Motherhood in the Context of Fragile X Syndrome: Implications for Caregiving, Work, and Romantic-Partner Relationships

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Abstract
Sondra J. Smolek Jones. Motherhood in the Context of Fragile X Syndrome: Implications for Caregiving, Work, and Romantic-Partner Relationships (Under the direction of Dr. Andrew Perrin)

This dissertation reports on findings from a qualitative analysis of mothers’ accounts of caregiving, work, and couple relationships in the context of having one or more children with special needs, based on semi-structured interview data (n=57) from the Family Adaptation to Fragile X Syndrome Study. Each family involved in the study had at least one child diagnosed with fragile X syndrome, the leading inherited cause of intellectual disability. Additional semi-structured interviews were conducted with a subset of respondents (n=15), and data displaying work and family changes over time were collected.

Findings reveal that one aspect of mothers’ experiences was a profound sense of responsibility for advancing their children’s development in multiple areas. Findings regarding work-family interplay describe juggling that took place within families and between work and family domains; the concept of articulation work is used to illuminate families’ experiences. Employment decisions by families are shown to relate to configurations of resources and demands in both work and family domains, and results show how families make use of strategies to influence fit between work and family domains. Findings also suggest that for some, alignment on parenting is significant in assessments of couple relationships, and that there may be certain complexities associated with aligning on parenting when children have special needs. Together, these findings provide insight into
commonalities as well as variation in mothers’ perspectives and experiences, and contribute to literature on caregiving, work-family interplay, and romantic-partner relationships.
Acknowledgements

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Chapter 1

Introduction

In a widely-cited and often-reprinted 1987 essay, “Welcome to Holland,” writer Emily Perl Kingsley wrote of her experience raising a child with a disability. To describe planning for a baby’s arrival, she uses the metaphor of excitedly planning a vacation to Italy, and she likens learning of the diagnosis of a child’s disability to the shock of learning that one’s plane has landed in Holland, instead, and that one must stay there. She writes, “So you must go out and buy new guidebooks. And you must learn a whole new language. And you will meet a whole new group of people you never would have met. It’s just a different place. It’s slower-paced than Italy, less flashy than Italy. But after you’ve been there a while and you catch your breath, you look around and you begin to notice that Holland has windmills. Holland has tulips. Holland even has Rembrandts.”

She describes people coming and going from Italy, talking about their wonderful trips there. “And for the rest of your life, you will say, ‘Yes. That’s where I was supposed to go. That’s what I had planned on.’” She acknowledges that the pain of that will never go away, but closes by emphasizing that “if you spend your life mourning the fact that you didn’t get to Italy, you may never be free to enjoy the very special, the very lovely things about Holland” (Kingsley 1987, cited in National Down Syndrome Congress 2010).

I learned of this essay through mothers of children with fragile X syndrome (FXS) who are involved in the Family Adaptation to Fragile X Syndrome Study. Multiple participants mentioned it and described how it was deeply meaningful for them. The essay
reflects more than a few commonalities with respondents’ experiences, especially related to learning of a diagnosis, and the process of adjusting to a new reality that for most, was very unexpected. Further, many respondents described the unique rewards that they have experienced through parenting a child, or children, with FXS. And, for many, there are or were challenges associated with raising children with FXS.

This project is about using a sociological perspective to understand mothers’ experiences with certain aspects of living in “Holland.” It explores three key areas of respondents’ lives – caregiving, work, and romantic-partner relationships – and provides both a description of respondents’ accounts and an analytical examination of ways in which sociological theories and concepts can shed light on patterns in women’s experiences. This project situates respondents’ accounts within a broader literature on families of children with disabilities and theories about how the family domain relates to the larger social context.

Fragile X Syndrome

Fragile X syndrome (FXS) is the leading cause of hereditary intellectual disability and can also cause problems with sensory input and social and behavioral problems akin to autism in some ways (National Fragile X Foundation 2006). Individuals with the syndrome may exhibit some or all of the following characteristics: mental impairments, attention deficit and hyperactivity, anxiety and unstable mood, and autistic behaviors. Seizures affect about 25% of people with FXS (Fragile X Research Foundation 2008). FXS may also have certain physical characteristics associated with it; individuals may have a long face, large ears, flat feet, and may also have hyperextensible joints (Fragile X Research Foundation 2008).

FXS is caused by a single, identified gene, but the phenotypic outcomes can vary widely; for example, individuals diagnosed with the syndrome may range from having mild
learning disabilities to being severely intellectually disabled. Further, there are no standard medical treatments, and there is a potentially complicated and uncertain treatment path, so once parents receive a diagnosis, it is not necessarily clear how to proceed and families may experience a trial-and-error process as they attempt to establish an effective treatment plan. As the child grows, treatments or interventions may need to be instituted, altered, or discontinued based on the child’s changing needs. It is important to note that FXS does have a variety of possible treatments to promote development and manage symptoms, including specific therapies, services, and medical interventions (National Fragile X Foundation 2006) but here the point is that what will work best for an individual may not necessarily be immediately obvious or straightforward.

For these reasons and others, as I describe further in each chapter, there are many ways that FXS may impact family life. This dissertation addresses three related sets of research questions:

• How is caregiving handled within the household, what meaning does caregiving hold for mothers, and how does this relate to broader notions about motherhood?
• Over time, how have mothers juggled work and family responsibilities, and in particular, how have they handled decisions about employment? What factors have influenced their decisions?
• How do mothers describe the impact—if any—of FXS on their romantic-partner or marital relationships?

Central to this project is the fact that there is a very real and well-described biological reality underlying the inheritance of FXS; it is the result of a genetic change on the X
carriers of FXS, meaning that they carry an altered form of the gene (National Fragile X Foundation 2008). Yet there is also a social context within which this condition is experienced, separate from its biological characteristics, and it is this context that this project will consider. Individuals who are carriers do not receive news of their status in a socio-cultural vacuum. Nor do they experience parenting a child with special needs, particularly an inheritable disorder, in the absence of a social context. In this dissertation, mothers’ subjective experiences of managing aspects of life with FXS, in particular, caregiving, employment, and romantic-partner relationships, are explored through an analysis of transcripts from existing interviews, and, for the second and third papers, 15 follow-up interviews gathering detailed information on these topics.

The first paper, focused on caregiving in early childhood, uses semi-structured interviews from waves 1-3 of the Family Adaptation to Fragile X Syndrome Study to examine how mothers talk about their roles and responsibilities toward their children, especially focused on the meanings that mothers attach to caregiving. In the three waves of the study, some mothers experienced a shift away from early intervention services, when professionals often work closely with parents to administer needed therapies and services, into a school setting for their children. In past research, Leiter (2004) has found evidence of a “therapeutic imperative” in early intervention settings, where mothers experience pressure from professionals to learn the techniques and employ them in the home outside of the formal therapy schedules. In the current paper, I adapt the concept of the therapeutic imperative to better understand mothers’ accounts of caregiving. Among many mothers in the study, I find evidence of a “developmental imperative,” or a profound sense of
responsibility for advancing their children’s development to reach their utmost potential, within a context of uncertainty about eventual outcomes. Interestingly, in this analysis no major shifts in meanings attached to caregiving were found over the three waves of the study. That is, a developmental imperative was found in each wave of the study, suggesting that it may not be tied to children’s ages, or that it may arise as part of the early intervention setting, but not remain limited to the time frame of early intervention. In this paper I also argue that this developmental imperative reflects a distinct set of experiences related to meanings of caregiving and motherhood, and that it is tied to both the broad cultural context of motherhood and the specific context of raising a child with FXS.

In the second paper, I turn to the topic of employment decision-making and the management of work and family demands. Both the focus on time as a limited resource and the notion of work and home as spheres that “pull” on people are key concepts that frame this analysis. Coser (1974) argues that the conflicting demands of these “greedy institutions,” work and family, are not solely the result of time constraints, but also result from conflicts in “allegiance” that can arise, especially for women. Women experience cultural pressure to make the family their primary focus and, at the same time, work “just like men” (Coser 1974). The relevance of these notions of conflicting “allegiances” and cultural pressures, particularly for women, is reflected in contemporary literature on work-family interplay, and provides the backdrop for the findings in this study. In this paper, I explore the relationship between these “pulls” – these potentially conflicting allegiances and demands in different domains – and respondents’ experiences in managing work and family demands (“juggling”), as well as how demands and resources in the two domains are related to employment decision-making. In this paper, using concepts from Voydanoff’s (2005) conceptual model of
work-family fit, I illustrate how respondents describe a work realm and a family realm that are not necessarily easily compatible, and the variety of strategies and resources that respondents and their families mobilize to actively address demands in conflicting domains.

In the third paper, I address an area that has been studied yet is not fully understood: the impact of children with special needs on parents’ romantic-partner relationships. Research has shown that children with disabilities are more likely than other children to reside with single mothers (Cohen and Petrescu-Prahova 2006) and that having a child with a disability may be linked to a higher risk of divorce or separation (Hartley, Barker, Seltzer, Floyd, Greenberg, Orsmond, and Bolt 2010; Risdal and Singer 2004). Other evidence has suggested variability in impacts on relationships (Eddy and Walker 1999; Taanila, Kokkonen, and Jairvelin 1996). Rather than focusing on risk of divorce, this paper examines respondents’ accounts of couple relationships in the context of FXS. The analysis reveals variation in respondents’ accounts; some identify impacts of FXS on relationships with spouses or partners, whereas others emphasize factors other than those linked to FXS. In addition to characterizing these descriptions, I theorize that a phrase used by some respondents, being “on the same page,” captures a sometimes complex process of aligning on parenting goals, behaviors, and strategies. Through the use of concepts from Swidler’s work on cultural repertoires (1986; 2001), I examine how the notion of being “on the same page” may provide insight into ways in which features of the social context – specifically, the gendered division of labor within some households with regard to researching, scheduling, and attending therapy appointments and services – relate to respondents’ accounts of relationships.
Lacking in the literature is nuanced information from mothers themselves regarding challenges they face and their experiences managing these challenges. More information is needed about how women describe their daily lives (Ryan and Runswick-Cole 2008) especially with regard to providing or arranging care for their children. Beyond exploring the challenges in these women’s lives, though, we must also be open to potentially complex and multifaceted views these mothers may hold of themselves and their role or roles, which necessitates a qualitative approach. By carefully examining how people tell the stories of their daily lives we can better understand their perspectives, and in particular, how they make meaning in their lives (Ferguson 2001). The notion that descriptions of everyday lives and activities can yield important insight into parents’ perspectives is a recent but valuable development in research on families of children with disabilities (Ferguson 2001). For example, while everyday caregiving for children may seem mundane, it is a set of patterned behaviors that highlights many areas of interest to sociologists including gendered expectations for caregiving behaviors, exchanges between family members and medical professionals, cultural notions of appropriate parenting (especially mothering), and the impacts of policy on individual lives.

Past studies of mothers of children with disabilities largely focus on psychological outcomes (Ryan and Runswick-Cole 2008) in general using standardized measures and scales. Instead, in this study, I focus on mothers’ subjective accounts and the meanings that particular practices hold for mothers, which is a needed contribution to research on the performance of social roles in general (Rogers 1996). Further, this project fits with a broader pattern of researchers attending more carefully to the sociocultural context within which families experience disability. As Skinner and Weisner (2007) explain, this approach
encompasses studies with a wide variety of research techniques and perspectives, yet all have in common an emphasis on “meanings, constraints, and opportunities that individuals with disabilities and their families encounter and engage in throughout life, and how these evolve within broader social and political contexts.” Overall, this project centers on how these mothers describe their experiences in this particular social, cultural, and institutional context. The result is a better understanding of situations these mothers experience, resources they draw upon, and how they make sense of certain areas of their lives.

Further, a contribution of this project is an illumination of mothers’ experiences within a particular social structure that places caregiving squarely on the shoulders of women, a feature of the social context that has largely been neglected in disability studies. As Traustadottir (2000) argues, disability studies have increasingly focused on the families of children with disabilities, but “the differences in activities and experiences of individual family members are routinely ignored. This…hides the difference between mothers’ and fathers’ experiences within the family, as well as the gendered nature of care work in families.” While not a comparative study of mothers and fathers, by specifying and theorizing aspects of mothers’ experiences, the current research is a step toward answering some of these questions currently under-examined in the literature on families of children with disabilities.

In particular, a question of interest for the present project is how beliefs about motherhood may be described and experienced by mothers of children with a particular inheritable condition, at this particular point in history. The current context involves changing gender norms and expectations related to work and family life, with women
continuing to move into the workforce, and yet gender inequality in patterns of household labor allocation and family caregiving remains (Walker 1999).

Regarding some of the topics covered in these papers – especially meanings of caregiving, demands in both the work and family realms, and experiences in romantic-partner relationships – it is important to note that, while the focus of this project is on FXS, it is just one element of these families’ lives. In their accounts, respondents described many different factors impacting these areas of their lives, and the intent of this project is not to narrowly interpret everything in families’ experiences as linked to FXS. Importantly, in the interpretation of mothers’ accounts, I noted cases where respondents did not feel there was an impact of FXS since that is an important aspect of their perspectives. As disability rights advocates have pointed out for individuals with disabilities, while a disability may be “an integral part of who they are, it alone does not define them” (United Spinal Association 2008), and that perspective may apply for families of children with disabilities as well. Therefore, I emphasize here that families’ complex experiences and perspectives cannot be reduced to simply the result of having an FXS diagnosis as part of their lives; instead, it is one part of their lives. Though the goal of this project is to better understand experiences of mothers of children with FXS in an effort to add to knowledge on family adaptation in that context, the discussion of FXS in these respondents’ lives is not meant to negate the many other factors that matter, nor is it meant to imply that families are fundamentally defined by having members who are diagnosed with FXS.

The rich qualitative data provide insight into commonalities as well as variation in respondents’ perspectives and experiences. Ultimately these papers add to the research on family experiences in the context of disability, but also might contribute to the design of
policies and programs, as professionals work to better understand what is beneficial to families and what challenges they face.
References


Chapter 2
Forms and Meanings of Caregiving

In this paper, I explore how mothers of children with fragile X syndrome (FXS) talk about caregiving, how they and their families manage their children’s special needs, and what meanings those activities hold for these mothers. The three research questions investigated in this paper are: How is caregiving handled within the household, what meaning does caregiving hold for these mothers, and how does this meaning relate to broader notions about motherhood? Before describing the findings related to these research questions, I outline some of the relevant literature that situates the research questions and findings in a broader framework. Then, I describe the data and analysis procedures, and conclude with a discussion of the major themes that emerged from the analysis, how they relate to broader cultural traditions in America, and their implications for policy.

Background and Significance

The focus of this paper is on accounts of caregiving given by mothers of children with FXS. To assess the meanings that these mothers attach to caregiving, I have examined their accounts of the daily care they provide for their children, discussions of their parenting strategies and philosophies, and descriptions of how they perceive their roles and responsibilities with regard to their children. Thus, “caregiving” in this context has a broad definition, including not only daily tasks such as dinner and baths, but also tasks related to children’s special needs, such as making appointments, engaging in therapeutic play and activities, and paperwork or advocacy for services and interventions on behalf of their child.
As I show below, elements of the latter category of tasks, such as therapeutic play and activities, and efforts to obtain and coordinate services and interventions for their children, were clearly integrally linked to other forms of caregiving and to mothers’ sense of their roles and responsibilities with regard to their children.

Despite evidence of recent changes in the hours of unpaid work performed by men (e.g., Bianchi, Milkie, Sayer, and Robinson 2000), women still perform the majority of carework and household labor (Bianchi, Milkie, Sayer, and Robinson 2000; DeVault 1991). Women still perform the majority of the care for children in families, and that pattern holds true in cases where children have special needs (McKeever and Miller 2004; Read 2000). In the current data, while some respondents described a fairly even division of labor between themselves and their partners when it comes to therapy- and service-related tasks, in line with the literature on the topic many respondents indicated that they were responsible for the majority of the coordination of those activities.

The specific pressures related to caregiving and childrearing experienced by mothers are unique in many ways compared to the pressures experienced by fathers. As Risman and Ferree (1995) point out, women have long borne the costs associated with childrearing with few rewards, while providing a social good that benefits the public at large. The work associated with childrearing, which I include in the broad term “caregiving,” is often unacknowledged and may continue well into the children’s adulthood (Risman and Ferree 1995). There may be many elements of caregiving, including not only the physical acts and service coordination involved, but also a high level of emotional investment and an accompanying strong sense of responsibility for the cared-for individual, a feeling that “they
have to ensure that things are made to happen” (Read 2000). This may be particularly true of a child with special needs (Ryan and Runswick-Cole 2008).

Beliefs about Motherhood

Beliefs about motherhood are always historically and culturally situated. Researchers have illustrated how these beliefs have shifted with social, scientific, and cultural transformations (e.g., Apple 1995; 2006). The current project takes the perspective that these mothers are embedded in a particular social, cultural, and historical context. The context for the mothers in the present study is one in which technology has given them unprecedented information about their – and their children’s – genetic makeup, but stops short of being able to offer a cure or standardized treatment. In the wake of a FXS diagnosis, while experiencing grief or other emotions related to the implications of that diagnosis, mothers may also redefine what it means, and what it will mean in their futures, to mother in that context.

Another aspect of the social context of the diagnosis involves the supports available: the children are eligible for early intervention services with a diagnosis of FXS (Bailey, Skinner, Sparkman, Moore, Olney, and Crawford 2002), yet with a consumer-driven health care system and sometimes cumbersome bureaucratic organizations, parents – especially mothers – may need to be strong advocates for their children to get services, which requires a certain degree of skill, time, and energy. In a study of a slightly smaller sample of the same mothers in this study, mothers of children with FXS identified their roles as caregiver, teacher, mother, and advocate (Brady, Skinner, Roberts, and Hennon 2006). Other studies have also found that caregivers take on an advocacy role (Grant 2007), often directly on behalf of their children (Litt 2004) and draw on their unique parenting experiences and
knowledge of their child’s particular characteristics to assert themselves in interactions with medical practitioners (Grob 2006; Schaffer, Kuczynski, and Skinner 2008).

One aspect of the cultural context is the expectation of intensive mothering; mothers feel the pressure to be good mothers by investing a good deal of time and energy in their children (Arendell 2000; Hays 1996). This may be especially true for mothers of children with special needs, with expectations of selfless devotion to their children’s care at the expense of other areas of their lives (McKeever and Miller 2004). Indeed, in the case of FXS the early childhood years may be crucial for maximizing children’s outcomes because the brain is still developing and early intervention services and therapies may help significantly increase the child’s potential (Eunice Kennedy Shriver National Institute of Child Health and Human Development 2003). Further, the home environment and family setting have been shown to influence the development and behavior of children with FXS (Bailey 2007). Treatment regimens may require investments of time and energy by parents – often mothers – in order to carry out exercises and other activities at times when therapists and other service providers are not present. Yet while much is demanded of mothers, little social recognition is given to them for their labor (Read 2000).

In work on the sociology of responsibility, such as Heimer and Staffen’s research (1998) on parental responsibility for children in neonatal intensive care units, responsibility is theorized not as a moral imperative, ethic, or virtue, but rather as the product of a set of social and organizational relationships. Heimer and Staffen (1998) define the concept in order to examine the nature of responsibility as a theoretical construct, and to answer questions about who takes responsibility in what contexts. They define those who take responsibility as distinct from others in five ways: by “taking the interests and needs of
others seriously, focusing on both present actions and future outcomes, defining obligations broadly (even following them across organizational boundaries), using discretion to meet unforeseen contingencies, and accepting whatever costs and benefits are entailed” (Heimer and Staffen 1998). In other work on the sociology of responsibility and caretaking, Timmermans and Freidin (2007) studied mothers’ uptake of responsibility for their children’s asthma care, and illuminated ways in which diffuse asthma caretaking tasks necessitated articulation work on the part of mothers. While focused on parenting in a different setting, the current study reflects a similar conceptualization of responsibility, and the findings describe ways in which the respondents in the current study take responsibility, in the sense that is defined above, for their children.

Past research has shown that mothers of children with disabilities may face a unique situation with regard to expectations of mothers, such as feeling as though their parenting behaviors are “under a microscope” because of the way that their children’s development is consistently evaluated by professionals, and the mothers themselves are simultaneously evaluated by experts who are in a position of power (Read 2000). Parents may also go to great lengths to obtain specialized knowledge. An ethnographic study of parents whose children have a genetic diagnosis revealed the strong sense of responsibility that some parents experience when it comes to searching for information on their children’s conditions and treatments via the Internet. Some parents “conveyed a heavy sense of responsibility, a moral obligation, to keep looking for information that might make a difference to their child’s health and development. If only they could search harder and longer, they might find the crucial bit of information that could make a difference” (Skinner and Schaffer 2006). Evaluation and comprehension of the information is just one part of the process; it is likely
that parents have already expended a great deal of time and energy obtaining the information in the first place.

In addition to the broad sociocultural expectations regarding intensive mothering faced by mothers of both typically developing children and children with disabilities, there is also evidence in the literature that mothers of developmentally delayed children encounter a “therapeutic imperative” through their interactions with the doctors and therapists caring for their children (Leiter 2004). That is, mothers are expected to learn the therapeutic techniques practiced by these professionals and employ them in the home (Leiter 2004). In the literature, it appears as though these mothers of children with special needs may experience the dual pressures to be both a good mother and a good “medical manager.” The term “medical manager” is intended to reflect both the therapeutic work that these mothers may be expected to do, or may feel they ought to do, as well as the work associated with coordinating services, therapies, and medications for their child as necessary. Below, I explain how these dual roles are intertwined in accounts of maternal roles and responsibilities, and the ways in which these respondents take responsibility for maximizing their children’s development in multiple areas.

Fragile X Syndrome

Fragile X syndrome (FXS) is the result of a genetic mutation that inhibits a particular gene (FMR-1) on the X chromosome from producing a protein necessary for brain development (Centers for Disease Control and Prevention 2006). Specifically, it is known as a nucleotide repeat disorder; in individuals with FXS, there are excessive repeats of the CGG trinucleotide sequence on a particular gene. The mutation of the gene goes through particular stages as it is passed down, and individuals with 55 – 200 CGG repeats of DNA and a normal
mythelation (whether a gene is turned on or off) pattern are typically considered to have the premutation form of the gene (National Fragile X Foundation 2008). Those classified as having the full mutation typically have over 200 repeats and the gene is methylated – turned off so that it does not produce any, or enough, of the necessary protein (National Fragile X Foundation 2008). FXS occurs across all races and ethnicities, and it affects about 1 in 4,000 males and 1 in 8,000 females (National Human Genome Research Institute 2007). Other estimates place the rate of occurrence at 1 in 3600 males and 1 in 4000 to 6000 females (National Fragile X Foundation 2006). Males are more likely to be symptomatic than females because the mutation is on the X chromosome, and since they only have one, they are more vulnerable to the mutation’s effects (Bailey and Nelson 1995). In women, their other X chromosome can sometimes outweigh the impact of the gene with the mutation. By some estimates, about 1 in 250 women and 1 in 800 men are carriers of the premutation, which contains fewer repeats of the DNA sequence, compared to those classified as having the full mutation (National Fragile X Foundation 2006). Individuals with the premutation may have some symptoms of FXS or fragile X-associated conditions, such as premature ovarian failure or fragile X-associated tremor/ataxia syndrome (FXTAS), a Parkinson’s-like tremor, or may have no symptoms at all (National Fragile X Foundation 2008). The gene responsible for the syndrome was discovered in 1991 (National Fragile X Foundation 2005), although the syndrome itself was first detected in the late 1970s. Once the gene was identified, FXS could be definitively diagnosed, people could be tested for both the full mutation and carrier status, and prenatal testing became possible (McConkie-Rosell, Finucane, Cronister, Abrams, Bennett, and Pettersen 2005).
The National Institute for Child Health and Human Development classified symptoms of FXS into five categories: intelligence and learning; physical; social and emotional, speech and language; and sensory symptoms (see Table 2.1). In addition, certain disorders sometimes appear alongside FXS or share characteristics with the disorder. These include autism, attention deficit disorder/attention deficit hyperactivity disorder, connective tissue problems, seizures, as well as later onset disorders of carriers, such as premature ovarian failure for women and FXTAS (Eunice Kennedy Shriver National Institute of Child Health and Human Development 2003; National Fragile X Foundation 2008).

Table 2.1 Characteristics Associated with Fragile X Syndrome\(^1\) (continued next page)

<table>
<thead>
<tr>
<th>Category</th>
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<tbody>
<tr>
<td><strong>Intelligence/ Learning</strong></td>
<td>Impaired ability to think, reason, and learn</td>
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<tr>
<td></td>
<td>Lower than average IQ score; those with full mutation tend to have IQ between 40 and 85, considered mild to moderate impairment, though females less affected than males</td>
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<tr>
<td></td>
<td>Good memories for visual patterns and pictures</td>
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<td></td>
<td>Difficulty with abstract ideas, organizing information, planning ahead, solving problems</td>
</tr>
<tr>
<td></td>
<td>Make progress with learning but may need additional time, special environment/teaching methods</td>
</tr>
<tr>
<td><strong>Physical</strong></td>
<td>Infants and young children usually have no physical signs; may have softer skin than average, or a slightly larger head</td>
</tr>
<tr>
<td></td>
<td>Adolescents often develop an elongated face and larger, more noticeable ears</td>
</tr>
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<td></td>
<td>May not be as tall as expected</td>
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<tr>
<td></td>
<td>May experience seizures (20%)</td>
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<tr>
<td></td>
<td>Males develop enlarged testicles (macro-orchidism)</td>
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<tr>
<td></td>
<td>Weak connective tissues may predispose individuals to hernias, frequent ear infections, heart murmurs</td>
</tr>
<tr>
<td></td>
<td>Females with the premutation may experience premature ovarian failure (16 - 19%)</td>
</tr>
<tr>
<td><strong>Social/ Emotional</strong></td>
<td>Often experience social anxiety, especially boys; may stop them from being social, or from seeking out new experiences or contact with others</td>
</tr>
<tr>
<td></td>
<td>Males tend to be easily upset, overwhelmed, or distressed, particularly if senses are overloaded; may become upset by changes in routine</td>
</tr>
</tbody>
</table>

\(^1\) Note that there is usually a great deal of variation in characteristics of individuals with FXS. This table reflects some characteristics that have been associated with FXS, but many individuals will not have these characteristics.
Table 2.1 Characteristics Associated with Fragile X Syndrome (continued)

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<th>Category</th>
<th>Characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>When upset or anxious, take longer to calm down than peers</td>
</tr>
<tr>
<td></td>
<td>Becoming upset may manifest as tension or rigidness, tantrums, or repetitive motions; may result in trouble at school</td>
</tr>
<tr>
<td></td>
<td>Adolescents may have more dramatic outbursts due to hormone levels</td>
</tr>
<tr>
<td></td>
<td>Females may have social problems but will likely be milder than males’</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Speech/Language</th>
<th>Problems communicating: mild stuttering to difficulties with pronunciation or communication through speaking and writing, tendency to ramble or speak off-topic; problems regulating tone of voice, pitch</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Often begin talking later than expected; most around the age of 4, but sometimes age 6 – 8; some remain nonverbal</td>
</tr>
<tr>
<td></td>
<td>Severe language problems rare among females; males tend to have moderate to severe problems</td>
</tr>
<tr>
<td></td>
<td>Males may also have problems processing written or spoken instructions</td>
</tr>
<tr>
<td></td>
<td>Some language difficulties likely linked to social anxiety and shyness</td>
</tr>
<tr>
<td></td>
<td>Males may be very interested in communicating but may face challenges processing relevant signals, conversational cues, etc. in others</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Sensory</th>
<th>May have problems with balance, coordination</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Sensitivity to loud noises or other sensations may cause outbursts or distraction</td>
</tr>
<tr>
<td></td>
<td>May avoid physical contact if they find it overwhelming</td>
</tr>
<tr>
<td></td>
<td>Therapy may assist with helping individuals manage sensory overload</td>
</tr>
</tbody>
</table>


There are key differences in symptoms by gender; girls are likely to exhibit milder forms of intellectual disability as well as the behavioral and physical characteristics associated with FXS (National Fragile X Foundation 2006). For several reasons, including its wide range of symptoms, co-occurrence with other conditions and disorders, and the fact that it is not widely known, FXS is often not diagnosed until a child is around 3 years old (Bailey, Skinner, Hatton, and Roberts 2000; Bailey, Skinner, and Sparkman 2003; Bailey et al. 2002). There is no routine screening at birth and characteristics may emerge slowly over time; the family may first struggle with whether the characteristics they are seeing are truly problems,
and may be assured by medical professionals that everything is fine or that the child is simply a “late bloomer.”

Families may undergo a “diagnostic odyssey,” which refers to the long process of searching for an explanation for the symptoms that they see in their child (Bailey, Beskow, Davis, and Skinner 2006; Bailey, Skinner, and Sparkman 2003; Carmichael, Pembrey, Turner, and Barnicoat 1999). One study revealed that the journey to a genetic diagnosis was often circuitous and exacted a toll on parents’ resources, both emotional and financial. The age at diagnosis was an average of 18 months or longer after initial concern about the child’s development (Bailey, Skinner, and Sparkman 2003). Bailey et al. (2006) summarized specific costs of this long road to the diagnosis of FXS: children miss, on average, 2 years of early intervention services; parents question their abilities when professionals assure them that “everything was OK”; parents may make 10 or more visits to professionals seeking a diagnosis, incurring costs, and in the interval between the child’s birth and the diagnosis, many parents have another child with FXS, not realizing that their other child’s condition was hereditary (Bailey, Beskow, Davis, and Skinner 2006; Bailey, Skinner, and Sparkman 2003).

Once parents receive a diagnosis of FXS, there are therapies, services, and interventions that have been found effective but there is no standardized medical plan of action for treating the condition. One reason for this is the wide spectrum of symptoms that accompany the condition. FXS, as of the time of this research, has no cure; the treatments for the child usually involve prescription drugs, behavioral therapy, and speech or occupational therapy, among other options, to manage symptoms and promote development (Eunice Kennedy Shriver National Institute of Child Health and Human Development 2003; National
Fragile X Foundation 2006). The medical aspects of the treatment may be aimed at managing aggression, anxiety, hyperactivity, short attention spans (National Fragile X Foundation 2006), sleep disturbance, hyperarousal or sensory overstimulation, obsessive-compulsive disorder, and seizures (Eunice Kennedy Shriver National Institute of Child Health and Human Development 2003).

Data and Methods

The results presented here are based on data from the Family Adaptation to Fragile X Syndrome Study (FAFXS). The FAFXS study includes data on 108 carrier mothers and 27 fathers from all over the United States. For the purposes of this study, I focused on the cohort of 60 mothers whose children, for the vast majority of the sample, were less than 36 months old at the time of the first interview (Table 2.2). Fifty-six (93%) of the mothers had the premutation form of the gene, while 4 (7%) had the full mutation, and all had at least one child with the full mutation. The FAFXS study sample also reflects a range of incomes. The mothers’ ages ranged from 20 – 43, with a mean of 32.3 and standard deviation of 5.11. Five respondents (8%) were African American, one respondent was Hispanic, and one respondent was categorized as “other.”

