Integrating Care and Paid Work – The Career Development of Parents of People with Disabilities in Brazil

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Dedication

I dedicate this work to those who care for me and those I care for. To my mother, who is one of the most caring individuals I know and who taught me that care can be delightful and exhaustive at the same time. To my daughters, Marina and Luisa, for helping me learn about unconditional love, for transforming my life, and making me a better person.

For all caregivers who deeply and daily engage in care work, particularly exceptional care work, this work is also for you. I hope you can care for yourself, too. I wish you joy, rest, and hope.
Abstract

Parenting a person with disabilities (PWD) is an experience that transforms one’s beliefs, family relationships, social connections, financial stability, and professional trajectory. Parents of PWD engage in what scholars call *exceptional care* – intense, lifelong, cyclical, and crisis-driven care. For them, caring is a central part of their lives, crossing boundaries between family and work domains and driving most of these parents’ career decisions. Studies show that parents of PWD often experience heightened work-family conflict and physical, emotional, and financial stress. Significantly, individuals identifying as women are disproportionally impacted as they assume most of the care work. Nevertheless, employment is critical for these parents’ financial and mental health, as work provides necessary income and personal fulfillment. This study applied a grounded theory methodology to investigate how Brazilian parents of PWD make career decisions to accommodate care and paid work, also examining the systemic factors that influence these decisions. In-depth interviews were conducted with 27 college-educated mothers and fathers of PWD to map their career trajectories and main career decisions. The findings of this study contribute to advancing and integrating career development and work-life theories, highlighting the importance of social identities and organizational and social dynamics. New frameworks are proposed to explain how parents of PWD, and potentially other caregivers, make ongoing career decisions and manage their family and work arrangements to attain more satisfactory work-life relationships. Additionally, this study offers practical implications for career development professionals, HRD practitioners in organizations, and public policymakers on how to support the professional development of caregivers.
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Chapter 1: Introduction

Background

Caring for someone is a natural part of any adult’s life. At some point in life, all adults will care for a child, an elder parent, a sick partner, a relative, or a friend. At some point in life, we all have been cared for and will be again. Caring needs and care responsibilities are negotiated frequently in our daily routines. However, care is a topic mainly discussed in the private spheres of our lives and kept apart from our professional selves (Tronto, 2013).

For working parents of people with disabilities (PWD), keeping care responsibilities restricted to their private lives can be challenging. These parents experience what some scholars label as exceptional care – intense, lifelong, cyclical, and crisis-driven care (Stewart & Charles, 2021). Unlike parenting a child with no disabilities, caregiving for a PWD requires a considerable additional amount of time and is often associated with heightened work-family conflict and physical, emotional, and financial stress (Brennan et al., 2016; Jang & Appelbaum, 2010; Stewart, 2013). Consequently, it is not uncommon for parents of PWD to reduce their participation in the workforce or leave it altogether to attend to their children’s intense care demands (Brown & Clark, 2017).

Definitions for disability vary significantly across countries, making it complex to estimate the number of individuals living with a disability worldwide. The World Health Organization defines disability as “the umbrella term for impairments, activity
limitations, and participation restrictions, referring to the negative aspects of the interaction between an individual (with a health condition) and that individual’s contextual factors (environmental and personal factors)” (2011, p. 4). The organization estimates that 15% of the world population lives with some disability, and around 200 million have considerable functioning difficulties. It is estimated that 95 million children between 0-14 years old live with disabilities (World Health Organization, 2011). Notably, the number of people with disabilities living with their families has considerably increased in the past decades due to technical advances in treatments and health support, improved life expectancy, changes in social attitudes, and reduced government support in many countries (Lewis et al., 2000a; Randall, 2017).

In Brazil, the national census considers individuals with disabilities those who report having either “a lot of difficulties to do” or “cannot do at all” the activities included in the criteria. The last census, done in 2019, reported that 8.4% of the population above two years old has some disability (IBGE, 2022). The census also identified that PWDs are present in 19.8% of the households in the country (IBGE, 2022).

Several studies report the negative impacts of caring for a PWD on parents’ participation in the workforce, particularly for women who often assume a more significant portion of care work in most societies (see: Brekke & Nadim, 2017; DeRigne & Porterfield, 2017; Ejiri & Matsuzawa, 2019; Vinck & Van Lancker, 2020; Wright et al., 2016). In Brazil, adults living in households with a PWD have lower participation in the workforce compared to households without a PWD. While 9.5% of the Brazilian adult population (15-59 years old) is out of the workforce, when considering only adults
in households with children with disabilities, this number jumps to 13.2%. This difference reaches 5.4 p.p. for women, with 16.1% of women in families with children with disabilities out of the workforce (IBGE, 2022).

**Problem Statement**

Despite the challenges of integrating work and family demands, maintaining paid work is vital to these parents’ emotional and financial health. The elevated costs of exceptional care make having a stable income and access to health insurance essential. In addition, having a job helps these parents cope with the stress of intense caregiving by providing distraction and personal fulfillment (Jang & Appelbaum, 2010; Scott, 2010). Also, as for any other human being, paid work is essential to these parents’ sense of self (Scott, 2018; Shearn & Todd, 2000).

Therefore, parents of PWD constantly seek ways to accommodate their professional and personal lives, leveraging available workplace support (e.g., flexible working arrangements, family-supportive policies, supervisory and co-workers support) and family and community support (e.g., care work distribution, childcare, care services, family, and friends support). Still, maintaining their employment is often difficult for these parents, particularly those who identify as women, single parents, less educated, and from lower social classes (Scott, 2010).

Most of these parents face significant challenges in sustaining care and paid work as many organizations still hold the expectation of the ideal worker – a professional who is fully dedicated to work and keeps work and private lives apart (Acker, 2012; Kossek et al., 2021; O’Brien et al., 2021). Organizational practices that overlook family and
stigmatization toward the adoption of flexible work arrangements contribute to the marginalization of parents of PWD, particularly women, as they assume a disproportional portion of caregiving responsibilities (Scott, 2010; Tronto, 2013).

Peter Kuchinke (2017) argued that one critical purpose of the Human Resources Development (HRD) field is to help human beings achieve autonomy, freedom, and self-actualization through work. Further, Laura Bierema (2020a) advocated for critical HRD research that questions exclusion in pursuit of social justice and sustainable organizations and communities. In this sense, understanding the working experiences of parents of PWD can be relevant to the HRD field in several aspects. It can shed light on how to support an increasing population of caregivers to fulfill their needs for survival, social connection, and development through work while supporting their families’ caring needs, contributing to a more socially just workplace.

Existing literature demonstrates the negative impacts parents of PWD experience in their professional lives. Examples are reduced working hours, lower income, higher levels of missed work, and career derailments (see: Crettenden et al., 2014; DeRigne & Porterfield, 2017; Ejiri & Matsuzawa, 2019; Stewart, 2013). These studies describe the frequent unfavorable career changes these parents undertake to accommodate their family and professional lives, including transitioning to part-time positions and moving to jobs that require less time, responsibility, or concentration, often in lower-level job posts or areas different than their initial vocational option (Crettenden et al., 2014; Randall, 2017; Scott, 2010, 2018).

Research also indicates that a lack of family-supportive workplace policies, family-unfriendly organizational cultures, and unsupportive supervisors contribute to the
high level of work-family conflict experienced by parents of PWD (Brown, 2014; Brown & Clark, 2017; Brown & Sumner, 2019). Family-unfriendly cultures and stigmatization toward disability discourage parents of PWD from disclosing their family situation and asking for support (Brennan et al., 2016; Crettenden et al., 2014; Randall, 2017; Stewart & Charles, 2021). Additionally, several studies show that gendered social norms, organizations, and work structures disproportionately impact the careers of individuals who identify as women and assume the primary caregiver role in their families (Baker & Drapela, 2010; DeRigne & Porterfield, 2017; Scott, 2010).

Amid these sad stories, there are remarks about how parents of PWD create strategies to perform their family and work roles as satisfactorily as possible (Rosenzweig et al., 2002; Scott, 2010, 2018; Stewart & Charles, 2021). Some studies suggest that these parents develop skills that help them attain work-family integration, including communication, negotiation, and time and boundaries management (Scott, 2018; Stewart & Charles, 2021). Moreover, these studies insinuate that these parents redesign their careers, crafting work opportunities and renegotiating their professional and personal aspirations (Rosenzweig et al., 2002; Scott, 2010, 2018).

Still, very limited empirical research investigates the career changes these parents undertake, the systemic factors that influence these changes, and the outcomes of this process. Career development theories have generally overlooked other aspects of individuals’ lives and the systemic aspects influencing career decision-making (De Vos et al., 2020; Greenhaus & Kossek, 2014). Furthermore, work-family scholarship minimizes the effects of gendered social norms and expectations (Moen, 2011). Lastly, there is a lack of studies about the professional lives of parents of PWD in developing countries, as
most of the existing literature focuses on women’s experiences in North America and European countries.

**Purpose of the Study**

To contribute to a better understanding of the issues described in the previous session, this study intends to answer the following research question: How do parents of PWD develop their careers to attain work-family integration in the Brazilian context? Following a grounded theory methodology, this investigation examines the systemic forces influencing these parents’ career decisions and the outcomes and implications to caregivers, organizations, and society more broadly.

**Significance of the Study**

In a broader sense, this study aims to contribute to the development of healthier and more humanized relationships with career and work and foster more caring and inclusive organizations. Although the experiences of working parents of PWD are unique, they represent extreme cases of work-family challenges, and their experiences may offer valuable information on how to better support working caregivers in general.

This study integrates and advances career development and work-family theories, highlighting the implications of intersecting identities and organizational and social dynamics. Revisiting current HRD theories and practices in light of the experiences of these caregivers might prompt discussions about the role of the field in developing working practices that are more compatible with caregiving responsibilities. Further, since these parents’ experiences in the workplace are connected to issues of gender
inequality and disability stigmatization, the findings of this study might indicate possible strategies to foster more diverse and inclusive organizations. Also, I hope this study contributes to underscoring the importance of preparing future HRD professionals with a critical perspective to challenge discrimination and oppression in the workplace.

For practice, I offer insights on how organizations can better support caregivers while promoting gender equity and anti-ableism. Moreover, I hope this research will prompt meaningful discussion around family-supportive organizational initiatives and public policies. Finally, I hope the learnings from this study can bring attention to the crucial role of organizations and policymakers in promoting the importance of care as a social practice necessary for the sustainability of our society.

Chapter 2: Literature Review

This chapter starts with an overview of the existing literature that discusses the professional experiences of parents of PWD, mainly in the fields of disability, family, and women studies. Next, an overview of the Brazilian context regarding gender social roles and family-supportive policies is presented to help situate the study. The chapter ends with an overview of the main theoretical frameworks underpinning this study: gender, gendered organizations and care work, work-life scholarship, and career development theories.

The Impacts of Parenting a PWD on Parents’ Professional Experiences

Although studies examining the professional experiences of parents of PWD are not extensive, they overwhelmingly indicate that caregiving for a PWD increases work-
family conflict and negatively impacts these parents’ participation in the workforce. Most of the studies conducted in the past twenty years were done with mothers of individuals with disabilities in the US, Europe, and a few in Australia, Japan, Taiwan, and South Korea.

**Elevated Work-Family Conflict**

The intense demands that caring for a PWD comprises associated with the lack of social and organizational support result in higher levels of work-family conflict for parents of PWD, impacting their ability to perform their work and family roles effectively. Brown and Clark (2017) revised the literature on the work-family balance of parents of PWD and identified individual and organizational factors that influence this balance. Individual factors include married status, age of children, type and severity of children’s disability, availability of childcare, family support, and the quality of work-role; organizational factors include flexible working policies, family-friendly organizational culture, and supportive supervisors.

Caring for a PWD involves time-consuming and stressful activities that typical parents usually do not perform, including managing multiple medical and specialized service providers, learning about their children’s conditions, advocating for rights, and educating other people (Crettenden et al., 2014; Gordon et al., 2008; Jang & Appelbaum, 2010). These parents engage in a high degree of care coordination, which involves intense and complex articulation work, “invisible but innumerable tasks needed to coordinate a particular activity” (Brennan et al., 2016, p.7). Parents reported having long days and a rigid schedule to accomplish all their care demands (Rosenzweig et al., 2002) – “like having a full-time job” (Jang & Appelbaum, 2010, p. 323). Moreover, parents
mentioned that their need to be always available in case of unexpected crises or breakdowns in childcare imposes a significant obstacle to their professional lives (Crettenden et al., 2014; Shearn & Todd, 2000).

Lack of family-supportive workplace policies, family-unfriendly organizational cultures, and unsupportive supervisors and co-workers profoundly contribute to parents of PWD’s high work-family conflict levels (Brown, 2014; Brown & Clark, 2017; Brown & Sumner, 2019). Non-family-supportive organizations often uphold the expectation of the *ideal worker*, presuming a total separation of personal and professional lives and full-time commitment to work, which is unrealistic for parents of PWD and significantly impacts these parents’ ability to care for their children (Lewis et al., 2000a; Scott, 2018). Besides, the perception of unsupportive cultures might prevent some parents from disclosing their children’s disabilities due to the anxiety of suffering career derails and losing their jobs (Brennan et al., 2016; Lewis et al., 2000a; Stewart & Charles, 2021).

Brennan et al. (2016) argued that parents of PWD face ‘double jeopardy’ stigmatization as they are discredited both in their professional and parenting abilities.

Parents of PWD report that stigmatization toward disability makes conversations about their children hard to happen outside private spheres, preventing them from accessing support in the workplace (Randall, 2017; Stewart & Charles, 2021). Lewis et al. (2000a) interviewed parents of PWD and noted that fathers are particularly reluctant to disclose their children’s disabilities and ask for flexibility, demonstrating the gendered aspects of the workplace. Albeit reluctance and fear, most parents disclose the situation at some point, as their need for flexibility becomes urgent (Crettenden et al., 2014; Stewart & Charles, 2021). The lack of supportive supervisors and co-workers is one of the main
obstacles impacting parenting’s ability to sustain care and paid work (Crettenden et al., 2014). Unsupportive supervisors preclude the adoption of flexible working arrangements even when formally available (Brown & Clark, 2017; Lewis et al., 2000a).

**Reduced Participation in the Workforce and Career Changes**

Elevated levels of work-family conflict negatively impact these parents’ careers and participation in the workforce. Several quantitative studies demonstrate that parents of PWD are less likely to have full-time employment than typical parents. Qualitative studies describe the various changes parents of PWD undertake to better attend to their family and work demands.

Crettenden et al. (2014) compared the experience of married mothers of PWD and mothers of non-disabled children in Australia. They found that although these mothers have similar participation in the workforce (62% and 65%, respectively), only 18% of the mothers of PWD worked full-time, compared to 43% of typical mothers. Two studies with parents in the U.S. found no significant difference in employment status between parents of PWD and typical parents (DeRigne & Portfield, 2017; Stewart, 2013). However, parents of PWD were more likely to have work absences (DeRigne & Portfield, 2017), hourly-based payments, and a smaller average income than typical caregivers (Stewart, 2013).

Hope et al. (2016) analyzed longitudinal data in the U.K. and found that mothers of PWD were less likely to be employed and had a higher risk of disrupted maternal employment and of never being employed than typical mothers. Ejiri & Matsuzawa (2019) found that mothers of PWD have significantly higher levels of unemployment than typical mothers in Japan, even though 57% of the mothers of PWD declared they
would like to be employed. A study with a large dataset in Belgium revealed a significant negative relation between parenting a PWD and parents’ employment, with more substantial negative impacts for single parents and parents with lower education levels (Vinck & Van Lancker, 2020).

Qualitative research describes the many changes parents caring for a PWD undergo to accommodate family and professional lives. Among the changes, parents reported transitioning to part-time positions (Crettenden et al., 2014; Rosenzweig et al., 2002), moving to jobs that require less time, responsibility, or concentration, often in lower-level positions or areas different than their original careers (Randall, 2017; Rosenzweig et al., 2002; Scott, 2018). Parents of PWD expressed avoiding jobs that require much traveling (Rosenzweig et al., 2002).

To accommodate care and work, parents of PWD asserted that they would make changes in their careers even if it implies not doing what they like, assuming positions below their qualifications, or accepting lower payment and reduced benefits (Jang & Appelbaum, 2010; Lewis et al., 2000b; Rosenzweig et al., 2002). In a mixed-method study, Wright et al. (2016) interviewed fathers of PWD in Australia who reported that financial concerns led them to stay in jobs they did not like, but that offered stability. Often, mothers quit their jobs entirely, particularly if they have a partner who can guarantee a reasonable income or when their salaries are lower than the cost of caregiving (Scott, 2010). Mothers of PWD shared having a belief that long interruptions and job changes severely impact their chances for re-employment. They reported feeling insecure about their skills after being out of the workplace for extended periods (Shearn & Todd, 2000). Crettenden et al. (2014) concluded that mothers of PWD undertake a long-term
impact on their professional lives, as many of them do not return to full-time work even when their children grow older, impacting their provision for retirement and financial stability. Mothers of PWD reported grieving the loss of their professional identities (Scott, 2010; Shearn & Todd, 2000). Scott (2010) claimed that, in general, mothers of PWD with higher levels of education experience more anger and frustration with the decision to change or stop working since they often have career aspirations and a consolidated professional identity.

*The Gendered Effect*

Gendered social norms and gendered organizations and work structures intensify work-family conflict for mothers of PWD and disproportionately impact their professional experiences. The disproportional impact on women’s work lives is demonstrated in quantitative research. Two studies in the U.S. pointed out that mothers were more negatively impacted (undesired changes and perception of impact) in their work lives than fathers (Baker & Drapela, 2010; DeRigne & Porterfield, 2017). In another study in the U.S., fathers of PWD reported having some or a lot of flexibility at home to manage work and childcare issues (Sellmaier, 2019). Sellmaier concluded that these fathers relied heavily on their spouses or other relatives to provide the care work and argued that work-family fit for them was “achieved at the expense of gender equity” (p. 76).

Olsson & Hwang’s (2006) study in Sweden showed that mothers of PWD worked fewer hours than fathers of PWD, and both were more likely to work less than 20 hours/ per week than typical parents. Brekke & Nadim’s (2017) study in Norway found that mothers of PWD had lower annual incomes than typical mothers. In contrast, there
was no significant difference between fathers of PWD and typical fathers. Both authors claimed that gendered patterns seem more prominent among families of PWD, even in countries with a solid gender equality ideology.

Qualitative studies also suggested that the association between women and caregiving seems stronger for families of PWD (Lewis et al., 2000a, 2000b; Scott, 2010; Shearn & Todd, 2000). Scott (2010) claimed that the “moral imperative that mothers must care for their children was intensifiﬁed such that mothers of children with disabilities felt as though it was their duty to be ‘special, selfless’ mothers whose place was exclusively in the home” (p. 691). Gendered social norms determine that disability and illness require maternal care, and consequently, mothers of PWD are not supposed to be employed (Lewis et al., 2000a, 2000b). On the other hand, fathers are considered less able to provide care. Thus, their roles as breadwinners and secondary carers are naturally accepted (Lewis et al., 2000a, 2000b; Shearn & Todd, 2000). A study with mothers of adults with intellectual disabilities in Taiwan demonstrated that even when women were the primary income providers, they also assumed the main caregiver role (Chou et al., 2013). The authors reported that “no mother complained about the inequity of care responsibilities between themselves and the fathers; some even expressed gratitude for their husbands’ support. They viewed taking care of their adult children with intellectual disabilities as their responsibility” (p. 141).

The reviewed studies bring an ample demonstration of the unequal distribution of care work, with women often assuming primary caregiver responsibility for their disabled children (Chou et al., 2013; Jang & Appelbaum, 2010; Lewis et al., 2000a, 2000b; Randall, 2017; Rosenzweig et al., 2002; Scott, 2010, 2018). Women’s role as primary
caregivers can be a preference or a choice. However, this choice is often constrained by
gendered social norms in the community, gender discrimination in the workplace, and
gendered family-supportive programs that target women and discourage men from
adopting them (Gordon et al., 2008; Scott, 2010; Shearn & Todd, 2000).

The distribution of care work between mothers and fathers and maintenance of
paid employment often involves a complex combination of social, structural, economic,
and ideological elements, yet are regularly viewed through a gender lens. Despite many
families reporting the income potential as a significant factor defining the distribution of
care work, research shows that ideologies of appropriate gender behavior are a more
decisive influence (Chou et al., 2013, 2016; Lewis et al., 2000b). Lewis et al. (2000b)
studied dual-earner parents of PWD in the U.K. and found that even when the women
had a higher salary, families prioritized men as primary providers and women as principal
caregivers, using a gendered logic. The authors also observed that dual-earner couples
approaching employment decisions in a gender-neutral way handled the burden of care
better. These couples adopted flexible work arrangements and defined a more
proportional distribution of care work. Lewis et al. (2000b) contended that caring for a
PWD can be so exhausting that these families do not seem to have time and energy to
discuss gendered assumptions. Still, not discussing them reinforces expectations of
appropriate gender behavior.

Organizations’ cultures and processes strongly contribute to the disproportionate
work-family conflict endured by mothers of PWD (Gordon et al., 2008). Jobs are not
gender-neutral; instead, they “are organized by masculine norms that require
unencumbered workers to rely on the presence of a homemaker to perform all of the
reproductive labor” (Scott, 2018, p. 2678). These gendered norms intensify work-life conflict for mothers of PWD and hinder men’s engagement in caregiving work (Brown & Clark, 2017; Chou et al., 2016; Scott, 2018). Rigid conceptions of career and competence generate stress on mothers who report fearing they are not seen as reliable workers (Shearn & Todd, 2000). Working mothers of PWD consider that their need to reduce working hours or adopt flexible working arrangements disrupts their careers. Several mothers of PWD reported feeling discriminated against and not receiving good job opportunities or promotions because of their part-time or flexible work status (Crettenden et al., 2014; Lewis et al., 2000a; Rosenzweig et al., 2002; Shearn & Todd, 2000). A quantitative study found that supervisor reprimands quadrupled the odds of mothers’ employment being affected compared to fathers (Baker & Drapela, 2010).

Furthermore, gender discrimination and the wage gap significantly influence the decision of married parents of PWD about who will sacrifice their professional lives. The necessity for a stable income and benefits due to the high costs involved in caring for a PWD combined with the assumption that men have more stability in their jobs and more potential to achieve higher salaries than women privileges fathers who often maintain their full-time jobs, (Lewis et al., 2000b; Randall, 2017; Scott, 2010). Likewise, when available, organizations’ family-supportive policies often target women and are much more frequently adopted by them (Brennan et al., 2013; Padavic et al., 2020), contributing to women’s prolonged employment pauses and career disruption (Lewis et al., 2000b; Padavic et al., 2020).

At the community level, health, education, and other service providers usually assume that “there is always at least one parent (usually the mother) available at all
times” (Lewis et al., 2000b, p. 426). Mothers of PWD reported that social service providers do not seem to consider that they would like to work (Shearn & Todd, 2000). At the national level, welfare policies reinforce the gendered pattern of caregiving work when they prioritize long leaves for women instead of actions that enable women to work, for example, providing accessible childcare (Lewis et al., 2000b).

**Seeking Work that Works**

Studies show that maintaining paid work is crucial for these parents’ financial and emotional stability. Stable income and benefits such as health insurance are critical elements to support parents’ ability to care for their children (Chou et al., 2013; Jang & Appelbaum, 2010; Lewis et al., 2000b; Randall, 2017). Furthermore, statistics show that many mothers of PWD are abandoned by their spouses and become single parents (Scott, 2010). Thus, employment becomes crucial to their ability to pay for the cost of exceptional care.

Quantitative research has shown a relationship between paid work and parents’ well-being and mental health. Morris (2014) analyzed data from the National Survey of American Families and found that work provides additional mental-health benefits to mothers of older disabled children compared to other groups, including mothers of disabled children up to 6 years old, fathers of PWD, and typical parents. Further quantitative studies found a positive relationship between paid work and well-being for parents of PWD in Sweden (Olsson & Hwang, 2006) and a better quality of life for mothers of PWD in Taiwan (Chou et al., 2016). Einam & Cuskelly’s (2002) study with Australian mothers found that paid work outside the home was associated with maternal
mental health, independent of child disability status. However, their study also showed that mothers of PWD were less likely to have outside-home employment.

In qualitative studies, mothers of PWD mentioned that paid employment helps them keep a sense of identity, provide self-fulfillment, financial independence, and respite from the intense caring demands (Brown & Clark, 2017; Lewis et al., 2000b; Scott, 2010, 2018; Shearn & Todd, 2000). Parents reported that their work provides them some “relief from thinking about family demands or stress” (Jang & Appelbaum, 2010, p. 328). Shearn and Todd (2000) interviewed mothers of children with intellectual disabilities in the U.K. to understand their attitudes toward employment and concluded that work has a special significance for them, “they felt that they would be unable to carry on caring without a break from their children, and an escape from the isolation of being at home and the unfulfilling nature of housework” (p. 124). Nevertheless, organizational support is critical for the positive effects of employment on these parents’ mental health (Jang & Appelbaum, 2010; Shearn & Todd, 2000).

Given the importance of maintaining a job and attending to the caring demands of their disabled children, most parents craft creative ways of performing both family and work roles as satisfactorily as possible (Gordon et al., 2008; Rosenzweig et al., 2002). Parents of PWD look for family-friendly organizations and use flexibility and resourcefulness to combine work and family demands, frequently revisiting and renegotiating professional and personal aspirations and arrangements (Lewis et al., 2000b; Rosenzweig et al., 2002). Parents reported changing their careers and finding more balanced jobs in community support institutions attending PWD and their families. These parents mentioned that these institutions understand their needs, and they feel they
can leverage their personal experience and knowledge about managing exceptional care (Rosenzweig et al., 2002; Scott, 2010, 2018). Nevertheless, achieving work-life integration is not an easy task, and parents of PWD narrated going through many difficult experiences before finding a “work that works” (Scott, 2018, p. 2667).

The Brazilian context

Gender Roles and Women in the Workforce

Brazil is a country with deeply rooted Christian and patriarchal traditions that sustain strong gender role division. Women are the family’s primary caregivers, including caring for the house, children, the elderly, and even husbands (Belato et al., 2019; Fernandez, 2019; Hirata, 2016). Moreover, Brazil’s long history of slavery and colonialism, with the development of a dominant social class built upon bourgeois ideals, contributed to maintaining traditional patriarchal family structures and well-defined gender roles (Fernandes & Nascimento, 2021).

The first Brazilian Civil Code, established in 1916 in substitution to the colonizer’s legislation that was still in place, stated that men were the heads of the household and that married women could only work with their husband’s approval. Only in 1962 did married women gain the right to work outside their household (Ministério dos Direitos Humanos e da Cidadania, 2014). Although after the end of slavery in Brazil, most formerly enslaved women joined the workforce, occupying low-paid positions in households, factories, and shops, it was only in the 1930s, with urbanization and industrialization, that white women gradually entered the workforce and joined the
cultural life in the urban centers. The ratio of women working outside the home would not vary considerably until the 1970s when it reached 21% (Saffioti, 1978).

With a significant increase in women’s participation in the workforce since the 1980s, men’s attitudes toward care and domestic work started to shift, although at a much lower speed (Melo & Castilho, 2009). However, changes in the gender-based division of labor are minimal (Melo & Morandi, 2021). Data from 2019 shows that Brazilian women spent, on average, 21.4 hours per week in domestic and care work, almost two times more than men, who spent 11.0 hours (IBGE, 2021). Even among dual-earner couples, men are considered the household reference person, while women perform a larger amount of household activities (Berlato et al., 2019). The disproportional time dedicated to domestic and care work directly impacts women’s participation in the workforce. In 2019, 54.5% of women were in the workforce compared to 73.7% of men. This difference reaches almost 35 percentage points for 26-49-year-old adults in households with children under the age of three (Agência IBGE Notícias, 2021). Moreover, women engaged more frequently in part-time work, with 29.6% of employed women working part-time, compared to only 15.6% of employed men (IBGE, 2021).

The solid patriarchal culture is also observable in occupational distribution and wage disparities. Women are disproportionately overrepresented in fields related to well-being, care, and early childhood and primary education, occupations typically associated with gender social roles and with lower salaries (Silvia & Vaz, 2022). For example, 88.3% of students in courses related to well-being were women in 2019 (Agência IBGE Notícias, 2021). Additionally, even though Brazilian women have a higher education level than men, their salaries are, on average, 12% lower than men’s (Secretaria de
Inspeção do Trabalho, 2023). The wage gap is higher in leadership jobs, where women earn 77% of the salary of men in similar positions (Agência IBGE Notícias, 2021).

As a country with significant social inequality, motherhood in Brazil is experienced differently depending on the intersection of one’s race and socioeconomic status. In 2018, more than half of the Brazilian population (56.9%) declared themselves as non-white, and around one-third (31.8%) of the Brazilians live under the poverty line; this proportion increases to 41.7% for the non-white population (IBGE, 2019). Women in higher social classes, primarily white, generally count on one or more domestic servants to care for their families and house. These domestic workers, mainly black, care for the children and the house, allowing upper and middle-class women to have paid work outside their homes (Quintela, 2017). The prevalence of domestic work in households is intrinsically connected to enslavement and the abolition process in Brazil (Acciari, 2019; Pinho, 2015).

**Family-Supportive Policies**

Brazil complies with most of the International Labor Organization’s proposed standards for family-supportive policies (Addati et al., 2022). In Brazil, there are, in general, two different employment types: employees working for organizations under the Brazilian Consolidate Labor Law (CLT) and professionals working as self-employed in different legal and fiscal configurations. The CLT regulates the rights and duties of employers and employees and ensures essential benefits, such as vacations, social security, and pension, as well as protections for caregivers. For individuals working for

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1 Brazil census asks for a declaration of race or skin color. Non-white includes black 9.3%, brown 46.5%, and 1.1% yellow and Indians.
organizations in CLT contracts, the federal government guarantees 120 days of paid maternity leave, five days of paid paternity leave, and protection against discrimination during the pregnancy and leave periods (Decreto-lei no 5.452, 1943).

Maternity leave is a well-established right in Brazilian society and is often exercised by most women. It is a benefit paid by social security, not employers, and all women can access it, including CLT workers, self-employed, and informal workers\(^2\) (Ministério da Previdência Social, n.d.). Moreover, the government provides public and free childcare to children under four years old, and primary education to all children from four to seventeen years old (Fernandes & Nascimento, 2021).

However, the Brazilian Constitution defines the family as having the primary responsibility for providing care, resulting in limited investment in public institutional care services (Guimarães, 2021; Hirata, 2016). Consequently, the implementation of childcare is far from perfect, with low availability and questionable service quality (Finco et al., 2015; Sorj & Barbosa Fraga, 2022). Moreover, although the law protects employment during pregnancy, the leave period, and five months after the leave period, there are frequent reports of women’s dismissal after the protection period, particularly among low-skilled workers (Sorj & Barbosa Fraga, 2022).

