

Counting All Kids

Equity Through Data Disaggregation in New York's Early Childhood Systems

April 2024

Disaggregated data are critical to ensuring all of New York's children and families have **equitable access to the services they need to thrive**. By understanding who is and who is not being served by the state's early childhood systems, we can better **identify and address systemic inequities**.

Despite its importance, disaggregated program data are often difficult to access because New York's child-serving systems are **dispersed across several state agencies** (Dept. of Health, Office of Mental Health, Dept. of Education, Office of Children and Family Services, etc.) and there is **no universal approach to data collection, disaggregation, or publication**.

Data disaggregation = breaking down large data categories into more specific demographic sub-categories like race/ethnicity, gender, socioeconomic status, and geographic location

This project, a collaboration between three of the state's leading children's advocacy organizations, seeks to advance the state of data disaggregation by:

1. Gaining an **understanding** of the current status of publicly available data in New York's early childhood systems
2. Identifying **gaps** in data access for key disaggregated categories
3. Developing a set of **recommendations** to improve data disaggregation in NYS

Overview of Key Findings

Early Intervention

- Some data available in yearly federal reports
- Yearly NYC report could serve as a model

Child Care

- Virtually no system-wide data on children receiving care
- Limited data on families enrolled in subsidized care

Pre-Kindergarten & Preschool Special Education

- Disaggregated Pre-K data included in annual reports
- No additional data on students enrolled in Special Education

Behavioral Health

- Complex system with minimal disaggregation of access and utilization data

Recommendations

For State & Local Leaders

- 1** Review data currently being collected to **identify additional opportunities** for disaggregated categories in collection and public reporting
- 2** **Develop uniform standards** between state-level agencies requiring the collection and publication of disaggregated data
- 3** **Create or improve public-facing data platforms** that make information more accessible to wide audiences

For Advocates

- 1** **Educate your networks and elected officials** on the importance of accessible disaggregated data for equity among New York's children
- 2** Consider the **disproportionate impact of the bills** you support on subgroups made vulnerable by factors like systemic racism and poverty
- 3** **Advocate for data reporting bills** which mandate transparency through data disaggregation, and ensure adequate funding is included in the bill



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Data Disaggregation in New York's Early Intervention System

April 2024

The Need

New York's children need **equitable access to timely Early Intervention services**. Knowing who is being served and who is not is critical so we can fix systemic gaps and inequities. This requires **public access** to enrollment and service data **separated out by demographics** like race/ethnicity, gender, socioeconomic status, and disability status.

The Solution

New York needs **uniform standards for state agencies** requiring them to collect and publish data on **children's services**. The reports should include enrollment and service data **by demographic categories**. The data should be analyzed and published **annually** and explore the **intersections** between different demographics.

Available Data & Why It Matters

The Bureau of Early Intervention has made more statewide data available than other child-serving systems in New York. However, it still lacks the county-level and intersectional data (e.g., race and gender) necessary to address known disparities. This makes it difficult to ensure the State is providing equitable access to timely Early Intervention services, especially for children of color, low-income children, and those in rural or large urban areas.

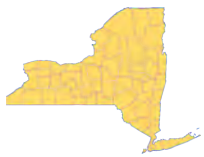


Federal IDEA Reports

Annual (year delay) statewide **enrollment** data by **age group, race/ethnicity, and gender** publicly available

NYS Dept of Health

Statewide data by **race** on the number of children who completed each step of the Early Intervention **process** obtainable by FOIL request



County Health Depts

Inconsistent **enrollment** and **program data** including types of services (OT/PT/Speech), **waitlists**, and the use of **telehealth** obtainable by FOIL request

NYC

NYC Bureau of Early Intervention Annual Reports

Annual (year delay) **enrollment** data by **race, gender, language, and zip code** for each step of the Early Intervention **process**, as well as the **timeliness** of services publicly available

See reverse for more details on the availability of disaggregated Early Intervention data in New York