Table 2.2 Family Adaptation to Fragile X Syndrome Study: Sample Characteristics

<table>
<thead>
<tr>
<th>Maternal Characteristics: Young Cohort</th>
<th>Total (N=60)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age in Years</strong></td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>32.32 (5.11)</td>
</tr>
<tr>
<td>Range</td>
<td>20 - 43</td>
</tr>
<tr>
<td><strong>FX Mutation Status</strong></td>
<td></td>
</tr>
<tr>
<td>Full Mutation</td>
<td>4 (7%)</td>
</tr>
<tr>
<td>Premutation</td>
<td>56 (93%)</td>
</tr>
<tr>
<td><strong>IQ</strong></td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>107.23 (14.3)</td>
</tr>
<tr>
<td>Range</td>
<td>55 - 130</td>
</tr>
</tbody>
</table>
Table 2.2 Family Adaptation to Fragile X Syndrome Study: Sample Characteristics (continued)

<table>
<thead>
<tr>
<th>Maternal Characteristics: Young Cohort</th>
<th>Total (N=60)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Education</strong></td>
<td></td>
</tr>
<tr>
<td>Less than high school</td>
<td>3 (5%)</td>
</tr>
<tr>
<td>High School Graduate</td>
<td>3 (5%)</td>
</tr>
<tr>
<td>High School; Some College; Associate’s Degree</td>
<td>22 (37%)</td>
</tr>
<tr>
<td>College Degree or Higher</td>
<td>32 (53%)</td>
</tr>
<tr>
<td><strong>Race/ethnicity</strong></td>
<td></td>
</tr>
<tr>
<td>White/Caucasian</td>
<td>53 (88%)</td>
</tr>
<tr>
<td>Black or African American</td>
<td>5 (8%)</td>
</tr>
<tr>
<td>Hispanic or Latino</td>
<td>1 (2%)</td>
</tr>
<tr>
<td>Other</td>
<td>1 (2%)</td>
</tr>
<tr>
<td><strong>Annual Gross Household Income</strong></td>
<td></td>
</tr>
<tr>
<td>≤ 26,000/year</td>
<td>8 (13%)</td>
</tr>
<tr>
<td>26,001 – 45,000/year</td>
<td>13 (22%)</td>
</tr>
<tr>
<td>45,001 – 65,000/year</td>
<td>11 (18%)</td>
</tr>
<tr>
<td>65,001 – 100,000/year</td>
<td>16 (27%)</td>
</tr>
<tr>
<td>≥ 100,001/year</td>
<td>12 (20%)</td>
</tr>
<tr>
<td><strong>Low Income (200% of poverty line or below)</strong></td>
<td>14 (23%)</td>
</tr>
<tr>
<td><strong>Mother’s current marital status</strong></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>50 (83%)</td>
</tr>
<tr>
<td>Divorced/Separated</td>
<td>3 (5%)</td>
</tr>
<tr>
<td>Single, Never Married/Engaged</td>
<td>7 (12%)</td>
</tr>
</tbody>
</table>

(Source: Dr. Debra Skinner, Co-Investigator, Family Adaptation to Fragile X Syndrome Study)

This analysis uses data from three semi-structured interviews that were conducted with each mother, with 18 months between each interview. For the purposes of these analyses, I analyzed interview and demographic data for 57 respondents: 56 respondents at time one, 53 at time two, and 45 at time three. At the beginning of the study the children were an average of 29 months old, or 2.4 years, and ages ranged from 10 months to 4 years. The interviews covered many different aspects of family adaptation to FXS, including respondents’ perspectives on their roles and responsibilities toward their children and accounts of respondents’ approaches to parenting. For the purposes of this analysis, content on respondents’ ideas about their roles and responsibilities as well as content related to
respondents’ ideas about parenting (their parenting philosophy or approach) were indexed using NVivo8.

In part, the accounts of respondents’ roles and responsibilities toward their children were responses to questions from the semi-structured interview guide at each of the three waves of the study: “In general, what do you consider to be your roles and responsibilities in relation to (child)? [If the family is enrolled in Project 2 sib study, ask how these roles and responsibilities in relation to the child are the same or different as for the target sibling.] What do you see your role as being when (child) is an adult?” In addition, elsewhere in the interview respondents described feeling or being responsible for certain tasks in general. This information, as well as that where respondents described themselves as having a particular role outside of the context of that question, was captured as well. For example, responding to a question about her self-understanding, one respondent said:

Respondent: I’m a wife and a mother. And a Christian. And a [job title]. Even though I’m not working, I still identify myself that way. I’m a mother of a disabled child. I’m a friend. I’m a daughter. I’m a sister. Those are the main things I guess.
Interviewer: And how does fragile X figure into your self-understandings?
Respondent: I guess just that I have more on my plate than ever. That I need to rise up to the occasions for it.
Interviewer: Has that changed over the years?
Respondent: Not really. I think there’s just more pressure now. To be a good parent. To figure out what the right thing to do for him. Unfortunately there’s no cookie cutter answer for anybody to tell me how to raise him. So it’s like I do it by the seat of my pants. I read. I have friends who have kids with fragile X. I don’t know. I think parenting any child is like a journey. But this one – there’s so many unknowns. (420-I3)

While the question addressed how she thought about herself, her response indicates certain responsibilities, which is important information to capture for an analysis of respondents’ perceptions of their “job descriptions” as parents of children with FXS. This quote, then, is
offered as an illustration of how the conceptual boundaries for the content coded for roles and responsibilities were broad, and not limited to the questions that solicited their opinions on the topic directly.

Further, the above quote is an appropriate one to illustrate key elements of mothers’ experiences. In particular, this respondent indicates that she feels responsible for figuring out “the right thing to do for him” with “no cookie cutter answer.” In her view, the metaphor of a “journey” is appropriate for parenting any child but in her particular journey, “there’s so many unknowns.” These three points – about figuring out the right thing to do, no cookie cutter answers, and the unknowns involved in parenting a child with FXS – echo the experiences of many of the respondents. Below, I elaborate on these and related points, explain connections among them, and show that they are an important aspect of mothers’ accounts of their responsibilities in the context of FXS.

Content related to respondents’ broader notions of their parenting strategies, parenting philosophy, and influences on their parenting styles was also found throughout the transcripts. When defining the boundaries of these concepts in order to address the research questions for this project, I was less concerned with identifying specific parenting or caregiving behaviors of respondents; rather, the focus was on why mothers chose those behaviors or actions, and what they had to say about the broader purpose or meaning of those behaviors. As a result, information on specific behaviors (e.g., ‘we reward our son for good behavior using praise and clapping’) may be included in the content indexed for parenting strategies, but the focus is on explanations for why they choose that strategy, or other features of their account that give insight into their broader beliefs about, and approaches to, parenting.
There was a considerable amount of data related to these categories of information on parenting roles and responsibilities. This is to be expected, as the study was focused on family adaptation to FXS, and certainly accounts of broad notions about parenting and roles and responsibilities will arise during discussions about adaptation. Therefore, because of the structure of the study I cannot draw any conclusions about the centrality of these topics to these respondents’ experiences based solely on the amount of text related to these topics. However, the analysis revealed ways in which the content of their accounts reflected the significance of caregiving to their experiences.

I performed a close reading of the interview data on parenting approaches and philosophies to inform my interpretation of the data on roles and responsibilities, but given the specific research questions for this paper, the detailed analysis focused on the content related to respondents’ roles and responsibilities. There was also a degree of overlap between the coded categories. A query for segments coded for mothers’ roles and responsibilities yielded data for 55 respondents at time one, 53 respondents at time two, and 44 respondents at time three. Forty-two respondents had data for roles and responsibilities at all three times, 11 respondents had data at two times only, and 4 respondents had data at one time only. Using query results, I developed a matrix that aided in the analysis of the coded content for each interview. The matrix helped reveal patterns for each respondent, relationships among their accounts over time, and comparisons across cases (Miles and Huberman 1994).

I used NVivo8 to create the matrix, which resulted in cells that linked to the corresponding references, or segments of text. Each respondent’s accounts over the three waves were examined in consecutive order, and key passages, notes about changes, similarities, and continuities were generated for a separate table. The table contained a
summary of relevant quotes, comments, observations, and notes for each respondent, and formed the basis for this analysis, although the original text segments were revisited as necessary. This process allowed me to distill the concepts in the data through creating the summary notes and memos, while attending to the original details of the data by continually revisiting the coded segments of the transcripts. These aspects of the process had features of a grounded theory approach (Silverman 2006). In addition, I used existing literature and sociological theory to inform the analysis.

Following the creation of the summary table, I made another pass through the data, inserting notes, comments, and observations as appropriate, and highlighting to distinguish the passages related to three important aspects of the analysis: changes over time, the developmental imperative, and ideas about specific roles or responsibilities. I made multiple passes through the data to evaluate the applicability and appropriateness of the major themes that I identified, and to identify contrasting cases and alternative themes or relationships.

My analysis strategy was influenced by Attride-Stirling’s (2001) description of the development of thematic networks. An initial step in developing a thematic network to describe and explain the content of qualitative data is the development of basic themes, which are the “lowest-order theme” that the textual data yield. These are “simple premises characteristic of the data” that, alone, do not characterize the data, but when interpreted in light of other basic themes, shed light on higher-level statements about the data. Basic themes, in combination, yield organizing themes. These organizing themes are higher level statements that are “clusters of signification that summarize the principal assumptions of a group of Basic Themes.” As a result, the organizing themes provide a more abstract summary of the data, but are rooted in the themes that are “closer” to the data. If a global theme can be
identified at an even higher level of analysis, it represents a grouping of organizing themes and the “core” of a thematic network. These global themes “encompass the principal metaphors in the data as a whole” (Attride-Stirling 2001).

Findings and Discussion

The discussion highlights significant findings that emerged from a thematic analysis of the data, and how those findings relate to the literature. I show that mothers of children with FXS perceive themselves as having a wide range of roles, with the role of “mother” being a central aspect of their self-understandings, and that they express a profound sense of responsibility for their children’s development and progress in multiple areas. I argue that, taken together, basic themes in the data reflect the concept of a “developmental imperative,” an organizing theme related to caregiving. After describing features of the developmental imperative, I discuss the relationship between the developmental imperative and characteristics of families’ experiences with FXS. I conclude with policy considerations.

The results of this study complement findings in a related study that investigated mothers’ roles and responsibilities. According to that research, mothers described their roles as caregiver, teacher, mother, and advocate (Brady, Skinner, Roberts, and Hennon 2006). Here, I confirm those findings, but also examine in more depth the ways that these respondents talked about their roles and responsibilities. My focus is exploring whether and how their accounts relate to existing literature on beliefs about motherhood, the sociology of responsibility, and theories about parenting and family life in contexts other than families living with FXS (e.g., Hays 1996; 1997; Heimer and Staffen 1998).

In general, mothers indicated that they held the primary responsibility for scheduling and attending service and therapy appointments, often making decisions about service and
therapy options, and daily caregiving. This is in line with existing research on the division of labor in households with children with special needs (McKeever and Miller 2004; Read 2000; Traustadottir 1991). Below, I show that the caregiving performed by these mothers is not only caregiving directly provided to children, such as feeding and baths, but that one large part of their perceived responsibilities as mothers is to serve as mediators between their children and the institutions and organizations that provide services and therapies to them. They describe interactions with representatives of institutions (e.g., schools) or organizations (e.g., health insurance companies) as a significant aspect of their roles and responsibilities. Further, I show how this work is one dimension of a broader set of “musts” for these respondents.

Parent as Advocate

A key role or responsibility that mothers discussed was their position as their child or children’s advocate. This was phrased in several different ways, using terms like “advocate” and “caseworker” but also describing actions and behaviors related to advocacy. For example, one respondent said of her roles, “To be his advocate. To be his voice. To find out as much as possible. And then, to be able to one day when he’s older, I pray that he’ll be able to understand. That I’ll be able to share all that I’ve gathered and all that I know with him.” (160-I1) While others have reported similar findings regarding roles of mothers of children with FXS (Brady, Skinner, Roberts, and Hennon 2006), and of parents of children with special needs more broadly (e.g., Kratz, Uding, Trahms, Villareale, and Kieckhefer 2009; Litt 2004; McKeever and Miller 2004; Prussing, Sobo, Walker, and Kurtin 2005), in this analysis I also illustrate the relevance of that role to the overall organizing theme of the
developmental imperative, and how it contributes to broader theorizing about responsibility among mothers of children with FXS.

It is important to note the range of services, therapies, and institutional settings in which these mothers advocate for their children. These settings include speech therapy, occupational therapy, behavioral therapy, school settings, and medical settings (for example, talking to doctors about medications or medication adjustments). When asked about her roles and responsibilities with regard to her son, a respondent went beyond describing the daily caregiving tasks associated with parenting – “feed him, shelter him” – to describe responsibilities with regard to accessing therapists in multiple domains and meeting specific developmental goals.

Of course feed him, shelter him, all those things. And then to really make sure that his goals and expectations from his IFSP are carried out, and to make sure he sees the people that he needs – the therapists that he needs to, that he gets the braces in his shoes that he needs to. And just to make sure I am giving him every opportunity and getting him every service that he can that’s available, OT, PT, speech, all that. (800-I1)

This respondent, like many others, clearly viewed herself as positioned between her child and service providers, and saw her role as maximizing both the impact of the therapies, by making sure that specific goals and expectations are met, and maximizing the quantity and types of therapies and services to which her son has access. A majority of respondents’ accounts reflected similar viewpoints: that seeking out, advocating for, or obtaining therapies and services are important aspects of their responsibilities.

Similarly, another respondent described therapy- and service-related tasks involving interactions with multiple actors and settings. Here, she described working with a social
service coordinator to obtain a government waiver, as well as working with doctors, insurance, and therapies.

I do the doctors, I do everything. I make sure that he’s getting his social service coordinator to do what she’s supposed to do, that he’s going for his – when he turned three – for his med waiver intake, whatever you would say. I do everything. Again, the doctors … the insurance, the referrals, all the therapy. We also do swimming. I’m the one who will introduce new – I do everything. (940-I1)

In addition to advocating for therapies, respondents described serving in an advocacy role with regard to their children’s education. For example, one respondent specifically said that she felt it was her job to intervene when her daughter was going to have a new teacher who may not know much about FXS.

Everything. Name it. Everything. Number one is education director. Making sure that when somebody says “Well, [respondent’s daughter]’s coming into my classroom in three days. I haven’t really read up on fragile X. But [someone] said that she had some information for me.” That to me is like “Okay. This is my job. I better make some phone calls. And I better write some e-mails. Because this woman doesn’t have a clue. And she’s going to be in charge of my kid in three days. No. Not okay.” (1040-I3)

The idea that a teacher or other professional may not know much about FXS was discussed by some other respondents, as well; sometimes they were describing a hypothetical concern, and sometimes describing situations they have encountered (though, certainly, respondents also described positive experiences with teachers and professionals). The fact that FXS is currently not widely known among the general public may contribute to some mothers’ feelings of responsibility when it comes to intervening on behalf of their children to ensure that their needs are met, especially in terms of helping others understand the nature of those needs.
In each of the examples above, mothers described advocating for their children and intervening on their behalf in many different contexts. This description of their responsibilities is in line with two dimensions of the definition of responsibility offered by Heimer and Staffen (1998) in their research on the uptake of responsibility among parents whose children are in a neonatal intensive care unit: those who take on responsibility consider the needs and interests of others as well as their own, and they define their obligations broadly and will “follow them” across multiple institutional or organizational settings. In addition to formal settings such as Individualized Education Plan meetings for school, or medical appointments regarding medications, a few mothers described coordinating the efforts of others in informal settings as well, such as in the example below.

Well I guess I at least try – these goals that I told you I have for him for the next year, I want to work on them personally and I also want the nanny to work on them. So I tell her, “You sing that ABC song in the car all the time, and you work on these colors.” And I told people at school. So if I set the goals for him, then my role is to make sure everybody is working on them consistently, … everybody. So other than taking good care of him and making sure he’s happy and warm and loved, my responsibilities are to make sure he reaches his goals. (180-I1)

Other respondents also described multiple settings and situations in which they advocated for their children’s needs and interests across various institutional and organizational boundaries, as well as in less formal settings.

*Developmental Imperative*

In mothers’ accounts of caregiving and roles and responsibilities, one significant theme is the sense of responsibility for learning and employing therapeutic and management techniques, as well as obtaining all relevant services, in order to maximize their children’s full potential for development. I describe this as a *developmental imperative*. This concept is an adaptation of Leiter’s (2004) notion of a “therapeutic imperative,” which she uses to
explain her finding that, through early intervention services, professionals create an
effect of therapeutic work to be performed by mothers, outside of what is carried out by
the professionals. Leiter links this imperative to larger social factors such as early
intervention’s “family-centered” approach to managing disabilities in children that is
supposed to involve both professionals and families in active participation in children’s
therapies. Leiter’s (2004) discussion of the therapeutic imperative, described from the
perspectives of the professionals and mothers, centers on expectations for mothers and
mothers’ responses to those expectations, and highlights related complexities and multiple
problematic aspects of that imperative.

Here, I adapt that concept to help explain the perspectives of mothers of children with
FXS regarding caregiving. Mothers’ accounts of their roles and responsibilities toward their
children exhibited a developmental imperative, a profound sense of responsibility for shaping
their children’s developmental outcomes in multiple spheres. Depending on the child and
family, these spheres sometimes included social, behavioral, educational, physical, and moral
development. Rather than conveying a sense of the involuntary, the term “imperative” here is
meant to indicate the sense of “musts” in these respondents’ perceived roles and
responsibilities, and the strong obligations they expressed regarding promoting their
children’s development.

To be clear, by arguing that a developmental imperative was evident in respondents’
accounts of their roles and responsibilities, I do not mean to imply that developmental
outcomes are the sole outcome of interest for respondents, or that all caregiving and
parenting behaviors were keyed on encouraging development in their children. The evidence
for a developmental imperative in the data does not preclude other meanings that these
respondents attach to caregiving and parenting. While not the focus of this analysis, respondents’ descriptions of their goals and expectations for their children often emphasized that they simply want their children to be happy, rather than solely focusing on developmental goals and expectations. Future research could more closely examine mothers’ descriptions of their goals and expectations for their children, both currently and in the future, but this point is offered here to make clear that respondents are not solely focused on encouraging their children to meet developmental targets. By identifying and characterizing the developmental imperative present in many mothers’ accounts, I seek to illuminate this common aspect of their perception of their responsibilities toward their children and explore its implications for their experiences and for sociological understandings of responsibility, while acknowledging that it does not encompass the entire range of meanings that caregiving may hold for mothers. Instead, it is understood to be one important aspect of their accounts.

As mentioned, a key aspect of the developmental imperative is a strong sense of responsibility for the child’s developmental outcomes in the future. As one respondent noted, “I just feel the need to do everything I can to make him as good as he can be.” (280-I1) Other respondents’ accounts reflected this sentiment:

Well I feel like my role is to still be there for her, I still have things I have to do for her and my responsibility is to have her to communicate better so she can go to school next fall easier and my expectation of myself is to hopefully get her somewhat potty trained, somewhere, somehow. (820-I2)

When asked about her roles and responsibilities, this respondent listed two specific developmental goals: better communication and toilet training. While this respondent did not explicitly discuss a general sense of responsibility for the child’s overall development, this account fits with the concept of the developmental imperative because, when presented with an open-ended question about her roles and responsibilities with regard to her daughter, her
response focused on two specific developmental goals as part of this respondent’s “responsibility” and “expectation of [her]self.”

Other respondents more explicitly described a general sense of responsibility for their child’s developmental outcomes. The example below is in response to a question about whether or how this respondent’s responsibilities for her child with FXS differ from her responsibilities for her child who does not have FXS.

I think it’s huge because if I ever see … I feel like it’s my fault because we didn’t work with her as hard, we didn’t follow … as hard because – so I guess, yeah, as far as role, I feel it’s the same as [daughter without FXS]; responsibility, I think weighs much heavier with [daughter with FXS] than with [daughter without FXS] because I mean maybe I didn’t work with her enough on this. I think it always falls back on us. I don’t know. That’s kind of how I feel. (740-I1)

In this account, stating that “it always falls back on us,” this respondent expressed a viewpoint that others have also reported in mothers of children with special needs – that ‘the buck stops with them’ (Read 2000). In a similar fashion, the excerpt below clearly reflects this respondent’s sense of responsibility for making the choices that will best help her son (emphasis added).

Should he have more sensory integration therapy to make him be able to live easier and focus more? Should he have meds? I think all of that is a great responsibility that you cannot leave to the schools to tell you or a doctor to tell you. You have to listen to all of their recommendations. But ultimately no one can make that decision. We have to do all the research. And, we have to live with it here. And decide what’s worth it. And even the Ritalin was the last med trial. There were some positive things happening with the Ritalin. But when it wasn’t positive, it seemed like the negatives were worse than his base line negative. And so, we had to make a decision. And we did see Dr. [X] last August. And she’s who’s helping us with all these. And even though I call her an FX guru, it’s still not her choice. It’s still our choice. And so you listen to all that. And then you kind of go with what you think is going to be the right thing for you and your family. (860-I2)
This respondent stressed that, from her perspective, the role of professionals – here, schools and doctors – is to make recommendations, but parents ultimately make the decision about their children’s treatments. In this case, she went on to identify herself as the one who does research on those matters, and that her husband helped her make decisions but she was “more the decision-maker” about therapies and medications. In other accounts, mothers also portrayed themselves as responsible for researching, suggesting, and assessing treatments.

Another respondent’s account exemplified an additional aspect of the developmental imperative: a sense of responsibility for being attuned to any lapses in progress and the impact on future outcomes for her daughter.

[Time two:] Making sure she keeps on track. And once she starts slipping, I need to take care of it right then and there. And that’s the problem I had with [son]. If I’d started a lot of these services when he was much younger, he probably would have been a little more advanced.
[Time three:] I think I’m her molder. Whatever she gets from me right now is extremely important for her later. (1000)

An emphasis on planning for the future, and the close relationship between parents’ present actions and children’s outcomes in the future, was expressed by several mothers. In addition to the future-oriented therapeutic work, caregiving, and service coordination that respondents described, a few also mentioned the importance of preparing for their children’s care in the future in the event that the parents would be unable to care for them. These discussions included shifting funds to special needs trusts, investing well, and preparing siblings for the possibility of having to look after their brother or sister with FXS.

This aspect of parenting in the context of FXS parallels one of the five key aspects of the theoretical conceptualization of responsibility described by Heimer and Staffen (1998). They note that “[r]esponsibility necessarily entails thinking about the future as well as the
present and making trade-offs between today and tomorrow, always with the full knowledge that no one can know what exactly tomorrow will bring.” A key aspect of responsibility, both in Heimer and Staffen’s work, and in accounts of mothers in the present study, involves being oriented toward outcomes for the future for one’s child, and taking action in the present day to work toward particular results.

Research on the ideology of intensive mothering holds that one feature of that ideology is the expectation that, to be good mothers, women must devote a great deal of time and energy to raising their children (Arendell 2000; Hays 1996). The respondents in interviews expressed a similar sense that, when possible, it is essential to dedicate considerable time and energy to their children’s care. For example, some mothers who were not employed outside of the home, or who worked part-time, described their decisions about employment in terms of the need to spend more time caring for their children, and some respondents specifically described decreasing work hours in order to increase therapy hours with their children or to focus more on meeting their children’s needs. Many respondents described performing extra therapy-oriented work or play with their children outside of their children’s regular therapy appointments with professionals, and a few stated that they wished they had the time or financial resources to do more with their children. While generally respondents expressed the sense that ‘more is better’ in terms of time and energy spent with children on developmentally-oriented tasks, some women expressed alternative perspectives, as well: that it is possible to overemphasize therapies and developmentally-oriented activities.

Related to the dedication of considerable time and energy to their children’s care and therapies, mothers often gave accounts of significant efforts to help their children reach their
academic or developmental goals. Several respondents noted that these efforts are a constant part of everyday life, interwoven with everyday caregiving, play, and special outings or activities. For example, for some mothers there are constant efforts to teach their children or influence their development through various interactions, such as conversations, or activities, such as games. In a few cases, when asked for specific descriptions of things they do to help their children learn, respondents had difficulty identifying particular examples, and instead said that, essentially, they are always trying to help their children learn. In other cases, as in the example below, respondents described making changes to their homes, such as creating appropriate play rooms, or obtaining certain toys, activities, or equipment with the goal of enhancing their children’s development.

I also see – because, from a motor perspective he’s very weak. His tone is very low. But I notice that as he gets bigger and as he gets a little stronger, it gives him a little bit more self-confidence. So I’d like to see that. That’s why we got him a tricycle. Try to – we have a trampoline in the back yard. We like to let him go out there and jump around. That sort of thing. (720-I3)

In the example above, this respondent encouraged the use of the tricycle and trampoline to enhance her son’s physical development (muscle tone) as well as his emotional development (self-confidence). This example is illustrative of a common theme: that progress toward developmental goals and learning are integrated into everyday activities, such as play, or that often, toys and activities are chosen for the child with an eye toward the impacts they may have on future development.

The language used by mothers and the focus on therapies and children’s development in the developmental imperative fit with elements of the individualism found in Bellah et al.’s (1985) research on moral discourse among middle-class Americans. One element of the forms of individualism they found involved the frequent use of therapeutic language in
connection to autonomy and self-reliance; the development of one’s self, and the expression of that self, were held up as central aims. Indeed, “the therapist” was one of several “representative characters” the authors use to describe key elements of American culture, each serving as “a public image that helps define, for a given group of people, just what kinds of personality traits it is good and legitimate to develop.” As a moral dimension of American culture, the connection between self-fulfillment and individualism is key. As Bellah et al. (1985) note, “[…] the meaning of one’s life for most Americans is to become one’s own person […]” and certainly, in the current project, an emphasis on children becoming as independent as possible and feeling fulfilled was evident.

Bellah et al. (1985) also comment that American culture does not necessarily provide clear instructions for how to “fill the contours of this autonomous, self-responsible self” yet they do note two significant areas for “finding oneself.”

One of these is work, the realm, par excellence, of utilitarian individualism. Traditionally men, and today women as well, are supposed to show that in the occupational world they can stand on their own two feet and be self-supporting. The other area is the lifestyle enclave, the realm, par excellence, of expressive individualism. We are supposed to be able to find a group of sympathetic people, or at least one such person, with whom we can spend our leisure time in an atmosphere of acceptance, happiness, and love.

While respondents did not necessarily emphasize that their children become “self-supporting” though their work lives, many did mention their hope that their children would eventually hold jobs that they find productive, enjoyable, or satisfying. Similarly, respondents spoke of the social connections that they hoped their children might one day have, such as friendships, or their desire that their child would feel safe, loved, and accepted. Detailed analyses of the segments of the interviews that address mothers’ goals and expectations for their children may yield additional insight into the connections between the
developmental imperative and mothers’ hopes for their children, a point I revisit in the conclusion.

These insights from Bellah et al. may reveal ways in which the developmental imperative and these mothers’ – or perhaps, parents’ – wishes for their children are connected to deeper systems of meaning in America. That is, the work of these mothers to advance their children’s development in multiple areas – academically, physically, socially, and morally – to fulfill their greatest potential might reflect not only their hopes for children’s measurable outcomes, but also their hopes for their children to tap into, and become part of, systems of meaning that are ingrained in American culture. In other words, it underlines ways in which these mothers wish for their children not only to take part in the significant life experiences and achieve outcomes as described in the interviews, but also to achieve a vision of a good, satisfying life (Bellah et al. 1985) that so many in America hold dear.

Uncertainty

One element of the developmental imperative is the uncertainty underlying eventual outcomes for children with FXS. Many mothers at time one expressed a degree of uncertainty about, for example, what level of education their child would achieve, their child’s level of independence as an adult, and their child’s needs in general in the future. The quote below illustrates this uncertainty. Answering a question about her goals for her son in five years, one respondent articulated her hopes for specific achievements, as well as a degree of uncertainty about whether those expectations are appropriate (emphasis added).

To be in as much regular classes as he possibly can in school. […] He just loves books and he loves to be read to so I hope that he can recognize letters and I hope that he can count. I hope that he can better communicate. He’ll count. Like we’ll count the steps every time we go up and down the steps, and he’ll kick in on eight and 10
and 12. So some of those I see him picking up on, and I’d like for him to be able to
count to 15 or 20 by seven and a half. **I don’t know. I’m just going by the other**
**people that I know with fragile X.** My one friend has a nine year old that can only
count to 10. So maybe – I don’t know. I’d like for him to be able to count higher than
that. And I’d like for him to be able to recognize letters and possibly read a few
words, you know. **I don’t know if those are too high expectations or not. I mean
we’re really just one day at a time and try. [...] I wonder sometimes if my expectations are too high, and sometimes I wonder if they’re not high enough, you know.**
You know his six month expectations with [his service plan], we usually
master them right away because I work so hard on mastering them, you know. And
then we just keep practicing those until the next time. (800-I1)

This respondent expressed a commonly shared perspective: wondering whether her
expectations for her son are too high or not high enough, reflecting a concern that her
expectations may not align with his capabilities at a given point in time. The following
quotation illustrates a similar perspective, but in response to a question about this
respondent’s roles when her child is an adult.

> Um, I’m still gonna be his mother, but I really don’t know how much – at this time I
do not know how much he’s gonna need from me. I’ve seen grown children with
fringe X on all different levels. So I know what to expect. I know that he might need
assisted living and things like that. I do understand that. And he might be able to live
on his own. So I’m just gonna be there for him whichever way. Just be there for him
is all I can say. Just take it one day at a time and just see when we get to that point
what happens. (60-I1)

She explained that she had seen adults with FXS who are “on all different levels” and that
her son may need assistance or may be able to live independently.

> Two dimensions of uncertainty, at least in the context of mothers of young children,
may be related to the developmental imperative. Because these respondents appeared to
perceive a range of possible outcomes for their children in the future, the developmental
imperative may be linked, in part, to the desire to maximize their children’s outcomes within
the span of what is possible. Some respondents were reluctant to set boundaries on their
children’s ultimate capabilities, while others expressed a desire to set their expectations neither too high, nor too low. As one respondent stated:

I think I try not to have any expectations and at the same time not having any limitations. I try to look at him just kind of like an open book. I don’t know if he will … and I don’t think anybody does. And it wouldn’t matter if I had an IQ number, it wouldn’t matter … might be a good … but it’s not going to tell you the end result because I think that’s … A lot of it has to do with the effort put into it and the family situation. (100-I1)

A second dimension of uncertainty is tied to developmental delays and the timing of particular milestones: in discussing developmental milestones, respondents made statements about knowing that their children would reach milestones, but not knowing precisely when that would happen.

Much of the literature on FXS describes the syndrome as having a wide range of characteristics and varying degrees of severity and associated challenges, especially between males and females (e.g., National Fragile X Foundation 2010). In the context of uncertainty of outcomes and timing of particular milestones for their children, and hopes for those outcomes, mothers may feel additionally responsible to try to further their children’s development to the greatest extent possible. This degree of uncertainty is reflected in mothers’ statements about the future, such as being unsure about whether their children will be able to live independently, and in statements about being happily surprised at milestones their children meet and their capabilities.

Importantly, in this project I cannot locate sources of the developmental imperative; that is, I cannot determine whether the imperative is rooted in interactions with professionals such as therapy or service providers, interactions with other parents, resources and parent education materials provided to parents by professionals and peers, other sources, or a
combination of sources. However, I would argue that for the purposes of this project, the  
source of this imperative is not a key element of the analysis, since the goal is to describe and  
understand mothers’ perspectives in this context. Regardless of the source, it is significant to  
identify this developmental imperative as a part of the experiences of many mothers in this  
sample.

Though the sources of the developmental imperative cannot be determined from this  
analysis, characteristics of FXS and aspects of mothers’ accounts may shed some light on  
that question. A characteristic of FXS is that there is a significant amount of variation in how  
it impacts individuals. These mothers, as participants in a study of family adaptation to FXS,  
may likely be aware of that key piece of information, perhaps learning about FXS through  
parent resources or interactions with professionals or organizations, conference attendance,  
or through informal channels such as parent-to-parent communications online or membership  
in support groups. Further, accounts indicate that a certain degree of uncertainty about  
eventual outcomes or the timing of milestones may characterize many mothers’ experiences,  
whether that is because they do not know much about FXS, or because they do know of the  
considerable variation that is possible with FXS.

Because these respondents were mothers of young children, there may be an elevated  
degree of uncertainty about the children’s developmental trajectories, since they were at the  
beginning of their development. For a few respondents, the young age of their children  
seemed to be important in their decision to prioritize obtaining services and therapies, engage  
in careful decision-making, and work with their children outside of the therapy schedule.

So I have to really this fall really explore pretty seriously some options. So for him  
it’s not just picking where is his friends going. It’s what’s the best environment for  
him to be the most he can be. And learn. And starting right now. Because this is the  
key time. So I feel like an educator. I feel like – I’m not just – I’m more than a parent.
When I got the diagnosis, I still didn’t know that much. So it really wasn’t until this conference that I learned what some of these behaviors could represent in the future. So just kind of trying to do what we can to control the things we can control or work with early. So I think I’m doing – trying to recognize that this could lead into this.

(640-I1)

In the example above, this respondent whose child was younger than age three believed that “this is the key time,” which was a sentiment expressed by other respondents as well. Related to the importance of intervening early expressed in the example above, in the quotation below, the emphasis on early therapies was recommended by a doctor.

