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So Long as the Baby is Healthy:
The Effect of Disability in Children on Mother's Subsequent Childbearing Decisions

Introduction

If you ask expectant parents about their hopes for their unborn child – do they want a boy or a girl, for the child to have his nose or hers – almost without fail the reply will be, "We don't care, so long as the baby is healthy." Which, of course, raises the question: what happens when the child is not? Health and physical well-being are normatively valued states. The experience of disability or poor health can have significant implications for both the life of the affected individual and for the lives of his or her family members. We see throughout the literature that the experience of disability can affect the life trajectory of the individual. A person with a disability must face physical and social barriers to inclusion. Moreover, living with a person with a disability can influence the lives and well-being of family members – those of siblings, parents, spouses, or even extended family members. This paper explores one dimension of family life that may be influenced by a child's disability status – the subsequent fertility decisions of his or her parents.

We might expect a child's disability status to affect the subsequent fertility decisions of his or her parents for several reasons. Having a child with a disability is usually an unanticipated event that poses special challenges to parenting. That is not to suggest that disability is uniformly a negative experience, nor to downplay the many significant rewards that come to parents from raising a child with a disability. However, most parents would not wish anything upon their children that would make their lives more difficult than necessary. Not only is the experience of disability often difficult for the affected individual, but it can also be stressful for members of the family. Raising a child with a disability can be taxing on parents, both financially and emotionally. We might expect that parents of a child with a disability will forgo further childbearing in an attempt to conserve resources so as to provide for the needs of the children they already have, in particular the child with a disability, but also any older siblings that child might have.

However, a focus on the psycho-social dimensions of parenthood reminds us that when adults decide to have a child, they likely have some idea of what this experience will be like; such expectations are shaped by both personal observations and cultural norms and values. A would-be father may imagine himself teaching his daughter to ride a bicycle in the driveway or his son how to throw a spiral pass. A mother might envision herself at her son's college graduation or hushing giggling girls during her daughter's sleepovers. Clearly, many children may not live up to idealized parental expectations. Yet a child's experience of disability often disrupts an expected pattern of parenthood and childrearing more so than do other characteristics that a child may have. Parents of non-disabled children may be able to adjust their expectations and find other outlets in which their child may be considered a success. For parents whose child has a disability, these outlets may be quite limited. The affected child may be unable to act and interact in anticipated ways. Parents of a child with a disability may desire "typical" parent-child interactions that are difficult or impossible to achieve, and may, in turn, decide to have an additional child or children in an attempt to ensure that they are able to have these experiences and interactions.

To explore the ways in which child disability may influence parents' subsequent fertility decisions, this study draws upon several literatures, in particular, those of disability in the family, caregiving, childbearing in the United States, and the meaning of parenthood and value of children. Both quantitative and qualitative methodologies provide insight into this topic, elucidating the often complex interrelationship between a child's disability status, family experiences, and subsequent fertility decisions.

Literature and theory

Disability in children and the family

In the contemporary United States, between 12 and 18% of children live with a limiting or disabling physical, developmental, behavioral or emotional condition.

(Newacheck et al., 1998; Hogan et al., 1997). To date, there is no universally agreed-upon criterion regarding what constitutes disability. There is considerable range regarding what types of indicators are used in individual surveys, as well as how expansive definitions of disability are. For example, some instruments may consider all chronic health conditions to constitute disability, while others include only those that impact the ability of an individual to perform age-appropriate tasks. Some instruments focus exclusively on activities of daily living (ADLs),[1] while others focus on an individual's ability to perform social roles, such as their ability to attend school or work.

Regardless of the criterion used, we see consistently that disability affects a sizable minority of children. Yet as family systems theory reminds us, that which affects one member of the family has a significant influence on the lives and well-being of all members of that family. Thus, I explore childhood disability with special attention to its ramifications for family functioning generally, and for parents in particular, looking to understand how the presence of a child with a disability affects further childbearing for that child's parents.

Though the study of the impact of child disability on the family is still in its early stage, we can see in the literature that caring for a child with disability can have noteworthy consequences for the well-being of the family. These impacts may be both positive and negative. For example, on the positive side, growing up with a child who has a disability may impart a greater sense of acceptance for others among siblings of a child with disability. Many families indicate that the experience of raising a child with disability has served to unify the family. As one respondent shared,

> But we always went as a family and no one ever stayed home. Wherever we went, we all went together…. That's one thing this family has learned, because when you deal with a situation like this, you're…they…we used to go…we would be here, four of us. We would come for therapy together. Stephen [son with cerebral palsy] went to horseback riding therapy, we'd all go to horseback riding therapy with him, you know. We did everything together. That impacted my other children's life. They know how to act around other children… You know what I mean, if they see children with –adults – anybody with a disability, it's not

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[1] ADLs are tasks required for self-care, such as the ability to bathe or feed oneself.

