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## The Long-Term Impact of Children's Disabilities on Families

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**Copenhagen  
Business School**  
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# **Department of Economics**

**Copenhagen Business School**

**Working paper 06-2019**

**The Long-Term Impact of Children's Disabilities on Families**

**Snaebjorn Gunnsteinsson  
Herdis Steingrimsdottir**

# WORKING PAPER

## The Long-Term Impact of Children's Disabilities on Families\*

Snaebjorn Gunnsteinsson<sup>†</sup>      Herdis Steingrimsdottir<sup>‡</sup>

June 18, 2019

### Abstract

Childhood disability is a major health shock that affects parents early in their working life. We estimate its impact on parents' career trajectories, their balance sheets, and major life decisions using detailed register data from Denmark. To identify the causal effect of childhood disability we use an event study approach, where we control for a rich set of pre-birth variables and focus on conditions that have no or weak associations with socioeconomic determinants. We find that having a child with a disability has strong negative impact on mothers' earnings. The effect is persistent and the wage penalty appears to grow over time. Fathers' earnings are also affected but the impact is notably smaller. We find that both parents are less likely to be employed in the long run and are less likely to ascend to top executive positions. The long-term structure of the household is also affected as subsequent fertility is lower and partnership dissolution is more common. Finally, despite this financial shock, long term net worth of families is not affected or may be positively affected, potentially due to help from government transfers and lower cost associated with having fewer other children, or due to a stronger savings motive for the long term care of the disabled child.

*Keywords: disability, children, child, insurance, earnings, income, labor force participation, fertility*

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The birth of a child with a severe disability or congenital disorder is not only an emotional shock for the parents but can also have profound economic implications. For example, the probability of being in poverty in the U.S. is 50% higher among families who have a disabled child than among families that do not have a child with disability status (OECD, 2012). Childhood disability is a major health shock that affects the child's parents early in their work lives, and can potentially entail a long-lasting impact on their employment and earning trajectories. Yet, our knowledge on how the economic well-being of these children and their families is affected, is surprisingly limited. Given the paucity of available evidence and the importance of the problem, producing reliable estimates on both the short-term and long-term impact of having a child with a disability is critical.

In this paper we use an event study approach to examine how families fare after having a child with a severe disability. The majority of existing studies focus on the impact on mothers' labor market outcomes at a single point in time. However, to understand the impact on families' well-being it is important to study the effect on other household members, and to distinguish between temporary adjustments in labor market supply and earnings, and permanent effects on career trajectories. We therefore study the impact on both mothers' and fathers' labor market outcomes over the first fifteen years after their child is born. We use register data that includes the universe of births in Denmark in 1992-2005, and detailed information on each family before and after birth. This allows us to provide an unusually complete picture of the impact on families, through changes in parents' labor market participation, earnings, wealth accumulation, fertility and marital status.

The interpretation of our findings as the causal impact of childhood disability relies on the assumption that affected and unaffected parents would have similar outcomes if their children had the same health status. However, it is well known that disability rates vary across social groups; in particular, they tend to be higher in lower-income families (Stabile and Allin, 2012). It is also possible that the probability that a child is diagnosed depends on family characteristics, as some parents may be more likely to take their children to the doctor. Moreover, if children's conditions are observable during pregnancy, selective abortions may also lead to differences between the affected and unaffected group. We therefore include controls for observable characteristics such as parents' age, level of education, average earnings, and labor force participation in the six years before birth. To alleviate concerns that the childhood disability status is correlated with unobserved characteristics of the parents, we check the robustness of our results to only including severe disabilities that have no or weak associations with socioeconomic determinants; and by excluding all cancers and conditions for which prenatal testing was available during the study period.<sup>1</sup> In addition, by using official health records,

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<sup>1</sup>One exception is spina bifida, which is included in the DW definition and may be detected in-utero. This accounts for less than 5% of the sample in our main overall definition so potential endogenous abortion would not have a great effect on the overall findings. We may exclude spina bifida in future revisions.

rather than survey data, to identify child's disability status, we are able to avoid the potential bias caused by parental assessment of their children's health.

We find that child's disability has profound effects on household's finances and major life outcomes. The effects are persistent, and moreover we find that the impact is larger in the long run than in the short run. Affected mothers and fathers earn 13% and 3% less, respectively, compared to other parents, 11-15 years after the birth of their child. They also have 9% fewer subsequent children and split up their partnership at a higher rate (by 12%) than the comparison parents. Combining earnings from both parents, affected families have about 6.4% lower earnings in the long run despite having on average fewer children to care for and fewer pregnancy-induced labor force interruptions.

Our paper contributes to the growing literature on the impact of health shocks on family members. A number of recent studies have examined the impact of adverse health shocks among adults on their spouses, and on household finances. In general these studies find that spouses' labor supply is not significantly impacted in the case of (non-fatal) adverse health shocks (see e.g., Braakmann, 2014; Fadlon and Nielsen, 2017; Dobkin et al., 2018), although one study (Meyer and Mok, 2018) finds that wives decrease their labor supply following the onset of their husbands' disability. However, there is a significant impact on households' economic outcomes in terms of increased expenses, lost earnings, consumer borrowing, and poverty (see e.g., Meyer and Mok, 2018; Dobkin et al., 2018). Furthermore, Braakmann (2014) reports that partner's disability reduces wives life-satisfaction considerably.

While, adverse health shocks among spouses lead directly to lost household earnings because the person who experiences the shock is unable to work, the impact of adverse health shocks among children stems from parents making different labor market decisions due to the care that their child needs. Moreover, health shocks to children are different in that they impact labor market decisions of family members early on in people's careers, while health shocks among spouses are likely to occur when people are closer to retirement. Adverse health among children can therefore have long lasting impact on parents' labor market outcomes.

The theoretical foundation for this literature stems from the work of Mincer (1962) and Becker (1965). Their work introduces household responsibilities into people's labor supply decisions, thereby providing some testable implications in terms of the impact of children's health on parents' decision-making and labor market behavior. On the one hand, the child's disability amplifies financial pressures on the family and may lead parents to work more. On the other hand, more time may be required to care for the child, and therefore, the disability may incur a negative effect on parental labor supply. Initially the literature focused on mothers' decisions to spend their time either on work or childcare. Later work has expanded the framework to consider the collective nature of the household, and how couples jointly make decisions on the division of labor in the household, and thereby on their labor supply (see, e.g., Chiappori, 1988, 1992; Browning et al., 1992).

The empirical literature on the impact of childhood disability on families has been surveyed by Jacobs and McDermott (1989), Anderson et al. (2007) and Stabile and Allin (2012). The literature on parents' labor market outcomes focuses almost exclusively on maternal labor supply. The existing studies consistently find that childhood disability is associated with lower maternal employment in the range of 3% to 15%, depending on the severity of the disability (Stabile and Allin, 2012). The majority of these studies focus on the correlation between childhood disability and mothers' labor market outcomes at a single point in time, although a couple of recent studies exploit panel data in an attempt to assess the causal effect (see, e.g., Powers, 2003; Frijters et al., 2009; Kvist, Nielsen and Simonsen, 2013; Burton et al., 2017). If, however, one is interested in the impact of children's health on household's finances, it is critical to include fathers in the analysis. Yet, with the exemption of couple of recent studies, the impact on fathers has been largely left unexplored. Notably Burton et al. (2017) look at the impact of childhood disability in Canada on mothers' and fathers' labor supply and find evidence of increased specialization among parents when they have a child with disability. In contrast Kvist, Nielsen and Simonsen (2013) estimate the impact of having a child with ADHD on parents' labor supply in Denmark, and find that both parents have decreased labor supply on the intensive margin compared to other parents.

Childhood disability can also have a major impact on the well-being of the child and their family through its effect on family structure. Having a child with a disability can cause marital stress and increase the risk of marital dissolutions. The findings of the empirical literature point to decreased marital stability among parents who have children in poor health (see, e.g., Reichman, Corman and Noonan, 2004, 2008; Kvist, Nielsen and Simonsen, 2013). However, marriages can also provide some insurance against both the emotional and financial shock associated with having a child with a disability and Reichman, Corman and Noonan (2008) argue that childhood disability can reduce divorce risk because parents become closer as they work together to care for the child. Black et al. (2017) look at the impact of having a sibling with disability on child's educational outcomes. Their results suggest that siblings are adversely affected through time and financial resource dimensions.

Finally, our analysis also adds to the literature on the gender wage gap. Despite decreasing disparity between male and female earnings, a substantial gap remains. It is well documented that children have a negative impact on women's earnings (see, e.g., Lundborg, Plug and Rasmussen, 2017). Kleven, Landais and Sogaard (2019) find that in Denmark the arrival of children creates a long run gap in earnings between fathers and mothers of around 20%. Evidence suggests that absenteeism explains a large fraction of the wage penalty for mothers. Simonsen and Skipper (2012) find that motherhood has a negative impact on wages in Denmark, mainly due to mothers' higher level of absence from work. In contrast, they find a positive wage premium for fathers. In line with this explanation Daly and Groes (2017) find that mothers are responsible

for their children’s doctor visits over 90% of the time. We contribute to this strand of research by looking how children who need exceptional level of care impact labor market outcomes of both mothers and fathers.

The remainder of the paper is organized as follows. The Danish context and the data used in this study are described in Section 1. Section 2 presents the empirical strategy and Section 3 presents the results. Finally, we conclude in Section 4.

## 1 Context and Data

### 1.1 The Danish Context

Denmark has one of the most generous welfare systems within the OECD. The government provides universal health insurance that covers almost all medical costs.<sup>2</sup> All pregnant women are offered prenatal classes, check-ups, counseling, and prenatal examination, free of charge. The prenatal examination includes two ultrasound scans that check for Down Syndrome, severe deformities, and severe congenital diseases.<sup>3</sup>

Until 2004 the standard practice was to offer pregnant women placenta test (chorionic villus sampling) or a test of the amniotic fluids (amniocentesis) to test for chromosomal defects if they were aged 35 or more, were at increased risk of carrying a fetus with Down’s syndrome based on a so called triple test in the second trimester, or if they were at risk of an inherited disease. These tests are not without risks, and one out of every hundred cases results in a miscarriage. In 2000 the uptake of these invasive tests among pregnant women aged 35 or more, was less than 50% (Ekelund et al., 2008). In 2004 the Danish National Board of Health introduced revised guidelines for prenatal diagnosis which recommended all pregnant women to be offered prenatal screening consisting of nuchal translucency measurement, and the double test ( $\beta$ -hCG and PAPP-A). This practice reduced the number of invasive procedures by 55% (Vestergaard, Lidegaard and Tabor, 2009) and halved the number of infants born with Down’s syndrome (Ekelund et al., 2008). Until week twelve of the pregnancy every woman may opt for abortion without special permission. After week twelve an abortion requires permission from a regional committee, consisting of two doctors and one social worker. Terminating a pregnancy after week 22 is not allowed in Denmark unless in the case of a lethal fetal anomaly.

In addition to free health care, families of disabled and chronically ill children receive various governmental support. Financial support is given to parents of children with disability by the municipalities to make it possible for a disabled child to live with their families and to live a life as normal as possible. This assistance includes a grant to cover additional expenses due to the disability of the child (which is neither means-tested

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<sup>2</sup>The exceptions include dental care, and limited out-of-pocket prescription costs.

<sup>3</sup>The first scan is carried out between the 11th and 14th week of the pregnancy, and the second one between 18 and 20 weeks of pregnancy.

nor taxed), and compensation due to loss of earnings (United Nations, 2016). In Denmark, municipalities are obliged to provide day-care services to children with disabilities. They can either be integrated into regular day-cares with special support as needed, or the municipality can set up day-care institutions for disabled children exclusively. Parents of children with severe disabilities can also choose to care for their children at home, in which case they receive a compensation for loss of earnings. In total around 15,000 families receive such allowances annually. If a child becomes ill and/or needs to be hospitalized a parent can also get a temporary leave from work to stay with their child, in which case they are paid fixed benefits. Some employers compensate their employees to receive their full salary while on temporary leave.

## 1.2 Data and Sample Construction

Our data is constructed from several administrative registers from Statistics Denmark, including tax registers and various health registers. The registers are based on public records and contain information on the whole population of Denmark. The registers are linked using unique person-level identifiers, and these identifiers are also used to link children to their parents and siblings.

The sample we use is based on the universe of births in Denmark in 1992-2005, a total of 562,725 births. We limit our analysis to first singleton births in households with exactly two adults (one of each gender) where the parents are married or living together at the time of the birth. We are interested in the effect of caring for a disabled child and therefore exclude births if the children do not survive up to age 18. We also limit the sample to births where the mother and father are both between 22 and 40, the former to limit the number of parents who are still in school and the latter to exclude particularly high risk and unusual pregnancies. Finally, we also drop families where parental education is unknown. The resulting sample has 263,979 births.

Out of these restrictions the one on child survival is most likely to introduce a possible selection bias. In fact, conditional on diagnosis for many of the conditions we study, we find that survival is higher in higher SES families. Based on the data it does not seem this is due to higher SES families getting their children diagnosed earlier (the rate of diagnosis over time in different groups is roughly proportional). Rather, it appears that either children in lower SES families have more serious versions of these conditions or that higher SES families are able to improve their children's survival through, for example, better adherence to a drug or treatment regimen. We will explore this issue further in future revisions but our current interpretation is that this issue is likely to introduce a bias towards zero long term impacts and that our findings therefore underestimate the impact. This is because, since we condition on a range of socioeconomic variables, the remaining bias would be due to unobservables such as intelligence, drive, conscientiousness or a favorable



family background – all of which are likely to both increase survival and would have lead to better labor market outcomes in the absence of the child’s disability.

