Developmental Screening Part 2: Views, Experiences, and Recomendations from Parents and Early Care and Education Providers

By

Mhora Lorentson, Ph.D.
Lisa Honigfeld, Ph.D.

Prepared for:

The Connecticut Office of Early Childhood and United Way of Connecticut

October, 2015

ACKNOWLEDGEMENTS

- (designee to attend on behalf) Eileen McMurrer, Public Awareness Coordinator, CT Birth to Three System
- Heather Spada, ECCS Project Manager, United Way of CT*
- Sherri Sutera, Sr. Vice President for Child Care Services, United Way of CT*
- Deborah Watson, Consultant, Help Me Grow Campaign, CT Office of Early Childhood/Family Support Services Division
- Grace Whitney, Director, Connecticut Head Start State Collaboration Office*
- Jillian Wood, Executive Director, CT Chapter- American Academy of Pediatrics
- Robert Zavoski, M.D., Connecticut Medicaid Medical Director, CT Department of Social Services
- (designee to attend on behalf) Eva Forrest, Registered Nurse Consultant, CT Department of Social Services
- Elaine Zimmerman, Executive Director, CT Commission on Children

*Individual is also a member of the ECCS Evaluation Subcommittee

About Lorentson Consulting and the Child Health and Development Institute of Connecticut:

Lorentson Consulting is an evaluation firm specializing in the design and implementation of high quality rigorous mixed method evaluations framed by the theories and practices of organizational change and conducted collaboratively with clients to increase their capacity to conduct evaluations and use evaluation data in program improvement. Lorentson Consulting works with clients in education and health to support them to collect and use information to improve and expand their programs. Our areas of inquiry include early childhood, K-12 and health education, behavioral health, health care and nutrition, and infrastructure development in K-12 and early education organizations.

The Child Health and Development Institute of Connecticut (CHDI), a subsidiary of the Children's Fund of Connecticut, is a not-for-profit organization established to promote and maximize the healthy physical, behavioral, emotional, cognitive and social development of children throughout Connecticut. CHDI works to ensure that children in Connecticut, particularly those who are disadvantaged, will have access to and make use of a comprehensive, effective, community-based health and mental health care system.

Information about the Child Health and Development Institute can be found at www.chdi.org or by contacting the program at:

270 Farmington Ave., Suite 367
Farmington, CT   06032
Phone: 860-679-1519

Information about Lorentson Consulting can be found at www.lorentsonconsultingllc.com or by contacting the organization at:

39 Old Middle Road
Brookfield, CT. 06804
Phone: 203-898-5693
E-mail: mlorentson@lorentsonconsultingllc.com

DEVELOPMENTAL SCREENING PART 2: VIEWS, EXPERIENCES, AND RECOMMENDATIONS FROM PARENTS AND EARLY CARE AND EDUCATION PROVIDERS

INTRODUCTION

The Connecticut Office of Early Childhood (OEC), United Way of Connecticut, and their Early Childcare and Education (ECE) partners know that the ability of Connecticut's young children to thrive depends on our success in identifying and addressing developmental and behavioral delays and associated risk factors as early as possible. These partners are poised to develop a comprehensive plan to ensure that all young children are able to grow and develop to their fullest potential.

As part of the development of this plan, the Office of Early Childhood and United Way of Connecticut applied for and received three years of funding from the United States Department of Health and Human Services—Health Resources and Services Administration (HRSA). Funding was awarded to complete a statewide needs assessment over a three year period and to plan additional activities designed to enhance Connecticut's ability to monitor young children's development and connect children with, and at risk for, developmental delays to intervention services to ensure school readiness at age five and lifelong outcomes. As a first step in the implementation process, the partners created the statewide Early Childhood Comprehensive Systems (ECCS) Advisory Committee to guide and support the work. The Advisory Committee includes representation from a broad array of early childhood stakeholders in Connecticut, including center and home-based childcare and preschool programs; state agencies overseeing health, child welfare, Medicaid, early intervention and home visiting; as well as philanthropy and private health care providers.

The ECCS grant committed the State to addressing developmental screening across early childhood settings to ensure the early identification of children at risk for development delays and their connection to intervention services. The partners and the ECCS Advisory Committee retained the Child Health and Development Institute (CHDI) to conduct an ongoing evaluation of progress in implementing the ECCS grant. CHDI has extensive expertise in system building to support developmental screening, including policy development, education of primary care child health providers, and continuous monitoring of State progress in implementing screening. With support from the Early Childhood Education Cabinet, in 2013 CHDI prepared and released a report of developmental screening in Connecticut, "*The Earlier the Better: Developmental Screening for Connecticut's Young Children.*"[1]

CHDI hired Mhora Lorentson, from Lorentson Consulting to collaborate on the ongoing evaluation of ECCS activities and participate in the preparation of the current document. This report provides a review of the highlights of *The Earlier the Better* and extends that work to address ECE providers' and parents' views on developmental surveillance and screening, including:
- developmental and behavioral surveillance and screening activities in early childcare settings;
- procedures for storing and maintaining screening data; and
- coordination of referrals to services for children for whom surveillance and screening show concerns.

IMPORTANCE OF DEVELOPMENTAL SCREENING AND SURVEILLANCE IN EARLY CHILDHOOD

"*The Earlier the Better*" provides a comprehensive summary of research supporting the importance of young children's early development to their later success in education and life. Studies indicate that

children who experience delays in early development typically continue to perform more poorly than their peers as they age and have a greater risk of ongoing delays and poorer outcomes in education, careers and social connections.

A variety of factors have been shown to impede healthy development. Factors typically identified as increasing a child's risk for developmental delay and learning disabilities include poverty, participation in the child welfare system and trauma exposure. Similarly, a number of factors support healthy development and enhance learning and growth outcomes for children. These factors include quality early care and education, supportive parenting and strength-based approaches to services for children supported by public policy.

We know that children need to begin school in kindergarten ready to learn. The ability of a child to learn is dependent upon their having the appropriate developmental, social and academic skills to be successful. A large national study determined that 56% of kindergarten children did not have the adequate skills for succeeding in kindergarten.[2] The ability of these children to succeed and thrive is dependent upon early detection of developmental challenges and provision of services to address these challenges. Developmental screening contributes to early identification of these children.

In addition to recognizing the value of developmental screening with a validated tool, the American Academy of Pediatrics (AAP)[3] also endorses developmental surveillance. The AAP defines surveillance as eliciting parental concerns, documenting and maintaining a developmental history, observing the child, identifying risks and protective factors and maintaining an accurate record of findings over time, including input from others such as schools. The AAP recommends that surveillance be incorporated into every well child visit, and that developmental screening with a validated tool be conducted at the 9, 18 and 24 or 30 month well child visits.

"The Earlier the Better" provides data on the extent of developmental screening in pediatric primary care in Connecticut, concluding that the State has made great progress in screening. *"The Earlier the Better"* also reviews reports from Head Start and home visiting programs, both which show high rates of developmental screening. Despite these encouraging findings, CHDI's report highlights the lack of coordination in the systems of surveillance and screening in Connecticut which results in some children receiving multiple services, while others fall through the cracks and are not screened and/or connected to follow up services. The report concludes with recommendations for specific actions to help Connecticut build a system of early identification and linkage to services of children with developmental and behavioral health needs. The authors emphasize that the underlying principle in each recommendation is that all children should be screened within an integrated system that ensures that: 1) their results are available across the services they use, 2) they are connected to services they need, and 3) all involved providers are engaged in developmental promotion in partnership with families.

