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Workforce Engagement of Caregivers of Children with ID/ASD: Child Health Insurance Effects

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Abstract:	For many families of children with intellectual disabilities and autism (ID/ASD), private health insurance and public programs, such as Medicaid and the Children's Health Insurance Program (CHIP), are critical sources of support. The purpose of this study was to examine the impact of health insurance coverage on workforce engagement of parents of children with ID/ASD. The study utilized 2014-2018 pooled National Health Interview Survey data to construct national estimates and test the effects of health insurance status on parent workforce outcomes. Primary findings indicate significantly higher odds of workforce absence (OR = 2.83, $p < .0038$) and unemployment (OR = 8.91, $p < .0038$) among parents with children with ID/ASD using public health insurance, compared to the reference group. Additionally, parents of children with ID/ASD who were uninsured were found to experience significantly higher unemployment (OR = 4.86, $p < .0038$) than the reference group. Findings have policy and research implications related to workforce engagement for parents, including issues impacting health insurance coverage, specifically related to Medicaid and CHIP.

Abstract

For many families of children with intellectual disabilities and autism (ID/ASD), private health insurance and public programs, such as Medicaid and the Children's Health Insurance Program (CHIP), are critical sources of support. The purpose of this study was to examine the impact of health insurance coverage on workforce engagement of parents of children with ID/ASD. The study utilized 2014-2018 pooled National Health Interview Survey data to construct national estimates and test the effects of health insurance status on parent workforce outcomes. Primary findings indicate significantly higher odds of workforce absence (OR = 2.83, $p < .0038$) and unemployment (OR = 8.91, $p < .0038$) among parents with children with ID/ASD using public health insurance, compared to the reference group. Additionally, parents of children with ID/ASD who were uninsured were found to experience significantly higher unemployment (OR = 4.86, $p < .0038$) than the reference group. Findings have policy and research implications related to workforce engagement for parents, including issues impacting health insurance coverage, specifically related to Medicaid and CHIP.

Keywords: Intellectual disability, autism, health insurance, workforce engagement, family caregivers

Many families are raising children with intellectual disability and/or autism spectrum disorder (ID/ASD). A child's disability diagnosis is a multilayered event that involves both positive and negative experiences for the family unit. Having a child with a disability can have a positive impact on a family, including an increased sense of purpose and a closer relationship built within the family unit (Sim et al., 2019; Stainton & Besser, 1998; Waizbard-Bartov et al., 2019). While families experience many positives as a result of having a child with a disability, challenges also occur. One study describes the interplay between the positive and negative impacts of having a child with a disability as finding the positive meaning to life while at the same time acknowledging the difficulties and increased stress of having a child with autism (Myers et al., 2009).

The stressors related to raising a child with ID/ASD can often be a destabilizing event for a family unit (Abbeduto et al., 2004; Bristol et al., 1988; Chan et al., 2018; Chan & Leung, 2020; Gunty, 2021; McStay et al., 2014; Myers et al., 2009; Yamada et al., 2007). In order to adapt to the changes involved with raising a child with ID/ASD, families rely on a variety of formal and informal supports (McCubbin & Patterson, 1983). Formal supports may include federal and state systems of supports, while informal supports may include family and friends who are able to provide childcare, mental health support, or other needed accommodations to help families adjust to their changing circumstances. Both formal and informal supports are critical to helping families adapt to these changes.

While many families of individuals with ID/ASD rely on extended informal networks of family and friends for support, formal supports such as private and public health insurance programs aid in meeting the needs of the family. Two national, income-based health insurance programs, Medicaid and the Children's Health Insurance Program (CHIP), provide access to

medical care through affordable healthcare insurance coverage, which assists in supporting the health needs of the child and their family. Medicaid and CHIP insurance offers coverage and protection to families and therefore decreases the financial burden of medical services (including those that are preventative and therapeutic). These two insurance programs increase the accessibility of healthcare to families of children with ID/ASD.

Disability and Family Socioeconomics

An integral part of maintaining personal family functioning is the relative health of family socioeconomics, such as family income and parental education level (Takeuchi et al., 2019). Poverty, a well-known risk factor for adverse health outcomes (Lee et al., 2021; Maalouf et al., 2021), can impact a family's ability to maintain healthy family functioning. Families report sacrificing a secure financial future, including experiencing bankruptcy, to provide needed therapy for their child with autism (Cidav et al., 2012; Rogge & Janssen, 2019). Having the resources necessary to support the family financially is critical to ensuring ongoing functioning, and for families of children with ID/ASD, personal finances are particularly significant (LaVelle et al., 2014).

Insights into the relationship between disability and socioeconomic status highlight the ways in which the financial health of the family can be impacted by raising a child with a disability. There has been much research on this link within families with children with ASD. A recent systematic review found that caregivers of children with ASD are burdened with a wide range of financial costs, including medical, therapeutic, educational, and informal care, in addition to loss of earnings potential and productivity of family members (Rogge & Janssen, 2019). Parents report that having a child with ASD has adverse effects on their employment (Eskow et al., 2011), including reduced employment hours or potentially having to leave the

workforce entirely due to their child's support needs (Kogan et al., 2008). In addition, the resulting poverty disproportionately impacts women (Cidav et al., 2012; Emerson, 2003; Emerson et al., 2006). Overall, research has shown that having a child with an intellectual or developmental disability can have negative impacts on the financial health and subsequent well-being of a family.

