ITCA Annual Survey:
State Challenges and Responses
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2018 Part C Implementation: State Challenges and Responses

For the thirteenth 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 June 2018. 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 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:

- 35 states responded that there are no discussions related to dropping out of Part C;
- 1 state responded that they are having discussions about possibly dropping out of Part C during the 2018-2019 year;
• 2 states responded that they are having serious discussions related to continued participation in Part C;
• 3 states 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
• 4 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 twelve states that responded to this question:
• 2 states indicated increased costs;
• 7 states indicated state budget availability;
• 4 states indicated program growth rate;
• 1 state indicated increased costs of children with complex needs;
• 1 state indicated a reduction in federal Part C funds; and
• 2 states identified reduction/changes in other federal funds such as Medicaid.

Q 3. Will your state be able to continue participation in Part C through June 30, 2019?

Of the forty-four states that responded to this question, 41 indicated that they would be able to continue participation through June 30, 2019. One state indicated that it is possible that they will not be able to continue participation through June 30, 2019 due to lack of funding. Two states provided additional comments.

Q 4. 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 3.8% (Range: 0% to 19%). This is a slight decrease from 4% in 2017.

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

Sixteen states provided data in response to this question and reported an average declination rate of 13.6% (Range: 0% to 87%). This is a decrease from the 2017 average declination rate of 18%.
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 thirty states that responded to this question:

- 1 state implemented family fees;
- 1 state increased family fees;
- 1 state required families to use their private insurance or be placed on a fee schedule;
- 4 states reduced provider reimbursement;
- 1 state required prior approval for hours of service that exceed an identified amount;
- 2 states narrowed eligibility for services;
- 2 states made changes in the state Medicaid plan to increase coverage for Part C services;
- 2 states added Autism coverage in the Medicaid state plan;
- 1 state developed legislation related to the use of private insurance; and
- 16 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 twenty-nine states that responded to this question:

- 1 state will implement family fees;
- 1 state will increase family fees;
- 2 states will require families to use their insurance or be placed on a fee schedule;
- 3 states will reduce provider reimbursement;
- 1 state will narrow eligibility;
- 9 states will make changes in the state Medicaid plan to increase coverage for Part C services;
- 1 state will add Autism coverage in the Medicaid state plan;
- 3 states will develop legislation related to the use of private insurance; and
- 16 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-three states that responded to this question:

- 38 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;
- 1 state has broadened eligibility criteria;
- 3 states are planning to change eligibility in the 2018-2019 fiscal year; and
- 6 states provided additional comments.

Q 9. If you are changing eligibility criteria in the 2018-2019 year, please check the answer that describes what you are planning.

Three states responded to this question. Two states indicated their eligibility criteria will be more restrictive and one state indicated its eligibility criteria will be broader.

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

Three states responded to this question. Two states indicated they refer them to other community agencies. One state indicated it is looking at dropping at risk and having home visiting follow these children as they will refer back to Part C if needed.

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 seventeen states that provided data to answer this question:

- The number of planned service hours per child per month ranged from 1.8 hours to 8 hours with a median of 4.4 hours and an average of 4.6 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 fourteen states that provided data to answer this question:

- The number of delivered service hours per child per month ranged from 2.5 hours to 6 hours with a median of 4.5 hours and an average of 4.3.
Q 13. What is the average length of time a child is in your Part C system?
Of the twenty-six states that provided data to answer this question:
  • The average length of time a child was in the Part C system ranged from 8 months to 20 months with a median of 13 months and an average of 13.7 months.

Q 14. What is the average age of referral for a child in your Part C system?
Of the twenty-nine states that provided data, the range was 12 months to 30 months with a median of 17.3 months and an average of 17.8 months.

Q 15. Which statement describes the status of your state funding for Part C for 2018-2019?
Of the thirty-eight states that provided data for this question:
  • 17 states had their state funding increased;
  • 14 states had their state funding frozen;
  • 1 state had their state funding decreased; and
  • 6 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-three states that responded to this question:
  • 2 states indicated that they had agencies/organizations decline to continue because of fiscal constraints;
  • 24 states indicated they did not have any agencies/organizations decline to continue because of fiscal constraints;
  • 16 states indicated this question did not apply to them; and
  • 1 state responded other and made additional comments.

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:
  • 15 states indicated that they had agencies/individuals decline to continue because of fiscal constraints;
• 19 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
• 2 states provided additional comments.

