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# Adapting parenthood: an online resource and education platform for occupational therapy practitioners supporting parents with physical disabilities

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Doctoral Project

**ADAPTING PARENTHOOD:  
AN ONLINE RESOURCE AND EDUCATION PLATFORM  
FOR OCCUPATIONAL THERAPY PRACTITIONERS SUPPORTING  
PARENTS WITH PHYSICAL DISABILITIES**

by

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requirements for the degree of  
Doctor of Occupational Therapy

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## **DEDICATION**

I would like to dedicate this work to all who wish to live in world that is open to diversity, supportive of difference, and celebrates adaptability and creativity.

## **ACKNOWLEDGMENTS**

I applied for the Post-Professional Doctor of Occupational Therapy (PP-OTD) program at Boston University during a shift in global health, my career, and my parenting journey. In the spring of 2020, I had been preparing to apply for new jobs and send both my young children to school for the first time. However, when the world came to a standstill during the COVID-19 Pandemic, so did many of the meaningful occupations that defined my identity as a friend, professional, and individual. Suddenly, I found myself in the roles of stay-at-home parent, educator, and entertainer, losing some of the outlets that had previously nurtured my mental health. To reclaim both my sanity and my identities, I decided to take a leap and return to school.

Thank you to my supportive and loving husband, Nathan, for the constant encouragement and confidence in me. Thank you to my daughters, Hadley and Riley, for their sweet hugs and everlasting love and admiration. Thank you to my parents for being there for me, and helping out with the girls when I needed it most. Thank you to my OT Bestie, Amy, for paving the possibility of going back to school and encouraging me to do more of what I love. Thank you to my business partner and co-founder, Gayle, for your cheerleading and your support every step of the way. Thank you to my friends and family for your advice, words of encouragement, and company. And last, but certainly not least, thank you to my peer mentor, Emily Scannell, my academic mentor, Karen Duddy, my classmates, and instructors of the PP-OTD Program at Boston University.

## **PREFACE**

This manuscript is in part influenced by the educational background, life experience, gender, ethnicity, culture, roles, and identity of the author. The author does not identify as a disabled person, however, is an Ally and advocate for disabled and neurodiverse individuals.

This manuscript uses both person-first and identity-first language to honor and include the preferences of the disabled community and within the profession of occupational therapy to “prioritize working for social change” (Harrison et al., 2021, para 1).

**ADAPTING PARENTHOOD:  
AN ONLINE RESOURCE AND EDUCATION PLATFORM  
FOR OCCUPATIONAL THERAPY PRACTITIONERS SUPPORTING  
PARENTING ROLES AND OCCUPATIONS**

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**ABSTRACT**

Parenting roles and occupations are complex and become even more challenging when navigated with a physical disability. Physical, social, and political barriers are among many factors that shape experiences in parenting and disability. Occupational therapy practitioners (OTPs), with their holistic and client-centered approach, are ideally positioned to provide professional support to alleviate or adapt to environmental barriers. However, OTPs confront their own barriers to providing services, including a deficit in and accessibility to occupation therapy-specific resources and education on disability and parenting. These factors together result in a gap in service between disabled parents and occupational therapy.

This doctoral manuscript offers a potential solution to these issues in the form of *Adapting Parenthood*, an online resource and education platform for OTPs. The platform is designed to provide occupational therapy specific professional education for practitioners working with parents who experience barriers in their parenting roles due to disability or related factors.



*Adapting Parenthood* offers a user-friendly, digital interface that allows users to navigate at their own pace, fostering autonomy, and learning motivation. It incorporates a range of multimedia resources, catering to various learning styles and preferences, to enhance user engagement and information retention.

The platform is organized into topic areas comprised of resources and educational modules. The resources include a diverse range of documents, manuals, recommendations, and legal information intended to supplement interventions and enhance the practice of healthcare professionals. The educational modules focus on topic areas where practitioners may need to refine their skills and knowledge when working with parents with physical disabilities. These topics include adapting parenting occupations, home modification and universal design, as well as disability-affirming education on interdependence, social support, and disability rights related to parenting.

The content and design of *Adapting Parenthood* underscores the importance of disability-affirming practice. It emphasizes understanding the unique lived experiences of disabled individuals, particularly those who are parents, and the development of support that mitigate and alleviate the challenges they face. Ultimately, this dissertation provides an in-depth analysis of the unique challenges faced by parents with physical disabilities and proposes a comprehensive online platform to support and educate OTPs working with this population. *Adapting Parenthood* aims to bridge the service gap and foster a more inclusive and supportive environment for disabled parents.

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## GLOSSARY

**Adapt:** The process of modifying or adjusting behaviors, environments, practices, or tools to better fit the needs and abilities of an individual (Oxford English Dictionary, n.d.). In the context of disability, adaptation can involve creative problem-solving to enable participation and engagement in various life areas, including parenting roles and occupations. Adaptation recognizes the interaction between the individual and their environment and seeks to enhance accessibility and inclusivity.

**Co-occupation:** An activity which necessitate the participation of both the caregiver and the recipient (AOTA, 2020).

**Disability-affirming:** An approach or attitude that acknowledges, respects, and values the full potential of disabled individuals (Wasserman & Aas, 2011). Disability-affirming perspectives seek to promote a positive understanding of disability, challenge prejudiced views, and advocate for inclusivity, accessibility, and equity. In this context, this approach emphasizes the importance of understanding disability as an aspect of diversity and human experience rather than a deficit.

**Occupational therapy practitioner (OTP):** An individual who is trained and licensed to practice occupational therapy (AOTA, 2020). In this context, this includes OT clinicians who work directly with clients in various settings, OT educators who teach and mentor students in academic settings, and OT students who are enrolled in an accredited academic program in occupational therapy.

**Parent:** An individual who assumes the primary responsibility of raising and nurturing a child. This term is inclusive and recognizes biological, adoptive, honorary, and situational parents, as well as others who may not fit traditional definitions but who play a substantial role in a child's upbringing and development (Oxford English Dictionary, n.d.).

**Parenthood:** The state or role of being a parent, which involves raising and nurturing a child. Parenthood encompasses a wide range of responsibilities and activities, including but not limited to, daily caregiving, teaching, guiding, and supporting a child's emotional, social, and physical development. This term recognizes that parenting can take on different forms and structures across different cultures, societies, and individual circumstances and can evolve over time as the child grows and the parent's role changes (Oxford English Dictionary, n.d.).

**Parenting occupations:** In this context, the range of activities and tasks involved in raising and caring for a child. This can include, but is not limited to, daily care tasks, teaching, guiding, supporting emotional development, and participating in leisure activities with the child. Parenting occupations acknowledge the complexity and diversity

of tasks involved in parenting and recognize their significance in both the parent's and child's lives.

**Parenting roles:** In this context, the responsibilities, functions, and identities that a person assumes or is assigned when becoming a parent. This can encompass a wide array of roles including caregiver, teacher, protector, provider, role model, and more. Parenting roles can vary based on cultural, societal, familial, and individual factors, and can evolve over time as the child grows.

**Physical disability:** In this context, a condition or identity that involves long-term or temporary physical differences which may affect an individual's mobility, sensory systems, physical capacity, stamina, or dexterity. This term acknowledges a broad spectrum of experiences and recognizes that disabilities can be inherent or acquired, visible or invisible, and can impact life in diverse ways.

## **CHAPTER ONE – Introduction**

Parenthood embodies the adjustment to new roles, occupations, routines, and identities. Parenting can be challenging, requiring physical, emotional, and social efforts, as well as the acquisition of new skills. Parenting involves numerous co-occupations, which necessitate the participation of both the caregiver and the recipient to perform a task (Boop et al., 2020).

The Occupational Therapy Practice Framework - Fourth Edition (OTPF-4) refers to parenting in the context of occupations, roles, routines, and personal factors (Boop et al., 2020). Addressing challenges of parenting aligns well with occupational therapy due to the profession's holistic, client-centered nature (Terasoff, 2017). Occupational therapy interventions related to childcare or parenting may result in increased participation and satisfaction in co-occupations, reduced parenting-related stress and anxiety, and enhanced well-being (Lim et al, 2022).

About 6% of parents with dependent children have a disability (Wint et al., 2016). The challenges related to parenting activities are magnified for disabled individuals due to environmental barriers and a lack of sufficient support. As a result, disabled parents often face a shortage of necessary resources and struggle with some aspects of parental roles and occupations (Boop et al., 2020). These obstacles can lead to decreased mental and physical well-being, increased risk of injury, and safety issues. Social and professional support for these obstacles is often needed and frequently not received (Lightfoot et al., 2018). In addition, support that is offered frequently fails to consider the context or environment in which the disability exists (Brennan & Swords, 2021).



As healthcare practitioners, OTPs commonly address occupational barriers related to disability. Parenting is a common role and likely to be a meaningful part of the lives of occupational therapy clients. It is crucial for practitioners to understand occupational performance skills related to parenting within the context of disability.

The scope of the problem addressed in this paper highlights two main issues faced by disabled parents. First, these parents experience environmental barriers that affect their participation and identity as parents. Second, while occupational therapists are well-suited to support parents with physical disabilities in their performance and participation in parenting occupations and identity, they often lack the knowledge, tools, or professional or clinical structure to do so effectively (Lim et al., 2022). These issues combined result in a gap in care between disabled parents and OTPs.

In light of the identified gap, the author proposes *Adapting Parenthood*, an online resource and education platform designed to provide accessible and comprehensive support for OTPs and other interested parties. *Adapting Parenthood* consists of two principal components: a resource library with informative and instructional materials, and educational modules that offer professional development and Continuing Education Units (CEUs). The resources aim to address aspects of parenting with a physical disability, and the modules strive to either supplement existing clinical skills or introduce new topics of interest. This project operates under the documented need for comprehensive, disability-affirming, and profession-specific information to enhance treatment strategies and ultimately improve support for parents with physical disabilities (Kirshbaum, 2013; Lim et al., 2022 & Wint et al., 2016).

In the context of this manuscript, physical disability is defined as a condition or identity that involves long-term or temporary physical differences which may affect an individual's mobility, sensory systems, physical capacity, stamina, or dexterity. This term acknowledges a broad spectrum of experiences and recognizes that disabilities can be inherent or acquired, visible or invisible, and can impact life in diverse ways. The author acknowledges that disability is multi-factorial. Though physical disabilities are the focus of this manuscript, much of the information is also relevant to other types of disabilities.

The rest of this paper will further explain the problem to be addressed and the proposed solution. Chapter Two presents an in-depth analysis of the problems facing parents with physical disabilities and identifies the factors contributing to these challenges. Chapter Three provides a comprehensive literature review, illustrating the current state of occupational therapy support and resources for disabled parents. In Chapter Four, the author introduces the proposed solution, *Adapting Parenthood*—a digital platform designed to enhance the competency and knowledge of OTPs working with this population. Chapter Five outlines the plan for evaluating the effectiveness of the *Adapting Parenthood* platform, providing detailed methodologies and strategies. The methods for disseminating information about the platform to the relevant audiences are discussed in Chapter Six, while Chapter Seven offers a funding plan to ensure the financial sustainability of the project. Finally, Chapter Eight concludes the paper by highlighting the potential significance of the *Adapting Parenthood* platform in the field of occupational therapy.

## **CHAPTER TWO – Project Theoretical and Evidence Base**

This chapter offers a comprehensive review of the unique obstacles faced by parents with physical disabilities. It will also investigate the obstacles that professionals working in the field encounter when attempting to address the challenges related to parenting roles and occupations for disabled parents. The combination of factors affecting both the population and service delivery sides contributes to a notable gap in care.

### **Significance**

The significance of the challenges confronted by parents with physical disabilities is substantial and multi-layered. An estimated 6% of parents with dependent children have a disability (Wint et al., 2016). These parents often require social and professional support in their parenting roles; however, they frequently do not receive the necessary assistance (Lightfoot et al., 2018). These facts underscore the importance of addressing the hurdles faced by parents with physical disabilities and providing appropriate support and resources to promote their well-being and successful parenting experiences. The subsequent sections explore the ramifications of physical disability on physical health, mental wellbeing, and parental rights.

### **Health Outcomes**

Physical health and safety of parents with disabilities can be a concern. Parents with physical disabilities may worry about their own and their children's physical safety, particularly when it comes to lifting and carrying (Brennan & Swords, 2021). Namkung (2019) found that parents with physical disabilities were at a higher risk of frequent physical distress, obesity, smoking, and insufficient sleep compared to parents and non-

parents without disabilities. Furthermore, physically disabled parents often struggle to meet basic needs such as housing, childcare, and finances (Lightfoot et al., 2018).

There is ample evidence of poor mental health outcomes, such as depression, anxiety, and decreased self-esteem, in parents with disabilities (Mazur, 2006). The increased need for planning ahead and securing additional physical, social, or safety support often leads to isolation (Brennan & Swords, 2021). Parents with physical disabilities can also feel that their parenting, particularly around discipline, is ineffective, which can negatively affect their self-esteem and self-worth (Brennan & Swords, 2021). These parents often lack social support, as they report fewer social contacts compared to their non-disabled counterparts (DeZelar & Lightfoot, 2021). Furthermore, social stigma and perception can undermine a parent's self-esteem (Crawford, 2003).

### **The Role of Occupational Therapy**

OTPs are remarkably well-equipped to provide vital services to this population. Their holistic approach, which encompasses the physical, emotional, cognitive, and social aspects of an individual's health and well-being, empowers them to identify and meet specific needs in a comprehensive, personalized manner (Boop et al., 2020). Applying activity analysis, OTPs can adapt or modify parenting tasks to better align with an individual's capability of performing an activity "efficiently, safely, with ease, and without assistance" (Boop et al., 2020, p. 55). Equipped with an understanding of environmental factors and familiarity with assistive technologies and adaptive equipment, OTPs can recommend, customize, and train parents to effectively use these tools to address certain environmental barriers. Their client-centered approach ensures that

interventions are tailored to the unique needs of each individual (Law et al., 1998), and their ability to collaborate across disciplines enables the integration of various services to address complex needs. Therefore, the specialized knowledge, skills, and approach of OTPs make them ideally suited to support disabled parents. Their contributions help navigate the challenges encountered in parenting occupations, ultimately enhancing the overall quality of life and well-being of their clients and families.

### **Occupational Therapy Practice Framework**

The issues faced by parents with disabilities are firmly within the scope of occupational therapy, aligning with the Occupational Therapy Practice Framework - Fourth Edition (OTPF-4) (AOTA, 2020) in several ways. First, these parents often encounter obstacles in their participation in occupations. A study involving mothers with disabilities resulting in upper extremity weakness highlighted some of the difficulties encountered in child-rearing occupations due to disability and environmental limitations (Wint et al., 2016). Tasks such as night-care, bathing, and carrying an infant emerged as particularly challenging due to the physical nature of the activities and safety concerns for both parent and child (Wint et al., 2016).

Parents with disabilities often face barriers in thriving within certain environments or contexts. Aspects contributing to physical, social, political, cultural, and economic environments create barriers to occupational performance. Performance patterns are also disrupted for disabled parents. They may experience deficits in performance skills, which necessitate re-training and accommodations for both parent and child (Wint et al., 2016).

Client factors are “specific capacities, characteristics, or beliefs that reside within

the person, group, or population and influence performance in occupations” (AOTA, 2020, p.17) and significantly impact a person's definition of disability, experience, and identity. Parents with weakness or physical limitations often require adaptations for transportation, feeding, and co-sleeping with their infants and children (Wint et al., 2016). Those with upper extremity or torso differences often resort to unconventional methods or risk injury while carrying their babies (Wint et al., 2016). However, the extent to which physical differences affect the performance of a skill vastly differs and is influenced by lived experience, identity, environment and family and social dynamics.

Parenting is a skill and experience that requires lifelong learning, a familiar concept for disabled individuals. Having had to adapt throughout their lifetimes, parenting becomes a new occupation that necessitates further adaptation. The pre- and post-natal periods, in particular, require unique adaptations, including baby-care modifications, breastfeeding supports, and post-partum planning (Powell et al., 2019).

In conclusion, the challenges faced by parents with disabilities align with multiple aspects of the OTPF-4 (AOTA, 2020) including limitations in occupational participation, environmental barriers as contexts, disrupted performance patterns, performance skill deficits, and the influence of client factors on lived experience and identity. Given that parenting requires lifelong learning and specific adaptations during pre and postnatal periods, occupational therapy plays a pivotal role in facilitating these adaptations, enhancing the quality of life, and promoting independence in parenting occupations. This alignment with the OTPF underscores the importance of meeting the unique needs of disabled parents within the occupational therapy practice scope.

## **Theoretical Framework**

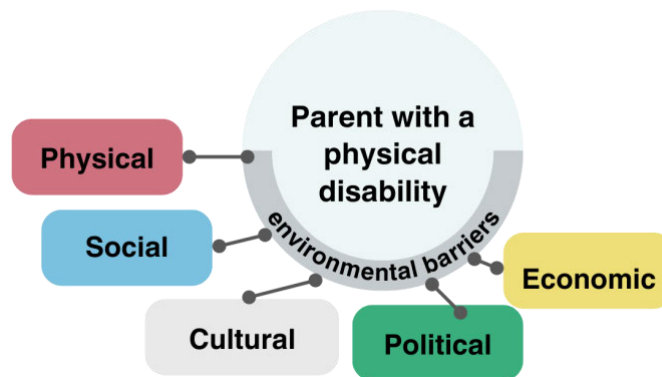
Biomedical models, which do not differentiate between the person and their disabilities, are prevalent in healthcare and social structures. These models often overlook the context or environment in which the disability exists, failing to adequately address roles, or clusters of occupations, such as those required for parenting. These models' focus on body systems, structures, and symptom reduction may limit their effectiveness due to not addressing environmental or contextual barriers (Brennan & Swords, 2021).