We extract information on earnings and labor market participation from income registers that are based on people’s tax records, and from the Integrated Database for Labour Market Research (Integreret Database for Arbejdsmarkedsforskning, IDA). IDA is a universal database that contains longitudinal data connecting individuals and firms.<sup>4</sup> We observe parents’ labor market status and their type of occupation (based on ISCO - the International Standard Classification of Occupations). We use total taxable income aggregated over all jobs as our measure of market earnings. Our gross earnings measure also includes payments that compensate parents for lost earnings when taking care of a disabled child.

As described in Section 1.1 parents in Denmark are entitled to various assistance due to their child’s disability. This assistance includes grants to cover additional expenses, and compensate parents for their loss of earnings. We use data from the municipalities to account for these benefits received by parents. The data contains information on what kind of benefit parents receive and the amount received each month.

Our data on births and family composition come from the birth records and the National Population Register. We identify children’s parents from their birth records and consider parents to be together if they are married or cohabiting at the time of the birth. Cohabitation is common in Denmark and around 50% of children are born to unmarried parents. We consider parents to have separated if they are divorced or no longer share the same address. In the main analysis we focus on first births and the fertility outcome is based on subsequent fertility of the mothers.

Summary statistics for the outcome variables are given in Table 1. Wages are given in constant 2015 Danish Kronas (currently 6 DK = 1 USD). As can be seen in rows 3 and 4, employment rates in Denmark are notably high compared to other countries. Our sample size is reduced in years 11-15 of the panel because we do not have a full fifteen year follow up on the more recent births in our data (the labor market data ends in 2013 and our fertility data ends in 2012). When we look at the data on partnerships in the last row it’s important to remember that, by construction, all couples are partners at the time of birth.

### 1.3 Definitions of Disability

Traditional notions of disability use definitions based on specific categories of diseases or health conditions. Alternative definitions have emphasized defining disabilities within the social (and even technological) environment Halfon et al. (2012). New definitions combining these two approaches have been developed by the World Health Organization and the United Nations. Building on those definitions and defining disability

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<sup>4</sup>The links between individuals and firms are observed at one point at any given year, namely at the end of November. This means that we do not observe seasonal jobs and multiple job changes within a year.

specifically in childhood, Halfon et al. (2012) emphasized a definition that takes into account what is developmentally appropriate functioning and developed the following definition: “A disability is an environmentally contextualized health-related limitation in a child’s existing or emergent capacity to perform developmentally appropriate activities and participate, as desired, in society.” Although these newer definitions allow for a broader conception of disability, we focus on definitions of disability based on specific health conditions. The reason for this is that in the analysis we focus on estimating the impact of childhood disability on families and to do that we must compare two families that are as similar as possible but who differ in the disability status of their child. If the family environment is part of the disability definition, this comparison becomes impossible.

We define three disability groupings based on a list of International Classification of Diseases (ICD) codes. In each case, a child is considered to be in a grouping if they are diagnosed with one of the conditions in the group by age ten.<sup>5</sup> We refer to these three groups as SSI (for Supplemental Security Income), DW (for Disability Weight) and MDD (for Mental Retardation and Pervasive Developmental Delay). We then create a combined definition, referred to as COMB, defined as those children diagnosed with any of the conditions in any of the three lists before age ten, which is the main disability definition we use.

**SSI Group** Our first definition of disability is to define a child to be disabled if he or she is diagnosed in their first ten years with one of the conditions on the US Governments’ Social Security Administration List of Compassionate Allowances Conditions. These are conditions that would confer automatic eligibility for a child’s family to receive Supplemental Security Income (SSI) from the SSA (provided the family income is below the SSA income threshold) in the United States.<sup>6</sup> About 0.24% of children in Denmark in our sample were diagnosed with one of these conditions before the age of five. This list is not dominated by any specific condition (the fifteen most common conditions account for about 1/6th of the overall number) so this definition captures a set of rare but serious conditions. We exclude all cancers and conditions (listed in Appendix B.3) for which prenatal testing was available during the study period (1990-2005).

**DW Group** The Disability Weight (DW) group is defined as those children who are diagnosed with a condition that has a disability weight above 20% based on the Global Burden of Disease Study. Based on the 2013, 2010, 2004 and 1998 reports<sup>7</sup>, we included blindness (ICD H540, H541), deafness (H913),

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<sup>5</sup>For each child we include diagnoses up to the end of the 10th calendar year after birth because of the way our data is set up. Therefore, children born early in the year are followed longer. Since the conditions we focus on are very rarely diagnosed for the first time in the 10th year, this differential follow up should have little effect on the results. In regressions (not reported here) where we interact the disability with month of birth for our key outcomes we see no particular pattern across month of birth.

<sup>6</sup>The list can be found at <https://www.ssa.gov/compassionateallowances/conditions.htm> (we used the January 2016 version).

<sup>7</sup>See Stouthard (2000), World Health Organization (2008), Salomon et al. (2012) and Salomon et al. (2015). See Appendix for details on the decisions made for each disease.

moderate to severe intellectual disability (IQ < 50; F71 and F72), cerebral palsy (G80), schizophrenia (F20), bilateral renal agenesis (Q601), encephalopathy (G934), autism (F841 and F842) and spina bifida (Q05). This definition is dominated by cerebral palsy (about 64%) followed by autism (11.5%), spina bifida (10%), blindness (4.5%) and intellectual disability (4%) with the remaining 6% covered by the other conditions. 0.4% of the children in our sample were diagnosed with one of these conditions before the end of their tenth year.

**MDD Group** In the third group we include children diagnosed with mental retardation (ICD codes F70 through F79) or pervasive developmental delay (ICD code F84) in the first ten years of life.<sup>8</sup> Of the children in our sample, 0.33% fit the definition of mental retardation or pervasive developmental delay.

**COMB Group** The children in the COMB group, those fitting at least one of the other three definitions, account for 0.87% of children in our sample.

To construct the measures of disability we use the national patient registers (NPR). The NPR covers both inpatient and outpatient activities (from both private and public hospitals), emergency room contacts, and activities in psychiatric wards. Diagnoses in years before 1994 are based on Version 8 of the International Classification of Diseases (ICD-8), but from 1994 onwards they are coded using the Version 10 of the ICD (ICD-10). The ICD-8 classification system was established in 1965 and did not include codes for many of the diseases on the SSI list. Because of this we only use diagnoses recorded from 1994 onwards. However, in an effort to increase our sample size we opted to include births from 1992 onwards rather than only from 1994. This improves our power, particularly for longer term outcomes, but has the drawback that some children who receive a diagnosis in the first 1-2 years of life but do not have a diagnosis code recorded later will be misclassified as without disability. Our findings are very similar if we exclude birth years 1992-1993.

## 2 Empirical Strategy

We estimate event study models, comparing families who have a child with a disability to families who have a child at the same time without a disability. We also compare our main results to estimates where we match families based on pre-birth observables.

We start by estimating models of the form

$$Y_{ij} = \sum_{j=-6}^{15} \{\alpha_j A_j D_i + \beta_j A_j + \gamma_{kj} A_j X_j\} + \epsilon_{ij} \quad (1)$$

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<sup>8</sup>ICD code F84 includes autism (F840 and F841) as subcategories

where  $Y_{ij}$  is an outcome variable for family  $i$  in year  $j$  (set to zero at birth),  $A_j$  is an indicator for number of years elapsed since (or leading to) the birth,  $D_i$  is an indicator equal to one if family  $i$  is affected,  $X_j$  is a vector of  $k$  control variables and  $\epsilon_{ij}$  is an error term. We control for age, months of education, the average earnings and labor force participation in the 6 years before birth, for both mother and father (8 variables total, all centered). The  $\alpha_j$ 's estimate the difference between affected and unaffected families by year. We estimate these models with OLS but cluster the standard errors at the level of the family, allowing correlations across years. Figures 1 through 7 plot  $\beta_j$  (comparison group) and  $\beta_j + \alpha_j$  (affected group) coefficients on the left hand panels, and the  $\alpha_j$  coefficients (differences) on the right hand panels, for a variety of outcome variables. Table 3 shows estimated coefficients for the following equation:

$$Y_{it} = \alpha_k D_i + \beta Z + \epsilon_{it} \quad (2)$$

where the variables are as before except that  $t$  is an indicator for one of three time periods: 1-5, 6-10 or 11-15 years after the birth and the outcome variables are averages over the corresponding time period. All regressions include indicators for the year of birth. Except when fertility is the outcome, the regressions include controls for pre-birth values of the outcome averaged over years 1-5 before birth. Earnings and employment status regressions for mothers (fathers) include controls for mother's (father's) age and detailed education categories (as listed in Appendix Table A.4). The relationship status regression includes controls for both mother's and father's age.

In the appendix we compare these results to those obtained by using nearest neighbor matching (Abadie and Imbens, 2006). We match affected families to other families giving birth in the same year and match on age, length of education, average of earnings in years 1-5 before birth for both parents as well as their average relationship status in the five years before birth. Since we have multiple continuous matching variables (which leads to inconsistent ATE estimates) we include a bias adjustment based on Abadie and Imbens (2011) using all matching variables. The results from the matching are given in even columns in Tables A.1 through A.3, whereas the odd columns replicate the regression results.

## 2.1 Balance and Identification

The interpretation of our findings as the causal impact of child's disability on family outcomes relies on the assumption that the child's disability status is uncorrelated with the error term. For the identification assumption to hold, the disability conditions that we look at should impact families relatively randomly. If this is the case, the affected and unaffected families should be comparable before having their child, the two groups should be equivalent in their potential later life outcomes, and there should be no anticipatory

behaviour with respect to a potential child's disability.

There are several reasons why these assumptions may not hold. First, some families may be more likely than others to take their child to the doctor and get diagnosis. If this is the case, the diagnosis status may be correlated with family characteristics. To avoid this, we focus on serious conditions where it is highly unlikely that any child would not be diagnosed given its disability status. Second, if a child's disability condition is detected in utero some families may choose to terminate the pregnancy. We therefore exclude conditions, for which prenatal testing was available during the period. A final, and perhaps the main concern, is that children's health status at birth is correlated with parents' socioeconomic status. Mothers' nutritional choices, alcohol consumption, and smoking during pregnancy are for example correlated with socioeconomic determinants and can have a considerable impact on children's birth outcomes.

Table 2 shows the average values of key pre-birth observables and the standardized difference between affected and unaffected families, using the COMB definition. In Columns 1-4 we use the full sample and in Columns 5-8 we look at the matched sample. These two groups are not very dissimilar. The largest absolute standardized difference is 0.12 for mother's education as the affected mothers have less education by 0.25 years of schooling. Table A.4 shows that the key difference in education comes from there being 5 percentage points greater number of both mothers and fathers with only elementary education in the affected group. Balance for the three sub-definitions of the combined definition is shown in Tables A.5 through A.10. These tables show that the largest imbalances come from the disability weight (DW) and mental (MDD) definitions, whereas the supplemental security income (SSI) definition is remarkably well balanced. Because of the imbalance in the DW and MDD groups, we control for pre-birth outcomes in our regressions. Our first assumption then is that controlling for these pre-birth outcomes is sufficient to balance the two groups in terms of unobserved heterogeneity. Because of (1) the good balance in the SSI group, (2) the fact that these diseases were selected by the US government to be those that could be automatically admitted into the SSI program, and (3) we are not aware of any risk factors for the vast majority of these diseases, we believe any remaining imbalance between the affected and unaffected groups can reasonably be assumed to be very small, whereas some imbalance may remain in the DW and MDD groups. The results are quite consistent across these three sub-definitions, suggesting that the bias may be relatively small compared to the true impact we are estimating.

## 3 Results

### 3.1 Mothers' and fathers' labor market outcomes

We start by looking at the impact on affected parent's earnings. Figures 1 and 2 plot the difference in outcomes over time for three key outcome variables for mothers and fathers, respectively. In each figure, the panels in the top row show market earnings, comparing the affected and unaffected parents on the left and showing the difference between them on the right. The panels in the middle row show the amount of government social transfers meant to compensate the parent for lost earnings due to time spent caring for the disabled child. The panels in the final row show gross earnings, which is the combination of market earnings and transfers. Estimates for these outcome variables based on Equation 2 are given in the first four columns of Table 3.<sup>9</sup>

The earnings of affected mothers are substantially affected, lagging progressively further behind the comparison mothers for the first twelve years after birth. By 12-14 years after birth, in the raw sample they earn about 40,000 DKK less per year from a base of about 300,000 for comparison mothers (13%). Part of this earnings loss is compensated by the government through direct transfers, shown in the panels in the second row. The majority of the earnings loss is compensated in the first few years after birth but by 12-14 years of age, the compensation is only about half of the lost earnings.

The earnings of affected fathers are also reduced but considerably less than those of the mothers (about 10,000 DKK after 12-14 years) and after taking account of the compensating transfers there is no detectable difference in gross earnings between the affected and unaffected fathers.

