

## **NYS Early Intervention Program SSIP Phase III: Implementation**

### **Summary of the SSIP**

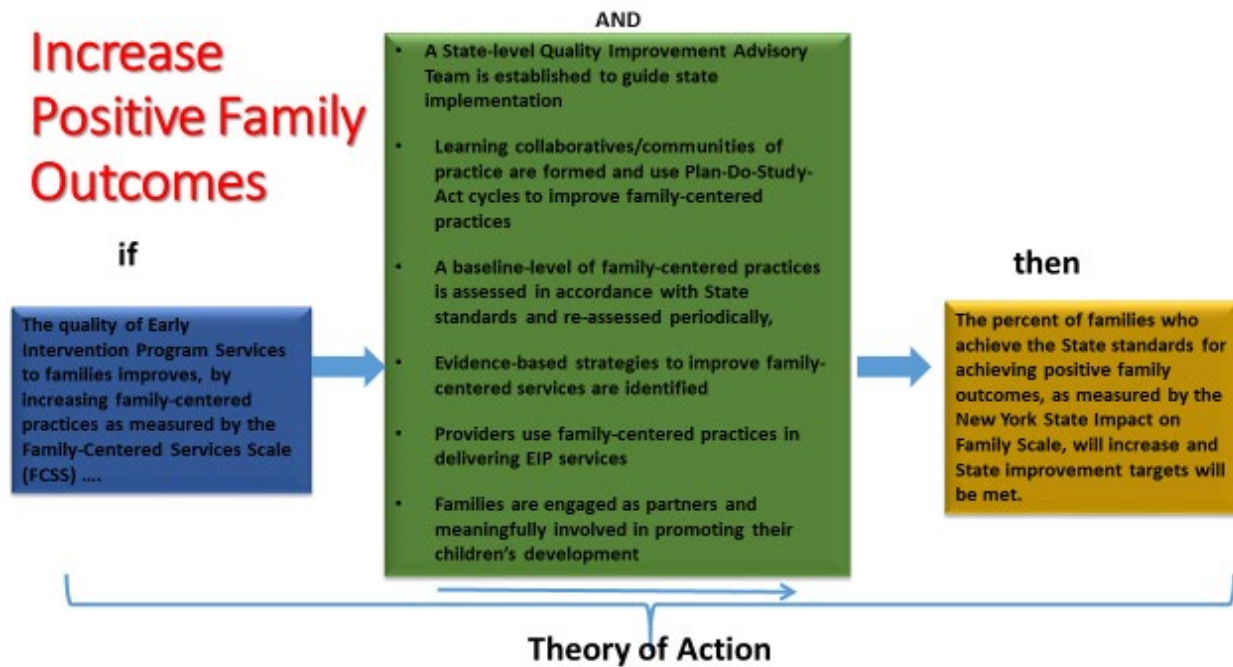
The New York State Department of Health (Department), which serves as the lead agency for the New York State Early Intervention Program (NYSEIP) has identified family outcomes as the area of improvement that will be the focus of the State Systemic Improvement Plan (SSIP). The State-identified Measurable Result (SiMR) is to increase the percentage of families exiting the NYSEIP who report that NYSEIP helped them achieve the level of positive family outcomes defined in conjunction with stakeholders as representing the State standard. The State standard is the percent of families who have a score  $\geq 576$  on the New York Impact on Family Scale (NYIFS). Families with a score at or above the standard have a very high likelihood of agreement with all the NYIFS items having a location on the scale that is lower than, or equal to, the location of the item, “Early intervention services have helped my family use services to address my child’s health needs.”

The State standard encompasses all three Indicator 4 family outcomes (percent of families participating in Part C who report that early intervention services have helped the family know their rights; percent of families participating in Part C who report early intervention services have helped the family effectively communicate their children’s needs; and, percent of families participating in Part C who report that early intervention services have helped their child develop and learn). Therefore, families who meet the State standard will have achieved all three Indicator 4 family outcomes. The State’s Early Intervention Coordinating Council (EICC) unanimously supported the selection of family outcomes for the focus of the SSIP and the use of the State standard for the NYIFS as the SiMR.

Based on extensive data analysis, reported as part of Phase I and submitted on April 1, 2015, the Theory of Action (below) was developed. The State will improve family outcomes by improving the quality of the Early Intervention Program by ensuring the program and the services provided are family-centered. If the quality of Early Intervention Program services delivered to families improves, by making sure they are more family-centered as measured by the national Family-Centered Services Scale (FCSS), then the percentage of families who achieve the State standard for positive family outcomes, as measured by the NYIFS will increase, and SIMR targets will be met. The NYS Family Survey has recently undergone revisions based on stakeholder feedback. The version that has been used up to this point is attached as Appendix 1 and the revised version is attached as Appendix 2.

The Department will use the NYIFS, which is being collected annually by surveying a sample of families as they exit the NYSEIP, to evaluate progress toward the SiMR. The FCSS, which is part of the same survey that is used to collect the NYIFS, will be used to evaluate the Theory of Action and progress toward the goal of improving positive family outcomes. The Theory of Action is shown in Figure 1.

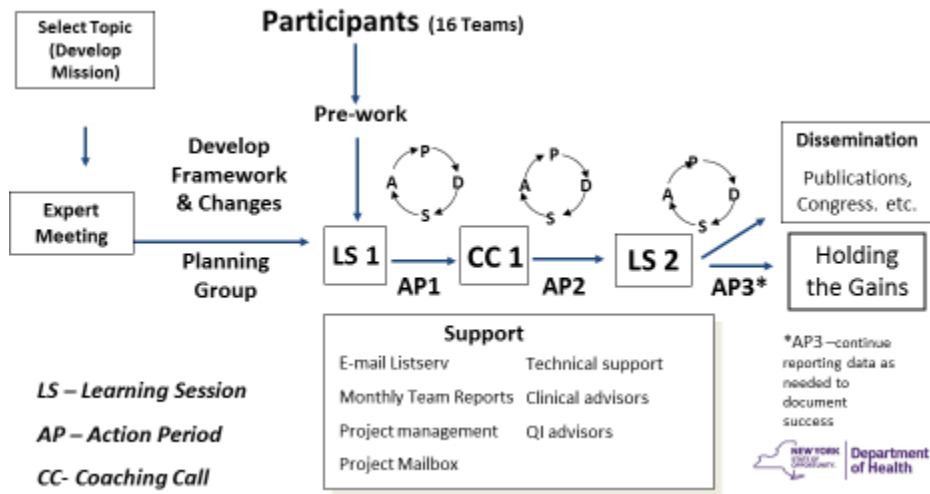
Figure 1. Theory of Action



The Department has selected a well-tested and proven improvement strategy to work with NYSEIP local programs and service providers to increase the percent of families receiving family-centered services: the breakthrough series approach developed by the Institute for Healthcare Improvement (IHI) ([www.ihl.org](http://www.ihl.org)). IHI uses the science of improvement to assist health care organizations in making “breakthrough improvements” in the quality and value of health care services. Improvement science is an applied, multidisciplinary approach that emphasizes innovation, rapid-cycle testing in the field, and the concept of “spread” to generate learning about what changes, in what settings and contexts, to yield improvement in the quality of service delivery (<http://www.ihl.org/about/Pages/ScienceofImprovement.aspx>). The science of improvement draws on clinical science, systems theory, statistics, and other fields in its approach to working with health care organizations to improve the quality of care.

The “breakthrough series” is an evidence-based approach to working with organizations and professionals to achieve improvements in the quality of service delivery through “Learning Collaboratives.” A Learning Collaborative is a systematic, time-limited approach to quality improvement in which multiple organizations come together with faculty to learn about and create improved processes in a specific topic area. The expectation is that the teams share expertise and data with each other; thus, “everyone learns, everyone teaches.” Teams engaged in healthcare “Learning Collaboratives” have achieved dramatic results, including reducing waiting times by 50% percent, reducing worker absenteeism by 25%, reducing intensive care unit costs by 25%, and reducing hospitalizations for patients with congestive heart failure by 50%. (See *The Breakthrough Series: IHI’s Collaborative Model for Achieving Breakthrough Improvement*. IHI Innovation Series white paper. Boston: Institute for Healthcare Improvement; 2003; available on [www.IHI.org](http://www.IHI.org)). Figure 2 shows a depiction of the Breakthrough Series framework.