Uniform Disaggregation Categories

Early Intervention - Specific Data

Disaggregation Category	Data Collected	Publicly Available	Timely Release	Available Statewide	Available by County	Available in NYC	Available by Locality
Race/Ethnicity	✓	✓	✓	✓	FOIL only	✓	
Age	✓	✓	✓	✓	FOIL only	✓	
Gender	✓	✓	✓	✓	FOIL only	✓	
Disability Status	✓						
Socioeconomic Status							
Geography	✓					✓	
Language	✓					✓	
McKinney-Vento/ Homeless Status							
Diagnosis/ Service Type	✓						
Medicaid/ Insurance Status	✓						
Timeliness of Services	Some Counties				Some Counties	✓	
Telehealth vs. In-Person	Some Counties				Some Counties		
Enrollment in Steps of the EI Process	✓			FOIL only		✓	



Counting All Kids

Data Disaggregation in New York's Child Care System

April 2024

The Need

New York's families need **equitable access to affordable, high-quality child care**. Knowing who is being served and who is not is critical so we can fix systemic gaps and inequities. This requires **public access** to enrollment and service data **separated out by demographics** like race/ethnicity, gender, socioeconomic status, and disability status.

The Solution

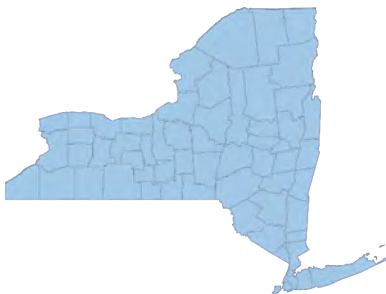
New York needs **uniform standards for state agencies** requiring them to collect and publish data on **children's services**. The reports should include enrollment and service data **by demographic categories**. The data should be analyzed and published **annually** and explore the **intersections** between different demographics.

Available Data & Why It Matters

There is little publicly available data regarding New York's child care system, and **no disaggregated data at all on the child care workforce or the children and families statewide** who benefit from their services. Limited state-level disaggregated data are available on the children enrolled in subsidized care, though this represents only a small percentage of families and the information is several years delayed.



The only dataset the state regularly publishes on the child care system provides information on the **location of OCFS regulated programs and the number of children per age group each is allowed to care for**. While this is helpful for analyzing child care capacity around the state, it lacks critical information to tell the story of how workers and families are experiencing the system and if their needs are truly being met.



Having disaggregated data is important to inform both county- and state-level policy decisions on a number of issues, including:

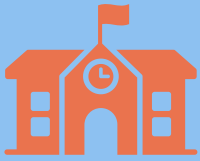
- Ensuring children with disabilities have access to the care they need
- Identifying and addressing barriers families face in accessing child care assistance (e.g., language access)
- Ensuring the State's quality rating system is inclusive of diverse cultural values and understandings of what makes a program "quality"
- Identifying tailored supports that would allow the members of the workforce to advance their education and careers in the field

See reverse for more details on the availability of disaggregated Child Care data in New York

Uniform Disaggregation Categories

Disaggregation Category	Data Collected	Publicly Available	Timely Release	Available Statewide	Available by County	Available in NYC	Available by Locality
Race/Ethnicity	Subsidy only	Subsidy only	Subsidy only	Subsidy only			
Age	Subsidy only	Subsidy only	Subsidy only	Subsidy only		FOIL only	
Gender							
Disability Status	Subsidy only	Subsidy only	Subsidy only	Subsidy only			
Socioeconomic Status							
Geography	✓	✓	✓	✓	✓	✓	✓
Language	Subsidy only	Subsidy only	Subsidy only	Subsidy only			
McKinney-Vento/ Homeless Status	Subsidy only	Subsidy only	Subsidy only	Subsidy only			
Modality (Family, Group Family, Center, School)	✓	✓	✓	✓	✓	✓	✓
Waitlists							
Exclusionary Discipline							
Unmet Care Needs							
Capacity by Age	✓	✓	✓	✓	✓	✓	✓

Child Care - Specific Data



Counting All Kids

Data Disaggregation in New York's Pre-Kindergarten and Preschool Special Education System

April 2024

The Need

New York's children need **equitable access to quality early childhood education**. Knowing who is being served and who is not is critical so we can fix systemic gaps and inequities. This requires **public access** to enrollment and service data **separated out by demographics** like race/ethnicity, gender, socioeconomic status, and disability status.