> a problem with them. They know how to handle it. You know, that is a learning experience. That's something…it's good in life. I look at it…I mean it makes everybody…it made them better.[2]

Likewise, as Klinnert et al. (1992) have posited, the presence of an ill child or a child with disability may actually serve to strengthen the family by increasing the couple's commitment to their relationship. As another respondent indicated, "It actually made it [her relationship with her husband] stronger. Yeah, because you know, you rely on someone so much, you don't realize how much until you have to go through something, so it actually made you stronger than it did weaken you. 'Cause you needed that extra support. You needed that person there."[3]

However, raising a child with a disability can be costly, both economically and emotionally, and these costs can give rise to a variety of stresses. Aspects of the caregiving role may be seen as potentially stressful and burdensome (Marks, 1998; Kim et al., 2003). Caregiving for a child with a disability can be seen as what Marshak et al. (1999) describe as "the endless burden." "The chronicity of care that families with a child or adult with a disability anticipate constitutes a major feature that distinguishes them from families confronting more acute crises. For some families, the care is necessary 24 hours a day, 7 days a week, for many years" (Marshak et al., 1999, p 25).

This ongoing caregiving burden may lead to feelings of despair or hopelessness, which may in turn give rise to various poor psychological, physical, and relational outcomes. That is, we see throughout the literature that raising a child with disability increases the risk of experiencing a variety of outcomes that may be detrimental to the well-being of primary caregivers and other family members. For example, caring for a disabled family member may leave caregivers unable to participate in the workforce (Brandon, 2000; Porterfield, 2002; Rogers and Hogan 2003; Spearin, D'Ottavi, and Park, 2004), may lead to increased rates of illness among caregivers (Marks, 1996) and siblings who are without disability (Hogan, Park, and Goldscheider, 2003), and may lead to increased rates of marital dissolution among mothers of children with disability

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[2] Taken from interview 050408_125, father of four children, one of whom has cerebral palsy. For more information on this study's respondents, see Chapter Three and Appendix A.

[3] Taken from interview 050316_321, mother of twins, one of whom had cerebral palsy.

(Mauldon, 1992; Joesch and Smith, 1997; Spearin, Park, Goldscheider, and D'Ottavi, 2003).

Childbearing and child rearing in the United States

We must consider the nature of childbearing and fertility in the contemporary United States generally in order to understand the impact of child disability upon fertility. The modern American fertility regime is one in which women have great control over their childbearing. This context is one in which individuals have options – to have few or no children, to have children within or outside of a marital context (Morgan, 1996). Given that having a small number of children is socially-normative, and that women can control their childbearing via contraception and abortion, child disability can have an effect on childbearing decisions. Were we to study a time or place where large families were expected and abortion/contraception banned, we may not anticipate that having a child with a disability would influence subsequent fertility, simply because the context in which such decisions were made was quite restrictive.

Childbearing decisions can be considered using something of a rational choice framework. Most famously articulated by Becker (1981), this framework emphasizes that parents consider the expected costs and benefits associated with raising a(nother) child, and act accordingly in deciding whether or not to attempt to have a child. The costs and benefits may be both pragmatic and sentimental – based on financial resource assessments or social-psychological principles. Childbearing in the modern United States is largely considered to be motivated by social/psychological forces; that is, parents usually are motivated to bear a child by the desire to rear that child, to experience typical parent-child interactions. In this light, childbearing is motivated by the "intrinsic, nonsubstitutable pleasure derived from watching one's own children grow, interacting with the child, and participating with the child in particular events or tasks" (Pollard and Morgan 2002: p602).

Given this context, how might the disability status of a child influence this calculus? Raising a child with a disability may be seen as raising the costs associated with further childbearing. That is, the economic and emotional stresses associated with caring for a child with a disability may constrain the desire for additional children.

Parents must consider the resources required to care for the children that they currently have when they make decisions about future childbearing. We might thus anticipate that the additional caregiving burden associated with raising a child with disability would increase the costs of raising that child such as to reduce the desirability of further childbearing. By foregoing further childbearing, these parents would be able to more fully dedicate their existing family resources – time, monetary, and emotional – to meeting the needs of that child.