He gets speech therapy one hour a week. And he’s supposed to be getting developmental therapy one hour a month. But when we talked to Dr. [X], she would like to see him get occupational therapy as well as more developmental therapy. Not because he necessarily needs it. But because as he gets older, things could show up. And the hope is that by getting more therapies now, we can avoid those things that may show up. So, we’re working on that. (680-I1)

In this case, the reason for obtaining therapies that are not necessarily needed yet was that the intervention may prevent problems later in the child’s development. Together, these examples illustrate how the information about FXS that parents receive, either formally or informally, can impact their caregiving and therapy-related priorities and behaviors. Further, the young age of the children in this sample may play a role in the developmental imperative because for some mothers, it may be a response to the point that significant early intervention can be important for later outcomes (Eunice Kennedy Shriver National Institute of Child Health and Human Development 2003) and that the family setting and environment can impact the development of children with FXS or other disabilities (e.g., Bailey 2007).
‘I Just Want to be Mom’

In the interviews, there was a key tension regarding the developmental imperative. Several mothers described a need sometimes to just be “mom” instead of “teacher” or “therapist,” or described a process of becoming less strict, “backing off,” or making games and activities less about the learning and more about fun while learning. In some cases this tension is characterized as somewhat fleeting, or as a desire to “sometimes” not focus on learning or therapies with their children. One respondent said that she “wish[ed]” they could just play without the activity being learning-oriented.

[…] it seems like I do, like everything we do is geared towards learning and sometimes I wish we could just sit and play and not have to worry about that. But that’s just a factor of him having that disorder. So that can be a little frustrating sometimes. You know, I feel like I’m the therapist now. Everything I’m doing is – I feel like, “Oh, got to work on something here.” (1120-I1)

This respondent expressed frustration that “everything” with her son was aimed at enhancing learning, then stated that it was “just a factor of him having that disorder.” At the same time, she was pulled toward playing with her son without the focus of working on learning. The specific aspect of the developmental imperative related to this tension is the idea that activities should be goal-oriented and focused on their impacts on future development. The quotation below is an example of an account that combined elements of the developmental imperative with this tension.

I think my job with him right now is to give him as much of a normal childhood as he possibly can tolerate. And at the same time get him as much help. So that the lag isn’t as tremendous as it could be with him and other children. And there’s a fine line between being like – I don’t want to be like that militant parent who has like a schedule of the thirty hours of therapy a week. I think it’s really important for kids even with issues just to be children. He’s going to have a lifetime full of therapy and intensive academics and school work and stuff like that. It’s hard though when your kid is that young to not – you want to do so much for them so that they can catch up.
But, at the same time, he needs to be a baby. So I think my job is to find that line and make sure we stay on it. (720-I1)

The tension between being ‘militant’ and not doing enough for her child is clearly evident here, and for this mother, there is a balance that can be struck. Her perspective was that it was her “job,” or responsibility, to seek out and achieve that balance.

Less common, but still important to note, is that for a few respondents, this tension resulted in a relatively permanent shift in their approach to parenting, and a reinterpretation of their perceived roles and responsibilities with regard to their children. As one respondent stated:

One thing I’ve had to really focus on – like I told you earlier – is I just need to be his mom. I’ve had to back off being his therapist. Back off being his nutritionist. And, just being his mom.

Interviewer: Last time we met, you mentioned something about you felt like you were his case manager.
Respondent: Oh, yeah.
Interviewer: Is that – do you still have – does that still feel the same? Or, is that any different now?
Respondent: No. I still feel like I have to search out things. And, any parent does. I mean I search out where schools are. […] And so, am I as anal about it? No.
Interviewer: You think that’s changed?
Respondent: Oh, yeah.
Interviewer: Why do you think that’s changed?
Respondent: I just had to – just like I said before, I don’t have expectations. Whatever we get, we get. Whatever we’re facing, we face. I have to. To not be disappointed in him. (20-I2)

While not a dominant theme, a tension between ‘being a therapist’ or ‘case manager’ and ‘being a mom’ was expressed in some respondents’ accounts.

This dimension of respondents’ experiences elaborates on the connection among three features of responsibility as defined by Heimer and Staffen (1998): planning for the future, defining obligations broadly, and taking others’ needs and interests into account. In the
experience of some mothers of children with FXS, the sense of responsibility that they feel for their children’s development and their well-being creates a difficult balancing act. They perceive potential future benefits to their children of certain therapies, activities, and services, and yet also perceive a need for their children to ‘just be babies.’ Because of this, and the fact that their responsibilities are defined so broadly – to include direct caregiving, advocacy efforts on behalf of their children, and therapy and service coordination and activities, among other tasks—for some mothers it may not be obvious which to pursue in order to best meet their children’s needs at a given point. As a result, some respondents experienced pulls in conflicting directions: to minimize therapies and developmentally-oriented activities, and to engage in them.

The findings from this study may be relevant for efforts aimed at helping families, particularly mothers, adapt to parenting a child with FXS. Further, the findings in this project may assist service providers, practitioners, and clinicians in better understanding the perspectives of some mothers of children with FXS. If therapies or interventions are less successful than hoped, or if children’s development doesn’t progress as well as families and therapists might have hoped, professionals may need to better understand how those instances might impact mothers negatively if they hold themselves even partly responsible for their child’s development. In addition, parent education regarding what can and cannot be done as far as advancing children’s development may be beneficial.

In sum, these findings reveal a strong sense of responsibility that many respondents feel for their children’s development as one facet of their experiences with caregiving. Their efforts to maximize their children’s development could include many different areas, including speech or communication, social development, physical or motor development, and
moral development. To explain aspects of the concept of a developmental imperative, I adapted Leiter’s (2004) notion of a therapeutic imperative. The findings also highlight connections between mothers’ experiences and work that examines the social organization of responsibility in other contexts (Heimer and Staffen 1998; Timmermans and Freidin 2007). In addition, findings identified potential links between mothers’ perspectives on caregiving and broader cultural influences. Findings suggest that contextual factors, such as a degree of uncertainty regarding timing of milestones for children with FXS, may impact some mothers’ experiences with caregiving. A tension was identified for some mothers, between their efforts to assist their children’s development, and their desire to ‘just be mom’ or to deemphasize learning-oriented or therapeutically-oriented activities at times. Together, results reflect multiple dimensions of the meanings attached to caregiving, and highlighted connections with the broader social and cultural context.
References


Chapter 3

“I Put on my Super Cape”: Stories of Work, Family, the Impossible, and the Possible

This paper explores the accounts of mothers of children with fragile X syndrome (FXS) related to issues of employment decision-making and work-family conflict and balance. The central questions are: over time, how have these mothers juggled work and family responsibilities, and in particular, how have they handled decisions about employment? What factors (such as workplace policies or childcare availability) have influenced their decisions? The goal of this paper is not to develop a specific model of decision-making, nor to identify an exhaustive list of causal factors that shape women’s decisions about employment. Rather, in the approach of cultural analyses such as Hochschild’s *The Time Bind* (1997), this is an examination of the ways that these respondents talk about these issues, and what that may reveal about the context within which these aspects of life – work and family – are experienced. As Hochschild describes, work and home can be viewed as “gravitational fields” that exert a certain degree of force on individuals. Recent research on time use, gender, and the household division of labor (Bianchi and Milkie 2010) continues to emphasize both the current relevance of these topics, and the importance of a sociological perspective on seemingly mundane phenomena, including the household division of labor, or balancing work and family.

This paper provides insight into two key aspects of work-family interplay. First, I describe experiences with “juggling” for respondents in this study, and explain how the
management of demands can be understood as “articulation work,” labor constituted by often invisible yet critical “linking” actions that help to coordinate the efforts of the family to meet its goals (e.g., Timmermans and Freidin 2007). In the second part of the paper, I describe themes in respondents’ accounts of work and family, and use ideas from Voydanoff’s (2005) conceptual framework of the interplay between two domains, work and family, to explain how decisions about employment for these respondents and their families reflect within-domain and boundary-spanning resources and demands, and give examples of ways in which respondents use boundary-spanning strategies in efforts to influence work-family fit and balance. Voydanoff describes two dimensions of work-family “fit” that contribute to global assessments of work-family balance: 1) work demands – family resources fit, and 2) family demands – work resources fit. The argument is that appraisals of fit and balance are influenced in part by the correspondence between individuals’ capacities or abilities (resources), and expectations (demands) in these two realms (Voydanoff 2005).

Background and Significance

This project asks key questions about mothering in the context of having children with disabilities, and situates those questions in the broader literature on work-family intersections. The study of gender as it relates to the domains of work and family has been a subject of great interest for family scholars, particularly with the relatively recent and dramatic increase in women’s involvement in the workforce since World War II (Oppenheimer 1994). This trend has sparked interest in, for example, wage inequality, impacts on family dynamics, maternal and child wellbeing, gender inequality more broadly, and theoretical questions about how maternal employment might reflect – or shape – gendered expectations for caregiving and the household division of labor. It has been argued
that the experience of balancing work and family is different for men and women, in large part due to the societal pressures on women to serve as caregivers, and because of the difficulty of combining that work with paid work (Risman and Ferree 1995). In addition, some researchers have pointed out that the issue of achieving “balance” between work and family realms is almost exclusively the task of women as opposed to men, as women are the ones expected to make adjustments (Moen and Yu 2000).

While existing research does give some insight into impacts of children with special needs on mothers’ employment status, more information is needed about the specific factors that influence parents’ employment in the context of having children with disabilities (Loprest and Davidoff 2004). Several studies have examined labor force participation of mothers of children with disabilities and generally demonstrate that having a child with a disability negatively impacts maternal labor force involvement (e.g., Landis 1992; Lukemeyer, Meyers, and Smeeding 2000; Powers 2001; 2003). Without specifying the gender of the primary wage-earner, Hodapp and Kranser (1994) found that families in which a child has a disability were more likely to have only one wage-earner, compared to families of typically developing children.

Finding appropriate childcare is one area that may pose particular challenges for families whose children have disabilities—especially those headed by single mothers—and its availability and affordability may have an impact on whether a mother joins or remains in the labor force. Landis (1992) studied 65 U.S. mothers of young children who were involved in a home-based early intervention program; the proportion of women working was not different from that of the general population, but the intensity of work was lower; these mothers were more likely to be employed part-time or work irregular hours. Further, the
study found that care for these children was primarily based in the home with spouses providing a good deal of the child care while the mother worked. This could be explained by the expense of childcare as well as the difficulties that parents face in finding appropriate care; Booth-LaForce and Kelly (2004) found that a host of issues confront families seeking childcare for their special-needs children. Some issues are the same that families of typically developing children face, such as finding accessible and affordable care, but there are also additional issues, such as finding a facility or person that can provide the appropriate care to accommodate special needs.

Similarly, in a study of 44 mothers of 5-year-old children with special needs, Warfield and Hauser-Cram (1996) found that the primary problems the mothers encountered were the expense, quality, and ability of the childcare facilities and staff to meet their children’s needs. The findings regarding the difficulty of locating childcare, as well as the primacy of informal, in-home childcare, highlight the need for further research on how mothers manage juggling of work and family demands.

Mothers whose children have disabilities may be under increased pressure to work due to financial need, but may also experience pressure to care for their children and to engage in particular therapeutic activities with him or her as part of the child’s treatment plan. On the other hand, mothers of children with disabilities may value paid work outside the home for several reasons including intangible ones. In a qualitative study done with mothers of school-aged children with disabilities in the UK, though the majority of the mothers did not engage in paid work, they identified several perceived benefits associated with employment in addition to the financial benefit for the household, including financial autonomy or reduced dependence, the opportunity to engage with peers, feeling that they are
performing valued tasks, having an identity separate from that of ‘caregiver,’ and feeling included in the worlds of their peers (Shearn and Todd 2000).

The meanings attached to work and caregiving for these mothers deserve further attention in research on maternal employment, especially using a qualitative approach. In a study of 51 dual-earner married parents of children with special needs in the northeastern United States, Warfield (2005) found that among mothers who valued their work highly, having a child with more behavior problems predicted greater stress compared to women who were less interested in their work; among women who placed a low value on their work, the level of behavior problems exhibited by their children did not significantly affect stress levels. Interestingly, this variable was not statistically significant for fathers; only the availability of quality childcare significantly impacted paternal stress levels.

In contrast to the above-listed potential benefits of employment, in studies of families whose children have disabilities, work demands were found to significantly predict parental stress (Warfield 2005). For mothers of children with disabilities, there is also the chance of one’s role as mother “breaking through” to her role as employee; there may be medical appointments for the child during the day, or in general she may be “on call” in case she is needed to assist her child (Shearn and Todd 2000). With regard to its impact on psychological well-being, the caregiver role may differentially affect parents of children with disabilities depending on the amount of work-family conflict they experience (Marks 1998), which underscores the importance of examining the interplay between these two domains.

Structural factors are at play in decision-making, such as the availability of childcare and its compatibility with services and treatment regimens, but so are financial factors, particularly since children with special needs may require treatments, medicines, and
therapies that may not be covered by insurance, or are expensive despite the insurance coverage. In addition, for parents whose children’s ability to live independently as adults is not necessarily assured, concerns about finances in the future are also an issue. And last, in the current social context with so many women obtaining college and postgraduate degrees, and likely expecting to have a certain career path, it is important to explore their experiences in cases where they are, or are considering, reducing their work hours or altering their career plans.

Findings such as these point to the need for a qualitative investigation of how these areas of women’s lives interact, including an exploration of the meanings assigned to the tasks performed in various realms. This study adds to the research that focuses on subjective experiences of women making decisions about whether or how much to work. In addition to describing findings about the respondents’ subjective accounts of their strategies and decision-making, I explore particular characteristics of their family demands and their workplaces to identify perceived barriers – or supports – influencing maternal employment. This aspect of the research contributes to the literature on child disability and maternal employment by drawing on rich data capturing mothers’ perspectives on several different aspects of their lives.

*Work-Family Linkages among Mothers of Children with FXS*

The relationships among paid work, unpaid caregiving activities, family formation and dissolution decisions, and intergenerational responsibilities are “dynamic linkages” (Seltzer, Bachrach, Bianchi, Bledsoe, Casper, Chase-Lansdale, DiPrete, Hotz, Morgan, Sanders, and Thomas 2005) and are not yet well-understood; this project addresses that issue.
by using a qualitative approach and by examining these mothers’ retrospective accounts of
decision-making and experiences over time.

As described above, in some ways, we already know a certain amount about the
context within which choices about employment are made. For example, certainly the extent
to which engaging in paid work, or not, is perceived as a choice does, in fact, vary within my
sample. Further, according to existing literature, it is to be expected that many of these
mothers experience challenges trying to manage demands on their time, regardless of
whether they work for pay, or work outside of the home. This analysis describes some of
those challenges and explains the active strategizing that takes place within families to
mitigate the impacts of challenges. I argue that the negotiation of demands and resources
constitutes “articulation work” (e.g., Timmermans and Freidin 2007) undertaken by these
mothers. In addition, I detail ways in which employment decision-making for these mothers
is not only a function of their own goals and priorities, but is also shaped by the powerful
weight of other family members’ situations and needs, and that there are “boundary-
spanning” resources, demands, and strategies (Voydanoff 2005) associated with their
experience of work-family interplay. To further shed light on some respondents’ perspectives
on work and family, I describe how certain dimensions of work-family interplay are
portrayed as possible or impossible.

As mentioned above, past research has shown that mothers of children with special
needs may face certain circumstances – such as financial need due to particular treatment
expenses for their children, or a “therapeutic imperative” (Leiter 2004) or ‘developmental
imperative’ (see paper one) to assist with their children’s therapies in the home – that may
result in the need to orchestrate different activities, manage various pressures in multiple

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spheres, take advantage of certain resources, and strategize in order to meet many demands that they may experience. The findings discussed below present and explain some of those facets of their experiences. The main research question for this paper was about decision-making around employment, how mothers of children with a particular diagnosis talk about their decisions, motivations, and other issues related to employment, and how they juggle work and family.

While the respondents’ employment statuses will be discussed for context, the goal of this paper is not to explain causal mechanisms that explain the specific outcomes of their decision-making processes. Rather, the objective is to characterize mothers’ accounts and features of the contexts for those decisions. Through an exploration of mothers’ discussions of their choices, resources, and constraints, we can better understand their perspectives on their decisions, while acknowledging that there may be additional factors at work in a complex process of decision-making related to employment.

Further, I am not claiming to compare these mothers of children with FXS with mothers of typically-developing children; the experiences of the mothers in this study may be quite similar to those of mothers with typically-developing children, and I am not making claims about differences between the two groups. Instead, I seek to investigate the lives of these mothers on their own terms, using their language and highlighting variation, tensions, and complexities that exist within this group. This sheds light on their experiences and perhaps on the experiences of other mothers as well, although future research would be needed to answer comparative questions. In sum, my aim is not to isolate and explain an independent “effect” of FXS; rather, my aim is to describe and interpret the accounts of these
mothers with the view that FXS is a part of their lives, along with the myriad other social, historical, cultural, and economic factors.

**Fragile X Syndrome**

Fragile X syndrome (FXS) is the result of a genetic mutation that inhibits a particular gene (FMR-1) on the X chromosome from producing a protein necessary for brain development (Centers for Disease Control and Prevention 2006). Specifically, it is known as a nucleotide repeat disorder; in individuals with FXS, there are excessive repeats of the CGG trinucleotide sequence on a particular gene. The mutation of the gene goes through particular stages as it is passed down, and individuals with 55 – 200 CGG repeats of DNA and a normal methylation (whether a gene is turned on or off) pattern are typically considered to have the premutation form of the gene (National Fragile X Foundation 2008). Those classified as having the full mutation typically have over 200 repeats and the gene is methylated – turned off so that it does not produce any, or enough, of the necessary protein (National Fragile X Foundation 2008). FXS occurs across all races and ethnicities, and it affects about 1 in 4,000 males and 1 in 8,000 females (National Human Genome Research Institute 2007). Other estimates place the rate of occurrence at 1 in 3600 males and 1 in 4000 to 6000 females (National Fragile X Foundation 2006). Males are more likely to be symptomatic than females because the mutation is on the X chromosome, and since they only have one, they are more vulnerable to the mutation’s effects (Bailey and Nelson 1995). In women, their other X chromosome can sometimes outweigh the impact of the gene with the mutation. By some estimates, about 1 in 250 women and 1 in 800 men are carriers of the premutation, which contains fewer repeats of the DNA sequence, compared to those classified as having the full mutation (National Fragile X Foundation 2006). Individuals with the premutation may have
some symptoms of FXS or fragile X-associated conditions, such as premature ovarian failure or fragile X-associated tremor/ataxia syndrome (FXTAS), a Parkinson’s-like tremor, or may have no symptoms at all (National Fragile X Foundation 2008). The gene responsible for the syndrome was discovered in 1991 (National Fragile X Foundation 2005), although the syndrome itself was first detected in the late 1970s. Once the gene was identified, FXS could be definitively diagnosed, people could be tested for both the full mutation and carrier status, and prenatal testing became possible (McConkie-Rosell, Finucane, Cronister, Abrams, Bennett, and Pettersen 2005).

The National Institute for Child Health and Human Development classified symptoms of FXS into five categories: intelligence and learning; physical; social and emotional, speech and language; and sensory symptoms (see Table 3.1). In addition, certain disorders sometimes appear alongside FXS or share characteristics with the disorder. These include autism, attention deficit disorder/attention deficit hyperactivity disorder, connective tissue problems, seizures, as well as later onset disorders of carriers, such as premature ovarian failure for women and FXTAS (Eunice Kennedy Shriver National Institute of Child Health and Human Development 2003; National Fragile X Foundation 2008).

Table 3.1 Characteristics Associated with Fragile X Syndrome

<table>
<thead>
<tr>
<th>Category</th>
<th>Characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intelligence/</td>
<td>Impaired ability to think, reason, and learn</td>
</tr>
<tr>
<td>Learning</td>
<td>Lower than average IQ score; those with full mutation tend to have IQ between 40 and 85, considered mild to moderate impairment, though females less affected than males</td>
</tr>
<tr>
<td></td>
<td>Good memories for visual patterns and pictures</td>
</tr>
<tr>
<td></td>
<td>Difficulty with abstract ideas, organizing information, planning ahead, solving problems</td>
</tr>
</tbody>
</table>

Note that there is usually a great deal of variation in characteristics of individuals with FXS. This table reflects some characteristics that have been associated with FXS, but many individuals will not have these characteristics.
Table 3.1 Characteristics Associated with Fragile X Syndrome (continued)

<table>
<thead>
<tr>
<th>Category</th>
<th>Characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Make progress with learning but may need additional time, special environment/teaching methods</td>
<td></td>
</tr>
<tr>
<td>Infants and young children usually have no physical signs; may have softer skin than average, or a slightly larger head</td>
<td></td>
</tr>
<tr>
<td>Adolescents often develop an elongated face and larger, more noticeable ears</td>
<td></td>
</tr>
<tr>
<td>May not be as tall as expected</td>
<td></td>
</tr>
<tr>
<td>May experience seizures (20%)</td>
<td></td>
</tr>
<tr>
<td>Males develop enlarged testicles (macro-orchidism)</td>
<td></td>
</tr>
<tr>
<td>Weak connective tissues may predispose individuals to hernias, frequent ear infections, heart murmurs</td>
<td></td>
</tr>
<tr>
<td>Females with the premutation may experience premature ovarian failure (16 - 19%)</td>
<td></td>
</tr>
<tr>
<td>Often experience social anxiety, especially boys; may stop them from being social, or from seeking out new experiences or contact with others</td>
<td></td>
</tr>
<tr>
<td>Males tend to be easily upset, overwhelmed, or distressed, particularly if senses are overloaded; may become upset by changes in routine</td>
<td></td>
</tr>
<tr>
<td>When upset or anxious, take longer to calm down than peers</td>
<td></td>
</tr>
<tr>
<td>Becoming upset may manifest as tension or rigidness, tantrums, or repetitive motions; may result in trouble at school</td>
<td></td>
</tr>
<tr>
<td>Adolescents may have more dramatic outbursts due to hormone levels</td>
<td></td>
</tr>
<tr>
<td>Females may have social problems but will likely be milder than males’</td>
<td></td>
</tr>
<tr>
<td>Problems communicating: mild stuttering to difficulties with pronunciation or communication through speaking and writing, tendency to ramble or speak off-topic; problems regulating tone of voice, pitch</td>
<td></td>
</tr>
<tr>
<td>Often begin talking later than expected; most around the age of 4, but sometimes age 6 – 8; some remain nonverbal</td>
<td></td>
</tr>
<tr>
<td>Severe language problems rare among females; males tend to have moderate to severe problems</td>
<td></td>
</tr>
<tr>
<td>Males may also have problems processing written or spoken instructions</td>
<td></td>
</tr>
<tr>
<td>Some language difficulties likely linked to social anxiety and shyness</td>
<td></td>
</tr>
<tr>
<td>Males may be very interested in communicating but may face challenges processing relevant signals, conversational cues, etc. in others</td>
<td></td>
</tr>
<tr>
<td>Sensory</td>
<td>May have problems with balance, coordination</td>
</tr>
<tr>
<td>Sensitivity to loud noises or other sensations may cause outbursts or distraction</td>
<td></td>
</tr>
<tr>
<td>May avoid physical contact if they find it overwhelming</td>
<td></td>
</tr>
<tr>
<td>Therapy may assist with helping individuals manage sensory overload</td>
<td></td>
</tr>
</tbody>
</table>

There are key differences in symptoms by gender; girls are likely to exhibit milder forms of intellectual disability as well as the behavioral and physical characteristics associated with FXS (National Fragile X Foundation 2006). For several reasons, including its wide range of symptoms, co-occurrence with other conditions and disorders, and the fact that it is not widely known, FXS is often not diagnosed until a child is around 3 years old (Bailey, Skinner, Hatton, and Roberts 2000; Bailey, Skinner, and Sparkman 2003; Bailey, Skinner, Sparkman, Moore, Olney, and Crawford 2002). There is no routine screening at birth and characteristics may emerge slowly over time; the family may first struggle with whether the characteristics they are seeing are truly problems, and may be assured by medical professionals that everything is fine or that the child is simply a “late bloomer.”

Families may undergo a “diagnostic odyssey,” which refers to the long process of searching for an explanation for the symptoms that they see in their child (Bailey, Beskow, Davis, and Skinner 2006; Bailey, Skinner, and Sparkman 2003; Carmichael, Pembrey, Turner, and Barnicoat 1999). One study revealed that the journey to a genetic diagnosis was often circuitous and exacted a toll on parents’ resources, both emotional and financial. The age at diagnosis was an average of 18 months or longer after initial concern about the child’s development (Bailey, Skinner, and Sparkman 2003). Bailey et al. (2006) summarized specific costs of this long road to the diagnosis of FXS: children miss, on average, 2 years of early intervention services; parents question their abilities when professionals assure them that “everything was OK”; parents may make 10 or more visits to professionals seeking a diagnosis, incurring costs, and in the interval between the child’s birth and the diagnosis, many parents have another child with FXS, not realizing that their other child’s condition
was hereditary (Bailey, Beskow, Davis, and Skinner 2006; Bailey, Skinner, and Sparkman 2003).

Once parents receive a diagnosis of FXS, there are therapies, services, and interventions that have been found effective but there is no standardized medical plan of action for treating the condition. One reason for this is the wide spectrum of symptoms that accompany the condition. FXS, as of the time of this research, has no cure; the treatments for the child usually involve prescription drugs, behavioral therapy, and speech or occupational therapy, among other options, to manage symptoms and promote development (Eunice Kennedy Shriver National Institute of Child Health and Human Development 2003; National Fragile X Foundation 2006). The medical aspects of the treatment may be aimed at managing aggression, anxiety, hyperactivity, short attention spans (National Fragile X Foundation 2006), sleep disturbance, hyperarousal or sensory overstimulation, obsessive-compulsive disorder, and seizures (Eunice Kennedy Shriver National Institute of Child Health and Human Development 2003).

Data and Methods

The results presented here are based on data from the Family Adaptation to Fragile X Syndrome Study (FAFXS). The FAFXS study includes data on 108 carrier mothers and 27 fathers from all over the United States. For the purposes of this study, I focused on the cohort of 60 mothers whose children, for the vast majority of the sample, were less than 36 months old at the time of the first interview (Table 3.2). Fifty-six (93%) of the mothers had the premutation form of the gene, while 4 (7%) had the full mutation, and all had at least one child with the full mutation. The FAFXS study sample also reflects a range of incomes. The mothers’ ages ranged from 20 – 43, with a mean of 32.3 and standard deviation of 5.11. Five
respondents (8%) were African American, one respondent was Hispanic, and one respondent was categorized as “other.”

Table 3.2 Family Adaptation to Fragile X Syndrome Study: Sample Characteristics

<table>
<thead>
<tr>
<th>Maternal Characteristics: Young Cohort</th>
<th>Total (N=60)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age in Years</strong></td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>32.32 (5.11)</td>
</tr>
<tr>
<td>Range</td>
<td>20 - 43</td>
</tr>
<tr>
<td><strong>FX Mutation Status</strong></td>
<td></td>
</tr>
<tr>
<td>Full Mutation</td>
<td>4 (7%)</td>
</tr>
<tr>
<td>Premutation</td>
<td>56 (93%)</td>
</tr>
<tr>
<td><strong>IQ</strong></td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>107.23 (14.3)</td>
</tr>
<tr>
<td>Range</td>
<td>55 - 130</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
</tr>
<tr>
<td>Less than high school</td>
<td>3 (5%)</td>
</tr>
<tr>
<td>High School Graduate</td>
<td>3 (5%)</td>
</tr>
<tr>
<td>High School; Some College; Associate’s Degree</td>
<td>22 (37%)</td>
</tr>
<tr>
<td>College Degree or Higher</td>
<td>32 (53%)</td>
</tr>
<tr>
<td><strong>Race/ethnicity</strong></td>
<td></td>
</tr>
<tr>
<td>White/Caucasian</td>
<td>53 (88%)</td>
</tr>
<tr>
<td>Black or African American</td>
<td>5 (8%)</td>
</tr>
<tr>
<td>Hispanic or Latino</td>
<td>1 (2%)</td>
</tr>
<tr>
<td>Other</td>
<td>1 (2%)</td>
</tr>
<tr>
<td><strong>Annual Gross Household Income</strong></td>
<td></td>
</tr>
<tr>
<td>≤ 26,000/year</td>
<td>8 (13%)</td>
</tr>
<tr>
<td>26,001 – 45,000/year</td>
<td>13 (22%)</td>
</tr>
<tr>
<td>45,001 – 65,000/year</td>
<td>11 (18%)</td>
</tr>
<tr>
<td>65,001 – 100,000/year</td>
<td>16 (27%)</td>
</tr>
<tr>
<td>≥ 100,001/year</td>
<td>12 (20%)</td>
</tr>
<tr>
<td><strong>Low Income (200% of poverty line or below)</strong></td>
<td>14 (23%)</td>
</tr>
<tr>
<td><strong>Mother’s current marital status</strong></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>50 (83%)</td>
</tr>
<tr>
<td>Divorced/Separated</td>
<td>3 (5%)</td>
</tr>
<tr>
<td>Single, Never Married/Engaged</td>
<td>7 (12%)</td>
</tr>
</tbody>
</table>

(Source: Dr. Debra Skinner, Co-Investigator, Family Adaptation to Fragile X Syndrome Study)

This analysis uses data from three semi-structured interviews that were conducted with each mother, with 18 months between each interview. For the purposes of these
analyses, I analyzed interview and demographic data for 57 respondents: 56 respondents at
time one, 53 at time two, and 45 at time three. At the beginning of the study the children
were an average of 29 months old, or 2.4 years, and ages ranged from 10 months to 4 years.
The interviews covered many different aspects of family adaptation to FXS.

No specific questions about employment status were asked during the semi-structured
interviews, but the general information sheet administered at the time of each interview
included a field for participants to list their current occupations. The topic of employment
also came up spontaneously during some interviews, and specific questions about juggling
work and family were asked in interviews at two times. Respondents’ employment status,
changes, and decisions were raised in discussions about accommodations or adjustments by
the family, and major decisions. The relevant questions related to juggling from semi-
structured interview guide three in the Family Adaptation to Fragile X Syndrome Study
were: “Are there things you have to do to juggle all your responsibilities and school and child
care? Please describe. [If the mother works outside the home, ask: how do you juggle work
with these other things?] How do you manage to do everything that needs to get done? What
do you feel you don’t have time to do?”

As these were semi-structured interviews, the questions were asked in a similar way
for each respondent, though not in an identical way. It is important to note the variety of
family structures present in the data; in some cases, the respondent is a single mother, or a
single mother whose own mother has extensive involvement in raising the focal child, or
opposite-sex partners, married or unmarried, where the male partner is not the biological
father of the focal child. In some cases, shared custody arrangements influence decision-
making about employment, even though the parents are no longer partners or members of the
same household. In descriptions of the data, where relevant, I have included the information about family structure that relates to respondents’ quotes.

For the second phase of the project, I re-contacted 15 respondents from the original study to gather in-depth information about their employment histories and decision-making using a work-family calendar (see Appendix A) and semi-structured phone interviews. Work-family calendars were collected from 14 respondents, with missing data for 1 respondent. The sample for the in-depth interviews was diverse (see Table 3.3), including respondents who were married, divorced but in a relationship, and single. The sample included respondents with a range of family sizes: from one child only, who has FXS, to families with five children, three of whom have FXS. And, finally, the sample included mothers who work full-time, part-time, and mothers who do not work for pay. According to classifications at wave three of the Family Adaptation to Fragile X Syndrome Study, five families were classified as low-income (200% of the poverty line or lower).