Figure 4 shows that affected mothers' level of employment is about 2 percentage points lower and fathers also have somewhat lower employment levels. This explains less than one fifth of the earnings drop so a majority of the earnings loss is due to lower earnings conditional on working.<sup>10</sup> Figure 9, which shows heterogeneity by education and previous earnings, shows that the impact is felt across the income and education distribution for mothers but only for those below the median in education or income for fathers. However, a disabled child does reduce both parents ability to climb the ladder to a top position. Figure 5 shows that affected mothers and fathers are both about 20% less likely to become a top executive (mothers from a base of 2-3% and fathers from a base of 7-8%).

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<sup>9</sup>Comparison of regression and nearest-neighbor matching estimates for market earnings and gross earnings for mothers and fathers is shown in Table A.1 in the Appendix.

<sup>10</sup>Government transfers for lost earnings are paid by municipalities and in some municipalities those who are getting transfers to stay with their disabled child are counted as "working", i.e. on the payroll of the municipal government. Therefore, these results on labor force participation may understate somewhat the degree to which affected parents are out of the labor force.

## 3.2 The Financial Shock of the Household

Combining the earnings of both parents, shown in Figure 3 and Columns 5-6 in Table 3, we estimate that market earnings in years 11-15 are 57,000 DKK lower in the affected families. The cumulative earnings loss up to the child's 18th year, evaluated in the 18th year and assuming a 4% interest rate, is about 680,000 DKK (after tax assuming a fixed average tax rate of 38%) or about 108,000 USD. About 2/3 of this loss is compensated through direct payments for loss of earnings.

In addition to lost wages, the costs involved in caring for a disabled child are often many times those of typical, healthy children. In Denmark, these costs are in theory fully reimbursable by the government but we do not have any direct consumption data so we cannot estimate directly the level of additional expenses that are not reimbursed. However, to understand the level of financial shock that might be involved in other contexts we can rely on some evidence from the literature. Dobson and Middleton (1998) report on a detailed study of the costs of caring for a child with disability in the UK and find that necessary expenses are on the order of three times higher for children with disabilities compared to typical healthy children. Based on focus groups and detailed budgeting exercises with over 300 parents of children with disabilities, they estimate that necessary expenses for a healthy child are 3,400 GBP or 34,000 DKK per year, not including direct medical expenses which are, like in Denmark, covered by the national health care system.<sup>11</sup> In contrast, they estimate that these expenses are 12,000 GBP or 120,000 DKK per year for a disabled child. The difference is 86,000 DKK or 13,600 USD per year. Over an 18 year period (using the same 4% interest rate), this additional cost, valued in the 18th year, adds up to 2.4 million DKK or 380 thousand USD.

In total, before the Danish welfare state steps in, we estimate that the total financial shock up to year 18 equals 486,000 USD. If we assume that 80% (90%) of costs are reimbursed and subtract the 2/3rd of lost earnings that are compensated, the financial shock after taxes and transfers amounts to 112 thousand USD (74 thousand USD).

How do families respond to this financial shock? In particular, does this translate into lower consumption in the short run, the long run, or both? To gain insight on this we can look at the trajectory of the accumulation of assets and liabilities for affected and unaffected families, shown in Figure 7 and Column 8 in Table 3. Affected families have less asset accumulation, in particular in the long run. They also accumulate less liabilities over time, and we estimate that net worth in affected families is about the same as the unaffected families after 11-15 years. If the net worth data is winsorized to limit the impact of outliers then we do see that the net worth among affected families is lower in the short run (2-6 years after the birth of the child), but in the long run their net worth is about 50,000 DKK (8,000 USD) higher (Panel D of

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<sup>11</sup>All values are in 2015 prices.

Figure 7). Overall, it appears that net worth is not affected much. The financial shock translates into lower consumption (including in subsequent children) throughout the childhood of the disabled child rather than being deferred to a later date.

### 3.3 Fertility and Partnership Dissolution

In addition to the financial shock, a child's disability can have profound effects on major life decisions in the family. We examine the decision of whether to have more children and whether the couple continues their partnership. Figure 6 and the last two columns of Table 3 present our main findings for these outcome variables. We find that affected families have 0.09 fewer subsequent children, translating to a 9% reduction in subsequent fertility. Figure 9 shows that this effect is considerably stronger among those with higher education and higher previous earnings. The estimates in the last column show that affected families are furthermore more likely to split up. By 11-15 years after the child's birth, affected couples are still partners at a lower rate by 4 percentage points translating to a 12% greater rate of partnership dissolution since 33% of comparison couples have ended their partnership.

The long run earnings trajectory of affected mothers may be shaped not only by caring for the disabled child but possibly also by the lower completed fertility. However, a recent paper by Lundborg, Plug and Rasmussen (2014) using the same registry data from Denmark and using IVF treatment for identification finds that the effect of fertility at the intensive margin (second birth or later) on long run employment earnings of mothers is negligible (their point estimate is small and positive). This would suggest that our estimates of the impact of disabilities on long run employment earnings of mothers would be similar if there were no fertility response to the disability. However, their sample, mothers seeking IVF treatment, may not be representative of women in general.

### 3.4 Heterogeneous Effects by Disability Definition

In Section 1.3 we discussed the various disability definitions that we apply in our analysis, and in Section 2.1 we showed how balanced the various groups are with the unaffected families. We now look at these groups separately to see whether our results are sensitive to our definition of disability. Figure 8 shows event study graphs for key outcome variables for the four disability definitions. We see the largest impact on earnings of mothers in the MDD group, where the child has mental retardation or a persistent developmental delay. This group also has the highest probability of marital dissolution. However, this group is least impacted in terms of father earnings, and subsequent fertility. The SSI group, which we found to be observable equivalent to the unaffected group, has the largest impact on father earnings, and on subsequent fertility. However, the



estimated effects are overall, relatively similar across all groups.

### 3.5 Heterogeneous Effects by Mothers' Characteristics

In Figure 9 we look at the impact on fertility and earnings by mother's level of education, age, and her previous earnings. While all mothers appear to be affected in similar ways, the impact is larger for younger, and less educated mothers, and for mothers' whose previous earnings were below the median.

## 4 Conclusions

Giving birth to a child with a severe disability is one of the largest uninsured (or largely uninsured) financial risks that young families face in many developed countries. A substantial amount of anecdotal evidence suggests that the additional financial cost associated with the care of a child with a severe disability (above the cost of a typical child) is often very high and that the child's disability can also have profound implications for families' decisions, in particular the labor force participation of parents. However, the evidence available in academic literature on the full costs of care of children with severe disabilities has been limited. Better knowledge of the cost associated with child disability is essential in aiding governments and policy makers to design effective social insurance.

In this paper we are able provide an unusually complete picture of the financial impact on families. We use comprehensive Danish registry data to study the impact of, and responses to, having a seriously disabled child. We find that families that have children with a disability have lower market earnings, lower employment rates, less asset accumulation, fewer subsequent children, and higher divorce probabilities. Moreover, the impact on these families is persistent, and the economic impact appears to increase over time. This implies that children with severe disabilities grow up in families with lower income, they are less likely to grow up in households with both their parents, and are less likely to have siblings.

Our results show that the economic impact of having a child with disability is considerable even in Denmark, that with its strong welfare state is able to reduce the shock by about 75%. In many other contexts, such as the United States, families would undoubtedly be left with a much larger shock.

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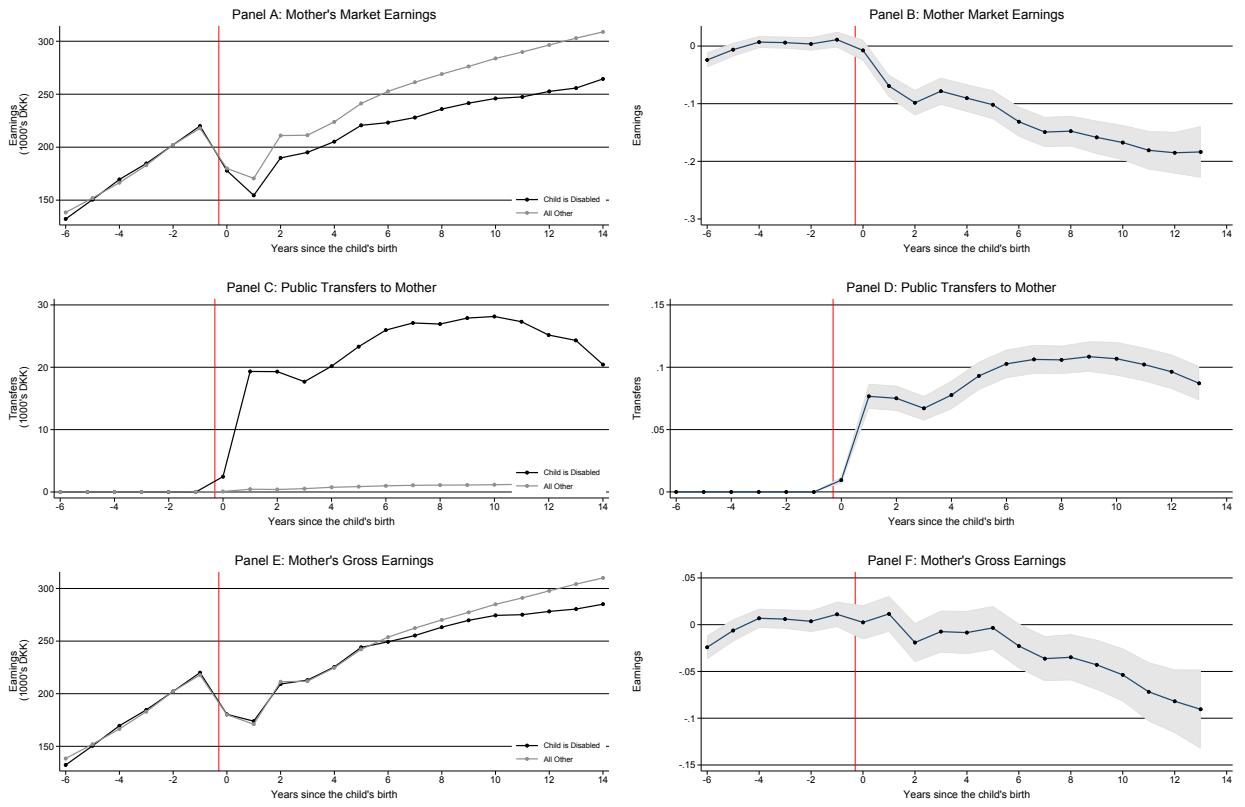


Figure 1: Event study graphs of the impact of childhood disability (COMB Definition; see text) on mothers' earnings.

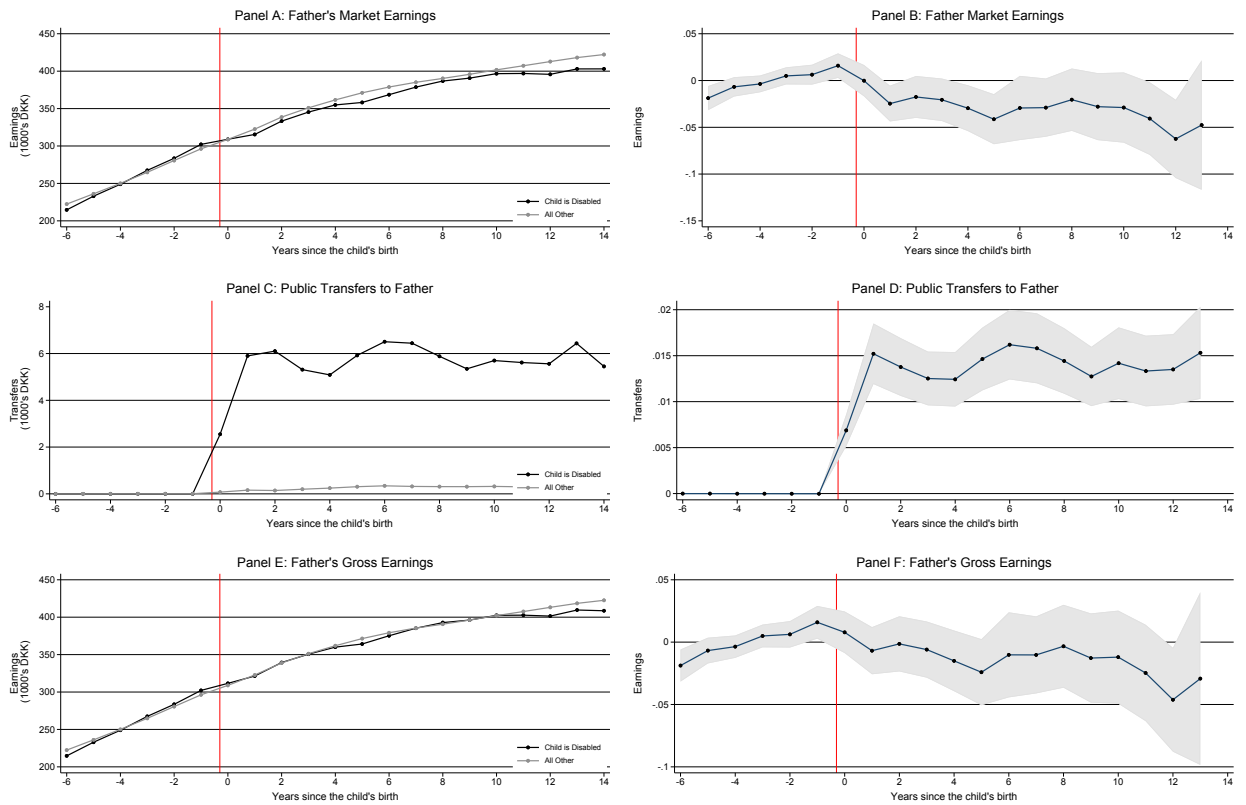


Figure 2: Event study graphs of the impact of childhood disability (COMB Definition; see text) on fathers' earnings.



