

Parenting with Intellectual or Developmental Disabilities in Washington State

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Background

The impetus for this study was a request to the Center for Excellence in Developmental Disabilities (UCEDD) to answer a simple question—i.e., how many mothers with IDD had their infant removed by Washington State Child Protective Services (CPS) at birth or within the first year. Based on an earlier community forum and a multi-year project funded by the Kennedy Foundation to provide supported parenting assistance to families with IDD at risk of losing custody of their children, we were familiar with the issues.

Phase I of the study included two questions—i.e., the prevalence of involvement with CPS of mothers with IDD and the reasons given for initiation of an investigation. We conducted secondary analysis of the NCANDS child file from Washington State but were unable to answer our research questions or cross the NCANDS dataset with other available disability administrative data.

We explored alternative approaches to determine the prevalence of mothers with IDD who were involved with CPS during the first year of the child's birth. This became the second phase of the project described here.

Objectives

Phase II utilized linked administrative data to understand when and how CPS interacts with children born to mothers with IDD in Washington State.

- 1) What is the prevalence of children born to mothers with IDD diagnoses and their interactions (reports and removals) with CPS?; and
- 2) When are these children interacting with CPS

Findings and Discussion

Of the 1,271,419 births in Washington State between 1999 and 2013, 567 babies were born to mothers with IDD diagnoses, which is 4.5 per 10,000 births or 0.045%. The percentages by diagnosis is presented in Table 1.

Children born to mothers with IDD diagnoses were more likely to have contact with CPS at both time intervals (one year and four years). Of all infants born to mothers with IDD diagnoses, 21.7% were the subject of a CPS report within one year and 35.8% within four years. For mothers with an ID diagnosis, almost half of their children were reported in the first year (48.3%) and two thirds were reported in the first four years of life (66.7%). These are both higher rates than with infants born to mothers without an IDD diagnosis at 6.3% (one year) and 9.9% (four years).

CPS removal of children born to mothers with IDD diagnoses was 6.5% within the first year and 8.6% by four years compared to 0.9% within the first year and 1.8% within four years for children born to mothers without an IDD diagnosis. The removal rate for children of mothers with an ID diagnosis was 18.3% within one year and 23.3% within four years. Full results are presented in Table 2.

Table 1. Percentage of Children Born to Mothers with IDD Diagnosis by ICD-9 Code (N = 567)

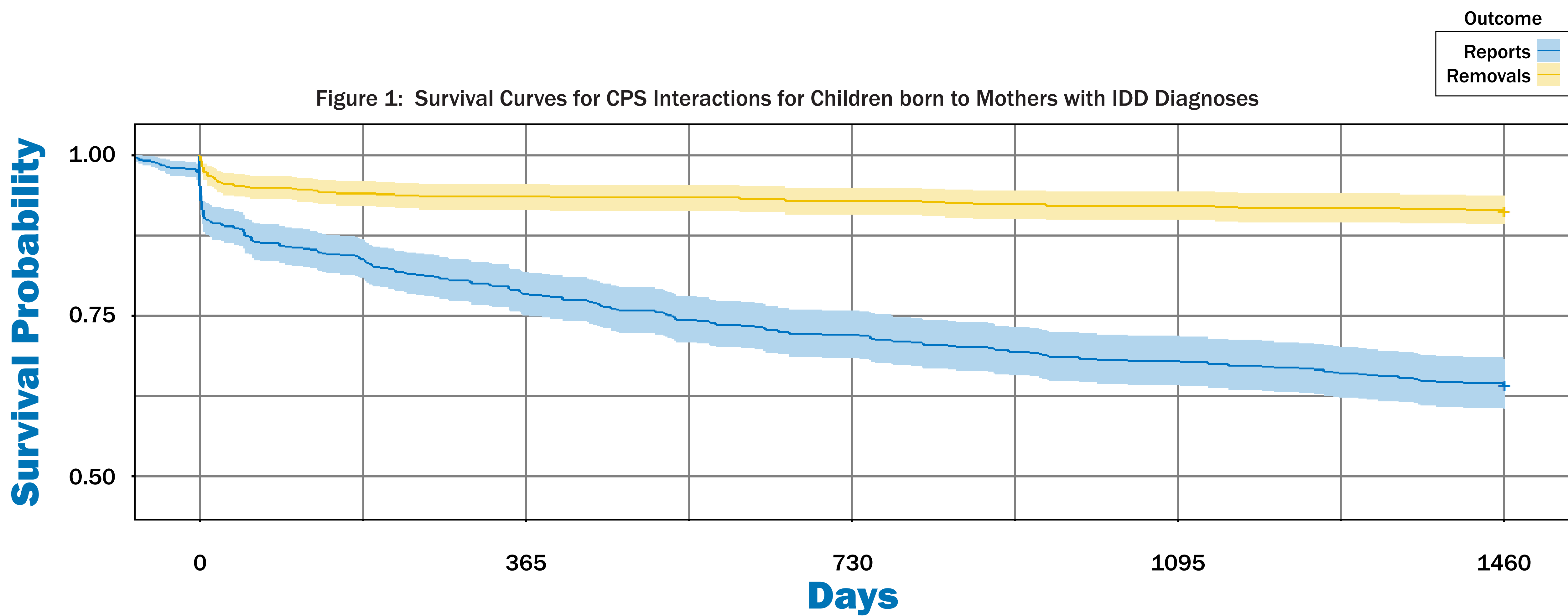
| Diagnosis (ICD-9 Code) | % |
|---|------|
| Cerebral Palsy (343) | 39.7 |
| Spina Bifida (343) | 26.3 |
| Traumatic Brain Injury (907) | 9.9 |
| Unspecified Intellectual Disability (319) | 6.9 |
| Pervasive Developmental Disorder (299) | 4.9 |
| Mild Intellectual Disability (317) | 3.2 |
| Down Syndrome (758) | 2.5 |
| Fetal Alcohol Syndrome (760.71) | 2.1 |
| Tuberous Sclerosis (759.5) | 1.6 |
| Fragile X Syndrome (759.83) | 1.2 |
| Cerebral Degeneration (330) | 0.9 |
| Moderate Intellectual Disability (318) | 0.5 |
| Prader-Willi Syndrome (759.81) | 0.2 |
| Lesch Nyhan (277.2) | 0.2 |
| Rett Syndrome (330.8) | 0.0 |
| Cri du chat (758.31) | 0.0 |