Recommendations provided in "*The Earlier the Better*" are incorporated into the activities of ECCS grant in Connecticut, led by the OEC and United Way as follows:

- **OEC serves as the lead agency** for ensuring the early identification of children with developmental and socio-emotional risks, as well as their connection to assessment and intervention services.
- **OEC convenes a group of stakeholders** that is representative of the providers who screen, state agencies with screening programs, and parents of young children and has charged this group to develop a screening protocol for young children in Connecticut that includes developmental, socio-emotional and psychosocial screening. The ECCS Advisory Committee serves as this group.

- **OEC explores models of efficiently providing assessments** for children for whom screening shows concerns.
- **Options for expansion of the role of Connecticut's Child Development Infoline, housed at the United Way,** as the central point of access for connection to assessment and intervention services to ensure that all children in need of further services receive them and that connections are documented.
- **OEC develops a data system to monitor development of Connecticut's young children**. The early childhood data system under development should include, child-level data on screening, screening results and services provided across primary care, home visiting, Head Start and other programs that screen and assess children.

Accomplishment of many of these objectives is encompassed in Connecticut's ECCS work. Further, the development of a comprehensive system for early childhood surveillance and screening in Connecticut requires that stakeholders understand the current status of surveillance and screening, data storage and retrieval and connection to services within the State. This knowledge can then inform the development of a system that meets the needs of families, childcare providers and child health providers, and optimally utilizes existing resources and addresses existing gaps.

ECE and Family Views on Surveillance and Screening

Overview

To further address topics raised in the *Earlier the Better,* from January 2014 to December 2014, Lorentson Consulting designed and implemented an investigation to identify ECE and family views on the current status of developmental surveillance and screening, use of data, and coordination of referrals throughout Connecticut. The ECCS Evaluation Team provided input into and partnered on the implementation of all research activities, which they considered as a needs assessment for the State and ongoing ECCS work.

The needs assessment was designed to address the following key questions about developmental surveillance and screening in Connecticut:

1) What processes guide developmental and behavioral health surveillance and screening in early care and education?
2) How are developmental and behavioral health screening data maintained?
3) How are referrals to evaluation and intervention services coordinated for children for whom developmental and behavioral health surveillance and screening show concerns?

Data Collection Methods and Activities

Data collection methods included qualitative focus groups with ECE providers (center and home-based) and parents, and on-line surveys for parents, and center and home-based ECE providers. The final data include responses from:

A. Eight semi-structured focus groups with center-based providers and one semi-structured focus group with family-based child care providers;
B. 329 responses to the *"Early Childcare and Education Provider Survey 2014",* developed by Lorentson Consulting for Connecticut's ECCS work*;*
C. 924 responses to the "*Early Childcare and Education Parent Survey 2014"* (in English and Spanish), developed by Lorentson Consulting for Connecticut's ECCS work.

Focus Groups

Focus group interview questions for Connecticut ECE providers were designed to identify perceptions of developmental surveillance and screening, data storage and retrieval activities and coordination of referrals currently used by early care providers. Center Directors selected participants for each focus group based on the surveillance and screening activities within their center. Each focus group took approximately one hour to complete. A breakdown of participants is provided below:

- Administrators: 10
- Classroom Teachers: 15
- Family Child Care Providers: 12
- Educational Consultants: 5
- Health Consultants: 1
- Behavioral Health Consultants: 1
- Support Staff: 2
- Early Intervention: 4
- Parent: 4
- DCF Investigator/Out-posted worker: 2

Early Childcare and Education Provider Survey 2014

ECCS Advisory Committee members, the OEC and United Way distributed links to the online ECE provider survey. Three hundred and sixty two individuals began the on-line survey, of which 223 completed the demographic questions. Twenty-four (10.8%) represented state-funded, center-based, programs, 16 (7.2%) were federally funded, center-based programs, 93 (41.7%) were privately funded center-based programs, 56 (23.8%) were center-based programs funded both privately and publicly, 32 (14.3%) were family-based child care providers and 5 (2.2%) were representatives from group childcare homes. Respondents represented childcare programs in each of the 8 Connecticut counties. Almost half of respondents (179 or 65.8%) were licensed as childcare centers, approximately one fifth of respondents were licensed as family childcare home providers (34 or 12.5%) or year-round programs (52 or 19.1%). Responding centers represented sites caring for children ages birth to four.

Early Childcare and Education Parent Survey 2014-2015

The *Early Childcare and Education Parent Survey* obtained information about parent involvement with, perceptions of and satisfaction with the surveillance, screening and referral process in their child's ECE setting. Nine hundred and twenty four (924) individuals completed either an on line or hard copy survey. Slightly over half (59.2%) completed a hard copy survey and 40.8% completed an online survey. 724 surveys were completed by English speakers and 200 by Spanish speakers. The majority of the 818 respondents who answered the question (691or 84.5%) did not have any children with developmental delays. Slightly over one tenth (104 parents or 12.7%) of respondents had one child with developmental delays, 20 individuals (2.4%) had two children with developmental delays and three respondents had three or more children with developmental delays. Child care settings utilized by parent respondents were located in each of the eight Connecticut counties.

Parents described the settings in which their childcare programs were located as urban (59.7%), rural (12.8%) and suburban (27.5%). Of the 652 individuals who provided information, the majority of respondents were white (73.6%), 5.7% were Asian and 19.3% were black. The remaining were pacific islanders.   Almost half (45.1%) of respondents were Latino. Slightly over one tenth (13.3%) of parents

had completed some high school, 24% had a high school diploma, 25% had completed some college or received a two year college degree and 37.6% had a four year degree or higher.

ECE PROVIDERS' AND PARENTS' VIEWS ABOUT DEVELOPMENTAL SURVEILLANCE AND SCREENING IN ECE SITES

Focus Group Responses

"I think that the key is the trust that I can feel from the teacher. Before I came here, my kid was in another school and I didn't have that at all. I didn't have any feedback and here, as soon as I came back, the first day I already have feedback—this was the opening for me to say "Yeah, I have this concern, can you help me." Trusting is very very key."

--A parent--

"Sometimes it's hard to find out if the child has some needs. For most of the parents, the children, they are great and perfect, no matter what. So, one kid nine years ago, I had a kid with some problems—I had no education then which I have now. But, I know the kid was different, very different, because I had six kids. So five are doing what they're supposed to do, this kid never do it. He was behind in everything. So, I say to the mother, you need to check with the pediatrician. So the mother was upset and told me I was wrong. I waited and tried again. She just got mad. Then, he finally went to school and at 7 he was diagnosed with autism. They say why did no one diagnose him? Why did he not get screened?"

--A Spanish-speaking home-based provider—

"How do we gain information about parent concerns? We have an enrollment package with some questions but they are pretty vague. And they only apply when kids sign up—obviously it can change. I know the yellow forms are used but honestly don't ever remember seeing anything to check with doctor about. We do have a nurse consultant who looks up health records to make sure they are up-to-date and asks teachers if they have concerns about the kids. She comes in for an hour a week. We talk to parents when we have a question or there is a change being made. Other than that, we pretty much just keep an eye on things. But it works well."

--A privately funded center-based staff member—

"When we first get new kids we all keep notebooks on hand, just to jot down things, so when you speak with the parents at conferences you can have specific incidences to go back to—then, in mid-October, we start a more formal identification, checklist of things to test children on. There is a three and four year old progress report, Pre-kindergarten and Kindergarten progress reports. Our Infant-Toddler programs do not have progress reports but we do things like hand out potty training articles, or biting articles if it is pertinent to what is going on in the room. We talk with parents if we are concerned. We put into the progress reports recommendations if needed and our Director tries to identify phone numbers to call if needed for services. "

--A privately funded center-based staff member —

"We have the family center, where we divide children into play groups or we are working with children that are in preschool classrooms. We have the family center do the ASQ. Based on the information we gather from the ASQ's we can provide support in the classroom and in the parent's place. We provide material for parents to work with at home and we immediately refer the child to birth to three. When the

teacher has a concern, we take the time to serve the child in different areas to see if it is more social or something we need to work on. We communicate first with the parents to establish. We do hearing and vision for all kids, we connect with the child's doctor and the mother on health issues directly. We use the yellow forms only in school readiness. If we have a specific concern after the child has started, we discuss with the parents and get all the necessary information. Then we create a team composed of the teacher, parent, Director, Assistant Director, family Specialist and ECCP as well as someone from the Board of Education if needed. Then we screen if we need to and create an action plan."

