American Journal on Intellectual and Developmental Disabilities

Youth with Intellectual Disability and Family Perceptions of Individualized Education Program Meeting Participation During Secondary Education

--Manuscript Draft--

Manuscript Number:	AJIDD-D-24-00069R2
Article Type:	Research Report
Keywords:	transition planning, intellectual disability, secondary data, student involvement
Corresponding Author:	Karrie A Shogren University of Kansas LAWRENCE, Kansas UNITED STATES
First Author:	Karrie A Shogren
Order of Authors:	Karrie A Shogren
	Ashley Taconet
	Tyler Hicks
	Allison Lombardi
	Graham Rifenbark
Manuscript Region of Origin:	UNITED STATES
Abstract:	The importance of youth attendance and leadership during Individualized Education Program (IEP) meetings is widely acknowledged; however, there remain persistently low rates of youth attendance and leadership particularly for students with intellectual disability. This paper describes an analysis of data from the National Longitudinal Transition Study 2012 on youth and parent perspectives of youth with intellectual disability's participation in IEP meeting meetings, specifically the exploration of convergences and divergences in youth and parent report across diverse racial and ethnic groups. The findings affirm low rates of attendance and leadership by youth with intellectual disability across racial and ethnic groups, with high agreement between youth and family members. Implications for future research, policy, and practice are discussed.

Youth with Intellectual Disability and Family Perceptions of Individualized Education Program Meeting Participation During Secondary Education

Abstract

The importance of youth attendance and leadership during Individualized Education Program (IEP) meetings is widely acknowledged; however, there remain persistently low rates of youth attendance and leadership particularly for students with intellectual disability. This paper describes an analysis of data from the National Longitudinal Transition Study 2012 on youth and parent perspectives of youth with intellectual disability's participation in IEP meetings, specifically the exploration of convergences and divergences in youth and parent report across diverse racial and ethnic groups. The findings affirm low rates of attendance and leadership by youth with intellectual disability across racial and ethnic groups, with high agreement between youth and family members. Implications for future research, policy, and practice are discussed.

Youth with Intellectual Disability and Family Perceptions of Individualized Education Program Meeting Participation During Secondary Education

Policy requires supporting youth and family involvement in their Individualized Education Programs (IEPs; IDEA, 2004), and research justifies these requirements given demonstrated impacts of youth and family involvement on postschool outcomes (Burnes et al., 2018; Mazzotti et al., 2021). For example, youth autonomy and decision-making, which can be fostered during involvement in IEP meetings, is a predictor of postschool success (Mazzotti et al., 2021). Youth can be supported to develop these skills through research-based interventions such as Whose Future is it Anyway? (Wehmeyer et al., 2011), the Self-Directed IEP (Martin et al., 2006), and the Self-Determined Learning Model of Instruction (Shogren et al., 2024). When youth turn 16, or earlier in many states, part of this IEP meeting participation also involves planning for the transition from school to postschool activities. However, there remain systemic and attitudinal barriers to youth and family involvement in IEP meetings and associated transition planning (Hirano et al., 2018; Scott et al., 2021). This includes the persistent, low adoption of research-based interventions to promote youth leadership and family involvement in IEP meetings and transition planning (Martin et al., 2004; Martin et al., 2006; Wehmeyer et al., 2011). A wide array of research has explored predictors of IEP and/or transition planning meeting participation, finding differences across disability groups. For example, researchers have found, using nationally representative data on the experiences of secondary students with disabilities from the National Longitudinal Transition Study (NLTS), that youth with certain disability labels, such as intellectual disability, are some of the least likely to be invited and take on leadership roles at their IEP meetings (Johnson et al., 2022; Shogren & Plotner, 2012).

Recent research has also begun to examine the impact of other factors, such as race/ethnicity, economic hardship, and English learner status, on IEP and transition planning meeting participation recognizing the impact of intersectionality on student and family's school experiences (Lombardi et al., 2024; Trainor et al., 2019). For example Lombardi et al. (2024) found Black youth with intellectual disability were less likely to provide input and take on leadership roles than White youth with intellectual disability. While research directly focused on race/ethnicity and transition planning meeting participation is limited, other researchers have described ways that the identities of students and families can impact IEP meeting participation.. Cobb (2014) noted that for culturally and linguistically diverse families, IEP meetings are mainly led by educators and families report not feeling that they are equal partners. A similar sentiment was reflected in Trainor et al. (2019), where families who were culturally and linguistically diverse more often reported IEP goals being developed by school personnel instead of collaboratively. There is also general reported lower involvement in school for families who are first generation immigrants (Freeman & Kirksey, 2023). All of this work suggests a need for ongoing focus on student and family experiences in IEP meetings and transition planning, with a specific focus on understanding the experiences of youth and families who experience intersectionality.

As a part of this ongoing work, it is important to note that there has been variation in how involvement and leadership in IEP meeting and transition planning is conceptualized using available data. Lombardi et al. (2024) created a unidimensional indicator of IEP meeting participation using variables from NLTS2012 (the most recent NLTS study, with data collected in 2012-2013). They used mostly parent-reported items to examine the relationship between IEP participation with youth disability, race/ethnicity, and economic hardship (Lombardi et al., 2024).

Johnson et al. (2020) grouped variables into different domains of participation (e.g., attendance, role in the meeting, contribution during the meeting). This was used to determine if there were differences between IEP participation and students' self-advocacy skills, communication skills, functional skills, and relationship with teachers (Johnson et al., 2020). Still others using NLTS2012 or NLTS2 data (the previous wave of NLTS data collection from 2001 to 2009) have examined specific indicators (Shogren & Plotner, 2012; Trainor et al., 2019). For example, Shogren and Plotner (2012) focused on the experiences of youth with intellectual disability, autism, and other disabilities, while Trainor et al. (2019) focused on the experiences of English Learners with disabilities.

