April 18, 2016

<p style="text-align:center">Recommendations regarding Child Find Data Collection</p>

Background

Developmental screening is the use of screening tools to track the development of young children. Regular developmental screening allows for early identification of developmental delays and disabilities and child/family strengths. Developmental screening is a critical step in the process of identification and referral of all infants and toddlers who may be eligible for Part C Early Intervention (ages 0 to 3) and Part B Early Childhood Special Education (ages 3 to 5) under the Individual with Disabilities Education Act (IDEA). Identifying developmental concerns as early as possible and connecting families to appropriate services leads to more effective and cost-efficient intervention, giving children the best possible chance of entering kindergarten with the supports and skills needed to fully reach their potential.

In 2014, recognizing the critical importance of early and ongoing screening, the federal government launched a new initiative, *Birth to 5: Watch Me Thrive!* This is a coordinated federal effort to encourage healthy child development, universal developmental and behavioral screening for children, and support for the families and providers who care for them. *Birth to Five: Watch Me Thrive!* is spurring new efforts to screen children ages 0 to 5 across the country. Our recommendations (as described below) move us forward on a path to be able to look at how we are doing in meeting this goal of every child getting screened.

In the state of Illinois (the "State" or "Illinois"), families have access to developmental screening through a variety of providers. Namely, health providers, child-care providers, Early Intervention (EI) providers, home visitors, Head Start/Early Head Start (HS/EHS), local education agencies (LEAs), Preschool for All (PFA) and/or Prevention Initiative (PI) providers, and parents, among others, may provide developmental screenings to young children. In some areas of the State, initiatives through Innovation Zones and other early childhood collaborations, are increasing the number of children screened and referred to appropriate services when needed. Developmental screening is incorporated into ExceleRate Illinois, as early care and education providers must meet standards for developmental screening policies and procedures in order to earn Silver or Gold Circles of Quality. The ability to analyze − through quality data − whether all children are being screened, referred, and connected with appropriate services is essential to ensure that all children in the State enter kindergarten ready to learn.

The Child Find Project in Illinois

Since 1998, the Illinois State Board of Education (ISBE) has operated the Child Find Project (the "Project" or the "Child Find Project"). The Project is funded through IDEA Part B, Preschool Discretionary funds to develop and disseminate public awareness materials to LEAs, Special Education Cooperatives, and the Child and Family Connections (CFC) offices. In addition, the Project has provided public awareness activities over the years. The goal of the Project is "to educate the public about the importance of early intervention and early childhood special education services for eligible children as early as possible in their development" (Home: Child Find Project, n.d.).

One activity of the Project is to collect data on the number and location of developmental screenings taking place across the State for children between 0 to 5 years of age. There is a single Project Coordinator for the Project (the "Project Coordinator"), who receives data monthly from the 25 CFC sites across the State. The CFCs are the system point of entry for EI under the Illinois Department of Human Services (IDHS), and are required to report data to the Project. The CFCs complete a form (a copy of the current version is attached hereto as *Exhibit A*) using information gathered by the Local Interagency Council (LIC) coordinators, from school districts, early care and education providers, HS/EHS, PFA and PI programs, and others completing screenings in their regions. LIC coordinators gather information on behalf of their local CFC through outreach to providers. Providers are not required to report screening and referral data to LICs.

The Project Coordinator also receives data related to screenings on a quarterly basis from IDHS, which obtains such data from the Cornerstone data entry system. Specifically, the data from Cornerstone includes information from health departments (including the City of Chicago's health department and any county health departments), health clinics, Illinois Department of Children and Family Service (DCFS) pertaining to its wards, the Women Infants and Children (WIC) program, and family case management (FCM). The information from the Cornerstone system does not include data about referrals made in relation to any screenings. In recent years, data from the Cornerstone system has accounted for more than half of all the data submitted to the Child Find Project.

Some grantees in Cook County report their screening efforts directly to the Project, then send referrals to a CFC. In addition, the Erikson DCFS Early Childhood Intact Program (the "Erikson Intact Program") provides data to the Project.

