The Life Course of Fragile Families: the disability of a child as a shaping factor of parents' family and fertility behaviors.

Nicoletta Balbo[1], Danilo Bolano[1], Øystein Kravdal[2] and Jonathan Wörn[3]

1 Bocconi University – Dondena Center Milan (IT)
2 University of Oslo – Department of Economics (NO)
3 Norwegian Institute of Public Health (NO)

Presenting Author: Danilo Bolano danilo.bolano@unibocconi.it

Abstract Prepared for EPC2024 Meeting

Short Abstract

This paper investigates the effects of child disability on parent's life course by using Norwegian register data comparing family life course of parents with and without a disabled child. Within the group of parents with a disabled child, we distinguish those who have a likely expected case of disability in their newborn (Down syndrome) from those who have an unexpected child disability (cerebral palsy). We might find more disruptive events for parents with a disabled child (higher union instability), but also higher immobility (lower fertility) in the life course of parents with an unplanned disabled child. Preliminary findings on the likelihood of divorce and of having another child show the highest risk of divorce and the lowest fertility for parents with children having cerebral palsy, who unexpectedly had to face such a traumatic experience. Parents with children having Down syndrome seem to be less vulnerable and the most likely to have additional child.

Introduction and theoretical framework

Disability not only impacts the lives of those who are directly affected, but it also has important spillover effects on family members. While most of the studies focus on disability among older adults and relative care (Arora and Wolf 2014; Pinquart and Soresnsen 2003; Schulz and Sherwood 2008), this study shifts the attention to an understudied shaping factor of parents' life, namely child disability. This study aims to analyze the effects of child disability on parental life course trajectories – for now with a specific focus on fertility and union dissolution dynamics -- by exploiting a population approach using population register data from Norway.

Having a child with a disability affects the lives of their parents in many ways. Existing literature, which is rather scattered, has provided some suggestive evidence that child disability may impact parental life course outcomes, although with conflicting findings. Some studies have shown that a child's disability is associated with a higher frailty, e.g., a higher risk of divorce for parents due to lower satisfaction with family life and higher stress (Hogan et al. 2012; Mauldon 1992; Loft 2011), whereas others provide the opposite evidence because of higher costs of marital dissolution, stronger bonds of affection, feeling of guilt, and ability to adjust (Risdal and Singer 2004; Urban and Hodapp 2007). Similar mixed findings can be found for fertility: there is evidence for both higher (Burke et al. 2011) or lower (MacInnes 2008, Loft 2022) fertility for such parents compared to their counterparts without a disabled child. Higher fertility has been explained by the need to provide a sibling as a future caregiver (Hogan et al. 2012), whereas lower fertility might be driven by the uncertainty about the future, and by the decision to devote all parental resources, material and time-related, to the disabled child (Loft 2011). Besides some exceptions (Hogan et al. 2012), most of these studies rely on data from small convenience samples, often focusing on one specific type of child disability only. Therefore, they rarely have sufficient data to consider important heterogeneous effects, as well as confounding factors. All this makes any generalizations about the population level unfeasible, and can partially explain the existing conflicting findings.

By using a population approach, leveraging rich register data of the entire Norwegian population, we contribute to the existing literature by offering a comprehensive and sound analysis of the spillover effects of child disability on parents' life course trajectories, distinguishing by type of disability. Specifically, we focus on two types of child disability, namely, cerebral palsy (CP) and Down syndrome (DS). Our decision to study these two specific diseases is motivated by several reasons: i) by their relatively higher prevalence (2.1 for CP and 1.3 for DS every 1,000 newborns in Norway) compared to other child disabilities (e.g., rare genetic diseases); ii) by the timing of these conditions. Both are congenital diseases (besides very few exceptions for CP), which means that both disabilities affect children - and their parents - from birth. Other types of disability might have their onset later (e.g., cancer) in the life course of the children likely shaping in a different way the life trajectories of family members; iii) by their different epidemiological characteristics. Specifically, CP is undetectable before birth, whereas DS can be diagnosed before childbearing through prenatal screenings,

that now are widely used, and that were introduced in Norway in 1983 (Berg 1997). We leverage this difference in the presence of the prenatal diagnosis -- that in the case of DS may lead parents to choose to abort their pregnancy upon learning of their child's health status – to study the effect that selection may have on parents' life course outcomes. By therefore comparing life course outcomes (i.e., divorce and fertility) of parents who had a healthy (i.e. the "more normative group"), DS, or CP child, we can better uncover the effect of unpredictable and undetectable child disability on parents' lives, while also estimating the selection effects.

