Title V Data Integration State Example: North Carolina

Background: State System

In 2012, North Carolina received funding through Race to the Top - Early Learning Challenge to build the infrastructure for an Early Childhood Integrated Data System (NC ECIDS). This system is one of the most advanced in the country and it continues to grow more useful for its stakeholders. The first data sources added to this system were programs such as the NC Pre-kindergarten program (NC Pre-K), Early Intervention, Infant/Toddler Program (also called IDEA Part C), Exceptional Children (IDEA Part B), and Subsidized Child Care Assistance (SCCA). NC ECIDS is now working to expand to include data from other programs, such as Head Start/Early Head Start, Temporary Assistance for Needy Families (TANF), early childhood workforce, child care regulatory data. The system only includes children who are receiving publicly-funded services, not all children who live in North Carolina. For example, while there was interest in adding data on immunizations, health screenings, and hearing screenings, these are not considered "services" so the full datasets cannot be included in the system. However, subsets of these children, for example those who received services based on referrals from screenings, could be included in the system in the future depending on the agencies' needs. This is an example of how state data systems have limitations but can change based on reporting needs and state priorities. To sustain the system after Race to the Top – Early Learning Challenge grant funding ended, the state allocated ongoing funding into its budget.

Integration and Use of Public Health Data

In addition to the data sources listed above, NC ECIDS includes public health data sources such as Food and Nutrition Services (SNAP), and Child Protective Services (CPS). The state is interested in adding Women, Infants, and Children (WIC) as a data source in the future once updates to the state's WIC data system have been completed. Adding public health data to the system, particularly SNAP enrollment information and demographics, will allow programs to better understand populations they serve and improve services coordination. For example, families who qualify for SNAP likely qualify for other services, which they may or may not be receiving. Having access to these data may identify barriers to access, helping programs plan and execute more effective outreach strategies.

North Carolina has also considered adding data on sickle cell anemia but it would be difficult to report on small populations without the data becoming identifiable and consequently being suppressed (referred to in North Carolina's reports as VTSTS, or Values Too Small To Show). Reporting data on small populations is a common struggle across the nation as states integrate data.

Data Sharing

NC ECIDS has a very active governance council, which creates policies for operation of the system and provides feedback to inform the development of NC ECIDS data application, web portal, and workflow processes. It includes an Executive Committee and a Program Management Committee. The Executive Committee, which is made up of leadership from contributing divisions and agencies, includes the agency heads of the state's Division of Public Health and Division of Social Services, which contribute health-related data to the system. The Program Management Committee includes program managers from each contributing data source, such as SNAP and CPS. Each year, the governance council reviews and approves the numbers pulled from their specific program for publicly shared standard reports.

Requests for data from external researchers or participating agencies sources are made through the NC ECIDS secure web portal. Each data request must include the purpose for the request, the intended analysis, and a list of requested data elements. In addition, all data requesters must sign a Data Use Agreement which includes requirements on data use, security and confidentiality. Each agency contributing the data being requested receives an email and must log into the system to approve or reject the request. If the request is approved, each agency also approves the data to ensure there are no discrepancies before it is sent to the requester.

Reports & Dissemination

- The NC ECIDS website includes aggregate level standard and customizable reports that pull data from the system. The standard reports answer the following questions:
- How many children used NC early childhood services during recent fiscal years?
- How many children received a combination of two program during recent fiscal years?
- How many children used two or more programs during recent fiscal years?
- How many NC Pre-K age eligible children are receiving NC ECIDS services?

The reports are intended for the public, participating state agencies, policymakers, and researchers. Many local agencies use these reports to inform their work, as users can select which county, programs, and sub-groups to include. Figures 1 and 2 show an example of the options and results for a customized report from the NC ECIDS site.

Figure 1: Options for Custom Report from NC ECIDS site

Total and Unduplicated Number by NC ECIDS Service

The total number of distinct, unduplicated children enrolled across all NC ECIDS Services is: 339,413. Of this total, 247,074 children were enrolled in only one program; 92,339 were enrolled in more than one program.

