Inclusion

Disability Eligibility Patterns in Head Start Programs: A Comparison of Puerto Rico and Mainland United States of America
--Manuscript Draft--

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Abstract

Population-based research can identify eligibility patterns in diverse disabilities and cultures, and the Head Start ECLKC gathers relatively controlled data of students in the United States (US) and Puerto Rico, providing an opportunity to directly compare cultures. We compared preschool diagnostic eligibility categories in the US and Puerto Rico for Speech/Language Impairment (SI), Autism Spectrum Disorder (ASD), Developmental Delay (DD), and Intellectual Disability (ID) across three years (2016-2018). We observed higher reporting of ASD in Puerto Rico as compared to the US, suggesting increased awareness and education towards this diagnosis. There was higher identification for SI and for ASD but lower identification for DD and ID in Puerto Rico, which suggests cultural differences impact how these typologies are defined and assessed.

Keywords: Head Start ECLKC, Developmental Delay, Speech/Language Impairment, Autism Spectrum Disorder, Intellectual Disability

Disability Eligibility Patterns: A Comparison of Puerto Rico and Mainland United States of America

Population-based research is used to study trends around the world to gain insights into incidence and prevalence of health threatening conditions (National Academies of Sciences, Engineering, and Medicine, 2017). Medicine and related fields benefit from this research approach to identify disease patterns in the population to address health-threatening conditions (Rose, 1985). However, population approaches have been minimally employed in the speech-language pathology field and related disabilities studies, largely foregoing the benefits of valuable and interpretable data that may yield unique insights on these conditions (Raghavan et al., 2018). This approach could identify risk factors in the population that are not obvious in patient level data and improve health-related data collection and reporting (Gourevitch, 2014), resulting in valuable information to inform policy and resource development towards disabilities (e.g., monetary support, increase awareness, creation of support centers, increase of research).

Although there is consensus on the importance of this perspective, the procedures to access and analyze these data objectively and validly can be challenging. In particular, variations on the country of origin, cultural aspects involved, and disabilities data reporting (Elsabbagh et al., 2012). For example, although there are a number of resources worldwide that are being developed and evaluated to gather population data, low to medium-income regions within countries may be affected by the limited capacity to access resources and education (Elsabbagh et al., 2012). But in the field of disability reporting and for speech-language pathologists serving people and families with disabilities, there is a striking paucity of databases that can be utilized for the kinds of cross-cultural studies that can be especially informative (Raghavan et al., 2018). Also, there are even fewer databases that include high risk populations (e.g., minority communities, young children from low income families)

Velazquez-Gonzalez et al. (2014) explained the difficulties in collecting data on current diagnosis and primary reason of the present disability in young populations with developmental conditions in Puerto Rico. These data collections utilize some assessment and data reporting frameworks similar to mainland United States of America (US) procedures and processes, but nonetheless may yield different results and interpretations. A potential difference, for example, could arise from their report that parents do not report information on disabilities until they notice significant needs or delays in their children, which can often happen at later ages than in the US. Such a difference, if observed in the public health data could be important for people and families of people with disabilities such as Autism Spectrum Disorder (ASD) and with intellectual disabilities because early identification of needs and service delivery can enhance developmental progress and significantly help future outcomes (e.g., Zwaigenbaum et al., 2015). Therefore, understanding the incidence and prevalence of developmental disabilities of the younger population is extremely important to inform current needs on services, community outreach, and research focus.

A possible database that can help to inform minority early childhood populations is the Head Start Early Childhood Learning & Knowledge Center (Head Start ECLKC). They have been collecting data on developmental disabilities in Puerto Rico for decades using a standard platform across regions. Head Start ECLKC has promoted the inclusion of children with disabilities since 1990 (Head Start ECLKC, 2019). And, since 2009, both Puerto Rico and the mainland US have gathered yearly data of enrolled students both with and without identified disabilities using the Head Start ECLKC reporting protocol. At present, Head Start ECLKC continues to serve young children (e.g., birth to five years of age) with diverse backgrounds, low-income status, and with special needs, becoming a potential database to compare similar samples across cultures.

The availability of this database can be particularly important for the field. First, because the data includes the Puerto Rican population which is a minoritized/under-represented community in research on intellectual disabilities and related conditions such as ASD. Second, it includes low-income populations across Puerto Rico and mainland US because Head Start is focused on low income families across sites. Third, it includes the early childhood population, which could inform the incidence of disability diagnosis of children in preschool to compare proportions across Puerto Rico and mainland US samples.

Broadly, for children to be eligible for services through Head Start ECLKC, they must be from a low-income family and/or diagnosed with a disability defined by the Individual Disabilities Education Act (IDEA) (2004). For those students enrolled based on disability eligibility, Puerto Rico and the US have similar established protocols and criteria that permit direct comparisons. First, a referral for an evaluation is made with parents' consent. An interdisciplinary team convenes to discuss the evaluation results and determine eligibility. If eligible, an Individualized Educational Plan (IEP) is written and services are provided (*Estado Libre Asociado de Puerto Rico del Departamento de Educación,* 2004; US Department of Health and Human Services, n.d.[a]).