Table 3.3 Maternal Characteristics: In-depth Interviews (continued next page)

<table>
<thead>
<tr>
<th>Maternal Characteristics: In-depth Interviews</th>
<th>Total (N=15)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age in Years</strong></td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>39.93 (4.04)</td>
</tr>
<tr>
<td>Range</td>
<td>34 – 49</td>
</tr>
<tr>
<td><strong>FX Mutation Status</strong>*</td>
<td></td>
</tr>
<tr>
<td>Full Mutation</td>
<td>1 (7%)</td>
</tr>
<tr>
<td>Premutation</td>
<td>14 (93%)</td>
</tr>
<tr>
<td><strong>Child Age in Years</strong></td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>9.63 (3.38)</td>
</tr>
<tr>
<td>Range</td>
<td>0.75 - 16</td>
</tr>
<tr>
<td><strong>Number of Children</strong></td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>2.53 (1.25)</td>
</tr>
<tr>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>3</td>
<td>5</td>
</tr>
</tbody>
</table>
Table 3.3 Maternal Characteristics: In-depth Interviews (continued)

<table>
<thead>
<tr>
<th>Maternal Characteristics: In-depth Interviews</th>
<th>Total (N=15)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of Children (continued)</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>0</td>
</tr>
<tr>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>*<em>Education</em></td>
<td></td>
</tr>
<tr>
<td>Less than high school</td>
<td>0</td>
</tr>
<tr>
<td>High School Graduate</td>
<td>2 (13%)</td>
</tr>
<tr>
<td>High School; Some College; Associate’s Degree</td>
<td>3 (29%)</td>
</tr>
<tr>
<td>College Degree or Higher</td>
<td>10 (67%)</td>
</tr>
<tr>
<td>*<em>Race/ethnicity</em></td>
<td></td>
</tr>
<tr>
<td>White/Caucasian</td>
<td>13 (87%)</td>
</tr>
<tr>
<td>Black or African American</td>
<td>2 (13%)</td>
</tr>
<tr>
<td>Hispanic or Latino</td>
<td>0</td>
</tr>
<tr>
<td>Other</td>
<td>0</td>
</tr>
<tr>
<td>*<em>Annual Gross Household Income</em></td>
<td></td>
</tr>
<tr>
<td>≤ 26,000/year</td>
<td>3 (20%)</td>
</tr>
<tr>
<td>26,001 – 45,000/year</td>
<td>3 (20%)</td>
</tr>
<tr>
<td>45,001 – 65,000/year</td>
<td>2 (13%)</td>
</tr>
<tr>
<td>65,001 – 100,000/year</td>
<td>1 (7%)</td>
</tr>
<tr>
<td>≥ 100,001/year</td>
<td>6 (40%)</td>
</tr>
<tr>
<td>*<em>Low Income (200% of poverty line or below)</em></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>5 (33%)</td>
</tr>
<tr>
<td><strong>Employment Status</strong></td>
<td></td>
</tr>
<tr>
<td>Not employed for pay outside the home</td>
<td>4 (27%)</td>
</tr>
<tr>
<td>Employed part-time (1-39 hours/wk)</td>
<td>7 (47%)</td>
</tr>
<tr>
<td>Employed full-time (40 or more hours/wk)</td>
<td>4 (27%)</td>
</tr>
<tr>
<td><strong>Mother’s current marital status</strong></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>9 (60%)</td>
</tr>
<tr>
<td>Divorced/Separated</td>
<td>5 (33%)</td>
</tr>
<tr>
<td>Single, Never Married/Engaged</td>
<td>1 (7%)</td>
</tr>
</tbody>
</table>

* Data from wave 3 of the Family Adaptation to Fragile X Syndrome Study

Topics in the in-depth phone interviews included respondents’ goals and aspirations in early adulthood, specific decisions to move into or out of the labor force, decisions to change workplaces or number of hours worked, factors impacting those decisions, and
respondents’ experiences with those transitions and arrangements. Where issues of juggling responsibilities or tasks were raised, probes explored respondents’ accounts of resources, challenges, and strategies. To differentiate between the two sources of data, the interviews in the second phase will be called “in-depth interviews,” whereas the first phase will be called “semi-structured interviews.”

The analysis strategy for the semi-structured interviews involved thematic coding, where relevant or recurring ideas and concepts were identified in the data, tracked using notes, memos, and codes in NVivo 8 and systematically examined for their prevalence – or lack thereof – in the data (Ayres 2008; Firmin 2008). Because the research questions for this paper centered on respondents’ talk about work – their decisions, motivations, choices, and constraints – the major focus when reading the entire interview was, first, to identify passages where respondents discussed employment, and code all of those as being relevant to the research questions. At time one, there was data on employment for 47 respondents, at time two, 48 respondents, and at time three, 43 respondents.

Second, the particular passages where decisions about employment were mentioned were identified with a sub-code (‘decisions about work status’ for the decisions pertaining to that respondent’s work, and ‘decisions about work status – partner’ for decisions that related to their partner’s work). This code included major decisions about changes in work status (e.g., “I quit work”) as well as decisions about work on a daily basis (e.g., “I had to take days off”). The reason for including both in one ‘decisions’ code was that, conceptually, issues related to both major and day-to-day decisions about work appeared to be similar in initial assessments of the data.
Regarding decisions about work status, for 17 respondents there was relevant text in all three interviews. For 20 respondents, there was relevant text in two interviews, and for 17 respondents there was text in one interview. For 3 respondents, there were no relevant segments in any of the interviews. In terms of the distribution of relevant text across the three data collection points, there were 37 respondents in time one with data relevant to decisions about work status, 37 in time two, and 30 in time three.

Other relevant segments related to the research questions were the accounts of how respondents juggle work, school, family, and other responsibilities. These were identified and coded in NVivo8, with data for 34 respondents at time two and 43 at time three. The coded segments addressing the juggling and management of work and family demands were found in interviews two and three; no specific questions on that topic were found in interview one. Within those segments, I completed another round of coding with NVivo8, identifying important emerging topics that related to my research question. The codes capturing these topics are sub-codes within “the juggle.” The concepts captured by sub-codes included resources: things or people that make juggling easier; constraints: things or people that make juggling more difficult; family juggle, capturing descriptions of juggling of within-family demands (as opposed to juggling work and family); metaphors that respondents use to characterize their experience with juggling; motivation, any mention of their goals or reasons for juggling everything; strategies, tools, approaches, or methods that respondents use to juggle demands, and what gives, things that respondents forego in order to juggle other things.

After creating the final coding scheme for segments related to juggling work and family responsibilities, I coded the data and then generated reports for specific sub-codes. I
did this for each code, with the exception of *resources, constraints, and strategies*. The occurrences of those three codes overlapped a good deal, and it was worthwhile to examine them as a set. In each report, I read for emerging themes that addressed my research question, identifying responses by theme, and then working to understand how these responses and themes relate to one another and how they shed light on my research question. This approach to analysis allowed me to examine related segments as a set, to look for recurring concepts and themes that seemed to be common across respondents’ accounts (Ayres 2008). At the same time, alternative or contrasting situations were also identified. This comparison across the cases with regard to the emerging themes enhances the rigor of the analysis (Saumure and Given 2008) through an in-depth examination of the themes’ presence in the data relative to other related themes. The themes that emerged and the relationships among them are described further below.

The analysis strategy for the in-depth interviews involved assessing notes taken during the interviews, and re-visiting interview transcripts if available, or audio-recordings of the interviews if necessary. De-identified demographic data about respondents was entered into a matrix, as well as data about current occupation, hours worked, and other relevant work-related information. The matrix included notes, observations, and, in some cases, quotations relevant to areas that are central to this analysis: demands, resources, strategies, aspirations when young, and future goals. This approach not only distilled the data into a manageable format, but also allowed me to sort based on different characteristics, such as marital status or number of children, and evaluate the data from different perspectives.

The goal of the in-depth interview analysis was to identify specific resources, demands, and strategies in respondents’ accounts, as well as attend to the richness of the
detailed data in terms of understanding the particularities of each respondent's situation. The in-depth interview data were interpreted in light of the findings from the initial analysis of the semi-structured interviews, meaning that the main focus at this stage was to determine whether and how these detailed accounts either compared or contrasted to the broader themes that emerged from the semi-structured interviews, and how the details of mothers’ situations and accounts of changes over time might add richness or complexity to the themes present in the semi-structured interview data. As with the semi-structured interviews, in the in-depth interviews, attention to negative cases was key, in keeping with a process of constant comparison of observations (Denzin and Lincoln 2005).

Findings and Discussion

Dynamics of Work-Family Arrangements

Below, I describe main themes that emerged across multiple respondents’ accounts, and identify contrasting themes and accounts that did not fit with the general pattern, striving for comprehensive data treatment (Silverman 2006). First, I describe mothers’ accounts of juggling tasks and responsibilities. By explaining different dimensions of those experiences as well as variability, I “map the woods” (Silverman 2006), generally explaining the features of these forms of management in the lives of respondents, but also raise issues that relate to mothers’ employment decision-making. I also explain how this juggling can be conceived of as a form of labor: “articulation work.” Then, I describe and theorize accounts of employment decision-making with a focus on work-family fit and balance, using elements of Voydanoff’s (2005) conceptual model. Ultimately, the findings illustrate complex and active decision-making over time on the part of the respondents and their families, in response to shifts in demands and resources. They help to address an underdeveloped area in the existing
literature on work and family: acknowledging the role of agency, and “active strategiz[ing] to maximize work-family balance” (Bianchi and Milkie 2010).

One key element of the experience of work-family fit for these respondents is that the boundaries between these spheres are dynamic, and when shifts occurred in one area, especially in terms of allocations of time or money, other aspects necessarily changed in response. This was found in descriptions of juggling these spheres on a day-to-day basis, and in respondents’ accounts of changes in resources and demands over time. In particular, the idea that time is a limited resource that must be thoughtfully allocated was a theme that formed the backdrop of many respondents’ discussions of work choices. The following quote illustrates how time was portrayed in many accounts; this statement is made in response to a question about any decisions in relation to FXS, in which employment is offered as one example (emphasis added).

[Husband]’s would not have changed. Mine I may have – I’ve had opportunities to work part-time in the evenings like for a counseling center. Having some private clients or some groups. But I’ve kind of substituted that. It’s kind of a substitution thing again. Instead of being paid for my work, now I lead a special needs parent support group. […] And, that involves a lot of my time. […] So I think it’s substitutions again. Maybe I would have done more in my [career]. But I’d still want to be home with my kids anyway. But maybe I would have kept in my profession maybe even like four hours a week or something. Just to keep current with it. But now I have other things going with that time. (420-I2)

As in other accounts, time is a scarce resource: because of limitations on time this respondent made “a substitution” and opted to participate in support group activities related to supporting other parents of children with special needs, instead of working for pay part-time or pursuing other activities related to her career. Notably, she states that her partner’s work status would not have changed in relation to FXS.
Tied to the notion of time as a limited resource, in cases where the respondent did not work for pay or works part-time, work decisions for both partners were often framed as an issue of time allocation, with the time of one partner (usually the man) allocated to work, so that the time of the other partner (usually the woman) could be allocated to home. In those cases, a spouse’s employment served as a boundary-spanning resource (Voydanoff 2005), discussed further below, that allows the family to meet their child’s needs. Notably, having one partner – most often the mother – stay home to care for the home and children while the other partner serves as the main provider was an arrangement chosen by many couples. Using respondents’ self-reported occupations from the general information sheets completed at each wave, I assessed the numbers of “stay-at-home mothers” (SAHMs). To be coded SAHM, the respondent must have entered only “stay at home mom”, “mother”, “mom”, or “homemaker,” indicating that they are not employed outside of the home.  

Those who entered “self-employed” or “student” were not coded as SAHM. In cases where occupational data were missing from the general information sheets (n=3 at wave two, and n=5 at wave three), the interviews were used to obtain information about the mother’s work situation, if possible. At wave one, 28 respondents were SAHMs (0 missing), at wave two, 21 respondents (3 missing), and at wave three, 19 respondents (5 missing). In all, 30 of 57 respondents were classified as a SAHM in at least one wave of the study.

This arrangement can be explained using the concepts of boundaries, demands, and resources. Here, I am adopting the conceptualization of “resources” and “demands” used by Voydanoff (2004, cited in Voydanoff 2005): “[d]emands are structural or psychological claims associated with role requirements, expectations, and norms to which individuals must respond or adapt by exerting physical or mental effort. Resources are structural or

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3 Respondents who entered “unemployed” were included as SAHMs.
psychological assets that may be used to facilitate performance, reduce demands, or generate additional resources.” This arrangement would represent a boundary-spanning resource in the sense that it provides “family-based family support” which Voydanoff argues would be likely to increase role performance by “adjusting the level of work involvement to accommodate family responsibilities and activities” (Voydanoff 2005). Voydanoff goes on to state that “family members are likely to coordinate their work and family responsibilities more effectively when they receive work-family normative support from spouse and kin” because that support offers “cohesion to a family’s efforts to combine work and family life” (Voydanoff 2005). While a claim about cohesion cannot be empirically evaluated with the current data, it points to one mechanism through which within-domain and boundary-spanning demands, resources, and strategies may be tied to family dynamics and outcomes.

There was some support for this idea in the data; a few respondents described a shift after leaving their jobs, where they perceived lower stress in the household following that change.

Representing an alternative and much less common perspective, one respondent discussed the possibility that her husband might continue to work long hours even if she worked part- or full-time for pay. In this case, she was currently employed but worked two part-time jobs that did not require many hours per week. At the second interview, she said, “[…]
since I’ve become a stay at home mom, he works all the time. He works twelve hour days.” The following quote is from the third interview, when the respondent was asked about her husband’s roles and responsibilities (emphasis added).

He’s gone [when] the kids wake up. And he doesn’t come home a lot of times. Maybe at supper time for a little bit. A lot of times when they’re in bed already. Or when they’re getting ready to go to bed. So the responsibility of raising the kids is really my responsibility.

[…]
But he’s also – I mean he’s not around near as much because of his situation. The reason he has that situation is because I have to be home with the kids. Because I used to work full-time. But now I have two [part-time] jobs. And that’s it. (400-13)

This respondent explained the fact that her husband works a certain amount of hours as necessarily tied to her not working full-time. However, she went on to speculate about what it would be like if she worked part-time once her child is in school, and concluded that his work situation probably wouldn’t change – not only because they would need the extra money that her hypothetical part-time job would provide, but because he is a “workaholic.”

I would like him to be able to be home. And I think maybe when [child]’s in school next year I can maybe get a job. Or I can at least work part-time. I don’t think I’ll ever be able to do an 8:00 to 5:00 thing again. I really think that’s unrealistic for a family. But maybe I could get a part-time situation where maybe [husband] wouldn’t have to work as much. But, knowing [husband], he’s a workaholic. So it probably won’t change. It would probably just maybe give us a little bit more money. (400-13)

The situation above presents a counter-example to the themes of time and children’s needs as factors influencing employment decision-making, because in this situation there is another factor (that he is a “workaholic”) that impacts her husband’s work hours.

In another perspective in the interviews, rather than emphasizing time, some respondents emphasized changing their allocation of financial resources, or expectations for material goods. For example, one respondent changed from working full-time outside of the home to having an in-home business, resulting in decreased income, and explained subsequent decisions using a framework of changes in “perspective and priorities.”

Interviewer: Now what kind of other major decisions have you made in relation to [daughter]?
Respondent: I previously put we changed our whole lifestyle for [daughter]. I quit [job]. We bought a cheaper house. And a lot of this was [another child] was born, too. And, she’s got fragile X. That changed things. This was going to be our starter home. And now, it’s going to be our finished home. And we’re just going to live here. It’s just funny how your expectations or what’s important to you changes. […] But three
weeks after [child] was born, the stress was too much for [husband]. We had another special kid. Like “Okay. What are we going to do?” So, he quit so he could find something. And I had enough budgeted so we could make it through three months without his salary. And then he decided to work […] in this intermediate job […] But then he discovered he liked [it]. And it’s not a lot of money. But we realized it doesn’t matter anymore. Money’s not that important. […] We’ve never – so, if we can function – everybody has that. I think we expect a big house. Two brand new cars. All these things. And those things just aren’t important. They’re not what we need. And those things have changed because – not just [daughter]. But I mean we would have done it for our own kids. But maybe I might still be [working in job] if [daughter] didn’t have fragile X. I don’t know.

[…]

Interviewer: Now, how have these changes worked for you guys? Worked for [daughter] and your family.
Respondent: No. Really, really good. It just changed our perspective. I think two things have changed. Our perspective and our priorities. And we’re the poorest we’ve ever been. We’re the happiest we’ve ever been. So it’s just funny how things change when you start making family your focus. And other things fall into place. (740-I2)

In the example above, the response to decreased household income was not the other partner increasing work hours, but rather a change in “perspective” and “priorities,” and, in this respondent’s account, the overall impact was a change in their “whole lifestyle.” It is possible that, in this example, the other partner could not increase work hours to compensate, so the result was an unavoidable readjustment of priorities. However, the way that the respondent described the family’s decisions is significant: she discussed profound changes in lifestyle and expectations in response to their children’s needs, and framed those changes as active, shared re-assessments of what matters, and maintained that, as a result, the family is happier.

Using concepts from Voydanoff’s (2005) model of perceived work-family fit and balance, a reappraisal of expectations and priorities could serve as a boundary-spanning strategy.

Voydanoff (2005) describes boundary-spanning strategies as “actions taken on the part of individuals and families to reduce or eliminate misfit between work and family demands and resources.” As a result of decreased demands in one domain, as Voydanoff (2005) explains, “enabling resources and psychological rewards in another domain are better able to meet
these lowered demands.” The adjustment described by this respondent and others decreases certain demands within the family domain, making the resources in the work domain a better fit with the lowered demands.

However, with regard to this aspect of employment decision-making, certainly there is a financial reality that families must consider. Adjusting household budgets to compensate for decreased or eliminated income is not always a viable option, or may result in hardship. One in-depth interview respondent, a single mother, experienced that situation. In addition to describing financial challenges, because of her son’s medical condition (not FXS) she felt that she could lose him at any time and as a result she prioritized time with her son over material goods. She said, “[It’s] not like he wants anything, but I’d love to give him everything that I think that he would want, but in the end it’s like I’m happier just being his mom.” Discussing her decision to stay home with her son, and what she found valuable about that, she gave the following account.

I always said that I would go nuts being a stay at home mom. That I could never do it. I never wanted to stay home with [child]. I love him to pieces, but I’m thinking I just – there’s no way I could have ever done it you know, and I guess after moving to [state] it was like “Okay. You know let’s give this a shot. You know let’s do the stay at home mom.” And I absolutely – I love it. I love being here when he gets home from school. I love seeing him get off the bus.

[…] So I guess now just my viewpoint is kind of like I could lose him any day. You know I mean we could all lose our kids on any day. We could all lose our families and anybody. You know we could go at any day, but actually having that knowledge really kind of changes the way I view things. So it’s like every day is precious. Every minute you know just being there with him is huge. You know every laughter.

[…] – it’s hard because I’m spending the time with [child]. I’m being his mom, and I’m loving it, but on the flip side I can’t go get a house. I don’t have money for an apartment. I mean I’m kind of stuck at the moment you know. You know I still have my unemployment from [state], but […] that’s going to run out, and at that point you know I’m determined to be a stay at home mom now whatever it takes. So we’re going to file for the SSI because between the fragile X, the [other condition], and whatnot he’s certainly eligible for it. (520-ID)
Respondents’ decisions and motivations related to their own employment status were very much connected to the situations of other members of the family, and were formed against a backdrop of time as a limited resource, the needs of their children, especially with regard to therapies and other appointments and obligations, and their partners’ work statuses. Further, the idea that certain family demands are often seen as non-negotiable – specifically, children’s education, services, and therapies, and other activities and behaviors tied to children’s development or well-being—may clarify part of the process related to the negative impact on maternal employment of having children with special needs. When particular demands in the family domain cannot be lessened or reduced, where possible, families exercise agency to find solutions to work-family misfit.

Experiences with Juggling

In the semi-structured interviews, respondents were asked how they juggle work, school, family, and other responsibilities. For the purposes of this analysis, I argue that it is appropriate to conceptualize juggling as the management of competing demands. Significantly, it implies actions on the part of individuals, families, or others. Below, I describe respondents’ experiences with managing competing demands. It is important to note that, in at least one wave of the semi-structured interviews, five respondents stated that they do not have to do anything to juggle their responsibilities; however, some of them went on to describe particular things that they don’t have time to do, or “get[ting] everything squeezed in,” which both imply some limitations on time. Four of the five respondents were classified as low-income at the time of their response about juggling. In one such case, the respondent, a single mother with two children with FXS, worked a schedule that varied and had an involved partner who worked full-time.
Interviewer: [...] How do you manage to juggle taking care of work stuff that you need to do and the kids? How do you feel like you get it all done? Respondent: Work stuff I take care of at work. Then, by that time I’m done. I go home. And, I’m doing whatever I have to do with the kids. [...] Interviewer: Is there anything that right now you feel like you don’t have time to do that you wish you did? Respondent: Honestly I really can’t say that I – I mean I really can’t say that I do. Because, [...] the baby-sitter takes him – both the kids – two hours before I have to go to work. So, I get a couple hours by myself to do whatever I need to do. And then [Partner] – if I need to do anything at night or evening. Or if I want to go out on a weekend, he’s there. He lets me. He’s cool with it. I mean I don’t feel like – I’m not really stressed at all for wanting to do anything or not getting anything done. [...] Interviewer: So what kind of things do you think he has to do to juggle helping you with the kids and taking care of work and all of that? Anything? Respondent: I mean we take turns with certain things. Like I mean other than cooking. He cooks. He comes home. He relaxes for a little bit. And then he starts cooking. And then after dinner we clean up. We pretty much do everything together. We’ll take turns giving the kids baths. We’ll lay them down. We do everything together. (680-I2)

In contrast, many respondents described balancing or juggling activities and obligations as an ongoing and constant part of their lives. This sentiment was expressed throughout the accounts of juggling using phrases such as “constantly going,” “run and run and run,” “always putting out the next fire,” “always feel like there’s never enough time to do everything,” and, “[w]e start early. And, we end late.”

Touching on multiple therapies, the respondent’s work schedule, and necessary household tasks such as food shopping, the quotation below highlights key examples of matters that were common across many of the accounts.

Interviewer: And are there things that you have to do to juggle your responsibilities and with school and childcare and work and all that kind of thing? Respondent: Always. I mean always juggling something. Right now I’m trying to figure out my juggling schedule for the fall. For therapies. For OT, PT, speech. Because, do I do it in the house? Do I do it out of the house? If I do it out of the house, what time do I have to leave work? How many days a week is it? Then that means I can’t do other things the two days a week for in-home. And, yes. It does. Can’t go food shopping. All the juggling. (940-I3)
Considering ways in which competing demands impact one another, it is easy to see how balancing or juggling could be a constant element of the respondents’ lives. The quotation above illustrates the ripple effect of one decision on many other areas. When one thing changes (e.g., the child’s occupational therapy schedule, or whether it takes place in the home), most often other areas must change in response. Below, I argue that avoiding or managing these changes represents a form of labor undertaken by mothers.

Connected to the idea of a constant balancing of multiple needs and tasks is one respondent’s description of a feeling of being “on call” as a parent of a special-needs child. When asked whether there is anything she does not have time to do, she describes around-the-clock vigilance that she attributes to having children with special needs.

Well, I mean nobody ever has enough time to do what – but, not really. I mean one of the hardest parts of being a parent of a special needs child – especially a special needs child – is that you have to be like not just on call. But literally sort of alert in some form twenty-four hours a day. And it’s mentally exhausting. I mean like even when they’re asleep, I have the monitor on. And if [child 1] cries or [child 2] cries, I have to get up. Deal with it. And so sometimes that’s – so, just knowing that I have to do that is exhausting. (500-I3)

This quotation and similar ones reflect a certain degree of uncertainty about family routines, schedules, and agendas that may be linked to some characteristics common to FXS (such as the possibility of meltdowns occurring or the difficulty of sleeping through the night).

However, regardless of whether children have FXS, there is certainly always the possibility of unexpected events that may occur, altering a family’s routine or agenda. It is unknown from these data whether there is greater vigilance about that possibility among these mothers compared to mothers of typical children. From mothers’ descriptions of managing daily life with young children with FXS it does seem evident, though, that some perceive a degree of unpredictability regarding how situations may unfold, and that may contribute to challenges
in planning, carrying out, or maintaining routines or activities.

In some accounts, respondents touched on the reasons why juggling can be 
challenging, and there were different perspectives on whether they were linked to having a 
child with special needs, or were part of being a parent. Some parents described specific 
characteristics of their child, such as a need for things to be done a certain way or having 
difficulty in certain settings that made it more difficult to juggle activities and tasks, and 
those characteristics were often ones associated with FXS. However, other parents explicitly 
stated that *all* parents must struggle with some of these issues of balance and getting 
everything done, and that it was not tied to having a child with special needs.

*The Possible and the Impossible*

In accounts of the interface between work and family, certain aspects of respondents’ 
experiences and decisions were assumed to be possible and taken for granted, while others 
were portrayed as impossible or extraordinarily difficult. In these interviews, combining 
mothers’ part- or full-time employment with young children’s needs often fell into the latter 
category. As an example, this married semi-structured interview respondent worked full-time 
before the birth of her child, decided before he was born that she wouldn’t be going back to 
work, and stated that his diagnosis “confirmed that it’s not going to happen” (emphasis 
added). When asked whether the change has worked well for the child and her family, she 
responded with:

Yes. I don’t know how women can do that. Working full-time. Or even part-time. 
And having a child with special needs like this. Between all the driving. I just don’t 
know how you do it. So I feel fortunate that I don’t have to. It is definitely a full-time 
job. Researching the new school that he was going to go to. And just driving him 
everywhere. And getting the therapists. And all the communication back and forth. 
Oh, yeah. It’s definitely a lot of work. But obviously worth it. (1120-I2)

In addition, in some other cases, employment-related decisions were framed in terms of the
impossibility or extreme difficulty of satisfactorily meeting the needs of the family while also engaging in full-time paid work outside of the home. Two respondents framed this idea in terms of the needs and policies of a hypothetical workplace, compared with the needs of their children and family; below is one example.

So there was no way I was going to be able to work and take him to work with me. And I was of the mind set I’m not going to let somebody else raise my child. Because making so much money per hour as a part-time mom – nursing and having a pump and putting my son in daycare. It wasn’t worth it. So we said “Well, when he goes to kindergarten, I’ll go back to work.” […] When it became obvious that I wasn’t ever going to go back to work. Because who’s going to hire a mom that is not focused on her job? That is leaving. Can’t come in until 9:30. Has to leave at 2:00. And has meetings three times a month. Or, four times a month. Who’s going to hire me? A special ed preschool would hire me for eight bucks an hour. It’s not worth it. (1040-I3)

The married mother of two children, one with FXS, explained the reasoning for developing an in-home business based on one of her hobbies. The in-home business allowed her a flexible work schedule and requires a minimal time investment to maintain. Another respondent in the in-depth interviews, a married mother of five who worked with a close relative part-time, said, “[…] I could never get a real job right now, in case - I don’t have a back-up plan, in case someone gets sick, there’s nowhere to send the kids […].” When discussing necessary characteristics of a hypothetical workplace, the respondent explained that “[…] it would just have to be 100% flexible that if I couldn’t make it in then, you know - if someone was sick or, if I had an IEP meeting - and you know, and those things usually last all day. Not all day, but if it’s 11 in the morning, that’s like your whole day - 11 or 1, you know it’s like your whole day. So I think it would have to be something that would - that I could just take off if I needed to and not be penalized. And that doesn’t exist today, but – […] and thankfully I don’t need to get a job, my husband has his own […] business and it’s doing very well […].” (220-ID) In this way, the respondent frames the prospect of finding a
job that would meet the needs of the family as very difficult, stating that “it doesn’t exist today.” This statement also demonstrates the role of resources in respondents’ experiences; in this case, the respondent and her husband had always intended to have a large family and for her to stay home while he worked. In this case, their financial resources allowed them to achieve that goal for their family. Below, I will re-visit these points as they relate to employment decision-making, demands, and resources in the work and family domains, and the fit between those domains.

Notably, respondents’ explanations of how they managed to juggle everything contrasted with the sense of the impossible described above. To an outside observer, the prospect of balancing work and family demands – or just family demands, particularly if there is a child with special needs or multiple children with differing needs – might seem exceedingly difficult. However, in respondents’ accounts of how they managed to juggle everything a major theme was that they “just do it.” That is, these mothers mobilize informal resources and strategies to manage many responsibilities, making “the juggle” possible. What is important to understand about accounts related to juggling demands is that what is possible – “just do[ing] it” – contrasts sharply with what, for many, is impossible or exceedingly difficult, namely, combining full-time paid work and family obligations. And, importantly, the accounts of these respondents line up with traditional gender roles, as well as with current theorizing about what makes a “good” mother (see paper 1).

Articulation Work: Juggling, Prioritizing, and Letting Go

“Just Do It”

One of the most frequent responses when respondents are asked how they juggle their responsibilities is, “I just do it.” This response is sometimes accompanied by “I have to.”
This finding points to the idea that the strategies, resources, and constraints, as well as tensions and tradeoffs, while ever-present, are still seemingly ‘behind the scenes’ in the workings of these families. Many respondents, even if their response includes the notion that they “just do it,” also offer specific strategies, resources, and actions taken to meet many different demands. The “I just do it” response reveals that, on the surface, these are ‘automatic’ family processes, but respondents’ accounts illustrate some of the complex calculations and delicate weighing of various options and priorities that must occur for these mothers to juggle their multiple responsibilities.

Analyses of the sub-codes within the content related to the juggle in the semi-structured interviews revealed that processes related to ‘just doing it’ are complex, involving many different activities and needs that are juggled, mobilizing multiple forms of resources, and using various strategies. In addition to the fact that these processes often go unrecognized as part of the work-family juggle (or within-family juggle), the apparently invisible labor that goes into these processes also has an element of inevitability for some respondents. As one respondent said, “I just do it. I don’t have a choice really. It’s just the way it is. And, it has to happen. I mean you just make it work.” (1120-I2)

Prioritizing and Letting Go

A frequent response about maintaining balance had to do with setting and re-evaluating priorities. Many respondents said that they prioritize, or change priorities, in order to juggle what needs to be done. The backdrop for this strategy was often the idea that everything was not going to get done, so certain things need to be selected as most pressing or most important, in order to ensure that those tasks or activities are completed. Importantly, most who described prioritizing said something about putting their children first.
As an example of this strategy, this married mother of one child worked part-time, but described having to take a month off to “set [her] priorities again,” because she began to feel like she was “drowning in things.” The quotation below from that respondent continues that conversation, and in it, she illustrates the idea of prioritizing that was found across many respondents. In addition, it illustrates a strategy related to work and family: in her position, she was able to take a month off of work to re-assess her priorities.

Interviewer: Has it always been like that? Easy for you to kind of know when too much is going on?
Respondent: Yeah. But, it’s usually after like an eye opening event. Like I can see my frustration very thin with [child]. And then, I know. I have to set my priorities again. [Child] is first.
Interviewer: Are there things that you feel like you don’t have time to do? […]
Respondent: When I don’t work? When I’m just working the one day? No. I think I get it all in. Might not be exactly when I wanted to get it in. But, I get it in. When I’m working three and four days a week.
Interviewer: What things would go when you’re working?
Respondent: Laundry. I mean nothing with [child]. I mean that has to come first. Now, I guess the piece that affects that is am I less patient with him because I’m frustrated myself because I’m drowning in things to do? Or I’m tired. Or whatever. And I don’t like being rushed. I just don’t like being rushed. I don’t like to feel like I’ve got ten things to do today. And then, when I get him, I’m like-
Interviewer: Another task.
Respondent: Yeah. For [child]’s sake, I cannot do that. I just cannot do it. (20-I3)

A frequent statement about prioritizing was about having to “let go” of certain activities or responsibilities that they decide are lower on the priority list. Often household chores or yardwork were common responses when respondents were asked about what they don’t have time to do.

A few respondents described a shift over time toward doing less, and letting more things go. In the quotation below, the respondent describes letting go of entertaining, and learning “not to care so much” about cleaning and organizing.

Interviewer: So, how do you manage to do everything that needs to get done?
Respondent: I probably let some things go. Like I’d probably like to have more
entertainment. Entertain friends. And, other families over. But I just – anything above and beyond the day to day maneuvering is almost like one more thing. It’s like a total stress. Rather than enjoyment. So, we just kind of let some of that go.

Interviewer: So what do you feel you don’t have time to do?
Respondent: Probably I don’t have time to keep up the house as well. Like to deal with just the cleaning out of stuff and organizing. Doing that behind the scenes stuff. I can do the day to day. Like getting them fed and dressed and ready for the next day. Doing the homework. But anything that has to like add on to some of that is – I don’t do a good job of that. I guess I’ve learned not to care so much. (640-I3)

Related to prioritizing and letting certain things go, several respondents in the semi-structured interviews described not taking time for themselves to attend to their own physical or mental health needs. Some respondents described having difficulty taking any time for themselves, not only in terms of logistics, but also in terms of being away from their children. The quotation below illustrates the tension: balancing one’s own needs (in this case, social) against the needs of their children (or respondents’ perceptions of their children’s needs). A key resource in this situation is a woman, described as “like part of the family,” who was hired to help with the respondent’s son.

Interviewer: So I know you have the two kids to take care of and lots of therapies and everything going on. So, how do you feel like you manage to get everything done that you need to get done?
Respondent: Well, I don’t have any problem doing that now. Because I have P. She helps. She cleans. So I mean I’ve just somehow gotten really lucky. Because I’m able to have a life now. Which I never had. I mean since [child] was born, I felt like I have just dropped anything about me. And then, in the last year I’ve gotten a lot of it back. And of course I went a little crazy. And I’m president of the [organization] at [child]’s school. So, then I was all wrapped up in her school and fund raising. […] And so that took a ton of my time. Which then of course I also felt like that wasn’t about me. That was about her. Which was fine. So just recently I’ve gotten – I’ve joined the [sport] team. And I’m playing a lot of [sport]. Which I love. And so I feel like I have my own friends that are non-kid friends. They’re not parents of my kids’ friends. Which is really nice to have people – like I actually know people that I go to lunch with that don’t know my kids. That’s weird. Because those are the only people I know before.

