

Developmental Surveillance and Screening in Early Care and Education:

Family and Provider Perspectives

Prepared for the Connecticut Office of Early Childhood and Connecticut United Way

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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.

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Family and Provider Perspectives

INTRODUCTION

A child's optimal development depends on early nurturing and attention to developmental and behavioral delays, challenges, and associated risk factors. Knowing this, child care centers, pre-schools, home visiting programs, and child health providers are incorporating developmental and behavioral screening into their programs and practices. The American Academy of Pediatrics and other early childhood organizations support such screening, but some providers are only screening for health issues or not at all. Furthermore, screening results are not always shared between health, early care and education (ECE), and home visiting providers resulting in duplicate screenings and/or missed opportunities for screening for some children.

Connecticut is working hard to address this. Together, the Connecticut Office of Early Childhood (OEC), United Way of Connecticut, and their early childhood partners are developing 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, OEC and Connecticut United Way applied for and received three years of **Early Childhood Comprehensive Systems Planning (ECCS)** funding from the United States Department of Health and Human Services — Health Resources and Services Administration (HRSA). The ECCS grant will support state activities toward completion of a needs assessment over a three year period and planning of additional activities to enhance Connecticut's ability to monitor young children's development and connect children with, and at risk for, developmental delays to intervention services.

A **statewide ECCS Advisory Committee** guides and supports the grant funded work and 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 ongoing monitoring of Connecticut's progress in implementing screening. With support from the Early Childhood Education Cabinet, in 2013 CHDI prepared and released an IMPACT publication on developmental screening in Connecticut, "*The Earlier the Better: Developmental Screening for Connecticut's Young Children*," which serves as a precursor to this IMPACT.¹ *The Earlier the Better* report summarized research and best practices for developmental screening and reviewed the use of available screening tools across Connecticut.

This second IMPACT focuses on the implementation of developmental screening across early childhood settings and provides a deeper understanding of the views and experiences of ECE providers and the families they serve. CHDI engaged Mhora Lorentson from Lorentson Consulting to collaborate on this evaluation and report. The report analyzes focus group and survey responses on ECE providers' and parents' views related to developmental surveillance and screening activities, procedures for handling data, and coordination of referrals to services for children showing concerns. It provides the ECCS Advisory Committee with recommendations for addressing early childhood developmental and behavioral needs as part of a comprehensive statewide plan to ensure children arrive at Kindergarten ready to learn.

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.

BACKGROUND

IMPORTANCE OF DEVELOPMENTAL SCREENING AND SURVEILLANCE IN EARLY CHILDHOOD

Many studies have documented the importance of healthy development in the very earliest years of life to children's educational and overall life outcomes.² As summarized by Honigfeld and Meyers, 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.¹

A variety of factors have been shown to impede healthy development (See Figure 1).³ 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.

A large national study determined that 56% of kindergarten children did not have adequate skills for succeeding in kindergarten.⁴ The ability of these children to succeed and thrive is dependent upon early detection of developmental challenges and

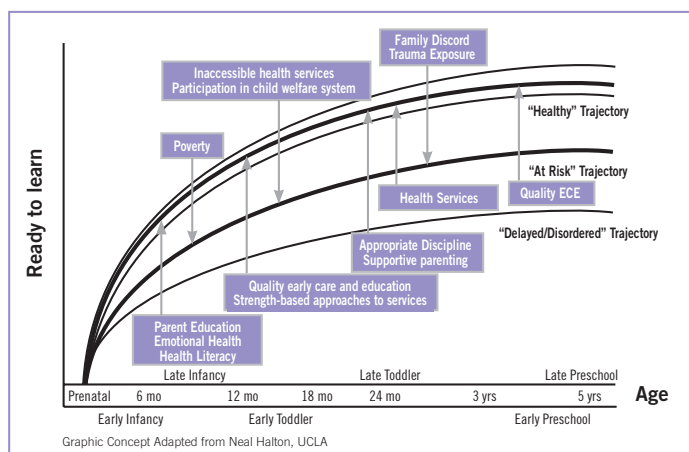
provision of interventions to address these challenges. Developmental surveillance and screening contribute to early identification of these children. For several years, early childhood experts have recommended surveillance and screening that begins early in life and is repeated throughout childhood, using reliable and valid screening tools appropriate to each child's needs.⁵ Early and frequent screening either in a pediatric office or in an early care and education setting has been consistently recommended to identify potential problems as early as possible and increase the ability to effectively provide the child with services and supports.⁶

In addition to recognizing the value of developmental screening with a validated tool, the American Academy of Pediatrics (AAP)⁷ also endorses developmental surveillance. 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. AAP recommends that surveillance be incorporated into every well-child visit, and that developmental screening, which includes use of a formal and validated tool, be conducted at the 9, 18 and 24 or 30

month well-child visits. As a result of the AAP recommendations, developmental surveillance and screening are increasingly part of pediatric well-child care services.