In contrast, the Social Model of Disability (SMD) is a theoretical framework that views disability as a societal construct, shaped largely by societal barriers (Anastasiou et al., 2016). The challenges faced by parents with physical disabilities can be more holistically understood through the SMD. This model illuminates the significant impact of the environment on the lived experiences of disabled individuals. It emphasizes the importance of tackling societal attitudes and environmental obstacles to enhance the participation of parents with disabilities in parenting-related occupations. By framing disability within the context of maladaptive social and environmental structures, the SMD opens avenues for creative problem-solving and improving long-term social outcomes (Kirshbaum & Olkin, 2002).

In connection with the SMD, the concept of ableism demands recognition. Ableism defines "disability as a state of exception," perceiving disabled individuals as separate, deviant, and other (Daniels, 2019; p. 115). Research indicates that environmental factors often pose functional and participatory limitations for those with physical disabilities, including physical barriers inherent in environments designed for

non-disabled users, and societal barriers related to bias, discrimination, and judgment (Santos et al., 2019; Farber, 2000; Gitlow, 2021; Parchomiuk, 2014). An ableist society can devalue disabled parents, viewing them as "less-than" or incompetent, often reacting with surprise when a disabled parent displays competent parenting. These societal attitudes can undermine mental health and self-perception of parenting efficacy. More disturbingly, entrenched ableist systems in society can lead to devastating consequences, such as the disproportionate and often unfounded legal removal of parental rights (Powell, 2023).

### **Environmental Barriers**



**Figure 1**

#### *Environmental Barriers for a Parent with Physical Disability*

As illustrated by Figure 1 *Environmental Barriers for a Parent with Physical Disability*, physical, social, cultural, political, and economic barriers contribute to challenges with parenting roles and occupations. The following section, discuss these barriers in detail.



### ***Physical Barriers***

Individuals with disabilities often face physical barriers when performing parenting tasks. The physical environment largely affects mobility, accessibility, and successful engagement in meaningful occupations (Powell et al., 2019; Wint et al., 2016). It is crucial to consider body functions and structures when understanding the context within which occupation and health operate. Even though the motivation, meaning, and desire to carry out occupations exist independently of the physical body, navigating a world designed for a specific body type and function can be challenging, if not impossible. Therefore, it becomes necessary to modify or design furniture, homes, and community spaces to accommodate mobility devices and diverse bodies and abilities.

**Inaccessible Spaces.** Parents with disabilities often find that inaccessible spaces substantially affect their ability to perform parenting roles and tasks. Public spaces like playgrounds, schools, restaurants, shops, and walkways can pose significant challenges for these parents and their children (Wint et al., 2016). In some cases, even areas within their own homes, such as children's bedrooms, can present substantial obstacles (Farber, 2000).

Moreover, childcare devices like swaddles, toys, changing tables, cribs, and other pieces of furniture are frequently designed with "average," non-disabled caregivers in mind, which may not consider the unique needs of disabled parents. The design of objects and architecture can restrict mobility or access for those who do not conform to a certain functional standard (Gitlow, 2021). For instance, parents reliant on wheelchairs often grapple with accessibility issues within their own homes (Wint et al., 2016). A crib with

high, non-adjustable rails, for instance, could be physically taxing or even inaccessible.

**Physical Isolation.** Due to the increased need for planning and securing additional physical, social, or safety support or access, disabled parents often experience physical isolation (Brennan & Swords, 2021). One study (Casey et al., 2022) reported that disabled parents with often found accessible entrances and exits separate or different areas from non-accessible exits, leading to forced separation from others or the main activity. The use of “a different door” drew visual attention to the differences between the disabled parents and the non-disabled parents (Casey et al., 2022).

**Equipment Use.** Another type of physical barrier pertains to the use of mobility devices or other equipment. Parents who use mobility devices have reported problems with proximity to their children (Casey et al., 2022). A study of wheelchair users found that access to children was often limited or blocked by physical aspects of the wheelchair itself or by the user’s static or low position, which also increased the difficulty and risk of injury when lifting, carrying, or accessing children. Issues such as being at a fixed height, not being able to make eye contact, or match the gait or speed of their children were identified as sources of frustration by parents using wheelchairs (Casey et al., 2022).

### ***Social Barriers***

Social barriers significantly impact the challenges faced by individuals with disabilities who have expressed feelings of frustration and a sense of their disabilities being magnified due to social contexts driven by stereotypes, biases, taboos, and inaccurate portrayals (Fraser & Llewellyn, 2015). Social contexts directly impact policies and regulations that overlook or ostracize disabled parents. Societal attitudes can

diminish mental health and self-perception of parental effectiveness (Namkung, 2019).

**Societal Portrayals and Perceptions.** Disabled parents often endure dual discrimination from society based on both their disability and parental status (Namkung, 2019). Historically, society has struggled to support the intersection of parenting and disability as a feasible and healthy scenario (Wint et al., 2016). This discrimination is amplified by societal norms and perceptions, frequently negatively or inaccurately portrayed by popular media (Fraser & Llewellyn, 2015).

Bias, generalization of disability, and stereotypes are prevalent in society, leading to confusion can undermining the capability of disabled parents. These societal perceptions can prompt doubt from family, friends, communities and professionals regarding parental competence (Gitlow et al., 2021). Disabled parents may face pressure not to have children or to give up their children due to societal biases and expectations (Crawford, 2003).

The role of a mother can be particularly scrutinized. Society often views women with disabilities as passive and dependent (Grue & Lærum, 2002) creating a disparity when considering them as capable caretakers of their children. Mothers in a study by Grue & Lærum (2002) reported feeling compelled to visibly "perform" expected mothering duties in public settings. They often lacked social support, reporting fewer social contacts than their non-disabled counterparts.

**Lack of Professional Knowledge and Resources.** Social contexts influence how disability and parenting are perceived, and these, often negative, portrayals contribute to societal bias, generalization, and inexperience or lack of resources among professionals

who could provide useful services. The acquisition of adaptive equipment often relies on professionals who lack adequate knowledge and tools to address the specific needs of parents with physical disabilities (Evans & Orpwood, 2007). A 2019 study surveying OTPs working with disabled populations about parenting occupations reported that there is “an urgent or moderate need for more resources and information related to adaptive equipment, childcare techniques, intervention plans, and evaluation” (Lampe & Gabriel, 2019 p. 241).

Healthcare systems and professionals accessed during the perinatal period influence the beginning of a parenting journey. Perinatal healthcare professionals and educators have reported little, incomprehensive, or inaccurate education on disability within their fields (Smeltzer et al., 2022). In fact, a recent systematic review concluded,

“women with physical disabilities are made to feel different due to negative societal attitudes and unaccommodating environmental structures. Women with physical disabilities face several barriers in accessing maternity care and describe suboptimal care experiences” (Blair et al., 2022 p. 22).

Moreover, studies have also shown that healthcare providers fail to adequately address issues like breastfeeding and pain related to disability after childbirth (Hall et al., 2018).

### ***Cultural Barriers***

Cultural barriers significantly impact the experiences of disabled parents. In many cultures, disability carries an unfortunate connotation of diminished skill in performing tasks that are socially, physically, or environmentally expected (Powell et al., 2019). This

perception, often referred to as ableism, is compounded by cultural norms that do not consider the challenges or capabilities of disabled individuals.

Furthermore, there is an apparent lack of representation of disabled parents in popular media, product design, marketing, and even among peer groups. This absence amplifies their visibility due to external differences and places undue pressure on them to conform to social expectations and prove their competence as parents (Casey et al., 2022; Santos et al., 2019).

Cultural barriers are also present within healthcare systems, which are traditionally focused on minimizing negative health outcomes. This focus often overlooks the positive health experiences, characteristics, and strengths related disability. Traditional models of disablement, centered on pathology, deficits, disease, injury, and illness, often fail to separate the person from their disabilities, neglecting the context or environment in which the disability exists (Brennan & Swords, 2021). These models contribute to a limited representation of positive health outcomes, which can be just as distressing as poor health outcomes themselves. Thus, cultural barriers continue to present a significant challenge for disabled parents, calling for a more inclusive and nuanced approach in healthcare and society at large.

### ***Political Barriers***

Political barriers significantly contribute to the challenges that parents with disabilities face. These range from restrictive modern safety regulations which limit the adaptability of aftermarket caregiving devices and furniture, such as cribs with drop-down rails (Wint et al., 2016), to limited funding and insufficient access mechanisms for

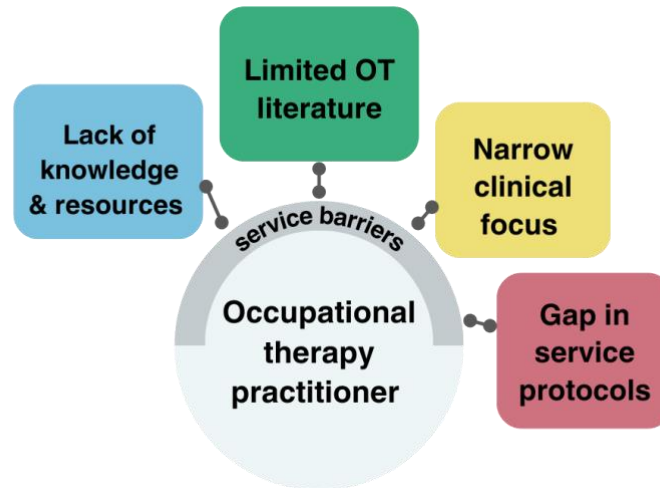
assistive technology. Particularly detrimental are the societal perceptions of incapacity that can exacerbate the difficulties faced by these parents in maintaining their parental rights when they are legally contested (Farber, 2000; Gitlow et al., 2021). In some states, the mere existence of a disability can be used as the primary reason for the removal of parental rights, even in the absence of evidence of abuse or neglect (Gitlow et al., 2021).

Social policies related to disability also pose additional political barriers. Often, there is insufficient funding and unclear support for parenting among disabled individuals. Parents with disabilities frequently confront discrimination, become involved with child welfare systems, face professional biases, and experience a disproportionate rate of parental rights termination (Lightfoot et al, 2018).

### ***Economic Barriers***

Economic barriers pose additional challenges for disabled parents. These parents often grapple with high costs of healthcare, specialized equipment, and basic necessities such as housing and childcare (Lightfoot et al., 2018). The high expenses associated with obtaining assistive technology or modifying existing equipment or environments to accommodate their needs, can limit their ability to utilize these resources (Powell et al., 2019). Furthermore, parents with disabilities may find it difficult to access necessary materials, equipment, or funding for these modifications (Bailey, 2019; Gitlow et al., 2021). Alongside the economic trade-off between income and benefits, the financial pressures associated with these costs can significantly impede the ability of these parents to provide adequate or desired levels of care or resources for their children.

## Service Barriers



**Figure 2**

### *Service Barriers for the Occupational Therapy Practitioner*

As illustrated in Figure 2, *Service Barriers for an Occupational Therapy Practitioner*, multiple barriers exist that prevent or limit the use of occupational therapy as a direct service for parents with physical disabilities. In the following section, we will explore these barriers in more detail.

### *Narrow Clinical Focus*

OTPs (OTPs) should ideally be well-equipped to support parents with disabilities in achieving their parenting goals. However, professional and structural barriers often limit the utilization of occupational therapy for this population. One prevalent issue is the narrow clinical focus among OTPs. While many OTPs express interest in providing services for childcare occupations, research suggests they often complete their entry-level education with a limited understanding of how disability impacts parenting (Lampe, 2019; Wint et al., 2016). Misconceptions about parental and family dynamics, as well as

abilities, can lead to misdirected referrals or a complete absence of appropriate referrals (Crawford, 2003). Interestingly, although OTPs recognize the necessity of parenting support as part of occupational intervention, these same professionals often neglect to set parenting-related goals for their clients (Lim et al., 2022).

### ***Limited Literature and Knowledge***

Healthcare professionals' understanding and education about parenting with disabilities are often insufficient. A seminal report by the National Council on Disability (NCD), reports "a scarcity of accurate and comprehensive information about parenting with a disability" (Lampe et al., 2019; p. 234). In particular, it is well-documented that perinatal care providers often lack adequate training and education on caring for mothers with disabilities during pregnancy and the postnatal period (Powell et al., 2019). The occupational aspect of parenting is largely unaddressed in entry-level occupational therapy education (Lim et al., 2022).

Furthermore, existing research on parenting with disabilities is riddled with issues such as pathological assumptions, failure to consider key distinctions among disabilities, and confusion between correlation and causation (Crawford, 2003). The limited diversity in research, which predominantly features white, female subjects, restricts the application of findings to diverse populations (Lim et al., 2022). Also, the existing literature tends to focus on parenting in terms of the role or emotional experience, rather than viewing parenting as a unique set of occupations. A comprehensive review unlimited to year of publication found only 105 peer-reviewed journal articles and book chapters were found parenting as an occupation. Of these, only 27% dealt with parents with disabilities,



including those often ambiguously categorized under having a "health condition" (Lim et al., 2022).

### ***Lack of Occupational Therapy Resources***

Insufficient documentation, training and use of direct occupational services for parents with disabilities hinder the development of effective interventions (Lim et al., 2022). The procurement of adaptive equipment often relies on professionals such as OTPs, but little information exists that would help guide selection of equipment for parenting-specific tasks (Evans & Orpwood, 2007). Kirshbaum (2013) states there is “an unmet need for occupational therapy services for parents with physical disabilities and a related need for occupational therapist training” (p. 64). A pilot study by Lampe et al. (2019) concludes that there is “the need for resources and information to assist parents with a physical impairment achieve health, well-being and quality of life related to their roles as parents” (p. 244).

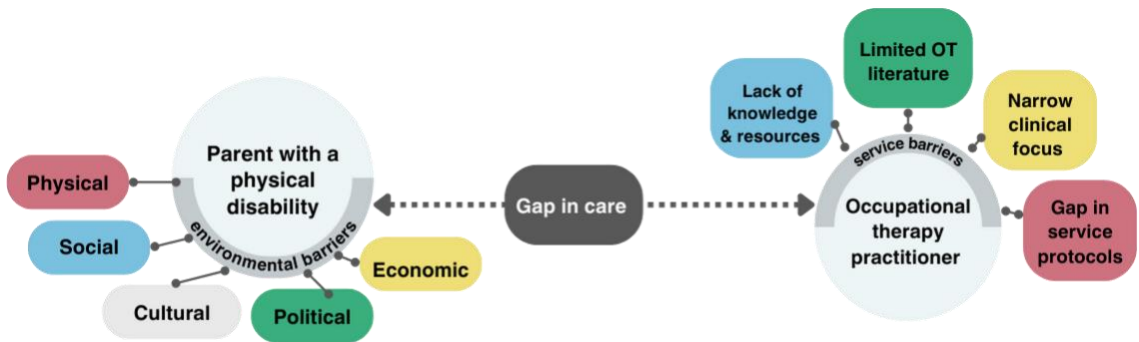
### ***Service Protocol Gap***

OTPs face service protocol gaps, primarily due to a lack of precedent and documentation of direct services for parents with disabilities (Lim et al., 2022; Powell et al., 2019). When asked in one study, one participant who had tried working with an occupational therapist stated it "wasn't helpful," explaining that professionals "had no idea what to suggest" when it came to strategies for interacting with their children (Powell et al., 2019 p. 894). Moreover, there is a dearth of evidence-based research on best practices for supporting parents with disabilities, leading to calls for a more individualized approach to providing informal support for this population (DeZelar &

Lightfoot, 2021).

In conclusion, to deliver effective services to parents with physical disabilities, OTPs must navigate numerous professional and structural barriers, a lack of literature, and insufficient resources. Addressing these challenges requires further research to develop best practices and to enhance the knowledge and skills of OTPs and other healthcare professionals who work with parents with disabilities.

### A Gap in Care



**Figure 3**

#### *A Gap in Care Between Parents and Occupational Therapy Practitioners*

The environmental barriers to parenting occupations and roles for parents with physical disabilities and the barriers to serving those needs by occupational therapy result in a gap in care. This interaction, as illustrated by Figure 3, *A Gap in Care Between Parents and Occupational Therapy Practitioners*, demonstrates a two-way isolation between parents with physical disabilities and occupational therapy. Though the needs of the population and the expertise of the service match well, the barriers of one reaching the other is often insurmountable and result in very little interaction between the two.

### **The Importance of a Disability-Affirming Approach to Care**

Parenting with a physical disability is a unique and valuable experience that offers significant benefits for the individual parent, their children, and the family unit. Central to understanding this experience, and integral to the holistic view of this doctoral project, is the recognition and validation of the lived experiences of the individuals in question. It is through these lived experiences that a disability-affirming and justice-driven approach to understanding and supporting the world of parenting within the context of disability is fostered.

Parents with physical disabilities demonstrate extraordinary adaptability. For those living with congenital disabilities, or whose disabilities preceded their parenting journey, adaptation is an ingrained part of their lives. They have spent years, or even a lifetime, adjusting to a world that is often not designed with their needs in mind. Through these experiences, they have developed the expertise to tailor tasks to their unique physical functions and personal needs. They have expertly adapted to their circumstances, modifying their environments and routines to meet their individual and family needs and desires.