Interviewer: Did that change mostly with P you think?
Respondent: Yeah. I mean it changed just in the fact that I didn’t have to be somewhere all the time. I had some – and, with him going to school. Because we can afford her, it’s really nice. But sometimes I feel like I tend to take advantage a little
bit. And I don’t see him as much as I should. So I then try to be here more. Just the whole thing. (280-I2)

The respondents’ accounts of juggling can be understood as articulation work, work that occurs often invisibly, ‘behind the scenes,’ and yet is crucial to the smooth functioning of family life and care of children (Hampson and Junor 2005; Timmermans and Freidin 2007). Articulation work is a concept introduced by Gerson and Star (1986, cited in Timmermans and Freidin 2007) to capture work that “keeps everything else on track.” Characteristics of articulation work include the fact that it is often invisible or easily overlooked, generally unspecified, is considered “unskilled menial work, and it often fails to qualify as ‘real’ work but it is absolutely necessary for jobs to be done” (Timmermans and Freidin 2007).

Timmermans and Freidin (2007) used the concept of “articulation work” to explain the day-to-day work performed by mothers in their care of children with asthma. They describe that caretaking as “a diffuse responsibility with the potential to expand as contingencies demand it” (Timmermans and Freidin 2007). This characterization of responsibility and contingencies is common to mothers of children with FXS, as well. For example, respondents described having to intervene in school days when emergencies like illness, behavior problems, or bathroom accidents required the involvement of a parent, or made it necessary that a parent arrange for someone else, such as a friend or relative, to intervene.

Similarly, care for a child with FXS is also a “diffuse responsibility” (see paper one) that can involve the coordination of, and possibly transportation to, multiple interventions, therapies, and services, activities, and medical and dental appointments. This is particularly true of families where there are multiple children with FXS who may be participating in
different interventions, activities, and therapies due to their developmental stages or the services for which they are eligible. In addition, where there are typical children in the home as well, the needs of those children also involve coordination of school schedules, which may differ from the school schedules of children with FXS, medical appointments, homework, activities, and other commitments. One in-depth interview respondent, married with three children, one of whom has FXS, mentioned this point about coordination and preparation in the context of expectations about motherhood; following the quoted segment below, she went on to describe rewards she experiences as a parent.

But, you know, [the diagnosis] changed where our expectation and life was going to go. But it’s not been – I still wouldn’t say it’s necessarily a negative thing. It causes a lot of stress and it causes us to make a lot of decisions, and changes and you know, things are just a lot harder and require a lot more planning … than I ever thought I was going to have to do as a parent. I can’t just wing it. You know, you can’t just fly by the seat of your pants and oh, let’s go here and do this and that and, you know, we try to do that as much as possible and just be spontaneous and do things – sometimes it works out, sometimes it doesn’t. But our perspective is, we don’t know any different. I don’t know if it would be the same you know, if we had all kids without a diagnosis. I don’t know. (560-ID)

One key finding related to the notion of “articulation work” is that respondents, even if they do not work for pay, do a great deal of juggling of many types. This calls attention to the fact that there is juggling that takes place within the work and family realms. Often respondents describe managing many demands on their time, regardless of whether their schedule involves paid work in or out of the home. Significantly, implying that only mothers who work for pay must manage conflicting demands would deny the reality of many stay-at-home mothers’ lives. In part, here I am arguing for a broader conceptualization of “juggling” to include other aspects of lives, in addition to paid work. I am also arguing that there should be greater recognition of the work that goes into this form of management within families. The quotation below highlights the contrast between a typical conceptualization of
“juggling,” and the reality of this respondent’s life. Her account made clear that though she said that she did not have to juggle work and family, particularly during the week she and her husband worked to make time that they could spend together.

Interviewer: Now all families have to balance childcare and work and school activities and all the work that goes into managing a home and a family. We’d like to know the different ways that families manage to do this. Are there things that you have to do to juggle your responsibilities with school and childcare?
Respondent: No.
Interviewer: Because you don’t work outside the home. Right? So, you don’t have to juggle anything.
Respondent: No.
Interviewer: So, you’re here when the kids get home. And, you’re able to take him and pick him up. And, all that kind of thing.
Respondent: Yeah.
Interviewer: How do you manage to do everything that needs to get done?
Respondent: I have no idea. I just do.
Interviewer: What do you feel like you don’t have time to do?
Respondent: I don’t have time to spend that much with my husband. By the time he gets home, there’s three kids. Dinner. Baths. And we have to try to make time and talk when we can. And then the kids come into sight. “What are they up to? They’re being quiet.” And so it’s just it seems like during the day I’m busy at home getting laundry, dishes, whatever. Or out running errands. Paying bills. And then [husband]’s gone so much at work. And it’s like “Okay.” Most of the responsibilities are on me. And I have to make decisions with or without him. I have to pick up the kids. I have to do this and do that. [Husband]’s at work. And on the weekends it’s just not stressful at all. We just hang. But I wish I had time for just a bit more time with [husband]. (820-I3)

Another form of juggling that sheds light on these respondents’ experiences is their efforts to manage the needs of all of their children. As one respondent said, “[E]ach kid needs me in different ways.” (200-I3) Respondents depict careful attention to the unique needs of family members.

Interviewer: Are there things that you have to do to juggle all your responsibilities in school and childcare?
Respondent: Yeah. I think for us I think just being organized is the only way that we survive. Because [son] has a lot more needs. Being sure that we can get all of his appointments and things scheduled. And at times that don’t necessarily take away from [daughter] or our time as a family in the evening as well, too. We try to be sure to do as much in that time while she’s at school. So that when she comes home, she’s
still on somewhat of a routine. And she still feels like she has that time with just us. And we try to keep as much time in the evenings just for us. Where we’re not doing anything. We’re just kind of hanging out together as we can. Because I think that’s part of the reason that we do better in our own family. Because we have that time where it’s just – which is down time for us. Just to kind of all decompress together and be okay. (600-I3)

The quotation above illustrates a form of management that takes place within families. In this case, the respondent described strategies she and her husband (she says “we”) used for balancing the needs of her son with FXS with the needs of her daughter, who is minimally affected by FXS. She also mentioned the need of the family as a whole to “decompress together and be okay.” Here, the strategy involved scheduling her son’s appointments at times when her daughter was in school, and also preserving as much family time in the evenings as possible. Another aspect of this form of management within families is negotiating the amount and quality of time and attention given to children, if there are multiple children in the home. Several accounts contained a similar theme: balancing attention and time among multiple children, and concern for each child’s individual needs and wellbeing, and necessarily having to evaluate and negotiate the variation across children’s developmental stages and types of needs.

Below is an example that illustrates that type of within-family balancing, which involves a respondent’s concern that her daughter, who does not have a diagnosis of FXS, is missing out on activities and having things “put on hold” due to her sibling’s special needs related to FXS. In this case, the mother had to weigh her daughter’s desire to play a sport against her son’s limitations on activities and settings.

[…] I have a hard time with my daughter. I can’t take her to any kind of – I take her to [sport]. Because it’s a set time. But she wants to play [sport]. We can’t. We tried it. He won’t go to a [sport] field. So a lot of things have to be put on hold for her. She doesn’t get to do a lot of things that she normally would be doing. Because he doesn’t want to go out of the house. (960-I2)
While the concern in this example was focused on the typically-developing child, some parents expressed concern that they were not doing enough to meet the therapy needs of their child or children with FXS due to everything else they have to juggle, so this type of concern—providing individualized time and attention according to a child’s specific needs—applied to both children with FXS and typically-developing children.

I would argue that there are several dimensions of the juggle described above that would meet the definition for articulation work. Specifically, being organized, prioritizing, and letting some things go necessitate assessment and adjudication among many competing demands and obligations. Coordinating family members’ schedules, including activities, school events, therapies, and other engagements also requires a certain degree of work, although some respondents explained that they are naturally “planners” and organized, so they do not feel it is difficult. Nonetheless, it requires time and effort, and contributes to the overall functioning of the household. Further, the statement by many respondents about juggling demands— that they “just do it”—highlights the invisible nature of this work. By identifying these crucial tasks as “work,” they are brought to light, and previously “invisible” labor—the performance of which is described as “just do[ing] it”—is rendered visible and recognized as a legitimate form of work (Hampson and Junor 2005).

What Gives?

In semi-structured interviews, respondents were asked what they don’t have time to do. Above, I described one of the common responses: household chores, maintenance, or yardwork tasks. Other specific related tasks were laundry, house-cleaning, and painting or organizing projects. However, the quotation below vividly illustrates another point that many of the respondents also made, of lacking time for themselves.
I guess I just make it look easy I guess. I see myself as – I put myself in a nice pretty little Christmas box. With pretty ribbon and wrapping paper. Put myself on a shelf in a closet. And, forget the fact that I’m there. And the reason I do that is because I’m so busy with my three kids. And nothing else matters but my three kids. And I live and breathe all three kids and my husband. And I forget about the fact that I exist in the world. And I’m not that important. That’s how I kind of see myself. (820-I3)

The quotation above is atypical in its vivid imagery and that the respondent used the metaphor of a box on a shelf in a closet, but it is typical in the sense that many respondents described a similar idea, setting aside their own needs. In some cases this pertained to certain hobbies or activities that they used to or would like to pursue, that they do not have time for (such as shopping, scrapbooking, or reading). Some mentioned their own health including sleeping and exercising, or spending time with friends, and in other cases it was more general, about having “alone time.” Twenty-five respondents described lacking time for themselves at wave two, wave three, or both. One of those respondents lacked time for herself at time three, but had time for herself at time two.

There was some variation in terms of respondents setting aside time for their own interests, activities, or time alone or with friends. Eleven respondents at either time two or time three said that they had enough time or deliberately take time for themselves. Four of those mentioned that part of the benefit of having time for themselves was that it made them better parents. In the quotation below, one respondent, a mother of one who did not work outside the home, described a shift after breaking off her relationship with the child’s father and how that changed the balance to allow more time for herself.

Interviewer: Is there anything in particular that’s either related to him or just things that you personally want to do that you just feel like you don’t have time to do?
Respondent: Not so much anymore. Because I feel like I have more time now that [child’s father]’s actually been taking him than I ever did before. Because really when he was traveling and home but not home, I had him all the time. And then I never – I would only get a couple hours to really do anything by myself. And now I actually

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4 Respondents’ descriptions of lacking time for themselves were not all negative in tone.
get a couple days. Which is just really nice. And I never got that before. I was pretty much felt like a single parent even though I was married. And I think I’m a better parent to [child] now. Because I actually get some time to myself to re-group and do things for myself that I never did before. And he’s actually had to be a parent to [child] and spend more than just a couple hours with him. (1100-I2)

Demands, Resources, and Strategies

In respondents’ accounts of employment decision-making, certain structural factors or issues were depicted as non-negotiable and, when they came into play, had a significant role in some respondents’ decisions. Among the structural factors described were the availability and suitability of childcare, financial necessity, and obtaining health insurance. Other seemingly non-negotiable factors impacting mothers’ employment decision-making were tied to children’s needs: specifically, their emotional and developmental needs in general, as well as therapy appointments, doctor’s appointments, and the administration of medications. These issues were portrayed as significant in many respondents’ accounts of their decisions about work status.

Given existing research on factors that impact workforce participation among mothers of children with disabilities, in the current research it is reasonable to employ a framework that takes account of demands and resources to explore how they relate to women’s accounts of workforce participation. In addition, because the notion of the “fit” between work and family domains is implicitly or explicitly an element of research on women’s workforce participation, a useful model accounts for fit and also allows an exploration of mechanisms connecting work-family fit and employment decision-making. I frame the findings related to work-family interplay and accounts of employment decision-making for these respondents using concepts from Voydanoff’s (2005) conceptual model, which outlines connections
among demands and resources in work and family domains, boundary-spanning resources, demands, and strategies, and work-family fit and balance.

As others have noted, this model can provide a framework for improved understanding of employment experiences and decisions for mothers of children with disabilities (Gordon, Cuskelly, and Rosenman 2008). Specifically, respondents in the current study made use of boundary-spanning strategies, or encountered certain boundary-spanning demands and resources, in the process of managing the work-family interface and making decisions about employment. Below, I give examples to illustrate the complexity of managing work-family interplay, and show how particular resources influence respondents’ experiences of work-family interplay. A model that includes demands, resources, and strategies lends conceptual clarity to “muddy,” multifaceted decision-making processes.

To provide context for discussion of boundary-spanning demands, resources, and strategies, it is important to first explain certain within-domain demands and resources commonly mentioned by respondents. With regard to within-domain family demands, the backdrop to the discussion of employment decisions is the fact that mothers are making those decisions in a context where there are particular challenges within the family domain. In the case of raising children with FXS, these involve time-based and strain-based demands (Voydanoff 2005). As examples, related to the former, there are sometimes multiple therapists, doctors, and service providers such as early intervention professionals who are involved with the children; scheduling, transporting to and from, and attending appointments can be time-consuming. Related to the latter, strain-based demands, depending on a child’s unique characteristics there may be additional demands associated with caring for a child with FXS, such as handling behavioral issues, difficulties associated with speech and
communication, sleep problems, sensory integration issues, and working with the child on therapy-related activities outside of the scope of the professionals’ work with the child. Generally, mothers are often responsible for much of the daily care associated with these time- and strain-based demands (see paper one).

The language used by respondents was not that of “demands” and “resources,” but the analysis revealed factors that fit conceptualizations of demands, resources, and strategies used in theories of work-family interplay, so those are the terms used here in order to understand respondents’ experiences within a sociological framework. Characterizing child-related factors as “within-family demands” for theoretical purposes is not meant to indicate that respondents perceived or described tasks related to children’s care as “demands” or burdens. To the contrary, many respondents described their children as joys and blessings, emphasizing the rewards of parenthood. It is important to acknowledge that in respondents’ accounts, within-domain demands associated with parenting children with disabilities are accompanied by the rewards of parenting, which are within-domain resources (Voydanoff 2005). These coexist in respondents’ accounts, and limiting a discussion of demands and resources to the challenges associated with parenting would neglect a crucial aspect of respondents’ experiences.

In discussions of decisions about employment, accounts given by these mothers focused in large part on the needs of others, and how those needs impacted their decision-making. While often the needs of children were portrayed as paramount in decision-making, other family members’ needs, such as those of partners, husbands, or extended family, were also included as significant in accounts. Perhaps not surprisingly, given existing research,
children’s needs were very often raised as a crucial reason for a respondent adjusting work
hours, schedules, or decisions about whether to work for pay at all.

With regard to the reduction of work demands, for some respondents, the decision not
to work for pay was made after the children were born or after delays and difficulties
emerged, whereas for others, they had already planned not to work before their child’s birth,
or before they learned of their child’s diagnosis. In the first wave of the study, when the focal
child’s age was between infancy and age 3, there was data on employment decision-making
for twenty-one respondents who were not employed outside of the home. Of those 21, six
respondents described their decision not to work outside the home as being unrelated to their
child’s diagnosis. For one respondent, married with two children with FXS, the initial
decision was the result of the expense of daycare relative to her salary but she also
commented that the change worked well because of the time commitments of therapies.

“And, it’s worked – it’s worked very, very well for us. And now, with [child 1]’s therapies –
and, during the summer, we have to take [child 2] to his therapies. And, I don’t know how we
would do it if I wasn’t home.” (600-I1)

As mentioned above, other respondents had always planned not to work outside of the
home, and having a child with special needs confirmed that decision. One in-depth interview
respondent, married with five children, described a past decision to leave her job to work out
of her home, and stated that it was not initially because of her child having FXS. She said, “It
was a choice because I wanted to be home with my kids. So even if [child] would have been
normal, I would have been home with my kids. […] So it wasn’t – it wasn’t like a
devastation, ‘I quit [job]. Oh, my life is over. I did that.’ But at that time when I was pregnant
with [child], that’s when I found out that I was a carrier. So I was extra. I was like, ‘We’re
going to make this work just in case we have a special needs kid.’ And then sure enough she was.” Later in the interview, she explained, “We always knew especially after we did have a special needs kid we will have a parent at home no matter what. That was just our decision no matter if we had to eat beans and rice or whatever […].” (740-ID) Therefore, while the family had already decided that having one parent out of the workforce to care for children was important, having children with special needs solidified that decision.

Related to the notion of family demands, therapy schedules and medical appointments were cited by several mothers as factors that impacted their decisions about work, such as in the example below. This account is from a married mother, classified as low-income, who has three children, two with FXS.

Interviewer: Has fragile X syndrome affected any other decisions that you’ve made?
Respondent: My decision to stay home with the kids more. If they were normal developing, I’d probably feel more comfortable sending them to daycare and stuff. And I’d probably be working and going to school and stuff like I was. I was working even when I was pregnant. And when we found out, I was still working. I had just finished some training. Had planned to go on to the next step in school. I just kind of stopped it all. Well I worked a little while after that. But then I started getting so scared about everything we had to do. There started being so many doctor’s appointments and so many therapy appointments. There’s not time for all of this. They’re not going to be able to do therapy and progress. Or I’m not going to be able to work. So I just stopped working. So I could have time to do this. Because between the two of them and just regular mommy and kid stuff, we’ve got like five thousand appointments and places to go and medications to give. So I think if they were normal developing kids, I would be working still. (320-I1)

In the example above, the respondent clearly described multiple facets to her decision, involving her feelings about daycare, the number of medical appointments and therapy appointments for her children, her children’s progress, and the ‘either-or’ decision that she faced with regard to her employment status.
These findings are in line with related research in the current project (see paper 1) that highlights the emphasis on children’s needs and the strong sense of responsibility that many of the respondents feel for their child’s development. It also fits with other literature that compares theories of workforce participation for women with theories for mothers of children with disabilities. Gordon, Cuskelly, and Rosenman (2008) note that theories and research on women’s workforce participation suggest that many mothers consider “their child/children’s developmental and parenting needs, and expected lessening or change in the nature of such needs with maturation” when making decisions about employment. Focusing on research on employment decisions among mothers of children with disabilities, Gordon, Cuskelly, and Rosenman (2008) point out that it “suggests that both the greater and longer duration of the child’s dependency needs and the expectation of higher support needs in the post-school phase impact on such decision-making processes.”

In both areas of research, trajectories of children’s expected needs are factors in employment decisions, but the anticipated needs of children with disabilities have the potential to be qualitatively different than the anticipated needs of typically-developing children, and those anticipated needs are likely to influence decision-making and planning for the future. Cases in the in-depth interviews supported this; for example, as one part of her decision not to pursue a full-time position that was opening at her workplace, and move to a part-time position in another workplace, one mother described being unsure about what life would be like when her child with FXS entered kindergarten: “…I was pregnant with [child], and they had decided at [organization] […] [they] were looking for an assistant manager […], which would have been a full-time position, and not something that I was even remotely considering doing when I was having my third kid, my oldest who has special needs
was going to start kindergarten, I mean it was, there was just too many things going on in our life for me to even think of taking a full-time position, and the [workplace] was supposed to open while I was on maternity leave. So there was just no way that I could have even remotely taken that. […] [B]ut I was going to stay on there […] and just work you know, whenever I could, ‘cause, not knowing what our life was going to be like when [child] went to school and then having a third kid, and how it was just going to change the dynamic, and knowing that we were not expecting [relatives] to watch the kids, because it’s just too much to have three kids, you know, and it was just too much.” (560-ID) While many parents might be uncertain about the impact on family dynamics when a child starts kindergarten whether that child has special needs or not, for this respondent the fact that their child has special needs was one part of the concern related to the prospect of taking a full-time job. Other points of concern included the addition of another child to the family and issues related to childcare. As with other discussions of employment decision-making in the in-depth interviews, the decision had multiple dimensions.

Respondents in the in-depth interviews who worked for pay, either currently or in the past, described several forms of within-domain resources and demands associated with the work domain. Respondents described the rewards associated with meaningful work, identified by Voydanoff (2005) as resources in the work domain that function as psychological rewards. Similarly, respondents described other rewards, including enjoying coworkers’ company, being around other people, and the atmosphere at work, feeling like they are good at their jobs, enjoying earning a paycheck and contributing financially to the household, and satisfying a need to be busy. With regard to within-domain demands in the work domain, some respondents described the challenges associated with time-based
demands (Voydanoff 2005), including nonstandard work schedules, such as working night
shifts, and working long hours, while some respondents described strain-based demands
(Voydanoff 2005), including large amounts of stress and responsibility associated with the
job, or jobs being “boring.”

**Boundary-Spanning Strategies**

Having outlined some of the issues for respondents in decision-making about work
and family, here I describe the complexity of work-family decisions for some respondents as
far as the resources and demands at play, and describe some strategies, including
employment decision-making, used by respondents and their families to enhance work-
family fit. In many cases, children’s needs were related to respondents’ choices of particular
lines of work, decisions not to work, or to reduce their work hours. Across the three waves of
the Family Adaptation to Fragile X Syndrome Study, of 51 respondents with occupation data
at all three waves, 11 respondents (22%) moved into or out of paid work during the study
(Table 3.4).

**Table 3.4 Respondents’ Changes in Paid Work Status over Three Waves of the Family
Adaptation to Fragile X Syndrome Study**

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As shown, in this small set of respondents there was not a consistent pattern of entrance into or exit from paid work. However, importantly, this simple account of whether or not respondents worked for pay masks the dynamic nature of respondents’ employment over time, which became apparent in both semi-structured and in-depth interviews. Taking a longer view in discussions of their work histories over their adult lives, most respondents described multi-faceted decisions to shift into and out of the labor force, change between part-time and full-time work, change workplaces, and change work schedules. I argue that often, the decisions related to these transitions can be conceptualized as boundary-spanning strategies in response to certain configurations of demands and resources at a given point. At the same time, respondents who wanted to stay in a particular position or situation – itself a decision – also made use of boundary-spanning strategies when necessary, to manage demands and use resources.

To illustrate the range of experiences with employment transitions\(^5\), of 14 in-depth interview respondents with detailed work history information, there were an average of 3.7 employment transitions each in the years since, and including, the year their first child was born. However, the range of transitions experienced was 0 – 10, which points to the variation in respondents’ experiences of transitions. While not a generalizable finding, in this small sample, the number of employment transitions did not appear to be clearly tied to the respondents’ marital status or socioeconomic status. However, a closer look at the particularities of situations reveals ways in which certain resources have some bearing on respondents’ experiences with work and family. Particularly when assessing respondents’

\(^5\) In the measurement of employment transitions, a change into or out of a position is counted as a transition. Consequently, changing jobs, from a position at one organization to a position in another organization, would be counted as two transitions: one transition out of the first position, and another transition into the new position. Situations where respondents experienced administrative changes, such as a company being purchased by another company but the respondent’s job remaining the same, did not count as transitions.
situations vis-à-vis their goals or their ideal work-family situations, in some cases resources allowed a respondent’s reality to more closely align with her goals. An example of that was noted above; a respondent’s husband had a successful business that allowed her to care for their children, as they had planned, rather than being employed out of necessity. In this way, that income serves as one boundary-spanning resource that assists the family in achieving its ideal work-family situation.

Two other cases highlight ways in which particular configurations of demands and resources may influence mothers’ experiences. In an in-depth interview, one married mother of three children, two who have FXS, enjoyed her job and had always planned on having a career in her current line of work. She had experienced no work transitions since the birth of her first child. She moved to being in the office part-time after her second child but worked from home as necessary, currently working close to full-time hours. In addition, she had a permanent position within her organization. She had certain resources in place, and most helpful to her were her husband and nanny. The nanny also helped with laundry and cooking; the respondent said she had to have someone to help with the kids, otherwise she “couldn’t work.” (180-ID) She had an “amazing” husband, who sometimes traveled for work, “[…] but if he’s home, I can count on him to pick up and help.” Supportive school environments for her children have meant that they have not had to ‘fight for things.’ She described her children as happy and independent without behavior or anger issues. This is not to imply that there are no challenges: she described some of the work it required to stay on top of her children’s schoolwork and activities, and coordinate the many aspects of the family’s schedule and their multiple commitments and responsibilities. In addition, she experienced some challenges related to one child’s schoolwork, but she and her husband divided their
efforts to help him: “My husband helps a lot with his homework stuff, yeah, a ton. Which he’s just sort of – it’s been recent, but it’s been just because he’s needed to be more involved, especially with my [son] who just doesn’t want to listen to me harp at him.” Discussing her job, she said, “You get to where you can’t really find anything better. You’ve figured it out, you’ve got an amazing benefits package, and a good salary, and a great schedule, and it’s just sort of hard to beat it.”

To illustrate the variation in mothers’ experiences, a contrasting case is that of a divorced mother, classified as low-income for wave three of the FAFXS study, who was employed full-time and also had experienced no work transitions since the birth of her child. She had particular resources in place, including relatives nearby who assisted her with childcare, and the child’s father who also cared for the child one night each week. Her job had good benefits, and the respondent emphasized that her job was very flexible and allowed her to work around her daughter’s schedule. However, this respondent expressed less satisfaction regarding some aspects of her work-family life; she had considered finding another job since she had become “kind of bored” (1140-ID) with her job, but was limited by the opportunities in her area. Further, she had considered relocating to a place with a larger population that might have more daycare possibilities for her child, because her child had behavioral challenges that had resulted in her ‘running out’ of daycares in her town. This respondent said that “maybe when [daughter]’s older and if she’s able to stay home by herself […], then I could do something different with my job, so […] And that way I wouldn’t have to worry about daycare somewhere.” She said, “[…] so I thought about something like that [relocating], then I’m always afraid, what if it doesn’t work out?” In this
case, the balance of resources and demands meant that she remained in her job, despite the fact that she would have been interested in seeking another job.

Clearly, these brief sketches do not capture all factors affecting each respondent’s life, and generalizations about the relative impacts of these various factors on employment decisions or other outcomes cannot be made from these data. Rather, the objectives are to illustrate both the complexity of the configurations of resources and demands that respondents encounter, and key differences between the situations of two respondents, both of whom had remained in their respective employment settings but who had different perspectives on their circumstances. These cases lend insight into how certain resources and demands may impact the experience of work-family fit and employment decision-making.

Taking a broader view, respondents in semi-structured and in-depth interviews who worked for pay described several boundary-spanning resources that helped them manage resources and demands in both the work and family domains. In particular, part-time work and flexible schedules served as resources for many respondents. Others that were mentioned included self-employment, cutting work hours or the amount of responsibility at work, and finding jobs with hours that accommodate children’s schedules. Decisions related to employment – such as seeking out these types of employment arrangements – were strategies used by respondents to help families increase the fit between the demands and resources across the work and family domains.

What Matters?

Below, I expand on revealing themes in respondents’ accounts of decision-making about work status and describe how they relate to boundary-spanning demands, resources,
and strategies. These themes yield important information about respondents’ accounts of what matters when making employment decisions. Reflecting a common theme, the respondent in this example explained a connection between children’s needs and employment status. She was married with one child, who has FXS, and worked part-time (“And, thank God I don’t work full-time”). Below is part of her explanation for why she worked part-time; she believed her son would “be in a different place” if she worked full-time.

Because if I worked full-time, I could not do the things I do for him. And I know he would be in a different place. If I didn’t stop doing the jumping and the flapping. If I didn’t stop, I know he would be in a different place. I mean I think when parents have to work full-time. And I mean some of them have to. I think they grow up differently. Just like if [son] had been blessed to my sister and her family or anybody. I mean he would be a different person. Good and bad. I don’t know. But he would be different. So I think that just a parent who has as much time to spend or dedicate to whatever it is he needs at that time. If it’s writing or reading or medications or whatever. I think it makes a difference. On who they’ll be. I know he’ll be different. (20-I3)

Reducing work hours in order to accommodate children’s needs is a boundary-spanning strategy that originates in the work domain, lessens demands in that domain, and increases resources in the family domain (Voydanoff 2005).

Notably, in a few cases in these data, one boundary-spanning strategy was to increase work hours, because the resulting increase in resources in the work domain can also benefit the family domain. In some cases, the motivation for working, or for a particular work arrangement, is closely linked to children’s needs. For example, one respondent, a single mother of one, specifically stated that her motivation for work lies in the money that she provides for her son rather than in an “urge to work.”

And then I also do, I had mentioned about how he comes first, and other things come second. Even beyond at my job. Because I need money for my son. Not because I have this undying urge to work. If I could stay home and get paid to do it, in a heartbeat. (240-I1)
Other respondents tied their decisions about work to the cost of daycare, but also to children’s needs. In interview one, a respondent described leaving a demanding job which, while it was an adjustment and they had to be “more careful with money,” she was glad that she did it because she, her husband, and her children had lower levels of stress as a result. In this example, cutting out her work hours reduced both family and work demands and increased resources in the family domain. The fact that she cut her work hours and took over more family responsibilities improved the fit between the work and family domains. In interview two, she talked more about that decision.

But I did leave my – I was working somewhere for fourteen years. And it was really the expense of daycare for her. And then my son would have to be there before the bus and after the bus. And that was still pretty pricy. So that was just really taking a large percentage. And plus I felt it would be better if I was home with all these therapists that would be working with her. They told me that they do work with people in like nurseries. But the mother’s not there. And so they don’t really understand their notes and how to help the child. So I think it’s been worth it. We’re really in tune with each other. I know how to communicate with her. And, I think it’s helped her progress faster. So, that’s a big change. (260-I1)

Decisions by respondents about employment are illuminated by examining connections between work-family fit, balance, and the strategies that individuals and families use to achieve better fit. Specifically, in the case above, which involved therapists and the expense of childcare, there was work-family misfit (Voydanoff 2005) with regard to demands and resources. In particular, there were within-domain demands in the family sphere (related to both the scheduling of therapies and the mother’s desire to learn the therapeutic techniques employed by the professionals) as well as within-domain demands in the work sphere (the mother’s paid work hours) (Voydanoff 2005). These factors – childcare, the timing of and participation in therapies and services, and the timing or amount of work hours – were frequently mentioned in respondents’ accounts. As discussed elsewhere, therapies, services,
and medical appointments are often understood to be non-negotiable by many respondents, as a result of the misfit, this respondent’s decision was to stop working.

As mentioned, in addition to discussions of children’s needs, another specific factor, childcare, emerged in semi-structured and in-depth interviews as impacting respondents’ decisions about work. Confirming existing research (e.g., Booth-LaForce and Kelly 2004), several respondents mentioned the issue of the availability and suitability of childcare. The ways in which respondents talked about childcare emphasized its operation as a boundary-spanning strategy. In Voydanoff (2005) hiring dependent care is an example of a boundary-spanning strategy originating in the family domain, that increases resources in that domain, resulting in enhanced ability to meet demands in both the work and family domains. In the current study, in some cases, having quality childcare made working outside of the home possible for the mothers. However, more often mothers cited the lack of childcare or their discomfort with having their children in childcare as factors that related to their work hours or their employment status. For example, one respondent said, “I had to cut back on my hours before because I didn’t have anybody to watch [child]. Now, I’ve increased them since I got somebody to watch him.” (880-I3) Both the availability and the suitability of childcare, including the capacity to handle a child’s special needs in an appropriate way, were issues raised by respondents.

As stated, the act of obtaining suitable childcare can be interpreted as a boundary-spanning strategy that increases available resources in the family sphere and positively impacts work-family fit (Voydanoff 2005). In addition, formal arrangements, such as paid nannies, respite care, or state-provided aides also served as important resources for some families in terms of work and family. Few respondents in the in-depth interviews had their
children enrolled in formal childcare, but one reason for that may be that the children were somewhat older, ranging in age from 9 months to 16 years old, with an average age of 9.63. But as in the example above, during the semi-structured interviews when children were younger, it is essential to note that the availability, affordability, or suitability of childcare for children with special needs was limited for some respondents, rendering this strategy unrealistic for some families.

As Seltzer et al. (2005) point out, with regard to managing work and family demands, “[s]ingle parents are an interesting and unique case…because their work and family negotiations almost by definition cross household boundaries. They have to negotiate assistance from nonresident parents and extended kin or friends, either those who coreside or those who live elsewhere.” In a similar fashion, especially in the case of single mothers, in the present study negotiations and decision-making about work and family were not always limited to the household. Single mothers described coordinating time with a non-residential partner, as well as seeking the help of family and friends in providing care for their children and performing other tasks related to work and family. In three cases across the semi-structured and in-depth interviews, respondents who were single mothers described living with their parents or other extended family for at least some time after having their children. In some cases, respondents were in relationships with co-residential or non-residential partners who assisted with things like children’s homework, bathing and feeding children, and other tasks related to daily caregiving.

