

Title V Data Integration Use Case: Autism

As more states face a higher incidence of autism, they must focus resources on the identification, diagnosis, and intervention of autism in children. Research suggests signs of autism present early in childhood, allowing communities that invest in identification to provide treatment and interventions earlier.¹

Data on autism will help Title V programs coordinate efforts to improve screening opportunities and services for children and families. The number and location of children diagnosed with autism, age of diagnosis, services received, and other types of data allow early childhood state systems to fill existing gaps and measure the impact of coordinated efforts.

When Title V programs participate in ECIDS, they can use autism data from local and state agencies to strategically plan for improved identification programs and services, thus improving early childhood developmental health.

Use Case Questions

1. How many children birth through age 5 have a documented autism diagnosis?
2. At what age were children birth through age 5 first diagnosed with autism?
3. What percentage of children birth through age 5 were diagnosed with autism based on a referral as a result of a screening or assessment?
4. In which early childhood programs are children diagnosed with autism participating?
5. Of the children diagnosed with autism, what percentage are receiving IDEA Part C services? What percentage are receiving IDEA Part B services?

Analytic Considerations

The focus of these questions is early childhood outcomes following a diagnosis of autism in children from birth to age 5. Therefore, all children included in the analysis must have been diagnosed with autism by a clinician.

When analyzing autism data, it is important to consider the 2013 DSM V criteria changes². These changes included eliminating autism sub-diagnoses (Autistic Disorder, Asperger Syndrome, Pervasive Developmental Disorder Not Otherwise Specified, Disintegrative Disorder)

¹ [Environmental Scan: State Strategies and Initiatives to Improve Developmental and Autism Screening and Early Identification Systems](#)

² The American Academy of Pediatrics. (2013). DSM V diagnostic criteria changes for autism spectrum disorder (ASD). <http://www.aappublications.org/content/early/2013/06/04/aapnews.20130604-1>

in favor of one diagnosis known as Autism Spectrum Disorder (ASD). Additionally, DSM-IV symptoms changed from three areas:

1. Social Reciprocity,
2. Communicative Intent, and
3. Restricted and Repetitive Behaviors

To:

1. Social Communication/Interaction and
2. Restricted and Repetitive Behaviors.

Due to these changes, Title V programs should consider analyzing data with a data set before 2013 or after 2013, as opposed to one including data from before and after the change.

Although this use case offers suggestions for analytic considerations, Title V programs should adapt the information to fit the needs of their state and Title V program. For example, Title V programs may wish to analyze all children diagnosed with autism within their states or may wish to look at the data aggregated by demographic variables, such as, age, race/ethnicity, and/or ZIP code. Decisions on how to analyze the data should be made in collaboration with ECIDS staff.

Data Set

The data set for this analysis includes children birth through 5 who have been diagnosed with autism. As there are multiple questions and sub-questions, each question and sub-question will be broken down individually.

Question 1: How many children birth through age 5 have a documented autism diagnosis?

The recommended data elements for this analysis are listed in the table below. For states using the Common Education Data Standards (CEDS), the link to the CEDS element has been provided.

Data Elements – Autism Question 1



Click the hyperlinks in the table to see more information about the data elements in CEDS. The links will take you to the individual elements and do not require a CEDS login to access. Where available, links to CEDS are included. Where not available, data elements that are likely to exist in Title V data systems have been suggested. These elements will be submitted to CEDS for consideration.

Variable	Data Element Choices	Element Definition	Option Set	Considerations
Child	Child Identifier	A unique number or alphanumeric code assigned to a child by a school, school system, state, or other agency or entity.	Alphanumeric	Although the questions in this analysis can be reported on aggregately, child information is needed to create the data set. After data have been pulled, children's personally identifiable data may be stripped.
	First Name	The full legal first name given to a person at birth, baptism, or through legal change.	Alphanumeric	Although the questions in this analysis can be reported on aggregately, child information is needed to create the data set. After data have been pulled, children's personally identifiable data may be stripped.
	Middle Name	A full legal middle name given to a person at birth, baptism, or through legal change.	Alphanumeric	Although the questions in this analysis can be reported on aggregately, child information is needed to create the data set. After data have been pulled, children's personally identifiable data may be stripped.
	Last or Surname	The full legal last name borne in common by members of a family.	Alphanumeric	Although the questions in this analysis can be reported on aggregately, child information is needed to create the data set. After data have been pulled, children's personally identifiable data may be stripped.
	Generation Code or Suffix	An appendage, if any, used to denote a person's generation in his family (e.g., Jr., Sr., III).	Alphanumeric	Although the questions in this analysis can be reported on aggregately, child information is needed to create the data set. After data have been pulled, children's personally identifiable data may be stripped.

Variable	Data Element Choices	Element Definition	Option Set	Considerations
Child Age	<u>Birthdate</u>	The year, month, and day on which a person was born.		Although the questions in this analysis can be reported on aggregately, child information is needed to create the data set. After data have been pulled, children's personally identifiable data may be stripped.
Diagnosis	<u>Disability Status</u>	An indication of whether a person is classified as disabled under the American's with Disability Act (ADA).	Yes	For this question, only the children that have been classified as disabled (an option set of yes) should be pulled for the data set.
	<u>Primary Disability Type</u>	The major or overriding disability condition that best describes a person's impairment.	Autism: Autism is the major or overriding disability condition that best describes the person's impairment.	Although there are many disability types, only the children with autism listed in the option set should be pulled for the data set.