In the last decades, with Brazilian women progressively entering the labor market, new initiatives have been discussed at the federal level to support women’s work and tackle the unequal division of care work (Fernandes & Nascimento, 2021; Quintela, 2017). One initiative, sanctioned in 2008, is a new law that offers fiscal incentives,\(^2\)

\(^2\) Paid maternity leave is guaranteed to all mothers registered and contributing to social insurance, including cases of adoption and stillbirth.
including tax deductions, to organizations that adopt the Programa Empresa Cidadã (Lei n° 11.770, 2008). The program includes 180 days of maternity leave and 20 days of paternity leave. Since its beginning, 25,000 organizations have adhered to the program (Santiago, 2023). Nevertheless, this number represents a small portion of the total number of employers in the country and is concentrated in large and multinational organizations (Sorj & Fraga, 2022). Specifically, for parents of PWD, a new law from 2016 allows federal public servants to reduce their working hours by 20 to 50% while keeping their integral salaries (Lei n° 8.112, 1990). State and city public servants were also granted this benefit in 2022 (Supremo Tribunal Federal, 2022).

Although Brazilian family-supportive policies are aligned with the ILO standards, they reinforce patriarchal norms and contribute to gender inequality in the workplace and an uneven division of unpaid care work. Projects that propose different configurations for parental leave, with the mother and father sharing the leave period, move slowly in the federal senate (Fernandes & Nascimento, 2021). Additionally, the recent wave of conservatism with a more significant proportion of far-right and religious politicians in the Brazilian government imposes more obstacles to advancing feminist agendas regarding reproductive labor rights.

**Gender, Gendered Organizations, and Care Work**

Gender is a relevant factor in examining the professionals’ experiences of parents of PWD, their careers, and work-family interactions, given the different ways men and women have historically experienced family and professional roles (Lewis et al., 2003; Schultheiss, 2020).
In their seminal work *Doing Gender*, West and Zimmerman (1987) asserted that gender is “the activity of managing situated conduct in light of normative conceptions of attitudes and activities appropriate for one’s sex category” (p.127). In this sense, we ‘do gender’ in our social interactions by adopting and reinforcing these conceptions of what it means to be a man and a woman in a binary paradigm (Ridgeway, 2009; West & Zimmerman, 1987). It is important to acknowledge that gender comprises other identities beyond the binary female and male, including a blend of both or neither of them (Bierema, 2020b). Parental roles – mother and father – have also been traditionally connected to gender identity and biological sex. Nevertheless, new family configurations and assisted conception complicated this direct association (Callus, 2019).

Normative gender conceptions have deep roots in our patriarchal societies and their images of family and work (Acker, 2012; Ridgeway, 2009). These normative conceptions determined expected behaviors and social roles for men and women. Women are assumed to be nurturing, emotional, and natural caregivers devoted to family, whereas men are rational, decisive, and the main breadwinners (Acker, 2012; Padavic et al., 2020). Padavic et al. (2020) argued that the “family-devotion schema assigns women, and not men, the primary responsibility of childrearing and housework and holds them accountable” (p. 65).

Normative gender conceptions are entrenched and reproduced in organizations’ structures, processes, and culture (Acker, 2012; Ridgeway, 2009). Organizations are gendered structures where “inequalities are built into job design, wage determination, distribution of decision-making and supervisory power, the physical design of the workplace, and rules, both explicit and implicit, for behavior at work” (Acker, 2012, p.
Acker contended that paid work is ideologically male-dominated and is radically separated from unpaid domestic work, which is ideologically a domain of women. This separation is evident in the notion of the ideal worker – a full-time committed professional utterly devoted to the organization and who is often assumed to have an unpaid spouse or a paid maid to care for their house and family. Oppositely, women, particularly mothers, are automatically categorized as ‘non-ideal workers’ (Acker, 2012; Kossek et al., 2021; Padavic et al., 2020). Mothers are discriminated against in the workplace, facing career derails and the ‘motherhood wage penalty’ (Bian & Wang, 2019; Kossek et al., 2017). Likewise, individuals who deviate from gendered breadwinning and caregiving norms also experience discrimination in the workplace (Kossek et al., 2017).

Care work is gendered and undervalued (Tronto, 2013). Mohanty (1984) claimed that a woman’s position in society is not an outcome of what she is or does; instead, it is a product of the meaning and values that social context attributes to her activities. The issue, then, is not the biological reproductive function of women but “the value attached to mothering” in different societies (p. 68). The work ethic embedded in most societies, mainly Western and Westernized cultures, determines that valued work produces monetary outcomes and occurs in the public sphere, meaning the workplace and not home. Accordingly, valued workers are those who work hard in the workplace (Tronto, 2013). Tronto contended that this view downgrades both caregivers and those who are dependent, which puts parents of PWD on the margins of society. Furthermore, the low value attributed to care work involves not only underlying sexist assumptions but also intersects with race, ethnicity, and social class (Acker, 2012; Tronto, 2013).
Work-Life Scholarship

Scholarship examining the many relationships between work and other domains of individuals’ lives is extensive. However, until recently, this discussion was disconnected from social identities and contextual constraints. The literature greatly ignored the lack of choice imposed on some groups and its contribution to social inequity (Lewis et al., 2003; Moen, 2011). For parents of PWD and other caregivers in general, managing their work-life interactions is critical to their well-being and ability to care (Lewis et al., 2000a, 2000b).

Initial discussions about work-family can be traced back to the 60s and are mostly related to women’s entrance into the workplace and the supposed adverse consequences for their children (Moen, 2011). In the 70s, second-wave feminists challenged the social expectation of women being restricted to the household and demanded equal access to education and employment opportunities. However, women entered the workplace accepting the current work organization of full-time jobs and total dedication while still keeping most of the responsibility for reproductive labor. It was “at this time that ‘balance’ became the watchword. Only, it seemed, just women were to do the balancing” (Moen, 2011, p. 84). In the 90s, the work-family discussion started to involve men and fathers, and the work-life concept emerged to include individuals who did not have families (Moen, 2011).

In the last decades, the work-life discussion gained increased importance due to progressively blurred boundaries between work and personal life, excessive working hours standards, advancement of women in the workforce, and the increasing number of single parents and dual-earner households (Greenhaus & Powell, 2006; Lewis et al.,
Twenty years into the twenty-first century, women still face the challenges of conciliating work, family, and other life demands. Nonetheless, little has been discussed about the social organization of work and the traditional work structure. Although flexible working arrangements have become a reality in some workplaces, there is still a stigma related to those who adopt them, primarily women (Kossek et al., 2021; Moen, 2011).

Scholars have developed numerous concepts to explain and assess work-family interactions, and there are still disagreements on definitions and measurements (Kossek & Lee, 2017). For example, although work-family is a specific aspect of work-life interactions, these two terms are frequently used interchangeably in the literature (Kossek & Lee, 2017). Most of the studies about the professional experiences of parents of PWD use work-family constructs.

Work-family balance is related to the individual assessment of the level of effectiveness in meeting work and family demands, given the available work and family resources (Voydanoff, 2005). Some scholars argued that work-family balance exists in the absence of work-family conflict, while others claim that work-family balance is an independent concept (Kossek & Lee, 2017). Greenhaus and Beutell (1985) defined work-family conflict as “a form of interrole conflict in which the role pressures from the work and family domains are mutually incompatible in some respect” (p.77). Their proposed model of work-family conflict includes different factors that contribute to time, strain, and behavior-based conflicts. Some scholars challenged the concept of balance, arguing that it overlooks unpaid work, assuming it is included in the ‘non-work’ part of our lives (Lewis et al., 2003). Moen (2011) claimed that the concept of balance puts focus on
individuals’ private problems, minimizing the implications of cultural and social structure and putting the burden of finding balance on women rather than on couples or families.

Lewis et al. (2003) suggested work-personal life integration as a preferred term to “capture the synergies and connections between the different parts of life and the ways in which they feed into each other” (p. 829). Voydanoff (2005) proposed work-family fit “as a form of inter-role congruence in which the resources associated with one role are sufficient to meet the demands of another role such that participation in the second role can be effective” (p. 822). Greenhaus and Powell (2006) developed a model of work-family enrichment, defined as “the extent to which experiences in one role improve the quality of life in the other role” (p. 73). Work-family positive spillover, enhancement, and facilitation are other concepts defined by researchers investigating the positive interactions between work and family (Greenhaus & Powell, 2006). Moen (2011) argued that the work-family concept is outdated and proposed life-course fit as a broader concept defined as “the cognitive assessments by workers or family members of the congruence (or incongruence) between the claims on them and their needs and goals, on the one hand, and available resources on the other” (p. 91).

Scholars studying parents of PWD professional experiences have suggested that constructs like work-family integration and fit might be more helpful in describing the experience of these parents as they often try to integrate their personal and professional lives to attain financial and emotional well-being (Brennan et al., 2016; Rosenzweig et al., 2002; Scott, 2018; Shearn & Todd, 2000).

Kossek et al. (2021) argued that although work-family and careers research are interdisciplinary fields that intersect to discuss how employers and individuals can
develop satisfactory professional and personal lives, there is still a noticeable need to develop research that integrates these scholarships. Kossek claimed that “research that describes and analyzes the experiences of increasingly diverse workers and their career paths represents an opportunity to gain insights on how organizations can adapt not only to support individuals in the face of career and family turning points but also to an economic and socially-shaped future career landscape that is in flux” (p. 15).

**Career Development**

Career development theories have historically been built under the assumption that individuals have equal access to resources and that self-agency is the main factor determining career movements, often neglecting contextual factors and other parts of professionals’ lives (Akkermans et al., 2018; Greenhaus & Kossek, 2014; Schultheiss, 2020). Moreover, discussions about career development have ignored issues of gender inequity and discrimination in the workplace, gender role stereotypes in organizations and society broadly, and unpaid care work (Moen, 2011; Schultheiss, 2020). Early career development theories focused on matching individuals’ interests and characteristics with the job environment are inadequate for populations that face contextual constraints, including those with caregiving responsibilities (Kossek et al., 2021).

Although Super’s life-span, life-space career theory discusses life roles other than paid work, it does not consider contextual constraints that limit access to resources and individuals’ choices (Schultheiss, 2020). Evolving from Super’s theory, Savickas (2020) proposed the Career Construction Theory, contending that individuals develop by adapting to their environments and co-constructing themselves through interpretive and
interpersonal processes. Likewise, Social Cognitive Career Theory (Lent, 2020), widely used in career development research, discusses the influences of contextual elements in individuals’ identity shaping and learning experiences. Nevertheless, these career theories limit the role of contextual elements and still consider career decision-making an individualistic endeavor “based on the merit of independent thought and judgment” (Schultheiss, 2020, p. 294).

An opposing perspective was more recently provided by scholars who argued that career development is a relational process, emphasizing the existing interdependencies between work and the rest of individuals’ lives. Blustein (2011) proposed the relational theory of work, underscoring how working and individuals’ relational contexts are intertwined and how relationships shape career movements. It builds on critical and feminist perspectives and recognizes that for many individuals, career choices are not only self-determined but are surrounded and influenced by external interactions. Schultheiss (2020) underlined that weighing the influence of family on the complexities of career development is one of the principles of relational approaches.

Greenhaus and Powell (2012) proposed the concept of “family-relatedness of work decisions” to describe decision-making processes that consider family factors aiming to benefit the family domain. The authors highlighted that this discussion had been overlooked in work-related decision-making scholarship. Even though they consider the impact of individual, organizational, and societal contexts on the level of family-relatedness of work decisions, they seem to put family needs as something that one can choose to attend to or not, ignoring the gendered implications of this assumption.
In a related perspective, Greenhaus and Kossek (2014) proposed a work-home perspective on careers that acknowledged the interdependencies and interweaved relationships between work and home. They defined home in broader terms to include family, friends, community, leisure, and self-development. As a newly developed theory, there is still a need for future research, and the authors pointed out relevant topics that need to be discussed from the work-home career perspective, including career self-management, global careers, ideals of career success, and sustainable careers over the life course.

Two other career concepts – career shock and sustainable careers – also provide a systemic perspective emphasizing how contextual factors influence individuals’ agency. Career shock was first proposed by Akkermans et al. (2018) to describe the impact of disruptive events on an individual’s life that leads to a deliberate reflection process about career, often resulting in positive and negative effects. The idea of career shocks acknowledges the unpredictability of life, but there is still limited empirical research investigating how these events impact individuals’ career development (Akkermans et al., 2021; Van der Heijden et al., 2020).

Sustainable career is defined as “the variety of paid and unpaid work experiences that provide continual growth and renewal and that intersect multiple life contexts resulting in meaning and well-being for individuals over time” (McDonald & Hite, 2018, p. 350). While the concept of sustainable career puts the individual as the central actor, it also considers the interconnected systemic forces and stakeholders influencing individuals’ agency (De Vos et al., 2020). De Vos et al. (2020) stated that a sustainable career is a cyclical and self-regulatory process happening in a changing context, where
the positive and negative experiences an individual goes through serve as learning opportunities and inform career decisions. The authors argued that this systemic approach differentiates sustainable careers from other contemporary theories, including boundaryless and protean careers. However, indicators proposed by the author to assess a sustainable career, namely happiness, well-being, and productivity, are still seen from the perspective of work, and bringing a work-home perspective to it might be valuable (Greenhaus & Kossek, 2014; Hirsch & Koen, 2021).

Sustainable career is also a concept in its early development stages (De Vos et al., 2020; McDonald & Hite, 2018), and there is a need to further examine several aspects of this theory, including the application with different type of professionals, particularly self-employed and entrepreneurs, indicators of a sustainable career, the interaction with career shocks, and how sustainable careers evolve over time (Van der Heijden et al., 2020).

In summary, most well-known career development theories overlook the contextual constraints caregivers face, particularly those providing care for PWD. Although more recent career development approaches have adopted a systemic perspective, incorporated contextual elements, and considered the impact of relationships and family on career decision-making, these theories are in their early stages of development, and more empirical studies are needed to refine and advance them (De Vos et al., 2020; Greenhaus & Kossek, 2014; Van der Heijden et al., 2020).
Chapter 3: Methodology

This chapter describes the methodology used for this study – constructivist grounded theory. It details the research design, data collection, data analysis, research positionality, and ethical considerations.

Method - Constructivist Grounded Theory

The Grounded Theory (GT) methodology is a research approach that aims to move beyond the description of phenomena to generate a theory about a process, an action, or an interaction (Merriam & Tisdell, 2015). It can be beneficial to investigate processes and ongoing changes related to a phenomenon and to define an agenda for a phenomenon that has not yet been well explored (Egan, 2002; Merriam & Tisdell, 2015). In addition, one of GT’s tenets is to bring practical application with the potential to provide findings that can contribute to the development of organizational practices (Egan, 2002). All these points resonate with the relative newness of my topic and my expectations for my research contributions.

In this study, I used the constructivist GT method proposed by Charmaz, which embraces a feminist lens (Clarke, 2012) and is well aligned with my epistemological beliefs. The constructivist perspective assumes that reality is multiple and socially constructed and takes into account the researcher’s positionality, privilege, and perspective (Charmaz, 2014). This approach makes sense to this study because it allows me, as a researcher and also a member of the group under investigation, to reflect on my own positionality as part of the data collection and analytical process.
Clarke (2012) claims that constructivist and postmodernism GT are adequate methods for feminist research. The author points out that GT’s roots in pragmatism and symbolic interactionism emphasize lived experiences, situatedness, and multiplicity, enabling the representation of the multiple perspectives of those studied and the researcher. Moreover, GT is a suitable method to study social justice issues as it allows us to interrogate how injustice and inequalities happen in the empirical world, considering the individual and their interactions with organizations, social institutions, and public policies. Ideologies and constructs related to power and oppression are not equally understood or accepted by individuals under investigation, and the GT approach allows these different understandings to emerge, enabling the researcher to collect data on how matters of social justice are experienced and perceived by individuals in their contexts (Charmaz, 2014).

Barney Glaser and Anselm Strauss first proposed the GT method in their book *The Discovery of Grounded Theory* (1967). They defined GT as “the discovery of theory from data” and offered a structured empirical process of collecting and analyzing data inductively to develop a theory that explains the studied phenomena and provides practical utility (Glaser & Strauss, 1967, p. 1). The authors claimed that their research method generates “theory as process, that is theory as an ever-developing entity, not as perfected product” (p.32), which allows for situating the generated theory into a social context and gives space for further evolution. Over the decades, scholars proposed modifications to the original method, including disagreements between Glaser and Strauss and the adoption of different epistemological lenses (Charmaz, 2014).
Charmaz (2014) proposed a social constructivist approach to GT where the researcher and participants’ interactions are part of the process of building theory from the data to offer explanations of the phenomenon under investigation. Her method brings a flexible non-linear structure that includes the following stages, not in a linear sequence: decisions for gathering rich data, crafting and conducting intensive interviews, initial coding, focused coding and categorizing, memo writing, theory building, and writing. Overall, Charmaz’s constructivist GT follows a structure similar to the original method proposed by Strauss & Glasser but adds flexibility and reflexivity and embraces variation of perspectives (Charmaz, 2014; Clarke, 2012).

Although many researchers use interviews as their primary source of data, the GT approach may utilize other sources of information (Charmaz, 2014). Charmaz states that the type of data collected depends on the topic and access to information. Nevertheless, the author underscores the importance of collecting rich data, meaning detailed, focused, and complete, that “reveal participants’ views, feelings, intentions, and actions as well as the contexts and structures of their lives” (p. 23). The author also highlights that a key characteristic of the GT approach is the simultaneous analytical process that happens with data collection, enabling the researcher to adjust data collection to follow the leads emerging from the ongoing analysis. As the foundation of GT is to build theory from the data, existing literature and theoretical frameworks are used as sensitizing concepts, which give “initial but tentative ideas to pursue and questions to raise about their topics” (p.30).
In the following sections, I describe the data collection approach, including participant selection, recruitment, and interviews. Next, I discuss the approach to data analysis following the constructivist GT method.

**Data collection**

My primary source of data was in-depth interviews with parents of PWD. My data collection also included census data, social media posts from profiles advocating for PWDs and their parents, news media discussing the topic, and documentation related to public policies and organizational initiatives targeting PWDs and their caregivers. Nevertheless, while primary data was carefully coded, secondary data sources were used as reflective material, contributing to situating the narratives from primary data collection into the country’s social, political, and economic context. Secondary data collection, particularly data related to public policies, was also crucial in probing participants’ stories and in developing rich memos throughout the analytical process. Besides official governmental pages with public policies and census data, other relevant sources of secondary data were posts on advocacy-related Instagram pages, including @think.eva, @think.olga, @papodefica, @direitodasmulheres, @maternativa, @marianarosa, @cientistaqueviroumae, @InstitutoCaue, @mundo.imperfeito, @mariadeantonia, @eu.maepcd, @carolrezende, @semacucarecomamor, @carolautistando, @ajornadadapassarinha.

An important characteristic of GT is the use of theoretical sampling, which seeks to gather additional information that can help the researcher elaborate on preliminary findings and categories emerging from the parallel and ongoing process of data analysis.
In this study, theoretical sampling was applied as a strategy to include additional primary and secondary data sources. The following paragraphs describe participant selection, recruitment strategies, and the interview process.

**Participant selection**

Considering GT’s theoretical sampling as my data collection approach, my research question drove the definition of the study’s initial sampling. As data collection evolved, emerging findings from the simultaneous analytical process guided the selection of additional participants, as well as other sources of data (Charmaz, 2014).

Because this study aims to examine career changes while caring for a PWD, it necessarily included individuals who have engaged in initial career decision-making (e.g., going to college, choosing a major, finding a first job, etc.) and who usually have an investment on developing their careers (Berlato et al., 2019). Thus, having a college degree was used as a sampling criterion. Additionally, it was important that these individuals have had a significant period of parenting a PWD while maintaining a professional life. Therefore, the initial sampling targeted college-educated Brazilian parents who were currently performing paid work or have performed paid work in some capacity for at least two years while caring for their offspring with a disability. Because elements of the context that play an essential role in career decision-making (e.g., social roles, institutional and organizational policies) are often determined by social identities (McMahon & Patton, 2018; Schultheiss, 2020), the sampling criteria did not include any restrictions related to gender, sexual orientation, family configurations (heterosexual couples, same-sex couples, single parents), race, and other social identities.
Nevertheless, it is imperative to mention that by focusing on college-educated parents, this study population is restricted in terms of socioeconomic class since, in Brazil, a significant portion of the college-educated population is in higher socioeconomic strata. Unfortunately, due to the considerable socioeconomic and education inequalities existing in Brazil, the experiences of parents of PWD with or without a college education are usually drastically different. For unprivileged families, career choices are limited. Overall, this difference was highlighted by most of the participants, as they ensured to comment about their privileged position in Brazilian society compared to other parents of PWD.

**Recruitment**

I started my recruitment by accessing parents of PWD through my personal network. I contacted these first parents, whom I knew matched the sample criteria, through WhatsApp messages, sharing about the study and attaching a formal invitation with more details. Those who responded with openness to participate received the informed consent form. After their acceptance, we scheduled the interview. Some of these personal acquaintances asked if they could publicize the study in their WhatsApp groups of parents with kids with similar disabilities and in the disabilities associations they were part of.

Very quickly, the invitation to participate circulated among several of these groups, and interested parents started to contact me to inquire more about the research. In the initial communication with these new parents, I introduced myself and explained the research purpose. Then, I sent the formal invitation and asked for some information about the individual to assess their fit with the study criteria. For those who matched the criteria
and were open to participating, I clarified the interview format and underscored the voluntary participation aspect of the study. I sent them the informed consent and got their approval through WhatsApp message or email.

Given the unequal distribution of care work in Brazilian society, most of my initial participants identified as women. Additionally, most of them were self-employed professionals. Therefore, I started a second recruitment effort, now connecting with personal acquaintances and telling them about my research. I asked if they knew any mothers and fathers of PWD working in organizations and if they would feel comfortable sharing the invitation to participate in the study. From this effort, I received some contacts and followed the same procedure: I sent the formal invitation, and, following that, I sent the informed consent form to those interested. In this second effort, I was able to include more women working in organizations and some fathers. I also used the snowballing sample technique (Weiss, 1995) to recruit additional fathers.

It is meaningful to mention that I had encountered almost no resistance from mothers to talk about their experiences. Except for one mother, who shared that they prefer no talk about their kid as a disabled person, I received overwhelmingly positive responses. At some point, given that I had a significant portion of self-employed mothers, I started to thank them and say I had the number of interviews I needed. On the other hand, it was challenging to find fathers willing to participate. Three of the eight fathers interviewed were personal connections, and the other five were invited through snowballing sampling. Most parents involved in disability association groups are women, which is unsurprising, given the distribution of care work in Brazil. However, scholars
conducting studies about parenting a PWD in other countries also found similar challenges (Scott, 2010; Stewart & Charles, 2021).

Analysis was conducted in parallel to data collection, allowing for the determination of theoretical saturation. Theoretical saturation is achieved when robust categories and their properties are well-developed and no new properties emerge from the data (Charmaz, 2014).

All recruitment materials, including initial communication, study invitation, and informed consent, were in Portuguese, the native language of the researcher and participants. Participants’ agreements to the informed consent were collected through print screens of WhatsApp messages or saved email files and archived. Recruitment invitation, informed consent, and Institutional Review Board (IRB) approval from the University of Minnesota can be found in Appendix A, B, and C, respectively.

**Interviews**

I conducted intensive interviews following Charmaz’s (2014) constructivist GT approach. Intensive interviews aim to deeply explore and collect detailed information about participants’ experiences, perspectives, and meanings through open-ended questions and gentle guidance. This approach allows the research to follow unexpected leads that may emerge during the interviews. Still, interview questions to gather demographics and facts about events (e.g., places, dates, duration, job positions, etc.) were also used. Although I had a detailed interview guide (Appendix D), this guide served as a supporting tool and helped me ensure that most areas of my inquiry were covered. Interviews followed a natural flow, and some additional questions were asked as the data collection and analysis processes evolved.
I started all interviews informing participants about the study goals and clarifying that they were free to decide not to answer any of my questions or to withdraw entirely from the study without any consequences. I confirmed their agreement with the informed consent and with the interview recording. Interviews were conducted in Portuguese, the participants’ and the researcher’s native language. In total, 27 interviews were conducted. They varied between 36 and 112 minutes, with an average of 77 minutes, totaling almost 35 hours of interviews. Most participants preferred to be interviewed over Zoom; therefore, I interviewed only three participants in person. Interviews conducted over Zoom were recorded using the University of Minnesota’s secure Zoom platform, while in-person interviews were recorded on my mobile phone. Right after the end of the interviews, recordings were downloaded and saved in a safe Box drive from the University of Minnesota. Downloaded recordings were immediately deleted from my mobile phone.

It is important to notice that although most of the interviews were interrupted one or more times by telephone calls from co-workers, partners, therapists, and the participants’ kids, who were often around, all interviews were satisfactorily completed and were very illustrative of these parents’ daily routines. All interviews were transcribed and de-identified, with each participant receiving an alias name. Interview transcripts were also stored in a safe Box drive from the University of Minnesota.

**Data Analysis**

The analytical process started in the recruitment stage and continued throughout the interviews. As I planned my approach to potential participants and started contacting
these individuals, I also initiated a research diary, where I recorded the study’s progress, reactions from potential participants, exchanges with interviewees, overall perceptions of the interview process, and monitoring of my own thoughts and feelings.

Right after each interview, I wrote a one to three-page analytical memo with my overall perceptions, surprising aspects, and relevant points to investigate and compare in future interviews. Additionally, I sketched the participant’s career trajectory, noting main changes, interruptions, and relevant dates, including the years of the children’s birth and disability diagnosis. During the recruiting and interview process, I followed social media posts from parents of PWD, people with disabilities, and advocacy organizations, and their insights contributed to developing my ideas.

Aligned with the GT methodology (Charmaz, 2014), I started the transcription and coding process while I was still conducting interviews. I used NVivo software for transcribing and coding, and I opted for coding interviews just after transcribing each one of them. This process allowed me to deeply immerse myself in each participant’s history, as I would be working with that interview for around 12 hours, usually spread over two days. Moreover, conducting the analytical process in parallel with the interviews allowed me to further adjust my participant selections and investigate specific questions. For example, I noticed that my initial interviews coincidentally included more self-employed professionals, which led me to an effort to recruit more participants working on full-time contracts in organizations so I could have both perspectives. In qualitative research, word choices are critical (Saldaña, 2021), and for this reason, all analytical processes were conducted in Portuguese to preserve the meaning and richness of participants’ stories.

In the following sub-sections, I detailed my analytical approach.
Transcription and initial coding

I started by listening to the interview audio and making the necessary corrections in the transcription generated automatically by the NVivo Transcription Module. Next, I downloaded the transcriptions and de-identified them, assigning an alias name to each participant. While revising the transcription, I memoed my impressions and recorded elements that caught my attention, for example, how long the participant took to mention their disabled son/daughter, what triggered this mention, and what feelings emerged. I also noted interesting expressions, such as, “My child’s disability crossed my professional career.” My memos also included similarities and differences between the interviews in a constant comparing and contrasting process.

Next, I uploaded the transcription into NVivo and started the coding process. I used NVivo software as a tool to code my data, and following GT methodology, I had no initial framework. Although I followed the guidelines from Charmaz’s (2014) book Constructing Grounded Theory, in the coding process, The Code Manual for Qualitative Researchers written by Saldaña (2021) was instrumental in supporting my analytical process. For Saldaña, a code symbolizes the researcher’s interpretation and attributes meaning to each datum. The collection of codes will serve later to identify patterns, develop categories, generate propositions, and build theory (Saldaña, 2021). As I read the transcripts during this initial coding cycle, I separated pieces of information with specific meanings without worrying much about what those codes would lead me into (Saldaña, 2021). In this initial coding cycle, I used Process Coding, Values Coding, and In Vivo Coding as my primary coding methods (Saldaña, 2021).
Process coding uses gerunds to represent participants’ actions (Charmaz, 2014; Saldaña, 2021). Since my focus was on understanding parents of PWD career decisions, process coding was an appropriate approach to identify the sequence of actions and the intertwined factors that influenced or were consequences of these actions (Saldaña, 2021). Examples of process codes include organizing care to keep paid work, planning life and work to become a mother, deciding who in the couple will sacrifice the career, and questioning the workload.

As participants pondered about their decisions and assessed the outcomes, values coding helped me map the values and beliefs driving their actions. Values are personal principles and moral codes that define right from wrong, while beliefs reflect their interpretations of the social world (Saldaña, 2021). Examples of values codes include ableist society, patriarchal culture, professional fulfillment, recognizing privilege, and maternal guilt. In Vivo coding method uses participants’ own words and expressions as codes (Saldaña, 2021). Although In Vivo coding was not my primary approach to coding, it was used when participants’ expressions brought rich meaning, characterizing an action, value, belief, or attitude specific to that community or representative of the Brazilian culture. Examples of these codes include meu mundo caiu (my word crashed), você não pode ter tudo (you cannot have it all), and me tornei uma pessoa melhor (I became a better person).

Although I initially followed Charmaz’s (2014) guidelines and coded the first three transcripts line-by-line, I moved to an incident-to-incident approach for the remaining interviews. The initial line-by-line approach generated an enormous number of codes, and experimenting with this coding approach was vital in keeping me grounded in
the data. Nevertheless, as the process evolved, I noticed that several codes were not closely related to my research question, and an incident-to-incident approach seemed more productive. Scholars argue about the advantages and disadvantages of both approaches; as I opted for the incident-to-incident method, I kept myself attentive to my own biases (Charmaz, 2014; Saldaña, 2021). Some strategies I applied to mitigate this risk were writing about my career trajectory and decision-making process and keeping a research diary where I reflected on my feelings about the participants’ narratives.

While coding, I was also developing coding memos. In these memos, I noted down those codes that seemed more relevant to the focus of my research and the codes that I thought needed further clarification. My coding memos also included comparisons between codes created in previous interviews and suggestions for codes I should check and refine, maybe combining or splitting in different ways. Thus, after finishing coding each interview, I reviewed my notes and refined the codes that had been developed so far. Although this process was time-consuming, it ensured that I was constantly comparing and contrasting interviews and helped me to refine my list of codes progressively. All these memos and note-taking for transcripts and coding processes were done in a notebook. This immersion and the familiarity I developed with each participant’s story and the intense comparison process contributed to the credibility of the analysis (Charmaz, 2014).

