>

Health (12/13) | Education (5/5) | Other (12/12)
Other Adverse conditions that were identified were:

- Postnatal maternal depression;
- Mental health;
- Complex family needs/risk factors; and
- ACEs

36. **What specific activities are you implementing to address the needs of infants prenatally exposed to substance use/neonatal abstinence syndrome (NAS)?**

Thirty states identified activities that they were conducting. The following are their responses:

- HB140 Aiden's Law creates plan of safe care under DFS; no formal linkage with Part C; revising an MOU to address formalizing referrals to Part C;
- Included in automatic eligibility (established condition), fund NICU early intervention program that captures most infants with NAS in the state, increased coordination with CPS;
- Increasing our technical assistance providers knowledge of the issue, partnering with other state agency involved with parents who are in needs of plans of safe care to understand the processes in place by other state agency;
No new activities are currently being implemented specifically for this population other than provider training planned for this fiscal year;

Our state is looking at an 1115 waiver for many services;

Significant focus on family engagement and attachment;

The Department of Public Health and Human Services have convened work groups in the Children's Special Health Services Bureau to develop infrastructure to support the needs of this population;

Training for practitioners - considering eligibility criteria changes;

Worked with other offices in the department to prepare and submit an Innovation Accelerator application to CMS --Working with DCFS to evaluate needs and develop processes to address increased numbers of referrals for substance exposure in specific areas of the state;

Working collaboratively with Birthing hospitals to do an EI introductory visit prior to discharge to establish a positive relationship; allow collaboration and preparation for continuity of care upon release;

Task force was developed to address this issue in certain areas of the state. Single team, single plan initiative was developed and rolled out to various counties to coordinate the state services provided;

Statewide coordinated campaign;

Planning for a work group of physicians and state/regional staff to consider how to refer appropriately given the state’s current eligibility criteria;

Dependent on location in my state (i.e. northern regions struggle with opioid addiction)

Cross-system training - Home Visiting, Child Protective Services, EI;

Auto-eligibility, PD to regional providers, Part C Coordinator sits on the State Substance-Exposed Infant Task Force;

Working closely with local NICUs and our Child Welfare state and local programs;

Working closely with Dept of Public Health;
With the implementation of the Plans of Safe Care, Part C programs will be the lead of the plan in several categories of families when there are not concerns related to the safety of the child;

- Webinars available online, discussion at system leader meetings, project to improve referrals from NICUs;
- Significant activities; on Part C Coordinator and other state staff are on a statewide NAS taskforce, Part C Coordinator partnered with Governor’s office and several experts to develop a 4-part educational video series on the Opioid Crisis and NAS, State office staff regularly send out information on NAS trainings, State office staff collaborated with experts to conduct a training on NAS for EI providers, many more initiatives;
- NAS is an automatically qualifying medical diagnosis for EI services in our state. We just had legislation passed designating June as Neonatal Abstinence Syndrome Awareness Month and will be working to include information about EI in any awareness campaign materials;
- Infants exposed prenatally to substance abuse may be eligible for services under the high-risk category;
- Exploring legislation to secure funding;
- Data sharing with DPH for child find;
- Comprehensive referral and screening;
- Collaboration with Children/Family Services to establish joint referral/service policies/procedures;
- Collaborating with newborn screening program to consider eligibility for substance exposed newborns vs. those showing withdrawal at birth;
- Collaborated on a perinatal substance use practice bundle, one of my state’s representatives at the Region V Head Start meeting on OUD, provided learning collaboratives for home visitors on understanding OUD and how to work with children and their families, dialogue to improve data on SEN and NAS via CPT codes at referral, working with HMG to improve screening for children referred from DCS; and
- Added NAS to our automatic eligibility diagnosis list; provided training in the Brazelton Institute's Newborn Behavioral Observation (NBO) system; provided training in NAS; looking at other supports (e.g., expanding utilization of social work services).

Provider Issues

37. 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 in the last three years?

Forty-one states responded to this question. Two states (4.9%) responded yes. Fifteen states (36.6%) responded no and 23 states (56.1%) responded that this did not apply to them. One state indicated that had not happened yet though some have raised concerns about continuing to contract to provide these services due to continued level funding.
38. If your state uses contractors (agencies/individuals) to provide direct services, did any of those contractors decline to continue because of fiscal constraints in the last three years?