Insurance Status and ID/ASD

Health and wellness, access to care and insurance, and poverty are inextricably linked in the United States. Several studies have highlighted the linkages between having insurance and improved health outcomes (Hadley, 2003; Hoffman & Paradise, 2008). The uninsured are more likely to report poorer health than those who are privately insured (Hoffman & Paradise, 2008; Hadley, 2003). Children with health insurance, including children with disabilities, are more likely to have access to care and to receive services than children without insurance (Heck & Makuc, 2000). Literature on health insurance status has predominantly focused on the impact on access to care (Wang et al, 2013). One study using a nationally-representative sample found that children with special health needs had higher usage of Medicaid coverage, lower family incomes, and parents who were less likely to be working in full-time employment (Heck & Makuc, 2000).

Recent years have seen substantial national growth in Medicaid and CHIP coverage for children with working parents (Strane, et al., 2019). This is due to a variety of factors, including high out-of-pocket costs and more generous coverage (McMorrow et al., 2014). The two public programs provide insurance coverage to a broad population of children and families, enrolling over 83 million individuals in insurance coverage as of 2021 (Centers for Medicare and Medicaid Services, 2022). While both of these federal programs are intended to provide

insurance coverage for low-income families, each state is provided flexibility to implement the program to address local needs. Medicaid coverage may decrease the financial burden of raising a child with ID/ASD, providing medical insurance coverage for low-income families (Centers for Medicare and Medicaid Services, 2020a).

Reimbursement through Medicaid state plan services and CHIP can be provided for a variety of services and supports which address the complex health needs of individuals with ID/ASD, including but not limited to wellness checkups, immunizations, inpatient/outpatient services, preventative services, therapy services, and services of other licensed practitioners (Centers for Medicare and Medicaid Services, 2020b; Mann, 2014). While Medicaid and CHIP cannot directly provide services, their reimbursement structures provide necessary economic relief for families to protect them from excessive billing and potential bankruptcy (Gross & Notowidigdo, 2011). Both Medicaid and CHIP provide a valuable role in making critical medical care accessible for the children of low-income families through medical insurance coverage.

Many people with ID/ASD may also receive services through the Medicaid Home and Community-Based Services (HCBS), an optional state funding source that provides long-term services and supports to people with ID/ASD. While eligibility, access, and service array vary by state, the focus is on maintaining and supporting community-based living and services, preventing institutional placement. Examples may include music therapy, respite services, psychological services, and pre-vocational services, among many others. Past research has shown that such services can serve in reducing the odds of a parent of a child with ASD leaving the workforce (Leslie et al., 2017). Medicaid HCBS is distinguished from Medicaid state plan services in that it provides services not covered by Medicaid state plans and eligibility

restrictions limit the number of people that can access HCBS at any given time (Kitchener et al., 2003).

Both the Medicaid and CHIP programs provide tangible benefits to recipients, and research has begun to indicate that there are indirect impacts on the family in addition to financial relief. Research on the effects of Medicaid and CHIP on caregiver workforce and employment outcomes is limited, though preliminary results indicate that involvement in Medicaid is associated with increased family quality of life (Eskow et al., 2019; Eskow et al., 2011). While these findings are encouraging, there is limited research analyzing the inter-relationship between families of children with ID/ASD and health insurance status, and specifically how health insurance statuses potentially mitigate the effects of disability diagnosis on workforce engagement.

Purpose

There is a dearth of literature on health insurance status and outcomes related to workforce engagement of caregivers of children with ID/ASD. The purpose of this study was to expand this limited line of research to examine the differential impact of health insurance statuses on mitigating the known socioeconomic impacts of having a child with ID/ASD. While there are a growing number of studies examining family experiences, this research examined the workforce engagement of caregivers of children with ID/ASD to broaden what is known about the interplay between ID/ASD diagnosis and health insurance utilization on family caregiver workforce outcomes. This research sought to identify the factors that relate to employment outcomes, utilizing a nationally representative dataset. Using the National Health Interview Survey (NHIS) survey data, a number of factors were examined to determine their impact on

caregiver workforce participation and employment. The specific research question and hypotheses include:

1. Compared to caregivers of children without ID/ASD, what effect does having a child with ID/ASD and health insurance status have on caregiver workforce engagement?

Hypothesis 1: a. Caregivers of children with ID/ASD experience higher levels of workforce absence and unemployment than caregivers of children without ID/ASD.

b. Health insurance moderates the relation between outcomes.

Hypothesis 2: Caregivers of children with ID/ASD that are uninsured experience higher odds workforce absence and unemployment.

Methods

Data Source and Sample

This study utilized 2014-2018 National Health Interview Survey (NHIS) pooled data. The NHIS is a nationally representative annual cross-sectional household interview survey conducted by the Centers for Disease Control and Prevention (CDC). The NHIS is the principal source of information for studying illness, disability, and health of the civilian noninstitutionalized population of the United States. These data are widely used in public health and public policy to understand related demographic, socioeconomic, community, and familial factors, and to conduct program evaluation. The data used were shared with, and made publicly available by, the University of Minnesota's Population Center IPUMS data system. The IPUMS data system harmonizes data across time, provides detailed supporting documentation, and easily exportable datasets for public use (Blewett et al., 2019).