Two competing hypotheses are postulated: on the one hand, we might expect to find higher levels of instability and more disruptive events for parents with a disabled child, in line with the Pattern of Disadvantage Paradigm. Conversely, we might instead find a higher level of immobility in the life course trajectories of parents with a disabled child, assuming a sort of "disability trap" similar to the poverty trap. We are testing such hypotheses by focusing on the likelihood of two key life events: divorce, as a disruptive event, and on the probability of having subsequent children, considering lower fertility a sign of higher immobility. We expect to find a higher risk of divorce and lower fertility for the group of parents who had a child with CP, who had to face a totally unexpected and traumatic life-changing event. Conversely, being parents of a child with DS likely selected, both in terms of religious values and/or higher emotional, educational, and economic resources, we envision finding them more resilient in terms of partner stability and more likely to have other children. In further analyses, we plan to study in a more comprehensive way family life course trajectories considering marital status and childbearing as intertwining dynamics (e.g., the chance of re-partnering and having an additional child with another partner).

We will furthermore investigate the heterogeneity of such differences by parents' gender, socio-economic status, cohort, migration status, and place of residence. Even in a country with a strong and supportive welfare system like Norway, we expect to find mothers of disabled children being more likely to follow unstable working pathways, and families from a low SES background or with a migration background having more difficulties in following "standard" life trajectories.

Data and Methods

Data

We draw data from the Norwegian Population Register, Employment Register, and Health Care Register. All persons who ever lived in Norway are included in Population Register with a unique identifier (NIP). The NIPs allow both to link across administrative registers and to link individuals belonging to the same household (mothers and children, partners, siblings, and so on). Marital status information is available from 1975 and allows distinguishing between the following statuses: i) single; ii) married (together with the NIP of the partner; iii) separated or divorced; iv) widow; v) in a registered partnership. Information on cohabitation is instead available only since 2005. The exact date of birth of each child is available as well together with the NIP code of both parents.

In future analyses, we will also include information on the place of residence and employment. We classify municipalities by their degree of centrality, i.e., geographical position – travel time to workplaces and services, from 1 to 6: higher indexes indicate most central municipalities. As far as the employment status is concerned, by retrieving information from the Employment register we can reconstruct the entire working career of all Norwegian residents.

Information on whether the child has some form of disability comes from the health register integrated with the birth register. We identify children with disability from the Medical Birth Register as well as from the ICD-10 codes present in the specialized care services data – assigned to minors in case of diagnoses related to physical or cognitive disability. In this study, we focus on two specific cases of disability: i) having a child with Down syndrome; ii) having a child with cerebral palsy (CP).

Methods

In our preliminary analyses, we conducted multivariate regression models to estimate the risk of divorce and the likelihood of having an additional child for the three groups of parents under study: those who had a healthy child, those who had a child with Down syndrome, and those who had a child with cerebral palsy. We stratified the analysis by parity, where for parities higher than zero parents' outcomes are conditional to the fact of having existing children who are healthy. This initial investigation into these critical life course transitions represents the first important step in understanding whether child disability plays a significant role in shaping parents' family life.

The life course paradigm posits the profound interconnection between related individuals (spillover effects among children and parents in our case) and across life domains. We aim to further enrich our study by investigating the complete family histories of parents (looking simultaneously at marital status and fertility decisions), accounting as well for potential residential movements, and employment decisions on the labor market. The heterogeneity of the effects by socio-economic status, gender and origin of having a disabled child on family life decisions will be tested as well.

First Descriptive results

Sample description

To investigate the link between having a disabled child and parents' life course, we will exclusively focus on parents residing in Norway who were born after 1960. We focused on these cohorts for two primary reasons. First, detailed marital information has been available since 1975. Looking only at those aged 15 or younger at the beginning of the observational period we can reconstruct almost surely their whole family trajectory up today. Second, general Down syndrome screening in Norway began in 1983. Focusing only on prospective parents aged 20 or younger when the general DS screening started, we can claim with a certain confidence that by distinguishing between CP and DS we are able to estimate the effect of two

different sources of disadvantage: one likely unexpected at the time of birth of the child (CP), the second one (DS) potentially foreseen.

We have identified approximately 13,700 parents who had children affected by either cerebral palsy (CP) or Down syndrome among the more than 1.7 million residents in Norway born after 1960. Among these parents, 24.45% (N=3,355) have children affected by cerebral palsy, while the remaining 75.55% have children with Down syndrome. Cerebral palsy is more prevalent among firstborn children (in 51.73% of cases, the child with CP was the firstborn). In contrast, among parents with a child affected by Down syndrome, 36.75% of cases involved the firstborn, and an additional 36.6% involved the second-born. As expected, the mean age of the parents at the time they had a child with Down syndrome is higher (33.14, with a standard deviation of 6.05) compared to the average age of the parents when they had a child with CP.