As my initial interviews were mostly with self-employed mothers, I opted to analyze the interviews in three main groups – self-employed mothers, CLT mothers, and CLT fathers. When I finished the initial coding process for the first group, I engaged in the focused coding stage, organizing the most frequent and salient codes into large
categories and subcategories (Charmaz, 2014; Saldaña, 2021). I used NVivo colors to classify these broader categories and the top-level codes to organize codes into subcategories. After finishing the second group of interviews, I conducted a second cycle of focused coding, refining previous codes, categories, and subcategories before starting the next group. I followed the same process with the third group. This process helped me manage a large number of codes and insights. Moreover, I used NVivo’s case classifications to compare existing codes for each of the three groups. After completing these two cycles of focused coding with all three groups of participants, I moved to a more conceptual level of analysis, which I describe in the next subsection. Table 1 provides an example of selected categories and subcategories after this initial coding process.
Table 1

Example of Selected Coding Categories and Sub-categories

<table>
<thead>
<tr>
<th>Categories</th>
<th>Description</th>
<th>Selected sub-categories</th>
</tr>
</thead>
<tbody>
<tr>
<td>Societal beliefs</td>
<td>Participants’ perceptions about social roles, Brazilian culture, the labor market, and the corporate world.</td>
<td>Ableism, Patriarchy, Work in corporate, Women cannot have it all</td>
</tr>
<tr>
<td>Barriers at work</td>
<td>Barriers participants experienced at work to accommodate care demands</td>
<td>Competitive and masculine environment, Fear of being seen as a poor soul, Uncaring organization, Uncaring leader, Judgmental peers</td>
</tr>
<tr>
<td>Facilitators at work</td>
<td>Elements that helped participants to accommodate care demands</td>
<td>Caring leaders, Family-supportive organization</td>
</tr>
<tr>
<td>Caring needs</td>
<td>Participants report about their caring demands and their need to provide adequate care</td>
<td>Exceptional care demand, Managing exceptional care, Being close, Educating people, Self-care needs</td>
</tr>
<tr>
<td>Challenges</td>
<td>Impacts and challenges participants experienced for parenting a PWD</td>
<td>Emotional impact of the diagnosis, Maternal overload, Maternal guilt, Impacting work</td>
</tr>
<tr>
<td>Learnings</td>
<td>Participants’ narratives about how they changed as individuals and professionals after becoming parents of PWD and what they have learned from their experience</td>
<td>Attention to D&amp;I, Becoming a better person, Becoming a better leader, Resilience and problem-solving, More flexible and tolerant</td>
</tr>
<tr>
<td>Perceptions about work</td>
<td>Participant reports about their values and perceptions about work, career, and success</td>
<td>Meaning of work evolves, Initial meaning of work, Reframing work, Reframing career, Reframing success</td>
</tr>
<tr>
<td>Process</td>
<td>Career decision-making process, influencing factors, and outcomes</td>
<td>Planning to become a mother, Organizing care to keep paid work, Reducing work after diagnosis, Making career decisions with partners, Questioning status quo, Adjusting work to make it work</td>
</tr>
</tbody>
</table>
**Transitioning to conceptual coding**

After the initial and focused coding process described in the previous sub-section, my next step was returning to my notebook and revisiting my memos. Memoing intensely during data coding was crucial for identifying core categories, relationships, and variation patterns (Clarke, 2012). Following Charmaz’s (2014) guidelines, I generated a diagram using post-its (Figure 1). In this diagram, I organized my main categories to illustrate the different career decisions the interviewees made across their professional lives, including categories representing the key influencing factors and the main outcomes of these decisions. Going back to codes and memos, I also identified how the three defined groups of participants navigated through these decisions differently. This process helped me to confirm the initially noted differences between the three groups.

**Figure 1**

*Development of Conceptual Coding Diagram*
As a next step, I scanned my memos and code descriptions again to look for inconsistencies and missing pieces. This process added more details to my explanations and additional connections, which are represented in my diagram by notes made with markers and additional post-its. Lastly, I started the writing process, which was also an exercise of organizing and explaining the relationships among the main final categories. The outcome of this process was an explanation of how parents of PWD think about the relationship between their different life domains and how they make career decisions and engage in career development actions.

During the process of data collection and analysis, it was essential to maintain a critical stance and observe how my beliefs and experiences interweaved my data analysis and interpretation. Exploring different perspectives and interrogating opposing values are critical elements in the GT method and must be considered to develop a robust and rigorous analysis (Charmaz, 2014). Therefore, it is important to expose my positionality and reflect on how it may have influenced my analysis and report.

**Researcher Positionality**

It is paramount to position myself as part of my research population. I was born in Brazil and lived there for more than forty years before moving to the U.S. I am married and a mother of two young adults (20 and 18 years old). My youngest daughter was born with a rare syndrome that causes cognitive, developmental, and physical disabilities. Her care involves constant supervision, specialized medical appointments and some therapies, specific and expensive medication, and frequent interaction with the school.
I have always been a working mother. During my professional life, mainly in the HR field, I underwent several career changes, starting as a management strategy consultant, followed by an experience as an organization development manager in the corporate world, then as a self-employed independent consultant, and later as an entrepreneur, running my own consulting and coaching business. My career changes were influenced by a desire to learn new things, a necessity for flexibility and control of my schedule, and a wish to keep my employability in the long term. Although my first career change was pretty much an individual decision, all other changes were made in a joint discussion with my husband. Likewise, he also discussed his career change with me. Our decision to move to the US when he received a job offer was a family decision and included a discussion about my career, the plan to start a doctoral program, and trying an academic occupation afterward.

Another important aspect is that I am part of a privileged group. I am a cis, hetero woman, and white, considering how I identify myself in the Brazilian context. Although I was born into a working family in Brazil, I had access to good private education, which allowed me to achieve higher education degrees and access good employment options.

My interactions with other caregivers of PWD, primarily through disability associations, showed me that families’ experiences and how they make sense of their situation vary as intersectionality comes into play. Moreover, different values and ideologies strongly influence social role expectations, family ideals, and beliefs about disability. As a feminist researcher, being conscious of my values, ideologies, and beliefs is paramount to the rigor of my investigation and, importantly, ensuring respectful and caring interactions with my participants. Additionally, although my position as a mother
of PWD helped me develop rapport with my study participants, the fact that I was pursuing a doctoral degree might have raised different feelings and reactions and contributed to the often-common power imbalance in the researcher-participant interaction, influencing their responses. I strove to make my participants feel comfortable and ensured they also had any questions related to the study answered. I am aware that my positionality might also play a role in my analysis. For this reason, I registered my own career trajectory and decision-making process in one of my initial memos before advancing in the analysis of the interviews. Additionally, maintaining my research diary and the specific individual memos after each interview was instrumental in identifying and registering my personal feelings and judgment of each situation, serving as a strategy to keep myself honest about my potential biases (Peshkin, 1988).

**Ethical Considerations**

A critical aspect of ethical research is clearly understanding how it will contribute to a better world (AHRD, n.d.; Creswell & Creswell, 2018). While it is still important to generate awareness of the challenges these parents face and the lack of support they receive from their families, employers, communities, and governments, describing their experience is not enough. Various studies describe these parents’ experiences, mostly bringing a scenario of struggles and distress, which is, unfortunately, an authentic portion of their lives (Brown & Clark, 2017).

In this sense, I wanted to ensure that this study also aimed to uncover aspects of these parents’ experiences that are not well explored and that I believe can contribute to
their well-being and promote healthier work relationships and work environments. I intentionally asked about the learnings and noticed the transformations these caregivers went through as they navigated their career decisions, managed their professional lives, and advocated for their children’s care. I also aimed to investigate how organizational practices hinder or facilitate these parents’ professional development and how organizations can be more supportive and promote the importance of care as a social practice. I hope investigating these aspects helps parents of PWD view their experiences through new lenses. Furthermore, I communicated these expected contributions in my study materials and exchanges with participants so they were aware of the reasons driving this study and the relevance of their participation.

Attention to research ethics was critical during the data collection stage. It was essential to be critically aware of how my positionality put me simultaneously as an insider and outsider to the group and how this position fostered a sense of shared experiences but also might have created power imbalances (Hale, 2016; Johnson-Bailey, 1999). In all interviews, I introduced myself as a researcher and a parent of a PWD. I used my initial interviews to assess how my positionality was being received and to refine my approach (Creswell & Creswell, 2018). I attempted to interact with my participants with integrity, demonstrating respect for their stories, values, and choices (Creswell & Creswell, 2018; Johnson-Bailey, 1999).

For some participants, sharing their career stories brought memories of challenges, hardship, loneliness, and discrimination. Often, the interview got highly
emotional. In these moments, I offered them a pause, checked if they were okay with continuing, and thanked them for their openness. Thus, the interview process required a lot of care and respect, and it was not uncommon that we laughed and cried together as I saw different parts of my life trajectory represented in their narratives, and I could relate to their feelings. The purpose of this study was never to explore the suffering, and I hope my questions focusing on possibilities, development, and learning were helpful to the participants. In general, I received positive feedback from them.

Additional strategies that I applied to ensure an ethical study were stating my research objectives at the beginning of each interview, checking their understanding of the process, and confirming again their agreement with the informed consent and with the recording of the interview. I also asked if they had any questions about the contributions of the study and the use of the data. Moreover, memoing intensely throughout the process was also essential to keep me aware of participants’ reactions and necessary adjustments.

Ethical principles are also crucial in reporting research findings. I want to ensure that my writing is done with consideration for these caregivers’ trajectories and the individuals they care for. Asking for input from participants, academic peers, and disability rights advocates will be an important step (Creswell & Creswell, 2018) when communicating my findings to broader audiences in the future. Additionally, an essential aspect of realizing my research contribution is sharing my findings with various stakeholders – parents, caregivers, disability and gender equity advocates, grassroots institutions, policymakers, organizations, and scholars. To do so, I plan not to limit my
writing to this dissertation and academic publications. Following Creswell & Creswell’s (2018) recommendations, I plan to write my reports in English and Portuguese and use appropriate language for different audiences. I also plan to connect with disability and gender equity grassroots institutions to offer my findings to support their advocacy activities. Lastly, I will send reports to fellow HRD practitioners and OD consultants to instigate the discussion around the topic.

Chapter 4: Findings

This chapter presents the findings of my study, and it is organized into eight sections to provide insights that help answer the central research question: How do parents of PWD develop their careers to attain work-family integration in the Brazilian context? One important forewarning is that quotes from interviews and my explanations of findings might contain ableist language. Some of the parents interviewed declared that they were raised in an ableist society and are still in the process of learning and transforming their own beliefs. I grew up in a similar environment, and as much as I am committed to being an anti-ableism advocate, I apologize in advance for any ableist content in my writing.

The first section provides a general description of the three main groups of participants. Describing these groups and their defining characteristics is essential to explain the differences in how they approach their careers to accommodate care and paid work. The second section explains contextual elements of the Brazilian culture and society as perceived by the participants and which influenced their career decisions. The
third section describes exceptional care and its demands, and the fourth section reports the challenges these parents experience because of both care demands and context. The fifth section discusses the role work plays in these parents’ lives.

While the first five sections of this chapter provide relevant information to understand these parents’ context and needs, section six provides a detailed response to the study’s central question, exploring the decision-making process that mothers and fathers undertook to handle care demands while guaranteeing their ability to work. This section encompasses sub-sections discussing the different decisions they took, influencing factors, and outcomes of these decisions. Section seven illustrates these parents’ learnings with their experiences. The chapter concludes with the eighth section exploring how organizations contributed to these parents’ experiences and decisions.

Overview of Participants

In total, 27 interviews were included in this study: 19 mothers and eight fathers, all of them in heterosexual relationships when their disabled children were born. Most of them remained married to their partners, but six were divorced. There was only one couple among the participants, but they were interviewed separately. These parents’ age varied between the mid-30s and late 50s. Half of the participants had only one child, and the other half had two, with their disabled kids’ ages varying in an extensive range, between four and 23 years old, at the time of the interview. Disabled kids have a variety of diagnoses, including Cerebral Palsy, Down Syndrome, Autism Spectrum Disorder (ASD), and rare syndromes (AADC Deficiency, Kleefstra Syndrome, Lissencephaly,
Prader-Willi Syndrome, Pitt-Hopkins Syndrome, and Spinal Muscular Atrophy), all requiring moderate to intense levels of care.

When considering how to accommodate care work and their professional lives, some characteristics of the participants shaped their decision-making processes in different ways. The first notable difference was related to gender. Both women and men had an initial implicit belief that family care was a female concern. Although this belief was softer in a few couples with a more gendered-neutral approach to family roles, it influenced their career decisions and outcomes. In general, women naturally worried about the impact of having kids in their professional lives, and some of them made changes to their work schemas in preparation for becoming mothers. Conversely, the idea that becoming a parent could impact their professional lives was not raised by any of the interviewed men. While experiencing exceptional care shaped all participants’ relationships with work and career decisions, it happened in significantly different ways depending on gender.

The second difference was the type of work these participants had when their disabled child was born. Almost seventy percent of the participants in the study worked in long-term contracts regulated by Brazilian Consolidate Labor Law (CLT)\(^3\) by the time their children were born or diagnosed. This group includes four public servants with additional benefits such as job stability and the possibility to work part-time while maintaining their integral salary\(^4\). The other thirty percent of the parents were self-

\(^3\) The Consolidation of Brazilian Labor Laws, called CLT contract in Brazil, regulates the rights and duties of employers and employees and includes important guidelines for caregiving, including maternity and paternity leaves, protection of pregnant women employment, social security, and pension.

\(^4\) Law 13.370 from 2016 grants a reduced working schedule (usually around 20-50% reduction) to Federal public servants with disabilities and their caregivers (spouses and parents), with no impact on
employed women, usually working on temporary hourly-based contracts or entrepreneurs running their own businesses. For these self-employed mothers, the ability to manage the number of hours they worked led more often to decisions to reduce or interrupt work for some time after receiving their children’s diagnosis. Additionally, at the time these women became mothers of disabled kids, most of them were married to a partner who was able to financially support the family for some time as the only income in the household.

On the other hand, professionals working under CLT contracts for private and public organizations had a different experience. For them, reducing their working hours was rarely a possibility, and rescinding their long-term contracts had important financial implications for the couple due to the compensation and benefits package, particularly health insurance, as well as a perception of job stability. All these parents kept their jobs after their children’s diagnosis and relied on their partners (mostly wives with more flexible jobs or who did not work), parents, and paid caregivers to help with exceptional care needs. In this group of CLT working parents, gender played a significant influence as women and men made different decisions while experiencing exceptional care. These two notable differences resulted in three groups: *self-employed mothers*, *CLT mothers*, and *CLT fathers*. These groups are briefly described in the following three sub-sections.

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compensation. Exceptional care needs to be proven by an official medical board. Since 2022, this law also applies to public servants in all Brazilian states and cities.
Self-employed mothers

This group includes nine mothers of children with developmental disabilities and intense levels of care. At the time of the interview, these women were between their mid-30s and late 50s. All of them were married to the father of their disabled child, except for one who was divorced. Half of them had more than one child, and their disabled kids’ ages varied between four and 23 years.

The women in this group were self-employed professionals and entrepreneurs in the fields of psychology, education, and law. As self-employed, they had considerable flexibility in defining their work location, schedule, and workload. Nonetheless, this flexibility was limited somehow by their need to accommodate client needs and ensure a reasonable income, not to mention their desire to develop their businesses and develop themselves as professionals. Consequently, decisions around how much time they could dedicate to their work impacted their financial outcomes and professional development.

All these mothers assumed most of the care work, including making decisions about treatment, scheduling and accompanying their kids to medical appointments and therapies, interacting with school and health providers, and arranging care logistics. Some of these mothers made a conscious and negotiated choice with their partners, while others naturally occupied the place of primary caregiver, primarily because of a combination of factors: beliefs about gender roles, the flexibility of their work, and lower income and benefits compared to their partners.

Although many of these mothers reduced their workload after their disabled kid was born or diagnosed, most of them made arrangements to keep working. While, at times, the intensity of exceptional care has taken a toll on their ability to care for
themselves, their relationships, and their careers, most of them felt that, after some time, they had reached a good spot and were able to manage care and paid work in a satisfactory way. Nevertheless, they emphasized the cyclic nature of this balance, given that their care needs and work conditions changed over time, and new arrangements were always needed.

Most of these women felt that they had evolved professionally and reported being satisfied with their trajectories. Working for them is essential for their personal fulfillment and ability to provide good care for their children. Many mothers sought to satisfy their needs for professional growth by engaging in education and professional training, especially when they felt that their child-caring schemas were organized. They shared their plans to keep developing professionally, advancing their education, and perhaps creating new businesses where they can include their adult kid in the future.

### Table 2

*Background of Self-Employed Mothers*

<table>
<thead>
<tr>
<th>Alias</th>
<th>Marital status</th>
<th>Background and current occupation</th>
<th>PWD age</th>
<th>Summary of professional trajectory</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bianca</td>
<td>married</td>
<td>Education - owns a language school</td>
<td>11</td>
<td>She was not working when her kid was born. She started working at a reduced capacity after three years as a self-employed service provider to schools. Later, she became the owner of a language school.</td>
</tr>
<tr>
<td>Paula</td>
<td>married</td>
<td>Law - runs her own legal office</td>
<td>12</td>
<td>She had a well-established law practice with a partner when her daughter was born. She interrupted her work when her child was born and resumed at a reduced capacity after six months.</td>
</tr>
<tr>
<td>Alias</td>
<td>Marital status</td>
<td>Background and current occupation</td>
<td>PWD age</td>
<td>Summary of professional trajectory</td>
</tr>
<tr>
<td>-------</td>
<td>----------------</td>
<td>----------------------------------</td>
<td>---------</td>
<td>------------------------------------</td>
</tr>
<tr>
<td>Lucia</td>
<td>married</td>
<td>Education - service provider to schools</td>
<td>11</td>
<td>She had her own business (school) when her child was born and kept working at a reduced capacity. School closed due to COVID-19 impacts. She was seeking flexible but more stable job opportunities.</td>
</tr>
<tr>
<td>Irina</td>
<td>married</td>
<td>Psychology - therapist and research coordinator</td>
<td>4</td>
<td>She worked two jobs when her daughter was born - research coordinator and therapist. She organized care work and resumed her professional activities at a slightly reduced capacity. She had recently started a doctoral program.</td>
</tr>
<tr>
<td>Erica</td>
<td>married</td>
<td>Psychology - therapist and researcher</td>
<td>6 and 9</td>
<td>She kept working at a slightly reduced capacity as a therapist and researcher. She invested in her own clinic to have more flexibility, and sometimes, she had to put her research on hold. She was preparing to start a doctoral program.</td>
</tr>
<tr>
<td>Lilian</td>
<td>divorced</td>
<td>Psychology - therapist and lecturer</td>
<td>12</td>
<td>She kept working at a slightly reduced capacity as a therapist. She got divorced and sought more stable jobs. Worked in a hospital and a college to complement her income. She was working as a lecturer and therapist and starting a doctoral degree.</td>
</tr>
<tr>
<td>Laura</td>
<td>married</td>
<td>Psychology - therapist</td>
<td>13</td>
<td>She worked as a teacher at a school and as a therapist and stopped working to assume care work. After five months, she went to work part-time in her mother’s business for some time and slowly resumed her practice as a therapist. Currently working as a therapist with a busy agenda.</td>
</tr>
<tr>
<td>Mel</td>
<td>married</td>
<td>Physical education - personal trainer</td>
<td>6</td>
<td>She interrupted her work as a personal trainer for about two years. Resumed at a reduced capacity when her students asked her to return. She was planning to become a nutritionist for families with rare syndromes that require a specialized diet.</td>
</tr>
<tr>
<td>Gabi</td>
<td>married</td>
<td>TV &amp; radio production - retired</td>
<td>23</td>
<td>Worked as a TV producer but became a self-employed teacher when she decided to have kids. Kept working self-employed at a reduced capacity after her son’s birth. Went back to TV for financial reasons and worked fulltime for a long time. Had a burnout after a change of supervisor. Left her job after and retired.</td>
</tr>
</tbody>
</table>
**CLT mothers**

This group includes ten interviews with women between mid-30s and late 50s years old with kids with disabilities and moderate to intense levels of care. Their disabled kids’ ages varied between 5 and 18 years old at the time of the interview. Three of them were divorced, and all the others were still married to the father of their disabled child. Half of these mothers had more than one child. They all worked as full-time employees for organizations under the CLT regulation when their kids were born or diagnosed.

These mothers kept their full-time jobs and assumed most of the care work management, defining therapeutical schemas, interacting with school and health providers, arranging care logistics, and managing paid workers. Most of them counted on their husbands, parents, and domestic workers to execute part of the care work. Although a few of these women had their husbands doing a fair amount of work, this was different from the general rule. As a result, these mothers felt the impact of accumulating care and paid work on their mental and physical health, reporting high levels of stress and feeling guilt for not dedicating enough time to their children. For most of these professionals, the dynamics of organizations, leaders, and peers significantly impacted their professional decisions. Also, stable salaries and good benefits heavily weighed their decisions to maintain their corporate employment for some time, even in unideal situations.

Over the years, these mothers reviewed their care and work arrangements. Some left the corporate world to become self-employed professionals with more flexibility and autonomy, others kept their jobs as full-time employees in more supportive organizations, and others fluctuated between these employment modalities according to their caring and financial needs. Two of these mothers were public servants benefiting from their right to
work part-time while maintaining their integral salary. Overall, having flexibility, working remotely, contracting paid care workers, having family support, and sharing care with their husbands were the main factors that enabled these women to keep their jobs.

Despite the challenges and sometimes the back and forth between work modalities, most women from this group reported feeling well about their careers and professional lives. They kept their desire to develop and evolve, and finding jobs that would fulfill these desires was often as important as having flexibility. Most of them reached top-level positions or gained recognition in their fields. For these women, maintaining their jobs was vital for their ability to provide good care, guaranteeing income and health benefits. Moreover, for them, work is a place where they find self-realization and feel valued as professionals and individuals.

**Table 3**

*Background of CLT Mothers*

<table>
<thead>
<tr>
<th>Alias</th>
<th>Marital status</th>
<th>Background and current occupation</th>
<th>PWD age</th>
<th>Summary of professional trajectory</th>
</tr>
</thead>
<tbody>
<tr>
<td>Elena</td>
<td>divorced</td>
<td>Education - therapist and influencer/speaker</td>
<td>8</td>
<td>She quit her job as a full-time teacher after one year of exceptional caregiving to start a self-employed career as a therapist. She was finishing her doctoral program and applied her research and motherhood experience as a D&amp;I speaker and influencer on social media.</td>
</tr>
<tr>
<td>Sandra</td>
<td>divorced</td>
<td>Communication and public relations - lecturer and consultant</td>
<td>18</td>
<td>Worked for eight years in organizations while caring for her daughter. Quit her job to pursue academic degrees and a more flexible career. She was working as a lecturer and D&amp;I consultant.</td>
</tr>
<tr>
<td>Olga</td>
<td>divorced</td>
<td>Psychology - HR professional, coach, and therapist</td>
<td>12</td>
<td>Worked in corporate for many years, then ventured into self-employed as a coach, therapist, and consultant, seeking flexibility. She went back to work in organizations for</td>
</tr>
<tr>
<td>Alias</td>
<td>Marital status</td>
<td>Background and current occupation</td>
<td>PWD age</td>
<td>Summary of professional trajectory</td>
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<td>----------------------------------</td>
</tr>
<tr>
<td>Carla</td>
<td>married</td>
<td>Psychology - HR professional</td>
<td>9</td>
<td>Worked as an HR professional in organizations for a long time. She kept her work in the corporate world when her disabled daughter was born, but with time, she crafted a position where she could work remotely and have more flexibility.</td>
</tr>
<tr>
<td>Jade</td>
<td>married</td>
<td>Psychology - HR professional</td>
<td>13</td>
<td>She changed jobs a couple of times but always worked in organizations. Had a burnout in her last position and was fired. Considered becoming self-employed but accepted a new position in a more supportive organization after negotiating for flexibility.</td>
</tr>
<tr>
<td>Daniela</td>
<td>married</td>
<td>Law - contracts executive in an organization</td>
<td>15</td>
<td>Worked in corporate for a long time while her husband assumed most of the care work. Quit for a combination of reasons (maternal guilt, exhaustion, and low job satisfaction) and paused working for eight months. She went back to corporate in a remote position.</td>
</tr>
<tr>
<td>Lorena</td>
<td>married</td>
<td>Law - partner in a legal office</td>
<td>5</td>
<td>She grew her career in a law firm and reached a top leadership position. She was dissatisfied and considering a job change but was afraid of not having similar flexibility in a new job.</td>
</tr>
<tr>
<td>Fatima</td>
<td>married</td>
<td>English language - senior executive in a large corporation</td>
<td>17</td>
<td>She worked in corporate all her life and had a VP position in a large company. Delegated care work to a robust net of paid workers and praised herself for not feeling guilty and not letting motherhood impact her career.</td>
</tr>
<tr>
<td>Tais</td>
<td>married</td>
<td>Engineering - state auditor</td>
<td>9</td>
<td>Started her career in consulting. Applied to become a public servant, aiming to have a less intense job to care for her kids. She regretted her decision and fulfilled her needs for development by pursuing advanced education. She was working at a reduced capacity and finishing her doctoral degree.</td>
</tr>
<tr>
<td>Lola</td>
<td>married</td>
<td>Pharmacy - project manager for a research institution</td>
<td>9</td>
<td>Worked as a researcher until she received the diagnosis of her son during pregnancy. Moved to an administrative, less intense, and part-time job. Regretted her decision and experimented different fields. Finally, she settled as a project manager.</td>
</tr>
</tbody>
</table>
**CLT Fathers**

This group includes eight men between 40 and 60 years old at the time of the interview. They had disabled kids with ages varying between 5-23 years old and moderate to intense levels of care. Two of them were divorced, and all the others were married to the mother of their disabled child. Half of these fathers had more than one child. They were all working in long-term CLT contracts for organizations when their disabled kids were born. Five of them were still working under similar conditions at the occasion of this interview; one was unemployed, and two had become self-employed professionals, although not necessarily because of their disabled kids.

With few exceptions, most of these fathers would execute specific parts of the care work while their spouses managed the overall care plan. For example, they would attend some medical appointments and share the commuting to therapists and schools. They explained that their wives assumed most of the care work because they had more flexible jobs or were not working when their kids were born. Fathers who engaged in a more significant part of care work did so because their spouses had solid careers and contributed equally or more to the couple's income.

Some of these fathers reported becoming more cautious about their career movements, avoiding risks to maintain their stable income and health benefits. Many felt that the care needs of their children limited their career opportunities. Although some of these fathers had made risky job changes in moments of critical childcare needs, including quitting their jobs to move to a different city or country with better care options, in general, the impacts of exceptional care in their careers were less intense with brought fewer consequences when compared to interviewed mothers who experienced
financial drawbacks and significant changes in their field of work or modality. Overall, many of these fathers reported feeling accomplished with their careers, while a few declared being more focused on maintaining their jobs and enjoying their lives.

**Table 4**

*Background of CLT Fathers*

<table>
<thead>
<tr>
<th>Alias</th>
<th>Marital status</th>
<th>Background and current occupation</th>
<th>PWD age</th>
<th>Summary of professional trajectory</th>
</tr>
</thead>
<tbody>
<tr>
<td>Igor</td>
<td>married</td>
<td>Advertising - director at an advertising agency</td>
<td>12</td>
<td>Grew his career in advertising agencies and was in a top position when his disabled son was born. After some months, he was highly stressed with his son’s diagnosis and intense work and decided to quit his job. Worked as a self-employed consultant for some years, sharing care work with his wife. Accepted a job in an agency to ensure more stability.</td>
</tr>
<tr>
<td>Danilo</td>
<td>married</td>
<td>Management - supply chain manager</td>
<td>13</td>
<td>Grew his career as a supply chain professional. After her daughter was born with a severe rare condition, he focused on preserving his job. He has been working in this organization for 17 years and has more flexibility than his wife; thus, he executes a lot of care work.</td>
</tr>
<tr>
<td>Bruno</td>
<td>divorced</td>
<td>Engineering - R&amp;D executive in a large corporation</td>
<td>18</td>
<td>Had a fast-tracked career with heavy workload and intense travel routine. His wife assumed care work as she did not work. He made a risky career move when his child needed a specific care provider but kept growing in his career. He divorced and moved to the US and keeps financially providing for his kids and ex-wife while she continues caring for them.</td>
</tr>
<tr>
<td>Eduardo</td>
<td>married</td>
<td>Engineering – currently unemployed</td>
<td>9</td>
<td>Worked for 20 years in the same company, achieving leadership positions. Decided to move to a different country with better conditions for their kids’ development. He was doing a master’s degree and considering new work possibilities.</td>
</tr>
<tr>
<td>Alias</td>
<td>Marital status</td>
<td>Background and current occupation</td>
<td>PWD age</td>
<td>Summary of professional trajectory</td>
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</tr>
<tr>
<td>Jonas</td>
<td>married</td>
<td>Dentistry – auditor for the state</td>
<td>9</td>
<td>Worked as a dentist for some years while studying to become a public servant. He wanted to pursue a career as a public servant because of the payment and stability. Got a position as state auditor and reached the top of his career. He has significant flexibility and does not envision future changes.</td>
</tr>
<tr>
<td>Silas</td>
<td>married</td>
<td>Law - legal director for the municipality</td>
<td>5</td>
<td>Worked as a lawyer for a few years while studying to become a public servant. Moved to various cities due to his work and has reached the top level of the public servant career track. His focus was on preserving his job.</td>
</tr>
<tr>
<td>Greg</td>
<td>married</td>
<td>Engineering – owner of a consulting business</td>
<td>20</td>
<td>Had a fast career growth, reaching top positions in large companies and in different countries, working and traveling a lot. Quit his job in Europe and moved back to Brazil due to his son's caring needs. Started his own business as a consultant, keeping his intense working rhythm. Shared being an absent father in the beginning but feels more present in the family life in the last years.</td>
</tr>
<tr>
<td>Marcos</td>
<td>divorced</td>
<td>Engineering (incomplete) – leads his own business and has a social enterprise</td>
<td>23</td>
<td>Grew his career as a salesperson. He quit his job once to move to a different city because of his child's health needs but quickly started a new one. He became well-known in his field and changed jobs a couple of times, always negotiating flexibility so he could be closer to his daughter. He is currently running his own business and developing a social enterprise.</td>
</tr>
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</table>

**Brazilian Context from the Interviewees’ Perspective**

Participants discussed the Brazilian context as they reflected on their career decisions and experiences. In general, the main characteristics of the Brazilian culture and social contexts raised by the participants were related to patriarchy and ableism. The
patriarchal culture shaped these parents’ beliefs about gender roles, the impact of parenthood on parents’ careers, and the options (or lack of) they have about their professional lives. Another aspect of the context that significantly impacted the career decisions of these parents is related to beliefs about work and careers in corporations. Lastly, almost all participants saw themselves as privileged individuals compared to the average Brazilian population. Although some of them were raised in mid-low social classes and were first-generation students in college, they all have college degrees and declared themselves to be of medium-high socioeconomic status. This privileged social-economic condition defined the choices these caregivers had when deciding about their careers. In the next sub-sections, I describe these contextual factors in more detail.

**Patriarchy**

The impact of the Brazilian patriarchal culture showed up in most women’s accounts when they discussed their unequal amount of care work compared to their male counterparts. They explained that Brazilian society, including their families, husbands, employers, co-workers, and often themselves, see care work as a feminine role. Elena summarized:

The woman, having a child with a disability or not, is the one who cares, who takes care of the children, takes care of the partner, takes care of the parents, the in-laws, the people who fall ill in the family, the people who have health problems.

Lola explained that Brazilian men are not taught to care:
We marry the children of other women who may not have been as aware in their
time. So, we choose a husband who, despite being deconstructed, is that guy who
often doesn’t know how to cook, who isn’t familiar with a broom.