Q 18. What is the status of provider reimbursement in your state over the last three years?
Check all that apply.
Of the forty-four states that responded to this question:
• 27 states indicated provider rates remained the same;
• 4 states decreased provider rates;
• 7 states increased provider reimbursement rates;
• 1 state will increase provider rates in the next 12 months; and
• 9 states provided additional comments.

Q 19. Is your Part C system involved with your state’s Home Visiting Initiatives?
A total of forty-four 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>System Component</th>
<th>(1) Always</th>
<th>(2) Sometimes</th>
<th>(3) Sometimes</th>
<th>(4) Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>Common Personnel Training (43)</td>
<td>0</td>
<td>6</td>
<td>19</td>
<td>10</td>
</tr>
<tr>
<td>Shared Policies (41)</td>
<td>0</td>
<td>4</td>
<td>11</td>
<td>7</td>
</tr>
<tr>
<td>Joint Services (43)</td>
<td>1</td>
<td>1</td>
<td>23</td>
<td>6</td>
</tr>
<tr>
<td>Joint Facilities (42)</td>
<td>3</td>
<td>0</td>
<td>6</td>
<td>10</td>
</tr>
<tr>
<td>Monitoring (42)</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Shared Data (43)</td>
<td>0</td>
<td>2</td>
<td>18</td>
<td>8</td>
</tr>
<tr>
<td>Combined Staff Meetings (44)</td>
<td>3</td>
<td>0</td>
<td>8</td>
<td>9</td>
</tr>
</tbody>
</table>

Q 20. Have you collaborated with your MIECHV program to discuss how the joint guidance document could be implemented in your state?
Forty-four states responded to this question. Twenty-five states responded yes, fifteen states responded no and four states responded not yet but planned.
Q 21. Is your state addressing the developmental needs of infants with the following conditions?
Forty-four states 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 (44)</td>
<td>13</td>
<td>17</td>
<td>11</td>
<td>3</td>
</tr>
<tr>
<td>ZIKA Virus (44)</td>
<td>7</td>
<td>15</td>
<td>3</td>
<td>19</td>
</tr>
<tr>
<td>Lead Poisoning (43)</td>
<td>10</td>
<td>19</td>
<td>7</td>
<td>7</td>
</tr>
<tr>
<td>Fetal Alcohol Syndrome Disorder (44)</td>
<td>11</td>
<td>21</td>
<td>5</td>
<td>7</td>
</tr>
<tr>
<td>Other Adverse Conditions (30)</td>
<td>7</td>
<td>7</td>
<td>6</td>
<td>10</td>
</tr>
</tbody>
</table>

Q 22. Is your state experiencing shortages in qualified providers?
Forty-four states responded to this question. Forty of the forty-four states indicated they were experiencing shortages of qualified providers.

Q 23. What type of providers are you experiencing shortages in? Check all that apply.
Forty states responded to this question:
- 35 states have a shortage of speech-language pathologists;
- 31 states have a shortage of physical therapists;
- 28 states have a shortage of occupational therapists;
- 18 states have a shortage of special educators;
- 13 states have a shortage of audiologists;
- 12 states have a shortage of psychologists;
- 15 states have a shortage of vision specialists, including optometrists and ophthalmologists;
- 10 states have a shortage of orientation and mobility specialists;
- 7 states have a shortage of family therapists;
- 6 states have a shortage of registered dieticians; and
- 4 states have a shortage of social workers and nurses.
Demographics of States Responding to the Survey

ITCA received responses from forty-seven states and jurisdictions (hereafter referred to as states). For the purpose of analysis, states self-identified their status for eligibility criteria, type of lead agency and state infrastructure. While OSEP has discontinued categorizing states by eligibility criteria, 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.

![State Eligibility Graph](image)
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.

![Lead Agency Chart]

<table>
<thead>
<tr>
<th>Category</th>
<th>Health (18)</th>
<th>Category B (20)</th>
<th>Category C (9)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health (18)¹</td>
<td>7</td>
<td>7</td>
<td>4</td>
</tr>
<tr>
<td>Education (10)</td>
<td>4</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>Other (19)</td>
<td>7</td>
<td>9</td>
<td>3</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**: Thirty-two states (68.1%) 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**: Six states (12.8%) responded that their infrastructure is primarily composed of programs/agencies that are responsible for referral to initial IFSP development including

¹ In charts or tables that provide answers by these categories, the number of total respondents by those categories is included in parentheses
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:** Five states (10.1%) 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.