Figure 2. Breakthrough Series Framework



### Overview of the Plan

As previously stated in the Theory of Action, there are three main SSIP steps that the Department will complete to achieve the goal of improving family-centered services. They are as follows:

1. Establish a State-level Quality Improvement Advisory Team to guide the state implementation
2. A baseline-level of family-centered practice is assessed in accordance with State standards and re-assessed periodically
3. Centers of Excellence Implement the SSIP
  - A. Evidence-based strategies to improve family-centered services are identified
  - B. Learning collaboratives/communities of practice are formed and use Plan-Do-Study-Act cycles to improve family-centered practices
  - C. Providers use family-centered practices in delivering NYEIP services

### Progress Implementing the SSIP

#### 1. Establish Advisory Group

The Department has made significant progress in implementing the SSIP in the past year. The Department has established the SSIP Advisory Group. The SSIP Advisory Group includes Department staff, representatives of the EICC and Early Childhood Advisory Council (ECAC), parent representatives, state agency partners, NYSEIP local program staff (Early Intervention Official (EIO) or Early Intervention Manager (EIM)) and service provider representatives. The SSIP Advisory Group is responsible for advising and assisting the Department in all aspects of implementation of the SSIP Family-Centered Practices Learning Collaboratives. The members have been informed of Department proposed plans for SSIP implementation through webinars and other communications. Six webinars with the SSIP Advisory Group team have been

convened. Additional webinars will take place in the coming year and feedback from the Advisory Group will continue to be integrated back into the SSIP.

The list of members of the SSIP Advisory Group is below:

- Steven Anderson – EIP Provider
- Linda Beers – Essex County EIO
- Evelyn Blanck – EIP Provider, ECAC Member
- Marie Casalino – NYC EIM/EIO, EICC Member
- Lisa Chester – Niagara County EIO, EICC Member
- Sherry Cleary – EIP Provider, ECAC Member
- Amy DeVito – Parent, EICC Member
- Judy Gerson – EIP Provider, EICC Member
- Steven Held – EIP Provider, EICC Member
- Bradon Josephson – EIP Provider
- Talina Jones – Parent, EICC Member
- Paola Jordan – Parent, EICC Member

The Advisory Group aided the Department in creating brochures for the recruitment of participants in the Learning Collaboratives. The brochures were discussed on four webinars with the Advisory group and Department staff. Based on their feedback, the brochures were individualized for the four different types of participants (i.e., a parent brochure, a provider brochure, a service coordinator brochure, and a EIO/EIM/EIOD brochure). The Group provided the language for the materials and provided feedback on the design of the brochures.

Along with recruitment, it was decided that parents and providers who wished to participate in the Learning Collaborative would be asked to complete applications. The Advisory Group provided feedback on the questions that should be included and the formatting of the applications. Parents and providers completed the application prior to the in-person, kick-off meeting. For a few individuals, the application was completed at the in-person meeting. Completing the application was important for two reasons: 1) to collect information about parents and providers, including experience with the Early Intervention Program and professional and personal background information to help us engage and support them, and 2) so they understood the expectations and formally agreed to participate for the longevity of the project to the best of their abilities.

The Advisory Group also discussed that the State Systemic Improvement Plan was not a family friendly name and was not specific to the state's project. After multiple brainstorming sessions and discussions with other staff and experts, the Advisory Group agreed to the name, Improving Family Centeredness Together (IFaCT).

## *2. Establish Baseline-Level and Measures*

The State-identified Measurable Result (SiMR) is to increase the percentage of families exiting the NYSEIP who report that NYSEIP helped them achieve the level of positive family outcomes defined in conjunction with stakeholders as representing the State standard. The State standard is the percent of families who have a score  $\geq 576$  on the NYIFS. The baseline was established in 2008-2009 and 2013-2014 at 65.09% of families who responded to the NYS Family Survey who

met the state standard of  $\geq 576$ . In FFY 2014-2015 it dropped to 57.04% with a much lower response rate, then increased to 61.63% in FFY 2015-2016. In FFY 2016-2017, there was an 8.49% increase in the percent of families who met the state standard (70.12%), as well as almost 400 more responses from the previous year. The Department believes that the increase is attributed to the SSIP increasing awareness of the importance of the survey for families, as well as translating the survey into five additional languages. Further information regarding the data and changes being made can be found in the Data Stakeholder involvement and Data Quality Issues sections.

### *3. Centers of Excellence Implement the SSIP*

The Department has executed contracts that comply with federal requirements for the oversight and administration of the SSIP. Three Universities of Excellence in Developmental Disabilities (UCEDDs) were chosen based on their experience and work in the field of children with disabilities, as well as their locations in the state. All three UCEDDs have Leadership Education in Neurodevelopmental and related Disabilities (LEND) programs. Each UCEDD has designated staff to work with counties and stakeholders to improve family outcomes. They have coordinated the first in-person meetings and monthly calls, are tracking PDSA data, and continually provide reports to the Department on their progress. The UCEDD staff are helping coach and train professionals to improve the quality and family-centeredness of early intervention services. Below is a description of each of the UCEDDs.

The Rose F. Kennedy University Center for Excellence in Developmental Disabilities is located in the Bronx, New York. The RFK UCEDD opened in 1956 as a Children's Evaluation & Rehabilitation Center (CERC) providing interdisciplinary services for children with Cerebral Palsy in the Department of Rehabilitation and Pediatrics. In the 1960's they received federal funding to support an Intellectual and Developmental Disabilities Research Center (IDDRC) and created an Early Childhood Center to work with families of children under 5 years of age. The RFK UCEDD LEND Program serves over 1,000 professionals a year who receive long-term, intermediate-term, and short-term training. More than 35% of their trainees are from underrepresented groups, reflecting their commitment to building a workplace which reflects the population they serve. The Early Intervention Program (EIP) at CERC began in 1993 and has a 17-year history as an evaluation site and for service provision. The majority of the UCEDD's patients are local Bronx residents who live in the poorest Urban county in the United States, however they also have families who travel nationally and internationally for their Autism Diagnostic Evaluations and treatment recommendations. Approximately 6,000 children and adults are seen annually with 40,000 units of service.

The RFK UCEDD SSIP team includes the Director Ted Kastner, MD; the UCEDD Co-Director Karen Bonuck, PhD; the UCEDD Associate Director Joanna Siegel, LCSW; Director and Associate Director for Infant Toddler Team/Relate and NYS ACT Early Ambassador Lisa Shulman, MD, and Deborah Meringolo, MA, MS; UCEDD Dissemination Coordinator Natalie Adler, PhD; and Research Project Manager Shaina Brady. The RFK UCEDD working supporting the five boroughs of New York City (NYC), which are Bronx, Queens, Richmond, New York, and Kings, and the two counties of Long Island (Suffolk and Nassau).

The Westchester Institute for Human Developmental (WIHD) is located in Valhalla, NY. WIHD was established originally in 1961 as a clinic for children with disabilities and interdisciplinary training for graduate students in NYC. In 1970 they relocated to their current site in Valhalla (Westchester) and in 2005 became an independent non-profit, but still maintained their affiliation with New York Medical College. In 2010 WIHD received national recognition by the Association of University Centers on Disabilities (AUCD) for its work promoting family and self-advocate partnerships in all its activities. The WIHD LEND program is a two-semester interdisciplinary leadership training program with a strong curriculum focus on cultural competence, family partnerships, life course perspective, interdisciplinary and evidence-based practice.