Fertility decision after the birth of a disabled child

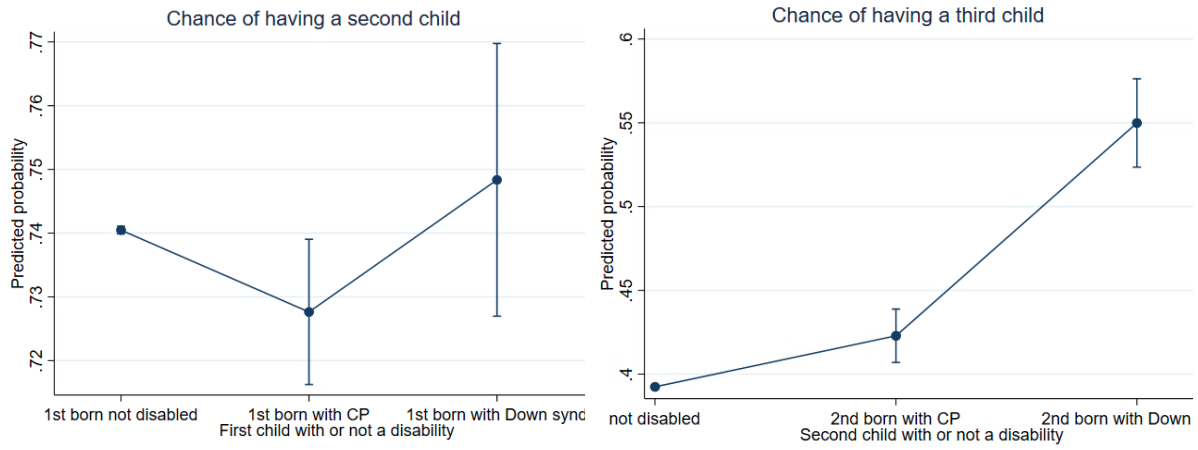
Using a series of multivariate logit models, we estimate the likelihood of having an additional child given the disability status of the last born. Table 1 reports the results in terms of odds ratio, while in the figure the predicted probability of moving to higher parity. Since having more than three children is quite rare in Norway (the Total Fertility Rate in 2022 was 1.41), we decided to focus on the transition from parity 1 to parity 2 (M1) and from parity 3 to parity 4 (M2).

Table 1. The likelihood of having an additional child. Odds ratio.

	Having a second child (M1)	Having third child (M2)
Disability status of the child*		
No disability (ref)		
With cerebral palsy	**0.928** (0.031)	**1.145** (0.042)
	[.025]	[<.001]
With Down syndrome	1.047 (0.069)	**2.026** (0.122)
	[.475]	[<.001]
Number of individuals	1,767,356	1,303,806

Note: * the disability status refers to the first child in M1, the second child in M2. Logit models controlling for cohort, gender of the parent, and age at first child. P-values reported in square brackets.

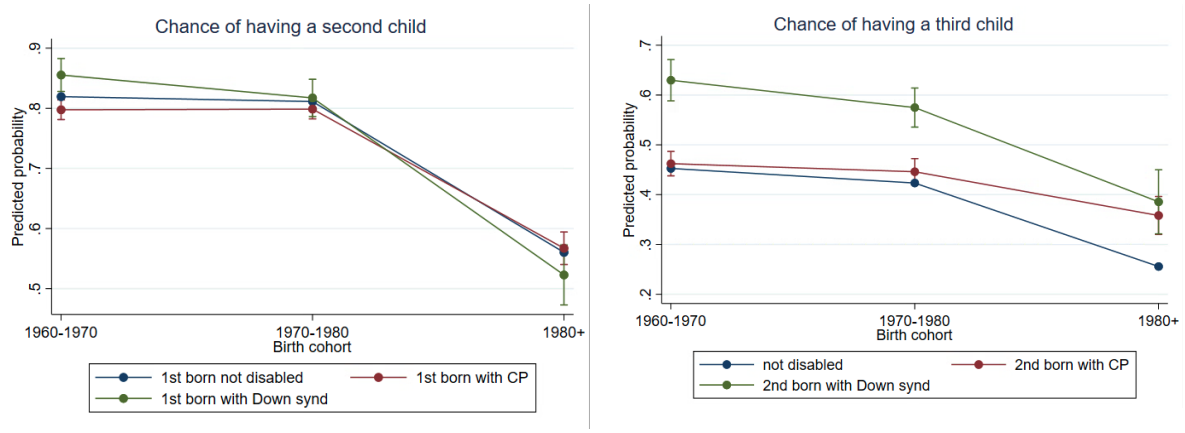
Figure 1. Predicted probabilities of having an additional child by disability status of the previous born