Steps for Analysis – Autism Question 1

- Identify the timeframe for analysis. For example, you may wish to look at the data by calendar or fiscal year.
- Identify the geographic boundary for analysis. For example, you may wish to look at the data by county or ZIP code.
- After applying the timeframe and geographic boundary filters, pull the subset of children birth through age 5 with a documented autism diagnosis in the specified timeframe and geographic boundary.
- Calculate the number of children with a documented autism diagnosis.
- Check for data quality issues such as outliers or missing data.
- Calculate the percentage by dividing the total number of children with a documented autism diagnosis by the total number of children birth through age 5 in the identified timeframe and geographic boundary. Multiply by 100 for a total percentage.

Data Visualization – Autism Question 1

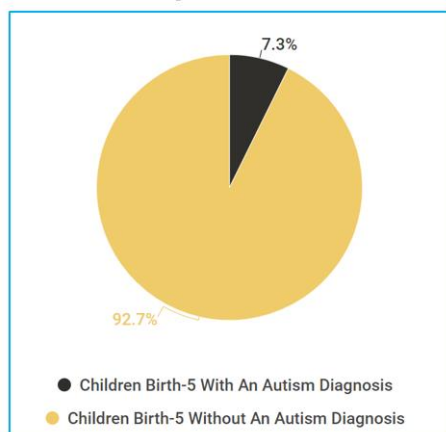
Effective data visualization is critical for conveying the Title V program message and telling your story. When looking at the data provided by ECIDS, what do you notice? What are the patterns and/or trends? These questions will help Title V programs identify the story the data tell.

Consider this example using fictitious data:

2015 Total Children Birth-5 in “Any State USA”		N=22,933
	N	%
Children Birth-5 with an autism diagnosis	1,661	7.3%
Children B-5 without an autism diagnosis	21,272	92.7

Title V programs may wish to visualize the data as:

7.3% of the Children in “Any State USA” Have Been Diagnosed with Autism



The 1,661 Children, Birth-5, Diagnosed with Autism In 2015 Would Fill 30.8 School Buses



Possible Actions Based on Data – Autism Question 1 The data from this question can be used at many different levels. For example, legislators and school districts would be interested in the data as they show the number of autistic children who will be entering the school system.

Question 2: At what age were children birth through age 5 first diagnosed with autism?

The recommended data elements for this analysis are listed in the table below. For states using the Common Education Data Standards (CEDS), the link to the CEDS element has been provided.

Data Elements – Autism Question 2



Click the hyperlinks in the table to see more information about the data elements in CEDS. The links will take you to the individual elements and do not require a CEDS login to access. Where available, links to CEDS are included. Where not available, data elements that are likely to exist in Title V data systems have been suggested. These elements will be submitted to CEDS for consideration.

Variable	Data Element Choices	Element Definition	Option Set	Considerations
Child	Child Identifier	A unique number or alphanumeric code assigned to a child by a school, school system, state, or other agency or entity.	Alphanumeric	Although the questions in this analysis can be reported on aggregately, child information is needed to create the data set. After data have been pulled, children's personally identifiable data may be stripped.
	First Name	The full legal first name given to a person at birth, baptism, or through legal change.	Alphanumeric	Although the questions in this analysis can be reported on aggregately, child information is needed to create the data set. After data have been pulled, children's personally identifiable data may be stripped.
	Middle Name	A full legal middle name given to a person at birth, baptism, or through legal change.	Alphanumeric	Although the questions in this analysis can be reported on aggregately, child information is needed to create the data set. After data have been pulled, children's personally identifiable data may be stripped.
	Last or Surname	The full legal last name borne in common by members of a family.	Alphanumeric	Although the questions in this analysis can be reported on aggregately, child information is needed to create the data set. After data have been pulled, children's personally identifiable data may be stripped.
	Generation Code or Suffix	An appendage, if any, used to denote a person's generation in	Alphanumeric	Although the questions in this analysis can be reported on aggregately, child information is needed to create the data set.

Variable	Data Element Choices	Element Definition	Option Set	Considerations
		his family (e.g., Jr., Sr., III).		After data have been pulled, children's personally identifiable data may be stripped.
Child Age	Birthdate	The year, month, and day on which a person was born.		Although the questions in this analysis can be reported on aggregately, child information is needed to create the data set. After data have been pulled, children's personally identifiable data may be stripped.
Diagnosis	Disability Status	An indication of whether a person is classified as disabled under the American's with Disability Act (ADA).	Yes	For this question, only the children that have been classified as disabled (an option set of yes) should be pulled for the data set.
	Primary Disability Type	The major or overriding disability condition that best describes a person's impairment.	Autism: Autism is the major or overriding disability condition that best describes the person's impairment.	Although there are many disability types, only the children with autism (an option set of autism) should be pulled for the data set.
	Date of Diagnosis ³	The date of initial diagnosis.		Although there may be multiple dates recorded for different diagnosis, only the earliest date of autism diagnosis should be pulled for the data set. The date of diagnosis is compared to the child date of birth to determine the child's age at diagnosis.

³ This data element is not currently in CEDS but has been submitted for consideration.