-- A publicly funded center-based staff member —

The Screening Process

ECE providers expressed a range of understanding and knowledge related to appropriate surveillance and screening activities and various degrees of comfort and competence in identifying and addressing developmental challenges experienced by children in their care. In general, privately owned facilities and family child care providers were less likely to be aware of or to use formal screening tools or to have specific protocols in place by which behavioral needs and challenges are identified and addressed than their larger, publicly funded peers. Publicly funded center-based programs were generally more knowledgeable about appropriate surveillance and screening practices and tools and more likely to have the necessary staff and expertise to be able to efficiently identify and address children's needs. However, even within these larger centers the surveillance and screening services provided to families and children varied widely.

Larger publicly funded centers typically used at least one formal screening tool consistently following explicit protocols, which include screening at the time of enrollment. Head Start and Early Head Start programs, as required by federal regulations, adhered to structured protocols for screening and ongoing surveillance. Within publicly funded centers, the Ages and Stages Questionnaire (ASQ) and/or the ASQ-Socio-Emotional (ASQ-SE) were the most frequently used tools.

Additionally, ECE providers reported that screening occurs based on the results of surveillance activities or when developmental and/or behavioral challenges are identified. In the majority of centers, participants reported that screening is conducted by staff trained in the use of the specific tool. When trained staff were not available, screenings were conducted by an individual perceived to be most appropriate to conduct the screening, such as the health consultant, social workers, speech and language consultants, and mental health consultants.

Some tools, such as the ASQ, prompted parental input and involvement in screening activities. Some center staff reported completing the screening tool in partnership with the parent. Additional strategies for parental engagement included: permission slips for parents that either allow or disallow the completion of the screening for their child, a team-based approach to make decisions related to screening and referral which includes parent membership on the team, and "debrief" meetings with parents subsequent to screening. All centers reported the use of strategies designed to support parent involvement in the screening process.

Surveillance activities within larger centers, while varied across centers, were also generally more structured than those occurring in the smaller private and family child care sites. Focus group participants cited parent conferences, home visits, open-houses for parents, informal and formal conversations with parents, and parent feedback as strategies for ensuring parental input into development surveillance activities. Conversations with health and education consultants were often part of the process, with some centers engaging in structured conversations on a consistent basis and others "*reaching out*" as needed.

Smaller privately-funded centers and family child care providers generally did no formal screening, with the exception of one family child care provider who screened children with the Ages and Stages Questionnaire at six months. Small sites relied heavily on "*informal observations*" in combination with some of the following to implement surveillance, including:

- teacher observation notebooks
- formal progress reports for older children
- use of the CT Early Learning and Development Standards (ELDS) checklist for keeping track of stages
- daily observations
- developmental milestone checklists
- ongoing informal and/or formal conversations with parents
- the use of incident reports

Smaller centers and family child care providers engaged parents in surveillance and screening primarily through informal, as needed discussions or occasionally more formally through registration packets, parent interviews, parent-teacher conferences or open-house discussions.

Use of the Early Childhood Health Assessment Records for Developmental and Behavioral Information

Centers reported a variety of uses for the Early Childhood Health Assessment Records, completed by parents and physicians and required for attendance in licensed ECE sites. Smaller private providers typically described using the Health Assessment Records primarily for physical health information such as immunizations and often on a sporadic basis. They stated that they rely heavily on the ability of parents to be upfront with them regarding their child's health concerns rather than on the form. One provider stated that the form was used intensively for behavioral concerns. Larger, publicly funded centers typically reported using the Early Childhood Health Assessment Records upon intake and subsequent to well child visits. Information on the records was typically reviewed and concerns forwarded to site staff as appropriate. Participants stated that, as needed, forms were used to support communication with health providers and were typically used primarily for information related to medications and immunizations. The primary challenge identified in the use of these forms was the receipt of incomplete, or even blank forms, from parents after visits with medical service providers and from child health providers. The majority of centers relied on center staff to interact with parents to obtain completed information as needed.

Satisfaction with Surveillance and Screening Process

Smaller private programs and family child care providers expressed overall satisfaction with the generally more informal processes they used. In the words of one individual, "*Haven't had a need to do it any other way, if there were a need, we would do it differently.*" Concerns mentioned included challenges in bringing up issues and concerns with parents, discomfort among staff in how to hold these conversations and difficulties obtaining services for children when challenges are identified.

The majority of larger programs expressed satisfaction with the processes used for both screening and surveillance. Strengths of the processes used included the existence of consistent procedures and policies across programs and locations, the consistent use of data in planning, the use of observations, the specific tools used, the use of collaborative processes within the center to enhance communication and improve decision-making and the inclusion of parents in the process.

Centers also described a number of challenges including:

- Decreased time and efficiency due to screening requirements;
- Scheduling and communication challenges when working with a Board of Education to ensure services for preschool age children for whom screening shows concerns;
- Specific tools used;
- Lack of appropriate physical space within the program for use when completing screenings;
- Obtaining parental "buy-in" to the process;
- Lack of understanding among pediatricians related to the use of screening tools and screening timeframes and of how to access Birth to Three services;
- Working with data and personalities across various parts of the child care systems; and
- Inadequate time or staff to complete either surveillance or screening to the degree to which it is needed.

Recommendations to Enhance Statewide Use of Surveillance and Screening

Respondents provided a range of recommendations and suggestions to improve surveillance and screening in ECE sites. They cited the need for articulated connections between the tools and processes for developmental promotion and implementation of the Connecticut Early Learning and Development Standards (ELDS). Participants stated that the academic impact of the ELDS was typically emphasized and easily understood by parents and that connecting surveillance and screening to these standards would encourage parental buy-in and involvement.

Suggestions for enhancing parental involvement in the screening and surveillance process included strategies designed to involve parents within the classroom setting to observe their child, an open door policy for parents and parent conferences at least three times a year with the incorporation of discussions regarding strengths and challenges faced by the child.

Early Childcare and Education Provider Survey Responses

Responses on the ECE provider survey supported information gleaned from focus group discussions. ECE providers used a variety of developmental surveillance strategies in monitoring children's development. Most of these strategies involved parents. Table 1 shows the most frequently cited strategies.

Table 1: **Strategies Used by ECE Programs to Monitor Children**
Percentage of Respondents Using Strategy
N=329

	Number Using	Percent Using
1) Ask parent about concerns regarding the child's development, behavior and/or health while child is enrolled.	294	89.4%
2) Ask parents about concerns regarding the child's development, behavior and or health upon enrollment.	284	86.3%
3) Document the child's developmental progress in program records	275	83.6%
4) Review the Early Childhood Health Assessment Records for child health provider concerns	245	74.5%
5) Review the Early Childhood Health Assessment Records for parental concerns	239	72.6%
6) Document parental concerns in program records	231	70.2%

Respondents experienced a number of challenges to monitoring the behavior and development of young children in their ECE program. Most notable were concerns about discussing behavioral and development with parents and lack of providers to whom to refer children for whom screening showed possible delays. Challenges are summarized in Table 2.