The WIHD UCEDD SSIP team includes the Co-UCEDD Director Karen Edwards, MD, MPH; Director of Research Patricia Patrick, DrPH; Community Training Coordinator Jenna Lequia, PhD; and UCEDD Project and Evaluation Coordinator Katie Borrás, MS. WIHD is supporting 28 counties from Downstate, the Capital Region, and Upstate counties, which are Albany, Broome, Chenango, Clinton, Columbia, Delaware, Dutchess, Essex, Franklin, Fulton, Greene, Hamilton, Herkimer, Madison, Montgomery, Orange, Otsego, Putnam, Rensselaer, Rockland, Saratoga, Schenectady, Schoharie, Sullivan, Ulster, Warren, Washington, and Westchester.

The Strong Center for Developmental Disabilities (SCDD) at the University of Rochester Medical Center is located in Rochester, NY. SCDD began in the 1960s as a Community Diagnostic Clinic in the Department of Pediatrics in the University of Rochester School of Medicine and Dentistry. In 1978 University of Rochester program became a satellite UCEDD, until 1981 when they became a fully recognized UCEDD. Similar to the other two UCEDDs, SCDD also has a LEND program focused on collaborative interdisciplinary training focused on improving the health of children with neurodevelopmental disabilities and special healthcare needs. SCDD offers multiple programs like Health Disparities which focuses on reducing disparities in care for people with intellectual and developmental disabilities; Child Well-Being provides services to families and organizations serving youth with disabilities placed in foster care; Community Consultation Program provides evidenced-based technical assistance and training to school teams and agencies working with individuals with disabilities or behavioral challenges; and the Rochester Regional Center for Autism Spectrum Disorder delivers various autism spectrum disorder-related informational resources, programs, and services to families and professionals throughout NYS.

The Rochester UCEDD team includes the Associate Professor of Clinical Pediatrics for the Department of Pediatrics, Developmental and Behavioral Pediatrics Kelley Yost, PhD; The Associate Professor of Pediatrics and Education, and UCEDD Director Susan Hetherington, PhD; and the UCEDD Coordinator Valerie Smith, MS. The Rochester UCEDD is supporting the Central and Western Region of New York, which are Allegany, Cattaraugus, Cayuga, Chautauqua, Chemung, Cortland, Erie, Genesee, Jefferson, Lewis, Livingston, Monroe, Niagara, Oneida, Onondaga, Ontario, Orleans, Oswego, Schuyler, Seneca, St. Lawrence, Steuben, Tioga, Tompkins, Wayne, Wyoming, and Yates.

### *3.A Evidenced-based Strategies are Identified*

As described in the SSIP, New York State has implemented the evidence-based strategy for quality improvement statewide in January and February of 2018. The New York State Early Intervention Program is using the IHI Breakthrough Series, which is an evidence-based framework to effect and sustain positive systems change. Within the IHI framework, evidence-based strategies have been identified and implemented with the Learning Collaborative teams at the local level. The following evidence-based strategies have been identified and integrated into the in-person meetings, which were held in January and February 2018 and included parents, municipal officials, and early intervention professionals:

- Family-Centeredness
  - Division of Early Childhood of the Council of Exceptional Children Recommended Practices on Family Engagement  
<https://divisionearlychildhood.egnyte.com/dl/tgv6GUXhVo>
  - Early Childhood Technical Assistance Center (2017)  
Checklist for practitioners to assess for family-centered practices.  
[http://ectacenter.org/~pdfs/decrp/FAM-1\\_Fam-Ctrd\\_Practices\\_2017.pdf](http://ectacenter.org/~pdfs/decrp/FAM-1_Fam-Ctrd_Practices_2017.pdf)
  - Puckett Institute (2015)  
Family-centered practices from an integrative approach that references research.  
[http://www.puckett.org/presentations/Incorp\\_Family-Centered-App\\_RP\\_youngautism\\_FINAL.pdf](http://www.puckett.org/presentations/Incorp_Family-Centered-App_RP_youngautism_FINAL.pdf)

The RFK UCEDD has developed the content for the webpage that will be integrated into the Department's website in Spring 2018. The first section of the webpage includes an introduction to the SSIP, what the SSIP is, who is involved, and information regarding the IHI and PDSA methodology. The website incorporates information on the UCEDDs including their histories, staff and contact information. The Department's public webpage will include the compendium of resources that SCDD has developed as well. The webpage is scheduled to be completed in Spring 2018 and will serve as a sustainable resource even after the SSIP ends.

WIHD has developed the evaluation plan that is being used by all three UCEDDs to create uniformity in the data collected and tracking. The report discusses the evaluation methodologies, the tools to collect the data, data from family surveys, learning sessions, monthly calls, IFSP reviews, technical assistance to teams, and stakeholder interviews. The end of the report discusses conclusions drawn from the data and the next steps that will take place. This report will be updated quarterly. WIHD has also developed tools for all three UCEDDs to use to collect feedback from the learning collaboratives, data from record reviews, and forms for counties to use to submit their data. (Appendix 3)

SCDD has created a draft of a compendium of resources for parents and providers. This resource guide provides information regarding common questions and concerns families may have, organizations in the community, and links to different sites with additional information. It also contains information for providers including programs and additional resources. The compendium includes evidence-based practices and best practices for family-centered services.

Attached is a copy of a draft of the resources (Appendix 4). This compendium will be posted on the SSIP webpage on the Department of Health's public website in Spring 2018.

### *3.B Learning Collaboratives*

As described in Phase III, the Family-Centered Practices Learning Collaboratives using the IHI Breakthrough series model has been implemented in three regions of the state. The first cohort in each region started in January and February 2018. By the end of the SSIP, each region will have two cohorts, made up of teams with three to seven participants per team, to ensure statewide involvement. For the first cohort, WIHD and SCDD both had 14 teams for each county involved, while NYC had eight teams, which cross over the five boroughs. Each cohort has begun to work together for a 12-month period. Recruitment began in the Fall of 2017, with the three in-person Learning Sessions completed January 18, 2018 in NYC, January 22, 2018 in Kingston, NY and February 2, 2018 in Fayetteville, NY. The first cohort will continue to work together until early January-February 2019. Coaching calls and ongoing technical assistance with the UCEDDs began in February and March 2018. Teams will participate in monthly calls and webinars with their team and other teams in their region. The coaching calls are facilitated by the regional UCEDD. Participant feedback about each call has been and is being collected and used to improve the support of the cohort

The second cohort recruitment has gradually begun, but will be a focus in the Spring and Summer of 2018, prior to having the second set of three learning collaboratives in October 2018. The recruitment materials have been finalized and were distributed to the counties and UCEDDs. (Appendix 5) The brochures will be updated for the second cohort based on stakeholder feedback and infrastructure changes.

#### *3.B.1 Recruitment*

The recruitment process was labor intensive and involved a great amount of coordination between Department staff, UCEDD staff, and County staff. The teams were made up of at least one Early Intervention Official (EIO), Early Intervention Manager (EIM), or Early Intervention Official Designee (EIOD), one or more parents of a child who is or had received early intervention services in the last 24 months, and at least one service coordinator and/or provider of early intervention services. The Department facilitated three webinars for each of the UCEDDs to introduce their staff to the county staff involved in the first cohort. To promote the initiative throughout the counties, on April 6, 2017 the Department presented at the New York State Association of County Health Officials (NYSACHO) general membership meeting and on September 13, 2017 at the New York State Association of Counties (NYSAC) county conference. Department staff attended five Local Early Intervention Coordinating Council (LEICC) meetings: a joint LEICC of nine counties in Central/Western NYS on April 28, 2017, EIP West Wyoming County Health Department on June 9, 2017, NYC Department of Health and Mental Hygiene on July 14, 2017, Rensselaer County Health Department on September 22, 2017 and Rockland County Health Department on December 12, 2017.

The Department Staff also presented to the Leadership Education in Neurodevelopmental and related Disabilities (LEND) program at Westchester on April 20, 2017. LEND is an



interdisciplinary leadership training program, funded by the Maternal and Child Health Bureau of the federal government at 52 sites around the country. LEND trainees include graduate students and post-doctoral fellows; self-advocates; and family members of children and adults with disabilities.