The data collected through the Project is then compiled on an annual basis, and the Project Coordinator creates a year-end screening report (the "Report"). The Report provides the number of screenings, results of screenings, and referrals reported by every CFC, the City of Chicago District 299 (CPS), DCFS (other than with regard to DCFS wards), and the Erikson Intact Program. The number of screenings is additionally broken down according to the age of the child, and the number of referrals is reported according to the type of service to which the family was referred. Services included in the Report are EI, HS, EHS, Early Childhood/Special Education (ECSE), PFA, and "other" services. The Report also lists the number of screenings that did not result in a referral, and the number of screenings that resulted in a recommendation for another screening at a later date. The data from the Cornerstone system (i.e., screenings undertaken by health departments, health clinics, by DCFS pertaining to its wards, WIC, and FCM) includes the number of screenings *only* and does not include the results of screenings or any referrals reported by such entities.

The Report is sent by the Project Coordinator to ISBE, IDHS, DCFS, CPS, CFC managers, and the Erikson Intact Program, which are the only parties that are currently provided with the Report.

<u>Analysis and Recommendations</u>

The data collected through the Project represents an incredible amount of effort, and has the potential to provide critical information about how the State is doing in ensuring that all children ages 0-5 receive developmental screenings and where those screenings are taking place. While developing an unduplicated count of the number of children 0-5 who receive a developmental screening is the ideal, our system in Illinois is not currently equipped to create and use a unique identifier for each child. Recognizing the current limitations of our system, the recommendations that follow offer an interim solution for identifying where screenings are occurring and where referrals are being made.

Further, it is unclear, if the organizations provided with the Reports currently use this data to inform their efforts. Stake holders who participated in the development of these recommendations, including early childhood providers and early childhood collaborations, would like to be able to use this screening data to better inform their outreach efforts to families, and to increase screenings as indicated.

As outlined herein, there are a number of ways in which the Project's data collection could be improved to provide information that is more comprehensive and useful. The Project's years of effort to collect screening and referral data present both an immediate opportunity for analysis, as well as an opportunity for improved data collection in the future.

Our recommendations for improvement fall into four categories: (i) recommendations relating to the analysis and dissemination of current data; (ii) recommendations for improvements and enhancements to the Form and its related directions (the "Directions"); (iii) recommendations relating to future data collection and general recommendations for Child Find; and (iv) a recommendation for future consideration. Each is outlined below. A copy of the current versions of the Form and the Directions are attached hereto as *Exhibit A* as each will be referenced throughout the recommendations.

We acknowledge that these recommendations, if approved and implemented, would modify the current Child Find Project on multiple levels (e.g., what data is requested and collected, and who gets contacted). In order to effectively implement these recommendations, we would envision that training and other systems support mechanisms be provided by various State agencies.

Furthermore, we acknowledge that the Child Find Project may not be the most appropriate or best tool to gather and analyze a variety of data related to developmental screenings in the State. (Such limitations are noted within the recommendations where applicable.) For example, a unified data system (UDS) may be the most appropriate tool in the long-term for the collection of cross-system data, including data related to developmental screenings. While a UDS is being explored and discussed by cross-systems, it is not operational. Until such time, the recommended changes to the Child Find Project offer an interim opportunity to better understand where and how programs are already collecting data and using systems.

Recommendations for Analysis and Dissemination of Current Data

Recommendation #1

Analyze current Project data for trends in screening and referral activity across the State in order to better inform decision-making and resource allocation, and produce an annual report of such analysis (the "Annual Analysis") that is shared with appropriate State agency heads and posted on the Project's website. It is envisioned that such analysis and possible data collection will be undertaken by a cross-systems structure, such as the proposed state system supports or the Governor's Office of Early Childhood and Development, which may require that it enter into data sharing and other applicable agreements with appropriate parties.

Recommendation #2

Identify areas of the State where the number of screenings and/or referrals could be increased.

Recommendation #3

Explore ways to incorporate current Child Find Project data into community needs assessments required under different funding streams, to inform community collaboration efforts focused on EI/Special Education identification, and to support enrollment in early care and education programs and early childhood intervention activities.