Children are enrolled in the Head Start ECLKC program in Puerto Rico and the US using similar criteria for disability eligibility arising from these standard procedures. The availability of this standard process across sites permits numerical and proportional comparisons between populations. Therefore, we examined the overall data available from the Office of Head Start Program Information Reports at the state and national level in this study (Office of Head Start, 2016[a]; Office of Head Start, 2016[b]; Office of Head Start, 2017[a]; Office of Head Start, 2017[b]; Office of Head Start, 2018[a]; Office of Head Start, 2018[b]). We analyzed the proportion of disability classification patterns between countries with a direct focus on children between the ages of three to five qualified under the following broad

disability categories: Intellectual Disability (ID), ASD, Developmental Delay (DD), and Speech/Language Impairment (SI). We utilized this information to address the following questions: (1) Are there differences in eligibility classification between Puerto Rico and the US?, if so, (2) Which disabilities categories are different? and (3) Are any differences replicated across all three years?

We hypothesized *a priori* that the identification of ASD in Puerto Rico would be lower than in the US, because several studies have shown that Latinx populations tend to under report developmental concerns, there are disparities on diagnosis patterns, and there is evidence of less service provision and later diagnosis of ASD in Lantinx samples (Magaña et al., 2014; Palmer et al., 2010; Zuckerman et al. 2018). This is especially true for those from low-income communities, where there is often less familiarity and experiences with developmental disabilities and methods for accessing services (Zuckerman et al., 2018). Although we did not make assumptions about the identification rates of ID, there is literature suggesting that this diagnosis might be well accepted and supported by mothers in Puerto Rico from childhood to adulthood (Blacher et al., 2013; Hughes et al., 2008; Magaña et al., 2002). If the label, in fact, is well-accepted, we would not anticipate differences across samples. We had no a priori hypotheses regarding SI and DD classification and thus would not have been surprised if these were similar across sites.

In order to address these questions and hypotheses systematically, we first provide the descriptive statistics of the data and the ways in which we analyzed the data to reflect our criteria of inclusion. Then, we present the statistical analyses that address our study questions regarding the proportion of disabilities typologies in the mainland US and Puerto Rico data. Finally, we discuss possible cultural implications that might be driving differences in eligibility diagnosis and how these results can inform future research and infor clinicians and policy makers. We also present limitations and additional future directions.

Methods

We utilized the Head Start ECLKC data, because there is relatively uniform information across databases (Puerto Rico and US) in the preschool population from low income communities and diverse backgrounds across sites. The data include reporting on Intellectual Disability in addition to other conditions such as SI and DD. We gained access to the database of the Head Start ECLKC, granted through an email request to *help@hsesinfo.org*. We classified the databases for age and disability eligibility classifications.

As described in the introduction, the Head Start ECLKC data are relatively uniform information across databases (Puerto Rico and the US). According to the office of Head Start ECLKC (n.d) general requirements, all enrollees are children from families of low-income social-economic status and the enrollees range in age from birth to five-years-old. Similarly, with regard to disability eligibility, IDEA (2004) explains that after children are enrolled in the local Head Start program, they can be assessed for eligibility for special education services. The eligibility process broadly in Puerto Rico and the US follows federal guidelines, and also includes classification criteria. The disability incidence is reported in the databases provided to us along with the demographic information.

We examined the Program Information Reports (PIR)[1] from both Puerto Rico and the US from the Head Start ECLKC database (Head Start Enterprise System), which are created for every school year through the United States Department of Health & Human Resources (U.S. Department of Health and Human Services, n.d.b). The reports include the following: general information; funded enrollment; disabilities services; family and community partnership staff. Data are included and categorized by eligibility typology within the

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[1] The PIR supplemental materials are available from the author by request.

disabilities services section, which includes our four disabilities classifications of interest: ID, ASD, SI, and DD.

All PIR information is obtained through a survey-based document and, per the Head Start ECLKC guidelines, must be completed and submitted annually by each program in Head Start ECLKC. The current version of the reporting form was dated in 2008 (US Department of Health and Human Services, 2008) and was consistently utilized for all the reporting years we examined (2016, 2017 and 2018), which were the most recent available. All US federal based programs, which include Head Start, Early Head Start, and/or affiliated programs, submit this standard form. The guidelines note that all programs are required to submit their PIR data electronically using the web-based PIR reporting system at https://www.pirweb.net, which ensures a standard reporting format across sites. Therefore, the survey enables Head Start ECLKC to gather uniform representative data on their enrollees and provide data on our interest topic: comparison of culturally diverse (Puerto Rico and US) preschool-age low-income populations with disabilities using a relatively controlled platform across programs, which enables meaningful comparisons.

The Head Start Enterprise System disabilities section includes data between the years of 2009 and 2018, allowing us to search general information of enrollment, funding, disability services, and family and community partnerships staff gathered between such year ranges. For the purpose of this article, we chose to use the following criteria: (1) The data had to be no more than five years old (in order to capture current referral patterns), (2) it had to yield total enrollment by year, (3) it should include the number of children with IEP eligibilities, and (4) include the number of children diagnosed by each disability category of students between the ages of three to five (preschool). Based on these criteria, we analyzed data between the years 2016 through 2018 (the most recent years available at the time this

study was conducted) of children between the ages of three through five (preschoolers) of Puerto Rico and the US (all 50 states aggregated) population.