- **Structure 4:** Two states (4.2%) responded that its 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.

Two states responded they had a different structure:

- State and program/local agency staff are responsible for Service Coordination. EI service are provided through a statewide central reimbursement system that pays providers.

- State staff responsible for service coordination activity. Local program also provide service coordination and early intervention services/supports.

![State Infrastructure by Lead Agency](chart)

<table>
<thead>
<tr>
<th>Structure</th>
<th>Health (18)</th>
<th>Education (10)</th>
<th>Other (19)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Structure 1</td>
<td>77.8%</td>
<td>60.0%</td>
<td>63%</td>
</tr>
<tr>
<td>Structure 2</td>
<td>16.7%</td>
<td>20.0%</td>
<td>5%</td>
</tr>
<tr>
<td>Structure 3</td>
<td>5.6%</td>
<td>20.0%</td>
<td>11%</td>
</tr>
<tr>
<td>Structure 4</td>
<td>0%</td>
<td>0%</td>
<td>11%</td>
</tr>
</tbody>
</table>
**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.

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

Forty-seven coordinators responded to this question. Seventeen of the forty-seven coordinators (36.2%) reported their state has a Part C Coordinator with two years or less of experience. Thirty-three states (70.2%) have coordinators with 5 years of experience or less. The chart below compares data from 2005 to 2018 data.
The percentage of experienced coordinators continues to decline. The chart that follows demonstrates the reversal of experience since 2005.

Note: Since these data were collected, three more states have had a change in leadership.

Did you have Part C experience prior to becoming the Part C Coordinator? Check all that apply.

Forty-six coordinators responded to this question. Twenty-three (50%) 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:

- 12 years in Child Protective Services.
- I worked in Medicaid policy and in clinical settings as a nurse.
- My background included 17 years working directly and in program/policy with children with special needs and families in the child welfare system.
Is Part C your only responsibility?

Forty-seven coordinators responded to this question. Thirty coordinators (65.9%) responded that Part C is their only responsibility. Part C as the only responsibility responses by Lead Agency: Health (72%), Education (70%) and Other (58%). Respondents were asked to identify additional programs for which they are responsible. Responses were:

- Interim Maternal and Child Health Services Director;
- Also Branch Manager: Newborn Metabolic Screening and Foods and Formulas, HANDS (state and federal home visiting), Early Childhood Mental Health, Child Care Health Consultation and several initiatives headed by staff in Branch;
- Director of Part B 619, Home Visiting and Family Centers;
- Early Childhood staff in our division serve as liaisons birth to kindergarten;
- Early Hearing Detection and Intervention;
- Early Hearing Detection and Intervention Program, Head Start Collaboration Office;
- The state’s Autism Initiative;
- Head Start Collaboration Office;
- Home and Community Based Services Waiver monitoring;
- I also oversee two other small Medicaid programs/services for children with special health care needs;
- I am the Director for Early Childhood Special Education services, Birth to 5, thus I oversee/supervise the Part C and B/619 programs;
- I oversee a Title XX program entitled Family Education and Support for children and young adults with developmental disabilities age 3 to 21;
- I’m also responsible for oversight of 619 and incidental k-12 duties;
- Part C is my primary task although there are many task that are done daily for IDEA Part B;
- Part C services are embedded in a broader statewide program of health promotion, prevention and early intervention services. Therefore, I monitor services in 4 regions of the state related to the broader program and participate in policy and program development for that broader program while also holding coordination duties for Part C services specifically;
- The I/DD Medicaid waiver program, Training Unit for all Services in our Division: Medicaid waivers, Person Centered Planning, In house orientation, compliance etc.; and
- Worked as the Maternal and Child Health Services Director for 6months.
What percentage of your salary is supported by resources other than Part C?

Forty-six coordinators responded to this question. Twenty coordinators (43.5%) indicated that 100% of their salary is paid for by Part C. Twelve coordinators (26.1%) indicated that 100% of their salary is paid for by other funds. Six coordinators (13%) indicated that less than 30% of their salary was paid for by other funds. Five states (10.8%) responded that other funds supported 31-50% of their salary. One state (2.2%) responded that other funds supported 51-74% of the salary and two states (4.3%) responded that 75-99% of salary was supported by other funds.