Program	Total Children Enrolled[2]	Children Enrolled Only in this Program[3]	
Child Protective Services	90	38	42.2%
FNS	1,086	944	86.9%
Infant Toddler (IDEA Part C)	33	19	57.6%
Subsidized Child Care Assistance	137	30	21.9%

This table shows the total duplicated and unduplicated counts of children enrolled in only one program who participated in NC ECIDS during the 2014-2015 State Fiscal Year.

Figure 1: Resulting Custom Report from NC ECIDS site

The standard reports have proven very valuable to the state, and have sparked interest in additional reports. For example, based on state interest in how many four-year-old children were being served in public programs, the state developed a "Pre-K Age Eligibility" report, to examine which age-eligible children were participating in NC Pre-K as well as in other programs. By looking at program participation and demographic data, the state gets a better picture of children's eligibility for and access to programs.

Beyond the NC ECIDS, other groups in the state are using public health data to improve programs. The North Carolina Partnership for Children, produces annual reports for Smart Start, North Carolina's network of nonprofit local partnerships, with statewide data on various programs serving children and families. These annual reports do not use data from the NC ECIDS but instead report on measures that correlate to the state's goals for quality early childhood education, early literacy, supporting families, and children's health and development. Figure 3 shows a chart from the Smart Start Annual Report for Fiscal Year 2015-2016 which shows the value the state has placed on sharing and using data. The chart shows statewide data from an early childhood assessment and are the key indicators for measuring children's healthy development.
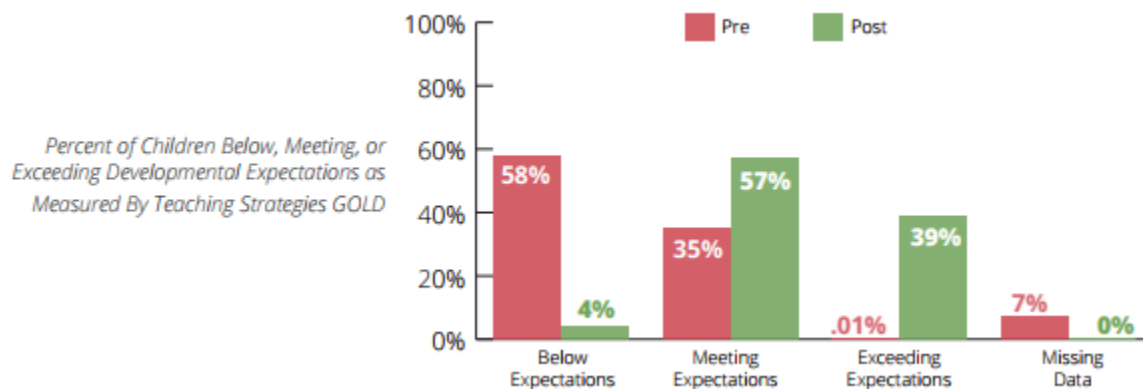
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Figure 2: Chart from Smart Start Annual Report for Fiscal Year 2015-2016

In the future, North Carolina hopes to develop a statewide profile with additional integrated data that answers questions beyond those in the NC ECIDS standard reports showing data across sectors and providing actionable information to stakeholders.

Value Added

One of the key accomplishments for NC ECIDS is getting a distinct count of children in programs. For some public health programs, these initial counts have sparked more questions that will lead to additional analyses and improved health outcomes.

While some agencies may have initially been unsure about data sharing outside of their agency, they are now asking for more data and reports to be included in the system. For example, the Division of Public Health initially had questions related to privacy and confidentiality as it applies to HIPAA. Since the launch of NC ECIDS, they are asking to include more data in the system on children who receive referrals based on infant hearing screenings. The impetus behind this request is partially based on a federal reporting requirement, something that often incentivizes agencies to contribute to integrated data systems. The request was due to an increased understanding by the Division on the value of contributing to the system.

Key Takeaways

Data sharing can certainly be complicated, but North Carolina has learned that being transparent with contributing agencies about how the system works and what it means to participate has eased some concerns. Addressing privacy and security concerns has allowed them to more effectively engage stakeholders. Their solid governance structure and engaged governance committee members have allowed them to effectively communicate with participating programs and to bring more data sources into the system.