The decisions made about what variables to use to recognize, understand, and support the complex identities and experiences that each student and family brings to their education and to IEP meeting participation are consequential in making recommendations for research and practice. One consistent finding from NLTS and other associated research is that youth with intellectual disability, particularly Black youth with intellectual disability, are less likely to take on leadership roles at IEP meetings (Lombardi et al., 2024). However, one inconsistency in NLTS research is how IEP and transition planning meeting participation and leadership is defined and examined using available data. Across the NLTS studies, information from youth with disabilities themselves as well as their families and their educators has been collected (Burghardt et al., 2017; SRI International, 2000; Wagner, 1992). Many secondary analyses of these variables, including recent studies using NLTS2012 data, have exclusively used parent reported data and/or combined or looked concurrently at youth and parent report data on youth involvement. However, little work has compared youth and parent report as well as convergences and divergences in youth and parent report based on other factors such as race and ethnicity,

despite the broad understanding that youth and family perceptions are distinct and could be separately influenced by an array of factors.

For example, there is a large body of literature suggesting differences in youth and family perceptions of youth's disability and disability-related support needs, youth's educational and transition experiences, and youth and family expectations for youth's future education and employment. Together, this body of work suggests the importance of careful measurement and consideration of both youth and family perspectives, although this does not always occur in research. In terms of disability-related support needs, researchers have found when people with intellectual disability are included as respondents on the Supports Intensity Scale, a standardized measure of support needs (Thompson et al., 2023), alongside family members and professionals, support needs scores are lower when the person with an intellectual disability is included (Hagiwara et al., 2021). The means that including the perspective of people with intellectual disability to generate ratings of their support needs leads to different, and lower, consensus ratings of the intensity of support needs across life domains than when the person with an intellectual disability is not included. This highlights the importance of having varied perspectives, especially including the person themself (Linnenkamp & Broussard, 2024). Regarding transition experiences, researchers have found that youth and families rate the importance of specific aspects of support during transition planning differently, as well as youth's transition skills and attitudes. Powers et al. (2009) found that parents place more emphasis on the importance of teacher support during transition than students do; however, students report more barriers to their transition planning than do their families. Youth, though, report more confidence in their abilities to navigate around these transition barriers than their families. Researchers have found divergence in the expectations of parents and youth with

disabilities for postschool employment, education, and community living, particularly for students with intellectual disability (Bouck et al., 2020; Kirby et al., 2019; Qian et al., 2020; Wu et al., 2024) which may also influence what goals are prioritized during transition planning (Powers et al., 2009).

While this body of research has established differences in family and youth perspectives, there has been limited focus on how other factors, such as youth and family's race and ethnicity, influences convergences and divergences in perspectives. Given this, as well as the general push in the disability field for a greater focus on self-reported measures to ensure people with intellectual disability are given opportunities to report on their perceptions of their current status and future status (Shogren et al., 2021), there is a need to gather information from youth as well as families on IEP and transition planning experiences. This information can then be used to understand the range of experiences and perspectives held by all members of a transition and IEP team and inform planning and supports and services.

Thus, a major focus of this paper was to separately examine youth and family perceptions of youth's involvement in and leadership of IEP meetings and transition planning and examine if factors such as race and ethnicity, influence convergences and divergences. Focusing on self-perceptions separate from family perspectives aligns with best practice recommendations in the intellectual disability field highlighting the importance of considering self-reported perceptions and not substituting proxy perspectives. Instead, the goal is to examine each source of data as a separate and important indicator of experiences and predictor of outcomes (Shogren et al., 2021). Further, as youth and their families have different interactions leading up to and during IEP and transition planning meetings, perspectives of youth's participation may be distinct across youth and families. For example, literature suggests clear differences between youth and family and

educator perspectives about transition planning (Carter et al., 2014; Shogren & Plotner, 2012), which may be even more pronounced for culturally and linguistically diverse families (Aleman-Tovar & Burke, 2022). But this literature had tended to merge youth and family perspectives.

Given these issues, the purpose of this study was to build on other work that has explored data from NLTS2012 to inform understandings of IEP and transition planning participation of youth with disabilities from intersectional identities (i.e., Lombardi et al., 2024), and specifically focus on patterns of divergences and convergences of participation from the perspectives of diverse youth with intellectual disability and their families. Again, the goal is to explore if there are unique aspects of the experiences of youth and families that shape their perceptions of youth experiences that should be considered in research, policy, and practice to improve transition planning and IEP participation.

We focus on youth with intellectual disability as this is one of the groups who has consistently experienced disparities in all indicators of participation (i.e., not having a meeting, not being invited to the meeting, not participating in a meeting, participating only a little, providing input, and taking a leadership role), and because there have been noted disparities based on racial and ethnic identities of youth with intellectual disability (Lombardi et al., 2024). However, no research, to our knowledge, has compared youth's report on these indicators of participation to parent's report of youth's participation on these same indicators, with a focus on the interaction with racial and ethnic identities of youth as well as the impact of economic hardship. Our specific research questions were:

1. Are there differences between youth and parent perspectives on IEP/transition planning meeting involvement items for youth with intellectual disability across different races and ethnicities?

2. If there are such differences, does economic hardship moderate the size of the difference?

Following quality indicators of secondary data analyses studies consistent with open science practices (Lombardi et al., (2023), this study was pre-registered on the Open Science Framework: https://osf.io/q6fkm/?view_only=88582a0d44be4916a9d084e7ad5e2c4a.

Methods

Data Source

This study used the National Longitudinal Transition Study- 2012 (NLTS2012) restricted use dataset, via a restricted-use data license obtained by the study team from the National Center for Education Statistics. As noted, NLTS2012 is the third study in a series of studies funded by the United States Department of Education on the secondary, transition, and postschool experiences of a nationally representative sample of secondary students who received services under the Individuals with Disabilities Education Act (Burghardt et al., 2017).