![Percentage of Salary Supported by Resources other than Part C](chart1.png)

![Percentage of Salary Supported by Resources other than Part C by Lead Agency](chart2.png)
What is the highest education degree you have achieved?

Forty-seven coordinators responded to this question. Twenty-seven coordinators (57.4%) indicated they had a Masters degree. Fourteen coordinators (29.8%) indicated they had a BA/BS. Two coordinators (4.3%) had doctoral degrees. Four coordinators (8.5%) indicated that they had other types of degrees including:

- Associates Degree. Working on my B.S. right now;
- Specialist; and
- J.D. (2).

![Highest Educational Degree Chart]

![Highest Education Degree by Lead Agency Chart]
Please indicate your salary range.

Forty-seven coordinators responded to this question. The most frequently cited salary range was $61 – $70,000 and represented twelve coordinators (25.5%). In 2005, the most frequently cited salary range was $51-60,000 representing 31% of the respondents.
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. Thirty-three states (70%) responded that lack of providers to meet service needs was the most stressful. Twenty-six states (55%) responded that lack of staffing at the lead agency level was stressful and twenty-four states (52.08%) indicated that insufficient funding for services was stressful.

Other factor identified included:

- Legal demands with children involved in Child Welfare
- Lack of early childhood support by state level elected officials
- Provider turnover
- OSEP state contacts - varying levels of knowledge and engagement with states, and inconsistent guidance/TA
- Being housed in the same Department and Division as Child Welfare
- Conservative Government - inability to obtain more state staff positions
- Contractors living in rehab/clinic requirements and IDEA, Part C requirements at the same time
- Managing all the parts and pieces of a statewide early intervention system;
- 3 data systems (Part C, PCG, MMIS) not quite linking correctly 100% of the time;
- Day to day oversight;
• General lack of understanding of the program by administrative staff that leads to lack of initiatives getting started or being successful. Data complexities and lack of expertise at state staff level;
• Insufficient number of employees at the state lead agency level to conduct all the work required;
• Lack of staff in the local programs (due to poor pay and lack of administrative support); state contracting requirements which are considerable barriers to meeting timelines and providing timely services; antiquated technology and resources;
• Lack of state/Medicaid FTEs to provide they type of high quality, relationship-based services desired. We need higher reimbursement levels for services, more staff to monitor quality, higher salaries to attract high quality staff and resources to support staff so that they are able to provide high quality services with fidelity;
• Many initiatives occurring at the same time. They are all very important and valuable to our Part C system to improve the outcomes for children and families;
• Multiple years of flat funding and resultant wage stagnation limits the programs ability to complete for already scarce qualified personnel;
• Politics;
• Rates for services are low which has an effect on turnover and recruitment;
• Regional Center service coordinators have high caseloads;
• SSIP;
• State government operations issues: developing RFPs and contracts, budget management and reporting, responding to leadership requests;
• The culture of the Department of Health is not supportive and the bureaucracy is cumbersome for hiring staff etc.;
• The politics of the position;
• Trouble filling qualified data analyst positions;
• Turnover at the state and local level; and
• With so many responsibilities there isn’t enough time for real in-depth training when you take over in this role. Deadlines are coming due all the time and you are required to just jump in and take over and learn on the job immediately. Manuals would help tremendously—something that I could refer to when I have questions. These manuals could also list the online systems where things are reported or where additional information can be found. Step
by step guides that are kept online and can be downloaded or printed. It would also be helpful to have a calendar of when things are due.

What types of supports would new coordinators need to be more effective in the first two years? Check all that apply.

Forty-two states responded to this question. Thirty-six states (85.7%) identified a toolkit for new coordinators as the most important support. Thirty-one states (73.8%) identified peer mentoring/coaching from a seasoned coordinator and an individualized and customized technical assistance plan for the new coordinator. Twenty-seven states (64.3%) identified written guidance on reporting requirements. Twenty-four states (57.1%) identified written guidance on available technical assistance and twenty-two states (52.4%) identified a meeting with their OSEP state contact within their first year.
Other Comments include:

- Assistance (just in time) with reporting requirements and available TA;
- One TA consultant from one of the centers who can facilitate discussions across all of them;
- Self-care; and
- Encouragement to feel free emailing their State Lead at OSEP any time they have a question.