In order to interpret the data across samples, we analyzed proportions of disability classification. Note that to ensure we were not double counting enrollees, we subtracted the total cases from the Puerto Rico PIR data from the total cases in the US data, because the Puerto Rico cases were originally included in the aggregated national level US data (Table 1). Proportions were computed by dividing the number in each category (individually) by the total number in Puerto Rico and US respectively. Then, the unique data from Puerto Rico and the US were compared using Chi Square analyses using SPSS software. That is, the proportions of all categories (e.g., SI, ASD, DD, ID) were compared across mainland US and Puerto Rico samples. A Chi-Square approach was utilized because it does not require assumptions of normality or homoscedasticity and includes proportional representation within each database.

Results

Enrollment: 2016, 2017, 2018

We focused on the enrollment of the target population or interest herein: Three to five year-old preschool students enrolled in Head Start ECLKC (see table 1). In Puerto Rico the following number of students were enrolled by year: 33,572 in 2016, 31,166 in 2017, and 25,674 in 2018. The following number of students were enrolled in the US by year: 836,814 in 2016, 802,643 in 2017, and 775,859 in 2018 (with Puerto Rico students removed from the total US data).

Eligibility Classification

In Puerto Rico, in 2016 there were a total of 7,273 students eligible in special education categories, in 2017, 6,688, and in 2018, a total of 4,869. In the US, in 2016 there were 101,251 students eligible for special education services, in 2017, 98,832, and in 2018 a

total of 97,505. Proportions were computed by dividing the number in each category

(individually) by the total number in Puerto Rico and US respectively. Note that the US

analysis did not   include any cases that were included in the Puerto Rico sample, so that no

student was counted in both categories.

Differences in Disability Eligibilities

Intellectual Disability. For ID eligibility patterns between countries; in Puerto Rico, in

2016, 0.05% of children were made eligible under this category, in 2017 0.04%, and in 2018

0.03%, which is a relatively stable proportion. In the US, 0.13% were classified as ID in

2016, 0.08% in 2017, and 0.08% in 2018. Thus, there were significant differences across sites

with higher relative incidence in the US, but a significant lower incidence rate in both

countries than existing overall population estimates would suggest.

<div align="center">INSERT FIGURE 1 HERE</div>

ASD, SI, and DD. The overall analysis indicated that there were differences in

eligibility between Puerto Rico and the US. When the data in each year was analyzed

proportional to the total of students enrolled of ages three to five years in Puerto Rico and the

US, it revealed a significantly lower proportion of ID in Puerto Rico (Figure 1) but a

significantly higher proportion of ASD reported in Puerto Rico (Figure 2) when compared to

the US in all three years. Also, there were significant differences in children classified as DD

versus SI (Figure 3) between the countries, with a significantly higher proportion of SI in

Puerto Rico and lower proportion of DD relative to US reporting.

For ASD data in Puerto Rico, in 2016 0.70% of students were made eligible under

this category, 0.66% in 2017, and 0.74% in 2018. In the US, in 2016 0.39% were made

eligible with ASD, 0.42% in 2017, and 0.47% in 2018. These proportions were significantly

higher in the Puerto Rico sample.

<div align="center">INSERT FIGURE 2 HERE</div>

For SI and DD eligibility between countries; in Puerto Rico, in 2016 19.99% of children were made eligible with a SI and 0.01% with a DD; in 2017 19.84% SI and 0.01% DD; and in 2018 17.32% with SI and 0.03% with DD. But in the US, in 2016 6.53% were made eligible with SI, 6.68% in 2017, and 6.82% in 2018. For DD, in the US in 2016 4.22% were made eligible under this category, in 2017 4.35%, and in 2018 4.5%. These proportions were significantly different across Puerto Rico and the mainland US samples.

INSERT FIGURE 3 HERE

Statistical Analysis

An omnibus analysis was conducted to determine whether there were differences in the distribution of classifications between sites (Puerto Rico as compared to the US). The results of this analysis indicated that there is a significant difference between sites ($\chi^2 = 50.85$; $p < .0001$). Because this analysis revealed that there were differences between sites, post hoc χ^2 tests were conducted and the tests were replicated each year. The post hoc analyses indicated that there were differences in the proportion of SI and DD students across sites. In 2016, $\chi^2 = 4135.08$, $p < .00001$, for 2017 $\chi^2 = 3851.00$, $p < .00001$; and for 2018 $\chi^2 = 2824.78$ $p < .00001$. In each year, there were significant differences in the proportion of SI relative to DD cases with the US reporting a far larger proportion of cases as compared to Puerto Rico.

Similarly, the proportion of ID was different between Puerto Rico and the US, with a significantly lower proportion of ID in Puerto Rico ($\chi^2 = 32.45$, $p > .0001$). This was also seen in ASD, but the reported incidence was significantly higher than expected values in Puerto Rico ($\chi^2 = 152.82$, $p > .00005$).