Early care and education presents an additional opportunity to detect developmental concerns and connect children to

Figure 1. School Readiness Trajectories



Although best practice guidelines support the implementation of developmental screening within ECE settings, there is a paucity of information available to understand the extent to which screening or surveillance are occurring and how screening information is used to ensure improved developmental outcomes for children.

intervention services. The proportion of three to six year old children (not yet in kindergarten) in the United States who attend center-based early childhood care and education increased from 55% in 2007 to 61% 2012. These numbers do not include the large number of children receiving care by licensed family child care providers. Surveillance and screening in early care and education settings can contribute to the identification and treatment of developmental challenges and risks. Although best practice guidelines support the implementation of developmental screening within ECE settings,^{8,9} there is a paucity of information available to understand the extent to which screening or surveillance are occurring and how screening information is used to ensure improved developmental outcomes for children. Three available sources of information are the Head Start program¹⁰, the Race to the Top: Early Learning Challenge¹¹, and the Preschool Development Program.¹²

Head Start is a federally funded program that provides early education, family support, health, dental, nutrition, and social services to low income children ages three and four and their families. The program's goal is to support school readiness for our nation's most vulnerable children. Head Start has served more than 30 million children since its inception in 1965. Head Start regulations require programs to perform developmental screening and ongoing monitoring for enrolled children and to report rates of screening and screening outcomes to the Administration for Children and Families annually. As outlined in the Head Start Child Development and Early Learning Framework, Head Start requires that 11 domains be monitored and requires Head Start programs to select "assessment instruments that are reliable and valid: developmentally, linguistically, and culturally appropriate for the population served."¹⁰ This performance standard provides the only comprehensive guidance nationally to inform how children's development is assessed in early care and education programs and applies to Head Start programs only.

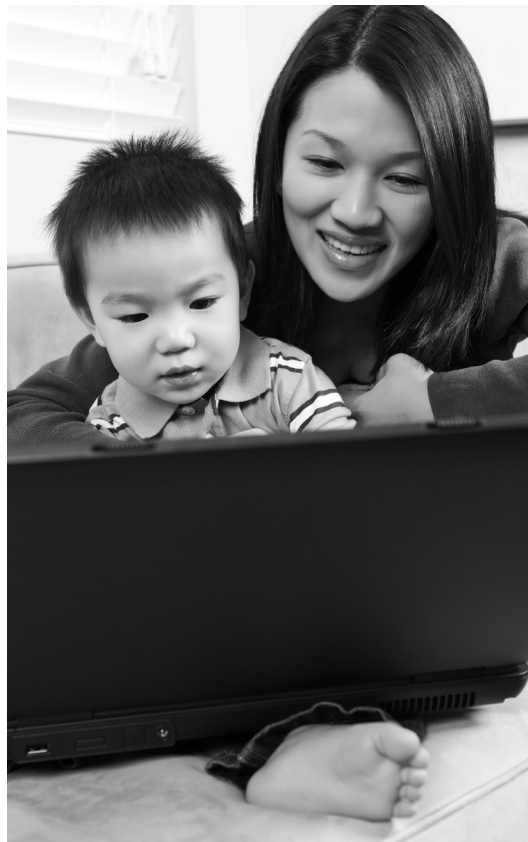
The national Race to the Top: Early Learning Challenge has provided federal funding to twenty states to develop high quality child care systems.¹¹ As part of their system building work, nine of the funded states are focusing on connections between health and early learning sites. Eight of the nine are promoting developmental screening in ECE sites and connection of children for whom screening shows concerns to follow-up evaluation and intervention services. Preliminary results indicate that child care providers and state level personnel are committed to the integration of developmental screening training into their Tiered Quality Rating and Improvement System (TQRIS). They recognize that the collection of screening data provides an opportunity to track progress within programs. States have identified a lack of access to baseline screening data and information about appropriate resources when screening is positive as significant challenges to improving statewide early detection of development concerns.

In further support of the development of high quality child care systems, the United States Department of Education has provided federal funding to states to build or enhance a preschool program infrastructure to enable the delivery of high quality preschool services to children. States can also expand high quality preschool programs in targeted communities to serve as models for expanding preschool to all 4 year olds from low and moderate income families. These grants are intended to prepare states to participate in the Preschool for All formula grant initiative currently proposed.¹² In both grant programs, high quality preschool is defined, in part, as a preschool providing comprehensive services including screenings and referrals, family engagement, nutrition services, coordinated early intervention services, physical activity services, family community services, onsite coordination of services, and additional support services determined by the state.¹³ In 2014, five states received development grants and 13 states, including Connecticut, received expansion funding under this initiative.

A comprehensive literature review did not yield any published studies that address how surveillance, screening, and referrals are occurring in early care and education settings. In Connecticut, stakeholders involved in the ECCS planning process are striving to address these issues and develop a plan that ensures that ECE sites maximally contribute to the State's school readiness aims by ensuring the early detection of children with and at risk for developmental delays and their connection to follow up services. Towards this end, from January to December 2014, Lorentson Consulting designed and implemented an investigation to identify ECE provider and family views on the current status of developmental surveillance and screening, use of data, and coordination of referrals throughout Connecticut. The study was designed to address the following key questions about developmental surveillance and screening in Connecticut:

- I. What processes guide developmental and behavioral health surveillance and screening in early care and education?
- II. How are developmental and behavioral health screening data maintained?
- III. How are referrals to evaluation and intervention services coordinated for children for whom developmental and behavioral health surveillance and screening show concerns?