Forty-one states responded to this question. Fifteen states (36.6%) responded yes to this question. Nineteen states (46.3%) responded no and five states (12.2%) indicated this did not apply to them. Three states (7.3%) provided the following comments:

- Local programs struggle with this issue;
- There was a shortfall in funding that impacted service providers, but they will be reimbursed after the budget is enacted; and
- Not yet, but some have threatened to stop serving due to continued level funding.
39. What is the status of provider reimbursement in your state over the last three years?
Forty-two states responded to this question. Twenty-six states (61.9%) indicated that rates have remained the same. Eight states (19%) increased rates and two states (4.8%) decreased rates. Five states (11.9%) will increase rates over the next 12 months.
40. Is your state experiencing shortages in qualified providers?

Forty-two states responded to this question. Forty-one states (97.6%) are experiencing a shortage in qualified providers.
41. Which type of providers are you experiencing shortages in?

Forty-one states responded to this question. The following data reflects the percentage of states who identified shortages by provider type:

- Speech Therapists: Thirty-seven states (90.2%);
- Physical Therapists: Thirty-four states (80.9%);
- Occupational Therapists: Twenty-eight states (68.3%);
- Special Educators: Seventeen states (41.5%);
- Psychologists: Fifteen states (36.6%);
- Orientation and Mobility Specialists: Thirteen states (31.7%);
- Audiologists: Twelve states (29.3%);
- Vision Specialists: Twelve states (29.3%);
- Social Workers: Eight states (19.5%);
- Nurses: Seven states (17.1%);
- Registered Dieticians: Six states (14.6%); and
- Family Therapists: Four states (9.8%).
42. What are you doing to address the shortages?

Forty states responded to this question and their comments are included below:

- Asking corporations that provide services to hire them to provide early intervention services;
- Working with University and ICC;
- Statewide there is not a shortage, however, in very rural communities it is challenging to keep providers;
- Recruiting - training outreach - local agencies recruiting - mailing and calling;
- Partnering with State Dept of Education, Higher Education and Professional Organizations;
- Recruiting through word of mouth, recruiting fairs, college job fairs;
- Deaf educators (add to provider type shortages) Increased frequency of reviews of service needs to pull in regional staff to "trouble shoot" Developing region-specific strategies to address needs in certain areas. e.g. geographically based teams using combo
of direct and consultation services. About to start with a teletherapy approach through a grant that the university is applying for;

- Increase rates, professional development on leadership and coaching;
- This is specifically in remote regions of the State. Telehealth is slow to move forward but is a reimbursable service through Medicaid and private insurance for SLP and PT;
- Statewide coordinated meetings, looking at standards for certification;
- Working with Higher Education to develop more EI/Early Childhood degrees and/or certificate programs. Work closely with the EI provider community in the establishment of a fair and equitable rate to recruit skilled workforce;
- Sharing providers among localities, encouraging school providers to work in EI over the summer, asking for increased rates;
- Regional recruitment plan and networking between regions;
- Trying to raise rates for providers;
- Part of special education work group for recruitment and retention;
- Slight rate increases, working with higher education to improve preservice education, providing presentations to college students about early intervention and viable career options, strengthening relationships with college professors and their understanding and feelings about home visiting, working with a university on creating a DT association, improved and simplified the enrollment and credentialing process, created better PD opportunities;
- Increase in SLP rates since it's the greatest need; working with MDOE to address the recruitment and retention issue of qualified personnel 0-20;
- State has loan forgiveness programs and tuition reimbursement;
- SSIP Staffing Workgroup seeking recruitment and retention strategies that can be used by all EI agencies. Partnering with other department/agencies on initiatives/grants related to workforce; contracted a mainland based telepractice contractor to provide service at one (1) Demonstration site; and usual participation at job fairs;
- Add Teachers of Deaf/Hard of Hearing... We are looking at how to continue PSP but with a less expensive SC... which is NOT what we want. Also looking at tweaking personnel standards to include Speech Tx assistants...;
- Hiring exceptions, support to programs;
- Exhibiting at job fairs, doing presentations about career opportunities in EI to university classes;
- Explore innovative strategies for recruitment and retention;
- Supporting contract agencies with recruitment and retention, exploring and hopefully will be able to implement rate increases this next year, partnering closely with higher education, utilize TA resources, many more initiatives;
- 1. Developed agreements with some preservice training programs to provide field experiences (SLPs); 2. Partnered with University to implement a new online Early Intervention master’s degree (for special instructors); 3. Partnered with EHDI on standards of practices for pediatric audiologists; 4. Convened new Strategic Planning Team to implement revamped CSPD to prepare, credential, recruit, retain early intervention/early childhood special education and related service personnel (includes higher learning, professional associations, agencies, Inservice providers, etc.);
- Partnerships with higher ed, advertisement, planning of IFSP development for whole child - less dependent on discipline specific, talks of Rate Study to ensure pay scale is competitive;
- Recruitment efforts are ongoing;
- Developed and implemented new EI EPSDT SPA benefit. Work with the Idaho universities, especially the one that has SLP, PT and OT programs;
- Collaboration with school district staff;
- Information sharing among programs;
- Continuing to work with state IHEs
- Providing tuition assistance to via our state university system. Developed a Task Force to address the topic;
o Attempting to raise salaries for State Staff to be competitive. Preliminary discussions with IHEs;