Table 2:   Challenges to Monitoring Behavior and Development of Young Child
**   N=278**

		Number Experiencing	Percent Experiencing
1)	Concern that discussing developmental concerns with parents would be perceived as insulting	138	25.4%
2)	Lack of quality service providers for referrals	96	17.7%
3)	Lack of time	74	13.6%
4)	Lack of comfort talking to parents about developmental concerns	48	8.8%
5)	Lack of knowledge about how to advise parents if concerns are identified	48	8.8%
6)	Lack of sufficient staff understanding of expected developmental progress	47	8.7%
7)	Limited ability to store or use data collected from monitoring	46	8.5%
8)	Lack of laws requiring that our program monitor children	28	5.2%
9)	Lack of information regarding the purpose or importance of monitoring	18	3.3%

More than half of respondents who completed the question about formal screening stated that their program either currently relies on screening tools to identify potential developmental problems or risk factors (191 or 60.1%) or anticipates the administration of such tools in the future (78 or 24.5%). Fewer than one fifth of respondents (49 or 15.4%) stated that their program neither relies on screening tools currently nor anticipates future administration of such tools. Respondents cited several challenges to screening, mostly related to trained staff, time and money.

Table 3:   Challenges to Screening Young Children
**   Percentage of Respondents Experiencing Challenge**
**   N=206**

	Number Experiencing	Percent Experiencing
1) Lack of staff trained to conduct screenings	96	46.6%
2) Lack of time	87	42.2%
3) Lack of money	86	41.7%
4) Lack of access to appropriate screening tools	81	39.3%
5) Lack of quality service providers for referrals	63	30.6%
6) Lack of information regarding appropriate screening tools	59	28.6%
7) Limited ability to store or use data collected from screenings	33	16.0%
8) Lack of laws requiring that our program screen children	25	12.1%
9) Lack of program accountability to existing laws requiring screening of children	17	8.3%
10) Lack of information regarding the purpose or importance of screening	16	7.8%

Table 4 lists the most commonly used screening tools, with the ASQ and ASQ-SE most frequently cited.

Table 4: **Screening Tools Used by ECE Programs**
Percentage of Respondents Utilizing Tool
N=164

		Number Utilizing Tool	Percent Utilizing Tool
Don't Know		**15**	**9.1%**
1)	Ages and Stages Questionnaire (ASQ)	101	61.6%
2)	Ages and Stages Questionnaire: Socio-Emotional (ASQ-SE)	63	38.4%
3)	Devereux Early Childhood Assessment (DECA)	29	17.7%
4)	Brigance Early Childhood Screens III	25	15.2%
5)	Early Screening Inventory (ESI)	23	14.0%
6)	Battelle Developmental Inventory	16	9.8%
7)	Modified Checklist for Autism in Children (M-CHAT)	12	7.3%
8)	Devereux Early Childhood Assessment-Infant Toddler (DECA-IT)	10	6.1%
9)	Pediatric Symptom Checklist (PSC)	9	5.5%
10)	Preschool and Kindergarten Behavior Scales-2 (PKBS-2)	9	5.5%
11)	Parental Evaluation of Developmental Status (PEDS)	8	4.9%
12)	Temperament and Atypical Behavior Scale (TABS) Screener	6	3.7%
13)	Denver Developmental Screening Test II	6	3.7%
14)	Developmental Indicators for the Assessment of Learning (Dial 3)	3	1.8%
15)	Brief Infant Toddler Socio-Emotional Assessment (BITSEA)	2	1.2%

The overwhelming majority of ECE providers who indicated that their childcare program screened children identified a high degree of parent involvement in the process and the use of specific protocols to enhance validity of results. A summary of responses is in Table 5.

Table 5: **Screening Processes Used**
Percentage Agreement
N= (approximately) 175

In my ECE program…	Strongly Disagree/ Disagree	Agree/ Strongly Agree
1) When a referral is needed, ECE staff work with parents/guardians to identify providers.	3.3%	**96.7%**
2) Parents/guardians are told that their child will be screened before the screening occurs.	5.7%	**94.3%**
3) Parents/guardians are given the information they need to understand why screening is recommended for their child.	5.5%	**94.5%**
4) We use information from developmental monitoring practices to support screening information.	6.4%	**93.6%**
5) Parents/guardians are told of the results of the screening.	6.3%	**93.8%**
6) Information provided by parents is used as part of the screening process.	8.6%	**91.4%**
7) Staff who conduct the screenings are trained to use the screening tool.	9.6%	**90.4%**

In my ECE program…	Strongly Disagree/ Disagree	Agree/ Strongly Agree
8) If a teacher or parent identifies behavior that may indicate a concern, the child is screened.	9.8%	**90.2%**
9) We have protocols or procedures which we follow when we screen children.	11.7%	**88.3%**
10) Parents/guardian must give permission before their child is screened.	15.8%	**84.2%**
11) A protocol or procedure is in place to decide which staff member will screen a child.	17.1%	82.9%
12) We have staff who have been trained to give developmental and behavioral health screenings.	20.9%	**79.1%**
13) I am satisfied with the ability of our ECE program to conduct screenings.	21.3%	**78.7%**
14) All children are screened.	37.6%	**62.4%**

Parent Survey Responses about Surveillance and Screening

More than half (65.2%) of parents responded that that the childcare provider had asked about concerns they had for their child. A slightly greater percentage (76.4%) of respondents stated that their child health provider had asked about their concerns. One quarter of parents (25.2% or 202 individuals) stated that they had noted concerns on the health form. Of these parents, 82.2% stated that the childcare provider asked for additional information subsequent to submission of this form, and 82.9% stated that the child health provider had asked for additional information. Although data was not available to identify the location in which screenings occurred, almost half (411 or 48.4%) of the 849 responding parents indicated that their child had been screened with a formal questionnaire during the past year. Fifteen percent (141 parents) stated that they did not know if their child had been screened. Of the 357 parents who stated that their child had been screened, 57 individuals (16.0%) had children who had been identified as at risk for having developmental delays. Thirty seven individuals (10.4%) did not know what the screening results were for their child.

Table 6: **Parent Perceptions of Screening Process**
Percent Response
N=849

> **Note:** The percentage of individuals responding "Don't Know/Does Not Apply" is provided for informational purposes and is not included in the calculations of agreement.

	Strongly Disagree/ Disagree	Agree/ Strongly Agree	Don't Know/ Does Not Apply
1. I want to be involved in conversations related to my child's developmental progress.	5.0%	95.0%	3.0%
2. My childcare provider listened to my concerns related to the screening process.	6.1%	93.9%	15.6%
3. I was comfortable with the way the screening process was handled for my child.	6.5%	93.5%	7.9%
4. I would recommend my childcare center to a friend who had concerns about her/his child's development.	6.9%	93.1%	6.7%
5. I was given the information I needed to understand why my child was being screened.	7.2%	92.8%	7.7%

	Strongly Disagree/ Disagree	Agree/ Strongly Agree	Don't Know/ Does Not Apply
6. The results of my child's screening were shared with me in a way I could understand.	7.5%	92.5%	9.7%
7. I felt sufficiently involved in the screening process.	9.1%	90.9%	10.8%
8. I was asked for my thoughts about my child's development BEFORE my child was screened.	15.7%	84.3%	12.4%
9. I was told that my childcare provider had concerns regarding my child's progress BEFORE my child was screened.	34.5%	65.5%	25.3%

When asked about which aspects of screening were important for parents to be involved in, respondents expressed a high degree of interest in parental involvement in almost all aspects of screening, with less interest in parental involvement for selecting screening tools.