The researchers employed focus groups and surveys to answer these questions. A technical reference report that discusses complete data collection and analysis methodologies and data strength and weaknesses is available from the United Way. http://www.eccsct.org/files/2015/10/ECCSCT_TechnicalReport.pdf



Data for the current report were derived 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 this project)
- C. 924 responses to the “Early Childcare and Education Parent Survey 2014” (in English and Spanish), (developed by Lorentson Consulting for this project)

FINDINGS

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

The Surveillance and Screening Process

Focus group results showed that the larger, **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. In general, small privately owned facilities receiving few or no public funds 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 to identify and address behavioral needs and challenges.

Larger publicly funded centers 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 including health consultants, social workers, speech and language consultants, classroom teachers, and mental health consultants.

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, with 86% of the 329 respondents saying they ask parents about concerns regarding their child's development, behavior, or health sometime during the enrollment process. Providers said they document both the child's developmental progress (83.6%) as well as parental concerns (70.2%) in program records, and also review the Early Childhood Health Assessment Records, health forms required for enrollment in ECE programs, for child health provider concerns (74.5%) and parental concerns (72.6%).

The 329 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 behavior and development with parents

Respondents experienced concerns about discussing behavior and development with parents (25.4%) and lack of providers to whom to refer children whose screening showed possible delays (17.7%).



(25.4%) and lack of providers to whom to refer children whose screening showed possible delays (17.7%). Other challenges included lack of knowledgeable staff able to understand expected developmental progress (8.8%) and advise parents when concerns are identified (8.7%). In terms of the ability to monitor children's behavior and development, a few respondents cited a limited ability to store or use data from monitoring, and lack of laws requiring (5.2%), and information regarding (3.3%), monitoring.

Surveillance activities within larger centers, while varied, 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.

Survey respondents cited several challenges to screening. The most pressing issues were lack of staff, time, and money.

Survey responses showed that **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 ASQ at six months. Small sites relied heavily on “*informal observations*” in combination with the use of some of the following to implement surveillance, including:

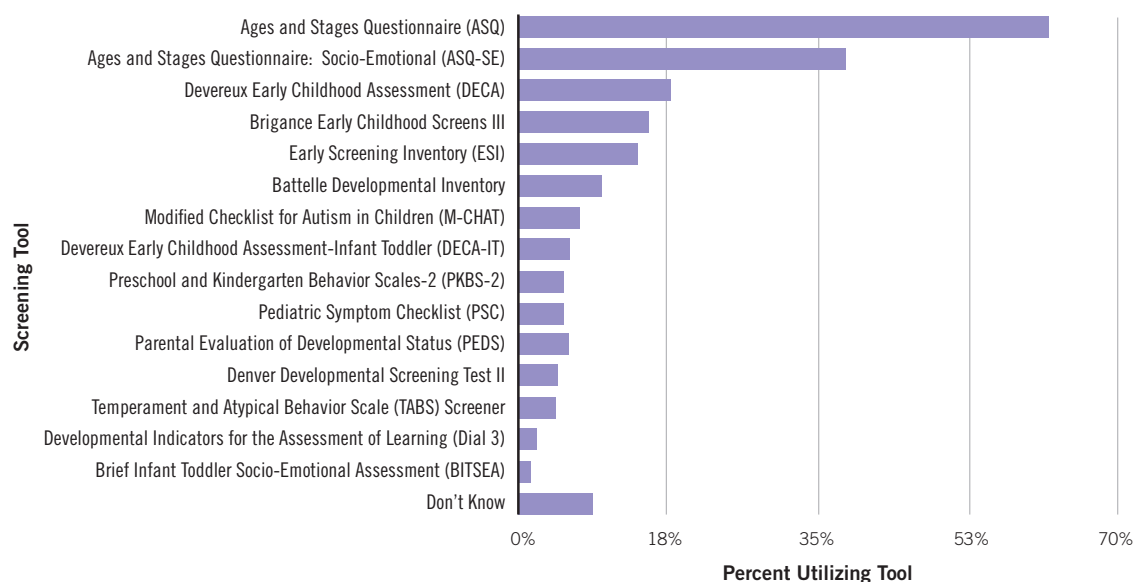
- teacher observation notebooks
- formal progress reports for older children
- use of the CT Early Learning and Development (ELD) standards checklist for keeping track of stages
- daily observations
- developmental milestone checklists
- ongoing informal and/or formal conversations with parents
- the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

Screening Tools

More than half of the 164 respondents who completed the survey question about formal screening stated that their program either currently relies on screening tools to identify potential developmental problems or risk factors (60.1% of the 164) or anticipates the administration of such tools in the future (24.5% of the 164). Fewer than one fifth of these 164 respondents (15.4%) stated that their program neither relies on screening tools currently nor anticipates future administration of such tools.

Figure 2 shows the most commonly used screening tools, with the ASQ and ASQ-SE most frequently cited.

Figure 2. Screening Tools Used by ECE Programs (n=164 programs)



Almost half of the 849 responding parents indicated that their child had been screened with a formal questionnaire during the past year.