To generate additional interest from parents, Department staff also presented at a Family Initiatives Coordination Services Project meeting on November 17, 2017 and worked with organizations like Parent to Parent and Early Childhood Direction Centers (ECDCs) to share the project initiative. The New York City Early Intervention Program used a text messaging system to reach out to parents and family members of children in the EIP to inform them of the program and gain interest.

To aid in the recruitment of providers, the Bureau of Early Intervention Provider Approval Unit utilized email listservs and provider connections to disseminate information about the SSIP and encourage participation. The Bureau has linked participation by providers at the in-person SSIP meeting and the monthly calls to the required professional development hours required in the Department's Provider Agreement.

For more than 10 weeks, the UCEDDs followed up weekly with the county point person to check on recruitment status for all team members. For counties requiring additional support, the frequency of emails and phone calls was increased by both the UCEDD and Department staff. By the end of January 2018, all counties involved in the first cohort (36 teams total) had successfully recruited at least one parent, provider, and county staff for each team.

### *3.B.2 In-Person Session*

Each UCEDD has held their first in-person Learning Session for the first cohort teams. The Rose F. Kennedy University Center for Excellence in Developmental Disabilities at Albert Einstein College of Medicine (RFK) first in-person session was held on January 18, 2018 at the College. Their first collaborative included eight teams composed of members from across the five boroughs. New York City's Learning Collaborative is based around the agencies working in NYC and not counties. There are eight agencies participating. While the other regions each have 14 teams, eight team have the same number of total members. The expectation was modified based on the size of agency in terms of staffing and the population of young children served by the agencies. Attendance included seven parents, 25 providers, three service coordinators, and nine county staff.

The Westchester Institute of Human Development first in-person session was held on January 22, 2018 at the Best Western in Kingston, New York. Their first collaborative included teams from each of the following counties: Broome, Chenango, Columbia, Delaware, Dutchess, Greene, Madison, Orange, Otsego, Putnam, Rockland, Sullivan, Ulster, and Westchester. Attendance included 12 parents, 17 providers, 13 service coordinators, and 18 county staff.

The University of Rochester Medical Center first in person session was held on February 2, 2018 at the Craftsman Inn & Conference Center in Fayetteville, New York. Their first collaborative included teams from each of the following counties: Cayuga, Chemung, Cortland, Jefferson,

Lewis, Oneida, Onondaga, Oswego, Schuylers, Seneca, St. Lawrence, Tioga, Tompkins and Yates. While Jefferson and Tioga were part of the first cohort, due to winter weather conditions, they were not able to participate in the in-person Learning Session. However, UCEDD and Department staff have worked with the groups directly to orient them and support the initiation of their quality improvement plans. Attendance included 10 parents, 12 providers, nine service coordinators, and 14 county staff.

To encourage consistency throughout the state, each in-person learning session by the three UCEDDs followed the same agenda and format (see Table 1). The learning session began at 9:45am with registration followed by a welcome and introduction. Department staff provided an overview of the SSIP and explained the IHI Quality Improvement Model. At each Learning Session a parent of a child with developmental disabilities, who received Early Intervention services, presented on their family perspective of the EIP and challenges. Each speaker was powerful, moving, and was well received.

Table 1. Agenda for SSIP In-Person Learning Session

<b>Time</b>	<b>Activity</b>	<b>Presenter</b>
9:45-10:00 am	Registration	UCEDD staff
10:00-10:20 am	Welcome and Introductions	Marie Ostoyich
10:20-11:00 am	Improving Family Centeredness Together (IFaCT): Overview Institute for Healthcare Improvement Quality Improvement Model Overview	Kirsten Siegenthaler UCEDD Staff
11:00-11:15 am	Parent Perspective	Parent Speaker
11:15-12:00 pm	Group Activity 1: Systems Mapping	Facilitated
12:00-1:00 pm	Lunch	
1:00-1:15 pm	Group Activity 2: What will we do? (AIM Statement)	Facilitated
1:15-1:45 pm	Group Activity 3: How will we do it? (Plan, Do, Study, Act -PDSA)	Facilitated
1:45-2:00 pm	How will we measure it?	UCEDD staff
2:00-2:15 pm	Break	

2:15-2:45 pm	County Team Sharing: Report Out	Facilitated
2:45-3:00 pm	Evaluation & Next Steps	UCEDD staff

Once the participants had the background information of the project, they worked in their groups on Systems Mapping from the parent role. Systems mapping is part of the Title V Maternal and Child Health Services Block Grant (MCHSBG) strategy to help gather information regarding the impacts on families, the environment surrounding them, and provide a visual understanding of the early intervention influences. Each team completed a system map from the parent member’s perspective since the family perspective is the focus of New York’s SSIP. The information gathered from the systems mapping exercise helped teams formulate their local quality improvement project, and is also being used by the Department of Health to inform the work of the Title V Bloch grant and the Children with Special Healthcare Needs Program.

In the next group activity, the county teams worked together to formulate their team’s AIM statement. The AIM statement is a goal that is specific to what the team wants to achieve, can be measured, is attainable, relevant to family outcomes, and is timely. The teams reviewed and selected evidence-based strategies that support the expected high-quality services included in the FCSS scale (see Table 2). The FCSS collects feedback from families about the ways in which early intervention services was delivered to ensure they were family-centered. The items are listed in Table 2, and sorted by the likelihood families agree that early intervention services were family-centered (i.e., the items at the top are the ones families are least likely to agree to).

The family-centered practices on the FCSS include connecting parents of children with similar needs and helping families take part in typical activities for children and families in their community. Once the team completed their AIM statement and established the goal of what they want to achieve, they then moved on to create their Plan, Do, Study, Act (PDSA). Each team used the PDSA methodology to decide what small change would be made to improve family outcomes, how it would be done, study the impact the change has made, and then act on it. If the change improved family outcomes the team would increase its use, and if the change does not help the team would reevaluate and adjust accordingly. The teams then finalized how they would measure and track their modifications.

Table 2. FCSS Items

Family-centered Services Scale Items
Someone from the Early Intervention Program went out into the community with me and my child to help get us involved in community activities and services.
My family was given information about ways of connecting with other families for information and mutual support.
Someone from the Early Intervention Program asked whether other children in the family needed help in understanding the needs of the brother or sister with a disability.
My family was given information about community programs that are open to all children.
My family was given information about where to go for help or support if I feel worried or stressed.
My family was given information about opportunities for my child to play with other children.
Someone from the Early Intervention Program asked if I was having any problems getting the services I needed.
My family was given information about how to advocate for my child and my family.
My family was given information about the public school system's programs and services for children age three and older.
My family was given information about what my options are if I disagree with a decision about my child's services.
Someone from the Early Intervention Program asked if the services my family received met our needs.
I was given help in preparing for the IFSP meeting.
The IFSP kept up with my family's changing needs.
My family was given information about activities that I could do with my child in our everyday lives.
My child transitioned from early intervention (birth to 3 program) to preschool special education without a break in services.
My family was given information about the rights of parents regarding early intervention services.
I was given information to help me prepare for my child's transition.
My child received all the supports for transition listed in our IFSP.
I was offered the chance to meet with people from the Early Intervention Program and the committee on preschool special education to plan for my child's transition to preschool special education.
I knew who to call if I had problems with the services and supports my child and family are receiving.
Written information I received was written in an understandable way.
My family's daily routines were considered when planning for my child's services.
I felt part of the team when meeting to discuss my child.

At the end of the meeting teams shared their AIM statements and what they planned to do to improve family outcomes.

Since the in-person Learning Sessions, the counties have been implementing the small change that their team has chosen. The UCEDDs have begun and are holding monthly calls with all teams in their first cohort to discuss details of their plan, accomplishments, and barriers they've encountered during implementation. The teams follow the PDSA cycle which includes implementing family-centered practices with a few of the families they serve in a short period of time. After reviewing data, the teams determine whether they should abandon (i.e., it did not work at all or had negative outcomes), adapt (i.e., it worked but needs to be tweaked), or adopt (i.e., implement with more families or across different settings). These cycles are continuing for a twelve-month period with coaching and mentorship from the UCEDD and peer support from other teams in the region.