Steps for Analysis – Autism Question 2

- Identify the timeframe for analysis. For example, you may wish to look at the data for all years since 2013.
- Identify the geographic boundary for analysis. For example, you may wish to look at the data by county or ZIP code.
- After applying the timeframe and geographic boundary filters, pull the subset of children birth through age 5 with a documented autism diagnosis in the specified timeframe and geographic boundary.
- Of the children identified in c., pull the earliest date autism disability appears in the child’s record or, if available, the date of initial diagnosis.
- Calculate the age first diagnosed by comparing the earliest date autism disability appears in the child’s record or, if available, the date of initial diagnosis to the child’s birthdate.
- Check for data quality issues such as outliers or missing data.
- Calculate the percentage by dividing the age of first diagnosis for each age group by the total number of children birth through age 5 with a first diagnosis in the identified timeframe and geographic boundary. Multiply by 100 for a total percentage.

Data Visualization – Autism Question 2

Effective data visualization is critical for conveying the Title V program message and telling your story. When looking at the data provided by ECIDS, what do you notice? What are the patterns and/or trends? These questions will help Title V programs identify the story the data tell.

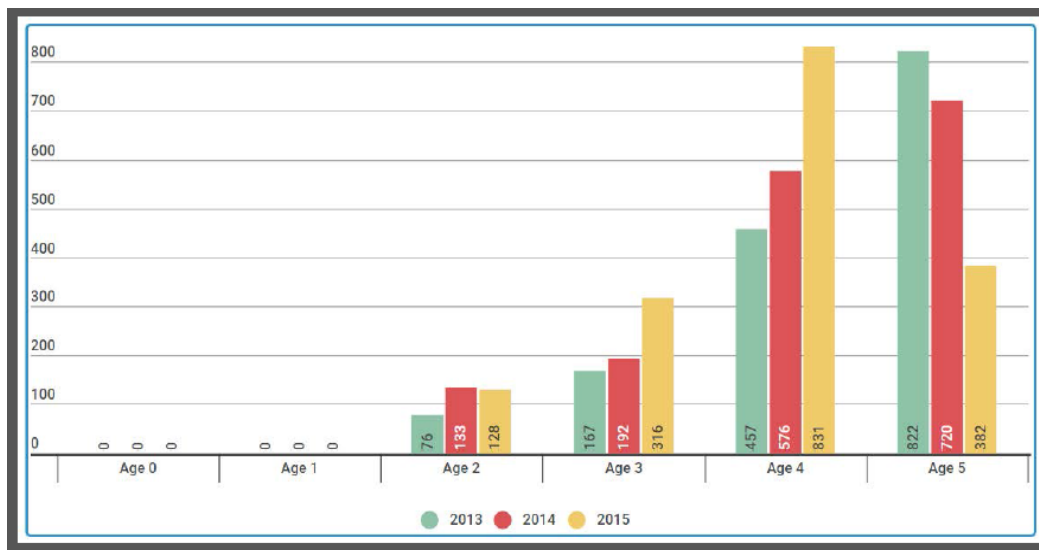
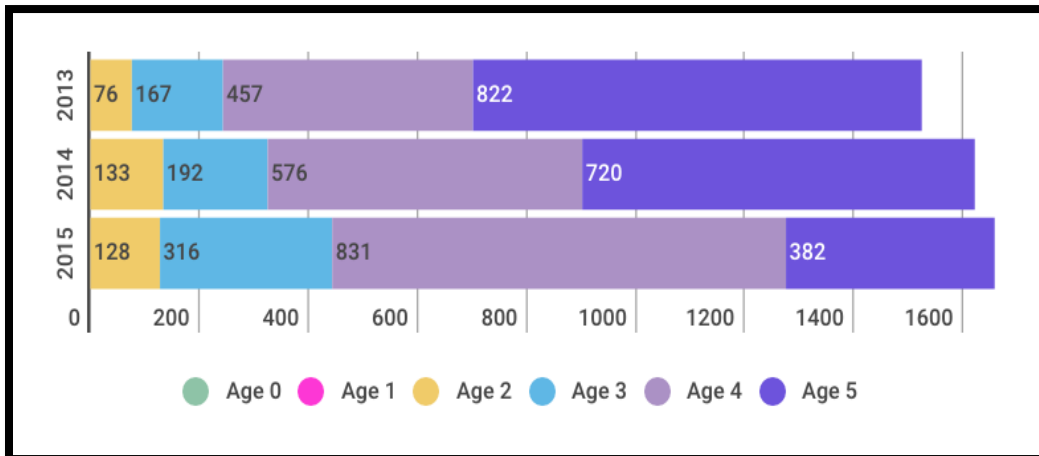
Consider this example using fictitious data:

2013 – 2016 - The Age Children, Birth-5, Were First Diagnosed with Autism in “Any State USA”						
	2013		2014		2015	
	N	%	N	%	N	%
Birth through 11 months	0	0%	0%	0%	0	0%
12 through 23 months	0	0%	0%	0%	0	0%
24 through 35 months	76	5%	133	7%	128	8%
36 through 47 months	167	11%	192	12%	316	19%
48 through 59 months	457	30%	576	36%	831	50%
60 through 71 months	822	54%	720	45%	382	23%
Total	1,522	100%	1,599	100%	1,661	100%

Title V programs may wish to visualize the data as:

From 2013 – 2016, Over 79% of the 4,782 “Any State USA” Children, Birth-5, Were First Diagnosed with Autism Between the Ages of 4 and 5

Or:



Possible Actions Based on Data – Autism Question 2

Research correlates early intervention with better child outcomes. The data show that most children are not being identified until the ages of 4 and 5. This leaves little time to provide interventions prior to kindergarten. Title V programs could use the data as a call to action for earlier identification.