However, a child's disability status may increase the perceived benefits to additional childbearing. The perhaps limited ability of children with severe health difficulties to participate in standard interactions may increase the anticipated gain from having another child. Parents with a child with a disability often cannot have the same expectations for that child as they would have for a healthy child. In such a way, we might expect disability in children to increase the perceived benefits to subsequent childbearing. The desire for a typical childrearing experience may increase the desire for an additional child among families with a child who has health difficulties. Alternatively, other forces may be at work to increase the desire for additional children among parents of children with disability. Our qualitative work suggests that some parents may view siblings as beneficial for their child with a disability. A sibling ensures that the child with a disability will have a playmate in the short run, and perhaps a caregiver later on. Parents of children with severe disability may, in some cases, view siblings as insurance that there will be a familial caregiver for the child with a disability when they pass away.

Hypotheses

These perspectives would predict opposite outcomes with regard to subsequent fertility. Attending to the costs associated with further childbearing – that is, by focusing on limited resources and caregiving burden – would predict a negative relationship between the presence of a child with a disability and their parent's subsequent childbearing. That is, the presence of such a child would be expected to decrease the likelihood that parents would proceed to have additional children. Yet, there may also be perceived benefits to having additional children. In attending to the importance of social interaction in childrearing, we might expect to see that parents whose child has a disability are more likely to have an additional child.

Data and Methods

To explore the ways in which mothers' fertility outcomes are affected by the disability status of their children, this study employs both qualitative and quantitative methodologies. This mixed-method approach is crucial to elucidating the relationship and underlying mechanisms at work linking disability in children with the subsequent childbearing of their mothers. These methodologies should be seen as complementary. Qualitative provide insight and examples, and guide hypotheses and suggest models to be tested in the quantitative data. Moreover, interviews also allow insight into the mechanisms at work. Quantitative analyses allow for the generation of population estimates, the systematic exploration of relationships and the testing of hypotheses derived from theory and from the qualitative interviews.

Quantitative data and methods

Quantitative data allow us to establish relationships between child disability and fertility outcomes with statistical certainty. Event history analyses assess how the risk of a subsequent birth is affected by the disability status of the child, simultaneously controlling for other covariates known to influence childbearing, such as race and parity. These analyses utilize data from large-scale nationally representative sources: the matched 1993 National Health Interview Survey (NHIS) and 1995 National Survey of Family Growth (NSFG) data. The NHIS-NSFG matched dataset is a unique resource for the study of child disability. The data match project was conducted by Brown researchers over the last several years. I had the opportunity to become involved with this data project over the summer of 2004, when I was placed in charge of programming necessary to publicly release the matched dataset. The matched data source provides sound indicators of disability in children and outstanding information on childbearing and reproductive behavior, marital status, and labor force participation throughout the respondent's life prior to the 1995 survey.

The NSFG-NHIS data are used to conduct multivariate analyses on children under the age of 18 in 1995 who were born to the NSFG sample of women age 44 and younger in 1995. The dataset contains information on 10,109 children, of whom 649 have disabling conditions; that is, about 6% of the children in this sample have a disability. Piecewise constant models are used to model the time from the birth of each child to the birth of another child. Piecewise constant models are estimated in SAS using PROC LIFEREG. Time is divided into intervals, and the model presumes that the hazard is constant within intervals, but can vary across intervals. Given J intervals, divided by break points $a_0, a_1, a_2 \dots a_j$, where $a_0=0$ and $a_j=\infty$, we can express the model for the hazard for individual i as:

$h_i(t) = \lambda_j e^{\beta xi}$ or $\log h_i(t) = \alpha_j + \beta x_i$ (Allison 2001).

In this model, then, time is divided into one year intervals[4]; for every year in which nothing happens – that is, another child is not born, mother is not sterilized, child does not turn 12, or the survey does not occur – the child contributes 12 months to the duration indicator. For the terminal record for each child, that child contributes some fraction of the 12 month period to the duration. For instance, if a younger sibling is born four months after the third birthday of a child, that child will contribute three 12-month duration records and a 4-month duration record.

Key variables

Outcome: Risk of a subsequent birth is measured in one-year increments from the date of the child's birth until the birth of another child, the child's 12th birthday, the mother's sterilization, or the date of the interview.

Child's disability: Child's disability status is measured using two central variables from the NHIS that assess whether each child is limited or unable to perform major activities such as school attendance or play. These indicators are coded to reflect whether the child has a limitation.