### *3.B.3 PDSA Begins with Support on Monthly Coaching Webinars*

The teams have begun collecting data on their progress and are completing a data tracking tool (example attached as Appendix 6) which is being used to populate a run chart (example attached as Appendix 7). Once data have been collected, it is provided back to the teams and the families on the teams. The teams are making decisions every month about what to adapt, adopt or

abandon, if necessary. Teams have begun reporting out to other teams during their regional cohort monthly Coaching Calls/Webinars. A PDSA worksheet, is completed monthly by local teams, is attached (Appendix 8).

For the monthly coaching calls, WIHD is facilitating calls with all 14 teams, with selected counties on each call presenting their AIM statement, their PDSA, progress made, and data collected. RFK and SCDD are facilitating calls in smaller groups, with only one or two teams on the call, and then merging all the teams and information together on one call.

As previously stated, the Department is working with the RFK UCEDD to create a webpage on the current Department's website that focuses solely on the SSIP. The webpage, which is in the Department's approval process, will provide the public with an overview of the SSIP, provide contact information for any parents or providers who are interested in participating in the quality improvement initiative, resources for families, and best practices for providers and counties. The Department is working with the staff from the University of Rochester to finalize a compendium, or list of resources for families and providers. The compendium has been drafted and includes links to websites and additional information that can help both families and providers.

### *In-Person Learning Session Feedback*

All three in-person sessions received an enormous amount of positive feedback from participants and provided a great starting point for the next 12 months of work. All participants at the end of the first Learning Sessions were requested to complete a survey on their experience. Questions measured the quality, usefulness, and relatability of each of the sections of the meeting outlined in the agenda above. Participants were also asked questions regarding the presenters' organization, knowledge, and understandability. Lastly, the participants were asked whether their understanding increased in regard to the IFaCT, PDSA, family-centered practices, and their overall satisfaction with the meeting. All categories were rated on a scale of Strongly Disagree (1), Disagree (2), Neither Agree nor Disagree (3), Agree (4), and Strongly Agree (5). All three UCEDDs, in every question provided, scored higher than 4 (Agree). The participants were also given a section to provide written comments regarding their favorite part of the day, what could be improved, and any additional comments they would like to share.

Some of the feedback from the people who participated in the first in-person session is summarized below by UCEDD; the NYS Early Intervention Program and the UCEDDs continue to analyze the feedback:

- Rose F Kennedy held the first meeting. Respondents provided suggestion for improving the session, and this feedback was used to improve the subsequent meetings:
  - More opportunities to ask questions or clarifications
  - More than one session over multiple days because of the amount of information and goal to produce quality improvement plans
  - More examples, clarity about who will do what
  - More parents (note: for the second cohort, we will discuss having more than one parent per team, see feedback from the third meeting below)

- Westchester Institute for Human Development held the second meeting. Overall, participants were satisfied with the learning session (90.0%), thought it was high quality (83.6%), and felt information was presented clearly (90.3%). Most participants (88.3%) responded with “Strongly Agree” or “Agree” in ratings for the overall learning session, presenters, learning session objectives, and overall satisfaction. The average rating across items was 4.32; 4.25 for the overall learning session, 4.51 for the presenters, 4.35 for the learning objectives, and 4.34 for overall satisfaction (1 = Strongly Disagree and 5 = Strongly Agree). This provides additional evidence that the learning session was effective and useful for IFaCT teams. Improvements were realized from the first meeting.
- University of Rochester held the third meeting. The participants liked the following the most: activity sessions, hearing the parent perspective & ideas from others, networking, location, interactions with parents & providers from other counties, the facilitators who truly have an understanding of EIP, real stories that show how the PDSA works, reminder of importance of family involvement in EI, and the opportunity to talk about needs within our county. One parent wanted involvement from more parents to increase the extent and diversity of the parent perspective, which was similarly expressed in the first meeting and will be taken into consideration for the next cohort.

This feedback is continuing to be analyzed by the NYS Early Intervention Program and the UCEDDs and will inform planning for the second cohort learning sessions.

### *3.C. Providers use Family-Centered Practices in Delivering EIP-Services*

The goal of the SSIP is for providers across the State to use family-centered practices in delivering EIP services. Based on the PDSAs that were created at the first in-person Learning Sessions, providers have begun to implement small changes into their everyday activities for select families. If the change has been demonstrated as successful based on data collected and reviewed on the monthly coaching calls, the team implements the change with more families and continues to collect data. Successes and challenges have been and are being shared on monthly coaching to calls with the goal of receiving feedback from the experts at the UCEDDs as well as their peers (providers, families and municipal staff from other counties) to share successes and to brainstorm solutions to challenges.

### **Stakeholder Involvement**

The Department has included stakeholders in all phases of the SSIP. The Department has engaged the EICC on multiple occasions to present the plan and to elicit feedback. The most recent presentation provided to the EICC is attached. (Appendix 9) The Department has convened and is actively working with the statewide advisory group for the SSIP. The statewide advisory group includes representatives across the Early Intervention system, including families, providers, and local officials. One of the presentations provided to both the SSIP Advisory Group and the UCEDDs is attached. (Appendix 10) On April 6, 2017, the Department presented at the New York State Association of County Health officials (NYSACHO) general membership meeting and on September 13, 2017, the Department presented the plan at the NYS Association of Counties (NYSAC) conference, which represents NYS counties and local EIP programs, as

well as local Early Intervention Officials (EIOs) and Managers directly responsible for program administration at the local level.

The Department engaged with the Executive Director of Parent to Parent of NYS (Family Voices of NYS). Parent to Parent of NYS, which began in 1994, is a statewide not-for-profit organization established to support and connect families of individuals with special needs. Parent to Parent of NYS has an extensive infrastructure with 11 offices located throughout NYS, which are staffed by Regional Coordinators, who are parents or close relatives of individuals with special needs. Parent to Parent of NYS offers networking and training opportunities to families of individuals with special needs and the professionals who serve them. Parent to Parent of NYS helps other families find support, and provides information, referrals, and trainings to parents. Their parent-matching program, which is based on a model program used across the country, assists a parent, who has a child with a developmental disability and/or special health care needs, by locating a volunteer support parent who has a similar experience. Based on analyses of the NYS Family Survey, families consistently provide feedback that the EIP was not helpful in connecting them with the community and to other families with children with disabilities. Parent to Parent of NYS is an important partner and stakeholder to ensure these connections are made. Parent to Parent helped with recruitment for parent members to participate in the SSIP and has helped share the work the Department and UCEDDs are doing.

The Department engaged with Family Initiative Coordination Services Project (FICSP) as well. The Department sought competitive proposals from qualified vendors to assist in the development, coordination, and delivery of a comprehensive Family Initiative Training Program that supports and develops parent involvement in all aspects of the Early Intervention Program. The purpose of this training is to help families develop leadership and advocacy skills to be able to better advocate on behalf of their children with special needs.

The FICSP facilitates, supports and develops parent involvement in all levels of the EIP. The FICSP develops and implements a training program, referred to as Partners, that provides parents with the opportunity to enhance their leadership skills, network with each other, and learn how to become better advocates for the care of their child with special needs on the local, state, and national levels. The FICSP also facilitates and supports parent attendance at national conferences on early childhood development, and facilitates parent involvement on the New York State EICC. There are six parent members on the EICC.

The Department also connected with staff throughout the state from the Early Childhood Direction Centers (ECDC). The ECDCs, funded by the New York State Education Department, provide free confidential information and referral for families and professionals about services for young children with suspected or diagnosed developmental delays or disabilities. They work with families regarding the NYSEIP, Preschool Special Education Services, and all Early Childhood settings, including transition and services, and they also provide family support services and medical, dental, and other health services. These centers are present throughout the state. ECDC staff aided in the recruitment process and will be included in future SSIP monthly calls and events. On a least one monthly call for each of the UCEDDs, ECDCs staff have

presented and will be engaged to present information about the ECDC and the services that they offer to support children and families.