Question 3: What percentage of children birth through age 5 were diagnosed with autism based on a referral as a result of a screening or assessment?

The recommended data elements for this analysis are listed in the table below. For states using the Common Education Data Standards (CEDs), the link to the CEDs element has been provided.

Data Elements – Autism Question 3



Click the hyperlinks in the table to see more information about the data elements in CEDs. The links will take you to the individual elements and do not require a CEDs login to access. Where available, links to CEDs are included. Where not available, data elements that are likely to exist in Title V data systems have been suggested. These elements will be submitted to CEDs for consideration.

Variable	Data Element Choices	Element Definition	Option Set	Considerations
Child	Child Identifier	A unique number or alphanumeric code assigned to a child by a school, school system, state, or other agency or entity.	Alphanumeric	Although the questions in this analysis can be reported on aggregately, child information is needed to create the data set. After data have been pulled, children's personally identifiable data may be stripped.
	First Name	The full legal first name given to a person at birth, baptism, or through legal change.	Alphanumeric	Although the questions in this analysis can be reported on aggregately, child information is needed to create the data set. After data have been pulled, children's personally identifiable data may be stripped.
	Middle Name	A full legal middle name given to a person at birth, baptism, or through legal change.	Alphanumeric	Although the questions in this analysis can be reported on aggregately, child information is needed to create the data set. After data have been pulled, children's personally identifiable data may be stripped.
	Last or Surname	The full legal last name borne in common by members of a family.	Alphanumeric	Although the questions in this analysis can be reported on aggregately, child information is needed to create the data set. After data have been pulled, children's personally identifiable data may be stripped.
	Generation Code or Suffix	An appendage, if any, used to denote a person's generation in	Alphanumeric	Although the questions in this analysis can be reported on aggregately, child information is needed to create the data set.

Variable	Data Element Choices	Element Definition	Option Set	Considerations
		his family (e.g., Jr., Sr., III).		After data have been pulled, children's personally identifiable data may be stripped.
Child Age	Birthdate	The year, month, and day on which a person was born.		Although the questions in this analysis can be reported on aggregately, child information is needed to create the data set. After data have been pulled, children's personally identifiable data may be stripped.
Diagnosis	Disability Status	An indication of whether a person is classified as disabled under the American's with Disability Act (ADA).	Yes	For this question, only the children that have been classified as disabled (an option set of yes) should be pulled for the data set.
	Primary Disability Type	The major or overriding disability condition that best describes a person's impairment.	Autism: Autism is the major or overriding disability condition that best describes the person's impairment.	Although there are many disability types, only the children with autism (an option set of autism) should be pulled for the data set.
Referral	Referral Reason	The reason for the referral.	Alphanumeric	
	Referral Outcome	The outcome of the referral.	Other: The outcome of the referral is in a category not yet defined in CEDS	This category may be used to identify children diagnosed based on a referral.

Steps for Analysis – Autism Question 3

- a. Identify the timeframe for analysis. For example, you may wish to look at the data by calendar or fiscal year.
- b. Identify the geographic boundary for analysis. For example, you may wish to look at the data by county or ZIP code.
- c. After applying the timeframe and geographic boundary filters, pull the subset of children birth through age 5 with a documented autism diagnosis in the specified timeframe and geographic boundary.
- d. Of the children identified in c., pull a subset of autistic children with a referral based on a screening or assessment.
- e. Calculate the number of children receiving an autism diagnosis based on a referral as a result of a screening or assessment.
- f. Check for data quality issues such as outliers or missing data.
- g. Calculate the percentage by dividing the total number of children receiving an autism diagnosis based on a referral as a result of a screening or assessment by the total number of children with an autism diagnosis in the identified timeframe and geographic boundary. Multiply by 100 for a total percentage.

Data Visualization – Autism Question 3

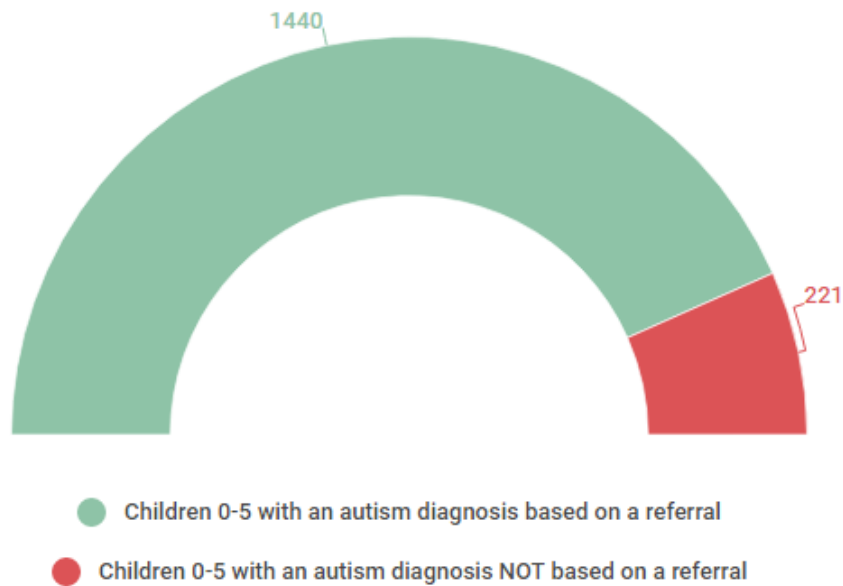
Effective data visualization is critical for conveying the Title V program message and telling your story. When looking at the data provided by ECIDS, what do you notice? What are the patterns and/or trends? These questions will help Title V programs identify the story the data tell.

