A Message from the ICC Chair, Jason Stein

Dear Governor Holcomb,

On behalf of the members of the Interagency Coordinating Council on Infants and Toddlers, I am pleased to submit the annual report of the ICC.

The ICC for 2019 is made up of 19 members, many of whom are new to the council, and will meet every 2-3 months next year to advise and counsel the First Steps Director. In particular, the ICC is currently prioritizing our 2019 objectives which consist of, awareness of services, adequate number of providers, funding, community engagement, family commitment and policy review. Ultimately our job is to ensure that First Steps is able to continue to provide quality services to all eligible participants, which will continue to be the filter through which our activities, discussion and guidance will be run.

The FSSA First Steps team has done a great job of insuring the infrastructure for the First Steps system functions as intended, despite budgetary constraints and limited staff. As Chair of the ICC, I am grateful for the commitment, dedication and hard work of the state’s First Steps administrative team.

In this report you will find details of a study as required by House Enrolled Act 1317 directed by FSSA/DDR to review provider reimbursement rates, revenue sources/fund recovery systems, identify new or improved ways to leverage existing funding, estimate service needs based on births with drug exposure and identify service gaps over the next 5 years. Also included in this report are the recommendations that came from this extensive and comprehensive study.

As ICC Chair, I wholly support the recommendations that resulted from the study. In particular, service providers have pointed out for several years that reimbursement rates have only gone down since the program began in 1996 and are currently less than the Medicaid rate for comparable services. The report estimates that provider agencies lose an average of 3% per year to provide First Steps services. From my perspective they do so as a result of their commitment to the program and with hope that the state will find the funding to adequately compensate providers in the near future.

Strain on the system has also been experienced at the System Point of Entry (SPOE) level. Service coordinators have struggled to keep pace with the growing number of referrals they must process. The average caseload has grown significantly while the budget to support the increase has not.

I am honored to be part of a wonderful team of parents, providers, state employees and other stakeholders who represent the early intervention community. As a group, we are committed to insuring the 0-3 year old population in Indiana will receive the services they need to grow and reach their full potential.

What is the ICC?

Indiana’s Interagency Coordinating Council on Infants and Toddlers (ICC) is a Governor appointed body required by Part C of the Individuals with Disabilities Education Act (IDEA) and established under IC 12-12-7-2. The Division of Disability and Rehabilitative Services (DDR), a division of the Family and Social Services Administration (FSSA), is designated as the lead agency. The ICC is charged with advising and assisting DDRS in its responsibility to develop an early intervention system of the highest quality, balancing family-centered services with fiscal responsibility. Comprised of members representing parents of children with special needs, state agency groups, early intervention service providers, legislators, and others, the ICC is committed to holding the vision of First Steps and to keeping abreast of issues, concerns, and trends which may affect the First Steps System.
**What is First Steps?**
Indiana’s First Steps System is a family-centered, locally-based, coordinated system that provides early intervention services to infants and toddlers with disabilities or who are developmentally vulnerable. First Steps brings together professionals from education, health, and social service agencies to provide skilled therapeutic interventions that promote age-appropriate development of infants and toddlers experiencing developmental delays.

**First Steps Services**
- Speech Therapy
- Occupational Therapy
- Physical Therapy
- Developmental Therapy
- Diagnostic Medical Services
- Nursing Services
- Nutrition Services
- Psychological Services
- Service Coordination
- Social Work Services
- Audiological Services
- Vision Services

**State Fiscal Year Funding Summary**
First Steps accesses a variety of funding sources. The ICC is committed to helping DDRS identify and coordinate all available resources from federal, state, local, and private sources, and use all applicable resources to the full extent possible.

As noted in the discussion of the First Steps fiscal analysis on page 3 of this report, it has been recommended that DDRS explore ways to increase the amount recouped from various sources, especially Medicaid.

**Increasing Service Levels**
First Steps received 28,689 referrals during state fiscal year 2018. This is a 16 percent increase from 2015 and about a 25 percent increase from 2012. The total number of children served in 2018 with an individualized family service plan, or IFSP, was 22,074. The data indicates that not only are referrals increasing, but so is the proportion of children who are eligible for early intervention services.

<table>
<thead>
<tr>
<th>Funding Source</th>
<th>Percent of Total Funding</th>
</tr>
</thead>
<tbody>
<tr>
<td>Temporary Assistance for Needy Families (TANF)</td>
<td>41%</td>
</tr>
<tr>
<td>Medicaid</td>
<td>18%</td>
</tr>
<tr>
<td>Federal Part C</td>
<td>16%</td>
</tr>
<tr>
<td>State Part C</td>
<td>10%</td>
</tr>
<tr>
<td>Private Insurance</td>
<td>7%</td>
</tr>
<tr>
<td>Social Services Block Grant (SSBG)</td>
<td>5%</td>
</tr>
<tr>
<td>Family Cost Participation</td>
<td>2%</td>
</tr>
</tbody>
</table>

In 2018, the annual count of children referred to First Steps was **28,689**

The number of children referred to the First Steps System has increased by nearly **4,700** over the past three years.