Challenges to Screening

Those survey respondents who screened children (N=164) cited several challenges to screening. The most pressing issues were lack of staff (46.6%), time (42.2%), and money (41.7%). Respondents also said that there are no laws requiring screening (12.1%) and little information available regarding appropriate screening tools (28.6%). Among those who screen, some said they not only have limited ability to store or use the data they collect (16.0%), but also require more appropriate screening tools (39.3%) and quality service providers to refer families to following positive screening results (30.6%).

Parent Engagement

The overwhelming majority of the 164 ECE providers who indicated on the survey that their child care program screened children identified a high degree of parent involvement in the process (96.7%) and the use of specific protocols to enhance validity of results (88.3%). These protocols include having staff members who have been specifically trained to give developmental and behavioral health screenings administer the screening, and using information provided by the parents as part of the screening process. Respondents indicated that parents are involved in the entire process, from being told when and why their child will be screened, to having the screening results discussed with them. Parents and teachers can also request that a child be screened if they have any concerns.

Survey responses also showed that 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 that includes parent membership on the team; and “debrief” meetings with parents subsequent to screening.

Smaller centers and family child care programs 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.

More than half (65.2%) of the 924 parents who completed the survey responded that the child care 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 these parents stated that they had noted concerns on the health form. Of parents who had noted concerns on the health form, 82.2% stated that the child care 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.

Almost half of the parents answering the screening question (849) indicated that their child had been screened with a formal questionnaire during the past year. A few (15%) of 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, 16.1% had children who had been identified as at risk for having developmental delays. Ten percent did not know what the screening results were for their child.

When asked about which aspects of screening were important for parents to be involved in, survey respondents generally expressed a high degree of agreement about parental involvement in almost all aspects of screening.

More than 90% of the 849 parents of children who received screening responding to the survey indicated that they wanted to and were able to be involved in the screening of their child, citing that the child care providers not only listened to any concerns they had, but also provided them with any information needed to understand the screening process. The majority of these 849 parents said that they were comfortable with how the screening process was handled (93.5%), and that the providers shared the results with them in a way that the parents could understand (92.5%). Although 84.3% of these parents stated that they were asked about their thoughts on their child's development before their child was screened, only 65.5% of responding providers indicated that they shared concerns with parents before the screening, underscoring the finding that a quarter of providers feel uncomfortable sharing developmental concerns with parents.

When asked about which aspects of screening were important for parents to be involved in, survey respondents generally expressed a high degree of agreement about parental involvement in almost all aspects of screening. At least 90% of the 924 responding parents thought that they should be involved in identifying delays in their child's development, finding service providers to help their children, providing input into the screening process, and planning the treatment for their child. A bit less important to parents was choosing the specific screening tests to use for their child (84.0%).

Satisfaction with Surveillance and Screening Process

In focus groups, smaller private providers 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 providers participating in focus groups 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 use of screening 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 in the classroom 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 about the use of screening tools and screening timeframes and how to access Birth to Three services
- Working with data and personalities across various parts of the child care system
- 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

Focus group respondents provided a range of suggestions to improve surveillance and screening in ECE sites. They cited the need for

better connection of screening efforts to the Connecticut Early Learning and Development Standards (ELDS). Participants stated that the academic implications of the ELDS were typically emphasized and easily understood by parents and that connecting surveillance and screening to these standards would encourage parental buy-in and involvement both to surveillance and screening and to the Standards.

Suggestions for enhancing parental involvement in the screening and surveillance process included:

- Development of strategies designed to involve parents within the classroom setting to observe their child
- An open door policy for parents encouraging parents to visit and observe at any time
- Parent conferences at least three times a year with the incorporation of discussions regarding strengths and challenges faced by the child

All respondents identified the need for ECE providers to be aware of and have access to appropriate surveillance and screening tools and processes when needed and to incorporate parent input into these activities.

Summary and Conclusions on Surveillance and Screening

Results from qualitative focus groups were supported by survey results and indicate overwhelmingly that the majority of providers in state and federally-funded programs, such as Head Start, 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 to help identify concerns 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 be aware of and have access to appropriate surveillance and screening tools and processes when needed 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-based 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 responded that they “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.

The majority of larger ECE centers used a combination of both hard copy and electronic data storage.

II. PROCEDURES FOR MANAGING DEVELOPMENTAL AND BEHAVIORAL HEALTH SCREENING DATA

Data Storage and Management Procedures

Once children are screened, or when developmental surveillance shows concerns, it is imperative that they receive follow-up assessment and intervention if necessary. Data tracking allows ECE sites to monitor development over time and track follow up activities. It can also allow the OEC to monitor implementation of screening and follow-up similar to what Head Start does.

Through focus group discussions it became evident that 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. One family child care provider kept a summary packet with records over time and provided it to parents to give to kindergarten teachers if desired. One individual did not store any information and requested guidance as to the importance of maintenance and use of these records.

Larger centers reported in focus groups 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. Birth to Three programs use an in-house data storage system. ChildPlus¹⁵ is used by other centers to store the results of the e-DECA and the Brigance while still other ECE programs used 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 vary by program and funder and often include client 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, focus group discussions yielded a variety of procedures that exist across centers to maintain data accuracy and privacy. Typically, data entry is done 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 required to access the database. Client privacy is typically 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 client identification



numbers. Typically, when children's data are stored within a database provided by a public agency, the agency also has access to the data and will utilize the data for reporting purposes.