The Solution

New York needs **uniform standards for state agencies** requiring them to collect and publish data on **children's services**. The reports should include enrollment and service data **by demographic categories**. The data should be analyzed and published **annually** and explore the **intersections** between different demographics.

Available Data & Why It Matters



Disaggregated Pre-Kindergarten (Pre-K) data are widely available thanks to the NYS Education Department's yearly Public School Enrollment reports. As with all grade levels, enrollment data are available for half-day and full-day Pre-K students by **gender, race/ethnicity, economically disadvantaged status, English Language Learner status, and disability status**. This information is available for every district and individual school, but only district-level counts are inclusive of students enrolled at community-based organizations (CBOs). Additionally, The Children's Agenda has obtained data on the use of **exclusionary discipline** in Pre-K through FOIL requests.



Preschool Special Education (PSE) data are far less available in New York. While the count of Pre-K students with disabilities is available statewide, there is **no additional disaggregation or information available on how those children are being served**. There is no distinction in the data between students in traditional classrooms, those in integrated classes with general education students, or those in special classes. Anecdotal reports reveal a shortage of preschool special education services statewide, but there is **no publicly available data on waitlists or how many students with disabilities are not receiving the services outlined in their IEPs**. This information is crucial to ensure students are receiving the supports they need to thrive in their future education.

See reverse for more details on the availability of disaggregated Pre-K data in New York

Uniform Disaggregation Categories

Disaggregation Category	Data Collected	Publicly Available	Timely Release	Available Statewide	Available by County	Available in NYC	Available by Locality
Race/Ethnicity	✓	✓	✓	✓	✓	✓	✓
Age	✓						
Gender	✓	✓	✓	✓	✓	✓	✓
Disability Status	✓	✓	✓	✓	✓	✓	✓
Socioeconomic Status	✓	✓	✓	✓	✓	✓	✓
Geography	✓	✓	✓	✓	✓	✓	✓
Language/English Language Learner	✓	✓	✓	✓	✓	✓	✓
McKinney-Vento/ Homeless Status	✓						

Pre-Kindergarten - Specific Data

Modality (CBO vs School)	✓						
Exclusionary Discipline	✓			FOIL only	FOIL only	FOIL only	FOIL only
Waitlists							
PSE - Diagnosis/Service Type	✓						
Enrollment in Steps of the PSE Process	✓						



Counting All Kids

Data Disaggregation in New York's Behavioral Health System

April 2024

The Need

New York's children need **equitable access to timely behavioral health services**. Knowing who is being served and who is not is critical so we can fix systemic gaps and inequities. This requires **public access** to enrollment and service data **separated out by demographics** like race/ethnicity, gender, socioeconomic status, and disability status.

The Solution

New York needs **uniform standards for state agencies** requiring them to collect and publish data on **children's services**. The reports should include enrollment and service data **by demographic categories**. The data should be analyzed and published **annually** and explore the **intersections** between different demographics.

Available Data & Why It Matters

Indicator Types

Children's behavioral health data are available through a number of different state agencies, primarily through the **Office of Mental Health (OMH)**. A range of data is available in terms of **utilization** of services from state-licensed providers, **capacity** of select services, **patient outcomes**, and **characteristics** of individuals receiving services.

Some **prevalence** data is also available, largely from the **Youth Risk Behavior Surveillance System (YRBSS)**. The YRBSS is a CDC survey conducted every two years within randomly-selected middle and high schools across the country, with the New York State Center for School Health (YYSCSH) facilitating the administration of the NYS YRBS to schools.

Service Settings & Categorization

Behavioral health needs are complex, and services are delivered across multiple settings to align with the type and intensity of treatment needed. Some data are based on the type of setting services are received in, such as inpatient services, outpatient services, or services delivered in an emergency department. Other data are based on how the child's service is categorized, such as mental health services, substance use disorder (SUD) services, or behavioral health services. Still other data is based on certain outcomes and conditions, such as readmission rates, self-harm hospitalizations, or patient perceptions of care.