The framework of disability justice, eloquently described by poet and writer Naomi Ortiz, encompasses the recognition and expectation of these differences and nuances. Ortiz wrote:

"Disability justice is the cross-disability (sensory, intellectual, mental health/psychiatric, neurodiversity, physical/mobility, learning, etc.) framework that values access, self-determination and an expectation of difference. An

expectation of difference means that we expect difference in disability, identity and culture. To be included and part of society is about being able to be our ‘whole self’ (all of our identities together)" (Ortiz, 2012, para 1).

This expectation of difference fundamentally recognizes the variation in disability, identity, and culture and champions the right for all individuals to be considered and celebrated within society.

Unfortunately, prevailing societal perceptions often eclipse the positive aspects of living with disability, leading to a deficit-based understanding of the experience (Olsen & Clarke, 2003; Meadow-Orlans, 2002). Many individuals with disabilities, however, operate within interdependent support systems that fulfill the needs and desires of the entire family. Parents with disabilities often collaborate with partners or caregivers to accomplish tasks based on physical abilities (Evans & Orpwood, 2007; Tuleja & DeMoss, 1999). In some instances, certain tasks, such as night care or diapering, may be designated to other caregivers to conserve energy for more personally meaningful tasks like play and quality time.

Undeniably, there are tasks that present challenges and require assistance, cooperation, or adaptation. Tasks necessitating repetitive or coordinated movements such as dressing or changing a child can be difficult (Casey et al., 2022; Kirshbaum & Olkin, 2002), as can tasks requiring significant physical exertion or mobility, like lifting or transporting a child, especially when using a mobility device (Tuleja & Moss, 1999; Brennan & Swords, 2021). Bathing a child safely and effectively was frequently cited as a challenging task that required adaptation or assistance (Wint et al., 2016; Fernando

1995; Tuleja and Moss, 1999).

Despite these barriers, parents with physical disabilities commonly deploy adaptive or compensatory techniques to successfully manage childcare tasks. The use of assistive technology (AT) and specialized equipment is prevalent, which can reduce strain, injury, and fatigue (Kirshbaum & Olkin, 2002; Powell et al., 2019; Tuleja & DeMoss, 1999). However, factors such as cost, availability, and lack of information or referrals can present barriers to AT utilization and require creativity (Powell et al., 2019). Modifications to the home environment can enhance access and facilitate parenting tasks, such as using a lower surface for diapering and changing or installing a ramp convenient for strollers.

The quality of life for parents with physical disabilities extends beyond overcoming physical challenges and is often defined in terms of occupational autonomy and their ability to serve as role models for their children (Edwards et al., 2017). Thus, understanding the experience of parenting with a physical disability requires an in-depth, disability-informed, and justice-driven approach that acknowledges and respects these lived experiences and the unique culture they create.

## **Conclusion**

In conclusion, Chapter 2 provides a comprehensive analysis of the problems faced by parents with physical disabilities and OTPs in addressing those problems. It demonstrates how the challenges faced by parents are multi-layered and extend beyond the individual level to impact their roles as parents and their interactions with their children. It also explores the complexity of the systemic challenges faced by OTPs in

providing direct services to this population. The chapter underscores the need for effective solutions that allow the population and profession to interact and address these challenges in a holistic and comprehensive manner. With a deeper understanding of the issues at hand, Chapter Three, will review the current approaches and methods used in occupational therapy to support parents with disabilities. This will identify existing gaps and inform the development of the proposed solution, *Adapting Parenthood*.

### **CHAPTER THREE – Overview of Current Approaches and Methods**

This chapter reviews the current state of occupational therapy support for parents with disabilities. Recognizing the scarcity of scholarly literature and practical resources on this subject, the literature review draws on a diverse sample of published and public resources, including first-hand narratives and comprehensive case studies from experts and parents with disabilities themselves. These resources provide rich insights into the lives and experiences of this population and highlight effective support strategies and approaches currently in use.

Services and supports available to parents with disabilities is underrepresented in both practical resources and scholarly literature, creating a significant gap in clinical practice, academic instruction, and professional development. Given the scarcity of research articles for review, this chapter features a sample of published and public resources that provide insight into the lives and experiences of parents with disabilities. These key texts are written by experts in the field, or parents with disabilities themselves. They offer first-hand narratives and comprehensive case studies that enrich our understanding of this population. By analyzing these works, practical, evidence-based insights into the most effective support strategies and approaches can be extracted.

#### **Guidelines on Supporting Parents with Disabilities**

Two sets of guidelines from two countries are discussed here as an example of resources that could be used by OTPs to guide disability-informed practice when supporting parents.

In the United Kingdom, the Disabled Parenting Project has developed the

Occupational Therapy Guidelines for Disability, Pregnancy & Parenthood, to provide best practice recommendations for occupational therapists working with parents with disabilities (Disabled Parenting Project, n.d.). These guidelines cover essential areas such as assessment, intervention, and collaboration with other professionals, and notably underscore the need for a family-centered approach and the empowerment of parents to participate in their child's care as independently as possible.

In the United States, the National Council on Disability (NCD), in partnership with The Lurie Institute for Disability Policy, released a comprehensive report, "Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and Their Children" in 2012. This report examines the obstacles faced by parents with disabilities and suggests valuable recommendations to improve policy and practice (National Council on Disability, 2012). It highlights the importance of service coordination, professional training and education, and the development of inclusive, disability-sensitive policies and services. The report offers a plethora of resources for professionals and a downloadable toolkit that can be utilized by families and professionals supporting parents with disabilities.

### **Examples of Direct Occupational Therapy and Related Services**

Service provision and program development specifically directed towards parents with disabilities remains minimal. This inadequacy highlights an essential area of focus in healthcare services, particularly in the field of occupational therapy. The following section offers a brief exploration of various programs, services and outcomes that have been identified through an extensive literature review and web-based search. These



programs, although not exhaustive, provide a representative sample of the current landscape. Each offers unique insights that could inform the content of *Adapting Parenthood* and underscore the potential for expansive growth and development in this critical area.

### ***A Case Study on Home Modification***

A case study published by Pickens et al. (2020) examined the effects of home modifications on both an individual and family. The modifications were made by a nonprofit organization in collaboration with an occupational therapist, and were based on the principles of universal design. The family who participated in the study was selected to receive modifications for improved accessibility. The researchers monitored the family's transition from their original home to the newly modified one funded by the nonprofit.

The family's selection was contingent upon the needs of the father, Robert, a 41-year-old with congestive heart failure. Robert faced mobility challenges from healing sores on his left foot while concurrently recovering from an amputation of the toes on his right foot. His day-to-day functional capacity fluctuated, often requiring him to use a powered wheelchair on his more fatigued days. Robert also made use of, a cane or walker for mobility.

Using the Person-Environment-Occupation (PEO) model, the study helps underscore how home modifications and physical environment can influence the fit between person, environment, and occupation. When the father's living environment was poorly suited to his needs, his occupational performance and satisfaction were negatively

impacted. The environmental constraints and limited opportunities within his home environment, in combination with his physical disability, resulted in stress and isolation from his family and hindered his participation in meaningful occupations (Pickens et al., 2020).

The Canadian Occupational Performance Measure (COPM) and a semi-structured interview were used to compile qualitative data for the study. These tools were used to assess changes in occupational performance and satisfaction in the areas of self-care, productivity, and leisure. Before the modifications, the family experienced significant obstacles related to physically accessing parts of the home, and barriers connected to self-care, caregiving, home management, socializing, leisure, and school activities (Pickens et al., 2020).

The study provides a comprehensive analysis of the effects of moving to a newly modified home on a family's overall performance, satisfaction, and quality of life. Both performance and satisfaction scores were significantly increased after the move in all identified goal areas on the COPM (Pickens et al., 2020). Additionally, the family reported three key benefits: accessibility, opportunity, and relief. The modifications in the home facilitated improved mobility, enabling enhanced physical access within the house. This newfound accessibility opened the door to a range of opportunities such as increased independence, socializing, and family bonding. The move also brought relief, particularly in reducing the caregiver stress experienced by the mother due to the previous home's physical barriers. The move to a modified home not only improved the father's self-care ability but also had significant social, emotional, temporal, and psychological benefits for

the entire family.

This study emphasizes the importance of a client's context, including their physical and social environment. It highlights the importance of including family members in assessments and integrating universal design principles into home modifications. Consequently, a comprehensive understanding of each family member's needs and the function of spaces within the home can result in improved outcomes for clients and their families.

### ***Perinatal Support by Spinal Outreach Team (SPOT)***

A 2003 research paper by Hunter & Coventry highlights the unique challenges of parents with spinal cord injuries (SCIs) and the role of occupational therapy in supporting them during the perinatal period. A needs analysis conducted with spinal cord injured persons and their carers/supporters identified fertility and parenting as areas of need. Based on the analysis, the Spinal Outreach Team (SPOT) was developed to provide early intervention and education services in social work, physiotherapy, occupational therapy, and nursing (Hunter & Coventry, 2003). The paper discusses the strategies and interventions found successful specifically by the occupational therapy team.

SPOT, a multidisciplinary community-based team, delivers services to people with spinal injuries. The team's philosophy is grounded in the belief in the therapeutic power of activity to achieve mastery over the clients' environment (Hunter & Coventry, 2003). The program considers the individual's circumstances, abilities, and environment when determining the most suitable services. SPOT adopts a client-focused approach, encouraging clients to identify individual goals, and focuses on collaborative problem-

solving.

SPOT's occupational therapists play an essential role in identifying equipment needs, providing resources, discussing suitable equipment options, and assisting with the trial and selection of suitable equipment. They advise clients on the adaptation of commercially available baby care equipment or potential items to manufacture. SPOT provides individualized assessments of hospital facilities on perinatal care for women with spinal cord injuries. The occupational therapists recommend appropriate modifications, educating hospital staff about specific needs of this population in planning for hospital admissions and discharges related to prenatal and obstetric care (Hunter & Coventry, 2003).

The SPOT program underscores the potential of OTPs in developing and implementing these interventions. Given their expertise in enabling individuals with disabilities to engage in meaningful occupations, occupational therapists can play a key role in helping parents with SCIs or other disabilities adapt to their new circumstances and perform their parenting roles effectively. This might involve modifying parenting tasks to accommodate the parent's physical limitations, recommending adaptive equipment, or advocating for more accessible community facilities (Hunter & Coventry, 2003).

The findings from this study can inform professional development education to include topics on assessing the parenting needs of individuals with SCIs and other disabilities, developing individualized intervention plans, and recommending adaptive equipment for parenting tasks. Advocacy for more inclusive policies and facilities in the

community is a key aspect of enabling parents to perform their roles effectively.

### ***Scoping Review on Maternal Care***

A scoping review by Blair et al. (2022) synthesized findings from 22 studies across eight countries to illuminate the experiences and access barriers encountered by women with physical disabilities during maternity care. The study highlighted that women with disabilities desire equitable treatment that doesn't objectify them, expressing the need to be respected and not made to feel like a "spectacle" (Blair et al., 2022, p.19). Emphasizing their independence and control, these women often confronted an increase in reliance on partners, family members, and maternity providers due to a decline in mobility and intensification of their physical disability during pregnancy (Bertschy et al., 2015; Iezzoni et al., 2015).

The review found that women wanted disability-specific knowledge to assist in making informed maternity care decisions. Gaining this knowledge not only bolstered their confidence but also improved their ability to plan support. However, the study acknowledged a considerable gap in the knowledge and attitudes of care providers towards disabled women. Many women reported having more favorable experiences when their providers acknowledged their pregnancies and trusted their parenting capabilities (Blair et al., 2022).

Physical access barriers in maternity facilities emerged as a crucial area of concern. The absence of disability-friendly infrastructure, like parking spots, ramps, automatic doors, adjustable examination tables, and wide corridors, not only affected women's choice of facility but also negatively impacted their experiences (Blair et al.,

2022). Manual transfers by staff or family members were often reported to make women feel "undignified" (Iezzoni et al., 2015).

Inter-provider and inter-disciplinary collaboration played an essential role in improving care experiences. However, poor communication among providers often led to women becoming messengers of complex medical information. Lack of understanding of other providers' roles resulted in fewer referrals to appropriate services like occupational therapists and adaptive equipment services (Blair et al., 2022).

The findings from this review can provide valuable insights for the professional development education of OTPs, highlighting the need for a better understanding of the unique needs of pregnant women with physical disabilities and the development of strategies to address these needs in the context of maternity care.

### ***Through the Looking Glass***

Through The Looking Glass (TLG) is perhaps the most well-established community program that directly serves parents with physical disabilities through occupational therapy. Through its advocacy and program development, the TLG program gives significant insight into the experiences of parents with physical, systemic, or visual disabilities. Grounded in community-based research, stakeholders of the program have documented and published their findings on the spectrum of experiences of disabled parents (Kirshbaum, 2001; Kirshbaum, 2013; Kirshbaum & Olkin, 2002).

Program development and experience within TLG underscores the diversity of parents with disabilities and emphasizes the need for a nuanced understanding of their unique needs and experiences. Specific challenges faced by parents with physical,

systemic, or visual disabilities, include physical barriers in performing parenting tasks, societal attitudes, and lack of support services including early intervention (Kirshbaum, 2001).

One of TLG's pioneering projects involved a video analysis-based study of the interactions between mothers with physical disabilities and their babies (Kirshbaum et al., 2002). Through observation of basic care activities such as feeding, bathing, and diapering from birth through toddlerhood, the videos documented the reciprocal process of adaptation to disability obstacles as it developed between mothers and their babies. It unveiled a range of strategies and adaptations employed by mothers in the absence of specialized adaptive parenting equipment or intervention, highlighting their inventiveness and resilience (Kirshbaum, 2001).

The findings from the video study led to the initiation of TLG's research on developing and evaluating the impact of babycare adaptations. Several projects were launched, specifically aimed at creating and assessing the effectiveness of babycare equipment for parents with physical disabilities. Equipment development was informed by the ingenious adaptations which mothers had invented within the initial study. The researchers concluded that such adaptations not only improved parent-infant interactions but also had a positive impact on the health of the mothers by reducing the physical demands of caregiving, and thus potentially preventing secondary disability complications (Kirshbaum, 2001).

However, TLG's research also shed light on the significant challenges and barriers faced by parents with disabilities. Transportation and housing accessibility

emerged as key issues, with a substantial number of respondents reporting problems in these areas (Kirshbaum, 2001). Despite these challenges, the majority of respondents made modifications to their housing using personal funds, illustrating the pressing need for better public support. Another major challenge was the lack of availability and affordability of adaptive parenting equipment in the market (Kirshbaum, 2001). The potential benefits of such equipment were underscored by parents who reported that it could have improved their independence, reduced fatigue, and made them feel more secure about their child's safety.

The TLG program further highlighted difficulties experienced during pregnancy or childbirth, primarily due to physical or communication access barriers, and a lack of disability expertise among professionals. Disturbingly, a portion of the respondents reported experiencing threats to their right to parenthood, including efforts to remove their children.

These findings have significant implications for the professional development of OTPs. It is crucial to enhance their understanding of the specific challenges faced by parents with disabilities and equip them with the knowledge and skills related to adaptive strategies and equipment for parenting. A deeper appreciation for the value of community-based models and in-home services within the family's natural environment is also necessary. Furthermore, they need to advocate for improved accessibility and resources for parents with disabilities and ensure their respectful and equitable treatment in maternity care. Ultimately, such targeted professional development will enable OTPs to better support parents with disabilities, facilitating their journey through parenthood.



### **Examples of Resources on Parenting and Disability**

The following section details examples of available resources that would be appropriate for an OTP to use to improve clinical skills and could offer resources for parents or supporters who want more information on parenting roles or occupations and disability.

#### ***The Disabled Woman's Guide to Pregnancy and Birth***

"*The Disabled Woman's Guide to Pregnancy and Birth*" by Judith Rogers (2010) is an example of a comprehensive resource for women with disabilities, families, and healthcare providers. As a disabled mother and a specialist at the non-profit, Through the Looking Glass, Rogers provides a first-hand perspective that can complement clinical practice. The guide encapsulates information about pregnancy, its effects on a disabled woman's body, childbirth, and the early postnatal period, drawing from personal experiences of many women with different types of disabilities (Rogers, 2010). The book follows the progression of pregnancy and provides an insight into the varying emotional and physical changes a woman may experience during this period. Topics range from planning a pregnancy to choosing an obstetrician and a birthing place, to detailing what happens at antenatal appointments. It provides valuable advice about physiological changes during pregnancy and how pregnancy affects bodies in relation to disability.

Although it is important to note that maternity care and practices may differ geographically, the book's strength lies in its use of personal narratives, providing an empathetic and comprehensive guide for parents with disabilities and their healthcare

providers. It demystifies medical terminology by providing disability-affirming explanations and supplements the text with useful appendices and resource sections, thus making it a valuable resource for OTPs and their clients navigating the journey of pregnancy and parenthood.

### ***Parenting and Disability***

*"Parenting and Disability: Disabled Parents' Experiences of Raising Children"* (Olsen & Clarke, 2003) is an example of a resource that offers a nuanced exploration of the intersection of parenting, disability, and mental health. Based on the first significant UK study on the subject, this book covers a broad spectrum of issues confronting disabled parents and their families. The authors provide insights into the lived experiences of disabled parents, which could inform both clinical practice and client resource provision.