NLTS2012 Study Procedures

To create the NLTS2012 data set, a two-stage sampling design was used to allow for generalization to the population of students in grades 7-12, including ungraded secondary classes, in the United States. Students with an IEP served under all disability classifications recognized by IDEA were sampled in addition to students with 504 plans and a small sample of students without disabilities. A total of 432 school districts were randomly selected in 2011 and 21,959 students were sampled from those school districts in 2012-2013. Data collection took place in two phases with Phase 1 occurring from February to October 2012. During Phase 1, about 18,000 parents were contacted via computer assisted telephone interviewing (CATI). After parents were interviewed, they were asked if they consented to their youth being interviewed. If consent was provided, the youth were surveyed next, also via CATI. For youth who were above

18 years of age, and their own legal guardian, consent did not need to be provided by parents. The second phase of data collection, Phase 2, took place from January to August of 2013. During Phase 2, 14,000 parents were contacted with 10,000 being repeat contacts who did not respond in Phase 1. In-person interviews and a web-based version of the survey were provided in Phase 2. A total of 12,988 parent and 11,128 youth surveys were completed across Phases 1 and 2. The unweighted and weighted response rates for parents was 59% and 57%, and for youth was 51% and 48% respectively.

Participants

The focus for this paper was youth with IEPs served under the educational classification of intellectual disability. This subset was identified in the data set using a district-reported variable on IEP disability classification (d_y_disability; *n* = 2,100 students were in the data set that had an IEP with a primary classification of intellectual disability). The mean age of youth in this sample was 16.8 (SD = 2.4). The majority of the sample was identified as male (*n* = 770) or female (*n* = 560), with a substantial amount of missing data (*n* = 760) [1]. Most youth (*n* = 830) had a household income level of $40,000 or less as compared to $40,001 or more (*n* = 380), with a substantial amount of missing data (*n* = 890). Race and ethnicity data were collected across multiple parent reported items on NLTS2012, and we created specific groups for this paper using multiple NLTS2012 variables, consistent with past research (Lombardi et al., 2022; Lombardi et al., 2024). Groups included: Non-Hispanic White (*n* = 570), Non-Hispanic African American or Black (*n* = 340), Hispanic White (*n* = 160), Non-Hispanic multiple races (*n* = 50), Non-Hispanic American Indian or Alaskan Native (*n* = 30), Hispanic American Indian or Alaskan Native (*n* =

[1] group sizes are rounded to the nearest ten per NCES, IES Data Security guidelines for restricted use license holders.

10), Hispanic Asian, Native Hawaiian, or other Pacific Islander, Hispanic African American or Black (*n* = 10), Hispanic multiple races (*n* = 10), Non-Hispanic Asian, Native Hawaiian, or other Pacific Islander, and missing race/missing ethnicity/missing both race and ethnicity (*n* = 890).

Variables

Predictor Variables

Two predictor variables were used in this study: the youth's race and ethnicity and the youth's household income. The youth's race and ethnicity were derived from the parent reported items; these items allowed for an examination of the intersection of race and ethnicity, whereas the district reported item did not. To create the groups listed previously for our analysis, we used parent report of the youth's ethnicity (G2: "Hispanic or Latino" or "not Hispanic or Latino) as well as the parent's report of the youth's race or races. Parents could select one or more of the following variables: American Indian or Alaskan Native (G3_01), Asian, Native Hawaiian, or other Pacific Islander (G3_02), Black or African American (G3_03), and White (G3_05). To create a combined race and ethnicity variable, items were recoded. If a youth selected multiple variables indicating that they identified as multiple races, they were coded as having multiple races. We merged these variables to create a total of ten race and ethnicity groups: (1) Hispanic American Indian or Alaskan Native, (2) Hispanic Asian, Native Hawaiian, or other Pacific Islander, (3) Hispanic African American, (4) Hispanic White, (5) Hispanic multiple races, (6) Non-Hispanic American Indian or Alaskan Native, (7) Non-Hispanic Asian, Native Hawaiian, or other Pacific Islander, (8) Non-Hispanic African American, (9) Non-Hispanic White, and (10) Non-Hispanic multiple races. See Table 1 for the sample sizes for these groups for our youth and parent reported outcome variables. Parent report of household income (p_h_income) was

regrouped into $40,000 or less and $40,001 or more, again consistent with past research (Lombardi et al., 2022).

Outcome Variables

We used NLTS2012 variables that asked about participation in the IEP meeting on the youth survey and parent survey. We focused on variables that were consistent across the two surveys related to attendance and participation. Specifically, we used youth items L1 (attendance = yes/no) and L2a (participation = 1, attended but did not participate; 2, attended but participated very little; 3, attended and provided some input; 4, took a leadership role; 5, attended but did not know about goals) and parent items E1a (youth attendance = yes/no) and E5 (youth participation = 1, attended but did not participate; 2, attended but participated very little; 3, attended and provided some input; 4, took a leadership role; 5, attended but did not know about goals). We merged and reordered these variables to create a new hierarchy, consistent with past research (Lombardi et al., 2024): (1) youth had no attendance at the IEP meeting, (2) youth attended their IEP meeting but did not participate, (3) youth attended their IEP meeting but did not know about their goals, (4) youth attended their IEP meeting but participated very little or not at all, (5) youth attended their IEP meeting and provided some input, and (6) youth attended their IEP meeting and took a leadership role. It is important to note that youth were asked these items when they were 16 or 17 years old, depending on the survey version, limiting the sample of youth data available (see Burghardt et al., 2017).

Data Analysis

All data pre-processing was conducted in the R environment (v4.1.1; R Core Team, 2021) and all data analysis was implemented in SAS environment (v 9.4; SAS Institute Inc, 2017). After creating our race/ethnicity variable and our two separate, six-point scales of youth and

parent perspectives of IEP meeting involvement, we used a generalized linear mixed framework (GLMM; Stroup, 2012) to address our research questions. This flexible framework offers canonical conditional distributions and link functions to model outcome variables that do not follow normal distributions. In this case, we selected a categorical conditional distribution with a generalized logit link function, resulting in a multinomial logistic regression analysis.