Covariates: The analyses also control for covariates known to affect both the likelihood of a subsequent birth and the likelihood of disability among children. I control for the

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[4] The first period is two years in length (from the child's birth date until their second birthday); all other periods are 12 months in length. The first two years were combined into a single period as very few children experienced the birth of a sibling within 12 months of their birth.

child's mother's race, age at the time of the child's birth, and completed education. I also include two lagged time-varying covariates. Mother's labor force participation indicates whether the woman worked at any point during the period prior. Mother's marital status indicates if she was married at any point during the year prior to the period. I also control for the sex of the child, and whether the child is their mother's firstborn or a higher order birth. Mother's economic status / poverty status is assessed at the time of the child's birth by looking at whether Medicaid covered prenatal and birth-related medical costs.

In-depth interviews

A colleague and I conducted interviews with parents of children with various types of disabilities in order to explore the nuances of their lives as caregivers, and how these realities have influenced their decisions about childbearing. These interviews are a wonderful complement to the quantitative analyses that were conducted. We completed twenty-four interviews with parents of children with disability who receive physical or occupational therapy at a local hospital.[5] These informal interviews, which lasted approximately an hour each, allowed respondents to share their experiences raising a child with a disability. Respondents were asked to speak not only about how raising a child with a disability has influenced their subsequent childbearing decisions, but about any and all dimensions of personal and family life that have been affected by their child's disability status. In these interviews we inquired about the effect of child disability on their work strategies, and asked how raising a child with a disability has influenced their relationship with their spouse, with their friends, with their other children. We spoke about their experiences navigating the health and therapy systems; securing appropriate services and educational provisions.

Results

Piecewise constant models

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[5] Twenty-six interviews were completed, but two were later eliminated from the study sample because the child and family did not meet criterion for inclusion.

To assess the effect of a child's disability status on the risk of their mother having an additional child, we look to a main effects model.[6] This model predicts the risk that a child's mother will give birth again, considering whether a child has any limitation while controlling for relevant covariates such as race, sex, mother's education, and the like. This model provides a simple test of the two main hypotheses. Finding that children with disability are at a lower risk would seemingly offer support for the stress hypothesis, while finding that they were at a higher risk would provide evidence for the value of children hypothesis.

Table 1 provides estimates of survival times as well as hazard ratios for this model. Let us begin by reviewing the effects of the controls. In this model, we see that children whose mother is black are at a 15% greater hazard of having a sibling born than are children whose mother is white, those whose mother is Hispanic are not significantly different from those whose mother is white, while children whose mother is of another race are at a 20% greater risk of having a younger sibling born. There also seems to be a slight effect for gender – female children are at a slightly lower hazard of having a younger sibling born to their mothers than are male children.

Education is associated with the risk of a sibling's subsequent birth. Compared to children whose mother has a college education, children whose mother has less than a high school degree are at a 48% greater hazard, while those whose mother has a high school degree are at a 7% higher hazard of having a younger sibling born. Likewise, the labor force participation of mothers in the period prior is associated with a lower risk – children whose mothers worked are 17% less likely to have a sibling born than children whose mothers did not work in the period prior.

We also see that mother's age is associated with subsequent fertility – mothers who were younger than 20 at the child's birth are at a 13% higher hazard, while those who were over the age of 30 are at a 42% lower hazard. Finally, children whose mother was married in the period prior are at a considerably higher risk of having a sibling born.

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[6] Alternative specifications of the model were run. I report findings from the simplest model here, as they tell the story in the clearest manner.

Table 1: Main effects, piecewise constant model

	Estimate	S.E.	HR	
<u>Key Independent Variables</u>				
Child with disability				
Child does not have a disability	--------	--------	--------	
Child has a disability	0.14	0.06	0.87	**
<u>Control Variables</u>				
Child's gender				
Male	--------	--------	--------	
Female	0.0526	0.029	0.95	+
Child's birth order				
First birth	--------	--------	--------	
Not first birth	0.49	0.03	0.61	***
Mother's age at child's birth				
Less than 20	-0.12	0.05	1.13	**
20-29	--------	--------	--------	
30 and older	0.55	0.05	0.58	***
Mother's race				
White	--------	--------	--------	
Black	-0.14	0.04	1.15	***
Hispanic	-0.07	0.04	1.07	+
Other race	-0.18	0.09	1.20	*
Mother's Education				
More than a HS degree	--------	--------	--------	
HS degree	-0.07	0.03	1.07	*
Less than a HS degree	-0.39	0.04	1.48	***
Mother's LFP (lagged)				
Did not work	--------	--------	--------	
Worked	0.19	0.03	0.83	***
Mother's marital status (lagged)				
Not married	--------	--------	--------	
Married	-0.62	0.04	1.85	***
Medicaid receipt at child's birth				
Birth not covered by medicaid	--------	--------	--------	
Birth covered by medicaid (impoverished)	-0.31	0.04	1.36	***
Year indicators				
Year 1-2	--------	--------	--------	
Year 3	-0.25	0.04	1.28	***
Year 4	-0.17	0.04	1.19	***
Year 5	0.08	0.05	0.92	
Year 6	0.19	0.06	0.83	**
Year 7	0.44	0.08	0.64	***
Year 8	0.71	0.10	0.49	***
Year 9	0.80	0.11	0.45	***
Year 10	1.07	0.15	0.34	***
Year 11	1.14	0.17	0.32	***
Year 12	1.67	0.24	0.19	***