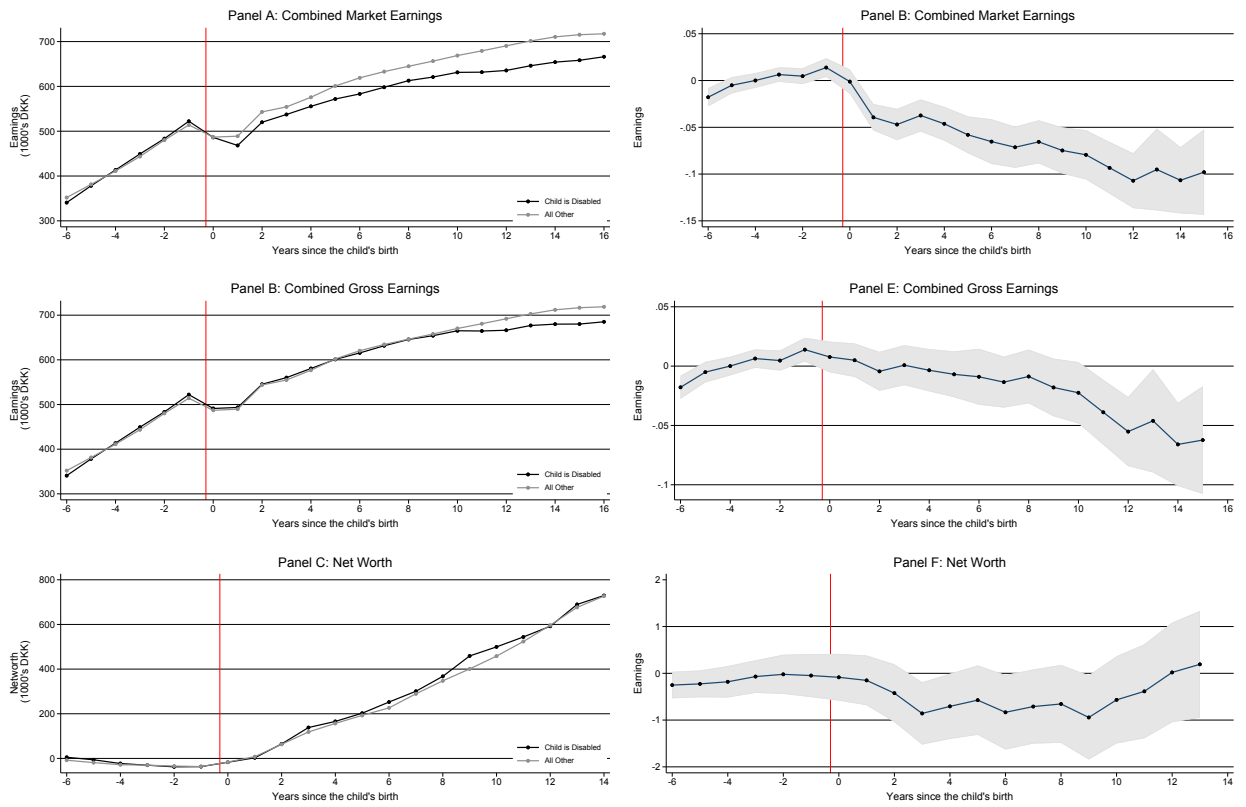


Figure 3: Event study graphs of the impact of childhood disability (COMB Definition; see text) on family earnings.

## Employment Status

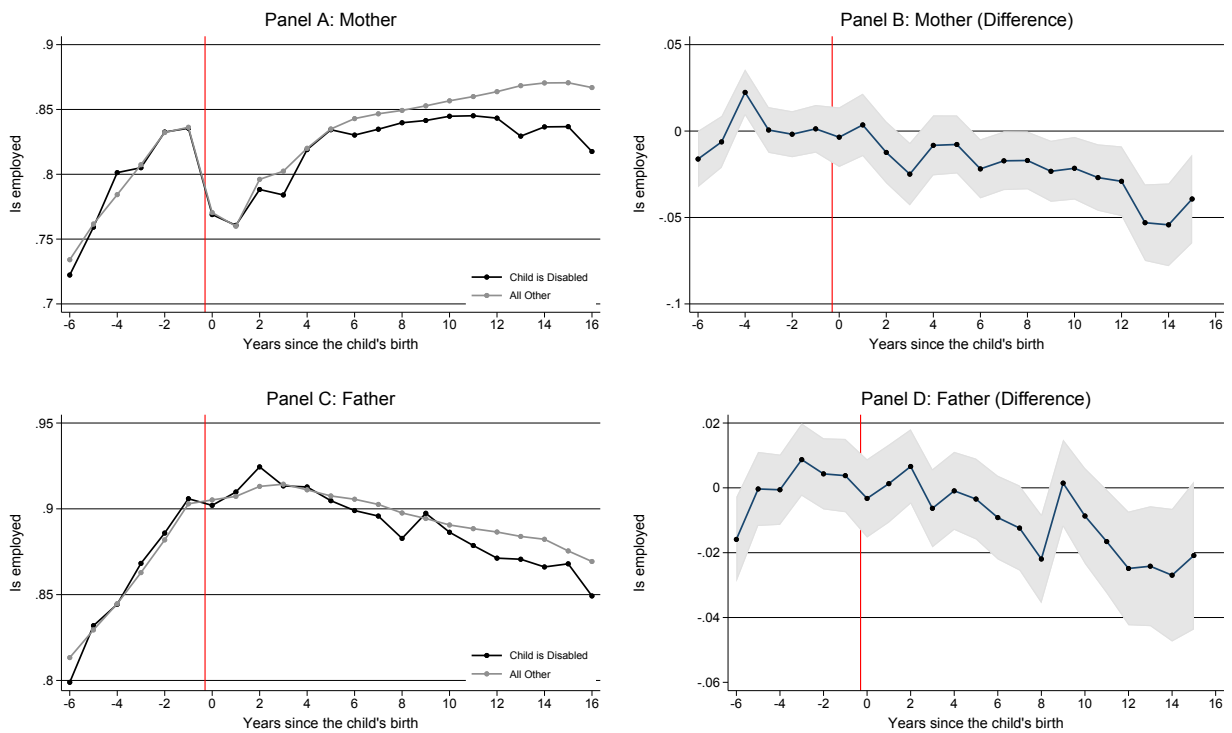


Figure 4: Event study graphs of the impact of childhood disability (COMB Definition; see text) on employment.

## Top Executive

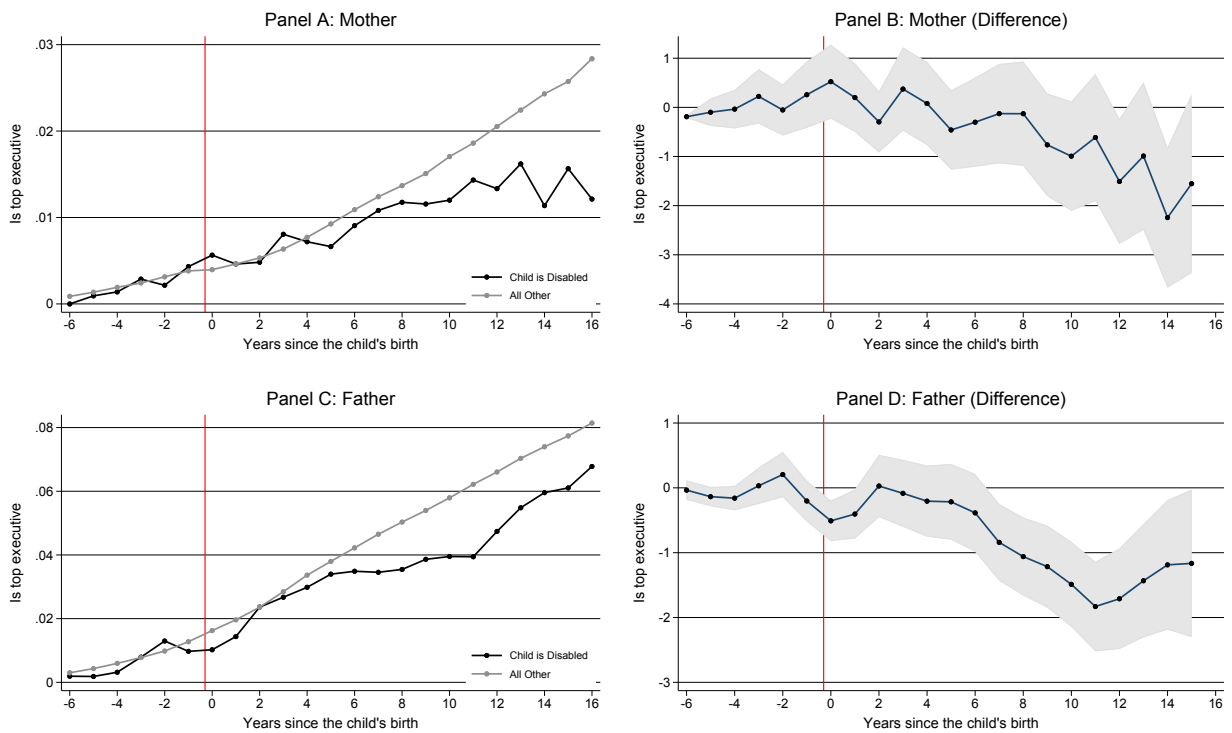


Figure 5: Event study graphs of the impact of childhood disability (COMB Definition; see text) on whether a parent is in a top executive role.

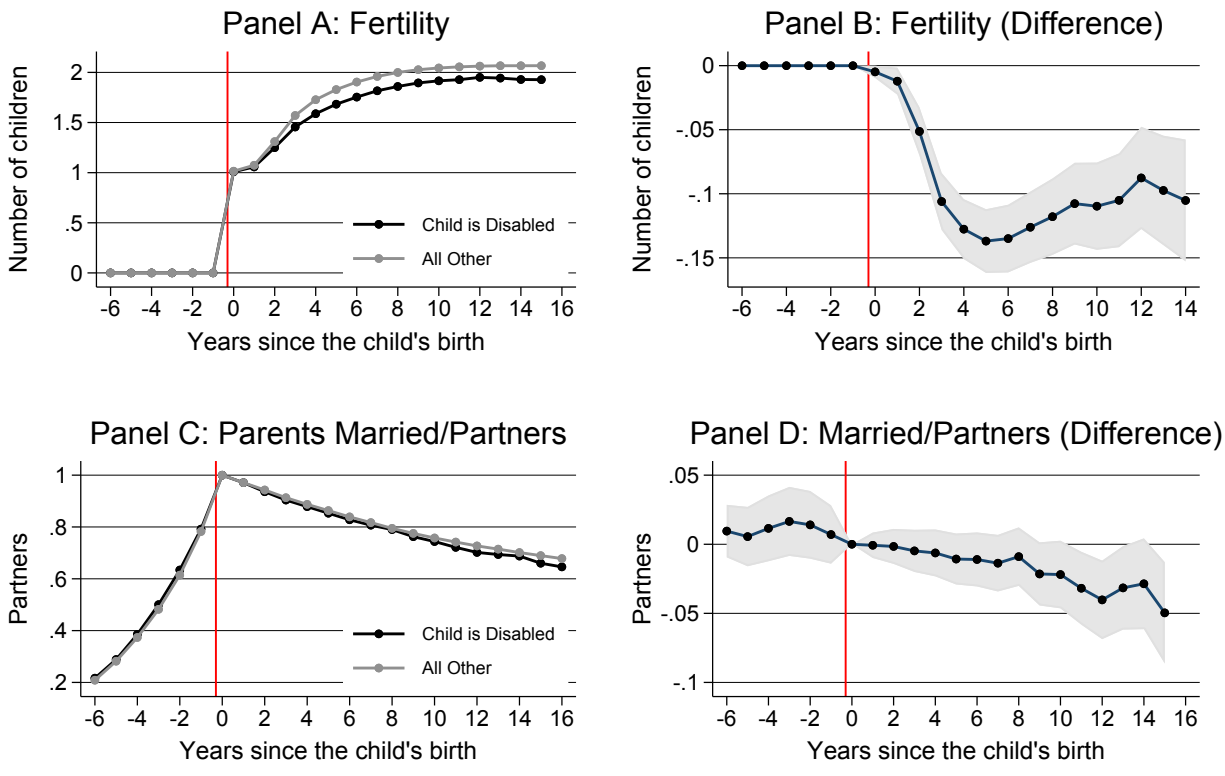


Figure 6: Event study graphs of the impact of childhood disability (COMB Definition; see text) on fertility and partnership dissolution.