Consider this example using fictitious data:

2015 Children Birth Through Age 5 with an Autism Diagnosis in “Any State USA)		N=1,661
	N	%
Children birth through age 5 with an autism diagnosis based on a referral	1,440	86.7%
Children birth through age 5 with an autism diagnosis NOT based on a referral	221	13.3%

Title V programs may wish to visualize the data as:

In 2015, 86.7 Percent of Children, Birth Through Age 5, Were Diagnosed with Autism Based on a Referral as a Result of a Developmental Screening or Assessment Tool



Possible Actions Based on Data – Autism Question 3

The data show the importance of referrals in identifying children with autism. Title V programs can use this information to increase screening and assessment buy-in throughout the state, leading to more funding for screening and assessment activities and reimbursements.

Question 4: In which early childhood programs are children diagnosed with autism participating?

The recommended data elements for this analysis are listed in the table below. For states using the Common Education Data Standards (CEDS), the link to the CEDS element has been provided.

Data Elements – Autism Question 4



Click the hyperlinks in the table to see more information about the data elements in CEDS. The links will take you to the individual elements and do not require a CEDS login to access. Where available, links to CEDS are included. Where not available, data elements that are likely to exist in Title V data systems have been suggested. These elements will be submitted to CEDS for consideration.

Variable	Data Element Choices	Element Definition	Option Set	Considerations
Child	Child Identifier	A unique number or alphanumeric code assigned to a child by a school, school system, state, or other agency or entity.	Alphanumeric	Although the questions in this analysis can be reported on aggregately, child information is needed to create the data set. After data have been pulled, children's personally identifiable data may be stripped.
	First Name	The full legal first name given to a person at birth, baptism, or through legal change.	Alphanumeric	Although the questions in this analysis can be reported on aggregately, child information is needed to create the data set. After data have been pulled, children's personally identifiable data may be stripped.
	Middle Name	A full legal middle name given to a person at birth, baptism, or through legal change.	Alphanumeric	Although the questions in this analysis can be reported on aggregately, child information is needed to create the data set. After data have been pulled, children's personally identifiable data may be stripped.
	Last or Surname	The full legal last name borne in common by members of a family.	Alphanumeric	Although the questions in this analysis can be reported on aggregately, child information is needed to create the data set. After data have been pulled, children's personally identifiable data may be stripped.

Variable	Data Element Choices	Element Definition	Option Set	Considerations
	Generation Code or Suffix	An appendage, if any, used to denote a person's generation in his family (e.g., Jr., Sr., III).	Alphanumeric	Although the questions in this analysis can be reported on aggregately, child information is needed to create the data set. After data have been pulled, children's personally identifiable data may be stripped.
Child Age	Birthdate	The year, month, and day on which a person was born.		Although the questions in this analysis can be reported on aggregately, child information is needed to create the data set. After data have been pulled, children's personally identifiable data may be stripped.
Diagnosis	Disability Status	An indication of whether a person is classified as disabled under the American's with Disability Act (ADA).	Yes	For this question, only the children that have been classified as disabled (an option set of yes) should be pulled for the data set.
	Primary Disability Type	The major or overriding disability condition that best describes a person's impairment.	Autism: Autism is the major or overriding disability condition that best describes the person's impairment.	Although there are many disability types, only the children with autism (an option set of autism) should be pulled for the data set.
Early Childhood Programs	Early Childhood Program Enrollment Type	The system outlining activities and procedures based on a set of required services and standards in which the child is enrolled.	Head Start: Head Start is the system outlining activities and procedures based on a set of required services and standards in which the child is enrolled. Early Head Start: Early Head Start is the system outlining activities and procedures based on a set of required services and standards in which the child is enrolled. State Preschool: State Preschool is the system outlining activities and procedures based on a set of required services and standards in which the child is enrolled. Public Preschool: Public Preschool is the system outlining activities and procedures based on a set of required services and standards in which the child is enrolled.	

Variable	Data Element Choices	Element Definition	Option Set	Considerations
			<p>Private Preschool: Private Preschool is the system outlining activities and procedures based on a set of required services and standards in which the child is enrolled.</p> <p>Early Childhood Special Education (619): Early Childhood Special Education (619) is the system outlining activities and procedures based on a set of required services and standards in which the child is enrolled.</p> <p>Home Visiting: Home Visiting is the system outlining activities and procedures based on a set of required services and standards in which the child is enrolled.</p> <p>Child Care: Child Care is the system outlining activities and procedures based on a set of required services and standards in which the child is enrolled.</p> <p>Early Intervention Services Part C: Early Intervention Services Part C is the system outlining activities and procedures based on a set of required services and standards in which the child is enrolled.</p> <p>Other: The system outlining activities and procedures based on a set of required services and standards in which the child is enrolled is in a category not yet defined in CEDS.</p>	
	<p><u>Program Participation Start Date</u></p>	<p>The year, month, and day on which the person began to participate in a program</p>		<p>The date of program participation is compared to the child's date of birth to determine if the children was birth through the age of 5 at the time of program participation.</p>

Variable	Data Element Choices	Element Definition	Option Set	Considerations
	Program Participation Exit Date	The year, month, and day on which the person ceased to participate in a program.		The date of program participation is compared to the child's date of birth to determine if the children was birth through the age of 5 at the time of program participation.