Table 2. CPS Interactions by Maternal IDD Diagnosis Status

| | All Births N = 1,271,419 % | No IDD Diagnosis N = 1,270,912 % | DD Diagnosis N = 507 % | ID Diagnosis N = 60 % | X² |
|---------------------------|----------------------------------|---|------------------------------|-----------------------------|-----------|
| CPS Report Within 1 Year | | | | | 379.99*** |
| Yes | 5.5 | 5.5 | 18.5 | 48.3 | |
| No | 94.5 | 94.5 | 81.5 | 51.7 | |
| CPS Report Within 4 Years | | | | | 305.42*** |
| Yes | 13.3 | 13.3 | 32.1 | 66.7 | |
| No | 86.7 | 86.7 | 67.9 | 33.3 | |
| Removal Within 1 Year | | | | | 316.81*** |
| Yes | 0.9 | 0.9 | 5.1 | 18.3 | |
| No | 99.1 | 99.1 | 94.9 | 81.7 | |
| Removal Within 4 Years | | | | | 234.63*** |
| Yes | 1.8 | 1.8 | 6.9 | 23.3 | |
| No | 98.2 | 98.2 | 93.1 | 76.7 | |

*** p < .001

The survival curves of the CPS interventions for children born to mothers with IDD diagnoses are presented in Figure 1. The time with the greatest number of children being reported or removed is right after birth. More than 64% and 91% of these infants are not reported to CPS and not removed, respectively, within their first four years of life.



Methods and Analysis

This retrospective cohort study utilized linked administrative data—including birth records, hospital discharge data from the child's birth, and CPS records—for all children born in Washington State from 1999-2013 (N=1,271,419). CPS records through the first quarter of 2018 were included.

- Variables of interest: 1) involvement with CPS (report filed) and 2) child removed by CPS. Binary variables for each outcome for within one year and within four years were identified.
- Mothers with IDD were identified with ICD-9 codes from hospital discharge records. A binary variable was used to divide the findings between mothers with ID and those with DD.

All analyses were performed using R version 3.4.1 (R Core Team, 2017). We first examined the distributions of our covariates between infants born to mothers with IDD diagnoses and those who were not, using chi-square tests to identify statistically significant differences by mother's disability diagnosis status. Similarly, the distributions of the CPS outcomes at both one year and four years were examined utilizing chi-square tests.

We used survival regression analysis to investigate the time it takes for children born to mothers with disability diagnoses to interact with CPS through reports and removals. Specifically, we used Cox proportional hazards regression to test multivariate models including our birth record covariates.

Limitations

We acknowledge the limitations in utilization of ICD-9 codes for identification of mothers with IDD as there is variation in how and who assigns these codes, debates about which impairments should be included in the umbrella term IDD as well as the fact that the ICD-9 diagnosis would be secondary to the medical coding related specifically to birth. In addition, the administrative data does not capture the complexities involved in CPS decisions regarding parental competency.

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