However, family and friends were an important source of assistance to married mothers as well; though married respondents in in-depth interviews often said that their husbands were their most important source of help with caring for children and managing
other work- and family-related responsibilities, several also described help from extended
family and friends as significant, as well. Notably, receiving assistance from a network of
connections beyond the immediate family was not limited to single mothers; instead, it was
an important resource for many respondents in both semi-structured and in-depth interviews.

It is possible that these mothers of children with special needs, because of the greater
demands on their time and, in some cases, limitations on formal childcare availability or
suitability, perform similar negotiations to the ones mentioned by Seltzer et al. (2005)
regarding single mothers with typically-developing children. In the complex calculus that
takes place in work-family accommodations, some respondents had to account for others’
needs, schedules, resources, and relationships beyond the confines of the physical household
or the boundaries of the nuclear family.

Related to the notion of work-family interplay transcending household borders, in a
few cases adjustments of work status or schedules were tied to relationships beyond the
nuclear family or the mother-child dyad. One respondent in the semi-structured interviews, a
married mother, described adjusting her work schedule and her availability because a relative
was handling too much of the therapy monitoring, which the child did not enjoy. The
respondent said, “I don’t want him hating her for something we were – like she would come
in and he would cry ‘cause he knew he was going to have to have therapy that day. So I
ended up switching to doing two 10-hour days a week so I go in [specific time] to [specific
time] so that way I’m home three days a week instead of two.” (560-II). Out of concern that
the child would associate his relative with therapy and resent her, the respondent adjusted the
timing of her work hours to minimize her relative’s involvement with the therapy schedule.
This represents a boundary-spanning strategy employed by a respondent: by changing her
work schedule, she gained resources in the family domain that allowed her to meet the demands of her child’s therapy schedule, improving the fit between work demands and family resources, with the ultimate goal of preserving her son’s relationship with the relative.

A case in the in-depth interviews illustrates a similar point about relationships impacting maternal employment decisions, but in a different way. One single mother, now a stay-at-home mother whose relative cared for her son in the past when she worked full-time, at the time began to feel as though her relative was “overstepping her boundaries.” Describing that gradual shift, she said, “[s]o it was like she would be doing a lot of things that I really thought that I should be doing. And so it kind of started off as a little bit of jealousy where it’s like ‘Okay. I’m working, and she’s doing this, and she gets to go on the field trips while I’m working.’” At that time, the assistance resulted in the respondent’s feelings of “jealousy” because of the relative’s role in her son’s life. In this case, there were also other factors that influenced the respondent’s employment decision-making, but part of her explanation of what she valued about being at home with her son was her role in his life.

(520-ID)

These types of situations reveal the breadth of the demands that can influence mothers’ employment decisions; focusing solely on children’s needs, mother-child dyads, or structural aspects may miss other relevant factors. Further, cases like these add complexity to the notion of extended-family support as a resource. While many respondents described such support in positive terms, there also may be complications such as roles being blurred or impacts on relationships, as in the examples above.

In the present study, as expected, generally partnered mothers’ accounts centered on their own changes in employment status, work schedules, or career plans, rather than their
partners’ changes. The overall picture that emerges, then, is in line with existing literature: accounts of changes in employment status related to managing work and family generally focus on the women’s employment (e.g., Moen and Yu 2000). There were a few notable deviations from this pattern where fathers did adjust their schedules, or their careers and jobs are impacted by family commitments. For example, one mother described how her husband continues with a long commute so that they could continue to live in a district with good schools for their children.

I don’t move out of my town because of the special ed services I get. Because I’m afraid that if I move some place to make my commute shorter to work or my husband’s commute shorter to work, that it might compromise the education that my kids are getting. (720-13)

It is certainly possible that, if this analysis included fathers’ accounts, there would be many examples of fathers’ decisions about work accommodations related to family life, or connections between their responsibilities at home and at work, but in this analysis of mothers, those accounts of employment-related adaptations centered on their employment rather than partners’ employment.

In sum, these findings shed light on multiple aspects of families’ experiences with juggling work and family demands, and with making employment decisions. One key finding is that juggling for families is not limited to juggling demands between work and family realms, but also includes juggling within the family. In addition, these findings show how these forms of juggling can be understood as articulation work (Hampson and Junor 2005; Timmermans and Freidin 2007). Results also highlight the notion that decisions about employment often consider the needs and schedules of others, including children and partners or spouses. Further, certain resources, such as suitable and affordable childcare, and certain demands, such as children’s needs or financial considerations, were factors as
respondents made decisions about employment. In general, these findings show that configurations of demands and resources are related to employment decisions and that multiple factors are considered in decision-making. Further, respondents and their families used employment decision-making in some cases as boundary-spanning strategies to reduce, prevent, or eliminate work-family misfit (Voydanoff 2005).

These findings expand current knowledge of work-family interplay for mothers of children with special needs, as well as mechanisms involved in work-family interplay more generally. In particular, those accounts illustrated respondents’ experiences with boundaries between work and family, and the management of demands and resources in both domains. In addition, these findings fit with other literature, including work that has found that there are multiple strategies for managing work and family (Becker and Moen 1999; Moen and Yu 2000), and that, at least among dual-earner couples, these are “always in flux,” and that “as job and family circumstances change, so do expectations and forms of adaptation” (Moen and Yu 2000). This research adds to those findings in another context, where children have special needs and parents have various work situations over time. Findings demonstrated the applicability of several aspects of Voydanoff’s conceptual model of work-family fit and balance to the context of employment decision-making in mothers of children with special needs, an area that has been underexplored (Gordon, Cuskelly, and Rosenman 2008).
### Appendix A: Work-Family Calendar

<table>
<thead>
<tr>
<th>Age</th>
<th>Family Events</th>
<th>Who lived in the home?</th>
<th>Education and Work</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Marriage/Divorce</td>
<td>Births/Deaths</td>
<td>Change of residence</td>
</tr>
<tr>
<td>17</td>
<td></td>
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<td>18</td>
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<td>22</td>
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<td></td>
</tr>
</tbody>
</table>

Notes: Original work-family calendar was proportional to landscape-oriented legal size paper and included rows through age 55. Adapted from a work-family calendar provided by Dr. Philip Cohen.
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Chapter 4

“On the Same Page”: Romantic-Partner Relationships

Much has been written in the popular press and in scholarly literature about impacts of having children with special needs on parents’ marital or romantic-partner relationships, including the risk of divorce compared to parents of typical children. For example, a research finding made major new headlines in May 2010 when it was reported that, in a study using 2007 National Survey of Children’s Health data, children with autism spectrum disorders (ASD) had comparable rates of living with two married biological or adoptive parents compared to children without an ASD, with rates of 64% and 65%, respectively (Kennedy Krieger Institute 2010). As media outlets and researchers noted, this contradicted common wisdom that says that parents of children with ASD experience divorce rates that are much higher than rates in the general public, with rates of 80% or higher sometimes cited (e.g., Park 2010).

It is seen as common knowledge that having a child with special needs creates strains in a relationship, and according to some research, couples with a child with a disability are more likely to be separated or divorced than parents of typical children though the effect size was found to be small in a meta-analysis of studies between 1975 and 2003 (Risdal and Singer 2004). Additional research has found specific kinds of gendered living arrangements among children with disabilities, with children with disabilities more likely to live with single mothers, and with women in general, than children without disabilities (Cohen and Petrescu-Prahova 2006). However, more research is needed that acknowledges the unique
features of different disabilities, conditions, and disorders that may result in a child having special needs, as well as the dynamics in families that may eventually lead to different outcomes. A greater understanding of the diverse situations faced by parents of children with special needs is needed, with special attention to the impacts on, or experience of, romantic-partner or spousal relationships in those contexts. In addition, little research has focused specifically on parents of children of FXS. Studies that do exist tend to use scales instead of semi-structured interviews to measure marital quality. While the focus of this paper is not specifically on marital quality as an outcome, existing research points to the need for a more nuanced understanding of the effects of child disability on marital and romantic-partner relationships, especially with regard to diverse family structures and impacts on everyday life related to the characteristics of conditions and disabilities.

While important recent research has attended to the socioeconomic, demographic, phenotypic, or behavioral characteristics of children and families that may predict rates of divorce or levels of marital satisfaction, still less is known about the specific impacts of having a child with special needs on romantic-partner relationships as perceived by parents. Further, there is less qualitative research exploring parents’ accounts of their relationships in this context. This research represents a step toward filling the gap in the literature on research on partners’ perspectives on relationships in the context of having a child with disabilities; it focuses on mothers’ views of and experiences with romantic-partner relationships. Further, a unique feature of the current study is that the respondents are genetic carriers \(^7\) for the syndrome with which their children were diagnosed. Little research has examined data where respondents are carriers for their child’s condition; this may add additional dimensions to

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partner relationships that warrant further exploration. The present research is an attempt to address the gap in existing research by exploring those facets of their experiences.

The emphasis of this paper is distinct from research that attempts to identify rates of divorce or partnership dissolution, or assess individual measures of marital satisfaction or psychological well-being. While those studies are certainly vital, this paper focuses instead on identifying what parents, themselves, believe is important regarding any impacts on their relationships, and what those impacts may look like from the mother’s perspective. The focus is not on objective assessments of relationship characteristics, but rather on themes in the subjective assessments and descriptions offered by mothers in accounts (Orbuch 1997) of their relationships. Thus, for this analysis I am not concerned with, for example, the precise number of times the couple argues; rather, I would be focused on what the respondent says about arguments, and I acknowledge that her perception may not match that of her partner.

Specifically, the research question that inspired this work was: “how do these mothers describe the impact – if any – of FXS on their romantic-partner or marital relationships?” In the findings and discussion below, I describe how the results of this analysis dovetail with other research on the experiences of families with children who have disabilities, with regard to institutional and contextual factors influencing their experiences. In particular, I discuss the organization of therapies and interventions and familial divisions of labor. I also address some ways that respondents talked about carrier status and romantic-partner relationships.

**Background and Significance**

*Marriage among Parents of Children with Special Needs*

It is perceived as common knowledge that having a child with disabilities creates strains in a couple’s relationship, and considerable research has been devoted to the topic
(see Risdal and Singer 2004). Rates of separation or divorce, or characteristics such as marital adjustment or satisfaction, are often used as outcome variables, or the impacts of marital status or adjustment are studied as potentially intervening variables, sometimes signifying social support, with regard to outcome variables with a psychological emphasis. While not the focus of this project, I will briefly outline some of the research in those areas to provide context for the findings in the current study. Most importantly, a key feature of the existing research is that it does not provide a clear picture of how child disability relates to romantic-partner relationships (McCoyd, Akincigil, and Paek 2010; Risdal and Singer 2004). While many studies do find that child disability leads to higher rates of divorce or relationship dissolution, others find that the experience of raising a child with a disability can have certain benefits for families (Hastings and Taunt 2002). Assessments of couples’ experiences may need to reflect more complexity than simply identifying an overall negative or positive impact.

One study of 40 Australian couples with at least one child with FXS between the ages of 4 and 18 found that marital satisfaction was significant in predicting psychological well-being for both mothers and fathers, after accounting for demographic factors, child characteristics, and other forms of social support. Their reported levels of marital satisfaction were no different than those in the general public (McCarthy, Cuskelley, van Kraayenoord, and Cohen 2006). With regard to marital relationships, both spousal support (e.g., Warfield 2005) and marital quality (Kersh, Hedvat, Hauser-Cram, and Warfield 2006; Trute and Hiebert-Murphy 2002) have been found to be significant for parental well-being in families who have children with disabilities.
There is some evidence that the subjective interpretation of the impact of having a child with disabilities is worth studying independently of measures of parental psychological wellbeing, since it may be a different construct. In the development of a clinical assessment tool to measure parents’ perceptions of that impact, Trute and Hiebert-Murphy (2002) studied 88 Canadian families of children with developmental disabilities, and followed up with 64 of the families seven years later. They found no evidence of differences in the way that mothers and fathers evaluated the impact of having a child with disabilities. However, they found that, for mothers, the influence of the marital relationship on psychological well-being might be higher than for fathers. Similarly, evidence shows that a mother’s perception of support from her spouse may be more important for adaptation than the actual type or amount of support received (Bailey 2007).

The present study of mothers’ descriptions of their relationships with current or former spouses or partners provides key insights into how intimate relationships may be affected by having a child with a disability. In addition, evaluating single mothers’ accounts of how their relationships with their romantic partners – or potential romantic partners – might be affected by having a child with a disability adds to our knowledge of this under-explored area. With the increase in rates of cohabitation, almost half of all children in the United States will live in a household with cohabiting adults at some point (Bumpass 2004). Generally more unstable unions (Bumpass and Lu 2000), cohabiting relationships are particularly likely to dissolve if a child is in poor health (Reichman, Corman, and Noonan 2004). Though children with FXS are not necessarily in poor health, depending on how health is defined, these studies indicate that research on families of children with disabilities must also take into consideration the potentially complex and dynamic nature of the family
arrangements in which children live. Focusing solely on married couples yields only a partial picture and, clearly, focusing only on divorce as an outcome may miss a large part of the impact of having a child with a disability on marital relationships. Married parents may experience stress, challenges, and changes in their relationships, but not divorce, as the findings below illustrate, contributing to a more nuanced understanding of families’ experiences.

While some research has focused on the negative impacts of child disability on marital or romantic-partner relationships, other work has showed that having a child with a disability could have positive impacts on marital or romantic-partner relationships or for families in general (Green 2007; Hastings and Taunt 2002; Michie and Skinner 2010) or may not have negative effects on romantic-partner relationships (Eddy and Walker 1999; McCoyd, Akincigil, and Paek 2010). Theorizing about families of children with disabilities often considers the child’s disability to be inevitably stressful for families, but in reality there is a great deal of variability in how families react (Bailey 2007; Eddy and Walker 1999; Ferguson 2001; Hastings and Taunt 2002). Positive interpretations of children’s disabilities are reflected in specific outcomes cited by parents, including coping skills and adaptability, family harmony and cohesiveness, spiritual growth and shared values, shared parenting roles, and communication (Ferguson 2001), outcomes that could be overlooked if the theoretical approach automatically frames a child’s disability as being a family tragedy as earlier research on disability and family has done (Hastings and Taunt 2002; Risdal and Singer 2004). As discussed below, the present research provides a certain degree of support for existing literature that demonstrates complexity in parents’ accounts of raising children with disabilities.
It is also important here to consider the family context: certainly, socioeconomic status and family structure variables such as the number of children, and number of children with FXS, have the potential to significantly impact couples’ experiences. Additionally, the characteristics of children’s behavior problems may matter. It has been found that the significance of children’s behavior problems, rather than the severity of children’s delays, explained variance in stress, depressive symptoms, anxiety, anger, and quality of life among mothers of children with FXS (Bailey, Sideris, Roberts, and Hatton 2008). As Bailey et al. (2008) point out, more research is needed to understand the contextual factors that explain those effects and, while the current findings may not be able to explain the effects, perhaps they shed some light on the issue, as I describe below.

**Fragile X Syndrome**

Fragile X syndrome (FXS) is the result of a genetic mutation that inhibits a particular gene (FMR-1) on the X chromosome from producing a protein necessary for brain development (Centers for Disease Control and Prevention 2006). Specifically, it is known as a nucleotide repeat disorder; in individuals with FXS, there are excessive repeats of the CGG trinucleotide sequence on a particular gene. The mutation of the gene goes through particular stages as it is passed down, and individuals with 55 – 200 CGG repeats of DNA and a normal methylation (whether a gene is turned on or off) pattern are typically considered to have the premutation form of the gene (National Fragile X Foundation 2008). Those classified as having the full mutation typically have over 200 repeats and the gene is methylated – turned off so that it does not produce any, or enough, of the necessary protein (National Fragile X Foundation 2008). FXS occurs across all races and ethnicities, and it affects about 1 in 4,000 males and 1 in 8,000 females (National Human Genome Research Institute 2007). Other
estimates place the rate of occurrence at 1 in 3600 males and 1 in 4000 to 6000 females (National Fragile X Foundation 2006). Males are more likely to be symptomatic than females because the mutation is on the X chromosome, and since they only have one, they are more vulnerable to the mutation’s effects (Bailey and Nelson 1995). In women, their other X chromosome can sometimes outweigh the impact of the gene with the mutation. By some estimates, about 1 in 250 women and 1 in 800 men are carriers of the premutation, which contains fewer repeats of the DNA sequence, compared to those classified as having the full mutation (National Fragile X Foundation 2006). Individuals with the premutation may have some symptoms of FXS or fragile X-associated conditions, such as premature ovarian failure or fragile X-associated tremor/ataxia syndrome (FXTAS), a Parkinson’s-like tremor, or may have no symptoms at all (National Fragile X Foundation 2008). The gene responsible for the syndrome was discovered in 1991 (National Fragile X Foundation 2005), although the syndrome itself was first detected in the late 1970s. Once the gene was identified, FXS could be definitively diagnosed, people could be tested for both the full mutation and carrier status, and prenatal testing became possible (McConkie-Rosell, Finucane, Cronister, Abrams, Bennett, and Pettersen 2005).

The National Institute for Child Health and Human Development classified symptoms of FXS into five categories: intelligence and learning; physical; social and emotional, speech and language; and sensory symptoms (see Table 4.1). In addition, certain disorders sometimes appear alongside FXS or share characteristics with the disorder. These include autism, attention deficit disorder/attention deficit hyperactivity disorder, connective tissue problems, seizures, as well as later onset disorders of carriers, such as premature ovarian
failure for women and FXTAS (Eunice Kennedy Shriver National Institute of Child Health and Human Development 2003; National Fragile X Foundation 2008).

Table 4.1 Characteristics Associated with Fragile X Syndrome\(^8\) (continued next page)

<table>
<thead>
<tr>
<th>Category</th>
<th>Characteristics</th>
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<tbody>
<tr>
<td>Intelligence/</td>
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<tr>
<td>Learning</td>
<td>Impaired ability to think, reason, and learn</td>
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<td></td>
<td>Lower than average IQ score; those with full mutation tend to have IQ between 40 and 85, considered mild to moderate impairment, though females less affected than males</td>
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<td></td>
<td>Good memories for visual patterns and pictures</td>
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<td></td>
<td>Difficulty with abstract ideas, organizing information, planning ahead, solving problems</td>
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<tr>
<td></td>
<td>Make progress with learning but may need additional time, special environment/teaching methods</td>
</tr>
<tr>
<td>Physical</td>
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<td></td>
<td>Infants and young children usually have no physical signs; may have softer skin than average, or a slightly larger head</td>
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<td></td>
<td>Adolescents often develop an elongated face and larger, more noticeable ears</td>
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<tr>
<td></td>
<td>May not be as tall as expected</td>
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<tr>
<td></td>
<td>May experience seizures (20%)</td>
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<td></td>
<td>Males develop enlarged testicles (macro-orchidism)</td>
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<tr>
<td></td>
<td>Weak connective tissues may predispose individuals to hernias, frequent ear infections, heart murmurs</td>
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<td></td>
<td>Females with the premutation may experience premature ovarian failure (16 - 19%)</td>
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<tr>
<td>Social/</td>
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<tr>
<td>Emotional</td>
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<td></td>
<td>Often experience social anxiety, especially boys; may stop them from being social, or from seeking out new experiences or contact with others</td>
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<tr>
<td></td>
<td>Males tend to be easily upset, overwhelmed, or distressed, particularly if senses are overloaded; may become upset by changes in routine</td>
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<tr>
<td></td>
<td>When upset or anxious, take longer to calm down than peers</td>
</tr>
<tr>
<td></td>
<td>Becoming upset may manifest as tension or rigidness, tantrums, or repetitive motions; may result in trouble at school</td>
</tr>
</tbody>
</table>

---

\(^8\) Note that there is usually a great deal of variation in characteristics of individuals with FXS. This table reflects some characteristics that have been associated with FXS, but many individuals will not have these characteristics.
Table 4.1 Characteristics Associated with Fragile X Syndrome (continued)

<table>
<thead>
<tr>
<th>Category</th>
<th>Characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adolescents</td>
<td>May have more dramatic outbursts due to hormone levels</td>
</tr>
<tr>
<td>Females</td>
<td>May have social problems but will likely be milder than males’</td>
</tr>
<tr>
<td>Speech/</td>
<td>Problems communicating: mild stuttering to difficulties with pronunciation or</td>
</tr>
<tr>
<td>Language</td>
<td>communication through speaking and writing, tendency to ramble or speak off-topic;</td>
</tr>
<tr>
<td></td>
<td>problems regulating tone of voice, pitch</td>
</tr>
<tr>
<td></td>
<td>Often begin talking later than expected; most around the age of 4, but sometimes</td>
</tr>
<tr>
<td></td>
<td>age 6 – 8; some remain nonverbal</td>
</tr>
<tr>
<td>Severe</td>
<td>language problems rare among females; males tend to have moderate to severe</td>
</tr>
<tr>
<td>language</td>
<td>problems</td>
</tr>
<tr>
<td>Males</td>
<td>May also have problems processing written or spoken instructions</td>
</tr>
<tr>
<td>Some</td>
<td>language difficulties likely linked to social anxiety and shyness</td>
</tr>
<tr>
<td>FX males</td>
<td>May be very interested in communicating but lack ability to process relevant</td>
</tr>
<tr>
<td></td>
<td>signals, conversational cues, etc. in others</td>
</tr>
<tr>
<td>Sensory</td>
<td>May have problems with balance, coordination</td>
</tr>
<tr>
<td>Sensitivity</td>
<td>to loud noises or other sensations may cause outbursts or distraction</td>
</tr>
<tr>
<td>May avoid</td>
<td>physical contact if they find it overwhelming</td>
</tr>
<tr>
<td>Therapy</td>
<td>may assist with helping individuals manage sensory overload</td>
</tr>
</tbody>
</table>


There are key differences in symptoms by gender; girls are likely to exhibit milder forms of intellectual disability as well as the behavioral and physical characteristics associated with FXS (National Fragile X Foundation 2006). For several reasons, including its wide range of symptoms, co-occurrence with other conditions and disorders, and the fact that it is not widely known, FXS is often not diagnosed until a child is around 3 years old (Bailey, Skinner, Hatton, and Roberts 2000; Bailey, Skinner, and Sparkman 2003; Bailey, Skinner, Sparkman, Moore, Olney, and Crawford 2002). There is no routine screening at birth and
characteristics may emerge slowly over time; the family may first struggle with whether the characteristics they are seeing are truly problems, and may be assured by medical professionals that everything is fine or that the child is simply a “late bloomer.”

Families may undergo a “diagnostic odyssey,” which refers to the long process of searching for an explanation for the symptoms that they see in their child (Bailey, Beskow, Davis, and Skinner 2006; Bailey, Skinner, and Sparkman 2003; Carmichael, Pembrey, Turner, and Barnicoat 1999). One study revealed that the journey to a genetic diagnosis was often circuitous and exacted a toll on parents’ resources, both emotional and financial. The age at diagnosis was an average of 18 months or longer after initial concern about the child’s development (Bailey, Skinner, and Sparkman 2003). Bailey et al. (2006) summarized specific costs of this long road to the diagnosis of FXS: children miss, on average, 2 years of early intervention services; parents question their abilities when professionals assure them that “everything was OK”; parents may make 10 or more visits to professionals seeking a diagnosis, incurring costs, and in the interval between the child’s birth and the diagnosis, many parents have another child with FXS, not realizing that their other child’s condition was hereditary (Bailey, Beskow, Davis, and Skinner 2006; Bailey, Skinner, and Sparkman 2003).

Once parents receive a diagnosis of FXS, there are therapies, services, and interventions that have been found effective but there is no standardized medical plan of action for treating the condition. One reason for this is the wide spectrum of symptoms that accompany the condition. FXS, as of the time of this research, has no cure; the treatments for the child usually involve prescription drugs, behavioral therapy, and speech or occupational therapy, among other options, to manage symptoms and promote development (Eunice
Kennedy Shriver National Institute of Child Health and Human Development 2003; National Fragile X Foundation 2006). The medical aspects of the treatment may be aimed at managing aggression, anxiety, hyperactivity, short attention spans (National Fragile X Foundation 2006), sleep disturbance, hyperarousal or sensory overstimulation, obsessive-compulsive disorder, and seizures (Eunice Kennedy Shriver National Institute of Child Health and Human Development 2003).

Data and Methods

The results presented here are based on data from the Family Adaptation to Fragile X Syndrome Study (FAFXS). The FAFXS study includes data on 108 carrier mothers and 27 fathers from all over the United States. For the purposes of this study, I focused on the cohort of 60 mothers whose children, for the vast majority of the sample, were less than 36 months old at the time of the first interview (Table 4.2). Fifty-six (93%) of the mothers had the premutation form of the gene, while 4 (7%) had the full mutation, and all had at least one child with the full mutation. The FAFXS study sample also reflects a range of incomes. The mothers’ ages ranged from 20 – 43, with a mean of 32.3 and standard deviation of 5.11. Five respondents (8%) were African American, one respondent was Hispanic, and one respondent was categorized as “other.”

Table 4.2 Family Adaptation to Fragile X Syndrome Study: Sample Characteristics (continued next page)

<table>
<thead>
<tr>
<th>Maternal Characteristics: Young Cohort</th>
<th>Total (N=60)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age in Years</strong></td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>32.32 (5.11)</td>
</tr>
<tr>
<td>Range</td>
<td>20 - 43</td>
</tr>
<tr>
<td><strong>FX Mutation Status</strong></td>
<td></td>
</tr>
<tr>
<td>Full Mutation</td>
<td>4 (7%)</td>
</tr>
<tr>
<td>Premutation</td>
<td>56 (93%)</td>
</tr>
</tbody>
</table>
Table 4.2 Family Adaptation to Fragile X Syndrome Study: Sample Characteristics (continued)

<table>
<thead>
<tr>
<th>Maternal Characteristics: Young Cohort</th>
<th>Total (N=60)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>IQ</strong></td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>107.23 (14.3)</td>
</tr>
<tr>
<td>Range</td>
<td>55 - 130</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
</tr>
<tr>
<td>Less than high school</td>
<td>3 (5%)</td>
</tr>
<tr>
<td>High School Graduate</td>
<td>3 (5%)</td>
</tr>
<tr>
<td>High School; Some College; Associate’s Degree</td>
<td>22 (37%)</td>
</tr>
<tr>
<td>College Degree or Higher</td>
<td>32 (53%)</td>
</tr>
<tr>
<td><strong>Race/ethnicity</strong></td>
<td></td>
</tr>
<tr>
<td>White/Caucasian</td>
<td>53 (88%)</td>
</tr>
<tr>
<td>Black or African American</td>
<td>5 (8%)</td>
</tr>
<tr>
<td>Hispanic or Latino</td>
<td>1 (2%)</td>
</tr>
<tr>
<td>Other</td>
<td>1 (2%)</td>
</tr>
<tr>
<td><strong>Annual Gross Household Income</strong></td>
<td></td>
</tr>
<tr>
<td>≤ 26,000/year</td>
<td>8 (13%)</td>
</tr>
<tr>
<td>26,001 – 45,000/year</td>
<td>13 (22%)</td>
</tr>
<tr>
<td>45,001 – 65,000/year</td>
<td>11 (18%)</td>
</tr>
<tr>
<td>65,001 – 100,000/year</td>
<td>16 (27%)</td>
</tr>
<tr>
<td>≥ 100,001/year</td>
<td>12 (20%)</td>
</tr>
<tr>
<td><strong>Low Income (200% of poverty line or below)</strong></td>
<td>14 (23%)</td>
</tr>
</tbody>
</table>

**Mother’s current marital status**

<table>
<thead>
<tr>
<th>Marital Status</th>
<th>Total (N=60)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Married</td>
<td>50 (83%)</td>
</tr>
<tr>
<td>Divorced/Separated</td>
<td>3 (5%)</td>
</tr>
<tr>
<td>Single, Never Married/Engaged</td>
<td>7 (12%)</td>
</tr>
</tbody>
</table>

Source: Dr. Debra Skinner, Co-Investigator, Family Adaptation to Fragile X Syndrome Study

This analysis uses data from three semi-structured interviews that were conducted with each mother, with 18 months between each interview. For the purposes of these analyses, I analyzed interview and demographic data for 57 respondents: 56 respondents at time one, 53 at time two, and 45 at time three. At the beginning of the study the children were an average of 29 months old, or 2.4 years, and ages ranged from 10 months to 4 years. The interviews covered many different aspects of family adaptation to FXS.
For the second phase of the project, I re-contacted 15 respondents from the original study to gather in-depth information about their employment histories and decision-making using a work-family calendar (see Appendix B) and semi-structured phone interviews. In the phone interviews, I also gathered data on daily schedules and family relationships. To differentiate between the two sources of data, the interviews in the second phase will be called “in-depth interviews,” whereas the first phase will be called “semi-structured interviews.” I collected work-family calendars from 14 respondents, with missing data for 1 respondent. These also captured relationship histories. The sample for the in-depth interviews was diverse (see Table 4.3), including 9 respondents who were married, 5 respondents who were divorced, and 1 who was single. The sample included respondents with a range of family sizes: from one child only, who has FXS, to families with five children, three of whom have FXS. And, finally, the sample included mothers who work full-time, part-time, and mothers who do not work for pay. According to classifications at wave three of the Family Adaptation to Fragile X Syndrome Study, five families were classified as low-income (200% of the poverty line or lower).

Table 4.3 Maternal Characteristics: In-depth Interviews (continued next page)

<table>
<thead>
<tr>
<th>Maternal Characteristics: In-depth Interviews</th>
<th>Total (N=15)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age in Years</strong></td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>39.93 (4.04)</td>
</tr>
<tr>
<td>Range</td>
<td>34 – 49</td>
</tr>
<tr>
<td><strong>FX Mutation Status</strong>*</td>
<td></td>
</tr>
<tr>
<td>Full Mutation</td>
<td>1 (7%)</td>
</tr>
<tr>
<td>Premutation</td>
<td>14 (93%)</td>
</tr>
<tr>
<td><strong>Child Age in Years</strong></td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>9.63 (3.38)</td>
</tr>
<tr>
<td>Range</td>
<td>0.75 - 16</td>
</tr>
</tbody>
</table>
Table 4.3 Maternal Characteristics: In-depth Interviews (continued)

<table>
<thead>
<tr>
<th>Maternal Characteristics: In-depth Interviews</th>
<th>Total (N=15)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Number of Children</strong></td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>2.53 (1.25)</td>
</tr>
<tr>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>4</td>
<td>0</td>
</tr>
<tr>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td><strong>Education</strong>*</td>
<td></td>
</tr>
<tr>
<td>Less than high school</td>
<td>0</td>
</tr>
<tr>
<td>High School Graduate</td>
<td>2 (13%)</td>
</tr>
<tr>
<td>High School; Some College; Associate’s Degree</td>
<td>3 (29%)</td>
</tr>
<tr>
<td>College Degree or Higher</td>
<td>10 (67%)</td>
</tr>
<tr>
<td><strong>Race/ethnicity</strong>*</td>
<td></td>
</tr>
<tr>
<td>White/Caucasian</td>
<td>13 (87%)</td>
</tr>
<tr>
<td>Black or African American</td>
<td>2 (13%)</td>
</tr>
<tr>
<td>Hispanic or Latino</td>
<td>0</td>
</tr>
<tr>
<td>Other</td>
<td>0</td>
</tr>
<tr>
<td><strong>Annual Gross Household Income</strong>*</td>
<td></td>
</tr>
<tr>
<td>( \leq 26,000 )/year</td>
<td>3 (20%)</td>
</tr>
<tr>
<td>26,001 – 45,000/year</td>
<td>3 (20%)</td>
</tr>
<tr>
<td>45,001 – 65,000/year</td>
<td>2 (13%)</td>
</tr>
<tr>
<td>65,001 – 100,000/year</td>
<td>1 (7%)</td>
</tr>
<tr>
<td>( \geq 100,001 )/year</td>
<td>6 (40%)</td>
</tr>
<tr>
<td><strong>Low Income (200% of poverty line or below)</strong></td>
<td>5 (33%)</td>
</tr>
<tr>
<td><strong>Employment Status</strong></td>
<td></td>
</tr>
<tr>
<td>Not employed for pay outside the home</td>
<td>4 (27%)</td>
</tr>
<tr>
<td>Employed part-time (1-39 hours/wk)</td>
<td>7 (47%)</td>
</tr>
<tr>
<td>Employed full-time (40 or more hours/wk)</td>
<td>4 (27%)</td>
</tr>
<tr>
<td><strong>Mother’s current marital status</strong></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>9 (60%)</td>
</tr>
<tr>
<td>Divorced/Separated</td>
<td>5 (33%)</td>
</tr>
<tr>
<td>Single, Never Married/Engaged</td>
<td>1 (7%)</td>
</tr>
</tbody>
</table>

* Data from wave 3 of the Family Adaptation to Fragile X Syndrome Study
This paper describes the results of a thematic analysis of one major topical code from the semi-structured interviews, which captured passages in the interviews related to romantic-partner relationships. Further, I use cases from the in-depth interviews to add nuances and complexity to the themes that emerged from the semi-structured interviews. The segments from semi-structured interviews were coded using NVivo8 and analyzed in multiple ways to take advantage of the longitudinal nature of the data where possible. The coded segments captured instances where the respondents give information related to their relationships with a spouse or partner, or when discussing hypothetical romantic partners (e.g., discussing dating in the future). The entire interview at each wave was examined for segments related to this code, which were found throughout the interviews without being tied to a particular question. However, in waves two and three, specific questions about the impacts of having a child with a disability on relationships were included in the semi-structured interviews, so in those waves, the discussions in response to that question were also included. The questions focused on how marriages can be affected by raising a child with a disability, how the respondent would characterize the marital relationship, and how it has changed over time. As a result of this approach, the coded segments reflect both spontaneous and solicited comments about romantic-partner relationships. At time one, the query generated data for 40 respondents; at time two, 36 respondents; and at time three, 45 respondents. Fifteen respondents had data at all three times, 34 respondents had data at two times, and 8 respondents had data at one time.