In one chapter, the authors explore societal and policy-induced invisibility experienced by disabled parents. They discuss how policy impacts the support received by disabled parents. Another chapter provides a close examination of the context and extent of children's involvement in domestic and caring roles within families with disabled parents. It also investigates influential factors that may dictate the extent and nature of this involvement. A third chapter aims to highlight disabled parents' experiences, including the evolving challenges and choices they face. These range from decisions around having children to changes in family composition and parental impairment and planning for the future. The final chapter acknowledges disability as a social experience impacting individuals and relationships within families. It delves into

the complexities of the experiences of impairment and disability, and their intersections with parenting.

*"Parenting and Disability: Disabled Parents' Experiences of Raising Children"* is a comprehensive resource that can significantly inform occupational therapy practice. These insights could be beneficial in shaping interventions and care plans and aid in the delivery of empathetic and timely care.

### ***Online Media***

Online communities, websites, personal blogs, podcasts and articles have emerged as pivotal sources of first-person information, providing unfiltered insights into the experiences, values, and life circumstances of parents with physical disabilities. This wealth of information serves as a crucial resource for OTPs, particularly those who lack personal experience with disability. By tapping into these firsthand accounts, practitioners can foster a more client-centered and culturally informed practice.

The podcast *"Parenting Done Differently"* (University of Minnesota, 2023) is hosted by University of Minnesota faculty. The host interviews academic experts within the field of disability who provide summaries of recent and seminal research in the field of disability and parenting.

*"The Wheelchair Daddy"* is an example of a personal blog (The Wheelchair Daddy, n.d.) that provides one father's firsthand account of fathering and disability. The blog offers insights, tips, and product recommendations.

DisAbility Maternity Care is a website and non-profit organization developed by an academic researcher and nurse midwife in Australia (Disability Maternity Care, 2017).

The Disabled Parenting Project website (Disabled Parenting Project, 2016) is a similar non-profit organization hosting a popular online forum for parents, caregivers and families living with disabilities. Both platforms provide online peer communities, training and education modules for professionals and families, articles discussing life experiences of mothers with disabilities, and in-depth trainings for professionals and families.

### **Conclusion**

In conclusion, Chapter Three provides a broad overview of current approaches and methods used to support parents with disabilities. Through the review of various resources, a deeper understanding of the landscape of available support, including its strengths and shortcomings is gained. This knowledge better informs the development of a more comprehensive and targeted solution, *Adapting Parenthood*, an online resource and education platform designed to enhance the competency of OTPs working with parents with disabilities. Chapter Four will further explore the platform's development.

## **CHAPTER FOUR – Description of the Proposed Program**

As discussed in detail in Chapter Two, disabled parents experience environmental barriers to parenting that would be appropriately addressed by OTPs. However, OTPs do not often have the knowledge or resources to address these barriers. A proposed solution to this bidirectional problem is presented in this chapter. Recognizing the scarcity of professional education and resources for individuals with disabilities who are also parents, this author proposes *Adapting Parenthood*, an online resource and education platform that provides organized, relevant, and evidence-based content. The selection of an online platform is informed by the need for professional development opportunities among OTPs and other professionals and supports working with parents with physical disabilities.

A full logic model for this solution can be viewed in Appendix A: *Full Logic Model for Adapting Parenthood*. The full logic model that reviews the process of the problem to be solved, the solution, and the anticipated outcomes.

### **The Need for *Adapting Parenthood***

The availability of professional education and resources that cater to individuals with disabilities and parenting responsibilities is currently scarce. Particularly within the field of occupational therapy, comprehensive trainings on this subject are virtually non-existent. This lack of accessibility is concerning, as it presents a significant barrier for both disabled parents and professionals seeking to improve their knowledge and skills in this area. To meet this need, this author proposes an online resource and education platform with organized, relevant, and evidence-based content for OTPs supporting

parenting tasks for disabled clients across practice settings.

The selection of an online learning platform as the foundation for *Adapting Parenthood* is based on the need for specific and widely accessible professional development opportunities among OTPs and students working with parents with physical disabilities. The purpose of this resource and education platform is to support practitioners in understanding and effectively addressing the roles and occupations of parenting through occupational therapy intervention and coaching. The platform chosen for this project will provide OTPs, students and related healthcare and community professionals, with an accessible and effective means to enhance their professional development and clinical practice.

### **Stakeholders**

*Adapting Parenthood* serves a broad spectrum of stakeholders, benefiting each in specific ways and strengthening the overall support system for parents with physical disabilities.

At the micro level, primary stakeholders include OTPs, related healthcare professionals, and students. These direct users of the platform gain access to evidence-based resources and education, enhancing their understanding of parenting roles and occupations for parents with disabilities, thereby improving their clinical practice, treatment outcomes, and decision-making. Secondary micro-level beneficiaries are the parents with disabilities, who receive improved services due to the enhanced knowledge and skills of the practitioners, thus enhancing their quality of life and participation in parenting roles. Parents with disabilities may also benefit from first-hand access to

content hosted on the platform to inform their own occupations.

At the meso level, primary stakeholders are occupational therapy providers, such as clinics, hospitals, and private practices. These organizations benefit from the platform by offering their practitioners access to tailored resources and education, enhancing service quality and their overall credibility. Secondary meso-level stakeholders include healthcare providers, social workers, and community providers who play vital roles in supporting parents with disabilities. Through the platform, they gain insight into the unique challenges faced by these parents and can develop more effective, collaborative care plans, supportive services and increase direct referrals to occupational therapy.

At the macro level, stakeholders include those operating within the Medical and Social Models of Disability and government and policy level entities. The Medical Model stakeholders gain a more comprehensive and nuanced understanding of parenting with a disability, which can inform more holistic interventions. *Adapting Parenthood* also encourages a shift towards a more person-centered approach. Stakeholders operating within the Social Model benefit by gaining access to resources that highlight the environmental barriers faced by parents with disabilities and provide adaptive solutions. Government and policy-level stakeholders can leverage the platform to understand the unique challenges and potential solutions for parents with disabilities, promoting more inclusive and supportive policies and funding.

### **Theoretical Basis**

The theoretical basis for the design of *Adapting Parenthood* draws upon two educational theories with the first being: Self-Directed Learning Theory (Knowles, 1975).

Self-Directed Learning Theory posits that adult learners are intrinsically motivated, self-guided, and capable of identifying their learning needs, setting learning objectives, finding resources, implementing strategies, and evaluating their learning outcomes (Knowles, 1975). This theory is particularly relevant in the context of professional development, where learners actively seek knowledge and skills to enhance their professional practice. *Adapting Parenthood* allows users to navigate their learning path and pace. Users can select modules relevant to their practice area and clientele, engage with the content at their convenience, and evaluate their learning through integrated assessments and reflections. This design encourages self-direction, autonomy, and motivation in learning, features that are crucial in professional development (Curran et al., 2019).

Barriers to self-directed learning, such as lack of time, inadequate access to resources, and low digital literacy, can hinder the effective implementation of online professional development programs (Jeong et al., 2018). *Adapting Parenthood* addresses some of these barriers by providing a user-friendly interface, flexible access to modules, and a design to enhance digital literacy. The platform also encourages self-directed learning by offering supports like learning guides, module overviews, and structured reflection prompts (Jeong et al., 2018).

The second theory supporting *Adapting Parenthood* is Multimedia Learning Theory, which emphasizes the importance of using different media types to enhance learning (Mayer, 2013). According to this theory, individuals learn better from words and pictures than from words alone (Mayer, 2013). *Adapting Parenthood* will incorporate a



variety of multimedia resources, including texts, images, videos, and interactive elements. The utilization of diverse media caters to different learning styles and preferences, enhancing user engagement and information retention (Clark & Mayer, 2016). It also allows complex concepts and procedures to be explained more effectively, which is critical in the context of occupational therapy where practitioners will also have to explain concepts and strategies to their clients.

### **Description of Key Features**

The *Adapting Parenthood* platform is divided into topic areas comprised of two main components: resources and educational modules or courses. The resources encompass a diverse range of documents, recommendations, manuals, legal information, communities, and provider lists. They serve to supplement interventions, provide clients with specific information, and enhance the overall practice of healthcare professionals. Careful curation has ensured that the resources address the unique needs of parents with physical disabilities and the practitioners supporting them. Initially, the resources will be sourced by the author and initial content contributors. Eventually, users will have the opportunity to contribute their own resources for vetting and inclusion on the website.

*Adapting Parenthood* centers its content on areas that practitioners may need to improve their clinical skills and knowledge when dealing with this demographic. Its main themes are divided into subtopics, each associated with an educational module. The themes and subtopics are presented in Appendix C: Visual Model of Adapting Parenthood Content Topics. The modules take the form of pre-recorded videos, podcast episodes, live online courses, and written articles. Each module culminates knowledge

assessment to ensure engagement and competence. Passing these tests is a prerequisite for earning Continuing Education Units (CEUs).

The modules are designed to supplement the users' clinical experiences and professional education. It is paramount that the content remains relevant and applicable to real-world scenarios. This facilitates practitioners' ability to translate their newfound knowledge into meaningful interventions and support for parents with physical disabilities.

### ***Content Topic Areas***

In discussing the topic areas of *Adapting Parenthood*, it is crucial to acknowledge the diversity and individuality within the disabled community. Everyone's experience of disability is unique; there is no one-size-fits-all narrative. Therefore, when sharing narratives and examples of how activities are performed by people with disabilities, it is paramount to avoid oversimplifications and generalizations. The complexity of tying certain diagnoses to abilities, particularly concerning parenting tasks and roles, must be thoroughly acknowledged, and thoughtfully handled. A diagnosis does not automatically equate to a particular ability or disability, and a range of factors, including personal characteristics, environment, and support systems, contribute to an individual's capabilities.

Privacy and protection of identities are another essential aspect to be considered. Anonymity should be maintained unless express consent is provided, and even then, the minimal amount of personal information necessary should be shared. The aim is to ensure the integrity and dignity of the individuals sharing their experiences are respected and

maintained throughout.

The content should be created and presented in a manner that promotes empowerment, focusing on abilities, adaptations, and accomplishments rather than deficits. A strengths-based perspective highlights the resilience, resourcefulness, and creativity of individuals with disabilities. The narrative must steer clear of fostering stereotypes or perpetuating stigmas, and instead, promote understanding, inclusion, and respect for diversity.

Cultural competency must be interwoven throughout the project. Understanding that disability and parenting are both influenced by many factors, the content should be sensitive to these influences and respectful of cultural differences. This involves seeking and incorporating input from a diverse range of individuals and groups, striving for representation and inclusivity in the narratives and examples provided. Therefore, the author's investigation into the parenting experiences of individuals with disabilities will be guided by these principles, ensuring our research is not only rigorous but also ethical, respectful, and empowering.

**Disability-Affirming Practices.** Disability-affirming practices emphasize a holistic understanding of individuals with disabilities, recognizing a person's full potential, and fostering an inclusive environment that supports their physical, emotional, and social well-being (Harrison et al., 2021). For occupational therapy, disability-affirming practices are fundamental to fostering justice, equity, diversity, and inclusion (JEDI), and they play a pivotal role in promoting disability rights and being culturally informed as to different dynamics at play (Brennan & Swords, 2023).

Embracing diversity and disability-affirming and empowering principles requires an understanding of the unique experiences of disability. Studies highlight the complex dynamics of parenting with a disability, where individuals face various challenges that amplify their disability, from practical issues related to strength and safety to societal attitudes and roles in parenting (Brennan & Swords, 2023). Two topics that are particularly relevant to achieving disability-affirming practice is a historic and comprehensive understanding of disability rights including issues of fertility and parenthood, as well as the concept of interdependence.

***Disability Rights.*** OTPs have a key role as healthcare professionals and client advocates in championing disability rights. They can contribute to this by providing care that acknowledges the rights of individuals with disabilities to parent, and by advocating for societal and systemic changes that support these rights. However, the challenges faced by parents with disabilities extend beyond accessibility and inclusivity issues.

The legal threats and fears that parents with disabilities often encounter represent a significant barrier that requires further attention. These fears are not unfounded; parents with disabilities frequently confront prejudiced attitudes and ableist assumptions in social and legal systems, which can jeopardize their parental rights (Sherwood & Kattari, 2023). Such discriminatory practices can manifest in various forms, including in the education system, where issues of ableism can be pervasive (Sherwood & Kattari, 2023).

OTPs have a crucial role to play in addressing these systemic issues. By advocating for reforms in legal and social systems, OTPs can help create environments that respect and uphold the rights of parents with disabilities. This requires a commitment

to challenging ableist assumptions, promoting inclusive practices, and ensuring that the voices of parents with disabilities are heard and respected. OTPs can also play a vital role in educating other professionals about the unique needs and rights of parents with disabilities, thus contributing to the broader societal shift towards greater inclusivity and respect for disability rights.

To supplement the education of disability rights, access to a variety of resources could be beneficial. These may include research articles, case studies, and handbooks that provide insights into the experiences and needs of parents with disabilities. For parents, this may include providing resources that inform them about their rights and strategies for support. Materials that educate the broader public about disability and parenting can help in fostering a more inclusive and understanding society (Brennan & Swords, 2023; Andrews et al., 2021).

### ***Interdependence.***

Understanding the concept of interdependence from a Disability Rights perspective can significantly inform treatment planning and professional-client rapport. This shift in perspective, from independence to interdependence, aligns with a more inclusive approach that recognizes the multiple relationships and interactions that shape a person's lived experience (Brady & Branham, 2018). Embracing interdependence means considering not only the individual client, but also their support systems. This might include family, friends, caregivers, or community resources that play a critical role in the client's life. By doing so, OTPs can develop treatment plans that leverage these relationships, facilitating outcomes that might be difficult to achieve through a focus on

individual capacities alone.

This perspective is not only respectful to a different set of values and cultures but also allows professionals to learn from interdependent support systems. These systems, which often draw upon the diverse strengths of different individuals to achieve a functional outcome, can offer innovative strategies for supporting people with disabilities. For instance, a client may already be part of a system where tasks and roles are shared according to each member's abilities and preferences. Recognizing and reinforcing such systems can help enhance the client's functionality and quality of life.

Family dynamics, particularly the dynamics of interdependence, can significantly influence the parenting experience of individuals with physical disabilities. Family members and other support people can provide support to both child and parent in various ways, such as assisting with caregiving tasks, providing emotional support, and advocating for each person's needs (DeZelar & Lightfoot, 2021).

Professional development in occupational therapy should focus on equipping practitioners with the skills to understand these dynamics and develop interventions that alleviate the challenges faced by parents with physical disability. Practitioners should be educated on the importance of fostering an inclusive environment that respects the parenting rights and support system dynamics of individuals with disabilities (Brennan & Swords, 2023).

**Perinatal Care.** The perinatal period is a significant time in a woman's life and can present unique challenges for women with physical disabilities. These challenges can be magnified in the areas of pregnancy, birth, lactation and breastfeeding, and

postpartum. With appropriate support and resources, women with physical disabilities can more successfully navigate these challenges (Blair et al., 2022).

***Pregnancy.*** Pregnancy can pose distinct physical and emotional challenges for women with disabilities. Occupational therapy can play a crucial role in helping women adapt to the changes occurring in their bodies and preparing for the arrival of their baby (Kirshbaum & Olkin, 2002). This may involve recommending adaptive equipment for mobility and self-care tasks, teaching energy conservation techniques, and providing emotional support (Gitlow, 2020).

***Birth.*** Women with physical disabilities may face additional challenges during birth, requiring added support and accommodations. OTPs can collaborate with the medical team to ensure a safe and positive birth and hospital experience. This might involve advocating for the woman's needs, assisting with positioning, and facilitating communication between the woman and the medical team (Hunter & Coventry, 2003).

***Lactation and Breastfeeding.*** Lactation and breastfeeding can be particularly challenging task, is complex, and multifaceted. Adaptive equipment such as breastfeeding pillows, pumps, and specially designed tools can support mothers in successfully breastfeeding their babies (Lim et al., 2022). OTPs can provide education and training in the use of this equipment, as well as techniques to facilitate breastfeeding. OTPs are skilled at evaluating and modifying co-occupations when physical or sensory differences may require additional adaptation on the part of both the breastfeeding parent and the infant.

***Postpartum Care.*** The postpartum period and early motherhood can be a challenging time. OTPs can provide crucial support during this time, helping mothers adapt to their new roles, managing physical and emotional health, and assisting with baby care tasks (Lampe et al., 2019). To provide effective support to perinatal women with physical disabilities, OTPs must be open to understanding the unique challenges these mothers face. This requires continuous professional development, including staying updated on the latest research and advancements in adaptive equipment and techniques for this population, but most of all being open to learning from the lived experience of clients and listening to their needs (Gitlow, 2020).

Resources that could be helpful when working with this population and developmental stage include educational materials on pregnancy, birth, and breastfeeding, online forums for sharing experiences, and community resources such as support groups and home-based services (Pomerantz et al., 1990).

***Equipment and Accessibility.*** Supportive equipment and accessibility are integral to enabling parents with physical disabilities to participate fully in parenting activities. Key areas in this regard include assistive technology, universal design and access, and home modifications (Blair et al., 2022).