Multinomial logistic regression can be estimated using a full information maximum likelihood approach, generally implemented by optimization, or using a Bayesian full information approach, typically implemented with Markov Chain Monte Carlo (MCMC) simulation methods to effectively handle missing outcome data. Fitting GLMMs by MCMC simulation offered a particularly flexible approach in this secondary analysis, as we were able to assign hierarchical priors over predictors to compensate for potential data sparsity in small cells to retain all cells (in this case, race/ethnicity). Bayesian hierarchical priors are valuable when seeking to understand patterns in data when certain groups or categories have limited observations due to complications, such as, unplanned missing data or intentional sampling strategies (Gelman & Hill, 2007). Applied to our research questions, Bayesian hierarchical priors allowed us to use what we know from groups with more information to make better estimates for groups with less information (McElreath, 2016). Thus, this method allowed us to consider all racial/ethnic groups in the analysis even if some cells are sparse.

Using this approach, to address our first research question (Are there differences between youth and parent perspectives on IEP/transition planning meeting involvement items for youth with intellectual disability and do they differ by race and ethnicity?), we regressed IEP/transition meeting involvement (coded: nominal) on race/ethnicity (dummy coded: nominal) using multinomial regression analysis twice: once using parent-reported data and once using youth-

reported data. Having recovered the model predictions for the entire scale of IEP/transition meeting involvement using youth and parent reports, we next looked at the correlation of the model-implied probabilities for each individual level of IEP/transition meeting involvement by race/ethnicity to quantify the similarity in reported involvement data across race/ethnicity to determine their convergence or divergence.

To address our second research question (If there are such differences, does household income moderate the size of the difference?), we first determined the degree of similarity in the model-implied probabilities of obtaining each level of IEP participation as reported by youth and parents by race/ethnicity. In this case, we considered r_{xy} equal to .10, .30, and .50 to be the boundaries of a weak, moderate, and strong linear association between youth reports and parent reports and then proceeded with moderation analysis (income x race/ethnicity effect) if the similarity was not considered strong.

Results

RQ1: Difference between youth and parent perspectives across different race/ethnicities

Table 2 presents a side-by-side comparison of model-implied probabilities derived from multinomial logistic regression of IEP meeting outcomes on race/ethnicity, as reported by parents and youth, respectively. Overall, across racial and ethnic groups we found high correlations between youth and parent perspectives of IEP meeting involvement, ranging from .739 to .954, indicating strong associations (> .50). Based on research suggesting potential differences in perspectives and impacts of race and ethnicity on outcomes, we initially hypothesized differences. However, the data did not support this hypothesis. Therefore, our analysis suggests that youth and parent reports were qualitatively similar generally and across race/ethnicity. One implication, further elaborated on in the Discussion, is that both youth and parent reports provide

complementary insights that enrich our understanding and that youth and their families who share identities and experiences align closely on participation, even if there might be differences on other constructs like expectations.

RQ2: Household Income as a Moderator

We opted against conducting moderator analysis due to the lack of any sizable difference in model-implied probabilities of IEP/transition involvement outcomes between youth and parent reports. That is, when no differences are found, there is nothing for moderators to moderate. In this case, RQ1 results show model-implied probabilities between parent and youth report are strongly correlated across different race and ethnicity groups. Therefore, logically, we concluded that household income does not moderate the relationship between youth and parent reports across different race/ethnicities because there are no sizable differences. Interestingly, this finding enhances our confidence in the robustness of the patterns of youth and their families across different racial and ethnic groups perceiving that the youth has very limited or no involvement/attendance at IEP meetings. For instance, irrespective of youth or parent report across racial and ethnic groups, high rates of not even attending IEP meetings persist. Across all racial and ethnic groups, only 62.06% of youth reported even attending their IEP meeting and only 69.82% of parents reported the same.

Discussion

The purpose of this study was to expand on existing research that has used nationally representative data from NLTS to explore the participation of youth with disabilities in their IEP meetings and transition planning (Johnson et al., 2022; Lombardi et al., 2024; Trainor et al., 2019). We specifically sought to further explore the experiences of youth with intellectual disability and their families who represent diverse racial and ethnic identities, given the

consistently low rates of reported participation in IEP meetings and transition planning for students with intellectual disability since the introduction of the student involvement and transition planning mandates into IDEA (Johnson et al., 2020; Shogren & Plotner, 2012), as well as identified disparities in participation based on race and ethnicity (Lombardi et al., 2024). Further, as researchers have often collapsed youth and family perspectives or focused on family perspectives, we sought to examine if there were congruences and/or divergences in how youth and their families perceived youth's participation and leadership of their IEP meetings, generally, and across racial and ethnic groups. This is critical, given the growing focus in the intellectual disability field on supporting self-reported perspectives, as well as the importance of understanding the experiences and perspectives of both youth and their families during transition planning and IEP meetings as both are important to inform supports and services. We specifically wanted to explore the impacts of intersectionality on perceptions and experiences, as youth and families who experience multiple forms of marginalization (e.g., systemic racism, ableism) may have specific experiences with schools that may hinder partnerships and participation for youth and families in unique ways (Burke, 2017; Johnston & Burke, 2024; Scott et al., 2021) and limited research has explored these issues. Little is known about how youth and families uniquely perceive these experiences as impacting youth's IEP meeting participation.

Overall, our findings suggest that across racial and ethnic groups, youth with intellectual disability and their families have high agreement about the level of participation youth have in their IEP meetings (r = .74 to .95; see Table 2). This suggests common and shared experiences and perspectives between youth and families across racial and ethnic groups, supporting other research suggesting that families are often key supporters and knowledge holders about youth's participation and supports (Burke et al., 2020). However, as there was not exact agreement, this

also suggests the importance of listening to both youth and their families, particularly to understand different experiences (e.g., youth may have different conversations and experiences at school and families may have unique interactions with teachers and other IEP team members). Overall, the findings inform discussions of the importance of giving voice to youth and family experiences, not assuming that each can report for each other. However, the findings also suggest that there is greater alignment in perspectives of current transition planning experiences and particularly student involvement, than postschool outcome expectations, as other literature has suggested more discrepancies in postschool outcome expectations across youth and their families (Bouck et al., 2020; Kirby et al., 2019; Qian et al., 2020; Wu et al., 2024). But this work has not explored differences based on intersectional identities, thus, more work is needed to explore the array of life experiences and systemic factors that influence congruence and divergence in youth and family perspectives as limited work has explored this in the context of IEP and transition planning participation. This body of work does suggest a critical need to ensure all sources of information are valued and used to inform efforts to achieve the aims of the transition planning and student involvement mandates. As families are a primary source of support, particularly as youth transition to adulthood, ensuring shared understandings and perspectives across youth and their families is an important part of the transition planning process.