NHIS Data Collection. The NHIS survey consists of a Core questionnaire that remains largely unchanged annually, with additional supplements, such as those sponsored by outside

federal agencies, which vary from year to year. Four main components make up the Core questionnaire. These include Household Composition section, Family Core, Sample Child Core, and Sample Adult Core. The Household Composition section collects information on basic demographic and relationship information about all persons in the household, defined as an occupied housing unit. The Family Core is administered separately for each family in the household, and collects information on all persons in the family, defined as an individual or group of two or more related persons who are living together in the same household. The topics on the Family Core questionnaire include socio-demographic characteristics, basic indicators of health, activity limitations, injuries, health insurance coverage, and access to and utilization of health care services.

If a child or children are present in the family, then one “sample child” aged 17 or less is randomly selected. Information about the sample child is collected from a knowledgeable adult and information about the sample adult is collected from the sample adult themselves. This study utilized the Sample Child Core and Sample Adult Core questionnaires, and while the questionnaires differ in some items for children and adults, both collect basic information on health status, health care services, and health-related behaviors (Centers for Disease Control and Prevention, 2019).

Response Rates and Representativeness. The NHIS survey has experienced annual declines in response rates over the last decade. During this survey, response rate ranges for the different survey modules were 73.1% in 2014 to 63% in 2018 for the Family component, 58.9% in 2014 to 53% in 2018 for the Sample Adult component, and 66.6% to 59% for the Sample Child component (Centers for Disease Control and Prevention, 2019). The NHIS program utilizes a weighting procedure to account for nonresponses and to calibrate for

representativeness. It applies a ratio adjustment to each person weight to correct for potential bias due to under coverage based on race and geographic make up. Next, using U.S. Census Bureau controls, the data undergo a post-stratification adjustment to ensure representativeness based on age, race, and sex (Blewett et al., 2019).

Sample. The current NHIS sampling plan, which is revised after each decennial census, consists of a sample of 428 primary sampling units (PSUs) drawn from approximately 1,900 geographically defined PSUs that cover the 50 states and the District of Columbia. A PSU consists of a county, a contiguous group of counties, or a metropolitan statistical area. The total NHIS sample is subdivided into four separate regional panels such that each panel is representative of the U.S. civilian noninstitutionalized population (Centers for Disease Control and Prevention, 2015). Finally, the CDC provides proper statistical weights for researchers, to ensure the sampling procedures are accounted for in population estimation.

The multi-level structure of the NHIS data allows for investigations of children and family units by way of data integration of individual, child, and family unit data. The population of interest in this study is U.S. families with householders as parent caregivers of children between the ages of three to 17 years. Thus, the householders that lacked a parent-child relationship or stepparent/unmarried partner-child relationship were excluded (e.g., grandparent or sibling). Householders with younger or older sampled children residing in the household were excluded from survey eligibility since relevant survey data was not captured from these groups. After setting these criteria, the subpopulation analyzed included 36,172 family units.

Measures

The first dependent variable indicated if the family caregiver was in or out of the workforce. If in the workforce, the second dependent variable indicated if they were employed or

unemployed. Thirteen independent variables were included to model employment outcomes of family caregivers. The variables included covariates and factors related to the family caregiver, family unit, and the child.

Workforce Engagement. Measuring workforce engagement was done at the householder level in two ways and used as outcome measures for this study. The first way was to gauge workforce absence in the last two weeks. This dichotomous measure was coded ‘0’ if a person was in the workforce, meaning they were employed or unemployed and searching for employment. Respondents were considered not in the workforce if they were unemployed and not searching for employment, this was coded ‘1’. This measure is a representation of the economy’s inactive workforce, meaning the proportion of the population that is disengaged from the workforce.

The second outcome, unemployment, captured if respondents were employed (coded ‘0’) or unemployed (coded ‘1’) in the last two weeks. This measure excluded all respondents that were identified as absent from the workforce. This measure represents the proportion of the population engaged in the workforce but currently out of work.

ID/ASD. Child developmental disability diagnosis is captured in the NHIS survey process. Parents are asked whether the sampled child, between the ages of 3-17 years of age, had ever received a diagnosis of ID and/or ASD from a doctor or other health professional. The responses were grouped to construct a single indicator representing a diagnosis of ID/ASD or no ASD/ID. In total, the unweighted child sample included 844 with ASD, 320 with ID, and 187 with ASD and ID, resulting in a total of 1,158 children. The remaining 36,612 did not have ID/ASD.

Health insurance status. Data about the sample child includes information about the kind of health insurance the child receives. For this study, insurance status was broken out into three categories. These categories included privately insured, publicly insured to denote Medicaid or CHIP utilization, and uninsured.

Control variables. Eleven control variables were included in the modeling procedures. Five of these controlled for caregiver characteristics. The respondent's age and level of education were entered as covariates. Education was coded from 0 (no high school diploma) to 5 (master's degree or higher). The remaining variables were categorical and entered into regression models as dummy variables. These included gender (male or female), race (Asian, Black or African American, White, and other or multiple races), and Hispanic ethnicity (yes or no).

Four variables were used to control for family-level characteristics. Two variables, family size and neighborhood social cohesion, were entered as continuous variables. Family size denoted the number of people that made up the family unit. Family neighborhood social cohesion measured the amount of community involvement, or informal supports (McCubbin & Patterson, 1983), which a family may have in the immediate vicinity. The family neighborhood social cohesion scale includes four items seeking ratings on how much respondents agreed or disagreed that people in their neighborhood are helpful, can be trusted, can be counted on, and that the neighborhood is close-knit. Ranging from 4 to 16, higher sum scores indicate greater cohesion. The scale reliability was high, with a Cronbach alpha of 0.93 (Yi et al., 2016).