Rationale for Recommendations #1-3

- The Project has gathered developmental screening and referral information from across the State since 1998, resulting in a wealth of information annually compiled into the Report.
- Data from the Report can provide new insights into screening and referral patterns across the State.
- Analysis of the available data can help to inform training and outreach efforts, as well as the allocation of scarce resources.
- These recommendations work to advance the State policy of developing and implementing, on a statewide basis, locally based comprehensive, coordinated, interdisciplinary, interagency early intervention services for all eligible infants and toddlers as articulated in the Early Intervention Services System Act and compliance with Child Find for ages 0 to 21 under IDEA.

Recommendation #4

Post all Reports and the Annual Analysis to the Project website. In connection with making the Reports and Annual Analysis publically available on the Child Find website, said website should state clearly what the data being posted means and clarify any content ambiguities with appropriate definitions or explanations.

Rationale for Recommendation #4

- Currently, the Report is disseminated annually to a limited number of parties.

- Data contained in the Report may be of use to a larger number of parties involved in efforts to increase and improve developmental screening and referral in Illinois and better align programs, standards and scarce resources.
- Posting all Reports and the Annual Analysis to the Project website will increase transparency with regard to said data.

Recommendations for the Child Find Screening Data Collection Form and Directions

Recommendation #5

In Section I of the Form, replace "CFC #", "Name of School District" and "District #" with "Name of Screening Agency", and make corresponding changes to Section I of the Directions. In addition, in Section I of the Form, include each of "Health Provider" and "Home Visitor" as a "Type of Program/Entity", make corresponding changes to the definition of "Type of Program/Entity" in Section I of the Directions, and clarify the distinction between "Health Providers" and "Health Departments" in Section I of the Directions.

Rationale for Recommendation #5

- Section I of the Form needs to be clarified so community-based providers (such as HS/EHS, PFA, or PI providers) completing the Form understand how to complete the information requested.
- The Form appears to anticipate that the parties completing the Form are school-based providers.
- Health providers, including primary care physicians, are an important source of developmental screening information for parents of young children.
- The American Academy of Pediatrics recommends regular developmental screening for all children as a part of well-child visits.
- Including "Health Provider" as a Type of Program/Entity on the Form will allow LICs to include data collected from health providers, in addition to the information that is collected quarterly from Cornerstone.
- Including "Health Provider" as a Type of Program/Entity on Form will demonstrate the importance of outreach to health providers, including primary care physicians, in LIC data collection efforts.
- Collecting data about the number of screenings completed by health providers can help to inform planning for training, outreach, and other initiatives of the Part B and Part C comprehensive systems for Child Find and Public Awareness.
- Including "Home Visitor" as a Type of Program/Entity on the Form will allow LICs to include data collected from home visitors and will demonstrate the importance of outreach to home visitors in LIC data collection efforts.

Recommendation #6

In Section I of the Form, include "Zip Code(s) of the Screenings" in the table capturing agency information.

Rationale for Recommendation #6

- While this change to the Form will collect information about the locations of screening events, we acknowledge that it will not collect information about the home zip codes of children receiving screenings, which is a limitation of the data collection.
- While collecting the home zip codes of children receiving screenings would enable agencies to identify communities that are not being adequately reached by developmental screening efforts, including this information in the Form may not be feasible at this time and would be better captured in the long-term when a UDS is developed and implemented by the appropriate systems.

Recommendation #7

In Section II of the Form, include the following additional categories of data: "Number of Children in Intact Family Services Screened," "Number of Children of Teen Wards Screened," and "Number of Children in Foster Care Screened".

Rationale for Recommendation #7

- Collecting data about the number of children in child welfare receiving screenings can inform efforts to provide the best possible services to those children.
- Data about the number of children in child welfare receiving screenings is not currently available in the Illinois Early Childhood Asset Map (IECAM).
- We acknowledge that this recommendation calls for the collection of data that screening entities may not currently collect. However, this data has the potential to provide valuable information.

Recommendation #8

In Section III of the Form, include "# Referred to Home Visiting" as a reporting category for Children Ages 0 to 3 and Children 3 to 5, and include the following definition of "Home Visiting" in Section I of the Directions:

Home Visiting – A voluntary program serving pregnant women and children up to the age of 5 that promotes positive parenting practices and builds healthy parent-child relationships, which makes them an essential strategy for reducing child abuse and neglect, improving health outcomes for mothers and children, and increasing school readiness. Home visiting services use evidence-based, intensive, outcome-driven models that promote parent-child attachment; provide developmental screening, monitoring, and referrals; and provide linkages to community resources and services.