### 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, thirty-five states (83.3%) responded that there are no discussions related to dropping out of Part C; one state (2.3%) responded they are having discussions about possibly dropping out of Part C during the 2018-2019 year. Two states (4.6%) responded that they are having serious discussions related to continued participation, and three states (7.1%) 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 four states (9.5%) provided comments.

Comments from four states included:

- Legislation was introduced (but failed) to break up Child Development Services, move 619 to the public schools, and move Part C to the Department of Health and Human Services.

- We are discussing changing eligibility as we are looking at a 2-million-dollar deficit starting the next fiscal year. We are also reviewing IFSP hours by agency.

- We are planning tighter budget controls and tracking, reporting expenditures resulting from the controls monthly.

- We are discussing how we, as a state, continue to participate in Part C (considering other agencies or organizational models).
Q2. If discussions are taking place, what issue will cause the administration to decide to drop out? Check all that apply.

Twelve states responded to this question. Seven states (58.3%) cited state budget availability. Four states (33.3%) cited program growth rate. Two states (16.6%) cited increased costs of the system and reduction/changes in other federal funds. One state (8.3%) cited reduction in federal Part C funds and an additional state cited increased costs of children with complex needs.

Q3. Will your state be able to continue participation in Part C through June 30, 2019?

Of the forty-four states that responded to this question, forty-one states (93.2%) indicated that they would be able to continue participation through June 30, 2019. One state (2.3%) indicated that it is possible that they will not be able to continue participation through June 30, 2019 due to lack of funding.

Additional comments include:

- We have a plan to ask the legislature for more monies to support a rate increase and to cover services.
- The Part C program was allocated additional funding by the Governor and General Assembly due to growth in the program.
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 3.8% (Range: 0% to 19%). This is a slight decrease from 4% in 2017.

Q5. Please estimate the percentage of families refusing access to private insurance.
Sixteen states provided data in response to this question and reported an average declination rate of 13.6% (Range: 0% to 87%). This is a decrease from the 2017 average declination rate of 18%.

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.
Thirty states responded to this question. Four states (13.3%) reduced provider reimbursement. Two states (6.67%) made changes in their state Medicaid plan to increase coverage for Part C services. Two states (6.67%) added autism coverage in their state Medicaid plan. Two states (6.67%) narrowed eligibility. One state (3.3%) required prior approval for hours of service that exceed an identified amount. One state (3.3%) implemented family fees, one state (3.3%) increased family fees, one state (3.3%) required families to use their private insurance or be placed on a fee schedule, and one state (3.3%) developed legislation related to the use of private insurance.

Sixteen states provided other actions:
- Completed a Salary/Rate Study which was used to submit a budget request of $2.7M for EI services;
• Fiscal Analysis/Rate-Time-Cost Study;
• Implemented a requirement that OT, PT, SLP must be enrolled Medicaid providers in order to serve children in EI;
• Implemented caps on administrative withholding and are in the process of shifting the flow of funding from Education to the lead agency DCYF;
• increased state funding;
• My state has not made any changes within the past 12 months related to fiscal issues;
• Made significant data system changes and enhancements, made significant changes in provider billing manual and released for public comment to increase accountability and ability to recoup funds with audit findings, updated policies and procedures;
• Negotiated with Medicaid to add administrative billing;
• Removed requirement for 1 team meeting to reduce service utilization;
• Scrutinized every contracted service and ensured Medicaid and billing to grant funds were maximized, reducing State GF payments for direct services as much as was practicable. Also, reduce State contracted administrative staff positions;
• Staff reduction, hiring freeze, appeared before the State Legislature to advocate for increased funding;
• Undertaking various streamlining and efficiency measures. Note: Medicaid therapy rates were reduced not in order to continue participation in Part C but due to legislative directives. The Part C program was not responsible for development of the private insurance legislation;
• We are planning a statewide needs assessment. Local programs lobbied for additional funds from the SGP and successfully obtained an increase of $1M;
• We are working on increasing the justification for approval for hours that exceed 16 hours;
• We have not made changes over the past 12 months; and
• We have requested state funding for the program.

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.