Two family-level factor variables were used in this study. The first, income-to-poverty ratio denotes the ratio of family income to the U.S. Census Bureau's poverty thresholds by family size for that year. To maximize the available data, this variable was recoded to present three categories that included ratios below 1.0 (i.e., in poverty), 1.0 to 1.99, and 2.0 and higher.

The final family-level variable was the number of parents in the household, one (coded as 0) or two (coded as 1).

Two variables were used to control for child characteristics. One categorical variable was used, gender, coded as male (0) or female (1). Age was entered as a continuous variable.

Analyses

Stata 14 statistical program, by way of the 'svy' command, was chosen for all analyses to account for the complex survey design of the NHIS survey. The IPUMS data system provides adjusted and integrated survey design variables to account for year-by-year difference in survey stratification and primary sampling unit, allowing for pooling of multiple years of data. All analyses optimized the entire NHIS dataset by way of conducting subpopulation analyses, ensuring the integrity of the full sample design was maintained while producing variance estimates (Blewett, et al., 2019). Analyses conducted included descriptive summaries of variables that comprised of proportions, means, and standard errors, and bivariate tests of independence with post hoc comparisons; and missing data were addressed using pairwise deletion. Weighted logistic regression was used to produce models of main effects and cross-factor interaction effects of ID/ASD and health insurance status. Regression analyses used listwise deletion to address missing data and employed the Bonferroni correction to maintain a familywise error rate of five percent by adjusting the *p*-value to account for the 13 predictors.

Results

Table 1 summarizes the demographic characteristics of survey respondents, as well as associated family and child-level variables. Using weighted estimates, the study found most of the sample was female (60%), White (79%), and non-Hispanic (80%). The average age of parent caregivers was 42 years old. Educationally, about 32% percent had a high school diploma or less,

whereas nearly 50% had an associate's degree or higher. Eighty-one percent were in the workforce, either working or looking for work; and, of those in the workforce, 95.5% were employed.

Respondents' families lived predominately two times or higher above of the poverty threshold, whereas 14.4% lived below the threshold for poverty. Seventy percent of respondents lived in homes where two parents were present, and the average family size was four people. On average, families scored 6.7 on the neighborhood social cohesion scale. Characteristics of the sample child indicated that on average children were about 10.3 years old and the slight majority were male (51%). An estimated 3.2% of the sample children had ID/ASD. Of respondents, 66% utilized private and 24.9% utilized public health insurance, and 9% were uninsured.

<<Table 1 about here>>

Table 2 assesses family caregiver, family, and child demographics by child ID/ASD status. All tests of independence were significant, suggesting variables are related in the population. Post-hoc tests found, compared to family members of children without ID/ASD, a significantly greater percent of parents of children with ID/ASD were female and non-Hispanic ethnicity, out of the workforce, and unemployed. Racially, using pairwise comparisons, a significantly higher percent of family members of children with ID/ASD was White, Black, or Other/multiple races, respectively. At the family-level, a significantly greater proportions of parents of children ID/ASD reported living under or at the poverty line and in single-parent households. Finally, a significantly greater proportion of children with ID/ASD were male and had public health insurance, whereas those with an ID/ASD diagnosis tended to be female and use private insurance.

<<Table 2 about here>>

Table 3 presents weighted logistic regression results testing hypotheses one and two related to workforce absence. The main effects model shows, after controlling for key variables and compared to parents of children without ID/ASD, parents of children with ID/ASD experienced significantly greater odds of workforce absence (OR = 1.47, $p < .0038$). Health insurance coverage also related to significantly higher workforce absence, compared to those using private insurance, parents of children using public health insurance had 1.68 higher odds ($p < .0035$). Parents of children who were uninsured did not significantly differ from the reference group ($p < .01$).

<<Table 3 about here>>

Table 3 also presents an interaction model to test the effect of having a child with ID/ASD on parent workforce absence, across different insurance coverages. Setting the reference group as those that have children with no ID/ASD and use private health insurance and control for key variables, two of the five comparison groups were found to have significantly higher odds of workforce absence. Compared to the reference group, both groups covered by public health insurance experienced higher odds of workforce absence. Caregivers of children that had public insurance that did not have ID/ASD had 1.66 higher odds of workforce absence, denoting a small effect size ($p < .0038$). The parents of children with ID/ASD that used public health insurance experienced small effects, with 2.83 higher odds of workforce absence ($p < .0038$). There were no statistical differences between those with children with ID/ASD with private insurance and both uninsured groups. Figure 1 presents a forest plot of the interaction effects, which includes point estimates and 95% confidence intervals.

Control variables in the workforce absence models saw minimal changes in the point estimates and no changes in significance between the main effects and interaction effects models.

Characteristics related to significantly higher odds of workforce absence included older age, female gender, residing in a two-parent household, and larger family size. Characteristics related to lower odds of parental workforce absence included Hispanic ethnicity, higher education, higher income-to-poverty threshold, and having an older aged child.

<<Figure 1 about here>>

Table 4 presents the weighted logistic regression results testing the odds of unemployment among parents, thereby addressing hypotheses one and two. Compared to those using private health insurance, the main effects model found parents of children covered by public health insurance and of children who were uninsured experienced 3.83 and 3.32 higher odds of unemployment, respectively (both sig. at $p \leq .0038$). These represent medium effects. Parents of children with ID/ASD experienced 1.87 higher odds of unemployment ($p \leq .0038$), compared to parents of children who did not have ID/ASD, denoting a small effect.