In New York State, local programs are required to maintain Local Early Intervention Coordinating Councils (LEICCs), whose members are appointed by the local EIOs, to advise EIOs on planning for, delivering and assessment of early intervention services for eligible children and their families; identification of service delivery reforms needed to promote the availability of services in natural environments; coordination of public and private agencies; and, other matters relating to early intervention policies and procedures identified by parents, EIP providers, and local public agencies. The membership of LEICCS must include parents, EIP providers, and representatives of local public agencies responsible for services for young children and their families. The LEICCs have been active participants in SSIP implementation. The Department presented at the a joint LEICC of nine counties in Central/Western NYS (April 28, 2017), EIP West Wyoming County Health Department on June 9, 2017, New York City (NYC) LEICC (July 14, 2017), Rensselaer County LEICC (September 22, 2017), and Rockland County LEICC (December 12, 2017).

The Department elicits feedback from stakeholders about the plan, implementation strategies, and short-term and long-term outcomes. The Department has identified specific staff who have taken the lead on the SSIP. Stakeholders have reached out directly with feedback, ideas and suggestions.

The Department will continue with the SSIP as described and planned. The IHI Breakthrough Series is an evidence-based framework for sustained quality improvement, and one that has resulted in demonstrated improvements on other Maternal and Child Health initiatives.

Stakeholders have had an enthusiastic response to the use of IHI quality improvement framework for the SSIP. Stakeholders have commented that the framework is feasible in that it embeds the use of family-centered practices into current interactions during Individualized Family Service Plan (IFSP) meetings and early intervention service sessions with children and their families.

During the SSIP start-up, the Department has been promoting the importance of providing family-centered services, presenting data on response rates and family survey results (including performance on family-centered services and family outcomes scales), and discussing the items included on the NYS Family Survey (attached as Appendix 1). The family outcomes data highlight the importance of continuing to focus on improving positive family outcomes. Based on NYS Family Surveys collected from the sample of families for reporting in the 2015-16 State Performance Pan/Annual Performance Report (SPP/APR), only 61.63% of families achieved the State standard for the NYIFS. For the 2016-2017 SPP/APR, 70.12% of families achieved the State standard for the NYIFS. The number of responses received also increased by 400 surveys from 1092 surveys in 2015-2016 to 1456 in 2016-2017.

The Department has revised the SSIP timelines to reflect the current status and planned actions. Procurement of the Centers of Excellence and alignment of the state's infrastructure, convening quality improvement leadership team, and engagement of stakeholders required more time than anticipated. The contracts with the Centers are now in place and the first cohort is now



underway. The first three Learning Collaboratives began their work in January and February of 2018, and will continue their work until January 2019. Recruitment for the second three cohorts will continue in the Spring and Summer of 2018. The second Cohort in-person Learning Sessions will be held in October of 2018, and their work will continue until October 2019. This overlap will allow for the two cohorts to complete their work prior to the end of the SSIP and allow for submission of the report by the due date of April 1, 2020.

### **Data on Implementation and Outcomes**

The Department has developed an SSIP that integrates data to support the evaluation. The Department is utilizing the existing NYS Family Survey with the NYIFS that measures the impact of the EIP on families. The NYS Family Survey previously included the FCSS, which assesses the quality and family-centeredness of the services. Both scales align directly with the Theory of Action. The benefit of aligning the SiMR and the SSIP with the current data collection process for Indicator 4 Family Outcomes reported in the SPP/APR is that the data collection is established and does not require new systems to be implemented. Additionally, the data have been collected over time to allow for the establishment of baseline and ongoing review of performance on the SSIP and SiMR. As described in the SPP/APR in Indicator 4 and in Phase I of the SSIP, the Department is using the NYSIFS to measure and report on the federally-required family outcomes. The NYIFS is composed of items generated by national and NYS stakeholders, including parents, and written in a manner that makes them understandable to parents. The NYS Family Survey, which includes the NYIFS and FCSS, was previously provided in English and Spanish. As of the 2016-2017 year, it has been translated into five additional languages (Chinese, Arabic, Russian, Bengali, and Yiddish).

SiMR data are reported below. These data demonstrate an improvement based on family responses collected from families during the FFY 2016-2017 (July 1- June30). While these data were collected before the full implementation of the evidence-based strategies, which occurred in January and February 2018, significant improvements were already realized. These improvements are likely a result of the state's efforts to align infrastructure, better disseminate evidence-based practices and statewide data about family outcomes, and to promote family involvement in the Early Intervention Program. SiMR data to evaluate the impact of the evidence-based strategies will be available and reported in the next SSIP report in April 2019. New York does not plan to make any changes in the SiMR or the target.

Table 3 below includes baseline data, data for each year, and targets established in Phase I.

**Table 3. Baseline and Progress Data**

<b>FFY (July 1-June 30)</b>	<b>Baseline (2008-09 to 2013-14)</b>	<b>2014-2015</b>	<b>2015-2016</b>	<b>2016-2017</b>	<b>2017-2018</b>	<b>2018-2019</b>
Of those families who responded to the NYS Family Survey from FFY 2008–FFY 2013, the percent who met the State standard of $\geq 576$ .	65.09% (4,245/6522)	57.04% (231/405)	61.63% (673/1092)	70.12% (1021/1456)	N/A	N/A
<b>FFY 2014-2018 Targets</b>	N/A	65.09%	65.09%	65.50% (+.41%)	66.00% (+.50%)	66.50% (+.50)

As described in the State Performance Plan/Annual Performance Report (SPP/APR) in Indicator 4, the Department has an approved sampling plan to collect Family Outcomes data. The NYS Family Survey is being leveraged to collect the SiMR for the SSIP, so this same sampling plan applies to data collection for the SiMR.

Department staff are in the process of performing more in-depth analyses of the Family Outcomes data by subgroups, by geographic regions, as well as at the county (i.e., local program) and early intervention provider level to identify any characteristics associated with the likelihood families agree that the early intervention services they received were helpful. The results of these analyses will be reported in the next SSIP report in April 2019.

### **Stakeholder Involvement**

Stakeholders have been engaged in the evaluation of the SSIP and have reviewed SiMR data. The Department engaged the EICC, NYSACHO, the statewide SSIP Advisory Group, and Parent to Parent of NYS. Stakeholders have identified additional analyses that should be done by subgroup and by region of the NYS. Stakeholders have continued to support the State’s focus on improving family outcomes based on data that have been presented.

Based on feedback from stakeholders including the EICC, the Advisory Group, parents, county staff, and the experts at the UCEDDs, the main concern was the length of the survey. The Department has evaluated the length of the form and has shortened it from 95 questions (two pages front and back) to only questions one through 36 which are the NYIFS questions (one-page front and back). The NYIFS data is used for both the SIMR and APR, the FCSS will no longer be on the survey, but data regarding the FCSS will be collected from the SSIP and Learning Collaboratives feedback. From discussions with the stakeholders involved, including the advisory group and UCEDDs, the Department believes that this shortened survey will increase the completion rate since it will be less daunting to busy families and take less time to complete. This shortened form will go into effect for 2017 – 2018 program year.

## Data Quality Issues

The Department is strongly committed to ensuring high quality data for the SPP/APR.

The NYS Family Survey, which included the NYIFS and the national FCSS, is mailed directly to a sample of families in a Scantron format with a letter inviting them to participate in the survey and a postage-paid return envelope. Surveys in other languages are provided based on information about the languages spoken in the NYSEIP administrative database. The survey is returned directly to and scanned by Department staff. The information is converted into an electronic file for analytic purposes.

In accordance with the recommendation made by the developers of the scales, data collected from families on the NYIFS were analyzed using the Rasch measurement framework. In the Rasch framework, a series of parametric models is used to estimate the properties of each survey or test item and each respondent in such a way as to locate individuals and items on a common metric. When the data meet the requirements for good measurement – adequate item fit, high reliability, and unidimensionality – then all the information available from an individual’s responses to the items is meaningfully captured in a single numerical value representing the person’s measure on the scale. The NYIFS was found to have excellent measurement properties for its intended use.