+p<0.1 *p<0.05 **p<.01 ***p<.001

We also see that the majority of sibling births seem to occur within the first four years of the child's life – during the third and fourth years of the child's life, they are at a higher risk of having a sibling born compared to during the first two years. Thereafter, though, the risk declines. The risk of a subsequent birth to their mothers is lower in years five through twelve compared to the first two years. What we see, then, is that the covariates behave as we'd expect from the literature. This can give us confidence that any association found between the disability indicators and outcome variables is likely not a manifestation of this particular dataset.

We now turn to our key independent variable – a child's disability status. To briefly review, this serves as a test of our central hypotheses. The increased caregiving needs of a child with a disability might lead mothers to forgo subsequent childbearing in order to more fully devote their time and other resources to caring for that child. Alternatively, if a child's disability status prevents typical parent-child interactions, and if these interactions are central to the purpose and meaning of parenthood, then we might see that a child with a disability is more likely to have a younger sibling born than otherwise similar children who do not have a disability.

Net of other characteristics, we see that children with disabilities are at a lower hazard of their mother having another child. That is, a child with a disability is at a 13% lower risk of having a younger sibling born than an otherwise similar child who does not have a disability. This is a significant reduction – the magnitude of the reduction in the hazard of a subsequent birth is roughly the same size as is the effect of a mother being black rather than white.

Outcomes and mechanisms: In-depth interviews

We see through the event history models that children's disability status does have an effect on the subsequent fertility of their mothers. A child with a disability is at a lower hazard of a subsequent birth to their mothers – that is, raising a child with a disability slows or prevents further childbearing. This pattern is also supported among the respondents in our interviews. Of half of the mothers we interviewed[7], their child

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[7] Twenty-two of the 24 interviews are useful for assessing the research question; two interviews were conducted with mothers whose child became disabled after they elected to have another child.

with a disability was their last child. Two others suggested that they spaced their children more widely than they might have otherwise because of their child’s disability, while two others suggested that their child’s condition led them to have another child. The remainder indicated that their child’s condition did not ultimately play a considerable role in their decisions about subsequent childbearing.

While the relative concordance between the outcomes we see in the piecewise constant models and the outcomes reported by the parental respondents in our interviews offers support that these patterns are robust, the in-depth interviews can offer us far more than insight into what relationship exists. These interviews allow us insight into the mechanisms at work. While the event history analyses seem to offer support for the stress hypotheses, the in-depth interviews allow our these mothers to tell us directly how their experiences of caring for a child with a disability influenced their decisions about whether and when to have another child.

Care giving demand, meeting needs, and fairness

Several themes seem to emerge when we look through the interviews. The first is that raising a child with a disability is difficult work - that it is usually time consuming and sometimes emotionally draining. Second, we see that parents want what is best for their children. They want to be sure that they help their child to achieve their fullest possible potential. Many are advocates for their children and serve as resources to other parents as they try to secure care and treatment through the school system, the medical system, insurance providers, and private foundations. In order to meet the needs of their children, these families seem to engage in a number of strategies. For example, many of the mothers in this study were not in the labor force, or participated part-time, worked from home, or in flexible schedule jobs. They reported that they had made these employment decisions in order to allow them to spend the time necessary to take their children to appointments with therapists, doctors and the like. Likewise, many of our respondents report that they chose not to have another child or spaced their children widely in order to allow themselves more time to meet their child’s needs.