***Assistive Technology.*** Assistive technology can greatly enhance the ability of parents with physical disabilities to perform various parenting tasks independently. This includes high-tech solutions such as voice-activated nursery equipment, as well as low-tech adaptations like modified baby carriers (Gitlow, 2020; Lim et al., 2022). OTPs can provide crucial support in recommending suitable assistive technology and training



parents in its use.

***Universal Design.*** Universal design principles advocate for environments and products that can be used by all people, to the greatest extent possible, without the need for adaptation (Evans & Orpwood, 2007). In the context of parenting, this might involve features such as adjustable-height cribs and baby changing tables, or strollers that can be attached to wheelchairs (Kirshbaum & Olkin, 2002). OTPs can advocate for the incorporation of universal design principles in the design of baby care equipment and environments (Gitlow, 2020).

***Home Modification.*** Home modification can significantly improve the accessibility and safety of the home environment for parents with physical disabilities and their families. This might involve changes such as installing ramps, widening doorways, or modifying bathrooms to accommodate the needs of the parent (Lampe et al., 2019). Installing lower countertops and accessible storage solutions may make performing tasks like changing diapers or preparing food more manageable (Kirshbaum & Olkin, 2002). OTPs can assess the home environment and recommend necessary modifications.

To effectively support parents with physical disabilities, OTPs must keep up to date with advancements in assistive technology, universal design principles, and home modification strategies. They also need to develop skills in conducting comprehensive assessments of the home environment and the parent's needs (Gitlow, 2020). Resources that could help in this area include informational materials on assistive technology, universal design and home modifications, as well as community resources such as home-

based occupational therapy services and equipment loan programs (Pomerantz et al., 1990).

**Supports.** Social and professional support play a vital role in enhancing client's experiences with care. Particularly important in this regard is the availability of disability-specific or informed information, family-centered practices and inter and intra-disciplinary communication between providers (Kirshbaum & Olkin, 2002; Blair et al., 2022).

Disability-specific services can provide crucial support to parents with physical disabilities. These services may include home-based occupational therapy services, equipment loan programs, and parent support groups (Pomerantz et al., 1990).

Legal services are also integral in advocating for the rights of parents with disabilities, helping them navigate legal issues related to custody, discrimination, and accessibility (Namkung et al., 2019). OTPs can play a key role in connecting parents with these services and advocating for their rights (Gitlow, 2020).

Various resources can supplement the education of OTPs and support their clients in their parenting journeys. These include educational materials on adaptive strategies, information on disability and legal services, and online forums, videos, and social media platforms for sharing experiences and advice (Pomerantz et al., 1990).

***Family-Centered Approaches.*** The mental health of a child and parent are intimately connected to the family environment and health. Family-centered approaches recognize this connection and aim to support the entire family system to promote the mental health and well-being of the infant (Kirshbaum & Olkin, 2002).

***Inter-provider and Interdisciplinary Collaboration.*** Inter-provider and interdisciplinary collaboration involve various healthcare and service providers working together to provide comprehensive support to the family. This can include, but is not limited to, occupational therapists, psychologists, social workers, medical professionals, and legal advisors (Blair et al., 2022).

Collaboration between providers ensures that the various needs of the family are met, from the physical and emotional health needs of the parent and infant, to the family's social, legal, and practical needs. This collaborative approach allows for a more holistic and effective service delivery, and better outcomes for the infant and family (Hunter & Coventry, 2003).

To effectively participate in inter-provider and interdisciplinary collaboration, OTPs need to develop specific competencies. These include skills in communication and teamwork, knowledge of the roles of other providers, and an understanding of how to coordinate and integrate services to provide comprehensive support (Gitlow, 2020). Ongoing professional development in these areas, as well as staying updated on the latest research and best practices in infant mental health and family-centered therapy, is crucial for OTPs who work with families where a parent has a physical disability (Lampe et al., 2019).

There are various resources that can supplement education and support in the areas of mental health and a family-centered approach. These include educational materials on child development and mental health, and community resources such as parent support groups and home-based services (Pomerantz et al., 1990).

**Adaptive Strategies.** Adapting parenting activities is often necessary for parents to care for children effectively and independently, while also enhancing their sense of autonomy and fulfillment in the parenting role. Adapting to the unique challenges posed by physical disabilities is not only a necessity, but also a universal experience for individuals whose needs do not align with the constraints of the physical environment (Olkin et al., 2006). Activity adaptations can help parents to perform their tasks more efficiently, minimize fatigue and prevent potential injuries (Kirshbaum & Olkin, 2002).

Parents often use a combination of innovative techniques to manage their parenting tasks effectively (Kirshbaum & Olkin, 2002). For instance, a parent with a mobility impairment might use adaptive equipment, such as a specialized crib that opens from the front, allowing the parent to access the baby from a seated position (Kirshbaum & Olkin, 2002). Assistive devices like voice-activated systems can also be of great help for parents with limited use of their hands or need to conserve energy (Olkin et al., 2006). Similarly, for tasks like feeding, parents might use specially designed highchairs or systems that are adjustable in height and angle, allowing them to feed their child comfortably from a seated or standing position (Kirshbaum & Olkin, 2002). A parent with a mobility impairment might use a motorized wheelchair equipped with attachments to carry baby items, such as bottles or toys, or even to securely transport the baby within the home (Kirshbaum & Olkin, 2002).

OTPs can play a role in identifying and supporting adaptive strategies for parenting occupations. A comprehensive resource library of videos and descriptions of adaptations used successfully by other parents will be valuable for professionals to

understand examples of strategies, tools, and modifications, that they can then share and adapt to their client's individual needs. Moreover, practitioners can supplement education on a range of relevant topics, such as ergonomics, energy conservation, and task simplification with parenting-specific professional development in these areas.

*Adaptive Infant Care.* Parents with physical disabilities often face unique challenges in caring for very young children. Adapting equipment for infant care tasks is a strategy to foster independence and enrich the caregiving experience for these parents (Kirshbaum & Olkin, 2002; Blair et al., 2022). Studies have demonstrated that adaptive equipment and modifications can significantly enhance the capacity of disabled parents to independently carry out baby care tasks. This includes feeding, changing, bathing, and transporting a child (Gitlow, 2020; Hunter & Coventry, 2003). These adaptations not only allow parents to perform tasks with greater ease and safety, but also contribute to the establishment of a nurturing and responsive relationship with their child.

Adaptations can range from simple, low-tech solutions, such as using a lap baby carrier or a modified changing table, to more complex, high-tech adaptations, such as voice-activated nursery equipment (Lim et al., 2022). Importantly, these adaptations should be individualized, considering the specific needs, preferences, and living environment of each parent (DeZelar & Lightfoot, 2021).

OTPs are ideally positioned to assess the unique needs of these parents, recommend appropriate adaptive equipment, and provide training in its use (Lampe et al., 2019). To optimally support parents with disabilities, OTPs must stay informed of the latest research and advances in adaptive equipment for infant care. They also need to

develop competencies in performing comprehensive assessments, devising individualized adaptation plans, and advocating for the rights and needs of parents with disabilities in various service settings (Gitlow, 2020; Blair et al., 2022).

There are various resources available to supplement the education of parents with disabilities and support them in caring for their young children. These include print and online resources providing information on adaptive baby care equipment, instructional videos demonstrating their use, and community forums for sharing experiences and advice (Pomerantz et al., 1990).

### ***Adapting Parenthood Case Study***

M.R. is an occupational therapist with over 20 years of clinical experience, primarily working in the inpatient rehabilitation setting in a large, urban hospital. He receives an occupational therapy order to see a young patient, C.G., a 30-year-old female who has had an acute stroke. C.G. has a 1-month-old infant at home and faces the challenge of not only caring for herself, but also her newborn baby, as she has right hemiplegia following the stroke.

M.R. is not a parent himself, and this is the first time a client has requested to work on infant care. He sees it is very important to C.G., and he feels like he can help, but he wishes he knew a bit more about parenting and disability. A colleague tells M.R. about the *Adapting Parenthood* website, which he explores to gain more knowledge and confidence in addressing C.G.'s needs.

M.R. uses the platform initially to learn more about how a stroke might impact parenting occupations. He reads an article written by a young mom with hemiplegia who

learned how to support her baby using a unique hold and a placement of a breastfeeding pillow to successfully breastfeed her newborn baby. He also discovers some online resources and support groups for mothers and parents who have suffered from stroke.

M.R. watches a video *Adapting Parenthood*, which shows a mother demonstrating a one-handed lifting technique on a baby and gives suggestions on how to allow the baby to assist with the transfer. Armed with this knowledge, M.R. returns to his client the next day. He asks her about some of these techniques and they are able to come up with a technique that is similar, but better meets her needs. She tells him she is planning to both breastfeed and bottle-feed her baby. Together they design a similar harness system as the one used in the video and try it out first using a weighted doll and then eventually in the inpatient rehabilitation setting with both her infant son and husband.

M.R. had learned from a continuing education course on the *Adapting Parenthood* platform about interdependency. C.G.'s husband works from home, has past caregiving experience, and plans to be fully involved in both C.G.'s care and recovery as well as the caregiving of their son. M.R. is able to take a family-centered approach and helps the couple navigate ways to modify the environment and work together to share parenting responsibilities. *Adapting Parenthood* proves to be an invaluable resource for M.R. in addressing the unique challenges faced by his client and her family, ultimately enabling them to build a supportive and adaptive environment.

### **Roles of Personnel**

A combination of personnel with various roles will be essential to developing,

maintaining, and updating the *Adapting Parenthood* platform. The roles and position descriptions are detailed in Table 4.1 *Personnel Roles and Descriptions*.

**Table 4.1**

*Personnel Roles and Descriptions*

<b>Role</b>	<b>Position Description</b>
Project Manager	Oversees the overall development and execution of <i>Adapting Parenthood</i> , ensuring that milestones are met, resources are allocated appropriately, and team members are collaborating effectively.
Web Developer	Responsible for the technical development and maintenance of the platform and features, including coding, debugging, and ensuring that the site runs smoothly on various devices and browsers.
Content Creator/Editor	Researches, writes, and edits of content ensuring that it is accurate, engaging, and relevant to the target audience. The content creator may collaborate with subject matter experts to ensure the accuracy and quality of the information.
Subject Matter Expert	These individuals have expertise in occupational therapy, parenting with disabilities, and related fields. They contribute their knowledge and insights to the development of content, ensuring that it is evidence-based and applicable to real-world scenarios.
User Experience (UX) Designer	Responsible for designing the platform layout, navigation, and overall user experience, ensuring that it is intuitive, accessible, and meets the needs of the target audience.
Graphic Designer	Creates visual elements for the platform, such as images, infographics, and videos, to enhance the user experience and support the content.
Marketing and Outreach Coordinator	Responsible for promoting <i>Adapting Parenthood</i> to the target audiences, using various marketing and communication strategies, including social media, email campaigns, and networking with professional organizations.
Accessibility Specialist	Ensures that the platform adheres to accessibility guidelines and best practices, making it usable and accessible for people with various disabilities and needs.
Data Analyst	Collects, analyzes, and reports on platform usage data, providing insights into user behavior and preferences to inform ongoing improvements and content development.
Legal and Compliance Advisor	Ensures that the <b>content and interface</b> adhere to relevant legal and ethical guidelines, including copyright, data protection, and privacy regulations.



### **Potential Barriers and Solutions**

The implementation and maintenance of the *Adapting Parenthood* platform may encounter several potential barriers and challenges.

Achieving professional buy-in and agreement to host content on the platform can be a significant challenge. Professionals who already host their content on other platforms may show reluctance in duplicating or relocating their resources. Additionally, maintaining the engagement of these professionals and encouraging them to regularly update their content may prove difficult.

The development of a user-friendly and accessible platform necessitates expertise in design and website maintenance. The platform needs to be intuitive, responsive, and accessible to individuals with diverse abilities, which can pose a design challenge. Furthermore, search engine optimization, a crucial aspect for visibility, requires specialized knowledge and consistent effort.

Given that *Adapting Parenthood* is not associated with a well-established professional education organization, gaining visibility and recognition can be a significant hurdle. Strategies to enhance the platform's credibility and visibility may include forming partnerships, implementing marketing campaigns, and gathering user testimonials.

Access barriers such as limited internet connectivity, digital literacy, or language proficiency could hinder user engagement with the platform or certain features. To facilitate user interaction and engagement, the platform may need to incorporate interactive features and provide content in multiple languages and assure that content can

load without high internet speeds.

The financial obligations related to maintaining and updating the platform can pose constraints. Additionally, legal considerations such as adherence to copyright laws, privacy policies, and user agreements must be thoroughly addressed to avoid legal infringements and ensure user trust.

### **Conclusion**

Chapter Four presents a detailed description of *Adapting Parenthood*. It outlines the need for the platform, the theoretical basis upon which it's constructed, and its design features, which include a variety of multimedia resources to cater to different learning styles and preferences. Having laid out the structure and purpose of the *Adapting Parenthood* platform, the next step is to discuss how the effectiveness of this program will be evaluated. Chapter Five will outline a comprehensive evaluation plan for the program.

## CHAPTER FIVE – Program Evaluation Research Plan

Chapter Five outlines the plan for evaluating the effectiveness of the *Adapting Parenthood* platform. Given the need for ongoing assessment to the success of any initiative, this author presents a framework for measuring the impact of the platform at both the individual and aggregate program levels. The aim is to ensure that the platform is achieving its goal of empowering OTPs to better support parents with physical disabilities. For a simplified logic model of this process, please refer to Appendix B: *Simplified Logic Model*.

The central concern of this project arises from the obstacles encountered by parents with physical disabilities, particularly the environmental barriers affecting their parenting roles and occupations. These barriers, ranging from physical aspects of the environment to societal attitudes, can make parenting a formidable task. Yet, these challenges are often exacerbated by a systemic issue within healthcare and support services- a pervasive lack of knowledge and resources among practitioners that can hinder effective services.

To address these challenges, *Adapting Parenthood* was perceived as a comprehensive and accessible tool aimed at bridging these knowledge and resource gaps. Designed as an online platform, the project provides real-time, widely accessible information and resources, enabling OTPs to quickly and effectively integrate newfound knowledge into practice. The decision to adopt a web-based model was driven by the desire to ensure maximum reach and facilitate instantaneous application, thereby making the much-needed resources readily available to practitioners who can directly influence

the lives of their clients.

To guide the project's progress and measure its success, a set of clear research aims, objectives, and questions have been established. These include: Will OTPs use a platform that includes resources and information about parenting with a disability? If they do use the platform, will it result in an increase in their competency on the subject? If there is an increase in competency, will this then translate into improved services that meet the needs of parents with physical disabilities?

This chapter will provide a comprehensive overview of the program evaluation plan. The methodology section delves into the specifics of the research design, the chosen methods, and their justification. It elaborates on ethical considerations, details of the sample population, recruitment methodology, and data collection and analysis. This is followed by a discussion on potential limitations and the strategies to mitigate them. Ultimately, this chapter aims to provide a logical, coherent, and robust plan for evaluating whether *Adapting Parenthood* achieves its core objectives.

## **Methodology**

This section delineates the methodological approach and lays the foundation for understanding how the project will be evaluated. The methodological approach for this evaluation is mixed method, using both quantitative (user data) and qualitative (user experiences and practice outcomes) data collection. This approach facilitates a comprehensive exploration of user experiences and outcomes while also providing quantifiable data to measure website usage and user competency increase. A longitudinal data collection strategy will be employed, thereby providing a more holistic

understanding of the *Adapting Parenthood's* impact over time.

The anticipated users of the *Adapting Parenthood* include OTPs and students, allied healthcare and community-based professionals, disabled parents and their support networks, and potentially the children of parents with disabilities themselves. Users are expected to primarily speak English, have access to the Internet, and possess a moderate literacy level. The precise number of users is uncertain, reflecting the unpredictability inherent in website usage.

Recruitment for the study will be primarily organic, reflecting the natural user base of the platform. This will be supplemented by convenience sampling, inviting users to test the platform and provide feedback. Strategic advertisement and outreach campaigns targeting organizations that support OTPs, parents, and individuals with disabilities will draw users. Lists of individual practitioners who work with parents with disabilities and academic occupational therapy institutions will also be targeted for recruitment of users.

Building on the multifaceted approach to data collection, this study will utilize advanced analytics software, such as Google Analytics, to gather quantitative user data. This software enables precise tracking of various usage metrics, offering valuable insights into user behavior and engagement with the online platform. User analytics collects a vast number of data points, including, but not limited to, the number of site visits, the source of visits (direct, referral, search, social, or other), the duration of each visit, which pages are visited, and the order in which they're viewed. This information paints a comprehensive picture of user engagement, allowing an understanding of which

resources are most useful to its audience and where potential improvements could be made.

Once collected, the data can be exported in a spreadsheet format for more in-depth analysis. This format allows the data to be sorted, filtered, and examined in various ways, facilitating a more nuanced understanding of user behavior. The spreadsheet data can then be imported into a statistical software package for quantitative analysis. Such software enables the application of various statistical methods to the data. This might include identifying patterns in user behavior, establishing correlations between different variables (such as time spent on the site and increased competency), and testing hypotheses derived from the research questions. All collected data will be stored securely, with privacy measures in place to protect user identities.

Potential limitations of this study may include time and budget constraints, potential selection bias, possibly small sample size, and potential issues with data collection and analysis due to the inherent unpredictability of website traffic and user engagement. These limitations will be considered and mitigated as much as possible throughout the evaluation process.