Table 7: **Parent Perceptions of Parent Involvement**
Percent Response
N=Approximately 800

	Not At all Important/ Somewhat Important	Quite Important/ Extremely Important
1. Planning a treatment program to meet any needs their child has which the screening identified.	3.2%	96.8%
2. Making decisions about how to use the information received from their child's screening.	3.7%	96.3%
3. Planning a treatment program for the child that will work for the family.	4.5%	95.5%
4. Identifying concerns related to their child's development.	4.8%	95.2%
5. Selecting service providers to meet their child's needs.	5.0%	95.0%
6. Providing input into the screening process.	8.5%	91.5%
7. Selecting developmental screening tests for use with their child.	16.0%	84.0%

Conclusions

Results from qualitative focus groups were supported by survey results and indicate overwhelmingly that the majority of state and federally-funded providers are aware of the importance of screening and surveillance activities and the importance of parent involvement in these activities and are making efforts to work with parents to monitor and screen children appropriately. Results also suggest that family child care providers and private providers are less likely to either be aware of or to be involved in surveillance and screening activities. When involved in screening activities, smaller programs typically relied more heavily on informal observations and self-identified tools to enhance surveillance while larger centers described the use of more structured screening and surveillance processes conducted by trained providers. The use of Early Childhood Health Assessment Records varied with larger centers reporting its use upon intake and subsequent well child visits in some cases and smaller centers and home-based providers using the forms less frequently. All respondents identified the need for ECE providers to have access to appropriate surveillance and screening tools, policies and guidelines concerning the appropriate use of these tools, and to incorporate parent input into these activities. Parent input was typically incorporated into surveillance and screening activities through a variety of formal and informal venues and strategies.

Smaller private programs and family child care providers typically did not screen and had few specific protocols in place for surveillance activities. The majority of providers expressed a moderate degree of satisfaction with their current ability to monitor and screen children and the vast majority expressed interest in the use of a statewide mandatory screening process for children with recommended protocols, procedures and tools in place.   Challenges to screening and surveillance were identified including inadequate time, fiscal and staffing resources, presence of a number of competing curricula and programs requiring or recommending the use of different tools and processes, a lack of staff trained to conduct screenings, a lack of parental engagement in the process and a lack of understanding among pediatricians related to the use of screening and surveillance.

Although the majority of providers stated that parents were consistently involved in monitoring and screening activities, a number of parents "did not know" if their children had been screened or, if screened, stated that they "did not know" the results. Almost all parent respondents expressed a high degree of interest in involvement in the monitoring and screening process.

PROCEDURES FOR MANAGING DEVELOPMENTAL AND BEHAVIORAL HEALTH SCREENING DATA

Focus Group Responses

"I work at DCF and am based at the Center. We do ASQ when kids come into care at DCF but they're already done at school. Why is everybody doing them when there could be a database that we could access where we know that it's already done, or what services, where it is all in one place?"

--A Department of Children and Families staff member—

"We use daily observations and the Dial 3 Screening tool. We do all the vision and hearing tests too. We have very specific protocols and processes and policies, which must be followed. For behavioral health we use the M-CHAT and other tests when we need to. The results are put into the Promise database. In September we are going to start inputting data into the Board of Education Power School system. But probably not the screening results—those are done when children first come in, long before they go to school."
--A publicly funded center-based staff member—

"We store our data in a database. The teachers have access to the database but not for Birth to Three. For Birth to Three only the administrator and the secretary have access. All staff have their own user name and password to get into the database which helps with accuracy. The hardest thing about sharing with key providers outside is a lack of a secure system—you can't use e-mail."

--A publicly funded center-based staff member--

Data Storage and Management Procedures

The small private centers and the family child care providers generally stored what information they collected in hard copy and provided one copy to parents. In one case, immunization and attendance records were stored electronically.

Larger centers claimed that they used a variety of data storage and management procedures. The majority of larger ECE centers used a combination of both hard copy and electronic data storage. Participants described the format of data storage as dependent upon the type of data being stored, the existence of

regional or program-specific databases accessible to center staff, and the recommendations or requirements of specific federal or state programs with which the ECE program is involved.   For example, one center uses the Dial 3 for behavioral assessment and stores and maintains these data only in hard copy form. However, the same center uses an electronic data base to store health assessment data including the results of hearing and vision screens and the PROMISE database to store results of activities collected for the Head Start program. Head Start programs that are part of other ECE centers do not all use the PROMISE database but may use Child Plus instead. Birth to Three programs use the State's Birth to Three data system to collect and store data. Child Plus is used by other centers to store the results of the e-DECA and the Brigance while still other ECE programs use School Chapters or Excel to store assessment results. An ECE program's funding source often dictates the software system used to store surveillance and screening data. The types of data stored varies by program and funder and often includes child names, dates of birth, contact information for the parent and child, communication events with the parents, events in the center, attendance, referrals, whether a screening occurred and the results of screens or family assessments.

Similarly, a variety of procedures exist across centers which are used to maintain data accuracy and privacy. Typically, data entry occurs by qualified staff such as teachers, home visitors and supervisors with each individual generally entering data specific to their role or program. Supervising staff are generally responsible to audit and check data accuracy. In some cases, data entry is limited to specific individuals with a unique password being required to access the database. Child privacy is maintained through the use of parent consent forms, the use of HIPAA documentation, access to data only by specific staff, the use of release forms signed by parents prior to the sharing of any confidential information, and the use of child identification numbers. Typically, when child data are stored within a database provided by the funder, the funding agency also has access to the data and will utilize the data for reporting purposes.

ECE programs describe a number of obstacles to using an electronic data system including:

- limited staff to enter data;
- lack of understanding of what types of data are most needed and what must be documented;
- need for training on the various software programs;
- need for strategies to limit access to and enhance accuracy of existing data;
- lack of financial resources; and
- lack of secure systems through which to transfer data.

Respondents also identified statewide barriers to data maintenance including:

- lack of consistent client and family identification number across programs;
- existence of a variety of databases across state agencies; and
- need to maintain privacy and confidentiality with data storage and transfer.

ECE Providers' Recommendations to Enhance Development of a Statewide Data Management and Storage System

The majority of participants expressed an interest in the development and use of a statewide, shared data management and storage system. Respondents believed that the existence of such a system would encourage screening and necessary follow-up evaluation and intervention. They also recognized that a centralized data base could increase access to services and facilitate tracking of children and families who move between or among ECE programs. However, respondents emphasized that such a system needs to maintain family privacy and confidentiality. Respondents recommended that a universal identifier be

created and used by all state and local agencies to track individual children and, similarly, a universal database be developed for use by all ECE programs. It is noted that although the development of this system if possible, it would only legally be possible for children receiving public funding. Participants noted the need for professional development and technical assistance in the use of such a system. Some respondents were concerned that a centralized data system could lead to "labeling" a child and bias teachers and caregivers in making decisions about a child's needs.

Early Care and Education Provider Survey

Of the 183 survey respondents who identified whether or not they used an electronic system to store data collected from developmental screening, the majority (145 or 79.2%) did not. Thirty-nine respondents provided information related to the type of software used.   Responses are summarized below.

Table 8:   Software System Used to Store Screening Data
**   N=32**

	Number Using Software
Don't Know	**1**
1) ChildPlus	19
2) Excel	5
3) Site-specific software system	4
4) **None**	4
5) Power School	3
6) PKIS	2
7) ACCESS	1
8) PROMIS	0
9) ETS (Efforts to Outcomes)	0

Survey data highlighted the challenges that ECE providers face in storing surveillance and screening data. As summarized in Table 9, lack of software, funding, trained staff and information about hardware and software were most frequently cited.