During focus group discussions, ECE programs described 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
- 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
- need to maintain privacy and confidentiality with data storage and transfer

During focus groups, ECE providers made a number of recommendations to enhance development of a statewide data management and storage system. The majority of participants endorsed 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 database could increase access to services and facilitate tracking of children and families who move between or among ECE programs. 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 is 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.

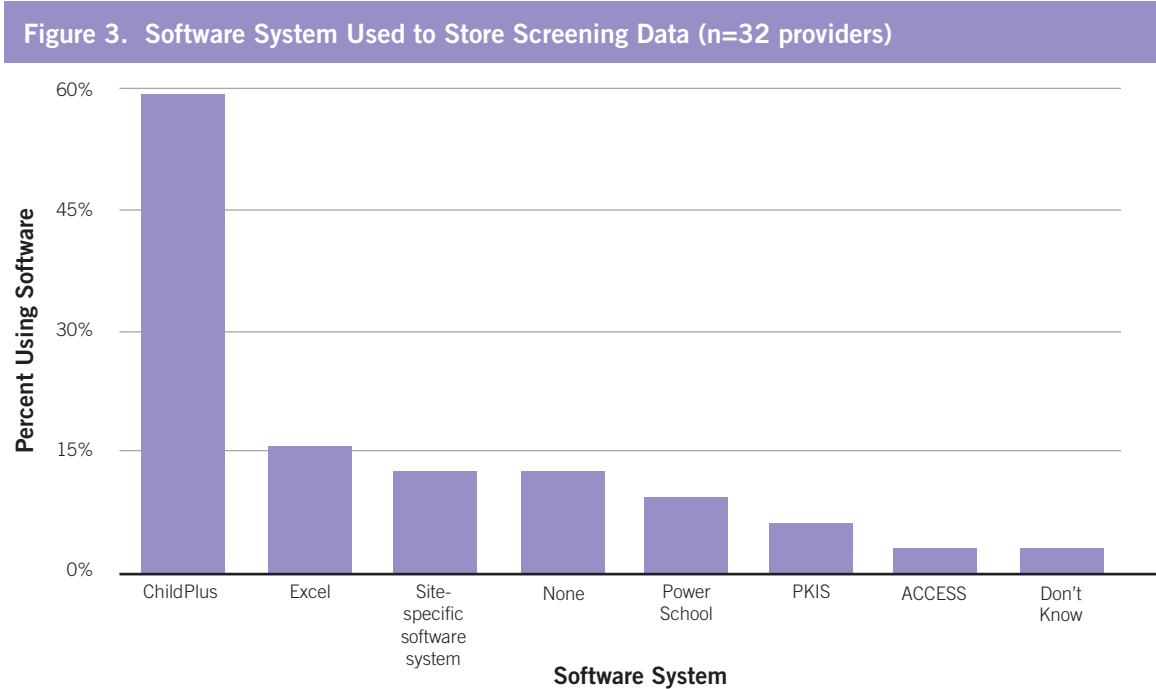
Of the 183 survey respondents who responded to questions related to the use of electronic systems to store data collected from developmental screening, the majority (79.2%) did not use an electronic system.

Of the 183 survey respondents who responded to questions related to the use of electronic systems to store data collected from developmental screening, the majority (79.2%) did not use an electronic system. Thirty-two providers supplied information related to the type of software used. Responses are summarized in Figure 3.

Survey data highlighted the challenges that ECE providers (N=183) face in storing surveillance and screening data. Lack of access to appropriate databases or software (60.0%) and lack of money (55.9%) were cited as the most frequent challenges that respondents faced to storing data electronically. Providers also mentioned lack of information about using the software (47.6%),

as well as lack of time (36.6%), staff (47.6%), protocols to keep data confidential (26.2%), and technological capacity as barriers (37.9%).

Thirty-two ECE programs provided survey responses indicating 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. Ninety-three percent of respondents kept an electronic database, and 97.1% of those said that they kept both data from the screening results and the child's date of birth in their electronic data system, with protocols in place to make sure that the electronic records related to developmental screening results are



accurate. Over 80% of the providers said that they also keep data related to the services provided to the child, and notes about their development, and 77.1% recorded the ethnicity of the child. The programs do have protocols in place to make sure that the data in the system remain confidential, but can also be shared or put into a statewide data storage system in order to make it easier to refer or track children. About half of the respondents said that the children screened had a unique identification number, which allows programs to put children's information into the statewide storage system.

Conclusions About Surveillance and Screening Data Storage

Focus group comments suggest and survey results indicate that the majority (79.2%) of the 183 ECE providers who responded to data storage questions do not store data electronically. Providers that indicated the system that they use (N=32), identified a wide variety of systems with only one system (ChildPlus)¹⁴ used by several 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 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 diagnosis, 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 obstacle identified to the creation of a statewide database was a lack of unique client and family identification numbers.

COORDINATION OF REFERRALS TO SERVICES IN PARTNERSHIP WITH PARENTS WHEN SURVEILLANCE AND SCREENING RAISE CONCERNS

The Referral Process

Small centers and family child care 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.