While carrying out the coding for text on this topic, I also noted initial observations of the data in memos, including concepts or issues that appeared to be mentioned repeatedly, or unique situations or responses that seemed noteworthy because they seemed to deviate from
emerging patterns in some way. In another phase of the analysis, to take advantage of the longitudinal nature of the data, I displayed the data in matrix form (Miles and Huberman 1994) to examine themes and content across time.

I examined all of the data as a set in order by time, reading all text for times one, two and three in order. Then, to begin to refine my understanding of each respondent’s account and, where relevant, changes over time, I read the relevant text for each respondent in chronological order after organizing the data into a table for that purpose. The table allowed me to examine the relationships among accounts at times one, two, and three, and observe any patterns, commonalities across respondents, and contrasting cases (Miles and Huberman 1994). I continued to note, evaluate, and examine common themes as they emerged, and used the multiple readings and demographic data to explore potential sources of variation in participants’ situations and responses. Original text segments were revisited as necessary for the analysis. This allowed me to distill the concepts in the data through creating the summary notes and memos, while attending to the original details of the data, by continually revisiting the coded segments of the transcripts. These aspects of the process had features of a grounded theory approach (Silverman 2006). In addition, I drew upon existing literature and sociological theory to inform the analysis.

In a subsequent phase of the analysis, I sought to identify distributions or patterns in the data with regard to respondents’ subjective appraisals of their relationships. Specifically, I was interested in differentiating between those who described their relationships in generally positive terms, versus generally negative terms, or others whose accounts changed dramatically over time or were too complex to identify as positive or negative. To do that, I created a table that consisted of notes and excerpts for each respondent, regarding their
romantic-partner relationships. I sought to understand whether there might be patterns in the accounts, such as certain themes or issues, that differed based on whether the respondent’s overall tone was generally positive or negative when discussing her romantic-partner relationship(s). There were multiple iterations of this analysis and repeated passes through the data to evaluate the applicability and appropriateness of the major themes that I identified, as well as to identify contrasting cases and alternative themes or relationships.

The analysis strategy for the in-depth interviews involved assessing notes taken during the interviews, and re-visiting interview transcripts if available, or audio-recordings of the interviews if necessary. De-identified demographic data about respondents was entered into a matrix, as well as information about accounts of relationships. The matrix included notes, observations, and, in some cases, quotations relevant to the current research questions. This approach not only distilled the data into a manageable format, but also allowed me to sort based on different characteristics, such as marital status or number of children, and evaluate the data from different perspectives.

The goal of the in-depth interview analysis was to identify cases that supported the themes that emerged from the semi-structured interviews and cases that did not fit. In that way, the in-depth interview data were interpreted in light of the findings from the analysis of the semi-structured interviews, meaning that the main focus at this stage was to determine whether and how these detailed accounts either compared or contrasted to the broader themes that emerged from the semi-structured interviews, and how the details of situations and accounts of changes over time might add richness or complexity to the themes present in the semi-structured interview data. As with the semi-structured interviews, in the in-depth
interviews, attention to negative cases was key, in keeping with a process of constant comparison of observations (Denzin and Lincoln 2005).

**Findings and Discussion**

Below I describe key findings from this analysis. In addition to broadly characterizing the relationships as described by the respondents, I briefly note the specific challenges faced by these couples, as depicted by respondents, and then discuss how they characterize the impact – or lack thereof – of FXS on their relationships. Finally, I devote more space to two areas that add to the literature on parenting a child with FXS, and perhaps literature on other parenting contexts as well: carrier status as it relates to romantic-partner relationships, and the way that ‘being on the same page’ was talked about in the data and the contribution of sociological theory toward understanding that finding.

The three waves of the interview data were gathered 18 months apart, so it is perhaps not surprising that there were few changes in partner status across those three waves; based on demographic data, only 9 of the 54 respondents had different marital statuses at times one and three. However, of the in-depth interview sample, two respondents had divorced between wave three and the in-depth interviews. Based on accounts in the semi-structured interview data, many of the relationships that existed at time one were intact at time three. There were many couples in the sample who remained married through the three waves of the study and in the in-depth interview phase, but the interview data reveal challenges, issues, strategies and subjective appraisals of relationship quality. The value of the interview data is that it illuminates those subtle changes and variations within the sample. That is, two couples, both

---

9 Examining marital status across the three waves of the study may not necessarily capture a change in partner. That is, it is possible that a respondent could have been engaged at time two to one individual, and then married to another individual at time three; it can’t necessarily be assumed that the partner is the same person in both of those cases. In those instances, wherever possible, I have used the interview data to determine whether partners stayed the same or differed.
categorized as married, may hold very different views of the issues in their respective relationships, and may have very different descriptions of their satisfaction with those relationships.

Descriptions of Relationships

In general, many respondents described their relationships in positive terms though several respondents also identified certain challenges in their relationships – some explicitly linked to FXS, some not. Some challenges have been identified elsewhere in literature on parents of children with special needs, but less has been written on FXS specifically. Here, I list specific challenges that were mentioned to provide context for later findings.

Mothers described a variety of relationship-related challenges and impacts of raising a child with FXS. Challenges mentioned included a lack of time together as a couple or “freedom” to spend time together without children (and, related to that, the difficulty in finding quality childcare or reluctance to leave children in the care of others). They also commented on a lack of energy. Financial matters were also an issue, such as limitations on funds or disagreements about work status of partners. Challenges related to children’s behaviors were mentioned by some respondents, such as children’s sleep disturbances or problems with reflux.

Descriptions of challenges were not always accompanied by a negative assessment of the status of the relationship. For example, when asked how she would characterize her marital relationship, one woman responded, “Stronger in a lot of ways. But we have less time together. And we certainly have less time to spend as a couple.” (540-I3) Here, the respondent acknowledges certain challenges (time together) but also states that the relationship is stronger. This was a theme shared by multiple respondents, where respondents
described challenges but also were generally positive about their relationships, stating specific strengths or benefits of the relationships.

Portrayals of the Impact of FXS on Relationships

Respondents had diverse perspectives on the impact that FXS had on their romantic-partner relationships. In particular, several respondents emphasized the positive aspects of raising a child with disabilities, and in some of those cases the positive view was tied to overcoming challenges as a couple, or the feeling that they “come together over adversity as opposed to split apart.” (280-I3) Others cited the feeling of having a common goal, or the idea that raising a child with special needs has helped them form a family identity. Interestingly, one respondent explained that the need for greater communication, linked to the complexity of managing their child’s treatment, was one reason for the closeness and strength of the couple’s relationship. Another respondent whose relationship had ended stated that having her child with FXS extended the length of the relationship, and that they would not have been together as long if not for the child – in her explanation, because he “is such a special little kid.” (760-I2)

A few respondents expressed the idea that having a child with disabilities represented a turning point in a relationship, or could either propel a couple together or apart. As one respondent said of her own experience, “[w]e only had two ways to go. Up or down.” (200-I3) In that view, having a child with disabilities can strengthen or dissolve a relationship, but the relationship would not remain static or neutral. From one respondent’s perspective, the permanent nature and impacts on daily life of FXS ‘force’ couples to confront it. This

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10 It is important to note here that these accounts were from the mother’s perspective. The father or male partner might have a different perspective, and it is possible that FXS does have an impact that the mother doesn’t realize or acknowledge, or that it has a different impact than what she describes. Again, the major goal of this analysis is not to objectively assess the impact of FXS on relationships, but rather to describe mothers’ subjective perspectives and experiences on the topic.
respondent said, “But it definitely make you be open with each other. And if you can’t do that with the littlest things. Because the littlest things can be huge for them. Just like it can with any child. But I think it forces you since it doesn’t go away in two months – they don’t outgrow it as quickly. It forces you to address it. And then deal with each other on how you’re going to deal with your life every day.” (40-I2)

Several respondents cited a “strong foundation” or “strong marriage” as important for having children at all or for raising a child with disabilities. This is distinct from the ‘turning point’ perspective in that it locates a major reason for the relationship status within the relationship. In one example, a respondent described her experience of the end of her marriage mainly in terms of not having had a strong marriage to begin with. This point is evident in the case of another respondent, married with two children, one of whom has FXS. She described a long relationship with her husband that was in place several years before their first child with FXS was born, and, without describing the specific division of tasks, the fact that they are “comfortable” with their division of labor.

So we definitely had a strong foundation before the problems started. And, which is incredibly important. Like it’s very hard for people to have even typically developing children right after they get married. You need to have some kind of a foundation of just two before you have to deal with all the issues of children. Whether they have special needs or not. And so it’s just very important. […] this is why I said it’s very important to have a huge foundation. Stable foundation. Before you even attempt to have kids. Because you never know what’s going to happen with kids. And so I mean that’s why so many marriages fail. Especially with special needs kids. Because they don’t have the kind of foundation they need to be able to either work together or divide the tasks and be comfortable with that. We have divided the tasks and are comfortable with that. (500-I3)

Another common perspective was the notion that there were – or there may be – stressors in a relationship, but that having a child with special needs was not necessarily one of them. Respondents described challenges associated with having children at all, whether or
not they have special needs, or explained that, as one woman who also characterized her marriage as “excellent” said, “[d]efinitely there’s strain. But if we didn’t have these kids, then there’d be other strains.” (540-I2) Similarly, when asked to comment on whether having a child with disabilities impacts relationships, in the in-depth interviews a divorced mother of one child said, “I would say a little bit, but that’s not like the reason why I left, but I would say a little bit ‘cause – well, I guess it all depends on the husband, but, just - you just need more help, it seems, you know, or you would like more help instead of you doing everything all the time.” (1140-ID) Here, the respondent mentioned the division of labor in the household, later clarifying that she was considering both help with the child and help with the home in her response, but also specified that FXS impacted the relationship “a little bit” and that was not why the relationship ended.

Respondents characterized the impact, or lack of impact, of FXS on their romantic-partner relationships in a variety of ways. Some cited ways in which FXS brought the couple closer together, or described how FXS was not a source of stress or tension within the relationship and instead cited other stressors or the prior stability of the relationship as mainly explaining relationship status. Overall, respondents tended to draw fine distinctions among aspects of relationships that they viewed as being affected by raising children with disabilities (for example, time spent together as a couple), versus those not affected.

Further, respondents explained relationships as being influenced by multiple factors, not solely impacted by raising a child with a disability, and explained various views on the impact of raising a child with FXS on relationships, including positive ones. These characteristics of respondents’ accounts highlight the importance of understanding various interpretations of the experience of having a child with disabilities within a romantic
partnership; just as mothers may describe benefits associated with mothering children with disabilities (e.g., Green 2007), they may realize, or choose to emphasize, benefits for their romantic-partner relationships. Approaching an analysis from the perspective that having a child with a disability is necessarily going to be perceived or constructed as negative may miss an important aspect of many people’s experiences (e.g., Ferguson 2001). An account from the in-depth interviews included both the notion that there are stressors in any marriage, and the notion that the children have kept them together rather than pulling them apart. The following quotation is from a married mother of three children, two who have FXS.

I just – you know there’s some little stressful things, but you know of course I think that’s in any marriage. I don’t know that – I would say the kids have kept us together more than pulled us apart.

[…] Well for one it take – you know it takes a lot of help to raise them. I mean to raise any kid really, but these guys take more, and you have to really – you need two parents involved. You know I don’t know how single parents do it. I honestly don’t. It’s – when you get burned out, and you need to walk away, you know he’d come home from work some days, and I would just say “Bye. I need to be out of this house.” And you know I could do that. […] And he knew you know that I needed to leave. So he was very supportive in that manner. (380-ID)

Further, though, these accounts also revealed the way that mothers’ perceptions of impacts of having a child with disabilities on their romantic-partner relationships were not necessarily straightforwardly positive or negative; respondents gave multidimensional accounts that, in several cases, simultaneously described challenges and difficulties, as well as positive aspects and in many cases, a positive assessment of the relationship as a whole. A married respondent in the semi-structured interviews who has two children, one of whom has FXS, describes how her relationship with her husband is “good” and has gotten better over time but also acknowledges challenges. “It’s very hard. And it does cause a lot of stress and friction. And there are fights. And it’s very hard.” (620-I3) Similarly, in the in-depth
interviews, a married respondent who is the mother of five children, three of whom have FXS, acknowledged “bumps in the road” but stated that their relationship has grown stronger, and attributed the enduring nature of their relationship to their vows and their willingness to work through difficulties.

I think it hasn’t made the relationship worse. I think it’s made the relationship stronger. I think we’ve gotten stronger through the years. The kids have held us together. Sure there’s been lots of bumps in the road you know, and there’s been disagreements about things, and but in the end we knew we had to – I think even without kids with special needs we would – we knew that we got married, and you know for better or for worse you know for all those vows, and then and that this was going to be it, and we were going to work through whatever […] (220-ID)

Accounts such as these point to the need for nuanced understandings of links between child disability and parents’ romantic-partner relationships to reflect a more accurate picture of parents’ experiences.

Further, research on the cultural mechanisms at work in people’s descriptions of romantic love and marriage are useful for interpreting these findings. Swidler (2001) identified two “cultures of love” in interviews with middle-class Americans: a mythic love and a prosaic-realistic view of love. The “love myth” is “an exclusive, unique passion, a decisive choice that expresses and resolves identity, a struggle to overcome obstacles, and a commitment that endures forever” (Swidler 2001). These features, she points out, are reproduced in the properties of marriage as an institution, and the myth helps guide action when it comes to entering or leaving a marriage. In contrast, the prosaic-realistic view emerges in the context of the everyday.

The culture of love flourishes because, while marriage is institutionalized, the process of getting married (or deciding whether or not to leave a marriage) and – in the contemporary period, the procedure for staying married – is not. As marriage has become more fragile, no longer fully settling the lives of those who rely on it, a second culture of love, prosaic realism, has blossomed alongside the old. This new
love culture helps people be the kinds of persons, with the kinds of feelings, skills, and virtues, that will sustain an ongoing relationship. (Swidler 2001)

Prosaic realism focuses on how couples get along on a day-to-day basis, where heroism and virtue are directed at sustaining enduring relationships (as opposed to a ‘love conquers all’ notion found in the love myth); the emphasis is on a mature love that deepens over time, a “down-to-earth, gradually evolving love” (Swidler 2001). Swidler reveals that, in people’s accounts, the everyday experience of love – the prosaic-realistic view – coexists with the mythic view of love, though they are mobilized in different contexts, and that both are cultural and serve as guides to action.

In the present study, respondents’ accounts of their relationships fit with Swidler’s notion of the prosaic-realistic ideal of love. Ordinary, everyday actions of partners were emphasized, perhaps because the context of the discussion was the experience of respondents’ relationships rather than decisions about whether to enter into, or stay in, marriages. While it may seem self-evident that respondents would talk about their partners’ everyday actions, this is precisely the ‘invisibility’ of culture; one could also imagine respondents describing their relationships in ways that align with the features of the love myth, outlined above, such as being together against all odds. Instead, respondents generally focused on everyday challenges and situations encountered by the couple, and characterized support provided by partners as related to routine events. These reflect the very traits that Swidler lists as examples of virtues in the prosaic-realistic ideal of love, “from honesty to a willingness to face change, to stamina and a willingness to stick by one’s commitments” (Swidler 2001). These, too, are virtues required to sustain marriage today, Swidler points out. One married respondent in the in-depth interviews, also quoted elsewhere, exemplified this notion in her description of her husband.
It’s easy to choose to love your kids. Making the choice to love your spouse, and I know you’re thinking I’m trying to talk to you about motherhood, but I have realized motherhood is so intimately tied to my marriage. […] I just had no idea because I always wanted to be a mom, but I never thought of the marriage part. [My husband] – he’s changed his whole world. He’s phenomenal. When [child] was born, he wouldn’t hold her for the first six months. He didn’t know what to do. He never babysat a kid, and we had a lot of come to Jesus talks. So even the thought that I would someday leave him at home with my children I would have laughed. So it’s amazing how we’ve changed both of us, but I guess my motherhood was intimately tied to my marriage. (740-ID)

In this example, fitting with the prosaic-realistic culture of love, a positive aspect of their marriage was the change that each had undergone. Further, the respondent emphasized the everyday – her husband providing care to their children – as part of the reason that her husband was “phenomenal.”

A possible paradox is introduced when the modern therapeutic emphasis on self-development and growth coexists with the voluntary commitment and reliance on others - within many social relationships, not limited to romantic-partner relationships (Bellah, Madsen, Sullivan, Swidler, and Tipton 1985; Swidler 2001). These are reconciled in part by the view that “change [is] the virtue out of which enduring relationships can come” (Swidler 2001). Above, the respondent emphasized the individual choice to love one’s spouse, as well as the change that each had undergone; each of these points to the connection between self-development and change as a source of strength in a relationship.

Risk of Divorce

Having described some of the ways that respondents characterized the impact of FXS on romantic-partner relationships, I turn now to another theme in respondents’ accounts that yields insight into a potentially unique aspect of their relationships: several respondents, single and partnered, cited a statistic of a particular divorce rate or made statements about high divorce rates among parents of children with disabilities. In some cases this was also
accompanied by a statement that the respondent ‘can see’ how FXS or raising a child with a disability could negatively impact relationships. Importantly, though, most respondents who mentioned this point drew a distinction between the statistics and their own relationships.

Well, I think a child with a disability greatly affects the marriage. But I don’t think that was the reason that [ex-husband] and I divorced. But I do believe that many people for whatever reason cannot work together any more. Or they blame one another. Or whatever, and I know that’s true, because what is it? Eighty-five percent of marriages now fail with a disability or whatever. But that wasn’t our case. So it was different. (800-I3)

Interestingly, in her interpretation of the “eighty-five percent” statistic, this respondent understood it as the percentage of marriages that fail because of having a child with a disability, and resisted that notion, although even if inflated, the statistic does not necessarily point to causality.11 Another respondent whose relationships had ended in divorce made a similar point when asked about whether her child’s disability was related to the relationship. She responded, “No. Absolutely not. I could see some people’s relationships being like that. But, not ours.” (1000-I2) In one contrasting case, the respondent acknowledged a risk of dissolution that is implied to be higher than that of couples with typically developing children, and describes features of daily life and within-couple dynamics that were part of her assessment that things take “more effort” and that “it’s very difficult” when a couple has a child with disabilities. However, this is an example of a case in which the respondent did not make a claim about the inapplicability of a statistic to her own relationship.

It’s hard, because there’s more effort that you need to put into things that you just don’t think about when you have normally developing children. There’s more doctors’ appointments. There’s more bills. There’s more just that emotional baggage of carrying around. I mean I think it’s easier with fragile X. Because we know it wasn’t our fault. We know we didn’t – there was nothing we could have done to prevent it. […] Individually we’re both dealing with it, and then, to try to relate to

11 I am grateful to Andrew Perrin for this observation.
each other when we’re both very different people. He doesn’t understand why I feel a certain way, and I don’t understand why he feels a certain way, and it is hard. It’s very difficult. And it doesn’t surprise me that so many marriages don’t make it. (460-I3)

In the case above, the respondent described aspects of parenting a child with FXS that, according to her, parents of typical children “just don’t think about,” and emphasized within-couple dynamics that pose challenges. Notably, however, she also characterized one aspect of FXS as “easier” – presumably, easier than other disabilities – because, as she said, there was nothing they could have done to prevent it.

While most of the respondents who raised this issue of high divorce rates stated that it did not apply to them, statements about certain statistics or perceived facts about high divorce rates suggest that there is a specter of divorce that some couples, or at least mothers, may encounter in the course of raising a child with disabilities. The impression of extremely high divorce rates among parents of children with disabilities appeared to be taken as fact by some respondents, though estimates may be greatly inflated, such as “ninety percent” in one case. And, as described above, some actively engaged with and resisted the notion of the risk of divorce, stating that they ‘can see’ how it is a possibility, but not for them.

Swidler (2001) describes certain structural features of marriage, noting that, “despite the prevalence of divorce, marriage still has this structure: One is either married or not (however ambivalent the underlying feelings may be); one cannot be married to more than one person at a time; marrying someone is a fateful, sometimes life-transforming choice; and despite divorce, marriages are still meant to last” (Swidler 2001). Certainly, the supposition of permanence is a key feature of the institution of marriage, despite widespread knowledge of the risk of divorce even among the general public. While Swidler (2001) points out that there is a sense of vulnerability in the general public regarding the possibility of divorce, for
at least some of these respondents, there seems to be a notion – though also actively resisted -
- of having a particularly ‘at-risk’ marriage. In addition, at least two respondents offered
cautionsary tales of others’ relationships, framed as examples of what can happen. Future
research should explore this ‘specter’ of divorce, including how couples evaluate their own
risk of divorce, how it may impact couple’s perceptions of their own relationships, and
explore under what conditions the risk is perceived as relevant to them, versus being
something they “can see” but that does not apply in their case.

**Carrier Status**

The respondents in this sample were all carriers for FXS, and because some
perspectives related to carrier status were found in the data on romantic-partner relationships,
here I briefly describe some of the respondents’ experiences and meanings of carrier status
narrowly tied to romantic-partner relationships, based on the semi-structured interviews.
Carrier status was not a domain covered in the in-depth interviews, although a few
respondents raised it unprompted. Points related to romantic-partner relationships and carrier
status generally related to three contexts: reproductive decision-making, when discussing
when someone should find out one’s carrier status, and in recounting their own experiences
discovering their carrier status.

In the semi-structured interviews there are rich data on experiences and decisions
related to carrier status, and broader and more extensive analyses of respondents’ experiences
as carriers, including detailed discussions of genetic identity, genetic responsibility, and
reproductive decision-making, are found elsewhere (e.g., Raspberry and Skinner 2011a; b;
Skinner and Raspberry 2011a; b).
With regard to romantic-partner relationships and carrier status, a few respondents described perspectives related to the communication of carrier status. While there were multiple viewpoints regarding the best time to learn one’s carrier status, one viewpoint was that people should know their status before a serious relationship or before marriage (see also Skinner and Raspberry 2011a). Part of the reason for that timing was because then, the individual could possibly give that information to a partner or potential partner. For one respondent in the semi-structured interviews, the reason centered on fairness to the partner or potential partner. She said, “I would have wanted to know because I think that would have been a fair thing to share with my partner.” (940-I3) Another respondent, a single mother of two children with FXS, framed the communication of the information about FXS as being similar to other types of medical information.

You have to know. It’s very important nowadays. Because, no man wants to know that ahead of time – a man wants to know ahead of time that he – what’s wrong? What’s in your family? Do you have this? Do you have that? Do you have high blood? Do you have sugar? People want to know that kind of medical stuff. Which it’s good to know it. Because that way if you have a child that has sickle cell. If you have a child that has a disability problem. You’re able to handle it head on. Instead of not – if you don’t say anything, the person’s going to hate you. ‘Why didn’t you tell me? Why didn’t you inform me? Why didn’t you say this and that?’ (920-I1)

In this example, the respondent sees implications for romantic-partner relationships if information about FXS is not shared “ahead of time,” and compares responsibility for communication about FXS to other medical information.

Points about fairness, communication, or giving people information they “want to know” can be understood, as others have discussed, as examples of respondents framing themselves as active and responsible ‘genetic citizens,’ with attendant rights and responsibilities (Raspberry and Skinner 2011a; Schaffer, Kuczynski, and Skinner 2008). The sense of responsibility to communicate genetic information to a partner or potential partner
highlights an important aspect of the social implications of genetic information. A similar finding resulted from a study on individuals who accept or decline testing for melanoma susceptibility; the authors interpret participants’ perspectives on the discovery, management, and communication of genetic risk as their active construction of themselves as good citizens through their treatment of genetic risk information (Polzer, Mercer, and Goel 2002). Novas and Rose (2000) argue that genetic information introduces new forms of obligations and a sense of “genetic responsibility.”

In this context, genetic forms of thought not only give life strategies a genetic coloration but also create new ethical responsibilities. When an illness or a pathology is thought of as genetic, it is no longer an individual matter. It has become familial, a matter both of family histories and potential family futures. In this way genetic thought induces ‘genetic responsibility’ – it reshapes prudence and obligation, in relation to getting married, having children, pursuing a career and organizing one’s financial affairs.

Similarly, too, Novas and Rose (2000) make a strong argument for the profoundly social nature of the implications of genetic information – an argument supported by the present findings.

Genetic identity is revealed and established only within a web of genetic connectedness, which is overlaid upon a web of family bonds and family memories, with their burden of mutual obligations and caring commitments, and with all the ethical dilemmas they entail. In becoming part of a genetic network, the subject genetically at risk may rethink their relation to their current family – lovers, potential and actual spouses, children, grandchildren and so forth – in terms of these issues of risk and inheritance.

In the present data, some respondents also described mitigation of guilt or self-blame regarding their children with FXS or their partners because they did not know their carrier status. As one woman said, “[...] I felt more guilty about that with respect to [husband]. But I mean I couldn’t have known. We never could have known. And it just happened. And so I didn’t do it intentionally. And so, no. I haven’t angst-ed over that too much.” (180-I3) As
described above, these concepts are analyzed more extensively elsewhere (Raspberry and Skinner 2007; Skinner and Raspberry 2011a; b). The present findings, though narrowly focused on points where carrier status emerged as related to romantic-partner relationships, align with existing literature regarding the construction of responsible genetic citizens and contribute to that literature by highlighting ways that this sense of “good genetic citizenship” can play a role in relationships not only with children, but also with romantic partners.

An interesting theme in a few discussions of respondents’ romantic-partner relationships and carrier status was an imagined alternative storyline for relationships. These respondents described perspectives similar to the example below, regarding other routes for their partner’s life, perhaps with a different partner. As in the example below, generally respondents who described this alternative storyline also took care to explain that their partner did not say negative things about their carrier status, or make them feel responsible for their children having FXS.

You know I think there were times when we were having a bad day thinking about it, both of us, I bet I did have some thoughts like, “God wouldn’t it be easier if [husband] was married to a woman who wasn’t a carrier of fragile X”. […] But you know that didn’t last very long. […] Well no, he never acted like that. (860-I1)

Raspberry and Skinner (2007) found that, in interpreting genetic information, individuals expressed an understanding of a “genetic body” reflecting a “profound historicity,” extending into the past, especially throughout a family’s history, and through the present and future. In this context of the “profound historicity” of the genetic body, for a few respondents, carrier status impacted their interpretation of their romantic-partner relationships going into the future, and into an imagined past. One woman described the way that it impacts how she currently interacted with her husband: “[…] I look at [husband]. And I think part of the reason why I do so much and let him have all of this extra time is because I feel bad. Because
if he didn’t marry me and didn’t have children with me, he wouldn’t have this life like we do.” (900-I2)

Related to the aspect of time, one noteworthy viewpoint on FXS and romantic-partner relationships was the way that a respondent described having to re-imagine her future life with her husband. This respondent described how she had expected to eventually have an ‘empty nest’ and time alone with her husband after raising children to adulthood, but that the possibility of having adult children who cannot live independently caused them to re-think that future, and imagine other possible scenarios. She said, “[…] I think the initial shock of how your entire future mindset is going to change and how your future with you and your husband – I’ve always thought of the day when [husband] and I – cause we had [two young children close together in age] like that (snaps fingers), and how I looked forward to the day that we’re alone someday. And the thought that we’ll always be raising this child I think is what really hit me hard. So it was that loss of our future freedom that really kind of shook me.” (740-I1) While other respondents talked about re-imagined futures, dreams, and expectations for children who have been diagnosed with FXS, this account revealed another area of re-imagining for one respondent, focused on her relationship with her husband. The diagnosis of FXS and the uncertainty about children’s needs as adults caused her to anticipate a different future with her partner than previously imagined.

With regard to existing social relationships (in this case, romantic-partner relationships), one of the dimensions of experiencing genetic information may be, for some, the process of imagining this alternative storyline for their partner’s relationships with an imagined ‘other.’ For future research, this suggests an unexpected way in which knowledge of carrier status may have ramifications not only for the individual and her biologically
related family members, but also for individuals’ visions, hopes, and expectations regarding significant social relationships.

“On the Same Page”

A theme that emerged in accounts of romantic-partner relationships involved the amount of agreement on parenting strategies and goals. Many respondents used the phrase “on the same page,” “see eye-to-eye,” or a similar concept to describe the extent to which they and their partner aligned on parenting goals and practices. For example, in the case below, the respondent described being ‘on the same page’ as her husband.

Because when you are fortunate to have somebody who gets it and understands what it means. Like not somebody telling – not somebody who disagrees with you and says “No. I don’t really think there’s a problem here. I don’t think he needs that extra hour of speech therapy.” We’re on the same page about our kids. And it just makes it so much easier. Like the day to day. (720-I2)

Other examples like this also emphasized positive aspects of being on the same page.

Therefore, to some degree, the extent to which respondents consider themselves ‘on the same page’ as their partner may be an important gauge and, perhaps, a source of satisfaction or frustration in some couple’s relationships.

A related concept was also described with regard to the interpretation of the child’s behavior and how to handle situations where a child may be acting in a way that is not what parents desire. Parents may differ in their perceptions of whether that behavior is due to FXS or not, and thus may differ on how to manage the situation or, if applicable, whether and how to discipline the child. In the example below, the respondent explained that different interpretations of their son’s behavior could lead to added stress in their relationship.

So it can be stressful in the fact that when he [husband] doesn’t have the patience, then I don’t like that. So then you argue about that. Because he gets frustrated because like why can’t he [son] sit there and just watch a movie? Well because he can’t. He can’t. And so I think that’s probably the biggest thing. Like it's just the
frustration that comes along with the “Why can’t he do this?” And “Why is everything so difficult?” That’s probably like the biggest thing. So that can be stressful. Added stress. (700-I3)

In other examples like the one above, respondents cited different perceptions of a child’s behavior. Another related theme was the notion of perceptions of children’s needs; some respondents described differences between partners regarding the perceived needs of the child, such as needs for particular services or therapies; daycare settings with certain characteristics; and settings for family activities – for example, the appropriateness of a particular restaurant setting.

[...] He totally doesn’t understand his needs like I do. He tries to – I mean how I say I don’t treat him special because of it. He totally thinks he doesn’t need anything special. He doesn’t even want to hear about that part. So it’s very different. Me, I know he needs it. But I’m not going to treat him different because of it. But I just know if he can’t do something, it’s because of it. So I don’t stress it on him. Whereas his dad would totally stress something. (340-I2)

Thus, for many respondents, it seems that an element of their experience of romantic partnerships and parenting a child with FXS involves “being on the same page,” agreeing on children’s needs, and agreeing on reasons for certain behaviors and subsequently how to handle those behaviors. These aspects of ‘being on the same page’ can be seen as spectrums, with respondents reporting varying degrees of consensus between partners in these areas.

An in-depth interview respondent, a divorced mother of one, describes her experience with having a perspective on her child’s needs that differed from the perspective of her ex-husband; she felt that he “babied” their child too much, whereas she was more focused on encouraging self-sufficiency as much as possible, saying, “[t]he world is going to be hard on [child]. Nobody’s going to say “Oh, my God. You have fragile X syndrome. Let’s give you a break.” She explained that there were “big-time differences” in how they approached parenting their son, which she thought were not only due to differences in their views of their
son’s needs but also due to differences in their backgrounds. Post-divorce, there are both positive and negative aspects to raising her child without a partner.