Interviewed men also saw this belief reflected in society – “Women, in the place
society has assigned to them, are the ones who have the duty to care, which is not
required of men.” (Silas). Eduardo, when commenting that his wife assumed most of the
care work, justified:

   Besides, without any type of sexism, I think the mother has a better emotional
condition to deal with [health and care] professionals. Anyway, I think the
mother’s affection is more, like, it is not that the father doesn’t have affection, not
that the father doesn’t have this type of attribution, but the mother has a natural
kind of care that I think makes more sense for her to be closer, right?

Although many of the interviewed mothers were critical of the social gender role
attribution, they believed that motherhood necessarily impacts women’s professional
lives because part of their time is dedicated to caring for someone. Some participants
concluded that women “can’t have it all” and saw this as a ‘choice’ women must make,
particularly if they want to be in the corporate world. Fatima, a well-accomplished
executive, explained:

   Women get exhausted; there is no way. So, I say, or you accept that you won’t be
a supermother, right? Because some women want to be, which is a choice you
must make in life. Either you’ll be a super mother or a super executive.

Patriarchal culture is also reflected in their perceptions and lived experiences of
sexism in the corporate world. Many of the CLT mothers reported working in
predominantly masculine environments. Pregnancy is considered a risk for these women’s careers, which drives many women to plan their careers considering their wishes to become mothers or plan their pregnancies according to their career status. Jade recounted situations she witnessed of female employees being dismissed after returning from maternity leave. Tais shared comments she heard when she was pregnant with her second child, “Wow, she got a job as a public servant to have kids! [She] had the first and is already pregnant with the second!” Lorena, pregnant with her second child and considering changing jobs, had little hope of getting an offer while pregnant. A perception that Sandra corroborated with her own experience:

I participated in a selection process, and I found out I was pregnant, […], then, in the final stage of the process, I was going to be interviewed by the executive, so I told the HR person [about her pregnancy]. On the interview day, they blew me off; I waited for one hour and a half. It was surreal! She could just have said, ‘Don’t come,’ right? But I think they didn’t want to disclose that they would not hire a pregnant person.

Interviewed men validated sexism in the Brazilian corporate environment, sharing situations of discrimination and harassment – “I saw situations, actually, I heard about some misogyny cases in the court. People that don’t like women because women can take [maternity] leave, you know?” (Silas). Igor shared that cases of moral and sexual harassment were common in the marketing agencies where he worked in the past.

Although the more recent experiences of interviewed parents give some hope about how organizations and leaders are dealing with the caring needs of their employees, some stories still show how the patriarchal culture disregards care in the corporate
workplace. Accounts of meetings scheduled after regular working hours, lack of planning to cover maternity leave, and leaders complimenting mothers who did not allow their motherhood to impact their work were common in the narratives of many CLT mothers. Lorena indignantly recounted when her boss told her, “Everybody is praising you because you didn’t let your motherhood mess with your work.” She continued, “I can say this to myself. My boss cannot say this.”

The perception of organizations’ lack of understanding of universal caring needs was also a belief held by self-employed mothers. Bianca, who runs her own business, shared:

For me, it [running her own business] means peace of mind, you know? I don’t need to keep wondering if they [employers] believe in me. Do they? Because I think people who work in institutions may have doubts […]. Because with so many things that happen to your kid, and to a disabled kid, even more stuff happens, perhaps this employer, this employer would say something like, ‘no, it is not possible that this woman makes up so many stories about her daughter’s health.’ So, I’m not making up stories for anyone. It is like this: if I’m not working, I’m with her. And, if I go to the hospital [with her daughter], I’m still answering WhatsApp, email, or whatever, and everything is fine.

Differently, many interviewed fathers perceived organizations’ reactions towards care as natural. Eduardo explained:

Private companies want to take out the most of it, right? […] I did not have the openness in my firm to say, ‘Look, I want a reduction in my working hours because I need to drive my son to therapy.’
Work and Careers in Corporations

In the interviews, participants shared common beliefs about work and careers in the corporate world. These perceptions came from their own experiences or experiences they witnessed happening with work colleagues, friends, and relatives and impacted their professional decisions. Two central beliefs were frequently mentioned: ageism and an expected time frame for career growth.

The belief that organizations are ageist, i.e., discriminate against people over a certain age, was present in many of the participants’ accounts – “The working age [in the corporate world] has a deadline, right?” (Bianca). This perception was often brought up when interviewees were talking about their plans for the future, as Sandra shared:

I know that in four or five years, they will fire me because I’ll be 45. I will be too old for the organization, you see? At that time, this was the deadline, right? 45 years old. Now is even less, right?

Although ageism was more present in the accounts of mothers, men also shared this concern, as Greg mentioned when he decided to quit his job in a multinational to start a career as an independent consultant, “I said to myself, if in two years I don’t succeed, I will find a job again. I was, we are talking about 2006, I was 38 years old, I was still marketable.”

The second belief was that the corporate world has its own time, and if you do not grow in the hierarchy or make certain career moves, like expatriation, within that time frame, you are at a disadvantage. Some mothers believed that if they could not follow the expected organizational career growth, it was more advantageous to be self-employed where the slow pace or even work interruptions were less damaging than in corporate
careers. As Bianca explained the family’s decision to relocate to a different country because of her husband’s job – “In the corporate world, or you do that [expatriation] at the moment it [the offer] happened, or this will go away, and you lose the timing.” On that occasion, Bianca was starting a new business and decided to interrupt her plans.

The career time expectation also happens in the academic setting, as Lola reported:

That is the reason you have such gender inequality, particularly in the health field. Because everyone wants to see what you did in your past five years. I had one year, I don’t know for sure, let’s say one year of not doing anything professionally since I had six months, an additional vacation month, so seven months in maternity leave, together with all adaptations in the final months of my pregnancy [when she discovered her son’s disability]. Thus, you get stuck for a year, which does not reflect only in one year; it reflects in more than one because [academic] articles did not materialize from one day to the next.

Fathers also shared this perception about the ‘corporate pace.’ Danilo, who shared that for a long time, “I couldn’t even write a CV, ah, how will I think about my professional career,” reflected:

I know my career is spoiled. I know this. I could be in a different place, so now it’s done. It won’t be in this life. […] So now what I want is to be happy in my work, like, if I am happy, doing, accomplishing, doing my stuff. If this pace that society asks for, I don’t have, or not that I don’t have, but I go in a different way, a different pace.
Ableism

Ableism is defined as discrimination against people with disabilities. These parents shared their own experiences of recognizing themselves as ableists, describing the shock of receiving the diagnosis and not knowing what it meant. Lola shared:

When we find out, we are still ableists. And I’m not saying to you that I’m not. I’m a person under construction, in deconstruction to rebuild myself. I think that when we receive this news, we are caught by surprise, and we think it is the very devil, right? Because we live in an ableist society.

Lorena told me that before her son was born, she had “never seen a person with Down Syndrome.” She added, “I didn’t know what a disabled person was, what that meant. For me, in my mind full of prejudice, a disabled person, a person with Down Syndrome, would be a baby for the rest of their life.” Parents reported that this unfamiliarity and ableism make the adaptation and acceptance of their children’s diagnoses much harder.

These parents also shared that their experiences as parents of PWD made them more attentive to ableism. They reported observing ableist situations in their kids’ schools, their working environments, and even in their own families. For example, Laura worked as a teacher in a private elementary school before becoming a mother of a disabled child and witnessed ableism. She quit her job at the school right after her daughter’s birth, “At the moment that I got the diagnosis, I had a special child; how would I work in a school like that?”

Importantly, these testimonials reflect how PWDs in Brazil are still segregated from social life, not allowed in many schools, and not welcomed in the workplace.
Prevalent ableism in Brazilian society contributes to the worries of many of these parents as they consider their kids' future and their ability to live and work. On a positive note, many parents took it as part of their mission to help fight ableism. Some actively engaged in advocacy and activism, while others proactively disclosed their child’s diagnosis as a way to normalize and educate people about disabilities. Bianca shared:

I’m engaged in the inclusion movement in many ways. My husband is a member of the D&I committee at the company where he works. I think this didn’t happen by chance in our lives. I think we started to see that inclusion made sense, and we fight for the inclusion of all people, of all kinds.

**Acknowledging Privilege**

Overwhelmingly, interviewed parents acknowledged their privileges when compared to other families with disabled kids. They saw themselves as privileged for having jobs with good salaries and benefits, financial conditions to pay for reasonable medical treatments, and the option to interrupt their work for some time to care for their children. Privilege also appeared when they shared about having the support of their organizations and leaders, which they did not see as the norm. Lorena, who considered herself a very privileged person, said, “I don’t know other people with stories like mine. It is not the majority. It’s a minority.” Marcos highlighted how being an accomplished professional with recognized expertise made him a privileged person when negotiating flexibility with his employer: “In any way, I had something [his expertise] to give in exchange, right? A blue-collar worker doesn’t have; he is a replaceable piece. It’s something very cruel to observe.”
Having family support and being married to a partner who shares some of the care work was also seen as a privilege, given the sad situation in Brazil, where many mothers of PWD are abandoned by their partners (Lourenço, 2021). Lola reflected on her situation, “I’m in a zone of comfort and privilege, but this is not, without any doubt, the reality of motherhood and disability. And there is more; my husband shares this [caregiving] with me.”

As these parents got in contact with the realities of other families of PWD, often through support groups, they realized their many privileges, and even with all the challenges they faced, they would put their struggles in perspective, as Lorena’s comment demonstrates:

Despite the fact of the Down Syndrome, which is obviously an emotional burden, a financial burden, a time burden, D. [child’s name] does not have any typical complications related to Down Syndrome. He does not have heart problems, he does not have renal problems, he doesn’t have problems in his pancreas, he does not have cataracts. He doesn’t have anything, anything beyond Down Syndrome and intellectual disability and all the demands of therapies.

**Exceptional Care and its Consequences**

This section brings parents’ testimonials about the caring demands of PWD, also called exceptional care (Stewart & Charles, 2021), and it is relevant because these demands differ significantly from standard care for children without disabilities. The intense, cyclic, crises-driven, and life-long care demands that exceptional care encompasses shaped these parents’ career decisions since it elicited an inescapable
concern about their kids’ health and future and required additional time, effort, and skills from them. Notably, besides exceptional care, many of these parents also reported other caring demands that are common in the lives of most adults, including caring for elderly parents and self-care.

These parents’ care demands were lively observed during the interviews, with several peculiar interruptions – “And actually, she [disabled daughter] is here, you know? She decided to stay here. She is lying on the floor, looking up to me and listening to the conversation” (Carla); “Let me just listen to the audio [WhatsApp audio message] that the physical therapist sent, I’ll be quick” (Elena); “He [her disabled son] wants to know how old you are” (Gabi).

**Exceptional Care - Intense, Cyclic, Crises-Driven, and Life-Long**

Aligned with findings described in many studies about exceptional caregiving (Brennan et al., 2016; Crettenden et al., 2014; Jang & Appelbaum, 2010; Stewart, 2013), participants in this study also expressed similar characteristics when narrating the care demands due to their children’s disabilities. Examples of the intense care demand were frequent in all interviews, from the full schedule of therapies – “Equine therapy, physical therapy, speech therapy, occupational therapy, all, a lot, five times per week” (Olga) – to support with everyday activities – “She needs to turn sides during the night, so I always, all my life, I was the one helping her during the night. She calls five, ten, fifteen times per night” (Marcos). Paula shared that her daughter needs supervision 100% of the time: “She can’t stay alone; she always needs to have someone supervising her.”

The crises-driven characteristic of exceptional care emerged as these parents described the impacts on their work routines. Danilo recounted the many times they had
to go to the hospital with his daughter, “She was hospitalized many times due to respiratory issues, also urinary infections.” Gabi shared that as crises happened without previous warning, “I had to leave [work] and rush to the [name of the hospital].” Igor, who told me that he recently had to leave a working meeting to attend a crisis at his son’s school. He pondered, “I can’t have my life completely taken [by work commitments] because a crisis, sometimes a crisis emerges, and it takes time.”

These parents also acknowledged the cyclic characteristic of exceptional care and reported learning to “live a semester at a time, instead of a long-term planning” (Mel). Tais explained how the cyclic characteristic makes exceptional care different than typical parenthood:

My daughter’s [care] demands were changing. We can’t look at a disabled child and say, oh, in four years, life will be this way, we can’t. This is the catch of atypical motherhood\(^5\). While in typical motherhood, you look and say, oh, in four years, he will be in this age range, and you have a parameter, in atypical motherhood, you don’t have this parameter; thus, you cannot plan four years ahead.

These different cycles required adjustments in their care schemas, the amount of necessary support, and, at times, re-arrangements in the parents’ professional lives. Depending on the type of disability, caring demands may stabilize or even reduce, although crisis might always be present, and some support will always be needed. As

\(^5\) Atypical parenthood is a popular term in Brazil to describe the experience of parenting a person with disabilities.
Lilian shared, “He is 12 and has less [caring] needs; he also gets sick less frequently than when he was younger, all the viruses, etcetera. But he is still a person who demands.”

Lastly, and present in almost all interviews, was the acknowledgment of the life-long caring need – “It is not a transitory condition, it is not something that will be cured next week. It’s something permanent. It’s a condition to be cared, probably, for the rest of her life” (Danilo) – which is also a key difference from typical parenthood and result in a significant change in the way many of these parents think about their careers and future, as Eduardo explained:

One clear thing is that even if we do all the necessary stimulations, with speech therapists, special educators, anyway, all these therapies that a child with special needs require, we know he will depend on us for the rest of our lives, right? So, this completely changes the way we plan our future.

As explored in the following sub-section, thinking about the future was a highly emotional topic for these parents.

**Fear of the Future**

The life-long caring needs and the uncertainties about these children’s ability to live independently when adults represent an enormous worry for most families. These parents were worried about ensuring a source of income if their kids cannot work and make a living for themselves and when they are too old to keep working. Therefore, guaranteeing stable jobs and long-term employability becomes paramount for many of these caregivers. Moreover, because of these children’s cognitive and developmental disabilities, many of them will likely need assisted living support, which in Brazil is still a limited and costly option.
Some of these parents dreaded thinking about the future and who would care for their children when they were deceased. Carla confessed:

Many nights, many nights asleep, crying. How will my daughter’s future be? […]

It’s an additional concern; geez, what if I die? And if I do, how it’s gonna be for her when I die? Truly? Because this will happen.

Irina also shared her fear of death:

My only fear, which I think is the fear of all mothers of kids with disabilities, or atypical mothers, is what is going to happen when we die, right? […] The only thing I fear about my future is this. Like, what will happen to him if I have a stroke tomorrow?

This concern made many parents consider their health and quality of life when making professional decisions. As Olga, who was also caring for her terminally ill elderly mother, explained, “I lost my dad very early in life, so she [her mother] raised us three and always neglected her self-care.” She continued, “We must care for our mental health, we must ourselves so we can be well to [care for] them, right?” These parents also worried about who will care for them when they are older and need to be cared for – “I care for my mother. My daughter won’t be able to care for me. My daughter will need someone to care for her forever” (Lucia).

Interestingly, although fathers also worried about the future, they were less vocal about fearing it. Nevertheless, Danilo, who assumes a significant part of his daughter’s care, contemplated:
My daughter is often hospitalized; we know that a person in this condition, like, if the natural cycle of life happens, she will go before me, right? Anyway, even because if I go, who will care for her? We need to think about this, right?

**Managing Exceptional Care Demands**

Despite the enormous challenges of exceptional care, it seems that, after some years, these parents incorporate the crisis, intensity, cyclic, and life-long aspects of exceptional care and develop a managerial approach. Tais asserted that she sees herself as a “managerial mother.” She added, “I started to see myself as the manager of that [her daughter’s] life […] For things to work long-term for her and for me, I need to be a manager. She likely will never have a hundred percent autonomy.” These parents expressed that organizing the care schema involves a set of activities, from identifying needs in partnership with the medical team, which commonly includes primary care and several specialists, selecting therapists, arranging therapy schedules, contracting paid care support, organizing commuting to therapies and school, dealing with school and teachers, helping with socialization, not to mention the initial tortuous phase of investigating and confirming a diagnosis. Bianca, who was not working when her disabled kid was born, laughed out loud when telling me that “in no moment I felt like I was not working because it was a lot of work!” She talked about recruiting and managing a team of care providers, “it is indeed managerial work.”

A well-organized and functional caring schema, which included family support, paid care workers, receptive schools, and a good team of health professionals, was critical to these parents’ ability to dedicate time to their work and professional development. Tais commented on her decision to put her doctoral studies on hold for some time:
I took a six-month block of time to dedicate to that project – organization and structure – my daughter. So then, I could have peace of mind to take two months to myself [to prepare for qualification exams and resume her studies].

These parents employed their managerial abilities to keep care work functioning; as Fatima described, “I’m extremely organized, her [daughter] calendar was all tidy. She always arrived on time, in the clinic, in the swimming class.” Erica also shared, “It is all timed; otherwise, it wouldn’t work.” Along the same lines, being in a city or neighborhood where they could access inclusive schools and have the support of their families and other paid caregivers was also a critical factor influencing job changes. Irina, who has help from her mother and a nanny to care for her son, confessed that without this support, “It would be impossible [to work].”

On the other hand, the importance of maintaining a well-organized caring schema posed barriers to career changes. Danilo shared that he and his wife turned down more than one offer to assume new positions in different countries:

How would we do? Which country would offer similar conditions? [...] Because here, for the good or the bad, we have this structure settled, and we manage it. Now there [a different country], we would have to rethink it all.

Conversely, in some situations, organizing the necessary care schema prompts non-ideal career changes, such as when Greg decided to quit his job in Switzerland and move back to Brazil, where he believed the health system and the support network would be better for his son’s needs.

The cyclical caring needs provoked frequent necessary rearrangements of the caring schema. Some parents emphasized that being closer to their kids was essential
during some of these caring cycles. This was a critical factor in some of these parents’
decisions to interrupt, reduce, or change work to more flexible or remote options. Olga
left a successful career in an organization to become self-employed when her daughter
needed additional support. She summarized the outcomes of her decision: “She
d[daughter] had an incredible progress, notable in her development.” Equally, Jade, who,
after being dismissed from a job, decided to look for new opportunities slowly and be
closer to her son, shared, “I oversaw his studies, I went with him the therapies, I followed
the therapists’ recommendations at home. It was a period when M. evolved a lot, a lot.
His development was significant.”

Lastly, with time, these parents also felt more empowered to recognize their limits
as care providers, more comfortable contracting specialized support, and less guilty for
investing in their professional development and careers. Danilo reflected, “With time, we
build an ecosystem to support us.” He continued, “M. has her life, and her life is her life.
Thus, I can’t let her life become my life or our life. If I let this happen, I will be done.”
Nevertheless, achieving this empowerment did not happen without the many challenges
described next.

**Challenges of Exceptional Care**

The challenges parenting a PWD brought to the personal and professional lives of
the interviewed parents are similar to what has been discussed in many studies (Brown &
Clark, 2017; Crettenden et al., 2014; Gordon et al., 2008; Jang & Appelbaum, 2010).
Receiving a diagnosis and dealing with the demands of exceptional care generated
emotional, physical, and financial challenges, which impacted these parents’ ability to respond to the demands of their work and influenced their career decisions.

*The Emotional Impact of the Diagnosis*

Before discussing how parenting a PWD impacts the professional life of these parents, it is essential to discuss the impact of noticing that “there was something different” (Bruno) with their kids. For many of the interviewed parents, having their kids’ diagnosis frequently involved an arduous period of medical investigation, especially in the case of rare syndromes. While some parents received a diagnosis early on or even during pregnancy, some parents endured a series of exams and visits to different medical specialties; as Greg recounted, “We went to, I think, like, fifteen specialists within two weeks.” Many parents invested their time searching for information online – “I was doing all the research” (Erica). Moreover, visiting the various expert physicians and doing specific exams incurred high costs and endless battles with health insurance providers. Tais summarized her memories of this period:

It is different in the case of cerebral palsy or Down that you recognize right away. So, it is all that process: two sessions, a genetic test... And the mother, gosh, is exhausted from that fight with the health plan.

Undoubtedly, receiving a diagnosis of a rare syndrome or the news that your child has a disability is dreadful for mothers and fathers. These parents described receiving the diagnosis as a clear cleavage in their lives. Gabi took a deep breath before sharing:

Then life turned 180 degrees and went the other way. I think it was not 180 degrees; maybe 90 degrees. I changed directions. I didn’t come back; I didn’t get to come back. I moved on but in another direction.
The diagnosis is often received as a shock – “I don’t even remember it clearly; it was like a hurricane” (Igor) – and many parents needed some time to process and react. Irina shared that in the weeks after she received her son’s diagnosis, “I cried every day, I was down,” and it impacted her ability to work for a while. Jade confessed that it took her and her husband some time to start talking about their son’s condition, “We took a long time, you know, to talk openly about the diagnosis, even in our house, because it was tough to accept it.” She mentioned that her husband got severely depressed and needed a medical license from his job for some time.

Naturally, the emotional impact of getting a diagnosis was reflected in these parents’ relationship with their work. Some of them declared not even thinking about work during those moments – “After the diagnosis, everything lost any sense,” said Mel. She blew “swoosh, flew in the wind. So, for me, it didn’t matter if I was working or not.” Others automatically thought about the impacts of that new situation on their professional lives. Olga remembered:

When I got B.’s diagnosis, I thought about the impact on my work. I actually remember the date when I got her diagnosis. My sister, the first thing she told me was: ‘You will have to think, rethink your work.’ It was the first thing she told me, ‘You’ll have to rethink your work, you’ll have to dedicate yourself to her, she will need help.’ Thus, not only did I think about it [the impact], but others surrounding me thought, too.

Although the emotional impact of receiving a diagnosis softens as the years go by, there is a constant worry about their kids’ health and their ability to provide good care. Some parents reported an elevated level of stress, particularly in moments when caring
demands are intense. Igor recalled, “The first year, I remember, was very hard, psychologically, and the second year, the second and the third year, logistically very hard.” Some parents report not having the mental space to deal with anything else; as Tais summarized her mood in the months before a critical surgery that her daughter went through, “feeling like, man, let the world blow off; I don’t know if my daughter will survive.”

After the initial shock of receiving a diagnosis, these parents started an intense journey of medical treatments and therapies, which, in most of the interviewed families, was managed by mothers. The following sub-section describes maternal overload, a critical challenge these mothers had that reverberated in their stress levels, health, and their work and careers.

*The Caring Women, Maternal Overload, and Guilt*

From the 27 interviews, most of the caring work was done by the mothers, even when they worked on full-time contracts. Therefore, in the vast majority of the interviewed families, mothers suffered a significantly higher impact on their careers than their partners. In rare exceptions, the father was executing most (1 out of 27) – “I have a husband who is a true partner, he does it, he does what he has to do” (Daniela) – or an almost equal part of care work (3 out of the 27) – “So we, we talk about it, we share between us. Last Sunday we were organizing November and December calendar, who will do what […] This is ongoing. It’s draining” (Igor).

In general, mothers made most of the decisions about the care schema. They often hired someone to help, distributed part of the care to their partners and other relatives, and executed part themselves. Elena lamented, “I never stop. My mind doesn’t stop.
Because, even though S.’s father is super proactive, like, I’m the one managing everything.” Sandra exemplified:

I did all the managing, like, I would say, ‘I need you to take her to the physician this month. But you need to ask this and that,’ so I mean, I had tripled my mental load when I asked him to take her.

Most fathers would help when needed or asked for – “Of course, when she couldn’t do, I would replace her” (Eduardo); “When it was needed, or when it was something important, he always would go” (Jade) – or would assume part of the caring responsibilities as long as they did not interfere with their work routines, as Laura explained: “The equine therapy, my husband takes her at seven or eight in the morning because then it so it doesn’t mess with his schedule.” Olga joked:

If we look at the whole, I always did a bit more, let’s put it this way. But he is super hyper-collaborative. He is the father who helps. Ops! We say we should not say this, but yes, he is the father who helps.

Some mothers saw this as natural, as part of the patriarchal culture – “The heaviest burden stays with the mother, here, here in my house, that’s the way it is” (Paula). Others rationalized the unequal distribution of care work:

So, actually, what happens is that, like, there is a reality, like, the fact that he is a physician, he obviously earns more than I do, right? So, like, one hour of his work is much more valued than mine. So then, I don’t even think there is a question of gender, but it is more a matter of occupation, right? So, it’s much more common that I have less professional availability than him. Thus, driving him [the son] to the therapy, to the doctor, this is totally on me. (Irina)
Another noticeable aspect of the interviews with mothers was the feeling of guilt many experienced, which was almost nonexistent in the experiences of the interviewed fathers. Once more, patriarchal culture contributed to this guilt. Some mothers talked about the cultural belief that the mother may be responsible for their children’s disability. Lilian explained that “the autistic spectrum was, even within psychanalysis, it was very linked to the mother, that the mother failed, so there was a, so it was very problematic, it was problematic to deal with these questions.” Carla shared, “I went through several stages to accept that it was not my responsibility, not my fault.” Additionally, they highlighted the societal expectation that mothers should dedicate their lives to their children. Irina recounted her mother-in-law saying that, “I worked a lot and that he [son] didn’t speak because of television and all that stuff.”

Although patriarchal values reinforced the role of women as primary caregivers, these mothers recognized how important it was for them to feel that they were dedicating time and caring for their kids. Lucia declared, “Because there is part of me that understands the importance of having time to care for other things, care for my daughter, care, I don’t know, about other things besides work, you know?” Therefore, these mothers were constantly struggling with the allocation of time to care and time to work, particularly those in full-time jobs. Lola explained the conflict:

Like, sometimes M. wants to nap in the afternoon, but he has therapy. Then I think I also wanted him to sleep because then I could work a little more, but it is not possible, right? And we always need to be vigilant because there is pressure on ourselves that, like, one month without therapy will impact his whole life. I already learned that it is not like this. But still, we have all this pressure, a heavy
pressure, right? I think when a mother is born, guilt is born together, a bag of guilt that never empties.

As most of these mothers assumed the care work and kept their professional lives to some extent, they emphasized the burden of this double shift. Paula shared, “It is an accumulation of functions; it is exhausting.” Many fathers recognized the onus in their wives’ lives. Marcos got emotional sharing about a time when he assumed all the care work:

Then I understood what it was to be A.’s mother, and it was, it was tough because I realized what a terrible father I was, right? […] Geez, that woman had to do all that, and I couldn’t see. How did she manage it?

In the next section, I describe how parenting a PWD sometimes affects these parents’ mental and physical capacity to work. It is important to mention that interviewees also shared the personal development and learnings they acquired from their parenting experiences, which are discussed in another section of this chapter.

**Impact of Parenting a PWD on Parents’ Ability to Work and their Careers**

Although parenting a PWD had positive long-term effects on these parents’ professional lives, as described in a future section, the demands of exceptional care sometimes impacted these caregivers’ ability to function properly at work and make career plans. Danilo shared his frustration, “It was all too much; I did not have time to think about this [career] in my life.” The impacts on these parents’ work productivity often led to financial downturns.
Some interviewed mothers who worked as therapists or educators reported challenges that they had initially due to the constant comparison with other children. Irina, who was working on a research project about child development, shared tearfully:

So, I got there to evaluate the babies, and the babies did a thousand things my two-year-old son could not do. So, like, sometimes, in the middle of the assessment, I had to leave. I cried, and I went back. So, the first [assessments] were dreadful. Later, I got better.

Mothers who assumed most of the care work and worked in organizations with less flexibility or support reported being diagnosed with burn-out, “then I said, it’s enough. I don’t know. Because I started having memory problems. That’s where the burnout got me” (Gabi). Jade, who was fired while suffering burnout, shared:

I had a severe burnout, and I did not notice it. I worked a lot, and I could not deliver anything. I felt extremely tired; I could not sleep, I had insomnia, I was not well. Anyway, in the end, I was dismissed.

Stress and depression also impacted the productivity of some fathers. Eduardo remembered, “I went through a period of, I was, like, very, very discouraged. Wow, I was very, very discouraged, without energy.” Sometimes, stressful moments impacted these fathers’ performance. Danilo lamented about a difficult moment with his daughter, “Then you have a hot head; I went to discuss a very sensitive matter with the vice president, and I was very unprepared. Then I messed up; they lowered my evaluation.”

For both men and women, the care demands of their kids undermined their financial prospects. For some mothers, this was a consequence of reduced working hours
due to care work demands. Irina, who works as a psychotherapist, felt a negative impact during the COVID pandemic:

For example, I can’t see a patient at eight pm anymore. Thus, we know that during the pandemic, there was a boom [increased demand for therapy], and my practice did not grow because it was when my son was very young.

Some mothers who left their corporate jobs to become self-employed professionals and have more flexibility felt the impact on their financial stability. Sandra shared, “It was ok; I managed to get by. I had a financial reserve, and then, soon after, I started teaching, earning much less, of course.” Olga reflected on the unpaid care work, “In a moment when all I did was for her, I reduced my working hours. But no one was paying me for this other work [caring]; nobody was paying me.”

Some fathers reported that parenting a PWD affected the speed of their career growth and, consequentially, their financial potential. They mentioned that they were willing to accept some work situations they would have previously argued about – “you get to swallow some bitter pills” (Danilo). Eduardo commented that he “stopped taking risks.” He added, “At that moment, I started thinking more about stability than growth.” Jade shared a similar perception about changes in husband’s career:

In the sense of taking his foot off the gas. And, like, accepting more some things. He didn’t risk too much so he wouldn’t lose, do you understand? […] I would say that maybe, not that he is not happy or feels accomplished. Yes, he grew and achieved a nice position in his organization, but it took him longer. Because I think he worked very gradually to ensure more stability, you know.
Only three out of the 27 parents declared they did not see an impact on their work and careers: two men who had reached the top positions in public servant careers and one top executive woman who affirmed that she consciously chose to focus on her career and delegate care work. Curiously, she also shared a conversation with one work colleague, “He said, ‘Fatima, now I know why you achieved this position […], it’s because you think like a man.’ So, I said, what? I don’t know if I take this as a critique or a compliment.”

It is undeniable that parenting a PWD brings challenges to these parents’ professional lives and their physical and mental health. However, as described in the next section, work is crucial for them for both affective and objective reasons.

**The Importance of Work**

The interviewed parents expressed that work holds a significant place in their lives as it is an essential aspect of their identities. They shared a common need to feel productive, useful, and evolving through their work. Many connected this importance of work to their parents, as Lucia explained: “I always had a strong link with career, with work. My mother is an executive, like, my parents are people who work, working people. I think that my brother and I, we had an education for work”. Moreover, most participants came from families where having both mother and father working was necessary to ensure a reasonable income and life conditions.

When talking about their professional lives, these caregivers identified their work with a vocation and underscored a desire for self-realization through continuous learning, development, and growth. Many had an affective connection with their work; as Lilian
declared, “Psychology has been an eternal love. I would say passion, but it is not passion. It’s love, long-lasting love.” Sandra told me about the role work had in her life:

I always thought about growing professionally, being able to do many things, getting to know many people, and getting to know many places. It [work] is like a passport to the world, you know? I thought my work would have this role in my life. And it had in a certain way.