Rationale for Recommendation #8

- Home visiting programs are an important aspect of the network of resources available to parents of young children.
- Children who are not referred to EI may benefit from being referred to other services, including home visiting programs. The availability of such other services has the potential to not overburden EI, while still providing parents and children with valuable and appropriate services.

- Including "# Referred to Home Visiting" as a reporting category for Children Ages 0 to 3 and Children 3 to 5 on the Form will allow providers to include data about referrals to Home Visiting programs.
- The Home Visiting community has requested that this data be collected.
- Collecting data about the number of referrals made to Home Visiting programs as a result of developmental screenings will contribute to the understanding of the accessibility and capacity of Home Visiting programs.
- Including a definition of Home Visiting will enable individuals completing the Form to have a better understanding of what Home Visiting offers.

Recommendation #9
In Section III of the Form, include "# Referred to Multiple Services" as a reporting category for Children Ages 0 to 3 and Children 3 to 5, and include a corresponding clarification in Section III of the Directions that if more than one of the other categories in Section III are applicable and have been checked (e.g., "# Referred to Early Intervention"), then agencies completing the Form should *also* check "# Referred for Multiple Services".

Rationale for Recommendation #9
- Some children may be referred to multiple services and we want to know that number.
- Including "# Referred to Multiple Services" as a reporting category on the Form will provide an explanation as to why the count for referrals made may exceed the count for the number of screenings undertaken.
- We recognize that this Recommendation is not an ideal option for obtaining an accurate count of actual referrals. Given that our systems currently cannot provide an unduplicated count of children and there is not a UDS, Recommendation #9 is a compromise position until a UDS is developed and comes on line, and it will help us obtain (less than ideal but nonetheless helpful) data in the interim.

Recommendation #10
Under Section III of the Form, replace "# Re-referred for Screening" with "# Referred for Rescreening", and in Section III of the Directions clarify the reasons why a child might be referred for rescreening under Section III of the Form.

Rationale for Recommendation #10
- The language currently used for this reporting category is repetitive (i.e., "Re-referred for screening").
- Currently, it is unclear what this reporting category is intended to capture. Accordingly, the Directions need to clarify what leads to a rescreening.
  For example, is it the situation in which a child scores a concern (in the grey area) but not enough for a referral to EI or ECSE, then said child could be rescreened within a few weeks to evaluate whether there is still an issue? Or, is it a rescreening due to additional circumstances that develop in the child's life?

Recommendation #11
Before Section I in the Directions, insert the following text:

Agencies are required to complete each section of the form.

Rationale for Recommendation #11
- Currently, all sections of the Form are not being completed by the agencies. For example, portions of Section III of the Form are sometimes left blank. We understand that portions of the Form may be left incomplete for a variety of reasons.
- Incomplete data makes it hard to discern whether and where needs are or are not being met.

Recommendation #12
In Section I of the Directions under the definition of "CFC # (Name/# of School District, if known)", the concept of "credit" should be removed. In lieu thereof, the following is the proposed text to insert following the definition of "Name of Screening Agency":

This information is gathered for data collection purposes only. If the screening is a joint effort between two or more CFCs or two or more school districts, indicate all CFCs and school districts involved in the joint effort, in order to show the area in which screenings are taking place. If a joint screening takes place with a CFC and a school district, the screenings will be attributed to the CFC or school district based on the ages of the children screened. Separate reports may be submitted if easier on reporting entities.

Rationale for Recommendation #12
- This recommendation is responsive to feedback we received from interested parties that encountered issues involving the concept of "credit" within their systems.
- Adding this text following the definition of "Name of Screening Agency" will clearly communicate to all parties involved in Child Find reporting that the purpose is for data collection only, and there are no incentives or punitive measures associated with the Project.