<<Table 4 about here>>

The interaction effects model of parent caregiver unemployment is also presented on Table 4. Of the five comparison groups represented in the interaction, four were found to have significantly higher odds of unemployment than the reference group, parents of children without ID/ASD covered by private insurance. Parents with children with public insurance experienced the highest odds of unemployment and included 3.71 for the 'No ID/ASD' group, 8.91 for the 'ID/ASD' group (both sig. at $p \leq .0038$), representing medium and large effect sizes. Among those with children who were uninsured, those from the 'No ID/ASD' group and 'ID/ASD' group experienced 3.30 and 4.87 higher odds of unemployment, respectively, compared to the reference group (both sig. at $p \leq .0038$). Lastly, parents of children with ID/ASD that used private insurance did not significantly differ from the reference group. Figure 2 presents a forest

plot of the interaction term that depicts the odds ratio point estimates and 95% confidence intervals.

<<Figure 4 about here>>

Between the main effects and interaction effects models related to unemployment, there were no changes in significance observed among the control variables. The only variable related to higher odds of unemployment was female gender. Three variables related to lower odds of unemployment, they included parental Hispanic ethnicity and higher levels of education, as well as higher familial income-to-poverty ratio.

<<Figure 2 about here>>

Discussion

This study is situated at the intersection of child disability, their health insurance coverage, and their caregivers' workforce outcomes. Though we do not know or establish the causal mechanisms here, this study does shine a new light on the interplay between these variables. Past research has established that caregivers of children with disabilities experience lower employment outcomes, including fewer hours and greater likelihood of quitting a job (Kogan et al., 2008; Stabile & Allen, 2012; National Alliance on Caregiving, 2009). Such outcomes often come with increased financial costs, reduced earnings potential, and greater familial stress (Rogge & Janssen, 2019). For many families of children with ID/ASD, health insurance programs serve as a critical mechanism to reduce these expenses and access general health care and specialized disability-specific services (Heck & Makuc, 2000). This research attempts to fill a research gap by providing greater clarity as to the effects child health insurance coverage has on moderating the relationship between child disability and caregiver workforce engagement outcomes.

This study illustrates the challenges parent caregivers continue to face in the U.S. labor market. First, confirming hypothesis 1a, as presented in the main effects models, caregivers of children with ID/ASD experienced significantly greater workforce absence (OR = 1.47, $p < .0038$) and unemployment (OR = 1.87, $p < .0038$) when compared to caregivers of children that did not have ID/ASD. This relationship, as shown in the interaction models, is moderated by health insurance coverage, confirming hypothesis 1b. Private health insurance was found to reduce the effects of ID/ASD on both outcomes, resulting in workforce absence and unemployment that were statistically equal to the reference group (caregivers of children without ID/ASD covered by private insurance). On the other hand, caregivers of children with ID/ASD covered by public insurance experienced a stronger effect. From an equity perspective, parents of children with ID/ASD on public health insurance experienced disproportionately steeper odds of workforce engagement, where they experienced 2.83 higher odds of workforce absence and 8.91 higher odds of unemployment (both sig. at $p < .0038$).

Related to hypothesis 2, caregivers of children with ID/ASD who were uninsured experienced mixed results. No statistical differences in workforce absence were found between this group and the reference group. However, this group was found to experience 4.86 greater odds of unemployment.

The statistical effects across the logistic regression analyses ranged from small to large, and indicate a practical significance and point to major inequities. It is unclear why families of children with ID/ASD experience lower workforce engagement, however, past research suggests many families with a child with special health care needs report spending significant time providing care or coordinating care for their child, which may prevent or impact workforce engagement (Heck & Makuc, 2000; Kuhlthau et al., 2010). It should be acknowledged the

increased coverage provided by public health insurance may itself be a factor in parents determining to leave the workforce. The findings align with previous work which has found that parents of children with ASD are more likely to stop working because of their child's condition (Kogan et al., 2008; Leslie et al., 2017; Gould, 2004; Cidav et al., 2012). This research contributes by expanding what is known to include families with children with ID in addition to those with children with ASD. Previous research has also found that parents of children with special health needs are less likely to have full-time employment while utilizing public health insurance more (Heck & Makuc, 2000).

This study found a statistically greater proportion of family caregivers of children with ID/ASD were sole caregivers (36.5%) and predominantly female (67.6%). As women were found to be the primary caregivers in families with children with ID/ASD, the findings related to absence from the American workforce rest within a large body of work demonstrating the disproportionate impact of poverty on female-headed households, as well as the disproportionate impact on women (Stabile & Allen, 2012; National Alliance for Caregiving, 2009). This study provides an additional perspective showing that public health insurance coverage relates to an added negative effect on employment. This disproportionately affects women, as they are more greatly represented in the role of parental caregiver nationally.

There is a prevailing attitude among many Americans that people accessing Medicaid and CHIP are not participants in the American workforce. Medicaid and CHIP are poverty programs, and research has demonstrated that a growing number of families are accessing these programs while employed, and sometimes opting to access these programs over employer-based programs due to a number of reasons, such as lower out-of-pockets costs and greater access to services. One study found that 53.1% of children in low-income families, 21.7% of moderate-

income families and 4.7% of high-income families utilize Medicaid or CHIP. Many of these children come from working families, whose enrollments have increased dramatically in recent years, ranging from 13% for those working in the public sector to 41% among those working in small private firms (Strane et al., 2019).