Becoming a parent of a PWD did not change the affective importance of feeling productive and attaining self-realization through work. Erica, who has two disabled kids, commented, laughing, “I can’t stay still. I do several things at the same time, various projects, and I keep having ideas and keep producing, producing, producing.” Silas confessed that he “always enjoyed working, always.” Mel, who is considering a new career, shared her plans, “I want to study again […]. I always enjoyed studying, and now I’m missing it.”

For those mothers who interrupted their work for some time to care for their disabled kids, resuming their careers helped them to recover their self-esteem and professional identities. Paula stated that her work “is when I think about myself. It is when I remind myself of the professional, the woman, everything.” She continued, “This space that work provides is rewarding for my self-esteem and my personal life. It is necessary.” Irina explained how important it was for her to keep developing professionally:

I felt valued again, you know? Professionally, as a mother, I saw that people had faith in me. Because I didn’t have so much faith in myself anymore. Because, like, when the diagnosis came, a sentence followed, like, I’m going to dumb
myself down because I won’t be able to cope because I’ll have to stay with the boy all around. And I think what happened is that I got into this vibe, and I was depressed. So, I’m one of those people who, when they start to get down, swamp in work to survive. Yes, my work is my fuel.

The concrete benefits of work are also critical to these parents’ ability to provide the care they need for their children. Daniela, who endured a long period in a job that she did not cherish nor feel valued, voiced, “I needed the money, even though that [job] was not what I wanted. Still, I had an excellent health plan, which weighed a lot given that it was so expensive.” Sandra explained:

You end up needing to build a supporting net, and it is a net that requires money, requires organization, requires everything. So, I said, I can’t stop working. If I stop working, I lose money, I lose everything, it’s over.

Additionally, for those women who reduced their working hours and consequently their salaries, keeping some work was critical to safeguard some financial independence; as Erica shared, “I went back to work because I am a very independent person. I want to have my money; I want to have my life.”

Last but equally important to all these parents, work represented the possibility of taking a break from exceptional caregiving. This interview passage illustrates this point:

Gabi: There is a phrase I used to say to my husband. Sometimes, depending on the situation, we used to say, ‘ok, tomorrow is Monday, we will have some rest at work.

Researcher: [laughing] Yep, I say the same many times.

Gabi: Right? We rest at work.
Mel added that even when the work was not ideal, having these moments of escape from exceptional care was imperative: “It was the possibility to be in another environment, one not dictated by [son’s syndrome].” She added:

Not because I was leaving home to work again. Not financially, I mean, it was good, that was good, but it was even better because I was not in that place, in that function, which was my function 24 hours a day.

Given the affective and objective importance of work for all these parents, despite the challenges, they made several career decisions and ongoing arrangements to maintain their professional lives while caring for their disabled kids. In the next section, I describe the decision-making process, the main factors influencing these decisions, and their outcomes.

**Careers Decision-Making Processes of Parents of PWD**

The interview process aimed to uncover parents’ decisions throughout their professional lives, starting with their first job after graduating from college. The goal of this retrospective was to identify how these decision-making processes changed after the event of their childbirth or diagnosis. Figure 2 illustrates the main career decisions these parents described in their interviews.
Although both men and women made early career decisions (A) in similar ways, the type of career decisions they made started to change when they initiated conversations about marriage and parenthood (B). Women were expressively more likely to make career decisions based on plans to start a family. Moreover, after the diagnosis of their kids, while a few couples engaged in discussions about how to provide the necessary care, most often care work was assumed by mothers due to a combination of established gender roles and the fact that they had lower salaries, more flexibility, or both (C). Career decisions made post-diagnosis aimed to accommodate exceptional caring needs (D) and were often made without much ponderation given the emotional charge of the moment.
In general, career decisions post-diagnostic (D) differed for the three participant groups: CLT men, CLT women, and self-employed women. Self-employed women tended to make more significant career changes after their childbirth or diagnosis. In contrast, CLT men did not make any changes to their careers in the aftermath of the diagnosis. Nevertheless, many of the interviewed fathers would make an abrupt career decision when faced with a critical crisis in their children’s health (E). Later, after some experience with exceptional care, parents, particularly mothers, engaged in an ongoing decision-making process to find a more satisfactory integration of paid work, care work, and other life activities (F). This ongoing process encompassed questioning their status quo, considering other possibilities, rearranging care and work, and reframing their beliefs about work and career.

In the following subsections, I describe these six decision-making processes, how they were made, which factors influenced these decisions, and their immediate consequences.

**Career Decisions Before Parenthood (A)**

Most participants started their careers in areas related to their field of study, and most also started as full-time employees in organizations under the CLT regulation. Some of the women interviewed started as self-employed, and some also kept more than one part-time job while establishing their practices as independent professionals. Two men
interviewed began their careers working in their fields while studying for the public servant exam⁶.

While some participants shared the professional dreams they had, like Bruno – “I had this idea that I would like a job in a multinational company where I could have the opportunity to travel and have some experience abroad” – and Sandra – “My dream was to get a job at the United Nations and live abroad” – the majority confessed that they did not have much clarity on their professional future. Jonas shared, “I was young, like, I didn’t have many plans, solid plans. I had just left college. I just wanted to get into the job market.”

Participants reported working intensely in the early years of their careers. Daniela, who started her career in a prestigious consulting company, shared, “So, I worked a lot. I worked late every day.” They also reported evolving quickly in their career, as Bruno shared, “I had a speedy growth and ended up leading an international project.” Likewise, Gabi told me, “By the age of 23, I was already in a managerial position.” Many participants connected their excessive work rhythm to the fact that they did not have a family at that time; as Carla explained, “I worked like crazy. I was single, I had a boyfriend, but I was single, I did not have kids.”

During these initial years, better salaries, ascending job positions, and growth opportunities were the main drivers of job change. Carla justified why she left a job in an organization she liked: “It was a better salary in an organization where I would have more authority, more autonomy, more responsibility.” Igor explained the several job

⁶ In Brazil, individuals who want to pursue a career as a public servant must apply and be approved in a written examination (Concurso Público - Public Service Entrance Exam) besides attending other specific requirements according to the position they are applying.
changes he made before his son was born: “It was a very heated [job] market. We received offers.” He continued, “So we stayed, like, stayed for one, two years, then an agency contacted you and raised your compensation significantly.” Nevertheless, some participants would also change their jobs because of toxic organizational cultures, as happened to Sandra: “I started looking for a job because I was unhappy there; it was an unhealthy place.”

Early career decisions were generally made individually and focused on career growth and financial accumulation. Nevertheless, this pattern changes for some of these professionals as they start to make marriage and parenthood plans, as described next.

*Let’s Have a Baby! Family Plans Shaping Career Decisions (B)*

A relevant change in how participants made career decisions was noticed when they initiated plans to marry and start a family. From then on, most participants began considering their partners’ careers and the potential necessary life adjustments to have kids in their professional decisions. Further, some of them started discussing career decisions together as a couple. Although both men and women started to look at the implications of their career decisions from a family perspective, none of the men interviewed considered or made any changes in their professional lives in preparation for parenthood. Conversely, women reported worrying about the impacts of motherhood on their careers and making significant changes in preparation for motherhood.

Even before getting married or having kids, the career decisions of many of the women interviewed were affected by the professional decisions of their male partners. For example, Lorena worked in a law office in Rio de Janeiro when her boyfriend was admitted to medical school in São Paulo. He told her about his plans to stay in the new
city, and they agreed that she would quit her job and move with him. She shared her conversation with her former employer: “Look, I need to move to São Paulo. I love to work here. I enjoy working with you, but I made a personal option to go with my boyfriend, anyway: future plans for marriage and family.” Ultimately, Lorena received an offer to join their office in São Paulo, which resulted in a change in her area of expertise.

A more drastic change happened to Bianca. She interrupted her work as a teacher and her entrepreneurial plans when her husband was expatriated to the U.S. – “I was starting to build that school, which would be my school, together with this other teacher. I was starting. And I gave up this dream that I was starting to follow my husband.” Likewise, Mel, who worked as a physical educator in an elementary school, shared that when her fiancée found a job in a different city, he told her, “There is no possibility for me to come back. We can keep the relationship at a distance and see what to do, where we get, or you go with me.” She quit her job and moved; she rationalized, “My work can be done anywhere; I have a broad range of working possibilities. So, I decided to move. We start all over again. I’ll restart.” As they needed more income to restart life in this new city, this decision also led her to work with something she did not love initially: “So that’s when I got my clients as a personal trainer. Not that, like, wow, I love to be a personal trainer. Of course, it is good; payment is much better.”

Most women interviewed wanted to have kids, and they reported that the decision to get pregnant was planned by the couple. In general, women would consider their professional situation and the potential adjustments needed in their work routines when they had kids. Erica told me lightheartedly:
I always said that when I had my clinic, I would stay with the kids during the morning\textsuperscript{7}, and then I would work in the afternoon and evening. That’s always, it was a pre-nuptial agreement.

Lola, who was a researcher in the pharmacological field, told me:

I already had this perception that, as a mother, I would need to adjust the way I worked. So, I used to work during the weekends, and it was all right. Sometimes, my experiments had a 12-hour incubation period, and it was okay if I left the lab at midnight […]. So, I knew I would have to adjust this, and that was all right.

There is no other way, right?

Tais, who was a consultant in an engineering company, made a significant job change even before getting pregnant, as she described:

I left the company and studied for the public service entrance exam. My husband had already been admitted; he was already a public servant, and I saw that, well, it was possible to have both sides, you know? I could have the financial reward and a more dedicated life to my family.

Tais disclosed that it was a heartrending decision because she enjoyed her work and was afraid of missing the challenge and dynamic aspects of her job, as it indeed happened: “And then I made this decision in favor of a motherhood that had not yet been built. And then I faced my worst nightmare. Gosh, is there nothing to do here? Just picking up the phone?”

\textsuperscript{7} An important contextual fact is that schools in Brazil are mostly part-time, either in the morning or afternoon. Additionally, basic public schools, in general, offer a poor education, which leads most middle-class families to pay for private school.
Gabi also planned her pregnancy during a gap at her work as a TV producer “because in television it is very complicated to work while you are pregnant and everything, it is too intense, too accelerated.” During this period, she became self-employed, working as an instructor in a professional course and doing some free-lancing.

Nonetheless, for a small number of the women interviewed, motherhood was not an automatic choice and happened as a couple’s decision. Irina shared, “I always wanted to be a scientist […]. So I never thought, like, oh, I’m gonna marry, have a kid, have a dog. It never crossed my mind. These things happened, and they were always second, third things.” Fatima was blunt:

It was never my desire. I didn’t want to have kids. I’m being very sincere with you. But my husband wanted […]. So, I said, my goodness! What now? I said, ok, ok, we will have [kids]. I led him on, led him on. Until a point when I said, ‘It’s now or never,’ because I was already 40 years old.

Although discussing what makes women to include their motherhood wishes in their career planning is not the object of this study – if it is a natural caring instinct, a consequence of the patriarchal system, or a combination of both – the propensity to consider and make work arrangements to become a mother seems to set the tone to their and their male partners’ future decisions on how to manage exceptional care, as we will see next.

**Who will sacrifice the career? Deciding how to manage exceptional care work (C)**

For most parents, the moment they receive a diagnosis for their kids’ disability triggers two major interrelated decisions: How are we going to provide care for this child, and how are we going to manage work while providing the necessary care? The answer
to the first question often drives the answer to the second. Still, for most couples, there is
an underlying question: who will sacrifice their careers to manage care? This
foundational question was sometimes openly discussed, but most of the time, it just
happened.

Decisions about managing care and paid work in the aftermath of a diagnosis
were often made without much ponderation and discussion between mothers and fathers,
given the emotional charge inherent in this moment. In general, mothers assumed the
initial organization and most of the operationalization of exceptional care, either
sacrificing their work by interrupting or reducing hours or sacrificing their physical and
mental health by accumulating paid and care work. The way these decisions were made
and the factors considered varied among the different groups of parents. Still, overall,
they were influenced by personal values, beliefs about gender roles, available family
support, and the working status of these parents, including salary, benefits, job stability,
and flexibility.

Most participants reported that mothers assumed caregiving as a natural part of
life. In general, this decision was not extensively discussed as a couple; as Erica shared,
“Things were happening. So, they were happening, and we were talking, happening and
talking. And they ended up being mine [responsibility].” Greg confessed, “It was the
natural flow of life; it was not a thing; I worked, she took care of the children, let’s put it
this way.” Marcos regretted not having had a more transparent conversation with his
wife. He believes this was the main reason for their divorce, “There wasn’t an agreement.
I think this is the serious part of the story because at no point we stopped and said, look,
so what are we going to do?” In addition, some mothers revealed that they decided by
themselves to assume caregiving soon after their kids were born – “There, in the hospital, I looked at my husband and said, I’m not going back to the school, I will dedicate myself to her” (Laura); “This is what I want, I want to dedicate myself to this because I think this is now the most important thing in our lives” (Mel).

For other couples, the decision was not fundamentally based on gender roles but on income, job stability, and perceived job flexibility. Some couples had explicit conversations about this decision; as Irina shared, “This is what we do; we check who will gain more financially, and we make choices, right?” Likewise, Lucia also recounted:

So much so that the agreement that I made with my husband because he has a job that is, let’s say, in quotation marks, more stable, he has more capacity to have a structured career because he is in the corporate sector, so the agreement is that he will invest in his career and I, I will find my way.

In other couples, this decision was implied, as Jade commented,

My husband, he had a more solid career than I had, you know? […] So, there wasn’t a discussion, but it was like an agreement. Do you get what I am trying to say? So, like, he focused [in his work]. I was taking him [son to the therapies], and he was paying.

Having more flexibility – or the perception that it would be feasible to have some flexibility – resulted in mothers assuming more of the care work even when they had full-time jobs in organizations. Lorena explained that her husband was a physician, “and a physician always has to be on call; he stays the whole day away […] so I got the burden, because I have this flexibility in my schedule, to live according to my son needs.”

Similarly, Silas justified,
[wife’s name] does [care work] more precisely because she works fewer hours than I do. She is a lecturer and has only one course; she got a reduction in her workload because of M.’s disability. So, even though she does another activity that takes a lot of her time, she was working on this other activity, but, like, in terms of a formal working schedule, it is much less, right?

Interestingly, Silas, who was also a public servant, had not asked for his right to reduce his working hours. Further, he considered his wife’s research work as not a “formal schedule.”

Less frequently, couples would share care work from the beginning. Among the participants, this situation happened in couples with a more gendered-neutral approach to family roles and when both mother and father had similar jobs and compensations. Tais disclosed: “We had the same job post, same workload, same salary. So, in a certain way, we saw each other on an equal footing. Thus, everything was always divided between us.” Nevertheless, she added, “We worked as equals on the operational side, in the operation, at the planning level, equality came much later.” In only one couple, the father assumed most of the care work. In this case, he was an entrepreneur and worked from home while she had a more stable job, better income, and less flexibility – “So here it worked this way, he did the things at home. And I had one or another nanny [to help him]” (Daniela).

Besides the deeply rooted gender role beliefs, three other factors contributed to women assuming a more significant portion of care work. One is that, in Brazil, all women have 120 days of paid maternity leave, while fathers have only five days (Secretaria de Inspeção do Trabalho, 2023). Therefore, mothers with disabled kids
diagnosed when they were born already started organizing care during their maternity leaves, getting sometimes trapped in this circumstance; as Mel shared, “I had the intention to stay four to six months at home with him, which is regular maternity leave, right? And then I would go back to work. But I didn’t return [to work].” The second factor is the larger distribution of women in careers connected to care, including health and education, which, in Brazil, have lower status and compensation (Alpaca, 2022). Erica, who is a psychologist, argued: “I think that if I were a banker, then he would, like, well, what do we need to do? And then both of us would investigate, both of us would.” The third factor is that participants believed organizations are more forbearing to women than men about caregiving needs. Sandra argued when telling me that her ex-husband helped only sporadically, “I think he was not the only problem. Really, companies have a certain forbearance, but rather halfheartedly, towards mothers that they don’t have towards fathers.” Organizational culture and policies had a crucial impact on many of these parents’ decisions, as discussed in further sections.

**Career decisions post-diagnosis (D)**

Parallel with deciding how to manage the exceptional care demands of the newly diagnosed child came the decision about how to adjust work in this new scenario. Among the participants, this decision resulted in different situations, including stopping working for some time, reducing working hours, changing jobs to a less intense or one that better accommodates caring needs, and not making changes at all. Notably, there were specific patterns in the decisions made by each group of participants. Self-employed mothers reduced their working hours, and some stopped working for some time after their kids’ diagnosis, whereas most CLT mothers continued working full-time, some changed jobs,
and some reduced their working hours. Oppositely, CLT fathers did not make any changes to their jobs right after receiving their children’s diagnosis. Markedly, despite their decisions, all these families leaned on the support of their relatives and paid caregivers to accommodate care and paid work activities.

A few self-employed mothers initially interrupted their work to dedicate themselves to childcare: “The diagnostic happened, the hospitalization happened, the surgery happened. So, like, I really moved away from the office, you know, for about six months or so” (Paula). However, after a couple of months or years, they all resumed their professional lives at a reduced capacity; as Mel explained, “I returned little by little, […] And I was also organizing myself according to F.’s agenda.” Some of these mothers mentioned they went back to work because they missed it; Laura shared, “I told my husband, oh, I’m longing to resume my practice [clinic], I will go back to practice.”

Overall, self-employed mothers reduced their working hours when their kids were diagnosed. Their autonomy and flexibility as self-employed helped them adjust their dedication to work and maintain their careers. As Lilian explained:

So, we started speech therapy, occupational therapy, physical therapy, and equine therapy. And then I could organize it with my schedule in the clinic, you know? We would go [to therapies] in the morning, and I would start at the clinic later, or I would finish [work] early and take him [to therapies] in the afternoon. And so, I started organizing it.

Most of these women either had financial reserves or were married to partners who could provide financially for the couple. Nevertheless, as some of these women reported, the decision to reduce dedication to paid work put pressure on their husbands to
maintain their jobs and ensure necessary income and health benefits. Mel shared that her husband “started looking for a new position, with better pay, better health plan, which was something we needed. Actually, a job with a better health plan because the one we had was not meeting our needs.”

For CLT mothers working in organizations, decisions were different, given that most of them did not have the alternative of reducing working hours. Further, many of these women’s jobs were crucial to ensure the family could cover their kids’ health care needs. Thus, most of them kept their full-time jobs, although they reported worrying about how their children’s caring demands would affect their work and how their employers would perceive them. Olga shared, “I literally lived at the hospital for one month. So, this impacted [work]. And then I worried, you know, about how it will be or won’t be.” Consequently, these mothers strove to minimize the impact of exceptional care work in their working routines.

Anticipating this impact and fearing being unable to perform satisfactorily, a few of the interviewed CLT mothers sought to migrate to jobs with less responsibility or workload. Lola, who was an accomplished researcher, shared, “I won’t be able to, maybe within my conception, I think I will be mediocre, and I don’t want to, and I don’t know if I want to continue doing research because I don’t think I can do it.” She negotiated in her institution to migrate to an administrative position. Later, she told me it was a tough move for her, “I was completely out of my comfort zone. I didn’t have any knowledge to do that job.” As a public servant, Lola also accessed the available support for parents of PWD and reduced her work schedule without a salary reduction. Two other public
servant mothers (one whose husband was interviewed) also requested reduced working hours.

Notwithstanding, most CLT mothers kept working full-time jobs. A few mothers reported changing employers just after their child was born, influenced mainly by factors related to their children’s needs, including better salary and health benefits or reduced time commuting to work. Carla affirmed, “The salary was higher, and the health plan was very good, which was a very relevant factor to me.” The urge to accommodate care logistics influenced these decisions, even acknowledging that a job change could add some pressure to their lives, as Sandra explained:

Of course, when I went to [company’s name], I was very apprehensive, right? It was a new way of working. It had a positive aspect; it was much closer to my house. This was positive because the other company was very distant. I had to pick L. up at the daycare, so this was an aspect that impacted me positively. But, anyway, thousands of anxieties.

CLT mothers in executive positions and good salaries reported building a network of paid caregivers and domestic workers to preserve their professional lives. Additionally, because of their top leadership positions, these women declared having flexibility when needed. Fatima recalled, “I hired two nannies, one for the day and one for the night. I already had a cleaner and a driver. Thus, I had four employees in my house so I could work in peace.” Lorena followed a similar strategy:

We will have a cleaner and a nanny at home. We will live like rich people. We have money to pay, and we will do this because I want to have the peace of mind that my son is supported so I can work.
Differently, CLT mothers in middle-management positions and with fewer financial conditions had to carefully organize their children’s care schema and rely on the support of grandparents and other relatives to minimize the impact on their work. Maintaining their jobs was crucial for these mothers to ensure they could cover their kids’ healthcare needs. Managing these logistics was often challenging, resulting in a significant overload. Sandra described her intense routine:

She [daughter] had a physical therapist who would go to my house four to five times a week. She had hydrotherapy on Saturdays. Occupational therapy was at school. Huh, what else? And, like, in the way it was possible. I killed myself to fit everything in, to go to the medical appointments, to get her prescription at the hospital every month.

Many of these mothers felt they could keep their productivity levels unaffected, even with the often invisible but massive work of managing multiple care providers. Daniela shared, laughing:

I don’t think I changed my productivity level, no. I just used the telephone more to ask about stuff, call home, check on them, and ‘don’t forget this, don’t forget that.’ But no, related to work, I don’t think so. I just put some extra small things on my agenda.

The effort to avoid or compensate for the impact of exceptional care in their professional lives greatly affected their physical and mental health. Sandra commented that she overworked and tried to be an exemplar professional, and described her constant strain:
I did everything I could to avoid any problem. I did everything not to mess it up. I did everything to find a physician who would make appointments during the weekend or in the evening, you know? [...] I did everything not to be perceived as someone that was using this [her daughter’s disability] to have any type of advantage, you know?

Gabi felt the same way, “It was a concern that I had to deliver more and always more and try not to let it impact my work.” Olga shared, “It was really tough in the first year. So, I started taking prescriptions for blood pressure; obviously, my body would not bear it.”

For both self-employed and CLT mothers, maintaining their professional lives was vital not only to contribute to the family’s income but also because they saw work as an essential part of their identities – “My work, it gives me my identity, I see myself in my I work, my values” (Olga). Further, work had an important role for some mothers in the months after the diagnosis; as Erica confessed, “It was an escape.” Curiously, for some mothers and fathers, the possibility to escape from their realities at home resulted in improved performance at work, as Irina shared:

It was interesting that in my work, in my therapeutical practice, my patients had a big upgrade. Because I think that was my escape, where I was the expert and I could do my best and help my patients to develop at their best, help them.

The career decisions these mothers made in the turbulent moments after the diagnosis brought them different consequences. For self-employed mothers, the flexibility to care conflicted with their desire to dedicate more time to their careers and invest in their development. Lucia shared, “This is something that, like, I had critical
moments when I struggled, when I said, dang! Because, like, how many things couldn’t do!” Those women on fast-paced career tracks struggled with acknowledging that care work could damage their professional lives. Lorena, who spent most of the interview affirming that her son’s disability had not impacted her career, broke down when asked how the experience of exceptional care changed her as a professional:

Wow, I would say, I don’t know, wow, what a difficult question […] But I think that I, I mean, I don’t know if I also, maybe it can be an emotional thing, that I want to believe that this [her son’s disability] doesn’t make a difference. It shouldn’t make a difference, right? And, this issue, my vision that women, that being a mother and being a professional are not excluding things. I think sometimes it can be a bit instinctive to separate them naturally, to believe they don’t contaminate each other, but perhaps they do, and I just can’t see it. But I think my mind tries really hard to believe that these things don’t bother each other, and if they don’t bother, they don’t benefit from each other either.

Although these initial decisions about care and paid work impacted the professional lives of these mothers, many of them engaged in future revisions of their care-paid work arrangements, as discussed in future sections.

Remarkably, most of the fathers interviewed had not made changes in their work. All of them kept their jobs and full-time schedules, including those working as public servants who had the right to ask for reduced working time without changes in compensation. Some fathers described slightly adjusting their schedules to assume specific parts of caregiving – “As I’m a night person, the prescriptions he took overnight were my responsibility […] I mean, I arrived a bit later [at work] than I
should, but that was the only possible way” (Silas) – while others, confessed that they used their work as an excuse not to face the initial challenges of exceptional parenting – “This stage, I went through it by escaping from my reality and immersing myself into work. I think this is a very common thing, particularly among men” (Marcos).

Nevertheless, most fathers reported an increased concern about preserving their jobs to ensure income and health benefits. Eduardo shared:

We started to understand that we needed to take fewer risks and have a more stable life. This crossed my mind, the risks and opportunities that I was letting go of in my career, not only inside my firm but outside as well.

Other fathers also shared their concerns about preserving their jobs, particularly those with a supportive work environment. Danilo explained:

I’ve been with the company for 17 years. The company has changed, the people have changed, you know, but I managed to create great relationships. So, I have a huge network. Nowadays, I have to consider this, right? So, am I going to move to another company with a different culture, a different traction? So, that’s what I talk about a lot with my wife; I’m free to think and do what I want. I am free to lead. Oh, are there things that that I can’t do? There are things I can’t do. Are there things that take me a while to achieve? Yes. But, like, I’ve already developed a network, I’ve already developed relationships, right? People know me, they know me, they already know who I am. So, of course, this weighs heavily in my career decision, whether to change or not, right?

Additionally, interviewed fathers reported the many opportunities they declined because of their children’s caring needs, mainly to retain their flexibility, be close to their
families, and avoid disturbing their children’s care schema. Marcos told me about when he declined an invite to assume a top leadership position in his organization overseeing the Latin American market: “I would start traveling – Guatemala, Ecuador, Peru – sensational! – Guiana […] I thought about my life, and it was automatic. I said no, thank you.” He added, “My career could only happen where I could be there to support my daughter. So, I was offered several opportunities that I passed up.”

These fathers felt their mobility restricted because of their children’s needs. Igor concluded his interview by saying:

I just want to emphasize that, like, the [son’s syndrome name] has had a strong impact in our careers [his and his wife], strong impact. I decided not to do a lot of things because of it. Because I thought it would wreak havoc, like, it would mess up. I have the impression that often, in this journey, family stability is what is left to us.

Nonetheless, as described in the next section, some interviewed fathers made drastic career decisions to address their children’s care needs on critical occasions.

**Abrupt Career Decisions to Overcome Crisis (E)**

Many of the interviewed fathers made impulsive career decisions when facing a critical situation related to their children’s conditions and health needs. Marcos, who suddenly moved to an entirely new city, explained:

The doctor said, ‘She will die, she will die.’ So, I said, ‘But what do I need to do so she doesn’t die?’ And he told me, ‘Look, if she gets a little better, you got to leave São Paulo because the weather here is terrible; you need to go somewhere
with better weather. So, she got a little better. And then, we got our clothes, got in the car, and went away. [...] Like, I didn’t care, you know, about the company.

Marcos shared that he tried to negotiate with his employer to continue working remotely in this new city but was unsuccessful. Nevertheless, he quickly found a new job opportunity. Likewise, Bruno described his decision to accept a position in a smaller company and a different field on an occasion when her daughter needed a specific and costly therapy that was not offered in the city where they lived: “It was a big risk, my career was evolving very well, it was very consolidated at [former company’s name],” he added, “So it was like, well, excellent salary-wise, but in terms of professional risk, it was a move that perhaps I wouldn’t have made if I hadn’t had that set of issues pressing me.” Indeed, as he told me later, it was a frustrating career move, yet he was able to find a better opportunity some years later.

Other fathers also left their jobs to try new things in risky movements. However, their decisions were more influenced by dissatisfaction with their former careers, potentialized by the experience of exceptional parenthood. Eduardo was feeling depressed and worried about his ability to provide good care to his son in Brazil. Thus, he decided to quit his job and start a new life in Canada:

In short, I left a 20-year career in an organization where, despite having all the risks of a private company, I was in a very comfortable situation. I literally got completely out of my comfort zone with the perspective of offering safer conditions to my kids.

At the time of the interview, Eduardo was doing a master’s degree and evaluating new career opportunities in the corporate world or as an entrepreneur.
Despite these drastic changes, most of these fathers kept growing professionally. Their narratives indicate that, after leaving their jobs, most of them went back to a similar working style, intense and full-time, and with very few exceptions, these fathers did not change their participation in care work after this change. Moreover, some fathers benefited from the period after change to implement career plans or experiment with some possibilities. For example, Greg, who quit his job in Europe after a difficult situation with his son and decided to move back to Brazil due to the country’s health care system, shared that he decided to put in place his plan to open a consulting business. Igor mentioned, “During this period, I took the opportunity to test various projects I had in mind and things I wanted to do.”

Later in their careers, they reported negotiating for some flexibility – mostly remote work – to be close to their children when they needed to or, in some cases, to split care work with their wives. Most believed their solid performance and established trusted relationships with their employers gave them this flexibility. Bruno commented, “Because I’ve always put a lot of effort, they trusted me.” Marcos, who changed jobs a couple of times, driven mainly by compensation and growth opportunities, shared that he always negotiated health insurance and flexibility. He exemplified:

When I joined [company’s name], I said, ‘Look, I won’t have a schedule; I won’t follow this way. I’ll have my way. I have a lot of contacts; I have a strong network here. I can help a lot, but not your way.

Interviewed fathers talked less about the future. Still, some of them shared a concern about keeping their employability in the long term. Eduardo commented that this changed how he thought about his career planning, “I have to keep in mind that I need to
have longevity and conditions to support my son way longer than I would have expected.” Igor also shared a similar concern:

I’m constantly thinking about when I’ll be 80 [years old]. So, this guides my decisions. The decision to stay in this job. The decision to stay in a place that offers certain stability, even the decision to, perhaps, go back to teaching, because it is an extra income […] I always joke that it’s also another vine; if everything goes wrong here, I’ll cling there.

To sum up, fathers’ career decisions seemed more focused on preserving their ability to provide financially for their families. While they reported that parenting a PWD had imposed some restrictions and triggered some unexpected career moves, most of them grew in their professional trajectories and attained a satisfying situation.

Differently, as described in the following sub-section, women’s professional trajectories included more questioning and rearrangements.

**Continuous career decisions to integrate work-life (F)**

Over the years, these parents engaged in other career decisions. While most of the fathers followed the pattern described in the previous section, many mothers engaged in an ongoing decision-making process where they would question their situation, consider other possibilities, and design new care and paid work arrangements, seeking to attain a more satisfactory configuration. In this process, they reported a constant reassessment and recognition of their children’s changing needs, as well as changes in their professional interests and career expectations. Moreover, as these women got more experienced with the demands of exceptional care, they started to pay greater attention to their own needs – self-care, personal and professional development, relationships, and
leisure – which had been regularly ignored in the initial years of caregiving. These questioning-rearranging movements caused many of these women to reflect on their beliefs about work and careers, reframing some of their original conceptions.