Recommendation #13
In Section II of the Directions, clarify what constitutes a "referral" by including a definition of the term. The following is a proposed definition that we may want to consider adding to the Directions:

A referral occurs when a provider completes a screening and provides information on how to connect families to a service provider that can meet the child and family's needs as indicated on the screening. Guidance on referring families may be found at the websites for (i) ExceleRate Illinois (including, the following link:

http://www.excelerateillinoisproviders.com/docman/resources/91-three-steps-to-screening/file) and (ii) U.S. Department of Health and Family Services—Office of Administration for Children and Families for *Birth to 5: Watch Me Thrive!* (including, the following link: https://www.acf.hhs.gov/sites/default/files/ecd/ece_providers_guide_march2014.pdf).

Rationale for Recommendation #13
- The understanding of what constitutes a referral varies between agencies completing screening.
- Currently, the referral counts may be incomplete, due to many programs leaving this section of the Form blank when providing data to the Project. Programs that do report referrals may have varying definitions as to what constitutes a referral.
- Clarifying the actions that constitute a referral will improve the quality of the data collected by the Project, ensuring that agencies are providing data on comparable referral activities.
- Clarifying the actions that constitute a referral will contribute to a shared understanding of referral best practices.
- A cross-reference to applicable guidance on referring families is included in case any individuals completing the Form need clarification on this matter.
- From a systems perspective, adding a definition of "referral" to the ExceleRate Illinois materials/guidance should be considered and the definition used in ExceleRate Illinois and Child Find should be consistent.

Recommendation #14
In Section II of the Directions, include a clarification about counting referral totals. The following is proposed text for inclusion in Section II:

> The "total children screened" count from Section II should equal the number of children referred *plus* the number of children not referred.

Rational for Recommendation #14
- Requiring the total number of screenings to equal the referral and non-referral counts combined will help to ensure that screening outcomes are accurately and completely reported.
- Reporting the screening outcome for all children who received a screening will produce higher quality data.

Recommendation #15
Additional recommended modifications to the Form and Directions are attached hereto as *Exhibit B*, which is the proposed new version of the Form and Directions. Furthermore, additional modifications to the Directions and Form may be required once it is determined which recommendations herein are approved and will be implemented.

Recommendations for Future Data Collection and General Child Find Recommendations

Recommendation #16

The State should develop a plan for regular data collection (including parameters as to *when* data need to be submitted to the Project), analysis of data and continuous quality improvement, and distribution of data. For example, the plan may include following parameters:

(i) Data is submitted to the Project Coordinator

(a) On a quarterly basis, for data from IDHS/Cornerstone system and any related to DCFS, and

(b) On a monthly basis, from all other parties (e.g., CPS and CFCs); and

(ii) Such data (regardless of how and when it is collected by the Project Coordinator)

(a) Reflects a specified date for each submission,

(b) Is consistent for each submitting entity

(c) Is clearly identified as to when/how it is collected, and

(d) Is used by the Project Coordinator to produce and post (1) quarterly reports (instead of monthly reports) in which all data is shown in a quarterly basis format, and (2) an annual report in which all data is shown in an annual basis format.

Rationale for Recommendation #16

- Data from the Report can provide new insights into screening and referral patterns across the State.
- Analysis of the available data can help to inform training and outreach efforts, as well as the allocation of scarce resources.
- The current policy does not prescribe when data needs to be submitted, which can lead to inconsistent data collection for each year.
- Currently, the Project Coordinator receives data from certain parties (i.e., CFCs and CPS) on a monthly basis but data from other parties/sources (i.e., DCFS and IDHS from its Cornerstone database) is received on a quarterly basis.
- In order to evaluate trends in developmental screenings throughout the State, a quarterly report of data (in lieu of monthly ones) would most likely be sufficient.

Recommendation #17

Programs receiving Early Childhood Block Grant funds, DCFS Protective Services funds, and Home Visiting funds should be required to participate in monthly Project reporting through their CFC. If some entity other than Child Find is charged with collecting this data in the future, then said entity should be responsible for collecting it.

Rationale for Recommendation #17

- Developmental screening is a critical step in the process of identification and referral of young children who may be eligible for Part C Early Intervention and Part B Early Childhood Special Education. Quality Child Find data is needed to evaluate the effectiveness of Child Find efforts.

- Data showing where screenings are taking place, and who is administering screenings, can help to inform planning for training, outreach, and other initiatives of the Part C and Part B systems for Child Find and Public Awareness.