Within the Department, the data analysis and evaluation activities are overseen by Dr. Kirsten Siegenthaler, who is the Part C Data Manager and has a PhD in Epidemiology from the State University of New York at Albany (dissertation on evaluating the NYS Early Intervention Program), as well as Dr. Yan Wu, who is a senior biostatistician and has a PhD in Biostatistics from the State University of New York at Albany. Additional analytic support was provided by Dr. Ying Huang, who is a junior biostatistician with the Department from January 2016 until January 2018. Dr. Huang has a PhD in Pharmacy and a Master’s of Science in Biostatistics from Rutgers University.

One challenge with the data is a low family response rate. The response rate for FFY 2015-2016 was 10%, which increased in FFY 2016-2017 to 14.56%. The Department is working with stakeholders, including families, local programs and early intervention providers, to determine effective ways to improve family responses. The Department has an approved sampling plan, and the respondents have been representative of the early intervention population being served based on analysis of gender, race/ethnicity, and age at referral.

In 2016-2017, along with the English and Spanish surveys previously used, the Department translated the survey in to five additional languages: Arabic, Bengali, Chinese, Russian, and Yiddish. These languages were chosen as they are the seven most common languages found in NYS based on demographic data. Providing families with a survey in their native language helped contribute to the increase in completed surveys.

As previously stated, to increase the response rate based on stakeholder feedback, the survey used to collect the data will now only be the 36 questions that make up the NYIFS, and the remaining questions that focus on the FCSS will be removed. This causes the survey to go from

95 questions (two pages front and back) to 36 questions (one-page front and back). The Department believes that this shortened survey will increase the completion rate since it will be less daunting to busy families and take less time to complete. This shortened form will go into effect for 2017 – 2018 program year.

When speaking with families and other stakeholders, many suggested an online version may be easier for families to complete or have access to it. Based on this feedback, the Department is in the process of creating an online survey. To continue to track county family outcomes data, the families will be given a unique identifier to enter in to the online survey, which will be connected to the child. Without the cost of printing and mailing the surveys, the size of the sample can be increased once the online survey is in place. The Department is hoping to have the online survey available for the 2018-2019 year.

### **Progress Toward Achieving Intended Improvements**

#### *Infrastructure Changes*

The Department has made significant changes to infrastructure to better align and support the SSIP, including allocation of Part C funds to support SSIP implementation. The following specific actions have been taken.

The Department has executed contracts that comply with federal requirements for the oversight and administration of the Early Intervention Program. The Department has a contract to support Comprehensive System of Personnel Development (CSPD) with a new five-year contract cycle that went into effect in June 2017.

The Department has also executed contracts with the state's three federally designated University Centers of Excellence in Developmental Disabilities (UCEDDs), which were chosen based on their experience and work in the field of children with disabilities, as well as their locations in the state.

The IHI Breakthrough Series was selected as an evidence-based framework for effecting sustained quality improvement of a system. The model requires expertise in developmental disabilities, especially working with young children and their families, as well as staff who can train other professionals, facilitate webinars and coach local learning collaborative team members and implement the evaluation plan. In the final year, the Centers of Excellence will be focused on "spread" to share best practices and lessons learned with early intervention providers who were not able to participate and to create sustainable resources to share as new providers join the NYSEIP.

Each UCEDD has designated staff to work with counties and stakeholders to improve family outcomes. They coordinated the in-person meetings, monthly calls, track PDSA data, and provided progress reports to the Department. Each cohort is receiving and will receive coaching and mentorship support from their regional UCEDD staff to implement their plans improve the quality and family-centeredness of early intervention services. The execution of these three contracts was delayed beyond the original date targeted in the original plan and in the update from last year.

As described previously, the contracts are with the Rose F. Kennedy University Center for Excellence in Developmental Disabilities at Albert Einstein College of Medicine (RFK) is located in the Bronx, New York. Staff at RFK are supporting the five boroughs of New York City and the two counties that make up Long Island (Suffolk and Nassau). This UCEDD has taken the lead regarding the content for a website focused on the SSIP and family outcomes that will be hosted on the Department's website. The Westchester Institute for Human Developmental (WIHD) is supporting counties from Westchester to Franklin county. This UCEDD has been designated as the lead regarding the data and evaluation information collected and analysis of the data from the three UCEDDs.

The Strong Center for Developmental Disabilities at the University of Rochester Medical Center (Rochester) is supporting the Central and Western Region of New York. This UCEDD has been designated the lead on creating a compendium of resources for parents and stakeholders that has been shared with the first cohort and will be incorporated shared on the Department's public webpage in Spring 2018.

Despite the delay, the SSIP is on track to achieve statewide involvement and to achieve the State-Identified Measurable Result goal by the end of the SSIP. While the contracts were being developed and executed, the Department of Health worked to align its infrastructure to support the long-term sustainability of the quality improvement efforts.

Department staff within the Bureau of Early Intervention have been deployed to support the SSIP. As reported in Phases I and II, Kirsten Siegenthaler, PhD, was appointed to serve as the NYSEIP State Systemic Improvement Planning Coordinator and is currently the Assistant Director for BEI. In addition, Marie Ostoyich, RN, MS, was employed by BEI from June 2016 to February 2018 to support the SSIP. Ms. Ostoyich has extensive experience as a pediatric nurse and served as the Public Health Director for a NYS county and was the President of NYSACHO, and provided much of the work to develop the recruitment materials and to recruit cohort 1 participants. Katherine Reksc has provides support and management of the project.

An internal BEI team was established to support the SSIP. For the first two Phases the team included Dr. Donna Noyes and Brenda Knudson Chouffi, Co-Directors for the Bureau of Early Intervention and Mary-Lou Clifford who was the former Director of the Information Systems Quality Improvement (ISQI) section, who have now retired. Constance Donohue, Au.D., current BEI director and Part C Coordinator for New York State has now joined the team; she provides management oversight and leadership for the SSIP. Additional support has been provided by the bureau managers and staff from the functional units within the Bureau, including, Jessica Simmons, from the ISQI unit; Margaret Adeigbo, Manager of Provider Approval and Due Process (PADP) unit and Kelly Callahan from that unit; Ken Moehringer, Manager of the Fiscal Planning and Policy section; Yan Wu, Manager of the Data and Program Evaluation Unit.

The Department has also worked on changing the structure of the Family Outcomes Survey. For the 2016-2017 sample, in addition to the English and Spanish surveys that were previously available, the survey was translated into the next top five most common languages found in New York State (Arabic, Bengali, Chinese, Russian, and Yiddish). For the 2017-2018 sample year,

the survey was reduced from 95 questions to 36 questions. The Department has worked hard to improve the outreach to non-traditional living arrangements by contacting counties to confirm the identity and contact information for families of these children. The Department also strives to make sure the sample is representative of NYS demographics. For the 2016-2017 year, there was an improvement in return rate which may be attributed to not only the additional translations, but also the promotional work that has been done by the Department and county staff to explain the survey and the importance of the data to families exiting the program.

These changes will support the implementation, scaling up and sustainability of the quality improvement initiative during the SSIP and for future years.

### *Evidence of Fidelity*

The Department has approached the plan to implement the IHI Breakthrough Series with fidelity. The framework has served as the road map for the work to implement the quality improvement efforts, as described in Section 1.