Twenty-nine states responded to this question. One state (2.78%) will implement family fees and one other (2.78%) will increase family fees. Two states (5.56%) indicated that they will require
families to use their private insurance or be placed on a fee schedule. Three states (8.33%) will reduce provider reimbursement. One state (2.78%) will narrow eligibility. Nine states (25%) indicated they will make changes in the state Medicaid plan to increase coverage for Part C services and one state (2.78%) will add Autism coverage in the Medicaid state plan. Three states (8.33%) will develop legislation related to the use of private insurance. Sixteen states (55%) identified the following other actions that will be considered:

### Actions in Next Twelve Months

<table>
<thead>
<tr>
<th>Action</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Make changes in state Medicaid plan</td>
<td>28%</td>
</tr>
<tr>
<td>Develop insurance legislation</td>
<td>10%</td>
</tr>
<tr>
<td>Implement Family Fees</td>
<td>7%</td>
</tr>
<tr>
<td>Add autism coverage to Medicaid</td>
<td>3%</td>
</tr>
<tr>
<td>Reduce Provider Reimbursement</td>
<td>3%</td>
</tr>
<tr>
<td>Require prior approval for excess service</td>
<td>3%</td>
</tr>
</tbody>
</table>

**Additional actions identified by states:**

- Add administrative billing to Interagency Agreement with Medicaid;
- Having conversations with state Medicaid program regarding coverage of services;
  - conversations are also happening regarding legislation related to private insurance and a potential trust fund idea for Arizona, new EI contracts are upcoming in 11/2018 and will have a lot of changes in the fiscal section, as well as an enhanced and stricter billing section with changes in rates and billing requirements;
- Implement changes in the state Medicaid plan;
- Making changes to provider reimbursement for travel;
- May pursue legislation related to the use of private insurance;
- Revise the insurance statute;
- Statewide needs assessment and fiscal TA for local programs around Medicaid and private insurance billing;
- Submit state legislative request for additional funds;
• The implementation of state funding for early intervention;
• The state Medicaid agency is shifting to Managed Care for EI and taking the services out of FFS. The same rules and coverage apply;
• Utilize Medicaid reimbursement for MOE;
• We already use a sliding fee scale and allow families choice with use of insurance. We would like to increase reimbursement rates and negotiate different (higher) rates for services with both public and private insurance. We also have changed provider contracts to require that they must bill both public and private insurance and not solely accept public insurance cases;
• We are considering narrowing eligibility (this is only one possibility). We are exploring ways to increase TCM reimbursement. We will be request additional funding from the state legislature. We are exploring how to get Medicaid reimbursement for telehealth. We will continue to seek CHIP reimbursement for special instruction. We will continue bulk purchase of the BDI-2 to reduce costs;
• We are looking at approval for more than 10 hours, right now it is 16 hours;
• We HOPE to make changes in the state Medicaid plan to increase coverage for Part C services; and
• Work with legislation on increasing state allocation.

Q8. Which statement describes the status of eligibility in your state for the last three years?

Of the forty-three states that responded to this question, thirty-eight states (88.3%) indicated they have made no changes in eligibility criteria and have no plans to make any changes; one state (2.3%) has made eligibility criteria more restrictive; one state (2.3%) has expanded eligibility criteria. Three states (6.9%) are planning to change eligibility in the 2017-2018 fiscal year and six states made additional comments.
**Additional Comments include:**

- However, we have received a lot of push back from our ICC;

- Preterm infants must meet DD criteria at 1 year of age to remain in the program, are eligible with medical diagnosis prior to that time;

- Proposed changes are being recommended;

- Revisiting eligibility to determine if changes are to be made;

- We are planning to clarify eligibility as the % of delay did not correspond to the SD (the %s are 33% & 25% and the SD are 2 & 1.5) - we're changing to 1.5 & 1.25 - most just use % of delay at this time; and

- We have not changed eligibility but are considering narrowing eligibility.

**Q9. If you are changing eligibility criteria in the 2018-2019 year, please check the answer that describes what you are planning.**

Three states responded to this question. Two states indicated that their eligibility will be more restrictive and one state indicated its eligibility criteria would be broader.

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

Three states responded to this question. Two states indicated they refer them to other community agencies and one state indicated it is looking at dropping at risk and having home visiting follow these children and refer back to Part C if needed.

**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 seventeen states that provided data to answer this question, the number of planned service hours per child per month ranged from 1.8 hours to 8 hours with a median of 4.4 hours and an average of 4.6 hours.
Q12. What is the average number of delivered hours of direct service (excluding service coordination and evaluation/assessment) per child per month?