You know we have another IEP meeting. What do I focus on? Is it more important that the aide be on the bus, or you know is it more important that I worry about you know his education? It’s like every little decision that has to be made it’s all me, and that sucks.

Interviewer: Yeah. That would be a challenge.
Respondent: I make the wrong decision, and it’s like crap. It’s you know my child. […]

[Discussing positive aspects of being a single mother:]
Respondent: Oh, it definite was a lot of positive aspects. You know I can’t imagine that [child] didn’t feel the tension that was in the house. I mean it had to have been awful for him. I mean I know growing up what it was like when my parents fought, or not that [ex-husband] and I ever fought because we didn’t. It was the non-verbal thing. It was just I was angry at him. He was angry at me. Don’t talk, stay in separate rooms, but that tension was there you know, and it’s like I didn’t feel like I was a good mom because I was so stressed out and tense and upset about the marriage and everything going on there. It was hard to be fun loving and do things with him. So it’s like that feeling of just having your stomach in your throat twenty-four hours a day is gone. Seemed to me like [child] became much happier. I know I was happier. So again it’s hard to make decisions by myself, but it’s probably easier making them myself than it is to get a conflicting opinion. (520-ID)

This respondent characterized the difficulty of making decisions alone, which is itself a challenge, as being less than the difficulty associated with making decisions when opinions conflict between two partners. Further, post-divorce, she viewed the lessening of tensions in the home as an important positive change for herself and her child.

A divorced in-depth interview respondent who is now in a long-term relationship and is the mother of two children, one of whom has FXS, described a delicate balance between her boyfriend being involved in her children’s lives and ‘crossing that line,’ as she put it, into parenting. However, she spoke highly of her boyfriend’s role in her children’s lives, saying that he is “there for them” and that “[h]e, I think, over the last two years has learned a lot about fragile X, so he’s definitely done his research on it too, and kind of understands where
[son]’s coming from. And you know the greatest thing is he chooses to be there. He doesn’t have to be there, and he chooses to be there. So you know that’s a good thing.”

She explains that she is protective of her son, which is why she draws boundaries between her boyfriend and her son. “[…] [Son]’s been with me for [son’s age] years, obviously. And so I know him better, and I just - I kind of have to guide my boyfriend too. It’s like we’re to the point now where I’m like, ‘You need to - you’ve got to stand up for yourself. Don’t let him run over you.’ But at the same time he’s got to do it - I don’t know. He’s got to do it in the way that I do it which is a loving – so that [son] doesn’t feel rejected. He feels loved, but he understands that you know what he did was wrong.” (960-ID) This respondent not only illustrated a sense of wanting to be “on the same page” without using that term, by emphasizing the importance of her boyfriend following a strategy that is similar to the approach that she would take, but also highlighted some of the complexities involved in the process of incorporating another adult into a set of relationships within the home.

Another respondent, a married mother of five children also quoted above, reflected on what it means for partners to be on the same page. “You know what? It’s kind of like it’s – well, I think having kids with you know fragile X you have – or just special needs you really have to be on the same page, and I think if we weren’t – you know I mean because it is – you have to have the same goals and know where you’re going in life and what’s expected of both of us or – because there is you know all that just added stress that is in the picture you know with the kids – you know with the kids with fragile X.” (220-ID) The emphasis on goals in life and expectations of one another is broader than just being limited to parenting strategies, although those broader factors may also impact everyday parenting behaviors.
One account, by a divorced mother of two children with FXS, who is in a long-term relationship, illustrated connections between ideas from Swidler (2001) and the notion of being on the same page.

So there’s no way that anybody will ever be able to understand that except for a parent, but as far as just the understanding of fragile X and what it does and what it can cause he understands that. I think that we’re on the same page about as far as the definition, or you know he may not understand it as much, or I’m sure he’s never read articles about it kind of a thing you know, but he tries to understand as much as he can.

When asked to describe what “being on the same page” means to her, she replied:

Well, I think it has to do with your values, your beliefs. For me anyway it has to do with my values and my beliefs. We have to. We’re raising a family together. We have to be on the same page about discipline. We have to be on the same page about rewards, about what our needs are, what our desires are, what our expectations are because if we’re not on the same page, then obviously we’re miscommunicating, and if people are not communicating, then you really have nothing because you’re either not talking, or you’re just arguing, and then that’s just disaster. (940-ID)

The emphasis on sharing and communicating one’s own needs, desires, and expectations – and the consequences if partners are not communicating – echoes the centrality of both self-development and the sharing of those selves that is so central to modern romantic-partner relationships (Swidler 2001).

Close attention to the metaphors used, particularly when they are repeated by multiple respondents, can shed light on additional meanings of the words. Miles and Huberman (1994) characterize the metaphor as “halfway from the empirical facts to the conceptual significance of those facts; it gets you up and over the particulars en route to the basic social processes that give meaning to those particulars.” The literal image of “being on the same page” is that of two or more individuals reading or following along together in a document. It indicates that the individuals are at the same point at the same time, regardless of what “pages” have come before or will come after. The content may vary; above, examples
include more abstract ideas such as values and beliefs, but also everyday parenting practices such as disciplinary strategies, and I noted that those often may be connected. Below, though, I explore further the significance of this image as a metaphor for respondents’ experiences, and highlight some of the ways in which sociological theory can shed light on the social process that gives meaning to the metaphor (Miles and Huberman 1994).

In the context of FXS, it is important to consider the fact that two parents attempting to be “on the same page” is likely a complex endeavor. They are parenting one or more children with, in many cases, multiple disabilities and potentially complex treatment and intervention strategies, as well as often-complicated efforts to obtain therapies, services, and meet their children’s educational or developmental needs. Sociological theory can contribute to this finding an exploration of the question of what it means to parent in the context of raising a child with FXS, and what it means to ‘be on the same page’ as another individual (one’s partner) with regard to parenting in that particular context: here, Swidler’s ‘strategies of action’ linking social structure and culture are instructive (Swidler 1986; 2001). The differences between partners could potentially be framed in various ways by respondents, but the language chosen by several respondents was that of alignment on parenting and perceptions of FXS. The context of FXS is one where the developmental trajectory for children is somewhat uncertain, the information related to FXS that must be processed by parents is complex, and there is a strong emphasis, at least among many mothers in the current study, on maximizing a child’s potential for development (see paper 1). The concept of ‘being on the same page’ likely represents a complex alignment of goals, expectations, and practices.
Parents of children with FXS often encounter and interact with many institutions in the course of parenting their children: medical doctors, therapists and early intervention specialists, the education system, and even perhaps the legal system. However, based on the findings of the current study as well as on existing literature, being a parent of a child with FXS is not itself institutionalized, and in a sense, their experiences may match that of Swidler’s concept of “unsettled lives.” In addition, Swidler (2001) describes how culture emerges and thrives in the “gaps” between institutions.

People consume and create more cultural “stuff” – that is, they elaborate more self-conscious symbolic meanings – when their lives are unsettled, when they must construct new lines of action. In this sense culture provides complements or reciprocals to institutional structures. The aspects of institutional life that are firmly structured do not require cultural elaboration. Individuals instead develop cultural supports for lines of action that link them to institutions.

The image of parents of children with FXS consuming more cultural “stuff” and constructing new lines of action fits with the existence of parent support groups dedicated to raising a child with FXS – there are many – and existing literature such as research showing that parents of children with genetic conditions (Roche and Skinner 2009) and FXS, in particular (Schaffer, Kuczynski, and Skinner 2008), often turn to the Internet, if it is available, to seek out information about their children’s conditions. Support groups and internet research are two examples of cultural “stuff” that exists as a means for parents to construct new lines of action in response to a diagnosis of FXS.

In Swidler’s influential work, a strategy of action “involves a characteristic way of solving problems and characteristic sets of problems to be solved. Such strategies depend on skills, styles, habits, and capacities for organizing self and action that are learned through culture” (Swidler 2001). Explaining the relationship between culture and action, Swidler argues that culture shapes action by influencing the “cultural equipment” upon which
individuals may draw. Thus, the idea of ‘being on the same page’ may reflect two partners having the same strategies of action with regard to parenting their children with FXS. Conversely, to not be on the same page is to have dissimilar strategies of action.

In existing literature on children with disabilities and in the present study, it is often mothers who are largely responsible for seeking out information about FXS, coordinating therapies and services, attending appointments with doctors, therapists, and teachers, and performing other daily tasks related to caring for their children (Traustadottir 1991). The “paraprofessional” work that mothers of children with disabilities often do (Leiter, Krauss, Anderson, and Wells 2004; McKeever and Miller 2004), and the interactions within social structures that encourage and educate mothers to perform those tasks, may put them in a situation where their ideas about proper goals and parenting practices – their strategies of action related to parenting – may differ somewhat from those of their partners.

Indeed, many respondents described being mainly responsible for coordinating, researching, and attending therapies, medical, and service appointments (see paper one). Some respondents who described that type of division of labor in the home between two partners also described efforts associated with communicating about therapies, services, and activities, not only in terms of scheduling and logistics but also with regard to the goals of certain endeavors. One married mother of three children, two of whom have FXS, described a past perspective: “You know he may have made some doctor’s appointment, but I didn’t see a whole lot of effort for the therapy so he can know what’s going on and how do we help [our son] at home. I felt like I had to go, come home, explain to him, but then I guess his thing was he’s out working. Somebody has to work.” (160-ID)

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12 This does not indicate that it was necessarily portrayed as a challenge for respondents, but rather that it generally took a certain degree of effort.
Similarly, a respondent in the semi-structured interviews, a married mother of two children, one of whom has FXS, said, “I mean I definitely wish that he was here more. And, could have the time to spend with him to learn more about things. Because, I feel like he comes home. And then, I’ve got to download him on everything. And, teach him how to interact with him. That’s kind of frustrating. Because, I don’t want to be the parent to him, too. He’ll do something. I’m like ‘No. No. That’s not the way we should be doing it.’ And so, it’s kind of balancing.” (1120-I3) In this example, the respondent articulates the transfer of specialized information as “downloading” to her husband, and describes the resulting frustration when their parenting practices are not aligned. While other respondents did not articulate this link so explicitly, I argue that the gendered nature of day-to-day caregiving may result in partners not always “being on the same page,” which could have impacts on their perceptions of their relationships.

*Change Over Time*

The changes over time that respondents described in their relationships were as variable as their descriptions of current relationships. A few respondents in the semi-structured interviews described ways in which learning of the diagnosis and their status as carriers related to changes in their relationships over time. Specifically, some discussed feeling guilty at first, and then over time the guilt lessened. Describing that process, some respondents described their husband or partner’s role in the diminishing guilt, saying, for example, that they had reassured the respondents by pointing out that they did not intentionally pass on the mutation to their child. More extensive analyses of respondents’ experiences in this area and related areas are found elsewhere (Raspberry and Skinner 2011a; Skinner and Raspberry 2011a; b).
Respondents sometimes described more neutral changes – that their relationship has “evolved” but not gotten worse, for example – or a relationship that has grown stronger or closer over time. A married respondent in the in-depth interviews explained changes in her relationship with her husband over time that she attributed to the fact that they each sought counseling individually and then each learned about how the other had dealt with the news of the FXS diagnosis. She described realizing that, in the past, she had put herself and her marriage “on the back burner” in an effort to help her son when they learned of the diagnosis. She described positive changes in their relationship since then.

I think now we talk more. If something is bothering me, instead of me holding it inside I am now communicating it. So it’s kind of we came to we can agree to disagree. We realized too that we have to put each other first. We have to take care of each other, take care of ourselves also, so our kids will be fine because if we don’t take care of each other and don’t have each other, then that means our family can be divided. Our family will be apart, and then who will hurt in the meantime? Our kids. Our kids would suffer.

When asked to describe what “taking care of each other” means to her, she responded:

What can I do for my husband today? When he comes in, not to bombard him with everything about the kids, kids, kids, kids. There’s a time. It’s kind of like you make – now we make time. There’s a time and a place for a conversation. So you know when the kids are in bed and settled down, then we can have some us time. Just carving out that time for us […] (160-ID)

As in other accounts, there was an emphasis on communicating, sharing, and understanding each other’s perspectives, all of which echo themes in the culture of love identified by Swidler (2001), and “the natural sharing of one’s real self” (Bellah et al. 1985). Taken together, the nature of FXS, the nature of genetic information and related self-understandings (Raspberry and Skinner 2011a; b), and the dynamic nature of relationships over time all point to the need for continued longitudinal research on the relationships and experiences of families living with genetic conditions, including FXS, or knowledge of their carrier status.
With regard to genetic information, Novas and Rose (2001) maintain that a genetic consultation and imparting genetic information have a clear relationship to time, impacting “identity in terms of a genetic past, a genetic present and a genetic future.” This temporal dimension of genetic information and the changes over time in its implications in the present data highlight the importance of future research to better understand how the experience of genetic information changes over time.

Sources of Variation

In a relatively small sample, it is difficult to determine causality and sources of variation in accounts. Notably, attributing difficulties in relationships to FXS, or stating that FXS was not tied to the status of the relationship, did not seem to be closely linked to the number of children or respondents’ socioeconomic statuses. It is also difficult to determine from these data whether there are characteristics of the parent-child dyads that might shape respondents’ accounts. In general, when discussing romantic-partner relationships and parenting, there was some discussion about certain difficulties and behaviors tied to FXS, which tends to correspond to gender, but there were few discussions precisely focused on the impact of the child’s gender.

Studying 40 couples who have a child with FXS, of which 75% of the children in the sample were boys, McCarthy et al. (2005) found that fathers’ psychological stress increased as problem behavior increased, whereas that finding did not hold true for mothers. The authors pointed out the need for further research on perceptions of same-gender children, and the accounts of the mothers in the current research may shed some light on their finding. Two respondents raised the issue of partners’ gendered expectations for behavior, linking their partner’s difficulties with FXS to unrealized expectations and hopes for certain activities with
his son, such as playing sports together. While the respondents tied the fathers’ difficulties to the fact that he has the same gender as the child, it is possible that the behavior problems were more severe because the affected child was a boy (National Fragile X Foundation 2006), and that the severity was the source of the difficulties.

Above, I describe the way that agreement on parenting emerged as significant in these respondents’ accounts. Research evaluating connections between agreement on parenting and perceptions of romantic-partner relationships among families of children with disabilities is limited.\textsuperscript{13} One study of parents of typical adolescents found that trajectories of conflicts over parenting aligned with assessments of marital satisfaction, suggesting a relationship between the two over time (Cui and Donnellan 2009). The question of how agreement on parenting relates to romantic-partner relationships is an area where the causal relationship may be difficult to ascertain, since those with lower levels of relationship satisfaction may be less likely to agree with their partner’s approaches to parenting, or, conversely, differences in parenting may negatively impact the relationship. The data for the current study do not permit an assessment of causality, but these findings, in the context of other literature that points to a possible link between agreement on parenting and characteristics of marital relationships, indicate an important area of further research on parents of children with disabilities.

Further, as described above, Swidler’s ideas about mechanisms linking social structure and action through culture may also contribute to our understanding of how parents’

\textsuperscript{13} A related but distinct concept, ‘coparenting,’ has been explored at length in psychological and developmental literature, often with a focus on whether and how coparenting, or different dimensions of coparenting, influences outcomes such as specific parenting behaviors or child adjustment (e.g., Gable, Sara, Keith Crnic, and Jay Belsky. 1994. “Coparenting Within the Family System: Influences on Children's Development.” \textit{Family Relations} 43:380-386; Teubert, Daniela and Martin Pinquart. 2010. “The Association Between Coparenting and Child Adjustment: A Meta-analysis.” \textit{Parenting-Science and Practice} 10:286-307.) Other research has specifically examined post-divorce coparenting. These represent approaches that are different from that in the current treatment.
romantic-partner relationships are situated in a larger social and cultural context, and how that context may influence the dynamics of their relationships. By better understanding the interpersonal dynamics within families, from the mothers’ perspectives, and the ways that social structure may be linked to those dynamics, we can better theorize family processes and their contexts, as well as consider the practical implications of those theories for interventions and family services. In this case, it seems that parents ‘being on the same page’ – or not – deserves further investigation as a mechanism that may explain some of the connections between the social contexts within which parents operate, and characteristics of their romantic-partner relationships.

In their accounts of romantic-partner relationships, several respondents emphasized the idea that their relationship status or quality was not related to FXS. For some, explanations and attributions for relationship characteristics were located within the couple, as emphasized by some themes that emerged. Solutions or strategies, likewise, emphasized within-couple actions, such as spending more time together alone, going on trips or outings without children, and talking about things other than children. Interestingly, though, it was an outwardly-focused characteristic of relationships that repeatedly emerged as significant in mothers’ accounts of their romantic-partner relationships – the extent to which the couples are ‘on the same page’ about parenting behaviors and goals for their child. As explained above, the uncertainty associated with FXS and the additional caregiving and therapy tasks associated with having a child with a disability, as described in the existing literature, may lead to special challenges for couples getting to the same page.

Past research has found some differences between the experiences of parents whose children have FXS and parents whose children have other conditions such as Down
Syndrome. While the study was generally focused on family well-being and adjustment and carrier status of mothers was unknown, Poehlmann et al. (2005) suggest that among other factors, for the respondents in the families with FXS mothers’ carrier status may potentially contribute to differences found between the two groups. Findings in the current research suggest that discovery of one’s carrier status may impact perceptions of romantic-partner relationships. In addition, respondents’ points related to relationship changes over time with regard to their carrier status suggest the need for more longitudinal research to examine the trajectory of those ties, perhaps investigating contexts or characteristics that shape how carrier status relates to perceptions of romantic-partner relationships. Further research could examine, comparatively, couples whose children are typically developing and couples whose children have FXS, in order to better understand how ‘being on the same page’ may be similar or different.

In sum, these findings show that respondents’ characterizations of couple relationships often involve multiple influences on those relationships. Further, they show that, in several cases, respondents viewed raising a child with a disability as having positive impacts on their relationships. At the same time, in several cases respondents identified certain challenges. In addition, one theme in responses was the notion that alignment on parenting strategies was related to some respondents’ accounts of relationships. Using Swidler’s (1986; 2001) notion of strategies of action, it is suggested that parents may hold similar or different “repertoires” regarding their perceptions of FXS or their strategies toward parenting in general, which may be related to their perceptions of couple relationships. On the whole, this analysis highlights nuances of respondents’ experiences and interpretations,
and may shed light on some of the unclear findings regarding couple relationships and child
disability in the existing literature.
Appendix B: Work-Family Calendar

<table>
<thead>
<tr>
<th>Age</th>
<th>Family Events</th>
<th>Who lived in the home?</th>
<th>Education and Work</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Marriage/ Divorce</td>
<td>Births/ Deaths</td>
<td>Change of residence</td>
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<tr>
<td>17</td>
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<td>22</td>
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<td></td>
</tr>
</tbody>
</table>

Note: Original work-family calendar was proportional to landscape-oriented legal size paper and included rows through age 55. Adapted from a work-family calendar provided by Dr. Philip Cohen.
References


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Chapter 5

Conclusion

In the three substantive topics of interest in this dissertation -- caregiving, work, and romantic-partner relationships -- findings reveal key processes and mechanisms that help describe and explain respondents’ experiences raising children with FXS. Further, the findings are connected to broader sociological concepts. In the chapter on caregiving, findings illustrate how aspects of motherhood in other contexts, such as the notion of “intensive mothering” (Hays 1996), may be connected to motherhood in the context of raising children with FXS. This is reasonable, since these mothers are embedded in the same cultural context that gives rise to particular models of motherhood identified in other situations. However, findings also suggest ways in which distinctive aspects of motherhood in the context of FXS, such as some of the uncertainty associated with timing of milestones or eventual outcomes, may contribute to particular experiences for respondents. Respondents expressed a strong sense of responsibility for fostering their children’s development, and findings related to this “developmental imperative” highlight motivations for particular caregiving tasks and the meanings that mothers assign to those actions. Further, notions of individualism in American culture identified by Bellah et al. (1985) shed light on how culture may influence those meanings.

With regard to the juggling of multiple demands, these findings illustrate another context in which the notion of “articulation work” may be applied. Others have discussed the concept of articulation work in different areas (Hampson and Junor 2005; Timmermans and
Freidin 2007), and these findings identify additional ways in which the concepts are relevant. In particular, I argue that actions taken to manage competing demands both within and between the work and family domains can be understood as “linking actions,” and identified as work that is seen as unskilled, generally unspecified, but crucial to the functioning of family life (Hampson and Junor 2005; Timmermans and Freidin 2007). This adds to the literature on articulation work by suggesting that it applies in another context, the management of demands for families of children with disabilities, and highlights articulation work that takes place within families as well as between work and family domains. Further, it brings to light tasks that are less often acknowledged, and identifies them as a form of work (Hampson and Junor 2005; Timmermans and Freidin 2007).

Findings related to employment decision-making address the need for more attention to the ways in which families and individuals actively make decisions about work and family (Bianchi and Milkie 2010) by showing that responses to, or anticipation of, configurations of resources and demands are useful to examine. Results reinforce the notion that it is necessary to understand how couples and families make employment decisions as a result of multiple factors. In the current study these factors included, but were not limited to, childcare availability, affordability, and suitability, and children’s and partners’ needs and schedules. Further, findings show that employment decisions can be seen as boundary-spanning strategies that families may utilize to improve the fit between work and family domains (Voydanoff 2005). In addition, this work further supports existing literature that shows that, rather than being individual-level decisions, employment decisions may be made at the couple or family level with consideration of multiple family members (Moen and Yu 2000).
Findings related to respondents’ accounts of romantic-partner relationships fit with research that points out that the impacts of having a child with disabilities on relationships are not necessarily negative and may be highly variable, and that to consider it a tragedy may not accurately reflect people’s experiences (Ferguson 2001; Hastings and Taunt 2002). The findings in the present study showed multifaceted views of relationships, often combining challenges and rewards to discuss experiences. Findings also show how mothers’ accounts of romantic-partner relationships and alignment on parenting strategies can be related to Swidler’s (1986; 2001) ideas about strategies of action and cultural repertoires, suggesting that in some cases, similarities or differences in parenting strategies may be linked to perceptions of romantic-partner relationships. This finding may help shed light on connections between marital adjustment and parenting stress that are seen in the literature (e.g., Trute and Hiebert-Murphy 2002).

In addition, findings reveal certain themes that explain relationships among the three domains. As described in chapter two, necessary measures taken to meet children’s needs, whether the children are typically-developing or diagnosed with FXS, were a prominent theme in mothers’ discussion of managing work and family and making employment decisions in chapter three. Points related to the developmental imperative described in chapter two emerged in discussions of the demands involved with meeting children’s needs and encouraging children’s development when they are diagnosed with FXS; they pose particular challenges in terms of combining those efforts with paid work. In response to those challenges, respondents described exercising agency and using certain strategies that would assist them in combining work and family if that was desirable or necessary. At the same

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14 Again, here I emphasize that this term is used in the theoretical sense; respondents did not generally use the terms “demands” and “resources” to explain their experiences.
time, respondents that sought to focus on home and family rather than working for pay also
made use of strategies to manage certain demands in that situation. Importantly, for some,
certain resources – or lack thereof – influenced whether their ideal work-family situation
matched their reality. Additionally, themes in the accounts of romantic-partner relationships
echoed some of the findings from chapter two on caregiving; some respondents described an
impact of the division of labor in the home on romantic-partner relationships. Other findings
about romantic-partner relationships that were linked to caregiving involved the specialized
information that many mothers received as a result of their involvement with children’s
therapies and other appointments and how that may, in part, influence their approaches to
parenting their children. The romantic-partner relationships paper explores the potential
implications of that division of labor when it comes to couples “being on the same page”
about FXS and parenting.

Are These Findings Specific to FXS?

While the discussion in each paper pointed out features of FXS that could be related
to the findings about respondents’ experiences, this analysis cannot address the comparative
question of whether or how mothers’ accounts are different according to whether their family
contains only typically-developing children or children diagnosed with FXS. The data reveal
some aspects of mothers’ experiences, and characteristics of FXS, that may illustrate how
some specific features of FXS itself may contribute to shaping mothers’ experiences. As an
example, when one respondent talked about her experience with the diagnosis, she said, “I
was looking for someone to tell me, ‘This is where your children need to go. This is what
your children are going to be like.’ I wanted a bluebook on how to raise my children and
finding out there is none.” (440-I1) Whether respondents hope for specific guidance about
what to expect with regard to FXS or not, most probably come across the information that
this respondent did – the fact that, though there are several common strategies and courses of
action for managing FXS, there is not a one-size-fits-all approach.

One aspect of FXS that may impact the developmental imperative is its complexity.
Besides the variation in severity across individuals, FXS may also have different
characteristics. That diversity associated with FXS may lead to a range of interventions,
therapies, and efforts on the part of many mothers to influence their child’s development
positively. Some respondents said that they researched interventions based on their children’s
needs, not necessarily based on FXS. This need for individualized approaches to
interventions may or may not be unique to FXS. Either way, as a respondent above noted,
there is no “blue book,” as she put it, to tell mothers exactly what FXS will be like for their
child, and what strategies and interventions will work for their child. The range of possible
interventions that may help their children is not limited to FXS, and those facts are important
to bear in mind when considering how the developmental imperative is experienced in the
context of FXS.

Further, respondents’ experiences with employment decision-making and managing
work and family may be impacted by the diversity of therapies and interventions in which
children were often involved, and many families had multiple children with FXS, which
meant further coordination of schedules, transportation, and other logistical implications.

Limitations

There are multiple limitations to this study that must be acknowledged. For the in-
depth interviews, income data, including precise household income and measures of whether
respondents were low-income (measured as 200% of the poverty line or lower), were taken
from wave three of the FAFXS, and thus may be out of date for some respondents in the in-depth interviews.

A weakness of the study relates to the nature of FXS itself: it is an inherited disorder, so mothers in the samples may have characteristics of FXS related to their ability to obtain and maintain employment, or to difficulties in couple relationships. For example, I cannot know whether work experiences are linked to the FX gene or other factors. Respondents may report few job opportunities or difficulty obtaining employment, but I cannot determine the reasons for reduced opportunities. In this project, though, I do not attempt to make causal arguments about reasons for mothers’ employment transitions. I am focusing instead on the mothers’ perceptions of the factors influencing their employment, their decision-making, and the existing resources and demands that provide context for those decisions. As we know from past research, some of those resources and demands are tied to social structure. However, I am not objectively measuring nor attempting to capture all aspects of social structure shaping these mothers’ experiences; the emphasis is on how these mothers describe and talk about them, which is an often-overlooked aspect of past research on work and family for mothers whose children have disabilities. Further, in the in-depth interview sample, the sample is relatively homogenous with regard to mutation status: all but one respondent had the premutation form of the gene.

While effort was made to include individuals with a range of characteristics, the samples for both the semi-structured and the in-depth interviews are comprised of mothers who had time and availability to participate in the study, so these findings only reflect the accounts of respondents who were able to participate in the study. Further, these respondents are involved with a longitudinal study that has involved years of participation and multiple
data collection points, so the findings may be limited to mothers who interested in being involved in research efforts. For these reasons, in addition to the small sample in the in-depth interviews, this study does not capture the full range of experiences for all mothers of children with FXS. Accordingly, I do not claim that these findings represent the perspectives of all mothers of children with FXS, nor do I claim that the findings presented here are universally applicable for all mothers involved in this study. There was a great deal of variation within the sample, as well as changes over time for respondents and families; thus, the findings are not generalizable.

A further limitation is that these findings from in-depth interviews reflect respondents’ talk in retrospective interviews, and it is possible that respondents have re-constructed narratives that portray themselves as more agentic and purposeful during times of transition than perhaps they actually were at the time of the decision-making, or that they re-interpret events in ways that are not true to the actual events of the time. In view of that, throughout the discussions of findings I have reminded the reader that findings are based on accounts, where appropriate. However, sociologists have argued that the accounts people give are valuable to study (Orbuch 1997). The ways that people construct and order events, assign meaning, and discuss what matters in different contexts (Skinner and Weisner 2007) are all important objects of study and give distinct insights into their experiences.

**Future Research**

Certain findings in this project invite further research and elaboration. For example, in some responses addressing caregiving, some respondents talked of efforts to enhance children’s development as a constant part of everyday life, interwoven with everyday caregiving, play, and special outings or activities. This may be related to statements by some
respondents that FXS is “always there” or always a consideration. Yet other respondents specifically stated that when they look at their children, they do not see FXS, but just the child. Similar contrasts within the samples were found with regard to discipline; for some respondents, FXS was a large consideration when they chose disciplinary strategies or interpreted children’s behaviors. Others did not express the same reasoning, or discussed the difficulties associated with trying to determine the “source” of children’s behaviors. Several respondents described puzzling over whether a particular behavior was due to temperament, a developmental stage, or if it could be a characteristic of FXS. For some respondents, this determined how they addressed the behavior. Based on these observations of how respondents talked about perceptions of their children, future research could further investigate meanings that parents attach to the “source(s)” of children’s behaviors, and how that relates to parenting strategies. Another area of focus for future research is the way in which mothers’ specific goals and expectations for children, both in the short term and as adults, may relate to both the developmental imperative and the therapeutic view and notions of individualism described by Bellah et al. (1985). A better understanding of their hopes for their children in the future may help elaborate broader meanings attached to the sense of responsibility that mothers feel for their children’s development in multiple areas.

Regarding the interface between work and family, this research points to the need for further research on the impacts of family processes on certain outcomes, including general assessments of fit and balance, which were not explored in detail in the present research. Further, implications for these decision-making processes for relationship quality and satisfaction in partnered parents may be a fruitful area of inquiry, given the expectation that normative support for work-family interface leads to greater cohesion in families with regard
to work-family balance (Voydanoff 2005). Additional research could investigate those processes.

While this project investigated aspects of the lives of mothers of children with FXS, future research could focus on fathers’ experiences in the same areas. Especially in the context of recent changes in gender roles, the experiences of fathers with caregiving and managing work and family commitments are important to investigate, and fathers’ perspectives on impacts of FXS on romantic-partner relationships may differ from those of mothers. Existing research has shown negative impacts on fathers’ labor force participation when a child is in poor health (Noonan, Reichman, and Corman 2005), and since gender norms may result in dissimilar experiences, motivations, constraints, and decision-making between fathers and mothers, more attention to fathers in research on employment and work-life balance is needed. This is particularly true since gender norms have shifted somewhat over the past few decades, with expectations of greater involvement of men in the care of children and in household tasks –though there are questions about the extent to which men have increased their share of household labor (Press and Townsley 1998) –and given that existing research points to different mechanisms influencing subjective feelings of work-family imbalance between men and women (Milkie and Peltola 1999).

Together, the findings in these three papers make a strong case for the need for further longitudinal research on families of children with special needs, as well as the families of children with FXS. In particular, the topic of romantic-partner relationships is in need of further longitudinal research to try to better understand changes over time in partner relationships, especially across children’s developmental stages. Similarly, related to the topic of employment and managing work and family demands, the features of institutions and
programs such as early intervention services, child care, and school attendance and schedule should not be underestimated, and additional policy-oriented longitudinal research can further investigate decision-making about employment in each of those contexts.

Nonetheless, the project sheds light on three areas of life for these respondents – caregiving, work, and romantic-partner relationships – and illuminates a range of different experiences within those realms. Additional research is underway to further investigate the findings in the current study as well as better understand sources of variation in mothers’ experiences. Much more work remains to be done, but this study represents an expansion in our knowledge about ways in which some mothers of children with FXS experience these areas of their lives.

These papers describe a unique study that examines aspects of the lives of mothers who are carriers for a specific inheritable condition with which their children have been diagnosed, and that has certain implications for family life. I examine how they describe caregiving, the management of work and family and employment transitions over time, as well as romantic-partner relationships. In sociological literature on families, these areas are shown to be connected; in the current research, each paper contains unique findings relevant to that topic, yet there are findings about broader themes that transcend the substantive focus of each paper. This work adds to knowledge on diverse family circumstances and provides a better understanding of these mothers’ lives, but also advances sociological knowledge on caregiving, work, and family.

These are major areas of interest to sociologists, and this project investigates questions about how certain key dimensions of the current social and cultural context intersect to influence these women’s lives as well as their interpretations of events in their
lives. Ultimately, this project shows ways in which these mothers talk about their lives – challenges, constraints, resources, decisions, and imperatives – and how their talk sheds light on relationships between their individual experiences and the broader social context.
References