While there was agreement between youth and families, what the agreement reflects was troubling. Youth and their families reported high rates of youth with intellectual disability not attending IEP meetings across racial and ethnic groups; 30-51% from youth's perspective and 29-63% from family perspective. While overall there was high agreement, there was variability in rates of attendance across racial and ethnic groups suggesting that there may be unique experiences with access to and support for IEP meeting attendance and participation, which

necessitates further research with more targeted samples and expanded data collection to better understand the experiences of multiple marginalized youth and families. It is also important to note that, even when youth and families reported that youth did attend meetings, youth and families reported there were low levels of engagement, knowledge of goals, participation, and leadership (see Table 2). Despite policy reflecting the importance of advancing the involvement of the student and their family as a part of the IEP and transition planning team, these data continue to suggest this is not a reality in schools for youth with intellectual disability, and that there are pervasive and persistent barriers for youth with intersecting identities, despite research on best practices to advance youth participation (Sanderson & Goldman, 2020). As such, educators should seek to include both youth and families throughout the IEP process, ensuring all shareholders have a seat at the table and effective supports for their participation. For youth, practitioners can use established interventions to support IEP involvement like the Self-Directed IEP or the Self-Determined Learning Model of Instruction. When partnering with families, including families from diverse racial and ethnic backgrounds, focusing on creating an inclusive environment through culturally responsive practices, such as fostered relationships over time, providing flexible meeting times and plain language communication, is important (Suk et al., 2020).

These findings suggest the ongoing lack of implementation of policy mandates and research-based predictors and recommendations for youth and family engagement (Martin et al., 2006; Mazzotti et al., 2021; Sanderson & Goldman, 2020). It is important to also note that the NLTS 2012 data is dated, as it was collected in 2012. There is a pressing need to collect more contemporary data to explore ongoing changes, particularly in the aftermath of the COVID-19 public health emergency. Families and youth can bring important information about their

strengths, goals, and community and cultural resources, particularly when planning for the transition from school to adult life (Burke, 2017; Johnston & Burke, 2024; Scott et al., 2021). However, when space is not made at meetings or in planning for infusing these perspectives, it is unclear how meaningful IEP goals and transition plans can be established, which may contribute to the persistent disparities in postschool outcomes for youth with intellectual disability, particularly for youth with intellectual disability from marginalized racial and ethnic groups. There is a need for greater attention to making systemic changes to create opportunities for meaningful IEP and transition planning participation for youth with intellectual disability, advancing accountability in schools for the student and family involvement mandates of IDEA. In addressing these issues, there should be a clear and concentrated focus on building new systems of supports that advance culturally sustaining approaches to youth and family engagement in IEP and transition planning that empower teams to recognize the strengths and resources young people bring to their education (Wint et al., 2022) and have these celebrated in the IEP and transition planning process (Love et al., 2021) through use of culturally responsive practices in transition education (Suk et al., 2020). Indicators to advance anti-ableist and anti-racist practices into ongoing research, policy, and practice (Scott & Shogren, 2023) can provide a foundation for guiding change to challenge these ongoing disparities.

Limitations and Future Directions

While a strength of this study was being able to explore the experiences of youth and families from 10 intersectional racial and ethnic groups, non-white groups were underrepresented in the data and some groups had very small sample sizes, which could limit the generalizability of findings. As shown in Table 1, the available sample sizes for six of the groups were very sparse. The use of Bayesian hierarchical modeling helped mitigate this limitation by pooling

information across groups to optimize estimates, allowing us to present patterns within and across groups, but this is still a limitation that must be addressed in future research. This includes designing sampling plans of national studies to represent diverse racial and ethnic identities. Thus, great caution in interpretation for estimates for these six groups is warranted but these estimates are still valuable from a Bayesian perspective as they can be used as priors in future research to increase the available data for these populations. In addition, despite NLTS2012 being a nationally representative study, the utilized sampling plan resulted in missing data. For example, there was missing information on the participation in IEP meetings of 16-year-olds and younger students, necessitating a full information approach to missing data. Hence, there is a need for careful and mindful sampling design and planning in future large-scale data collection efforts that will allow for rigorous analysis both based on age, but also other intersectional identities. For example, given our interest in the differences between races and ethnicities, it was not appropriate to use sample weights. Sample weights adjust the composition of the sample to reflect population proportions for broad generalizations. However, the estimates in this study are intentionally adjusted to resemble those that would be obtained if the composition of the sample had equal sizes across races and ethnicities.

Second, another strength of the study is the focus on youth and family voice and the finding of the alignment of these voices in understandings of youth IEP meeting participation and leadership. However, the data analyzed reflect self-reported perspectives of youth and the perspectives of family members on youth participation on a limited number of survey items. We did not have access to qualitative data on youth and families' perspectives on their experiences or data from IEP teams or IEP or transition planning documents to document other factors that may influence participation and leadership. Relatedly, IEP meeting participation and leadership

is shaped by multiple factors over time and youth and their families experience multiple meetings (or should have access to multiple meetings) over their education and multiple interactions with schools and IEP teams. The cross-sectional nature of the available data does not allow us to establish causality between variables or to more robustly examine the systemic or longitudinal factors that impact IEP and transition planning involvement. Ongoing work is needed, building on work of other research groups that are addressing ways to advance youth and family participation in IEP and transition planning, including efforts to change systemic barriers that limit opportunities and supports for participation for youth and families who are marginalized by existing school structures and practices.