Of the fourteen states that provided data to answer this question, the number of delivered service hours per child per month ranged from 2.5 hours to 6 hours with a median of 4.5 hours and an average of 4.3 hours.

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

---

2 The numbers in parentheses reflect number of states providing planned/delivered services
Q13. **What is the average length of time a child is in your Part C system?**

Of the twenty-six states that provided data to answer this question, the average length of time a child was in the Part C system ranged from 8 months to 20 months with a median of 13 months and an average of 13.7 months.

![LENGTH OF STAY IN PART C](image)

<table>
<thead>
<tr>
<th>Year</th>
<th>Health (13)</th>
<th>Education (5)</th>
<th>Other (8)</th>
</tr>
</thead>
<tbody>
<tr>
<td>2012</td>
<td>12.9 months</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2013</td>
<td>15 months</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2014</td>
<td>14 months</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2015</td>
<td>15 months</td>
<td></td>
<td>12.5 months</td>
</tr>
<tr>
<td>2016</td>
<td>13.2 months</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2017</td>
<td>13.7 months</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2018</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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

Of the twenty-nine states that provided data, the range was 12 months to 30 months with a median of 17.3 months and an average of 17.9 months.

![AVERAGE AGE AT REFERRAL](image)

Thirty-eight states responded to this question. Seventeen states (44.7%) had their funding increased. Fourteen states (36.8%) had their state funding frozen. One state (2.6%) had their funding reduced and six states (15.7%) 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-three states responded to this question. Two states (4.65%) indicated that they had agencies/organizations decline to continue because of fiscal constraints. Twenty-four states (55.8%) indicated they did not have any agencies/organizations decline to continue because of fiscal constraints and sixteen states (37.2%) indicated this question did not apply to them. One state responded other. The comment was:

- One program declined to continue but received a complaints and angry feedback from the local community and rescinded their discontinuation letter.

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. Nineteen states (43.2%) indicated they did not have any contractors (agencies/individuals) decline to continue because of fiscal constraints. Fifteen states (34.1%) indicated that they had agencies/individuals decline to continue because of fiscal constraints and seven states (15.9%) indicated this question did not apply to them. Two states (4.5%) provided additional comments.
Additional Comments include:

- Our local leads contract with providers for direct services and some have seen providers drop out of providing services due to financial reasons; and
- We had some long term agencies at the local county level that did renew their contracts because of fiscal restraints.

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

Forty-four states responded to this question. Twenty-seven states (61.4%) indicated provider rates remained the same. Four states (9.1%) decreased provider rates. Seven states (15.9%) reported they increased provider reimbursement rates. One state (2.3%) will increase provider rates in the next 12 months.

Nine states (20.5%) provided the following comments:

- The reimbursement rate to providers has increased because our federal support have increased;
- We completed a rate study and hope to offer increases in FY 2020;
- If there was an increase it was very small;
- Unknown - provider reimbursement occurs at the local level;
- We do not have state reimbursement rates;
- We are working with State Budget and Legislature on increasing rates for providers for SFY20;
- Federal has decreased, state has increased;
• Provider rates align with broader State Medicaid rate structure and are under review regularly as part of that system. Some rates increase and others decrease by State Medicaid rate-setting formulas; and
• Rates have not gone up for 8 years.
Q 19. Is your Part C system involved with your state’s Home Visiting initiatives?

Forty-four states responded to this question. The following chart documents the degree of their involvement with seven system components:

<table>
<thead>
<tr>
<th>Component</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 (43)</td>
<td>0</td>
<td>6</td>
<td>19</td>
<td>10</td>
<td>8</td>
</tr>
<tr>
<td>Shared Policies (41)</td>
<td>0</td>
<td>4</td>
<td>11</td>
<td>7</td>
<td>19</td>
</tr>
<tr>
<td>Joint Services (43)</td>
<td>1</td>
<td>1</td>
<td>23</td>
<td>6</td>
<td>12</td>
</tr>
<tr>
<td>Joint Facilities (42)</td>
<td>3</td>
<td>0</td>
<td>6</td>
<td>10</td>
<td>23</td>
</tr>
<tr>
<td>Monitoring (42)</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>4</td>
<td>36</td>
</tr>
<tr>
<td>Shared Data (43)</td>
<td>0</td>
<td>2</td>
<td>18</td>
<td>8</td>
<td>15</td>
</tr>
<tr>
<td>Combined Staff Meetings (44)</td>
<td>3</td>
<td>0</td>
<td>8</td>
<td>9</td>
<td>24</td>
</tr>
</tbody>
</table>

Q 20. Have you collaborated with your MIECHV program to discuss how the joint guidance document could be implemented in your state?