Steps for Analysis – Autism Question 4

Typically, children attend multiple early childhood programs. The value of integrating Title V data into an ECIDS is the ability, through the assigning of a unique identification, to better understand of the number children accessing multiple programs.

- a. Identify the timeframe for analysis. For example, you may wish to look at the data by calendar or fiscal year.
- b. Identify the geographic boundary for analysis. For example, you may wish to look at the data by county or ZIP code.
- c. After applying the timeframe and geographic boundary filters, pull the subset of children birth through age 5 with a documented autism diagnosis in the specified timeframe and geographic boundary.
- d. Of the children identified in c., pull a subset of children with early childhood program information.
- e. Using the early childhood program enrollment type, program participation start date, and the program participation exit date, calculate the number of children in the state participating in each early childhood program for the designated time frame and geographic boundary.
- f. If the Title V program would like the data broken down by early childhood programs, collapse data into the desired early childhood programs using the early childhood program enrollment type.
- g. Check for data quality issues such as outliers or missing data.
- h. Calculate the percentage of autistic children participating in early childhood programs. Divide the total number of autistic children participating in early childhood programs by the total number of autistic children in the identified timeframe and geographic boundary. Multiply by 100 for a total percentage. If the Title V program broke the data into early childhood program categories, divide the total number of autistic children in each early childhood program by the total number of autistic children in the identified timeframe and geographic boundary. Multiply by 100 for a total percentage.

Data Visualization – Autism Question 4

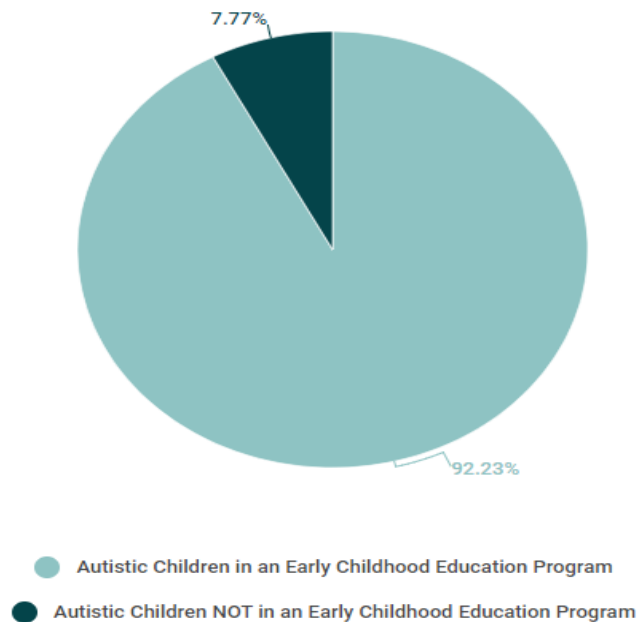
Effective data visualization is critical for conveying the Title V program message and telling your story. When looking at the data provided by ECIDS, what do you notice? What are the patterns and/or trends? These questions will help Title V programs identify the story the data tell.

Consider this example using fictitious data:

2013 Children with a Documented Autism Diagnosis in “Any State USA”		N=3,322
	N	%
Children birth through age 5 with autism participating in an early childhood program	3,064	92.2%
Children birth through age 5 with autism NOT participating in an early childhood program	258	7.85%

Title V programs may wish to visualize the data as:

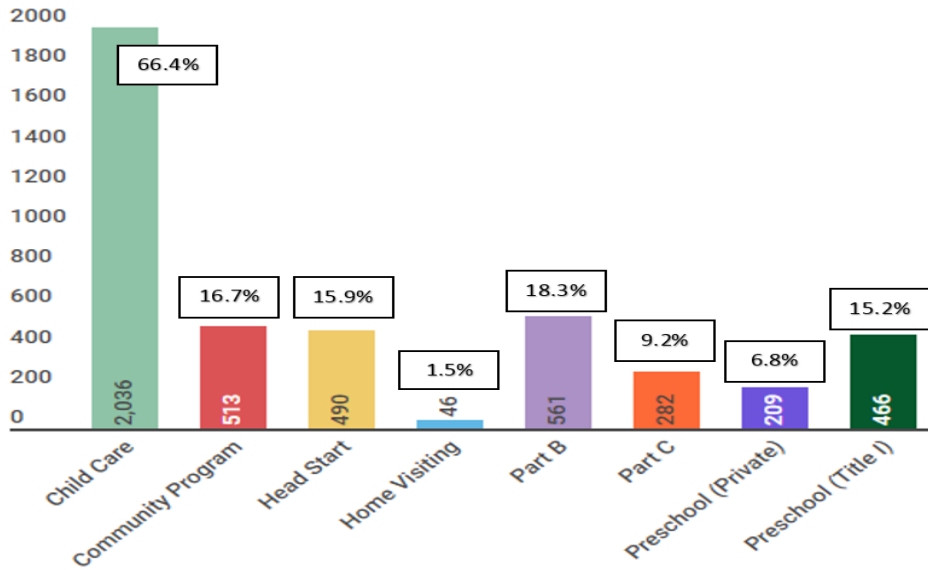
In 2013, 92% of “Any State USA” Autistic Children, Birth Through Age 5, Were Participating in an Early Childhood Education Program