Discussion

The purpose of this study was to utilize the Head Start ECLKC data to compare the low-income preschool populations across the three most recent years of available data and

compare eligibility patterns in Puerto Rico and the US for four disability typologies directly

and indirectly related to intellectual disabilities: ID, ASD, DD, SI. Three primary findings

emerged: 1) There were differences of ID identification across sites with lower identification

in Puerto Rico, but a significant low rate on the incidence of this diagnosis across sites; 2)

there was a higher proportion of ASD eligibility in Puerto Rico; and 3) there were significant

differences in proportion of SI and DD eligibility in Puerto Rico as compared to the US, with

higher DD in the US and higher SI in Puerto Rico.

ID Incidence

Before going into detailed discussion of the analyses, it is important to consider the

relatively low numbers of reported ID across Puerto Rico and the US data. It is also important

to note that the Head Start ECLKC data included preschoolers, so perhaps it is not surprising

that rigorous eligibility testing for ID that includes standardized measures of intellectual

ability may not have yet been completed (see Camarata & Swisher, 1990, Camarata, 2014a).

The actual reported numbers in Puerto Rico were 16, 11, and 8 in 2016, 2017, and 2018

respectively, which is far lower than would be expected. With that caveat, the results of the

chi-square analysis comparing intellectual disability identification in Puerto Rico to that of

the US are nonetheless intriguing.

Our ID comparison showed two main results: lower incidence of ID in Puerto Rico

when compared with the US and significantly lower reporting of ID in both countries relative

to overall population estimates of ID in the US (McKenzie et al., 2016). Although we did not

hypothesize *a priori* the incidence of this diagnosis, we did speculate that there might not be

differences across countries. This speculation was primarily driven by the fact that there are

several studies indicating a high acceptance over ID diagnosis by parents in latinx   samples

(Blacher et al., 2013; Hughes et al., 2008; Magaña et al., 2002). For example, Hughes and

colleagues (2002) surveyed Latina mothers of children with special needs. In their findings,

they discussed how mothers, regardless of the diagnosis of their child, were accepting of their needs, treated them as if they would treat their other children without a disability, and expressed the hope of supporting their development to the highest level possible.

Similarly, Blacher and colleagues (2013) found in their longitudinal study, that Latina mothers' perceptions towards their children with or without disabilities showed high positive impact scores on parenting when compared to anglo mothers. More specifically, across seven time points, Latina mothers of children with ID consistently presented high positive impacts on child-rearing, whereas Anglo mothers showed lower results. All of these findings suggested that we might find similar incidence of ID across sites, but our data shows the opposite.

Regarding the significantly low incidence rate of ID in Puerto Rico, there are several potential explanations that cannot be directly tested empirically in these data. First, special education eligibility often includes standardized assessments of intellectual ability, which may not be widely implemented to preschoolers either in the US or perhaps even more so in Puerto Rico. For example, Courchesne et al. (2019) discussed the challenges with intellectual assessment in preschoolers and Camarata and Swisher (1990) argued that intellectual assessment in preschoolers is often confounded with language ability. It is also perhaps noteworthy that in several regions of the US, there has been, over the last decade, a proportional reduction in the identification of intellectual disability associated with an increase in identification as ASD (see for example, Bertelli, 2019). To be sure, the rise in ASD in the US is not solely attributable to the decline in ID (see Nevison & Blaxill, 2017) but it is possible that at least a portion of the increased incidence of ASD in Puerto Rico, which was unanticipated, may have been associated with the lower rate of intellectual disability. Future studies can directly examine the extent to which eligibility migration (if

any) from ID to ASD contributes to the relatively higher reporting for ASD and lower reporting for ID in Puerto Rico.

With regard to the proportion of ID in the US sample, this was significantly higher than in Puerto Rico, but lower than the overall population rate in the US (e.g., McKenzie et al. 2016). This leads to the question of whether this finding may relate to the relatively high numbers of generic DD reported in the US. That is, one wonders whether any, and if so what proportion, of cases that are identified as DD in the preschool years are subsequently identified as having intellectual disability. Again, the current database does not permit direct testing of these questions, but the speculations are plausible accounts for some of the differences in ASD, ID, and DD seen herein. Additional replication and longitudinal data can be utilized to directly test these speculations.

ASD Reporting

A second finding in our study was the difference in eligibility of ASD in across countries. We found a higher relative proportion of ASD cases in Puerto Rico. This was in direct contrast to our hypothesis, which was founded on previous reports that ASD in the Latinx communities tends to be identified later and at lower rates (see Ratto et al., 2016). One reason for the results herein could be due to increased awareness of ASD in Puerto Rico. For example, In 2011 the Department of Health in Puerto Rico created and conducted a new survey (at that time) to analyze the prevalence of ASD of minors between the ages of 4-17 (Torres et al., 2013), showing that 1.62% of the population between 4-17 years of age had been identified with ASD. This positioned Puerto Rico as one of the highest in ASD incidence when compared to other states in the US. Then, the BIDA law (*Ley para el Bienestar, Integración y Desarrollo de las personas con Autismo,* P. de la C. 2278) was created, which established the importance of early identification and intervention of ASD,

and promoted the creation of programs where families are involved and professionals are continuously educated about this disorder (P. de la C. 2278)

Afterwards, programs such as the Puerto Rico Autism Center and the participation of STAR Autism Support in the Puerto Rico Autism Project were created. These programs promoted family education and engagement, staff education on diagnosis and treatment, and a follow up system to determine progress in the implementation of learned skills. Also, research studies were conducted, showing that families involved in the program are in need of appropriate interventions and diagnosis supports (Torres et al., 2013) and then STAR Autism Support, which is an organization that provides guidance on developing appropriate practices for families and children with ASD, reported improvements on preschool and secondary classrooms (STAR Autism Support, n.d): increase of functional communication in preschool classrooms and collaboration with parents to use supporting strategies independently.