By comprehensively addressing each of these components, this methodology ensures a thorough and ethical evaluation of *Adapting Parenthood*, facilitating an understanding of its effectiveness in bridging the knowledge and resource gaps among OTPs serving parents with physical disabilities.

### **User Recruitment**

Various methods can be used to recruit or identify potential users of the *Adapting*

*Parenthood* Platform. Collaborating with related organizations and support groups that serve parents with disabilities, OTPs, and related professionals can be an effective way to promote awareness of the platform. The use of social media platforms and engagement with relevant online communities and groups can help reach a broader audience.

Representation at conferences, events, and professional networks related to occupational therapy, disability, and parenting can facilitate connections with potential users of *Adapting Parenthood*. Distributing educational and informational materials at rehabilitation centers, hospitals, clinics, and community centers can also raise awareness about the platform. Hosting webinars, workshops, or seminars on topics related to parenting with disabilities and occupational therapy can attract potential.

### **Desired Outcomes**

*Adapting Parenthood* aims to empower individuals and instigate systemic change by providing valuable resources to both parents with disabilities and professionals, ultimately promoting more inclusive and effective parenting practices. In the short term, individual learners, including parents with disabilities and professionals, are expected to gain knowledge and understanding of assistive technologies, environmental modifications, activity adaptations, and disability rights and culture. Parents should be able to apply this knowledge directly to their parenting tasks, increasing their confidence and self-efficacy. Professionals, on the other hand, should be able to implement these insights in their practice, improving their capacity to support disabled parents more effectively.

In the long term, *Adapting Parenthood* aims to foster a community of informed,

empowered parents and skilled professionals who can advocate for and implement better support systems for parents with disabilities. This knowledge dissemination is expected to lead to systemic changes in the way society perceives and supports parents with disabilities. This includes more comprehensive and targeted policies and interventions at a societal level, improved occupational therapy services, and a broader, more inclusive understanding of parenting. Ultimately, *Adapting Parenthood* seeks to contribute to a world where parents with disabilities are fully supported and empowered in their parenting journey.

### **Conclusion**

In conclusion, Chapter Five provides a comprehensive plan for evaluating the *Adapting Parenthood* platform. By establishing clear metrics and methods for data collection, this chapter sets the stage for the ongoing assessment and refinement of the platform. With an evaluation plan in place, the focus now shifts to the dissemination of information about the platform to the relevant audiences. This leads us to Chapter Six, where this author presents strategies for reaching these audiences and discusses the anticipated impact of these dissemination efforts.



## **CHAPTER SIX – Dissemination Plan**

Chapter Six lays out a detailed plan for disseminating results of the *Adapting Parenthood* platform. Recognizing the importance of effective communication in ensuring the success of this initiative, this author outlines strategies for reaching the relevant audiences, which includes OTPs, students, and related healthcare professionals. The goal is to raise awareness about the platform, elucidate its purpose and benefits, and encourage its use among the target population.

### **Program Description**

*Adapting Parenthood* is an online resource and education platform, designed to meet the professional development needs of OTPs working with parents who have physical disabilities. This program is comprised of resources and educational modules built to enhance practitioners' clinical knowledge and skills. Each module prepares practitioners for the unique needs and considerations of serving parents with physical disabilities by presenting disability-affirming treatment ideas, information, and adaptations. The resources furnish practitioners with a foundation of tools and strategies, not only enriching their professional practice but to facilitate their interactions with the parent population they serve.

### **Target Audiences**

The primary target audience for *Adapting Parenthood* is OTPs. Dissemination efforts for this group are intended to improve direct occupational therapy services for parents with physical disabilities. By providing practitioners with education and resources tailored to their professional needs, the platform aims to empower them to

enhance their services, leading to accessibility of care provided to the parent population.

The secondary audience consists of potential referring providers for parents with physical disabilities to occupational therapy services. This audience includes, but is not limited to, healthcare and community professionals like primary care physicians, pediatricians, social workers, and psychologists. Dissemination efforts targeting this group aim to increase referrals to direct occupational therapy services for parents and caregivers with physical disabilities. Furthermore, these efforts strive to foster greater understanding among this audience about the role and impact of occupational therapy interventions, promoting increased support and a more nuanced understanding of the environmental barriers faced by this population and the services available to address them.

## Key Messages

**Table 6.1**

*Summary of Key Messages*

<b>Key Messages for Occupational Therapy Practitioners as a Primary Audience</b>
<ul style="list-style-type: none"> <li>• <i>Adapting Parenthood</i> equips OTPs with tools and knowledge to integrate disability-affirming strategies into clinical practice and academic research.</li> <li>• Occupational therapy interventions can mitigate environmental barriers faced by parents with physical disabilities.</li> <li>• <i>Adapting Parenthood</i> enables OTPs to immediately enhance their approach and treatment strategies for parents and caregivers with physical disabilities in their current practice setting.</li> </ul>
<b>Key Messages for Professionals, Parents and Supporters as a Secondary Audience</b>
<ul style="list-style-type: none"> <li>• <i>Adapting Parenthood</i> serves as a valuable resource to effectively implement disability-affirming strategies in interactions with parents and caregivers with physical disabilities.</li> <li>• Occupational therapy plays a clear role in improving the health and well-being of parents with physical disabilities.</li> <li>• All individuals, groups and organizations can play a crucial role in reducing or removing environmental barriers to parenting.</li> </ul>

Key messages provide clarity and consistency when disseminating outcomes of *Adapting Parenthood* to stakeholders. This section is divided into primary and secondary audiences. Table 6.1 *Summary of Key Messages* provides a quick reference to key messages for each audience.

### ***Primary Audience***

For the primary audience, namely OTPs, three key messages are centered around the tools, resources, and improvements brought about by the *Adapting Parenthood* program.

1. *Adapting Parenthood* equips OTPs with the essential tools and knowledge required to integrate disability-informed strategies into their practice. This targeted approach enhances their ability to support parents with physical disabilities in actively engaging in parenting roles and participating in related occupations.
2. Occupational therapy interventions, as facilitated through the resources offered by *Adapting Parenthood*, possess significant potential to mitigate some of the cultural, social, physical, political, and economic barriers faced by parents with physical disabilities, particularly in social, physical, and political realms.
3. Utilizing the resources and completing the educational modules on the *Adapting Parenthood* platform enables OTPs to immediately enhance their approach and treatment strategies for parents and caregivers with physical disabilities in their current practice setting.

### ***Secondary Audience***

The secondary audience, encompassing allied healthcare, social, and community professionals, also have three key messages tailored to their context:

1. *Adapting Parenthood* serves as a valuable resource, providing allied healthcare, and social and community professionals with the tools and knowledge to effectively implement disability-affirming strategies in their interactions with parents and caregivers with physical disabilities.
2. Occupational therapy plays a clear role in improving the health and well-being

of parents with physical disabilities. This understanding lays the groundwork for advocacy, encouraging an increase in referrals for parents with physical disabilities and a focus on parenting goals during OT services.

3. Parents with physical disabilities encounter numerous barriers in their environment. Allied healthcare and social and community professionals, equipped with the tools and knowledge from *Adapting Parenthood*, can play a crucial role in reducing or removing these barriers.

### **Sources/Messengers**

For the primary audience, namely OTPs, the following influential entities can help spread the key messages from *Adapting Parenthood*:

1. The American Occupational Therapy Association (AOTA) and the World Federation of Occupational Therapy (WFOT) are professional bodies with considerable reach and credibility within the occupational therapy community. They are well-positioned to disseminate resources and promote initiatives that aim to improve occupational therapy practices. Notably, the AOTA is also a respected provider of Continuing Education Units (CEUs), adding further weight to their endorsement of the program.
2. The Coalition of Occupational Therapy Advocates for Diversity (COTAD) is a non-profit organization with a mission to “To empower occupational therapy leaders to engage in practices that increase justice, equity, diversity, and inclusion (JEDI); anti-racism and anti-oppression for a transformative occupational therapy profession” (COTAD, n.d.). This organization is a

powerful platform to share *Adapting Parenthood* will OTPs who are actively seeking to improve diversity-affirming practices to their clinical approaches.

For the secondary audience, comprising potential referring providers for parents with physical disabilities, the following organizations will be key influencers:

1. Easterseals (Easterseals, n.d.) is a national organization that provides support to families and support systems of individuals with disabilities. Long known for their advocacy of occupational therapy services for individuals with disabilities, they command a significant presence in medical and social communities, making them an ideal source for spreading *Adapting Parenthood's* key messages.
2. The National Research Center for Parents with Disabilities (The Heller School at Brandeis University, n.d.) is a highly respected organization dedicated to conducting research and training aimed at improving the lives of parents with disabilities and their families. Given its reach among professionals, families, and working with or supporting parents with disabilities, it can effectively disseminate the resources and strategies proposed by *Adapting Parenthood*.

### **Dissemination Activities, Tools/Techniques, Timing, and Responsibilities**

For the primary audience of OTPs, the dissemination plan includes written information, electronic media, and person-to-person contact. Each activity or tool may incur a cost. The budget for dissemination is reviewed in detail in Table 6.2:

*Dissemination Budget For Primary Audience*, and Table 6.3: *Dissemination Budget For Secondary Audience*. As the first priority, articles discussing the purpose, usage, and

outcomes of *Adapting Parenthood* will be submitted to publications such as *OT Practice*, published by AOTA, *The Bulletin*, published by the World Federation of Occupational Therapy (WFOT), and the National Research Center for Parents with Disabilities (NRCPD) at Brandeis University. These articles could be written by this author, along with various experts, especially those who have contributed to or created educational content on *Adapting Parenthood*.

Electronic media is prioritized second. Podcast interviews with various occupational therapy podcasts like AOTA's *OT Podcast Channel*, *Spill The OT*, and *Occupied* will reach the target audience, particularly those who are interested in improving practice. While reaching out for these opportunities will be a primary activity, actual interviews can be scheduled over time according to the availability of myself and other contributors.

Person-to-person contact will be carried out by the author as the first priority through a short course and a research poster at the AOTA annual conference, as well as the author's home state conference by the Texas Occupational Therapy Association (TOTA).

The secondary audience, potential referring providers, will also be engaged through written information, electronic media, and person-to-person contact. The first priority will be written articles focusing on the role and services of occupational therapy for parents with physical disabilities. These articles will target websites like Medscape, or even broadly read publications such as *The New York Times*. The articles could be authored by myself, in collaboration with other researchers on the topic, with a request to

include a mention of *Adapting Parenthood*.

In terms of electronic media, podcast interviews will be published on *Parenting Done Differently*, a podcast by the University of Minnesota Center of Advanced Studies in Child Welfare. Also, a webinar will be featured on the disAbility Maternity Care website, an Australian organization providing professional development on parenting and disability. These efforts will be secondary priorities and can be undertaken by this author or contributors to *Adapting Parenthood*, depending on opportunities and availability. Finally, as the third priority, person-to-person contact will be made at the 2023 collaborative care conference in Australia by disAbility Maternity Care, which will take place on August 31st and September 2nd, 2023



**Table 6.2***Dissemination Budget for Primary Audience*

<b>Activity</b>	<b>Expense</b>	<b>Cost</b>	<b>Time Required (hours)</b>
Podcast Interviews	Preparation and Interview Time	\$0	2 per interview
	AOTA's OT Podcast Channel	\$0	2
	Spill The OT	\$0	2
	Occupied	\$0	2
AOTA Inspire Conference	Conference Registration	\$350	-
	Hotel (4 nights)	\$1,000	-
	Flight (round trip)	\$400	-
	Food (4 days)	\$200	-
Writing Articles	Writing/Co-authoring Time	\$0	3–4 hours per article
	Texas Occupational Therapy Association Conference 2024		
	Conference Registration	\$350	-
	Hotel (2 nights)	\$360	-
	Food (2 days)	\$100	-
	Travel (300 miles round trip @ \$0.65/mile)	\$195	-
<b>Total</b>		<b>\$2,555</b>	<b>16–18 hours</b>

**Table 6.3***Dissemination Budget for Secondary Audience*

<b>Activity</b>	<b>Expense Type</b>	<b>Cost</b>	<b>Time Required (hours)</b>
Writing Articles	Writing/Co-authoring Time	\$0	2–3 per article
	Article for Medscape	\$0	3
	Article for The New York Times	\$0	3
Collaborative Care Conference	Conference Cost	\$95	-
	Flight	\$4,000	-
	Room and Board (4 days)	\$1,200	-
Webinar (disAbility Maternity Care website)	Production Time	\$200	4
		(\$50/hr x 4 hours)	
<b>Total</b>		<b>\$5,295</b>	<b>8–10 hours</b>

**Evaluation**

The success of the dissemination efforts for *Adapting Parenthood* will be gauged primarily through audience metrics associated with each type of effort. This involves quantifiable aspects such as the number of views for written articles, the number of downloads or subscriptions for podcasts, and the number of attendees or completed Continuing Education Units (CEUs) for webinars. Similarly, for in-person activities such as short courses, research papers, and presentations, the number of attendees will serve as a key metric for evaluating the reach of these efforts.

While quantitative metrics provide a source of assessment of the dissemination efforts, they do not fully capture the qualitative impact of the program. Therefore, the true effectiveness of dissemination will also be measured through personal interactions, stories, and responses to the program. Anecdotal evidence will provide a more nuanced

understanding of how *Adapting Parenthood* is being received, interpreted, and applied by its target audiences. Collecting this data will involve actively seeking and recording feedback and experiences from both the primary and secondary audiences, offering valuable insights into the real-world impact of the program. Combining both quantitative and qualitative methods will enable a more holistic appraisal of the dissemination efforts.

To assess the effectiveness of the dissemination activities, an evaluation plan will measure both quantitative metrics and qualitative aspects of review. This combined approach will provide an in-depth understanding of the impact of the *Adapting Parenthood* program and guide any necessary improvements or modifications to the dissemination plan.

In conclusion, Chapter Six presents a dissemination plan for *Adapting Parenthood*. By defining the primary and secondary target audiences and presenting key messages, this author sets the groundwork for ensuring that the platform reaches the individuals and groups who can benefit most from it. With a dissemination strategy in place, attention now turns to the financial sustainability of the project. This leads to Chapter Seven, where this author outlines a funding plan to ensure the long-term viability of the *Adapting Parenthood* platform.

## CHAPTER SEVEN – Funding Plan

Chapter Seven outlines a funding plan to ensure the long-term sustainability of the *Adapting Parenthood* platform. Recognizing the financial investment required to develop, maintain, and improve an online resource and education platform of this magnitude, this author identifies potential sources of funding that align with the goals of the project. The aim is to create a comprehensive financial strategy that will allow the platform to provide valuable resources to OTPs and ultimately contribute to improved outcomes for parents with physical disabilities.

### **Program Description**

The proposed project, *Adapting Parenthood*, an online resource and education platform, will function as an invaluable tool to foster a comprehensive understanding of the unique challenges and needs that come with parenting with a physical disability. The aim is to create an engaging, accessible, and informative space that enables practitioners to deepen their understanding and enhance their professional practice while contributing to improved outcomes for parents.

Ensuring the financial sustainability of this initiative necessitates identifying appropriate and feasible funding sources. A considerable number of grants exist that directly or indirectly support individuals with disabilities. However, eligibility criterion for many of these funding opportunities requires the recipient to be a non-profit organization. Consequently, our funding strategy must consider this factor to secure the resources required to sustain and develop *Adapting Parenthood*.

## **Program Expenses**

### ***Project Management***

To ensure *Adapting Parenthood's* success, one of the primary expenses is compensating the project manager, who is also an occupational therapist. Their salary will be based on an hourly rate of \$50 for approximately 80 hours of work. Their responsibilities encompass the comprehensive management of the project, which includes the development of the initial project draft, liaison with domain experts, and orchestrating the creation of the online platform. The project manager's expertise as an occupational therapist will be vital to ensure the content and overall direction of *Adapting Parenthood* are not only relevant but also provide tangible value to our target audience.

### ***Web Infrastructure***

Next, a crucial expense is securing a reliable hosting service, which is foundational for maintaining the platform's performance and constant availability. *Adapting Parenthood* also utilize a digital learning and community platform. This structure will aid in effectively organizing and delivering educational content, track user engagement, and manage access to course materials.

### ***Content and Design***

Funds will be allocated for graphic design. The designer's role will be to enhance the platform's aesthetic appeal and ensure consistency in branding across all interfaces. A large part of the budget is also dedicated to content acquisition, which will enable continuous expansion of our content and resources. A continuing education development professional will create engaging and enlightening learning modules that are not just

educational but also relevant and meet the unique needs of our audience.

### ***Platform Development and User Experience***

The expense for platform design and creation follows the standard website cost and one-time expense for the website development company, EZ Marketing (EZMarketing, 2019). Crafting a professional and user-friendly platform is paramount in to not only attract, but also retain the user audience. To ensure the visibility and outreach of *Adapting Parenthood*, investment in regular Search Engine Optimization (SEO) services at EZ Marketing's standard cost will be included in the budget. SEO will play a critical role in making the platform easily discoverable by potential users. In the endeavor to be inclusive, an investment will also be made in software that makes the platform compliant with the Americans With Disabilities Act. This will make the platform accessible to all potential users, including those with disabilities.

### ***Professional Development Accreditation***

Another key aspect of expenditure involves becoming an American Occupational Therapy Association Approved Provider (AOTA, n.d.). This certification not only boosts credibility within the occupational therapy community but also guarantees continued recognition as an AOTA approved provider, which testifies to the quality of the platforms' professional development courses. Approval will ensure compliance with AOTA standards and deliver valuable content to our audience.