Importantly, this continuous decision-making process embraced not only the cyclic nature of exceptional care but also the life cycles of these women and their children. It also incorporated the dynamic nature of organizations and the job market. In this sense, often satisfactory new configurations did not last long, and new questioning-rearranging-reframing was necessary, prompting a new cycle of career decision-making. Among the mothers interviewed, some had already completed one or two cycles of this process, while others were still in the first questioning stage. Albeit to a lesser extent, a few fathers also engaged in a similar decision-making process and made some rearrangements in their careers.

The factors prompting these decision-making processes were generally different for self-employed and CLT mothers. For self-employed mothers, the main driver was a desire to invest in their professional development or businesses, which many had put on hold to dedicate time to exceptional care. Bianca shared, “I think about going back to college, for example, doing a graduate degree, something like that. I think it would be good for me.” For CLT mothers, the driver was often a combination of overtiredness from accumulating care and paid work, guilt for not spending more time with their children, and low job satisfaction. Daniela recalled that at some point, she said to herself:

Until when? And how much is it all worth? […] It has been so many years here. I want to take better care of my son. He is attending the first grade, and I almost never took him to school.
Sandra lamented, “I felt indebted to everything and everyone, and, in my mind, I was an awful mother because I saw my daughter from 8 to 9 p.m. every day.”

Differently from the career decisions they made in the aftershock of the diagnosis, these were well-thought decision-making processes, often including evaluating possible options, financial planning, and discussions with their spouses. Daniela, for example, received a good severance package and decided that she would stay one year focused on her son; she jokingly called this the “rich mommy moment.” Elena, who was considering some options as self-employed, described her thought process:

I think that it was the idea of diversifying your investments. That was my idea. Like, ok, I want something different. I’m not happy where I am. I have a son who needs me. My job doesn’t give me much joy anymore […]. What will I do?

As these mothers engaged in this decision-making process, they were, in general, looking for more flexibility, autonomy, self-realization, as well as reasonable pay and health benefits. Only sometimes would a job provide all these elements, and they would make decisions according to their family priorities. Therefore, these mothers made different career changes, including leaving CLT jobs to become self-employed, finding or crafting more flexible job positions, navigating between work modalities (CLT, self-employed, entrepreneurs), and investing in their education to expand work opportunities. These changes also included decisions in the distribution of care work in the family and adjustments in their kids’ care logistics.

Some CLT mothers left their jobs and became self-employed, while others found new jobs with more flexibility. Elena, who quit her job as a full-time teacher to work as a therapist, social media influencer, and speaker, shared, “It was a good sensation that I
could work less and earn the same and feel less stressed.” Sandra, who left her corporate job soon after a promotion to become a consultant and lecturer, commented, “I returned to an accelerated work rhythm, 40 hours a week, only that I was defining my schedule, you know?” Daniela, after almost one year of being a “rich mommy,” found a new job completely remote. Carla negotiated a new position with her employer, which allowed her to work remotely most of the time.

Some mothers navigated between work modalities, depending on their families’ needs. Gabi, who was self-employed and reduced her working hours when her son was born, went back to her former career in TV production with a CLT contract, mainly for financial reasons. She recounted that, at that moment, her six-years-old son had started speaking, and she felt more confident to let him with a paid caregiver; she also redistributed care work with her husband – “It was good because I could reorganize my life, you know, phew, to have my money to pay the bills, have a health plan, everything.” Olga, who quit her job in the corporate world and became a self-employed consultant, returned to corporate after some years, seeking more financial stability. She is now considering self-employment again due to her daughter and her elderly mother’s caring needs, but also because she misses her autonomy. Caring for elder relatives was a common occurrence in these women’s lives that often prompted career questioning and rearrangements. As Bianca recounted, “I remember that I decided to quit [her job as a contractor] when my father-in-law passed […] because it’s like this: since I’m caring for my children, I can care for my mother-in-law.”

Along with this reflection process, these women also started questioning their care arrangements and made decisions to reorganize their children’s care schema and
negotiate care distribution with their partners. Bianca shared that when she received a proposal from a friend to buy a school, she had a conversation with her husband—“And he supported me, he said, ‘Bianca, go. This is the moment.’ [...] Things were more stable. He said, ‘Bianca, go, we will handle it.’” Laura, who works as a psychotherapist, shared the many changes she made to her daughter’s care providers to accommodate her work better:

A support teacher comes here [her house] on Mondays. [...] She has Pilates and physical therapy in my clinic on Wednesdays. There is a professional there, and I changed her [former therapist for this one]. So, I pick her up, and she goes [to the clinic] with me. She stays the whole afternoon with me.

Although almost all mothers interviewed had questioned their status quo at some point, a few had not made new decisions and were still considering their options. Lorena, who was not feeling recognized in her company and was eager for a career change, shared that she was worried about not finding another job with similar pay and flexibility, “I realized that perhaps I have settled into this position. Because I earn so well. And then, I started to feel like almost a hostage to this company.” Likewise, Tais confessed:

If I leave my public servant career, I will always carry this weight, like, ok, perhaps this other job is better, but in this other job, I won’t have the pension I have here. Thus, it becomes like I’m chained to an iron ball.

Another relevant factor triggering the questioning-rearranging-reframing process was a concern with maintaining their employability in the long term. Many mothers invested in their education to fulfill new career interests and to expand their work opportunities. Elena, Erica, Irina, Lilian, and Tais were doing doctoral programs, while
Sandra was already planning her post-doc. Lucia shared, “I am doing a bachelor’s in languages […] as an investment for the future. I don’t know, if everything goes wrong, when I’m in my 60’s, I can find a job as a teacher.” Many self-employed mothers sustained two lines of work to maintain possible future avenues, like Lilian, who taught at a university and had her psychotherapy clinic. These mothers shared that they intended to work for as long as possible. Laura, who was planning to change her therapeutical focus from kids to adults gradually, explained:

As my husband says, I’m our retirement. He, there will be a moment when he will be dismissed from the job market, and I will keep working. I imagined, I imagined myself working until my early 70’s […]. So, I think that if I were 70 years old, I could easily work with adult women. I won’t have any patience to work with children, and teenagers won’t want to see me anymore.

Another interesting trend among these mothers was leveraging their motherhood experiences with PWD to boost their current professions or open new possibilities. Elena was studying parents’ adaptability to disability in her doctoral program and planned to monetize the results of her research in some way. Sandra provided consulting services to support D&I efforts and inclusive communication in organizations. Mel, whose son requires a specific diet due to his disability, was planning to study to be a nutritionist – “I want to have scientific evidence to everything that I had already studied on my own, and then share with other families and say, ‘look, I have, I have, I am both theory and practice, right? I have both.”

Moreover, for many mothers, thinking about future career alternatives also involves considering how to include their kids in some professional activity when they
are adults. Lilian explained, “We imagine starting some business, a bed and breakfast, something along these lines, so he can be part of it, as he’s very sociable, he has that, he’s very outgoing, he could work and feel helpful.” Lucia also talked about her ideas,

I think that it would be cool if I had a business where I could take her. I already thought about opening a school, a playroom, open, open a business where she could be there, working, anyway, a place where she could belong when she is an adult, you know?

As a result of this process of questioning the status quo and crafting short and long-term work opportunities that fit their and their family’s needs, these women reflected on how their beliefs about work and careers transformed with their experiences. Sandra affirmed that she “changed the parameters for my expectations, realigned certain words like success, like a good day, like happiness, right? Those are things that we have to realign.” These mindset changes were also significant in facilitating future career and family decisions. Among the main themes brought by these mothers as part of this reframing process were a recognition of care work as meaningful and productive work, increased comfort with setting limits to paid work, an acceptance of the blurriness boundaries between care and paid work, and a new perspective about career success and growth.

Some mothers shared their increased recognition of caregiving as important and challenging work. Lola confessed that before having children, she used to look at her colleagues who were mothers and think, “Gosh, she doesn’t do anything!” She continued:
Wow, I was a bad person! How couldn’t I understand that having four kids is not like having four experiments to conduct at the same time? It is so much more complex! It’s not only physical work; it’s intellectual work.

This recognition led to a new way of thinking about dedication to work and feeling comfortable setting some limits. Lola shared:

Yes, I have, I have two kids, but I am capable of doing many things in my time. Sometimes, I can’t do it at the time you want, but that is the time I have. I think I’ve been working on it [setting limits] more recently.

Indeed, putting limits to paid work was a common aspect of these mothers’ evolving experiences. Olga gave an example:

I had to leave at 5:30 pm sharp. Then, it was 5:20 pm, and this person knocked on my office door and said, ‘The directors want to talk to you.’ I said, ok, it was not the directors, it was the president, the vice-president […] I had to say, ‘I can’t today. I can’t today, but tomorrow I’m available.’ […] And I remember that I was pretty surprised when I arrived the next day and saw that the meeting was rescheduled for the next week. So, urgency level. Right? It was cool because, at that time, I was feeling able to say no more often.

Setting limits to paid work also meant reassessing the importance of work in their lives; as Paula reflected, “I think my work is a huge part of myself, but I don’t live for it.” Olga reached a similar conclusion, “Now I seek to acknowledge that it [work] is a part of my life, not all.” The new place that work seemed to hold in these women’s lives also gave them more comfort in negotiating their needs; as Jade recounted:
I was very straightforward in the recruiting process. I said, look, this [burnout] happened to me; I want to work in this way, I want to have autonomy, I want to have certainty that the company is open to doing this. I don’t want to be disappointed again.

Interestingly, Jade, who worked her whole life as a recruiter in the corporate world, shared her perception: “This is a very masculine characteristic; men do this much more than we do; they impose themselves; they discuss and negotiate more.”

These mothers also developed an easiness in embracing the blurring boundaries between care and paid work. Many of them would narrate episodes where work and care happened simultaneously. Irina shared that when she needs to see a patient with some urgency, she warns them: “Look, I can talk to you, but you will hear “Colorful Hen” [Brazilian cartoon] in the background. That’s ok, right? And he [her son] might interrupt us at any time.” Daniela added:

For example, I stop, oh, there is homework, ok, let’s do it, let’s help, ‘you [son] go on.’ I go back to my laptop. […] I have things to do, things to deliver. I have deadlines, and I’m doing my work.

Tais elaborated on this point:

This morning, I was making coffee alone in my kitchen and thinking about my work. I was already working. I don’t need to be in front of the computer to be working. So, I think I’m seeking to solidify this concept within, so I feel, so I don’t feel bad for not being in front of the computer because, in reality, my work is mental. My work is creative, mental.
Remarkably, these mothers shared how they learned to look with greater acceptance at the necessary accommodations of care and paid work and the consequential career changes, including sometimes tolerating a job that might not be the most desirable. Gabi reflected,

It is a scale, and you gotta keep measuring. If you want to pay for a specific school, for treatment Y, doctor Z, you need a differentiated salary to do all that. So, you will have to work to get it […]. For a long time, I got stuck in this duality – […] I could be doing this; I could be doing that. So, it is a process, and you have to be very clear about your goals so you don’t go crazy. Otherwise, you think, you transfer, you spoil both sides.

Tais also meditated on this during the interview and concluded:

One of my learnings, especially now going through this retrospective reflection, is to realize that, in reality, a lifetime is made of big blocks of dedication to certain aspects of my life. So, a block of time will be dedicated to organizing my family life. And will I keep working? I will. Will I be able to give my max? Possibly not. There will be other moments when that block [family] is organized, and I will give more than my max to my work, and then, let’s say, I will contribute more during that period. So, I think it’s a vision of organizing, prioritizing things in your life, you know?

Overwhelmingly, these mothers reported being happy and proud of their careers. They shared their conceptions of success as focused on doing something they like and feel recognized for. Lola said, “My expectation is to have recognition, to be able to do things, to see my work progressing.” Mel added, “For me, nowadays, professional
success is to see that my students are achieving their goals. It is not to have a busy agenda.” They also acknowledged and made peace with the fact that careers are impacted by life occurrences that are often out of their control. As Lucia declared:

Life happens, right? So, sometimes, there is no way. Otherwise, you become this 40-year-old adult feeling defeated, feeling that you did not achieve anything in your life. And life, life is like this, right? How many times have people had to reinvent their careers? Had to restart something?

Sandra concluded, “We realize that often the plans we made back then do not materialize, but other plans that we hadn’t ever imagined materialize and turn out to be as good or better.”

Unlike mothers, since parenting a PWD had a less significant impact on fathers’ overall careers, their conceptions about work, career, and success were primarily unaltered. However, some fathers who felt their careers were affected by their experiences of exceptional care shared some reflections. Danilo, who wished he had the chance to pursue an international career, said that now he puts his focus on his retirement and living a good life – “What I want today is to feel joy in my work, producing, realizing, doing my things.” For a few of them, the long-term experience with their disabled kids generated significant changes in their approach to work, as was the case of Greg. He commented that it took him a long time to integrate his son into his life, “and then, perhaps that was the biggest transformation from my past ten years […] it changed my work, it effectively changed the way I see the world.”
In fact, for both mothers and fathers, the experience of parenting a PWD was life-changing and brought personal development and learning, which are detailed in the next section.

**Learning and Development**

It was clear from the interviews that these parents’ experiences transformed them as individuals and professionals. When asked how the experience of parenting a PWD has changed them as professionals, their responses were almost automatic, “made me better” (Bianca). Marcos summarized: “Transformed me into a better human being, a better father, a better person, a better professional.”

Parents shared that they developed a more humane vision and the ability to interact empathetically with others. Lilian shared, “I think we became more generous, more reflexive, and more careful with others’ wounds.” Similarly, Bruno affirmed, “I would say that the main thing was empathy. I have it very clear to me that we don’t know the struggles each one is facing.” They described being more accepting and respectful of individual differences – “I learned to accept people as they are, independently if they had a disability or not” (Fatima). Bianca mentioned that her daughter helped her learn that each person has their own rhythm, “I know that she has a rhythm that is different, very different than mine. And I had to respect it.” She added that her experience also helped her to “put me in the shoes of these people that were not acknowledged, that somehow were not welcomed.”

These parents also reported an increased attention to diversity and inclusion. Many parents engaged in advocacy organizations and were more vocal about this topic in
their workplaces. Jade commented about this aspect in her work as a recruiter, “Because I had diversity in my house, I had a differentiated perspective; this helped me make decisions and analyze some situations more carefully.” Daniela shared:

Like, I have a son that needs to be welcomed by this community in the future, in the job market, in a college or a school, and all that. So, this became a pillar for me. And it has to be for real, not only marketing but for real.

Parents also provided examples of how these learnings showed up in their leadership styles. Lola explained, “Above all, M. changed my lenses to the world, how I look at people, and how I deal with them. And I think this shaped, shaped my leadership.” Tais shared:

I think it changed me as a manager, you know? I look at the human being that is there, complete, whole. […] I have to see all the aspects of that individual, social, environmental, familiar, so I can get the best of them, professionally speaking.

Marcos added that his experience prepared him to be a leader who aims that “the working environment is appropriate to all diversity of people, and everyone understands that this mixture is what makes things beautiful.”

Greg, who works as an organization development consultant, shared that his son completely changed the way he thinks about his work, bringing a more appreciative and generative approach:

When I gave up having expectations, no problem was left. Because the problem only exists in relation to an expectation. So, as I don’t have this anymore, I have to, I had to develop an appreciation for the individuals’ vital forces, their essence, their potency.
Other common themes brought by many parents were their improved resilience and ability to solve problems. Igor affirmed that he gained streetwiseness, “We gain an incredible logistics management ability. A wisdom, like, streetwise in this sense.” Lorena shared that her experience helped her “to understand about expectation and reality, about acceptance, to be less strict, less perfectionist. To understand about control, that you can’t control everything. Certain things are completely out of your control.”

Sandra explained, laughing:

Oh! I’m a much more resilient person. I think, as a professional, I am much calmer. Nothing scares me anymore in the corporate world. I know that everything can be solved. You know? […] After I became her mother, and after all the crises I endured in my life, we learn how to deal, we learn how to find ways. I think that is the biggest thing; being an atypical mother made me look for new ways, new solutions for certain things.”

Therefore, these parents developed skills that are highly relevant to most professions and valuable for organizations. Unfortunately, some parents encountered challenges in their work environments. Yet, many parents reported how supportive organizational cultures and leaders made an enormous difference in their lives, as discussed next.

**The role of organizations**

As parents shared their experiences and the various factors contributing to their career decisions, they raised the roles of organizations, supervisors, and work colleagues. Overall, they highlighted the importance of having supportive work environments and
caring leaders. These parents shared inspiring stories of caring leaders but also situations of disrespect and harassment.

One relevant aspect is that both mothers and fathers, at some point, disclosed their families’ situation to their employers. Most parents would share about their children’s disability to ask for flexibility and, in certain situations, some time off. Jonas commented on his rationale for disclosing, “If I need to be absent or be less available, I think this helps, you know?” Daniela explained that when they started to investigate their son’s diagnosis, she was very unsettled, and she decided to share with her supervisor, “I told him, look, please don’t mind if I cry, but I have to tell you, I’m not being able to work.” Her supervisor allowed her to use all the vacation days she had to process the diagnosis. However, Daniela confessed that she “would never talk about this with my previous supervisor.” Parents stated that organizations that foster diversity and leaders who show they care helped them feel more comfortable disclosing their family situation. Other parents also mentioned disclosing the information to normalize and educate others about disability. Lorena explained that talking about her son’s disability is “my way to try – I think, in my mind – help to change the world.” She added, “I like to share with others because I think that, when you share, people acquire this knowledge, and it is easier to have empathy.”

Most parents commented there were no formalized policies for flexible working arrangements in the organizations in which they worked. Therefore, having flexibility depended mainly on their supervisors; as Carla shared, “It depended on the department, the boss.” Eduardo, who had some flexibility “on special occasions,” explained: “But receiving some support is different than institutionalizing a norm. ‘Ah, Eduardo has a
special need, has a situation of special need in his family; we will evaluate a possible work schedule reduction.’ This I knew wouldn’t happen.”

Additionally, although most of these parents were able to have some flexibility, some commented on the lack of comprehension or willingness to understand their family situation. Mothers reflected on the unfairness of the workload and performance expectations. Tais pondered about meritocracy, “I believe in meritocracy, [...], but it's not like that; it can’t be rigid. I think there are moments and moments when you need a breather with these rules.” Sandra lamented, “It’s [the corporate world] extremely cruel to women. Even more cruel to mothers and gigantically cruel to atypical mothers. No one wanna know; no one cares.” Jade shared:

But the support was more the flexibility I had to manage my work. But it was not like, of, ok, go [to care for your son], it’s ok, you can count on us [to help with the work here]. As I had a managerial position, I could define my work schedule, I had more autonomy. So, they weren’t asking what I was doing. Or if I needed any help. No.

Surprisingly, there were few mentions of the Human Resources (HR) department as a source of support and dialogue during the interviews. One mother commented about a very positive experience in one of the organizations where she worked when the department proactively called her to check if she needed any support when her daughter was hospitalized for some time – “For the first time, I experienced a Human Resources [department] that was really human” (Sandra). Oppositely, Carla, who worked in the HR team, shared that she prefers not to talk a lot about her daughter with her peers; she explained, “But with people that will not influence my career, I share.”
From their narratives, these parents had inconsistent experiences in the organizations where they worked, which might indicate that few had family-supportive cultures and policies. In the absence of formalized policies, leaders played a critical role and often contributed to these parents’ decision to maintain or leave their jobs. Although many parents felt supported by some of their supervisors, they also shared painful experiences. Jade recounted a situation during the COVID pandemic:

My supervisor did not have the sensibility to connect, to think that I was a mother; he knew it. To think that I was a mother who had to change her routine and who had to do, to deliver everything. And I told him it was challenging. And he started criticizing me, saying that I was not performing [...]. My supervisor [was from] HR; he fostered diversity! So, this had such a bad impact on me that I got to the point of questioning if I was good at my work. And I said to myself, I don’t want to work anymore.

Some parents also shared about a lack of empathy from their colleagues at work. Carla shared that she oversaw an exchange between two of her peers:

The two [colleagues] were talking about me, ‘Ah, where is Carla? Ah, you know, Carla, she has her own schedule.’ Like, because I leave to take my daughter to therapy and all. My supervisor never bothered, but people around me did.

Carla, who now works remotely, mentioned that, if possible, she would never return to an office to avoid this type of peer judgment. Tais faced a similar situation with working colleagues and shared that at some point, she blurted out, “Look, if I’m not here, I’m not at the beach; I’m at a doctor’s appointment, ok?”
Nonetheless, most parents found, at some point in their careers, caring leaders who significantly impacted their ability to work and care. Parents shared that these leaders were flexible – “He was always super flexible with me” (Danilo) – and allowed them to work remotely when necessary, including when they needed to be in different cities or countries due to their children’s medical procedures. Gabi asked to work remotely when she decided to take her son to Israel for a revolutionary treatment – “Because at that time there was not this online work thing, now everyone knows it is possible, but I worked online a lot from there. And it was wonderful […] his treatment was incredible.”

Moreover, parents reported feeling supported by these leaders during challenging moments. Marcos got very emotional when he shared about the support he received from two leaders when his daughter stayed for 58 days in a coma in a hospital in a different city. He recounted that, besides allowing him to keep working in another office, they covered the hotel costs for him and his wife, “I have an immense gratitude for these men, for their humanity, for their sensibility.” Elena, who worked as an elementary teacher when her son was born disabled, narrated her conversation with her employer:

I told her I thought that I wouldn’t be able to handle a classroom, and, in fact, I asked to leave. But she said, ‘No, don’t make this decision yet; let me see what I can do.’ So, she reassigned me to this support staff post.

Caring leaders incentivized these parents not only to maintain their jobs but also offered the possibility for them to return to work on occasions they needed a break – “They said, Erica, go, take the time you need […] the doors are open” (Erica) – and stimulated them to keep their professional development. Irina shared a conversation with
her supervisor and advisor during a moment when she was feeling discouraged, “[She] said, look, you have one month to submit your doctoral project because it is absurd that you, with all this competence, don’t have a project that is yours.”

Although more rarely, some parents encountered organizations with supportive cultures, even when policies were not formally implemented. Igor shared, “They respected people’s schedules, people’s lives […], and they knew about my story with J. [his son], so it was perfect.” Jade concluded, “When you perceive that the company supports you, offers help, you don’t want to leave; you will give your best to them.”

In summary, supportive cultures, flexible working arrangements, and caring leaders played a crucial role in the ability of these parents to maintain their careers and professional development while also caring for their kids. Additionally, it is also clear from the interviews that leaders, peers, and work environments are key factors influencing these parents’ career decisions. Therefore, it is paramount that organizations implement formal supportive policies to avoid parents depending on the discretion of their supervisors. Some parents described experiencing completely different situations in the same organization but with distinct leaders. Further, as also noticed in the interviews, while women strove not to “abuse the existing flexibility” and not let exceptional care needs impact their work, fathers seemed much more comfortable negotiating flexibility when they needed it, which is likely an outcome of patriarchal values and gendered organizations.

This chapter summarized the main findings of the interviews. In the next chapter, I discuss how these insights contribute to advancing career development theories and new conceptions of work-life interactions.
Chapter 5: Discussion

This study aimed to examine how parents of PWD develop their careers to attain work-family integration in the Brazilian context, identifying the systemic forces influencing these parents’ career decisions and the outcomes and implications to caregivers, organizations, and society more broadly. In this chapter, I discuss how the findings of this study respond to this question and help in the development of new conceptions of work-life relationships and in advancing career theories. The chapter starts by considering what it meant to parents of PWD to attain work-family integration and how this understanding informs a different way of thinking about life domains’ relationships. Next, learnings from these parents’ career decision-making processes are described and compared to current career development theories, and a new framework is proposed to explain the career development of caregivers and in which ways this model can be applied to other individuals. Then, the limitations of this study and recommendations for future research are discussed, followed by implications for practice, including potential outcomes for individuals, organizations, policymakers, and society more broadly. The chapter closes with an overall conclusion.

Work-Family Integration – Expanding the Perspective

The narratives of the interviewed parents revealed that their considerations of the different disputing demands and interests in their lives encompass aspects that are not clearly stated in the most well-known conceptions of work-family or work-life relationships existing in the literature. In the following paragraphs, I argue that a new conception of life domains is necessary to describe the experience of these caregivers
more adequately and propose a new framework to explain how these parents manage these different life domains and their disputing interests and demands.

An Expanded Conceptualization of Life Domains’ Relationships

Although at the beginning of their experiences as parents of PWD, their focus is largely on managing paid work and caring demands of their children, with time, many of these parents turn their attention to other important domains of their lives, including professional development, self-care, personal relationships, and leisure. They have both interests and demands competing for their time and skills in all these various aspects of their lives. For example, these parents must allocate time to paid work so they can keep their jobs or businesses and consequently have the means to survive and provide care. At the same time, the vast majority of them are also interested in dedicating time to paid work as it allows for self-actualization and respite from care demands. Likewise, caregiving for their kids is an obligation and can be burdensome, but at the same time, parents underscore the importance of caring and the desire to be close to their kids. Although self-care was not a focus of this study, parents confessed their necessity to invest time in caring for themselves so they could be healthy enough to accomplish their care and paid work; yet, self-care can also be a source of fulfillment, particularly if we consider that it includes leisure, personal relationships, and personal development (Sanchez-Reilly et al., 2013). Thus, it is not only about conflicting demands but also conflicting interests and fulfillment needs.

Additionally, since work is a central part of these parents’ lives (as it is for most people), the work-life term does not seem appropriate, as it could imply that work is not part of an individual’s life (Frone, 2003; Lewis et al., 2003). Moreover, many of these
parents consider that caring for their kids was work – managerial and operational work – and, given the intensity of exceptional care, it seems crucial to recognize care work as an essential and specific domain of their lives. Further, care work might include other activities not restricted to the family domain. In the case of parents of PWD, educating others about disabilities, advocating for diversity and inclusion, supporting other families of PWD, and serving in disability associations were activities reported by them and linked to care work. Considering that caring for others and caring for our communities and environment are essential activities of any adult, if we want to live in a just and sustainable society, it might make sense to emphasize care as a vital domain in any person’s life (Tronto, 1993, 2013). Therefore, I developed a Life Domains model that underscores the essential activities that compete for resources, including time, skills, and mental and emotional capacity, in the lives of adults (Figure 3).

**Figure 3**

*Life Domains Model (developed by the author)*
Some scholars pointed out existing inconsistencies and overlaps in the various life domains’ taxonomies (Beigi et al., 2019; Kossek & Lee, 2017; Morris & Madsen, 2007). Beigi and colleagues (2019) developed an extensive study to identify terminologies used by scholars from 1960 to 2011, and, besides the many different nomenclatures for life-domain relationships, they noticed that studies used narrow and broad concepts to describe non-work life domains. Among the many nomenclatures found by them, narrow concepts include work-family, work-home, and work-leisure, while broader concepts include work-social systems, work-non-work, and work-life (Beigi et al., 2019). The work-family combination and relationships between these two domains are one of the most studied (Frone, 2003). However, although work-family is a narrower concept than work-life or work-non-work, these terms are often used interchangeably (Frone, 2003; Kossek & Lee, 2017). Moreover, work-family studies originated from discussions based on traditional gender roles, and many authors adopt these terms without significant reflection on their gendered implications (Beigi et al., 2019; Moen, 2011).

Besides the concerns mentioned above, the existing concepts are not entirely helpful in explaining the experiences of parents of PWD. For example, although the non-work domain might include work performed as a parent or as a student (Frone, 2003), as it is frequently not explicitly stated in many studies, the unpaid work carried out by parents might be overlooked, contributing to the low value often attributed to reproductive work (Lewis et al., 2003). Moreover, the work-family nomenclature, when adopted without a critical lens, might reinforce gender roles (Moen, 2011). Additionally, self-care is not an aspect included in most of these nomenclatures, although some consider leisure and personal growth to be part of the non-work domain (Beigi et al.,
To further theorize about the experiences of parents of PWD, it is vital to define clearly which life domains are being studied (Beigi et al., 2019; Frone, 2003). The Life Domains model (Figure 3) has two main goals: to provide a description of life domains that represent the experience of caregivers and center care as a critical endeavor in everyone’s life, not only caring for others but also caring for oneself.

The expanded model includes three main spheres: professional, care for others, and self-care. The professional domain includes activities that are financially compensated and can be performed in different manners, as self-employed or as an employee of an institution. This domain also involves professional development activities necessary to access employment and maintain paid work. Some may argue that professional development can be part of self-care (Sanchez-Reilly et al., 2013); however, given the pervasiveness of paid work in our lives (Lewis et al., 2003), professional development often conflicts with time for self-care initiatives unrelated to paid work. For this reason, I propose that professional development should be included in the professional domain, although the self-care domain might include personal development activities to promote well-being and personal growth. Additionally, I have purposefully separated care work from paid work, locating each one in specific spheres – professional and care, respectively – to avoid an issue previously reported by other scholars where care work gets lost in the “work” domain (Lewis et al., 2003), contributing to the low value attributed to care in our society (Tronto, 1993). Similarly to what other scholars stated, boundaries between life domains in the proposed model are not impermeable; activities and interests might overlap, and resources might be transferred from one domain to another (Greenhaus & Powell, 2006; Voydanoff, 2005).
My description of the care domain is based on Berenice Fisher and Joan Tronto’s (1990) definition of care:

“[A]ctivity that includes everything that we do to maintain, continue, and repair our ‘world’ so that we can live in it as well as possible. That world includes our bodies, ourselves, and our environment, all of which we seek to interweave in a complex, life-sustaining web” (p.40)

Albeit Berenice Fisher and Joan Tronto’s definitions include aspects of self-care – “our bodies, ourselves” – for the purpose of this model, I also separate care for others and self-care to ensure that they are both acknowledged as essential parts of adults’ lives and to prevent self-care from getting overrun by other professional and care demands (Kossek et al., 2021; Schultheiss, 2009). In the proposed model, the care domain includes the activities we do to satisfy the needs of others – humans and non-humans – as parts of our consciousness of the existent interdependence between us and as human moral obligations. Fisher and Tronto (1990) claimed that care activities involved four cyclical phases: caring about, which means recognizing that care is necessary; taking care of, which means assuming responsibility and defining how to respond to the care needs; the actual act of caregiving, which often involves physical work and proximity with the object in need of care; and, lastly, care-receiving – when an assessment of the effectiveness of caring needs occurs and new needs are identified. This definition is important because, as described in the next paragraphs, assuming responsibility for care does not always translate into care completion.

The self-care domain involves activities performed by individuals to promote and maintain personal health and well-being throughout their lives, including practicing
healthy habits, nurturing close relationships, investing time in leisure, and developing spirituality (Sanchez-Reilly et al., 2013). All these life domains include activities that demand time, skills, and mental and emotional capacity but also offer positive outcomes that attract individuals’ interest. I argue that this model can be applied to all individuals, providing that care and self-care is, or at least should be, a natural part of any adult’s life.