Recommendation #18

Building off the guidance provided by ISBE, prepare and disseminate statewide a one-page document, endorsed by both ISBE and DHS, which explains, in plain language, the Child Find requirements, including Child Find for children from birth to 5 years old.

Rationale for Recommendation #18

- In a Memorandum dated March 25, 2015, ISBE provided guidance to Directors of Special Education, Early Childhood Special Education Coordinators and Child Find Coordinators on the responsibilities of Local Education Agencies with regard to Child Find for children birth to 3.
- A lack of consensus and interpretation regarding Child Find responsibility can impede efforts to improve screening and referral rates.
- The quality of the data provided in the Report is highly dependent on how actively LICs pursue data, and on the willingness of providers to share data with LICs.
- Clear guidance on roles and responsibilities within Child Find supports collaborative efforts, and could help collaborating agencies avoid conflict.
- Effective Child Find activities that work toward identifying all children who may be eligible for Part C Early Intervention and Part B Early Childhood Special Education require clear delineation of responsibility.

Recommendation #19

Explore additional opportunities for providers to upload developmental screening and referral data directly to the Project or for the Project to pull the data electronically from different systems. Convene a conversation (most likely involving the Early Learning Council's Data, Research and Evaluation Committee (DRE) and IECAM) about current data collection and future opportunities for expansion within applicable systems.

Rationale for Recommendation #19

- Enabling providers to electronically report screening and referral data to the Project would remove the monthly responsibility of data collection from LICs, and allow for more efficient information gathering.
- This recommendation would enable data to be received and evaluated in "real-time," creating the potential for better feedback loops throughout the referral and evaluation process, and streamlining the referral process
- A number of providers are required to conduct developmental screenings and make referrals for appropriate services, including Head Start/Early Head Start, PFA/PI, and Home Visiting, and pulling data already collected from such entities/programs would allow for a more accurate count of screenings being completed within the State.
- We should explore whether IECAM represents an opportunity for making data needed for Child Find easier to share. We should also discuss with DRE (i) where

related systems are currently in terms of data sharing, (ii) the opportunities for future development in this area, including a unified data system, and (iii) any interim opportunities available until a UDS comes online.
- While additional opportunities may be created for uploading data electronically, it is likely that some manual submission/collection of data may be required.

Recommendation #20
Work towards ensuring at least one screening per child in Illinois and explore best ways to accomplish this objective.

Rationale for Recommendation #20
- The focus of this recommendation is the number of children being screened not the number of screenings.
- The primary goal of this recommendation is not to reduce duplication of screenings but to ascertain whether every child is receiving at least one screening and we do not have that capability currently.
- We are trying to reach every child in Illinois so we can strengthen systems and identify where existing gaps may exist.
- The ability to disaggregate demographic data on each child will enable us to evaluate developmental screenings in Illinois through an equity lens, and analyze whether and what disparities may exist across and within groups of young children.
- We will need a broader systems conversation about the development of a unique identifier to minimize the possibility of people creating different identifiers by program. Our next steps may include a cross-committee discussion with the DRE to ensure that a unique identifier is a data priority and to address the following issues: (i) what is being done already with electronic data sharing; and (ii) what needs to be done to build a new system for electronic data sharing.

Recommendation for Future Consideration

Recommendation #21
The Form should be modified so the numbers of families who are successfully connected with services are reported.

Rationale for Recommendation #21
- Currently, the Form does not capture how many families are successfully connected to services.
- Data collected through the Project should enable us to determine how many families are successfully connected to services.
- Analysis of this particular data can help to inform training and outreach efforts, as well as the allocation of scarce resources and reasons why families decline or discontinue services.
- A number of issues would need to be explored before this recommendation can be realized (e.g., privacy, data collection).

- This recommendation may be best implemented by a cross-system or community system entity.

References

Home: Child Find Project. (n.d.). Retrieved from Child Find Project Web Site: http://www.childfind-idea-il.us/

List of Exhibits

Exhibit A – Current Form and Directions
Exhibit B – Proposed New Form and Directions

Exhibit A

Current Form and Directions

Exhibit B

Proposed New Form and Directions