Having a child with CP as first-born reduces the likelihood of having a second child (OR of 0.928, p-value of .025) compared to parents whose firstborn is healthy. Conversely, the probability of having an additional child increases – even if the result is not statistically significant - if the first-born is affected by DS. Moving to parity 2, parents of disabled children are more likely to have a third child. This is observed for both parents of children with CP (OR of 1.145, p-value of .001) and in the case of a child with Down syndrome: parents of a child with DS are two times more likely (OR of 2.026, p-value <.001) to have a third child respect to their counterparts with healthy second-born. When examining the transition from a third to a fourth child (results not reported here), the pattern is reversed with higher chances of having a child among parents of children with CP, although the differences are not statistically significant due to the relatively few residents born after 1960s who had three or more children.

We investigate whether such associations vary by the cohort of parents (see Figure 2). When focusing on the first cohort (1960-1970) and the last cohort (after 1980), two interesting patterns emerge. In all three transitions considered, for the cohort of 1960-1970, parents with a child with Down syndrome are relatively more likely to have an additional child. In the younger cohort, while the relatively lower chance of having an additional child is not surprising (also considering that their reproductive period is not yet close to its end), it is noteworthy that parents of a disabled child are significantly more likely to have a third child compared to parents of healthy children.

Figure 2. Predicted probabilities of having an additional child by disability status of the previous born and cohort of the parents



Marital stability after the birth of a disabled child

Using a discrete-time hazard model, we estimate the likelihood of divorce or separation after the birth of a child. We conducted the analysis stratified by parity one and parity 2. Results in terms of odds ratio are reported in Table 2. Figure 3 shows the corresponding estimated probabilities.

Table 2. Likelihood of divorce/separation by disability status of the children – odds ratio. P-value in square brackets.

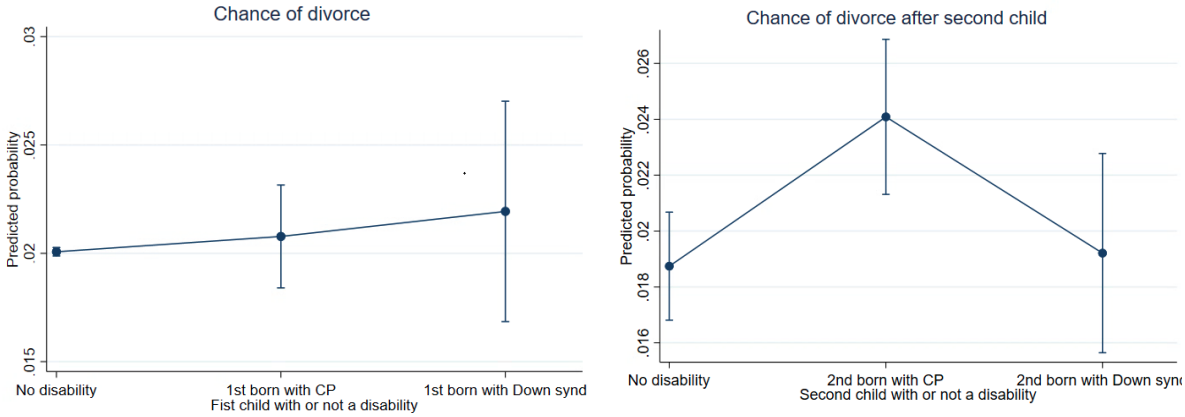
	After first child (M1)	After 2nd child (M2)
Disability status of the child No disability (ref)		
With CP	1.055 (.063) [0.529]	**1.231 (.0091)** **[<0.005]**
With Down syndrome	1.064 (.147) [0.657]	0.972 (.105) [0.792]
N of individuals	498,359	645,287
N of data points	7,411,824	9,153,559

Note: Discrete-time event history analysis controlling for cohort, gender of the parent, and age. In the first model M1, the individual is considered at risk of divorce or separation after the birth of the first child. In Model 2, the individual is considered at risk of separation after the birth of his/her second child.

Descriptive statistics show that in our sample if the first child is affected by Down syndrome, the average marriage length is 12.5 years against around 15 years for couples with a healthy child and around 16 if the child is affected by CP. After controlling by cohort, gender and age, no statistically significant differences in the risk of divorce are observed at parity 1, even if in magnitude the probability of divorce remains slightly higher among parents of children with Down syndrome (Figure 3). Moving to parity 2, we observe an

increasing risk of divorce after the second-born if affected by CP. No differences in the risk of divorce are observed instead between those with a second born healthy and those with a child with DS.