o Doing outreach with our contractors;

o Providing data on children needing services areas to encourage providers to expand their coverage areas. Rates for certain services will increase over the next year;

o The ICC is looking at our service delivery model. We have added the traveling teams and Special Educator positions. We are looking into tele-therapy on the use of OTA, PTA, and SLPAs.

o We are experiencing shortage of the above in certain areas of the state. Lead Agency staff continue to work with University staff, ICC and stakeholders to address this matter;

o Using data to inform strategic planning and providing aligned training opportunities;

o We are participating in the PDG work and are wrapping up a statewide needs assessment to identify gaps and opportunities; and

o Teletherapy; regional health centers.

**Home Visiting**

43. Is your Part C system involved with your state's Home Visiting initiatives?

Forty-two states responded to this question:

<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>4.8%</td>
<td>9.5%</td>
<td>50%</td>
<td>7.1%</td>
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<tr>
<td>Shared Policies</td>
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<td>33.3%</td>
<td>7.1%</td>
<td>50%</td>
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<tr>
<td>Joint Services</td>
<td>4.9%</td>
<td>4.9%</td>
<td>36.6%</td>
<td>21.9%</td>
<td>31.7%</td>
</tr>
<tr>
<td>Joint Facilities</td>
<td>2.4%</td>
<td>4.9%</td>
<td>17.1%</td>
<td>21.9%</td>
<td>53.7%</td>
</tr>
<tr>
<td>Monitoring</td>
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<td>2.4%</td>
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<tr>
<td>Combined Staff Meetings</td>
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<td>66.7%</td>
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### Joint Facilities

<table>
<thead>
<tr>
<th>Category</th>
<th>Other (16)</th>
<th>Education (8)</th>
<th>Health (17)</th>
</tr>
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<tbody>
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<tr>
<td>2</td>
<td>6.3%</td>
<td>0.0%</td>
<td>5.9%</td>
</tr>
<tr>
<td>Sometimes</td>
<td>12.5%</td>
<td>25.0%</td>
<td>17.6%</td>
</tr>
<tr>
<td>4</td>
<td>25.0%</td>
<td>25.0%</td>
<td>17.6%</td>
</tr>
<tr>
<td>Not at All</td>
<td>56.3%</td>
<td>37.5%</td>
<td>58.8%</td>
</tr>
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### Monitoring

<table>
<thead>
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<th>Category</th>
<th>Other (16)</th>
<th>Education (8)</th>
<th>Health (15)</th>
</tr>
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<tbody>
<tr>
<td>Always (1)</td>
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<td>0.0%</td>
<td>0.0%</td>
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<tr>
<td>2</td>
<td>12.5%</td>
<td>12.5%</td>
<td>6.7%</td>
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<tr>
<td>Sometimes</td>
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<td>12.5%</td>
<td>6.7%</td>
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<tr>
<td>4</td>
<td>6.3%</td>
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<tr>
<td>Not at All</td>
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### Shared Data

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<th>Education (9)</th>
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<tr>
<td>Always (1)</td>
<td>6.3%</td>
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<td>0.0%</td>
</tr>
<tr>
<td>2</td>
<td>6.3%</td>
<td>33.3%</td>
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<td>Sometimes</td>
<td>37.5%</td>
<td>33.3%</td>
<td>23.5%</td>
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<td>4</td>
<td>18.8%</td>
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<tr>
<td>Not at All</td>
<td>31.3%</td>
<td>22.2%</td>
<td>35.3%</td>
</tr>
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</table>
44. Have you collaborated with your MIECHV program to discuss how the joint guidance document could be implemented in your state?

Forty-three states responded to this question. Sixteen states (37.2%) responded yes. Fifteen states (34.9%) responded no and twelve states (27.9%) responded not yet but planned.
Note: Thank you to all states and jurisdictions that completed this survey and help to provide a picture of the status of Part C systems.