As reported in focus groups, 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.

In all centers, conversations related to referrals were described by participants as open and productive. ECE center staff also discussed a variety of procedures to assist parents in connecting children to appropriate evaluation and intervention service providers.

ECE providers also discussed in focus groups several ways that they initiate conversations with parents about the need for further evaluation and services as a result of surveillance and/or screening. Strategies used by center staff 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.

ECE center staff also discussed 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.

ECE focus group 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 that make coordination challenging
- lack of qualified 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
- scheduling challenges, which result in referral sources having insufficient time available to observe the child

Providers discuss developmental and behavioral concerns and positive screening results with families and less frequently discuss these concerns with child health care providers. ECE providers consistently discussed positive screening results with families and other individuals less often after screening than they did when detecting concerns through surveillance.

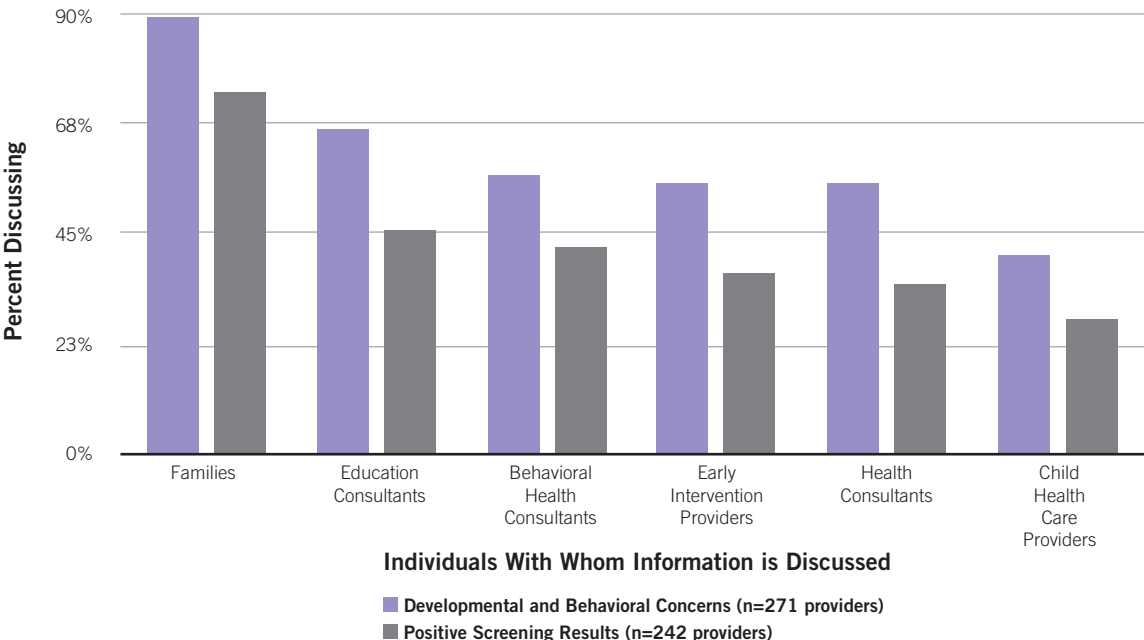
Through the online survey, 329 ECE providers shared their perceptions of processes and procedures used to follow up when developmental and behavioral surveillance and screening raised concerns. Responding providers discuss developmental and behavioral concerns and positive screening results with families (88.4% and 74.4% respectively) and less frequently discuss these concerns with child health care providers after receipt of parent permission (41.3% and 28.1% respectively).

Figure 4 shows with whom ECE providers reported that they discuss information for both developmental and behavioral concerns detected

through surveillance and positive screening results. ECE providers consistently discussed positive screening results with families and other individuals less often after screening than they did when detecting concerns through surveillance. This supports the need for more training and direction about the evaluation and intervention process following positive screening results.

Survey respondents (N=329) also provided their perceptions of the processes used to support families in obtaining services when needed. In general, respondents who do not screen children and therefore provided information based on the use of surveillance processes only were less likely