Table 7.1, *Funding Budget* provides a breakdown of the budgeted expenses for the first and second year of the project. Each expense is justified and categorized accordingly.

**Table 7.1***Funding Budget*

<b>Expense</b>	<b>Budgeted 1st Year (\$)</b>	<b>Budgeted 2nd Year (\$)</b>	<b>Justification</b>
Project Manager (Occupational Therapist)	4,000	4,000	Hourly rate approximated at \$50 per hour for an estimated 80 hours of labor.
Equipment	0	0	The author will use computers already owned.
Website Hosting (Squarespace)	480	480	Squarespace Business Plan (\$40 per month, billed annually).
Digital Content Platform (Kajabi)	3,564	3,564	Kajabi Basic Plan (\$297 per month, billed annually).
Graphic design	20,000	0	<a href="https://www.jessicaoddi.com/design-accessibility">https://www.jessicaoddi.com/design-accessibility</a>
Content Acquisition	15,000	15,750	Fees for purchasing rights to existing professional development modules, articles, or other relevant content.
Website Development	20,000	0	. <a href="https://www.ezmarketing.com/website-design-development/">https://www.ezmarketing.com/website-design-development/</a>
SEO Services	15,000	15,750	<a href="https://www.ezmarketing.com/website-design-development/">https://www.ezmarketing.com/website-design-development/</a>
AOTA Approved Provider Program Application (Tier 2)	1,125	0	Fee for application for the AOTA Approved Provider Program (10-49 activities annually).
AOTA Approved Provider Program Annual Fee (Tier 2)	500	500	Annual fee for the AOTA Approved Provider Program. (10-49 activities annually).
AOTA Approved Provider Program Activity Approval (10 activities)	750	750	Fee for getting each professional development activity approved. (\$75 per activity, assuming 10 activities per year)
ADA Compliance Software (UserWay)	490	490	Annual cost for AI-powered software ensuring ADA Compliance for the platform. (Small Site plan up to 100K pageviews per month).

Continuing Education Development	12,940	12,940	Assuming 500 hours of work per year for developing 10 modules with an hourly rate of \$25.88.
Domain Purchase (Google Domains)	12	12	Annual fee for domain name purchase and renewal ( <a href="http://www.adaptingparenthood.com">www.adaptingparenthood.com</a> ). This domain name is crucial for establishing the platform's identity and making it accessible to our audience.
Dissemination Primary Audience	2,555	0	
Dissemination Secondary Audience	5,340	0	
<b>Total</b>	<b>100,631</b>	<b>71,611</b>	

### **In-Kind Resources**

The virtual nature of *Adapting Parenthood* presents an advantage to tap into a global network of resources and expertise. The absence of geographical constraints makes it possible to draw upon the skills, time, and knowledge of professionals, experts and parents from all corners of the world. This diverse pool of contributors will not only enrich content, but also add a broad range of perspectives and experiences, further enhancing relevance and applicability.

The author will actively seek voluntary contributions from practitioners in the field of occupational therapy and disability. These individuals possess practical, real-world experiences and insights. Their shared expertise will help not just their professional peers, but also the broader community of parents with physical disabilities and their supports.

It is likely that a significant percentage of the platform's content will be derived from volunteers who are passionate about the cause. Given the number of individuals



already engaged in advocacy work related to parents with physical disabilities, the author anticipates a strong willingness to contribute to the project. This could take the form of content creation, user support, or even guidance in the project's strategic direction.

The digital landscape offers a plethora of free or low-cost tools that facilitate collaboration and communication. Video conferencing platforms, such as Zoom, can be used free of cost to conduct meetings with stakeholders, project teams, and volunteers, thus eliminating the need for a physical meeting space. Free services like Google Docs can be utilized for collaborative content creation and project management.

Volunteer-based resources such as SCORE (*SCORE*, n.d.), offer free business mentoring services. Their expertise can prove invaluable during project development and management, ensuring the project stays on track and address potential challenges.

## **Potential Funding Sources**

### ***Partnering with a Non-Profit Organization***

Partnering with an existing non-profit organization could be a viable strategy for funding all or part of the *Adapting Parenthood* platform. One such organization is the Adaptive Parent Project (APP), a 501(c)(3) advocacy group dedicated to supporting parents with disabilities (Adaptive Parent Project, n.d.). APP has a track record of successfully obtaining grants, including state-level funding from California (Personal communication, 2023). By forming a partnership with APP, *Adapting Parenthood* could align with their mission, leveraging their non-profit status to access grant opportunities that would otherwise be inaccessible to individuals or for-profit entities. Notably, APP has previously been recognized by external campaigns. The founder of APP, Alesha

Thomas, was one of the 23 women who won a \$20,000 grant in 2021 from the Aerie's Real Changemakers campaign (Korn, 2021). This campaign supports women leading initiatives that effect real change in their communities. As APP and *Adapting Parenthood* share a common goal of enhancing services and education for parents with disabilities, a potential partnership could yield benefits in terms of both mission alignment and access to additional funding sources.

### ***Creating a Non-Profit Organization***

Transitioning *Adapting Parenthood* into a non-profit organization could be a feasible approach to securing external funding. This route aligns logically with the mission of *Adapting Parenthood*, to disseminate knowledge to professionals for the collective good. Profit generation is not the core objective of *Adapting Parenthood*; instead, it prioritizes the widespread sharing of resources and education for OTPs serving parents with disabilities.

Non-profit status involves a series of steps as outlined by the Internal Revenue Service (Internal Revenue Service, n.d.). The application process is comprehensive and involves the presentation of a clear mission and a robust project proposal, detailing the organization's intentions and activities. Once a 501(c)(3) status is secured, *Adapting Parenthood* can then apply for grants specific to non-profit organizations. This could significantly widen the pool of potential funding sources, as many grants targeting the enhancement of services and education for individuals with disabilities are exclusively accessible to non-profit entities.

## **Funding Sources**

The following funding sources are well-suited for the mission and goals of *Adapting Parenthood*.

- The U.S. Department of Education offers discretionary and competitive grants via the Office of Special Education Programs. These grants are geared towards parent training and information centers that cater to parents with children with disabilities (Darling, 2023). Funding opportunities have potential for initiatives focusing on educational technology, media, and materials aimed at individuals with disabilities.
- The Hearst Foundations offer grants ranging between \$30,000 to \$200,000 to projects centered on "education/outreach" that aim to enhance the health and quality of life of individuals (Hearst Foundations, n.d.). Unfortunately, eligibility for these grants necessitates a non-profit status and a minimum annual budget of \$1,000,000.
- The Administration for Children and Families provides grant funding designed to “promote the economic and social well-being of families, children, individuals, and communities” (Administration for Children & Families, 2022), however no current funding opportunities align directly with the objectives of *Adapting Parenthood*.
- The most notable example of funding in support of its professional development initiatives for healthcare professionals serving parents with disabilities is from the Paralyzed Veterans of America Education

Foundation. This organization not only offers grants, but also demonstrates the substantial impact such grants can have on professional development projects. In April of 2023, the Foundation's Board of Directors recognized the professional development and community education efforts of four grantees (Paralyzed Veterans of America, 2023). These grants, awarded for a one-year period totaled \$94,755 and were divided into two categories: Professional Development and Education, and Conferences and Symposia. A notable recipient within the Professional Development and Education category was Kristin Musselman from the University of Toronto, Canada. She received an award of \$49,755 for her project entitled “Development, Dissemination, and Evaluation of a Functional Electrical Stimulation Toolkit for Healthcare Providers” (Paralyzed Veterans of America, 2023).

## **Conclusion**

Chapter Seven provides a funding plan for the *Adapting Parenthood* platform. By identifying potential sources of funding and outlining a strategy to secure them, this author sets the foundation for the financial sustainability of the project. With a clear plan in place for program evaluation, dissemination of information, and funding, the final chapter, Chapter Eight, synthesizes the key points from each section and discusses the potential significance of *Adapting Parenthood* in the field of occupational therapy.

## CHAPTER EIGHT – Conclusion

Chapter Eight serves as the conclusion of this manuscript, synthesizing the key points from each section and examining the potential significance of *Adapting Parenthood* to the field of occupational therapy. This chapter is intended to provide a comprehensive summary, highlighting the innovative nature of the *Adapting Parenthood* platform and its potential to revolutionize occupational therapy as a facilitator for a pivotal and substantial life role of individuals and families. This author reflects on the journey of this project, from identifying the problem to proposing a solution, and contemplates the potential impacts and future directions of the project.

### **The Alignment of *Adapting Parenthood* and Occupational Therapy**

OTPs can play an instrumental role in supporting parents with physical disabilities, offering essential services to enhance their participation in various parenting tasks and roles. Through interventions such as adaptive techniques, assistive technology, environmental modification, and family education, they can directly address some the environmental challenges these parents face (Wade et al., 1999; Fernando, 1995; Tuleja et al, 1999; Wint et al., 2016; Evans & Orpwood, 2007). OTPs establish a core focus on 'doing', which considers clients' abilities and their unique contexts (Lim et al., 2022). This approach emphasizes recognizing the client as an expert on their abilities and needs and prioritizes the collection of comprehensive history before setting goals.

*Adapting Parenthood* is an innovative professional development platform that holds the potential to contribute to the improvement of practice in the field of occupational therapy and is a testament to the intersection of professional development

and the crucial, often overlooked, lived experience of disability. The parenting journey can present obstacles for individuals with disabilities. Barriers, often born out of societal attitudes, structural inequalities, and practical constraints, can potentially disrupt parenting roles and occupations. However, with appropriate support and resources, some of these challenges can be lessened.

*Adapting Parenthood* offers holistic approaches in comprehending the challenges faced by parents with physical disabilities. It underscores the need to address societal attitudes and environmental barriers, fostering increased participation of parents with disabilities in parenting-related occupations. Despite significant advances in advocating for disability rights, there is a persistent need for action, and occupational therapy's role in advocacy is important. *Adapting Parenthood* acknowledges this responsibility, embodying the profession's core values and principles by strongly advocating for the rights and necessities of individuals to participate in meaningful occupations that drive positive health outcomes.

*Adapting Parenthood* aims to cultivate a culture of continuous learning and improvement among OTPs by providing diverse resources and topics of education. The platform ensures the comprehensiveness, effectiveness, and engagement of its educational materials by adopting a multimedia and self-paced approach. This platform, while being accessible to OTPs, remains relevant to other healthcare professionals who may interact with parents with physical disabilities.

Understanding the unique needs of each individual, OTPs can leverage their comprehensive understanding of physical health, mental wellness, and societal dynamics

to devise tailored interventions. In doing so, they aim to mitigate practical barriers, challenge societal biases, and endorse systemic changes that promote an inclusive and supportive environment for parents with physical disabilities.

The lack of understanding among professionals and communities about the potential role of occupational therapy in supporting parents with physical disabilities can inhibit treatment. Recognizing that a community is the gateway to obtaining the support that could lead to change, the program underscores the need for professionals to make appropriate referrals.

*Adapting Parenthood* challenges its users to engage in knowledge that influences health and wellness with a more comprehensive understanding of parenting as a developmental and life stage. OTPs are positioned to address the multifaceted barriers faced by parents with physical disabilities. Realizing this potential necessitates OTPs to equip themselves with the right knowledge and resources. *Adapting Parenthood* provides accessible educational resources to enhance practitioners' capacities to serve this population effectively.

## **Conclusion**

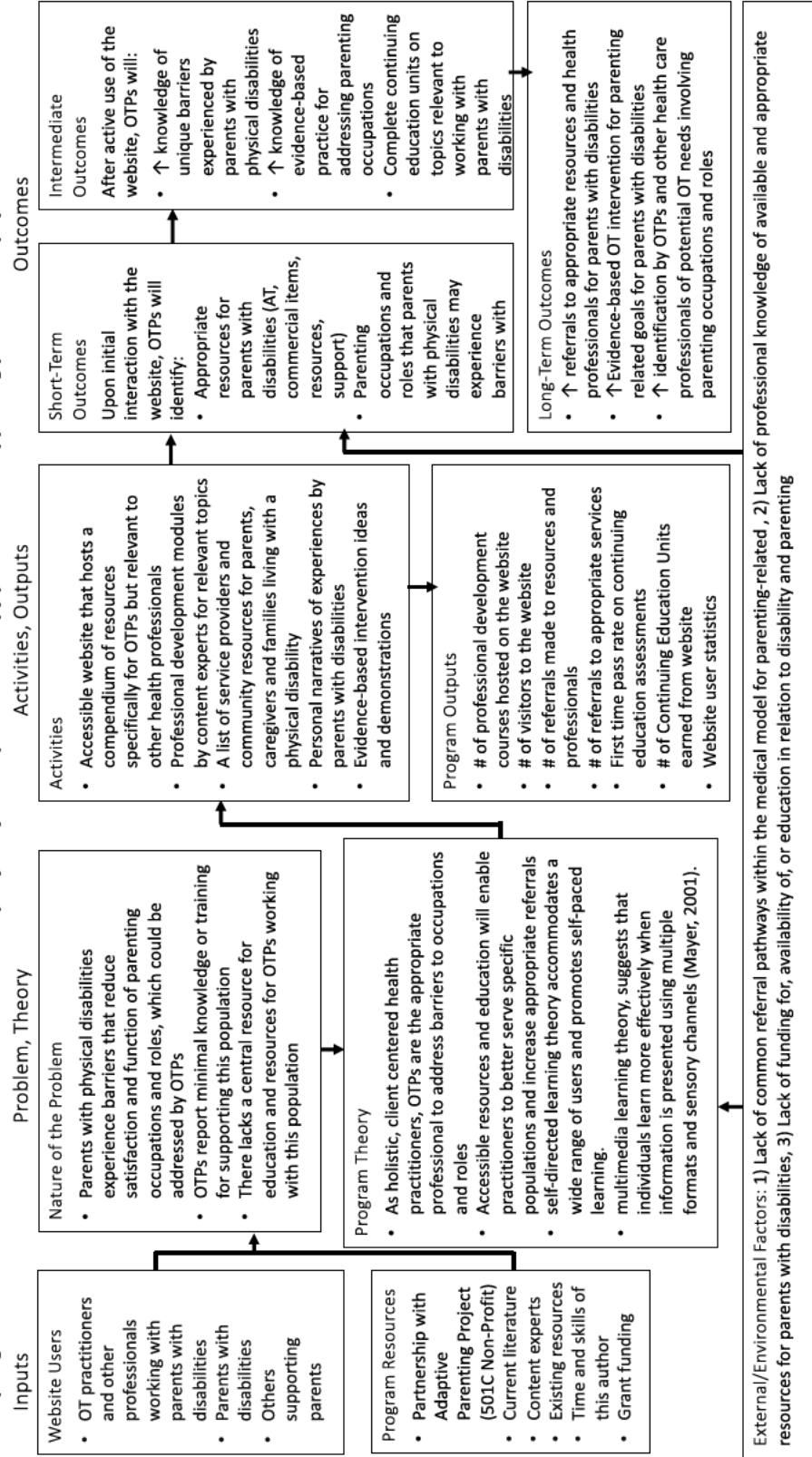
In conclusion, *Adapting Parenthood* represents an innovative solution to a pressing issue in the field of occupational therapy. By providing a resource and education platform dedicated to supporting parents with physical disabilities, this project addresses a significant gap in professional development and improves meaningful occupations and roles of clients and their families. It serves as a testament to the intersection of professional development and the lived experience of disability, highlighting the

importance of inclusive, disability-affirming practices. Looking forward, this author envisions the *Adapting Parenthood* platform as a catalyst for change, not just in the field of occupational therapy, but also in broader societal attitudes towards disability and parenting. With continued development and support, *Adapting Parenthood* has the potential to create a more inclusive and supportive environment for parents with disabilities, ultimately contributing to a more equitable society.