Finally, as mentioned, while NLTS2012 is the most recent nationally representative dataset on the experiences of youth with disabilities and their families during transition, over 10 years have passed since the data was collected and there have been massive changes in the world including not only the COVID-19 pandemic, but other national and global movements for racial and disability justice. For these reasons, there is a critical need to consider how to collect new, contemporary data to further understand the degree to which poor IEP and transition planning engagement persists and seek to further expand understandings of the systemic barriers including the lack of full integration of anti-racism and anti-ableist practices into education systems.

Conclusion

Our analysis of NLTS2012 data suggests that youth with intellectual disability and their families from diverse racial and ethnic groups perceive that youth have low attendance at IEP meetings and when they do attend, extremely low leadership at their meetings. While there are some differences across youth and family reports there is overall agreement, suggesting the importance of considering all perspectives on participation and leadership but also seeking to

make systemic changes in how students and families are supported to be a part of establishing IEP goals, identifying plans for the future, and leveraging strengths that they bring to their lives and their learning. This lack of attendance and participation must be understood as a systemic issue that needs to be addressed through new and different approaches to how youth and families are recognized as the leaders of their future planning, with new supports centered around their strengths, goals and priorities for schools and life.

References

Aleman-Tovar, J., & Burke, M. (2022). A review of the literature about transition planning experiences among culturally and linguistically diverse families of youth with disabilities in the United States. In R. M. Hodapp, D. J. Fidler, & S. Lanfranchi (Eds.), *International Review of Research in Developmental Disabilities* (Vol. 63, pp. 51-102). Academic Press. https://doi.org/https://doi.org/10.1016/bs.irrdd.2022.09.002

Bouck, E. C., Long, H. M., & Costello, M. P. (2020). Parent and youth post-school expectations: Students with intellectual disability in rural schools. *Rural Special Education Quarterly*, *40*(1), 14-23. https://doi.org/10.1177/8756870520945572

Burghardt, J., Haimson, J., Lipscomb, S., Liu, A. Y., Potter, F., Waits, T., & Wang, S. (2017). National Longitudinal Transition Study 2012: Design Documentation. NCEE 2017-4021. *National Center for Education Evaluation and Regional Assistance*.

Burke, M. M. (2017). Examining empowerment, family–school partnerships, and advocacy among rural and urban Latino families of children with disabilities. *Rural Special Education Quarterly*, *36*(2), 56-63. https://doi.org/10.1177/8756870517707218

Burke, M. M., Rios, K., Garcia, M., & Magaña, S. (2020). Examining differences in empowerment, special education knowledge, and family–school partnerships among Latino and White families of children with autism spectrum disorder. *International Journal of Developmental Disabilities*, *66*(1), 75-81. https://doi.org/10.1080/20473869.2018.1487502

Burnes, J. J., Martin, J. E., Terry, R., McConnell, A. E., & Hennessey, M. N. (2018). Predicting postsecondary education and employment outcomes using results From the Transition

Assessment and Goal Generator. *Career Development and Transition for Exceptional Individuals*, *41*(2), 111-121. https://doi.org/10.1177/2165143417705353

Carter, E. W., Brock, M. E., & Trainor, A. A. (2014). Transition assessment and planning for youth with severe intellectual and developmental disabilities. *The Journal of Special Education*, *47*(4), 245-255. https://doi.org/10.1177/0022466912456241

Cobb, C. (2014). Critical entanglement: Research on culturally and linguistically diverse parental involvement in special education 2000-2010. *Exceptionality Education International*, *23*(1). https://doi.org/10.5206/eei.v23i1.7703

Freeman, J. A., & Kirksey, J. J. (2023). Linking IEP status to parental involvement for high school students of first-generation and native-born families. *Exceptional Children*, *89*(2), 197-215. https://doi.org/10.1177/00144029221108402

Gelman, A., & Hill, J. (2007). *Data analysis using regression and multilevel/hierarchial models*. Cambridge University Press.

Hagiwara, M., Rifenbark, G. G., Shogren, K. A., & Thompson, J. R. (2021). Impact of different pairings of respondents on scores on the Supports Intensity Scale-Adult Version (SIS-A). *American Journal of Intellectual and Developmental Disabilities*, *126*(5), 361-376. https://doi.org/10.1352/1944-7558-126.5.361

Hirano, K. A., Rowe, D., Lindstrom, L., & Chan, P. (2018). Systemic barriers to family involvement in transition planning for youth with disabilities: A qualitative metasynthesis. *Journal of Child and Family Studies*, *27*(11), 3440-3456. https://doi.org/10.1007/s10826-018-1189-y

Johnson, D. R., Thurlow, M. L., Wu, Y.-C., LaVelle, J. M., & Davenport, E. C. (2020). IEP/Transition planning participation among students with the most significant cognitive

disabilities: Findings from NLTS 2012. *Career Development and Transition for Exceptional Individuals*, *43*(4), 226-239. https://doi.org/10.1177/2165143420952050

Johnson, D. R., Thurlow, M. L., Wu, Y.-C., Qian, X., Davenport, E., & Matthais, C. (2022). Youth and Parent participation in transition planning in the U.S.A.: Findings from the National Longitudinal Transition Study 2012 (NLTS 2012). *Journal of International Special Needs Education*, *25*(2), 61-73. https://doi.org/https://doi.org/10.9782/jisne-d-21-00009

Johnston, A. N., & Burke, M. M. (2024). Family-professional partnerships in low-resourced communities: A systematic literature review. *Exceptionality*, *32*(1), 1-20. https://doi.org/10.1080/09362835.2023.2263598

Kirby, A. V., Dell'armo, K., & Persch, A. C. (2019). Differences in youth and parent postsecondary expectations for youth with disabilities. *Journal of Vocational Rehabilitation*, *51*(1), 77-86. https://doi.org/10.3233/jvr-191027

Linnenkamp, B., & Broussard, R. (2024). Our lived experiences with language, ableism, and supports: Implications for the education of people with intellectual and developmental disabilities. In K. A. Shogren, L. A. Scott, E. E. Dean, & B. Linnenkamp (Eds.), *Handbook of research-based practices for educating students with intellectual disability* (pp. 2-8). Routledge.