Figure 4. Individuals With Whom ECE Providers Discuss Information



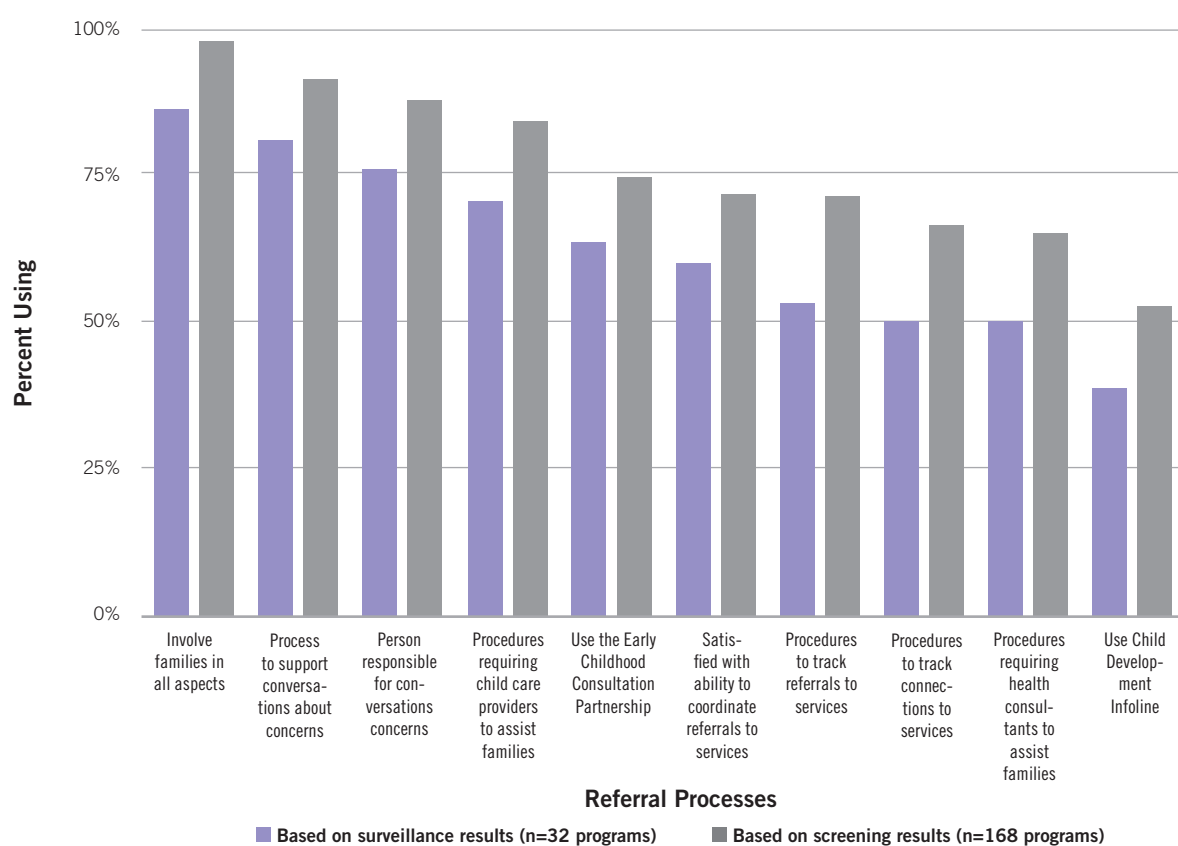
Of the respondents who answered questions based on screening results, more than 90% stated that families were involved in all aspects of the referral process and that protocols and procedures were in place to support families to locate services.

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 90% 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.

Figure 5 shows the referral processes reported by ECE programs on the survey, comparing the referrals based on surveillance versus those based on screening results. Respondents who performed a formal screening for children were more likely to use any referral process than those who obtained information only from surveillance, suggesting the use of formal screening tools might result in better linkage of children to follow-up evaluation and intervention services.

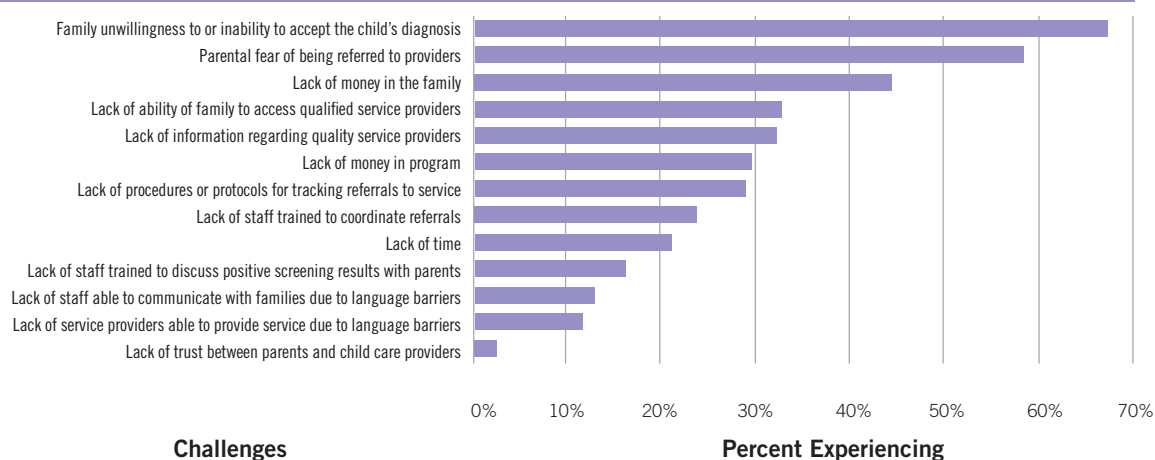


Figure 5. Referral Processes Used by ECE Programs Based on Surveillance and Screening Results



The parents felt that they were not only able to express concerns about the results of the screening but that they also had plenty of support in finding the proper service provider.

Figure 6. Challenges Faced When Referring Families (n=211 providers)



A number of survey respondents noted challenges faced in the referral process, many of which relate to sensitivity communicating with parents due to the parents being unable to accept a diagnosis, fear of being referred to providers, and not trusting the providers. Other challenges involved a lack of time and resources on behalf of providers and families to properly refer patients. Figure 6 shows the percent of programs that said they faced specific challenges when referring families.