We speculate that the establishment of dedicated legislation, resources and community outreach programs described above may have increased awareness of ASD, improved diagnostic protocols, and promoted appropriate testing. Moreover, our results might suggest that perceptions of ASD in Latinx cultures (at least in Puerto Rico, but see also Pedersen et. al, 2012) may be changing towards a broader understanding and community awareness of the condition, becoming more accepting and recognized regardless to offset prior knowledge and beliefs reported in previous studies. Additionally, our findings may suggest that Head Start EC   LKC screening and evaluations might be effective, by identifying ASD regardless of the country or culture.

SI and DD Differences

Another unexpected finding was the statistical differences of DD and SI between Puerto Rico and mainland US samples. A plausible explanation for higher SI and lower DD

in Puerto Rico is that there are different standards to identify DD in Puerto Rico as compared to the US. Although this is true across states in the US, differences were not expected to be as significant. Mainly because there are universal guidelines in Head Start ECLKC in both countries and both based themselves on IDEA definitions. But also because developmental delays are common in early childhood and could be identified in regular appointments (Choo et al., 2019). Choo and colleagues explain that in different countries it might be difficult to identify this diagnosis due to lack of knowledge and how it can be recognized. Although Choo and colleagues (2019) are aware that DD can present itself differently in each child (Mithyantha et al., 2017), there is need for training on this diagnosis and what it entitles to be diagnosed based on its qualifications (Choo et al., 2019). This might be true in Puerto Rico, where the diagnosis might be defined and diagnosed using different criteria.

For example, in several governmental documents in Puerto Rico, the concept of "developmental delay" for early intervention services, which are provided by an agency called "*Avanzando Juntos*" (P. de la C. 1469), and in Autism Speaks (2018) is used as a descriptive concept for the program, but not as a eligibility diagnosis. It can also be considered a severe or chronic condition, including deficiencies in physical and/or cognitive skills (*Consejo Estatal sobre Deficiencias en el Desarrollo*, 2018). This same definition is used in the University of Puerto Rico (UPR) Medical Sciences campus website, where a certification is offered to support graduate professions in the provision of early interventions services (UPR Recinto de Ciencias Médicas, 2020). Therefore, it is evident that a DD diagnosis in Puerto Rico is considered a severe condition relative to the US, meaning that children with mild overall development delays might not be identified under this eligibility category in Puerto Rico.

Implications

The results analyzed and discussed above can have significant impacts for service providers and the development of policy for children with disabilities. Clinically, service providers might use these data to inform their decision making in regards to eligibility testing, diagnosing, and treatment approaches. From a public health perspective, the data might be useful in terms of potential need for education and protocol modifications whenever the data indicate that disparities arise from inadequate education on disabilities for families and/or providers or from disability eligibility predicated on incomplete and/or inadequate information (see Camarata, 2014a, b for discussion on eligibility and differential diagnosis).

Clinical

The results discussed herein can be informative for clinicians in the field of developmental disorders in young children with diverse backgrounds. It informs clinicians about cultural impacts in diagnostic definitions and eligibility criterias. For example, the results of the ID comparisons suggest an under identification in both Puerto Rico and mainland US. On the one hand one could argue that so long as the children who ultimately qualify for ID are made eligible for support in another category (i.e., SI or ASD) there are likely no long-term adverse impacts to children or their families. On the other hand, it is vitally important that supports actually match a child's (and their family's) needs. As an example, when a child qualifies for ASD services, these supports rightly focus on increasing motivation for social interaction and on reducing repetitive behaviors and/or compulsive routines that may be interfering with learning. In contrast, ID has long been known to require broad support for learning due to reduced speed of learning (and the need for more intensive and focused instruction on content), but not   to require extrinsic motivation for social communication (see Kanner, 1943; Camarata, 2014b). Thus, it is important to differentiate ID from other eligibility to ensure appropriate support.

The information on this study can also inform clinicians about children diagnosed under SI in an IEP from Puerto Rico, specifically understanding that children with SI could also present red flags under the DD category, based on the assumption that children with mild overall development delays might not be identified under DD in Puerto Rico due to its classification as a severe condition. The SI and DD difference in Puerto Rico can be especially informative for the country's eligibility procedures and knowledge. Clinicians in Puerto Rico can use these data to understand how their eligibility process of DD might be used differently if warranted. Therefore, our data might inform special education programs about ways in which children can be showing multiple developmental needs, not necessarily at a severe level, and still be eligible under a DD eligibility and potentially receive a variety of supports to better improve diverse skills (in addition to speech and language supports). It is also possible that these data inform program managers and leaders in regards to the potential need for additional continuing education related to diagnostic criterias and how these can improve eligibility classifications.