Lombardi, A. R., Rifenbark, G. G., Hicks, T., Taconet, A., & Challenger, C. (2022). College and career readiness support for youth with and without disabilities based on the National Longitudinal Transition Study 2012. *Exceptional Children*, *89*(1), 5-22. https://doi.org/10.1177/00144029221088940

Lombardi, A. R., Rifenbark, G. G., & Taconet, A. (2023). Quality indicators of secondary data analyses in special education research: A preregistration guide. *Exceptional Children*, *89*(4), 397-411. https://doi.org/10.1177/00144029221141029

Lombardi, A. R., Rifenbark, G. G., & Taconet, A. (2024). An intersectional examination of economic hardship and Individualized Education Program meeting participation. *Exceptional Children*, *90*(4), 148-163. https://doi.org/https://doi.org/10.1177/00144029231184568

Love, H., Nyegenye, S. N., Wilt, C. L., & Annamma, S. A. (2021). Black families' resistance to deficit positioning: addressing the paradox of black parent involvement. *Race Ethnicity and Education*, *24*(5), 637-653.

Martin, J. E., Huber Marshall, L., & Sale, P. (2004). A 3-year study of middle, junior high, and high school IEP meetings. *Exceptional Children*, *70*(3), 285-297. https://doi.org/10.1177/001440290407000302

Martin, J. E., van Dycke, J. L., Christensen, W. R., Greene, B. A., Gardner, J. E., & Lovett, D. L. (2006). Increasing student participation in IEP meetings: Establishing the self-directed IEP as an evidenced-based practice. *Exceptional Children*, *72*(3), 299-316. https://doi.org/10.1177/001440290607200303

Mazzotti, V. L., Rowe, D. A., Kwiatek, S., Voggt, A., Chang, W.-H., Fowler, C. H., Poppen, M., Sinclair, J., & Test, D. W. (2021). Secondary transition predictors of postschool success: An update to the research base. *Career Development and Transition for Exceptional Individuals*, *44*(1), 47-64. https://doi.org/10.1177/2165143420959793

McElreath, R. (2016). *Statistical rethinking: A Bayesian course with examples in R and Stan*. CRC Press.

Powers, K., Geenen, S., & Powers, L. E. (2009). Similarities and differences in the transition expectations of youth and parents. *Career Development for Exceptional Individuals*, *32*(3), 132-144. https://doi.org/10.1177/0885728809346302

Qian, X., Johnson, D. R., Wu, Y. C., LaVelle, J., Thurlow, M. L., & Davenport, E. (2020). Parents' postsecondary education expectations for students with autism, intellectual disability, and multiple disabilities: Findings From NLTS 2012. *Research and Practice for Persons with Severe Disabilities*, *45*(4), 256-270. https://doi.org/10.1177/1540796920962423

R Core Team. (2021). *R: A language and environment for statistical computing [Computer software manual]*. R Foundation for Statistical Computing.

Sanderson, K. A., & Goldman, S. E. (2020). A systematic review and meta-analysis of interventions used to increase adolescent IEP meeting participation. *Career Development and Transition for Exceptional Individuals*, *43*(3), 157-168.

Scott, L. A., & Shogren, K. A. (2023). Advancing anti-racism and anti-ableism in transition: Equity-oriented indicators for research. *Career Development and Transition for Exceptional Individuals*, *46*(4), 237-248. https://doi.org/10.1177/21651434231189665

Scott, L. A., Thoma, C. A., Gokita, T., Bruno, L., Ruiz, A., Brendli, K., Taylor, J., & Vitullo, V. (2021). I'm trying to make myself happy: Black students with IDD and families on promoting self-determination during transition. *Inclusion*, *9*(3), 170-188. https://doi.org/10.1352/2326-6988-9.3.170

Shogren, K. A., Bonardi, A., Cobranchi, C., Krahn, G., Murray, A., Robinson, A., Havercamp, S. M., & The Nisonger RRTC on Health and Function. (2021). State of the Field: The need for self-report measures of health and quality of life for people with intellectual and

developmental disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, *18*(4), 286-295. https://doi.org/10.1111/jppi.12386

Shogren, K. A., Bruno, L. P., Rentschler, L. F., Raley, S. K., & Burke, K. M. (2024). *The Self-Determined Learning Model of Instruction Teacher's Guide (2nd ed.)*. Kansas University Center on Developmental Disabilities.

Shogren, K. A., & Plotner, A. J. (2012). Transition planning for students with intellectual disability, autism, or other disabilities: Data from the National Longitudinal Transition Study-2. *Intellectual and Developmental Disabilities*, *50*(1), 16-30. https://doi.org/10.1352/1934-9556-50.1.16

SRI International. (2000). *National Longitudinal Transition Study-2 (NLTS2): Study design, timeline and data collection plan*.

Stroup, W. W. (2012). *Generalized linear mixed models: Modern concepts, methods and applications*. CRC Press.

Suk, A. L., Sinclair, T. E., Osmani, K. J., & Williams-Diehm, K. (2020). Transition planning: Keeping cultural competence in mind. *Career Development and Transition for Exceptional Individuals*, *43*(2), 122-127. https://doi.org/10.1177/2165143419890308

Thompson, J. R., Bryant, B. R., Schalock, R. L., Shogren, K. A., Tasse, M. J., Wehmeyer, M. L., Campbell, E. M., Craig, E. P. M., Hughes, C. M., Rotholz, D. A., & Silverman, W. P. (2023). *Supports Intensity Scale-Adult (SIS-A)* (2nd ed. ed.). American Association on Intellectual and Developmental Disabilities.