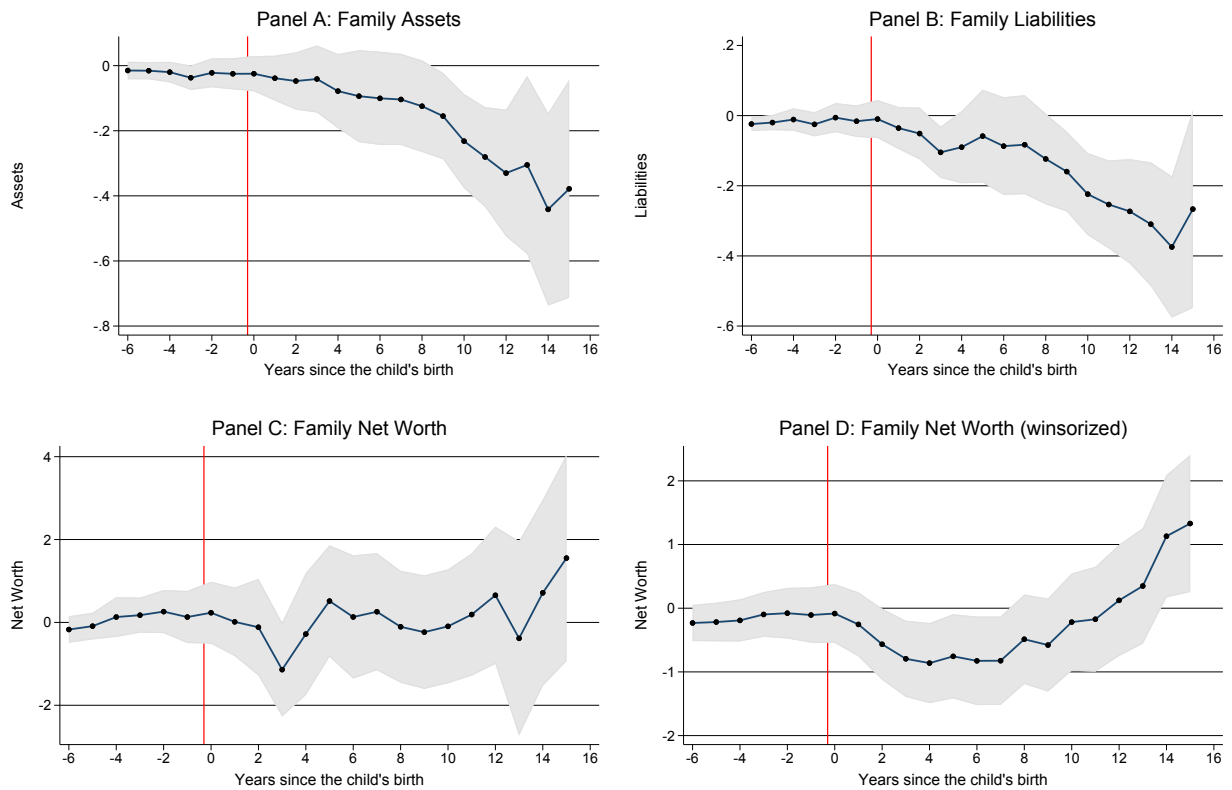


Figure 7: Event study graphs of the impact of childhood disability (COMB Definition; see text) on family outcomes.

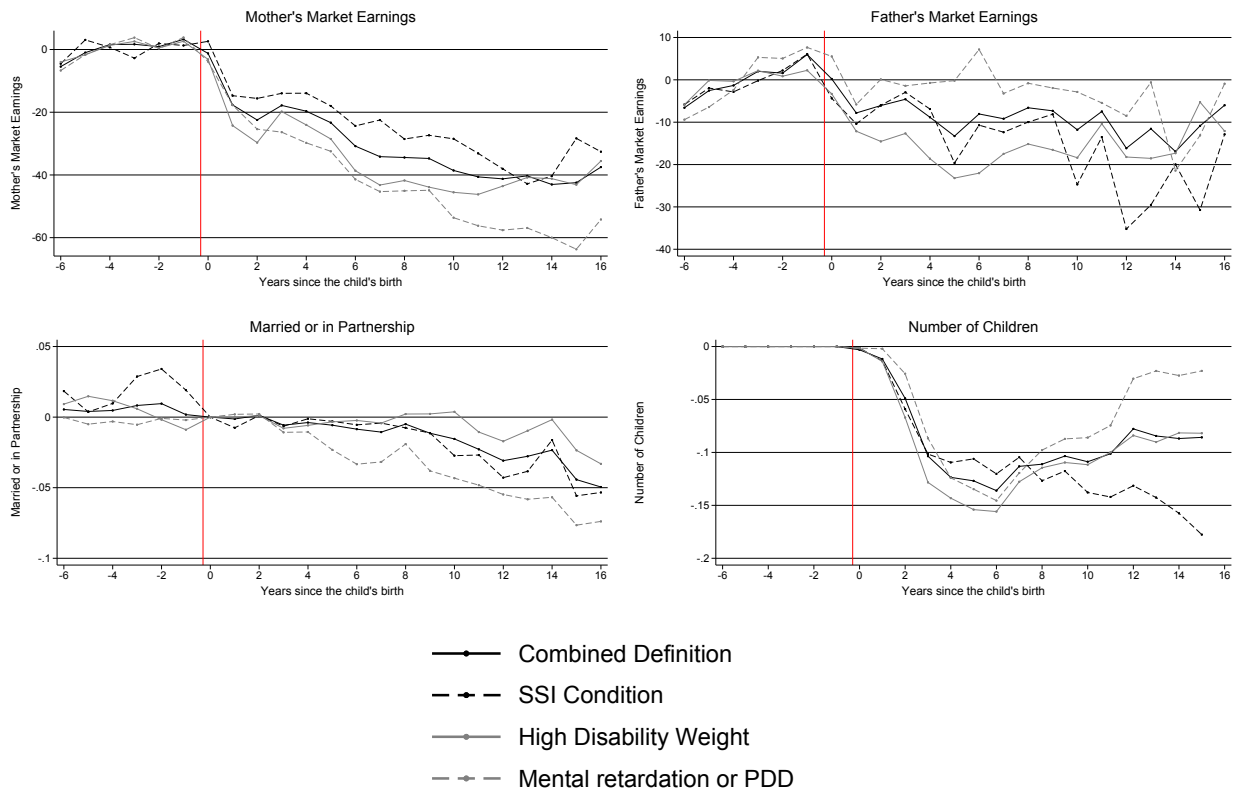


Figure 8: Event study graphs of the impact of childhood disability on family outcomes by four different definitions of disability: (1) Mental retardation or pervasive development delay, (2) cerebral palsy, (3) the SSI definition, and (4) a combined definition of the first three.



Figure 9: Impact of children's disabilities on mother's and father's market earnings and subsequent fertility by education and age.

Table 1: SUMMARY STATISTICS FOR OUTCOME VARIABLES

	Years 1-5			Years 6-10			Years 11-15		
	Mean	(SD)	N	Mean	(SD)	N	Mean	(SD)	N
Mother's gross earnings	216.54	(132.67)	263,259	273.99	(154.51)	261,124	301.68	(177.49)	203,556
Mother's market income	215.80	(132.72)	263,259	272.68	(154.86)	261,124	300.23	(177.94)	203,556
Father's gross earnings	363.90	(211.00)	262,991	409.61	(276.49)	260,217	430.53	(336.69)	202,194
Father's market income	363.66	(211.01)	262,991	409.26	(276.54)	260,217	430.21	(336.76)	202,194
Mother's employment status	0.81	(0.30)	263,979	0.86	(0.28)	263,979	0.87	(0.30)	206,949
Father's employment status	0.92	(0.20)	263,979	0.91	(0.23)	263,979	0.89	(0.27)	206,949
Completed fertility	1.52	(0.38)	263,979	2.05	(0.64)	263,979	2.16	(0.74)	188,670
Married or in partnership	0.92	(0.22)	263,738	0.80	(0.37)	263,738	0.71	(0.44)	206,737
Public transfers (combined for family)	12.76	(45.68)	263,979	14.22	(54.78)	263,979	14.85	(61.58)	206,949
Mother's public transfers for lost earnings	0.73	(8.28)	263,979	1.30	(12.78)	263,979	1.42	(13.89)	206,949
Father's public transfers for lost earnings	0.24	(4.00)	263,979	0.34	(6.03)	263,979	0.30	(6.13)	206,949

Earnings are given in 1000's of Danish Krona's in constant 2015 prices (currently 6 DKK = 1 USD).



Table 2: SUMMARY STATISTICS AND BALANCE

	Raw sample				Matched sample			
	Affected	Unaff.	Mean	Std. Diff.	Affected	Unaff.	Mean	Std. Diff.
Birth year	1998.92	1998.50	1998.50	0.11	1998.92	1998.91	1998.91	0.00
Mothers age	28.58	28.28	28.28	0.08	28.58	28.44	28.44	0.04
Fathers age	30.70	30.36	30.36	0.08	30.70	30.58	30.58	0.03
Mother's education (years)	12.79	13.04	13.04	-0.12	12.79	12.80	12.80	-0.01
Father's education (years)	12.88	13.08	13.08	-0.08	12.88	12.89	12.89	-0.00
<b>Averages over 1-5 years before birth:</b>								
Mother's wages	178.90	185.00	185.00	-0.06	178.90	178.18	178.18	0.01
Father's wages	258.78	265.84	265.84	-0.05	258.78	258.25	258.25	0.00
Mother's employment status	0.78	0.81	0.81	-0.10	0.78	0.80	0.80	-0.05
Father's employment status	0.84	0.87	0.87	-0.11	0.84	0.86	0.86	-0.07
Married or in partnership	0.48	0.48	0.48	-0.01	0.48	0.48	0.48	0.00
N	2,296	261,683	261,683		2,293	11,176	11,176	

This table shows balance between the affected and unaffected families in the analysis sample for the combined definition. Columns 1-2 and 5-6 show means of affected and unaffected families. Columns 3 and 7 report standardized differences between the means and Columns 4 and 8 the associated p-value. Earnings are given in 1000's of Danish Krona's at constant 2011 prices (currently 6 DK = 1 USD).

Table 3: IMPACT OF CHILDHOOD DISABILITY ON WAGES AND EMPLOYMENT.

Independent variable Estimation	Mother's Earnings		Father's Earnings		Combined Earnings		Earnings		Family-level	
	Market	Gross	Market	Gross	Market	Gross	Transfers	Net worth	Fertility	Partnership
<i>Years 1-5</i>										
Disabled Child	-21.65 (2.06)	-2.82 (1.94)	-9.89 (2.98)	-4.90 (2.95)	-26.43 (3.71)	-2.83 (3.63)	34.74 (1.71)	-6.76 (19.48)	-0.08 (0.01)	-0.01 (0.00)
Number of Affected	2,296	2,296	2,294	2,294	2,296	2,296	2,296	2,296	2,296	2,293
Number of Comparisons	260,963	260,963	260,697	260,697	261,683	261,683	261,683	261,683	261,683	261,445
<i>Years 6-10</i>										
Disabled Child	-34.67 (2.65)	-9.16 (2.46)	-9.34 (4.76)	-4.11 (4.75)	-35.85 (5.71)	-5.36 (5.62)	19.95 (1.67)	-32.06 (25.88)	-0.11 (0.01)	-0.02 (0.01)
Number of Affected	2,280	2,280	2,270	2,270	2,296	2,296	2,296	2,296	2,296	2,293
Number of Comparisons	258,844	258,844	257,947	257,947	261,683	261,683	261,683	261,683	261,683	261,445
<i>Years 11-15</i>										
Disabled Child	-39.89 (3.65)	-18.96 (3.47)	-14.39 (6.38)	-9.75 (6.37)	-46.89 (7.53)	-21.74 (7.48)	10.82 (1.91)	-0.12 (30.86)	-0.09 (0.02)	-0.04 (0.01)
Number of Affected	1,774	1,774	1,758	1,758	1,800	1,800	1,800	1,800	1,621	1,797
Number of Comparisons	201,782	201,782	200,436	200,436	205,149	205,149	205,149	205,149	187,049	204,940
Affected Pre-Birth Mean	180.64	180.64	262.89	262.89	437.34	437.34	10.29	-31.34		0.48
Comparison Pre-Birth Mean	187.20	187.20	269.67	269.67	451.76	451.77	7.52	-26.59		0.48
Difference	-6.56	-6.56	-6.77	-6.78	-14.43	-14.43	2.76	-4.76		-0.00
SE (Difference)	2.32	2.32	3.21	3.21	4.64	4.64	0.53	16.29		0.01

This table shows the impact of caring for a child with a disability as defined by the COMB definition (see text) on parents earnings and employment status. Each coefficient in odd columns is obtained from a separate regression that in the top (bottom) panel includes controls for mother's (father's) age, mother's (father's) education, mother's (father's) pre-birth earnings and year of birth. Each coefficient in even columns is the average treatment effect estimated using a nearest neighbor matching algorithm. Families are matched on county, year of birth, parent's age, parent's length of education, parents pre-birth earnings and parents pre-birth relationship status. At the bottom of each panel we report the mean of the outcome for affected and comparison families one to five years before birth. We report robust standard errors (in parenthesis) in the OLS regressions (odd columns) and the standard Abadie-Imbens SE's in the matching estimations (even columns).