It is known that economic resources are an important part of family functioning. Income and poverty affect one's health (Marmot, 2002). They influence factors across the sociocultural determinants of health including housing, neighborhood, education, health care services, nutrition, and access to transportation. Research has found that children with ASD with special health care needs are more likely to live in families that report financial problems (Kogan, et al., 2008). This study advances what is known by providing national estimates that show these financial challenges remain. Children with ID/ASD disproportionately come from lower-income households, with nearly 40% living in households under twice the federal poverty level, compared to 23% of households without a child with ID/ASD, resulting in significantly lower household socioeconomic status.

These findings have direct policy and programmatic implications suggesting family caregivers whose children access public health insurance programs may have additional family support needs to allow them to fully engage in the workforce. For example, Medicaid HCBS has been shown to support continued workforce engagement for caregivers (Leslie et al., 2017) but access to those supports are limited. In this study, we are unable to distinguish between those receiving Medicaid or Medicaid HCBS. Future research would benefit from a more holistic understanding about how these public health insurance programs and long-term services and supports interact to support family caregivers. At present, there is no known additional research

investigating the intersectional relationship of child health insurance, child disability status, and caregiver workforce experiences.

Limitations. The research presents a number of limitations that should be acknowledged. First, the use of cross-sectional data for correlational research prevents any causal inferences and determination of trends over time. The gender categories used in the survey, like other federal surveys, are limited to a gender binary of “male” and “female” for both adults and children, excluding non-binary or other gender responses. Additionally, some of the disability and health insurance status groups resulted in relatively smaller cell sizes, resulting in decreased power and increasing the possible Type II error rate. As a self-response survey implemented across the country, the NHIS includes an unknown level of error related to response bias, non-response, inaccuracies, and sampling. It is unknown why respondents drop out of the workforce and many explanations are possible. For respondents who are employed, it is unknown what level of employment they are engaged in. Finally, the analyses required the researchers to select key variables, thus omitted variable bias is also a concern.

Conclusion

Public health insurance programs are designed to be a resource to families, and for families with a child with a disability these programs play a uniquely important role. This study highlights how programs such as Medicaid and CHIP may moderate the impact of having a child with ID/ASD on the workforce engagement of caregivers. Policymakers and advocates should consider more effective ways to provide family-based services and supports to help these families maintain engagement in the workforce.

This study exploits the power of the NHIS through the linking of comprehensive health related surveys of parents, families, and children to provide a more holistic picture of parental

workforce experiences. The large, nationally representative sample and the use of sample weights allows for national estimates that can account for sampling challenges and representation. Collectively, these strengths provide the backdrop for robust findings that have implications for practice and policy.

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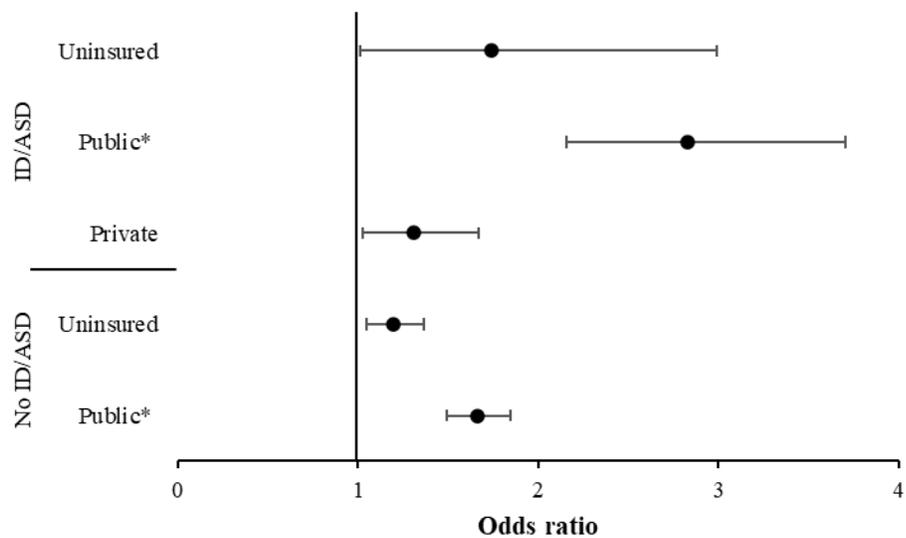
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Figure 1