The evaluation plan includes measures to assess fidelity. In the Phase III report submitted in April 2017, the following questions were created to be addressed as the SSIP progressed. These questions have been used to guide the evaluation of the SSIP in the second year of Phase III. The results of the evaluation of activities since April 2017 are reported below:

1. *Did the statewide quality improvement team convene, and were they actively engaged in the process of preparing for the learning collaborative?*
  - The statewide quality improvement team convened via webinars six times over the past year. The advisory group helped create the brochures for the recruitment, as well as aided in finding volunteers to participate in the learning collaboratives. The team also helped with developing a public friendly name for the SSIP (Improving Family Centeredness Together or IFaCT) and creating provider and parent/family applications that were used to gather additional information about the providers and parents interested in participating. The last webinar included introducing them to the staff at the UCEDDs where they discussed the project timeline, recruitment process, and the next steps. One of the main focuses of the next steps was discussing the agenda for the future Learning Collaboratives.
2. *Were three regionally based Centers of Excellence established, and were they able to develop a website, identify evidence-based strategies, and operationalize the evaluation plan for the SSIP?*
  - Three regionally based Centers of Excellence were established and contracts were completed.
  - NYC and Long Island are working with the Rose F. Kennedy University of Excellence in Developmental Disabilities at Albert Einstein College of Medicine (RFK). Einstein staff are currently working on developing the content that will be displayed on the SSIP website, while Department staff are completing the forms for the internal leadership approval process.

- The Strong Center for Developmental Disabilities at the University of Rochester Medical Center (SCDD) is working with counties in Central and Western NY. Rochester is creating a compendium of resources and materials for both providers, counties, and parents that will support and encourage family outcomes.
  - The Westchester Institute of Human Development (WIHD) is working with counties from Westchester county up to Franklin county. WIHD has developed the evaluation plan for the SSIP that all three UCEDDs are utilizing and help analyze the data from the In-Person Meetings and all teams PDSAs.
  - All three UCEDDs are employing the identified evidence-based strategies to improve family outcomes.
  - The UCEDDs participate in biweekly calls facilitated by the NYS Early Intervention Program to ensure consistency across the state in the implementation of the SSIP and to identify any concerns or barriers as well as best practices that can be shared across the three regions.
3. How many learning collaborative teams were successfully recruited?
- For the first Cohort, there were a total of 36 teams successfully recruited. Both SCDD and WIHD had 14 teams each at their learning collaboratives, while RFK had eight teams. RFK based their teams around the eight agencies that are participating, which work with families throughout all five NYC boroughs, whereas the other two UCEDDs are based on the counties that are included in their first Cohort. This Spring and Summer, recruitment will continue for the second Cohort which will include additional NYC teams, Long Island Counties, and the remaining counties upstate.
4. How many members were successfully recruited to participate in the teams?
- Between the three UCEDDs, 149 members were recruited and attended the first in-person Learning Collaborative, with additional members who are participating in the first cohort but who were unable to attend the in-person session.
5. Were the team members representative (i.e., early intervention officials/designees/managers, parents, service coordinators, therapists, quality assurance personnel at agencies, etc.)?
- Each team had members representing Early Intervention stakeholders. Of the 149 members that attended, 29 were parents, 54 providers represented multiple disciplines (physical therapy, speech language pathology, occupational therapy, and teachers of special education), 25 were service coordinators, and 41 were county staff such as Early Intervention Officials (EIOs), Early Intervention Managers (EIMs), and Early Intervention Official Designees (EIODs). The recruitment efforts were evaluated. Lessons learned from the recruitment of cohort 1 will be used to inform and improve the recruitment of cohort 2 in Summer 2018.
6. Were the initial in-person or virtual Learning Sessions held?
- Each UCEDD held an in-person Learning Session for their first cohort. RFK held their Learning Session on January 18, 2018, WIHD held theirs on January 22, 2018, and SCDD held theirs on February 2, 2018. They will each be holding a second in-

person Learning Session in the Fall of 2018 for the teams participating in the second cohort. The evaluation of these sessions is being analyzed and will be used to make improvements to the second cohort which will begin in Summer/Fall 2018.

### *Progress toward Short-Term and Long-Term Objectives*

The Department is making progress toward achieving short-term outcomes related to infrastructure alignment and engaging stakeholders to gain support of the long-term goal to improve outcomes for families. The Breakthrough Series framework is inherently data-driven with short-term process and outcome measures. The Department is leveraging the current system for collecting family outcomes and quality of family-centered services by using the NYS Family Survey to measure, track and report on the SiMR each year in the SPP/APR.

### **Plans for Next Year**

During the next year, the focus will be on working with the three Centers of Excellence to support the implementation of the PDSAs that were created at the first in-person Learning Sessions, collection of data, analysis and distribution of data monthly, and coaching and training of professionals to improve the quality and family-centeredness of early intervention services.

The Department continuously reviews the allocation of staff and resources for the Part C grant. The Department will continue to support the three UCEDD contracts, the collection of family outcomes through paper and online surveys, and professional development and family training ensuring the SSIP is infused in all areas. The Bureau will continue to assess staffing resources. The SSIP work is formally integrated into the unit with thin the Bureau responsible for overseeing quality improvement, training and technical assistance. Bureau staff will be further integrated into the effort to support cohort 1, recruit and support cohort 2, and promote best practices and successes achieved to the larger stakeholder audience.

The SSIP Advisory Group will continue to meet by webinar at least quarterly to review the SSIP, discuss the evaluation plan, and outcomes of the SSIP. The next planned webinar for the Advisory Group with the three UCEDDs is April 20, 2018.

The Department will continue to engage stakeholders. Webinars and in-person presentations will be scheduled again with the EICC, NYSACHO, counties and their LEICCs, and parent advocate groups. Bureau staff are planning presentations at LEICC meetings in Nassau and Washington County.

The Department will continue to work with the SSIP Advisory Group and the local municipal programs on the recruitment of teams for the second cohort. The recruitment package, which explains the learning collaborative, the benefits of participating, and the commitment that is required, will be updated based on stakeholder feedback. Key participants of the local teams, including early intervention officials and their designees, service coordinators, therapists from different disciplines, and family members, will be identified in the Summer 2018.



Learning Collaboratives for the counties in the second Cohort will begin with an initial in-person meeting followed by monthly coaching webinars or calls to discuss the previous month's PDSA cycle, review data, and determine next steps for the upcoming month. The second cohort will begin in October 2018 and run until October 2019.

The Department sponsors an Early Intervention Partners in Policymaking training program twice each year in the fall and spring. The training is offered on a rotating basis in different regions throughout the state. Parents receive substantial information regarding the NYSEIP legal and regulatory framework and process. The training also helps parents develop advocacy and leadership skills related to early intervention services. Information about the SSIP and the goal of improving family outcomes is being incorporated into future training sessions, and participating families will be provided opportunities to work locally and at the state level on the SSIP. Bureau staff are presenting at a Partners training in Syracuse in June 2018 to recruit families for the second cohort.

For the 2017-2018 Family Survey, as previously stated, has been reduced from 95 questions to 36 questions (two pages front and back, down to one-page front and back). The Department will compare the return rate against previous years to see if the shortened survey increased participation by families. The Department staff is creating an online version of the survey for families to complete. The paper survey will still be available, however increasing the availability on different platforms will hopefully increase the response rate as well. The Department is hoping to put the online survey into effect in the 2018-2019 program year.

Statewide, short-term and long-term outcome measures will be reviewed by Department leadership as well as stakeholders, who will provide advice and input in the process and the outcomes of the initiative. More in-depth data analysis by region and subgroups will continue and will be presented to stakeholders for feedback and direction on next steps for analyses and to determine if any changes to the SSIP are needed. New York has already achieved the target set for the SiMR. The State anticipates that the gains made in FFY 2016-2017 will be maintained or exceeded since the evidence-based strategies have been successfully implemented. Coaching and mentorship of cohort 1 began in February and March 2018. Very preliminary feedback has been overwhelmingly positive and the quality improvement plans have been tailored to the local needs of the county with input from parents and ongoing data collection has been initiated and will continue to evaluate the SSIP. These data will be reported in the next SSIP report in April 2019.

Department staff will continue to participate in the Family Outcomes Cross-State Learning Collaborative supported by the National Center for Systemic Improvement. The Department has been actively involved in the Learning Collaborative, which has provided many opportunities for sharing of resources and ideas to improve family outcomes. Staff will participate in the upcoming cross-state collaborative meeting in Syracuse, NY in May 2018. The Department has participated in in-person meetings, webinars and conference calls. The Department will also continue to work with other national technical assistance centers, including the Early Childhood Technical Assistance (ECTA) Center and the IDEA Data Center.