## A Appendix Tables and Figures

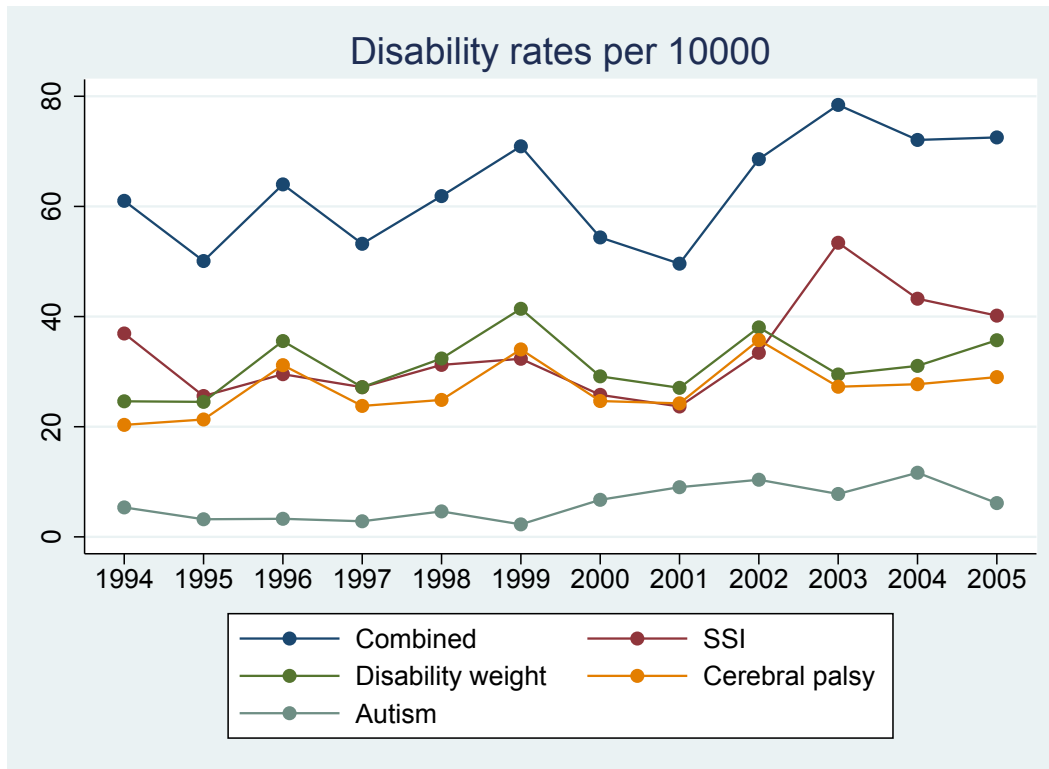


Figure A.1: Rates of disabilities by year. Cerebral palsy and Autism are included in the 'Disability Weight' definition. For this figure only, the 'Combined' definition is the union of the SSI definition and the Disability Weight definition.

Table A.1: IMPACT OF CHILDHOOD DISABILITY ON WAGES AND EMPLOYMENT.

Independent variable Estimation	Market Earnings		Gross Earnings		Employed	
	OLS	NN Match	OLS	NN Match	OLS	NN Match
<u>Panel A: Mothers</u>						
<i>Years 1-5</i>						
Disabled Child	-21.65 (2.06)	-19.56 (2.22)	-2.82 (1.94)	-0.81 (2.11)	-0.01 (0.01)	-0.03 (0.01)
Number of Affected	2,296	2,293	2,296	2,293	2,296	2,293
Number of Comparisons	260,963	11,124	260,963	11,124	261,683	11,122
<i>Years 6-10</i>						
Disabled Child	-34.67 (2.65)	-33.49 (2.86)	-9.16 (2.46)	-8.08 (2.69)	-0.02 (0.01)	-0.03 (0.01)
Number of Affected	2,280	2,277	2,280	2,277	2,296	2,293
Number of Comparisons	258,844	11,045	258,844	11,045	261,683	11,122
<i>Years 11-15</i>						
Disabled Child	-39.89 (3.65)	-37.28 (4.03)	-18.96 (3.47)	-16.53 (3.84)	-0.03 (0.01)	-0.04 (0.01)
Number of Affected	1,774	1,771	1,774	1,771	1,800	1,797
Number of Comparisons	201,782	8,582	201,782	8,582	205,149	8,709
Affected Pre-Birth Mean	180.64	180.88	180.64	180.88	0.78	0.78
Comparison Pre-Birth Mean	187.20	179.44	187.20	179.45	0.81	0.80
Difference	-6.56	1.43	-6.56	1.43	-0.03	-0.01
SE (Difference)	2.32	2.44	2.32	2.44	0.01	0.01
<u>Panel B: Fathers</u>						
<i>Years 1-5</i>						
Disabled Child	-9.89 (2.98)	1.52 (3.34)	-4.90 (2.95)	6.51 (3.32)	-0.00 (0.00)	-0.01 (0.00)
Number of Affected	2,294	2,291	2,294	2,291	2,296	2,293
Number of Comparisons	260,697	11,112	260,697	11,112	261,683	11,122
<i>Years 6-10</i>						
Disabled Child	-9.34 (4.76)	4.12 (5.24)	-4.11 (4.75)	9.25 (5.22)	-0.01 (0.01)	-0.02 (0.01)
Number of Affected	2,270	2,267	2,270	2,267	2,296	2,293
Number of Comparisons	257,947	10,996	257,947	10,996	261,683	11,122
<i>Years 11-15</i>						
Disabled Child	-14.39 (6.38)	-2.07 (7.24)	-9.75 (6.37)	2.58 (7.18)	-0.02 (0.01)	-0.03 (0.01)
Number of Affected	1,758	1,755	1,758	1,755	1,800	1,797
Number of Comparisons	200,436	8,515	200,436	8,515	205,149	8,709
Affected Pre-Birth Mean	262.89	263.06	262.89	263.06	0.84	0.84
Comparison Pre-Birth Mean	269.67	260.90	269.67	260.90	0.87	0.86
Difference	-6.77	2.16	-6.78	2.16	-0.03	-0.02
SE (Difference)	3.21	3.26	3.21	3.26	0.01	0.01

This table shows the impact of caring for a child with a disability as defined by the SSI definition (see text) on parents earnings and employment status. Each coefficient in odd columns is obtained from a separate regression that in the top (bottom) panel includes controls for mother's (father's) age, mother's (father's) education, mother's (father's) pre-birth earnings and year of birth. Each coefficient in even columns is the average treatment effect estimated using a nearest neighbor matching algorithm. Families are matched on county, year of birth, parent's age, parent's length of education, parents pre-birth earnings and parents pre-birth relationship status. At the bottom of each panel we report the mean of the outcome for affected and comparison families one to five years before birth. We report robust standard errors (in parenthesis) in the OLS regressions (odd columns) and the standard Abadie-Imbens SE's in the matching estimations (even columns).

Table A.2: IMPACT OF CHILDHOOD DISABILITY ON COMBINED EARNINGS AND NET WORTH.

Independent variable Estimation	Market Earnings		Gross Earnings		Net Worth	
	OLS	NN Match	OLS	NN Match	OLS	NN Match
<i>Years 1-5</i>						
Disabled Child	-26.43 (3.71)	-17.11 (4.14)	-2.83 (3.63)	6.42 (4.07)	-6.76 (19.48)	37.53 (22.18)
Number of Affected	2,296	2,293	2,296	2,293	2,296	2,293
Number of Comparisons	261,683	11,122	261,683	11,122	261,683	11,116
<i>Years 6-10</i>						
Disabled Child	-35.85 (5.71)	-27.19 (6.24)	-5.36 (5.62)	3.08 (6.15)	-32.06 (25.88)	37.99 (29.89)
Number of Affected	2,296	2,293	2,296	2,293	2,296	2,293
Number of Comparisons	261,683	11,122	261,683	11,122	261,683	11,116
<i>Years 11-15</i>						
Disabled Child	-46.89 (7.53)	-38.14 (8.43)	-21.74 (7.48)	-13.20 (8.35)	-0.12 (30.86)	85.27 (32.78)
Number of Affected	1,800	1,797	1,800	1,797	1,800	1,797
Number of Comparisons	205,149	8,709	205,149	8,709	205,149	8,707
Affected Pre-Birth Mean	437.34	437.75	437.34	437.75	-31.34	-31.40
Comparison Pre-Birth Mean	451.76	435.32	451.77	435.32	-26.59	-37.70
Difference	-14.43	2.43	-14.43	2.43	-4.76	6.30
SE (Difference)	4.64	4.87	4.64	4.87	16.29	11.03

This table shows the impact of caring for a child with a disability as defined by the SSI definition (see text) on parents earnings and employment status. Each coefficient in odd columns is obtained from a separate regression that in the top (bottom) panel includes controls for mother's (father's) age, mother's (father's) education, mother's (father's) pre-birth earnings and year of birth. Each coefficient in even columns is the average treatment effect estimated using a nearest neighbor matching algorithm. Families are matched on county, year of birth, parent's age, parent's length of education, parents pre-birth earnings and parents pre-birth relationship status. At the bottom of each panel we report the mean of the outcome for affected and comparison families one to five years before birth. We report robust standard errors (in parenthesis) in the OLS regressions (odd columns) and the standard Abadie-Imbens SE's in the matching estimations (even columns).

Table A.3: IMPACT OF CHILDHOOD DISABILITY ON COMPLETED FERTILITY AND RELATIONSHIP STATUS.

Independent variable Estimation	Completed Fertility		Married or in Partnership	
	OLS	NN Match	OLS	NN Match
<i>Years 1-5</i>				
Disabled Child	-0.08 (0.01)	-0.08 (0.01)	-0.01 (0.00)	-0.01 (0.01)
Number of Affected	2,296	2,293	2,293	2,293
Number of Comparisons	261,683	11,122	261,445	11,122
<i>Years 6-10</i>				
Disabled Child	-0.11 (0.01)	-0.10 (0.01)	-0.02 (0.01)	-0.01 (0.01)
Number of Affected	2,296	2,293	2,293	2,293
Number of Comparisons	261,683	11,122	261,445	11,122
<i>Years 11-15</i>				
Disabled Child	-0.09 (0.02)	-0.08 (0.02)	-0.04 (0.01)	-0.02 (0.01)
Number of Affected	1,621	1,618	1,797	1,797
Number of Comparisons	187,049	7,840	204,940	8,709
Affected Pre-Birth Mean			0.48	0.48
Comparison Pre-Birth Mean			0.48	0.48
Difference			-0.00	0.00
SE (Difference)			0.01	0.01

This table reports the impact of caring for a child with a disability as defined by the SSI Definition on completed fertility (of the mother) and relationship status. Pre-birth means are empty in the first two columns because pre-birth fertility is zero by construction. Estimation procedures and standard error calculations are identical to Table A.1. Column 1 includes controls for mother's age and education, and the year of birth. Column 3 includes controls for mother's and father's age, year of birth and pre-birth relationship status. Matching variables used in Columns 2 and 4 are identical to those used in Table A.1.

	Raw sample				Matched sample			
	Mean	Unaff.	Std.	p	Mean	Unaff.	Std.	p
	Affected		Diff.		Affected		Diff.	
<b>Mothers education group:</b>								
Elementary education only	0.20	0.15	0.15	0.00	0.20	0.19	0.02	0.36
Regular high-school	0.11	0.11	-0.02	0.30	0.11	0.11	-0.01	0.60
Business high=school	0.04	0.04	-0.03	0.14	0.04	0.04	-0.01	0.55
Vocational training - retail	0.23	0.24	-0.04	0.07	0.23	0.25	-0.06	0.01
Vocational training - other	0.14	0.13	0.02	0.27	0.14	0.13	0.04	0.10
Short higher education	0.05	0.05	0.00	0.93	0.05	0.04	0.04	0.06
Vocational bachelor education - teacher	0.04	0.04	-0.01	0.50	0.04	0.04	-0.01	0.70
Vocational bachelor education - nurse	0.03	0.04	-0.06	0.01	0.03	0.04	-0.04	0.11
Vocational bachelor education - other	0.08	0.08	-0.02	0.45	0.08	0.07	0.02	0.39
Standard bachelor degree	0.02	0.03	-0.09	0.00	0.02	0.03	-0.06	0.02
Master, doctor or professional degree	0.06	0.07	-0.00	0.83	0.06	0.05	0.06	0.01
<b>Fathers education group:</b>								
Elementary education only	0.22	0.17	0.11	0.00	0.22	0.21	0.02	0.35
Regular high-school	0.06	0.07	-0.04	0.09	0.06	0.06	0.02	0.47
Business high=school	0.02	0.03	-0.03	0.22	0.02	0.02	0.01	0.68
Vocational training - retail	0.12	0.13	-0.02	0.27	0.12	0.13	-0.04	0.08
Vocational training - metal work	0.13	0.14	-0.02	0.34	0.13	0.14	-0.04	0.06
Vocational training - construction	0.10	0.09	0.01	0.56	0.10	0.09	0.01	0.61
Vocational training - other	0.07	0.08	-0.04	0.07	0.07	0.08	-0.03	0.22
Short higher education	0.08	0.08	-0.01	0.68	0.08	0.07	0.01	0.77
Vocational bachelor education	0.10	0.10	-0.01	0.81	0.10	0.09	0.02	0.38
Standard bachelor degree	0.02	0.02	0.01	0.79	0.02	0.02	0.03	0.20
Master, doctor or professional degree	0.08	0.09	-0.03	0.20	0.08	0.07	0.02	0.27
N	2,296	261,683			2,293	11,176		

Table A.4: This table shows balance in detailed education categories of parents between the affected and unaffected families for the combined definition.