Forest Plot of Odds of Workforce Absence of Parent Caregiver

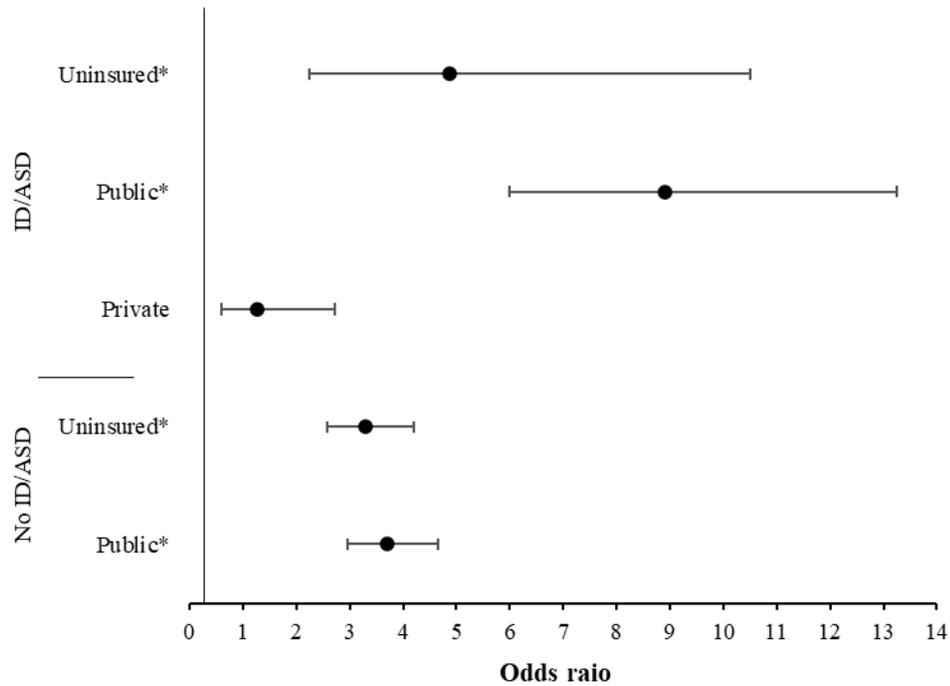


Note. ^a Reference group was set to private insurance and no ID/ASD.

*, denotes significant differences in odds ratios from the reference group, $p < .0038$.

Figure 2

Forest Plot of Odds of Unemployment of Parent Caregiver



Note. ^a Reference group was set to private insurance and no ID/ASD.

*, denotes significant differences in odds ratios from the reference group, $p < .0038$.

Table 1: Sample characteristics of caregiver, family and child: 2014-2018 National Health Interview Survey (N = 36,172)

	Weighted	Unweighted
	%/Mean	%/Mean
	<i>se</i>	<i>se</i>
<i>Parent caregiver-level</i>		
Age (yrs)	41.6 <i>0.07</i>	41.4 <i>0.05</i>
Gender (%)		
Male	40.0 <i>0.39</i>	39.3 <i>0.26</i>
Female	60.0 <i>0.39</i>	60.7 <i>0.26</i>
Race (%)		
Other or multiple	1.8 <i>0.14</i>	2.2 <i>0.08</i>
Asian	6.1 <i>0.21</i>	6.4 <i>0.13</i>
Black/African Amer.	13.4 <i>0.35</i>	13.3 <i>0.18</i>
White	78.7 <i>0.45</i>	78.2 <i>0.22</i>
Hispanic ethnicity (%)	19.6 <i>0.50</i>	22.2 <i>0.23</i>
Education (%)		
No H.S. diploma	11.8 <i>0.27</i>	13.4 <i>0.18</i>
H.S. diploma or equiv.	20.3 <i>0.29</i>	21.1 <i>0.21</i>
Some college	17.4 <i>0.27</i>	17.8 <i>0.20</i>
Assoc. or voc. degree	12.9 <i>0.23</i>	13.0 <i>0.18</i>
Bachelor's degree	22.9 <i>0.32</i>	21.4 <i>0.22</i>
Master's degree or higher	14.8 <i>0.33</i>	13.4 <i>0.18</i>
Workforce engagement (%)		
In workforce	81.2 <i>0.25</i>	80.8 <i>0.21</i>

Not in workforce	18.8	19.2
	<i>0.25</i>	<i>0.21</i>
Employment (%)		
Employed	95.5	95.2
	<i>0.15</i>	<i>0.13</i>
Unemployed	4.5	4.8
	<i>0.15</i>	<i>0.13</i>
<i>Family-level</i>		
Income-to-poverty ratio (%)		
Below 1.0	14.4	15.9
	<i>0.29</i>	<i>0.19</i>
1-1.99	19.4	21.0
	<i>0.30</i>	<i>0.21</i>
2.0 or higher	66.2	63.2
	<i>0.46</i>	<i>0.25</i>
Two parent household (%)	70.0	69.2
	<i>0.37</i>	<i>0.24</i>
Family size (#)	4.0	4.1
	<i>0.01</i>	<i>0.01</i>
Neighborhood cohesion score	6.7	6.7
	<i>0.05</i>	<i>0.04</i>
<i>Child-level</i>		
Age (yrs)	10.3	10.2
	<i>0.03</i>	<i>0.02</i>
Gender (%)		
Male	51.3	51.6
	<i>0.31</i>	<i>0.26</i>
Female	48.7	48.4
	<i>0.31</i>	<i>0.26</i>
ASD/ID status (%)		
No ASD/ID	96.8	96.9
	<i>0.12</i>	<i>0.001</i>
ID/ASD	3.2	3.1
	<i>0.12</i>	<i>0.001</i>
Health insurance status (%)		
Private	66.1	63.8
	<i>0.41</i>	<i>0.25</i>
Public	24.9	26.7
	<i>0.36</i>	<i>0.23</i>
Uninsured	9.0	9.5
	<i>0.19</i>	<i>0.15</i>

Table 2: Demographic by Child ID/ASD Status: 2014-2018 National Health Interview Survey