This idea that caring for a child with a disability was difficult, and that one way to increase one’s ability to need that child’s needs was by curtailing subsequent childbearing, was expressed clearly by Debra.[8] Debra's son, Ricky, was born with a brain abnormality; he is her only child. When I asked whether she intended to have only one child, or if Ricky's condition factored into their decision-making, she replied,

> D: We wanted two.
>
> I: And then?
>
> D: And a neurologist told us that we had an extremely slight chance, extremely slight that this could happen again because we already have a child with a disability. So our chance is greater than the general public that doesn't have a child with a disability. So we were like 'no, forget it.'
>
> I: Really?
>
> D: No.
>
> I: So it was fear of it happening again that was the major…?
>
> D: Yeah. Because I would have had three more. … But I mean, you go back and forth. Okay, it's extremely slight so chances are it's probably not going to happen again. But what if it did. How are you going to meet both their needs? So then… I mean, you know, if it didn't happen again would it be fair to a baby to always be bringing a baby to therapy? You know. Because he's going to be in therapy I'm sure for a very long time. So no, full attention, full focus is on Ricky. [laughter][9]

In this exchange, Debra emphasizes the need to place "full attention, full focus" on her son with a disability. Very similar themes emerged in Karen's interview. Karen's son, Brandon, was born with multiple disabilities.

> K: [W]e wanted more than one child. But after I got pregnant, and I was bedridden for seven months, and I almost lost him at 24 weeks, 26 weeks, 28 weeks, finally made it to 36 weeks and had him, and he was born dead and I had no blood pressure. I laid on the table in that distress, could barely talk, and said, 'tie them. Now'. And he looked at me, and said,

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[8] All names are pseudonyms. In interview excerpts, I: indicates the interviewer.
[9] Taken from interview 050218_109.

> ‘are you sure?’. ‘Yes, I get pregnant, I come after you, ‘cause I don’t want to have another one’. I couldn’t do it again, but then, now that I see all the problems I go through, I could not handle another one. I have too many problems with the one I have. I see a lot of moms here who have more than one, and they are more…they are really stressed out, because they have children that are so-called, what they call “normal,” and then their special needs children. And the other children feel left out because the special needs takes up all their time.[10]

Debra and Karen both speak about the difficulties of raising a child with disabilities – the increased caregiving demand brought about by increased need. They also mention a third theme which appears in many of our interviews – the idea of fairness, of caring fully and fairly for one’s children. Both Debra and Karen explained their decisions not to have a second child in part because it wouldn’t be “fair” to either their child with a disability or to a hypothetical second child. These fears seem to exist regardless of a presumption about the disability status of a second child. Debra fears that a second child would suffer, even if the child did not have a disability, because the child would have to be brought to therapy frequently while Ricky received his treatments. Worse still if the child were to have a disability – she fears she wouldn’t be able to meet both children’s needs. Karen also speaks about her perceptions that the healthy siblings of children with disabilities suffer. She describes second-hand observation of family dynamics she has observed among parents and children receiving physical or occupational therapy. She talks about sibling resentment, and the stress mothers seem to feel because of these experiences.

This theme of “fairness” or concern about being fair or equitable in the treatment of one’s children was mentioned by other respondents as well. Our respondents talked about trying to be sure that they made all of their children do chores, or trying to spend special time with their other children so as to stave off resentment. One mother talked about special lunches out that she and her daughter scheduled to make up for the time she spent with her other child who had a

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[10] Taken from interview 050211_302.

disability, "Yeah, she has her own special things. Like she goes with Nanni [a relative] and you know. We have, see she's only on half a day [at kindergarten] so we go out for lunch a lot…. So that's all evened out."[11] Another mother, Susan, spoke about her determination to be sure that both of her daughters realized that they were equally important. Susan's older daughter, Amelia, had cancer that resulted in an amputation. She took care of Amelia fully for almost a year, leaving care of her younger daughter, Charlotte, to her husband Jeff. Susan expressed that she made a conscious effort to be sure that Charlotte realized how important she was to her and to the family, that she did not feel neglected because so much attention had to be directed to Amelia. Susan was speaking about the impact that Amelia's cancer, its treatment, and resultant disability had upon Charlotte. Susan shared,

> S: Charlotte is very empathetic. And nurturing. So that's what we saw come out when her sister was in treatment. Now, you know, except for the like the trouble she's having in school and how she's…you know, her self-confidence. For the most part, she's good. But I make sure, since then I'm way there for her. She's my baby and she knows it.
>
> I: Yeah, make up for lost time in way.
>
> S: Exactly. So she…just because I wanted to make sure she knows she can count on me and it wasn't because of her…
>
> I: That you were spending all your time with…
>
> S: That I was with her and that she has my undivided attention now. As well as her sister. You know?[12]

This emphasis on fairness ties closely to the themes of meeting needs and the difficulties of raising a child with special needs. Parents often spoke of their attempts to make sure they met the needs of not only their child with a disability but also the needs (in particular the emotional needs) of their other children.