2013 Children with a Documented Autism Diagnosis in “Any State USA” Early Childhood Education (ECE) Program Participation Type		N=3,064
	N	%
Child Care	2,036	66.4%
Community Place-Based Program (e.g. Help Me Grow)	513	16.7%
Head Start	490	15.9%
Home Visiting	46	1.5%
Part B	561	18.3%
Part C	282	9.2%
Preschool (Private)	209	6.8%
Preschool (Title I)	466	15.2%
*Totals will not equal 3,064 as a child may be in more than one program		

Title V programs may wish to visualize the data as:

2013 “Any State USA” Autistic Children, Birth Through Age Five, Early Childhood Education Program Participation



Possible Actions Based on Data – Autism Question 4

As the incidence of autism spectrum disorder increases, it is important to know which programs autistic children are participating in. This helps Title V programs know which programs they should support through resources and training. For example, knowing that high numbers of autistic children are in child care programs, Title V programs can provide training and teaching strategies to child care providers through Child Care Resource and Referral (CCRR).

Question 5: Of the children diagnosed with autism, what percentage are receiving IDEA Part C services? What percentage are receiving IDEA Part B services?

The recommended data elements for this analysis are listed in the table below. For states using the Common Education Data Standards (CEDs), the link to the CEDs element has been provided.

Data Elements – Autism Question 5



Click the hyperlinks in the table to see more information about the data elements in CEDs. The links will take you to the individual elements and do not require a CEDs login to access. Where available, links to CEDs are included. Where not available, data elements that are likely to exist in Title V data systems have been suggested. These elements will be submitted to CEDs for consideration.

Variable	Data Element Choices	Element Definition	Option Set	Considerations
Child	Child Identifier	A unique number or alphanumeric code assigned to a child by a school, school system, a state, or other agency or entity.	Alphanumeric	Although the questions in this analysis can be reported on aggregately, child information is needed to create the data set. After data have been pulled, children's personally identifiable data may be stripped.
	First Name	The full legal first name given to a person at birth, baptism, or through legal change.	Alphanumeric	Although the questions in this analysis can be reported on aggregately, child information is needed to create the data set. After data have been pulled, children's personally identifiable data may be stripped.
	Middle Name	A full legal middle name given to a person at birth, baptism, or through legal change.	Alphanumeric	Although the questions in this analysis can be reported on aggregately, child information is needed to create the data set. After data have been pulled, children's personally identifiable data may be stripped.
	Last or Surname	The full legal last name borne in common by members of a family.	Alphanumeric	Although the questions in this analysis can be reported on aggregately, child information is needed to create the data set. After data have been pulled, children's personally identifiable data may be stripped.
	Generation Code or Suffix	An appendage, if any, used to denote a person's generation in his family (e.g., Jr., Sr., III).	Alphanumeric	Although the questions in this analysis can be reported on aggregately, child information is needed to create the data set. After data have been pulled,

Variable	Data Element Choices	Element Definition	Option Set	Considerations
				children's personally identifiable data may be stripped.
Child Age	Birthdate	The year, month, and day on which a person was born.		Although the questions in this analysis can be reported on aggregately, child information is needed to create the data set. After data have been pulled, children's personally identifiable data may be stripped.
Diagnosis	Disability Status	An indication of whether a person is classified as disabled under the American's with Disability Act (ADA).	Yes	For this question, only the children that have been classified as disabled (an option set of yes) should be pulled for the data set.
	Primary Disability Type	The major or overriding disability condition that best describes a person's impairment.	Autism: Autism is the major or overriding disability condition that best describes the person's impairment.	Although there are many disability types, only the children with autism (an option set of autism) should be pulled for the data set.
IDEA Services	IDEA IEP Status	The status of an individualized services plan for a specified reporting period or on a specified date.	Active: Active is the status of an individualized services plan for a specified reporting period or on a specified date.	Although an IEP can be active or inactive, only the children with option set "active" should be pulled for this analysis.
	IDEA Indicator	A person having intellectual disability; hearing impairment, including deafness; speech or language impairment; visual impairment, including blindness; serious emotional disturbance (hereafter referred to as emotional disturbance); orthopedic impairment; autism; traumatic brain injury; developmental delay; other health impairment; specific learning disability; deaf-blindness; or multiple disabilities and who, by	Yes No	This element is used to identify IDEA children with autism.

Variable	Data Element Choices	Element Definition	Option Set	Considerations
		reason thereof, receive special education and related services under the Individuals with Disabilities Education Act (IDEA) according to an Individualized Education Program (IEP), Individual Family Service Plan (IFSP), or service plan.		
	<u>Primary Disability Type</u>	The major or overriding disability condition that best describes a person's impairment.	Autism: Autism is the major or overriding disability condition that best describes the person's impairment.	Although there are many primary disability type options, only the children with autism should be pulled.
	<u>Service Entry Date</u>	The year, month, and day on which a person begins to receive early intervention, special education or other services.		The date of service is compared to the child's date of birth to determine if the children was birth through the age of 5 at the time of service.
	<u>Service Exit Date</u>	The year, month, and day on which a person stops receiving early intervention or special education services.		The date of service is compared to the child's date of birth to determine if the children was birth through the age of 5 at the time of service.