In terms of ASD eligibility, clinicians can be somewhat comfortable with accepting an ASD diagnosis coming from an IEP conducted in the Head Start ECLKC program in Puerto Rico, based on the similar to slightly higher incidence of this eligibility diagnosis when compared to the US. However, clinicians could decide to conduct additional testing to confirm the diagnosis. Clinicians can also feel somewhat comfortable educating parents about and ASD diagnoses. This can be true based on our data indicating increased knowledge and acceptability towards ASD, providing the opportunity to clinicians on conducting psychoeducational components and parental involvement when their children are diagnosed with this disability.

Public Policy, ID, ASD, SI and DD

Our data shows that there is a significant low incidence of ID across sites, even more so   in Puerto Rico. These low rates of ID could help inform policy makers and public health programs in Puerto Rico and the US about the need to educate and train educators and service providers of early childhood with disabilities, which has been an area of interest and need for a decade (see Cumella, 2010). If our speculations about the DD (in the US) and ASD (in Puerto Rico) incidence being the reason for decreased ID is true, a significant public policy opportunity and call for more research in this particular area has been identified. More specifically, this could mean that there is a need for further training of service providers on using adequate assessment protocols, on the understanding individuality between diagnosis, and identifying appropriate diagnostic procedures to correctly conduct differential diagnosis between eligibility categories (e.g., Schalock et al., 2007; Schalock et al., 2015). If this is done, it could increase appropriate and best service for children with disabilities and potentially predict better outcomes in adulthood. Another reason for policy to pay close attention to this finding is that re-analysis and modification of eligibility criteria for ID, DD, and ASD might be needed, in a way that special education teams can identify and reach the correct consensus of the appropriate diagnosis (Schalock et al., 2007; Shogren et al., 2009). .

Limitations and Future Directions

There are several important limitations in this study, which should be addressed in future research. First, we discussed speculations on why the ID eligibility category is being diagnosed at lower rates across sites and how it could inform clinicians and policy makers. However, there is limited evidence to support our speculation at this time due to limited population level research in this area. Although it is a significant finding, we suggest that future research pay close attention to these data and identify whether it is replicable. If these data are replicable, it could imply the need for the creation of training programs for providers and families in both Puerto Rico and the US in order to improve diagnostic procedures and

treatment plans for each individual child. We also speculated on the potential for migration from ID to ASD as one potential contributor to this finding. Although the three years we studied did not show a direct reduction in ID that was offset by an increase in ASD, longer term and larger samples would be better suited to testing this speculation.

Second, we discussed how the ASD incidence in Puerto Rico was higher when compared to the US reaching statistical difference. Even though it is an innovative and interesting finding, expanding the amount of years analyzed and the sample size can help to directly attribute the increase to the addition of laws and programs related to the diagnosis (e.g., BIDA Law and STAR).

Third, this data set is representative of a single Latinx community particularly of low-income families in the caribbean. Because of this, results and suggested reasons discussed in this manuscript might not be applicable or generalized to other Latinx populations and socio-economic status, showing poor external validity. Future studies should expand and find replicable results in other Latin American countries and Latinx populations within the US to compare data across years and samples. Doing this could provide a better understanding of the incidence of ASD across cultures, potentially showing indication towards the need for increased research for these minority cultures and expansion of resource availability for families and children.

Fourth, we only utilized the Head Start ECLKC database to analyze the target population, potentially limiting the interpretation of results across regions and cultures as well as age levels. However, the results herein can serve as a foundation for future studies, replicating its effects within the same population and across other Latinx countries. To this, future studies can (1) use the Head Start ECLKC database to analyze previous and future years of data, and (2) use other database engines such as Medicaid or Medicare to analyze

similar data related to developmental impairments (e.g. ASD, SI, DD, ID) and determine if there are patterns across data sets.

Fifth, we found limited details in the procedures that the Head Start ECLKC uses to verify their data. Other than knowing that each program has to fill out and submit an online document in a timely manner, no other information on procedures is provided to the public. This makes it difficult to analyze procedural fidelity and provide consistent results across samples. Therefore, future studies should request and report more detailed information regarding these procedures in order to examine the reliability and validity of the data.

Finally, there is limited population-based research and other types of design studies conducted with young Puerto Rican children with developmental disabilities, and the database had limited information on the nature and extent of ID in Puerto Rico. This made our discussion points and informed speculations difficult to objectively support or refute. This is particularly noteworthy due to the importance of understanding a population's risk conditions in order to inform and support policies on the development of resources to continue accurate identification, assessment and, ultimately, providing evidence based services to families and children with ID and other types of disabilities.