	ID/ASD		No ID/ASD		Sig. of χ^2
	%	<i>se</i>	%	<i>se</i>	
<i>Parent caregiver-level</i>					
Gender					***
Male	32.4	1.64	40.2	0.38	
Female	67.6	1.64	59.8	0.38	
Race					**
Other/multiple	1.9	0.47	1.8	0.14	
Asian	3.7	0.60	6.3	0.22	
Black/African Amer.	14.5	1.25	13.5	0.35	
White	79.9	1.39	78.4	0.45	
Hispanic ethnicity	15.2	1.13	20.0	0.51	***
In workforce	73.0	1.51	81.2	0.28	***
Employed	91.5	1.12	95.6	0.14	***
<i>Family-level</i>					
Income-to-poverty ratio					***
Below 1.0	17.5	1.24	14.3	0.29	
1-1.99	23.2	1.40	19.3	0.30	
2.0 or higher	59.4	1.62	66.4	0.46	
Two-parent household	63.5	1.68	70.3	0.36	***
<i>Child-level</i>					
Gender of child					***
Male	73.5	1.52	50.6	0.30	
Female	26.5	1.52	49.7	0.30	
Insurance status					***
Private	59.4	1.625	66.5	0.4477	
Public	31.5	1.62	24.8	0.39	
Uninsured	9.1	0.97	8.8	0.21	

*, $p < .05$; **, $p < .01$; ***, $p < .001$

Note. Bold represents significantly higher pairwise result optimizing the Bonferroni correction ($p < .025$).

Table 3: Workforce Absence of Householder Parent Caregivers - Main and Interaction Effects Models: 2014-2018 National Health Interview Survey (Weighted)

	Main Effects Model			Interaction Model		
	Odds Ratio	se	Sig.	Odds Ratio	se	Sig.
Parent caregiver-level						
Age	1.06	0.002	*	1.06	0.002	*
Female	6.00	0.283	*	5.99	0.283	*
<i>Race</i>						
Asian	1.13	0.187		1.13	0.186	
Black/African Amer.	0.87	0.133		0.87	0.132	
White	1.27	0.187		1.27	0.187	
Other or multiple (ref.)						
Hispanic ethnicity	0.75	0.036	*	0.75	0.036	*
Education	0.82	0.010	*	0.82	0.010	*
Family-level						
<i>Income-to-poverty ratio</i>						
< 1.0 (ref.)						
1-1.9	0.55	0.030	*	0.55	0.030	*
2.0 <	0.32	0.020	*	0.32	0.020	*
Two-parent household	2.43	0.109	*	2.43	0.109	*
Family size	1.12	0.016	*	1.12	0.016	*
Neighborhood connectedness	1.00	0.002		1.00	0.002	
Child-level						
Age	0.93	0.004	*	0.93	0.004	*
Female	0.98	0.034		0.98	0.034	
<i>Insurance status</i>						
Private insurance (ref.)						
Public health insurance	1.68	0.089	*			
Uninsured	1.20	0.080	†			
<i>ID/ASD</i>						
No ID/ASD (ref.)						
ID/ASD	1.47	0.129	*			
<i>Insurance status by ID/ASD interaction</i>						
Private health insurance*No ID/ASD (ref.)						
Private health insurance*ID/ASD				1.31	0.164	
Public health insurance*No ID/ASD				1.66	0.090	*
Public health insurance*ID/ASD				2.83	0.390	*
Uninsured*No ID/ASD				1.20	0.081	
Uninsured*ID/ASD				1.74	0.481	

Constant 0.01 0.002 * 0.01 0.002 *

Note. a. Observation = 36,172. b. Main Effects Model: $F(17, 891) = 203.93, p < .001$. c. Interaction Model: $F(19, 889) = 184.67, p < .001$. d. Bonferroni correction applied to p -value.

*, $p < .0038$, †, $p < .01$

Table 4: Unemployment of Householder Parent Caregivers - Main and Interaction Effects
Models: 2014-2018 National Health Interview Survey (Weighted)

	Main Effects Model			Interaction Model		
	Odds Ratio	se	Sig.	Odds Ratio	se	Sig.
Parent caregiver-level						
Age	1.00	0.005		1.00	0.005	
Female	1.33	0.107	*	1.33	0.107	*
<i>Race</i>						
Asian	0.75	0.235		0.75	0.235	
Black/African Amer.	1.15	0.308		1.15	0.309	
White	0.76	0.196		0.75	0.197	
Other or multiple (ref.)						
Hispanic ethnicity	0.64	0.060	*	0.64	0.060	*
Education	0.91	0.024	*	0.91	0.024	*
Family-level						
<i>Income-to-poverty ratio</i>						
< 1.0 (ref.)						
1-1.9	0.47	0.037	*	0.46	0.037	*
2.0 <	0.31	0.037	*	0.31	0.037	*
Two-parent household	1.15	0.096		1.15	0.096	
Family size	0.94	0.025		0.94	0.025	
Neighborhood connectedness	0.99	0.005		0.99	0.005	
Child-level						
Age	1.00	0.010		1.00	0.010	
Female	1.07	0.073		1.07	0.073	
<i>Insurance status</i>						
Private insurance (ref.)						
Public health insurance	3.83	0.433	*			
Uninsured	3.32	0.406	*			
<i>ID/ASD</i>						
No ID/ASD (ref.)						
ID/ASD	1.87	0.288	*			
<i>Insurance status by ID/ASD interaction</i>						
Private health insurance*No ID/ASD (ref.)						
Private health insurance*ID/ASD				1.27	0.495	
Public health insurance*No ID/ASD				3.71	0.432	*
Public health insurance*ID/ASD				8.91	1.803	*
Uninsured*No ID/ASD				3.30	0.408	*
Uninsured*ID/ASD				4.86	1.910	*

Constant 0.09 0.032 * 0.10 0.033 *

Note. a. Observations = 29,240. b. Main Effects Model: $F(17, 891) = 54.46, p < .001$. c. Interaction Model: $F(19, 889) = 49.53, p < .001$. d. Bonferroni correction applied to p -value.

*, $p < .0038$