Figure 3. Predicted probabilities of divorce by disability status of the children



Abridged Conclusions

To our knowledge, this is the first empirical work that investigates the effect of having a disabled child on parental life course at the population level. The project contributes to life course and social stratification research in two main ways. First, it investigates an understudied source of social inequality, that is child disability using population-level data. Second, it takes a novel upward approach to life course spillover effects (Bernardi et al. 2019) from children to parents.

This study focuses its attention on two types of congenital disability: Down syndrome (DS) and cerebral palsy (CP). Given that in Norway generalized prenatal screening for DS started in 1983 while CP cannot be predicted during pregnancy, studying the family life decisions of residents born after 1960 (i.e., those who were not older than 23 when the screening started), with children with CP, Down syndrome, or healthy, we can disentangle the effects of an unexpected child disability (CP) on parents family life decisions from the ones of a potential expected case of disability (DS). Our results show that parents facing an unexpected case of disability (CP) show signs of higher uncertainty and instability in their life course: they are more likely to divorce (especially if the disabled child is the second-born) and less likely to have an additional child when compared with parents of children affected by DS.

For the PAA Annual meeting, this work will be extended in several ways. First, life domains are strictly interconnected. We will therefore study in a more comprehensive way family life course trajectories considering marital status and childbearing as intertwining dynamics (e.g., the chance of re-partnering and having an additional child with another partner), and we will also include employment and residential mobility dynamics in our analyses. Second, we will investigate the heterogeneity of such effects by gender, origin and socio-economic status.

References

Arora, K., & Wolf, D.A. (2014). Is there a trade-off between parent care and self-care? *Demography*, 51(4):1251-70. doi: 10.1007/s13524-014-0309-6.

Bernardi, L., Huinink, J., & Settersten, R. (2019). The life course cube: A tool for studying lives. *Advances in Life Course Research, 41*

Burke, M. M., Urbano, R. C., & Hodapp, R. M. (2011). Subsequent births in families of children with disabilities: Using demographic data to examine parents' reproductive patterns. *American Journal on Intellectual and Developmental Disabilities*, *116*(3), 233-245.

Hogan, D., Msall, M. E., Goldscheider, F. K., Shandra, C. L., & Avery, R. C. (2012). *Family Consequences of Children's Disabilities*. Russell Sage Foundation.

Loft, L. T. G. (2011). Child Health and Parental Relationships: Examining Relationship Termination among Danish Parents with and without a Child with Disabilities or Chronic Illness. *International Journal of Sociology*, *41*(1), 27-47.

Loft, L. (2022). The importance of child characteristics: children's health and mothers' subsequent childbearing. *Journal of Population Research*, *39*(4), 599-616.

MacInnes, M. D. (2008). One's enough for now: Children, disability, and the subsequent childbearing of mothers. *Journal of Marriage and Family*, *70*(3), 758-771.

Mauldon, J. (1992). Children's Risks of Experiencing Divorce and Remarriage: Do Disabled Children Destabilize Marriages?. *Population Studies*, *46*(2), 349-362.

Pinquart, M., & Sörensen, S. (2003). Differences between caregivers and noncaregivers in psychological health and physical health: a meta-analysis. *Psychology and aging*, 18(2), 250

Schulz, R., & Sherwood, P.R. (2008). Physical and mental health effects of family caregiving. *Journal of Social Work Education,* 44(sup3):105-113.

Risdal, D., & Singer, G. H. (2004). Marital Adjustment in Parents of Children with Disabilities: A Historical Review and Meta-Analysis. *Research and Practice for Persons with Severe Disabilities*, *29*(2), 95-103.

Urbano, R. C., & Hodapp, R. M. (2007). Divorce in Families of Children with Down Syndrome: A Population-Based Study. *American Journal on Mental Retardation*, *112*(4), 261-274.

Fundings

Danilo Bolano acknowledges the financial support received from Fondazione Cariplo, Project Rif. 2022-1427: chilDfam – Families and child disability. Nicoletta Balbo acknowledges the financial support received by the European Union (ERC FRAILIFE—Child Disability and Family Life, G.A. 101077533) under the European Union's Horizon 2021-2027 research and innovation program. Views and opinions expressed are however those of the authors only and do not necessarily reflect those of the European Union or the European Research Council Executive Agency. Neither the European Union nor the granting authority can be held responsible for them.