Conclusion

The Head Start ECLKC database was a useful tool to analyze populations of young children with diagnosed disabilities for this study. It showed preliminary findings on how ASD, which is reported to be under-diagnosed in Latinx populations, can be recognized and diagnosed at higher rates in comparison to a region and latinx group that has increased knowledge on diagnostic and treatment procedures for the diagnosis. It also identified differences of definitions and eligibility categories across cultures for DD and SI even when the stated criteria and procedures for identifying these classifications are standard across sites. The database provides a range of data over multiple years that offers the opportunity to

replicate, validate, and identify trends of eligibility diagnosis across cultures and include

supplemental studies to detect potential cultural differences in ID reporting and in other

disability typology reporting. The database can be a great tool to use as baseline data and try

to expand and identify trends of diagnosis. Although there are several limitations related to

the use of this database, the differences in DD and SI across cultures, including ASD, are

particularly intriguing, as well as the significantly low incidence of ID across sites.

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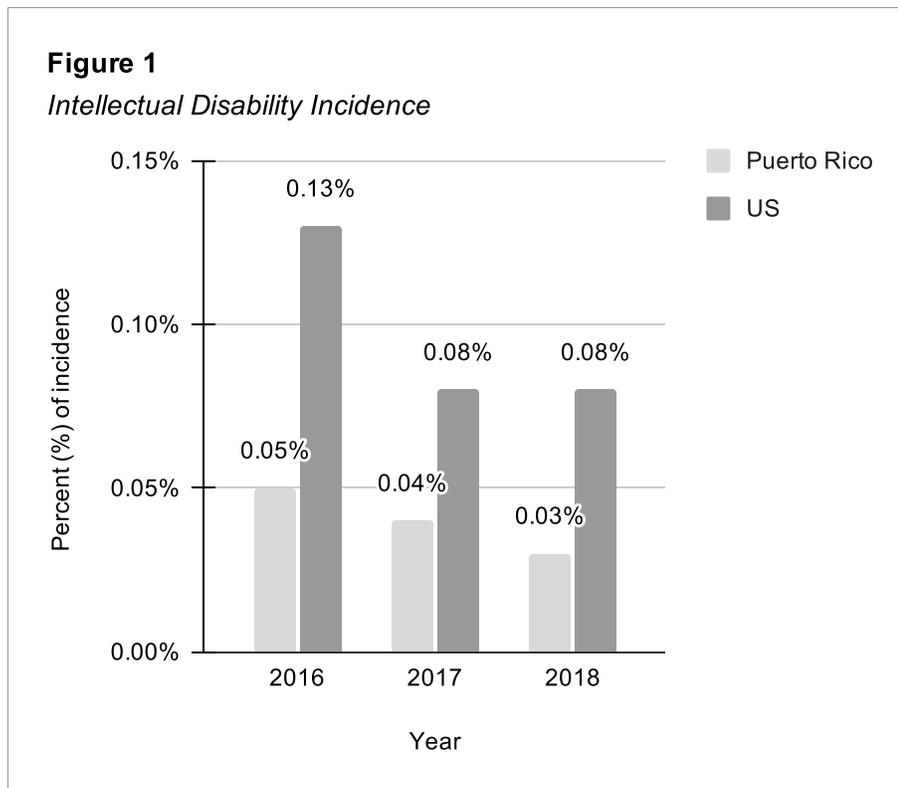*disorder (ASD) in 4-17 years old population: Puerto Rico, 2011* [Abstract].