As individuals navigate through their different life stages and circumstances, the focus of their attention and the way they prioritize their resources between these three life domains – professional, care, and self-care – will fluctuate. Similar to the parents interviewed, individuals make conscious or unconscious decisions about distributing their resources to satisfactorily respond to the needs and fulfill their interests in these various realms. Importantly, these decisions are often dependent on contextual factors that can either offer more possibilities or more restrictions. For example, in the case of the mothers of PWD, although many of them underscore the importance of caring for themselves, social gender roles and lack of supportive networks – family, care providers, organizational support, and public policies – restrict their ability to allocate more time to self-care. Also, in many interviews, parents described occasions when they had to reduce the time dedicated to their professional lives due to the demands of exceptional care. As noted before, the boundaries between these life domains are permeable, and transfers between these domains result in both positive and negative outcomes (Greenhaus & Powell, 2006; Voydanoff, 2005). In the next sub-section, I discuss the observed relationships between these different life domains and how the interviewed parents managed these interactions.
It is pertinent to state that the concept of work-family or work-life integration, conflict, or balance did not emerge in any of the interviews. In real life, parents of PWD think about the relationships between their many life domains in different terms. They discussed their attempts to manage the many demands they had from their professional, care, and self-care domains, understanding that these demands – and their ability to handle them – change dynamically and are shaped by external factors, including beliefs about gender roles, organizational cultures and policies, public policies, and available support in their families and communities.

Nevertheless, it was possible to map different work-family relationships in their narratives. Significant levels of work-family conflict – when there are incompatible role demands from work and family domains (Greenhaus & Beutell, 1985) – seemed to occur in the initial stages after the birth of a child, during and after the disability diagnosis process, and again when crises, characteristic of exceptional care, occurred. In the case of parents of PWD, the conflict happened not only in terms of time but significantly in terms of strain – when stress generated in one domain impacts the individuals’ effectiveness in another domain (Greenhaus & Beutell, 1985). The increased level of work-family conflict in working parents of PWD was reported previously in other studies (Brown, 2014; Li et al., 2015; Morris, 2014).

Research shows that work-family/work-life conflict is bi-directional, in the sense that work interferes in family/life, and family/life interferes in work (McMillan et al., 2011). In the interviews, it was possible to observe the different interferences depending on where these parents decided to focus in a given period. For example, for self-
employed mothers who prioritized care work versus paid work, demands of care work more significantly impacted their ability to dedicate themselves to paid work.

Conversely, for mothers and fathers who maintained their full-time jobs, paid work demands impacted their ability to respond to care demands more significantly. Self-care was usually these caregivers’ last priority, and both paid work and care work interfered with their ability to self-care. Consequently, self-care interference in paid and care work was noticed less. Still, this directionality was often fluid and changeable due to an ongoing assessment of pressing needs, inclinations, and priorities. In this sense, it is possible to argue that conflict is always present in the experiences of these caregivers, considering that, besides the demands of their paid work and their interest in fulfilling professional goals, caring demands are extensive while resources, in particular time, are limited (Fisher & Tronto, 1990).

The strong influence of gender roles was noticeable in the higher levels of life domains conflict reported by women, as they assumed most of the care work. Despite all the advances of women in the workforce, gender roles are still deeply ingrained in Brazilian families, with women spending significantly more time in caring activities (IBGE, 2021). Mothers felt an internal conflict between their desire and need to work – ensuring fulfillment, financial independence, and respite from caregiving – and the need to care for and be closer to their children. On the other hand, for fathers, caring demands were translated into ensuring financial stability, which is located in the professional realm; in this way, although they still faced conflicts related to a desire to be closer to the family and take care of themselves, the overall demands outside the professional domains were smaller for men compared to women, resulting in lower levels of conflict (Brekke &
Nadim, 2017; Olsson & Hwang, 2006; Sellmaier, 2019). As Tronto (1993) argued, only providing financial resources does not sufficiently address care needs; it can be one part of the care activity – ‘taking care of,’ but it does not translate to the action of caregiving or even the understanding of the effectiveness of the care being provided.

Nevertheless, conflict is not the only relationship between these parents’ various life domains. Another relevant aspect observed in these parents’ experiences was illustrative of the work-family enrichment (Greenhaus & Powell, 2006) and work-family fit (Voydanoff, 2005). Many parents described how they transferred skills they developed in their work, for example, planning and time management, to administer the many demands of exceptional work. They also reported how dealing with the challenges of atypical parenthood honed these same skills and added new ones, including resilience and problem-solving, helping them work more efficiently. They described how caring for a disabled child and getting in contact with the realities of other families with similar experiences transformed them into professionals and leaders with a human-centered perspective and more attentive to issues of diversity and inclusion.

Beyond skill transference, a significant phenomenon occurring with these parents was the buffer effect on their stress levels, which many reported when working in environments that offered flexibility and support. A positive experience at work was described by many parents as a place of respite and the opportunity to reconnect with their professional identities and feel competent, which aligns with the idea that positive work experiences can offer a buffer to stressful situations at home and the other way around (Barnett & Hyde, 2001; Voydanoff, 2005). Moreover, in workplaces with a supportive environment, parents found additional social support from their leaders and
co-workers, contributing to their ability to care and promoting an overall positive experience (Barnett & Hyde, 2001). It is crucial to emphasize that the positive gains from playing multiple roles depend on job quality and available support (Barnett & Hyde, 2001). As some reports from mothers of PWD exposed, toxic work environments contribute to experiences of burnout.

The experiences of these parents showed that work-life enrichment does not eliminate conflict, although it can ameliorate it. With time, these parents developed strategies and skills that enabled them to move from a state of increased conflict to a more satisfactory state where aspects of their various life domains flow, collaborate, and correlate. Parents described this state as feeling satisfaction with their arrangements in the three domains – care work, paid work, and self-care. In care work, it means having their children’s care demands organized and functioning properly in terms of logistics and adequate treatment plans and providers. In paid work, attaining an occupation they like and where they feel recognized for their contributions. And lastly, having time for self-care, including caring for their health, personal relationships, and development.

These parents also acknowledged that it was rare, if not unfeasible, to achieve an ideal state in all three domains; thus, for them, it is critical to have the autonomy and flexibility to manage these main blocks of activities and continuously reassess and reprioritize. Additionally, for this satisfactory state to happen, fundamental elements need to be in place, including awareness of self and others’ care needs, negotiated roles with partners, a structured network of care, supportive working environments, and supportive public policies. Because some of these elements depend on the context, achieving this state is a social endeavor, not an individual effort. Moreover, considering that context
changes, parents recognize the impermanence of this satisfactory equilibrium and the need for ongoing adjustments. Therefore, when changes in the context or care needs happen, it is likely that conflict between these life domains arises.

Existing concepts defining more positive work-family/work-life interfaces only partially capture what these parents described as their experiences. However, given the plentiful definitions of work-family/work-life relationships (McMillan et al., 2011), it is likely that I have not reviewed all of them. Table 5 lists some constructs that correlate to the accounts of these parents when experiencing a positive relationship between work and other life domains.

Table 5

*Selected Definitions of Positive Work-Family/Work-Life Constructs*

<table>
<thead>
<tr>
<th>Concept</th>
<th>Definition</th>
<th>Authors</th>
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<tr>
<td>Work-Life Harmony</td>
<td>“…an individually pleasing, congruent arrangement of work and life roles that is interwoven into a single narrative of life” (p.15)</td>
<td>McMillan et al. (2011)</td>
</tr>
<tr>
<td>Work-Family Balance</td>
<td>“…accomplishment of role-related expectations that are negotiated and shared between an individual and his/her role-related partners in the work and family domains” (p. 458)</td>
<td>Grzywacz &amp; Carlson (2007)</td>
</tr>
<tr>
<td>Work-Personal Life Integration</td>
<td>“…synergies and connections between the different parts of life and the ways in which they feed into each other” (p. 6).</td>
<td>Lewis et al. (2003)</td>
</tr>
<tr>
<td>Work-Life Integration</td>
<td>“Integration includes a healthy system of flexible (i.e., malleability) and permeable boundaries that facilitates and encourages equal attentiveness and connection with priorities and valued activities originating in the work–life, family-life, and community-life domains” (p. 442)</td>
<td>Morris and Madsen (2007)</td>
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</tbody>
</table>

The concept of work-life harmony offered by McMillan et al., 2011, closely relates to the experiences of parents of PWD but lacks a more precise description of what
work and life domains entail. Additionally, the model proposed by McMillan and colleagues (2011) posits that work-life harmony results from an equation between conflict and enrichment. However, the findings from this study show that other elements not included in the work/life enrichment construct are important for these parents’ appraisal of a satisfactory state between their life domains. Fundamentally, these caregivers’ experiences exposed that it is not only about how activities in one domain enrich activities in a different domain but also about managing, prioritizing, or even reducing activities in one domain to more sustainably accomplish goals in all domains in the best way possible. Therefore, the way parents of PWD experience their work-life relationships opposes the expansionist idea of role accumulation (Barnett & Hyde, 2001).

Based on this study’s findings, I advance the work/life harmony concept, proposing a new model to describe more closely how caregivers manage the relationships between their life domains to accommodate caring needs and their other demands and interests. I theorize Life Domains Synchrony as an integrated and sustainable arrangement of expectations and resources that are continuously negotiated, enabling an individual to fulfill their professional and personal needs while caring for their families, communities, and environment in the best way possible. Synchrony is defined as “a state in which things happen, move, or exist at the same time” (Merriam-Webster, n.d.), which represents well the idea that our life domains do not exist apart from each other, but they coexist and are interdependent. Moreover, synchrony, or the state of being synchronous, presupposes a delicate arrangement that can become disturbed.

It is essential to highlight that life domains conflict and synchrony, as proposed in this study, refer to an individual appraisal of the quality of the relationship between
demands and interests in the various roles a person has in their lives. Nevertheless, these relationships are social phenomena, considering that contextual elements and social identities impact individuals’ ability to negotiate expectations and access supportive resources. Moreover, the expectation and level of appreciation from others, including employers, co-workers, spouses, children, and other relatives, strongly influence this individual appraisal (Poelmans, 2005).

Additionally, assessing what constitutes *Life Domains Synchrony* involves reframing and recalibrating internal expectations and challenging ideal notions – often established collectively in the marketplace – about what it means to be a productive and successful professional. It also requires acknowledging that priorities and the level of accomplishment and satisfaction will vary in the various life domains at different times. In this sense, “in the best way possible” is a critical element of the description of this construct, as it recognizes that an ideal state is rarely attained. The continuous negotiation of expectations and resources is a critical element and underscores the fluidity, interdependence, and impermanence of such a state.

Finally, my definition of *Life Domains Synchrony* includes integrated and sustainable as fundamental characteristics. Integrated because it assumes that boundaries between life domains are permeable; they can be managed but not contained. Sustainable because it strives to ensure that resources – time, money, skills, mental capacity, and health – are used in a way that they are not drained or damaged and that although increased levels of life domain conflict may happen, individuals can still reconfigure and cope.
**Attaining Life Domains Synchrony**

So, what does it mean to “attain work-life integration” from the perspective of these parents? The findings show that, as these parents experienced the challenges and transformations resulting from exceptional caregiving in a patriarchal and ableist system, they seemed to achieve a stage where they actively and continuously manage the many roles they play, aiming to reduce conflict and extend the duration of a state of Life Domains Synchrony. Their reports revealed that they rarely entirely attain “work-life integration,” or Life Domains Synchrony, as proposed. However, they develop skills and strategies that enable them to better manage the multiple demands in their life domains. This does not mean that they develop the ability to control things. As exposed in their narratives, when new contextual factors or changes in demands occur and existing resources are not sufficient to sustain the harmonic arrangements, parents might experience increased levels of conflict. In these occasions, elevated levels of life domain conflict prompted these caregivers to pursue new configurations, which might include a reassessment and reprioritization of needs, renegotiation of expectations, search for new supportive resources, and, not uncommonly, new career decisions. Figure 4 illustrates these dynamic processes between conflict and Life Domains Synchrony.
Contextual factors and individuals’ social identities will dictate the level of complexity in managing these relationships and influence individuals’ ability to remain in a more integrated and harmonic way for extended periods. Contextual factors comprise the specific caring demands of the person as well as the level of support available from family, community, organizations, and government. Support at the organizational level includes flexible working arrangements and other supportive policies, as well as supportive leaders and co-workers. At the governmental level, it involves public policies supporting caregivers, availability of public childcare and health care, and specific policies supporting self-employed professionals, as they might not have the same guarantees and benefits offered by organizations to their employees. National culture and the country’s economic and regulatory context also significantly influence available support and work opportunities. In the case of Brazil, one critical element mentioned by
many parents is the availability of childcare and schools prepared to receive and work with children with disabilities, which is a highly problematic topic in the country (Castro, 2023).

Importantly, the complexity of contextual factors is also dictated by individuals’ social identities. The impact of gender on the complexity of managing life domains is dramatic. Even though most of the interviewed couples were dual-earners, and the Brazilian census shows that 50.8% of the country’s households are sustained mainly by women (DIEESE, 2023), social expectations still ascribe to women the primary caregiver role and assume men will be main breadwinners (Berlato et al., 2019; Fernandez, 2019; Hirata, 2016). Interestingly, care is perceived by mothers and fathers as a shared responsibility, yet they tackle this mission in different ways, according to gender roles. A family’s ability to provide care involves both financial resources and human resources to execute the care work, including contracting and managing paid care workers and other supportive services – nannies, childcare, school, extra school activities, and in the case of exceptional care, therapists, and health providers. Due to how society attributes family roles to men and women, and because of the gendered way marketplace and organizations are structured, most families follow the traditional path – women will manage and execute care, and men will provide the financial resources. Consequently, mothers and fathers have different appraisals of the level of satisfaction with their roles in the care domain and the level of conflict between care and other life domains (Figure 5).
For men, investing in their professional domain enables them to accomplish an important part of the care, providing financial resources and stability, which is often seen as their responsibility. In Fisher & Tronto’s (1990) definition of care, providing financial resources only accomplishes the two initial stages of care – care about and taken care of. Caring requires completing the four stages of the care cycle, including caregiving and care receiving, which comprise the actual active care work and are executed mainly by women. Thus, from the perspective of these fathers, combining their and their wives’ contributions, care demands were fulfilled. For fathers, attaining Life Domains Synchrony seemed easier, except perhaps for the self-care realm, which was often overlooked. On the other hand, although most mothers also wanted to fulfill their professional goals, and many of them significantly contributed to the family income,
investing in their working life conflicted with their ability to accomplish their part of care work – managing and executing care – which was naturally perceived as their responsibility by their partners, and often by themselves. Additionally, the still pervasive notion of work devotion and the ideal worker (Acker, 2012; Kossek et al., 2021; Padavic et al., 2020), ingrained in most organizations and in the mindsets of professionals, put women in a state of insecurity and need to prove themselves as competent and reliable professionals constantly, contributing to elevated levels of life domains conflict.

Therefore, fathers experienced lower levels of life-domain conflicts compared to mothers, and they did not feel the urge to make changes, particularly in their professional domain, because of stress related to a lack of synchrony between life domains. As their reports showed, fathers sought to maintain their jobs so they could do what they believed was their part in fulfilling the family life goals. Meanwhile, the elevated sense of life-domain conflict drove many of the interviewed mothers to make adjustments, including in their careers, as they sought to reestablish a satisfactory level of Life Domains Synchrony. Overall, the mothers interviewed made significantly more adjustments in their careers than their partners and the fathers interviewed, defining different approaches to career development, as discussed in the next section.

It is worth mentioning that even in families where parents of PWD were divorced, they still kept somehow similar responsibilities – fathers would be mostly focused on financial aspects while mothers would manage and execute the care work. Therefore, the dynamic described previously about levels of conflict and career changes was similar for most divorced couples. For some divorced couples, when the father contributed less financially, the level of conflict for the mother would be even higher, as the possibility to
reduce or change jobs to accommodate caregiving demands was restricted due to the need to ensure sufficient income.

It is also important to emphasize that parents in this study are part of a very privileged group in Brazilian society – middle class and college-educated – which gives them more possibilities for support and more professional choices that other less privileged families do not usually have. Moreover, the parents interviewed were all in heterosexual relationships, and most of them were white. Although this study has not explored the impact of other social identities, some studies show that intersectionality plays a significant role in the ability of individuals to gain the trust of their supervisors and access flexible working arrangements and family-supportive policies (Ryan & Briggs, 2019; Williams et al., 2013).

Even though the dynamic processes between conflict and synchrony described the experiences of parents of PWD interviewed for this study, it is likely that other working individuals, particularly caregivers, experience a similar dynamic in perhaps different levels of complexity and intensity. Still, I believe this can be a valuable explanation of life-domain relationships and how individuals, in a family context, manage them by adjusting expectations, negotiating resources, prioritizing demands, and making career changes. Fundamentally, career development seems to be a critical strategy to attain a more satisfactory life configuration. The next section discusses how learnings from these parents’ career trajectories advance career development theory.

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8 Based on the researcher's observation. Skin color in Brazil is self-declared, and this data was not collected in the interview through a direct question.
Parents of PWD Career Decisions Inform New Possibilities for Career Development

Before discussing how parents of PWD professional experiences inform new possibilities to think about career development theories, it is important to define “career development.” I adopted the definition proposed by McDonald & Hite (2023), “Career development is the process of acquiring and experiencing planned and unplanned activities that support attainment of life and work goals.” (p. 3). This definition correlates to these parents’ experiences in many ways. It does not constrict career development within an organizational environment, validating the professional experiences of self-employment and entrepreneurship. It also links career development with “experience activities” rather than hierarchical growth, financial gains, or job status. Further, it acknowledges the possibility of career events being planned and unplanned. And most importantly, it proposes that career development aims to support both work and life goals, which is critical to these parents.

The professional trajectories of the parents of PWD who were interviewed revealed that the way they think about their careers altered significantly as they navigated different life stages and engaged more or less actively with all the stages of the caring process (Fisher & Tronto, 1990). More specifically, the experience of parenthood, and particularly, caregiving for someone with intense care demands, transformed these parents’ career perspectives and decision-making process as planning and managing their life domains and careers became intrinsically connected. Relevant changes were evident in how these caregivers defined their professional and personal goals, the inputs they considered when making decisions, the moderators or influencers of these decisions, the way they evaluated the outcomes, and the learnings they acquired from these career
movements. These changes were particularly common in the narratives of the parents who engaged more strongly in care work, frequently women.

Changes in these caregivers’ career decisions happened primarily in three stages of their lives: when they initiated plans to have a family, after the event of childbirth or the confirmation of a disability diagnosis, and after experiencing exceptional care for some time. Although it is not new that career decisions change in the life span (Hartung, 2020), traditional developmental career theories do not explain the changes observed in these parents’ narratives as they fail to properly incorporate the influence of contextual elements and social identities in career development (McDonald & Hite, 2023). Some more contemporary career development theories (Table 6) only partially explain these parents’ experiences, and there are opportunities to advance these concepts to better represent these caregiver’s career development. In the following subsections, the main changes in terms of career goals and career decision-making are discussed.

For these caregivers, work and life goals changed over time, becoming more and more interconnected. While in the early stages of their careers, work and life goals were considered from an individualist perspective and strongly focused on financial and vocational aspects, this approach changed as family relationships and contextual factors shaped and integrated their working and personal lives and professional goals started to be considered in light of goals in other life domains.
<table>
<thead>
<tr>
<th>Theory</th>
<th>Main characteristics</th>
<th>Points of attention</th>
</tr>
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</table>
| Job Crafting (Wrzesniewski & Dutton, 2001)  | - Employees build their work by shaping job tasks, and relationships in their work environment  
- Individuals engage in job crafting to fulfill needs related to their work                                                                                                                          | - Focused on employees and job in organizational settings  
- Does not consider the influence of factors external to work in the motivation for job crafting                                                                                                      |
| Kaleidoscope Career (Mainiero & Sullivan, 2005) | - Highlight differences in career approaches of women and men  
- Women’s careers are relational  
- Career patterns change as individuals seek to adjust relationships and roles in different life domains                                                                 | - Assumes difference in approach is driven by gender, reinforcing gender roles and gendered careers - “women’s career”                                                                                           |
| Family-Relatedness of Work Decisions (Greenhaus & Powell, 2012) | - Family factors influence decisions in the work domain with the goal of benefiting the family domain  
- Contextual factors at the individual, organizational, and societal levels determine the strength of family situations in work decisions | - Subject the decision to integrate family to personal values and to the availability of organizational and societal support, overlooking the gendered implications of this assumption |
| Work-home perspective (Greenhaus & Kossek, 2014) | - Recognizes the interdependencies between work and home domains  
- Work-home relationships shape and are shaped by career decisions  
- Acknowledge the effect of gender norms in how women and men engage in work and home domains                                                                 | - More a lens than a framework, but indicates valuable areas for future research, including how to think about career self-management, career success and sustainable careers from the work-home perspective |
| Career shocks (Akkermans et al., 2018)      | - Supplement other career theories by considering how chance events (positive or negative) affect careers  
- Career shocks are caused by events often out of individuals’ control  
- Shocks lead to career reflection and behavioral transformation                                                                                                                            | - Explain the impact of the diagnosis and other challenging situation experienced by parents of PWD but does not explain how career related behaviors are transformed and the outcomes of these new behaviors |
| Sustainable career (De Vos et al., 2020; McDonald & Hite, 2018) | - Integrated work and life domains  
- Context and interlocked systemic forces influence individuals’ agency  
- Cyclical and self-regulatory process  
- Learnings from positive and negative experiences inform career decisions                                                                                             | - Indicators of sustainable careers focused on individual sustainability, and does not include care for others as an important element of a sustainable life. |
Career Goals – Interconnecting Professional and Life Goals

Integrating work and life goals got more intricate when exceptional care became a reality. Findings revealed that for most of the interviewees, the primary goal became managing and reducing conflict between the many domains in their lives. Over time, as they experienced exceptional care, some parents turned their attention to achieving and sustaining Life Domains Synchrony, which entailed fulfilling their professional goals, being able to organize the necessary care structure for their children, and being able to care for themselves. For many, professional goals also changed in nature, transitioning from an initial focus on growth, often related to salary and status, to a more subjective perspective of continuous development, recognition, satisfaction, and impact on others (Greenhaus & Kossek, 2014; Mainiero & Sullivan, 2005). This was clear in their testimonials about how the meaning of career, work, and success changed for them.

These changes in career goals were also reported in research investigating women’s careers (Mainiero & Sullivan, 2005). Mainiero and Sullivan are proponents of the Kaleidoscope Career, which postulates that women’s careers are relational and usually less linear than careers described by men. Their research showed that women’s careers more frequently involve job crafting, career interruptions, pursuing more recognition and learning opportunities, and concerns with other life domains, including self-care. Nevertheless, in this study, both mothers and fathers of PWD detached from a career orientation purely focused on career achievements and work goals. This distancing was more common among those parents more involved with care work, which leads me to argue that this difference in career orientation is fundamentally related to the place caring for others holds in one’s life, rather than necessarily being a man or a woman. It is
true, though, that even those men more engaged in care work did not face challenges in accommodating family demands or sustaining jobs in organizations as many women did, which might also explain their more linear careers. Because of expectations related to gender roles and gendered organizations, men more easily achieved Life Domains Synchrony, particularly in corporate jobs, than women. Consequently, although the Kaleidoscope Career Model is somehow illustrative of parents of PWD approach to careers, particularly women in their mid-late career stages, this model, perhaps unintentionally, reinforces gender social roles. Additionally, the Kaleidoscope Career Model assumes a typical evolution of family demands, which is not always a reality for the crisis-driven and life-long demands of exceptional caregiving.

In this study, changes in work and life goals were present in both mothers’ and fathers’ narratives. They increasingly aimed to attain and preserve synchrony among their various life domains as they experienced exceptional caregiving, and they were concerned about the family’s ability to accommodate work and care. However, as argued before, while professional goals are connected to the individual professional domain, for caregivers, a significant part of life goals are linked to the satisfactory provision of necessary care, which is located in the care domain and seen as a shared family responsibility. Here is where social gender roles and gender inequality in the workplace set the course of caregivers’ career trajectories. While men invested in their professional realms to fulfill their mission as family breadwinners, women made career adjustments to accommodate care work and their professional interests, often also contributing significantly to the family income. The next subsection discusses how career decision-
making evolves, driven by changes in work and life goals depending on life stage and involvement in care work.

**Parents of PWD Career Decision Making**

Parents of PWD career decision-making processes exposed the strong influence of their personal values and the social context in which they were immersed. While at the beginning of their careers, the effect of contextual elements was lighter, as they progressed in their life stages, with marriage, children, diagnosis of disability, and sometimes divorce, the impact of contextual elements became stronger. Moreover, these parents increasingly included family needs and the consideration of their partners’ careers in their career decision-making, and some of them had joint discussions about their careers and negotiations considering their family needs (Greenhaus & Kossek, 2014; Greenhaus & Powell, 2012). Consequently, how parents made decisions at the beginning of their careers significantly differed from career decisions in the later stages of their professional trajectories. In the next paragraphs, I discuss these parents’ career approaches in different stages of their lives. Table 7 provides a summary of the main aspects of their career decisions.
Table 7

*Key Elements in Career Decisions Parents of PWD Across Lifespan*  

<table>
<thead>
<tr>
<th>Life Stage</th>
<th>Goals</th>
<th>Moderators and influencers</th>
<th>Decision Process</th>
</tr>
</thead>
</table>
| Early career after college                     | § Financial independence
§ Fulfill vocational interests
§ Professional growth                                  | § Personal values
§ Socioeconomic status
§ Educational background
§ Available opportunities                           | § Focused on individual needs and interests
§ No extensive reflection about factors               |
| Career decisions influenced by plans to have a family | § Have a family
§ Professional growth
§ Family Financial Provision (M)
§ Accommodate care when needed (W)                   | § Personal values
§ Beliefs about gender roles in the couple
§ Couple’s assessment of the value of each one’s occupation (status, stability, growth potential, reward) | § Decision mostly individual but considering factors as a couple (W)
§ Sometimes include explicit negotiations in the couple |
| Disability diagnosis and other challenging situations | § Accommodate care needs
§ Minimize impact on work to the maximum extent possible
§ Maintain family/care financial provision          | § Personal Values
§ Beliefs about gender roles in the couple
§ Couple’s assessment of the value of each one’s occupation’s (status, stability, growth potential, reward)
§ Available support (family/employers)               | § Drastic decisions driven by urgent care needs
§ No focus on career – ‘career shutdown’
§ Couple’s joint decision although not explicitly discussed or negotiated |
| After some years of exceptional care             | § Attain and sustain Life Domains Synchrony for longer periods
§ Provide good care
§ Professional fulfillment
§ Ensure long-term employability                     | § Personal Values
§ Family care and self-care needs
§ Ability to provide good care (financial, skills, and time resources)
§ Available support (family/employers)
§ New conceptions of work and career
§ Developmental opportunities                          | § Questioning-reframing-rearranging process - well thought decision considering all life domains
§ Decision discussed and negotiated in the couple (when married) |

*(W) and (M) denote elements more frequently reported by women and men, respectively.*
Early Career After College. The interviewees’ initial career decisions after college graduation were usually made without too much reflection. They followed an almost automatic process focused on building financial patrimony and asserting themselves in their career of choice – connected to their field of study. The main criteria driving these early career decisions were mostly based on job characteristics, particularly the connection to their vocational interest, compensation, and potential for professional growth. These career decisions were also made from an individualist perspective, although those with contextual constraints – for example, needing to help their parents with additional income or ensuring enough income to survive by themselves – considered the expectations and needs of their families when making these early career decisions. Consequently, some opted for jobs that would provide needed income in lieu of their vocational interests.

Although Social Cognitive Career Theory (Lent, 2020) provides a comprehensive framework and offers a good explanation to describe these professionals’ initial career decisions, this theory does not account for the unpredictable factors that could significantly impact these parents’ careers and the consequential changes to career decision-making approaches in the later stages of their lives.

Career Decisions Influenced by Plans to Have a Family. Particularly for women, the way these parents made career decisions changed significantly as they started to consider marriage and motherhood. At this stage, women’s career decisions were not individually focused anymore. They considered their partner’s careers and envisioned necessary changes to have a family and accommodate care work (Greenhaus & Kossek, 2014; Greenhaus & Powell, 2012), even if motherhood was still only a plan. Thus, career
planning moves from an individualistic to a negotiated approach, although this negotiation in the couple was often not explicitly conducted. Although most fathers did not make any significant changes in their career decision-making process at this stage, they considered family financial needs in their career decisions. Still, there was almost no mention of concerns about caring for children or their spouses’ careers.

Two main contextual factors influenced decisions at this stage: first, personal values and conceptions about gender roles, and second, an appraisal of the professional value of each member of the couple. By professional value, I mean not only which parent had a better-compensated job but also a perception of the potential for growth in terms of salary and status, and lower risk of becoming unemployed. In most of the interviews, these two influencing factors were evaluated from the perspective of the couple and, when combined, would favor men’s employment, not women’s, on most occasions.

Although this was not completely surprising, it was still striking to witness the gender factor weighting in career decisions at this stage. In the case of these parents, the perception of women’s and men’s professional values and definition of care attributions shaped career decisions even before motherhood was a concrete reality. Besides gender roles, gendered conceptions in the workforce and gendered organizations (Acker, 2012; Ridgeway, 2009) also shaped these decisions. In Brazil, women’s average income is 21% lower than men’s – a consequence of the gender wage gap in most professions, higher unemployment levels among women, and a disproportional presence of women in professions with historically lower salaries, including education, social services, and health sectors (DIEESE, 2023). Further, women more commonly work as self-employed than men, and according to interviewed parents, self-employed individuals can more
easily restart their careers than those employed by organizations. Hence, in a life stage when income and job stability are critical to having a family, the perception of lower value of self-employed or female-dominated professions or, presumably, women’s lower potential to achieve top positions and higher salaries or, again, apparently women’s higher risk of becoming unemployed, makes it easy and often automatic for a couple to decide which career is worth more and needs to be preserved.

As happened with the mothers interviewed in this study, it is paramount to notice that the decisions that women often make in benefit of the ‘family to become’ will likely keep happening when they effectively become mothers, and again in the case of a disability diagnosis in their children, and again when their parents, or other relatives, including spouses, became ill or elderly (O’Brien et al., 2021). This pattern reinforces perceptions in the workplace and society as a role, that women, and not men, are suited for care work and are less reliable or less productive professionals as they share their time and attention to care for everybody else (Acker, 2012; Padavic et al., 2020; O’Brien et al., 2021). It is imperative to say that I am not advocating for women to stop considering the caring needs of others in their career decisions. However, I will advocate in future sections that all individuals should consider caring needs, including their own self-care needs, in their career decisions, and this should be normalized by career counselors, human resource professionals, leaders, and organizations.

**Career Shocks and Career Shutdown.** The career stories of these parents showed that at the moment they received their kids’ diagnosis and also during other challenging situations – such as life-threatening health complications, lack of necessary treatment options, or a prolonged crisis – they experienced what has been described in the
literature as *career shocks* (Akkermans et al., 2018). Akkermans and colleagues defined career shocks as “a disruptive and extraordinary event that is, at least to some degree, caused by factors outside the focal individual’s control and that triggers a deliberate thought process concerning one’s career” (p. 4). Although these shocks can be related to events in personal and professional domains, they often prompt career reflections and may cause significant career impacts.