Table 9:   Challenges Faced to Storing Data Electronically
**   Percentage Experiencing Challenge**
**   N=145**

	Number Experiencing	Percent Experiencing
1) Lack of access to appropriate data bases/software	87	60.0%
2) Lack of money	81	55.9%
3) Lack of staff trained to enter and monitor data	69	47.6%
4) Lack of information regarding appropriate hardware and software systems	69	47.6%
5) Lack of time	53	36.6%
6) Limited technological capacity to store screening data	55	37.9%
7) Lack of protocols to allow for the safe and confidential storage and sharing of data	38	26.2%
8) Lack of information regarding how to use screening data	36	24.8%

9) We do not believe that it is necessary to store or share developmental screening data electronically	30	20.7%
10) Inconsistent or inadequate reporting or collection of screening data	23	15.9%

Thirty-two ECE programs provided their perceptions of protocols and procedures used in data management and storage and 35 programs provided detail on the types of information they maintained in their electronic systems. Responses are summarized in Tables 10 and 11 and indicate that many programs maintain screening data and information about developmental concerns.

Table 10: Data Management and Storage Processes
Percentage
N=32

In my ECE program…	Strongly Disagree/ Disagree	Agree/ Strongly Agree
1) We have protocols or procedures in place to make sure that electronic records related to developmental screening results are accurate.	6.5%	93.5%
2) We enter data from developmental monitoring activities into an electronic database.	6.5%	93.5%
3) We have protocols or procedures in place to make sure that data entered into our electronic data system is confidential.	9.1%	90.9%
4) We are satisfied with our ability to store and use electronic data.	12.5%	87.5%
5) We have protocols or procedures in place that allow us to share screening data to make it easier to refer or track children.	12.9%	87.1%
6) We are satisfied with our ability to share data as needed.	21.2%	78.8%
7) We have protocols or procedures in place that would allow our data to be put into a statewide data storage system (i.e., unique child identifiers, privacy procedures).	56.0%	44.0%

Table 11: Information Included Within Electronic Data System
N=35

	Number Including
1) Data from screening results	34
2) Date of birth of child	34
3) Data related to the services /programs provided to the child	30
4) Notes about concerns regarding the child's development reported by parents, staff or the healthcare provider	29
5) Ethnicity of child	27
6) Unique child identification number	19
7) Unique identification number for staff who perform screenings	10

Conclusions about Surveillance and Screening Data Storage

Both focus group and survey results indicate that the majority (79.2%) of ECE providers do not store data electronically. Providers that did store data electronically utilized a wide variety of systems with only one system (ChildPlus) used by a number of programs. As with the screening and surveillance process, larger federally-funded centers and programs were more likely to store data electronically than smaller private centers or home-based child care providers. Additionally, the software utilized by respondents was

typically dependent upon the types of subprograms within the center and the funding source. The primary obstacle to electronic storage of data was identified as a lack of access to appropriate software systems.

Thirty-five providers stated that they managed data electronically. These providers typically had protocols and procedures in place to ensure data accuracy but limited protocols or procedures in place that would allow their data to be incorporated into a statewide storage system (44%). Information consistently incorporated into the electronic system by providers included screening data, date of birth, services and programs provided to the child and notes about concerns regarding the child's development. Screening data typically includes the fact that a screening occurred and the type of tool used, but does not include the actual results of the screen.

Provider perception of the need for a statewide data-sharing mechanism was mixed. Focus group respondents typically expressed an interest in the ability to store and share data but emphasized concerns related to privacy, a desire to not "label" the child by informing others about the screening results, and resource limitations. The majority of participants stated that the ability to store and share data statewide would be of interest only if the concerns could be addressed. The primary obstacles identified to the creation of a statewide database were a lack of unique child and family identification numbers.

HOW DO ECE SITES COORDINATE REFERRALS TO SERVICES IN PARTNERSHIP WITH PARENTS WHEN SURVEILLANCE AND SCREENING RAISE CONCERNS?

Focus Group Responses

"My wish? I wish we had support to help us deal with challenging behavior. And my biggest wish is to gain the genuine trust of parents so when you make a referral, if they are in denial, they would trust you just enough to try it."

--A home-based provider—

"Barriers to referrals we face? Physicians are not always up-to-date on what is needed. Also, language can be a problem and transportation to and from resources is a huge problem. And our wish for the future? We really need a global resource list for services—for all kinds of health care providers but particularly the ones that parents have trouble getting into like Pediatric Neurologists, Developmental Pediatricians and Pediatric Audiologists. These usually have long waiting lists. We also really need the state to recommend a tool or at the very least to provide us with cross-walks between the tools—what tools are best for what?"

--A publicly funded center-based staff member--

"I'm 100% Hispanic. In my culture it is a shame or taboo having a child with disabilities, period. I think as a culture we need to be educated and we need to be able to look for information, learn new skills, and just learn to accept that human beings are—we're different. We're different in so many ways."

--A parent—

The Referral Process

Small centers and family childcare providers shared concerns about children's behavior and development with families, as well as health consultants, social service consultants, and Birth to Three providers when invited or when these individuals were already present at the site. They did not report formal processes in

place to encourage or support these discussions. Referral resources mentioned by these sites included All Our Kin, pediatricians, nurse consultants, Child Development Infoline, Help Me Grow, Birth to Three and Family Resource Centers. Each family child care or small center provider generally mentioned no more than one of these resources; a few individuals stated that they had no awareness of any of these resources.

The larger centers generally coordinate referrals to developmental and behavioral services utilizing a variety of processes. In some cases, the referral process is facilitated by a formalized team of individuals including the parent, health consultant, child health care provider and early intervention provider if appropriate. In centers utilizing a team-based approach, teachers or parents typically refer children to the center director, who decides who else to involve in the team process. Team members are typically internal personnel when these personnel are available. Outside providers are asked to participate in team meetings as available and appropriate. Other centers utilize a less formalized approach. In all centers, conversations related to referrals were described by participants as open and productive.

Conversations with parents about the need for further evaluation and services following as a result of surveillance and/or screening occurred through a variety of venues. Strategies used by center staff to initiate these conversations included inviting parents to the classroom to observe the child, providing information to parents related to expected educational and developmental progress, provision of parent education programs to parents, telephone calls, letters and ongoing conversations between parents and center staff. Health consultants and child health care providers were described as participating in team meetings and/or being provided information as needed by center staff. In some centers, staff members communicate directly with outside providers while in other cases conversations with outside providers occur predominantly or exclusively between the parent and the outside provider. All participants stated that parent permission is requested prior to any contact with outside providers. Conversations between parties were described as being initiated by either the parent, the center or the early intervention specialist and occurring as needed.

Centers used a variety of procedures to assist parents in connecting children to appropriate evaluation and intervention service providers. In some centers, the parent is connected to the provider directly by center personnel such as the teacher or the Family Advocate and, in some cases, center staff participate with the parent in the initial visit to the follow-up provider. Some service providers (Preschool Special Education, Early Childhood Consultation Partnership) may go to the child's home or to the center to meet with the child and parent in a more natural environment. In other centers, resource lists are provided to parents and direct connections are made by the ECE provider infrequently. ECE providers varied in the extent to which they were able to track completion of follow-up visits by the parent. Some centers stated that they follow up with parents consistently and others expressed no ability to track completion of referrals.

Respondents described a number of obstacles related to their ability to successfully track and complete referrals. These included:

- perceived lack of knowledge on the part of physicians related to both the identification of developmental needs and appropriate referral processes;
- language and cultural barriers;
- transportation difficulties faced by families;
- parent and provider work schedules which make coordination challenging;
- lack of qualified medical, mental health, early intervention or other service providers which results in the child waiting to receive needed services;
- lack of private space to hold conversations that should not be overheard by individuals who are not involved;

- parental resistance which may result in a lack of ability to release screening results so the child can receive follow up services; and
- scheduling challenges which result in referral sources having insufficient time available to observe the child.