Fifty-three parents reported on the survey that they have a child who had been identified as being at risk for developmental delay and responded to a question about support they had received from their child care provider. Most of these parents said that they were given information needed to understand the results of their child's screening (92.6%), the service provider they were then referred to met the child's needs (92.3%), and they were satisfied with these services (92.2%). The parents felt that they were not only able to

express concerns about the results of the screening (92.2%), but that they also had plenty of support in finding the proper service provider (90.4%).

There was only one recommendation that emerged from the ECE provider focus groups related to the referral process. Focus group participants expressed the need for more providers who were trained to do evaluations and interventions after screening showed concerns.

Conclusions About Referral Processes

Online surveys again supported results from focus group discussions and indicated overwhelmingly that the majority of ECE programs (88.6% of 329) 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 health care providers.

Data indicate that the referral processes used by ECE programs are generally less defined than the screening processes with only 50% of respondents stating that they had protocols in place to track connections to services.



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-based 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 stating that they had protocols in place to track connections to services.

Providers identified a number of challenges when referring families to follow-up services. By far the most frequently identified challenges 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 about 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 child care 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 and include:

- 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
- development and enforcement of regulations to hold both center and referral personnel responsible for completing and tracking screenings and referrals

RECOMMENDATIONS FOR ADDRESSING EARLY CHILDHOOD DEVELOPMENTAL AND BEHAVIORAL NEEDS

Analyses of focus group and survey responses provided a number of recommendations for consideration by the ECCS Advisory Committee, the Office of Early Childhood, and other early childhood stakeholders in Connecticut and beyond. These recommendations emphasize the need for infrastructure development and technical support statewide as well as the ongoing strengthening of partnerships and communication on state and local levels. Specific recommendations include the following:

1. Raise public awareness about the importance of surveillance and screening.

Parents and providers need to understand the value of monitoring young children's development, and how surveillance and screening contribute to early detection of children's developmental and behavioral challenges. With increased understanding and knowledge about developmental monitoring, stigma associated with the identification of concerns can be minimized. Public awareness materials need to address the linguistic and cultural needs of families across a wide range of racial and ethnic groups.

2. Provide training opportunities to a wide variety of professionals who can do surveillance and screening.

Early care and education providers can benefit from training on surveillance, screening, and linkage of children to assessment and intervention services when they have concerns. Several training opportunities exist through the OEC and elsewhere. These need to be coordinated and deployed so that provider capacity to monitor children's development follows evidence-informed protocols and ensures that children who need follow-up services receive them. Providers also will benefit from training on communication of screening results to parents and orientation to the services available through United Way 211 Child Development Infoline. These services are available to all families, and can be accessed by families, ECE providers, and health providers. A single position within the OEC to oversee training and implementation of developmental screening across public and private programs would provide a clear point of contact for ECE, health, and other early childhood providers.

3. Integrate surveillance and screening into other initiatives focused on young children's development.

The OEC has developed a robust set of Early Learning and Development Standards for ECE programs. These need to be deployed as part of a system

that includes developmental surveillance and screening. Beyond ECE programs and health care and family child care settings, surveillance and screening need to be integrated into the transition to kindergarten process to ensure that children at risk for delays continue to receive necessary monitoring and follow-up.

4. Develop and maintain a data system to track surveillance, screening, and connection of children receiving services funded by public dollars when surveillance and screening show concerns.

Under the Family Educational Rights and Privacy Act (FERPA) (20 U.S.C. § 1232g; 34 CFR Part 99), states are authorized to collect information related to individual children when children are receiving public funding. Connecticut's early childhood system can only track follow up of children for whom screening and surveillance show concerns if the State invests in a data system that captures screening and follow up information for these children. Such a system can help ensure that all children receiving ECE services in publicly funded programs are screened, and that when screening reveals needs that follow up assessment is conducted and that children receive intervention when warranted. In addition, developmental information can

improve transition of children from preschool services to elementary school by providing information on needs and strengths. The OEC can make this capability part of its Early Childhood Information System if data can be collected in a way in which families' privacy is protected and labeling of children is prevented. This system could serve as a model or guide for use by providers when addressing the needs of children who receive services in privately funded programs and can therefore be used to enhance screening and referrals for all children.

5. Strengthen the system of services for children who require developmental assessments and intervention services.

Although early intervention and Help Me Grow services are available for children with a variety of developmental needs, families need support in connecting with these services. ECE programs working in collaboration with the Child Development Infoline can ensure that families receive home visiting, support, and intervention across a variety of service sectors. The integration of local school district preschool special education services into ECE programs that are year-round would provide extended school readiness opportunities.

MOVING FORWARD IN CONNECTICUT TO SUPPORT DEVELOPMENTAL MONITORING IN ECE SITES

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 discussed in this 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 for implementation over the next two years to support the Office of Early Childhood, Connecticut United Way, and the ECCS partners in creating a system for early identification of children with developmental and mental health needs. The ECCS Action Plan will provide tasks and action steps for each ECE partner to use in supporting the



development of an early childhood system. Key goals to be addressed include the development of necessary infrastructure on the state and local levels to support development of the 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.

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