Interestingly, the findings of this study show that at ‘shocking moments,’ many parents experienced a ‘career shutdown.’ They declared not having any mental and emotional capacity to think about their careers. Although some of these parents had to make some decisions related to work in the aftermath of a shock, these decisions were driven by urgent caring needs and did not involve significant deliberation about future career implications. This phenomenon is aligned with what Akkermans and colleagues (2018) discussed as “differential impacts of career shocks,” when some individuals need more time to process the disrupting situation and deliberations about their career would come later, which happened with many of these parents.

In general, two main patterns were observed in the decisions made as an automatic reaction to the shock of receiving a diagnosis or experiencing challenging situations related to the care of their children. Some parents made drastic decisions prioritizing the urgent care needs of their children, including reducing working time, stopping working, or making sudden job changes. In the opposite direction, some parents did not make any changes and strived to avoid any disturbances in their work. In both cases, no significant career deliberation happened in the aftermath of the shock. Wordsworth and Nilakant (2021) examined the career decisions of professionals who
went through a disruptive natural catastrophe and also observed that not all individuals in
the study engaged in career reflections immediately after the shock. Likewise, the parents
in this study needed some time to process and start a career reflection. In the case of these
caregivers, this career deliberation process was more significant among those more
heavily involved with caregiving activities and was ignited by significant dissatisfaction
in their lives or by reaching a threshold after subsequent career shocks (Akkermans et al.,
2018; Wordsworth & Nilakant, 2021. Interestingly, experiencing exceptional care seems
to promote mindset transformation (Scorgie et al., 2004), which also contributes to career
deliberation, as discussed next.

**Engaging in Career Transformation.** Career shock theory posits that disrupting
circumstances often prompt career deliberations. Moreover, the depth of this reflection
process and the way individuals react to it and make career changes depend on the
interaction of individual and contextual factors, as well as the characteristics of these
disruptions – including duration, frequency, predictability, controllability, source,
duration, and valence (Akkermans et al., 2018). Aligned with this proposition, parents of
PWD went through different levels of deliberation after the initial shock of the disability
diagnosis.

At some point, after going through several critical moments, often resulting in
amplified conflict between paid work and care work demands, these caregivers started a
process of questioning their current situation. For some, a specific fact accelerated a
reflective process that was not completely overt; for others, the accumulation of several
incidents reached a threshold that triggered a more intentional process of reflection
(Akkermans et al., 2018). This more intentional deliberation process comprised reflecting
on their level of satisfaction in their many life domains, considering different professional possibilities, reframing engrained concepts of gender roles, work, and career success, adjusting their professional and life expectations, and lastly, making rearrangements on their work and care configurations. This process closely resembles what Mezirow (1994) defined as transformative learning experiences when a disorienting dilemma triggers an examination of beliefs and leads to an exploration of options, relationship negotiation, and a transformed mindset.

The disability diagnosis can be a disorienting dilemma for many parents (Scorgie et al., 2004). As parents experience exceptional care, other future disorienting dilemmas emerge related to the conflict demands between care work and paid work, the disputed interests between developing professionally and being close and connected to their children, or when these parents experience situations of ableism. All these circumstances prompt questions about their identities as parents and professionals and about their future life perspectives (Scorgie et al., 2004). Notably, those caregivers who were more intensely involved in care work engaged in deeper critical reflection about their professional and life goals. These parents were more exposed to crisis-driven needs of exceptional care and faced more frequent disruptions at work due to the unpredictable demands of their children. It was also evident that the interplay of individual factors, such as gender and contextual factors, including organizational and family support, contributed to a more critical reflection and significant mindset change (Akkermans et al., 2018; Wordsworth & Nilakant, 2021).

Job crafting was observable when these parents engaged in rearrangements of their work conditions (Wrzesniewski & Dutton, 2001). For those parents working as
employees in organizational settings, this crafting process included a diligent assessment of their work environment, job design, available support, and an explicit negotiation of their needs. It also entailed creating new professional opportunities and sometimes venturing into entrepreneurship. For self-employed parents, job crafting was visible as they reconfigured their services, started new activities, and invested in acquiring new skills or advancing their expertise. Additionally, it was interesting to observe how some of these parents leveraged the learnings and skills developed with the activity of exceptional care to craft new professional possibilities.

Remarkably, in these situations, the individual background or vocational interest went to second place, as the primary focus was on configuring a work that would bring satisfaction but also accommodate the needs of other life domains. While some individuals were able to leverage their education and passion when creating new work opportunities, others relied on their skills and braved into entirely new fields. Further, many of these parents invested in their education, aiming to prepare for new work opportunities they were pursuing, guarantee other future possibilities, and contribute to their plans of long-term employability. In a way, these parents became life-long learners. Excitingly, these caregivers reported developing an appreciation and taking pleasure in their new professional activities, which raises a question about the weight of a lower level of life domains conflict or a higher sense of synchrony in the overall evaluation of job satisfaction.

Another interesting aspect was that parents who were more engaged in caring activities were able to quickly identify and express the learnings they acquired from experiencing exceptional care and demonstrated self-awareness (Scorgie et al., 2004) and
strong career self-management skills (Hirschi & Koen, 2021). Their experiences parenting a PWD and going through several cycles of questioning-reframing-rearranging their careers equipped them with valuable skills that helped them navigate future career decisions, engage in successful job crafting, efficiently negotiate their needs, and accomplish their many demands in the various life domains. These skills included resilience, problem-solving, time management, flexibility, and self-regulation.

The intersection of exceptional care and career development also promoted two relevant learnings for these parents. First, the importance of self-care, as they realized they needed to care for themselves so they could care for others. Even though this learning came late in their stories and, for many of them, it was still a challenge to be addressed. Yet, being conscious of their needs for self-care was a significant insight. The second point to highlight is the development of empathy, respect, openness, and tolerance that almost all parents of PWD interviewed reported (Scorgie et al., 2004). Even those parents who did not engage as much in care work and did not significantly change their approach to career decisions acquired valuable learnings from their experience that transformed their mindsets and, in their own words, made them better human beings.

It is vital to underscore that despite all the learnings, this does not mean an easy path. These parents acknowledge the randomness of life and their limited ability to plan and control their careers. Nonetheless, when things would go out of control, and situations of conflict or dissatisfaction would occur, these caregivers would re-initiate the questioning-reframing-rearranging process but often starting it from an elevated patamar of self-awareness. Moreover, as these parents recognized the lifelong care needs of their children, investing in their long-term employability became imperative. Therefore, for
parents of PWD more involved in care work, career development became the process of questioning, reframing, and rearranging their professional experiences to attain professional fulfillment, provide good care, ensure long-life employability, and sustain states of Life Domains Synchrony for longer periods of time.

Parents of PWD career decisions in this last stage share many characteristics with what has been described in the literature as Sustainable Careers – an approach that involves opportunities’ renewal, adaptability, and integration across life domains (Newman, 2011). This vision aligns with how parents of PWD approach their careers as they make arrangements and changes to attain Life Domains Synchrony. Further, it connects with the concern of these parents to maintain their employability in the long term, so they respond to the life-long caring needs of their kids. De Vos et al., 2020, posited that the sustainable career concept comprises a systemic perspective, putting attention to context and the interrelatedness of life domains, acknowledging that individual agency is facilitated or constrained by contextual factors such as family norms, organizational policies, and cultural factors, which is very representative of the experiences of parents of PWD. Moreover, sustainable careers encompass a cyclical and self-regulatory process, where learnings from positive and negative life experiences are incorporated as individuals adapt and make career decisions (De Vos et al., 2020). This pattern is present in the questioning-reframing-rearranging cycle that parents of PWD described in their interviews.

The Sustainable Career approach, as proposed by De Vos and colleagues (2020), does not explicitly include care demands and care work in their understanding of what it means to have a sustainable career. Nevertheless, family relationships are incorporated in
their systemic perspective, and indicators of a sustainable career—happiness, health, and productivity (De Vos et al., 2020)—underscore self-care, as a concept that is fundamentally linked to the sustainability of the individuals and their professional careers. Other authors have also connected sustainable careers with family and motherhood (Greenhaus & Kossek, 2014; Herman & Lewis, 2012).

Learnings from this study show that parents of PWD, in their quest for Life Domains Synchrony, approach their careers considering the sustainability of the system, adjusting expectations and work arrangements in a way that they can fulfill their professional interests while caring for others and for themselves the best way possible. In this sense, while health, happiness, and productivity might be important for these caregivers, these also might be seen as ambitious and unsustainable goals, even though De Vos and colleagues (2020) argued that these indicators should be considered through long-term lenses. Perhaps long-term employability and Life Domains Synchrony would be more adequate indicators of career sustainability for these caregivers. Sustainable career theory is in its early developmental stages (McDonald & Hite, 2018), and the findings of this study contribute to the advancement of this theory by informing the process and conditions for the development of sustainable careers.

Proposing a Sustainable Career Development Theory

Parents of PWD who engage in the continuous process of questioning-reframing-rearranging, in the long term, develop careers with similar characteristics to what scholars have described as sustainable careers (De Vos et al., 2020; McDonald & Hite, 2018; Newman, 2011). Inspired by previous definitions of sustainable careers and my study
findings, I posit that sustainable careers promote mutual benefits for individuals, their relationships, and the surrounding context and preserve Life Domains Synchrony through renewal, resilience, and lifelong learning (De Vos et al., 2020; Newman, 2011). I theorize a Sustainable Career Development Process that aims to achieve sustainable careers through a progressing cycle of questioning-reframing-rearranging triggered by career shocks (Akkermans et al., 2018) and transformative experiences (Scorgie et al., 2004). Questioning comprises reflecting on the current situation, assessing needs and interests in the various life domains, and understanding the existing interdependencies of contextual elements. Reframing includes realigning expectations for professional and life goals based on new understandings of the demands and priorities and increased self-awareness. Lastly, rearranging involves taking action to negotiate new work arrangements or craft new job opportunities. Figure 6 illustrates the Sustainable Career Development Process framework and its expected outcomes.

While Sustainable Career Development Process, as proposed, is often initiated by experiences of disruptions and challenges that can occur in any life domain, engaging in the process of questioning-reframing-rearranging depends on the way individuals react to these career shocks (Akkermans et al., 2018). Individuals more intensely and frequently impacted by career shocks or other transformative experiences will engage in deeper critical reflection about their careers, resulting in mindset change and usually some type of work reconfiguration. Furthermore, individuals who undergo some cycles of questioning-reframing-rearranging increase their self-awareness and develop career self-management competence. These enhanced capabilities of self-awareness and career self-
management will trigger and facilitate new cycles of questioning-reframing-rearranging in situations of elevated life domain conflict due to unfulfilled needs or interests.

Figure 6

*Sustainable Career Development Process and Outcomes (developed by the author)*

In this sense, although a disruptive event can initiate Sustainable Career Development Process, individuals might proactively continue the process of questioning-reframing-rearranging driven by an increased propensity to critically assess their careers and reflect on their contexts. It is also likely that Sustainable Career Development Process can be instigated by investment in self-awareness, career self-management, or transformative learning experiences that prompt career deliberation. Learnings from the experiences of parents of PWD show that not every individual will pursue a Sustainable Career Development Process, and it is possible that some individuals will remain in the
initial parts of the cycle without progressing in the developmental spiral. Individual and contextual factors contribute to accelerating or deterring this process.

The combination of career shocks, transformative learning experiences, and career development cycles promotes the advancement of valuable skills that support job crafting and career self-management, including problem-solving, resilience, flexibility, and self-regulation (Hirschi & Koen, 2021). Hence, at each new cycle of questioning-reframing-rearranging, individuals will start from a place of increased self-awareness and personal growth (Hirschi & Koen, 2021).

The proposed Sustainable Career Development Process framework advances previous models and conceptualizations of sustainable careers by explaining the mechanisms through which sustainable careers are developed. This model also incorporates individual and contextual factors as intrinsic to the career decision-making process, as individuals question their status quo in a given context, reframe beliefs and expectations that are attributed to them because of their social identities and cultural norms, and rearrange elements that go beyond work, underscoring the integration of life domains and the fact that career decisions are not made in isolation, but in a relational process that includes negotiations with other stakeholders that are part of the system, including partners and other family members, employers, co-workers, and, sometimes other community members (e.g., service providers). Further, by setting Life Domains Synchrony and long-term employability as the main goals and expected outcomes of a sustainable career, I offer indicators – long-term employability and Life Domains Synchrony – that are more aligned with the concrete needs of caregivers, which can be further developed to assess career sustainability.
The Sustainable Career Development Process framework is not intended as a tool used in support of the early stages of career development. Instead, it aims to explain the career development of professionals with some working experience and whose careers are affected by contextual elements and conflicting needs in their various life domains. The model is suitable for individuals working in different settings – self-employed, entrepreneurs, or employees of organizations. It is a framework based on experiences of care, and therefore, it is probably valuable to adults engaged in any type of care activity. This framework is not a “women’s career model,” understanding that the disposition and acts of care should be considered a central part of any adult’s life and a human moral obligation (Tronto, 1993). However, it is critical to recognize the impact of social gender roles on the distribution of care work demands and the many ramifications of this impact in terms of organizational cultures and public policies. I hope that underscoring care and self-care as vital elements of a sustainable career will help to challenge gender norms in the long run.

In conclusion, considering care for others and ourselves as a human moral obligation and essential condition to ensure the sustainability of our lives, relationships, and environment, and considering the fast-changing and interconnected world, the proposed framework for sustainable career development can be valuable and applicable for adults in general. Moreover, the notion of sustainability applied to careers and career development is pertinent to the challenges individuals and organizations face in our current world with workload intensification, inequalities in the workplace, and the importance of lifelong learning (McDonald & Hite, 2018; Newman, 2011).
Limitations and Recommendations for Future Research

This study contributes to the advancement of theory in two multidisciplinary and interconnected fields – work-life relationships and career development. It responds to calls for more empirical studies that can support the advancement of career shocks theory (Akkermans et al., 2021) and sustainable career theories (De Vos et al., 2020; Van der Heijden et al., 2020) and to an integration of work-life and career development scholarship (Kossek et al., 2021). It also prompts new inquiries about these topics and opens new avenues for future exploration. Before discussing the recommendations for research, it is important to point out some limitations of this study, which might also contribute to identifying areas for further investigation.

Most limitations of this study are related to the choice of population and geography. This study focused on a specific population – parents of PWD in Brazil. Although these parents lived an intensified experience of care, they share many similarities with parents of small children or caregivers of elderly relatives. Nevertheless, some characteristics of exceptional care are exclusive to this population, which, combined with situations of ableism, may lead these parents to specific career decisions and career development processes. Additionally, the caregivers interviewed for this study are part of a privileged group with college degrees and part of the middle-class population living in large metropolitan Brazilian cities. These characteristics enable them to access and pay for resources (medical and educational) and supporting services (domestic workers and other paid support), as well as access more employment opportunities and career options.
Another limitation of this study is that it focuses on the Brazilian population. This is a strength given the dearth of research conducted in South American countries and published in English. At the same time, this is a limitation as the experiences of these parents are deeply connected with the cultural characteristics of the country, particularly the strong patriarchal culture. Although many of the parents interviewed had worked in large and multinational organizations with similar corporate practices to those of their headquarters in the northern hemisphere, Brazilian labor regulations and public policies related to parenthood significantly influence career decisions. Therefore, these particular aspects need to be considered when comparing the outcomes of this study with experiences of caregiving in different countries.

Additionally, while this study investigated the experience of both fathers and mothers, which resulted in a rich comparison, the number of fathers interviewed (n=8) is small compared to the number of mothers (n=19). It is likely that additional patterns could be identified with a larger number of interviews with fathers. Lastly, although it was not a restricting sampling criterion, all families interviewed were in heterosexual relationships. Investigating the experiences of couples in other family configurations, for example, same-sex couples, can contribute to a better understanding of the impact of social gender roles and intersecting social identities.

The limitations of this study indicate several areas for future research. It is necessary to conduct similar studies in different countries with different socioeconomic groups and different family configurations. It can be particularly interesting, for example, to conduct similar investigations in countries with more equitable notions of gender roles, like the Scandinavian countries, and countries with stronger division of gender roles or
more individualistic cultures. There is research reporting the impact of parenting a PWD on employment, work-family conflict, and parental well-being in different countries (see: Brekke & Nadim, 2017; Chou et al., 2013, 2016, 2018; Crettenden et al., 2014; Olsson & Hwang, 2006; Vinck & Van Lancker, 2020; Wright et al., 2016), but I have not been able to find research focused on career development. Examining how same-sex couples distribute care work, assess levels of satisfaction in the professional–care–self-care domains, and make career decisions can inform different, perhaps more equitable, career decision-making processes. Lastly, it is crucial to research families from less privileged backgrounds to inform the development of supportive public policies.

There is opportunity, and need, to conduct studies that examine the application of the two proposed frameworks – Life Domains Synchrony and the Sustainable Career Development Process – in other populations and with other methodological approaches. One potential starting point is to understand if these frameworks are congruent to the experiences of other caregivers, including parents of small children, adults caring for ill or elderly relatives, and adults living with chronic conditions that require increased attention to self-care. The Life Domains model (Figure 3), the concept of Life Domains Synchrony, and the Attaining Life Domains Synchrony Framework (Figure 4), and the Life Domains Dynamic from a Family Perspective (Figure 5) can be further explored in numerous ways. For example, it might be valuable to further explore how couples assess these different life domains and evaluate their collaborative efforts in the care sphere and how this impacts their participation in the professional domain. Moreover, examining individuals’ propensity and ability to engage in self-care is an area of study that deserves attention, given the increased discussion of how mental health is impacting the workforce.
and becoming a critical public health concern. Additionally, studies to build instruments and measurements to assess the level of Life Domains Synchrony and long-term employability as indicators of career sustainability might be a relevant avenue to further develop the Sustainable Career Development Process model.

Exploring the mechanisms of career shocks and how contextual factors shape reactions and consequences of career shocks is also an area where more research is needed (Akkermans et al., 2018). This study offered insights into how disruptions promoted critical reflection and mindset change in those professionals more strongly engaged in caring activities. There was also an indication that the transformative experience of exceptional care contributed to a continuation of the questioning-reframing-rearranging cycle that leads to sustainable career development. Therefore, transformative learning might be a strategy to foster sustainable career development, but more research is needed to evaluate this hypothesis. Further, there is an opportunity to examine which contextual elements can create environments that support individuals in processing and healing from career disruptions in more productive ways and that are conducive to sustainable career development.

From the organizational perspective, there are several ways future research can be developed by leveraging the findings of this study. Considering the important role of leaders, co-workers, and organizational culture in supporting caregivers to attain Life Domains Synchrony and develop their careers, it is important to investigate potential HRD strategies that can facilitate this process. Some questions that can be investigated: How can leaders and teams support individuals in the aftermath of career shocks? Which learning and development strategies are effective in preparing leaders and teams to cope
with disruptive situations, minimizing the impact on work while allowing space to process and heal? How do organizational structures, team dynamics, job designs, and flexible working arrangements need to evolve to embrace care as an essential part of any adult life? Which interventions can help an organization reflect on ingrained beliefs about gender roles and implement strategies to reduce the impact of gendered structures, processes, and policies? How can supporting an exceptional caregiver transform the mindsets of leaders and co-workers and contribute to more diverse and inclusive workplaces?

Because care is a topic that has been disregarded in the professional domain and organizational debate, there are extensive opportunities for future research and relevant implications for practice, which are described next.

**Implications for Practice**

This study offers practical implications for different stakeholders – career development professionals, human resources professionals, organizations, public policymakers, and society. Before detailing the implications for each of the above groups, I want to highlight two vital implications that should serve as a foundation for all others. First, the valorization of care as a critical social practice for the sustainability of our society and planet; and second, the importance of not assuming the inclination, competence, and duty for care as part of women’s nature but centering care as a collective responsibility.

For career development professionals, including career counselors, career coaches, and HR professionals, it is imperative to embrace more relational approaches to
career development, considering individual identities, contextual factors, and the integration of other life domains. Additionally, normalizing career shocks and the unpredictability of life is critical to motivating individuals going through disruptions to look for career support. The proposed frameworks for Life Domains Synchrony and Sustainable Career Development Process can help these professionals to have conversations that are more congruent with the experiences of many adults, particularly caregivers. The Life Domains Synchrony framework can support discussion about interests and the allocation of resources in multiple domains and motivate conversations about caring and self-care that are commonly disregarded. Career development professionals can also facilitate the questioning-rearranging-reframing cycles within the Sustainable Career Development Process framework and help individuals process career shocks, reducing the “career shutdown” period or avoiding drastic career decisions made in the aftermath of disruptions.

For human resources professionals working in organizational settings, one critical implication is the necessary preparation of these professionals to support employees experiencing high levels of life domains conflict. The interviews showed that many parents did not feel comfortable disclosing their family situation to human resources professionals. Oftentimes, this discomfort prevented them from seeking support from human resources or other internal supporting structures besides their leaders. Therefore, human resources professionals and other employees’ supportive structures within an organization should be prepared to deal with challenging situations that are part of human life and, when necessary, serve as a facilitator between employees’ needs (e.g., time-off, flexible working arrangements, job redesign) and their leaders and teams. Raising
awareness and providing training for leaders is also important so they can feel more comfortable handling conversations about disabilities, illness, and other life challenges. It is also important that leaders are informed about institutional supportive policies available so they can share and agree with their employees about adequate working arrangements and other supports. Having institutionalized supportive policies can facilitate the disclosure of difficult situations and can help professionals digest and cope with career shocks (Akkermans et al., 2018). Moreover, institutionalized policies minimize supervisors’ discretion and co-workers’ unfair judgment.

Fostering a caring culture is important if organizations want to support and retain employees experiencing challenging caregiving situations. A caring and family-friendly culture respects the needs adults have in the care and self-care domains of their lives. Enabling job redesign, workload reductions (Kossek & Ollier-Malaterre, 2020), and flexible working arrangements are essential strategies to accommodate caring demands. Together with these initiatives, it is paramount that performance evaluation processes and criteria are consonant with a culture that values care and self-care and does not penalize employees who adopt these work rearrangement strategies. Along the same lines, it is crucial that organizations be attentive to gender bias and ableism that significantly impact the experience of exceptional caregivers. As observed in the findings, many competent professionals quit their jobs in organizations due to a lack of support. The majority of them found more supportive employers or more flexible work opportunities and were successful in their careers. Additionally, these professionals developed valuable skills and could be strong champions of diversity and inclusion initiatives. Therefore, organizations may be losing good talent by not being more supportive of caring demands.
There are also important implications for policymakers. Self-employed professionals experiencing exceptional caregiving can face situations of vulnerability as they do not have the same benefits that employees in organizations have, particularly in Brazil, where the Consolidated Labor Law (CLT) offers some guarantees to employees in long-term employment contracts. Therefore, public policies should be implemented to support self-employed caregivers who need to reduce their workload with a negative impact on their income. Workforce development and career development initiatives could also be implemented to help those caregivers who need to make a change in their careers to accommodate care or who want to develop professionally to ensure their long-term employability. It is also critical that childcare and schools are prepared to receive children with disabilities so their parents can dedicate time to work. Public policies that ensure the rights of exceptional caregivers to reduce their workloads without losing their jobs could contribute to fewer people deciding to quit their jobs, particularly women, as well as reducing situations of burnout and other mental and physical health problems.

Conclusion

I close this dissertation with a quote from Joan Tronto (1993): “The world will look different if we move care from its current peripheral location to a place near the center of human life” (p. 101). Unfortunately, she wrote this 30 years ago, and not much progress has happened since then. Instead, we observe the worsening of mental health in the global population, an increasing amount of workload, and the advancing wave of neoliberalism that insists on ignoring interdependencies and the damages caused by the excessive focus on short-term performance. I urge the HRD field to reflect on our role in
supporting more sustainable human development and be more attentive to how individuals experience work in the broader context of their lives and relationships. I hope that this work, beyond its theoretical contributions, will raise awareness of our vulnerabilities and interdependencies and will challenge the centrality of work as the main aspect of our lives, our identities, and our worth as human beings.

Further, it is my wish that the inspiring stories collected in this study can serve as a motivation to other parents who find themselves in similarly challenging circumstances, as a reason to nurture hope and have a more positive perspective of what the future can offer when they engage in reflection, challenge established social norms, and join forces to combat patriarchy and ableism. Hopefully, these stories can also prompt transformation in other individuals, fostering respect for what is different and empathy for those who give and receive care.
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Appendix A: Recruitment Letter

Hello,

My name is Ana Carolina Rodriguez, and I am a Ph.D. student at the University of Minnesota (USA). For my doctoral thesis, I am researching how parents of people with disabilities make decisions about their professional careers to better accommodate their professional and personal lives.

I got your contact from __________. If you are a parent of a disabled person, have a higher education degree, and have or have had a professional activity for at least two years while also participating in the care of your child, I would love to hear about your experience.

If you accept my invitation, we will schedule an interview that should take around 60-90 minutes on a day and place of your convenience.

Your participation is completely voluntary, and you can choose not to participate without any consequences, even during the interview. Your identity will be kept confidential in the analysis and reporting of this research. In the attached document, you will find more information about the research, the interview, and how the collected data will be processed can be found in the attached document.

Please return this email, answering the questions below and adding any questions you may have. Your participation is of great importance to this research.

Thank you so much!

Ana Carolina
WhatsApp: + 1 612 703 4554
e-mail: rodr0667@umn.edu

Are you a parent of a disabled person? ☐ Yes ☐ No
Do you have a higher education degree? ☐ Yes ☐ No
Do you have or have had a professional activity for at least two years while participating in the care of your child? ☐ Yes ☐ No

Add here any questions you may have about this invitation and research:
Appendix B: Consent Form

Title of Research Study: Investigating career decisions of parents of people with disabilities

Investigator Team Contact Information:
For questions about research appointments, the research study, research results, or other concerns, call the study team at:

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<th>Investigator: Alexandre Ardichvili</th>
<th>Student Investigator: Ana Carolina Rodriguez</th>
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<td>Investigator Departmental Affiliation: Organizational Leadership, Policy, and Development – University of Minnesota</td>
<td>Investigator Departmental Affiliation: Organizational Leadership, Policy, and Development – University of Minnesota</td>
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<tr>
<td>Phone Number: +1 612 626 4529 Email Address: <a href="mailto:ardic001@umn.edu">ardic001@umn.edu</a></td>
<td>Phone Number/ WhatsApp: +1 612 703 4554 Email Address: <a href="mailto:rodr0667@umn.edu">rodr0667@umn.edu</a></td>
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What is this research?
This research aims to understand how parents of people with disabilities make decisions about their professional careers to better accommodate their professional and personal lives. The final purpose is to offer recommendations for human resources development practitioners, organizations, career counseling professionals, and public policymakers on how to support the professional experiences of these parents.

Why am I being invited to take part in this research study?
We are asking you to take part in this research study because you are a parent of an individual with a disability who also have or have had paid working experience while participating in the care work of your child. Your participation will contribute to the results of this study being relevant and applicable to the real world.

What should I know about a research study?
- Whether or not you take part is up to you.
- You can ask all the questions you want before you decide.
- You can choose not to take part.
- You can agree to take part and later change your mind.
- Your decision will not be held against you.

What happens if I say “Yes, I want to be in this research”?
We will schedule a 60–90-minute interview with you. The interview will be conducted by the student researcher (Ana Carolina) either in person or through a Zoom call. I will ask questions about your professional experiences and career decisions.
What happens to the information collected for the research?
With your permission, we would like to record our conversation for future data analysis. The recordings and transcripts of the research will be kept private, and all data collected will be securely stored in accordance with the protection policy of confidentiality of the University of Minnesota (reviewed by the Ethics Committee, Protocol No. xxxxxxxxx). Only researchers participating in this project will have access to recordings and transcripts.

The results of this research are expected to be presented at congresses and published. However, we will not include any information about you that makes it possible for you to identify yourself directly.

You are also free to refuse to answer any of the questions or request to interrupt or complete the recording at any time during the interview.

What happens if I say “Yes”, but I change my mind later?
You can leave the research study at any time, and no one will be upset by your decision. If you decide to leave the research study, contact the investigator so that the investigator can delete the interview recording and transcripts.

Is there any way that being in this study could be bad for me?
We do not anticipate any risks for you if you decide to participate in this study. If you experience any discomfort during the interview, inform the researcher, and they will interrupt the interview if you prefer.

Whom do I contact if I have questions, concerns, or feedback about my experience?
This research has been reviewed and approved by an IRB within the Human Research Protections Program (HRPP). To share feedback privately with the HRPP about your research experience, call the Research Participants’ Advocate Line at 612-625-1650 (Toll Free: 1-888-224-8636) or go to z.umn.edu/participants.

Consent:
- Do you agree to participate?
- I may need to cite part of this interview in publications and presentations resulting from this research. Do you allow me to quote your comments (without being possible your direct identification) in publications and presentations about the research?
- Do you accept that our conversation is recorded to assist in the analysis of the interview?
EXEMPTION DETERMINATION

March 7, 2023

Alexandre Ardichvili

651-489-0790
ardic001@umn.edu

Dear Alexandre Ardichvili:

On 3/7/2023, the IRB reviewed the following submission:

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Driven to Discover™
Appendix D: Interview Guide

1. Can you tell me about your first employment after college?
   a. What were your career expectations at that time?
   b. What did your work mean to you at that time?
   c. Which space did work occupy in your life at that time?
   d. What were your plans for the future at that time?

2. From your first job after college to now, what were the biggest career changes you made? [probe each one]
   a. Can you tell me more about how this change happened?
   b. How did you come to this decision?
   c. What factors did you consider while making this decision?
   d. What/who has helped you when making this decision?
   e. What/who has helped you while you were going through this change?
   f. How did you feel about this decision/change at that time?
   g. What were the outcomes of this decision/change?

3. How was it for you when your child was born/became disabled?
   a. How was your return to work?
   b. How did you feel about returning to work?
   c. What kind of support did you get from your employer/supervisor/team?
   d. What else could have helped you?
   e. What has changed for you after your return?

4. Thinking about the present moment, what does work mean for you?
   a. [If the meaning is different than before] What do you think has contributed to this change?
   b. How does your relationship with work differ, if so, from how it was before? [probe impact of parenting a PWD]
   c. What does professional or career success mean to you?

5. How have you changed professionally?
a. How would you describe the professional you were before and who you are now? What has changed?
b. Which factors contributed to this change?
c. How the experience of parenting a child with a disability has changed you as a professional, if at all?

6. How satisfied are you with your current work/career?
   a. What could improve your level of satisfaction with your work?
   b. [if dissatisfied] Do you envision any future changes? Can you share more about them? What would you need to make this change?

7. [for participants living with their partners] How has your partner's career changed after your child was born/became disabled?
   a. Do you think their experience with work was different from yours? How?
   b. Do you discuss jointly about your career decisions? How does this conversation happen?

8. Is there any other aspect of your professional experience being a parent of a child with a disability that I did not ask about but you think is important to share?

9. How do you feel about our conversation?

10. Do you have any questions for me?