Recommendations to Enhance the Referral Process

There was only one recommendation which emerged from ECE providers related to the referral process. Focus group participants believed that there was a need for more trained evaluation and intervention providers to follow up after screening showed concerns.

Provider Survey Responses

Through the online survey ECE providers shared their perceptions of processes and procedures used to follow up when developmental and behavioral surveillance and screening showed concerns. Responding providers discuss developmental and behavioral concerns and positive screening results with families (88.4% and 74.4% respectively) and less frequently discuss these concerns with child healthcare providers, after receipt of parent permission (41.3% and 28.1% respectively).
Responses are summarized in Tables 12 and 13.

Table 12: **Individuals With Whom Developmental and Behavioral Concerns are Discussed**
Percentage Respondents Discussing
N=271

	Number Discussing	Percentage Discussing
Not applicable: Our ECE program does not monitor children	**20**	**7.4%**
1) Families	240	88.6%
2) Education Consultants	180	66.4%
3) Behavioral Health Consultants	153	56.5%
4) Early Intervention Providers	150	55.4%
5) Health Consultants	148	54.6%
6) Child Healthcare Providers	112	41.3%

Table 13: **Individuals With Whom Screening Results Which Indicate Potential Concerns Are Discussed**
Percentage Respondents Discussing
N=242

	Number Discussing	Percent Discussing
Not applicable: Our ECE program does not screen children	**50**	**20.7%**
1) Families	180	74.4%
2) Educational Consultants	111	45.9%
3) Early Intervention Providers	101	41.7%
4) Behavioral Health Consultants	89	36.8%
5) Health Consultants	85	35.1%
6) Child Healthcare Providers	68	28.1%

Respondents provided their perceptions of the processes used to support families in obtaining services when needed.   Processes utilized by respondents who monitor children's development are summarized in Table 14 and processes used by respondents who screen children are summarized in Table 15. In general, respondents who do not screen children and therefore provided information based on the use of surveillance processes only were less likely to cite referral related services than providers who indicate that their program screens children. Of the respondents who answered questions based on screening results, more than ninety percent stated that families were involved in all aspects of the referral process and that protocols and procedures were in place to support families to locate services. Slightly more than half of respondents (52.4%) utilized the Child Development Infoline to locate services and resources.

Table 14:   Referral Processes Used by ECE Programs Based on Surveillance Results Percentage
N= 32

In my ECE program…	Strongly Disagree/ Disagree	Agree/ Strongly Agree
1) We involve families in all aspects of the referral process.	14.3%	**85.7%**
2) We have a process in place to support conversations about developmental and behavioral concerns among families, childcare providers, health consultants, and early intervention providers.	19.4%	**80.6%**
3) We have a person responsible for encouraging conversations about developmental and behavioral concerns among families, childcare providers, early intervention providers and health consultants.	24.3%	**75.7%**
4) We have protocols or procedures in place that require childcare providers to assist families to access resources and services.	29.4%	**70.6%**
5) We use the Early Childhood Consultation Partnership (ECCP) to locate resources and services for children and families.	36.7%	**63.3%**
6) We are satisfied with our ability to coordinate referrals to services based on developmental and behavioral concerns.	40.5%	**59.5%**
7) We have protocols or procedures in place to track referrals to services based on developmental and behavioral concerns.	46.9%	**53.1%**
8) We have protocols or procedures in place to track connections to services as a result of developmental and behavioral concerns.	50.0%	**50.0%**
9) We have protocols or procedures in place that require health consultants to assist families to access resources and services.	50.0%	**50.0%**
10) We use the Child Development Infoline (800 505 7000) to locate resources and services for children and families.	61.3%	**38.7%**

Table 15:   Referral Processes Used by ECE Programs Based on Screening Results
Percentage
N= 168

In my ECE program…	Strongly Disagree/ Disagree	Agree/ Strongly Agree
1) We involve families in all aspects of the referral process.	2.8%	**97.2%**
2) We have protocols or procedures in place that require childcare providers to help families to access resources and services.	9.1%	**90.9%**
3) We have a process in place to support conversations about screening results among families, childcare providers, health consultants, and early intervention providers.	12.5%	**87.5%**
4) We have a person responsible for encouraging conversations about screening results among families, childcare providers, early intervention providers and health consultants.	16.3%	**83.7%**
5) We have protocols or procedures in place that require health consultants to help families to access resources and services.	25.9%	**74.1%**
6) We are satisfied with our ability to coordinate referrals to services based on positive screening results.	28.7%	**71.3%**
7) We use the Early Childhood Consultation Partnership (ECCP) for help when children have challenging behaviors.	29.1%	**70.9%**
8) We have protocols or procedures in place to track connections to services based on positive screening results.	33.8%	**66.2%**
9) We have protocols or procedures in place to track referrals to services based on positive screening results.	35.3%	**64.7%**
10) We use the Child Development Infoline (800 505 7000) to locate resources and services for children and families.	47.6%	**52.4%**

A number of respondents described challenges faced in the referral process, many of which relate to sensitivity communicating with parents and lack of resources. Results are summarized in Table 16.

Table 16:   Challenges Faced When Referring Families
Percentage Experiencing Challenge
N=211

	Number Experiencing	Percentage Experiencing
1) Family unwillingness to or inability to accept the child's diagnosis	142	67.3%
2) Parental fear of being referred to providers	123	58.3%
3) Lack of money in the family	94	44.5%
4) Lack of ability of family to access qualified service providers	69	32.7%
5) Lack of information regarding quality service providers	68	32.2%
6) Lack of money in program	62	29.4%
7) Lack of procedures or protocols for tracking referrals to service	61	28.9%
8) Lack of staff trained to coordinate referrals	50	23.7%
9) Lack of time	44	20.9%
10) Lack of staff trained to discuss positive screening results with parents	34	16.1%
11) Lack of staff able to communicate with families due to language barriers	27	12.8%
12) Lack of service providers able to provide service to the family due to language barriers	24	11.4%

	Number Experiencing	Percentage Experiencing
13) Lack of trust between parents and childcare providers	5	2.4%

Early Care and Education Parent Survey

The 53 parents who had children who had been identified as being at risk for developmental delays provided their perspectives of support they had received from their child's childcare provider. Their responses are summarized in Table 17. The majority of parents who responded that their child had been identified as at risk for a developmental delay, expressed relatively high agreement with the follow up items, including, to a lesser extent, receiving help in finding services.

Table 17:   Parent Perceptions of Referral Process
Percent Response
N=53

> **Note:** The percentage of individuals responding "Don't Know/Does Not Apply" is provided for informational purposes and is not included in the calculations of agreement.

	Strongly Disagree/ Disagree	Agree/ Strongly Agree	Don't Know/ Does Not Apply
1. I was given the information I needed to understand the results of the screening.	7.4%	92.6%	0.0%
2. I am satisfied with the services my child received from the service provider (medical or care professional) that I was referred to.	7.7%	92.3%	1.9%
3. The service provider (medical or care professional) my child was referred to met my child's needs.	7.7%	92.3%	1.9%
4. My child's childcare provider listened to my concerns related to the results of the screening process.	7.8%	92.2%	3.8%
5. My child's childcare provider helped make sure that I was able to get my child to the service provider (medical or care professional) that he or she needed.	8.0%	92.0%	5.7%
6. I felt supported in trying to find the service provider (medical or care professional) to help my child.	9.6%	90.4%	3.7%
7. I was given a list of telephone numbers and names of service providers (medical or care professionals) that could meet my child's needs.	10.0%	90.0%	5.7%
8. My child's childcare provider helped me to find the service provider (medical or care professional) to meet my child's needs.	11.5%	88.5%	3.7%

Conclusions

Online surveys again supported results from focus group discussions and indicated overwhelmingly that the majority of ECE programs (88.6%) worked with parents throughout the referral process. Respondents emphasized interactions with a number of other relevant individuals in the referral process including education consultants, behavioral health consultants, early intervention providers, health consultants and child healthcare providers.