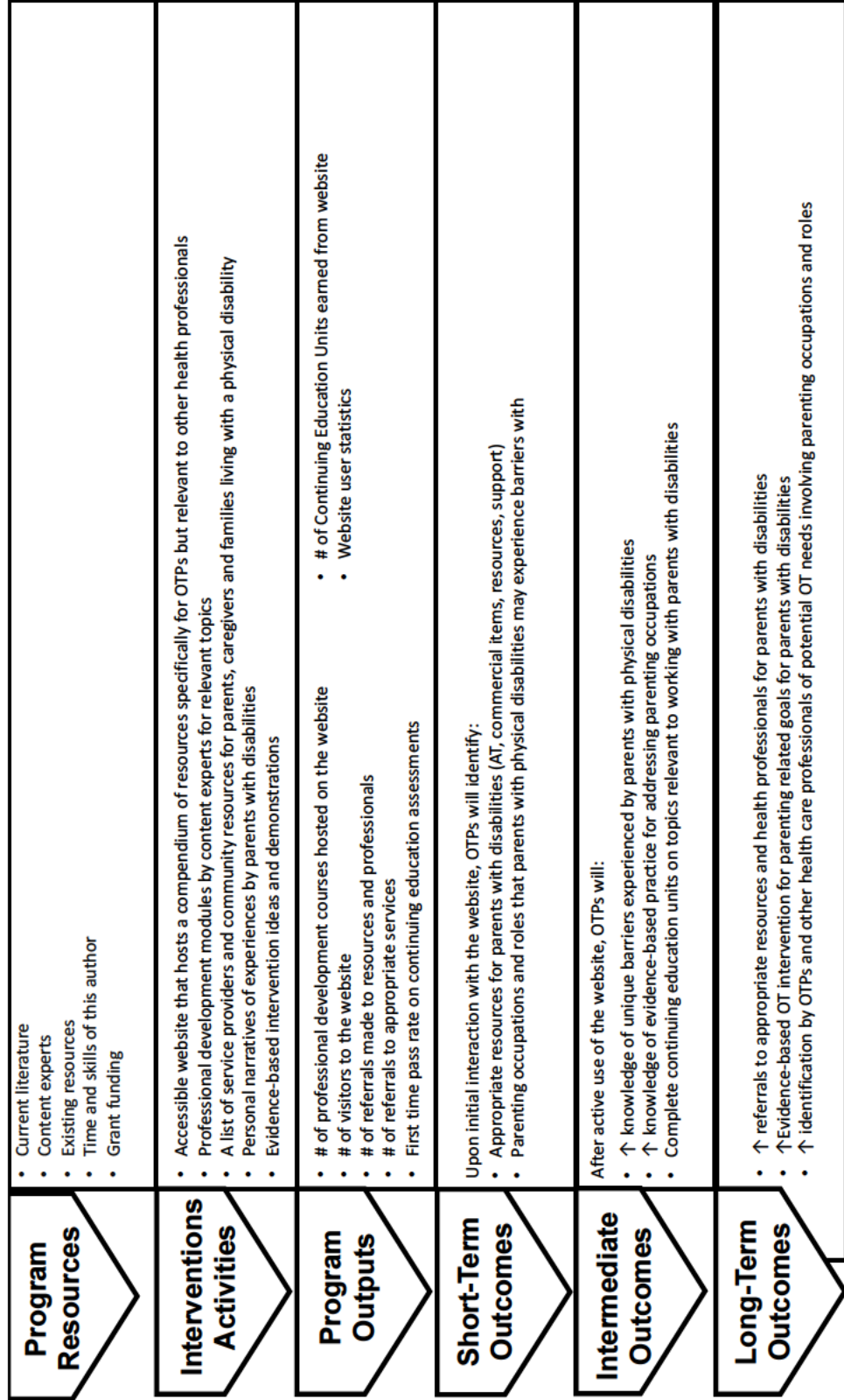


## APPENDIX A – Full Logic Model

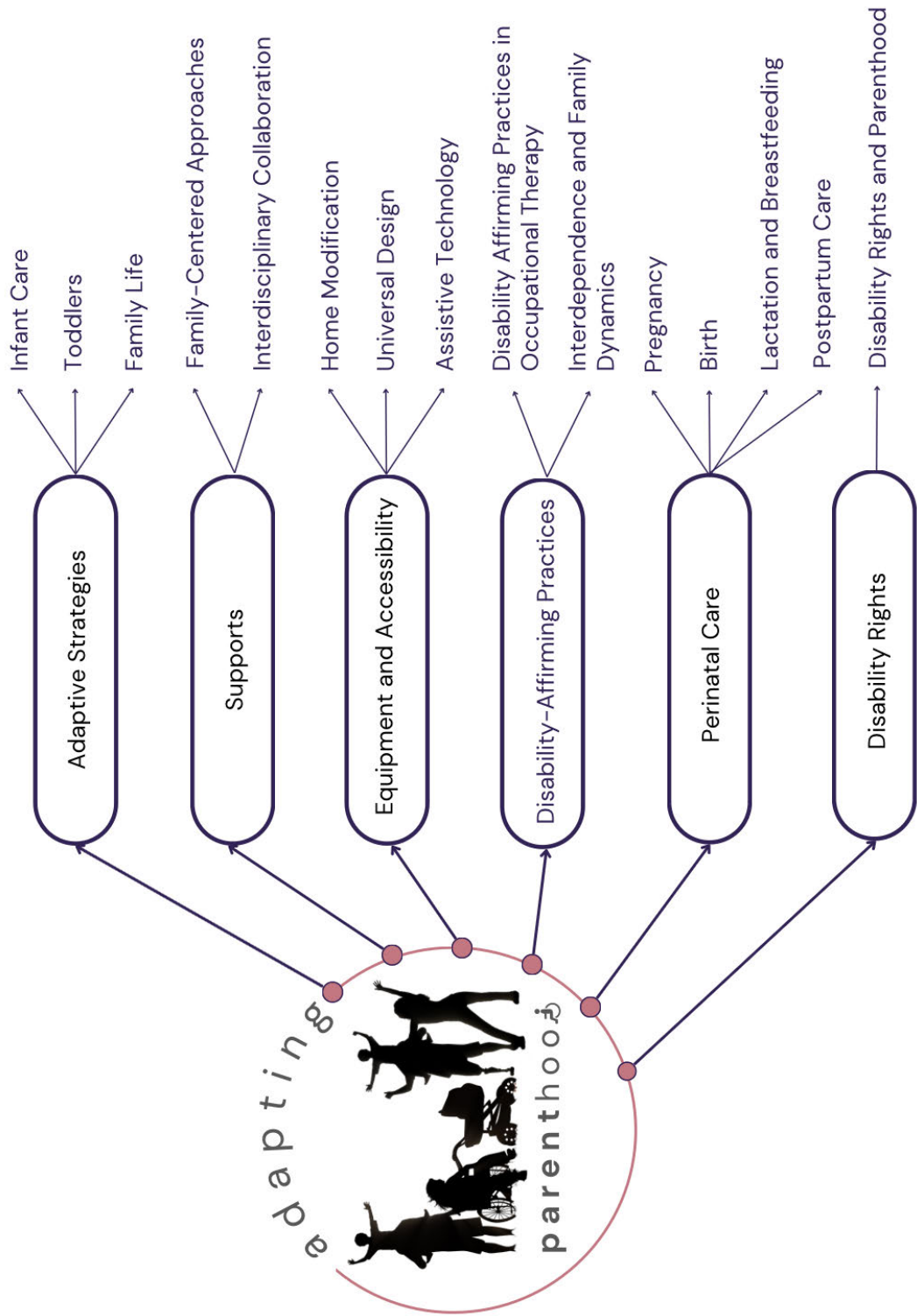
**Adapting Parenthood: an online resource and education platform for occupational therapy practitioners supporting parents with physical disabilities**



## APPENDIX B – Simplified Logic Model



**APPENDIX C – Visual Model of Adapting Parenthood Content Topics**



## **APPENDIX D – Executive Summary**

The journey of parenting is multifaceted and may present unique challenges for individuals with physical disabilities, particularly in the case of inadequate support systems and services (DeZelar & Lightfoot, 2021). Central to these challenges are environmental barriers that significantly influence their parenting roles and occupations. These may include an inaccessibly built environment, lack of suitable assistive devices, and the absence of personalized strategies for activity modification. Such barriers can restrict an individual's ability to complete daily parenting tasks effectively and as desired (Powell et al., 2019). Additionally, lack of understanding from service providers, societal attitudes, stereotypes, and inadequate professional development contribute to the failure to address the unique needs of parents with disabilities (Lightfoot et al., 2018; König-Bachmann et al., 2019).

Service and support systems often perpetuate these challenges rather than solve them. A critical problem lies in service delivery which frequently operates within a biomedical model. This model primarily focuses on the disability or impairment of the individual, neglecting the impact of the surrounding environment, such as physical barriers, societal attitudes, and service limitations, on the individual's functioning and well-being (Brennan & Swords, 2021).

Consequently, these issues have led to a significant gap in healthcare and support for parents with disabilities. A review of current literature and narratives reveals shortages in both resources and services (Pomerantz et al., 1990; Revell, 2019; König-Bachmann et al., 2019; Shpigelman, 2015). OTPs, are ideally suited to address

environmental barriers given their expertise in activity modification, adaptive strategies, and environmental modification, however, they often lack the necessary resources and education specific to parenting with a disability (Blochberger, 2009). The shortage of professional development and resources specific to occupational therapy compounds this problem. Thus, the need for an OT-specific education and resource platform is apparent and vital towards resolving these gaps.

### **Project Overview**

*Adapting Parenthood* is an online platform designed to support OTPs and students who work with parents with physical disabilities in their clinical practice. The platform features evidence-based and disability-affirming education and resources.

*Adapting Parenthood* is comprised of two main components. The first is a resource library of informative and instructional materials, such as videos, articles, handouts, podcasts, and websites. Narratives, case studies and video demonstrations offer practical guidance, and encourage reflection of real-world applications of parenting adaptations (Becker & Renger, 2017). These resources are selected to address various aspects of parenting with a physical disability to provide practical, disability-affirming and evidence-based insights that can assist practitioners when working with individuals with physical disabilities and parenting goals.

The second component consists of educational modules that offer professional development and continuing education units (CEUs). These modules are designed to supplement existing clinical skills or introduce a new topic of interest or supplement current knowledge, further enhancing the professionals' competence and confidence in

working with parents with physical disabilities. Module topics include addressing needs and identifying barriers related to assistive technology, environmental modifications, activity modifications, and disability rights.

This comprehensive approach to learning and resource provision ensures that OTPs are adequately equipped with the tools, knowledge, and skills they need to support parents with physical disabilities effectively.

### **Theoretical Basis**

The design of the *Adapting Parenthood* platform is rooted in adult learning theory, self-directed learning theory, and multimedia learning theory.

Adult learning theory acknowledges the unique characteristics and learning styles of adults (Mukhalalati & Taylor, 2019; Zaghaf et al., 2015). The platform's design considers the independence, self-direction, and life experiences of occupational therapists, enabling them to connect new knowledge with their existing professional experiences. Both the resource and education sections offer practical, immediately applicable information, fostering relevance, and promoting immediate engagement - all key tenets of effective adult learning (Merriam, 2001).

Self-directed learning theory emphasizes the individual's control over the learning process (Merriam, 2001). *Adapting Parenthood* applies this framework by offering flexibility in learning. Users can navigate the platform at their own pace, choosing the topics and resources most relevant to their needs and interests. Encouraging self-directed learning supports professionals in taking an active role in their own continuous education (Murad & Varkey, 2008).

Multimedia learning theory focuses on the effectiveness of using multiple forms of media to enhance learning (Moreno & Mayer, 1999). The platform uses this principle by integrating a mix of text, audio, video, and interactive elements in its content. By catering to various learning styles and promoting the processing of both visual and verbal material, the platform facilitates comprehension, retention, and application of knowledge (Kember et al., 2010).

In combining these three theories, *Adapting Parenthood* offers a user-centered learning experience, enhancing OTPs' capabilities and knowledge in supporting parents with physical disabilities.

### **Anticipated Outcomes**

The anticipated outcomes of *Adapting Parenthood* encompass both personal and professional development. The platform is designed to improve the understanding of adapting parenting roles and occupations through its resource library and professional education modules. The end goal is to foster a community of informed, empowered and skilled professionals who can advocate for and implement better support systems for disabled parents.

The first outcome is an increased acknowledgment and understanding of OTPs' roles in addressing parenting-related goals for clients with physical disabilities. The presentation of disability-informed interventions and strategies that align with the profession's distinct focus on occupations and participation, will provide concrete evidence of the unique contribution of OTPs in parenting.

By showcasing the specialized knowledge and skills OTPs bring to the table, the author hopes to raise the profession's profile within traditional and evolving clinical settings. More recognition should lead to an increase in appropriate referrals from various sources including other professionals, community members, medical systems, and even the clients themselves.

*Adapting Parenthood* seeks not only to improve professional practice and foster a supportive community but also to amplify the visibility and impact of occupational therapy within the broader healthcare and societal landscape. By offering a comprehensive, accessible, and OT-specific educational and resource platform, *Adapting Parenthood* proposes to solve the problem of limited availability of OT-specific interventions, education, and resources on parenting and disability.

### **Recommendations**

The recommendations in this section are intended for OTPs seeking to enhance their team's or their own continuing education, particularly in the context of serving parents with physical disabilities. The education modules through *Adapting Parenthood* are intended to be used cumulatively. Designed to build on each other, they offer occupation and role-specific knowledge that surpasses a generalized or medical-model approach to disability and parenthood. Following completion of the education modules, OTPs should utilize the resources offered by *Adapting Parenthood* secondarily. These resources serve as tools that can be recommended to clients and are designed to synergize with the knowledge gained from the educational modules. While these resources can function independently, they offer an enhanced benefit when used in tandem with the



education modules. The overarching goal of *Adapting Parenthood* is to equip OTPs to become client and family-centered clinicians who are disability-informed and understand the profound significance of parenting occupations and roles in the lives of their clients. By actively incorporating disability-informed information and evidence-based interventions, the occupational therapy profession can significantly enrich its service offerings to parents with physical disabilities.

### **General Conclusions**

*Adapting Parenthood* exists in response to the unmet needs of both OTPs working with parents with physical disabilities and the parents themselves. By offering a comprehensive online platform that integrates resources, professional development modules, and community support, the project promises to address the critical gaps identified in service provision and resources. *Adapting Parenthood* is anchored in learning theory relevant to promoting professional knowledge acquisition and skills development.

*Adapting Parenthood* holds significant potential to effect meaningful change in the realm of occupational therapy and beyond. By offering an innovative, accessible, and targeted solution to the identified challenges, it represents an invaluable tool for occupational therapists and other professionals and a much-needed resource for parents with physical disabilities.

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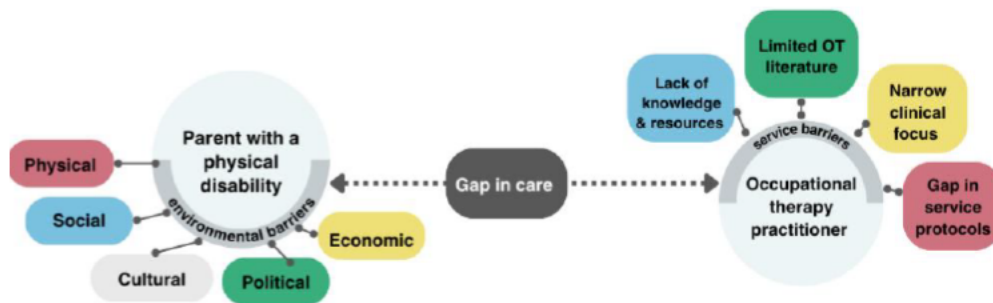
## APPENDIX E – Fact Sheet



# ADAPTING PARENTHOOD

An online resource and education platform for occupational therapy practitioners supporting parents with physical disabilities

Jessica Peterson, OTR, MSOT, PMH-C



**Parents with disabilities experience environmental barriers to parenting roles and occupations**

- About 6% of parents with dependent children have a disability (Wint et al., 2016)
- Social and professional support in their parenting roles is often needed and frequently not received (Lightfoot et al., 2018).
- Support that is given frequently fails to consider the context or environment in which the disability exists (Brennan & Swords, 2021).
- **Physical barriers**, inaccessible spaces and lack of specialized assistive technology can create challenges in participation in parenting roles and occupations (Brennan & Swords, 2021; Gitlow, 2021).
- **Social barriers**, such as lack of professional knowledge, bias, discrimination, stereotyping, negative portrayals and perceptions further contribute to a lack of support (Namkung, 2019; Fraser & Llewelyn, 2015).
- **Cultural, political and economic barriers** are also common experiences for PWDs (Lightfoot et al., 2018)

**Occupational therapy practitioners have barriers to providing services to address parenting**

- A study of OTPs working with PWDs (Lampe, 2019) found:
- Providing services to meet the needs of parents with physical impairments is within the scope of OT practice, yet further clarification is needed.
  - There is very little research that describes the role of OTPs in providing services to PWDs
  - OTPs reported lack of resources, lack of knowledge, and lack of reimbursement as the three most common barriers to providing OT services to PWDs
  - OT interventions addressing parenting frequently did not address activities rated among the most difficult by PWDs

**Though addressing environmental barriers to occupational participation in parenting is within the scope of occupational therapy, there is a *gap in care* between parents with disabilities and occupational therapy practitioners.**

## PROJECT DESIGN

Adapting Parenthood is a website comprised of two main components.

- A **resource library** of informative and instructional materials is curated to address aspects of parenting with a physical disability.
- **Educational modules** offer professional development and continuing education units (CEUs). They are designed to **supplement existing clinical skills** or introduce a new topic of interest, further enhancing the professionals' **competence and confidence in working with parents with physical disabilities**.

The content of the website is guided by **self-directed learning theory** which accommodates a wide range of users and promotes self-paced learning (Merriam, 2001). The design of the website is guided by **multimedia learning theory**, which suggests that individuals learn more effectively when information is presented using multiple formats and sensory channels (Mayer, 2001).



(Thomas, 2023)



## RESOURCE CATEGORIES

- Disability culture networks and organizations
- Peer support directory
- Legal information, resources and support
- Adaptations of parenting occupations
- First person narratives
- Case Studies
- Assistive Technology

## CONTENT TOPICS

- Adaptive Strategies
  - Infant Care
- Supports
  - Family-Centered Approaches
  - Interdisciplinary Collaboration
- Equipment and Accessibility
  - Home Modification
  - Universal Design
  - Assistive Technology
- Disability-Affirming Practices
  - Disability-Affirming Practices in OT
  - Disability Rights and Parenthood
  - Interdependence and Family Dynamics
- Perinatal Care
  - Pregnancy
  - Birth
  - Lactation and Breastfeeding
  - Postpartum Care



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**CURRICULUM VITAE**