Trainor, A. A., Newman, L., Garcia, E., Woodley, H. H., Traxler, R. E., & Deschene, D. N. (2019). Postsecondary education-focused transition planning experiences of English

learners with disabilities. *Career Development and Transition for Exceptional Individuals*, *42*(1), 43-55. https://doi.org/10.1177/2165143418811830

Wagner, M. (1992). Analytic overview: NLTS design and longitudinal analysis approach. In M. Wagner, R. D'Amico, C. Marder, L. Newman, & J. Blackorby (Eds.), *What happens next? Trends in postschool outcomes of youth with disabilities: The second comprehensive report from the National Longitudinal Transition Study of Special Education Students* (pp. 2-1--2-14). SRI Intervnational.

Wehmeyer, M. L., Palmer, S. B., Lee, Y., Williams-Diehm, K., & Shogren, K. (2011). A randomized-trial evaluation of the effect of Whose Future is it Anyway? on self-determination. *Career Development for Exceptional Individuals*, *34*(1), 45-56. https://doi.org/10.1177/0885728810383559

Wint, K. M., Opara, I., Gordon, R., & Brooms, D. R. (2022). Countering Educational Disparities Among Black Boys and Black Adolescent Boys from Pre-K to High School: A Life Course-Intersectional Perspective. *Urban Rev*, *54*(2), 183-206. https://doi.org/10.1007/s11256-021-00616-z

Wu, Y.-C., Qian, X., Lee, S., Johnson, D. R., & Thurlow, M. L. (2024). Postschool goal expectations for youth with intellectual and developmental disabilities. *American Journal on Intellectual and Developmental Disabilities*, *129*(2), 151-168. https://doi.org/10.1352/1944-7558-129.2.151

Stroup, W.W. 2013a. *Generalized linear mixed models*. CRC Press, Boca Raton, FL.

Table 1

Sample Sizes by Race/Ethnicity Crossed with Report Type

Race	***Youth***	***Parent***
AAPI/H	*	*
AAPI/NH	*10*	*20*
AIAN/H	*	*10*
AIAN/NH	*10*	*20*
B/H	*10*	*
B/NH	*180*	*230*
M/H	*	*
M/NH	*20*	*30*
W/H	*90*	*110*
W/NH	*300*	*420*

Source. U.S. Department of Education, National Center for Education Statistics, National Longitudinal Transition Study (2012).
Note. "AAPI" = Asian American and Pacific Islander; "AIAN" = American Indian and Alaska Native; B = "Black/African American"; "M" = "Mixed", "W" = White; H = "Hispanic"; NH = "Non-Hispanic." This table presents the sample sizes available in this secondary analysis. Hierarchical Bayesian modeling was employed to pool information across all groups, thereby deriving more stable estimates for groups with small sample sizes. This approach allowed for the inclusion of all intersectional race and ethnicity groups. However, estimates for groups with smaller sample sizes should be interpreted with caution. Despite this limitation, these estimates remain valuable as they can be used as priors in subsequent Bayesian analyses, thus contributing to the growing knowledge base. Group sizes are rounded to the nearest ten per NCES, IES Data Security guidelines for restricted use license holders. * Indicates sample size under 10.

Table 2

Model-Implied Probabilities of IEP Participation Outcomes by Race/Ethnicity

Race/ Ethnicity	r_{xy}	Youth Report: Participation in IEP Meeting						Parent Report: Participation in IEP Meeting					
		Did Not Attend	Attended But Did Not Participate	Attended, But Not Aware of Goals	Attended, Little or No Participation	Attended, Some Participation	Attended, Leadership Role	Did Not Attend	Attended, But Did Not Participate	Attended, But Not Aware of Goals	Attended, Little or No Participation	Attended, Some Participation	Attended, Leadership Role
AAPI/H	0.812	0.358	0.046	0.013	0.218	0.317	0.048	0.544	0.028	0.016	0.141	0.171	0.100
AAPI/NH	0.900	0.509	0.065	0.010	0.173	0.200	0.042	0.336	0.059	0.017	0.201	0.258	0.129
AIAN/H	0.739	0.342	0.041	0.024	0.274	0.267	0.052	0.626	0.023	0.013	0.111	0.143	0.084
AIAN/NH	0.954	0.411	0.032	0.012	0.238	0.258	0.048	0.427	0.041	0.016	0.193	0.199	0.124
B/H	0.948	0.300	0.043	0.014	0.251	0.343	0.049	0.287	0.037	0.035	0.234	0.269	0.138
B/NH	0.915	0.355	0.069	0.029	0.261	0.228	0.058	0.403	0.038	0.025	0.182	0.216	0.136
M/H	0.927	0.291	0.096	0.015	0.278	0.268	0.051	0.293	0.038	0.021	0.277	0.237	0.134
M/NH	0.896	0.395	0.043	0.011	0.286	0.213	0.051	0.444	0.035	0.023	0.152	0.230	0.117
W/H	0.912	0.343	0.110	0.020	0.245	0.234	0.049	0.442	0.041	0.023	0.203	0.190	0.101
W/NH	0.914	0.334	0.051	0.015	0.252	0.298	0.050	0.392	0.037	0.020	0.192	0.233	0.126

Source. U.S. Department of Education, National Center for Education Statistics, National Longitudinal Transition Study (2012).
Note. "AAPI" = Asian American and Pacific Islander; "AIAN" = American Indian and Alaska Native; B = "Black/African American"; "M" = "Mixed", "W" = White; H = "Hispanic"; NH = "Non-Hispanic." This table presents the model-implied probabilities of IEP participation outcomes across race/ethnicity groups. As an example, the model-implied probability that youth who are AAPI/H report not attending their IEP meeting is .349, meaning there is a 34.9% probability that youth who are Asian American or Pacific Islander and Hispanic report not attending their IEP meetings. Further, r_{xy} is the correlation between parent and youth reported data, in this example there is a .812 correlation between youth and parent report of participation, which indicates a strong positive linear association between reports from parents and youth on IEP participation for this group.