Table A.5: SUMMARY STATISTICS AND BALANCE

	Raw sample			Matched sample		
	Affected	Unaff.	Std. Diff. p	Affected	Unaff.	Std. Diff. p
Birth year	1999.42	1998.50	0.24 0.00	1999.42	1999.42	0.00 0.97
Mothers age	28.33	28.28	0.01 0.72	28.33	28.24	0.02 0.58
Fathers age	30.52	30.36	0.04 0.30	30.52	30.44	0.02 0.64
Mother's education (years)	12.94	13.04	-0.05 0.23	12.94	12.94	-0.00 0.98
Father's education (years)	13.08	13.07	0.00 0.91	13.08	13.09	-0.00 0.97
<b>Averages over 1-5 years before birth:</b>						
Mother's wages	183.53	184.95	-0.01 0.73	183.53	181.30	0.02 0.62
Father's wages	265.63	265.78	-0.00 0.98	265.63	264.00	0.01 0.80
Mother's employment status	0.81	0.81	-0.00 0.94	0.81	0.82	-0.02 0.64
Father's employment status	0.85	0.87	-0.09 0.02	0.85	0.87	-0.09 0.04
Married or in partnership	0.50	0.48	0.04 0.26	0.50	0.50	0.00 0.97
N	649	263,330		649	3,218	

This table shows balance between the affected and unaffected families in the analysis sample for the SSI definition. Columns 1-2 and 5-6 show means of affected and unaffected families. Columns 3 and 7 report standardized differences between the means and Columns 4 and 8 the associated p-value. Earnings are given in 1000's of Danish Krona's at constant 2011 prices (currently 6 DK = 1 USD).



	Raw sample				Matched sample			
	Mean	Unaff.	Std.	p	Mean	Unaff.	Std.	p
	Affected		Diff.		Affected		Diff.	
<b>Mothers education group:</b>								
Elementary education only	0.16	0.15	0.05	0.21	0.16	0.16	0.01	0.76
Regular high-school	0.11	0.11	-0.02	0.61	0.11	0.12	-0.04	0.30
Business high=school	0.04	0.04	-0.04	0.36	0.04	0.04	-0.00	0.94
Vocational training - retail	0.25	0.24	0.03	0.51	0.25	0.27	-0.04	0.35
Vocational training - other	0.16	0.13	0.07	0.08	0.16	0.13	0.09	0.04
Short higher education	0.04	0.05	-0.04	0.32	0.04	0.04	-0.01	0.86
Vocational bachelor education - teacher	0.04	0.04	-0.01	0.82	0.04	0.04	-0.01	0.83
Vocational bachelor education - nurse	0.04	0.04	-0.04	0.37	0.04	0.04	-0.01	0.79
Vocational bachelor education - other	0.08	0.08	-0.03	0.50	0.08	0.08	0.00	0.98
Standard bachelor degree	0.02	0.03	-0.10	0.02	0.02	0.03	-0.09	0.07
Master, doctor or professional degree	0.07	0.07	0.01	0.73	0.07	0.05	0.07	0.10
<b>Fathers education group:</b>								
Elementary education only	0.19	0.17	0.03	0.40	0.19	0.18	0.01	0.75
Regular high-school	0.07	0.07	-0.02	0.62	0.07	0.06	0.03	0.46
Business high=school	0.03	0.03	0.00	0.98	0.03	0.02	0.05	0.27
Vocational training - retail	0.13	0.13	0.00	0.95	0.13	0.13	-0.01	0.79
Vocational training - metal work	0.12	0.14	-0.03	0.44	0.12	0.15	-0.06	0.15
Vocational training - construction	0.11	0.09	0.04	0.28	0.11	0.10	0.04	0.39
Vocational training - other	0.05	0.08	-0.12	0.01	0.05	0.08	-0.11	0.01
Short higher education	0.08	0.08	0.00	0.91	0.08	0.08	0.00	0.96
Vocational bachelor education	0.11	0.10	0.02	0.52	0.11	0.10	0.02	0.72
Standard bachelor degree	0.03	0.02	0.04	0.34	0.03	0.02	0.05	0.23
Master, doctor or professional degree	0.09	0.09	0.02	0.66	0.09	0.08	0.03	0.43
N	649	263,330			649	3,218		

Table A.6: This table shows balance in detailed education categories of parents between the affected and unaffected families for the SSI definition.

Table A.7: SUMMARY STATISTICS AND BALANCE

	Raw sample				Matched sample					
	Affected	Unaff.	Mean	Std. Diff.	p	Affected	Unaff.	Mean	Std. Diff.	p
Birth year	1998.52	1998.50	1998.50	0.01	0.87	1998.52	1998.53	1998.52	-0.00	0.97
Mothers age	28.74	28.28	28.28	0.12	0.00	28.74	28.61	28.61	0.03	0.30
Fathers age	30.73	30.36	30.36	0.09	0.00	30.73	30.62	30.62	0.03	0.42
Mother's education (years)	12.75	13.04	13.04	-0.13	0.00	12.75	12.79	12.79	-0.01	0.65
Father's education (years)	12.81	13.08	13.08	-0.12	0.00	12.81	12.83	12.83	-0.01	0.80
<b>Averages over 1-5 years before birth:</b>										
Mother's wages	185.87	184.96	184.96	0.01	0.78	185.87	184.84	184.84	0.01	0.77
Father's wages	261.13	265.81	265.81	-0.03	0.29	261.13	260.37	260.37	0.01	0.87
Mother's employment status	0.79	0.81	0.81	-0.06	0.06	0.79	0.81	0.81	-0.05	0.15
Father's employment status	0.85	0.87	0.87	-0.06	0.03	0.85	0.86	0.86	-0.05	0.14
Married or in partnership	0.49	0.48	0.48	0.00	0.95	0.49	0.49	0.49	-0.00	0.89
N	1,074	262,847	262,847			1,072	5,304	5,304		

This table shows balance between the affected and unaffected families in the analysis sample for the disability weight definition. Columns 1-2 and 5-6 show means of affected and unaffected families. Columns 3 and 7 report standardized differences between the means and Columns 4 and 8 the associated p-value. Earnings are given in 1000's of Danish Krona's at constant 2011 prices (currently 6 DK = 1 USD).

	Raw sample				Matched sample			
	Mean	Unaff.	Std.	p	Mean	Unaff.	Std.	p
	Affected		Diff.		Affected		Diff.	
<b>Mothers education group:</b>								
Elementary education only	0.21	0.15	0.16	0.00	0.21	0.20	0.02	0.47
Regular high-school	0.09	0.11	-0.06	0.05	0.09	0.10	-0.01	0.70
Business high=school	0.04	0.04	-0.01	0.66	0.04	0.04	-0.00	0.90
Vocational training - retail	0.23	0.24	-0.03	0.33	0.23	0.26	-0.07	0.05
Vocational training - other	0.14	0.13	0.01	0.78	0.14	0.13	0.02	0.51
Short higher education	0.06	0.05	0.02	0.47	0.06	0.05	0.05	0.11
Vocational bachelor education - teacher	0.04	0.04	0.00	0.95	0.04	0.04	0.01	0.79
Vocational bachelor education - nurse	0.04	0.04	-0.03	0.41	0.04	0.05	-0.04	0.29
Vocational bachelor education - other	0.09	0.08	0.01	0.72	0.09	0.08	0.04	0.17
Standard bachelor degree	0.01	0.03	-0.13	0.00	0.01	0.02	-0.07	0.05
Master, doctor or professional degree	0.05	0.07	-0.05	0.11	0.05	0.05	0.04	0.27
<b>Fathers education group:</b>								
Elementary education only	0.22	0.17	0.11	0.00	0.22	0.21	0.02	0.46
Regular high-school	0.05	0.07	-0.08	0.02	0.05	0.06	-0.01	0.73
Business high=school	0.02	0.03	-0.03	0.34	0.02	0.02	0.02	0.49
Vocational training - retail	0.12	0.13	-0.02	0.59	0.12	0.15	-0.08	0.02
Vocational training - metal work	0.14	0.14	0.01	0.81	0.14	0.15	-0.03	0.31
Vocational training - construction	0.11	0.09	0.05	0.08	0.11	0.10	0.03	0.34
Vocational training - other	0.08	0.08	-0.01	0.83	0.08	0.08	-0.00	0.91
Short higher education	0.08	0.08	0.00	0.98	0.08	0.07	0.03	0.34
Vocational bachelor education	0.08	0.10	-0.05	0.09	0.08	0.08	0.00	0.96
Standard bachelor degree	0.02	0.02	0.00	0.98	0.02	0.02	0.04	0.20
Master, doctor or professional degree	0.07	0.09	-0.06	0.04	0.07	0.07	0.02	0.55
N	1,074	262,847			1,072	5,304		

Table A.8: This table shows balance in detailed education categories of parents between the affected and unaffected families for the disability weight definition.

Table A.9: SUMMARY STATISTICS AND BALANCE

	Raw sample				Matched sample					
	Affected	Unaff.	Mean	Std. Diff.	p	Affected	Unaff.	Mean	Std. Diff.	p
Birth year	1999.13	1998.50	1998.50	0.17	0.00	1999.13	1999.12	1999.12	0.00	0.96
Mothers age	28.61	28.28	28.28	0.09	0.01	28.61	28.45	28.45	0.04	0.26
Fathers age	30.83	30.36	30.36	0.11	0.00	30.83	30.68	30.68	0.04	0.32
Mother's education (years)	12.72	13.04	13.04	-0.15	0.00	12.72	12.72	12.72	-0.00	0.98
Father's education (years)	12.76	13.08	13.08	-0.14	0.00	12.76	12.75	12.75	0.00	0.97
<b>Averages over 1-5 years before birth:</b>										
Mother's wages	163.90	185.02	185.02	-0.19	0.00	163.90	164.91	164.91	-0.01	0.80
Father's wages	248.43	265.84	265.84	-0.12	0.00	248.43	249.29	249.29	-0.01	0.87
Mother's employment status	0.75	0.81	0.81	-0.22	0.00	0.75	0.76	0.76	-0.06	0.10
Father's employment status	0.83	0.87	0.87	-0.16	0.00	0.83	0.84	0.84	-0.05	0.20
Married or in partnership	0.46	0.48	0.48	-0.06	0.07	0.46	0.46	0.46	0.00	0.98
N	862	263,117	263,117			861	4,255	4,255		

This table shows balance between the affected and unaffected families in the analysis sample for the mental disabilities definition. Columns 1-2 and 5-6 show means of affected and unaffected families. Columns 3 and 7 report standardized differences between the means and Columns 4 and 8 the associated p-value. Earnings are given in 1000's of Danish Krona's at constant 2011 prices (currently 6 DK = 1 USD).

	Raw sample				Matched sample			
	Mean	Unaff.	Std.	p	Mean	Unaff.	Std.	p
	Affected		Diff.		Affected		Diff.	
<b>Mothers education group:</b>								
Elementary education only	0.22	0.15	0.20	0.00	0.22	0.22	0.01	0.74
Regular high-school	0.11	0.11	0.01	0.84	0.11	0.12	-0.01	0.72
Business high=school	0.04	0.04	-0.03	0.42	0.04	0.04	0.00	0.92
Vocational training - retail	0.20	0.24	-0.11	0.00	0.20	0.22	-0.06	0.11
Vocational training - other	0.14	0.13	0.01	0.68	0.14	0.13	0.03	0.39
Short higher education	0.05	0.05	-0.01	0.68	0.05	0.04	0.05	0.17
Vocational bachelor education - teacher	0.03	0.04	-0.04	0.22	0.03	0.04	-0.04	0.33
Vocational bachelor education - nurse	0.03	0.04	-0.10	0.01	0.03	0.04	-0.06	0.15
Vocational bachelor education - other	0.08	0.08	-0.01	0.73	0.08	0.07	0.03	0.49
Standard bachelor degree	0.03	0.03	-0.03	0.37	0.03	0.03	-0.03	0.45
Master, doctor or professional degree	0.07	0.07	0.03	0.40	0.07	0.06	0.07	0.04
<b>Fathers education group:</b>								
Elementary education only	0.24	0.17	0.18	0.00	0.25	0.23	0.03	0.44
Regular high-school	0.08	0.07	0.02	0.64	0.08	0.07	0.03	0.46
Business high=school	0.02	0.03	-0.05	0.15	0.02	0.03	-0.04	0.36
Vocational training - retail	0.11	0.13	-0.06	0.09	0.11	0.12	-0.05	0.20
Vocational training - metal work	0.11	0.14	-0.06	0.08	0.11	0.13	-0.06	0.13
Vocational training - construction	0.08	0.09	-0.03	0.35	0.08	0.08	0.00	0.91
Vocational training - other	0.07	0.08	-0.04	0.32	0.07	0.08	-0.02	0.58
Short higher education	0.08	0.08	-0.01	0.70	0.08	0.07	0.01	0.71
Vocational bachelor education	0.11	0.10	0.03	0.33	0.11	0.09	0.06	0.11
Standard bachelor degree	0.02	0.02	-0.01	0.78	0.02	0.02	-0.01	0.86
Master, doctor or professional degree	0.08	0.09	-0.05	0.16	0.08	0.07	0.02	0.64
N	862	263,117			861	4,255		

Table A.10: This table shows balance in detailed education categories of parents between the affected and unaffected families for the mental disabilities definition.

## B Details on the Definition of Disability

### B.1 Disability Weight Definition

We included the diseases in the disability weight definition using the following decisions:

**Autism:** We included autism based on disability weights of 0.262 from Salomon et al. (2015), 0.259 from Salomon et al. (2012), and 0.55 from Stouthard et al. (1997).<sup>12</sup>

**Bilateral Renal Agenesis :** We included bilateral renal agenesis based on a disability weight of 0.85 from World Health Organization (2008).

**Blindness:** We included blindness based on a disability weight of 0.187 from Salomon et al. (2015), 0.195 from Salomon et al. (2012), 0.43 from World Health Organization (2008), 0.43 from Stouthard (2000), and 0.43 from Stouthard et al. (1997).