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[11] Taken from interview 050215_104

[12] Taken from interview 050317_123

We see similar themes emerge among mothers who did proceed to have another child after the birth of their child with a disability, but chose to space their birth intervals widely. Some of our mothers reported that raising a child with a disability caused them to wait longer to have another child than they might have otherwise. Tara is the mother of three children. The eldest, Madelyn, is healthy. Her second born, Sadie, has cerebral palsy. Her third child, Mitchell, has a kidney disorder. Tara is also the sibling of an individual with a disability. Her younger brother has autistism, thus providing her with unique insight into the meaning and experience of disability in the family. When we asked Tara whether Sadie's disability had any influence on her decision about whether and when to have another child, she told us,

> I: …Did Sadie's condition affect your decision to have Mitchell?
>
> T: Yeah, we would have probably spaced our children closer together.
>
> I: Okay.
>
> T: You know, it took a long…it took a long time, not, I mean, I wasn't afraid of having another kid with a disability. Like that, you know what I mean? Like that wasn't the fear as much as um…just like literally not having time to think that I could do it. Until she was older and in school and…
>
> I: Yeah, and things were settling out.
>
> T: …Right. And then you know, I mean, again, like for us, it's always the fear of autism. Like, you know, I'm getting older now, like could we handle that, too? I felt like we couldn't have more kids until I felt like I could handle like if that happened. I don't want to, you know… So like once we were kind of like, 'okay we could deal with whatever came down the pike,' then we were like…
>
> I: Did you always want three?
>
> T: I wanted four.
>
> I: Are you thinking about having another one?
>
> T: No. [laughs] More just my own physical…like it just took too much out of me. Not so much like caring for them, although I think like, for us,

> you know, the added appointments … but it’s been a lot of extra.... ultrasounds, trips to the urologist …[13]

In this excerpt from Tara’s interview, we see yet again that raising a child with a disability is time consuming. Tara speaks about the added appointments, and how meeting the needs of two children with disabling conditions “took too much out of” her. That while she intended to have another child, she elected to wait until she was sure she’d be able to meet the needs of both her existing children and the needs of another child. Gloria also indicated that her child’s disability led her to space her birth intervals widely. Gloria’s second child, Emily, was born with spina bifida. Gloria did not have a third child until Emily was 8 -- “I waited a certain amount of time where I felt I would have the capability and the time to spend with other children.”[14]

This idea of waiting ties closely into the concept that having another child might be detrimental to the well-being of a child with disability, and that subsequent childbearing should only take place when parents are sure they’ll be able to meet both the needs of their child with disability and the needs of another child. This idea was mentioned by a respondent who did not go on to have a second child. Marilyn’s daughter, Erin, has cerebral palsy. Erin does not have a very severe case of cerebral palsy – she can walk with minimal assistance. Marilyn told us that she and her husband had wanted a large family,

> Our plan was always to have four or five kids. We went into it very open. I want a big family. He was ‘I want a big family.’ And I said, I got married later in life, I was thirty-three. And said to Robert ‘we need to start trying because I want a big family and my clock is boom, boom, boom.’ … And I just said, I could not, did not want to for whatever reason. I said that God has blessed us with that she kind of came out of the woods with all of this and is doing really well. And didn’t want to take another chance. I also didn’t want to give any minute of myself to another baby that would take

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[13] Taken from interview 050316 _320
[14] Taken from interview 050303_113

> time away from Erin. And then I thought a long time about, I didn't know where her challenges would take her. And I never wanted her to feel like she was second best. And I had another child that was completely typically and this rugged little football player or whatever, that she would take a second seat to that because she had these challenges. And I didn't know at the time when I was still in safe childbearing age, I didn't realize how well she would be right now. I'm so impressed with her. She's done so much.[15]

Here, Marilyn indicates that, given the unknown course of Erin's condition – that they did not know how severe her disability would be – they presumed the worst. They elected not to have another child presuming that they would need to invest considerable caregiving resources in Erin. Marilyn implies that had she known how self-sufficient Erin would become, how relatively slight her disability would be, that they likely would have had another child. This way of thinking was also apparent in Nina's interview. Nina is the mother of twins, one of whom has cerebral palsy. When I asked if she thought she might have any more children, she replied, "I would like some. That's out of the question for my husband. [laughs] No, we're…nothing's out of the question, but I think, um…once we get a feel for what the future holds for Vanessa, I think that will make the determination, if it comes to it that, you know, Vanessa's not going to be able to walk and she's going to be more dependent on us, we won't. I don't think I'd have any more kids. But if I saw that she was, you know, improving... Getting more independent, that would make us change our mind. But, as of right now, no. But, I don't know…"[16]