Overall, data again suggest that larger centers are more likely to have specific protocols and procedures in place to refer children than smaller centers and family child care providers. The data indicate that the referral processes used by ECE programs are generally less defined than the screening processes with only 50% of respondents stated that they had protocols in place to track connections to services.

The primary challenges perceived by providers when referring families to follow-up services were family reticence to accept the child's challenges and parental fear of the referral process. Other challenges frequently identified include a lack of qualified providers, lack of knowledge among pediatricians related to developmental needs, language and cultural barriers and transportation difficulties.

Provider survey responses and focus group responses identified an emphasis on parent involvement in the referral process. These results are supported by results of the parent survey. Ninety percent of parents indicated that they were given a list of service providers who could meet their child's needs and 89% stated that the childcare provider helped them to find the appropriate service provider.

ECE PARTICIPANT VISIONS FOR THE SURVEILLANCE, SCREENING AND REFERRAL PROCESS

At the completion of focus groups, each respondent provided a summary of their desired vision for developmental surveillance and screening in early care and education, data storage maintenance and sharing, and the referral process in Connecticut. These visions provide a succinct overview of ECE providers' perceived needs in Connecticut.

- standardized language related to screening, data management and referrals across all systems from birth to 18 years of age;
- open and enhanced discussion and education related to surveillance and screening to ease the stigma and support parents;
- universal screening for all children;
- development and implementation of a statewide standard that requires surveillance and screening and referral processes that incorporate teacher, family and professional input at all levels and supports child transitions from birth through grade 12;
- development and publication of a universal resource list for surveillance, screening and referrals;
- trained consultants to support local programs to coordinate referrals and increase access to services for low-income parents;
- training for providers in topics including how to discuss difficult issues with parents and develop and maintain parental trust and training in strategies to identify and address specific challenging behaviors;
- development of strategies to help parents to communicate clearly with health care providers and provision of education to parents to provide them the skills to hold these conversations;
- increase in the number of trained referral providers; and
- development and enforcement of regulations to hold both center and referral personnel responsible for completing and tracking screenings and referrals.

DATA STRENGTHS AND LIMITATIONS

This report summarizes data collected to inform Connecticut's early childhood stakeholders' planning in regard to developmental surveillance and screening in ECE sites.

The data collection effort has the following strengths:
- Diversified data collection strategies including focus groups and on-line surveys with broad representation throughout Connecticut.
- Excellent participation of representatives from each stakeholder group, from all Connecticut counties, and from urban, suburban and rural areas throughout Connecticut.
- Good participation of a variety of ethnic, socio-economic and racial groups in survey data collection.
- The administration of surveys in both English and Spanish and the completion of two focus groups in Spanish to support input from Spanish-speaking families and individuals.
- The use of quality focus group and survey tools reviewed by a variety of early childhood professionals prior to administration.

Data collection limitations include:
- Survey and focus groups were not completed in languages other than Spanish or English.
- Comprehensive reliability and validity assessment of data collection instruments were not completed.

RECOMMENDATIONS BASED ON ECCS NEEDS ASSESSMENT FINDINGS

Analyses of focus group and survey responses provided a number of recommendations for consideration by the ECCS Advisory Committee. These recommendations emphasize the need for infrastructure development and resource provision statewide as well as the ongoing strengthening of partnerships and communication on state and local levels. As findings are being utilized to support the ECCS planning process, recommendations are grouped by the three priority areas identified within the ECCS action plan.

Action Plan Priority Area #1: *Sufficient statewide infrastructure to support comprehensive screening and surveillance and referral linkages.*

    Recommendations for consideration:
    o Identification of a state-level individual to serve as a resource related to surveillance and screening and the use of a trained consultants to support local programs;
    o Universal screenings to remove the stigma from the screening process;
    o Development of strategies to support strong connections between the tools and processes utilized to enhance developmental surveillance and screening and the tools and processes used to support the implementation of the Connecticut Early Learning and Development Standards (ELDS).
    o Increase in the number of trained providers of screenings;
    o Development of new, and enforcement of existing, laws to hold providers responsible to complete and track screening and referrals in a timely fashion;
    o Provision of evaluation and intervention services by Board of Education providers during summer months; and
    o Development of a statewide, shared early childhood data management and storage system including unique identifiers and universal data capture.

Action Plan Priority Area #2: *Sufficient statewide outreach and communication to support comprehensive screening and surveillance and referral linkages.*

    Recommendations for consideration:
    o Provision of specialized support and ongoing outreach to ECE providers including opportunities to observe screenings;
    o Development of a standardized language, set protocol and expectations related to screening and surveillance at a state level including guidance on transition through kindergarten;

- o Increased information-sharing with pediatricians;
- o Enhanced communication regarding surveillance and screening including development of parent involvement and education programs with a focus on parents from non-English cultural and language backgrounds;
- o Increase in home-visiting and after birth visits for family members to inform screening efforts; and
- o Development and publication of a universal resource list for surveillance, screening and referrals.

<u>Action Plan Priority Area #3</u>: *Sufficient statewide training and technical assistance supports to facilitate screening and surveillance and referral linkages.*

Recommendations for consideration:
- o Provision of professional development to providers; and
- o Use of trained assessors to support screening and surveillance activities.

REFLECTIONS ON RECOMMENDATIONS PROVIDED IN "*THE EARLIER THE BETTER*"

Results of the first year of the ECCS needs assessment provide evidence that the recommendations described within "*The Earlier the Better*" are being implemented and are beginning to inform the processes and partnerships necessary to help Connecticut build a robust system of early identification of children with, and at risk for, developmental and mental health needs. The ECCS Advisory Committee and the ECCS Evaluation Team include a variety of ECE partners dedicated to the creation of such a system, which will be responsive to the needs expressed by ECE providers and parents as part of the current report.

The data gathered through the needs assessment process and summarized within this report are serving as the basis for the development of an action plan to support the Office of Early Childhood, United Way of Connecticut and the ECCS partners in creating a system for early identification of children with developmental and mental health needs within the context of available assessment and intervention systems, as well as promoting universal developmental screening. The ECCS Action Plan will provide tasks and action steps for statewide ECE partners to use in supporting the integration of an early childhood system. Key goals to be addressed include the development of necessary infrastructure on a state and local level in addition to the development of a statewide process to implement consistent and appropriate developmental surveillance and screening, data sharing and maintenance, and connection of children at risk for not being ready for school to intervention services.

References

[1] Honigfeld, L. and Myers, J. 2013. *The Earlier the Better: Developmental Screening for Connecticut's Young Children*. Child Health and Development Institute. Connecticut.

[2] Wertheimer, R., Coran, T., Moore, KA, Hair, EC. 2003. Attending kindergarten and already behind; a statistical portrait of vulnerable young children. Washington, DC: Child Trends.

[3] American Academy of Pediatrics Council on Children with Disabilities, Section on Developmental Behavioral Pediatrics, Bright Futures Steering Committee & Medical Home Initiatives for Children with Special Needs Project Committee. (2006). Identifying infants and young children with developmental disorders in the medical home: an algorithm for developmental surveillance and screening. Pediatrics. 118 (1) 405-420.