Forty-four states answered this question. Twenty-five states (56.8%) indicated they had begun discussions related to the guidance document. Four states (9.1%) responded that they had not done so yet but have plans to. Fifteen states (34.1%) responded that they have not collaborated with the MIECHV program regarding the joint guidance document.
Q 21. Is your state addressing the developmental needs of infants with the following conditions?

Forty-four states responded to this question. The chart below documents the extent to which the states are addressing the specific conditions.

<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 (44)</td>
<td>13</td>
<td>17</td>
<td>11</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>29.5%</td>
<td>38.6%</td>
<td>25%</td>
<td>6.8%</td>
</tr>
<tr>
<td>Zika Virus (44)</td>
<td>7</td>
<td>15</td>
<td>3</td>
<td>19</td>
</tr>
<tr>
<td></td>
<td>15.9%</td>
<td>34.1%</td>
<td>6.8%</td>
<td>43.2%</td>
</tr>
<tr>
<td>Lead Poisoning (43)</td>
<td>10</td>
<td>19</td>
<td>7</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>23.1%</td>
<td>44.2%</td>
<td>16.3%</td>
<td>16.3%</td>
</tr>
<tr>
<td>Fetal Alcohol Syndrome Disorder (44)</td>
<td>11</td>
<td>21</td>
<td>5</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>25%</td>
<td>47.7%</td>
<td>11.4%</td>
<td>15.9%</td>
</tr>
<tr>
<td>Other Adverse Conditions (30)</td>
<td>7</td>
<td>7</td>
<td>6</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>23.3%</td>
<td>23.3%</td>
<td>20%</td>
<td>33.3%</td>
</tr>
</tbody>
</table>

If you answered other adverse conditions, please identify the conditions:

- Infant Mortality;
- Birth defects initiative;
• New early check conditions (Fragile X, X-linked adrenoleukodystrophy and mucopolysaccharidosis Type I; 
• Maternal depression; 
• Trauma and toxic stress; 
• Hearing deficits; 
• The new agency focusing on addressing issues related to children involved with child welfare; and 
• Looking at CAPTA referrals and our role in serving the children referred.
### Zika Virus

<table>
<thead>
<tr>
<th></th>
<th>Other (19)</th>
<th>Education (10)</th>
<th>Health (18)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Extensive Efforts</td>
<td>11%</td>
<td>10%</td>
<td>22%</td>
</tr>
<tr>
<td>Some Efforts</td>
<td>26%</td>
<td>10%</td>
<td>50%</td>
</tr>
<tr>
<td>Beginning to Address</td>
<td>5%</td>
<td>10%</td>
<td>6%</td>
</tr>
<tr>
<td>Not at this Time</td>
<td>47%</td>
<td>60%</td>
<td>22%</td>
</tr>
</tbody>
</table>

### Lead Poisoning

<table>
<thead>
<tr>
<th></th>
<th>Other (19)</th>
<th>Education (10)</th>
<th>Health (18)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Extensive Efforts</td>
<td>11%</td>
<td>40%</td>
<td>22%</td>
</tr>
<tr>
<td>Some Efforts</td>
<td>42%</td>
<td>20%</td>
<td>50%</td>
</tr>
<tr>
<td>Beginning to Address</td>
<td>5%</td>
<td>10%</td>
<td>28%</td>
</tr>
<tr>
<td>Not at this Time</td>
<td>32%</td>
<td>10%</td>
<td>0%</td>
</tr>
</tbody>
</table>
Q 22. Is your state experiencing shortages in qualified providers?
Forty-four states responded to this question. Forty states (90.9%) responded they were experiencing shortages in qualified providers.
Q 23. Which type of providers are you experiencing shortages in? Check all that apply.

Forty states responded to this question. The top three provider shortages identified were Speech-Language Pathologists (87.5%), Physical Therapists (77.5%) and Occupational Therapists (70%). Eighteen states (45%) identified a shortage of Special Educators.