**Cerebral palsy:** We included cerebral palsy based on a disability weight of 0.436 from Bink (2008).

**Deafness:** We included deafness based on a disability weight of 0.215 from Salomon et al. (2015), 0.033 from Salomon et al. (2012), 0.229 from World Health Organization (2008), 0.37 from Stouthard (2000), and 0.23 from Stouthard et al. (1997).

**Down Syndrome:** We included down syndrome based on a disability weight of 0.187 from Salomon et al. (2015), 0.195 from Salomon et al. (2012), 0.43 from World Health Organization (2008), 0.43 from Stouthard (2000), and 0.43 from Stouthard et al. (1997).

Despite Down Syndrome meeting the criteria for being included with this group of diseases, we were forced to exclude it because of high levels of selective abortions conducted in Denmark. This is partly a result of the implementation of Down Syndrome Screening, which has greatly raised the number of elective abortions Ekelund et al. (2008). Since then, numbers of children born with down syndrome has gradually fallen. Since 2004 when a nuchal scan was offered to all pregnant women in Denmark, 98 percent of them who were carrying an unborn baby with Down Syndrome had an abortion.

**Encephalopathy :** We included encephalopathy based on a disability weight of 0.452 from World Health Organization (2008).

**Intellectual Disability:** We included intellectual disability based on a disability weight of 0.215 from Salomon et al. (2015), 0.033 from Salomon et al. (2012), 0.229 from World Health Organization (2008), 0.37 from Stouthard (2000), and 0.77 from Stouthard et al. (1997).

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<sup>12</sup>Note: All numbers we report from Stouthard et al. (1997) are given as 1 - the number given in the report to standardize versus the other reports (This report specifies 1.00 for full capacity while the other reports use 0.00).

**Schizophrenia** : We included Schizophrenia based on a disability weight of 0.187 from Salomon et al. (2015), 0.195 from Salomon et al. (2012), 0.43 from World Health Organization (2008), 0.43 from Stouthard (2000), and 0.43 from Stouthard et al. (1997).

**Spina Bifida** : Spina Bifida fits the definition based on a disability weight of 0.593 from World Health Organization (2008), 0.65 to 0.8 from Stouthard (2000), and 0.68 from Stouthard et al. (1997) but was ultimately excluded due to the possibility of detection in-utero and resulting selection bias.

## B.2 Mental retardation and pervasive development delay

## B.3 SSI Definition and Prenatal Testing Availability

The SSI definition is based on the list of compassionate allowances that confer automatic eligibility for US Social Security Supplemental Security Income. The list can be accessed at <https://www.ssa.gov/compassionateallowances/conditions>. We used the January 2016 version.

The following diseases were excluded in our SSI list because of the existence of a technical pre-natal test during the study period (1994-2000) that could lead to pregnancy termination.

**Gaucher Disease** : The gene for Goucher disease has been identified, and as a result heterozygote testing screening is available to prenatally determine whether a fetus has Goucher disease Kronn, Jansen and Ostrer (1998)

**Glutaric Acidemia** : Amniocentesis can be used to determine whether there are elevated levels of glutaric acid in the amniotic fluid, showing that the fetus has Glutaric Acidemia. Goodman et al. (1980).

**Infantile Free Sialic Acid Storage Disease**: Amniocentesis can be used prenatally to determine that the fetus has Free Sialic Acid Storage Disease by measuring whether there are elevated levels of free salic acid in the amniotic fluid. Vamos et al. (1986).

**Infantile Neuronal Ceroid-Lipofuscinoses**: Chorionic Villus Sampling can be used to determine whether unit-membrane bound inclusions typical of Infantile Neuronal Ceroid-Lipofuscinoses were in the endothelial cells, which shows that the fetus has Neuronal Ceroid-Lipofuscinoses Rapola et al. (1990).

**Menkes Disease**: DNA analysis can be used to make a prenatal diagnosis of Menkes Disease during the first trimester of pregnancy Tümer et al. (1994).

**Hurler Syndrome:** Hurler syndrome can be diagnosed prenatally through use of an assay of glycosaminoglycans of the amniotic liquor Crawford et al. (1973).

**Rhizomelic Chondrodysplasia Punctata :** An ultrasound can be used to prenatally diagnose Rhizomelic Chondrodysplasia Punctata during the second trimester of pregnancy Sastrowijoto et al. (1994).

**Smith Lemli Opitz Syndrome:** Smith Lemli Opitz Syndrome can be determined prenatally by congenital determined by ultrasound, or by amniocentesis Ryan et al. (1998).

**Tay-Sachs :** Tay-Sachs has widespread availability of pre-natal testing. This testing has been available since as early as 1970, and discussions about possible abortions as a result of this test have been around since 1980s Schneck et al. (1970).

Table B.1 lists the conditions in our definition except that all cancers are excluded.

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Acute Leukemia	Liver Cancer
Adrenal Cancer	Lowe Syndrome
Adult Non-Hodgkin Lymphoma	Lymphomatoid Granulomatosis–Grade III
Adult Onset Huntington Disease	Malignant Brain Stem Gliomas–Childhood
Aicardi-Goutieres Syndrome	Malignant Ectomesenchymoma
Alexander Disease (ALX) - Neonatal and Infantile	Malignant Gastrointestinal Stromal Tumor
Allan-Herndon-Dudley Syndrome	Malignant Germ Cell Tumor
Alobar Holoprosencephaly	Malignant Melanoma – with metastases
Alpers Disease	Malignant Multiple Sclerosis
Alpha Mannosidosis - Type II and III	Malignant Renal Rhabdoid Tumor
Alstrom Syndrome	Mantle Cell Lymphoma (MCL)
Alveolar Soft Part Sarcoma	Maple Syrup Urine Disease
Amegakaryocytic Thrombocytopenia	Marshall-Smith Syndrome
Amyotrophic Lateral Sclerosis (ALS)	Mastocytosis–Type IV
Anaplastic Adrenal Cancer	MECP2 Duplication Syndrome
Angelman Syndrome	Medulloblastoma
Angiosarcoma	Menkes Disease
Aortic Atresia	Merkel Cell Carcinoma – with metastases
Aplastic Anemia	Merosin Deficient Congenital Muscular Dystrophy
Astrocytoma - Grade III and IV	Metachromatic Leukodystrophy



Ataxia Telangiectasia	Mitral Valve Atresia
Atypical Teratoid/Rhabdoid Tumor	Mixed Dementia
Batten Disease	Hurler Syndrome
Beta Thalassemia Major	Hunter Syndrome
Bilateral Optic Atrophy- Infantile	Sanfilippo Syndrome
Bilateral Retinoblastoma	Mucosal Melanoma
Bladder Cancer	Multicentric Castleman Disease
Breast Cancer	Multiple System Atrophy
Canavan Disease	Myoclonic Epilepsy with Ragged Red Fibers Syndrome
Carcinoma of Unknown Primary Site	Neonatal Adrenoleukodystrophy
Caudal Regression Syndrome- Types III and IV	Nephrogenic Systemic Fibrosis
Cerebro Oculo Facio Skeletal (COFS) Syndrome	Neurodegeneration with Brain Iron Accumulation- Typ
Cerebrotendinous Xanthomatosis	NFU-1 Mitochondrial Disease
Child Neuroblastoma	Niemann-pick Disease (NPD) - Type A
Child Non-Hodgkin Lymphoma	Niemann-Pick Type C
Child Lymphoblastic Lymphoma	Nonketotic Hyperglycinemia
Chondrosarcoma—with multimodal therapy	Non-Small Cell Lung Cancer
Chronic Idiopathic Intestinal Pseudo Obstruction	Obliterative Bronchiolitis
Chronic Myelogenous Leukemia (CML) - Blast Phase	Ohtahara Syndrome
Coffin-Lowry Syndrome	Oligodendroglioma Brain Cancer - Grade III
Congenital Lymphedema	Ornithine Transcarbamylase (OTC) Deficiency
Cornelia de Lange Syndrome	Orthochromatic Leukodystrophy with Pigmented Glia
Corticobasal Degeneration	Osteogenesis Imperfecta (OI) - Type II
Creutzfeldt-Jakob Disease (CJD)	Osteosarcoma
Cri du Chat Syndrome	Ovarian Cancer
Degos Disease	Pancreatic Cancer
De Sanctis Cacchione Syndrome	Pallister-Killian Syndrome
Dravet Syndrome	Paraneoplastic Pemphigus
Early-Onset Alzheimer's Disease	Patau Syndrome (Trisomy 13)
Edwards Syndrome	Pearson Syndrome
Eisenmenger Syndrome	Pelizaeus-Merzbacher Disease—Classic Form
Endometrial Stromal Sarcoma	Pelizaeus-Merzbacher Disease—Connatal Form

Endomyocardial Fibrosis	Peripheral Nerve Cancer – metastatic or recurrent
Ependyoblastoma (Child Brain Cancer)	Peritoneal Mesothelioma
Erdheim Chester Disease	Peritoneal Mucinous Carcinomatosis
Esophageal Cancer	Perry Syndrome
Esthesioneuroblastoma	Phelan-Mcdermid Syndrome
Ewing Sarcoma	Pleural Mesothelioma
Farber’s Disease	Pompe Disease - Infantile
Fatal Familial Insomnia	Cardiac Amyloidosis- AL Type
Fibrodysplasia Ossificans Progressiva	Primary Central Nervous System Lymphoma
Follicular Dendritic Cell Sarcoma– metastatic or recurrent	Primary Effusion Lymphoma
Friedreich’s Ataxia	Primary Progressive Aphasia
Frontotemporal Dementia (FTD), Pick’s Disease -Type A	Progressive Bulbar Palsy
Fryns Syndrome	Progressive Multifocal Leukoencephalopathy
Fucosidosis–Type I	Progressive Supranuclear Palsy
Fukuyama Congenital Muscular Dystrophy	Prostate Cancer - Hormone Refractory Disease – or with
Fulminant Giant Cell Myocarditis	Pulmonary Atresia
Galactosialidosis–Early and Late Infantile Types	Pulmonary Kaposi Sarcoma
Gallbladder Cancer	Retinopathy of Prematurity- Stage V
Gaucher Disease (GD) - Type 2	Rett (RTT) Syndrome
Giant Axonal Neuropathy	Revesz Syndrome
Glioblastoma Multiforme (Brain Cancer)	Rhabdomyosarcoma
Glioma - Grade III and IV	Rhizomelic Chondrodysplasia Punctata
Glutaric Acidemia	Roberts Syndrome
Head and Neck Cancers	Salivary Cancers
Heart Transplant Graft Failure	Sandhoff Disease
Heart Transplant Wait List 1A/1B	Schindler Disease–Type I
Hemophagocytic Lymphohistiocytosis	Seckel Syndrome
Hepatoblastoma	Severe Combined Immunodeficiency – Childhood
Hepatopulmonary Syndrome	Single Ventricle
Hepatorenal Syndrome	Sjogren-Larsson Syndrome
Histiocytosis Syndromes	Sinonasal Cancer
Hoyeraal-Hreidarsson Syndrome	Small Cell Cancer

Hutchinson-Gilford Progeria Syndrome	Small Cell Lung Cancer
Hydranencephaly	Small Intestine Cancer
Hypocomplementemic Urticarial Vasculitis Syndrome	Smith Lemli Opitz Syndrome
Hypophosphatasia–Perinatal (Lethal) and Infantile Onset Types	Soft Tissue Sarcoma - with Distant Metastases or Recu
Hypoplastic Left Heart Syndrome	Spinal Muscular Atrophy (SMA) - Types 0 and 1
I Cell Disease	Spinal Nerve Root Cancer – metastatic or recurrent
Idiopathic Pulmonary Fibrosis	Spinocerebellar Ataxia
Intracranial Hemangiopericytoma	Stiff Person Syndrome
Infantile Free Sialic Acid Storage Disease	Stomach Cancer
Infantile Neuroaxonal Dystrophy (INAD)	Subacute Sclerosing Panencephalitis
Infantile Neuronal Ceroid-Lipofuscinoses	Tabes Dorsalis
Inflammatory Breast Cancer	Tay Sachs Disease, Infantile Type
Jervell and Lange-Nielsen Syndrome	Thanatophoric Dysplasia, Type 1
Joubert Syndrome	The ALS Parkinsonism Dementia Complex
Junctional Epidermolysis Bullosa Lethal Type	Thyroid Cancer
Juvenile Onset Huntington Disease	Transplant Coronary Artery Vasculopathy
Kidney Cancer	Tricuspid Atresia
Krabbe Disease (KD) - Infantile	Ullrich Congenital Muscular Dystrophy
Kufs Disease–Type A and B	Ureter Cancer
Large Intestine Cancer	Usher Syndrome- Type I
Late Infantile Neuronal Ceroid-Lipofuscinoses	Ventricular Assist Device Recipient — Left, Right, or E
Leigh’s Disease	Walker Warburg Syndrome
Leiomyosarcoma	Wolf-Hirschhorn Syndrome
Leptomeningeal Carcinomatosis	Wolman Disease
Lesch-Nyhan Syndrome (LNS)	X-Linked Lymphoproliferative Disease
Lewy Body Dementia	X-Linked Myotubular Myopathy
Liposarcoma	Xeroderma Pigmentosum
Lissencephaly	Zellweger Syndrome

Table B.1: List of Social Security Compassionate Allowance Conditions