Steps for Analysis – Autism Question 5

- a. Identify the timeframe for analysis. For example, you may wish to look at the data by calendar or fiscal year.
- b. Identify the geographic boundary for analysis. For example, you may wish to look at the data by county or ZIP code.
- c. After applying the timeframe and geographic boundary filters, pull the subset of children birth through age 5 with a documented autism diagnosis in the specified timeframe and geographic boundary.
- d. Of the children identified in c., pull a subset of children with an IDEA Part B and/or IDEA Part C service entry date in the specified timeframe and geographic boundary.
- e. Calculate the number of children receiving IDEA Part C services and the number of children receiving IDEA Part B services.
- f. Check for data quality issues such as outliers or missing data.
- g. Calculate the percentage of children receiving IDEA Part B services by dividing the total number of children receiving IDEA Part B services by the total number of children with a documented autism diagnosis in the identified timeframe and geographic boundary. Multiply by 100 for a total percentage.
- h. Calculate the percentage of children receiving IDEA Part C services by dividing the total number of children receiving IDEA Part C services by the total number of children with a documented autism diagnosis in the identified timeframe and geographic boundary. Multiply by 100 for a total percentage.

Data Visualization – Autism Question 5

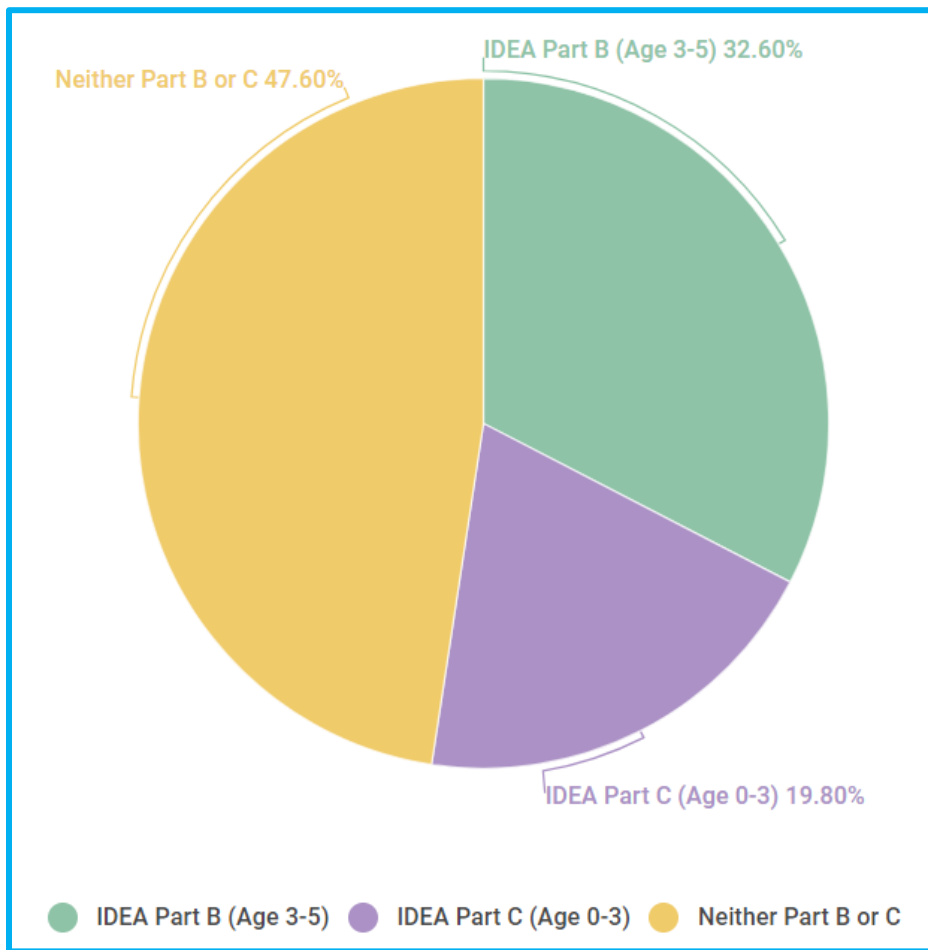
Effective data visualization is critical for conveying the Title V program message and telling your story. When looking at the data provided by ECIDS, what do you notice? What are the patterns and/or trends? These questions will help Title V programs identify the story the data tell.

Consider this example using fictitious data:

2016 Children Birth Through Age 5 with a Documented Autism Diagnosis in “Any State USA”		N= 5,462
	N	%
Children birth through age 5 with a documented autism diagnosis receiving IDEA Part B services	1,781	32.6%
Children birth through age 5 with a documented autism diagnosis receiving IDEA Part C services	1,080	19.8%
Children birth through age 5 with a documented autism diagnosis not receiving any IDEA services	2,601	47.6%

Title V programs may wish to visualize the data as:

In 2016, 41.87% of the 5,462 Autistic Children in “Any State USA” Were Not Receiving Either IDEA Part B or IDEA Part C Services



Possible Actions Based on Data – Autism Question 5

The data provides Title V programs with valuable information as they break down the number of autistic children receiving IDEA services. Based on the data, programs could explore why autistic children are not receiving IDEA services. Are the autistic children ineligible for services? Are the parents/guardians refusing services? Perhaps there are limited services in a rural community. Once Title V programs understand the barriers to autistic children receiving IDEA services, resources to address barriers can be allocated.