<table>
<thead>
<tr>
<th>Year</th>
<th>Referrals</th>
<th>Count of Children Served</th>
</tr>
</thead>
<tbody>
<tr>
<td>2015</td>
<td>24,054</td>
<td>19,782</td>
</tr>
<tr>
<td>2016</td>
<td>25,820</td>
<td>22,577</td>
</tr>
<tr>
<td>2017</td>
<td>27,971</td>
<td>23,612</td>
</tr>
<tr>
<td>2018</td>
<td>28,689</td>
<td>24,838</td>
</tr>
</tbody>
</table>

*Annual unduplicated count of children served regardless of IFSP. This includes eligible children who received an IFSP and early intervention services as well as children who were referred to First Steps and received evaluation and assessment services but were not eligible for early intervention services.*
HEA 1317 and the First Steps Fiscal Analysis

During Indiana’s 2018 legislative session, House Bill 1317 was introduced with a requirement that FSSA/DDRS conduct a study of First Steps reimbursement rates. In total, HEA 1317 required:

- A comprehensive rate and time study for First Steps providers and System Point of Entry (SPOE) personnel
- A comprehensive analysis of First Steps revenue sources and fund recovery systems
- The identification of new or improved ways to leverage available funding for early intervention services
- Consultation with other state agencies on the projected number of children who will need early intervention services as a result of drug exposure
- The identification of service gaps statewide and the number of early intervention professionals needed to provide First Steps services over the next five (5) years

A comprehensive fiscal analysis of the First Steps program was conducted in response to HEA 1317 and three reports were developed:

- The First Steps Rate Study Report describes the First Steps rate and time study and provides recommendations for DDRS around First Steps reimbursement rates
- The Revenue Recommendations Report looks at ways that DDRS can improve utilization of available funding sources for First Steps services
- The Program Growth and Workforce Needs Report addresses projected program growth, service gaps, and anticipated personnel needs over the next several years

FSSA hired Public Consulting Group, Inc. (PCG) to complete the rate study and revenue source analysis. The report on program growth and service gaps was compiled independently by FSSA/DDRS. All three reports developed on the fiscal analysis can be viewed at https://www.in.gov/fssa/ddrs/2812.htm.

Key Takeaways from the Fiscal Analysis

The ICC has identified several key findings and recommendations from the fiscal analysis to highlight in this report:

◆ The number of children served by First Steps continues to increase. This includes children who have been exposed pre- or postnatally to drugs, alcohol, or other toxic substances and are eligible for First Steps on the diagnosis of exposure alone. As an entitlement program, First Steps does not have a wait list for services, and the program must provide services to any eligible child.

◆ Only 18 percent of First Steps revenue comes from Medicaid despite the fact that more than 50 percent of children served by First Steps are enrolled in Medicaid. The Revenue Recommendations Report includes strategies for increasing recouptment. The ICC believes these strategies may be viable and offers its support as DDRS seeks to improve First Steps fund recovery.

◆ First Steps currently uses 867 billable rates for services. An analysis of CPT codes collected for the rate study indicates that many of First Steps rates are lower than what Medicaid reimburses for the same service.

◆ As the Rate Study Report recommends, First Steps rates should align with market salaries and capture all the expenses involved in service delivery, including mileage for home visits. The ICC supports the recommendation to increase reimbursement rates.

◆ As indicated in the Program Growth and Workforce Needs report, First Steps has a shortage of dietitians, interpreters, social workers, and psychologists. Prenatal exposure to alcohol, tobacco, and illicit drugs such as opioids can cause a wide range of physical, emotional, and developmental problems for young children. The ICC agrees that it is critical for First Steps to have the personnel necessary to respond to a wide range of needs as the demographics of those served by First Steps evolve over time.

The above list represents key takeaways and is not inclusive of all of the findings and recommendations from the First Steps fiscal analysis. The ICC is committed to its statutory charge to advise and assist DDRS as it considers and implements, where appropriate, the recommendations.
Future Demands

DDRS worked with the Indiana State Department of Health and FSSA's Division of Mental Health and Addiction through the Indiana Perinatal Quality Improvement Collaborative (IPQIC) and its Perinatal Substance Use (PSU) task force to identify the number of drug-exposed births that will result in an increased need for First Steps services.

- Service coordination and evaluation and assessment are entitlement services that must be provided at no cost to every family who is referred to First Steps
- First Steps Service Coordinators in Indiana already have an average caseload size of 73 families far exceeding the maximum effectiveness caseload size of 50 families. Anticipated program growth due to the opioid epidemic will further strain Service Coordinators
- Service Coordinators report a need of an additional 145 professionals will be needed to provide intake and service coordination services
- Based on the number of live births in 2017 with exposure to toxic substances (meets First Steps eligibility requirement) 5,800 additional children will have access to First Steps, which would be a 28% increase to the number of children currently served

What is the Risk?

In the first three years of a child’s life, more than one million new neural connections form every second. These early years are a time of great opportunity and great vulnerability. A child’s early experiences shape the brain’s architecture to either support a strong or fragile foundation for all future learning, health, and success in the workplace. (Getting ready for school starts at birth; State of Indiana’s infants and toddlers, 2016)

Services to young children who have or are at risk for developmental delays have been shown to positively impact outcomes across developmental domains, including health, language and communication, cognitive development and social/emotional development. Families benefit from early intervention by being able to better meet their children’s special needs from an early age and throughout their lives. Benefits to society include reducing economic burden through a decreased need for special education. (Goode et al, 2011) The ICC is committed to supporting and providing stakeholder input to DDRS/FSSA in its efforts to ensure that these crucial services continue to be accessible to Indiana’s youngest residents.

Key Findings

1. “Well-designed early childhood interventions have been found to generate a return to society up to $17.07 for each dollar spent on the program.”

2. “Early childhood intervention programs have been shown to yield benefits in academic achievement, behavior, educational progression and attainment, delinquency and crime, and labor market success, among other domains.”

References