Parents want to do what is best for their children, to maximize their potential, to care well for them. In many cases, that means either forgoing subsequent childbearing or spacing birth intervals widely. In some cases, though, that may mean having another child. In two of our interviews, we spoke with mothers who indicated that their child's disability spurred them to have another child. Lisa is a mother whose firstborn son Andrew has autism. Lisa indicated that she and her husband essentially had their second

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[15] Taken from interview 050216_105.
[16] Taken from interview 050316_321.

child for Andrew. She said that they knew he'd have trouble relating to people and would have difficulty with social relationships, and that they chose to have another child so as to give Andrew a friend, and someone who would help take care of him and provide for him.

Another respondent, Patrice, also indicated that her child's disability status led her to have another child. Patrice was born and raised in Ghana, and came to the United States in her 20's. She met her Ghanian-born husband in the US, where they've settled and had three children. Here, we see how significant culture and belief systems are when we think about the meaning of health and illness, and in turn, what effect it will have on personal and familial well-being. The second child of this respondent was born with a rare medical disorder, and when asked if this influenced her decision to have her third child she replied,

> P: You know, something funny happened to me when I had Nick. Well, we used to go to a church, but I stopped because… some people believe like in witches and all that…some of the people that we knew in the church, when I had Nick, I was trying to explain to them medically what is wrong with him… and they were all like, 'oh!', afraid, like, 'oh, maybe you did something and now God is punishing you!', 'or maybe you did something to somebody in Ghana and they make voodoo on you!'
> …I really want[ed] to have two. And I think what happen was, because [laughs] everybody was saying that, uh, 'oh, I did something and God punish me,' for some reason I decided to have the third one, to prove that…
> I: That it wasn't a punishment from God.
> P: Yeah. [laughs] So, that was really my intentions, yeah, because we were only planning on having two, because taking care of somebody with a disability is a lot of work.[17]

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[17] Taken from interview 050228_311.

This exchange emphasizes the range of factors that go into such a decision. Patrice talks about how raising a child with a disability is hard – “a lot of work” – but that their social context led them to have another child.

Discussion

Both the quantitative and qualitative components of this study present a picture of the ways in which raising a child with a disability influences parenting and subsequent childbearing. The event history models indicate that having a child with a disability does in fact suppress subsequent childbearing. Children who have a disability are at a lower hazard of having a sibling born than are otherwise similar children who do not have a disability, suggesting that the difficulties faced by families raising such children may discourage further childbearing. One theme that emerged during the course of our interviews was the idea that taking care of a child with a disability was hard, and that doing so required focusing on that child. As both Debra and Karen explicitly stated, their decisions not to have any additional children stemmed from a desire to be the best parents they could be to their child with a disability – to be able to focus fully on that child. They both also mentioned fears that to have another child would be unfair – both to their sons with disability and to a potential second child. Parents who reported that they spaced their children more widely than they might otherwise consider ideal also tap into this concept – their spacing was an attempt to ensure that they could fulfill their child’s needs, that they could take more time with that child.

Also in our interviews, some parents whose second child or third child had a disability expressed concern for the well-being of their nondisabled children – fear that they were suffering in some ways because they had a sibling who required more help, more time, and more attention. Some spoke of jealousy that the other child felt toward the amount of attention the child with disability received. Similarly, one parent expressed remorse that they couldn’t afford to go on family vacations because of the costs associated with caring for their child: “Well, one set of braces costs like sixteen or seventeen hundred dollars. .. She grows twice within a calendar year, that second set is on us. So how does it affect my kids? Well, that's our vacation... This was Disney, like right here."[18]

This study has implications for a more general understanding of parenthood and childrearing. What we see is that not all children are equal when it comes to the subsequent fertility of mothers. The characteristics of the child – here, the child's disability status – do matter, and we need to attend to them accordingly. We also see that parents employ all kinds of strategies to make sure that they can take care of the needs of their child with disability. In other studies, we found that parents of children with disabilities were more likely to engage in gendered specialization, where he served as the family's breadwinner while she withdrew from the labor force to dedicate herself entirely to caring for the children. Here we see that parents also seem to reduce their fertility. By having fewer children, these parents can allot greater resources – time, and money – to meeting the needs of their child. Finally, we see that considering disability as something that decreases the value of a child is not a helpful framework. What is central is the idea that parents are trying their best, and doing whatever they can, to meet the needs of their children and maximize their child's potential.

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[18] Taken from interview 050316_320.

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