Data Not Readily Available

Finally, there is some data available to the state that is not made publicly available. This includes data that necessitates a Freedom of Information Law (FOIL) request.

NYS also houses the **Psychiatric Services and Clinical Knowledge and Enhancement System (PSYCKES)**, which is a web-based platform developed by the NYS Office of Mental Health for sharing Medicaid billing claims and encounter data, other state health administrative data, and data and documents entered by providers and patients. While this is a rich source of data on behavioral health needs and utilization, it is only available to provider organizations, and is therefore not included as part of this project.

Findings from a Review of Publicly-Available Data

Although there is a robust array of publicly-available data on children's behavioral health, very little of that data is disaggregated into demographic and other categories. Sources were only included in the accompanying appendix if they included data for children and youth (categorized as age 0-24). Within many of these sources, children were further disaggregated by **age group**, though the age groupings varied source-to-source. The most commonly available disaggregation is at the **geographic** level – primarily at the **regional** and **county** level, with some data available at the **hospital** or **program/agency level**. Data on **race/ethnicity** was confined to a relatively small number of data sets, and was not further compared across age, geography, or other demographic indicators. A handful of data sources provided information on categories such as **diagnosis**, **plan type**, and **aid category**.

A full list of identified disaggregation categories is discussed below. If a category is not on this list, then to our knowledge no source of publicly available data exists that disaggregates by that category for New York State.

- **Region:** Varies by Region Type, such as OMH or Regional Planning Consortium (RPC).
- **County:** Some data sources indicate if certain county data is incomplete depending on whether hospitals and counties have fully reported.
- **Hospital:** Hospital-level data is available for psychiatric inpatient readmissions. Note that discharges from hospitals without licensed Children's beds are suppressed in the Children's sections. There are two exceptions to this: New York Presbyterian – Columbia Center/Allen Hospital and SUNY Health Center – University Hospital. Both hospitals averaged over 50 child discharges over the years in the report.

- **Program Type/Service Category:** Includes categories such as Clinic Treatment, Crisis Intervention, Mental Health Inpatient, Home and Community Based Services, Family Peer Support, and Residential Treatment Facility. May include additional service sub-categories.
- **Program/Agency:** Includes data for specific agencies/programs serving children. Note that not all programs/agencies have submitted data to the state so this category may be incomplete.
- **Race/Ethnicity:** Categories vary by data source.
- **Age Group:** Age groupings vary by data source and are indicated in the accompanying spreadsheet.
- **Sex:** The term sex is used rather than gender because no data source includes results based on comprehensive questions about gender identity.
- **Plan Type:** Includes the categories Fee-for-Service, Mainstream, Other Plan, and Long Term Care Mutual Aid Plan (LTC MAP)
- **Diagnosis:** Level of detail regarding diagnosis varies by data source.
- **Aid Category:** Includes SSI, TANF, and Other.
- **Sexual Orientation:** YRBSS identifies this category through questions about Sexual Identity and Sex of Sexual Contacts.
- **Needs and Functioning:** Based on the findings of the Child & Adolescents Needs & Strengths (CANS) assessment.

You can find a detailed analysis of available data below.

Importantly, certain data regarding children’s behavioral health needs and outcomes is unavailable even at a statewide, non-disaggregated level. This includes data on waitlists for services and the gap between services needed and received. In addition to further disaggregating existing data, it is critical for the state to implement strategies for better identifying the extent to which children, youth, and families struggle to access needed care.

As a result of the very limited instances of disaggregation within available behavioral health data sets, **it is extremely difficult to make comparisons or draw conclusions regarding the level of care and outcomes for children** across gender, race/ethnicity, socio-economic status, and other characteristics. These data limitations **inhibit the State and community-based providers from identifying and meeting the unmet needs of children** in the state, and prevent parents, advocates, and community stakeholders from being **fully informed** about the services they need in their communities.