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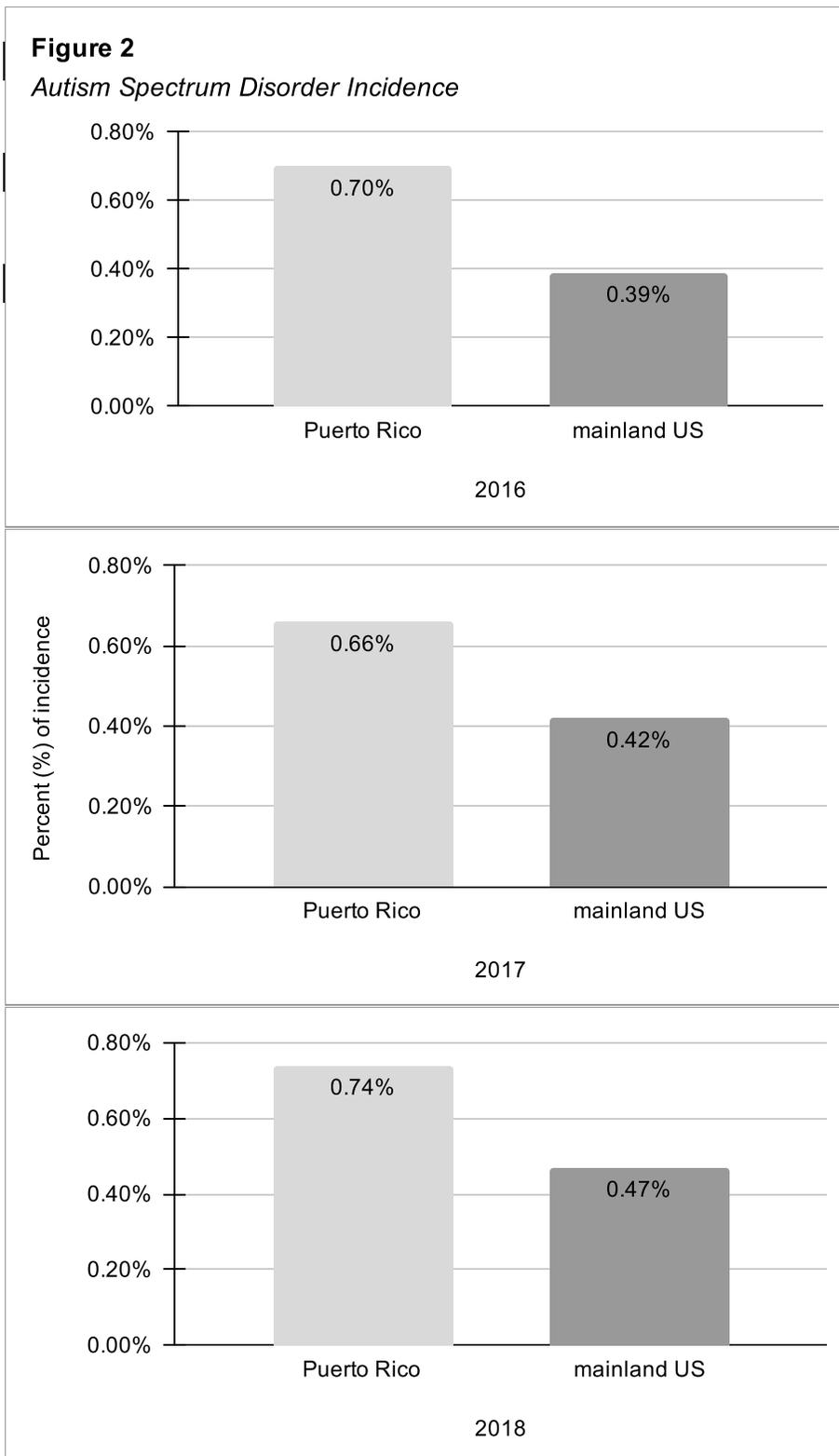of_autism_spectrum_disorders_ASD_in_4_17_years_old_population_Puerto_Rico_2

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Figure 1

Figure 1

Intellectual Disability Incidence

Figure 2 revised

Figure 2

Autism Spectrum Disorder Incidence

Figure 3 revised

Figure 3

Developmental Delay vs Speech/Language Impairment Incidence (2016-2018)
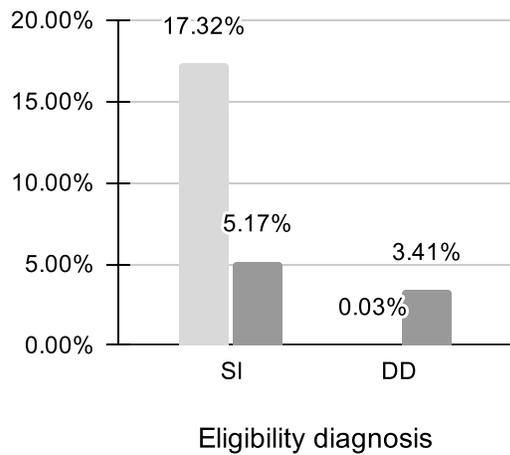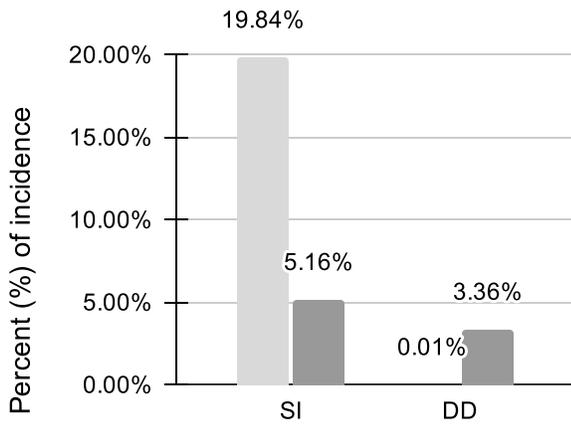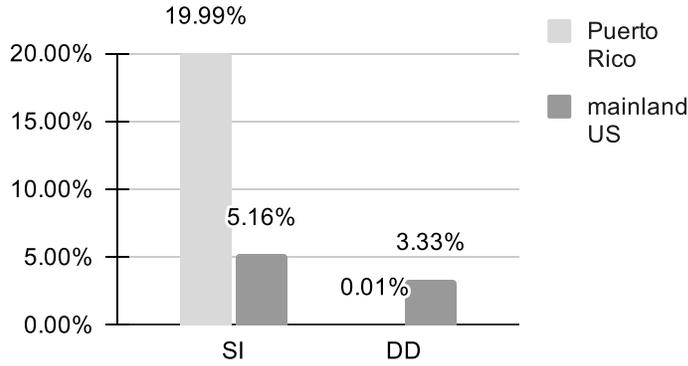
Table 1

Table 1

Background Data of the Preschool Head Start Population

Variable	Puerto Rico			Mainland US		
	2016	2017	2018	2016	2017	2018
Enrollment	33,572	31,166	25,674	836,814	802,643	775,859
Eligibility	7,273	6,688	4,869	101,251	98,832	97,505